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) 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
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 differentiated 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, policymakers 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)
PART 1: The Background

In 2012, Angelina Namiba created the Mentor Mother Project ‘From Pregnancy to Baby and Beyond’ funded by Janssen and MAC AIDS Fund and supported by Positively UK. She developed a London-based training programme for women living with HIV to train as Mentor Mothers to provide peer support to other women in London.

In 2016, Angelina and Salamander Trust acquired funding to expand the programme to make it UK-wide. The 4M Programme, ‘My Health, My Choice, My Child, My Life’, is an innovative peer-led project training women living with HIV across the UK to provide their peers with psychosocial support in their pregnancy journey and beyond. As a result of this work, 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.

Since then, 4M has developed into a UK-wide and international community network of women living with HIV. Through establishing safe community spaces and grassroots ownership, 4M specifically addresses the challenges women living with HIV experience as they navigate the perinatal journey. It continues to grow organically in varied ways.

In 2019, we secured funding from the mental health charity, MIND, to include a specific focus on perinatal mental health support through the 4M for Mental Health project (4M4MH). We also registered the 4M Mentor Mothers Network as a Community Interest Company (4MNet CIC), with Angelina Namiba, Longret Kwardem and Rebecca Mbewe as the CIC’s Directors, and an advisory steering group which includes Mentor Mothers, clinicians, academics and researchers.

### Part 2: A timeline: From Pregnancy to Baby and Beyond to 4M Mentor Mothers Network CIC

(For details, refer to the Annex, ‘A year by year account of our work’, later in this document)

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012-2015</td>
<td>Angelina, based at Positively UK, develops London-based programme From Pregnancy to Baby and Beyond, with a multi-disciplinary Steering Group training women as Mentor Mothers.</td>
</tr>
<tr>
<td>2016</td>
<td>The UK-wide 4M programme starts under Salamander Trust, with Mentor Mother training workshops across the UK in partnership with HIV organisations, and a slightly revised Steering Group.</td>
</tr>
<tr>
<td>2017</td>
<td>4M goes international (4M+), delivering workshops with PIPE Trust (Kenya) and Uganda Network of Young People living with HIV (UNYPA).</td>
</tr>
<tr>
<td>2018</td>
<td>4M and 4M+ Advocacy briefs launched. 4M and 4M+ present joint panel at AIDS2018; regular UK supervision/support sessions with MMs start; webinars start; talks across the UK start; BHIVA conference community research award; 4M holds a UK national Training of Trainers (ToT) workshop for Mentor Mothers in October; launches the 4M WhatsApp group for Mentor Mothers for mutual support (4MNet); and presents its work in posters at the British HIV Association Conference (winning a commendation) and the European AIDS Clinical Society Conference.</td>
</tr>
<tr>
<td>2019</td>
<td>4MNet CIC registered with UK Companies House; new webinars produced; 4M Mentor Mothers ToT manual; 4M4MH perinatal mental health project conducted, producing a mental health annex to the ToT manual and a concertina leaflet with contact details for mental health resources and organisations; poster presented at AIDS IMPACT Conference on our participatory evaluation of WhatsApp for digital peer support.</td>
</tr>
<tr>
<td>2020</td>
<td>4MNet CIC bank account opened; 4MNet CIC receives first grant in its own right for ‘4M on Fire’ work to respond to Covid-19; 4MNet receives first grant in its own right for ‘4M on Fire’ work to respond to Covid-19; Annex to manual on mental health developed; peer reviewed article on perinatal digital peer support published in AIDS Care Journal.</td>
</tr>
</tbody>
</table>
Part 3:
Our current priorities

Supporting Mentor Mothers’ priority needs during COVID-19

Virtual social connections and peer support

- Providing platforms for Mentor Mothers to meet virtually, increase our mental well-being, and share experiences of COVID-19 from our different locations including positive news, encouragement, support service information, self-care tips.
- Regular one-to-one check-ins to see how people are getting on and where they may need support.
- Regular updates on staying healthy during the COVID-19 pandemic.
- Filtering information shared to ensure it is relevant, useful and limits negative information.

Research

- Collection of evidence about how COVID-19 is affecting us and impacting on our sexual and reproductive health and rights, including evidence from our lived experiences.

