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Inter-generational issues between Caregivers and Children in the context of HIV and AIDS- Uganda September 2009



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**Report on Focus Group Discussions held with Older Care Givers in Luwero,
Uganda**

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Country: Uganda

Name of organisation conducting FDGS: Uganda Reach the Aged Association [URAA]

Date of discussion group: 09/2009

Number of participants in each discussion group:

A total of 36 older people participated in the focus group discussions and table 1 shows the number of participants per each group

Table 1: Number of participants per group

Groups of care givers	Number of participants
Older men	12
Older women	12
Mixed group of older men and older women	12
Total	36

Study Population and Setting

Geographical location:

Uganda has a population of 24,442,084 people according to the national census of 2002 and 4.5% of the total population are 60 years and above. It has an HIV prevalence of 6.1% (14-49 years) and it is estimated that there are about 2,430,000 orphans (0 - 17 years) in the country. The study in focus was conducted in Luwero District (about 55km Central of Kampala) where HelpAge International [HAI] implemented an advocacy project through its partner Uganda Reach the Aged Association [URAA] with funding from Swedish International Development Agency [SIDA]. The district has a total population of 341,317¹ and an HIV/AIDS prevalence of 7% which reduced to 3.1% rate².

Socio-economic context

The socio economic profile of Luwero District is characterized by agriculture and three quarters of the district is covered with savannah. The soils are generally red sandy loam, where as the southern part is relatively fertile and can support all kinds of crops. In the northern areas, some parts developed from sandy loam soils and fertility is low. In drear areas cattle farming is the dominant occupation. A wide range of food crops is grown in the district as well as cash crops. The district is predominantly rural, where farming is found to be the main occupation especially among women.

Major food and cash crops: In the northern area, there is mainly cassava, sweet potatoes, maize and bananas. In the southern and central, there are bananas, potatoes, cassava, beans, groundnuts, and horticulture crops like tomatoes, pineapples, cabbages and greens, upland rice as food crop. Cash crops for the southern and central region are coffee, vanilla, bananas, and the horticultural crops mainly pineapples, watermelons, passion fruits, tomatoes, cabbages and vegetables.

¹ 2002 Uganda National Population and Housing Census Analytical Report

² 2006 Integrated Community Based Initiatives [ICOBII]: Central Districts Home Based Voluntary Counselling and Testing Project Report.

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Problem Statement:

HIV/AIDS has had devastating effects of increased burden of care to OVC and PLWHIV in Uganda and Africa as a whole, at least 40% of children orphaned by AIDS are under the care of older people³. It also estimated that 93% of the OVC in Uganda are under the care of older persons especially older women who are already poor and with no source of income⁴. Despite the degeneration gap between the older carers and the OVC they care for and other issues affecting older people, older carers have taken up key roles/responsibilities to provide care for the OVC and PLWHIV. Even at the time when they need to be cared for by their daughters and sons, the pandemic leaves them with no option except caring for their orphaned grandchildren and PLWHIV. In carrying out their caring responsibilities, various intergenerational considerations have come into the focus between the older carers and OVC who they care for. With the ever-increasing burden of care of OVC by older carers, these challenges are equally increasing and placing additional care burden on the older carers in Uganda and Africa at large.

Study Objectives:

1. To identify intergenerational issues for older carers and children and interventions to support caregivers and children in relation to HIV/AIDS.
2. To identify lessons learnt, policy gaps and good practices in support mechanisms [e.g. parenting skills, peer to peer support groups etc.] to intergenerational relationships.

Methodology:

Focus Group Discussions [FGDs] and individual interviews with older persons were conducted followed by half-day meetings in Luwero District in the 3 sub counties (Butuntumula, Kalagala and Luwero Town Council).

Target group and Sampling Criteria:

Focus Group Discussions targeted older people aged 55 and above, groups of Orphans and other Vulnerable Children [OVC] well as PLWHAS under the care of older persons in the 3 selected sub counties within the district of study. The 36 older people who participated were selected from the beneficiaries of the SIDA Phase One Project which was aimed at *“Strengthening Regional Responses to Reduce the Impact of HIV/AIDS on Older Persons”* that was implemented by HelpAge International and its partner, Uganda Reach the Aged Association in Luwero District and at National level.

Focus Group Discussion Data Analysis

Table 2: Indicates the sources of income for 24 households of older persons who were interviewed.

