



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

ADVOCACY BRIEF, JUNE 2020

## From elimination of MTCT to ensuring SRHR Summary

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*In 2017, 1 in 3 people living with HIV in the UK were women, making up one quarter of all new HIV diagnoses. Of the 28,669 women living with diagnosed HIV, two thirds were Black African and 21% white. There are about 900 pregnancies annually among women living with HIV in the UK. Although the rate of vertical transmission in the UK is less than 0.3%, pregnancy continues to be a particularly challenging time for women living with HIV through persistent complex psychosocial problems that compromise maternal, infant and family wellbeing. Research shows that Mentor Mothers and perinatal peer support have benefits for the well-being of pregnant women living with HIV and their babies.*

### Introducing 4M Mentor Mothers Network CIC

In 2019, after a long history of work to deliver the 4M programme, first under the auspices of Positively UK as 'From Pregnancy to Baby and Beyond', and then as Salamander Trust, we registered 4M Mentor Mothers Network Community Interest Company.

There are other Mentor Mother programmes around the world – but not enough of them. In many cases they are clinician-led, with a biomedical focus on preventing vertical transmission and ensuring treatment adherence.

WHO (2017) [Consolidated Guideline on the Sexual and Reproductive Health and Rights of Women living with HIV](#)

WHO (2017) [Translating community research into global policy reform for national action: Checklist for implementing the Consolidated Guideline](#)

White Ribbon Alliance (2019) [Respectful Maternity Care Charter](#)

Salamander Trust (2017) [Developing a national network of Mentor Mothers to support women living with HIV through pregnancy – Executive Summary](#)

Knudsen-Strong & Positively UK (2011) [From Pregnancy to Baby and Beyond: Preliminary Findings from an Evaluation of the Pilot Programme](#)

BHIVA (2018) [British HIV Association guidelines for the management of HIV in pregnancy and postpartum 2018 \(2019 second interim update\)](#)

Positively UK, Steering Group (2016) [National Standards of Peer Support in HIV](#)

Namiba A, Kwardem L, et al (2017) [Developing a national network of 'Mentor Mothers' to support women living with HIV through pregnancy](#)

Salamander Trust (2018) [4M Advocacy Brief](#)

Our directors are Black women living with HIV from migrant backgrounds. Our advisory steering group includes Mentor Mothers, clinicians, academics and researchers of diverse ethnicities. Led by women living with HIV, by us, for us, with us, 4M is an innovative, peer-led, grassroots, UK-wide training programme and network enabling perinatal peer support.

At 4M, we believe we are the experts in the perinatal mentor mother peer support we need. Our approach is holistic – it's about our minds and spirit, not just our bodies. It's collaborative – we work closely with clinicians, organisations in the HIV sector, and organisations focused on housing, immigration, domestic violence, mental health, and other issues affecting women's lives.

And it's about building the movement for women's rights and the rights of women living with HIV. We are working to shift the narrative, from elimination of 'Mother to Child Transmission' (eMTCT) to ensuring our Sexual and Reproductive Health and Rights (eSRHR) throughout our lives.

Our evaluations show that 4M's perinatal mentor mother peer support has multiple benefits for the well-being of pregnant women living with HIV and their babies.

4M is centred on the principles of the 2017 WHO Consolidated Guideline on Sexual and Reproductive Health and Rights (SRHR) of Women living with HIV.

These principles are rights-based, gender equitable and women-centred. 4M's holistic approach, led by women living with HIV, recognises intersectionalities that exist for women and uses a trauma-informed approach to address these. 4M's work contributes to the attainment of Sustainable Development Goals with special emphasis on quality education (SDG4), good health and wellbeing (SDG3), gender equality (SDG5), and reduced inequalities (SDG10). It supports the Respectful Maternity Care Charter.

We are proud of what 4M has achieved. However, we face huge challenges, the most pressing of which is funding. We rely on project funding, which often barely covers the time we need to deliver activities. There is no core funding for our work and to support our development. We find ourselves in the funding 'starvation cycle', and despite our long

track record of delivering the 4M programme, we face donor barriers as a new organisation.

Because of the shortage of funding, much of our 4M work is done on an unpaid basis, combining it with other paid work. This leads to exhaustion, burn-out and capacity challenges.

As Mentor Mothers gain confidence, they seek employment opportunities. Without the possibility of paying them to do their peer support work, they find other jobs and have less time for their Mentor Mother roles, and 4M misses out on their expertise.

