## **Project Briefing**

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## HelpAge International

#### **Key points**

- The number of skippedgeneration households – comprised solely of older people and children – is rising as a result of HIV and AIDS and other shocks
- Limited livelihood opportunities increase their vulnerability and reduce their ability to cope and recover from crises
- Humanitarian and development agencies must assess intergenerational issues and incorporate them into programming at all stages

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# The loss of the middle ground: the impact of crises and HIV and AIDS on 'skipped-generation' households

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he global number of older people defined by the UN as those over 60 years of age - is growing at an unprecedented rate as a result of increased life expectancy. By 2050 there will be more than 2 billion people over 60, representing 22% of the global population, and doubling present numbers (United Nations, 2008). Older people have needs that are distinct from those of younger generations. They may be disproportionately vulnerable during crises because they are more likely to have chronic illnesses, and sensory, physical and cognitive disabilities. They are at risk of abuse and neglect, and there is a lack of understanding of their rights and entitlements. Yet older people make key contributions to society, including the transfer of knowledge and skills to younger generations (Wells, 2005).

Sub-Saharan Africa continues to be the region most affected by HIV and AIDS, accounting for 68% of adults and 90% of children worldwide living with HIV (UNAIDS, 2007). HIV and AIDS and other crises that disproportionately kill working-age adults also impact older people. At a time in their lives when many older people might expect to be supported and cared for by their children, a growing number are instead caring for younger adults living with HIV, and for the orphans and vulnerable children (OVC) they leave behind (HelpAge International, 2008).

HIV and AIDS has led to an increase in 'skipped-generation' households (SGHs) – households made up of the old and the young (Box 1). Such households also exist as a result of negative shocks that fuel demographic changes by raising mortality and migration among the middle generation, including conflict, war, epidemics and natural disasters. With emergencies, particularly those associated with climate change, expected to increase and intensify, particularly in Africa, the concern is that the existing vulnerability of SGHs as a result of their structure/composition, may increase. However, relatively little is known about a) the livelihoods and coping strategies of such households, b) how they are affected during emergencies, c) the role of community based support structures in assisting these households and d) how emergency preparedness and response could better address their needs.

To address these gaps in knowledge, HelpAge International (HAI), the Overseas Development Institute (ODI), the United Nations Children's Fund (UNICEF) and the Joint United Nations Programme on AIDS (UNAIDS), carried out a study to improve understanding on how these households cope during emergencies, and to provide recommendations on how emergency preparedness and response can better meet the needs of such households in the East and Southern African region. A literature review was followed by country case studies in Northern Uganda and Zimbabwe (Box 2) in which members of SGH households, both older people and children, and organisations involved in the emergency response were interviewed. This Project Briefing presents some key findings and policy recommendations from this study.

### Box 1: Skipped-generation household (SGHs)

SGHs occur when an older person, often a grandparent, becomes the primary caretaker for a child who has lost one or both parents, or whose parents are absent for a prolonged period of time. This is distinct from an **older person-headed household** where the middle generation may still be present; it is also distinct from a **child-headed household** in which there are usually no older people present, or if they are present they may be too sick to act as a household head.

#### **Box 2: Country contexts**

**Northern Uganda:** For the past 20 years the northern districts of Uganda have been caught in the conflict between the rebel Lord's Resistance Army (LRA) and the Government of Uganda. This protracted violence resulted in the displacement of 1.8 million northerners (Allio, 2006). For the past three years the conflict has quietened, and the region is now shifting towards relative peace and recovery. In response, humanitarian services are scaling back, internally displaced persons (IDP) camps are being decommissioned and people are re-constructing their homes in their villages of origin, resettlement sites and satellite camps. Although a positive development, it has exposed a population of vulnerable persons who are unable or unwilling to leave the camps.

