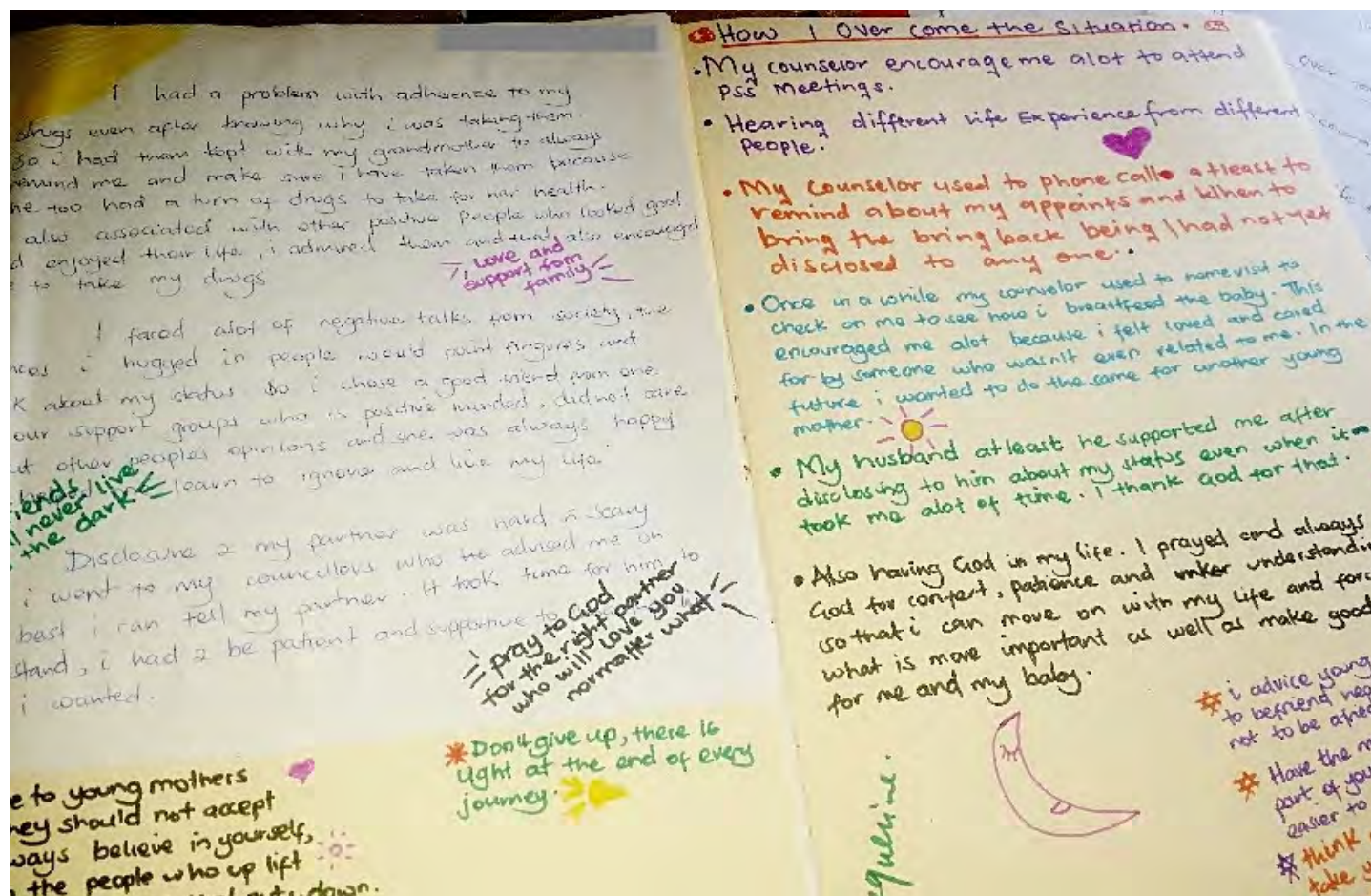


4M+: PERINATAL PEER MENTORING PROGRAMME FOR WOMEN LIVING WITH HIV

4M STANDS FOR MY HEALTH, MY CHOICE, MY CHILD, MY LIFE

Advocacy Brief about the 4M+ Programme



Handmade book filled with personal advice and coping strategies

BACKGROUND

During 2017, Salamander Trust, in collaboration with PIPE Kenya and UNYPA Uganda, implemented a Perinatal Peer Mentoring programme with young women living with HIV, with funding from the MAC AIDS Foundation.

