



4M: My health,
My choice,
My child,
My life

**Confinement: women HIV and pregnancy during the
2020 COVID-19 lockdown in the UK**

4M Mentor Mothers Network CIC

POSITION PAPER, OCTOBER 2020



“We acknowledge the anchoring and determination with which women in general have navigated life with HIV, regardless of the challenges and brought their families in all their myriad forms along with them.” (4M Mentor Mother)

“with regard to the sexual [and] reproductive health and rights of women, even as women sometimes we can forget ourselves...due to gender inequality, being mainly carers, culture and other reasons...we put other people first and society also puts others first. It means sometimes we get forgotten as individuals who also have human rights. So most of the time, when it comes to pregnancy and that is part of what 4M advocates for - is that the woman is an individual in her own right...because if the woman is okay the child will be okay...if the woman never gets the support that she needs, unfortunately that then translates to the child. So it is important we understand and promote that a woman’s rights are upheld as a human being first before anything else that is added, which includes the children, and that is not to say the children are not important, but the woman needs to be okay first.” (4M webinar 12, Mentor Mother)

Who is this paper for, who has written it, what does it cover and what are our Key Recommendations?

This paper has been written for:

- Policy makers
- Anyone with health or social care responsibilities to women who might be living with HIV and having children
- Any organisation dealing with women, especially if marginalised or migrants (documented and undocumented)
- All midwives and obstetricians in the UK
- Anyone living with HIV
- Anyone who knows someone living with HIV

We are an African migrant women-led network of Mentor Mothers who run a UK registered Community Interest Company (CIC), called 4M Mentor Mothers Network CIC (4M Net CIC). We support women living with HIV throughout their perinatal journey and beyond, to ensure their sexual and reproductive health and rights (SRHR).

This paper has been written by us and is based on our collective knowledge and experiences during the COVID-19 pandemic. We:

- present extracts from existing guidance in relation to COVID-19
- share how we have addressed the issues that have come up for women and how we have provided support
- observe outstanding intersectional issues that need to be addressed
- highlight some key background facts pre-dating, but exacerbated by, COVID-19
- share existing multi-sectoral guidance responses and recommendations from the 4M Network, to ensure our priorities are in focus.

Our Key Recommendations

1. **INEQUALITIES.** It is urgent *now*, to address persistent inequalities and intersectional issues which existed before the pandemic and have now been exacerbated by it. The associated economic shock and disruption of the pandemic, including disturbing levels of morbidity and mortality amongst people from **BAME** communities, must also be addressed. Ultimately, there is an urgent need for effective rapid test and trace processes, as well as vaccines for all; to enable physical connections that will be required to address these outstanding issues.
2. **BALANCE.** The emotional, physical and mental wellbeing of women going through the perinatal period must be in focus, with a good **balance** between COVID-19 prevention versus upholding their sexual and reproductive health and rights.
3. **RELEVANCE.** We cannot overemphasize the importance of ensuring that policies and programmes are those that are **relevant** and in line with women's **lived realities** and **priorities**. This is because, as issues have become worse, communities have become more 'out of reach' and services more inaccessible than before, with increased despair and destitution for individuals and communities. We as grassroots organisations are in touch with our peers and our communities and have provided evidence and recommendations that will enable the provision of **trauma-informed** supportive policies and programs, using a **feminist gendered approach** to the coronavirus response.
4. **MEANINGFUL INVOLVEMENT OF WOMEN** from the start is essential for respectful partnerships in decision making
5. **SUSTAINABLE FUNDING** will enable grassroots community groups like 4M continue to keep women meaningfully engaged, and keep the 'out of reach' in touch as evidenced by our proven track record of meaningful engagement.
6. **URGENCY.** Moving forward, we recommend especially that all the issues we have listed as points 1 to 8 in Section D of this report be addressed as a matter of **urgency**, in order to reduce the multiplier effects of COVID-19 – and potential other future pandemics – and to ensure that **our priorities** are in focus.

The COVID-19 pandemic continues to uncover existing health inequalities that threaten the sexual and reproductive health and rights of women, especially the most marginalized. Yet women carry on showing resilience, mobilising and supporting each other and our communities, mainly through small, trusted networks and community-based organisations in these challenging times.

As communities navigate their way through the ongoing lockdown changes, it is important that accurate and updated information is available and

accessible to women. It is also vital that women's voices are actively involved in the process of service reorganisation, to guarantee policies and services that are reflective of lived realities and which ensure and uphold our sexual and reproductive health and rights.

We also celebrate women living with HIV who have shown resilience through the HIV pandemic as well as through the COVID pandemic amidst all of these really challenging intersectional issues.

COVID-19 and Pregnancy: what do we know?

COVID-19 has transformed the way we live, and how we access health and social care services. Updated advice and guidance is frequently being issued by different authorities, as the pandemic and its effects become clearer. Although the paper focuses on COVID-19, most of the intersecting issues mentioned pre-date the pandemic. However, they affect how women cope with the COVID-19 challenge and will need to be addressed as services are reorganised to help women cope better post-lockdown.

Fortunately, pregnant women are not especially vulnerable to acquiring COVID-19 because of pregnancy. However, to be on the safe side, pregnant women living with HIV are being given the same advice about protecting themselves from COVID-19 as vulnerable people. The advice in the UK is to follow government guidance for people who are shielding, including social distancing. They are also advised to communicate regularly with their midwife and their NHS maternity team, in order to relay any concerns they may have¹.

As of 5th August 2020, people living with HIV were advised that HIV does not increase their vulnerability to acquiring COVID-19². If a woman does acquire COVID-19, pregnant women from Black and Ethnic Minority (BAME) communities are more likely than white pregnant women to end up in hospital because of severe COVID-19. This also applies to all older pregnant women, or pregnant women with obesity or hypertension. So pregnant women from BAME communities (or pregnant women who are older or with these other health conditions) are especially being advised to seek help from their midwife or obstetrician as soon as possible^{3, 4}.

Note: In the following sections we outline the official guidance on different aspects of perinatal care during the COVID-19 pandemic, so that women living with HIV know what they should expect of services. Extracts from official guidance from different authorities are interspersed by some quotes and information which come from 4M webinars. In March 2020, the pre-planned 4M webinar no. 11 addressed violence against women living with HIV and included reference to COVID-19. In May 2020, 4M webinar no. 12 addressed medical and psycho-social dimensions of perinatal care of women living with HIV in the context of COVID-19, to provide information and reassurance for pregnant women living in the UK especially. Both webinars were recorded and are freely accessible on the Salamander Trust vimeo channel⁵.

What covid-19-specific guidance is currently available?

In relation to HIV and pregnancy: the British HIV Association (BHIVA) issued a statement dated 25th March 2020 on management of a pregnant woman living with HIV and infant testing during Coronavirus (COVID-19) which says:

“Monitoring by HIV physicians may be reduced based on clinician assessment of HIV treatment and its efficacy but with a minimum of one initial contact/bloods (virtual or in person), one second trimester contact (virtual or in person) and one final visit in person at 36/40 for bloods and confirmation of the birth plan. Should further support be required antenatally and/or postnatally, virtual follow-up by phone is encouraged.

- 1 National Health Service NHS (2020) Pregnancy and coronavirus [online] Available at: <https://www.nhs.uk/conditions/coronavirus-covid-19/people-at-higher-risk/pregnancy-and-coronavirus/> [Accessed 6 August 2020].
- 2 British HIV Association (2020) BHIVA, DAIG, EACS, GESIDA & Polish Scientific AIDS Society Statement on risk of COVID-19 for people living with HIV [online] Available at: <https://www.bhiva.org/updated-BHIVA-DAIG-EACS-GESIDA-Polish-Scientific-AIDS-Society-statement-on-risk-of-COVID-19-for-PLWH> [Accessed 7 August 2020].
- 3 NHS (2020) NHS boosts support for pregnant black and ethnic minority women [online] Available at : <https://www.england.nhs.uk/2020/06/nhs-boosts-support-for-pregnant-black-and-ethnic-minority-women/> [Accessed 6 August 2020].
- 4 Salamander Trust & 4M Net Webinar No.12 (2020) *Perinatal care of women living with HIV in the context of medical and psycho-social dimensions* by Dr Alison Wright FRCOG of the Royal Free Hospital London and FIGO; and Elaine Cunnea, Head of Counselling at NAZ [online] Available at: <https://vimeo.com/423982356> [Accessed 6 August 2020].
- 5 Salamander Trust vimeo channel [online] Available at: <https://vimeo.com/442736775>

*Breastfeeding should be discouraged as it requires monthly maternal and infant viral load follow-up for the duration of the breastfeeding period and for 2 months post-cessation of breastfeeding”.*⁶

However, in line with our continuous advocacy for person-centred care, a Mentor Mother (MM) observes that

“The midwife will refer the mother to the breast-feeding specialist when that choice has been discussed with the mother and agreed as appropriate. In my experience during Covid-19, although breastfeeding is not being promoted for reasons discussed fully in the [4M infant feeding] report. At [our hospital], for those few women who were very aware of risk but committed to their decision, they have been supported to successfully breastfeed.” (4M MM)

In relation to pregnancy in general: The **Royal College of Obstetricians and Gynaecologists (RCOG)** provided guidance in May 2020 for healthcare professionals and information for pregnant women and their families who live in England. The guidance / information is regularly updated and available to access freely on the RCOG website.

