



# Uganda

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## KEY POINTS

1. Nearly 95 percent of pregnant women attend antenatal care services at least once during their pregnancy, but only 43 percent of all health facilities that provide ANC have integrated prevention of vertical transmission services- a missed opportunity.
2. Many clinics and other sites providing prevention of vertical transmission services experience regular stock-outs of ARVs and prophylaxis medicines due to problems related to inefficiencies in the supply chain and distribution system.
3. Mothers reported feeling they can afford neither exclusive breast-feeding nor the recommended alternatives. Stigma, poor nutrition (among mothers), cultural pressures and general poverty have forced many of them to the more risky mixed feeding practice.
4. The health infrastructure does not have the human or financial capacity to meet the increased demand created by women seeking prevention of vertical transmission services.

## RESEARCH PROCESS AND METHODOLOGY

The data presented in this report were gathered through a review of official documents as well as interviews with 12 key informants representing the national MoH; the Kamwenge District Health Office in western Uganda; the Ogur Health Centre IV in Lira District in northern Uganda; WHO; the Elizabeth Glaser Paediatric AIDS Foundation (EGPAF); CESVI (an Italian NGO); and the East Africa office of the International Community of Women Living with HIV/AIDS. The study team also held two focus group discussions with clients of ANC services in the Kamwenge and Lira districts. A total of 16 women participated in the group discussions. Out of the six who participated in the discussion in Lira, five offered to disclose they were HIV-positive. In Kamwenge, none of the 10 participants disclosed their status.

(Note: "\$" refers to US dollar amounts.)

## 1. BACKGROUND INFORMATION

More than 700,000 Ugandan women are living with HIV. The most recent data (from 2004-2005) indicate a national HIV prevalence rate among women of reproductive age of 6.5 percent. Without any intervention, the MoH estimates that about 30 percent of HIV-positive pregnant women transmit the virus to their babies during pregnancy, labour, delivery or post-partum through breast milk<sup>33</sup>. There thus could conceivably be some 27,300 HIV infections among newborns in 2009, based on estimates of about 1.4 million pregnancies in Uganda in that year<sup>34</sup>.

Nearly 95 percent of pregnant women attend antenatal care (ANC) services at least once during their pregnancy. They do not necessarily have access to comprehensive prevention of vertical transmission services, however, because just 43 percent of all health facilities that provide ANC and delivery services have integrated prevention of vertical transmission. This means that only about 50 percent of expectant mothers were estimated to have accessed prevention of vertical transmission services in the 12 months to June 2007. Between July 2006 and June 2007, a total of 533,436 new ANC clients visited prevention of vertical transmission sites and about 80 percent (419,171) of them received HIV testing, of whom 7 percent tested positive. About 80 percent of those diagnosed with HIV were given ARV prophylaxis for prevention of vertical transmission during pregnancy, and 12,601 babies (42 percent) were given ARVs after delivery.

<sup>33</sup> Programme for Prevention of Mother-to-Child Transmission of HIV, Annual Report (July 2006-June 2008), MoH, p.1.

<sup>34</sup> Interview with William Salmond, country director, Elizabeth Glaser Pediatric AIDS Foundation.

The MoH and UNICEF initiated a pilot prevention of vertical transmission program at three hospitals in Kampala in 2000<sup>36</sup>. In 2001, the MoH drafted a five-year scale-up plan, with a target of reducing transmission by 25 percent by 2005 through the provision of a comprehensive package of services to HIV-positive mothers, their spouses and their newborns<sup>37</sup>. The plan was to establish prevention of vertical transmission services in at least one health facility per district by 2004 and then scale up to Health Centre IVs<sup>38</sup> by 2005. The ministry upgraded the scale-up plan to a national prevention of vertical transmission policy in May 2003. The policy was last revised in August 2006.