The programme aimed to empower young women with knowledge on safe motherhood and HIV, primarily to uphold the young women's own sexual and

reproductive health and rights and, in so doing, to reduce chances of vertical transmission. The programme also focused on skilling the young mothers to support their peers in similar ways through their pregnancy journeys. The programme provides safe spaces for women to share, connect and support each other.

The 4M+ programme was led by Salamander Trust Associate Angelina Namiba, who has herself gone through the pregnancy journey whilst living with HIV. She originally created this programme in the UK with Positively UK in London, where it was called the “From Pregnancy to Baby and Beyond” programme. With Salamander Trust, the programme was then renamed 4M and has spread to centres across the UK.

The 4M+ programme, in Kenya and Uganda, has grown out of these grassroots, peer-led experiences, based on existing community knowledge and resilience. As such, it offers a peer-led grassroots model for peer mentoring as an alternative to other, more top-down models.

The training in Kenya and Uganda brought together 65 young mothers, aged between 17-49 years from Nairobi and Nakuru in Kenya and Kampala and Wakiso in Uganda.

Twenty four of these mothers were below 24 years. The training built a team of ‘Mentor Mothers’ who voluntarily supported their peers in the community and health facilities. The training lasted 3 days in each of the 4 locations. It was highly interactive and covered several topics, including pre-conception planning, antenatal and post-natal care, safe motherhood, creative visioning, writing and drawing, bookmaking and decision-making, amongst others. Each participant was also trained to make her own book to take home with her. This consisted of the creative drawings, charts and writing, full of emotions, ideas and plans, which she produced throughout the workshop stages.

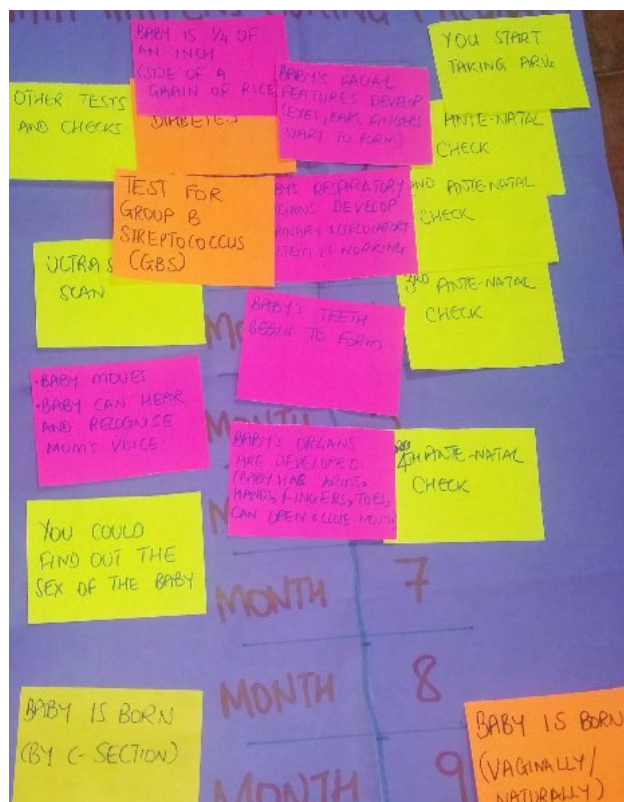
Input from in-country healthcare professionals throughout the different project planning, development and delivery stages was also most valuable. National PMTCT Program Manager, Dr Rose Wafula from Kenya, and Senior Paediatric and Adolescent Health



Angelina (Salamander Trust), Brenda (PIPE), Ellen (Salamander Trust), Valerie (PIPE) and Nell (Salamander Trust), Nairobi workshop

Specialist, Dr Sabrina Kitaka from Uganda, were programme Steering Group members, and both provided technical advice to the programme, in particular around country perinatal care ('PMTCT') guidelines. We also asked them to deliver the workshops' guidelines section. A representative from the Kenyan clinician's office came on the last Nairobi training day. Dr Kitaka delivered the guidelines session to one training session also.⁽¹⁾

Twelve of the young women who attended were pregnant and others had babies. We invited women to come with their babies. This was very important. In one workshop, we had one toddler and six breastfeeding babies, all aged under 1 month.



Participants discuss and chart what happens during pregnancy

SUCCESSES

Safe spaces: Throughout the training, the programme established safe spaces for participants to share their challenges and aspirations without fear of stigma and prejudice. This is a critical need for young people living with HIV in general and, more specifically, young women who are mothers, since stigma is still common in both countries. Consequently, some of the participants who had earlier refused to disclose their status felt comfortable to do so for the first time.

Realising rights: The programme was able to introduce unique and practical approaches. For instance, the creative visioning exercise for the pregnancy journey has enabled the participants to understand the kind of support that can, and should be offered to pregnant women at each stage of her journey, at community level or in the health facilities.

