

Impact case study (REF3b)

Institution: University of Oxford, Department of Social Policy and Intervention
Unit of Assessment 22: Social Work and Social Policy
Title of case study: Improving evidence-based policy and programming for AIDS-affected children in Sub-Saharan Africa
1. Summary of the impact
<p>Since 2005, a pioneering set of Oxford University studies has actively informed the development of evidence-based policy, practice, and programming for AIDS-affected children in Sub-Saharan Africa (totalling an estimated 85 million children, orphaned by HIV/AIDS or living with AIDS-ill caregivers). Key impacts include new policies: on psychosocial support; on 'young carers' of AIDS-sick parents as well as orphans; and on child abuse prevention for AIDS-affected families. These are based on Oxford findings that revealed major effects of parental AIDS on children's psychological, educational and sexual health. Crucially, the research has also identified modifiable pathways of risk and resilience that have been used to guide interventions. As a result, studies are extensively cited in policy documents of the South African government, US President's Emergency Fund for AIDS Relief (PEPFAR-USAID), UNICEF and Save the Children, and have been used to train over 10,000 health and community staff and to develop programmes reaching millions of children throughout the region.</p>
2. Underpinning research
<p>In partnership with the South African government, PEPFAR-USAID and major NGOs, Oxford University has led a team of researchers from the Universities of Cape Town, KwaZulu-Natal and Witwatersrand, in two projects aimed explicitly at informing policy and programming for AIDS-affected children. Impact has been maximised by our collaborative research approach, whereby governments and NGOs actively engage in research planning and co-produce findings and knowledge. Since their initiation in 2005, these projects have raised £3.8 million in research funding from a number of sources (see Section 3), produced 36 peer-reviewed journal articles, seven book chapters, an invited commentary in Nature and received four research awards.</p> <p>The Orphan Resilience Study: 2005-2011 (Section 3 references 1-3). PIs: Oxford University: Prof F. Gardner, Dr L. Cluver (University Lecturers); Dr S. Collishaw (Research Officer, left Oxford 2011); Prof L. Aber (Visiting Lecturer); Dr M Boyes (Research Officer); Prof M Orkin (Associate Fellow). This was the world's first longitudinal study of AIDS-orphaned children, following 1025 children over four years in high-deprivation urban South Africa, and with linked qualitative studies. Findings showed major and long-term impacts on child development, educational, psychological and sexual health (Cluver et al. 2012; Orkin et al. 2013). In 2005-6, AIDS-orphaned children had higher levels of psychological disorder than non-orphans and also than those orphaned by homicide, suicide or cancer (Cluver et al. 2007). Negative effects of AIDS-orphanhood worsened over a four-year period [Section 3: R1]. Findings showed causal factors directly related to the social sequelae of AIDS, including stigma, extreme poverty and bullying [R3; Cluver et al. 2008, 2009 a; 2009b; 2009c; 2010; Boyes et al. 2013]. The study also found threefold risk of child abuse in AIDS-affected families, and threefold levels of transactional sex, a major vector of HIV-infection for young African girls. The combination of parental AIDS, poverty and abuse raised the risk of transactional sex from 1% to 57% [R2].</p> <p>The Young Carers Study: 2009-2013 (Section 3 references 4-6). (www.youngcarers.org.za) PI: Oxford University: Dr L. Cluver; co-Investigators Oxford University: Prof F. Gardner; Dr M. Boyes; University of Cape Town: Prof. A. Dawes (Emeritus Professor); Dr L. Wild (Senior Lecturer). This study is, thus far, the world's largest study of AIDS-affected children, and uses rigorous longitudinal sampling to identify impacts of parental AIDS-illness and orphanhood. It has followed 6004 children between 2009-2012, using stratified random sampling in six urban and rural sites within three South African provinces. In addition, the study has interviewed 2500 primary caregivers (matched with children), and includes linked qualitative studies. Findings show that parental AIDS-illness leads to severe negative educational, sexual and psychological effects [R4; Lachman et al 2013]. For example, children's risk of contracting tuberculosis rises from 2% to 18% by providing medical care to sick adults (Cluver et al, 2013). Models show important interactive 'risk pathways' from familial AIDS to child vulnerabilities, via factors including abuse, parental disability, stigma and poverty [R5]. Recent longitudinal findings identify important HIV-prevention impacts of social welfare grants, with 50-65% reductions in incidence of HIV-risk behaviours amongst girls [R6].</p>