For pregnant women, the main advice, as at 31st July 2020, is that:

“Pregnant women should follow the latest government guidance on staying alert and safe (social distancing) and avoid anyone who has symptoms suggestive of coronavirus. If you are in your third trimester (more than 28 weeks’ pregnant) you should be particularly attentive to social distancing.

Follow the guidance on staying alert and safe (social distancing) and staying safe outside the home including appropriate use of face coverings for the general public and clinically vulnerable people, including pregnant women (this guidance covers England only - if you

live in Scotland, Wales or Northern Ireland, you should follow the specific advice in those parts of the UK).

Keep mobile and hydrated to reduce the risk of blood clots in pregnancy.

Stay active with regular exercise, a healthy balanced diet, and folic acid and vitamin D supplementation to help support a healthy pregnancy.

Attend all of your pregnancy scans and antenatal appointments unless you are advised not to.

*Contact your maternity team if you have concerns about the wellbeing of yourself or your unborn baby”.*⁷

In addition, as observed in the May 2020 4M webinar, with regard to pregnant women:

“Pregnant women with COVID-19 are not advised to have water birth because the virus can be found in faeces and sometimes faeces can be found in water. In terms of appointments with the COVID situation, some women are concerned about coming to antenatal appointments; however women should be assured they are entitled to at least 6 face-to-face appointments in pregnancy. It is important that antenatal care is tailored so women get the care they need. Holistic and multidisciplinary maternity care is vital for women. When it comes to breastfeeding which is a controversial topic for women living with HIV generally, advice is based on each setting, but women should be supported in their choices and encouraged to wash their hands and maintain hygiene as much as possible”.
(4M webinar 12, Dr Alison Wright, FRCOG)

Evidence provided by **Birthrights** in April 2020, on coronavirus and the impact on people with protected characteristics found an inconsistent, dispro-

6 We are disappointed by this statement. Please see our comment on this in our recent breastfeeding position paper: 4M Mentor Mothers Network CIC & Salamander Trust (2020) *Position Paper on Infant Feeding For Women Living With HIV* [online] Available at : www.tinyurl.com/4MProject

7 Royal College of Obstetricians and Gynaecologists (July 2020) *Coronavirus infection and pregnancy, Information for pregnant women and their families* [online] Available at: <https://www.rcog.org.uk/en/guidelines-research-services/guidelines/coronavirus-pregnancy/covid-19-virus-infection-and-pregnancy/#covid> [Accessed 6 August 2020].

portionate and inhumane response by some NHS Trusts. While some Trusts had been responsive and supportive, others have used policies with no person-centred approach, raising serious concerns around maternity care⁸. There have been some reports of women in great distress through their not being able to have a birth companion with them for ante-natal scans, as well as through labour and post-birth. Following this, in August 2020, Birthrights called for rights respecting care during the COVID pandemic and easing of visiting restrictions in maternity care⁹. We are glad to see that on the 9th of September, RCOG together with the Royal College of Midwives and others, introduced a framework to ease this restriction¹⁰.

“I am very grateful for the close working relationship I have established with ‘Birth Companions’ who help with financial and material provision for our most vulnerable mothers. As well as providing the service of a trained birth companion to attend at the birth, for our women who do not have a person they can ask to support them at this most special time”.
(4M MM)

In relation to perinatal mental health: the Royal College of Psychiatrists (RCP) on 24th July 2020 observed:

“this pandemic will inevitably result in an increased amount of anxiety in the general population, and this is likely to be even more so for pregnant women as it represents an additional period of uncertainty. Specifically these anxieties are likely to revolve around COVID-19 itself, the impact of social isolation resulting in reduced support from wider family and friends, the potential of reduced household finances, major changes in ante-natal and other NHS care with appointments being changed from face to face to telephone contact. The change in appointment style will also

make assessment for women experiencing domestic violence, women with safeguarding concerns and women who are misusing substances more difficult.”¹¹

As noted in the May 2020 4M webinar,

“It is important to recognize challenges and acknowledge concerns around emotional wellbeing in this pandemic. Women should be asked about their mental health at every contact with a healthcare professional. Post-traumatic stress in the intensive care unit can occur for anyone who has been through an intensive care experience especially for women having a baby in the pandemic. For the birth experience, it has been a real challenge for women who we say can only have one birth partner because sometimes women would like to have someone there...it is more challenging if the person they choose to have has COVID symptoms at the last minute and women end up having the baby completely alone. We encourage people to skype or facetime someone else while they are in labour...we are trying to be as creative as possible but also being kind, being aware that although we are doing all these things with the best intentions and to reduce the spread of infection, it is having an impact on women’s birth experiences.” (4M Webinar 12, Dr Alison Wright)

A Mentor Mother also shared experiences of mentees she supports:

“Some of the issues women are struggling with include emotional issues, weight gain, isolation, panic attacks, trying to support themselves, thinking about going out again but nervous about wearing masks, fear and worries about going out even to the park.” (4M webinar 12, Mentor Mother)

8 Birthrights (2020) *Coronavirus and the impact on people with protected characteristics* April 2020, Women and Equalities Committee [online] Available: <https://www.birthrights.org.uk/wp-content/uploads/2020/05/Birthrights-Covid-19-Maternity-Briefing-women-and-equalities-committee-final.pdf> [Accessed 6 September 2020].

9 Birthrights (2020) *Calls for easing of visiting restrictions in maternity services 20th August 2020* [online] Available: <https://www.birthrights.org.uk/wp-content/uploads/2020/08/Letter-to-NHSE-re-ongoing-visiting-restrictions.pdf> [Accessed 9 September 2020].

10 Royal College of Obstetricians and Gynaecologists, (2020) *RCOG and RCM statement on the reintroduction of visitors in maternity services in England 9 September 2020* [online] Available: https://www.rcog.org.uk/en/news/rcog-and-rcm-statement-on-the-reintroduction-of-visitors-in-maternity-services-in-england/?utm_source=Royal%20College%20of%20Obstetricians%20and%20Gynaecologists&utm_medium=email&utm_campaign=11820578_Weekly%20Member%20email%20%7C%20UK%20%7C%20160920&utm_content=Reintroduction%20of%20Maternity%20Services&dm_i=15N0,71CTE,0087WO,SE0AF,1 [Accessed 26 September 2020].

11 Royal College of Psychiatrists (2020) *Pregnant women and those in the perinatal period* [online] Available at: <https://www.rcpsych.ac.uk/about-us/responding-to-covid-19/responding-to-covid-19-guidance-for-clinicians/community-and-inpatient-services/covid-19-working-with-vulnerable-patients> [Accessed 6 August 2020].

It is important that pregnant women living with HIV also engage with their midwives to address any mental health concerns. As observed by a MM:

“The midwife in my experience is the person in the antenatal care team who will refer a pregnant woman who is experiencing anxiety, depression etc for perinatal mental health service. Other members of the team may identify concerns, but the midwife has the responsibility to initiate referrals to the appropriate services.” (4M MM)

Resources have also been developed by different organisations to assist with providing support. **The International Association for Suicide Prevention (ISAP)** released a Basic Psychosocial Skills Guide for COVID-19 Responders on 24th May 2020. This is a useful resource for those working on the frontline to help provide supportive services¹².

As services are reorganised, *“it is important to acknowledge that women-only spaces and services are supportive. As such, a gender-responsive and trauma-informed approach is vital for women’s mental health, especially for survivors of abuse and trauma. Women-specific peer support adds value to general mental health support, especially for women facing multiple disadvantages.”*¹³

As noted in the May 2020 webinar,

“...people are coping using already established relationships and informal peer support. Through those linkages, women support each other. HIV organisations have also been proactive having online groups and using platforms like zoom to educate, inform and socialise.” (4M webinar 12, Mentor Mother)

In addition, in May 2020, Birth Companions developed guidance for midwives supporting women facing multiple disadvantages during COVID-19. This addresses trauma, safety, and other complex issues¹⁴.