Making connections: The programme has facilitated access by young mothers to information and other related health services, including

Through the counselling sessions Mentor Mothers have contributed to the marked improvement in terms of mothers' adherence to taking medications and also honoring the clinic appointments as scheduled.

Health worker from a health facility in Nairobi

(1) The workshops were facilitated by Angelina Namiba, together with Salamander Associates Ellen Bajenja and Nell Osborne, with valued support from Betty Ogolla, Valerie Musavi, Brenda Nyambura and Christine Omas of PIPE in Kenya and Resty Nawalga, Jacqueline Alesi and Sharifah Nalugo of UNYPA in Uganda.



Above and below: Creative visioning of the type of support that can or should be available for pregnant women living with HIV in the home, community and health facility

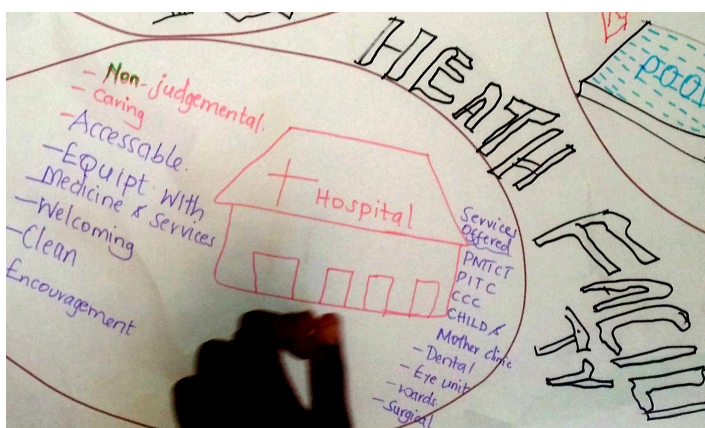
referrals and support groups for women who had not connected with other women living with HIV. Most of the young women supported were having their first baby.

Engaging men: Participants were able to discuss, more broadly, some of the challenges associated with achieving safe motherhood. For instance, in all the workshops they discussed the involvement of men as a critical issue. Participants in Kenya described male involvement in safe motherhood as the need for men to support women through the pregnancy journey, to avoid vertical transmission and to support the wellbeing of the woman and her child. They noted that effective male involvement requires advocating

for partner testing at the health facilities, sensitizing men about the importance of their involvement in HIV prevention and encouraging male-friendly programmes.

Linkages: The programme built links between the health facilities and the community. For instance, some of the trained 'Mentor Mothers' were posted to specific health facilities, where they provided voluntary counselling for young mothers who tested positive. They supported the young women by sharing their personal journeys. They referred women from the community to the health facilities, for services; and vice versa, from facility to community, for support groups and to connect with other women living with HIV. The health workers acknowledge the contribution the 'Mentor Mothers' are making in supporting their work in the health facilities.

Building advocacy skills: The programme strengthened the 'Mentor Mothers' confidence to challenge stigma and discrimination in their community and within health facilities. One testimony from Uganda revealed



that a 'Mentor Mother' attached to one of the health facilities challenged nurses who were found to have neglected a young adolescent mother during labour.

Mutual support and growth:

Additionally, the project facilitated linkages among the 'Mentor Mothers', which has enabled them to continue linking and learning from one another, share experiences and seek guidance during their work. One example is a Mentor Mothers WhatsApp group, which they created following the training in Nairobi. This has provided a platform for sustaining communication and interactions among the Mentor Mothers about various updates and opportunities, as well as sharing challenges and happy times.

Given that we are overwhelmed by the number of mothers (we receive about 20 mothers on average every day of the week) the Mentor Mothers are playing a very vital role in conducting the health education sessions and guiding the mothers. They are particularly helpful for young mothers who look at them as their peers.....we are increasingly getting more young adolescent mothers coming to the clinics and also the support groups.....at least 30% are young mothers below 25 years.....these Mentor Mothers have helped in keeping the mothers in general busy as they wait for their turn to visit the doctor for examination. They also are involved in guiding them when they test positive and they share their own experiences which encourages the mothers living with HIV to take their medicine.

