The experiences and priorities of young people who care for their siblings in Tanzania and Uganda

Research report

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Summary

This report presents key findings from a small-scale pilot research project that explored the experiences and priorities of young people caring for their siblings in sibling-headed households affected by AIDS in Tanzania and Uganda. Qualitative and participatory research was conducted with 33 young people living in sibling-headed households and 39 NGO staff and community members in rural and urban areas of Tanzania and Uganda. The report analyses the ways that young people manage transitions to caring for their younger siblings following their parents' death and the impacts of caring on their family relations, education, emotional wellbeing and health, social lives and their transitions to adulthood. The study highlights gendered- and age-related differences in the nature and extent of young people's care work and discusses young people's needs and priorities for action, based on the views of young people, NGO staff and community members. Meeting the basic needs of young people living in sibling-headed households, listening to young people's views, fostering peer support and relationships of trust with supportive adults, raising awareness and advocacy emerge as key priorities to safeguard the rights of children and young people living in sibling-headed households and challenge the stigma and marginalisation they sometimes face.

1. Background

Since the 1980s, the growing number of child- and youth-headed households in East and Southern Africa has been linked to the impacts of the AIDS epidemic (Foster *et al.*, 1997; Ayieko, 1997; Evans, 2005). In Tanzania, an estimated 12% of the 1.1 million children considered 'most vulnerable' lived in child-headed households in 2007 (MHSW, 2006). While the number of children living in child-headed households represents a minority of the total numbers of children orphaned by the epidemic, commentators suggest that the phenomenon is becoming increasingly widespread as numbers of orphans continue to rise in countries like Tanzania and Uganda affected by the 'long-wave impacts' of the epidemic (Foster and Williamson, 2000; Bicego *et al.*, 2003). Research has highlighted the residential mobility of orphaned children and suggested that some children face difficulties in adapting to new routines, expectations and relationships in foster households (Urassa *et al.*, 1997; Van Blerk and Ansell, 2007). HIV stigma and poverty may result in orphaned children being denied access to schooling, healthcare, inheritance and property, particularly in the case of girls (Barnett and Blaikie, 1992; UNICEF and UNAIDS, 1999).

Despite the cultural significance of 'sibling caretaking' in many African societies (Cicirelli, 1994; Weisner, 1982), Kesby *et al.* (2006) suggest that the situation of orphaned children growing up in child-headed households in the context of the AIDS epidemic challenges local understandings of childhood as well as universal models. While studies of child-headed households acknowledge young people's resilience and agency in adopting coping strategies, they also reveal the poverty, stigma and marginalisation they may face (Thurman *et al.*, 2006; Francis-Chizororo, 2008). Studies from Uganda and Zimbabwe suggest that the success of child-headed households may depend on the age and gender of the eldest sibling, with teenage girls identified as more able to ensure the household's survival due to their early socialization in domestic work (Barnett and Blaikie, 1992; Foster *et al.*, 1997). However, in Rakai, Uganda, the majority of child-headed households were headed by boys, although girls were more likely to head households over longer periods than boys and many became young mothers, caring for their siblings and their own young children (Luzze and Ssedyabule, 2004). Despite considerable concern about the vulnerability of orphans living in child- and youth-headed households in Sub-Saharan Africa, few studies have explored young people's socio-spatial experiences of caring for their siblings in these households following their parents' death.

2. Aims and objectives of the research

This pilot research aimed to provide greater understanding of the gendered and age-related experiences and support needs of young people who care for their siblings in sibling-headed households[1] in communities affected by HIV and AIDS in Tanzania and Uganda.

The objectives were:

1. To gain insight into the experiences and support needs of young people (girls and boys) caring for siblings in sibling-headed households in Tanzania and Uganda.
1. To pilot qualitative and participatory research methods with young people, community members and NGO workers in the research locations.
2. To prepare an accessible summary of the key findings for research participants in appropriate languages (Kiswahili and Luganda) and facilitate participatory workshops in the research locations in Tanzania and Uganda to engage in active feedback and dissemination with young people heading households, community members and NGO staff.
3. To liaise with NGO and other stakeholders in Tanzania and Uganda to develop collaborative relations for future research.

3. Research methods

A youth-focused qualitative and participatory methodology was considered most appropriate to gain an in-depth understanding of the perspectives and experiences of this marginalised group of young people, community members and NGO workers supporting them.

Phase 1 (2008)

A small purposive sample of children and young people (aged under 25) who cared for their siblings in sibling-headed households in Tanzania and Uganda were identified through contact with NGOs working in Kampala and Mpigi, Mukono, Wakiso and Luwero districts in Uganda and in Nshamba, Kagera region, Dar es Salaam and Mbeya in Tanzania. The research locations were specifically selected as areas that were severely affected by the HIV and AIDS epidemic and had high levels of orphanhood. Accessible information leaflets were given to young people prior to meeting the researcher. Following negotiation of consent to participate, semi-structured interviews were conducted with:

- 14 young people (9 girls, 5 boys, aged 12 - 23) from 11 sibling-headed households (the majority headed the household and cared for their younger siblings)
- 15 project workers from 5 organisations.

