

Scaling up Civil Society Role by Reducing the Impact of HIV/AIDS on Orphans in Kilimanjaro Region, Tanzania.

Presented at the Terry Sanford Institute of Public Policy, Duke University - October 2003

*by Dafrosa Kokulingilila Itemba, (B.A. Education,) Executive Coordinator of
KIWAKKUKI, Women's Group Against AIDS in Kilimanjaro, Tanzania*

Acknowledgements

Many people have assisted me in the course of completing this work and I am happy to mention some of them. Thanks to Bruce Jentleson, The Director of Terry Sanford Institute Duke University for giving me the opportunity to conduct my research at his

institute and a word of encouragement every now and then. I'm also grateful to Milissa Markiewicz, Fleishman's Programme Coordinator for her never ending support with practical assistance and motivation. Thanks also go to Bautista Logioco for technical advice.

I'm also indebted to other colleagues especially Dr John Bartlet and Trish Bartlet for their input on the experiences at the Duke HIV/AIDS Clinic. My thanks also go to Dr Nathan Thielman also of the Duke HIV/AIDS Clinic and Margaret Thielman for their support for analyzing the data for the KIWAKKUKI children's study. Many thanks to Dr Cathryn Whitten and Rachel Stevens of Health Inequalities Programme for sharing a lot of experiences in Public health Research with Children. You all assisted me in my reflections about my work in Kilimanjaro Tanzania.

Everyone's contribution was a resource that made me produce this study the way it is. However there are possibilities of errors , omissions, mis reporting, under reporting and other errors all of which remain my responsibility and I apologise. Dafrosa Kokulingilila Itemba

Contents

1.0 Introduction

- 1.1 Timing
- 1.2 The Purpose
- 1.3 The Methodology

2.0 The Problem

- 2.1 Statistical Background
- 2.2 The Role of the Tanzanian Government - Policy Formulation
- 2.3 The Role of the Civil Society - Policy and Power
- 2.4 The Role of KIWAKKUKI – Community Response

3.0 The Global HIV/AIDS Situation and its impact on children

- 3.1 Statistics and Situation in General
- 3.2 Global Commitment
- 3.3 HIV/AIDS and the Rights of the Children as per UN Regulations
- 3.4 Convention's perspectives to HIV/AIDS
- 3.5 Impact and Examples
- 3.6 Children's Risks, Challenges and Practice

- 4.0 Responses from selected African Countries Experiences: A Comparative Analysis Towards Mitigation of Impact caused by AIDS to the Orphans.**
- 4.1 Botswana
- 4.2 Uganda
- 4.3 Zimbabwe
- 4.4 Kenya
- 4.5 Malawi

5.0 Major Findings and Lessons learnt

- 5.1 Violations of the Rights of children Affected by HIV/AIDS
- 5.2 The Response of African Governments
- 5.3 Best practices of impact mitigation in selected countries.

6.0 Recommendations to the Government of Tanzania, the Civil Society in Tanzania and KIWAKKUKI on how to scale up her work of supporting orphans. in Kilimanjaro, Tanzania

- 6.1 The Tanzanian Government
- 6.2 The Tanzanian Civil Society
- 6.3 KIWAKKUKI
- 6.4 Scaling Up
 - 6.4.1 KIWAKKUKI Leadership.
 - 6.4.2 Surviving Parents/Foster Parents/Children heading families.
 - 6.4.3 Children's Capacity
 - 6.4.4 Leaders in Kilimanjaro
 - 6.4.5 Research
- 6.5 Conclusion

Introduction

1.1 Timing

I would like to start by saying that I really don't understand and perhaps you don't understand why the world had to wait for 20 years to notice the crisis of orphans and worse still, why the African states with the exception of Uganda never anticipated the impact of HIV/AIDS on the children! Surely, no parent would like it if they were told that when they die, there would absolutely be no future for their children? Nearly all children in Africa are potential orphans because they have to cross several health and social provision hurdles. We need to look at the world through the children's eyes.

Many leaders, writers and researchers describe the AIDS Epidemic as the worst disaster and the greatest challenge mankind has experienced.

In the speech of the UNAIDS Executive Director in Tanzania Peter Piot in December 2002 at the opening ceremony of the conference of the African Ministers of Education, he remarked that *"AIDS stands not only as the most catastrophic disease the world has ever faced and the deepest challenge to the development of Africa, but also the biggest obstacle to achieving Education for All"*.

The Uganda AIDS Commission, writing on the Evolution of the Epidemic said, *"Twenty years after the first clinical evidence of Acquired Immune Deficiency Syndrome was reported, it has become the most devastating disease humankind has ever faced."*

Deininger, et al observed that *"The AIDS crisis is believed to have expanded the human development agenda of countries and is already threatening the care giving capacity of communities"*. They raise a logical question as whether it will threaten the capacity of governments to handle the crisis.

HIV/AIDS came into the world at the time when many countries in the developing world especially Africa were slashing budgets and closing down abandoning social

infrastructure. This has necessitated the growing importance of the Civil Society as new channels for delivery of social services and implementation of development initiatives, not only in Africa but also throughout the world.

The paper covers such issues as conceptual views around policy and HIV/AIDS, the existing problem based on gaps around HIV/AIDS and roles played by both the government and the Civil Society with the case of KIWAKKUKI. Also discussed is the impact of HIV/AIDS on children's rights, health and related risks. There is also an analysis of how some African countries have responded to the scourge, lessons learnt and recommendations to Tanzania and KIWAKKUKI.

Concepts related to policy development and also to HIV/AIDS include:

Civil Society.

African Development Bank publication, 2001. Cooperation with Civil Society Organizations: Policy and Guidelines, February, 2003, defined Civil Society as “ *Social realm including NGOs, but extending well beyond them to encompass peoples' organizations, trade unions, human rights bodies, religious groups, community based organizations, associations of business, professional people and so forth.* ”

Shariff and Abee's views Civil society as “ *a term commonly used to cover a wide range of organized groupings which occupy the public space between the state and the individual citizen, . They are normally interest groups with different degrees of accountability to their membership basis:*

They include:

- *Non- governmental organizations(NGOs) both national and international*
- *Religious organizations*
- *Professional associations*
- *Trade unions*
- *Co-operatives*
- *Voluntary and self-help groups*
- *Organizations representing socially excluded groups such as women and people with disabilities*
- *Political parties*
- *The media*
- *Community- based organizations*
- *Legal and human rights groups*
- *Research organizations*

Scaling up, According to The Oxford American Dictionary of Current English, (1999) it means, “*make larger in proportion, increase in size*”.

The American Heritage College Dictionary, (2002) , it means “*to climb up or over, ascend. To alter according to a standard by degrees*”.

The South African Concise Oxford Dictionary, “*increase something in size, number or extent*”.

Orphan¹, all the above dictionaries define this word as, “*a child whose parents are dead*”, meaning both parents as Oxford puts it. However, the UN defines ‘orphans’ as “Children who lost one or both parents” and this is the definition followed by KIWAKKUKI.

A general consensus among HIV/AIDS actors is that unless the spread of the HIV/AIDS epidemic is scientifically arrested, any progress in poverty reduction will be put at risk. Adelman (2002)

1.2 The Purpose

The purpose of the study was to assess the approach used by the Civil Society and governments in some selected countries of Africa, working out the ways of scaling up my organization’s work and also to evaluate the potential for appraising the existing Tanzania HIV/AIDS and Education Policies regarding social delivery and how this could improve the livelihood of the poorest poor, that is the children orphaned by HIV/AIDS, their caretakers and the community at large and produce optimum outcomes.

KIWAKKUKI as one of the NGOs in Tanzania would like to enhance her participation in poverty reduction especially in recognizing and respecting the rights of the children orphaned by HIV/AIDS to sustainable livelihood. In this way this organization will be contributing to the Poverty Reduction Strategy of Tanzania.

The findings on success cases will enable KIWAKKUKI increase empowerment of the communities in Kilimanjaro for poverty eradication in an integrated approach to enable them care for orphans in the grassroots level.

The identification of ‘Best Practices’ could help to stimulate more inspiration into research, promote positive thinking, experience sharing and shares lessons about work being done on HIV/AIDS.

