

**Public-Private Partnership: The Role of Civil Society
in Scale-up of Prevention of Mother to Child
Transmission of HIV in Nigeria**

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Summary:

This was a month research project conducted at Terry Stanford Institute at Duke University, Durham. It involved literature reviews and HIV clinic visits to Duke University Medical Center, Durham NC to appreciate public private partnership and the role of civil society in prevention of mother to child transmission of HIV (PMTCT). This project highlighted need for collaboration towards comprehensive and effective program delivery in prevention of mother to child transmission of HIV in Nigeria. Civil society groups have tremendous contributions to make in HIV prevention and treatment programs. Mechanisms of partnership between civil society and government agencies should be put in place to reduce the emerging burden of pediatric HIV, which is of public health importance as partnership is needed to bridge the existing gap in reducing vertical transmission. This includes right to participate in policies, programs and processes to scale-up PMTCT. Moreover, civil society organizations are needed to argue the efforts of government in providing antiretroviral therapy to pregnant women as government cannot do it alone. Civil society and government are needed to adequately and effectively meet these challenges. Every sector has one or more expertise to offer in mitigating the impact of HIV among pregnant women and babies. The objective of this project was to examine ways in which government and civil society partnership could increase access to prevention of mother to child transmission of HIV service in Nigeria. The recommendation will be made to the Minister of Health in Nigeria towards increasing public-private partnership in the scale-up of prevention of mother to child transmission of HIV.

Introduction:

Public Private Partnership is an initiative where government agencies and private organizations work together towards a common goal.¹ This partnership in health is needed to allow for wide range of expertise, resources and strength for sound quality of healthcare delivery. Also, this partnership will promote program, clinical, scientific and technical issues in antenatal and postnatal HIV care. We need this collaboration for comprehensive and effective program delivery. This is crucial for an elaborate and long lasting impact. Likewise, civil society is made up of civic and social organizations that work towards a better society which includes professional associations, non-governmental organizations, non-profit organizations, faith-based organizations, community based organizations, charities, research institutes and trade unions. These organizations have extensive impact and influence on their societies and are at the forefront of identifying innovative ideas.² These organizations are engaged in activities locally, nationally, regionally and internationally. Additionally, they are involved in various activities such as policy making, health sector reforms, health advocacy, quality of care, monitoring and evaluation, and health education.³ Mother-to-child transmission (MTCT) of HIV occurs when an HIV positive woman infects her baby during pregnancy (in-utero), labor and delivery, or during breast feeding. Vertical transmission or mother-to-child transmission (MTCT) has the potential of increasing pediatric HIV/AIDS cases. Thus, there is a need to prevent HIV from the mothers to their babies.

Civil society groups have made tremendous contributions to HIV prevention and treatment in Nigeria such contributions include HIV awareness campaigns, treatment advocacy, call for public accountability, and HIV reporting and advocacy in new prevention technologies (NPT) as

in HIV vaccine and microbicides. These have led to significant influence and impacts on public health. Similarly, the initiatives of civil society groups are filling the gaps in national policy and programmatic responses.⁴ In Tanzania, Mutangadura et al, found community response as important component of meeting the material needs of families affected by HIV/AIDS.⁵

Civil society organizations have an important role in the scale-up of prevention of mother to child transmission of HIV (PMTCT) in Nigeria, and should be adequately engaged in this aspect of HIV prevention. Mechanisms of partnership between civil society and government agencies should be put in place to reduce the emerging burden of pediatric HIV which is of public health importance as partnership is needed to bridge the existing gap in reducing vertical transmission. This includes right to participate in policies, programs and processes to scale-up PMTCT.