Focus groups were conducted with a further 15 young people and five community leaders and NGO staff in Tanzania.

Phase 2 (2009)

Following transcription, translation and analysis of the data collected in Phase 1, an accessible summary report was produced in appropriate languages (Kiswahili and Luganda). Six participatory workshops were then held in the three main research locations of Kampala, Nshamba and Mbeya with:

- 33 young people (15 siblings heading households and 18 of their younger siblings)
- 39 NGO workers and community members.

Young people heading households who had participated in the first phase were invited to participate in a one-day workshop with one or more of their younger siblings. The workshops with young people used participatory diagramming (Kesby, 2000) and focus groups to verify initial findings, further develop understandings of the issues and involve participants in identifying key messages and priorities through the co-production of creative research outputs (art posters and video-recorded drama and music performances). Initial findings and young people's messages were then presented and discussed further in workshops with NGO workers and community members.

All participants received a summary report in Luganda, Kiswahili or English and expense payments to compensate them for their time and contribution to the research process. NGOs received a DVD copy of the young people's video-recorded performances. The project was granted ethical clearance by the University of Reading Research Ethics Committee and the safety and security of the participants and researcher in the collection and storage of the data and dissemination of the findings were of paramount importance throughout the study. All participants' accounts have been anonymised throughout this report and young people provided written consent for photographs to be used in research outputs. This small-scale study does not aim to be representative of young people caring for siblings in child- and youth-headed households in Tanzania and Uganda, but seeks to explore the diversity of experiences of this group of young people. The following sections discuss the key research findings, based on analysis of the empirical data gathered.

4. Transitions into caring

Most young people interviewed said that they started looking after their siblings when they were aged 12-15 years old. Many young people associated the start of their sibling caring responsibilities with their parent's death, which had caused major disruptions in their lives and changes in household composition. Many young people feared that relatives would grab their property and deny their inheritance rights if they moved away and articulated their transition to caring for their siblings in terms of a shared decision to continue living together in their inherited parental home. Some siblings moved to live with relatives after their parent's death, but found that they were mistreated compared to their uncle's or aunt's own children and decided it would be better to look after themselves and move back to the home they inherited from their parents. Some young people who did not have any younger siblings wished to continue living in the house they had inherited and asked for a younger cousin, niece or nephew to live with them, so that they would not be alone.

For some young people, their caring pathways started when a parent started to become ill, gradually providing more intensive nursing care as their health deteriorated. Following their parent's (usually their mother's) death, their caring responsibilities changed as they became the head of the household and continued to care for their siblings, following their parent's wishes that the siblings should stay together and look after each other. Although the young people expressed grief and sadness about losing their parent, they felt that the level of poverty they experienced and their care work for themselves and their siblings was less intensive and time

consuming than the time when they were providing nursing care for their parent. Young people who were able to access support from NGOs felt that their situation had improved, since the children were being supported in school and received food and health care support following their identification as 'orphans'.

Some young people had started caring for their siblings and heading the household when their parent had become ill and moved to the household of an extended family member to be cared for by relatives there. One young woman (aged 16) who was living alone at the time of the interview had cared for her younger siblings following her mother's death, but they experienced extreme poverty and hunger and their relatives decided to care for the two younger siblings. She continued to live alone in the house she inherited from their mother and received NGO support to continue at secondary school.

5. Young people's care work

Young people undertook a range of activities within and beyond the household to look after themselves and their siblings, which can be categorised under the headings of 'income generation activities', 'household chores', 'child care', 'self care', 'household management' and 'community engagement' as shown in Table 1.

Table 1: Young people's caring activities in sibling-headed households (see also Evans, in press a)

Caring activity	Examples
Income-generation activities	Cultivating crops and produce for sale, rearing livestock, casual agricultural and construction work, fishing, working in a factory, shop or bar, selling produce, cooked food, charcoal and other goods, domestic work, running errands for neighbours, begging
Household chores	Cooking, washing dishes, sweeping, cleaning and tidying, fetching water and firewood, laundry, heating water for baths, shopping, cultivating food for consumption, tending livestock, cutting wood, running errands
Child care	Bathing, dressing and washing siblings, getting siblings ready for school, supervision, giving advice and guidance, resolving arguments and conflict between siblings, help with school work, health care when siblings are ill, reminding them to take medication
Self care	Personal care, taking medication, getting ready for school, private study, developing

	life skills and livelihood strategies etc.
Household management	Allocating tasks, paying school contributions, organising school/vocational training, budgeting, resolving financial problems, future planning and decision-making
Community engagement	Maintaining social networks, seeking support from and cooperating with relatives, neighbours, friends, NGOs, members of faith community, participating in neighbourhood, school, faith community, youth and NGO meetings, activities and events, playing and spending time with friends.

