

POSITIVE WOMEN'S FORUM 4 July 2007

Report of Workshop on Motherhood for Positive Women Offered by ICW www.icw.org

Notes compiled by Marion Natukunda and Alice Welbourn

- The workshop was attended by over 30 HIV positive women from Africa, Asia-Pacific, Europe, N America and the Caribbean, all of whom would like to stay in touch and share further information.
- Some are mothers, some wish to be mothers, some have children who are HIV positive, others have children who are HIV negative - and some have children of both statuses. Some have foster children or adopted children. All of us want the best for all our children, now and in the future.
- The workshop ran for less than 60 minutes, owing to room changes. It could easily have run all day.
- All want to talk much more about this huge issue in HIV positive women's lives.

Negative experiences

Participants mentioned many negative experiences, which included the following points:

- Stigma from health workers, arising from fear, denial and lack of training
- Widespread testing of pregnant women without information or consent
- Health workers refuse treatment to HIV positive women
- Partners in denial about their own HIV status and don't get tested
- The fear of disclosing to one's partner, because of being abandoned or being chased away
- Children's lack of trust of parents if there is late disclosure to them about their parents' status or their own status
- USA - huge gap between HIV doctors and obstetricians (and many other places also)

Questions

Participants raised many questions, which included the following:

- ? When to tell your children that you are HIV positive and if they are HIV positive
- ? How to train health workers to be more understanding and supportive of women with HIV
- ? How and when to tell your partner that you have HIV so that you will be supported and won't be beaten, abandoned or thrown out

Positive experiences

Participants mentioned the following positive experiences:

- ✓ The positive effect of being able to share experiences
- ✓ The importance of sensitising whole communities to the issues surrounding HIV and surrounding positive motherhood, in order to reduce isolation and stigma

- ✓ The importance of having *knowledge*, for instance about nevirapine, about legal rights and about having HIV negative children
- ✓ The importance of treatment literacy and for it to include information around motherhood and around paediatric care and treatment

Specific examples of good practice based on personal experience:

Participants mentioned some of the good examples they have developed themselves or been involved in, to share with others:

- ✓ TAC in South Africa runs training programmes for health workers to sensitise them to the issues facing HIV positive women around motherhood <http://www.tac.org.za/>
- ✓ The Mama's Club in Uganda runs self-help peer groups around Uganda to support the psycho-social needs of HIV positive mothers (report attached)
<http://www.womensenews.org/article.cfm/dyn/aid/2835/context/archive>
- ✓ The Memory Book, first developed in Uganda, supports women to compile information for their children about their heritage. This process helps with disclosure
<http://users.wmin.ac.uk/~geibelo/nacwola/activities.htm>
- ✓ HIV positive women in Suriname have developed a book for children entitled "Brenda has a dragon in her blood"
- ✓ The Well Project in the USA has developed a website with information sheets and slides http://www.thewellproject.org/en_US/
- ✓ Mildmay in Uganda has developed a community-based awareness programme which promotes community-wide understanding and VCT, to share the burden of testing and take the stress off pregnant women being the focus of testing by health workers
<http://www.mildmay.org.uk/MildInt.html>
- ✓ The Stepping Stones programme has achieved similar results, to promote community-wide uptake of VCT www.steppingstonesfeedback.org

Discussion of ICW position on various issues

The following positions aired by ICW were discussed with the group to seek participants' opinions:

- Rights of HIV positive women whether or not to have (more) children
This was agreed unanimously
All women, irrespective of their HIV status, should have the right to decide whether or not to have sex, and whether or not to have (more) children. No-one else has the right to decide this for us.
- The ethics of testing women when they are pregnant - for the woman and for her unborn child. Concerns were raised about this, particularly in the light of recent research from the UK which shows that if a woman experiences stress during her pregnancy, this can also have an adverse effect on her unborn child
(<http://www.guardian.co.uk/science/2007/may/31/childrenservices.medicineandhealth>) On top of this there has been wide documentation of pregnant women who test HIV positive being blamed by family members, since they are the first to be tested in their families. This has led to violence, isolation and abandonment.