Mother to child transmission of HIV is largely preventable through interventions such as antiretroviral therapy during pregnancy, delivery and breastfeeding.^{6,7} Sadly, the level of coverage of prevention of mother to child transmission of HIV is low in Nigeria.^{8,9} According to National Agency for Control of AIDS in Nigeria (NACA - Nigeria), 220,000 HIV positive pregnancies are estimated yearly and the proportion of transmission from mother to babies (vertical transmission) is about 15-30% if there is no intervention.¹⁰ The number of pregnant women receiving prevention of mother to child (PMTCT) services was 22,900; the number of pregnant women receiving antiretroviral drugs was 600 and the number receiving counseling and testing was 22,200¹¹ (this is an old data as there is no recent data). Hence, the number on medication is small compared to the annual number of HIV positive pregnancies and there is a

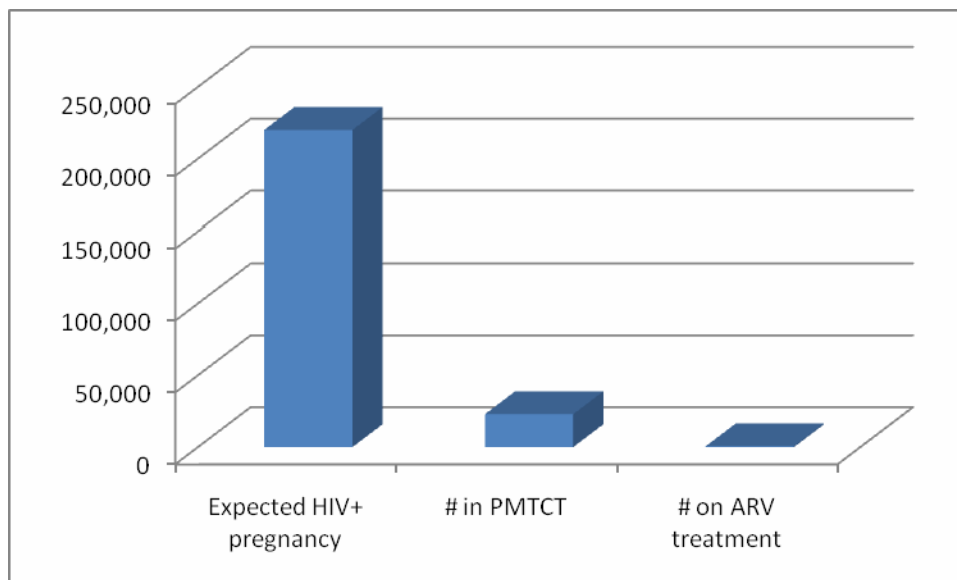
need to expand the service so that more HIV positive women could benefit through the partnership of government and civil society.¹²

Moreover, civil society organizations are needed to argue the efforts of government in providing antiretroviral therapy to pregnant women as the government cannot do it alone.¹³ Civil society and government are needed to adequately and effectively meet the challenges. Unlike in developed countries, these prevention efforts are within the reach of pregnant women, but are not readily available in Nigeria. The partnership of civil society organizations and government has a great potential in reducing transmission of HIV from mothers to babies. This initiative will help bridge the gap between developed countries and Nigeria. It is important to note that decentralization¹⁴ is needed for treatment and this is achievable with the cooperation of civil society groups. Every sector has one or more expertise to offer in mitigating the impact of HIV among pregnant women and babies. Indeed, grass-roots programs are sometimes difficult for government to implement. Partnering with civil society groups is means of filling the gaps for government inadequacies at local levels.

Although civil society has contributed significantly to prevention, advocacy and control; more is still needed to be done in terms of treatment and care. There is a need to stimulate the civil society organizations to participate, be committed PMTCT and to have their own treatment sites. It is therefore imperative that the civil society joins scale-up of treatment and care.^{15,16} People are dying and the government ought to be supported by private/civil society groups. In many developing countries, the civil society lobbied for increase in access to treatment and it is important that they actively participate in treatment programs themselves.¹⁷ Consequently, it is

time to advocate or mobilize for civil society partnership in mitigating the impacts of AIDS epidemic among pregnant women in Nigeria.

