

Models of care for Children made vulnerable by HIV/AIDS

Meeting their psycho-social well being in communities



<i>Table of Contents</i>	<i>Page</i>
Acronyms	4
Acknowledgement	5
Executive Summary	9
<i>Part 1</i>	
Chapter 1	
General Introduction	
1.1 Background to Research Study	15
1.2 Origin of Study	15
1.3 Purpose of Study	15
1.4 Justification of study	16
1.5 Specific Objectives of study	16
1.6 Study methodology	16
Chapter 2	
Literature Review: A conceptual framework of ECD in Uganda	
2.1. Definitions of concepts	17
2.2. Caring for children affected by HIV/AIDS	18
2.3 Linking ECD and HIV/AIDS	19
<i>Part 2</i>	
Chapter 3	
ECD interventions and practical models of care in Uganda	
3.1 Introduction	25
3.2 Sample selection of programmes for study	27
3.3 Data collection, management, and analysis	
3.4 Findings	
3.4.1 Service Delivery Models	
3.4.2 Home Based Model	
3.4.3 ECE (World Bank) model	
3.4.4 Community HIV/AIDS intervention model	
3.4.5 Guardian's economic support model	
3.4.6 Nutrition model	
3.4.7 Medical Care model	
3.4.8 Integrated ECD (UNICEF) model	
3.4.9 Integrated Community support systems (multi system)	
Chapter 4	
Conclusion, Recommendations and Way Forward	
4.1 Introduction	37
4.2 Conclusions	37
4.3 Recommendations	38
4.4 Way Forward-case study selection	39
Bibliography	45
Appendices	46

Acronyms

ACP	AIDS Control Programme
AFC	Action For Children
ARV	Anti Retroviral
AVIS	Italian Agency For Development
CABA	Children affected By Aids
CBO	Community Based Organisation
CDC	Child Development Centre
CHIBS	Children Brigades
CHINS	Children Nursing Service
COU	Church Of Uganda
CMC	Community Management Committee
ECCE	Early Childhood Care and Education
ECD	Early Childhood Development
ECDE	Early Childhood Development and Education
ECDNA	Early Childhood Development Network for Africa
ECE	Early Childhood Education
FAOC	Foundation for Orphaned Children
FAP	Family Preservation
FABE	Functional Adult Literacy and Education
FGD	Focus Group Discussion
FTCU	Feed The Children Uganda
GAS	Grandparent Action Support
HIV/AIDS	Human Immuno Virus/ Acquired Immuno Deficiency Syndrome
IAPSRs	International Assoc of Psycho Social Rehabilitation services
IEC	Information Education and Communication
IECD	Integrated Early Childhood Development
IGA	Income Generating Activity
MB	Memory Box
MCTC	Mother To Child Transmission
MM	Mild May
MOH	Ministry Of Health
NACWOLA	National Association of Women Living With AIDS
NGO	Non Government Organisation
NV	New Vision
OVC	Orphans and Other Vulnerable Children
PSS	Psycho Social Support
PRA	Participatory Rural Appraisal
PTCT	Parent To Child Transmission
REPSSI	Regional Psycho Social Initiative
STD	Sexually Transmitted Diseases
UCOBAC	Uganda Community Based Association For Child Welfare
UNAIDS	United Nations AIDS
U8	Under 8
UNESCO	United Nations Education, Science and Culture Organisation
UNICEF	United Nations Children Education Fund
USAID	United States International Development
UWESO	Uganda Women Effort to Save Orphans

Acknowledgement

This research would not have been possible without the support and cooperation of Action For Children and their partner, Bernard Van Leer Foundation (BVLf) that provided the initial funding. Special appreciation goes to Uganda Child Rights NGO Network (UCRNN) that funded the completion of the research case study.

Members of the research team that included the research partner, Rose Nalwadda; research assistant, Sarah Komugasho and staff of Action For Children, Lydia Nyesigomwe, Eric Kakoole, and James Doi, your great contributions are highly recognised.

The contributions of the UCRNN HIV/AIDS thematic group that discussed the initial findings and validated the study are appreciated. In addition, the contributions of the various organisations and communities that provided the information, the time, and resources, accepting to be interviewed, sharing their wealth of knowledge and experience, this report is credited to you. This is your information and it is my prayer that I have represented your views correctly. Any mistakes and misrepresentations are purely from my side, and accept my apology.

To the children of Uganda, those in the communities that shared their feelings, may this report contribute positively to the initiatives targeting your well being.

Bless you mightily,

Jolly P.T. Nyeko

Uganda Child Rights NGO Network
P.O Box 10293,
Kampala, Uganda.
Tel. 041 53 21 31
ucrnn@utlonline.co.ug

Action For Children
P.O Box 25417,
Kampala, Uganda.
Tel. 041 54 11 11
action@actionforchildren.org.ug

Foreword

One of the guiding principles of the United Nations Convention on the Rights of the Child (UNCRC) is the inherent right to survival, development and protection for all children. However, this Cardinal principle is threatened by the prevalence HIV/AIDS pandemic, which has victimized over fourteen million children through infection or rendering them Orphans. By 2003, there were over 14 million Children below the age of 15 who had been made double orphans or lost one of the parents due to this scourge. It is further estimated that by 2010, as many as 25 million children are likely to become orphaned as a result of the disease

Children particularly those below the age of eight years are more vulnerable and suffer profoundly after loosing their parents or care givers. Their experience is characterized by psychosocial distress and trauma caused by the illness and the death of their parents, economic hardships, malnutrition and they are exposed to all forms of abuse.

This study report creates a linkage between Early Childhood Development (ECD) and HIV/AIDS focusing on the child psychosocial wellbeing in their communities. It also enumerates the best practices, which can be replicated in other communities. These include; economic coping capacities of families and communities, how to reduce stigma and discrimination and to enhance protection, care and development of orphans and other vulnerable children in the various communities.

The report emphasizes seven models which are; Home based care, Educational, Happy Mother – Happy Baby, Social Economic Support, Nutrition, Medical care and Integrated models. This report explicitly spells out the need to design interventions to address the plight of the affected children

It is my humble prayer that this report inspires you to direct effort and resources towards the development of policies and community based programmes to provide care and support for children and families in need.



Stella Ayo - Odongo

National Programme Coordinator

Uganda Child Rights NGO Network (UCRNN)

Executive Summary

Models of care for children under 8 made vulnerable by HIV/AIDS: Meeting their Psycho social well being in communities

1.0 Introduction

This is a study conducted from 2003-2005 concerning models of care for young children under 8 years old affected by HIV and AIDS in Uganda. It links Early Childhood Development (ECD) and HIV and AIDS focusing on the psychosocial care of the affected children at community level. It also identifies some of the types of interventions carried out by 8 child care institutions in Uganda. The purpose of this exploration is to generate models of care that can be replicated in child care practice. But first, I will start with general situation of HIV/AIDS and children in Uganda.

2.0 Children and the impact of HIV/AIDS

In 2003, Save the Children (2003) reported that there were about 150,000 HIV infected children in Uganda. Out of these 66% were likely to die by the age of three, and the mean age of children with AIDS was 2.2 years. Today, however, there are reportedly increasing numbers (actual numbers unknown) of children with HIV/AIDS who are reaching age 15, though the effect of likeliness of losing their parents causes untold psycho social and emotional challenges.

The number of children orphaned by HIV/AIDS is ranging between 1.7-2.5 million. This makes HIV/AIDS a unique problem in that the magnitude of the problem is high Secondly, Uganda, just like many other African nations, is a nation that is already weakened by poor infrastructure and HIV/AIDS aggravates the situation even further. The young child is made even more vulnerable by the loss of both parents, yet this is in a society that has few social support systems outside the family and where basic social services are largely inadequate.

3.0 Caring for Children affected by HIV/AIDS

The great majority of orphans are taken care of by widowed mothers and grandmothers (and grandfathers in some few cases). In a situational analysis survey conducted by Dombo and Nyeko (2003), women were found to head three quarters of the households surveyed, with 40 % cared for by widows and one-third of the orphans being cared for by one or both grandparents. It was found that helping caregivers to provide basic needs is vital for the continued existence and well being of the household.

And to this end, Ugandans have responded with courage and compassion to combat the spread of HIV, responding to the needs of those with AIDS and caring for the children orphaned by the disease.

The big orphan population gives justification to a community based approach to the problem; institutional care would simply be unaffordable but a community based care aims at strengthening families and communities to care for the children.

The guiding principle in the care of the children is that the best place for children to be brought up is within the family and that when a child has to be placed in an institution for any reason this should be a temporary arrangement while a family home is being found. This applies also to the very young child, that child that falls in the category defined by Ministry of Education (2003) as Early Childhood Development (ECD).

4.0 Linking ECD and HIV/AIDS

The Ugandan newspaper, the New Vision, April, 19th 2004, reported that globally, in the year 2000, about 600,000 infants had HIV and over 90% were infected through their mothers. Ninety percent of the infant HIV infections were in Sub-Saharan Africa. UNAIDS (2000) estimated that, AIDS would increase infant mortality by 75 percent and under-five by more than 100 per cent if HIV infection through mothers is not contained. Paediatric HIV can be transmitted from mothers before and during delivery and after delivery through breast milk. Breast milk offers infants protection against infection, malnutrition and premature death during early infancy. However, HIV positive mother are advised to make informed choices to breastfeed or not.

In Africa where HIV/AIDS is an epidemic, the alternatives to breastfeeding are frequently unavailable, unaffordable and culturally unacceptable. Also lack of access to clean water and sanitation makes the use of alternatives to breastfeeding dangerous to the health of the child. The health benefits of breastfeeding for both mother and child are undisputable, and they are influenced by both the duration and intensity of breastfeeding and by the age at which the child receives complementary foods and liquids.

5.0 ECD interventions and practical models of care in Uganda

The government of Uganda general guidelines for orphans and other vulnerable children recommend the family and the community as the best place to care for orphans. An exploration of what models exist in the care of young children, eight (7) inter related approaches were identified. They have been categorized as Home Based care, education, motherhappy-babyhappy, economic support, medical, nutrition for health, and the integrated model.

