

Institution: University of Reading
Unit of Assessment: 17b Geography
Title of case study: Enhancing support for young carers and families affected by HIV
<p>1. Summary of the impact</p> <p>University of Reading research has raised awareness of a group that is often overlooked in policy and practice: young carers and families affected by HIV. It has revealed the factors that influence involvement and outcomes in young care-giving and identified the support needs for young people and those that they look after.</p> <p>The research has led to newly funded support services in East Africa and the UK, international and national practice guidelines, and capacity-building among professionals. The impact has predominantly been the enhancement of wellbeing, health and social care, education, children's and families' rights and welfare provision.</p>
<p>2. Underpinning research</p> <p>The research, carried out by Dr Ruth Evans (Lecturer in Human Geography 2007-13, Associate Professor in Human Geography 2013 onwards) has investigated the experiences, resilience and priorities of children and young people caring for family members in households affected by HIV and AIDS. This work has helped to raise awareness of children's often invisible caring roles and the time scarcity that young people may face as a result, which impacts on their present lives and future prospects. A typology of the different caring activities which young people perform in the context of the 'Global South' (the nations of Africa, Central and Latin America, and most of Asia) was developed, revealing the time-space patterning of their work in a range of contexts. The research also identified a number of practices, policies and support services that help to build the resilience of children and families affected by HIV in East Africa and the UK.</p> <p><u>Interviews and workshops</u></p> <p>In 2008-10, Evans conducted an exploratory research project on young people caring for their siblings in child- and youth-headed households affected by AIDS in Tanzania and Uganda, using an innovative qualitative, participatory methodology. Pump-Priming funding enabled Evans to make contact with a range of HIV support organisations in locations with high levels of orphanhood in Tanzania and Uganda and conduct semi-structured interviews with young people (aged 12-23) heading households and NGO workers. Following data analysis, six participatory feedback workshops were held in the three main research locations (Kampala, Nshamba and Mbeya) a year later, with young people heading households, their younger siblings, NGO workers and community members. These were used to verify the initial findings and involve participants in identifying key messages from the research and priorities for action through the co-production of creative research outputs (art posters and video-recorded drama and song performances). The findings and messages were subsequently presented to NGO staff and local community members at workshops to stimulate discussions on how to improve opportunities and support for young people living in child- and youth-headed households. The final report, incorporating stakeholders' views from the workshops, was published on the University of Reading website and disseminated via professional networks and seminars, in addition to feeding into a range of impact activities.</p> <p><u>Working paper</u></p> <p>One of the key messages identified by the research was the need to tackle inheritance disputes and the stigmatisation of orphaned young people living in child- and youth-headed households. The Chronic Poverty Research Centre (CPRC) commissioned Evans to research and write a CPRC Working Paper to conceptualise the links between asset inheritance, HIV-related stigma and the intergenerational transmission of poverty among widows and orphaned youth in Tanzania and Uganda.</p> <p><u>Book and journals</u></p> <p>During the REF period, Evans also wrote a series of journal articles and completed a book relating to an earlier ESRC-funded research project on children caring for parents with HIV in Tanzania and the UK that she had carried out with Professor Saul Becker, University of Nottingham, in 2006-7,</p>

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prior to joining the University of Reading.

Building on the University's longstanding reputation in feminist geography, Evans further developed her conceptual analysis of the gendered time-space patterning of informal care within the family and engaged in a range of public engagement and impact activities with professionals that drew on her earlier ESRC research and her research on sibling caregiving, asset inheritance and chronic poverty conducted at Reading.

3. References to the research

A co-authored research monograph, seven journal articles two book chapters and three research reports/policy papers have been published. These outputs have been internally assessed and considered to be of at least 2* quality.

Evans, R. (2012): 'Sibling caringscapes: time-space practices of caring within youth-headed households in Tanzania and Uganda', *Geoforum*, 43: 824-835; DOI: 10.1016/j.geoforum.2012.02.004

Evans, R. (2011): 'Young caregiving and HIV in the UK: caring relationships and mobilities in African migrant families', *Population, Space and Place*, 17(4): 338-360; DOI: 10.1002/psp.583

Evans, R. and Becker, S. (2009): *Children Caring for Parents and Relatives with HIV and AIDS: Global Issues and Policy Responses*, The Policy Press: Bristol

Evans, R. and Thomas, F. (2009): 'Emotional interactions and an ethic of care: caring relations in families affected by HIV and AIDS', *Emotions, Space and Society*, 2, 111-119; DOI: 10.1016/j.emospa.2009.08.003

Grant Funding:

Becker (PI) and Evans (Co-I): 'Hidden young carers: the experiences, needs and resilience of children caring for parents and relatives with HIV and AIDS in Tanzania and the UK'; ESRC - RES-000-22-1732-A, University of Birmingham/University of Nottingham; 2006-7; £80,282;

Evans; R: 'Young people caring for their siblings in child- and youth-headed households in Tanzania and Uganda', University of Reading: £3,000, 2007-8; Royal Geographical Society Small Research Grant: £3,000, 2009.