Health worker from Namugongo Trust Fund, Wakiso District, Uganda

I had a former school mate who was in form 2. We were not very close since I was older than her and in form 4. I rarely interacted with her. Time came when I was conducting a mentor peer group meeting at school, when the session ended she followed me to my class and she said she had something important to discuss with me. I walked with her to the school field and started the talk. She told me that she was raped by her uncle who infected her with the HIV virus. Since then her parents treated her differently. When her siblings went to school she was forced to stay at home and asked to go look for a job to work. She finally got a job as a house help, there she was also abused by her employer's husband. The day she was raped she lost her job and since then she had never had a place to call home. Her parents chased her saying she had failed to maintain her job. She was forced to sleep on the streets for some time and she had nothing to eat. It was a very tough time and she resolved to end her life. She started falling sick and a Good Samaritan saved her and took her off the street. She took her to the hospital where she was found pregnant and having the HIV virus. She was devastated and she isolated herself. One day during this trying time she bumped into her Dad who called her a prostitute and a bastard. I took time to talk to her after her story, I introduced her to a support group in our area where she received lots of support and she gained courage. She is currently faring well and she delivered a baby boy who is one year old now.

Mentor Mother, Kenya follow-up workshop

WIDER POSITIVE PROCESS ISSUES

Ownership/sustainability: The Sustainable Development Goals emphasize ownership and continuity at their heart. Yet programmes often do not achieve this. Implementation of the 4M+ programme through national partners who are themselves led by women living with HIV was considered critical for ensuring continuity of initiatives. Both PIPE and UNYPA have expressed commitment to carry on with providing support to the trained ‘Mentor Mothers’ voluntary work. Salamander Trust commits to continued support for the partners in both countries, where requested, as a way of ensuring partners’ ownership and sustainability of the interventions.

Participation: The participatory approach used during the training provided an opportunity for participants to share freely, belong to and own the project. Participants received positive feedback from the trainers on areas to improve. Education materials used during the training were user-friendly and detailed enough for easy understanding.

Authenticity: Having a ‘Mentor Mother’ as one of the lead trainers facilitated the peer-to-peer model. This enabled the majority of the participants to share their experiences openly without fear that they would be negatively judged or stigmatized.

Political empowerment: The programme has also demonstrated

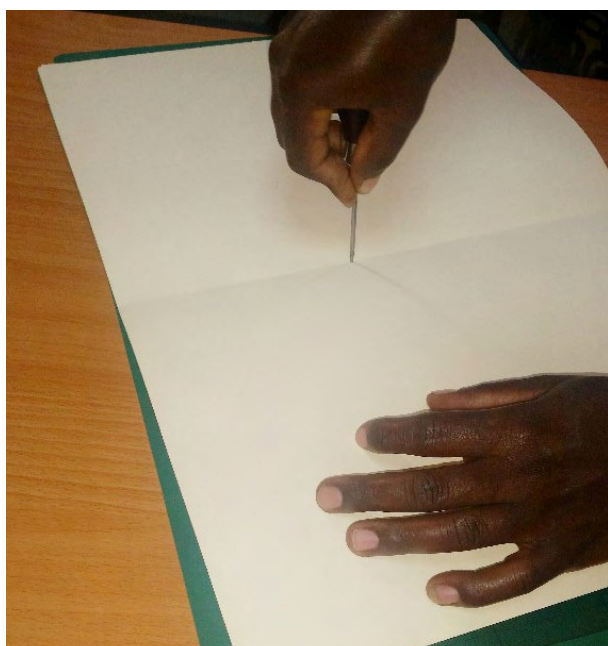
that when young women are supported with skills, they can challenge the factors that affect their wellbeing. For instance, in Nairobi, one of the ‘Mentor Mothers’ has been elected as a member of the National Committee of the Global Fund. While her nomination cannot be fully attributed to the project, she attested to having benefitted from the training as she was not a good communicator in meetings but she is now able to express her views without fear.

Opening up: Programme outcomes demonstrated that training young women living with HIV as mentors, who are facilitated to reach their peers, enhances sharing of their sero-status among other young women living with HIV. Some young women in sero-different relationships also agreed to share their status with their partners and told the Mentor Mothers that they found that this increased support from their partners.



*Identifying and appreciating individual values.
Translated into Swahili for Kenya workshops*

mHealth: Adopting technologies that are commonly used by young people can enhance the project outcomes. For instance, following the training in Nairobi, the 'Mentor Mothers' agreed to use their mobile phones to keep connected, share and support each other through WhatsApp. This virtual platform (now known as mHealth, where m stands for mobile) has enabled the 'Mentor Mothers' to support each other as well as access updates on the different health topics related to HIV among young women. Drawing on the success of this virtual platform, PIPE, with support from Salamander Trust, developed a pilot initiative for linking the virtual communication with the face-to-face interactions, to reach out to more young mothers within their community. A funding application for this initiative has been submitted to a donor for possible funding.