	Small business	Casual labour	Pension	Agriculture
24 Older Persons	4.2%	8.3%	8.3%	79.2%

Table 3 has notes of the responses of all the three groups during focus group discussions
Table 3: Responses of each group during the focus group discussions

³ HelpAge International Data, 2008

⁴ [2009] OVC Situation Analysis by Ministry of Gender, Labour and Social Development

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Questions	Group of older women care givers	Group of older men care givers	Both Older Women and Men Care Givers
<p>1a) What are the roles of older caregivers in raising orphaned and vulnerable children in this Community?</p>	<p>Provide food, clothing, shelter, medication, education, train them in domestic work, show them discipline, show them love and protect them</p>	<p>Groom them, Provide food, Educate, clothe them, medication, shelter, care and parental love, discipline the children under our care, train them in hygienic issues, domestic work, cultural norms, values and customs and religious matters.</p>	<p>Provide care and support to the children, Medical care, Clothing, Instil discipline and effectively guide them to grow up, Teach them cultural norms and values Show love and affection to the children</p>
<p>b) What difficulties are you facing in your role as caregivers?</p>	<p>Meagre resources, accessibility of services in terms of distance, shortage of food as a result of continued drought; mobility problems which makes it difficult to go to the fields, discrimination of OVC by helpers of older persons, discrimination of older persons by family relatives</p>	<p>Meagre resources/no source of income to provide their needs like school fees, medication, food etc, Increased care burden for instance caring for OVC and your own sons and daughters, Discrimination of these children by other members of the house hold, Frailness of older carers, Weak home administration like permissiveness among the care givers themselves.</p>	<p>Limited sources of income to provide for their basic needs, Children are exposed to early child labour in effort to meet their basic needs They are not able to feed the children properly and this affects their health growth and development</p>
<p>2 a) How do you communicate with the children under your care?</p>	<p>Through formal discussions on responsible living, story telling, Encourage and take them to visit people living with HIV/AIDS, then after the visit you ask them for their observations and interpretation of the situation, Advise them to be patient until the right time for marriage, Talk to them about the risks of unprotected sex and contracting HIV/AIDS.</p>	<p>Bring them closer to feel they are members of the family, Talk to them with love and care, You have to show the boys and girls the risks of getting involved in matters of sex before getting married.</p>	<p><i>By openly discussing sexual issues in relation to their age, bodily grow and development</i></p>

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<p>b) In your opinion, how do you compare caring for female OVC and male OVC with regard to the girl/boy-child?</p>	<p>Ten out of the twelve female older carers agreed that the girl child is easier to talk to and care after, they added that the girl child easily responds to caution and that when she gets married, she still supports older caregivers.</p>	<p>10 out of the 12 in the FGD agreed that the boy child is easy to care for, reason being girls are always diverted by the influence of other people especially in their early teenage stages.</p>	<p>All participants agreed that it is easier to provide care for the male OVC, Female care givers agreed that it is easier to care for the male child because their needs are limited and their level of tolerance is high, The male said, it is not easy to get the details of the feminine basic need</p>
<p>How do you handle sexuality and other sensitive issues – puberty/adolescence crisis, rites of passage – FGM; circumcision etc.</p>	<p>The OVC are encouraged to open up when they experience any bodily change and need help or guidance. The girl child can easily open up unlike the boy child</p> <p>You encourage to open up when they experience change e.g. menstruation.</p> <p>Boys and girls during this period ooze a smell but we as caregivers have the responsibility of providing herbal medicine to heal them.</p> <p>There is need to carefully caution the OVC on risks and consequences of premarital sex e.g. early pregnancies, unprepared for parenting.</p> <p>Rites of passage: Every culture has something to do as a rite of passage of every stage, but you as a</p>	<p>Rites passage: The male care givers in the FGD admitted that are no major rites of passage from child hood to adult hood, however, traditionally, a boy child would spend most of the time with his grand father to get prepared for marriage.</p>	<p><i>Participants called for a strong moral foundation to help the children graduate from child hood to adult hood.</i></p>