In the workshops, young people confirmed the relevance of this framework of the different dimensions of care work they were engaged in and provided more information on the gendered and age-related nature of their daily routines through participating in a bean diagram exercise. Participants indicated the number of hours they spent on the different caring activities each week (1 bean represented 1 hour). Table 2 presents the average number of hours per week participants spent doing each caring activity, based on the collated findings from the workshops in Kampala, Nshamba and Mbeya and disaggregated according to gender and position within the household[2].

Table 2: Average number of hours per week of unpaid care work of young people living in sibling-headed households, by gender and position in household

Caring activity	Average (mean) number of hours per week			
	Young women and girls heading households	Young men and boys heading households	Younger girls living in sibling-headed households	Younger boys living in sibling-headed households
Earning money	11	34	6	5
Household chores	21	19	22	14
Child care	27	31	3	2
Self care	15	33	23	11
Household management	26	19	0	1
Community engagement	11	16	11	13
Total: average hours per week spent on all caring activities	111	152	65	46

The research suggests that care work was usually shared between siblings, but girls were often expected to do more domestic tasks than boys. When young men and boys headed the household, they often allocated household tasks to their younger siblings (especially girls) and spent longer engaging in income generation activities to support the family financially. Indeed, Table 2 shows that boys and young men heading households reported that they spent on average 34 hours per

week earning money to support the family, while girls and young women heading households in contrast spent much less time (average of 11 hours a week) engaging in income-generation activities, due to gendered constructions of care and inequalities in access to employment opportunities, as previous research in a range of African contexts has shown (Langevang, 2008; Van Blerk, 2008). Young women who were the eldest sibling appeared to find it more difficult to allocate household chores to younger male siblings because of different gendered expectations of the girls' and boys' responsibilities for domestic work and reported spending more time performing household chores and managing the household in comparison to boys and young men heading households.

In terms of age differences between older and younger siblings, the findings in Table 2 suggest that young people heading households have far greater responsibilities for household management, child care and income-generation activities in comparison to their younger siblings. However, younger siblings spent considerable amounts of time undertaking household chores (younger girls reported spending slightly more time than their elder sisters) and self care activities. Young people commented that for younger siblings, the category of community engagement included playing and spending time with friends, which older siblings reported was more limited for themselves; 'community engagement' for them represented time spent seeking support from others and going to church/the mosque. Older and younger boys reported spending longer in community engagement activities outside the household compared to girls, reflecting conventional gender norms about the gendered division of labour within the household and boys' greater spatial mobility and freedom to engage with the wider environment (Katz, 1993; Koda, 2000).

When the data from the three research locations is compared, young men in Uganda reported that they spent particularly long hours earning money in construction, factory or agricultural work or the informal sector (average of 55 hours per week), almost seven times as many hours reported by young women heading households (average of 8 hours per week). Young women heading households in Uganda and Mbeya reported spending longer performing child care than young men and in Mbeya and Nshamba young women spent considerably longer undertaking household chores compared to young men.

Although the sample was very small and cannot be seen as representative of all young people living in sibling-headed households in Tanzania and Uganda, these findings reveal that young

people heading households *and* their younger siblings regularly undertake substantial and significant caring tasks. Children's care work in the global South is recognised as being much more intensive and time consuming than in the global North due to disparities in living standards (Evans and Becker, 2009). In particular, household chores in Africa are considerably more time consuming and labour intensive than in the UK and often require physical fitness and strength (*ibid*). In official surveys in the global North[3], children's (and adults') involvement in 50 or more hours of unpaid care per week is regarded as very substantial caregiving at the high end of the caregiving continuum, while 20-49 hours a week is regarded as substantial and significant (Evans and Becker, 2009; Dearden and Becker, 2004). If only the category of child care is defined as unpaid caregiving, the data in Table 2 suggest that young people heading households have substantial caring responsibilities (27 hours a week for young women and 31 hours a week for young men) and when this is combined with the other activities necessary to sustain households, it is clear that young people heading households (both young women and young men) undertake very substantial care work at the high end of the caregiving continuum. Further research is needed to survey a larger, more representative sample of young people in African countries to gain an understanding of young people's usual time contributions to their households as well as the time contributions of young people who have caring roles in households affected by illness, disability or other difficulties, in order to draw comparisons between the level of care work that young people perform in different contexts.