## 2. STATUS OF SERVICE DELIVERY AMONG AND FOR WOMEN

The MoH currently implements the prevention of vertical transmission policy through the Sexually Transmitted Diseases (STD)/AIDS Program. The policy provides for the four prongs of comprehensive services: primary prevention; family planning for HIV-positive women; prevention of mother-to-child transmission; and care and support for HIV-positive expectant mothers and their families. The national strategy focuses on integrating these services into the reproductive health service package; thus prevention of vertical transmission services in Uganda are provided in the general context of sexual and reproductive health services<sup>39</sup>. The entry point for prevention of vertical transmission services is antenatal care, which is provided by accredited public, mission (NGO) and private facilities at the level of Health Centre III and above<sup>40</sup>. Only a few Health Centre IIIs currently provide prevention of vertical transmission services.

The basic package for prevention of vertical transmission involves testing mothers and their partners for HIV and helping them make safe infant feeding choices. At higher levels of service provision, additional diagnostic tests are offered, ART and/or ARV prophylaxis are made available, and ancillary support such as food supplements and insecticide-treated mosquito nets may be offered.

35 Programme for Prevention of Mother-to-Child Transmission of HIV, Annual Report (July 2006-June 2008), MoH, p.9.

36 Bajunirwe F., et. al (2004): "Effectiveness of nevirapine and zidovudine in a pilot program for the prevention of mother-to-child transmission of HIV-1 in Uganda," African Health Sciences, Vol 4, No.3.

37 Programme for Prevention of Mother-to-Child Transmission of HIV, Annual Report (July 2006-June 2008), MoH.

38 In Uganda's health structure, a Health Centre IV is at the level of health sub-district and is the lowest referral facility, just below the level of a hospital.

39 Interview with Dr. Godfrey Esiru, national PMTCT coordinator, MoH.

40 In Uganda's health structure, a Health Centre IV is at county level; Health Centre III at sub-county; a Health Centre II at parish level; Health Centre I at village/community level.

The chart below provides a summary of key elements of the prevention of vertical transmission package and the level(s) at which they are provided.

|  | ANC | IYCF | HIV testing | IPC | PNC | sdN | AZT +sdN | AZT+3TC +sdN | HAART |
|--|-----|------|-------------|-----|-----|-----|----------|--------------|-------|
| <b>HC II Basic package</b>                   | √   | √    | +           | +   | +   | +   | –        | –            | –     |
| <b>HC III Intermediate package</b>           | √   | √    | √           | √   | √   | √   | +        | +            | –     |
| <b>HC IV/Hospitals Comprehensive package</b> | √   | √    | √           | √   | √   | √   | √        | √            | √     |

**KEY:**

- HC** = Health Centre  
**IYCF** = integrated infant and young child feeding counselling  
**ANC** = antenatal care  
**IPC** = intra-partum care  
**PNC** = post-natal care  
**sdN** = single-dose nevirapine  
**AZT** = zidovudine  
**3TC** = lamivudine  
**HAART** = highly active antiretroviral treatment  
**√** = service is provided  
**-** = service only available in some of the facilities  
**–** = service not provided at that level

Not all of these services are easily accessible, however. Comprehensive prevention of vertical transmission services are not readily available to all women and children who need them in Uganda, especially in remote rural areas as well as the northern region, which is in a post-conflict situation<sup>41</sup>. Many clinics and other sites providing prevention of vertical transmission services experience regular stock-outs of ARVs and prophylaxis medicines due to problems related to inefficiencies in the supply chain and distribution system.

Counsellors ordinarily give HIV-positive mothers the option to formula-feed or breast-feed, but it is almost routine for mothers to choose exclusive breast-feeding because it is what is nearest to what is possible<sup>42</sup>. The fact is that most mothers in Uganda, and especially those in post-

46 Interview with Dr. Godfrey Esiru, national PMTCT coordinator, MoH.

47 Interviews with Dr. Laura Kaddu, CESVI, and Dr. Vincent Mubangizi (DHO, Kamwenge), and findings from focus group discussion in Kamwenge.

48 Interviews with Dr. Godfrey Esiru (MoH), William Salmond (EGPAF), Dr. Vincent Mubangizi (Kamwenge DHO), and Mary Frances Okello (Ogur Health Centre).

