

**Speech at parallel event to
the 14th Session of the Human Rights Council on**

"Better Access to Testing and Treatment for HIV-positive Children"

Co-organised by the Association Comunità Papa Giovanni XXIII and Caritas Internationalis

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Rainbow Project, run by the Association Pope John 23rd, is a large-scale “model of care”, whose aim is to help orphans and vulnerable children (OVC) trying to keep them within the extended family.

Rainbow works in each compound through a networking system offering different answers to the different needs of OVC. The networking system links 34 local organizations (CBOs or NGOs) that are taking care of orphans and vulnerable children.

The orphans are supported through different actions (educational support, microcredit to the families, nutrition support, psychosocial support).

In Ndola district the Rainbow Project coordinates and supports the activities of 12 Supplementary Feeding Programs (SFP) and 6 Outpatient Therapeutic sites (Outpatient Therapeutic Program, OTP) for the cure of severely malnourished children without complication using Ready to Use Therapeutic Food (RUTF).

In the SFP local food is distributed on a weekly basis .Every month the Rainbow Office provides every centre with food according to the number of children. On the nutrition day, cooking demonstrations is done and one meal eaten at the centre. Health talks are carried out by the operators or by people from the local clinics. The children are screened for severe malnutrition using Mid Upper Arm Circumference (MUAC) and the presence of nutritional oedema. The children found severely malnourished are referred to the OTP.

SFP in the year 2009 catered for 1114 malnourished children.

In May 2010 31% of the children in the SFP were HIV positive and the children with unknown status at admission were 39%.

The OTP is run from within six local clinics in partnership with local Health District. Children are referred from local clinics , SFP, Arthur Davidson Children's Hospital (ADH) after intensive phase treatment and ART clinics.

From the beginning of 2009 up to now the OTP has admitted 434 severely malnourished children. The cure rate is 72%.

From December 2009 to May 2010 62 % of the severely malnourished children in the OTP were classified as “unknown status at admission” even if failing to thrive is one of the first symptoms of HIV infection and Voluntary Counselling and Testing (VCT) should be offered especially to severely malnourished. 13% of the children were found HIV positive at admission.

In the OTP clinics as well as in the SFP the mothers are counselled for VCT for themselves and for the children and those found positive are referred to the nearest ART clinic for treatment while nutrition support is given from OTP and SFP.

The Ndola district through the work of Rainbow Project was the second district in Zambia to start Community Based Therapeutic Care (CTC) for malnourished children.

Malnutrition is a very severe problem in Ndola, especially among the poorest layers of the society.

The Zambia Demographic Health Survey (ZDHS) monitoring data indicates that malnutrition is worsening; with levels of underweight reaching 28% , chronic malnutrition 47% and acute malnutrition 5%.

Severe malnutrition is associated with high morbidity and mortality. Widespread poverty and high HIV/AIDS rate are worsening the situation.

The estimated number of children with HIV in Zambia is 95,000. 11,602 are at the moment receiving ART.

Despite the encouraging increase in the number of children on antiretroviral treatment, the youngest cohort of children exposed to the virus – those under 1 year – are often not getting diagnosed and are missing out on treatment. As a result, large numbers of very young children are dying every year because of AIDS.

Some children referred from the SFP to the local clinics or OTP, die after infections, such as diarrhoea, pneumonia or malaria because they are discovered HIV + already on stage 3 of 4 of the WHO paediatric classification of HIV/AIDS.

The onset of AIDS in children is known to be much earlier than in an adult. A significant proportion of HIV-infected children will develop AIDS and die within the first 2 years of life.

Poor growth is common in HIV-infected children and has a significant adverse effect on survival independent of the degree of immune deficiency.

Secondary causes of growth faltering or failure, many of which are potentially preventable, reversible or modifiable, are involved. These include dietary insufficiency, diarrhoeal illnesses, and anaemia. Poor growth was among the first manifestations of HIV infection to be recognized in children and has a significant effect on short-term survival.

In 2008 a child targeted voluntary screening for HIV was conducted in the SFP.

The children attending the HIV screening were 148 out of 381 present. 95 were tested with rapid test and 53 referred per HIV/PCR.

Of the 95 tested with the rapid test (above 18 months) 9 were found positive as a new diagnosis. .

Ndola is the third city of Zambia with 374,757 habitants (Census from year 2000).