Discussion included the following points:

- a) *a voluntary informed test should always be available to women when pregnant.... However...*
- b) *all women need far more information about HIV and about the test, so that they can make an informed voluntary choice about whether and when they want to be tested*
- c) *pregnant women are placed under enormous pressure to be tested*
- d) *in Suriname, several pregnant women have killed themselves when they have learnt that they are HIV positive (and elsewhere too)*
- e) *in Kenya (and elsewhere too) the Government has officially established 3 requirements for HIV Testing: 1) one has to be counseled and educated before the pretest and after and be told about the HIV implications 2) No one will be tested without her consent 3) test results are confidential. But all the above requirements mean nothing to the health workers: they do it without your consent and the results are given in public. This means no counseling is done at all and no information is given at all about the test - women are just told that they are positive*
- f) *in New Zealand there are no other options for testing for women, other than at the ante-natal clinic*
- g) *rarely anywhere are women truly given a free, unpressured choice to test*
- h) *there is an enormous and critical need for health worker education in this area*

C. A woman's fears about the safety of her children if she leaves a relationship without them, and her anxieties over their custody mean that she often stays in a violent relationship for the sake of protecting her children, even though she is aware that this is making her vulnerable *This was agreed unanimously . Discussion included the following points:*

- a) *Women face huge economic issues as well a child custody issues, which limit yet further their choice over whether to leave the relationship or not*
- b) *Laws around child custody, child protection, and women's property and inheritance rights need both to be put in place where they don't exist and put into practice. Also training needs to be given to all concerned, so that communities understand the importance of these laws for all concerned.*

D. There are close links between children's rights and women's rights. Organisations which focus on saving orphans without also working to keep their mothers alive and well are not adequately addressing the rights of children

This was agreed unanimously . Discussion included the following points:

- a) *Organisations talk about CRC - the Convention on the Rights of the Child - as if it is something quite separate from CEDAW - the Convention for the Elimination of all Discrimination against Women. Yet all children deserve to have a healthy and happy mother, who is best placed to look after them*
- b) *Fathers should also be kept alive and well*

- c) Children also should have supportive fathers - many positive women have good partners who also need care, treatment and support
- d) Men who are in denial about their status or who are not supportive partners or fathers also need support to redefine their identity as men. “Dismantling patriarchy” needs to be a core part of the international HIV response. Certain groups, such as the Positive Men’s Union in Uganda, are trying to do this. The Mama’s Club in Uganda has made good links with this group.

MAMAS CLUB

BACKGROUND

In the 1980s, one of the commonest causes of infant mortality was HIV/Aids. The Advent of Nevirapine was a breakthrough in PMTCT (Prevention of Mother to Child Transmission) of the virus. The donation of the drug free to Africa made it possible to reduce the rate of transmission of the virus in Public Health facilities by over 60%. In spite of this, there was need for continuous follow up of the mother and the baby. This included psychosocial support for the mother. In the Post Natal Clinics a lot of counseling was given as well as educating the mother on how bring up a healthy baby. In many cases mothers came with their partners but these were very few. The biggest impact after disclosing their status was rejection by their spouses, continuous blame from the extended family, looking after other siblings without having money to feed them, falling sick and yet having to bring up the baby and many other difficult circumstances relating to social economic and cultural factors. It was realized that HIV positive mothers needed more than the counseling and Health education they got in the postnatal clinics. The time was short for them to express all their problems when they attended the clinics even in Aids service organizations which had counselors because of the large numbers.

The Mamas Club was founded in 2004 at TASO Mulago and launched in March 2005 by Her Royal Highness, the Nabagereka of Buganda, and Lady Sylvia Nagginda. The vision was to provide quality health for positive mothers and their children. The Club was founded by Dr Lydia Mungherera, herself a positive woman HIV activist, who felt that positive mothers were a very vulnerable group having to deal with disclosure and struggling to keep their children alive. Many of the mothers were single, either widowed or not supported by their partners and quite depressed. She collected a small group of positive mothers to meet. They were clients of TASO Mulago who had gained a lot of care and support over the many years of attending the clinic. The enrollment criterion was positive mothers, those expecting or those with children up to 3 years of

age. They came together to form the Club. The idea was shared amongst a group of her friends, women and men who worked in gender related programs who came together to form an Advisory Committee. One of the main goals of the Club was to form peer educators to go out to form other Mamas Cubs around the country and later on in other regions in Africa.

By first sitting down with the mothers and listening to their problems, it was clear that this psychosocial forum was greatly needed. The mothers revealed that many health workers in places like Labor wards discriminate positive mothers and they have to again face the same health workers in postnatal clinics. Because of this, many mothers feared to go back for PMTCT plus. This showed the urgent need to continuously sensitize health workers.

ACTIVITIES

The Mama's Club was launched with the theme, **'Male Involvement in PMTCT'**. The following year, 2006, the theme was **'Strides to Positive Parenthood'**. This year, with the involvement of young mothers the theme is **'Protect and support young mothers'**.