Expanding our reach

- Reaching out to women living in rural areas to provide them with a safe space (even a virtual one) where they can access support and tools.
- Ensuring all clinics in rural areas are aware of the Mentor Mother service and can refer to a peer led support pathway.
- Working towards this model to be available and accessible to women of all ages (shaped to their unique needs i.e. pregnancy journey, accessing healthcare or the menopause).
- Raising awareness of GPs so they have knowledge of this care pathway.
- Translation of 4M materials into other languages to be accessible to more women.
Our next steps include the consolidation and development of our network, our CIC, and our reach. Depending on the funding we are able to obtain, our ideas for the future development of 4MNet CIC include the following:

**Raise awareness and advocate**
- Work to increase HIV awareness and knowledge amongst health care providers, police, social services, and other service providers, especially about U=U (Undetectable=Untransmittable).
- Establish links with organisations that support women through the birthing process.
- Carry out social justice advocacy for equality in access to medication, education and housing.

**Address violence against women**
- Organise seminars and workshops to empower women to create safe spaces for dialogue about violence and to seek help.
- Use case work for discussions and education on how violence manifests in women’s lives, their rights, forms of redress and where they can seek support.

**Use our creativity**
- Have more creative spaces for Mentor Mothers.
- Enable creation of a calendar with 4M women to raise funds for further workshops and meetings.

**Increase training and facilitation skills-building**
- Run the 4M Mentor Mothers training course more regularly (ideally every 3 months). Where appropriate, extend it to cover more than two days.
- Given constraints related to COVID-19 and on-going funding challenges, organise workshops for Mentor Mothers in delivering virtual training and online facilitation skills.
- Where possible given COVID-19 restrictions, actively involve 4M ToT-trained Mentor Mothers in facilitating workshops in their local areas.
- Pair less experienced Mentor Mothers with more experienced ones.

**Expand our scope and reach out to more women**
- Increase national and international networking and have a wider reach with more Mentor Mothers trained and membership expanded.
- Improve links for Mentor Mothers with clinics and mentees.
- Collect different Mentor Mother peer support models from around the country for shared learning.
- Increase 4M’s profile and representation at events and conferences, and organise an open day.

**More peer research**
- Continue to provide a platform for peer research, collect best practice and work collaboratively, with opportunities for wider involvement in writing, reviewing and publishing articles.

**Develop our digital capacity**
- Increase Mentor Mother access to digital platforms and IT, including through subscriptions to communications platforms and one-to-one IT and social media support for Mentor Mothers.

**Professional development and support for Mentor Mothers**
- Where possible, provide more face-to-face group peer support, skills sharing and resilience-building meetings for Mentor Mothers, where we can catch up with and learn from each other.
• Keep Mentor Mothers informed about opportunities including placements and job links.
• Source paid work for Mentor Mothers, and pay Mentor Mothers to support the 4M messages.
• Provide Mentor Mothers with continuous support and guidance.

• Increase support for conference applications for Mentor Mothers.
• Increase one-to-one support for Mentor Mothers.

"There is breath, pain, moments of sleep – so deep -
waking to the urge to push
the cycle repeats over and over again
culminating
Birthing is imminent
That opened my eyes wide
into the gaze of my sister
I’m broken open
I am now the we; Mother & Child
That makes me whole”

Story written by Janine
Our current priorities and plans for next steps are based on our experiences so far, and are intended to build on our successes and address some of the challenges we have faced. In this section, we share 4M’s many successes, which have been achieved thanks to our women-centred, holistic and trauma-informed principles, our collective organising, our peer-led approach, and a considerable amount of passion and dedication on the part of the core team, Mentor Mothers, and advisory steering group.

**Strong peer-led governance and guidance**
- Led by Black African migrant women living with HIV, run in full collaboration with Mentor Mothers, and guided by a multidisciplinary steering group of some of the UK’s leading experts in perinatal care and HIV, including Mentor Mothers living with HIV, obstetricians, HIV clinicians, academic and peer researchers.

**Strong principles**
- Innovative, ethical, gendered, rights-based, women-centred, grassroots, holistic, collaborative, progressive and trauma-informed.
- Rooted in the WHO 2017 Consolidated Guideline on Sexual and Reproductive Health and Rights of women living with HIV.

**Strong relationships of trust**
- Created, led and run by us as peers who share experiences, which offers Mentor Mothers and the women they mentor a level of trust and confidence in 4M that is hard to match.
- A collectively formed, consistent group since October 2017 has meant sustainable and lasting connections within the network.
- Trusting relationships between the project team and Mentor Mothers, working in partnership to agree suitable ways of working that are unique to each Mentor Mother, so that each may receive and provide peer support in the most convenient and effective way.