5.1 Home based care Model: The example of Kamuti ECD centre

This is an individual-founded home based centre, a lady who, out of love for children, took up a responsibility to open her own home for children from the neighbourhood to come and meet there for play and emotional support. The parents later join in to offer some physical and material support.

Those who cannot contribute financially, they do so in kind, like bringing in maize flour, fruits, and bananas. But the centre is basically the responsibility of an individual concerned about the wellbeing of children.

5.2 Education model: The example of Nyazinga Nursery School

This centre like over 25 others in the country was a result of the World Bank/Government of Uganda Nutrition and ECD project. The community was given many options to choose from like nutrition, for example to look after milk producing cows, but for one community visited by researchers, Nyazinga residents, chose the education aspect, a Nursery school.

5.3 Mother happy - Baby happy model

This is a community HIV and AIDS Intervention targeting supporting the mother to reach the child implemented by an agency, Plan International, in Luwero district, central Uganda.

The model is a 'spill over' approach believing that a mother of an U8 who is happy, healthy, living well, that joy spills over to the child as well. In this approach, the strategy is to target the child before birth through provision of prenatal

services to the mother. If the mother is HIV positive, in addition to receiving AIDS care (either Navirapine or any other appropriate ante natal care) to protect her baby, she is encouraged to be open about it to herself and to the other children. This will in turn lead to an emotionally healthy mother and children. The belief is that the more the family accepts that death is eminent, the more they cope with the process leading to it, and it all starts from the mother to the children. Why mother? This is because culturally, it's the mother who spends most of her time with the children and so has greater opportunities to talk with them than their father.

5.4 Social-Economic support model

This model believes in the interrelatedness of economic stability and emotional well being of individuals. That a family living in dire poverty finds great challenges raising children in the way they would have loved to do, and this gets worse when there is an onset of HIV and AIDS in that family, where all the family resources are allocated to medical care.

Agencies involved in this model (Uganda Women Effort to Save Orphans (UWESO), and Foundation for AIDS Orphans Care (FAOC) try to meet children's well being through economic support of guardians. They mobilize affected families and communities as a whole to take up the role and responsibilities of caring for the orphans, while organized into credit and savings cooperative groups. The groups are provided small loans to support small scale projects. At the same time, they receive information about HIV/AIDS and its effects on children and the community as a whole.

The savings and credit groups use the economic support methodology to meet the psychosocial needs of the children. Through the weekly meetings of saving and credit women groups, the members are able to identify a child that needs help. This may be reported by a member of the group during periods of making their credit repayments, or a friend or neighbour. The members then will mobilize resources and attend to the particular child.

5.5 Nutrition for health

I have called this model the 'survivalist' model. It picks on the theoretical assumption that when a child is without malnutrition, that child is healthy and therefore happy¹.

It is an emphasis on the nutritional well being of the child to survive the perils of childhood. Food, and high nutritious food, is a basic commodity, yet it is one of those that goes diminishing quite fast at the onset of HIV and AIDS in the family since the 'bread-winners' are affected. Therefore the organisation involved, (Feed The Children Uganda (FTCU), targets providing food to affected children but specifically those living with HIV/AIDS.

The greatest concern in the field was how to get the children. As minors and vulnerable, they are invisible. The approach taken was to partner with the Paediatric clinic and provide the food to children coming to the AIDS clinic at Mulago Hospital.² This also attracted the guardians to bring the children for medical care as they received some food as well.

5.6 Medical care model

As mentioned above, this is another 'survivalist' strategy to reach the children with psychosocial support. The purpose is 'to rehabilitate children living with HIV/AIDS, improving their quality of life in a holistic nature' says a staff of Mild May International Children's Hospital, one of the centres where the model was implemented. The second centre was the paediatric clinic mentioned above.

¹ This needs to be studied more to see if there is any relationship between malnutrition and quality of life in children.

² The AIDS clinic categories of Paediatric cases. Friday 8:00am to 12:00 was allocated for the HIV/AIDS positive children who would specifically be brought in by parents or guardians for treatment of opportunistic ailments.

³ Clinical signs of AIDS are those that the doctors can diagnose especially after the patient has gone through an HIV/AIDS test.

Children brought to the hospital are assessed and referred by the doctor who identifies the most serious cases, the very ill, already with clinical signs of AIDS,³ very needy ones, especially those who are already orphaned and are in the care of a second or third generation guardian (orphaned children often pass through different hands of care)

In the assessment the doctor checks how the children feel, how they relate when angry, at school or home; how they feel when sick; they are asked, 'how is at school? They suggest, 'would you like us to come and help you in revealing your status to the classmates?' In turn the children often ask questions like, 'how come I develop this rash?' The conversation that goes on enables the doctor to recommend the child for further counselling services, nutrition and medical care.

5.7 Integrated community ECD Model

This is a model that combines all the six models described above, where the agencies involved attempt at providing what they have termed as 'integrated community ECD services'. The agency include those by the community themselves, as in the example of Nkukute Early Childhood Development (ECD) site, Kyazanga in Masaka District implemented by Masaka Local Government with funding support from UNICEF; Uganda Orphans Rural Development Programme (UORDP) and Action For Children (AFC) with funding support from Bernard Van Leer Foundation (BVLf).



Children at an ECD Centre. © AFC

Within the integrated approach, there is an ECD centre opened and managed by the community members who take care of the children and the caregivers (not called teachers), make the learning materials themselves. The curriculum called a 'learning framework' is based on an appreciative inquiry model. This is a model through which the positives are put in the fore front and other learning issues build on that. Rather than criticizing what the members have done with the children, they start by appreciating their efforts in whatever area and then build on.

HIV/AIDS education and training, Income Generation Activities in various forms, life skills training for children of all various ages from 2-8), food security (giving seeds to guardians, and ploughs to organized groups, and teaching nutritive care ; psycho social care for the elderly guardians (as in the Action For Children grandparents scheme), medical care where a community nurse visits the centres to treat children, carry out deworming, first aid for those that may need it and referring serious cases to the nearest health centres. Story telling and play are emphasized and most of the agencies identify a 'grandmother' to the children who plays a central role in providing psycho social care at the centre. The 'grannie' opens the centre every morning, prepares and serves porridge to the children, checks



ECD children playing at the Centre, Kyanja, Kampala. © AFC

the hygiene of the children and cleans those who need cleaning, trims hair and nails, identifies and counsels those that seem emotional uneasy, withdrawn, reserved and probes them and visits their homes to talk with the guardians. She also consults with the teacher of centre. She comforts those affected and infected by AIDS when ridiculed by other children. The children get used to her, love her and feel they have someone they can talk to when they are in a difficulty. A child is reported to have one day said to her, 'today am so hungry, can I have two cups of porridge?' The 'grannie' understood this child may have a problem at home and on visiting the home, found it so. The child had had no dinner the previous night as the guardian was unavailable.

6.0 Reflections

In this study, the research team made the following observations and conclusions:

- There is a general missing component of psycho social in the programs probably as a result of not understanding the concept. This resulted into few programmes found that are designed purely to meet the PSS needs of children affected by HIV/AIDS.
- Some programmes are designed to target adults in the hope of reaching the younger child 'if mother is happy, then the children are happy'
- Some PSS interventions of 'play' were designed for adolescents (12 above) because 'they can easily be organized, and controlled, while the younger ones cry for their mothers' as one respondent said. That the young ones cannot be kept at a centre for long hours.
- There is documentation on ECD and its various forms of ECCE, ECDE, ECEE etc, though little is available on PSS
- There have been almost zero attempts at linking HIV/AIDS and ECD except in terms of orphan care or medical attention to the unborn or at birth. But even then, the linkage is for treatment, prevention of mother to child, or improving nutrition, not PSS.

4.3 Recommendations

From the above observations, the following are the team's suggestions in terms of recommendations:

- What is available for adolescents can also be re-modeled for the Under 8 e.g. outings to amusement parks, Christmas parties etc. These are very good activities that promote the cognitive development of the young child. Where the fear of 'crying' for the children occurs, guardians and parents can be involved at some level to accompany the children. When the activity is regular, the children will get used to being away from their caretakers and the crying is likely to be reduced.
- There is need to define PSS and bring it to the level of the local population. The population considers it in terms of 'happiness', jovial, eating well, not being sick and playing easily with others.
- Design an appropriate intervention PSS to test out a mix of models.
- This will help in linking ECD with HIV/AIDS under a variety of models

7.0 Conclusion

The exploratory study was carried out to identify working models that can exist and can be replicated. It was not the purpose of the study to identify which model is the best or not. All models as long as they meet their targets are helpful in one way or another. It is therefore imperative for any practitioner to study the various models and select for himself or herself which approach he/she wishes to employ in the interventions. Each model has its own advantages and disadvantages. The advantages relate to the focus ness of the services given to the children. While the disadvantages may relate to the inadequacy of the interventions to meet the holistic nature of children's required basic needs, which the integrated model tries to achieve. All in all, the psycho social well being of the young child affected by HIV and AIDS may be said to be promoted by the conducive environment the child is living in relation to the economic, social and even political situations surrounding the child.

Background to the Research Project on ECD programs in Uganda

Chapter 1

Background to the Study

1.1 General Introduction

This section explains the history and origin of the study, justification, objectives, and methodology. The study is divided into three parts and has been conducted over a period of 2 years. Part 1 covers a documentary scan of ECD interventions in Uganda; Part 2 is an institutional assessment of interventions and an attempt at identifying working models of care that link ECD, HIV/AIDS but also with a strong psychosocial component involving or within a setting of community 'rooted' programmes. Part 3 highlights a case study for testing out a selected model.

1.2 Origin of the Study

During the year 1999, at a European ECD international conference, the topic concerning the Young child and HIV/AIDS came up. While the participants from outside Africa were interested in researching on the various issues concerning HIV/AIDS, the participants from Africa felt it was their obligation to conduct these studies. It was therefore agreed that interested countries identify the various relevant issues that concern them for research. The countries that agreed to participate were Uganda, Kenya, South Africa, Malawi, and Swaziland. Meetings were held to discuss the progress and identification of research topics.