Learning to make a book

ONGOING CHALLENGES

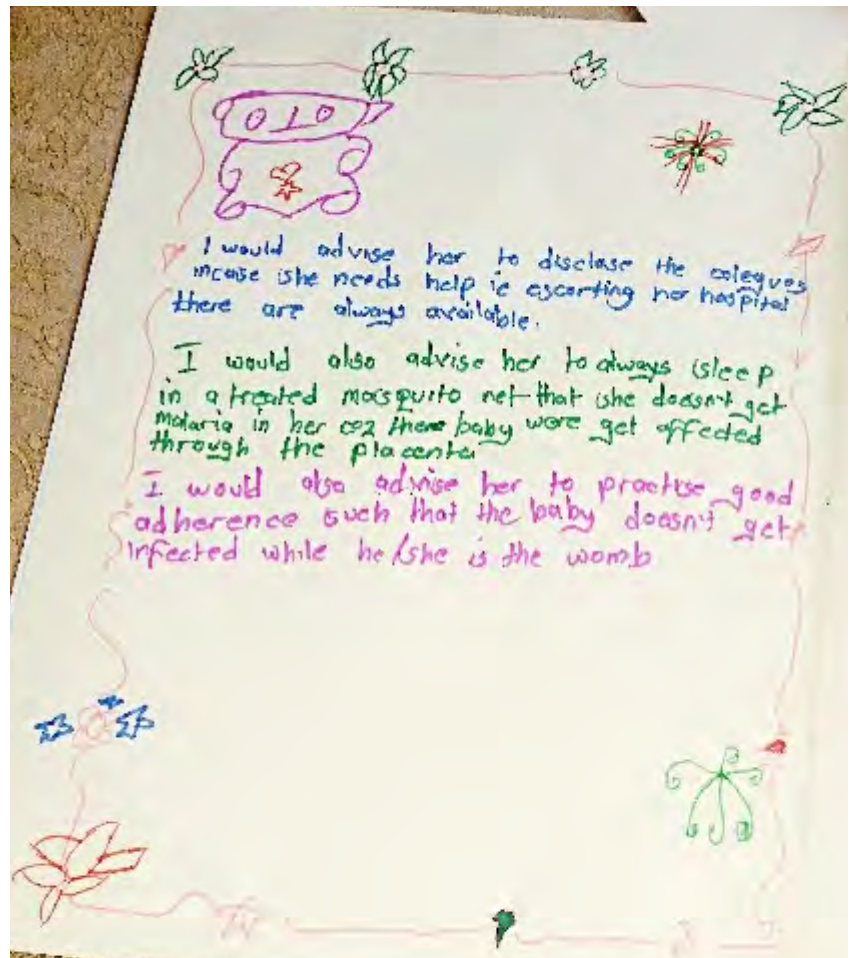
Geographic spread: There was a clear need for further capacity building. For example, in Kenya, PIPE covers a larger part of the Nairobi and Nakuru informal settlements. The trained 'Mentor Mothers' were not able to reach out to all facilities within their coverage areas. This calls for further training programmes, to reach out to and involve women in these areas also.

Language issues: Some of the sessions had to be conducted in the local languages and others required translations. In Kenya, some of the participants were not properly conversant with English. This necessitated development of materials and presentations in both English and ki-Swahili to convey the intended information in Kenya. Similarly, in Uganda, several participants could not read or write English. The limited literacy levels of some of the participants also affected their ability to record their visits/support to peers. This in turn made it difficult to arrive concretely at the total number of peers supported through the project. It would be good therefore in future to adopt other recording measures which are more suited to contexts with lower literacy.

Psycho-social stress: Some of the participants were not comfortable with sharing their experiences, as this was very new to them. In both countries, there were instances where participants broke down and (--> p.10)

Personally I find it hard to share a very emotional experience but this left a mark on my life. I went to the hospital to deliver and while there I noticed another young mother who appeared to be in extreme pain with no one to support her. I forgot my own pain and approached her to find out what her problem was. She told me that she had tested positive and the nurses had refused to attend to her. She was just being supported by a trainee nurse. The trainee was undertaking her practical while delivering this young mother.

**Young Mentor Mother, Kenya
follow-up workshop**



Sharing personal journeys, advice and coping strategies



Sharifa, Resty, (both from UNYPA), Ellen (Salamander Trust), Jacqui (UNYPA), Angelina and Nell (both from Salamander Trust)



In May 2017 after the training I met a mother aged 23 years at the ANC clinic. She lives in XXX division. She came to the clinic with her husband and they went through counselling and testing together. When the results were out, she found herself HIV positive while her husband was negative. The counsellor was very good to the couple and the gentleman seemed to understand. So I was called in to share my life experience with them.