*“One of the biggest barriers to women utilizing PMTCT services is limited male involvement. The program mandates husbands to accompany their wives when they go for ANC services and HIV testing, but women are not taught how to convince their partners to go with them or how to disclose a positive test to them. And don’t forget, some pregnancies don’t involve men who are visible or nearby; some may be a result of rape, some fathers deny responsibility, and some are no longer living. In general, the program demands too much from the woman.”*

Florence Buluba, ICW East Africa

war northern Uganda, currently cannot afford infant formula. On the ground, among the women interviewed, there was a feeling among pregnant women that their breast milk was insufficient due to moderate malnourishment, and they were likely to try to supplement it with other feeding, a step that eliminates the risk-protective factor of exclusive breast-feeding.

The health system does not provide free infant formula, the first recommended infant feeding option for women who might need it. Another major challenge is that the health infrastructure and staff do not have the human or financial capacity to meet the increased demand created by women seeking prevention of vertical transmission services.

#### **PREVENTION OF UNINTENDED PREGNANCIES**

Prevention of unintended pregnancies, even for women in the prevention of vertical transmission program, is the responsibility of family planning clinics within health facilities. Yet the options offered at family planning clinics for avoidance of unintended pregnancies are limited<sup>43</sup>. Antenatal clients at Ogur Health Centre in Lira District complained that they were offered only one brand of contraceptives – Pilplan and Injectaplan, which some women perceive to have high side-effect profiles – and male condoms, the use of which is not necessarily in women’s control<sup>44</sup>.

#### **PROVISION OF SERVICES FOR HIV-POSITIVE MOTHERS, THEIR PARTNERS AND THEIR FAMILIES**

Care and support for mothers and their infants is one element of the national prevention of vertical transmission policy that appears to have received particularly substandard attention. The programs to which mothers are supposed to be referred for nutritional support no longer exist<sup>45</sup>. From the focus group discussions, it emerged that most ordinary mothers feel they can afford neither exclusive breast-feeding nor the recommended alternatives. Stigma, poor nutrition (among mothers), cultural pressures and general poverty have forced many of them to the more risky mixed feeding.

#### **BARRIERS TO COMPREHENSIVE SERVICE DELIVERY AND LESSONS LEARNED**

Findings indicate that shortages of health workers and infrastructure and supplies are the most critical barriers to scaling up a comprehensive set of prevention of vertical transmission services in Uganda. The prevention of vertical transmission policy provides for the roll-out of services up to the level of Health Centre III (sub-county level). However, according to the MoH, only 53 percent of all HC IIIs were providing prevention of vertical transmission services by June 2007 due to a shortage of health workers to provide such services at that level.

43 The policy guidelines do not specify which family planning methods should be available at clinics.

44 Focus group discussion held at Ogur Health Centre in Lira District on 30 January 2009.

45 Focus group discussions in Lira (30 January 2009), and Kamwenge (23 January 2009).

It is also important to recognize that measuring coverage on the basis of the proportion of health centres providing prevention of vertical transmission services masks inequalities in the distribution of prevention of vertical transmission sites because distribution of health centres is not uniform across the country. In districts with few and scattered facilities, particularly those in Karamoja and northern regions, long distances to facilities limit access to services by expectant mothers<sup>46</sup>.

Other notable barriers to women utilizing prevention of vertical transmission services include medicine stock-outs, limited male participation and involvement, and HIV-related stigma and discrimination.