In Ndola district there are 5 ART clinics that are operating from within the local clinics in the compounds around town. Only three of those clinics are able to perform base line investigations as well as CD4 count.

The first children's ART clinic was opened at Arthur Davidson Children's Hospital (ADH) and it is still operating covering the compounds near the hospital setting.

ADH is equipped with PCR machine. Only three laboratories in Zambia have PCR machines: the University Teaching Hospital and the Kalingalinga Clinic, both in Lusaka, the capital, and the Arthur Davison Hospital in Ndola, in Copperbelt Province.

ADH receives samples from the Copperbelt, the Luapula, Northern and North-Western Province. (total population 4,198,620 habitants, 36 healths districts).

In most of the Districts Dry Spots Samples (DBS) are taken just from the major hospitals and few local clinic, with very low coverage.

In Ndola the samples are collected in all the local clinics.

The local clinics , as for national policy, are due to offer VCT to all the pregnant mothers going for antenatal clinic but , because of stigma and fear not all the mothers are being tested throughout the pregnancy period.

If the pregnant women are found positive they are asked to bring back to local clinics the newborn child at 6 weeks of age for PCR testing.

Samples coming from within the town of Ndola are picked up by a motor bike and usually return to health facilities within 2 weeks. For the samples coming from outside the town perimeter the situation is more challenging in terms of timely results.

Early infant diagnosis is facing with various challenge.

Delays and lost results are seen in the exchange process from local clinics and Children's Hospital and the burden of this situation is felt especially at rural area level and for the faraway provinces. Where a definitive diagnosis of HIV is not possible the recommendations are to do presumptive diagnosis and treatment in an infant with positive rapid HIV test and signs and symptoms of severe HIV disease.

The new Zambian official recommendations for initiating ART in infants and children of 2008 are to initiate all infants with definitive diagnosis of HIV regardless of a CD4% or clinical signs and symptoms and for older children under five the recommendation is CD4% < 20%.

The ART clinic conducted in ADH is the only ART clinic that gives nutrition counselling and support with RUTF.

Drugs are usually available in the ART sites even if adherence, dispensing and storing (secure cold chain), from our experience, still remain a problem.

In Ndola the possibility of testing the child from 6 weeks of age has increased the number of early diagnosis and treatment but paediatric HIV is still a hidden problem, even if many campaigns have started and scaling up of treatment has begun.

HIV test result many times is not shared within the family members, especially from wife to husband because of stigma and fear of being refused and neglected.

Women and children pay the consequences of stigma since in some cases they have to take ARVs hiding from the father/husband and fail to have adequate compliance to the therapy.

The infected children are not easily rescued from severe malnutrition, and the length they spend in the OTP or SFP before discharging as cured is longer than in the non-infected children.

To tackle the issue of paediatric HIV is important to face reality and approach the problem in a holistic way, fully comprehensive of all the components involved.

Some of the components are nutrition (key component for the treatment of HIV in children), availability of drugs in the nearest health centre (not only ART but also simple antibiotics such as Cotrimoxazole), compliance in the treatment that has to be "child friendly", availability of the test for early diagnosis and the CD4 count, counselling pre post and after starting the treatment, adherence counselling, general support to the child and the family.

I will use the last 3 minutes to tell you about Kangwa.....I will give him the possibility to speak directly to you.

I'm Kangwa.

I come from a little village in the rural area of Zambia. When my mother was pregnant of me she was living with my father and they had already 5 children. I'm the last born in the family.

Life was good in the village.

We were living about 3 hours walking from the local clinic. My mother arrived at antenatal clinic a bit late, I was already 28 weeks old..I was fine in the womb even if my mother was very tired I could feel she was getting thinner and thinner.....when she got to the clinic the first time she was asked to do the first HIV test. I remember that after the test she was crying but at that stage I was not able to understand properly what was all this about, going back in the village my mother wiped away the tears and for me life continued in the same old way....we never managed to go back to the clinic again.

Then there was the first difficult moment for me...the delivery....my mother was alone and someone from the village came to help her, I just remember that there was blood everywhere.

Then I came into this world everyone was happy, I was a nice boy, a bit small compare to my other brothers and sisters, but from the look of the faces of my big family they were all happy.