We emphasize the important role of midwives and their relationship with pregnant women living with HIV, as observed by one of the Mentor Mothers:

“...importance of the relationship between the pregnant woman and the midwife, especially in the time of COVID. The importance for the mother to communicate her concerns, issues and experiences with the midwife. The midwife is the pregnant woman’s guide to the health of the pregnancy - explaining, informing the mother of any changes identified in bloods taken or urine samples and appropriate actions that need to be taken. Providing the mother with assurances that the checks, monitoring of growth of baby, heartbeat etc is in line with expectation and reminding the woman of what to do in the event of any irregular signs such as lack of foetal movement or unexpected bleeding. In this era of COVID and with more virtual appointments, it is very important that women are aware of the opportunity these appointments represent to discuss fully their own health and that of foetus and allay any concerns or fears. The midwife is providing the woman with a balanced view and confidence if she is for example experiencing morning sickness and not keeping her ARV’s down or struggling to adhere to medication - which happens more often than I would assume, for a variety of reasons. However, with good communication between the mother and antenatal team, the mother can still be encouraged to adhere to the best of her ability. Late into the pregnancy, ARV regimens can be changed and decisions about modes of delivery can be agreed to ensure the health of mother and baby and minimise transmission risk to the baby.” (4M MM)

Maternity Action also has a ‘Frequently Asked Questions’ page on their website relating to rights at work and benefits during pregnancy and maternity leave during the Covid-19 pandemic. This is frequently updated and freely accessible¹⁵.

12 The International Association for Suicide prevention (2020) *Basic Psychosocial Skills- A Guide for COVID-19 Responders* [online] Available at : <https://interagencystandingcommittee.org/system/files/2020-05/Basic%20Psychosocial%20Skills-%20A%20Guide%20for%20COVID-19%20Responders.pdf> [Accessed 6 August 2020].

13 Agenda and MIND (2020) *Women Side by Side programme Policy report June 2020* [online] Available at: <https://www.mind.org.uk/media-a/5919/wsbs-agenda-report.pdf> [Accessed 6 August 2020].

14 Birth Companions (2020) *Supporting women facing multiple disadvantage during COVID-19: Guidance for midwives* [online] Available at: https://hubble-live-assets.s3.amazonaws.com/birth-companions/redactor2_assets/files/253/Supporting_women_facing_multiple_disadvantage_during_COVID-19_Guidance_for_midwives_FINAL.pdf [Accessed 7 August 2020].

15 Maternity Action (2020) *FAQs: Covid-19 – rights and benefits during pregnancy and maternity leave* [This page was last updated on 03 July 2020.] [online] Available: <https://maternityaction.org.uk/covidmaternityfaqs/> [Accessed 10 September 2020].

What have 4M and our Mentor Mothers been doing?

Mentor Mothers have been self-mobilising to support each other and the women we mentor during these times of COVID-19, lockdown and restrictions that affect daily life and the perinatal experience. We held two COVID-19-specific 4M webinars during lockdown to support Mentor Mothers. The first discussed violence against women living with HIV and offered some insights into what can cause conflict in relationships, as well as some suggestions about how to manage conflict, and we shared with MMs guides to useful organisations covering a wide range of relevant issues¹⁶. The second also provided practical tips and links regarding how to manage your mental health through the pandemic¹⁷. Some of the tips include: having a routine, identifying your needs, using your phone to proactively seek relevant connections, either 1-1 or in groups with others.

Below we describe some of the many initiatives and resources, grouped around some key areas we consider crucial.

Personalised care

“It is important that every woman has a positive personalised, safe birth.”

Dr Alison Wright, who said this in Webinar 12, also stated:

“Pre-COVID, the NHS has been developing a resource in collaboration with the RCOG. It is a personalised care and support plan where the woman discusses her plan with people looking after her antenatally, [i.e.] in advance of childbirth, so she knows what may or may not be offered to her at the time of birth. A decision-making tool for labour and birth is in development by the NHS and Birth Rights to ensure every woman decides what is best for her in pregnancy, childbirth and beyond, called “I-decide”. It will be piloted late in 2020 and will be rolled out afterwards...The idea is to move

away from paternalistic models that tell women what to do. Personalised care supports women be part of options and decisions. She is consulted and empowered to make those decisions”. (4M webinar 12, Dr Alison Wright)

One Mentor Mother described her own formula for offering personalised care during COVID-19:

“I have been running a lot of private groups which we set up to chat with each other, share meals, cocktail evening, keeps us calm, sharing our stories, relaxing etc. We have a private messenger group and WhatsApp and a public Facebook page. If anyone wants to join us, they are welcome” (4M webinar 12, Mentor Mother)

Confidentiality and talking about HIV

One of the major areas of concern for women is they want to be able to safely talk about a HIV diagnosis/status and thereafter, receive respectful support from family/friends and healthcare providers in primary/secondary health and social care settings. As observed by a MM,

“The mother sharing her HIV status with a significant other; partner or family member is often an issue that can assume increased priority but can be hard for the woman to come to terms with during pregnancy. It is always the woman’s choice to decide, she knows her life and the people in it the best. Issues of rejection or potential risk of domestic violence may make the issue of sharing her status a threat to the mother’s sense of wellbeing in pregnancy. Confidentiality is a priority for antenatal team and should particularly be highlighted on delivery wards, where breach is most reported to occur. This is most likely as a result of nursing care no longer strictly being provided by HIV specialist care staff.” (4M MM)

16 Salamander Trust and 4M Mentor Mothers Webinar Series (2020) *Some useful links for webinar no. 11 on Communication and Relationship Skills* [online] Available at: <https://salamandertrust.net/wp-content/uploads/2020/04/4MWebinar11ListofideasApril20201stEdition.pdf> [Accessed 8 August 2020].

17 Salamander Trust and 4M Mentor Mothers Webinar 11 (2020) *Links between violence against women and girls and (VAWG), our sexual and reproductive health and rights, including mental health, and HIV* [online] Available at <https://vimeo.com/407122621>. [Accessed 8 August 2020].

Mental health

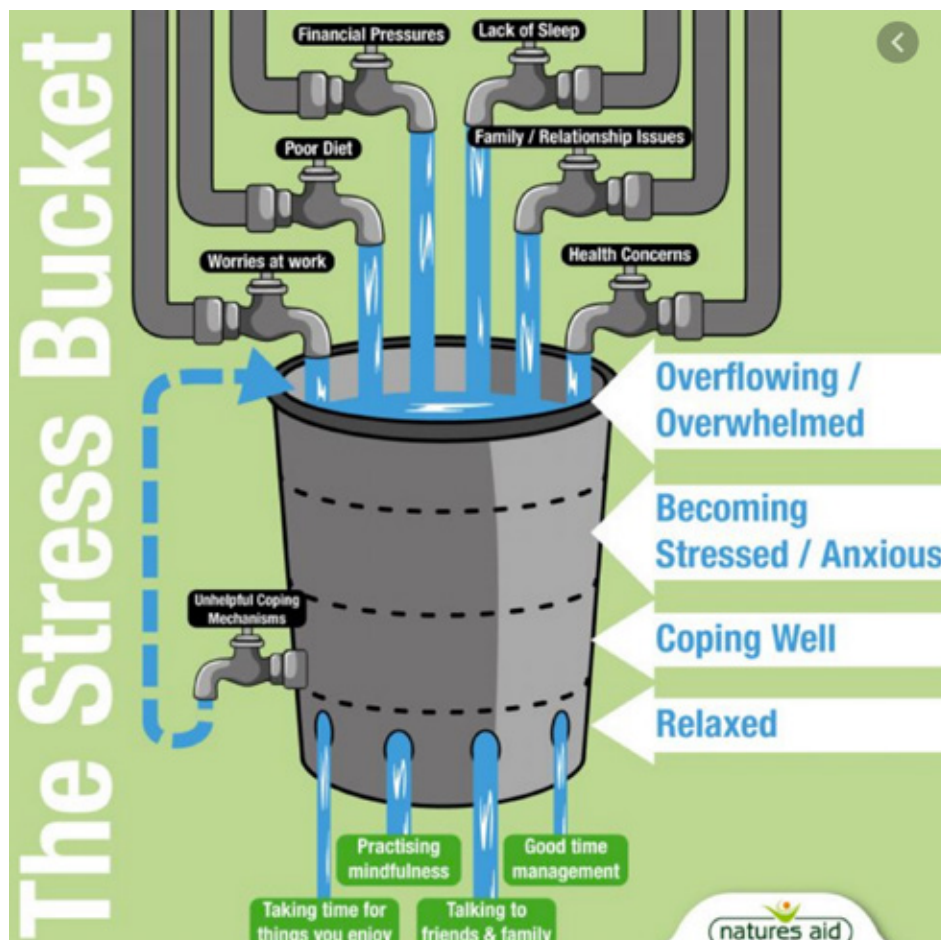
The Head of Counselling at NAZ Project London emphasised that when it comes to mental health:

“it is important to acknowledge that every woman’s experience of what COVID-19 means to her will be different. Challenges of COVID-19 for women supported so far include recognising loss, particularly for women. This loss includes job, income, housing, asylum or refugee issues as well as living with HIV. In addition, there are issues around bereavement, loss of a loved one, people can’t contact or visit for family support; health insecurity you may have with COVID-19 happening and disclosure, where your routine may have been private and unique for you, going for your medication but now with COVID-19, people are restricted in movement and at home noticing. So, if your family is not aware of your HIV status this is another issue. Children get stressed out by being at home too, so it is recognising what is going

on for your other children too as a new mum or expecting mum. Extended family loss where they are unable to support you and give you relief from the children, help with house chores etc especially being in a community where extended family is an important part of the network and ritual around having children and child birth. Connecting with other mothers and although you can WhatsApp, it’s a loss of physical relationship. Loss of intimacy, privacy and “me time”, the big day when you have been looking forward to, to be able to celebrate and connect with other people as you would have. Multiple losses can challenge people’s moods. Worries about going to hospital and having your baby, worrying about what services are available.” (4M Webinar 12, Elaine Cunnea, Head of Counselling at NAZ)

Elaine Cunnea also shared the diagram below, that illustrates how to manage stress using the stress bucket.