#### NOTABLE LESSONS LEARNED INCLUDE THE FOLLOWING:

*“The government has not given prevention the weight it deserves; it focuses too much on treatment. Food supplements are far cheaper than ARVs, so why can’t we put more money into food supplements for six-month-old babies to save their lives?”*

**Dr Vincent Mubangizi, district health officer, Kamwenge District**

- If accompanied by referral information and resources, outreach HIV testing tends to increase uptake of prevention of vertical transmission services and male participation. CESVI’s outreach-referral project in the Karamoja region’s Abim district and that of Catholic Relief Services (CRS) in western Uganda have resulted in an increase in women enrolling for prevention of vertical transmission. About 39 percent of individuals tested in these projects were male<sup>47</sup>. (Both projects have subsequently ended, although CESVI reportedly is planning to initiate a similar one in northern Uganda. Resource constraints, both human and financial, have hindered efforts to implement such projects over the longer term.)
- The implementation of the prevention of vertical transmission program has supported improvements in the quality of antenatal and delivery care. Vital training has been made available to health care personnel at facilities where the program is being implemented. Some facilities have also had their infrastructure renovated to create space for VCT services, including laboratories. EGPAF, for instance, allocates \$80,000 annually to each of 27 districts in which it operates, with the money targeted to support reproductive health programs<sup>48</sup>.
- Uganda’s experience with prevention of vertical transmission service delivery to date has demonstrated that coordination of the various service providers is necessary to avoid duplication and to ensure that adequate services are rolled out for hard-to-reach populations. The MoH has allocated distinct parts of the country for various NGOs to focus on. However, although this effort has successfully distributed services, effective coverage seems to vary with the capacity of the service provider. For example, EGPAF, which provides services directly

<sup>46</sup> Interview with Dr. Godfrey Esiru, national PMTCT coordinator, MoH. Interviews with Dr. Laura Kaddu, CESVI, and Dr. Vincent Mubangizi (DHO, Kamwenge), and findings from focus group discussion in Kamwenge.

<sup>47</sup> Interviews with Dr. Godfrey Esiru (MoH), William Salmond (EGPAF), Dr. Vincent Mubangizi (Kamwenge DHO), and Mary Frances Okello (Ogur Health Centre).

<sup>48</sup> Interviews with William Salmond (EGPAF) and Dr. Betty Mirembe (EGPAF).

to 64 percent (about 450,000 of 700,000) of prevention of vertical transmission clients, operates in only 33 percent (27 of 81) of the country's total districts<sup>49</sup>.

### 3. HIV TESTING: ACCESS AND OTHER ISSUES

HIV testing services are on average widely available in Uganda. (Other key diagnostic services, particularly CD4, viral load and organ function tests, are less commonly available, however.) Rapid HIV tests are available in both facility and outreach settings. In public facilities, HIV tests are free; in private not-for-profit facilities receiving support from government, clients pay for "consultation"; while private facilities charge direct fees<sup>50</sup>. HIV testing is voluntary in Uganda, but a provider-initiated policy is utilized in the prevention of vertical transmission program. This means that although HIV tests are strongly encouraged, pregnant women can decline (e.g., opt out). However, according to several respondents and focus group participants, it is difficult if not impossible for pregnant women to refuse an HIV test. Many said that an HIV test is in fact "a must" for pregnant women who visit health centres for ANC.

Where VCT services and counsellors are available, expectant mothers are provided adequate information on the benefits of testing for HIV for themselves and their babies. In such locations, uptake of services is higher because clients generally understand that an HIV test is just one of the various tests they should undertake for their own good and for the good of their babies. In remote and hard-to-reach rural areas, however, including in much of the north, the information mothers receive may not be adequate due to capacity limitations in terms of health care personnel and counsellors. In such disadvantaged locations, mothers are more likely to feel coerced into taking an HIV test.

Nevertheless, the opt-out policy, which in 2006 replaced an opt-in policy in which the client had to specifically request an HIV test, has apparently improved access to prevention of vertical transmission services. One indication is that uptake of HIV testing increased from about 60 percent of all new ANC clients in 2004 to 80 percent in 2006-2007<sup>51</sup>.

The official policy provides for confidentiality of test results. The patient registers are in principle kept under lock and key and are supposed to be accessed only by health personnel. However, women visiting prevention of vertical transmission clinics say confidentiality is in effect breached by the public nature of service provision, because some facilities have specific clinics for prevention of vertical transmission clients while other ANC clinics have specific days they serve clients.