The result was identification of the areas that included psychosocial support (Uganda), Safety Networks (South Africa), MCTC (Kenya), IEC (Swaziland), and Orphan care (Malawi) and each country embarked on soliciting for funding. In 2004, financial support for this study was availed by BVLFF through the ongoing project of Grandparent support of Action For Children and the study began in 2005.

1.3 Purpose

The study carried out in Uganda concerns Community models of care for young children made vulnerable by HIV/AIDS, digging deep into the psychosocial support strategy. It is aimed at finding ways of improving community based psychosocial support services to U-8 children affected by AIDS.

In Uganda, there are insufficient documented studies on the psychosocial interventions as far as children affected by AIDS are concerned. A USAID study into the well being of orphans and other vulnerable conducted in 2002, points out that earlier studies, especially the one done by the Community Based Association for Child Welfare (UCOBAC) highlighted the fact that there was a significant lack of information in the area of psychosocial aspects of AIDS and orphans (UCOBAC, 1993). This research is targeted at filling the gap.

1.4 Justification

In addition to little documented information, there is inadequacy of interventions responding to the rights of children in terms of the psychosocial support services, especially of the young children affected by AIDS. The on-going services provided by NGOs, CBOs and families tend to be inadequate; this has led to the international, national and local communities being insufficiently informed of 0-8 aged children's psychosocial needs and areas of interventions. This report highlights interventions that can be used to improve the quality of services to U-8 aged children affected by HIV/AIDS in Uganda and beyond, especially in the areas of psychosocial support

1.5 Specific Objectives

- 1.5.1 To provide reading material on ECD in Uganda.
- 1.5.2 To identify ECD programmes that are meeting the psychosocial needs of children affected by HIV/AIDS.
- 1.5.3 To generate models of care for providing psychosocial support for children U8

1.6 Methodology

This is an exploratory study that is more qualitative in nature than quantitative and bases its findings on descriptive analysis of what exists.

Methods employed included:

A literature review of what is existent, interviews of key respondents and Focus Group Discussions with emphasis on "Rights Based Approaches"

Chapter 2

Theoretical Framework of ECD in Uganda: A Literature Review

2.1 Definition of Concepts

This chapter identifies ECD concepts as they are understood and used in the Ugandan context.

2.1.1 Early Childhood Development (ECD)

National Council for Children (1999) defines Early Childhood Development in two parts; Early Childhood as one concept, and Development as another. Early childhood is defined as a period of a child's life from conception to below the age of six (0 - 5), and Development as the process of change in which the child masters more and more complex levels of moving, thinking feeding and interacting with people and objects in the environment. ECD is therefore a process by which young children grow and thrive physically, morally and socially. However, the Ministry of Education and Sports (2002) sees the early childhood period extending from 0-8 years, which includes the early years of school age.

These two definitions have culminated into government policy on children directed at addressing all aspects of child development in respect to children's rights as spelt out in the Uganda Children Act (2000). These are: education Rights, Care and Protection, Survival rights and Participation rights.

2.1.2 Early Child Education (ECE)

ECE relates to the early years that are critical for the acquisition of the concepts, skills and attitudes that lay the foundation for lifelong learning. These include the acquisition of language, perception, learning to read and write, basic numeracy concepts and skills. Much of this would be transmitted through 'family learning environment' in Africa as National Council for Children notes, 'traditionally, elders lived with families in the household and they played with the young ones telling them folk stories' (NCC, 1999)

2.1.3 Early Childhood Care and Protection

This includes a set of actions and behaviours undertaken by caregivers to ensure proper growth and development of a child starting from pre-natal to post natal care. There is need therefore to provide social support to the mother and child by providing comfort and affection. Increased care for the mother (by the father) in form of feeding, medical care, clothing, housing, sharing family roles can help to promote proper growth and development of foetus. There is need for parents to provide play materials and often to play with their children to help them develop mental, social, and physical and communication abilities.

It has however been noted that very few men in Uganda can be found spending time to play with their children. Many still consider it a waste of time and will prefer to be at a drinking venue with colleagues.

2.1.4 Early Childhood Health and Nutrition

In terms of health, this is defined as child survival that includes such areas of focus as:

- Safe motherhood to facilitate a viable baby being born:
- Integrated management of child illness
- Nutrition –adequate balanced diet for both mother and child
- Immunisation against main killer diseases and child communicable diseases prevention and control
- Disability prevention and management
- Safe environment for the children at household, community and institutional levels. This focuses on particularly safe water, sanitation and housing

Health of child is complete with a dialogue on the effect of HIV and AIDS.



Children seated together, most of these children in Masaka are affected by HIV/AIDS

2.2 Children and HIV/AIDS

2.2.1 General Information on HIV/AIDS

HIV is a short form for Human Immunodeficiency Virus (HIV), meaning the virus that affects human beings creating a weakness in the body's ability to fight off infections and disease. AIDS refers to the Acquired Immune Deficiency Syndrome, meaning that people are not born with the disease, but get it from a germ (Acquired), the body becomes very weak that cannot fight off infections (Immune deficiency) and develops a group of health problems or diseases that occur together (syndrome)⁴. HIV/AIDS is transmitted mainly through having unprotected sexual intercourse with an HIV infected person, through contact with HIV infected blood, transfusion of infected blood, sharing unsterilised contaminated skin piercing instruments, and from an HIV infected mother to her unborn or newly born child.

⁴ Save The Children, UK, 2003. Care for children infected and affected by HIV/AIDS. A training manual for Community health workers.

2.2.2 Children and the impact of HIV/AIDS

In 2003, it was estimated that there were about 150,000 HIV infected children and 3,789 cases of AIDS in children below the age of 12 years reported (Save the Children, 2003). Furthermore, it was reported that 66% of the children with HIV die by the age of three, and the mean age of children with AIDS is 2.2 years. However, there are increasing numbers of children with HIV/AIDS who are living longer than 2 years in Uganda today to even 15 years of age. However, the children that survive are heavily affected by loss of parental care.

The number of children orphaned by HIV/AIDS is ranging between 1.7-2.5 million. This makes HIV/AIDS a unique problem in that the magnitude of the problem is high (2.5 million orphans makes Uganda one of those countries with the highest number of orphans in the world!). Secondly, Uganda, just like the rest of Africa is a community that is already weakened by poor infrastructure and HIV/AIDS aggravates the situation even further. The young child is made even more vulnerable by the loss of both parents, yet this is in a society that has few social support systems outside the family and where basic social services are largely inadequate⁵.

Grief for such children starts long before the death of the parents; therefore the children find themselves having to care for ill parents, and their siblings, doing the household chores and gardening. And since HIV-related illnesses quite often take such a long time progressing from mild to life threatening, the children get exhausted by living in uncertainty and intermittent crises. And where there is little or unavailable relief for stress and anxiety, many children lose comfort and hope.

2.2.3 Caring for Children affected by HIV/AIDS

The great majority of orphans are taken care of by widowed mothers and grandmothers (and grandfathers in some few cases). In the Dombo and Nyeko situational analysis survey (2003), women were found to head three quarters of the households surveyed, with 40 % widows and one-third of the orphans being cared for by one or both grandparents⁶. It was found that helping caregivers to provide basic needs is vital for the continued existence and wellbeing of the household.

And to this end, Ugandans have responded with courage and compassion to combat the spread of HIV, responding to the needs of those with AIDS and caring for the children orphaned by the disease. The big orphan population gives justification to a community based approach to the problem; institutional care would simply be unaffordable but a community based care aims at strengthening families and communities to care for the children.

The guiding principle in the care of the children is that the best place for children to be brought up is within the family and that when a child has to be placed in an institution for any reason this should be a temporary arrangement while a family home is being found. This also applies to the very young child.

2.2.4 Linking ECD and HIV/AIDS

Sheila Gashishiri, in the New Vision, a newspaper in Uganda, of Tuesday, March 23, 2004, reports that globally, in the year 2000 about 600,000 infants had HIV and over 90% were infected through their mothers. Ninety percent of the infant HIV infections are in Sub-Saharan Africa. Paediatric HIV can be transmitted from mothers before and during delivery and after delivery through breast milk. Breast milk offers infants protection against infection, malnutrition and premature death during early infancy. However, HIV positive mothers are advised to make informed choices to breastfeed or not.

In Africa where HIV/AIDS is an epidemic, the alternatives to breastfeeding are frequently unavailable, unaffordable and culturally unacceptable. Also lack of access to clean water and sanitation makes the use of alternatives to breastfeeding dangerous to the health of the child. The health benefits of breastfeeding for both mother and child are undisputable, and they are influenced by both the duration and intensity of breastfeeding and by the age at which the child receives complementary foods and liquids.

⁵ Unicef, 1999. Children Orphaned by AIDS: frontline responses from Eastern and Southern Africa.

⁶ Dombo and Nyeko (2001) Community coping mechanisms for orphan care. A survey report.