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	responsible person on these children, you have to tell them why cultural ceremonies are conducted.		
<p>Division of labour in the household between boys and girls – major gender roles</p> <p>Specific contributions of girls and boys to the household</p>	<p>Girls do most of the domestic work at home, they learn easily because this prepares them for future responsibility in marriage and parenting roles.</p> <p>Boys only do hard work for instance looking after cattle, digging, and they are able to carry out business work which is tangible.</p> <p>Most of the domestic work at home is done by the girl children i.e. fetching water, cooking, washing and house cleaning.</p> <p>The hard work is for the boy child i.e. animal rearing, digging as well as providing security to the household.</p>	<p>Girls do most of the domestic work e.g. peeling, fetching water, cooking and collecting firewood.</p> <p>8 out of the 12 male older carers in the FGD agreed that all children work together</p>	<p>Girls do most of the domestic work while the boys do heavier though less duty</p> <p>Boys contribute towards income generating work, however, the domestic contribution of the girl child is not valued.</p>
<p>Implications regarding education for girls and boys in a situation where resources are limited, are boys given priority over girls in attending school?</p>	<p>Yes, 9 out of the twelve female older carers during the FGD agreed that the boy child is given first priority compared to the girl child. Reason being the boys are the determinants/controllers of family wealth and resources.</p>	<p>9 out of the 12 older carers in the FGD agreed that the boys do work which is commercial and tangible e.g. brick laying, animal rearing, they added that boy child stays at home for a longer period compared to the girls.</p> <p>But most of the domestic work at home is done by the girl child for instance cooking, fetching water, washing and cleaning the house.</p>	<p>7 out of the 12 participants agreed they would give first priority to the girl child on grounds that she grows very fast and can easily be tempted to drop out of school.</p> <p>However, the 5 said the boy child deserved priority because he ensures security and continuity of the family.</p>
<p>c) How do you handle discipline as well as parental</p>	<p>All the children are equally groomed to</p>	<p>After discussions among themselves on matters of</p>	<p>Bias is on the girl child</p>

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roles / skills?	become responsible adults, but emphasis is put on the girl child because they are expected to become role models to their children, Parenting roles are from experience and guidance from adults.	discipline, the male older carers agreed that the girl child should be given more skills on issues of discipline. They also contained that she is the discipline role model of the family	because she is the exemplary figure of the home, she therefore must be highly disciplined.
d) What are some of the psychosocial issues you have to deal with in the different ages and sexes of the children?	OVC tend to isolate themselves especially between the age of 13 and 15 years, Inability to effectively be provided of is attributed to the death of their parents.	OVC think they are deprived because their parents died, Discrimination by their fellow children who tell them that their parents died, Their attitude towards work is much influenced by their orphan hood e.g. when you send them to do something, they respond reluctantly.	Lack of basic needs leave them with the feeling of emptiness, Fear of being left alone to cope in case of death of their care givers, Feeling of self isolation and loneliness, Need for a sense of belonging and security
e) How do you attend to your own health needs and at the same time attend to the health needs of children and other household members under your care?	Encourage them to go for VCT, if found positive, tell them to go for ARV treatment, Monitor them thoroughly.	Encourage them to speak for themselves when they face health difficulties, Provision of medical care depends on the availability of the resources, The dozes of tablets is shared among the older carers and the OVC, They reported that they are not able to provide nutritional needs to the children	The priority is given to the OVC in case they are sick, while the carers and other members of the household may find alternatives e.g. use of herbs.
f) What are some of the challenges in accessing health care for the children and other members under your care as well as your own health care needs?	As a result from the FGD with the female older persons, one older carer reported she has two children who are infected however, the ART are easily availed to her, Limited resources/no source of income, Long distances to the health units hinder access to health care to the children as well as our older carers, They said that they are not able to provide balanced diet for the children since they have no source of income.	No source of income to afford the medication services, The OVC don't easily open up about their health problems, Insufficiency of drugs at public health units.	Increased cost of living, Changing attitude and health needs of the OVC.