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Building on the impact of the work described above, further engaged research continues to develop. For example, findings showing increased child abuse in AIDS-affected families have led to a set of randomised controlled trials of child abuse prevention programmes starting in 2013, in partnership with the WHO, UNICEF, the South African government and the University of Cape Town. These were pump-primed by an internal University Research Fund (2011-13) and have subsequently been awarded €1.46 million by the European Research Council (2013-18); 2.9 million South African rand from Ilifa Labantwana (2012-14) and 800,000 SA rand from the WHO and SA National Lottery (2012-14).

This research also highlighted the unmet needs of HIV-positive adolescents, and has led to a new, mixed-methods research study to identify risk and protective factors for their adherence to antiretroviral medication and access to sexual and reproductive health services. This study began in August 2013, is in partnership with UNICEF, the South African government and the University of Cape Town, and has been awarded £569,000 by the Nuffield Foundation (2013-16) and US\$145,300 from the International AIDS Society (2014-16).

3. References to the research

- [R1] Cluver, L., Orkin, M., Boyes, M. and Gardner, F. (2012) *Persisting mental health problems among AIDS-orphaned children in South Africa*, J. Child Psychiatry & Psychology, 53 (4), pp. 363-370.
 - [R2] Cluver, L., Orkin, M., Boyes, M., Gardner, F., and Meinck, F. (2011) *Transactional Sex amongst AIDS-orphaned & AIDS-Affected Adolescents Predicted by Abuse & Extreme Poverty*, JAIDS 58 (3), pp. 336-43.
 - [R3] Cluver, L. and Orkin, M. (2009), *Stigma, bullying, poverty & AIDS-orphanhood: Interactions mediating psychological problems for children in South Africa*, Social Science & Medicine, 69 (8), pp. 1186-1193.
 - [R4] Cluver, L. (2011) *Children of the AIDS pandemic*, Nature, 474, pp.27-29.
doi:10.1038/474027a
 - [R5] Cluver, L., Orkin, M., Boyes, M., Sherr, L., Nikelo, J. and Makhasi, D. (2013), *Pathways from parental AIDS to child psychological, educational and sexual risk: Developing an empirically-based interactive theoretical model*, Social Science & Medicine, 87, pp.185-193.
 - [R6] Cluver, L., Boyes, M., Orkin, M., Pantelic, M., Molwena, T., and Sherr, L. (expected Nov 2013) *Child-focused state cash transfers and adolescent HIV-infection risks: a prospective multi-site city in South Africa*, The Lancet Global Health.
- Grants awarded for the two projects:
- 2009-2013 ESRC and SA National Research Foundation (bilateral grant) £537,000. PI Cluver
 - 2008-2011 Nuffield Foundation £299,000. PIs Gardner, Cluver
 - 2011-2013 South African National Department of Social Development ZAR400,000. PI Cluver
 - 2010-2014 Claude Leon Foundation, South Africa ZAR411,000.00. PI Cluver
 - 2009-2010 Health Economics & AIDS Research Division, UKZN ZAR6,000,000. PI Cluver
 - 2008-2010 University Research Fund, £129,000. PIs Operario, Cluver
 - 2004-2008 ESRC D.Phil Studentship to Cluver.

4. Details of the impact

The phenomenon of children living in AIDS-affected families in sub-Saharan Africa was first identified in the mid-1990s, and has risen to massive proportions, with an estimated 3-4 million AIDS-affected children in South Africa alone. This programme of research has been explicitly designed to maximise impact on three key sets of stakeholders responsible for policymaking for AIDS-affected children: 1) the South African government; 2) NGOs (UNICEF, Save the Children and local NGOs providing care to AIDS-affected children); and 3) the US President's Emergency Fund for AIDS Relief (PEPFAR-USAID). The direct utilisation of these studies by policymakers and practitioners in sub-Saharan Africa has contributed to the mitigation of the effects of AIDS on some of the world's most vulnerable children.