2.3 Psycho-Social Support for Young⁷ Children

2.3.1 About Psychosocial Support (PSS)

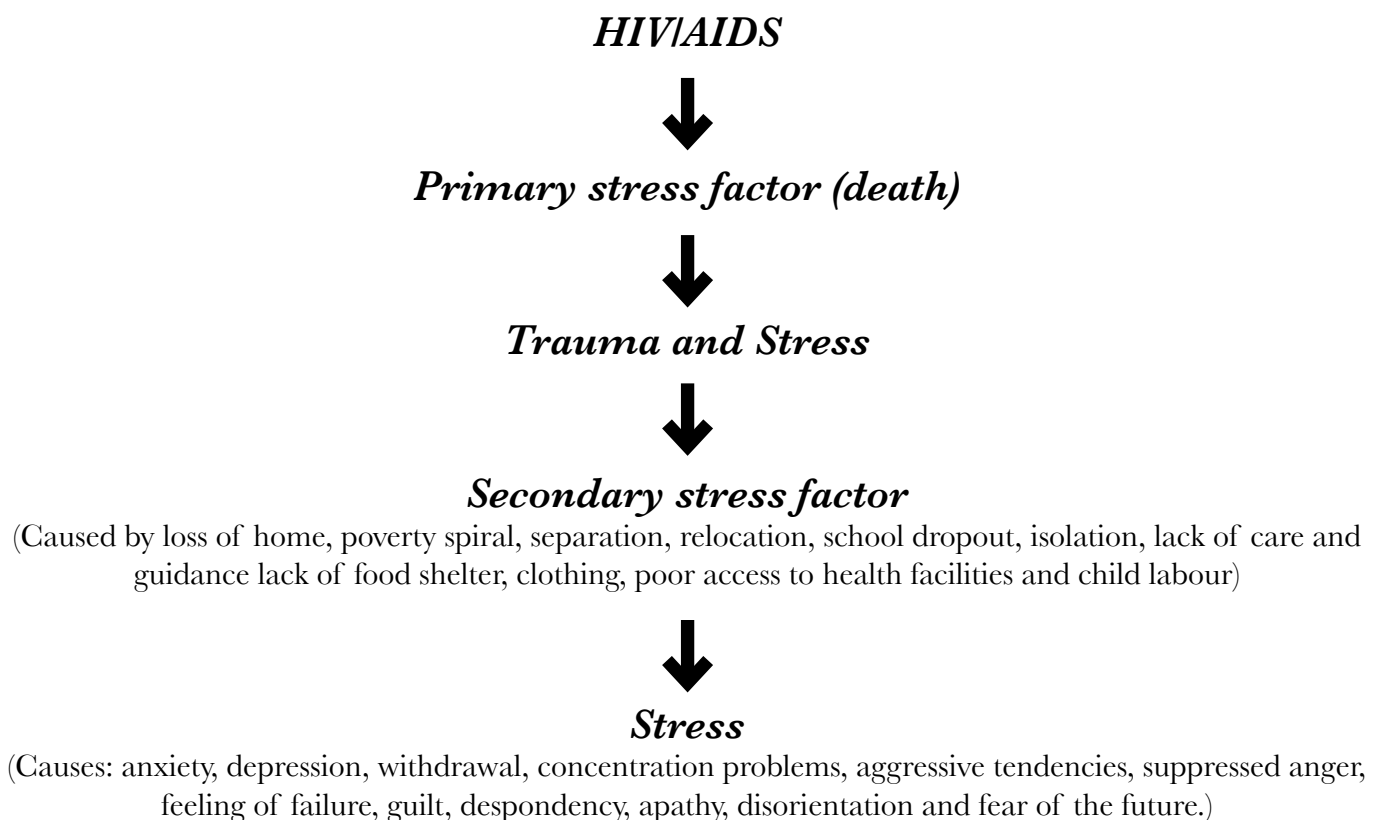
PSS can be simply defined as the provision of affection and attention that includes physical, visual and verbal interactions between caregivers and the children (AFC, 2004).

Save the children (2003) pilot draft on children in crisis noticed that a child's well being and health development require strong and responsible social support systems from the family to the societal levels. Children's development is inextricably connected to the social and cultural influences that surround them particularly families and communities that are children's life support systems. In all societies families try to protect and meet basic needs of children. Beyond the family, child development is influenced by peers, teachers, community members and increasingly through out the world by mass media. Where there is an effect of HIV/AIDS, this support system is undermined.

2.3.2 Effect of HIV/AIDS on the Psycho-Social well being of young children

There is a linkage between HIV/AIDS and psychosocial well being of young children. HIV/AIDS causes emotional difficulties for children, especially so, when they live in households devastated by the disease. Children affected by HIV/AIDS may suffer from loss of family and identity, psychosocial stress, loss of inheritance, forced migration, homelessness, malnutrition, and fewer opportunities for schooling, education and health care. These factors make vulnerable children more at risk of exposure to HIV infection - a vicious circle (World Bank 2002).

Stages of Psycho-Social damage caused to children by HIV/AIDS



⁷ Young children in this research refers to the children under 8 years of age.



AIDS orphaned children in Wobulenzi, Luwero District

Post traumatic stress disorder

Effects of Stress

The psychosocial effect of HIV/AIDS on children is often characterised by:

Anxiety:

Some parents find it difficult to talk to their children about HIV/AIDS. This lack of communication can confuse the children. The children may have their source of information outside the family and they draw their own conclusions. This creates anxiety as the children worry about their parents and their own future.

Loss of Self-Esteem and Confidence:

Loss of a father can deprive children of social and economic security while loss of a mother deprives them of emotional security. Children without their parents may lose their confidence and self-esteem as a result. Often they feel a sense of shame that one of their parents has died of AIDS because of the social stigma attached.

Stigma and discrimination:

Children have suffered stigma because in Africa, HIV/AIDS has been considered a form of punishment for wrongdoing and associated with promiscuity or witchcraft. Children have been both stigmatised and discriminated at home in their play environments. In most cases they are given nicknames, isolated and denied access to facilities.

Depression:

This is a deep sadness with long-term harmful effects on the health and development of the individual. When parents die, children not only miss their physical presence but also their love care and protection. Lack of support during the grieving process and inadequate help in adjusting to an environment without their parents may lead children to become depressed.

Children affected by HIV/AIDS can experience and show grief even before their parents die. Common feelings experienced by children when they lose their parents include guilt, anger and sadness.

Guilt:

Some children feel responsible for the death of their parents. If not helped to work through their assumed guilt they can become depressed. Many parents live for their children struggling to pay their school fees and get food for them. Sometimes they even take risks and get HIV/AIDS and this makes the children feel guilty as being the cause of their parent’s sickness.

Anger:

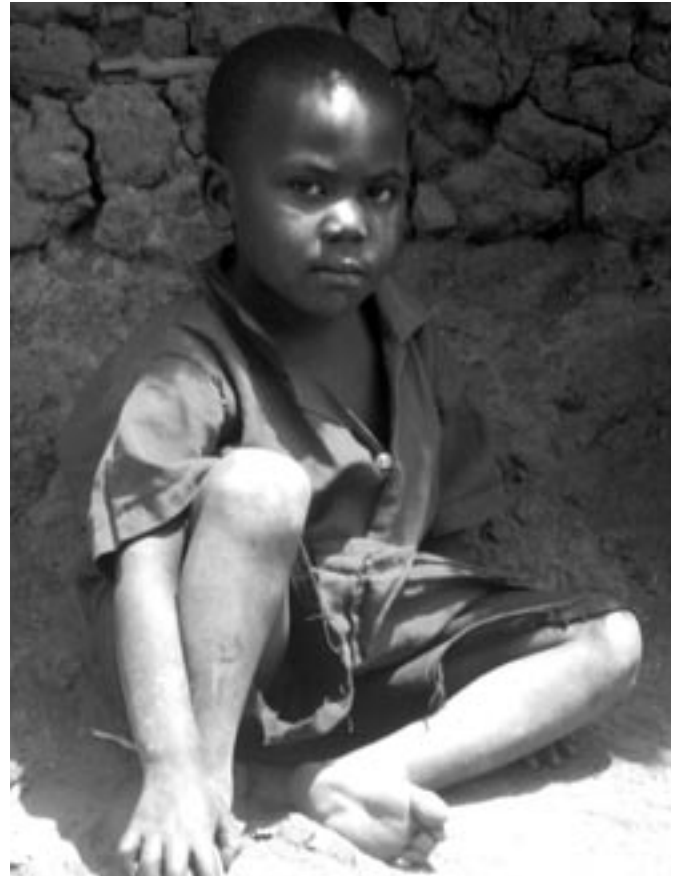
Some children especially adolescents feel angry at the loss of their parents. This anger may be directed at who ever they think caused the death of the parents. Counselling and support is required to work through this anger.

Sadness:

Children are often shielded from death when they realise their parents have gone for ever, they become depressed and take a long time to recover. This may result into “inhibited grief”, that is grief erupting later in the form of emotional disturbances, various kinds of phobias and eventually depression.

Poor Sense of Identity

Parents normally help children to develop a sense of self. Without that, many orphans- particularly those who have been institutionalised have difficulties with identity issues.



Alone: Derrick in Kyanja, Kampala

2.3.3 Effect of HIV/AIDS on the psychosocial well being of Care Givers⁸

Just like children, adult care takers also get emotional stresses as; Depression, grief and feelings of helplessness, withdrawal and isolation; Anxiety; Frustration, Confusion and Despair and loss of hope for the future. The care givers worry about the children in case they (adults) are not available. It gets worse especially when one parent is already dead. They get concerned how the children will get food; they ask themselves questions like ‘how will the children



Children and their caregivers in Masaka. Children with unhappy caregivers tend to be moody

⁸ Care givers include any person taking care of another, in this case, those taking care of children, such as grandparents, uncles, aunts, siblings and non biological guardians

survive? Will they find work? Will they be paid? Will they turn to begging?’ And often times there are hardly any answers. This creates a situation of hopelessness.

Strategies for Psychosocial support

- Encourage openness and truth
- Prepare for ill health and death of parents (communication between parents and children)
- Participation and involvement to enable children express their feelings
- Promote and strengthen community responsibility
- Use existing community structures to address communities about the impact of HIV/AIDS (youth clubs, traditional healers, child welfare forums and CBOs)
- Provide support to care givers
- Strengthen psychosocial support for children within families and communities
- Fostering and adoption (for example extended families, communal, formal and informal fostering)
- Provide opportunities for play and development of life skills

How do care givers communicate with children about HIV/AIDS?

Since the advent of HIV/AIDS in the 1980's, attention was first drawn to developing interventions targeting adults. So trends towards positive living and disclosure were geared towards adults. Over time however, there was a realisation that adults were finding it difficult to disclose to their children their status. And children were seeking for answers for questions like, ‘mama, why are you constantly sick?’ Parents had to find a way of responding. This led to the development of the Memory Book (MB)



Communication: A caregiver taking care of children by being closer

Keeping the memories of dying parents through the Memory Book (MB)

In Uganda, the Memory Book Project was started by a national agency called National Community of Women Living with Aids (NACWOLA) Uganda, who realized that mothers living with HIV/AIDS found it hard to discuss their status with the children.