Before the conflict, the north experienced rates of HIV prevalence comparable to other rural areas. However, research shows that transmission grew during the conflict. According to the Ugandan Ministry of Health, HIV prevalence in Uganda's northern-central region is now currently slightly over 8% – higher than the national average of 6.4%.

The prevalence of SGH within camps and sites of resettlement has not been documented comprehensively, though UNHCR data shows that those remaining in camps -- categorised as people with special needs -- are mostly OVC and people aged over 65, many of whom are living in co-dependent relationships. Data from 2001 shows that 26% of people aged 60+ throughout all of Uganda were living in a SGH (Zimmer, 2007); and data for 2007 indicates that 14% of households in northern Uganda are headed by an older person – though not necessarily skipped-generation (Bamuturaki, 2007).

**Zimbabwe:** Zimbabwe has been struggling under the influence of multidimensional crises for over a decade. Since 2000, recurring droughts, floods, cholera outbreaks, international isolation, the impacts of HIV and AIDS, and high levels of poverty and unemployment have characterised the landscape of this nation. During this time, healthcare, education and general security also became restricted for most households. Formal unemployment rose to 90% and many people left the country in the hope of gaining income in South Africa, Mozambique, Botswana and beyond. In 2003, the Government's Poverty Assessment Survey estimated that the living standards in Zimbabwe decreased by 150% in a ten year period.

Although Zimbabwe lies at the epicentre of the AIDS pandemic, a drop in the HIV prevalence rate from 26.5% in 2001 to 15.6% in 2007 has been seen over the past 10 years (UNGASS, 2008). More recent reports estimate that prevalence had decreased further to 13.7% among adults (15-49) (Ministry of Health and Child Welfare, 2009). One in five Zimbabwean children has been orphaned by AIDS. Though data capturing the number of these orphans living in SGHs remains unavailable, study respondents project that their numbers are high and estimate that the majority within their programmes live with older relatives. There are also estimates that grandparents (65+) care for roughly 60% of all orphans in Zimbabwe (UNICEF, 2007). Although more than a decade old, statistics from 1999 already show that older people were heading households with the middle generation missing – e.g. in 1999 24% of 70-74 year-olds were heading SGHs (UNDESA, 2005).

#### **Key findings**

**Prevalence of SGHs.** Limited rigorous data makes it difficult to quantify the prevalence of such households. However, all respondents perceived them to be numerous, yet ill considered within responses. In addition, HIV-related statistics, the numbers of orphans, the mortality rates of the middle generation as a result of HIV and the role of extended family structures in Africa, suggests that many older people are caring for children. Research undertaken by HAI and UNICEF in other country contexts supports this analysis. In Uganda the most vulnerable are becoming more visible as displacement camps phase out and they are left behind, and many of these comprise SGHs. **Vulnerability and caring.** The study showed that whilst the sex of a caregiver did not appear to impact the overall viability/stability of a household, their age and health did. Old age often led to a decrease in the quality of health and in physical capacity, resulting in less access to income generating opportunities and resources and more burden placed on children for productive and reproductive-related tasks. The age of children also impacts the household's capacity, with older people in Zimbabwe noting that it was more difficult caring for children aged o-5 than 5+.

Despite the fact that many older persons are ill equipped and underprepared for parenting, findings from both countries show that children living with grandparents are more likely to be looked after lovingly, and treated fairly, compared to those living with other extended family members and that children would rather live with their grandparents than with other relatives. In Zimbabwe it was also pointed out that multiple children from the same household were less likely to be split up if taken in by a grandparent. According to NGO-respondents, grandparents were also seen as being more reliable as caregivers.

Livelihoods, food security, resilience, migration. Regardless of health status, all respondents stated they were willing to work more; those who were working showed determination, industriousness and resilience. Yet, despite NGO-respondents in Zimbabwe reporting that older people were more reliable, hard-working and honest, NGO trainings and income generating activities targeted only the able-bodied and youths in both countries, leaving limited opportunities for older carers.