Figure: The Stress Bucket¹⁸



18 Brabban, A. & Turkington, D. (2002) *The Search for Meaning: detecting congruence between life events, underlying schema and psychotic symptoms*. In A.P. Morrison (Ed) *A Casebook of Cognitive Therapy for Psychosis* (Chap 5, p59-75). New York: Brunner-Routledge

Other strategies on how to manage stress include working out what your ‘love language’ is¹⁹ and what support you may need to get through these times. There were concerns about waiting lists for counselling being lengthy (up to 26 weeks), and so access can be challenging, exacerbating mental illness. The Black Asian and African Therapeutic Network (BAATN) is the largest community of Counselors and Psychotherapists of Black, African, Asian and Caribbean Heritage in the UK²⁰. They have compiled a list of UK organisations that will provide free or low-cost counselling. Women can check on the website to find what might be available in their local area. Racial inequalities also exist in mental health for people from BAME backgrounds and recommendations have been made on how to improve the situation²¹.

Our Meaningful involvement

At 4M we emphasise the value of our meaningful involvement. In terms of maternity care,

“Maternity Voices Partnerships are a way women can feedback their experiences and any concerns of care in their local area. If women don’t know how to access help or resources, they can contact the maternity partnerships. You can find your local maternity partnership in your local region...Women can make their voices heard through this forum and everyone can freely engage. They are open to everyone and they have regular dialogues. It is a way for women to feed back.”

(4M webinar 12, Dr Alison Wright)

A Mentor Mother recommends that:

“as resources are being developed, if it is possible to support community groups by making it a recommendation when developing new resources, in the process of developing that resource, that whoever is going to use it should find ways of engaging community groups to support women to be educated because one of the things I find in my experience is sometimes the resources are too far away for every-

day people but then if they have the support to learn through community groups then it is easier for them to use it but it means the community groups need to be supported with funding to educate” (4M webinar 12, Mentor Mother)

An integrated approach to care

“An integrated approach to care allows for a much more complete picture and discussion of how to meet the patient need. I also feel protected from taking on undue responsibility for the mother’s potential issues which might better be addressed by eg a community nurse specialist etc. As an antenatal team member and mentor mother I have played a role in supporting HIV positive pregnant women, providing an informed point of discussion for the mother to be and managing some of the social care and support referrals relevant to her case. However, I agree and report all my actions to the antenatal MDT and in particular the midwife. I know this to be a unique role and way of working. I wish to emphasise the benefits of this model.” (4M MM)

Working with young women born with HIV

We are also aware of the vital importance of supporting younger women living with HIV. COVID-19 is proving a trigger to some young women in their twenties, who have grown up with HIV, who are now facing pregnancy and motherhood during lockdown. These younger women are now struggling with emotions that have come up for them during the lockdown. There is a need to work with these young mothers and their parents to manage their status, that of their parents, relationships, bereavement, anger and blame they harbour, especially for their own mothers.

As one Mentor Mother described:

“through my work I come across young mums born with HIV with a lot of underlying issues. It seems there has been a lot of ill talking about

19 Chapman G, (1992) *The Five Love Languages: How to Express Heartfelt Commitment to Your Mate*. Northfield Publishing Chicago ISBN 978-1881273158.

20 Black Asian and African Therapeutic Network -BAATN (2020) [online] Available: <https://www.baatn.org.uk/> [Accessed 6 September 2020].

21 Atayero Sarah (2020) *Racial Inequality in Mental Health Care* in Supporting Women with HIV Information Network (SWIFT) symposia on Race, Ethnicity and Health Outcomes, Part 1. July 24th 2020 [online] Available at: <https://www.bhiva.org/BHIVA-webcasts> [Accessed 9 September 2020].

the mums from the fathers. These women now have resentment towards their mums because the fathers told them how evil the mums were by giving birth to them with HIV... [one young woman] is angry with the mum, even though the mum has passed away. Although the mother is dead, the impact still lives on. She wanted to engage with a peer support service but felt that if she did, she will be publicly saying she is HIV positive and will indirectly be telling about her father's status. So, because of her father, she would not engage...She is not connecting and she says [my] talking to her is triggering her anger and memories of her mum. With COVID-19 and isolation, not being able to go out, I can imagine how difficult things are. I tried my best to engage but it has not been easy. If there was a way to work with the young people including the father/parents to help them process these feelings and ill feelings about their mums..." (4M Webinar 12, Mentor Mother)

Working with families and across generations

The example above illustrates the importance of working holistically with young women (and men) as they grow up, to ensure that significant others in their lives are appropriately included in their support. Other Mentor Mothers made suggestions on how to approach some of the issues:

"Family therapy will be highly recommended engaging with places like CHIVA, Body and Soul who have fantastic resources and the fact that they can link in with other young people going through the same challenges makes it even better. The platform from which they come should be one where they work with the whole family to try and help them understand it's not the mother's fault, and that is not where the blame should lie" (4M Webinar 12, Mentor Mother)

"There is a great young people clinic at St Marys that was updated after research was carried out to make it accessible. Sometimes with young people they are dealing with issues

of growing up eg sexuality, being a teenager, navigating and then not being able to speak about HIV makes it difficult. Try and identify what the layers are but as a mother I think that what might help is engaging with a family therapist because it is really important to... the fact that we physically carry the baby we automatically get blamed for the fact that that is the route through which the child got the HIV but I think it is important that women's Sexual and Reproductive Health and Rights [SRHR] are upheld and within that, try and remove the element of blaming the mother: and that is where the term 'vertical transmission' emanated from. It's to try and remove that feeling that it came directly from...before we used to say 'mother to child transmission' even though it's a slightly more direct thing but actually no, the child acquired HIV vertically" (4M Webinar 12, Mentor Mother)

This issue of involving fathers when women want that involvement is, of course, not specific to COVID-19. However, the pressures of lockdown and banning of companions by many hospitals have exacerbated many existing family tensions such as these. In 2015, the World Health Organization (WHO) recommended a comprehensive approach to the perinatal period, that includes the complete family unit:

"Interventions to promote the involvement of men during pregnancy, childbirth and after birth are recommended to facilitate and support improved self-care of the woman, improved home care practices for the woman and newborn, and improved use of skilled care during pregnancy, childbirth and the postnatal period for women and newborns."²²

"The role of the father? Where is the dad? As a family unit, it is important everyone is involved. Some of the work that Salamander Trust has done with the Stepping Stones programme shows that the more family members are involved, and the more fathers are involved, the more comprehensive services are for the family²³. When it is possible, and safe it is important to get the fathers' input" (4M Webinar 12, MM)

22 World Health Organisation WHO (2015) *Recommendation on male involvement interventions for maternal and neonatal health* [online] Available at: <https://extranet.who.int/rhl/topics/improving-health-system-performance/who-recommendation-male-involvement-interventions-maternal-and-neonatal-health> [Accessed 6 August 2020].

23 Salamander Trust (2020) *Stepping Stones: Footnote for 4M* [online] Available at: https://steppingstonesfeedback.org/wp-content/uploads/2020/09/Stepping_Stones_Footnote_for_4M_Final_Sep_2020.pdf [Accessed 25th September 2020].