The memory project is a tool to enable people speak openly. Its origin is from the UK where cancer patients would have a box for keeping in jewellery for their children and grandchildren. It was used for disclosure. Topics included background information on family, kinship, family desires, the children and their wishes, photographs of events and

persons that the children can remember, and plans for the future.

In the era of traditional safety nets of extended families stretched to breaking point, distant relatives no longer having the means or inclination to care for the children, the MB at least give orphaned children a chance to save some memories of their parents and the knowledge that they were loved. MB also gives dying parents a chance to document their aspirations for their children in the form of a letter.

Making the Memory Box

Steps: Wooden or aluminium box made by a local craftsman. Give to the child. Child paints the box. When mother is ready to talk, discusses with children what to put in the MB. (She may be helped by the care team). Put in the box reminders of parents' love. Identify documents, photographs of family group at home, and letters from the parents or mother. As the paint dries, mother and children admire their work. Name the box.

2.3.5 Conclusion

Much has been written on Early Childhood and much more about HIV/AIDS. Little however is available on the impact of HIV/AIDS on the younger child especially, the psycho social well being. The literature confirms that HIV/AIDS has long lasting negative effect on the social well being of children in society just like the rest community members, but much more to the young child who takes on adult roles prematurely. This consequently makes a case for care of the young child to meet his/her psychosocial well being.

In the following chapters of Part 2, focus is on the models of care for the young child in Uganda, showing how the various agencies have attempted to meet the challenge.

Chapter 3

ECD Interventions & Practical Models of Care in Uganda

3.1.0 General Introduction

Although the concept of ECD has many descriptions, e.g. ECCE, ECD, ECE, etc, of most importance is to understand that it is the process in which a child is influenced and educated in her/his formative years. The 1991 and 2003 government of Uganda general guidelines for orphans and other vulnerable children recommended the family and the community as the best place to care for orphans. Equally all children whether vulnerable or not are best cared for by the family and the community and institutionalization should be a last resort. Africa has been credited for having positive child rearing practices. This is relatively true, considering the closeness to the child and his/her mother, the extended family arrangement and the collective community responsibility which was meant to provide protection and care for the child at all times.

It is important to note that the on-set of the modern economy has drastically changed gender roles and the child caring practices have been adversely affected and call for innovative ECD programs.

An assessment of existing ECD programs was made with a view to documenting practical models that can be enhanced and replicated.

3.1.1 Selection of ECD programs for study

Information on ECD programs in Uganda is very scanty and therefore selection of programs for the assessment depended on the general knowledge and networking of AFC with organizations implementing children's programs. Additionally, during a training workshop on ECD conducted by the Ministry of Education (2004) participants identified organisations that were implementing community based ECD programs. Arrangements were made with program managers for visits to the programmes. The criteria for selection were organizations that implement a mix of programs that include ECD, HIV/AIDS, Psychosocial support, and are community based. Within these components, most programs have additional activities like nutrition, education, economic support and medical care. A total of 14 programs were visited as listed in Table 3.1 on the next page:

Table 3. Organisations visited

Name of Organization	Program Focus	Target age in years	Location (District)
1. Foundation for AIDS Orphaned Children (FAOC)	IGA support through guardians School establishment	Orphan children 3-12 years	Mbarara
2. Bushenyi Probation Office	Psychosocial services Nutrition	Children below 18 years	Bushenyi
3. UWESO Masaka	Vocational Skills and PSS	Orphans below 18 years	Masaka
4. The Kamuti Home- based ECD Centre	Education and PSS	Children below 6 years	Masaka
5. Nyanziga Nursery School	Education	3-8 years	Bushenyi
6. UWESO (Micro credit Cluster) Butende	Economic support	Children below 18	Masaka
7. UWESO (Child headed Household – Agnes Nabukalu)	Shelter	Orphan below 6	Masaka
8. Action For Children, Kyanja Community	Counselling, community ECD centres, Grandparent support	0-8 years, cared for by 46-90 year olds.	Kampala
9. ECD Nkukute	Education	2-7 years	Masaka
10. Bamunanika Children's Centre (c/o Plan Intern)	Counselling, Recreation centre	6-24 years	Luweero
11. Feed The Children Uganda	Nutrition-hospital based	0-8 years	Kampala
12. Plan International	Psychosocial; shelter	6-8 years	Luweero
13. Mildmay Hospital and Jjajja centre	Treatment, nutrition, psychosocial, pre-school education	HIV infected children under 8 years in a radius of 10 Kms from the Hospital	Kampala
14. Family Basic Education (FABE)	Functional adult Literacy Education	Children and their parents	Bugiri
15. Paediatric Clinic	Health care	0-18 infected children	Kampala
16. Uganda Orphans Rural Development Programme	Orphan care, ECD, HIV/ AIDS prevention and care	Children 0-8, 9-18, guardians	Tororo, Masindi

3.1.2 Data collection, management and analysis

The data collected was largely qualitative and aimed at providing an in-depth understanding of the programs. Four topic guides were designed to facilitate collection of data from community leaders, program managers, children and beneficiaries (the general community), respectively. Discussions centred on establishing the meaning of the term psychosocial support by the various respondents, existence and understanding of ECD programs in general and their focus. Care was taken to find out whether programs were addressing the needs of the under eight year old children and those infected and affected by HIV/AIDS.

Data was collected from six districts in the western, central and eastern region of Uganda. A team of two staff from AFC who are trained and have experience in implementing and evaluating ECD programs conducted the assessment.



Researchers at the Foundation of AIDS Orphaned Children in Mbarara

Tape recorders complemented the taking of notes by the researchers during the interviews to ensure completeness of the data. A secretary was employed to enter the written notes into the computer and gaps filled in from the transcriptions from the tapes. Observations were particularly made to assess the psychosocial conditions/status of children and guardians.

Content analysis of the data was organized under three thematic areas of program focus/area, target and method/models of service delivery. Critical analysis of the methods of service delivery was done to single out innovativeness and possible elements of the models that could be replicated in the third phase of the research. The next section presents the results of the analysis.

3.2 Findings

The assessment investigated the understanding of the ECD concept and psychosocial support. There was appreciable knowledge about ECD and psychosocial support in all programs visited which were attributed to the intervention by UNICEF and the World Bank Nutrition and Early Childhood Development program. Expression like “Psychosocial Support can be through supporting children from rural settings like organizing parties, trips to other schools which perform well and would be challenged to work hard” FAOC Mbarara. This reflects knowledge and broad look to providing psychosocial support beyond the traditional counselling.

The data revealed that community-based ECD programs, designed purely for children under eight years of age are very few. Of all the fourteen programs visited only three programs were directly focusing on children under eight years of age. The three programs included Action For Children in Kampala, Nyanzinga Nursery School in Bushenyi district and ECD Nkukute in Masaka District. It is important to note that all programs had a community element although with varying degrees of involvement.

Secondly, programs designed purely for PSS were missing. Instead, there were programs that targeted adults with the hope that this would trickle down to the children ‘if mother is happy, the child will also be happy’ said one respondent.

3.2.1 Programs areas / focus and targets

Programs varied in focus and targets. Education and skills development was the most common major program focus. Other major program focuses included nutrition, treatment and shelter. All programs reported taking care of psychosocial needs of children in addition to the major program focus, though this was only limited to counselling and counselling mainly targeting the adults rather than the children.

3.2.2 Service delivery models identified

Most interventions found as implemented by agencies had a relationship with the emotional well being of the young child. For example, consider the following statements:

Education; ‘when I go to school and play with my friends, I forget my problems at home’ said an 8 year old double orphan.

Nutrition: children said, ‘when am not hungry, am happy’

Health care, ‘how can a child be happy when he or his mother is sick?’ a medical respondent

These have been identified as service delivery models, and they vary from individual initiatives to groups, but can be categorized under the following 7 models:

3.2.2.1 Home based Model: The Kamuti Home Based ECD centre

This is an individual-founded home based centre. The example of Kamuti care centre in Masaka district was started by a lady who, out of love for children, took up a responsibility to open her own home for children from



Kamuti Home based ECD Centre

the neighbourhood to come and meet there for play and emotional support. The parents later join in to offer some physical and material support.

Those who cannot contribute financially, do so in kind, bringing maize flour, fruits, and bananas. But the centre is basically the responsibility of an individual concerned about the wellbeing of children.

3.2.2.2 Early Childhood Education model

This is an education model more understood in terms of Nursery or kindergarten language, the example of the Nyazinga Nursery School in Bushenyi district which is an ECE centre. This centre was a result of the World Bank/ Government of Uganda Nutrition and ECD project where the community was given options to choose from like nutrition that is, looking after a cow for purposes of getting milk for children in the community. Nyazinga residents chose the education project – a Nursery school. The district administration assisted in training teachers on how to handle children aged 3 to 8 years.



Nvazinga Nursert School in Bushenyi District, an example of ECD Education Model

Asked what they do when they see children that tend to be moody, withdrawn and not playing with others, the respondents answered:

“We did what we were taught, especially, how to care and know the problems of children psychosocially looking at the child and knowing if he/she has problems. For instance if the child is not happy and try to find out the reason, know their parents through home visiting to know the problems these children are facing in the home with their parents. We teach them about cleanliness and what we were taught about. We teach children depending on the things around us and their parents, in most cases we teach them handwriting and then go to play, send them back home at midday.

When the children have a problem we normally ask the parents and they tell us because we normally have children who have diseases that really disturb us a lot like convulsions so you will be knowing how to keep that child and how you will send him/her back home. Concerning this disease, we have not yet seen any parents who have come in to declare to us that their children are sick among all the parents we have here.”

The children learn according to age and their understanding. The young ones learn to sort out things, learning which is which and through this they get to learn the names of such things. Most important is that they begin with mother tongue, then after that they learn other languages, i.e. those in baby class who do not know how to say anything and can only say words like mum, dad, ball, cup etc.

Everything taught is easily learnt simply because children begin when they are young, now like this one (pointing to a 3 year old) has already begun and can be able to differentiate between objects, she knows that, that is a cup, can be able to sing, she knows her names and can answer back a question. We give them time to play on the swings outside, balls and generally give them enough time to play” narrated a teacher at the school.