1.3 The Methodology

The study mainly involved the Literature review of local literature in Tanzania, international literature, reports, publications of research institutions, UNAIDS, UNICEF, WHO and UNDP which gave an assessment of the real situation of the HIV/AIDS Epidemic at the global level, the African continental level, with specific reference to 5 African countries (from, eastern and southern Africa) the assessment of the impact

¹ The different definition of orphan may distort statistics since some agencies subdivide orphans into single and double categories

mitigation of the epidemic in the country of Tanzania and by KIWAKKUKI in the region of Kilimanjaro.

I participated in different lectures held at the Terry Sanford Institute and also managed to hold talks with some people living with HIV/AIDS in the United States, members of the Duke AIDS Research Treatment Centre (DART). I also participated in a focused group discussion on the comparisons between the impact of HIV/AIDS in the United States and Tanzania, in weekly meetings of members of the Research Fellows in the Health Inequalities Programme and managed to participate in the AIDS Awareness Rally organized here in North Carolina. .

The following Data was collected:

- 1 Children's Rights, Needs and Risks as per UN Standards- Theory and Practice.
- 2 Household Survey on the socio economic state of orphans from 6 wards of Moshi Rural Districts of Kilimanjaro region.²
- 3 Relationship between HIV/AIDS, Policy Development and Response of Civil Society in Tanzania
- 4 Individual country Analysis in terms of the responses from the government and Civil society, types of services provided and also Achievements/ Challenges. This was for the countries of Kenya , Uganda , Malawi , Zimbabwe and Botswana.
- 5 Major Findings and Lessons Learnt basing on identified best practices of impact mitigation and conclusions.

The research results were used to further analyze the options for possible programs to be used for mitigating the impact on the children and finally make recommendations which could scale up KIWAKKUKI's current response to the HIV/AIDS epidemic in Kilimanjaro and scale up orphans' impact mitigation.

2.0 The Problem

2.1 Statistical background of Tanzania and HIV/AIDS Situation in general.

- Total Population as at 2002 was 34,569,232 (Source 2002 Population and Housing Census – General Report.
- 2 m. people are believed to be living with HIV/AIDS , 80% of which are in the productive age group of 20 – 44 years
- The average prevalence of HIV in the sexually active adult population (15 – 49) years is 12%
- Child mortality rate had declined in 1980s and 1990s but now reversed due to HIV/AIDS
- At least some 1.5 million children have been orphaned by AIDS and out of that only

² This survey was conducted in June 2003.

667,000 have survived.

- There has been an increase in the proportion of children > 15 years who are orphans by 2000. 1.1% had lost both parents and 6.4 had no father and 3.5 had no mother.
- Despite children being affected by HIV AIDS, some are HIV infected and they have no access to medication be it for opportunistic diseases or Anti Retroviral Treatment.
- Life expectancy at birth according to World Bank will be at 47 in 2010 as opposed to the projected 56 years.
- Notable achievements in Prevention efforts in Tanzania include observed decline in prevalence rates in Kagera and Mbeya regions most likely due to intensive HIV/AIDS prevention programmes in the regions.
- Despite efforts of HIV/prevention and Care, there has been very little impact measured.
- Poverty has been singled out as a retarding factor to the government, private sector and families.
- Kilimanjaro region has a total population of 1,381,149 people and an estimated HIV prevalence of 11%

2.2 The Role of the Government in Policy Formulation, Implementation and Evaluation in Tanzania

The literature available about the history of Policy Development in Tanzania as explained by an official of the President's office at a national HIV/AIDS Conference (2000) depicts that , it was dominated by a state centred conception of “ Ujamaa” policy which viewed citizens as ‘clients’ or ‘recipients’ of state delivered programmes like the ‘Villagization Programme, Universal Primary Education, Free Health care and others. In the developed economies social welfare recipients are viewed as consumers who participate through choice among a range of services.

The Health Sector Reform of 1994 decentralized the resources to the local government but eliminated free medical share and introduce a cost sharing policy. The immediate consequence was a drastic reduction in hospital outpatient records. Definitely , this had a gross impact on the orphans because they no longer enjoyed free medication.

In 1998 a non Governmental Trust, the Social Action Trust Fund a \$10million facility was established by the government of Tanzania, and funded by USAID to be able to promote private sector and supporting orphans' schooling. This was an excellent move since it is sustainable and is offering loans to the Tanzanian industries the profit of which is pumped to the needy orphans.

In December 1999 the president of Tanzania, His Excellency Benjamin William Mkapa declared HIV/AIDS a national disaster and called up on the entire society of Tanzania to intensify the fight against the epidemic and ordered AIDS top on all agenda in ministries and private sector.

When Dr Peter Piot Executive Director of UNAIDS visited Tanzania in 2001, he commended her for her growing and visible political commitment to the fight against HIV/AIDS.

The (December 2001) HIV/AIDS Policy document of Tanzania admits that poverty has created vulnerability to infection to many people and has been the cause of rapid progression of the disease due to malnutrition and inadequate access to social and health care services.

The National Multisectoral Strategic Framework (March 2003), regrets that the Poverty Reduction Strategy Paper (PRSP,2000) failed to provide the general development policy framework for dealing with the HIV/AIDS impact, resources allocation and challenges. In Tanzania there have been wide gaps between the laid down policies and the reality as far as **implementation** is concerned. Moreover, many policy documents are contradicted by the cost sharing policies especially in health.

To be precise there is no infrastructure for delivery of social services by the government to the orphans despite the good policy statement. The National AIDS Control Programme tried to some extent to establish prevention strategies throughout the country.

The cost sharing reforms introduced user fees as part of poverty reduction strategy and it went hand in hand with privatization of health services making cost sharing even more expensive. The waivers introduced with the reforms are not known to the beneficiaries, Newbrander and Sacca (1996). One study made in Tanzania revealed that not only are the poor not aware of the waiving of health costs but also the exemptions which are available. The whole thing then becomes a mockery.

A small study was made by KIWAKKUKI in collaboration with the department of Infectious diseases of Duke University to determine community response when they have to pay for VCT services and when they have not to pay and the results showed a marked increase in clientele especially among the youth, when the service was free.

In 2001, the Tanzania Commission for AIDS (TACAIDS), was launched to coordinate and monitor a multi sectoral response. It is the expectation of the Tanzanians that this body will demystify the policy process allocate resources to the marginalized groups and help the suffering children find the world a better place to live.

2.3 The Role of NGOs in Policy Formulation, Analysis and Implementation in Tanzania

Tanzania has more than 6,000 NGOs operating countrywide. The Tanzanian NGOs have

also been watching the utilization of good governance , the democratic participation of stakeholders and demanding transparency and accountability in project implementation and striving to be transparent themselves.

In his Human Right Monthly Report, Rwehumbiza, P (2003) observes that the process of developing policies using the example of the Tanzania NGO policy rose eyebrows because it didn't involve large spectrum of stakeholders from the beginning. The government selected people of its choice to participate in the discussion thus making it a free participation. and less democratic on the part of the civil society.

Despite mobilization for protest, by the Tanzania's Association of the Non Governmental Organizations, (TANGO) the policy was officially out in November 2001. Things went fast and in 2002 despite the largest opposition organized by the civil society outside the parliament building in Dodoma (the capital) against the bill, the Tanzania Parliament passed the NGO Act in 2002.

While the 2001 NGO policy reflected the government's recognition of NGOs as partners, the 2002 Act does not create a favourable environment within which these organizations can work. " There are many gaps in the act and we are demanding that the government makes these changes so NGOs can operate in a suitable environment.." says Mabwe, N, a Programme Officer of TANGO.

The NGO Coalition on Debt and Development (TCDD) and the Gender budget initiatives by the Feminist Activism Coalition(Fem Act) Tanzania Women lawyers Association (TAMWA) are part of the monitoring process for the efficient and effective utilization of resources.

Some NGOs are engaged in Capacity building, others in advocacy work and others in social service delivery although many cut across all fields. Some NGOS deal with children orphaned by HIV/AIDS and details will be given about KIWAKKUKI below.

Recent Newspaper reports from Tanzania inform us that the Tanzania Network of PLHAs has waged a campaign to the government for access to Anti retroviral drugs through " Treatment Action campaign ", chaired by Julius Kaaya, one of the commissioners in the Tanzania AIDS Commission

Can more be done?