49 Interviews with William Salmond (EGPAF) and Dr. Betty Mirembe (EGPAF).

50 "Consultations" and direct fees both require patients to pay, but the amounts differ greatly. Direct fees are usually up to 10 times higher than consultation fees.

51 PMTCT Program Annual Report (July 2006-June 2007), MoH, p.10.

#### 4. INFANT FEEDING GUIDELINES AND TRENDS<sup>52</sup>

The national prevention of vertical transmission policy officially recommends that HIV-positive mothers opt for replacement feeding if it is affordable, feasible, acceptable, sustainable and safe (AFASS). Yet at the same time the policy acknowledges that the majority of Ugandan mothers cannot be expected to meet AFASS standards because of the high levels of poverty, low status of women, stigma and an almost universal breast-feeding culture. As such, counsellors are instructed to i) explain to mothers the full implications of each choice for feeding, and ii) clearly indicate that exclusive breast-feeding for up to six months is the preferred option for mothers whose replacement feeding environment may not be AFASS.

*“We refer the mothers who test positive to the ART clinic, but some never show up there or ever return here for ANC. Stigma is a big problem; people are afraid of being seen at the ART clinic because everyone will conclude they have HIV. We don’t have funds to follow them up and we don’t know where they go next and where they deliver their babies.”*

Midwife at Padre Pio Health Centre, Kamwenge District

In practice, however, the main challenge is that most mothers are unable or unwilling to be consistent one way or another in terms of exclusive breast-feeding or exclusive alternative feeding. A mother may decide to breast-feed exclusively, but may start giving her infant additional fluids because she does not believe she has enough breast milk. Or she may opt for replacement feeding only, but soon find that she cannot afford formula regularly or faces strong social or family pressure to breast-feed at least some of the time. As one NGO worker observed, “A mother might make a decision to stop breast-feeding early, but when her mother-in-law visits she will breast-feed again.”<sup>53</sup>

#### 6. IMPACT OF VIOLENCE AND STIGMA

Uganda has achieved a high level of awareness of HIV/AIDS, but HIV-related stigma remains a serious problem. HIV-positive mothers face high levels of stigma within the family, in the community and at health centres. Many women are understandably fearful of disclosing their HIV status to family members—particularly husbands and other male partners, who may beat them or force them from their homes even if they themselves are positive or unaware of their own status.

At the community level, HIV-related stigma limits a woman’s freedom to choose how to feed her infant because, given the cultural norm of breast-feeding, it is often assumed that a woman who does not breast-feed is HIV-positive. Even if they are in fact positive, many women do not want their status assumed or known in their communities. In Lira, northern Uganda, respondents reported that women in the prevention of vertical transmission program were rejecting jerry cans provided by a charity because others in the community teased and avoided those seen fetching

<sup>52</sup> This report was finalized prior to the release, in April 2009, of new guidelines from the MoH recommending that all mothers (HIV-positive or not) initiate breast-feeding within one hour after delivery and exclusively feed the baby on breast milk for the first six months. The ministry also stated that mothers should be given the option of continuing to breast-feed for up to two years after birth if other feeding options are not realistically possible or safe.

<sup>53</sup> Statement by Dr. Laura Kaddu (CESVI).

<sup>54</sup> Interview with Mary Frances Okello, HC IV.

water in them<sup>54</sup>. During the focus group discussion with ANC clients in that district, one participant recalled that her neighbours regularly mocked her after learning that she was HIV-positive.

The situation is often not any better at health facilities. According to one respondent, HIV-positive mothers sometimes feel harassed by health workers who “treat them as though it were a crime to conceive after they knew they were HIV-positive”<sup>55</sup>.

## 7. ASSESSING THE WORK OF GLOBAL AGENCIES

As is the case with the general HIV/AIDS response in Uganda, the prevention of vertical transmission program is entirely donor-dependent for resources<sup>56</sup>. UN agencies, the Global Fund, PEPFAR and other bilateral programs as well as other international non-governmental partners are providing various forms of support, including funds, medicines, training, service delivery, and technical advice. Of the various UN agencies active in Uganda, most support for the prevention of vertical transmission program comes from UNICEF. WHO has been instrumental in technical assistance in policy formulation, developing training and IEC materials, and treatment guidelines.