The respondent later added that “the children that go through this centre are very different from those that join primary directly, they are normally brighter”. This was to emphasise the value of having the children at the centre according to their own observation.

3.2.2.3 ‘Mother happy-baby happy’ model: Supporting the mother to reach the child

This is model found implemented by Plan international in Luwero District. The model believes that if you support a mother of an U8 and is healthy, living well, that care of the mother spills over to the child, and the target should be the child before birth. But parents have to be open. The more they accept the eminence of death, the more they cope with the process leading to it. For example one mother asked her child, ‘if I died, what will you do?, can you be a doctor?’ At the funeral, the child said, ‘my mother wanted me to be a doctor, she is dead now, but that is what I will be.’”



Children take time off to play with their siblings, photo taken in Bushenyi

When there is no food, the baby will not be happy. But the mother can be helped and encouraged to make sure that ‘come rain, come thunder, the child is part of her’ says the staff.

3.2.2.4 Social-Economic support model

This model believes in the interrelatedness of economic stability and emotional well being of individuals. That a family living in dire poverty finds great challenges raising children in the way they would have loved to do, and this gets worse when there is an onset of HIV and AIDS in that family, where all the family resources are allocated to medical care.

Agencies involved in this model ie Uganda Women Effort to Save Orphans (UWESO), and Foundation for AIDS Orphans Care (FAOC) try to meet children’s well being through economic support of guardians. They mobilize affected families and communities as a whole to take up the role and responsibilities of caring for the orphans, while organized into credit and savings cooperative groups. The groups are provided small loans to support small scale projects. At the same time, they receive information about HIV/AIDS and its effects on children and the community as a whole.

The savings and credit groups use the economic support methodology to meet the psychosocial needs of the children. Through the weekly meetings of saving and credit women groups, the members are able to identify a child that needs help. This may be reported by a member of the group during periods of making their credit repayments, or a friend or neighbour. The members then will mobilize resources and attend to the particular child.

3.2.2.5 Nutrition for health

I have called this model the ‘survivalist’ model. It picks on the theoretical assumption that when a child is without malnutrition, that child is healthy and therefore happy⁹. It is an emphasis on the nutritional well being of the child to survive the perils of childhood. Food, and high nutritious food, is a basic commodity, yet it is one of those that goes diminishing quite fast at the onset of HIV and AIDS in the family since the ‘bread-winners’ are affected. Therefore the organisation involved, (Feed The Children Uganda (FTCU), targets providing food to affected children but specifically those living with HIV/AIDS.



Goat Project Support by FAOC Mbarara

The greatest concern in the field was how to get the children. As minors and vulnerable, they are invisible. The approach taken was to partner with the Paediatric clinic and provide the food to children coming to the AIDS clinic at Mulago Hospital.¹⁰ This also attracted the guardians to bring the children for medical care as they received some food as well.

3.2.2.6 Medical care model

As mentioned above, this is another ‘survivalist’ strategy to reach the children with psychosocial support. The purpose is ‘to rehabilitate children living with HIV/AIDS, improving their quality of life in a holistic nature’ says a staff of Mild May International Children’s Hospital, one of the centres where the model was implemented. The second centre was the paediatric clinic mentioned above.

Children brought to the hospital are assessed and referred by the doctor who identifies the most serious cases, the very ill, already with clinical signs of AIDS,¹¹ very needy ones, especially those who are already orphaned and are in the care of a second or third generation guardian (orphaned children often pass through different hands of care)

⁹ This needs to be studied more to see if there is any relationship between malnutrition and quality of life in children.

¹⁰ The AIDS clinic categories of Paediatric cases. Friday 8:00am to 12:00 was allocated for the HIV/AIDS positive children who would specifically be brought in by parents or guardians for treatment of opportunistic ailments.

¹¹ Clinical signs of AIDS are those that the doctors can diagnose especially after the patient has gone through an HIV/AIDS test.

Mulago Paediatric Care

The clinic started in 1988 with about 30 children but the numbers have increased to over 3,000 by 2005, and handle cases of children aged 0-19 years. The clinic started by operating twice a week, later to three days a week, and presently to 4 days a week as follows:

Monday, Wednesday, Friday -----	Children 0-12 years old
Tuesday-----	Adolescents 13-19 years old
Thursday-----	Administration and case conference
Friday-----	General clinic day

During clinic days, psycho social support is done through talks by the health workers, and sometimes, mothers who have been on the programme for a longer time as they share their experiences.

Parents can cause stigma unknowingly by overprotecting the children. They imagine, since the children are HIV+, they are very delicate, and the disease overtakes other social issues in life. There is over worrying about the child, and the child is treated differently from other children. May be given too much attention and protection and this affects the child. The child definitely gets suspicious and thinks something is wrong with her/him.

“Disclosure can be encouraged for children above 8years old depending on the ability of the children to understand or comprehend. In order to determine or gauge whether to encourage disclosure, one assesses level of intelligence, understanding, use topics that are studied in school that are knowledgeable to the child. Often when the child is infected, they know it, but deny until told by an adult counsellor at clinic”.

Children need to be allowed to talk, to be disclosed to, in the presence of their mothers or their older siblings whoever is the next of kin that is very close to the child. Children above 8 years have to be told why they are on ARVs otherwise the treatment fails when they don't understand why they are on these too many drugs. This disclosure and support is done through the post-test clubs. All the children 10-19 are members of the post-test clubs. An elected committee manages these with a chairperson, 3 counselors, doctors and home visitors. The adults meet just before the children to plan what to do and how to handle the meeting. The children meet once a month and discuss issues that affect them. In the previous period, it was noted that the children were becoming sexually active, so the discussions evolved around sexuality. The methodology of the meetings include prayer, pictures, prevention methods e.g. condoms use, children are given manila paper and write anything of interest and through this, one identifies what affects them. It is surprising to understand what children know.

The children are given a treat to go for outings to Didi's World. This makes them feel they are also like any other children; they can do anything any other children can do. So the clinic does medical, social and sports with the adolescents.

The question the research team struggled with was, **Can these be modelled for the younger children as well?**

“The younger children would need something like a day care. we don't know what to do or how to do it” the nurse admitted.

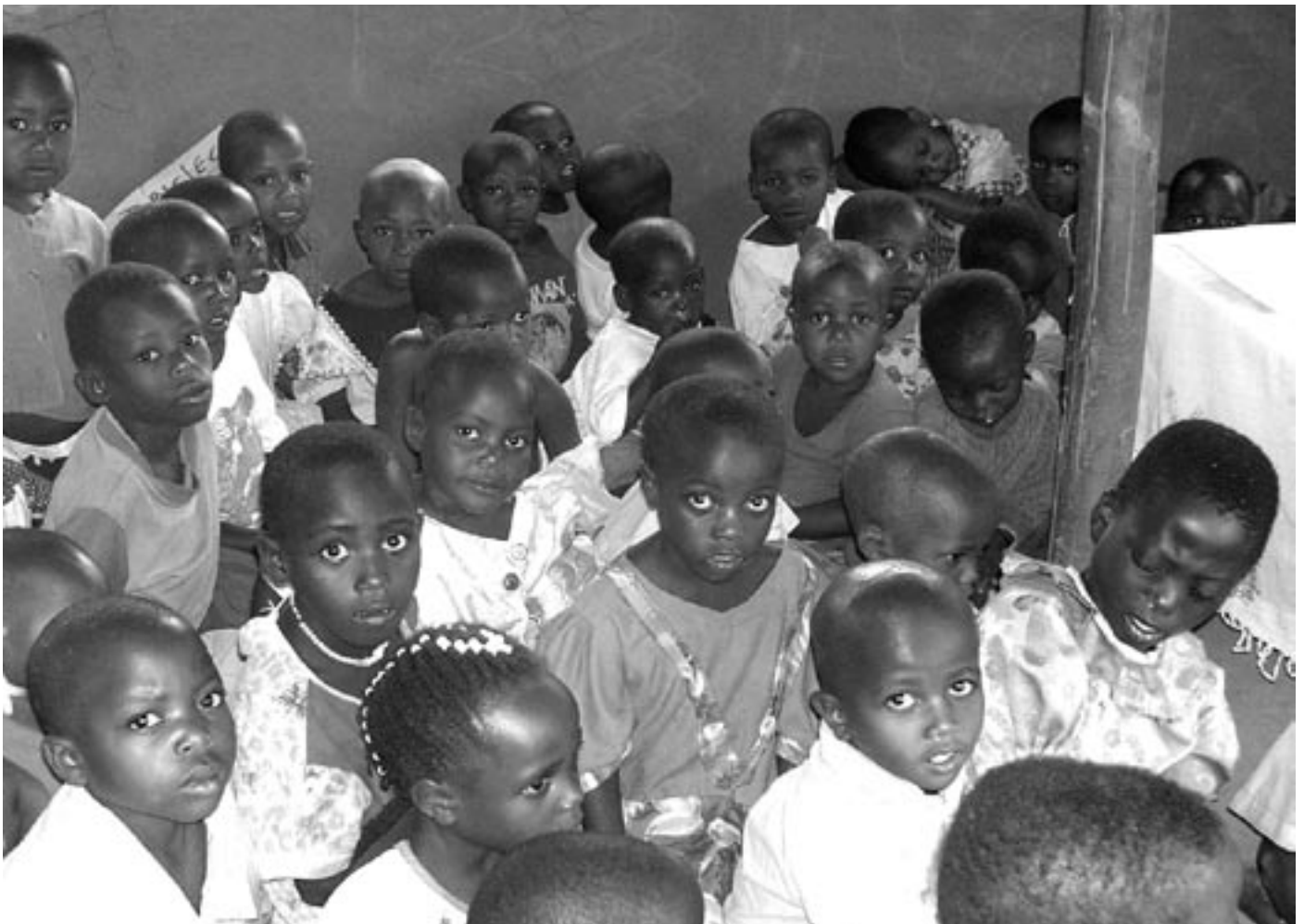
The clinic staffing includes 2 Paediatric doctors, 3 full time medical officers, 8 nurses, 4 counselors, 1 nutritionist, 2 laboratory technicians and 1 clinic manager.