Mentor Mother, Uganda follow-up workshop



Above and top: Sharing personal journeys, advice and coping strategies

(<-- p.7) had to be counselled and supported. This had been anticipated. In Kenya, PIPE focused on linking and referral to support groups and to local health facilities for continued growth. It is always good to ensure that counselling and other support is readily available for participants.

IT issues: The programme was also affected by communication barriers between the implementing partners (PIPE and UNYPA) and the Mentor Mothers. Several of the trained participants did not have access to a cell phone. This then presented challenges when it came to conducting post-training follow-up with them. It would be good for programmes to consider smart phone access for programme graduates.

Engaging men: Discussions with Mentor Mothers during the six-month post-training review meeting revealed the importance of involving men in such interventions if the young mothers are to be able to adhere to their treatment or go for ante-natal or MCH visits. Lack of involvement of male partners meant that some of the Mentor Mothers were also not able to attend the six-month post-training follow-up, owing to home obligations they had to deal with, as they are dependent on their partners. We know

The mother I supported was only 17 years of age and she had a boyfriend with whom she became pregnant. After she had given birth the husband decided to abandon her after he tested HIV negative and she was positive. She came to me in tears and desperately wondering whether she would have any support for herself and her baby. I called the husband and he responded and we sat together and talked about the problem. He said he was not going to stay with the girl since she is HIV positive. "It is better for me to stay alone now that she is HIV positive", he said.

However after a counselling session we managed to resolve the problem and they are now living together happily. The husband is now very supportive because he realized that they can still live together in a discordant relationship. This experience of supporting a couple that was discordant was very difficult for me at first. However later I realized that this young girl was one of my best clients but seeing her failing was really painful.

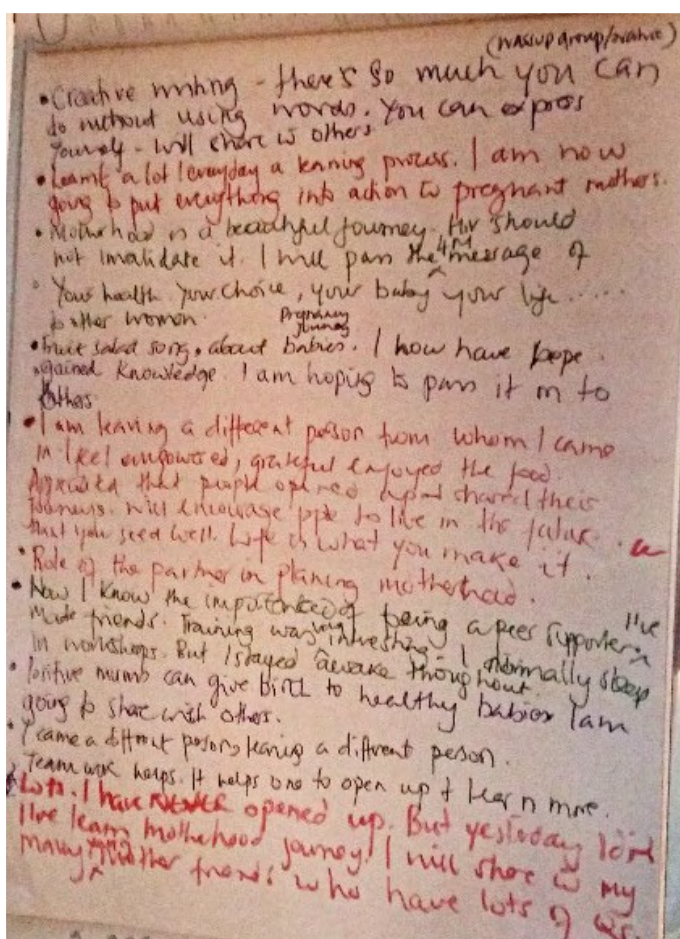
Mentor Mother, Uganda follow-up workshop

from our research with UN Women and partners that key barriers to women's access to anti-retroviral therapy include violence from intimate partners, as well as from wider family members, the community and in healthcare settings.⁽²⁾ This calls for expansion of the programme to include specific materials that engage men in a gendered way.⁽³⁾

(2) See a) UNWomen et al 2017 "Key Barriers to Women's Access to HIV Treatment: A Global [Review](#)" and b) Orza et al, 2017 "In Women's Eyes: Key Barriers to Women's Access to HIV Treatment and a Rights-Based Approach to Their Sustained Well-Being", Health and Human Rights Journal, 19, 2.