**We call on you to support the rights of women living with HIV and to ensure our sexual and reproductive rights during pregnancy and beyond, for life, and create the enabling environment for 4M to flourish. We ask you to:**

### **1. Value our work and recognise our expertise**

As a result of the work of 4M, Mentor Mother peer support is now promoted as good practice in the British HIV Association (BHIVA) National Pregnancy Guidelines, in line with the National Standards of Peer Support in HIV.

Yet we still struggle for visibility, recognition and resourcing for 4M. Support us by:

- Recognising and supporting peer-led Mentor Mother programmes and women's rights independent movement-building as critical for women's sexual and reproductive health and rights worldwide.
- Harnessing our value and expertise through partnership working, buy-in and referrals from clinicians and relevant NGOs, to ensure our services are known and available to women.
- Embedding the Mentor Mother service as an integral part of HIV clinic multidisciplinary teams, with a paid role and a peer support pathway in clinic.
- Recognising women as **leaders**, putting us at the heart of **decision making**, and actively involving us as the **experts** that we are.

**\*COVID-19 has exacerbated the need for all we do\***

## 2. Fund us

Women's rights organisations face a huge funding challenge globally: only 0.5% of international aid for gender equality goes to women's rights organisations. Women also face a gendered digital divide, yet we rely heavily on digital communications, particularly now. Sustainable funding for grassroots women's rights organisations is vital and requires funders to listen to what we say our priorities are, rather than prescribing priorities that do not fit our lived realities.

With the right funding, 4M could:

- Sustain and pay our small peer-led team, and pay Mentor Mothers for supporting 4M outreach, talks and trainings.
- Fund regular supervision for the project team from clinical psychologists.
- Develop our capacity through ongoing training for the project team and existing and new Mentor Mothers.
- Ensure Mentor Mothers have access to digital tools – mobile phones, data, internet – and the ability to use them.

## 3. Recognise the value of our model

The 4M approach to perinatal peer support works. The often top-down biomedical models of differen-

tiated services disempower us as women: 'eMTCT' or 'getting to zero' may ignore the principles of respectful maternity care, increase self-stigma and violate our sexual and reproductive health and rights.

We ask health care providers, researchers, policy-makers and other stakeholders to:

- **Listen to us... Learn from us... Work with us.** Recognise us as **equal partners** in our own **holistic quality of life**, well-being, healthcare and rights.
- Use sensitive, positive and safe language such as **'vertical transmission'** rather than 'MTCT'.
- Recognise and **address violence, disrespect and abuse in healthcare and community settings**, and promote the WHO Consolidated Guideline on the Sexual and Reproductive Health and Rights of Women living with HIV, the WHO Guideline Checklist, the Respectful Maternity Care Charter, and the principle of Meaningful Involvement of Women living with HIV.
- Commit to measuring success in ensuring our SRHR instead of eMTCT, using the WHO Guideline Checklist.

**THESE ARE OUR LIVES,  
NOT JUST PROJECTS....**

#metoo #blm #respectfulcare

*"As an HIV clinician, I have seen the impact that peer mentoring from 4M has on women going through their pregnancy journey, empowering them with the knowledge and agency to make decisions about their health that lasts well beyond pregnancy. 4M have advised on the 2018 BHIVA Pregnancy guidelines directly impacting on the clinical care of pregnant women in the UK. As Chair of the steering group, it has been a pleasure to work on a project led by women living with HIV and the development of 4M as a CIC has been a particularly impressive achievement. 4M's international presence has deservedly grown in recent years due to their prize-winning research and invited conference plenaries, as well as multiple collaborations."*

*(Steering Group Chair, Dr Rageshri Dhairyawan)*

### Acknowledgements:

We wish to acknowledge the inspiring 4MNet members for their passion and commitment, selflessly sharing their lives and expertise through the years to create a safe space for all of us, a sisterhood and a better community. We also acknowledge the ongoing support of 4M's incredible Steering Group members: Jane Anderson; Susan Bewley; Laura Byrne; Rageshri Dhairyawan (Chair); Gill Gordon; Fiona Hale; Vicky Johnson; Shema Tariq; Pat Tookey; Alice Welbourn; and Alison Wright. A massive thanks to our funders – MAC AIDS Fund, ViV Healthcare, MIND and our Anonymous donor who enabled all of this to happen.

Additional thanks to Nell Osborne, Ellen Bajenja (East Africa) and Silvia Petretti in their roles as trainers. Mel Rattue and Fungai Murau for carrying out evaluations. Salamander Trust as the project holder, Jane Shepherd for the beautiful, distinctive graphic design, Farai Sachikonye, Mel Rattue and Alice Welbourn for the 4M logos.

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