**Peer support for the supporters (Mentor Mothers)**
- Well-being support through regular one-to-one supervisions from the project team. Mentor Mothers share personal or mentoring issues and the project team works with them to resolve those.
- Being peers, the project team understands that sometimes Mentor Mothers may need time off and the team is flexible enough to adjust, so that Mentor Mothers can focus on themselves when required, while still receiving support from the network.
- 4MNet and Mentor Mothers have established a wide range of networks. Some Mentor Mothers are linked to HIV clinics and others volunteer independently, to provide perinatal peer support for women in their local areas.
- Mentor Mothers receive peer support through the 4MNet WhatsApp group, which enables them to both receive peer support for themselves and offer it to one another. It helps them to feel supported enough to provide peer support to their mentees.
- The project team also receive peer support from the project coordinator who, in turn, receives support from a pro-bono psychologist. In addition, from July 2020 onwards, each project team member will receive her own pro-bono support from a psychologist.

**Working holistically/collaboratively with multiple partners for mutual learning**
- 4MNet are keen advocates of working collaboratively and holistically across multiple sectors eg training student midwives, developing guidance with the National HIV Nurses Association (NHIVNA), the British HIV Association (BHIVA).
- 4MNet creates awareness among multisectoral services to better understand and utilise Mentor Mother services and has made links with non-HIV-related organisations working with and
around pregnancy, women's health and women's rights. These include MumsNet, Doctors of the World, MIND, Inclusion Healthcare Brixton, Praxis, Refugee Action, Refugee Council, Right to Remain, Agenda Alliance for women and girls at risk, Take her Hand, Birth Companions, Maternity Action, City of Sanctuary, Survivor's Voices, Women for Refugee Women, Southall Black Sisters, Greater Manchester Women’s Support Alliance and Women in Prison.

- 4M For Mental Health (4M4MH) perinatal mental health workshops were held at Positive East London, George House Trust Manchester, Brunswick House Hull, Hillingdon AIDS Response Trust (HART), Africa Advocacy Foundation (AAF) London, NAZ London. We have run some groups face-to-face in partnership with local HIV organisations. Talks on the subject were given at the British HIV Association (BHIVA) Annual Conference, National HIV Nurses Association Annual Conference, UK Community Advisory Board (UKCAB) Quarterly Meeting and the STOPAIDS Annual Members Meeting.

Peer and collaborative research

- 4MNet promotes peer research and active involvement of women living with HIV as equal partners. It has engaged in collaborative participatory research with University College London (UCL), London School of Hygiene and Tropical Medicine (LSHTM) and University of Northumbria with abstracts presented at conferences such as: European AIDS Conference Society October 2017; Boston International Conference 2018; BHIVA spring conference 2017 (highly commended poster) and 2018 (community award for best community research); International AIDS Society July 2018 Global Village: The HIV Howler Transmitting Art and Activism Newspaper; AIDS Impact Conference 2019 (details on the Salamander Trust website⁴). Longret Kwardem has been invited to make a presentation about 4M at the International AIDS Conference in July 2020 (AIDS 2020).

Preparation for a workshop about 4M and mentor mothers at George House Trust in Manchester, 2019

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⁴https://salamandertrust.net/project/4m-health-choice-child-life-perinatal-peer-mentoring-project-women-living-hiv/ [online] Available at: [Accessed 20 May 2020].
Education and sharing our experiences

- 4MNet runs a webinar series, and now has 12 on issues identified by the 4MNet members. Topics include the BHIVA guidelines; immigration; quality of life; talking to others about HIV; perinatal mental health; HIV trauma-informed care; living with HIV, sexual and reproductive health and rights and violence against women; and women; HIV and the menopause. They are recorded and available to access freely from our dedicated vimeo platform5.
- 4MNet improves knowledge and confidence of Mentor Mothers through training and networking to provide quality perinatal support to mentees.

Leadership/practical mentoring

- 4MNet members have opportunities to be involved in giving presentations about 4M, co-facilitating workshops, attending learning events, presenting in webinars, and contributing to development of 4M resources. Mentor Mothers report feeling empowered to be involved within the HIV community, and increased confidence in pursuing other activities outside the HIV sector, as a direct result of the training and engagement with 4M: a testimony to 4M’s role in developing their leadership skills.
- The project team also supports the Mentor Mothers with mentoring on practical skills like preparing for public speaking at conferences, job applications, developing presentations, encouragement to get involved with more activities for their well-being and other forms of support in their local areas, unique to each woman. 4M mentors Mentor Mothers with practical skills for their well-being, unique to each woman. Although some issues women face may not directly relate to HIV, they affect their ability to manage and live well with HIV6.