- Tanzania should not be satisfied by the good work being done by the Social Action Trust Fund . More Aid should be sought to promote both domestic work and impact mitigation in the fields of research and clinical trials..
- Tanzania still lacks transparency about her intent or no intent to consult or exclude the civil society in policy development. This slippery partnership has contributed to the retardation of the impact mitigation process on orphans
- The Tanzania HIV/AIDS Policy (2001) document and its accompanying multi sectoral strategy (2003) document have yet to be demystified.

- The majority of the Tanzania Civil Society lacks empowerment on Policy Monitoring and Advocacy.
- Mwingira (2001) remarked in her paper on the role of NGOs in development and the relationship with the government that in the developed world , the civil society sector plays a major role in influencing policies and the development trends and also acts as a pressure group for advocacy and affecting policy changes and choice of priorities.

Tanzania could learn from the Project Inform's Public Policy Department, San Francisco whereby the project advocates for access to treatment and quality health care for PLHAs (People Living with HIV/AIDS used direct advocacy, coalition network and grassroots organizations to communicate with their elected officials about the need for adequate funding for programmes and legislation that improves the lives of PLHAs. This has been achieved through 'Treatment Action network care.

2.4 The Current Role of KIWAKKUKI

KIWAKKUKI which is a Kiswahili acronym for a Women's group Against AIDS in Kilimanjaro Tanzania, has been in operational for the past 12 years and has been conducting 4 major programmes based on prevention, care, voluntary counseling and testing and offering support to children orphaned by HIV/AIDS. Although KIWAKKUKI has grown relatively tremendously in terms of size and finances, there has not been a clear tool , practice or role model which we have been following down the road.

However, KIWAKKUKI strongly believes that HI/AIDS is a human Rights issue and therefore protection of the rights of the child are at the centre of her HIV/AIDS programme.

The support to the children orphaned by HIV/AIDS or other causes has been on the policy of 'rights' based as follows:

- Offering the right to easy access to education by sponsoring about 2,500 children from pre school to high school in Kilimanjaro region.
- Giving them the right to legal protection and social welfare support by referring them to legal aid clinics and government Social Welfare Department.
- Creating a space for children to express their views and enjoy the right to being listened to through supportive counseling and monthly meetings and annual picnics for HIV positive children.
- Offering the right to shelter through house construction (13 houses built so far at an average cost of 2,500 US\$)
- Offering the right to accurate information on HIV/AIDS and Life Skills using Youth Alive Club initiated by KIWAKKUKI in 1998.
- Strengthening and supporting the capacity of a few selected families

(caretakers) to protect and care for orphans.³

- Giving HIV- positive children the right to treatment for opportunistic infections and in this we also collaborate with government hospitals, the Kilimanjaro Christian Medical College and foreign hospitals like the US based Duke University Hospital.⁴
- We also link children with HIV Testing Facility available at our centre since March this year. (*We owe our thanks to the Department of Infectious Diseases of the Duke University Teaching Hospital for donating this facility to KIWAKKUKI*)
- Use of volunteers; Much of the achievement is facilitated by KIWAKKUKI's attempt to make the community own the social service provision for orphans by an extensive use of volunteers⁵ and a network of grassroots groups scattered throughout Kilimanjaro, also in collaboration with local leaders and faith based leaders. About 60 groups of 20 or more women each work as grassroots volunteers and are a good opportunity for social capital commodity but not fully exploited. Plastow,J has reported the use of volunteers as one of the strengths of KIWAKKUKI

Social capital has been defined in several literature and may have several models such as small restricted access groups, small open access groups, community based groups and others. Building social capital has been seen as a task of 'second generation economic reforms' and Social capital as an informal norm that promotes cooperation between 2 or more individuals. All groups embodying social capital have a certain radius of trust, the circle of people among whom cooperative norms are operative

However, KIWAKKUKI women groups have no skills for effective participation, fully utilization of their capacities and monitoring the democratization process which Tanzania is undergoing.

- KIWAKKUKI also utilizes the existing government structures and personnel like the Village and Ward level leadership, the social workers and lawyers (for legal and other social problems). Others are nurses, doctors, teachers and administrators to carry out different activities in service delivery partnerships only.
- There is also a Youth Alive Club trained to reach other youth with behaviour change messages and life skills through a Youth Talk to Youth Approach as well as conducting a school health programme to reach the school children and in school youth with sexuality education but this is not fully utilized.
- We also do a little advocacy work for increased access to resources from the community by conducting regular consultations with caretakers,

³KIWAKKUKI has secured a small grant which she has donated to very needy families caring for children who are under 8 years.

⁴ The collaboration with Duke Medical School is through research and financial support to our clinic.

⁵ KIWAKKUKI relies heavily on volunteers for her community work. These are trained in community entry skills.

school administrators, faith based leaders and other local leaders. However, the whole approach is quite fragmented since it is highly dependant on “drop in clients” rather than a partnership endeavor between the community ,the government and KIWAKKUKI.

- A rapid survey conducted by a group of community health researchers on the number of orphans in 2000 gave an estimation figure of 50,000 while we are supporting only 2,500 children.

Although these efforts have cost us a lot time, energy, and resources, KIWAKKUKI is still challenged by her strategy of programming.

It is apparent that there is more to be done to scale up the impact mitigation by making the existing strategies more effective and sustainable in terms of giving children opportunity to express their feelings, worries, desires and ambitions.

Moreover KIWAKKUKI has another gap in terms of skills for advocacy coupled with policy relevant skills, partnership building and documentation of Best Practices.

Scaling up is also important in strengthening the existing Social Capital to facilitate provision of children’s needs including food, education, shelter and so forth.

3.0 The Global HIV/AIDS Situation and its impact on children.

3.1 Statistics and Situation in General

UNAIDS and UNICEF report that since its outset about 20 years ago HIV/AIDS has claimed more than 20 m. lives globally and about 42 m. people are currently living with HIV/AIDS including an estimation of 3 m. children below 15 years.

They remark that HIV/AIDS has created an orphans’ crisis by orphaning more than 13 m. children under 15 who have lost one or both parents and an estimated number of 25 m. orphans by 2010.

They add that in countries where 15% of adults are HIV+, a third of today’s 15 year olds are projected to become infected with HIV/AIDS

This crisis according to UNAIDS and UNICEF “ requires radically scaled up national, regional and community responses for at least 2 decades especially in Sub Saharan Africa where the children have been hardest hit.

Lyons, notes that children and young adults currently between the ages of 15 and 24 were born and grew up as the first generation to experience childhood during the HIV/AIDS epidemic. It is the same population that the new HIV/AIDS infection are concentrated. .

Deininger, et tal observe that,

“ The AIDS Epidemic has orphaned millions of children. Even if prevention campaigns become hugely successful and HIV infections drop dramatically, most people already infected with HIV are expected to succumb to AIDS – related illnesses.....” and adds

that in the early eighties about 2% of African children were orphans and today it is about 15-17% (see table below) 1 child is orphaned every 14 seconds in Africa.

AIDS Orphans and the Dependency Ratio in Selected Countries

| Country | Estimated Number | Percentage of total | Age dependency Ratio |
|---------------|------------------|---------------------|----------------------|
| Botswana | 66,000 | 10 | 0.82 |
| Burundi | 230,000 | 7 | 0.94 |
| Cote d'Ivoire | 420,000 | 6 | 0.87 |
| Kenya | 730,000 | 6 | 0.90 |
| Namibia | 67,000 | 9 | 0.84 |
| Uganda | 1,700,000 | 15 | 4.0 |
| Zambia | 650,000 | 15 | 3.0 |
| Zimbabwe | 900,000 | 17 | 0.80 |
| Tanzania | 1,500,000 | 4.3 | |

Source: Adopted from Deininger et al (2003) AIDS Induced Orphanhood as a Systematic Shock: Magnitude, Impact and Program Interventions in Africa, p 1202

Without HIV/AIDS, the number of double orphans (with both parents dead) would have declined in overall orphan's rates from 1990 – 2010.

There has also been a big controversy as to whether building more orphanages could be an effective way of providing care to growing number of children orphaned by AIDS. The general observation is that orphanages fail to meet the developmental and long term children's needs.