An additional 2-4 ECD caregivers on the staff would take care of the very young!

3.2.2.7 Integrated community ECD Model

This is a model that combines all the six models described above, where the agencies involved attempt at providing what they have termed as ‘integrated community ECD services’. The agency include those by the community themselves, as in the example of Nkukute Early Childhood Development (ECD) site, Kyazanga in Masaka District implemented by Masaka Local Government with funding support from UNICEF; Uganda Orphans Rural Development Programme (UORDP) and Action For Children (AFC) with funding support from Bernard Van Leer Foundation (BVLf).

Within the integrated approach, ECD centres are opened and managed by the community members who take care of the children and the caregivers (not called teachers), make the learning materials themselves. The curriculum called a ‘learning framework’ is based on an appreciative inquiry model. This is a model through which the positives are put in the fore front and other learning issues build on that. Rather than criticizing what the members have done with the children, they start by appreciating their efforts in whatever area and then build on.



Children in Nkukute ECD, Masaka

HIV/AIDS education and training, Income Generation Activities in various forms, life skills training for children of all various ages from 2-8), food security (giving seeds to guardians, and ploughs to organized groups, and teaching nutritive care ; psycho social care for the elderly guardians (as in the Action For Children grandparents scheme), medical care where a community nurse visits the centres to treat children, carry out deworming, first aid for those that may need it and referring serious cases to the nearest health centres. Story telling and play are emphasized and most of the agencies identify a ‘grandmother’ to the children who plays a central role in providing psycho social care at the centre. The ‘grannie’ opens the centre every morning, prepares and serves porridge to the children, checks the hygiene of the children and cleans those who need cleaning, trims hair and nails, identifies and counsels those that seem emotional uneasy, withdrawn, reserved and probes them and visits their homes to talk with the guardians. She comforts those affected and infected by AIDS when ridiculed by other children. The children get used to her, love her and feel they have someone they can talk to when they are in a difficulty. A child is reported to have one day said to her, ‘today

am so hungry, can I have two cups of porridge?’ The ‘grannie’ understood this child may have a problem at home and on visiting the home, found it so. The child had had no dinner the previous night as the guardian was unavailable. But because of this care, many children come to attend the centre.

An example is at the Nkukute centre in Kyazanga, Masaka reflected in the following table:

Table 4. Number of children at centre

Age	Male	Female	Total
2-4 years	25	42	67
5-7 years	23	22	45
Total	48	64	112

Interview with Children

The children define ECD as ‘young children’

Things that make children happy

- Eating favourite foods e.g. matooke, Irish potatoes, meat
- Playing freely with no adult interference
- Singing, writing, playing and story telling by their brothers/sisters (as they answer they also sing- the answers have been formulated into music)
- The children said they like domestic animals and when one hurts them, they get angry

Things that annoy:-

- When their elder siblings eat their food
- Being spanked especially by fathers
- Being verbally abused, especially called abusive names
- Over load of work e.g. fetching water using a 20 litre container for an 8 year old or even below
- Being barked at ‘as if we are dogs’
- Calling them names that are not theirs and have no meaning
- Drunkards ‘because they fall on us’ (abuse)

The children said they prefer to talk to their mothers because:-

- Mother is very understanding
- Sings along with us, dad is not usually around

4.0 Emerging Issues

ECD centres offer **parents opportunities to participate in the education** of their children. This creates bonding especially for the orphaned children that are not with their biological parents, and would have been at risk of abuse.

The community ECDs as implemented by AFC are a kind of a **non formal education** strategy. Participation of positive, motivated and of high morale parents and guardians in the care of children, coupled with intensive sensitization of the rest of community members helps the HIV/AIDS affected families be emotionally strong, the infected live positively, and therefore are able to care for the orphans and the other children made vulnerable by the adverse circumstances they face.

Psycho social issues are interwoven and hidden in other programmes. This has resulted into few programmes found that are designed purely to meet the PSS aspects of children that the community members refer to as 'issues of the mind'.

The **adults around the children** play a great role in bringing about these issues of the mind. The programmes that are designed to enable adults reach the younger child (motherhappy- childhappy) have a bearing on this state of affairs and are not futile.

There are some activities like **play, games and outings** that are designed for adolescents (12 above) which can be tailored for the younger children as well without the fear of 'babies cry for their mothers' as one respondent said.

There is **documentation on ECD** and its various forms of ECCE, ECDE, and ECEE though little is available on PSS

There has been hardly any attempt at **linking HIV/AIDS and ECD** except in terms of orphan care or medical attention to the unborn or at birth. But even then, the linkage is for treatment, prevention of mother to child, or improving nutrition, not in terms of psycho social support per se.

4.3 Conclusion

The exploratory study was carried out to identify existing working models that can be replicated. It was not the purpose of the study to identify which model is the best or appropriate. In the next chapter, a case study, selected from the 'integrated model' the GAS project (Grandparents Action Support) exemplifies a workable approach that can be studied further.



A grandmother and her grand daughter, Kampala

Chapter 4

Case Study: Grandparents Action Support (GAS) project

4.1 Introduction

GAS project is an Early Childhood Development project implemented by Action For Children (AFC). The project started in 2003 after realizing that in the AFC Family Preservation Programme (FAP) 80% of the children were under the care of grandparents, majority of whom were grandmothers for example, out of a cohort of 30 grandparents, 24 are grandmothers and only 6 grandfathers. Each of the grandparents had a child or two who were under the age of 8 and each family had an average number of 4 children aged 18 and below.

Table 1 showing no of families and grandparents from 2003-2006

	Year				
	2003	2004	2005	2006	
Number of families in C5	50	150	184	189	
Number of children in C5	250	600	736	756	
Grandparents in the program ¹²	30	177	200	208	
Children below 8years (cumulatively)	109	305	418	448	

Source: AFC annual report, 2006

The needs and abilities of the grandparents needed to be met differently. The elderly, complained they were weak and frail and thought they could not do anything, as one grandparent lamented ‘mwana wange, nze nkyansobola kukora?’ meaning ‘my child, can I still do any work?’ Yet these were the same guardians caring for very young children, even as young as 1 day old. It was a hopeless situation of **‘the very old, caring for the very young, the vulnerable caring for the most vulnerable’** Jolly Nyeko (2004).

The purpose of investigation was to see if it is possible to support these vulnerable grandparents to get out of the situation of hopelessness and if this would then trickle down to the vulnerable young children.

4.2 Methodology

The research based results from a structured questionnaire administered through home visits and general discussion with grandparents, both males and females, and children.

¹² Some grandparents are not registered in FAP, therefore the number of GAS participants in subsequent years is higher than those in FAP.

Other information was obtained through observing identified details related to behavioural interactions especially the psycho social aspects among the young children, e.g., mannerisms, physical presentations, hygiene etc. From these, deductions were made which were then discussed in group discussions especially with grandparents and community leaders.



The researchers and participants in a focus group discussion

4.3 Sampling and geographical coverage

The project is located in Kyanja Parish of Nakawa Division, Kampala district. The families were drawn from the villages of Kondogolo, Ttuba, Nazareth, Katumba, Kisaasi, Kasaana, Central Zone and Walufumbe zones in the parish, where AFC has been implementing the Family Preservation programme since 2000 and GAS project from January 2003

The study involved sampling families into 4 groupings, each with 30 households, and approximately 50 children.

Group I

This had children from households with 4 (mixed) interventions, ie.

- Community Child Counselling and Care Component (C5)
- Micro Enterprise Development Initiative (MEDI)
- Children Brigades (CHIBS)
- Grandparent Action Support (GAS) which is an ECD programme.

Within these interventions, activities conducted evolve around the following indicators: housing improvement, counselling, food security, education support, health, Income generating Activities, participation and mentorship.

Criteria for selecting households included:

- Households with children under 8 years.
- Households with mixed ages -0-18.
- Households with an HIV positive child.
- Households with HIV positive caretaker

Group II

These included children from households with 3 mixed interventions, but without an ECD component
Community Child Counselling and Care Component (C5) Households
Micro Enterprise Development Initiative (MEDI) Households
Children Brigades (CHIBS) Households

Group III

This included children from households with a single intervention- counselling, including HIV/AIDS counselling.

Group IV

These included children from households with no intervention at all by AFC but reside within the program locality. Some of them bring children to attend school at the community ECD centres yet are not project targeted households.

4.4 Findings

In 2003, with support from BVLF, AFC identified a group of 50 grandparents, with 91 children under 8 from the C5 families under AFC care that cared for young children. The criterion for selection was:

- The household had to be headed by a grandparent with over 40years.
- Had to be needy (as defined by the community).
- Had to be within Kyanja community.
- The household had to have children below 8 years.
- The household had to be known by the community leaders who included Local Council committee members and some opinion leaders.

4.4.1 Interventions carried out:

These were included as participants of GAS project to enable them come out of the situation of 'helplessness' to a situation of 'able' In AFC terminology –from rescue to stability.

Some of the activities carried out included:

Mobilising the grandparents into peer support groups called Action Support Groups (ASGs); Training grandparents in Early childhood Development (ECD) and establishing community ECD centres run and managed by the grandparents themselves, with help of some trained caregivers from the same locality; HIV/AIDS, caring for the sick, providing social and emotional support to children; provision of medical care at a community based child clinic (with a volunteer nurse from the community); economic support in form of income generating activities by grandparents.

4.4.2 Achievements in restoring hope to grandparents:

By the end of the first year, 2003, the grandparents that had been described as 'frail and weak' were calling themselves 'ba jjaaja abomurembe' the 'modern grandparents!' They were beaming with vigour, joy and hopeful. They participated in community functions, unlike before when they complained that no one cared about them, and therefore saw no reason for attending meetings!

The children were vibrant, lively, about 50 children who had been out of school joined primary schools. AFC was determined to continue with the project, and the donor (BVLF) approved a 3-year extended project. At the time of this research, (November 2005) the project is in its 3rd year, and there are notable changes, both in size of target population, from 50 to 200, children from 91 to 448 under 8 years and 908 altogether And geographical spread, from 5 to 9 villages. Also the programmes have expanded from grandparent trainings and to establishment of ECD centres, starting with 1 (2003), to 5 (2004) and 9 (2005).