Organisational working systems/Communication platforms

- 4MNet communicates and provides support using a variety of platforms including telephone, Skype, Zoom, WhatsApp and/or mobile phone text. We recognise that not all women have access to internet or IT and that they have varied needs and different levels of digital and other literacy, English language skills etc. Therefore women are sometimes seen face-to-face.
- 4MNet has an active twitter account and our activities are also posted on The Salamander Trust Facebook page and website, with our supporters and allies tagged and encouraged to share. Webinars, websites and social media are wide reaching. Our active 4MNet WhatsApp group uses include: information sharing and updates; mutual support; announcements about job opportunities events, meetings and opportunities to join advisory boards and steering groups; upcoming webinars and sharing recorded webinars; sharing achievements; requests for information to inform individual presentations.
- 4MNet CIC is in the process of developing its brand-new website.

Training the trainers

- Publication of the 4M Mentor Mothers Training of Trainers Manual in 2019 to train other women living with HIV to become Mentor Mothers. This was described by Professor Chloe Orkin, immediate past Chair of the British HIV Association, as ‘world class’. It has also been endorsed by leading UK charities and 4M Mentor Mothers themselves and is being accessed globally.

Advocacy

- 4MNet has been pivotal in influencing leadership by producing statements, taking up speaking and oral and poster presentation opportunities at conferences and All-Party Parliamentary Group (APPGs) meetings in Westminster.
- 4MNet members joined SWIFT (Supporting Women with HIV Information Network). This is a UK and Ireland Knowledge Network, bringing together healthcare providers, researchers, activists and advocates interested in research on HIV and women. 4 members of 4MNet (2

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Rebecca introducing the Mayor of London at the Fast Track Cities launch, 2019

Longret and Angelina representing 4M at the National HIV Nurses’ Association, 2019.
Mentor Mothers, the Peer Research Manager and the Project Manager) chaired sessions at the SWIFT Symposium on living well with HIV and getting involved in research, in September 2018. One Mentor Mother and two members of the project team are members of SWIFT’s Steering Group.

- Development of an Advocacy Brief with the Mentor Mothers in 2018 which included some ‘asks’.

**Respect for diversity**

- The 4M programme considers the different needs and priorities of women living with HIV in all our diversity and all are welcome. All experiences of women living with HIV are respected. We tailor our work and training to the priorities of the service users and their circumstances, for example delivery within an already established support group, availability of space, and literacy and levels of understanding of attendees.

**Importance of language**

- We are passionate about language. Language influences how we feel, think, act and react. We use and advocate the use of positive, affirming, solution-focused, forward-thinking language, which builds on the active agency of those involved. Our Project Team lead co-authored a policy brief on the importance of “the language of HIV” for the National HIV Nurses Association and talks on the topic regularly at conferences and other venues. 4MNet’s solution-focused approach validates experiences and uses positive language and approaches to enable agency and proactiveness among the members.

**Peer led and participatory mixed methods monitoring and evaluation approach**

- 4MNet is a completely participatory, peer-led initiative. As the UNAIDS-commissioned ALIV[H]E framework explains, a participatory approach means that those most affected by an issue are meaningfully involved in designing, implementing, monitoring and evaluating the initiative designed to address it. A participatory approach hands the power over from an academic researcher researching ‘on’ or ‘in’ women, to research instead ‘with’ women participants, who are often community members.

**Membership expansion**

- 4MNet has increased membership from 18 to 34 (28 in the UK, 6 in East Africa). With additional funding and capacity we could expand this further.

**Influencing policy through our lived realities**

- The impact of 4MNet’s work on the sexual and reproductive rights of women living with HIV going through the pregnancy journey has been profound. The programme has shifted understanding of pregnancy from a largely biomedical disease-prevention event, focusing primarily on “PMTCT” or “eMTCT” (“prevention or elimination of mother-to-child-transmission”) to a largely psychosocial life-creating journey of perinatal care, respect and support, to uphold the sexual and reproductive health, well-being and rights of women living with HIV, in line with the WHO 2017 Consolidated Guideline on this issue.