Resilience

In spite of these challenges' women have and continue to show resilience, as observed by a MM:

“My overwhelming experience as a woman living with HIV for the past 30 years is of at least 2 generations of women who are HIV positive raising children often single-handedly - in my opinion well. Very well! Sharing their status with those children who are able over time to

come to terms with their family dynamic. It may require some additional professional help from within HIV clinics, support groups, counsellors. These are modern families, working through issues, where children are experiencing life sometimes in the raw, but they learn and are capable of achieving educationally, have aspirations, and as a result of their background may be more aware of the complexities of sexual interactions and relationships than many of their peers.” (4MM MM)

It is really important that a woman is not made to feel guilt or blame for acquiring HIV or for getting pregnant, or for ‘passing HIV on’ to her children. Unfortunately, all too often, women are blamed by their partners - and even by healthcare providers - and this narrative gets passed on to her children. As we have seen with the story above, such ‘adverse childhood experiences’, as experienced by the young mother concerned, can result in on-going traumas across generations. No-one deserves this blame – neither the woman as the object of the blame, nor her children as the recipients of this blame narrative. In Salamander Trust’s *Stepping Stones* programmes, men have been supported to understand that this blame is inappropriate and a form of intimate partner violence²³. This blaming is often based on their own fears, hurts and needs, as we discussed in webinar no.12 above on violence. Through the programme, men start to feel able to get tested themselves and, if they test positive (and they often are), to start on treatment themselves. We have seen couples’ lives transformed by this process, and their children too can then grow up feeling happier, healthier and safer as a consequence. The mental health of the women improves dramatically, which also means that they can then start to adhere to treatment much better and therefore cope better with all of life’s challenges in general. This is one key example of what upholding the women’s SRHR really means in practice. The men too can start to speak more openly about their own HIV, or about having HIV in the family, and no longer live in silence, based on fear and shame. Once the men open up, the rest of the family can then start to feel safer to do so too. It’s a win-win for everyone, with HIV at last no longer being the hidden taboo family secret. At 4M we feel that such holistic, inclusive processes are needed to address the combined effects of HIV, violence and resulting mental health issues; and that they should be available in the UK too. A recent article highlights these same historical tensions, with a siloed age-gender divide in the global work around violence against women and violence against children. It echoes the need to move forward beyond these tensions and silos to examine the wider picture in a much more holistic way²⁴.

24 Maternowska C, Shackel R, Carlson C & Levkov R (2020) *The global politics of the age-gender divide in violence against women and children, Global Public Health* Available at: <https://www.end-violence.org/sites/default/files/2020-08/The%20global%20politics%20of%20the%20age%20gender%20divide%20in%20violence%20against%20women%20and%20children.pdf> [Accessed 4 September 2020]

Some Key Background Facts

Whilst these guidance statements are important, we also discuss here pre-existing issues which have been exacerbated by COVID-19.

As the UN Secretary General recently stated,

“COVID-19 has been likened to an X-ray, revealing fractures in the fragile skeleton of the societies we have built.”²⁵

It will be important for policy-makers and service providers alike to address these issues in an effective response to pregnancy and HIV when moving forward in the ‘new normality’ of COVID-19.

The UK Women’s Budget Group released a report on 9 April 2020 that outlines how Covid-19 affects women in the UK and makes recommendations for a gender-sensitive policy and programme response²⁶.

1. Immigration, the hostile environment and NHS charges

According to Ros Bragg, the Director of Maternity Action,

“The pandemic creates new dangers for pregnant women, and particularly for BAME women who are at greater risk of hospitalisation and death. We know from our advice service that there are women with high risk pregnancies who are avoiding maternity care out of fear of incurring a debt they cannot pay.”²⁷

The Government’s policy of creating a ‘hostile envi-

ronment’²⁸ for migrants means that some pregnant women and new mothers are being charged a fee of about £7,000 or more for accessing NHS maternity care. Many of these women are not allowed to work under the government’s immigration rules. So they cannot afford to pay the fee and experience debts and stress.

“We found that women are missing antenatal appointments and scans because of fears of incurring debt that they simply cannot pay and because of fears of being reported to the Home Office.”²⁹

The situation is also uncomfortable for doctors who would rather not be drawn into the hostile immigration policy *“As doctors, our purpose is to look after the sick. We did not go through six years of medical school to become border guards”³⁰*. (The Independent)

A report by Lancet Migration recommends *“Ensure urgent universal and equitable access to health systems, preparedness and response”* and *“Suspension of the NHS visitor and migrant cost recovery programme”*, among other recommendations³¹.

Undocumented women are particularly vulnerable and can find themselves in a vicious cycle where they end up destitute through domestic violence and/or relationship breakdown. Although they are subject to charges for NHS care, they have no right to work or to claim benefits and are thus unable to rent from private landlords. A lot of women have had their applications for asylum refused and are either

25 Nelson Mandela Foundation (2020) *Annual Lecture 2020: Secretary-General Guterres’s full speech*, 18th July 2020. [online] Available: <https://www.nelsonmandela.org/news/entry/annual-lecture-2020-secretary-general-guterres-full-speech> [Accessed 21 August 2020].

26 UK Women’s Budget Group, (9 April 2020) *Crises Collide: Women and Covid-19 Examining gender and other equality issues during the Coronavirus outbreak* [online] Available at : <https://wbg.org.uk/wp-content/uploads/2020/04/FINAL.pdf> [Accessed 6 August 2020].

27 The News Alert (2020) *Woman loses legal challenge to NHS charges for pregnant migrants* [online] <https://thenewsalerts.co.uk/woman-loses-legal-challenge-to-nhs-charges-for-pregnant-migrants/> [Accessed 21 August 2020].

28 Wikipedia (2020) *Home Office hostile environment policy - 2012* [online] Available: https://en.wikipedia.org/wiki/Home_Office_hostile_environment_policy [Accessed 20 July 2020].

29 Maternity Action (2018) *What Price Safe Motherhood? Charging for NHS Maternity Care in England and its Impact on Migrant Women* [ONLINE] Available at: https://www.maternityaction.org.uk/wp-content/uploads/WhatPriceSafeMotherhoodFINAL_October.pdf [Accessed 6 August 2020].

30 Patel P (2020) *As doctors, we look after the sick. We did not go through medical school to become border guards.* [online] *The Independent* Available at: <https://www.independent.co.uk/voices/doctors-nhs-surcharge-migrant-workers-hostile-environment-lockdown-a9526731.html> [Accessed 21 September 2020].

31 Patel P et al (2020) [online] *Policy brief: Including migrants and refugees in the British government’s response to COVID-19.* Lancet Migration. [online] Available at: https://1bec58c3-8dcb-46b0-bb2a-fd4addf0b29a.filesusr.com/ugd/188e74_620055fdbdaf445e9d7a26bb9073b563.pdf [Accessed 21 September 2020].

afraid to or unable to return to their country of origin because the country is unsafe for them: the reason they sought asylum in the first place. Meanwhile, annual increases in immigration fees makes it difficult to regularise their stay without support. Many women end up excluded, socially and economically vulnerable, facing sexual exploitation, with precarious living conditions and destitution.²⁹

“Although her pregnancy is the consequence of the actions of two people, only the woman is liable for the costs it entails in terms of healthcare and only her immigration status is restricted if she’s unable to pay it.”³²

Visa fees vary depending on the category³³. Current visa fees per person are £1,033 for a standard leave to remain. A mandatory £400 per year NHS fee is required in addition to regular taxes and National Insurance paid through work and any legal/solicitor fees.^a Most cases that are complex will require a solicitor to be successful and legal aid is no longer as available as it used to be. Women often find themselves on a 10-year route where they must re-apply every 2.5 years, resulting in at least 4 rounds of visa and solicitor fee payments per person to achieve indefinite leave to remain. Verbal information from a variety of women with recent experiences in our network, indicate that this can cost an additional £800-£2,500 in solicitors’ fees each time. This cycle perpetuates fatigue, poverty and mental health issues for women.

As observed in research by Maternity Action:

“Overall, midwives considered that charging had an adverse impact on their professional practice, increasing barriers to good relationships between midwives and women. Moreover, they felt that charges target the most vulnerable, affecting particularly women’s mental health and public health. Overall midwives felt that the burdensome impact of charges on the women they cared for, as well as on their own professional practice, outweighed any justification that was made for them.”³⁴

2. GP registration and access to healthcare

A pertinent issue that is not specific to COVID-19, but relevant to women’s experiences, is GP registration which affects their ability to access healthcare. Doctors of the World released a report in 2015, still relevant today.

“Pregnant women, children, refugees and homeless people are among the vulnerable people being wrongly turned away from GP surgeries in the UK. The biggest barrier was people’s inability to provide paperwork – be that ID or proof of address.”

Although NHS guidelines state that patients do not need proof of ID or address to register and see a doctor, there is still confusion in some practices where people are turned away by surgery staff.³⁵

During COVID-19, access to GPs has been further constrained as services have switched to using telephone, skype and email to reduce in-person contact.

3. Digital access and literacy

A Mentor Mother shared her experience of providing support to women in lockdown:

“In terms of our experience, digital literacy has been challenging for women. From the experience of COVID, for any digital resources [to be] made available it is important that there is recommendation and funding made for women to be supported by community groups to have digital literacy and have the funding to get the tools because not everyone has the tools and it is actually preventing people from accessing services.” (4M webinar 12, Mentor Mother)

With the lockdown, a lot of people have had to rely on digital tools. However, there have long been reports of digital exclusion; this might be based on ethnicity, income, skillset, gender and disability,

32 Reis Sara (2020) *Migrant Women and the Economy*; A report from the UK Women’s Budget Group [online] Available at: <https://wbg.org.uk/wp-content/uploads/2020/05/WBG-28-Migrant-Women-Report-v3-Digital.pdf> [Accessed 6 August 2020].