(3) Evidence-based programmes recognised to reduce intimate partner violence and promote male engagement include Salamander Trust's *Stepping Stones* programme and Raising Voices' SASA! programme. See here for more details: <http://steppingstonesfeedback.org/links-related-reports-resources/>

Health centre relationships: There were also challenges associated with the engagement of service providers. In particular it was reported that Mentor Mothers were/are often ignored and stigmatized by midwives in certain hospitals. This calls for an urgent need to raise awareness amongst healthcentre staff of their obligations to all those in their care, as well as the value of peri-natal peer support programmes, both in terms of their own workload and in terms of positive health outcomes for the women and babies in their care.⁽⁴⁾



Process evaluation at the end of one of the workshops

This is the story of what I experienced that left a lasting mark on my life as I supported young mothers. One day in the morning I went to the XXXX Clinic in Kampala. I met a young mother who was about 20 years of age. She was diagnosed with HIV and when she was given the results, she wanted to jump through the window of the clinic and end her life. I stood watching the nurses seeing her climb into the window and they were not bothered. I quickly ran to her and struggled with her. We were both weeping but the nurses were not concerned with our pain.

I consoled by sharing my own experience as a person who is living with the HIV virus, however she refused to believe. I therefore pulled out my medicine bottle but she still said I was lying. I then shared a paper of the national news that I always carry where I had shared my testimony and life story about my journey with HIV. It is only then that she believed me and calmed down. She accepted to take her medicine from the nurses. We grew close and I continued providing her with support each time she came to the clinic and I also followed her to her home. She later delivered a very nice baby boy. She is now happy and I too feel happy for this outcome. I realized I had saved a life which would have been lost. This experience gave me a lot of hope that there is something positive about sharing my experience. I feel that I can support young mothers to cope if they test positive.

Mentor Mother, Uganda follow-up workshop

(4) Recent relevant documents from WHO and UNAIDS include a) the 2017 WHO "Consolidated Guideline on the SRH&R of women living with HIV"; b) the 2017 WHO "Sexual health and its linkages to reproductive health: an operational approach"; and c) the 2017 "Joint United Nations Statement on Ending Discrimination in Health Care Settings".



End of Nakuru workshop. Christine (PIPE), Ellen (Salamander Trust) Brenda (PIPE) and Angelina (Salamander Trust)

WHAT WOMEN WANT: ADVOCACY ASKS OF MENTOR MOTHERS

\$ Fund us! The engagement with Mentor Mothers to champion the programme proved to have a marked impact, since it was an experiential and information-based project. Skilling up and building the capacity of young Mentor Mothers especially, to support their peers of similar ages can have hugely beneficial effects for all concerned. It can complement clinical care and make a positive impact on the lives of young women living with HIV who are also mothers. (This will no doubt also have a positive impact on their children's lives.) It is imperative that such programmes are funded and supported.

📖 Train more of us! Feedback from healthcare workers who were contacted six months after the training ended, indicated that the health workers valued the Mentor Mothers and found them to be useful. This included Mentor Mothers encouraging women to test, disclose their status,

attend ANC visits, deliver in health facilities, adhere to their ARV treatment and maintain their health and wellbeing. This further supports the need to train and skill up more Mentor Mothers who can be linked to clinics to support their peers.

🌐 Geographic Spread! Implementing partners, in particular PIPE in Kenya, cover large geographic areas. There is therefore, a need to increase the number of trained Mentor Mothers.

💬 Engage with men! Discussions with Mentor Mothers during the six month post training review meeting revealed their appreciation of the importance of involving men in such initiatives if the young women are to be able to adhere to their treatment or go for ante-natal visits. Subsequent scale-up for this programme (and other similar interventions) should include strategies for how to reach out to male partners or spouses of Mentor Mothers.



Change negative healthworker attitudes!

Mentor Mothers reiterated the continuing issue of stigma and discrimination, particularly among some health workers. They shared incidences where women living with HIV were neglected and, in one case, a mother lost her child. It is imperative therefore that initiatives and resources addressing the issue of stigma amongst healthcare professionals, and how to deal with it, be developed and implemented. This should include collaborative research with health workers on their behaviour and its effect on young women living with HIV.⁽⁵⁾



Livelihoods! Whilst the young mothers trained on the project volunteered to support their peers, most of them have no source of livelihoods. This affected their ability to reach out to many young mothers through lack of basic resources, such as transport. There is therefore, a greater need to integrate Income Generating Activities into programmes training and skilling up Mentor Mothers.



Salamander Trust team stopover on the way to Nakuru workshop



Makeshift crèche for babies in Wakiso workshop, Uganda

(5) See footnote (4) above for more on this.

The training gave me courage and self-esteem so I really helped my peers and friends as well. I have used my own experience to support others and they are now able to take their treatment. The experience I have is that of taking HIV treatment right from my childhood and it got to a time when I felt that I was going to die. However trainings like this one helped me to move on and to realize that it is not the end of the world.