Equally important, private-public partnership is needed between the governmental agencies and the civil society groups if meaningful scale-up of prevention of mother to child transmission of HIV will be effective in Nigeria.¹⁸ This partnership will enhance better integration of PMTCT program in the routine antenatal care services. This will enhance more pregnant women to be reached and prevent pediatric HIV. Research is needed to show how this partnership could be strengthened to assist HIV positive pregnant women. It is important to learn from civil society involvement or participations in other parts of the world like in the United States. If comprehensive approach and universal access to treatment are to be embarked on in Nigeria as in Brazil,¹⁶ there is an urgent need for civil society groups to be informed on ways of contributing meaningfully to better developmental outcomes.^{19,20} Decentralization of treatment is highly necessary in Nigeria and civil society should be empowered to contribute to it using both public health and clinical approaches.²¹ This participation in PMTCT should be accompanied by human rights advocacy for women living with the virus and a need to strengthen on-going community based projects and interventions. Therefore, civil society groups have to be motivated to overcome challenges to treatment and care of HIV/AIDS especially among pregnant women living with HIV and AIDS. Finally, the objective of this project was to examine ways in which government and civil society partnership could increase access to prevention of mother to child transmission of HIV service in Nigeria.



Graphical Representation of PMTCT Coverage in Nigeria (Data from CDC)¹¹

Methodology:

This research was conducted in Terry Stanford Institute of Public Policy at Duke University, Durham NC. It involved literature reviews using the library collections, papers, journal publications and online resources of Terry Stanford Institute of Public Policy and Duke University Library on current and previous works done by civil society organizations in Nigeria in prevention of mother to child transmission of HIV. Policy publications of international organizations like International Labor Organization (ILO), World Health Organization (WHO), UNAIDS, World Bank and UNDP on civil society participation in HIV/AIDS management were also examined. This was necessary to know the current level of participation and ways forward towards improving participation or partnership. Likewise, extract from the literature was needed on how policy can empower civil society participation and ways of introducing such policies in Nigerian HIV/AIDS national health policy program. In addition, this research involved visits to Duke University Medical Center to appreciate prevention of mother to child transmission of HIV

and pediatrics HIV/AIDS management to learn from their HIV treatment implementation models so as to document and recommend best practice from US to Nigeria. Their strength and challenges were also documented in treatment and adherence. This research was conducted from October 3- October 31, 2007.

Result/Project Output:

Works of civil society in PMTCT in US, Nigeria and other African countries were appreciated. I was able to appreciate the importance of developing good health policy in enhancing civil society participation and response to HIV/AIDS in US. Moreover, I was able to know evidence-based practices favoring their active participation in the US. This research was able to highlight ways to strengthen civil society participation/partnership towards scale-up of prevention of mother to child transmission of HIV. It is hoped that civil society in Nigeria will be able learn from and replicate the works of civil society groups that are partnering with government in the provision of prevention and treatment services in other developing countries and developed country like United States.

Public Private Partnership at International Level:

Players in international PMTCT initiatives must actively engage civil society groups if they wish to make meaningful impact in Sub-Saharan Africa. Alliance between international players and local civil society groups ought to be seriously promoted, as it will foster public private partnership that is capable of providing effective treatment deliveries to pregnant women and their babies. These international PMTCT initiatives include President's Emergency Plan for

AIDS Relief (PEPFAR), Call to Action Project, UN Interagency Task Team on MTCT, MTCT-Plus and the Global Fund.²²

PEPFAR has a commitment to reduce mother-to-child transmission by 40% in 14 focus countries with a long-term plan of treatment for infected mothers and babies.

While, Call to Action project was started by Elizabeth Glaser Pediatric AIDS Foundation in September 1999 as a public-private partnership initiative with funding from private and government agencies. Their goal is to prevent mother to child transmission and scale-up PMTCT programs in developing countries.

Additionally, the UN Interagency Task Team is an initiative formed by WHO, World Bank, UNICEF, UNFPA and the UNAIDS to work in collaboration with countries to establish the PMTCT program delivery.

Also, the MTCT-Plus was started by Columbia University School of Public Health in 2002 with funding from PEPFAR, Rockefeller Foundation and Gates Foundation. Their focus is on providing specialized care to HIV positive pregnant women and babies. Finally, Global Fund to Fight AIDS, Tuberculosis and Malaria is a very good example of a public-private partnership providing funds for HIV programs including PMTCT. One of their commitments is to reduce mother to child transmission of HIV in developing countries such as India, Haiti and Malawi.

Why is Prevention of Mother to Child Transmission Important:

- to improve the health of HIV positive expectant mothers
- to prevent new infections in babies

Besides, preventing HIV transmission to the babies, it should be appreciated that the health of the HIV positive mother is equally important. Antiretroviral therapy has the potential of improving their health especially when their CD4 count is low or the viral load is high.