In Uganda access to land impacts on household food security with those having a small plot being able to grow for consumption as well as for sale. However, access to land during the resettlement process for older people, especially women, is particularly problematic as many cannot prove they once owned land or were entitled to it through a husband or father. As a result, many prefer to remain in the camps.

For respondents in urban areas in Zimbabwe, home ownership also offers a form of security as older people are able to rent out rooms and, therefore, have access to a regular income.

As a last resort, older people in Uganda spoke about marrying their granddaughters early as a means of securing an income (dowry). The situation may also lead children to look for work, exposing themselves to the risk, therefore, of potential exploitation and other related vulnerabilities. Begging for food was also mentioned in Uganda as a desperation strategy. Grandparents in Zimbabwe spoke about going without food for the sake of younger children, often leaving themselves and older children malnourished, and spoke of foraging for roots and other wild foods, while teaching children to identify them.

SGH numbers are also increasing because of the migration of youth and adults in search of work, especially in Zimbabwe, leaving behind children and

grandparents. NGO-respondents also noted that children from SGHs are at greater risk of migrating because of limited household resources. Protection concerns were raised, with reports of harassment and imprisonment as a result of the large number of undocumented migrants, and the ability of older people to access documents for their grandchildren remains problematic.

**Traditional support structures.** Findings show that long-term crises have eroded family and community support: whilst older people are taking in grandchildren, they reported being unable to turn to family and others for support, that their contributions were no longer recognised, and they were seen as an additional burden to already overstretched households. 'In the past, grandparents were not caregivers' said one grandfather in Uganda, 'They were teachers. They shared stories about ways to live and behave. This is very different from becoming like a parent.'

Access to health and education. SGHs in camps in Northern Uganda are often reluctant to leave as they have become dependent on the services and facilities provided by the humanitarian organisations that are not yet present in return areas or are at a considerable distance. The health system in Zimbabwe is slowly rebuilding itself, but the costs of drugs and transport remain prohibitive for SGHs, particularly in rural areas. This results in them self-medicating, buying over-the-counter drugs, and/or sacrificing their own treatment for that of their grandchildren's, increasing the risk of poor health and slow recovery.

Educational costs in particular, both in terms of fees and loss of productive and reproductive potential of the children, remain major challenges. Older people in Zimbabwe, particularly in urban areas, have managed to defy the odds (high costs and school closures) to keep children in schools, often negotiating with schools to, for example, delay payments.

**Impacts of HIV and AIDS**. HIV and AIDS further impoverish SGHs. Those caring for someone who is sick may have to draw on already limited resources (financial and other), diverting them away from other, more productive, activities.

Findings from Uganda suggest that when compared to other households, some members of SGHs taking antiretroviral (ARVs) drugs are less likely to follow treatment schedules because their older carers may lack knowledge on how to take the drugs or are unable to provide the food with which to take the drugs or because they themselves are unable to access the drugs. Children on ARVs reported being turned away from ARV-distribution sites because they were on their own, their older carer being unable to accompany them.

Stigma remains a key challenge in both countries. SGH with an HIV-positive member are not open about their status for fear of discrimination and isolation, as stigmatisation can occur even within families. The emotional effect of this on both older caregivers and children under their care, can be immense.

Humanitarian response. In Uganda, the lack of

resources aimed at older people in general, and a failure to address the affect of the conflict on these households has left programmes ill prepared for the impact of the return and resettlement process on SGHs. The humanitarian workers interviewed acknowledge that the protection and care of older people and children under their care continues to fall between the cracks of responsibility. Older people in both Uganda and Zimbabwe are rarely included as participants in programmes and responses remain focused primarily on OVC, with the hope that assistance will 'trickle up' to older caregivers. The humanitarian cluster system in operation in both contexts is not adequately highlighting these gaps in response.