3.2 Global Commitment

In June 2002 the UN General Assembly Special Session on HIV/AIDS, called for new commitments to strong leadership at all levels of society. Two goals to children affected by HIV/AIDS were laid out:

- “ member countries will develop national policies and strategies that build and strengthen the ability of government community and families to support orphans and children infected with and affected by HIV/AIDS by 2003 and
- Member counties will implement these policies and strategies by 2005”

The UN organized a historic General Assembly Special Session on Children in May 2002 for the first time to discuss children's issues. Children spoke out their ideas hopes and dreams and governments declared commitment “to changing the world for and with children-----“ The theme was “The State of the Worlds' Children”

3.3 HIV/AIDS and the Rights of the Child

Effects of HIV/AIDS on children can be measured quantitatively and qualitatively

Human Rights, HIV/AIDS and Children

Human Rights Watch (2003) has cautioned that HIV/AIDS has been analyzed as an economic, social and development catastrophe but less well understood as a human right crisis. This is true when considering the way people at risk could be stigmatized in using services.

The UN Committee on the rights of the child is a body that monitors how well states are meeting their obligations.

HIV/AIDS as guaranteed under the Convention of the Rights of the Child stipulates that, *“The states are obliged to promote the realization of human rights of children. HIV/AIDS impacts heavily on the lives of all children by affecting all their rights- civil, political, economical, social and cultural.”*

Therefore it is believed that the conventions perspectives to HIV/AIDS should be the holistic child rights based approach by addressing a wide range of issues that relate to efforts to prevention treatment and care.

HIV/AIDS transmission tends to be high among groups that already suffer from a lack of human rights protection, and from social and economic discrimination or that are legally marginalized.

3.4 Convention’s perspectives to HIV/AIDS:

- (i) *The right to non discrimination – rights of each child to be respected without discrimination (Article 2)***
- (ii) *Best Interests of the child – shall be a primary consideration in all actions concerning children (Article 3)***
- (iii) *The Right of Life, Survival and Development (Article 6)***
- (iv) *The right to parental care (Article 18)***
- (v) *The right to appropriate shelter***
- (vi) *The right to express views and have them taken into account – as well as freedom of expression (Articles 12 and 13)***
- (vii) *The right to rest and leisure (Article 31)***
- (viii) *The right to be registered immediately after birth. (Article 7)***
- (ix) *The right to Education and with view to achieving this right progressively on the basis of equal opportunity (Article 28)***
- (x) *The Right to sustained and equal access to comprehensive treatment and care (part of Article 24)***
- (xi) *The Right to basic social services (Article 27)***

(xii) The Right to sustained and equal access to comprehensive treatment and care (part of Article 24)

(xii) The right to protection from drugs and Substance Abuse (Article 33)

(xiv)) Involvement of children in research (part of Article 24)

(xv)) The Right to Special Protection for Highly Vulnerable Children from economic exploitation.(Articles 32 and 34)

(xvi) The right to be protected from child labour

(xvii)The right to be protected from abuse or bad treatment(Article37)

3.5 Impact and Examples

3.5.1 Discrimination increases vulnerability of children to HIV/AIDS and greatly impacts the lives of HIV affected and infected children through stigma, denial access to information, education, health or social care.

3.5.2 Discrimination based on gender is associated with taboos and negative attitudes of sexual activity of girls which impedes their access to health related services and this type of discrimination often impacts girls more than boys in the context of HIV/ AIDS.

3.5.3 Discrimination based on status irrespective of child's or his/her parent's or legal guardians race, colour, sex , language , religion, political, national, ethnic, or social origin, property , disability, birth or other status.

- Recent survey results by Population Communication Africa disclosed that in Kenya, 28% of young persons surveyed , believed that HIV could be transmitted by mosquitoes and 32% didn't know that condom use was part of safer sex practice. This puts them at risk of inability to protect themselves from HIV transmission.
- 3.5.4 Policies and HIV prevention, care and treatment mostly aim at adults and do not put children at the center of response to the pandemic by strategizing on the needs and rights of children.

In many cases after the parent's death or even after the mother's death, children are split up into extended families without their consent or may be exposed to harmful traditional practices such as violating girls' rights through early or forced marriages and making them more vulnerable to HIV infection.

- Human Rights Watch reported researchers' observations that one Kenyan girl in 5 reports that her first sexual experience is coerced or forced.
- UNAIDS reports say that the myth that a virgin girl has a cleansing effect to HIV has prompted some men in Southern and eastern Africa, to sleep with young girls who often are not aware of the risks in it.
- Despite major campaigns against Female Genital Mutilation, this practice is still rampant in some parts of Africa. Girl children often suffer this especially when they are cared by grandparents.

3.5.5 Exclusion of children to participate in raising awareness by speaking out about the

impact of HIV/AIDS on their lives and development of HIV/AIDS policies and programmes. Children are expected to carry out their own initiatives and to participate fully at community and national levels in HIV policy and , programme design and implementation to encourage their **evolving capacities** and have their views expressed and heard to reduce stigma and discrimination.

3.5.6 The trauma and hardship that children affected by HIV/AIDS have to persevere is tremendous. They have to watch one parent after another gradually growing ill and dying. Usually there is little or no family future plan.

Once children realize that a parent may die, the future become a major concern. “Where will I go” and “Who will pay my school fees?” etc. When children are not given the opportunity to express their emotions about the situation, these feelings are left to fester and may have long term effects such as depression or nightmares.

- At the recent ICASA Conference in Nairobi, a representative of the Youth Forum for Africa challenged the organizers that the youth are the hardest hit but were being sidelined in decision making, “There is nothing for us without us

3.5.7 Many children in Africa are not registered and this impact will cost them in future, when processing their passports , social security and other documents.

No research findings were found to justify this observation but even before HIV/AIDS registration of births was not popular in Africa.

3.5.8 The urge by United Nations for states to ensure Primary Education is available to all children whether orphaned or otherwise affected by HIV/AIDS is still a big problem in seriously hit areas where children especially girls can’t stay at school and also increased death rates of teachers and other employees destroys children’s access to quality education.

- Uganda AIDS Commission reports that a study carried in South West Uganda shows school absenteeism in AIDS affected households is significantly higher among girls than boys.
- A Human Rights Watch reported a study in Zambia where 68% of orphans of school age were not enrolled in school, with 48% non orphans
- UNAIDS Report on Zimbabwe shows that 48% of Primary school age orphans had dropped out of school mostly after their parents’ illness or death.
- In Zambia reports indicate that teachers are increasingly dying of AIDS and many more show up occasionally to teach because of illness.
- Orphans school attendance rate as a percentage of non orphans attendance rate(1995-2001 in Tanzania was 72%

3.5.9 Children’s confidentiality is lost when they don’t utilize services that are friendly and supportive, providing a range of services and information and also geared towards their needs of accessing HIV specific care, treatment support and make plans for their futures in view of their evolving capacities.

3.5.10 Some orphans are HIV positive because they get the infection from their parents through Mother to Child Transmission (is it parents to child transmission?). So children can be infected during pregnancy, delivery or breastfeeding. Efforts to

prevent this will have a slow take off because of the existing health inequalities between nations which puts these groups at risk.

- In Malawi it is reported that 385 of women become mothers by age 18 and 57% of girls have reported that they feel it is easier to risk pregnancy than ask their partner to use a condom. In this way they contribute to the growing number of orphans.
- Young people in Tanzania told researchers that they treated themselves for STI's with the counter - medicines, rather than going to the health clinic.

3.5.11 Children living in difficult circumstances become more vulnerable to HIV/AIDS as a result of political, Economical, social, cultural and other factors making their livelihood being left with insufficient support to cope with impacts of HIV/ AIDS on families and communities. These may be children living in refugee camps, detention, institutions and armed conflict.

3.5.12 Vulnerability affect children orphaned by AIDS , children from affected families and from child headed households. They need legal, economic and social protection, proof of identity, and help to keep siblings together.

- A survey done in Zimbabwe by the Farm Orphan Support Trust in 2000 estimated that one third of children orphaned by AIDS on commercial farms had dropped because their families could no longer afford school fees.
- One lawyer, Director of the Kenya Ethical and Legal issues Network on HIV/AIDS was reported by Human Rights Watch to have told researchers that “There are so many cases where the nearest relative wants to take up the property but not care for the children.