In order for civil society groups to make significant impact on PMTCT, awareness campaigns to prevent HIV among women of reproductive age are needed. If they are not positive, no virus will be transmitted to the baby during pregnancy, delivery or breast feeding. Civil groups can also assist in the areas of contraceptive unmet needs in Nigeria. They can assist by in promoting contraceptive uptakes among HIV positive women to prevent unwanted pregnancies. Lastly, they can be active in setting-up treatment centers to prevent transmission in HIV infected pregnant women. Civil society can provide expertise to sustain and make public-private partnership to be successful. Partnerships have to maximize the strengths and resources available with government and private institutions to promote scientific, technical and social solutions to PMTCT. Partnership should be able to make best practices in treatment available and create a sustainable support system for clinical and technical areas of HIV prevention.

Obstacles to PMTCT:

Poor Healthcare Infrastructure

Limited number of trained healthcare workers

Poor Infrastructure for diagnosing HIV infections in babies/infants

Stigmatization

Cultural issues

Lack of integration of PMTCT into routine antenatal care

Inadequate number of voluntary Counseling and Testing Centers

Mixed feeding (combination of infant feeding and breast feeding)

Partnership between civil society group and government:

It is important for the government to see civil society organizations as partners and not competitors in achieving better health delivery and outcome for the people. Government has to create enabling policy environment for them to operate. This will make them to be more prominent in responding to HIV/AIDS prevention, treatment, support and care.⁴ Civil society groups have to be thoroughly engaged in designing, implementing, monitoring and evaluation of programs based on the goals of the organization and the skill sets offered by their members of staff. This engagement and incentives by government will lead to mobilization of various community or civil society groups. On the other hand, the government is limited in HIV/AIDS program delivery with a big country like Nigeria. Thus, empowering civil society groups will go a long way in helping scale-up of HIV activities. At national or federal level, civil society should be co-opted in designing national strategic plan for prevention of mother to child transmission of HIV. This collaboration is needed for broad-based national response to HIV among pregnant women and children as civil groups are stakeholders in prevention and treatment.⁴ Additionally, there is a need to stimulate the civil society participation through awareness, funding, recognition; and government should help to strengthen on-going community based projects and interventions by civil society groups. This will create enabling and motivating framework for reasonable action plan in addressing HIV challenges.

Risk factors or Predictors of vertical transmission in Nigeria - MTCT:

A) Prevention Perspective:

- 1) Acquisition of HIV during pregnancy; this is an acute primary infection which is characterized by high viral load with higher risk of HIV transmission to the baby
- 2) Substance Use
- 3) Late presentation for booking during antenatal care for an HIV positive pregnant woman
- 4) Early rupture of membrane
- 5) Infections in pregnancy for example malaria

B) Laboratory Perspective:

- 1) High Viral load > 1000 copies/mL
- 2) Low CD4 Count < 200 cells/mm³
- 3) Presence of genital herpes

C) Treatment Perspective:

- 1) Lack of ARV drugs
- 2) Poor adherence to medication
- 3) Stock-out of medication
- 4) Poor accessibility to treatment center
- 5) Late entry to care

D) Social Perspective:

- 1) Stigma

- 2) Lack of disclosure or partner notification
- 3) Lack of Support Group
- 4) Psychosocial problems- fear of medication, depression

From the 4 perspectives above, how can the civil society partner with government in Nigeria?