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8 https://www.nhivna.org/NHIVNA-Best-Practice

Part 6: Our challenges

We have of course faced challenges including personal, professional and collective challenges, and barriers arising from structural and systemic inequality:

- Personal and professional challenges and responsibilities sometimes prevent the Mentor Mothers from being as involved as they would like.
- Providing peer support can affect / trigger personal issues. However, involvement is also reported as a coping mechanism / support system.
- Over-involvement is also a challenge for some. Ongoing supervision enables women to talk through the different issues.
- Our aim is for Mentor Mothers to be integrated within clinic multi-disciplinary teams (MDT) but we have faced challenges and obstacles with this.
- There is a challenge around awareness of the Mentor Mother service and referral pathways within other community and social services.
- Much of our existing 4M work is done on a voluntary basis; this can lead to exhaustion, lack of capacity and burn-out.
- As migrant women living with HIV ourselves, we feel a close connection with the Mentor Mothers we work with. We know that this work takes huge time and effort, including a lot of volunteer time, to build trust and confidence between us as a group. This is a long-term process to build ethical, effective, and sustainable change.
- Funding for our work, as indeed for any grass-roots women’s rights-based organisation, is extremely hard to source. We are currently looking at new potential funding sources, which is challenging.
- The project team all work as part-time self-employed consultants to the project. 4M work takes a significant amount of our unpaid time and effort. Although we feel positive about our progress to date, being self-employed, we find ourselves having to compensate with other work.
- There is no core funding for the programme. A lot of unpaid time is dedicated to writing funding proposals and fulfilling funders’ reporting obligations.
- As Mentor Mothers become more confident and get other jobs (because we can’t afford to pay them), they have less time to volunteer their time supporting pregnant women
- Whilst it is a great success that MMs gain the confidence to seek employment opportunities elsewhere, this can also be a challenge. Because we are not able to provide paid opportunities, we as a network lose out on their valuable expertise. A possible solution would be to collaborate with other organisations that have the capacity to have Mentor Mothers ‘placed’ within their organisations so women can have the flexibility to work and earn in their role as Mentor Mothers.
- We have registered the CIC and are its directors. We have received our first funding award as a fully independent entity. There is still a lot of organisational structural set-up required, which needs funding. This is a huge challenge, as the recent Salamander funding brief describes.

Ideally we want to be training new Mentor Mothers who can take the place of current Mentor Mothers as they move on or develop, whilst also advocating for more funding within the sector to grow the movement sideways. This means that 4M need not necessarily expand, but that other projects develop, as a “mushrooming effect”.
Part 7:
Help us build our movement

We invite you to help us build our movement!

Volunteer

- We are seeking a volunteer treasurer to join our board of directors to support 4M Net with its accounting and compliance. Please do get in touch if you know of anyone who might have the right skill set and a couple of hours a week available.

Funding

- We warmly welcome any suggestions of new funding streams to support us – particularly flexible, long-term, unrestricted and core funding that is based on trust relationships.

Collaborations

- We want to increase working collaboratively with HIV organisations and organisations addressing housing justice, mental health, domestic violence, etc, to meet the increasing intersectional and multidimensional needs women have. Get in touch with us if you would like to explore collaborations.

How else can you support us?

If you are a healthcare provider: if you would like to connect with trained 4M Mentor Mothers near you, please contact us at the email below, for learning and knowledge exchange.

If you are a voluntary organisation: you can contact us at the email below to explore a collaboration with us, find out who is trained in your area, or to organise a training of more 4M Mentor Mothers.

If you advertise paid jobs in HIV, health, women’s rights or covering other relevant themes in the voluntary and community sector: please add us to your circulation lists so we can share job adverts with Mentor Mothers. Or if you can offer a paid internship or placement to a Mentor Mother, please contact us.

If you are a researcher: contact us for collaborative participatory research.

If you are a donor: we welcome your partnership and support at the email below.

If you are a woman living with HIV who has had a baby: do contact us about possible training opportunities, as well as how to join the 4MNetwork.

If you would like to be kept in touch about our progress: we can put you on an email list for further updates.

If you are passionate about the sexual and reproductive health and rights of women living with HIV, follow us on social media and share our work.

Twitter: @SalamanderTrust; @4Mproject
Facebook: Salamander Trust; 4M Mentor Mothers Network CIC

4MNet CIC is keen to hear from women and organisations across the globe who might want to develop something similar to our model. The training manual is available freely to download.
Part 8:
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; Longret Kwardem; Rebecca Mbewe; Angelina Namiba; Shema Tariq; Pat Tookey; Alice Welbourn; and Alison Wright.

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4M Mentor Mothers Programme Team:

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• With MAC AIDS FUND funding and in partnership with key HIV organisations, 46 women living with HIV in eight UK regions were trained to be Mentor Mothers (MMs).

• The two-day peer-led Mentor Mother training package ‘The Pregnancy journey and Beyond’ comprised coaching on clinical/psychosocial aspects of pregnancy and HIV and creative writing workshops. These diverse components were to encourage trainee reflection on their own pregnancy journey and also help them develop the skills to support other women in each of the 4M components – My health, My choice, My child, My life.