33 GOV.UK (2020) *Home Office immigration and nationality fees: 4 August 2020* [online] Available at: <https://www.gov.uk/government/publications/visa-regulations-revised-table/new-fee-from-4-august-2020> [Accessed 31 August 2020].

34 Maternity Action (2019) *Duty of Care? The impact on midwives of NHS charging for maternity care.* [online] Available at: <https://maternityaction.org.uk/wp-content/uploads/DUTY-OF-CARE-with-cover-for-upload.pdf> [Accessed 6 August 2020].

35 Doctors of The World (2015) *Registration refused: A study on access to GP registration in England* [online] Available at : https://uploads.doctorsoftheworld.org/2016/05/RegistrationRefusedReport_Mar-Oct2015.pdf [Accessed 6 August 2020].

a Update: on 6 October 2020, it was announced that the Immigration Health Surcharge will increase from £400 a year to £624 a year on 27 October 2020. <https://www.freemovement.org.uk/immigration-health-surcharge-rising-to-624-in-october-2020/> [Accessed 21 October 2020]

mainly among already marginalised or disadvantaged populations³⁶. The intersection of digital exclusion and financial exclusion is a serious risk that may exacerbate inequalities.

“There are 1.9 million households without internet access in the UK, and 9 million people can’t use a device on their own. People who would previously have been supported at their local community centre to access the internet were left disconnected, denied equal access to financial opportunities.”³⁷

In the 4M webinar series, Mentor Mothers shared their experiences of women either not having enough data, gadgets or not being digitally literate. In some cases, they were unable to afford any digital tools.

“Appointments and consultations online are difficult challenges, you get a form and have to explain the situation and condition.”
(4M webinar 12, Mentor Mother)

It is important that provision is made for women to gain digital literacy, and to feel connected and supported during and after lockdown.

“In terms of virtual appointments it will be really good to gather women’s feedback as we have been through this pandemic ... because some people are saying virtual consultations are great and we should do more of it moving forward but we are hearing that that’s not always the case for various reasons, digital literacy but also some women value the benefit of coming out of the house and able to speak more frankly out of their own home. It is useful to have women’s direct lived experience and feedback so that we are not making assumptions of what women want – we need to hear that from women directly ...” ***(4M Webinar 12, Dr Alison Wright)***

4. Violence in institutions and community

HIV has long been recognised globally as a cause and consequence of violence. With COVID-19, violence against women and girls has increased globally. In the UK, domestic abuse killings have been ‘more than double’ amid Covid-19 lockdown³⁸. An initial survivors survey, carried out in April 2020, by Women’s Aid found that:

“The Covid-19 lockdown measures expose survivors to worsening domestic abuse, whilst restricting their access to support. Perpetrators are using Covid-19 as a tool for coercion and manipulation, often using Covid-19 as a tool to induce fear. Prior to lockdown, fleeing abuse was already a challenging and tumultuous time for many survivors and the lockdown measures have made leaving an abusive situation harder than ever. Survivors face substantial challenges accessing specialist domestic abuse services, mental health support and maintaining informal contact with friends and family.”³⁹

On the global front, the International Federation of Gynaecologist and Obstetricians (FIGO) is looking at how women’s healthcare has been affected by the pandemic and recognises increased domestic violence and the effects. It emphasizes supporting pregnant women to access reproductive healthcare and best practices during pregnancy and post-partum. FIGO has stated (13th April 2020):

“Contraceptive and family planning services and supplies are core components of essential health services and access to these services is a fundamental human right.”⁴⁰

4M webinar no. 11, on violence against women and mental health issues in relation to the sexual and reproductive health and rights of women living with HIV, discusses the importance of trauma-informed care and offers some useful links for improving our communication and relationship skills in a short document⁴¹.

36 Office for National Statistics (2019) *Exploring the UK’s digital divide* [online] Available: <https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04#how-does-internet-usage-and-digital-exclusion-vary-for-men-and-women> [Accessed 28 August 2020].

37 Good Things Foundation (August 3rd 2020) *Finding policy solutions to digital and financial exclusion* [online] Available at : <https://www.goodthingsfoundation.org/news-and-blogs/blog/finding-policy-solutions-digital-and-financial-exclusion> [Accessed 6 August 2020].

38 Grierson, J. (2020) *Domestic abuse killings ‘more than double’ amid Covid-19 lockdown*. The Guardian [online] Available at: <https://www.theguardian.com/society/2020/apr/15/domestic-abuse-killings-more-than-double-amid-covid-19-lockdown> [Accessed 7 August 2020].

39 Women’s Aid (2020) *The impact of Covid-19 on survivors: findings from Women’s Aid’s Initial Survivor Survey* [online] Available at: <http://womansaid.co.uk/> [Accessed 7 August 2020].

40 The International Federation of Gynecology and Obstetrics (FIGO) (2020) *COVID-19 Contraception and Family Planning*. [online] Available: <https://www.figo.org/covid-19-contraception-family-planning> [Accessed 21 July]

41 4M Mentor Mothers Webinar Series (2020) *Some useful links for webinar no. 11 on Communication and Relationship Skills* [online] Available at: <https://tinyurl.com/y5wezj2e> [Accessed 6 August 2020].

In addition, on 18th June 2020, the World Health Organisation (WHO) released a brief of key actions for addressing violence against children, women and older people during the COVID-19 pandemic⁴².

Closely related to violence at home are issues of poverty and safe housing. We do not have space to address these issues adequately here, but include two comments from MMs about their effects.

“There is also a huge issue in general for pregnant women struggling due to poverty. Those receiving universal credit or in low paid jobs who are unable to make ends meet. During the Covid period in particular but also throughout the 6 years I have been working at the Homerton I have made countless referrals to the food chain and applied for grants from various charities to help pregnant women meet their nutritional requirement and access funds to buy essentials for themselves and their babies”. (4M MM)

“The dire situation of pregnant women and women with new born and young children who are living in wholly unsuitable accommodation or who are even homeless for lengthy periods of their pregnancy. Housing problems have become almost the dominant issue that carries me through working with women when they are pregnant and for several years post having their child and possibly going onto have subsequent children whilst living in often overcrowded, unhygienic, damp and mould infested rooms. Health and safety considerations regularly being disregarded. GPs, consultants, social care staff, MPs routinely write letters attesting to the negative impact of these conditions on the mothers and children’s health. We wait interminably and try and help women to survive the waiting game with support groups, referrals to lawyers, counselling, back to work schemes etc.. And the faith that eventually something, somehow will shift - their number will come up on the council waiting list. In my opinion the housing system is broken, and it is causing real casualties in people’s lives and

HIV positive pregnant women are not exempt from this. They too have their babies and are returned to hotel and hostel rooms in the wait for temporary accommodation! In particular what saddens me is to watch the joy and uplift of women delivering their HIV negative babies be gradually worn away at, over the course of years, as they try to survive their inadequate living conditions. There is invariably a negative impact on the mother’s mental health and outcome for their family.” (4M MM)

5. Access to Sexual and Reproductive Health (SRH) services

A survey of sexual health services as of 21st April 2020 found that services had reduced by a little more than 50%

“The survey results show that vulnerable populations are particularly at risk during this time, with almost 1 of 5 respondents saying they were only able to offer limited, or no care at all, to this group. Other challenging areas appear to be delivery of routine vaccinations (54% unable to provide) and provision of LARC [long acting reversible contraceptives] as preferred contraception (54% unable to provide). 9% said they were unable to maintain PrEP [Pre-Exposure Prophylaxis] provision.”⁴³

As at 7th August 2020, advice on accessing contraception and STI services includes restrictions of face-to-face contact with healthcare professionals and increased (online/telephone) consultations and prescribing⁴⁴. It is important that, as services go back to some form of normality, women remember to follow up with their yearly smear check appointments, which are vital for us⁴⁵.

“with regard to the sexual reproductive health and rights of women, even as women sometimes we can forget ourselves...due to gender inequality, being mainly carers, culture and other reasons...we put other people first and society also puts others first. It means some-

42 WHO (2020) *Addressing violence against children, women and older people during the covid-19 pandemic: Key actions* [online] Available at: [file:///C:/Users/44741/Documents/WHO-2019-nCoV-Violence_actions-2020.1-eng%20\(1\).pdf](file:///C:/Users/44741/Documents/WHO-2019-nCoV-Violence_actions-2020.1-eng%20(1).pdf) [Accessed 29 September 2020].

43 The British Association for Sexual Health and HIV (BASHH) (2020) *BASHH Covid-19 Survey Finds Over Half Of Services Have Been Closed* [online] Available at <https://www.bashh.org/news/news/bashh-covid-19-survey-finds-over-half-of-services-have-been-closed/> [Accessed 7 August 2020].

44 Virgin Care sexual health HUB (2020) *Important information about the Coronavirus (COVID-19)* [online] Available at <https://www.thesexualhealthhub.co.uk/faqs/where-can-i-get-free-contraception/> [Accessed 7 August 2020].