I was put on the breast and I tried to drink from my mother.....to tell you the truth it was not easy, I presume I was a bit small and also my mother was a bit too weak but we tried.

After two weeks my mother was not able still to come out from bed.

Everyone was concerned about her health and they tried one day to take her to the clinic..... we hired a bicycle from our next door neighbour and my father reached the clinic. I was with them.

At the clinic they told my father that the situation was serious. She had to be brought to the Hospital, in town, but my father said it was impossible since my brothers and sisters were at home, alone. So this is how we went back.

After 1 week my mother died. I remember I was of no help, I used to cry a lot, I was hungry...my mother was very skinny and I remember she was coughing a lot. It was a sad moment, all the family came to visit us, to decide what to do. I was going to stay with my grand mother with 2 of my brothers, my father was going to remain at the village with the older ones. The house of my granny was a bit far from my village but I thought that if father was taking that decision it was for my own good.

Then the problems started.....my grand mother tried to put me on her breast , but even if I tried my best, I can assure you, nothing was coming out ; so I was put on water and sugar, the taste was nice , but it was not enough for me, I tried to fill full but it was not possible.....Then I had my first diarrhoea...I discover for the first time that I was a burden. They tried to feed me with ORS (I had my first visit to the local clinic that was just 1 hour walking from the house of my granny) and also with porridge but since I was just almost two months old the diarrhoea just got worse.

Eventually that is how I end up in the Hospital.(another 1 hour walking from the clinic)..... there were nurses (few) and doctors (even less) that were trying to do the best for me. The perform a test called PCR to detect the HIV virus so my grand mother was told at discharge to come back in two weeks time for the results.

To cut a long story short for the next 4 months I was sick on and off, we got the results of PCR and I was reactive., I had to do CD4 count in an other local clinic (two hours walking from my house) because at the hospital the reagents were out of stock.

When I turned 6 months I finally started the drugs for HIV, but there was another problem...food. I was defined severely malnourished. In fact I was skin and bones and if any food in the house was available at times I was too weak to eat. That's how I end up in the Hospital again, in the ward for malnourished children....there they put me on a special diet and on discharge I was given some sachet, called Plumpy Nut, to eat at home. Review after 2 weeks.

I don't know what was going on at home while my grandmother was with me...I hope someone was taking care of my siblings.

When we reached home there was no food so granny decide to share the sachets with the others, I was happy at least I was the reason for them to eat something good, but my food finished very early and I was not putting on weight and I was sick again. The drugs were a bit complicated for my granny and I end up not taking them every day but I could understand that maybe it was too much for her. The other problem was that every time I had to take the drugs we had to go inside the house to hide from the others.....I think because she did not want to let the others know I had this disease; I though I did not have anything to be ashamed of but maybe granny was right.

After a while I was very sick again.We went back to the local clinic and we were told to get some more medicine but those medicine were not available at the clinic in that moment so they gave us prescriptions, for my grand mother to buy in town....at this point of the story you can easily understand how impossible it was for me to get those medicine, so we went back home and I tried to do my best to heal and not to give any other problems to my family.

After a while we went back to the hospital, I was coughing too much so I was given the medicine for Tb even if the diagnosis was not so sure.....we when back home but I was not very happy...other drugs to be taken.... I was tired, granny was tired and everyone was tired of me; I tried to do my best to be good, eat, not fall sick but the disease and the drugs and the lack of food, all that walking around, the suffering were just too much for me.

Maybe going back to mother was the best thing I could do.....that is how, just before my first year birthday, one night I stopped breathing. Finally I'm not a burden to anyone any more.

The story of Kangwa is a true story, is the summary of the many story we've heard during our work on the field and many more things could have been added .

Our nutrition program is tackling malnutrition and HIV trying to assure to children nutritional support and care. In every of our programs the importance of VCT is strongly emphasized. Unfortunately still many constrain are leading our children to suffer and die: in Ndola we are equipped with PCR/HIV but this is not the case for the majority of the children in Zambia. There is therefore the urgent need for new and more ready available tests for early diagnosis.

Continuous access to a supply of free ARV drugs as well as development of well functioning system for forecasting, procurement and supply management are essential components of a paediatric treatment programme. The limited formulations currently available for our children are significant barriers to optimal adherence and cure; therefore development of appropriate and new formulations to use in infants and young children is strongly essential for the survival of our children..