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<p>g) What other challenges have you faced in providing care for children in your household over the last few years?</p>	<p>Climatic changes that have resulted into drought and constant food shortage, The cost of living has increased and yet their sources of income are minimal.</p>	<p>Long distance and inaccessibility to health facilities, Change in climatic seasons</p>	<p>Lack of reliable incomes.</p>
<p>h) How have you overcome those challenges?</p>	<p>Try to rear some animals, Dig some food which is drought resistant like cassava</p>	<p>Borrowing and lending system from other people.</p>	<p>Soliciting for support from well wishers and trying possible avenues of generating income e.g. brick laying.</p>
<p>i) What do you see as the biggest difference in caring for your grandchildren compared to when you were caring for your own children?</p>	<p>Regarding our own daughters and sons we were able to care for them but now we are caring for the grand children yet frail, Today income is meagre and some times no source of income, The soils have become worn out, unproductive and crop pests.</p>	<p>The burden of care for OVC has increased among themselves compared to the time when they used to care for their own sons and daughters, Bodily weakness and frailness to care for OVC compared to the time when we were adults, Availability and accessibility of resources is not easy.</p>	<p>Nuclear family tendencies limit people's ability to help OVC unlike in the extended family system where there was collective responsibility, Permissiveness of the society, Increased cost of living making provision of basic needs difficult, There is no collective social responsibility in raising the children and this makes instilling discipline in the children difficult</p>
<p>3a) Have you received any formal training to support your roles as caregivers? If yes from whom? If no are there any specific training needs you have?</p>	<p>None.</p>	<p>None</p>	<p>None</p>
<p>b) What type of support are you receiving from the schools, community, peers, civil society organizations and the government to help you fulfil your role as a caregiver and assist you with intergenerational issues?</p>	<p>None</p>	<p>None</p>	<p>None</p>

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c) Which type of support has been most important? Why is this? How has it helped you in care giving?	None	None	None
d) Are you aware of the kinds of rights and entitlements that you deserve as older carer, a citizen and a member of this community?	Have knowledge but we still need clarifications. But we are thankful of the awareness campaigns which have reduced witchcraft accusations a lot.	Yes we know a number of rights like free access to health services for older people; access to cash transfer for vulnerable older people and free access to public transport for older people. However they do not enjoy the rights. They pay in public transport and in hospitals. Most vulnerable older people are not receiving the government cash transfer.	Yes we know some rights but unfortunately our rights are not honoured and on information is available to us about this.
4 a) What type of support would benefit you the most in fulfilling your role as a caregiver of OVC?	Support older carers in income generating activities, Provide scholastic materials like books, uniforms, pens etc, Getting sponsors for the OVC under the care of older persons, Provide social cash transfers to older carers	Scholastic materials for the OVC under their care, Medical care to OVC as well as their older carers, Provide special trainings to older carers on issues of children	Income support [social pensions and cash transfers], Medical and scholastic support to OVC
B) In your opinion, who is best placed to provide for such support?	As a result of the focus group discussion with the female older carers, they said that the government is suitable to provide such support	Government	Government
c) What lessons have you learned in caring for your grandchildren that you would share with other older persons starting to care for OVC now?	Avoid sharing of sharp instruments like razor blades as well as piercing materials, Provide care and love to the orphans and other vulnerable children, Always seek medical advice before the situation worsens, Providing good and balanced diet to children can health them grow healthy, Providing good shelter to the children is better for their protection.	Caring role involves a lot of loving and patience towards the OVC, Handle orphans and vulnerable children with special care, Take the responsibility to provide for the children.	There is need for collective effort and responsibility in supporting OVC

Key findings:

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20.8% older carers of children living with HIV and AIDS do not access ART due to lack of information on availability and accessibility of drugs coupled with the long distance.

98% older carers agreed that there is lack of information on the rights and entitlements of both the OVC and the older care providers [need to match rights and responsibilities].

Older persons reported that they are not able to provide nutritional needs to the children living with HIV/AIDS due to lack of resources, not able to provide adequate care to lack of information on care and treatment.

Older persons admitted that they can not openly communicate to children about sexual issues especially on the side of the male care givers.

They do not understand the psychosocial needs of the OVC under their care especially during their adolescent stage.

33.3% older carers of OVC agreed that there is discrimination of children by the helpers of the older carers of the Orphans and Vulnerable Children.

Despite the fact that the government initiated the Universal Primary Education [UPE], older persons can not provide scholastic materials for the children under their care.

Important quotes per section

2. Challenges /Issues

"We are doing our best in bringing up these children but there is always a challenge from the community members who interfere with our caring roles, these days no person in the community care about what the children are doing i.e. children walk into movie halls which entice them to doing immoral acts and no body takes the responsibility to guide them or stop them from watching movies in these halls over night. Besides that, children are exposed to early child labour in effort to meet their basic needs. In addition, we are frail and weak to hard work in order to provide nutrition for the children and this affects their health growth and development." Muniina Sande an older man of 55 years.

3. Type of support to be received

"We need money to pay school fees and buy scholastic materials, medication as well as other basic needs for our grand sons and daughters. There are many other costs at secondary schools which we are not able to pay for, but if we get cash, we can improve our caring role" Paskali an older man of 75 years

4. Recommendation for future support

"We want the government to expand the cash transfer for older people to all communities. Currently older people in our village are not receiving the cash transfer whilst older people in other villages are." Wamala David an older man of 67 years

Interviewers' notes

Other notes taken on the group of older men

2. a) a number of examples of what is happening in their community were given e.g. the scattering of used condoms around; pornographic films which are being watched in the village; cases of HIV/AIDS and others.