4.4.3 Effect of ECD interventions on Psycho social well being of young children

AFC approach to PSS intervention is through a combination of various interventions including counselling for both adults and children, provision of education for school going age, IGA support for care givers, housing/shelter improvement, food security, participation, health and mentorship. These are 8 indicators used to establish if a family has moved from rescue to stability stage and finally to permanency.



Happy and loving children from Jolly Angels ECD

Within the various groups, the study had the following findings:

Category 1 (all 4 interventions)

According to the survey carried out in the selected households, families in this category, the children going to the ECD centres seemed happy and very responsive. This was true especially in communities where the centres have existed for more than a year. However in centres that had just been established (less than a year), the children exhibited different aspects, eg, Malnutrition and non responsiveness was still observable.

Children with health problems at home, or who have sickly, worrying caregivers at home, find relief at the ECD centres. With the interaction and play at the centres the children are able to express themselves and off load their stress. The Nurse at the ECD centre attends to the children's health needs, while the centre teacher (caregiver) helps in counselling to meet the emotional needs.

The grandparents of these children were equally vibrant, receiving guests with open arms, different from those described as withdrawn and lonesome.

Category 2 (Only 3 interventions, no ECD)

Children in households in this category generally looked healthy especially where these interventions have been intensive and the family could afford the basics of life.

However the children were not as responsive tended to be dull and shy in most cases, for example, they hid from

visitors and had to be persuaded to come out for a greeting. Some of the children in a few households showed signs of malnourishment. The grandparents were happy, smiling and easy to talk with, excited about the programme, though still complained about low income especially for meeting children's education.

Category 3 (single intervention)

Households in category 3 have single intervention, with only counselling for adults. The children in these households, reflected sadness and looked withdrawn especially in cases where they have been affected or infected by HIV/AIDS. It's the older people in the households that were targeted, child counselling was missing, because it was assumed by the adults that children below eight years were too young to understand what was going on around them.

Category 4 (no targeted intervention at all)

The children attending the ECD centres but not in any targeted AFC programs had some marked differences from other children, according to their parents. Most of the caregivers happen to be the children's biological parents, (different from category 1-3) and during the survey reported that there was great improvement in the children's lives from the time they began attending the centres. For example, one parent in Kasaana village commented,

“By the time my child came to this centre, she wouldn't talk well and was selfish, but she has changed, she can now talk well, is happy and shares freely with others. These children are happy and healthy compared to their older or very young siblings back at home, who don't attend the ECD centres.”

4.5 Other findings

4.5.1 HIV/AIDS infected children.

During the survey it was very difficult to find children who are HIV/AIDS positive. Most children under this category were only suspected but are not tested. Two children who were in the programme diagnosed positive in 2002, died in 2004. It was found out that they were not on any antiretroviral as the drugs were not as accessible as today. Since then, only two other children from one household who were suspected to be positive have been tested. They were found negative, to the caregiver's joy.



Lovely twins: These spend almost all their daytime at Kyanja ECD Centre

Secondly, the information on the children's sero status was mainly given by the community leaders but not the caregivers, who tended to easily deny and shy away from the issues. This raises a question, does stigmatization and discrimination still exist or is it the issue on 'testing of children as a policy matter that is still unclear?'

The caregivers claimed that since children have not been targeted directly in terms of provision of Anti Virals (ARVs) there was no reason for testing them. Health care institutions only target the adults which have left out the children.

Responses from the health unit within the project area revealed that interpretation of the policy on testing children for HIV/AIDS led to lack of testing for children.

(The policy states that children should only be tested with the consent of an adult guardian. This seems to have been interpreted as children should not be tested. As long as there is an adult accompanying the child and gives reasons why the child should be tested for the doctors to be convinced that it is not for selfish reasons (usually as a way of presuming the sero status of a parent), the child deserves the right to be tested.)

4.5.2 Counselling

It was difficult to identify straight forward counselling activities within the program. They are mixed up into what the organization calls 'home visits'. Because of this, none of the grandparents responded 'yes' to having received 'counselling' nor could the guardian state if the child was counselled. Yet the entire programme is supposed to have counselling as a main activity. The question is, is it lack of counselling skills or is counselling easily overshadowed by other activities with tangible results like income generating projects?

4.6 Study recommendations

HIV/AIDS testing for children should be encouraged but after sensitizing the caregivers about its importance. And this has to be followed with availability of the medicines and treatment needed.

Intensified and structured counselling for both adults and children, peer to peer counselling for children should be planned and conducted. This may be especially designed for children between 6-8 years. At this age children can easily be open and talk about their problems and challenges.

ECD centre development has been found very helpful in meeting the psycho social needs of the children. This should be intensified but also introduce transition for the older children, those in the 5-8 year category who delay in the centres yet need to move on primary school.

More documentation of the activities that go on in the ECD centres should be made and shared widely with stakeholders and other interested parties.

4.7 Conclusion

Lessons Learnt from the integrated model

It is important and worthwhile to use many and different interventions, rather than applying only single interventions. The integrated approach of looking at the whole household and addressing its needs as they manifest provides an all round environment for emotional development of the young children.

For the children, there is great benefit in attending ECD centres. For those that have been adversely affected by HIV/AIDS e.g. who have lost parents and live in vulnerable households, (grandparent headed, child headed), they gain emotional strength from interacting with their peers at the centre, and receiving care from another caregiver other than the one at home.

Till children have been tested, there is just an assumption that most children who loose their parents as a result of HIV/AIDS related illnesses may be infected. This study showed that only 2 out of 109 children were proved positive after being tested. Others have not been tested at all, while even those tested were negative.

When children are emotionally healthy, the guardian is equally responsive. That is why the grandparents can now call themselves 'the modern parents'. They too are happy. But to be happy, what they call 'the state of the mind', they need concentrated interaction with them, to help out with basic items at home, to ensure they have a source of income so that they can afford to cater for the children's requirements, and can effectively integrate with the rest of the community members, that is , for the adults to benefit from peer to peer support.

For the young child, it is easy to observe and know how they feel because they 'act' them out. The adults may hide, but the child shows joy with laughing when happy, and cries when sad!

Bibliography

- AVIS, Psychosocial Support Programme. A community Based Intervention in Kitgum and Pader Districts, Northern Uganda, 1999-2002
- Biersteker , L. and Rudolph N. 2003. Protecting the rights of orphans and vulnerable Children aged 0-9 years. South African Action research Programme. Report on Phase one.
- Bramucci, G. L. et al 2001. Unearthed Grace. Stories from Northern Uganda.
- Christian Children's Fund Inc. Uganda. Strategic Plan 2001-2004. Strengthening Partnerships for Impact.
- New Vision Newspaper 2003, 2004
- Nyeko and Dombo: 2002. Community Coping mechanisms for Children Affected by HIV/AIDS. Unpublished Research report.
- Pollard E. L. P, Davidson L. 2001. Action Research in Family and Early Childhood. Foundations of child well being Centre for Child well being USA. UNESCO Education Sector Monograph No 18/2001
- Save The Children, UK, 2003. Care for children infected and affected by HIV/AIDS. A training manual fro Community health workers.
- Smith S. and Smith A. M., 1990. Christians in the Age of AIDS. How we can be good Samaritans Responding to the AIDS Crisis.
- Strode A. Barret Grant K., 2001. The Role of Stigma and discrimination in Increasing the Vulnerability of Children and youth infected with and affected by HIV/AIDS Save the Children, South Africa Programme. Research Report.
- The Government of Uganda, 2002. Situation Analysis of Orphans in Uganda. Orphans And Their Households: Caring For their Future – Today
- UNICEF, 1997. Eight is too late – The Urgent Need to Address Early Childhood Development. A report by the Early Childhood Development Task Force.
- UNICEF, 1999. Children Orphaned by AIDS: frontline responses from Eastern and Southern Africa.
- WHO and UNICEF, 1994. Action For Children Affected By AIDS. Programme profiles and Lessons Learned.

Appendix 1

People talked to

1. Tibamanya Gaudioza, chairman, ECD Nkukute – Malongo (Masaka)
2. Nalongo Hazidah of Kamuti home based EDC centre
3. List of children at Malongo ECD Nkukute centre

No.	Name	Age
1.	Gilbert Muyingo	4
2.	Lauben Kuhytunga	4
3.	Amons Sema	7
4.	Oliver Nabitende	10
5.	Kulubia Nawante	10
6.	Gloria Nuwensaba	4
7.	Josephine Nako	3 _
8.	Patricia Namukasa	3
9.	Oliver Olisaba	10
10.	Joseph Wasswa	3 _
11.	Provia Nampyja	5
12.	Derrick	6
13.	Ritah Babirye	3
14.	Nakato Brenda	5
15.	Isha Nakityo	5

- | | |
|-------------------------------------|--|
| 4. Rose Mwebaze, | Care giver, Nyazinga ECE centre in Bushenyi district |
| 5. Joselyn Kene, | Care giver, Nyazinga ECE centre, Bushenyi district |
| 6. Beatrice Nuwa | Senior Health Coordinator, Plan International – Luwero (Wobulenzi) |
| 7. Pamela Mugisa | Programme Coordinator, Plan International – Luwero (Wobulenzi) |
| 8. Boaz Buyinza | Founder, Foundation for AIDS Orphaned Children (FAOC) Mbarara |
| 9. Faith Amogin | Social worker, FAOC |
| 10. Zam Mbabazi | Social worker, FAOC |
| 11. Cheborion Jennifer Okwii | Project Officer, Feed The Children Uganda , Kampala |
| 12. Sandra Amodot | Project Officer , Feed The Children Uganda, Kampala |
| 13. MildMay | Jjajja Centre |
| 14. Dr. Addy Kekitinwa | Mulago Paediatric Clinic |
| 15. Uganda Rural Orphans Programme, | Tororo |
| 16. Rose Keishanyu | Action For Children |

Other Institutions visited

1. World Vision International
2. Save The Children in Uganda
3. Christian Children Fund
4. Uganda AIDS Commission
5. Action For Children-Kyanja Community Support group.