“Personally, the training gave me more courage to be able to speak about my story and secondly it gave me the courage to help another person. I didn’t feel like I was confident enough to help another person who is in the same situation as me but after the training I felt empowered, you know. I had the courage to face the people and I feel like I had the tools - not exactly everything, but at least I felt more confident to talk to someone else and tell them a piece of advice or just talk, you know have a chat with someone who’s going through the same situation. So I felt like I’ve been really empowered and ready to go to the next step.” (MM, training workshop)

Immediate post training¹, 6 months post-training² and one-year post-training evaluations³ found that for most women it had exceeded...
expectations and was empowering on an individual and community level. Women valued the medical information, and were using the creative writing techniques to support them in their mentoring.

“The training had a huge positive impact on me. I feel more courageous and confident to talk about my experience and to support other mothers and women in the same kind of situations. I have mentored one expectant mother and one with children, so two in total so far. I am ready and happy to do more.” (MM 6 months post-training)

“I have found that writing really helps to relax me when am stressed and mentoring a challenging person the creative writing and relaxation tips have been really helpful.” (MM 1 year post-training)

• MMs also identified barriers to providing peer-support, including their own personal and social circumstances; health issues; being a migrant, language, literacy, culture, social isolation, stigma and inadequate links with local HIV clinics and support services.

“It has made me more aware of what pregnant HIV positive women go through. I have not yet been able to support anyone as I feel I am not ready yet, but my time will come when I can do that.” (MM 6 months post-training)

“Yes, the training has helped me consolidate my understanding of guidelines and how they push us into a one size fits all which doesn’t fit our realities.” (MM 6 months post-training)

The 4M network of trained Mentor Mothers is a valuable resource available to complement the clinical care and management of HIV and pregnancy in the UK.
“I don’t remember walking home after I received my HIV diagnosis. But I do remember my mum, how she looked at me and how soft her lap felt as I lay my head there. That love, the acceptance and realisation that I was still her daughter, regardless of this little virus in my blood, gave me to strength to know that, three months pregnant at the age of 23, everything was going to be fine.

My mum had a plan. She told my dad who told the pastor who then prayed for my long life. This further made me believe that I was going to be fine. I was lucky then, and I still am, to have family, friends and a community that loves and supports me. People have tried to stigmatise me but with this foundation I keep standing. I have gone on to have two beautiful children, 15 years and 8 years old. I have mentored countless mothers, won an Inspirational Person of the year award and I am a trustworthy member of my community; all thanks to this love and support.” 

Patricia, Mentor Mother

- In 2017, with Viiv Healthcare funding, 14 Mentor Mothers from across the UK attended a Training of Trainers (ToT) residential weekend in Manchester to build their capacity to be recognised as qualified trainers and to enable them to deliver the Pregnancy Journey training to their peers.

- The training was peer-led by 6 trainers and included group facilitation skills; linking peer mentoring to the National Standards of Peer Support; creative writing; understanding and conceptualising sexual and reproductive health and rights: and an introduction to monitoring and evaluation.

“So much experience and knowledge gained beyond the boundaries of the facilitated sessions. The worth and beauty of this training is the connections made.” (MM ToT training)

“People don’t realise how strong we are and we underestimate how strong we are. Even though we are vulnerable, we are still strong and when we have our own space like today, I think it’s beautiful. I feel connected to everyone. I had goose bumps and said we actually need this because out there we don’t have that.” (MM ToT training)

- Participants practised facilitation skills in pairs throughout and were assessed by at least 2 trainers to determine their skills, confidence, capacity to deliver a workshop independently, and whether they needed further support. Results indicated that most of the women were ready to run an introductory workshop with a co-facilitator.

- Workshop participants reported that getting together with peers over three days in a safe space enabled the sharing of experiences and creation of a community which generated feelings of normalisation:

“The passion and love in this room is amazing, it made me feel normal, be myself. It is amazing what words can do, it brought a lot of emotions, It is something I am going to do to let my emotions out in writing.” (MM ToT training)

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• One outcome of the residential training was that the women decided they needed an ongoing safe space to connect; this resulted in the formation of the 4MNetwork. The chosen communication platform was WhatsApp as they felt it was and accessible and economical way to keep the safe space, trusting relationship, connection and bond formed during the residential training weekend.