45 Salamander Trust (2019) *Women Engage! Living with HIV and Cervical Cancer* [online] Available: https://salamandertrust.net/wp-content/uploads/2019/03/UPDATED_Women_Engage_Cervical_Cancer_Advocacy_Booklet_FINAL_Nov_2019.pdf [Accessed 2 September 2020].

times we get forgotten as individuals who also have human rights. So most of the time, when it comes to pregnancy and that is part of what 4M advocates for - is that the woman is an individual in her own right...because if the woman is okay the child will be okay...if the woman never gets the support that she needs, unfortunately that then translates to the child. So it is important we understand and promote that a woman's rights are upheld as a human being first before anything else that is added, which includes the children, and that is not to say the children are not important, but the woman needs to be okay first" (4M webinar 12, MM)

6. Black women and pregnancy in the UK

Black women in the UK are five times more likely to die during pregnancy and after childbirth compared to white women. However, additional research is also needed to understand why⁴⁶.

A 4M MM shares her experience:

"[Hospital name] has a policy of providing pregnant women with £280 worth of milk vouchers... This service is invaluable to our cohort of HIV positive pregnant women. Almost all of whom are black women and the majority of whom are journeying through their pregnancy largely unaccompanied. This is not to say that some do not have partners who may attend the birth but the responsibility of attending appointments, decision making about the pregnancy, how to care for herself, prepare for the baby's arrival and ensure as much as possible that HIV is not transmitted to the baby: this responsibility is almost wholly carried by the mother." (4M MM)

Research also shows that although women from BAME communities make up a quarter of the births in England and Wales, 55% of pregnant women admitted to hospital with COVID-19 were from a BAME background. Black pregnant women were found to be eight times more likely to be admitted to hospital with COVID-19 and Asian women four times as likely. In response to these statistics, on 27th June 2020, maternity units were asked to take

specific actions to minimise the additional vulnerability to COVID-19 for BAME women and their infants. These actions include:

"Increasing support of at-risk pregnant women – e.g. making sure clinicians have a lower threshold to review, admit and consider multidisciplinary escalation in women from a BAME background.

Reaching out and reassuring pregnant BAME women with tailored communications.

Ensuring hospitals discuss vitamins, supplements and nutrition in pregnancy with all women. Women low in vitamin D may be more vulnerable to coronavirus so women with darker skin or those who always cover their skin when outside may be at particular risk of vitamin D insufficiency and should consider taking a daily supplement of vitamin D all year.

Ensuring all providers record on maternity information systems the ethnicity of every woman, as well as other risk factors, such as living in a deprived area (postcode), co-morbidities, BMI and aged 35 years or over, to identify those most at risk of poor outcomes."³

7. No recourse to public funds or to support for COVID-19

Although the effects of COVID have been shown to be more severe for migrants and people in BAME communities, research has shown that an estimated 1.376 million people in the UK have no recourse to public funds (NRPF). This means they are unable to access support that may be vital to enable them to cope through the pandemic⁴⁷.

"The revelation that almost 1.4 million people have no recourse to public funds is shocking. Without the security of the welfare safety net, many have faced and will continue to face impossible choices concerning their health and that of their families". Dame Gillian Guy, Chief Executive of Citizens Advice

46 MBRRACE-UK, (2019) *Saving Lives, Improving Mothers' Care Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2015-17 Maternal, Newborn and Infant Clinical Outcome Review Programme*. ([online] Available at: <https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202019%20-%20WEB%20VERSION.pdf> [Accessed 6 August 2020].

47 Citizens Advice (2020) *Nowhere to turn How immigration rules are preventing people from getting support during the coronavirus pandemic* [online] Available at : <https://www.citizensadvice.org.uk/Global/CitizensAdvice/Nowhere%20to%20turn%20briefing.pdf> [Accessed 6 August 2020].

Although Boris Johnson pledged to review NRPF policy during the coronavirus crisis, he has since reversed that decision⁴⁸. NRPF has been exacerbating economic and gender inequalities in the UK for a while⁴⁹.

“To date, the easiest way to be free of the NRPF policy is through gaining ILR [Indefinite Leave to Remain]. Yet the path to residency rights and relief from the NRPF policy can last from five to ten years and is fraught with costly obstacles (visa and visa-associated costs alone can go higher than £15,000 before British citizenship is achieved), leaving migrant families with little provisions all the while being prohibited from carers allowance, child benefit, housing benefit and welfare support.”⁴⁸

According to a report from the Children’s Society,

“Our research has focused on the experiences of children and families who have NRPF and who are on the ten-year route to settlement. These are predominantly families from Black, Asian and ethnic minority backgrounds, many of whom are single parents, with British, UK-born or UK-raised children, living on very low income for prolonged periods of time. Having NRPF and being on the ten-year route means that many of these families will have been living hand-to-mouth for years; experiencing cycles of homelessness, sofa-surfing and sleeping on floors with other families, or in cramped accommodation; with spiralling debt and deep in poverty. Many of the families we interviewed were headed by single mothers working in low-paid but essential jobs such as care workers and NHS staff, supporting their families without top-up benefits, free school meals, childcare support or disability living allowance even though some were caring for children with disabilities or additional needs. Even for those who are supported by local authorities, the support was still extremely low: several families we spoke

to were surviving on under £3 per person per day. Many of the families we spoke to were already in debt from living on such low income and forced to borrow from friends and family or take out loans to pay for the extortionate and ever-increasing Home Office fees and Immigration Health Surcharge, which is again set to increase in October 2020. For some families this means paying around £10,000 every two and a half years. Having to consequently borrow or deplete whatever savings they might have, means being unable to save for their children’s university education or to buy a stable home to secure their children’s well-being and future”.

Recommendations from the Children’s Society report include, among others:

“Suspension of NRPF and a call for Local authorities to make clear on their website, through helplines and other mechanisms, the support available to NRPF families, including free school meals and local welfare provision where appropriate. There should be no gate-keeping on the basis of immigration status and nationality”⁵⁰

In addition, a report by The Unity Project observes that:

“Pregnancy/maternity, disability, age and sex are protected characteristics under the Equality Act 2010, and - with regard to those with NRPF - this research shows that women, pregnant people, disabled people and children are more likely to be impacted by the negative effects of the NRPF condition and that this impact will be more severe for these groups. Women are more likely to be single parents and - on account of being restricted from full access to free childcare schemes for disadvantaged families, as well as not being entitled to receive the childcare element of working tax credits - single mothers subject to

48 Merrick R, (2020) *Boris Johnson quickly drops pledge to explore extra help for migrants left destitute by benefit rules*. 3 June 2020 The Independent. [online] Available: <https://www.independent.co.uk/news/uk/politics/boris-johnson-migrant-nhs-funds-nrpf-coronavirus-job-retention-a9546951.html> [Accessed 9 September 2020].

49 MacRury J, (2020) *Guest Blog: Time to Scrap ‘No Recourse to Public Funds’ for Women*. Zero Tolerance [online] Available: <https://www.zerotolerance.org.uk/news/news-events/time-to-scrap-no-recourse-to-public-funds-for-women---guest-blog-by-ias/> [Accessed 7 September 2020].

50 The Children’s Society (2020) *A Lifeline for All Report Children and Families with No Recourse to Public Funds* [online] Available: <https://www.childrensociety.org.uk/sites/default/files/a-lifeline-for-all-report.pdf> [Accessed 7 September 2020].

NRPF are often unable to take up full time employment and are more likely to fall into destitution. The risk of being subject to domestic abuse is more acute for women, particularly migrant women, and for migrant women with NRPF who are subject to domestic abuse the NRPF policy can prevent them from accessing DV support services. Indirect sex-based discrimination resulting from the NRPF policy is also faced by pregnant women subject to NRPF who are at a high risk of destitution due to the fact that they are unable to work for a significant time before and after they give birth and will have higher outgoings due to their newborn baby.”

The report recommends, among other things, a suspension of NRPF and a simplified process of application for recourse to public funds⁵¹.

Most recently, in May 2020,

“A landmark case involving an eight-year-old boy and his single mother has resulted in new guidance with the potential to revolutionise thousands of families’ lives. Parents can now apply to have NRPF lifted in the event of ‘imminent destitution’. However, the change doesn’t go far enough. Already, migrants can seek support from local councils in the event of destitution, but Section 17 system is flawed and burdensome and too often than not leaves applicants at the mercy of a ‘postcode lottery’ where they are left without provisions.”⁴⁸

With all of these challenges there are limited resources available to support women with NRPF. The few available include Southall Black Sisters who provide regular online Advice and Support Surgery for agencies/professionals requiring support for their users with No Recourse to Public Funds. They also provide a No Recourse to Public Funds hardship grant for women facing violence⁵².