6. Impacts of young people's caring responsibilities on their lives

6.1 Family relationships

As noted earlier, siblings often shared domestic duties within the home and developed close, loving and interdependent caring relations. Young people who had negative experiences of living with foster relatives enjoyed their freedom and autonomy to manage the household independently of adult control. In the workshops, siblings identified close relationships and freedom to make decisions as positive aspects of living together and looking after themselves, in addition to the highlighting the poverty, lack of basic needs and loneliness they experienced (see Figure 1). Young people heading households said one of the best things about caring was that they got on well with their younger siblings and were respected by them as the eldest sibling who looked after them. However, there were sometimes arguments when younger siblings did not respect the eldest sibling's authority and did not do what they had been asked to do. Young people used different methods to settle arguments and fights with their younger siblings, such as using a cane, talking, advising and guiding them and asking for help from project workers. In the

workshops, younger siblings commented on both the positive and negative aspects of living with their older siblings: *"We're happy being brought up by our brother/ sister"*; *"listening to each other at difficult and happy times"*; *"We feel bad when we're harassed by our brother or sister"*; [we don't like] *"being beaten by brother/ sister without a reason"*.

Figure 1: Young people's life size art poster created in participatory feedback workshops in Mbeya, Tanzania. *"We are happy living together as a family"* (Evans, in press b).
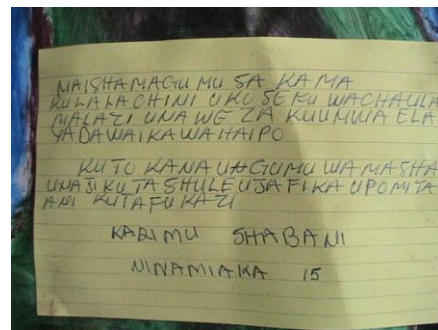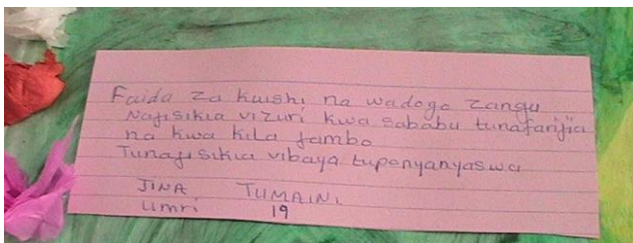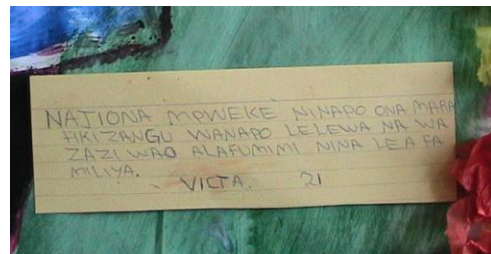

Figure 1a)

Figure 1b)

Figure 1c)

Young people's messages on the poster:

(a) *"The benefits of living with my younger siblings. I feel good because we comfort each other about everything. We feel bad when we're harassed. Tumaini[4], age 19"*.

b) *"I feel lonely when I see my friends being brought up by their parents and then there's me bringing up the family. Victa, 21"*.

c)*"Life is hard, like sleeping on the floor, lacking food, shelter, you can get ill and not have any money for medicine. Because life is so difficult, you find you're not able to go to school, you're on the street looking for work. Karimu, I'm 15"* (Evans, in press b).

Furthermore, many young people heading households saw themselves as parents or guardians of their younger siblings. As the eldest sibling, they felt a moral responsibility to care for their siblings and were proud of their caring role. Some young men were particularly proud of their role in providing for and protecting the family as the head of the household. Young people thought that they had become more mature and independent because of their caring responsibilities. Project workers also thought that young people gained useful life experience in managing a family, budgeting and making decisions, which helped to prepare them for future family life. However, some young people also expressed an ambivalence about their changed position in the family, as the eldest siblings having to take on a full-time parental caring role while they were still young people, as Juma (Tanzania) commented:

> *You see, us, we didn't want to be adults, but we had to be adults because of the things that happened with our parents. We would still like to be able to do the things we used to. To be able to play and laugh with our friends but my life is really a struggle and when I need help, I don't have an adult who I can ask. It's not as though I wanted to live on my own. Any problems that you have, you have to know how to deal with them. I have to be like both mother and father. So in this way I am an adult.*

Some young people sometimes felt overwhelmed by their caring responsibilities, missed their parents and felt that they lacked an adult who they could turn to for advice and guidance. Younger siblings in Nshamba also identified *'a lack of close advisors'* as a negative aspect of their experiences of living in a sibling-headed household. Some project workers saw the lack of a co-resident adult relative who could provide love, advice and guidance to children as a key difference between the situation of children caring for parents affected by chronic illness or disability and children caring for their siblings without a co-resident adult (Evans, in press a). Evans and Becker's (2009) research found that close, loving relationships between children and parents/ co-resident adults they were caring for represented a key protective factor in reducing the risk of negative outcomes for children with caring responsibilities. Young people heading households and

their younger siblings who lack a supportive adult figure they can turn to for guidance thus appear to be appear to be particularly vulnerable to negative outcomes.