#### **Policy recommendations**

Levels of vulnerability. Not all SGHs are equally vulnerable, however the health status of older carers, their age as well as the number of children in their care seems to have an impact on their livelihood chances and their household's capacity to survive. It is critical that vulnerability assessments take into account these different social and health issues, which impact on levels of vulnerability.

**Humanitarian response.** The unique needs of older people and their essential role in the household and community mean that it is vital to consider them when formulating humanitarian preparedness and response policies. The following are required:

- There is a need to move away from a narrow focus on specific vulnerable groups and individual agency interest groups, e.g. children, to ensure a more holistic and context specific understanding of vulnerability that looks at the entire household, its composition and intergenerational aspects. This should happen at all stages of a response, including recovery and resettlement when SGHs may be at particular risk of falling through the net in mass scale return and resettlement.
- Age and sex disaggregated data in all humanitarian response assessments and programmes are critical; age disaggregation can be split into five or ten-year age intervals and must include older people 60-69; 70-79; 80+.
- The presence of age and HIV focal points within the humanitarian clusters would increase awareness and analysis of SGHs and ensure that budgets and funding are allocated equitably.

**Resilience, resourcefulness and livelihoods.** Development of livelihood strategies for older people is essential for self sustainability and emotional wellbeing of SGH. The capacity, health and mobility of older people differs from younger generations and, therefore, require programmes to establish age appropriate viable options that offer skills building and utilise and build upon the existing skills and knowledge of older people.

**Health and HIV and AIDS**. Health programmes must target older people, including diagnosis and treatment of chronic diseases and other age-related conditions.

The following are required to ensure that SGHs are not excluded from HIV-related interventions:

- Extension of support programmes for people of all ages including those caring for HIV positive children.
- Strengthen HIV and AIDS prevention and treatment trainings for older people and caregivers to raise awareness of, for example, the importance of HIV-testing their grandchildren.
- Incorporate whole households into care and treatment programmes.
- Expand follow-up programmes with HIV positive members of SGHs to monitor treatment adherence and health in sites of return and relocation (Uganda).
- Continue to promote HIV awareness and mobilisation for testing and treatment programme enrolment in areas of return and relocation (Uganda).
- Expand home-based care networks to provide healthcare coverage for housebound individuals and isolated households.

In general, HIV-related statistics only disaggregate those who are 49 years and below, while those 49+ are grouped within a non-specific 'adult' category. If inclusive programmes are to be developed and implemented, more disaggregated age categories (50-59; 60-69; 70-79; 80+) are needed.

**Education**. Schools need to work alongside community members to identify ways of encouraging children to attend and remain in school. Schools can also help identify the most vulnerable children, including those from SGHs, referring them on for external assistance. Prohibitive cost-structures need to be reviewed, including ways in which the costs of schooling materials can be reduced. Schools can also raise awareness of the challenges facing SGH children and their families, including issues around stigma and discrimination both within and outside schools.

The role of communities. There is a need to raise awareness and encourage the use of community based knowledge, resources and information to identify and support the most vulnerable SGHs at local and district level.

**Coordination and multi-sectoral approach**. The vulnerability of SGHs needs to be addressed through a coordinated and multi-sectoral response driven by governments and involving a range of actors (UN, INGO, NGO) linking humanitarian, recovery and development interventions.

**Social protection.** Cash transfers should be developed as a recovery initiative for particularly vulnerable households such as SGHs. These should link into the development of broader Government country-wide social protection plans to reach the poorest. For example, HAI is currently working alongside the Government of Uganda and others to develop its capacity to deliver social protection, including the piloting of social assistance grants for empowerment in six Districts across the country.

**Data and research**. More research and analysis of global trends on SGHs would be useful to inform policy. Further research is needed on: longer-term household viability and level of community and aid dependency amongst SGH compared with non-SGH; potential livelihood strategies; and the impact that a 'missing generation' has on SGH grandchildren as they have families of their own and reach middle-age.

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#### **Project information**

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