3.5.13 Victims of Sexual and Economic Exploitation mainly girls and boys without means of survival due to HIV/AIDS may be subjected to sexual and economic exploitation like exchange of sexual services for money to support dying parents and younger siblings or to pay school requirements.

- Studies conducted in Malawi report that socio-economic conditions force orphans to engage in prostitution for economic security for themselves and their younger siblings. Social norms also encourage older men to seek sex with younger girls assuming that they are free of AIDS and in some countries HIV positive men believe that sleeping with virgins has a cleansing effect of the virus.
- UNAIDS and UNICEF report on trafficking of children in agriculture and domestic service which has recently emerged as a problem in sub- Saharan Africa. They estimate that out of 300,000 children about 120,000 are thought to have been coerced into military service either as soldiers, porters , messengers, cooks or sex slaves in various African countries.
- Several research results indicate that in sub- Saharan Africa women and girls are the majority of People Living with HIV/AIDS and also responsible for 50-80% of food production, including labour intensive work of planting, fertilizing irrigating, weeding, harvesting and marketing.
- The author agrees with the new definition of Poverty as a day -to - day struggle for life in which an individual may be unable to afford the "luxury" of worrying about HIV/AIDS.

- A recent study in South Africa of 141 street children revealed that more than half exchanged sex for food , money or protection.

3.5.14 Victims of Violence and Abuse (Article 19) including rape and other forms of sexual abuse in the family or foster setting or by teachers , employees of institutions working with children, prisons and others.

- In Rwanda during the genocide, more than 35% of women and half of them teenagers were raped and half of them tested HIV- positive compared to 11% who had not been raped.
- UNAIDS has observed that, the political will to establish HIV/AIDS policies is lacking in many countries , especially those policies that help women and girls.
- Mass rape, military sexual slavery, gang rape, and the rape of young girls have all been known to accompany war.
- In Harare, Zimbabwe, as many as 12% of 13-16 year olds at sexual abuse clinic tested positive for HIV.
- Use of alcohol and drugs may reduce the ability of children to control their sexual conduct and increase their vulnerability. One worker for orphans programme run in one of the slums in Nairobi supported by Action AID Kenya reported that they normally find children abused through survival sex and alcoholism.

UNICEF and WFP also developed concerns about the impact on nutrition needs of the orphaned children and this accelerates the food insecurity and levels of malnutrition. Studies conducted by FAO (2000) in 2 districts of Zimbabwe, report that children living in homesteads affected by illness and hunger are seriously disintegrated.

3.5.15 Children are used in HIV/AIDS research programmes⁶ that include specific studies that contribute to effective prevention , care , treatment and impact reduction for children

- A small study conducted by KIWAKKUKI in June 2003 revealed that the economic welfare of children orphaned by HIV/AIDS in Kilimanjaro and Tanzania in general is very poor.

3.6 Children's rights Risks and Challenges

When children had both been orphaned by HIV/AIDS and are denied their human rights, the following is the impact on them:

There is inadequate information and poor knowledge on their rights and the risks they may face.

There is a lack of accessible and affordable medicines to protect the right to life and the right to health and this increases their risk to vulnerability and finally death.

⁶ However , children are not required to serve as research subjects until an intervention has already been thoroughly tested on adults. Whatever the case, the consent of the child and the parent/guardian to participate is essential

There is lack of privacy, counselling, confidentiality to HIV testing and dignity and risk of further transmission.

There is discrimination due to gender, culture, colour, ethnic, religion, disability or other status.

This puts them to risk of stigma, rejection, violence(sexual abuse or Female Genital Mutilation) and increased vulnerability.

There is a lack of opportunity to express their views, worries, evolving capacities and this puts them at a risk of depression, nightmares, discrimination and stigma.

There is lack of legal identity by not being registered at birth and run risk being impacted in future.

There is lack of access to formal schooling and being put into the risk of economic and social exploitation an increased vulnerability.

There is lack of consent or the parent's /guardians consent to participate in research or drug trials and put them at risk of becoming guinea pigs.

There is lack of special protection caused by their difficult circumstances (like refugee camps, institutions, conflict areas, child headed households and others) and this disposes them to many risks based on legal political, social, economical, cultural and other factors.

There is lack of guidance and protection from prohibited behaviour and ends in the risk of drug and substance abuse.

There is no policy programming resource allocation which target orphans.

4.0 Responses from 5 selected African Countries. A Comparative Analysis Towards Mitigation of Impact caused by AIDS to the Orphans

I strongly agree with The Human rights Watch remark that the response of African Governments to The AIDS epidemic has been grossly inadequate, save for Uganda whose leaders recognized the crisis in the mid eighties when the rest were still silent and actually *"blaming others for bringing it into their countries."*

4.1 Botswana (HIV Prevalence-39%) Orphans' rate > 15% half due to AIDS

4.1.1 Government and Policy

-The National AIDS Coordinating Response was set up in 2000 to coordinate a multi sectoral response chaired by the president

- The National policy on AIDS was adopted in 1993 and Botswana has been the first country in Africa to provide ARVs to its citizens nationwide.
- Several initiatives and programmes are conducted by The African Comprehensive HIV/AIDS Partnerships(ACHAP) to support goals of Botswana government in decreasing HIV incidence and increasing the rate of diagnosis and treatment.
- The State has set up a National Orphans Programme as a partnership among government departments, NGOs, CBOs and private sector.....

4.1.2 Civil Society

- Reports indicate that several NGOs and CBOs do offer support to extended and foster families. They provide services ranging from family counseling, Day Care for orphans to providing basic needs. (However some reports reveal that some extended family members are taking advantage of children being minor and confiscating their property.

YOHO- Youth Health Organization conducted by African Youth Alliance in collaboration with the government agencies and international donors. They reach in school and out of school youth with HIV prevention messages.

4.1.3 Achievements/Challenges

- Has an annual per capital income of \$ 3,300 mainly out of diamond and has enjoyed peace since 1966
- However has the highest HIV prevalence rates in the world- 39% and life expectancy has declined from 72 before the epidemic to 39.
- Support offered by NGOs is good but fragmented and Unsustainable.
- Only country providing ARVs access to citizens.

4.2. Uganda (*HIV Prevalence-6.1% from 30%*))

4.2.1Government and Policy

In 1986 the Minister of Health announced the existence of HIV/AIDS in the country.

- Same year saw beginning of political openness and conducive environment for mass campaigns spearheaded by president Yoweri Museveni in collaboration with WHO's Global Programme on AIDS.
- In 1998 Uganda received an Excellence Prize Award for good results in combating HIV/AIDS/STIs by the Society for AIDS in Africa.
- National AIDS Policy has been undergoing review and has involved the Civil Society. (*Uganda AIDS Commission Reports*)
- The Universal Primary Education was adopted in 1997 by eliminating costs of schooling up to 4 children per family and 2 must be girls.
- A Children and Young people's Parliament was held in Kampala in 2001 and one girl participant remarked, "We were empowered with assertiveness and confidence and we began to think positively about our abilities.

4.2.2 Civil Society

- Uganda's response to HIV/AIDS epidemic has been a collective effort by the government,

national and international NGOs religious and community – based organizations, individuals living with HIV/AIDS local and international donors.

- 43% of families have assumed Household based foster care of orphans by relatives in an extended family. in Uganda.

Several other orphans are cared for in the orphanages mostly church managed.

- In Kampala there is a Mildmay palliative care unit (opened in 1998) which reduces suffering and improves quality of life.

Success in palliative care was due to the government willingness to support innovative approaches from outside. Mildmay is a referral centre and children and adolescents get free medicine.

4.2.3 Achievements/Challenges

- Half of Ugandans have access to health care (Reports)

- I agree with Deininger et al observation that the Household based foster care needs policy support since hosting extra children places additional strains on household's livelihood. There has been negative welfare impact on household capital accumulation.

- What was the outcome of the Children's Parliament?

What was the composition of participants and what issues were on the agenda? When is the next one?

- Although Uganda has developed one of the best HIV/AIDS programmes in Africa, there are still almost 2,000,000 orphans in critical need of help.

- Also ,reports indicate that HIV/AIDS activities are still fragmented and there is big need of resource support in Programming M and E and Documentation, for example Research results are not utilized..