6.2 Education

Young people in Tanzania who attended school said that their caring responsibilities affected their progress at school. They reported that they often lacked enough time to do their school work and when they arrived at school late, they were punished and missed even more lessons. Young people were often very tired and found it difficult to concentrate at school because they were worrying about caring for their siblings and needing to earn money to support the family. Several young people interviewed in Uganda had not been able to complete their primary or secondary school education because of their caring responsibilities and a lack of money for school fees, resulting in poor educational outcomes which reduced their employment opportunities. Young people in Uganda and Tanzania struggled to pay for their younger siblings' schooling, lacked money for uniforms, school materials, examination fees, school lunches etc. While they found some teachers were helpful, many young people said that teachers did not understand their problems or offer support.

6.3 Emotional wellbeing and health

Young people who received financial help regularly from organisations or relatives and had good relationships with friends and neighbours or other young people in similar situations enjoyed their independence and liked living together with their siblings. All the young people expressed their grief for their parents and missed the love and guidance they provided and as mentioned earlier, sometimes felt lonely and isolated. Younger siblings felt able to turn to their older siblings for emotional support, but older siblings said that they felt unable to share their feelings with their younger siblings, as they did not want to cause them further distress. They also found it difficult to talk to their friends or neighbours about their feelings due to cultural taboos about the public expression of emotions in Tanzania and Uganda (Evans and Thomas, 2009). Siblings heading households identified the management of their emotions as a key aspect they found difficult about their caring responsibilities, writing in the workshop: *"I'm forced to be happy all the time, even though I'm sad".*

Several young people had experienced health problems and struggled to pay for medical costs and for transport to hospital when they or their siblings were ill. Many young people were very tired

and exhausted by their care work and often did not have enough food to eat, usually only eating one meal a day. They often lived in poor quality, overcrowded housing and were exposed to the cold, rain and mosquitoes (see also Figure 1c).

6.4 Social lives and involvement in the community

Young people developed strong social ties with their peers, extended family members, neighbours, faith and community leaders whom they often relied on for material and emotional support. This included helping when young people did not have any food, providing money for medical treatment or school fees and materials and encouragement, advice and protection to young people. Relatives and neighbours also sometimes helped young people with their care work, such as doing some household chores or collecting medicines for them. Young people's friendships with their age mates and other young people in similar situations appeared to be significant in helping them to adapt to their changed role within the household. Peers sometimes helped those heading households with farm work, selling cooked food in the neighbourhood or with household chores and provided advice and encouragement about how to look after their siblings.

However, relatives, peers and neighbours were not always able to help and some young people found it difficult to spend time with their friends because of their caring responsibilities or because they were stigmatised, leading to isolation and loneliness. Indeed, several young people said the worst aspects of their caring responsibilities were feeling lonely and different to their peers: *"I feel lonely when I see my friends being brought up by their parents"* (see also Figure 1b) as well as the stigma and harassment they experienced for 'being poor' and being 'orphans' from neighbours, relatives and others in the community. Several young people were frightened at night by neighbours throwing stones at their house. Relatives sometimes exploited young people and denied their inheritance rights, taking away their land, property and other assets, such as rental income from property they inherited from their parents. People sometimes refused to pay young people for casual work they had completed. Girls and young women said that they were often harassed and pressured to have sexual relationships with men in exchange for food or money. They felt vulnerable to sexual abuse and exploitation and were at risk of unplanned pregnancies and sexually transmitted infections. Project workers thought that young men could be tempted to take drugs and/or drink alcohol and consequently neglect their caring responsibilities towards their siblings. Young men were sometimes viewed with suspicion and could be blamed for theft or for having sexual relationships with married women and be punished by the community. Indeed,

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young people identified being wrongly accused of causing trouble or damage in the community and having to put up with the judgement as a negative aspect of their caring responsibilities.

6.5 Young people's transitions to 'adulthood'

As noted earlier, many siblings heading households identified themselves as a parent/guardian for their young siblings. They therefore blurred the boundaries between 'childhood' and 'adulthood' by taking on 'adult' roles whilst they were still children and youth and were still treated as such by the community. Focus groups and interviews suggested that marriage continued to be seen as the major marker of adulthood in Tanzania and Uganda. However, marriage could be delayed or become more difficult for young people heading households, especially for young women, because a partner might not be willing for the younger siblings to continue to live with them. In interviews and workshop discussions, young people heading households expressed their commitment to care for their younger siblings until they were grown up and able to look after themselves. However, project workers thought that poverty, lack of outside help and disputes between siblings sometimes led to the break-up of the household. Siblings sometimes separated when they migrated for work in town, to live with other relatives or for their studies. When the eldest sibling migrated for work, studies or marriage, the next eldest sibling usually became the head of the household and assumed primary responsibility for looking after the younger children.