The mothers were encouraged to form their own executive committee members amongst themselves to run the club.

During the first year, the Club was run by donations from the Advisory Committee with the support of TASO offering space for meetings. The Advisory committee met in regular meetings to guide the members of the Club.. The drama group was formed with songs with messages and testimonies to be used for community sensitization. The mothers were encouraged to form their own executive committee and they now have a chairperson, secretary and committee members. The Advisory Committee became the Executive Board as plans got underway to register this Club as a Community based Organization. The need for empowerment of women by educating them, providing income generating activities was brought out in regular meetings.. The Club gave the mothers a chance to talk more about their relationships and by inviting fathers to come and visit the Club, this improved their relation ships at home. Strong partnerships with other groups like Positive Men's Union (POMU) were made to help in advocating issues like male involvement so partnership building is important.

From the beginning, the mothers guided by the Executive Board had invited speakers who provided them with life skills and topics like PMTCT, infant care, family care, legal issues, leadership, nutrition and more recently, adolescent reproductive health formed part of the curriculum.



The mothers drama group grew stronger singing songs which gave messages which encouraged other mothers to come for PMTCT and others encouraging fathers to come and support their children. The Executive Board consisting of gender activists, chaired by Dr Lydia, under the Patronship of Professor Florence Mirembe decided to meet quarterly to continue finding ways to raise funds for the Club.

. During a fundraising charity walk, Dr Alex Coutinho, the Executive Director of TASO, announced that the mothers will be given some money annually to support their transport costs. A volunteer Program Manager was recruited to help in bringing the mothers together and help run their monthly meetings. By this time the Mamas clubs was well known and were being invited to different National functions where they spread out good messages to fight stigma and discrimination encouraging other mothers to come out of hiding and go for PMTCT. Friends came in and gave the Club donations. The mothers opened a bank account to keep their money .Out of her community initiatives, the Nabagereka of Buganda sent the mothers a trainer to teach them slow dance movements which helped them with stress relief.

An annual newsletter was started and WHO offered financial support for its production and publishing. Last year, during The International Aids Conference in Toronto Dr Lydia carried 150

news letters to the International Aids Conference and met Steven Lewis, the special Envoy on HIV/Aids for the Secretary General who was well known to Dr Lydia. He suggested that a proposal be written to his foundation.

The proposal was written and approved and later, funding was available to rent 2 rooms, buy raw material for income generation and hire a tailor to teach the mothers how to use the sewing machine to make embroidered table cloths.

Raw material was bought for other handicraft, some of which the mothers are already selling.



Mother learning Embroidery/Sewing

The Executive Chair person, who is a trained reflexologist and knows aromatherapy, started sharing her skills with other members and this has become a weekly exercise.



Mothers being trained in reflexology by their chair person.

After discovering a market, one mother soon started cooking lunch while another mother started preparing juice and fruits which are being sold in surrounding offices. .

In recent years, the number of teenage pregnancies in Uganda has increased tremendously. Because of this challenge this year, 2007, Mamas Club recruited young mothers of ages 14-25 years to try to offer psycho-social to this age group.

There are now 15 young mothers in Mama's Club who are finding love and comfort for the first time in their lives. A great need was found to bring in trainers to talk about adolescent reproductive Health and Family Planning.

Trainers are invited for their monthly meetings to teach them about sexual and reproductive health, family planning, PMTCT, Antiretroviral therapy, community sensitization, disclosure to partners and more recently adolescent reproductive health.

A trainer was recruited to help them with their songs and drama

Out of many other activities, The International Community of Women Living with HIV/Aids (ICW) offered to train the mothers on TB/HIV sensitization. This was to equip them with skills to sensitize other mothers at PMTCT sites.

Another Mama's Club was formed in Masindi District 250 kilometers from Kampala where the clients of TASO mobilized over 100 mothers to form a Mama's Club. Representatives from

the Kampala Club traveled to Masindi to help this Club establish itself and elect their leaders.

Another group is being formed in a district called Fort Portal, 400 km from Kampala and the first group is going to travel there in August, next month to help nurture it.

The need for these community based groups is so great but each Club has to go through a curriculum of subjects that will fully equip the mothers with all the skills they need.



Mama's club addressing members of new club in Masindi

A week ago, two mothers with their counselor traveled to Nairobi, with the support of ATHENA, an inspiring group of gender activists who formed this network with Dr Lydia about two years ago. Attend the International Women's Summit on Leadership and HIV/Aids.