I always had family and friends saying I was going to die because I had AIDS. They said; "children born with HIV cannot live long" so I was always expecting to die anytime. I lost many friends as I was always sick, my family neglected me. We were many children at first but most of them died. I had several hospital admissions because I was very weak. However many people cannot believe that I survived and I am supporting other young mothers going through the same problem.

This training has now made me more confident to support my friends and all the girls out there who do not know their HIV status. I have encouraged many young girls to test them-selves.

Mentor Mother, Uganda follow-up workshop

I met Mary and she shared this experience.

She was sixteen and a major problem happened to her. I met her all alone on the street and she was in tears. She had a boyfriend who tricked her into sleeping with him and when she refused he raped her. When she told her parents, she was chased from home as her parents said it was her fault and she was now pregnant. I took her to hospital but what caused me pain was that she was ready to kill herself. I took her to her parents and talked to them until they accepted to take her in and support her. She accepted her status and the condition she is in and started taking her drugs. She is now a happy girl and she always thanks me for saving her life. She found a true friend in me.

Mentor Mother, Kenya follow-up workshop

I met a lady crying by the road side and I was forced to stop and find out what had happened to her. She told me that she had just had an HIV test and it was positive. She was determined to kill herself but I shared my own story with her. I advised to go back to the clinic and accept to take the treatment the nurses give her. We have since become great friends and she looks very healthy.

Mentor Mother, Uganda follow-up workshop



A participant charts her own pregnancy journey

NEXT STEPS

“PIPE is providing HIV testing services in 12 health facilities in Nairobi, most of our counsellors are living with HIV and this has resulted in good follow-up and linkage to care at 95%.

We have initiated discussions with our partner funding this project to support a few facilities for us to continue providing support for pregnant and lactating women living with HIV. We are waiting for their response.

Although PIPE host a monthly support group session with young women, we will organize separate support sessions for pregnant and lactating mothers.

I represented women living with HIV at the ‘PMTCT’ technical working group and I brought our lived experience at the meeting full of doctors and programme staff. We however lacked participation of young mothers. PIPE will follow up with NASCOP to have one Mentor Mother be included in this forum, then be supported through the WhatsApp group to engage meaningfully in that space.

We hope to get more funding to scale up what we did and reach out to other facilities and communities with the 4M+ project.”

Teresia Otieno, Founder/Director, PIPE

“This project was a unique intervention, with little funding and a short project life span, yet we were still able to register successes. I believe we can do more, reaching out to other mothers, especially those in the hard to reach areas of the country. In terms of the next plan, the peer mothers are all ready and need to be supported to continue with the mentorship groups for a multiplier effect. At this level, we need to invest more in documentation of success stories of these mothers, especially those that have managed to keep healthy negative babies, these documented experiences could help inspire other mothers within the community.”

Nick Niwagaba, Executive Director, UNYPA

FINAL WORDS

The 4M+ programme in its first year has already improved the sexual and reproductive health and rights of many young women living with HIV, who have been trained as Mentor Mothers and who have reached out to other young women as they go through the pregnancy journey whilst living with HIV. Whilst the numbers reached so far in this pilot programme are relatively small, the richness of the positive findings to date provide strong proof of concept for this grassroots, peer-led programme. The implementers of this initiative thank MAC AIDS Foundation for demonstrating its confidence in

funding us. We trust that other donors will also fund such grassroots, women-led initiatives, thereby supporting women living with HIV to uphold their own SRH&R, and to support others likewise. Achieving 909090⁽⁶⁾ will only be possible if the SRH&R of women living with HIV are upheld throughout the process. Quality of life is critical at all stages of the journey. This is what this women-centred and women-led programme, when properly funded and supported, and safe in the hands of those women who have already experienced it for themselves, can deliver.

Acknowledgements

The following individuals have made this programme work – huge thanks to you all!

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UNYPA Uganda: Jacquelyne Alesi, Resty Nalwanga, Sharifah Nalugo, and Nicholas Niwagaba.

Dr Sabrina Kitaka, Senior Lecturer, Paediatric and Adolescent Health Specialist, Department of Paediatrics, Makerere University College of Health Sciences, Mulago Hospital, Uganda.

Salamander Trust: Angelina Namiba, Ellen Bajenja, Nell Osborne, Alice Welbourn, Laura Pulteney.

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Salamander Trust:
www.salamandertrust.net

PIPE Trust: <http://pipekenya.org/>
UNYPA:
<https://www.facebook.com/unypa/>

For more information please go to:
<https://tinyurl.com/4MPlusProgramme>

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(6) See UNAIDS 2017 “Ending AIDS: Progress towards the 909090 [Targets](#)”.