Some young people in Uganda wanted to return to school or study for vocational training so that they could support their siblings better in future. Some were worried about depending too much on others for help and did not have much hope for the future. Some young people in Tanzania who received regular support thought their siblings would be able to manage if they were selected for a boarding school far away and tried to prepare their siblings to live independently. Others who had completed school however suggested that young people's transitions to independent employment might be adversely affected by their caring responsibilities. For example, one young woman (aged 24) caring for four younger siblings who wanted to set up a small business importing and trading goods over distance said: *'I'm not able to travel far for work for myself because of being afraid to leave them* [her siblings] *on their own'.*

Some young women interviewed had become mothers since they started caring for their siblings and struggled to provide for their siblings as well as their infant, usually without any support from the baby's father. Since they were often unmarried when they gave birth, young mothers heading households were not considered to have made successful transitions to 'adulthood' and were

further stigmatised. Young mothers were often unable to continue attending school due to negative attitudes of school staff, a lack of childcare facilities and poverty. However, one young woman who cared for her five year old daughter and three younger siblings had been able to return to secondary school with the support of an NGO in Tanzania.

The experiences of young people who were 18 or over involved in the research also highlighted the contradictory situation young people heading households may face when they reach the threshold of 18 years of age, since according to international development discourses and interventions, they are no longer considered dependent 'orphans' in need of support (Evans, in press b). Community members suggested that siblings heading households aged 18 or over may be considered to qualify for continued assistance only if the orphaned siblings they were caring for were aged under 18 and/or if the sibling heading the household was still attending school.

7. Support from non-governmental organisations

The non-governmental organisations involved in the study in Tanzania and Uganda provided young people with a range of services and support (although young people rarely received all of these services), including food, regular cash support, school fees, uniforms and materials, health care, emotional support, peer support clubs, life skills and vocational training, self-defence clubs, capital for income-generation projects, community volunteer schemes. Young people saw this support as crucial in helping them to care for their siblings and live independently. Young people reported that in general, they developed relationships of trust with project workers and felt able to talk to them about problems and ask their advice. Some organisations thought that it was important to provide training and opportunities for young people to develop life skills, so that they did not miss out on the teaching their parents would have provided about community values, personal hygiene and sexuality, sustaining their farm and developing other livelihoods. Young people appeared to value such opportunities for life skills training and commented that, alongside encouragement from peers in similar situations, this helped them to adapt to living independently in a sibling-headed household.

Several project workers interviewed thought it was better to support young people to continue to live together in their own home rather than for young people to live with relatives because of the difficulties children could experience in foster households and the fact that the property and assets they had inherited from their parent could be taken away by relatives. Project workers thought that girls were more vulnerable to sexual abuse than boys and that younger children

looking after themselves needed more care and closer supervision than older children. However, organisations were not able to provide all the support that young people needed. In Uganda, organisations had very limited means to help young people caring for their siblings in child- and youth-headed households. Project workers thought that raising awareness about young people's circumstances and involving the community more would help to ensure that young people were supported in their caring roles.

8. Young people's support needs and priorities for action

In individual interviews, young people identified a range of material and emotional needs and in the workshops, they collectively ranked these in order of importance. Table 3 shows the ranked needs they identified from the three research locations. Young people saw addressing their basic needs for food, good housing, health care, schooling, bedding and financial support as crucial, before other priorities could be addressed, such as employment and obtaining a regular income or emotional support. In Kampala, Nshamba and Mbeya, young people all saw adequate food as the number one priority, with good housing and health care following closely.

Young people in Tanzania ranked educational support higher than young people in Uganda, which is likely to reflect the fact that many of the Tanzanian young people were being supported by NGOs to attend school at the time of the research and had high educational aspirations. In contrast, Ugandan young people ranked emotional support ('someone to talk to'), information and guidance above financial support, regular income and schooling, which perhaps reveals the relative isolation and low educational outcomes of the young people interviewed in Uganda, who had received very little material or educational support from NGOs. Young people in Mbeya saw capital for income generation activities such as rearing livestock, agricultural inputs and other small business activities as well as life skills training as more important than their peers in the other research locations. This difference in priorities may be related to the older age of participants heading households in Mbeya, since several young people had completed their schooling and were more focused on developing livelihood strategies.