“I thought the focus on the practicalities, practising facilitation skills, was really a very good idea. It made it clear that we are capable with support, more than we might think. Very much enjoyed the opportunities to relax from absorbing information with creative writing. Emphasis on expressing self. I enjoyed group sharing and even the moment of verbal conflict was able to be resolved with time to reflect and honouring the positivity of the group and the very great love and respect shared by all. Thank you.” (MM ToT training)

The Mentor Mothers continue to develop immensely both personally and professionally. A better awareness of the service provided by Mentor Mothers, and uptake by health and social care professionals working in collaboration with Mentor Mothers in their local areas as equal partners and an integral part of the MDT team that provides care and support for women will better address the psychosocial issues women face in their perinatal journey and better utilise the MM service.
In 2018, with funding from MAC AIDS Fund and ViiV Healthcare, the 4M Network was able to develop its activities, building on the bond created between the MMs at the 2017 residential training and consolidating the WhatsApp group. Topics for webinars were discussed in the Whatsapp group, and organised in partnership with other service providers and relevant experts.

The project team began to provide regular one-to-one peer supervision and support to Mentor Mothers, to enable them to continue supporting mentees in their local areas and work.

“4MNet training is full of ladies who celebrate their womanhood, have a zest for life and uplift each other.”

(MM 1-year post TOT)

– Qualitative evaluations were carried out 6 months and one year after the 2017 residential training to assess longer term outcomes of the workshop. Most Mentor Mothers reported feeling empowered by the 4M Network which provided peer support, improved confidence, information, knowledge exchange, personal/professional development, engagement in advocacy, taking control of services and a valued community.
“I have supported several women during their pregnancy and post birth as part of my role as a peer navigator working at Homerton hospital. Approximately twice a month I am able to attend the maternity clinic for HIV positive women, working alongside the midwife, this allows for a very complete picture of the developmental stages of a pregnancy and the concerns, decisions the pregnant woman has to make on her pregnancy journey.” (6 months post-TOT)

“It has been a Positive result for me as I can take control of my life and get involved at any level.” (MM 1 year post-TOT)

• However, some personal and structural challenges, including ongoing trauma and residence status, were found to limit the capacity of some Mentor Mothers.

“I haven’t been as active as I hoped I’d be due to work constraints. I have to do double shifts as my visa is about to run out. It has been hard to be involved in webinars, supervision or even just attending the workshops. The stress of not knowing where I’d get almost £10000 for visa renewal has affected not only my mentoring but also my family life. I wish things were different and I could do more the way I used to.” (MM 6 months post-ToT)

Personal, external, and structural challenges continue for Mentor Mothers, and they need ongoing support and supervision from 4MNet.

(c) 4M Mentor Mothers Net
With funding from MAC AIDS FUND, the 4M Network virtual platform was expanded and consolidated. 4M increased membership from 18, to 34. (5 MM from East Africa, 23 in the UK, 4 Project members and two trainers). Currently, 4M directly supports 34 volunteers across the UK and East Africa.

In July 2019, 4M Network CIC was registered as an independent UK community interested company. Although registered and thus independent, it still takes time for a new organisation to be fully functionally independent, owing to various challenges and hurdles. An awayday was held in November to chart a path for the new CIC and in the coming years we will be developing the structures and strengthening governance and other organisational priorities while continuing to provide support to the Mentor Mothers and keeping abreast with all the other activities 4M has been involved with. In October 2019 the 4M Mentor Mothers training of trainers manual was e-published to enable the training of more Mentor Mothers, both in the UK and across the globe.

"The 4M training the trainers manual is a rich resource which will enable women with HIV who are interested in peer support to build up their confidence and skills as well increase the capacity of other women through becoming trainers. Peer support, sharing our lived experiences to encourage mutual learning and growth, is very effective in overcoming challenges such as receiving an HIV diagnosis during pregnancy. The 4M manual will make it easier to have a structured approach to peer support, which is fun, supportive, safe and respectful." (Silvia Petretti, CEO, Positively UK.)

With funding from MIND, a mental health charity, the project, ‘4M for Mental Health’ was developed. 4M+MH was designed to promote perinatal mental health awareness in HIV, and to explicitly address mental health alongside the psychosocial and medical issues addressed so far. Through peer support already provided by Mentor Mothers, and by working with them to provide additional peer support, a total of 116 women living with HIV across the UK now know more about mental health issues related to HIV and pregnancy, and the support available. These women living with HIV have had opportunities to connect with their peers in safe spaces, explore mental health issues, understand they are not alone, and experience improved mental health. 11 women who are 4MNet members have developed leadership skills and abilities to improve their own and their peers’ mental health.