8. Disproportionate impact of COVID-19 on Black, Asian, and Minority Ethnic (BAME) populations

Finally, and specifically in relation to COVID-19, we have seen how this virus too has had a disproportionate impact on Black, Asian, and Minority Ethnic populations, with people from BAME communities found to be more likely to become unwell and die with COVID-19, and pregnant women with COVID-19 more likely to be admitted to hospital. It has been observed that there are longstanding inequalities that affect BAME communities in the UK, such as those we have listed above, which the pandemic has exposed and exacerbated.

As observed by Dr Rageshri Dhairyawan (Chair of 4M Net CIC Steering Group),

“Longstanding prevalence of racial health inequalities, including clinical practices, entrench health inequalities which impact on quality of life. Addressing the socioeconomic inequalities caused by structural racism is essential. As healthcare professionals we have a responsibility to advocate for this.”⁵³

Additionally, in the Public Health England (PHE) report on the impact of COVID on people from BAME communities, stakeholders called for the exploration of how socio-economic, occupational, cultural, and structural factors (racism, discrimination, stigma) influence COVID-19 outcomes for people in BAME populations, both within and outside the health sector. A strong recommendation was made:

“for additional research, working in equal partnership with community, using community participatory research that integrates both mental and physical health dimensions. However, stronger calls were for immediate cross-government action for sustainable change that is culturally and faith sensitive.”⁵⁴

51 Woolley A, (2019) *Access Denied: The Cost of the No Recourse to Public Funds Policy on Women* [online] The Unity Project Available <https://static1.squarespace.com/static/590060b0893fc01f949b1c8a/t/5d0bb6100099f70001faad9c/1561048725178/Access+Denied+-+the+cost+of+the+No+Recourse+to+Public+Funds+policy.+The+Unity+Project.+June+2019.pdf> [Accessed 7 September 2020].

52 Southall Black Sisters (2020) Online Advice and Support Surgery for agencies/professionals requiring support for their users with No Recourse to Public Funds [online] <https://southallblacksisters.org.uk/press-releases/nrpf-immigration-remote-surgery-for-professionals/> [Accessed 21 September 2020].

53 Dhairyawan R (2020) *Racism and health outcomes* in Supporting Women with HIV Information Network (SWIFT) symposia on Race, Ethnicity and Health Outcomes, Part 1. July 24th 2020 [online] <https://www.bhiva.org/BHIVA-webcasts> [Accessed 9 September 2020].

54 Public Health England PHE (2020) *Beyond the data: Understanding the impact of COVID-19 on BAME groups* [online] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf [Accessed 6 August 2020].

Conclusion

This paper has documented extracts from existing guidance in relation to COVID-19. We have described some responses from 4M and our members in relation to pregnancy and HIV especially, and also identified some key background facts pre-dating, and exacerbated by, COVID-19. We have highlighted outstanding intersectional issues that will need to be addressed, including the disturbing levels of morbidity and mortality amongst people from BAME communities. COVID-19 is not going away in a hurry. It has exposed huge gaps in the basic structure of UK society's well-being as a nation. Of course, even if COVID-19 makes this work more urgent, it is also much harder to meet in larger groups if COVID-19 has not been con-

trolled. This is why there is also an urgent need for effective rapid test and trace processes, as well as vaccines for all.

As one reviewer of this paper rightly observed, “*what about the post-delivery period? Going to baby groups, seeing family and friends, to access feeding support⁵⁵, post-natal checks, visitors from health workers and more? And toddler groups? At least older children are back at school for now.*” However, much as all these questions also raise hugely important challenges in their own right⁵⁶, we have felt it best for now to limit this paper to focus on the perinatal period especially, since this is a particularly important time in a woman's life which often receives insufficient attention.

4M and other organisations that work among, reach and represent communities often considered ‘hard to reach’ (or rather, communities for whom services are often ‘out of reach’), have collected both anecdotal and formal evidence of what the issues are and provided examples of what is currently useful. Within this evidence are recommendations for what could be done to provide trauma-informed⁵⁷ supportive policies and programs, using a gendered approach to the coronavirus response, as recommended by Fawcett⁵⁸.

It is critical that, as situations and needs change frequently, funding and other necessary resources are made available and accessible to small community-based organisations. This will enable respectful partnerships and our meaningful involvement in decision-making, so that we can shape services that will be appropriate for, and support, us.

Moving forward, we have presented a list of recommendations at the start of this report. We recommend especially that all the issues we have listed as points 1 to 8 in Section D of this report be addressed as a matter of urgency, in order to reduce the multiplier effects of COVID-19 – and potential other future pandemics – and to ensure that our priorities are in focus.

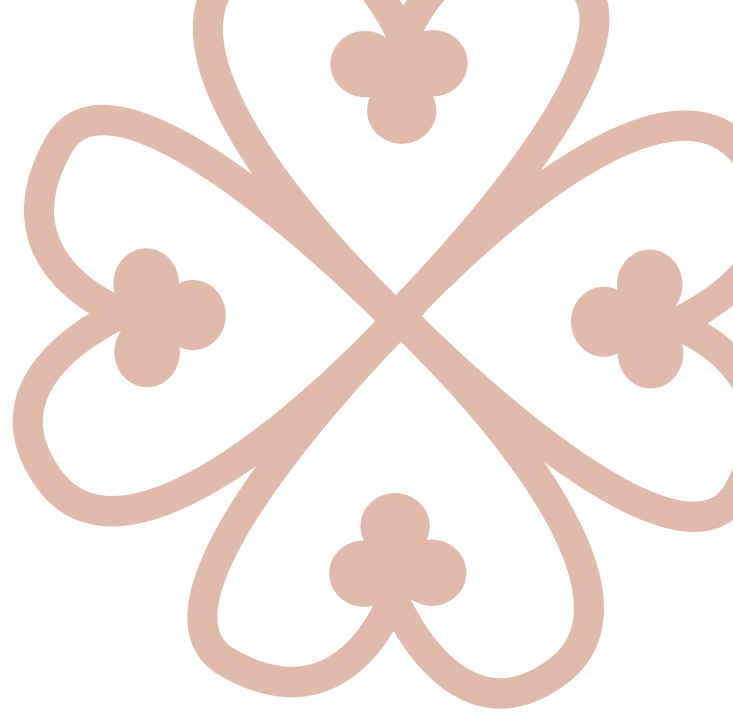
We offer our observations here, based on our own insights and experiences, in the hope that policymakers and service providers alike will engage with us to build on them, for the collective benefit of us all.

55 4M Mentor Mothers Network CIC & Salamander Trust, 2020, *Position Paper On Infant Feeding For Women Living With HIV*.

56 Hear also BBC Radio 4 (2020) File on 4: *Expecting Alone: The isolation of pregnancy during COVID*, 22 Sep 2020 <https://www.bbc.co.uk/programmes/m000mt11> [Accessed 23 September 2020].

57 Hall D, and Fraser S, (2019) *Becoming Trauma Informed*, 4M Webinar no. 8, Salamander Trust & 4M Net. [online] Available at: <https://vimeo.com/361065776> [Accessed 10th September 2020].

58 Fawcett Society (2020), *Exiting Lockdown: The Impact on Women* [online] Available: <https://www.fawcettsociety.org.uk/Handlers/Download.ashx?IDMF=a561cc61-04be-42f6-8461-dd90978f3dd2> [Accessed 10 September 2020].



ACKNOWLEDGEMENTS:

We wish to acknowledge the inspiring 4MNet members for their passion and commitment, to the network and mentees across the UK.

We also acknowledge the ongoing support of 4M's wonderful Steering Group members: Jane Anderson; Susan Bewley; Laura Byrne; Rageshri Dhairyawan (Chair); Gill Gordon; Fiona Hale; Vicky Johnson; Longret Kwardem; Rebecca Mbewe; Angelina Namiba; Shema Tariq; Pat Tookey; Alice Welbourn; and Alison Wright. Additional thanks go to Alison Wright, Elaine Cunnea, Janine McGregor-Read, Mel Rattue, Neo Moepe and Alice Welbourn in their roles as webinar presenters and/or providers of quotes; and all the amazing Mentor Mothers who attended and actively contributed in sharing about their work and experiences.

Our thanks to MAC AIDS Fund for supporting this publication.

Thanks also to our designer, Jess Nicholson.

DISCLAIMER: this policy brief reflects the collective views of members of 4M Mentor Mothers Network CIC. If you are a woman living with HIV in the UK, please consult your relevant health care advisers about your own healthcare. You can also contact us at info@4mmm.org if you would like to discuss your plans with us. These views do not necessarily reflect the views of all the members of our 4M Steering Group.

Suggested Citation: 4M Mentor Mothers Network CIC & Salamander Trust, 2020, *Confinement: women HIV and pregnancy during the 2020 COVID-19 lockdown in the UK.*
www.tinyurl.com/4MProject



Salamander Trust
ON THE RIGHT(S) TRACK

4M Network
My health, My choice, My child, My life