- The Free Education Policy coincided with the increase in user fees especially in the Health Sector, a measure to improve availability and quality of supplies. This reduced children's access to schooling.

4.3. Zimbabwe (Prevalence – 20%Orphans' rate > 15% half due to AIDS

4.3.1Government and Policy

The national HIV/AIDS policy was introduced in December 1999 Efforts to implement policy are spearheaded by the National AIDS Council which has put structures at national, provincial and district levels.

- However the civil society has not been involved.

- On may 27th the Zimbabwe government declared a state of National Emergency and decided to scale up especially treatment by overriding patent protection on ARVs and use generics which are cheaper and will reach twice as many patients compared to the WHO recommended cocktail.

4.3.2 Civil Society

- Farm Orphans' Support Trust (FOST) is a national community-based programme that solicits and facilitates support for children especially orphans on commercial farms. -On each farm FOST has recruited a Child care Representative who visits and supervises community childcare and encourages interaction between orphans and non orphans

.He/ She also reports to the local Farm Development Committee which deals with farm

social issues. At Kariri Farm School FOST Club, all children , orphans and non orphans participate in FOST Club .The belief here is that “Every child is a potential orphan” They have a gardening project and each child has a responsibility of watering it. They plant tomatoes and sell them and the profit goes to orphans at school

-Learning Life Skills through Adventure:

At The Salvation Army’s Masiye Camp, children learn through playing as it fosters social growth, skills development, provides them with relief from stress and enables them to cope This Camp, based on “Outward Bound” was started in 1998 to encourage trust and team building through adventure learning and Life skills development. It also gives them an opportunity to relax and express themselves to someone who listens. They also focus on Teenage Parenting courses like child headed homesteads and children living with ill parents.

This is done during the holidays. Recreational activities strengthen children’s interpersonal skills. Children’s minds and bodies are challenged, they overcome fears and challenges and manage to conquer the obstacles. In this way they are able to undergo dramatic transformation

- Positive Women Network use one tool for communication the “*Memory Book*”⁷
- which was introduced in Zimbabwe from Uganda. It is a journal of facts and memories for children who are facing loss or separation from a parent (including divorce, any terminal illness, or adoption) and is appropriate for any culture. It helps to avoid fading of memories and strengthens the child’s sense of belonging.

When using a Memory Book, a parent completes it and goes through it with the child who in turn will ask questions, visuals are used, it deals with the past present and future of the child, it facilitates disclosure about HIV/AIDS and helps a child to learn about HIV prevention and so it is an empowerment tool. Mothers in Zimbabwe who have learned about the Memory Book from the Positive Women’s Network say it made them aware of their children’s fears about the future and children get to know about the choices that are there after bereavement.

-The church in Zimbabwe has tried to improve the lives of orphans by organizing community members who agree to, visit them in their homes

4.3.3 Achievements/Challenges

-Zimbabwe’s present political, economical and HIV/AIDS situations have challenged individuals, families , communities and especially children living with HIV/AIDS. The inflation has impacted upon the country’s healthcare system including diagnosis of HIV and care of AIDS patients. Recent farm invasions have also affected children living on the farms.

- There are several innovations for impact mitigation practiced.

⁷ Research supported by UNAIDS and conducted by Humuliza, in Tanzania, has shown that children whose parents had talked to them about dying appreciated being able to use the time to share the information and advice like on how to household tasks or ask questions like, “ When you die, how should I do this?

4.4. Kenya (*Prevalence – 15%*)

4.4.1 Government and Policy

The first National Policy Statement was out in 1999 when President Moi declared HIV/AIDS a National disaster.

- The Children's budget is less than 1% of National Budget
- Cost sharing policy is used for education
- In 2001, a legislation was passed to facilitate importation and manufacturing of cheaper, generic ARVs and removed tariffs on imported condoms through the Industrial Properties Bill.
- In January 2001, the high Court of Nairobi established a Family Division to hear cases involving intra family disputes to handle among others, increasing legal issues of inheritance.

4.4.2 Civil Society

The Civil Society is assisting orphans to meet some educational costs like tuition, construction fees and others. Actually > 60% of school running costs are met by parents(UNICEF)

- AMPCAN is a leading NGO in child protection in case of abuse and neglect. They lobby with the government to remove school levies which bother the parents and care givers.
 - The Kariabangi community Home based care operates in Korogocho slums in Nairobi to offset the traditional child bearing capacity. They provide basic medicine and organizes home care through training of AIDS affected families. This is done by community based health workers supported by counselors, nurses and social workers.
- They also run a child crisis centre where children can stay temporarily when the mother is too sick or dies. HIV positive children are given medical care and others are taught how to live without parents. Its like a safe heaven.

4.4.3 Achievements/Challenges

Kenya 's Cosmos Pharmaceutical company is preparing to start producing generic ARVs by end of 2003.

4.5. Malawi (*prevalence-(16%) Orphans' rate >15% half due to AIDS*)

4.5.1 Government and Policy

The Malawi HIV/AIDS Strategy 2000-2004 is the country's first comprehensive plan on mitigation the impact of the epidemic. The National Consultative process was observed with representatives from the community sector, civil society, including chiefs and private sector. All this helped national ownership.

- Some support is given to orphans but was not elaborated in the literature.

4.5.2 Civil Society

Community - based Solutions

Save the Children has a programme known as COPE (Community based Options for Protection and Empowerment)_ which helps to break the silence about HIV/AIDS and help villages to help themselves, work hand in hand with expanded health services, improved education and micro enterprise activities. Village Orphans Committees have

a responsibility of monitoring the local situation.

-Community based programmes for primary and secondary schools by educating teachers on basic understanding of AIDS and in turn they pass the messages to children.

This has assisted many of them to delay sex and to gain family planning knowledge.

4.5.3 Achievements/Challenges

Although the civil society consultation was followed, the degree of participation by civil society HIV/AIDS mitigation is reportedly low.

5.0 Major Findings and Lessons Learnt

5.1 Violations of Rights of Children Affected by HIV/AIDS

- There is sufficient evidence of violation of the rights of the children in all countries studied.
- The economic welfare of children orphaned by AIDS is usually poor.
- Some young people have not been reached with accurate information on how HIV is transmitted.

- False beliefs and oppressive culture still dominate in southern and eastern Africa where HIV positive men sleep with virgins hoping to be cleansed.
- Female Genital Mutilation is still practiced and orphans have no say in this.
- Forced sex and forced marriages are still practiced especially in southern Africa.
- Many children in Africa have not been legally registered (even before AIDS)
- Orphans School Drop outs are common especially among girls.
- Negotiations for use of condom among young people is still difficult.
- There are no youth friendly health services.
- Many orphans are economically exploited through prostitution, child labour and military attendants.
- In areas of violence, girl children are commonly raped and become HIV positive.

5.2 The response of the African Governments

The fighting of the epidemic is a learning process. However, it is difficult to trace success stories and if one is spotted, it is limited in terms of representation due to the non availability of documentation of Best practices. According to the Uganda Networking of AIDS Services Organizations (UNASO) Vol. 3 Issue 1, August 2002, the goal of 'Best Practice in HIV/AIDS' should be to share experiences and practical solutions on what is working. It adds that 'Best Practice' procedures encompass those attributes that describe how programmes and policies should be designed and delivered to produce optimum outcomes.