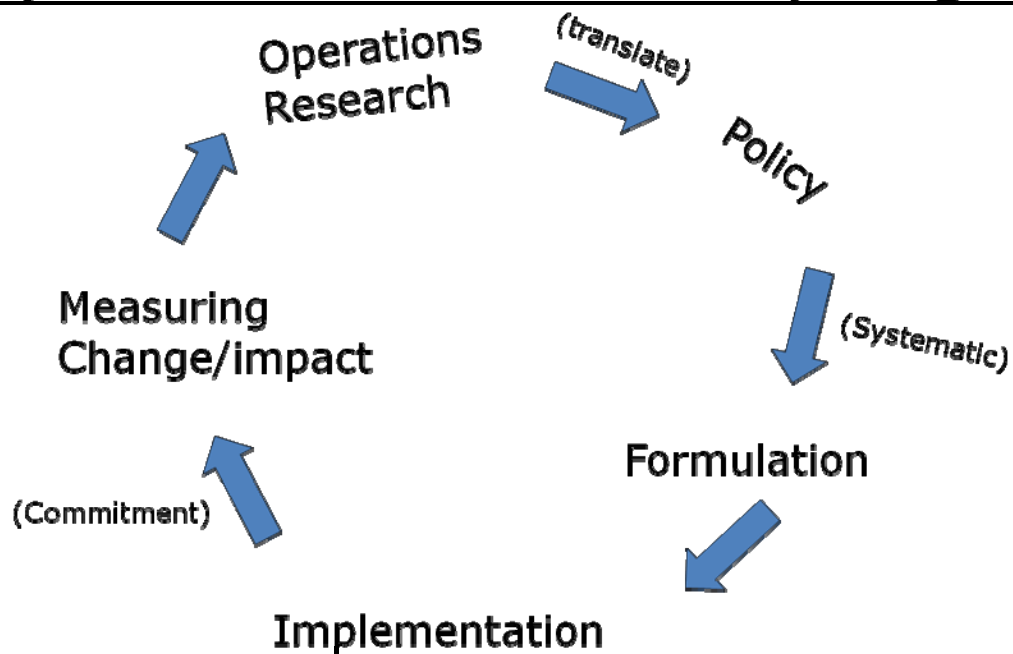
There are various opportunities to make the impact of the civil society groups felt in Nigeria. Civil society groups can be involved in organizing HIV awareness programs targeting pregnant women for early testing and antenatal booking to increase the utilization of prenatal services. Since Nigeria is a malaria endemic country, they could be involved in bed-net distribution to prevent mosquito bites as placental malaria is a risk factor in vertical transmission.²³ We need organizations to promote male partner involvement in antenatal care of mothers. HIV positive mothers need the support of their male partners and extensive awareness campaign is needed to educate men of their role in antenatal care of both HIV positive and HIV negative women. Voluntary counseling and testing (VCT) is the entry point in PMTCT program, civil society groups with expertise in laboratory services could help set-up VCT services in various locations across the country and with ability to conduct CD4 count, viral load and other laboratory tests that are needed in HIV management. Similarly, since the level of coverage of PMTCT is low, civil society should be committed to expanded treatment program or scale-up of treatment program in rural areas or places far from cities. These are often marginalized in HIV service delivery. Most interventions tend to occur in cities but we need to decentralize our delivery program to reach poorly accessible rural areas to benefit from HIV prevention.²⁴ Although civil society groups have been involved in support groups in Nigeria, we need to create new and

strengthen treatment support groups and family support system in our community mobilization program. Also, regular auditing of government treatment programs through evaluation or operations research is needed. Civil society should be given opportunities to evaluate government programs and vice versa. The essence of our HIV program delivery is to reduce new infections and improve the quality of lives of those living with HIV and AIDS. Thus, constant evaluation is needed to improve our programs, to identify existing gaps and proffer achievable and practicable solutions. Lastly, civil society groups should be actively involved in building capacity of health care workers working in government and private hospitals. We need competent hands for treatment and care programs, laboratory diagnosis and voluntary counseling. Training opportunities for healthcare workers should be paramount in scale-up of HIV by civil society groups.

Policy issues in civil society participation:

Civil society must be truly recognized as key and formidable partner in prevention of mother to child transmission of HIV. Civil society groups should not be seen as competitors but rather important partners capable of long-term scale-up of PMTCT program. Government should actively promote the engagement and participation of civil society. This is possible if sincerity, commitment and political will are demonstrated from the side of the government. Equally important, representation of civil society members in policy formulation, deliberation, implementation and decision making is necessary for scale-up. This is possible if they are welcome by the government in elaborate national response to PMTCT. Lastly, they should be involved and encouraged in the 4 C model of patients' management which are Comprehensiveness of care, Continuity of care, Coordination of care and Competence in care.