“I personally feel there is space for mental health specific/focused work in HIV pregnancy for the women I provide support for, because most women seem to be handling a lot in this period of time as most of them will have not long had their diagnosis. So dealing with the diagnosis, the pregnancy journey, the anxiety that comes with it, the uncertainties, relationship breakdown, domestic violence among others is always overwhelming for them. Most women seem to need lots of mental health support during this period.” (MM MIND funding application rapid survey 2018)

4M delivered talks and perinatal mental health workshops with women’s rights and health organisations so that they can better understand and address perinatal mental health and HIV.

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5 All volunteers are trained MMs and 14 have been through the Training of Trainers workshop. The East African MMs were trained in 2017 by Angelina, Ellen Bajenja and Nell Osborne in Kenya and Uganda, through partners PIPE Trust in Kenya and the Uganda Network of Young People living with HIV in Uganda. This “4M+” training was funded by MAC AIDS FUND (See previous 4M advocacy brief and information on 4M+ on Salamander Trust website.


• 4M developed three new resources: a webinar on mental health during pregnancy and in the context of HIV⁹; a concertina contact information leaflet of mental health resource agencies¹⁰; and a perinatal mental health and HIV annex link to the 4M Mentor Mother Training Manual.

“The benefits of being involved with 4M4MH is meeting people working in the mental health field who have helped me understand the complexities of mental health and implementation of interventions that have been proven to work.” (MM 4M4MH)

• We conducted a qualitative evaluation of the use of digital technology by the 4MNet Network with a PhD student from the University of Northumbria¹¹. This research found that Mentor Mothers primarily viewed the 4M Network as a professional community: a place for members to pursue the aims and goals of 4M by supporting each other and sharing personal and group achievements. Feelings of trust, respect, and community were established through an in-person group decision to use WhatsApp, and communal drafting of, and adherence to, group etiquette. Mentor Mothers found comfort participating in a national, accessible, and familiar forum, characterised by communal kindness and acceptance. Discussions often elicited positive feedback and empathy, providing support, and building community.

“There are other... HIV support groups that I belong to... but it’s not the same at all. There you get a lot of ‘oh I have blessings for you’ and ‘these pictures’ and a lot of, I don’t want to say it’s rubbish but, you know, but it’s wasting my time to look at that. And I don’t know how they managed it with 4M, but no one does that; they managed to create some kind of magical boundary that no one wastes—nothing there is wasteful. I’ll get home and have a look and it will be like 84 messages and I’ll think ‘oh I can’t bother’, but if there’s two on 4M I will look because it’s like ‘oh what’s happening?’ You know, if there’s something then it’s going to be worthwhile.” (MM digital research participant)

“Within the staff team we use WhatsApp to manage the project and communicate about stuff, do our work plans, meetings basically. Does that make sense? We use it as a team tool.” (Project team digital research participant)

• Despite some concerns, WhatsApp enabled Mentor Mothers to build a community and share knowledge. Our research was presented as a poster at the 2019 AIDS IMPACT Conference¹⁶, and has now been published as a peer reviewed article in the AIDS Care Journal¹².

Peer-led digital communication is acceptable and effective for women living with HIV. Understanding the barriers and valued features of these platforms among potentially marginalised groups is vital for informing responsible and inclusive innovation.¹¹

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• In May 2020 4MNet CIC was granted a year’s funding, the first in its own right, by MAC AIDS FUND. It will start in August 2020 and support our response to COVID-19. In this current crisis we expect to see increased chronic domestic violence and mental health problems amongst the MMs and mentees. There may be an increase in the number of women living with HIV becoming pregnant, due to women’s desire to have a baby (a common post-crisis response), or because of lack of access to contraceptives (already reported before COVID-19, and likely to increase because of global supply chain challenges), or because of lack of access to abortion as a consequence of COVID-19 lockdown. The 4MNet project team will continue to monitor these possible developments with MMs. From zoom discussions and a rapid survey with MMs, isolation is the main issue now faced by MMs and the women they support, and MMs report that mentees have high levels of anxiety during this time.

“How 4M can support the group: Keep up the updates on staying healthy during the COVID pandemic, live interactive discussions are invaluable for sharing and support, checking on each other, and tapping into individual resources.”

(MM rapid survey April 2020)

• 4MNet members have a strong track record of mutual trust which is invaluable during these extraordinary times. We are already comfortable using virtual IT for core teamwork and regular contact with the MMs. We aim to continue 1-1 supervision with the MMs and virtual drop-in sessions. We will provide accurate and up-to-date information about COVID-19 in the context of HIV, and especially during perinatal care, from trusted websites such as BHIVA, the Royal College of Obstetricians and Gynaecologists, and WHO, as well as continuing to update the emergencies contact list we have produced.