One observer noted that the bridge is there but needs to be mended, "its broken". The following has therefore been observed:

- Lack of uniformity in category across countries. Many programmes appear compartmentalized, unsustainable, hit and run efforts with a risk collapse if foreign funding is disconnected. This attitude of "business as usual", increases the number of orphans without means of survival.
- Generally slow political will to curb the epidemic for all African countries (except for Uganda)
- Despite advocacy efforts, things in many countries have mitigation frame works without operational plans to activate them and efforts to import generic ARV's are not satisfactorily reflected in the literature.
- No standard measure for HIV/AIDS prevention and impact mitigation processes which could inform the best practices.
- There is no sufficient literature to show national level success of collaboration between civil society and government (except to a small extent in Malawi, see above)
- Foreign Aid may be useful but there is little recorded momentum to prepare Africa for institutional and professional development in terms of forming partnerships in research, sharing clinical trials between peers in Africa and the developed world and such issues.
- Botswana's capacity and willingness to provide ARV's to all citizens is a

- welcome policy.
- Uganda's results of lowering the HIV prevalence, Palliative Care Approach and Memory Project are all worth adoption and well documented.
 - Although Zimbabwe has political problems, there are good recorded examples of impact mitigation.
 - Malawi's efforts to joint ventures with the civil society are also worth commending.
 - Kenya is doing very well in preparation for producing Anti Retrovirals inside the country.
 - The government of Tanzania has had some successes in Kagera and Mbeya regions and has been the first country in the Southern Africa Development Cooperation to document and NGO policy in a relatively democratic manner.
 - Civil society ownership of public policy is low in all countries.
 - The International Partnership Against AIDS in Africa , launched in 1999 in Lusaka as a coalition of actors who have chosen to work together to achieve a shared vision and to scale up efforts of curbing the epidemic is an important achievement and was urged by UNAIDS in September 2003 in Nairobi to start implementing programmes and stop resource mobilization.
 - In some countries some foster families are taking advantage of services provided for the children.

5.3 Best Practices of impact mitigation in selected countries

- Offering direct support to foster families Botswana, good for a start.
- Encouraging interactions between orphans and non orphans – Zimbabwe.
- Training orphans in life skills - all countries.
- Introducing a Memory Book Project Uganda and Zimbabwe and soon in Tanzania, to be initiated by KIWAKKUKI.
- Offering Recreation Activities to Orphans – Zimbabwe.
- Training AIDS affected families in home care and 'life without parents' – Kenya.
- Training orphans in community based self protection skills- Malawi.
- Establishing Fund for private sector development and orphan support – Tanzania. (See 2.2).

6.0 Recommendations

6.1 The Tanzanian Government

The steps taken so far are encouraging.

- However, the government has to have **greater leadership and establish communications and public relations strategies for informing civil society regarding government plans for partnership** and ensuring that stakeholders

participate in policy process. This will promote a more responsive, transparent and accountable government and increase citizen participation in public affairs. Tsikata (2001) The government will need to be *“flexible for a painful change process”*

For without an inclusive strategy, with everyone on board, we can't attain sustainable development and impact mitigation of HIV/AIDS

- The difficult circumstances faced by AIDS affected children can be mitigated by legal and policy protections and support from the Tanzanian government for provision of essential services to most vulnerable orphans using the Global Fund for HIV/AIDS, Malaria and Tuberculosis, waive cost sharing policy for the poor and the children.
- Free education is not yet free in Tanzania and as we saw in Uganda and Kenya, school levies contradict with the UN Education for All policy.
- The government needs to monitor the running of orphanages and other institutions regarding protection and discrimination of HIV/AIDS affected children.
- In a more serious tone it is good to remind ourselves of some of the National Strategies for implementing the Tanzania HIV/AIDS Policy (2003): *(i) “ Develop a social and economic framework to address the needs of the affected persons and communities. (ii) Develop policy guidelines and coordination of interventions for orphans. (iii) Address stigma and discrimination against HIV/AIDS orphans and (iv) Strengthen and expand integrated and innovative programmes for orphans especially at the district and community levels(education, healthcare, shelter, psychosocial counseling and life skills training)”*

6.2 The Tanzania Civil Society

- Latest developments in the local NGO work in Tanzania, indicate a recent establishment of a **Tanzanian Advocacy Partnership** Programme (TAPP) to build on the positive initiatives already started whereby civil society organizations are developing a greater role in public affairs, decision making and some government processes are becoming transparent. This needs activation.
- Tanzania recently got 77bn.US\$ from the World Bank to support the multi sectoral response in prevention, care and mitigation. It is also true that The Global Fund for HIV/AIDS, Malaria and Tuberculosis has allocated a huge amount of money to Tanzania and several other donor agencies have allocated financial Aid to Tanzania. I only hope that some of this money reaches the suffering children and this calls for strengthened partnership and moral accountability with foreign donations.
- Since both the government and civil society should carry equal status as development partners, transparency, accountability between the two parties is reciprocal.

This is an excellent way forward since it will re- fuel the earlier attempts by Fem Act, TAMWA, TCCD and others , although the main strategy will be to identify positive thinking allies in the government and to encourage more gender activists to join the politics. The motto should be "Civil Society is force for change" since as government partners, they are a development tool.

6.3 KIWAKKUKI / Community level: The Community is the second safety net for orphans

Current Situation

- The approach used by KIWAKKUKI to mobilize 60 women groups is limited to identifying the neediest orphans, providing direct support to their families or channeling support from KIWAKKUKI to them. But this is an existing opportunity for social capital development. KIWAKKUKI women would like to see orphans with a future. Moreover, KIWAKKUKI aspires to follow the model of Positive Steps Partnership, Scotland ⁸ of offering "Real Solutions to Real People " by prioritizing in effectiveness and efficiency.
- Indeed, a good number of practices found in the literature is practiced by KIWAKKUKI in one way or another but with little efficiency and effectiveness because KIWAKKUKI involves herself with an integrated approach which addresses issues of HIV/AIDS prevention, care and impact mitigation as per her mission and vision.
- It is easy to be carried away with the service delivery at the expense of handing over or sharing this responsibility with other civil society service providers and the government.
- The best approach for KIWAKKUKI now should be a more and outcome based, adoption and documentation of best practices which improve the quality of life of children.

6.4 Scaling up:

6.4.1 Increase leadership, responsibility, accountability and community based response of the KIWAKKUKI grassroots groups.

- ☐ KIWAKKUKI to provide capacity to the **community based grassroots groups to enable them to understand the concept of poverty, the needs of children**, listen to them, provide recreation, refer them to other service providers for increased access to their rights, slowly this will empower them in commitment and efficiency and be able to inform policy formulation on issues affecting orphans.
- ☐ KIWAKKUKI to provide **awareness and skills development programmes for grassroots on HIV/AIDS policy to facilitate their access to district**

⁸ Positive Steps Partnership is a very successful NGO based in Scotland which has managed to change the lives of people who had given up and also are reaching schools in a programme which is currently being spread in other parts of the world

HIV/AIDS, NGO/CBO fund through participatory Budgeting processes in which together with other stakeholders, they will debate, analyze, prioritize and monitor decisions about public expenditures and investments and be involved in issues beyond HIV/AIDS. This according to Makara (2000) will enable them to encourage good governance with accountability and transparency and also will make them responsible and facilitate ownership of community orphans' care. In this way they can lobby funding for supporting children deprived of their rights due to HIV/AIDS.

- Conduct **district level campaigns** through KIWAKKUKI grassroots groups, faith based organizations and, local and political leaders to open dialogues with the local government to be able to accelerate disbursement of the decentralized HIV/AIDS funds by TACAIDS to be able to support orphans' coping mechanisms. Decentralization is an administrative structure that promotes partnerships. The aim is to exploit the positive development of **decentralization** which targets provision of services to **the poorest of the poor**, in this case the orphans.

6.4.2 Support coping capacities for families which are caring for orphans (surviving parents/ foster parents and children heading households)

- KIWAKKUKI currently supports 90 families in 30 villages of Kilimanjaro (Study result) They carry out small businesses to meet immediate survival needs, depending on capacity and age. The target for scaling this up is to link it with the district impact mitigation plans and reach out to more families per each of the 6 districts of Kilimanjaro by end of 2005..
- Even the World Bank recognizes the **livelihood opportunities and quality of life of care givers**. Involvement of social workers is crucial as one social worker at the Duke HIV Clinic told this researcher that the clinic has a practice of supporting patients to exercise their power by talking to the guardians and a lawyer about the future plans of their children including will preparation and his allows them to die in peace.
- **Introduce 'Memory Book Project'** to scale up existing supportive counseling and to encourage parents who live with their children to do the same. '*All children are potential orphans*'. This project aims at giving support to children to share their fears, anxiety and worries with their parents and to acquire coping mechanisms when they eventually live without their parents

6.4.3 Strengthen capacity of children and young people to meet their own needs

This could be by;

- Conducting regular survey on school enrolment, attendances, especially for girls and other orphans who are caught in the pressure of serious poverty.
- Establishing of **forums for children at village/ward/district levels** with as many orphans as possible to allow them air their views and use such forums to empower children about their rights.