Anticipated Flowchart for PMTCT Policy in Nigeria



Challenges to Civil Society Participation or Partnership:

Inadequate funding is a key issue. Money to run programs and be involved in partnership is not adequately available. There is a need for government and international donors to increase funding to assist civil society groups participate with little or no restriction. Secondly, ineffective or weak collaboration among civil society groups within and outside Nigeria is another challenge to participation. It is high time civil society groups begin to identify their areas of strength and weakness, partner with other organizations that are better in areas of their weakness and form a solid team for collaboration. There is no perfect organization but there can be a perfect team of organizations that are collaborating towards a laudable goal. This consortium will lead to synergy of purpose. Prevention of mother to child transmission of HIV needs such synergy to improve coverage and ensure quality service delivery in the prevention program. Furthermore,

they need to be more involved in information sharing. No civil society can develop or make impact in isolation. Lack of information sharing can be a limitation to effective program delivery or getting feedback from other players in the field of HIV. In addition, implementation of donor-driven priorities instead of people or community-driven priorities should be avoided. Donors need to understand that there is a difference between observed need and felt need. Needs assessment should be effectively utilized in PMTCT program. Funding for project thematic areas is good to have focus in making lasting impact on the people. But, funding restrictions should be avoided as it may drive down innovation.⁴ Lastly, more often than none, quite a number of civil society organizations have poor practical and research skills, and dearth of training resources. Research should be embedded into programs so as to improve the operations of the program. We need capacity building program for staff of civil society groups to build their competence not only in program delivery but also in research. Governmental and donor agencies need to assist in training resources or materials to assist these organizations. This may also call for setting up of library where materials for HIV prevention can be readily accessible.

Best Practice from North Carolina (NC):

Pregnant women are tested for HIV at first and third trimesters unless they refuse or opt-out. Women will be tested at the time of presentation for labor especially if she has no HIV test indicated in her medical record.²⁵ HIV testing became mandatory from November 2007 in North Carolina. All the centers have till 2009 to make rapid testing available for HIV screening.

Rapid HIV testing is done in NC with:

-Ora Quick Advance

-Reveal G3

-UniGold

And HIV sero-conversion is confirmed with Western Blot in NC. However, rapid HIV test is quicker to perform with little expertise. Unlike in Nigeria, we use ELISA which requires expertise and we also confirm with Western Blot.

In North Carolina, there is a strong collaboration of obstetricians, gynecologists, pediatricians, nurses and social workers. The team work towards efficient patient management was laudable. Once in a year, they meet to discuss the recent happenings, best practices, policies and new treatment combinations in the state in the areas of mother to child transmission of HIV and pediatric HIV.

Additionally, North Carolina has very remarkable transition plan in place where HIV positive mothers will be referred to adult physicians during or after post-natal period; or how HIV positive children will be referred to adult physicians from 18 years of age. Despite referral to adult physicians, obstetricians and pediatricians through social workers still ensure that their former patients' continuum of treatment is well maintained.

Furthermore, if the viral load is >1000 copies/mL, the pregnant woman is scheduled for elective cesarean section (CS) in North Carolina, however, this may be difficult to implement in Nigeria given the cost of this operation.

Infant HIV testing after delivery is done with Polymerase Chain reaction (PCR). HIV positive mothers do not breastfeed; the babies are fed with infant formula.

At obstetrics and gynecology (OBGYN) clinic of Duke University Medical center, PMTCT program is effective with negligible transmission to babies. Commencement of treatment or prevention is usually at 14 weeks of pregnancy using mainly combivir (AZT and lamivudine) and Kelatra (lopinavir/ritonavir). While in Nigeria, due to resource constraint we normally commence therapy anytime from 28 weeks of gestation with Zidovudine or Stavudine, lamivudine, and nevirapine.

Risk factors to MTCT in NC:

- HIV diagnosed during pregnancy (primary infection)
- High viral load
- HIV not diagnosed until delivery or after delivery
- Non-adherence
- No anti-retroviral drug taken or no intake of highly active anti-retroviral drugs (HAART)
- Vaginal delivery with high viral load
- Substance Use

Why do we need Health Sector Reform in PMTCT in Nigeria?