Evans, R: 'Conceptualising stigma, gender and generational inequalities in asset inheritance and the intergenerational transmission of poverty for women with HIV and young people with caring responsibilities in Tanzania and Uganda', Chronic Poverty Research Centre/Overseas Development Institute, 2010, £5050.

4. Details of the impact

The research has helped to raise the profile of children and young people with caring responsibilities in families affected by HIV. By identifying the factors that influence involvement and outcomes in young care-giving, the research has led to an increased recognition of young people's and families' needs, enhancing awareness among professionals and helping them develop appropriate support services. The research has involved and been communicated to audiences both in the UK and internationally (Eastern and Southern Africa and beyond).

New policy and support services

Prior to this research, there was very little recognition in international development policy of children's caring roles in families affected by HIV and virtually no specific support for this marginalised group. Through engagement with professional networks and practitioners (such as UNICEF Better Care Network; the Eastern and Southern Africa Regional Inter Agency Task Team on Children, and OVCSupport.net), the research findings have led to new developments in policy and practice for care-giving children and have been used to secure new support services in East Africa.

After workshops in Kampala highlighted the priorities of children living in child- and youth-headed households, the National Community of Women living with HIV and AIDS in Uganda (NACWOLA) developed a grant proposal to support this group in East Africa. In collaboration with Healthlink Worldwide and Tanzanian and Kenyan NGOs, NACWOLA secured funding (£166,588 over three years reaching a total of 1800 beneficiaries from four districts in Uganda) from the UK Department for International Development's Civil Society Challenge Fund for a 'Children's Rights in Africa: Uganda, Tanzania and Kenya' project in 2009.

Publications

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- Dr Evans was consulted on the development of an international programme manual for working with young carers and their families, *Supporting Young Carers* (REPSSI, 2012), drawing on her expertise on sibling caregiving and children caring for parents with HIV.
- Evans' book with Saul Becker, completed after she joined the University of Reading, has attracted positive feedback, as evidenced in the following testimonial:
"Special thanks to Ruth Evans and Saul Becker for their excellent and comprehensive book published in 2009 - *Children Caring for Parents with HIV and AIDS: Global Issues and Policy Responses*, Policy Press. These guidelines drew heavily on this particular publication" (REPSSI, 2012, p.4).
- Evans co-authored a case study on dealing with distress in interviews with children for the UNICEF (2013) publication and web resource, *Ethical Research Involving Children*.
- Evans contributed to two national guidance brochures (published by The Children's Society and the National Children's Bureau in 2008) aiming to improve practice and support for young carers and families affected by HIV among professionals. These brochures have been widely disseminated to young carers support workers and health and social care professionals in the UK through capacity-building workshops and conferences and through online open access.
- Research reports and a news article about the findings are available on the University of Reading website. The findings have also been presented at two public seminars in the UK (at the University of Reading in December 2010 and Birkbeck College, University of London, in June 2011). This has raised awareness about the needs of young carers and families affected by HIV among members of the public.

Development of CPRC research

The project's identification of the desire among young people to tackle inheritance disputes and the stigmatisation of orphaned children led directly to policy-oriented research on asset inheritance commissioned by the CPRC. Evans presented the policy-oriented paper and young people's video-recorded dramas about property grabbing at the CPRC/Overseas Development Institute Roundtable on 'Inheritance and the Intergenerational Transmission of Poverty' in London in October 2010, and at public seminars. The peer-reviewed open-access paper was published on the CPRC website, and the findings have been published in academic journals, including those aimed at practitioners working in Africa, such as the 2012 special issue of the *African Journal of AIDS Research* on 'Resilience and Coping Strategies of HIV-affected Children in Sub-Saharan Africa'. This paper and the children's video were presented at an international seminar at the Resource Centre for International Development, University of Bergen, Norway in November 2012 and reviewed by OVCSupport.net in the *What's new in research?* November 2012 newsletter.