- Sensitizing orphans and children in general to make use of this opportunity
The KIWAKKUKI VCT Centre is free of charge to children and youth up to 24 years.
- Strengthening the “**Kilimanjaro Youth Alive Club**” to be able to reach as many grown up orphans (on top of the ordinary youth they meet) as possible with behaviour change messages and life skills. It has been reported that “Whenever there has been success, young people have been on the forefront of change’ (Uganda, Zambia, S. Africa)
- Expanding recreation activities for orphans and other children.

6.4.4 Promote Leaders Empowerment in Kilimanjaro.

- Establishing a shared sense of responsibility for action taking and making AIDS “their” problem too. These are the policy makers, community leaders, the media and faith based organizations on the impact of HIV/AIDS on children and families,
- Investing in leadership for designing policy. The World Bank has observed practices where empowering leaders like teachers, administrators and government institution mechanisms inspires and that **they become willing to commit their own resources** and improve the quality of schools.
- **Initiating round table monthly discussions** on strengthening collaboration between the government and the civil society and HIV/AIDS impact mitigation especially regarding orphaned children and other children in general.

6.4.5 Scaling up Research, Documentation, Monitoring and Evaluation Skills

- **Integrating gender variables and analysis into HIV/AIDS research** to be able to understand the health risks, outcomes, service utilization and lead to useable recommendations.
- Conducting further research on **the impact of existing interventions** supporting orphans to evaluate their effectiveness.
- Seeking donors who are promoting ongoing learning and knowledge sharing.
- Making the existing ‘social capital potential more effective in orphans care by **monitoring** the work done at grassroots level
- Maintaining a Documentation system for practices that are working, referrals for children infected/affected by HIV/AIDS, records of foster parents/care givers, children’s groups and income generation activities at different levels.
- Establishing a Register of Birth for children being supported but not officially registered. This could utilize the Hart and Hine Fellows both from Duke University currently working at KIWAKKUKI.

The expected development outcomes for children and society

- Strengthened poor peoples’ organizations

- ☐ Increased access and freedom for children
- ☐ Strengthened civil society
- ☐ Improved governance and
- ☐ Improved children's lives
- ☐ Efficient Monitoring and Evaluation system for orphans impact mitigation.

6.5 Conclusion

What challenges do we still have? It is obvious that if nothing is done about the spread of the epidemic and its impact, any progress in poverty reduction will be put at risk. This has also been observed by UNDP.

One dying woman told a researcher that she knew she was dying and she wanted to die in peace and so she asked the researcher, "Will you take care of my children" What answer does this woman deserve?

No one knows the proper entry point for the HIV/AIDS Policy implementation, if it is the civil society or the government or the private sector but the orphaned children's lives and rights depend on these three major pillars of HIV/AIDS impact mitigation.

Who is going to start? If the '*parents*' will not start, the civil society will make the *wearer of the shoes* to start for it is they who know *where it pinches*!

References

Mwingira M.J (2001) The Role of NGOs in Development and the Relationship with the government, A paper presented at TFTW Workshop, Dar es Salaam

Kalis, A (1999) Government NGO Partnerships for Social Service Delivery, Paper presented at the Southern African National Council for Child and Family Welfare.

The United Republic of Tanzania,(2000) Poverty reduction Strategy Paper. Paper prepared by the president's office.

Bolinger,L, Stover J and Riwa P(1999)The Economic impact of AIDS in Tanzania,the Policy Project, UNDP

UN OCHA Integrated Regional Framework Network(2003) Tanzania NGOs repeat call for NGO ACT to be reviewed.

Fredriksson J and Kanabus A(2002)The History of HIV/AIDS in Botswana.

Uganda AIDS Commission(2001)Twenty years of HIV/AIDS in the World. Evolution of the Epidemic and Response in Uganda.

Piot p, UNAIDS Executive Director(2002) Speech at the Opening Ceremony of the Conference of Ministers of Education of the African member states, Dar es Salaam.

Plastow,J Oxfam(2002) Ireland International Report on HIV/AIDS Programmes in Tanzania.

Rwehumbiza P Southern African Human Rights NGOs Network- Tanzania Chapter, Monthly Report, July.

World Bank(2002) Empowerment and poverty Reduction. A Sourcebook.

The United Republic of Tanzania, Prime Minister's Office(2001)The National Policy on HIV/AIDS, Tanzania.

The United Republic of Tanzania, Prime Minister's Office(2003) National Multisectoral Strategic Plan.

Chachage S(2001) Reflections on Civil Society in Tanzania: The Case of TGNP and AJM

Adelman,C (2002)Why AIDS is Winning.

Newbrander W and Sacca W(1996) Cost Sharing and Access to Healthcare for the Poor: Equity Experiences in Tanzania. Study.

UNAIDS(2002) Report on the Global HIV/AIDS Epidemic, Geneva: UNAIDS.

Family Planet () HIV in Malawi: Learning to Cope.

Human Rights Watch(2003). In the Shadow of Death.

UNAIDS Case Study(2001)Investing in our Future: Psychosocial Support for Children Affected by HIV/AIDS. A Case Study in Zimbabwe and The United Republic of Tanzania.

Children on the Brink(2002) A Joint Report on Orphan Estimates and Program Strategies.

Lyons M() The Impact of HIV and AIDS on Children, Families and Communities. Risks and Realities of Childhood during the HIV Epidemic. UNASO, Uganda Networking of AIDS Services Organizations. Vol. 3 Issue 1 August 2002.

Commitee on the Rights of the Child 32nd Session(2003)HIV and the Rights of the

Child.

Deininger K and Subbarao K() Induced Orphan hood as a Systemic Shock: Magnitude, Impact and Program Interventions in Africa.

Shariff W and Albee A(2000) Selected Studies of Civil Society in Tanzania: Policy, Social Capital and Networks of the Vulnerable

Narayan, D (2002) Empowerment and Poverty Reduction. A Sourcebook. The World Bank, Washington.

The Oxford American Dictionary of Current English , 1999 OUP.

The American Heritage College Dictionary(2002)4th Edition, Houghton Mifflin Company.

South African Concise Oxford Dictionary (2002)

Makara, S (2000)NGOs in Uganda: Their typologies roles and functions in governance.

Kanjaye,H(1999) Health Malawi. New strategy to Fight HIV/AIDS Underway.

Hatendi S,L,F, Assessment of The Level of Implementation of the Zimbabwe National HIV/AIDS Policy and Accessibility of the National AIDS Trust Fund by Civil Society.

UNAIDS (2003) HIV/AIDS and Human Rights Young People in Action.

UNAIDS Gender and AIDS Almanac(2001)

UNAIDS and UNICEF, Children Orphaned by AIDS

WHO and UNICEF(1994) Action for Children Affected by AIDS Program Profiles and Lessons Learned

UNAIDS and UNICEF(1999) Children orphaned by AIDS: Frontline Responses from Eastern and Southern Africa.

Abbreviations

| | |
|-----------|--|
| HIV | Human Immuno-defficiency Virus |
| AIDS | Acquired Immuno-defficiency Syndrome |
| UNAIDS | Joint United Nations Programme fo HIV/AIDS |
| USAID | US Agency for International Development |
| KIWAKKUKI | Kikundi cha Wanawake Kilimanjaro Kupambana na UKIMWI |
| UN | United Nations |

| | |
|---------|--|
| UNICEF | United Nations Children's Fund |
| UNDP | United Nations Development Programme |
| WHO | World Health Organizations |
| NGO | Non Governmental Organization |
| CBO | Community Based Organization |
| DART | Duke AIDS Research and Treatment Centre |
| TACAIDS | Tanzania Commission for AIDS |
| TANGO | Tanzania Association of Non Governmental Organizations |
| TAMWA | Tanzania Media Women Association |
| TCDD | Tanzania Coalition on Debt and Development |
| VCT | Voluntary Counselling and Testing |
| PLHAs | People Living with HIV/AIDS |
| Fem Act | Feminist Activism Coalition |
| ARVs | Anti retrovirals |
| FOST | Farm Orphans Support Trust |
| AMPCAN | |
| UNASO | Uganda Networking of AIDS Services Organizations |
| TAPP | Tanzania Advocacy Partnership |