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b) There was a heated debate on whether the education of a male OVC or a female OVC should be prioritised when resources are limited. There was a small group which argued strongly that they should be given equal chances. A compromise that boys should be prioritised was then reached after a lengthy discussion.

c) I felt that the men were not convincing on the issue of discipline. The conclusion was that it could not be their role to deal with disciplinary issues at home.

d) There was less contribution by older men on the issue. My opinion was that they might not be fully responsible with psychosocial support issues in their families.

3b) Storytellers are older people who have been trained to socialise with OVCs by telling stories of the past which also teach the children on good morals. It is an initiative of HelpAge International and its partners to encourage intergenerational relations and as a means of psychosocial support.

d) The Ugandan government has not yet started a national programme to give cash transfer to vulnerable older people which was supposed to begin during the beginning of 2010. The cash transfer will be administered by the Ministry of Gender, Labour and social Development. The cash transfer will be received monthly.

Other notes taken on the mixed group of older women and men

Monja was taking notes while Maureen asked the questions. The group was composed of 12 participants. The discussions took 4 hours. Progress was very slow as it took time to reach a consensus on certain issues. Both genders equally made contributions.

2b) A lively debate was held on the issue but there was no agreement that should be given the priority. Some older men and older women said boys should be given priority while others said it should be equal. A few older women said that it is better to send only girls as they would always take care of their parents.

c) The older men were more vocal on the issue of discipline than older women. They said that the girl child needs much more attention because she is the one meet many other people out there when she gets married.

d) Older carers reported that the lack of basic needs leave them with the feeling of emptiness, that the children have a fear of being left alone to cope in case of death of their care givers, they further analysed that OVC have a feeling of self isolation and loneliness most especially when their parents die and that therefore there is need for a sense of belonging and security towards these children.

e) Older carers said that for matters of dealing with health needs, first priority was given to the OVC in case they are sick, while the carers and other members of the household may find alternatives e.g. use of herbs.

f) Most of the older carers agreed that most common challenges that hinder them from accessing health care for the children and other members under their care are; increased cost of living and changing attitude and health needs of the OVC.

g) Both male and female older carers highlighted that the nuclear family tendencies limit people's ability to help OVC unlike in the extended family system where there was collective responsibility, they also said that issues of permissiveness of the society, increased cost of living making provision of basic needs difficult and that there is no collective social responsibility in raising the children and this makes instilling discipline in the children difficult.

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Appendix 1: List of participants

Table 4: List of participants

No.		Age	Gender
1.	Muniina Sande	55	Male
2.	Wamala David	65	Male
3.	Nsereko G. W	69	Male
4.	Isufu Kiwanuka	59	Male
5.	Kasasa Coloneli	62	Male
6.	Kakebe Christopher	61	Male
7.	Serunjoji Paul	69	Male
8.	Bira Kiwanuka	71	Female
9.	Bira Erika	58	Female
10.	Kiwanuka Sammy	68	Male
11.	Bikwarira S	62	Male
12.	Semogerere Mohamed	70	Male
13.	Mukeeka Rajabu	55	Male
14.	George Matovu	66	Male
15.	Muyomba P	68	Male
16.	Ruth Gwayambadde	55	Female
17.	Eriyusa Muwanga	56	Female
18.	Nabukeera Christine	78	Female
19.	Nabangya Josephine	57	Female
20.	Nabosa Deziranta	77	Female
21.	Roza Nakayanja	76	Female
22.	Milly Nalongo Mugerwa	70	Female
23.	Maria Navaah	50	Female
24.	Deborah Katumba	78	Female
25.	Margret Kanakulya	65	Female
26.	Margaret Busuulwa	67	Female
27.	Josephine Nabanja	64	Female
28.	Dorothy Nanfuka	62	Female
29.	Christine Nabuukeera	57	Female
30.	Gwayambadde Ruth	64	Female
31.	Deziranta Nabossa	60	Female
32.	Roza Nakayanja	70	Female
33.	Kasasa Coloneli	65	Male
34.	George Matovu	60	Male
35.	Paskali	75	Male
36.	Kakebe Christopher	63	Male