Capacity-building

The research enhanced the knowledge of professionals and enabled organisations such as The Children's Society and Africa Advocacy Foundation (AAF) to secure significant funding to develop capacity-building activities and new support programmes for young carers in the UK. In April 2010, AAF commented that the research 'enabled us to gain better understanding of the positive and negative impact of caring and the level of appropriateness of roles undertaken by our beneficiaries'. Furthermore, Dr Evans was asked to write a reference in support of a new AAF Young Carers project in London, which was funded by Comic Relief through The Carers Trust in 2010 (£73,433, over three years, with £5000 in additional small grants). The project has reached 137 young carers and 164 parents and over 500 families affected by HIV in London. The AAF young carers project also contributed to the development of a family-specific peer support programme within AAF adult HIV services, training of multi-agency professionals, training of 30 young carers as young champions and peer mentors and raising issues of concern with MPs in Parliament.

Dr Evans directly contributed to the development of new support services, training and capacity-building of professionals working with children and families affected by HIV in the UK through her participation in the National Steering Group of The Children's Society Young Carers Affected by HIV/AIDS Project, funded by the Elton John AIDS Foundation (£190,625, 2009-12), and through the presentations she gave at three national capacity-building events for multi-agency professionals organised by The Children's Society in London, in May and July 2010, and Manchester, in March 2011.

Presentations and other public appearances

Presentations given by Dr Evans at policy workshops have enhanced the knowledge of international development professionals about young people's caring responsibilities in the context of HIV. They include 'Getting Caregiving Children on the Agenda', given at the London School of Economics and Political Science, University of London, in 2011, and a presentation made at a Panos/Healthlink Worldwide seminar on orphans and vulnerable children in 2008. She was the plenary speaker at the following events for policymakers and practitioners:

- National Children's Bureau Conference on Children affected by HIV, London, November 2007
- Princess Royal Trust for Carers Annual Young Carers Workers' Conference, March 2008
- 'Young Carers and their Families International Roundtable Seminar', organised by The Children's Society, London, 9 November 2012
- 'Involving children and young people affected by HIV/AIDS in shaping up services in the East of England' Conference, organised by the Centre For All Families Positive Health, Luton, 1 July 2011

She facilitated the 'Young carers living with HIV in refugee families' workshop at a Children's Society seminar in London, March 2009.

Dr Evans was invited to a Reading HIV Multi-Agency Stakeholder Meeting in May 2009. Following this, she was invited to become a Patron of Thames Valley Positive Support, a third- sector organisation supporting people living with HIV in Berkshire – a role she continues to hold today.

5. Sources to corroborate the impact

Policy documents and professional guidelines:

Robson, E. and Evans, R. (2013) Case study on 'Dilemmas of dealing with distress in Interviews with children', in Graham, A., et al. Ethical Research Involving Children. Florence: UNICEF Office of Research Innocenti. URL: http://childethics.com/wp-content/uploads/2013/10/ERIC_Compndium_Case-Studies_Harms-and-Benefits_Elsbeth-Robson-and-Ruth-Evans.pdf

REPSSI (2012) *Supporting young carers. Programme guidelines for households in which young people are caring for other household members*. South Africa: Regional Psychosocial Support Initiative. <http://www.repssi.org/supporting-young-carers-2/>

The Children's Society (2012) *Supporting young carers in families with HIV. Information for HIV professionals*. <http://tinyurl.com/pxxqxed>

National Children's Bureau (2008) *Information Sheet No. 1: Young carers and HIV*. National Children's Bureau, London.

Professional websites and publications:

UNICEF Better Care Network web pages on Supported Child-headed Households:

<http://tinyurl.com/q3um7vd>

Evans, R 2012 AJAR article reviewed in *What's New in Research* November 2012 newsletter, OVC Support.net: <http://www.ovcsupport.net/s/index.php?c=244>

The Children's Society (2012) *Whole Family Pathway 2012. A Resource for Practitioners*, <http://tinyurl.com/nr4x58l>

Open access research reports:

Evans, R. and Day, C. (2011) 'Inheritance, poverty and HIV/AIDS: experiences of widows and orphaned youth heading households in Tanzania and Uganda', *CPRC Working Paper 185*, Chronic Poverty Research Centre, Manchester, <http://tinyurl.com/olahoea>

Evans, R. (2010) *The Experiences and Priorities of Young People who Care for their Siblings in Tanzania and Uganda*, Research Report. University of Reading, Department of Geography and Environmental Science, <http://tinyurl.com/p4wyw5l>

Individual users/beneficiaries:

Former Director of NACWOLA, Uganda (contact details provided separately)

Psychosocial Resource Person, REPSSI, South Africa. (Available upon request)

Programme Manager, The Children's Society Include Project (Available upon request)

Development Manager, Africa Advocacy Foundation (Available upon request)