Table 3: Needs identified by young people living in sibling-headed households, ranked in order of importance to the young people across the three research locations

Young people's needs, ranked in order of importance
1. Food
2. Good place to live
3. Health care
4. School fees and materials
5. Bedding
6. Financial support
7. Employment and regular income
8. Someone to talk to
9. Information and guidance
Capital for income generation
10. Life skills training

In the workshops, young people identified 'property grabbing' and harassment as key issues about which they wished to raise awareness in their locality. In Kampala and Mbeya, young people developed drama stories about orphaned children whose inheritance rights were denied, in one instance, by neighbours who claimed that the children's parents had sold their land to them before their death, forging a land deed agreement, and in the other, by an aunt who used corporal punishment and verbal abuse to chase the children out of the house. The drama from Kampala showed the young people seeking legal help from the local council chairperson, who considered the case and upheld young people's inheritance rights, arranging for the neighbours to be arrested by the police. Both drama stories and the song performed in Nshamba included messages and priorities for action about how they would like the community to respect them and safeguard the rights of orphaned children.

Young people appeared to value the opportunity to share their experiences with their peers, as the evaluation feedback gathered at the end of the workshops, demonstrates: *"I liked doing the drama because it's short but it can be easily understood and teaches people"* (Mbeya); *"Things I liked: We shared ideas about how to bring up our younger siblings and gain more experience"*(Nshamba); *"I have had fun with different friends, like sharing ideas, music, dancing and drama"* (Kampala). Aspects young people felt

could be improved concerned providing them with more guidance on how to deal with difficulties and for their priorities and needs to be met by NGOs. Young people's engagement with the drama, art and music activities as a way of disseminating the research findings and presenting their key messages and priorities for action to policymakers, practitioners and community members reveals the potential of safe spaces such as youth-led support groups for young people to collectively challenge their low social status and raise awareness about the problems they face within the community. The value of such opportunities for peer support and the collective mobilisation of marginalised groups is also reflected in the experiences of professionals and young people participating in child- and youth-led interventions with orphans and young carers and peer support groups of people living with HIV in Tanzania and other communities affected by HIV and AIDS in Africa (Madoerin, 2008; Evans and Becker, 2009; Save the Children, 2010).

Following the presentation of research findings and young people's messages and priorities, the workshops with NGO staff and community members discussed a number of ways to improve support for young people living in sibling-headed households and reduce the difficulties they face. As Table 4 shows, suggestions included advocacy work and greater coordination of efforts between policymakers, schools, community and faith leaders, governmental and non-governmental organisations to ensure that the most vulnerable children are identified and supported, as well as proposing a range of ways of addressing the material and emotional needs of young people caring for siblings and safeguarding their rights at local and national levels.

Table 4: NGO and community members' suggestions for ways to improve support and address the difficulties faced by young people caring for their siblings in sibling-headed households

How can support for young people caring for their siblings in sibling-headed households be improved?	NGO and community suggestions, based on workshop discussions in Kampala, Nshamba and Mbeya
Support to continue young people's education	• Involve family and community in identifying needs and problems facing children • Mobilise community to support children and share information between schools, local leaders and committees, faith communities, governmental and non-governmental organisations • Provide assistance with school fees, uniform, materials, transport for children who live far from school, food at home and school • Pool resources between NGOs and community donations to schools to

	meet the needs of the most vulnerable children
	• Government to improve education policies and implementation to ensure the most vulnerable children can access education
	• Motivate and encourage children to attend school, provide psycho-social support, love and care
	• Children's peer support groups
	• Sensitisation, education and advocacy about the rights of children with caring responsibilities.
Emotional support and guidance and ways to reduce stigma and harassment young people experience	• Offer psycho-social support within the community - be close to children, show them love and care, give them advice and guidance
	• Give young people space and freedom to talk and express their views and listen to them
	• Start children's clubs and involve young people in play, sports, drama, music and other fun activities with their peers
	• Increase efforts to sensitise community about the rights and responsibilities of children, not to stigmatise or ostracise young people, not to reprimand them without good reason and treat them the same as other children
	• Support children to secure the property they inherited from their parents and use existing policies to safeguard their rights
	• Visit children regularly at school and at home to provide encouragement and advice
	• Involve young people in local celebrations and events
	• Encourage parents to appoint a guardian to care for children before they pass away, identify other relatives who can help to support the family
	• Identify 'mother' and 'father' role models in community who children can approach for advice and comfort
	• Encourage people to be open and test for HIV
Opportunities to develop life skills and training in livelihoods	• Advocacy programmes with policymakers, schools etc.
	• Identify the most vulnerable children, recognise their needs and ensure support reaches those it is intended to
	• Assess young people's own and other resources available to them
	• Provide informal education in life skills eg. how to express their emotions, avoid bad peer groups
	• Community leaders, groups and individuals to provide informal education and skills training and support in acquiring life skills and livelihood strategies
	• Establish low cost vocational training centres.

NGO workers and community members also identified a range of barriers to developing services and support for young people living in sibling-headed households and ways that these could be

reduced. As Table 5 shows, these focus on issues related to constraints on the resources and capacity of organisations and communities, limited awareness and recognition of the problems and support needs of young people heading households and the siblings they care for and difficulties in implementing policies and programmes at the local and national levels.