- 1) We need to accelerate scale-up or coverage
- 2) HIV management is a shared responsibility of public and private sectors as stakeholders, both sectors should be motivated and mobilized

- 3) To maximize health sector's contribution and response to the HIV scourge.^{26,27}
- 4) Enable people and pregnant women to be tested as entry points for treatment programs

Challenges to Health Sector Reforms:

- 1) Poor Decentralization: to improve coverage, availability and accessibility of services especially in rural communities^{24,27}
- 2) Shortage of trained Health workers on anti-retroviral drug (ARV) Use
- 3) Poor Data collection system
- 4) Lack of Monitoring and Evaluation tools
- 5) Poor Linkage or partnership of health service delivery systems with communities and NGOs
- 6) Poor or lack of facilities such as laboratory for viral load or HIV infant testing with Polymerase chain reaction (PCR)
- 7) Inefficient Drug supply- stock-out sometimes occur due to lack of effective planning for procurement
- 8) Poor Antenatal attendance especially rural areas

Strength of this project:

- 1) This is to strengthen private organization or civil society participation in PMTCT in Nigeria
- 2) Produce a memo to the Minister of Health on models for increasing public-private partnership in the scale-up of PMTCT
- 3) Mobilize and empower civil society as an important stakeholder in HIV management

Limitations:

I was unable to obtain data on prevention of mother to child transmission from North Carolina Department of Health and Human Services website. Unlike, states like Massachusetts where most HIV prevention and treatment statistics are made available online. It is difficult to ascertain the number of pregnant women that are HIV positive per year and the number or proportion in PMTCT program and the number of HIV positive babies at birth in North Carolina. Apart from Duke Medical Center, I was unable to visit other PMTCT treatment sites. Lastly, there is no current data on PMTCT program in Nigeria, the number of HIV positive mothers that benefitted from it in 2006, the number of HIV positive babies born and the number of facilities providing the service. In addition, there was inadequate information about contributions of civil society in Nigeria on prevention of mother to child transmission of HIV.

Further Research Opportunities:

- Clinical trials to improve the standard of care for HIV positive pregnant mothers in resource limited settings
- Studying and measuring civil society performance in HIV prevention and treatment programs
- Understanding and Overcoming barriers to civil society participation
- How to strengthen partnership to assist HIV positive pregnant women.

Conclusion:

There is an urgent need to mobilize civil society groups for care and treatment actions, in order to fill the gap of public sector provision of these services. These organizations are needed to develop sustainable initiatives and capacity to treat HIV positive pregnant women with

antiretroviral drugs. The long-term impact of this project is to help build systems to scale up the response of civil society groups for treatment and care. It is very pertinent to expand access to HIV treatment through civil society participation and for our government to partner with the private sector/civil society groups. Funding access to treatment is important and the civil society groups should be encouraged to develop interventional treatment and care programs. Not only are they required to partner in treatment, but they should be encouraged to monitor the implementation of treatment by government and donor agencies. This will help funds to be well utilized and ensure good accountability and sustainability. There should be effective networking among civil society organizations towards information sharing on training and treatment, and a need to realize that they are very important in the decentralization of treatment and care programs. We need to promote and strengthen support groups, networks and consortiums of people living with HIV, and organizations that are willing to provide HIV/AIDS treatment and care program for HIV positive pregnant women.

Recommendations:

We need to explore ways of building new public-private partnership and strengthen existing ones towards scale-up of our prevention of mother to child transmission of HIV in Nigeria.

This is needed for direct and indirect impacts in treatment program of HIV positive pregnant women.

There is a need to expand the role of civil society groups in developing and strengthening health policies and systems.

From the above findings, recommendations from this project will be made to the Consultative Group of Civil society in Nigeria, Federal Ministry of Health, and National Agency for Control of AIDS in Nigeria about the ways in which civil society could be better involved in scaling up of treatment and care among HIV positive pregnant women.

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Abbreviations:

CDC-Center for Disease Control

ELISA- Enzyme-Linked Immuno-Sorbent Assay

PEPFAR- President's Emergency Plan for AIDS Relief

UNAIDS- Joint United Nations Program on HIV/AIDS (UNAIDS)

UNDP- United Nations Development Program

UNFPA- United Nations Population Fund

UNICEF- The United Nations Children's Fund

WHO- World Health Organization