Mothers who attended the International Women's Summit on Leadership and HIV in Nairobi

ACHIEVEMENTS

- The mothers have a forum where they can talk and laugh and share experiences and plans for their future
- The drama Club formed has shown that these mothers can be good peer counselors to help other mothers.
- Members of this Club are being invited to workshops and national functions.
- They have learnt more about positive prevention and PMTCT
- They have learnt more about their legal and human rights
- The mothers have gained experience in infant feeding, and basic nutrition.
- Some of the mothers have received more support from their spouses after being invited to some of the meetings
- Networking has included home visits to each other when sick, comforting those who are bereaved,
- The mothers feel confident to share their experiences with others.
- The idea of Mamas Club has been shared by Dr Lydia to her networks outside the country and a similar club has been formed in Zimbabwe and another one coming

up in Argentina. During the recent International Conference for Women in Nairobi, presentations about Mama Clubs raised global interest in mentor mother programs.

- Young mothers who joined the Club are getting counseling and learning more about how to control their lives.

FUTURE PLANS

- There are plans to find a teacher to teach the mothers adult literacy and help them get support to educate their children.
- Information Technology with computer training which will help mothers communicates with other networks.
- More Clubs will be opened in other districts using the first members as peer mother mentors.
- World Vision has planned to work with Mama Club to go to the Northern part of Uganda to form similar support groups in the IDP camps and in homes where the refugees are returnng.Many young mothers needing rehabilitation will benefit from this program.
- Filming a documentary about the Club will be done to publicize its activities
- A proposal will be developed to build the MAMA'S HOME, after seeking for a donation of a piece of land. This home will have a secretariat, children's play Centre, beds for mothers who suffer domestic violence, a resource centre with IEC material, a sick bay, counseling rooms, a training centre, a drama training room and farm land. For sustainability, the mothers hope to grow cash crops, rear livestock and open a restaurant and saloon and have a handicraft shop to display their work. This pilot home can then be replicated in other districts.

- To encourage Male Involvement, family days will be part of the programme.
- Community outreach to various communities will be a major part of the Club's Activities
- Family planning, besides other skill building activities will make up a curriculum which will be awarded with annual certificates.

CHALLENGES

- Increasing transport costs are still a constraint.
- The secretariat needs strengthening by building capacity of the staff and volunteers and acquiring more office equipment.
- Most of the mothers Live impoverished lives and can't afford proper feeding for their children. Infant feeding programmes are very hard to find.
- Denial by their spouses and domestic violence is still rampant and some of the mothers have been kicked out of their homes and their property taken away.
- The mothers lived in slum houses especially after their husbands had neglected them and can't grow any food or rear animals because they had no gardens
- Many of the mothers are caring for the sick relatives and organs and were worn out
- Mothers with spouses are by husbands living in denial to produce more children in spite of their weak conditions and extreme poverty.
- Community out reach is important and demands a lot of transport costs.
- There are many more mothers wanting to join the Club but it was impossible to afford recruiting more
- Few mothers know how to read and write and want adult literacy courses.
- Poverty has led to many of their children miss out on going to school because of extra costs on top of the UPE system.
- The mothers want land to farm, so as to raise more income.

RECOMMENDATIONS

- Education of the girl child is very important in empowering women to take charge of their lives. Resources should be made available in National programs to support this.
- There is a need to sensitize more women in the community to access PMTCT in the antenatal stage. By using mothers who have already gone through the experience as mentors, it is easier for them to relate to those who are still hiding due to stigma and encourage them to access PMTCT.
- Survival of infants in Africa depends very much on improving the psychosocial well being of the mother and empowering them to be financially independent so there is a great need for teaching them income generating activities.
- Home based couple counseling is very important because many men don't want to attend antenatal and post natal clinics. Partnerships with organizations like POMU (Positive Men's Union) is important for sensitization of fathers.
- There is a great need to sensitize health workers who work in Labour wards to treat these mothers with the same respect like other mothers and continuous sensitization and education must take place. This reduces the need for mothers to turn to traditional birth attendants because of stigma.
- Forums like this need to be replicated widely in the country and the region and finances should be given to help them grow. Young mothers can only cope if they are encouraged by others in the same situation so it's important to divide these clubs in certain times into age groups.
- Such Clubs like these should be recognized as part of the package of PMTCT for follow up so they should be supported by the government.

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- The Patron and members of the Executive Board
- ICW(The International Community of Women Living with HIV/AIDS)
- ATHENA
- The Volunteer trainers from TASO and other organizations

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