Table 5: NGO and community members' views of barriers to developing services and support for young people in sibling-headed households and the ways these barriers can be reduced

	Barriers to developing services and support	Ways that barriers can be reduced
Resources and capacity	Low income and lack of resources within the community Lack of capacity within organisations Over-reliance on donors and lack of sustainability	Mobilise resources locally and internationally Build capacity of programme implementers Develop sustainable programmes that use local resources rather than reliance on external support
Awareness and recognition of the issues	Limited understanding among teachers, community members about young people's problems and how to support them Stigma and discrimination Young people's voices not listened to	Educate, sensitise and mobilise community and schools to provide support for children and participate in programmes Involve young people at every stage and listen to their views
Implementation	Communication problems among committee members, NGOs etc. How to identify the needs of the most vulnerable and target support without causing resentment and isolation Lack of implementation of policies eg. Universal Primary Education, lack of monitoring and evaluation Embezzlement and wastefulness of some organisations and community leaders, aid not reaching the most vulnerable children	Develop plans to coordinate efforts between children, government, NGOs and community groups Information sharing with all stakeholders about policies, implementation and monitoring Systems and policies to check embezzlement and monitor provision of aid

9. Conclusions

This research suggests that a complex range of factors influences the formation and sustainability of sibling-headed households affected by AIDS in Tanzania and Uganda, including sibling birth order, changes in household composition and migration; cultural expectations of sibling care and parents' wishes for siblings to stay together after their death; access to formal and informal resources and assets, which may differ between rural and urban areas; the need to resist adult

exploitation and abuse of siblings' inheritance rights and the desire to develop a more autonomous space living with siblings in their inherited parental home. Young people caring for their siblings without a co-resident adult blur the boundaries between 'childhood' and 'adulthood', taking on 'adult' or 'parental' roles while they still considered themselves children and young people and were regarded as such by the wider community (Evans, in press b). Young people show considerable resilience and competencies in caring for their younger siblings, developing interdependent caring relationships within the household and sharing household chores, income-generation activities and other responsibilities, often according to conventional gendered and age-related hierarchies. However, their ability to exert control over their lives was often undermined by poverty, stigmatisation and wider processes of exclusion. While young people expressed long term commitments to caring for their siblings, this could have detrimental impacts on their education, emotional wellbeing and health, their social lives and involvement in the community and their transitions to adulthood. Their experiences also highlighted the arbitrary nature of strict age-based definitions of 'orphanhood' specified in international development interventions and the difficulties young people heading households may face if they lose access to NGO support when they reach the threshold of 18 years of age.

Young people saw meeting their basic needs for food, a good place to live, health care and schooling as crucial before their priorities for employment and a regular income, emotional support, information and guidance, capital and life skills training could be met. They identified the denial of their inheritance rights to property and other assets and the harassment and stigma they experienced by relatives, neighbours and others in the community as key issues about they wished to raise awareness within their locality and among policymakers and practitioners. The research suggests that meeting young people's basic needs, listening to young people's views, fostering the development of peer support and relationships of trust with supportive adults, awareness-raising and advocacy could help to safeguard the rights of young people living in sibling-headed households. The challenge for policymakers, practitioners, researchers and communities is to confront the stigma and marginalisation young people living in sibling-headed households may face and tackle barriers to the development and implementation of services and support for this group of young people at the local, national and global levels.

Notes

1. Studies use different definitions of child- and youth-headed/ sibling-headed households, including Foster *et al.*'s distinction between 'unaccompanied' and 'accompanied' child-headed

households; 'unaccompanied' child-headed households are defined as those where there were no adults present, in comparison to those where adults were present, but the adults were sick, disabled or elderly and considered to have little or no responsibility for the day-to-day running of the household ('accompanied'). This research focuses on children and young people who live in households headed by a sibling, who is aged up to 25 years of age, without a co-resident adult relative aged 25 or over. These households are referred to as 'sibling-headed households'.

2. This data on the number of hours spent undertaking different caring activities is presented with an awareness of the potential problems of self-reported time-use data in terms of gendered and age-related differences in perceptions of use of time and the valuing of different activities. Furthermore, these time allocations cannot be seen as representative of young people heading households, since the pilot research was based on a very small sample. The differences between younger and older siblings' perceptions of the amount of time they spend undertaking different activities in a typical week is nevertheless revealing.

3. For example, the 2001 UK Census included the question: 'Do you look after, or give any help or support to family members, friends, neighbours or others because of: physical or mental ill-health or disability or problems related to old age? Do *not* count anything you do as part of your paid employment: a) no. Time spent in a typical week: b) 1-19 hours a week. c) 20-49 hours a week. d) 50+ hours a week' (www.statistics.gov.uk/census2001/pdfs/engh1.pdf).

4. Young people were asked to choose pseudonyms when writing their messages in order to protect their identities.

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