The increased focus by donors and global agencies on evaluating and increasing prevention of vertical transmission coverage has had a positive impact on service delivery for the most part. Data collected to measure the impact of interventions has helped the MoH re-plan and identify solutions to challenges. In October 2008, for example, a joint review of the prevention of vertical transmission program identified stock-outs of medicines and test kits. The outcome helped UNICEF secure a commitment from UNITAID to donate test kits<sup>57</sup>.

Not all donor interventions are equally useful, however. Some donors provide their funding on budget, while funds from others are provided off-budget. Budget funding is preferable because it facilitates expenditure planning and optimization while at same time promoting a sense of ownership of the national response. Off-budget funding, on the other hand, tends to be based on the priorities of the individual donor in terms of the choice of intervention, timing, scale and location of the intervention. The persistent use of off-budget funding by some donors has to some extent diverted attention from essential elements of the health system which need to be strengthened. Donors generally do not provide funds for infrastructure development and staffing, which currently are the biggest barriers to the scale-up of prevention of vertical transmission services. This had led to situations in which access to vital materials and

55 Interview with Florence Muluba (ICW) and experiences reported during focus group discussions in Kamwenge and Lira districts.

56 Source: Dr. Godfrey Esiru (MoH).

57 Interview with Dr. Godfrey Esiru (MoH).

supplies has been denied; for example, the Clinton Foundation has in the past provided drugs for children that never reached prevention of vertical transmission centres because National Medical Stores (NMS) did not have adequate resources to distribute them<sup>58</sup>.

## RECOMMENDATIONS

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The following recommendations are aimed at improving access to, and the quality of, comprehensive prevention of vertical transmission services for all women and children and need:

- The Ugandan government should relax its staffing ceilings and mobilize resources to improve staffing at lower-level health centres. It should also provide health workers incentives to work in remote, hard-to-reach locations.
- The Uganda AIDS Commission in partnership with civil society organizations should devise new communication strategies to reduce HIV-related stigma and increase male participation in reproductive health through a systematic outreach/home-based mobilization program.
- The Uganda AIDS Commission should mobilize and encourage HIV-positive mothers to form or join psychosocial support groups that can also help them engage in income-generating activities.
- The Ugandan government should privatize the national medicine distributor, NMS, to improve efficiency and minimize medicine stock-outs at prevention of vertical transmission sites.
- The MoH, the Uganda AIDS Commission and non-governmental service providers should streamline reporting by initiating a Web-based format to improve access to quality data for program monitoring and evaluation. This step would also help facilitate efficient distribution of drugs, test kits and other supplies.
- The Ugandan government, the World Bank and the Global Fund should focus assistance and resources on strengthening the Ugandan health system, including the development of infrastructure in locations where it is thin and/or scanty, and equipping laboratories.
- The Ugandan government should work with multilateral organisations and programs (such as UNICEF, UNAIDS and PEPFAR) and other bilateral programs and international partners to step up their assistance in providing and distributing test kits to all prevention of vertical transmission centres in the country.
- The MoH should initiate an anti-stigma program targeting all health workers. Such a program should focus on providing extensive

58 Source: William Salmond (EGPAF)

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information about HIV prevention and treatment and include a discussion on the need to recognize the legal and human rights of PLWHA.

- The MoH should ensure that all health care workers receive adequate training in breast-feeding management and counselling, particularly as it pertains to HIV-positive mothers. This is necessary to ensure that all expectant mothers understand the potential risks and benefits of all options and feel as though they can make realistic choices that will help keep their infant as well-fed and healthy as possible. It is especially important that health care workers are familiar with the new MoH guidelines, announced in April 2009, that recommend exclusive breast-feeding for the first six months of every infant's life.
  - The MoH and non-government service providers should mobilize resources for nutritional support for replacement feeding for babies born to HIV-positive mothers who have registered for prevention of vertical transmission services.
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