Impact 1 - South African government policy and planning

In South Africa, three government departments have joint responsibility for AIDS-affected children: the Department of Social Development (lead), the Department of Health, and the Department of

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Basic Education. The research team has worked closely with all three departments at national level, and all were partners in the research design and implementation, including the former Minister of Social Development, Dr Zola Skweyiya. As a result, the South African government has extensively used and cited the research findings [Section 5: C1]. For example, at the South African National Orphans and Vulnerable Children conference (Durban 2013), the Minister of Health, Dr Aaron Motsoeledi, quoted the research in his plenary presentation (Cluver et al, 2013 on tuberculosis risks for child carers). The team's papers have been cited in a number of major policy documents that are used to determine the provision of services for AIDS-affected children. These include the SA National Action Plan for children affected by HIV/AIDS [C2] (5 citations), which provides a five-year national framework for all government agencies and NGOs working with these groups, and based on the findings now includes a requirement for programmes to support young carers, youth-headed households and psychosocial support. The research was also used in the development of the government's National AIDS Council's National Strategic Plan for HIV/AIDS Information Resource (7 citations), which provides a broader national framework for HIV/AIDS programming. Findings have been directly used in training manuals for government health and community workers, for example the Department of Social Development's 'Training in psychosocial support for orphans and other children made vulnerable by HIV/AIDS' [C3] (7 citations). In addition, the research has led to Dr Cluver being appointed, as one of only two researchers, onto the influential policymaking body the South African National Action Committee for Children Affected by AIDS (NACCA), as an advisor to the National Department of Basic Education, and the National HIV+ Paediatric and Adolescent Technical Working Group in the National Department of Health.

Impact 2 – International NGO policy and programming

Five key international NGOs and supra-national bodies are stakeholders in the provision of policy and interventions for AIDS-affected children in sub-Saharan Africa. The research team has worked closely with UNICEF, Save the Children, the Regional Interagency Task Team for Children Affected by AIDS and the Regional Psychosocial Support Initiative, and has engaged with World Vision, which works closely with PEPFAR-USAID (see below). The team's findings on child physical, sexual and emotional abuse and mental health influenced the development of Save the Children's programming for abuse prevention for AIDS-affected children, as set out in their 2012 policy document Child Protection in the Context of HIV and AIDS [C4] (5 citations). These findings were also instrumental in the child protection policy developed by UNICEF in 2013 Building protection and resilience: synergies for child protection systems and children affected by HIV and AIDS (15 citations). Both of these documents set out the intervention approaches that will be undertaken by Save the Children and UNICEF's direct programmes and beneficiaries, between them reaching millions of children in the region. By demonstrating the negative impacts of AIDS-related poverty on children, this research also contributed to UNICEF's 2012 report on HIV-sensitive social protection [C5] (8 citations) and was instrumental in their policy decision that AIDS-affected children required targeted social provision. In a further contribution to this debate, UNAIDS has invited Cluver to speak on a panel on HIV-sensitive social protection at the 2014 International AIDS Conference, alongside President Banda of Malawi and the Special Advisor to the UN Secretary General [R6]. In an example of direct influence on programming, the Regional Psychosocial Support Initiative, an African NGO reaching over a million children, used the findings of the Young Carers study to directly inform their 2011 training manual for community workers: Programme guidelines for households in which young people are caring for other household members [C6] (2 citations).

Impact 3 - US government foreign aid policy and programming

The President's Emergency Plan for AIDS Relief (PEPFAR-USAID) is the largest single funder of programming for AIDS-affected children globally, with a congressionally-mandated budgetary requirement of 10% of the US HIV/AIDS budget, comprising around \$4.6 billion annually. PEPFAR-USAID funds national government programmes as well as a large network of NGOs primarily within sub-Saharan Africa, all of which are required to follow their seven-yearly programming guidance. The research team were extensively consulted in the development of the PEPFAR-USAID Guidance for Orphans and Vulnerable Children Programming (2012) [C7] (7 citations), (more than any other research group), with six recommended in the 'Evidence Matrix'). The team's research was used to strengthen the evidence-base for the development of programming in

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psychosocial support, economic strengthening and child abuse prevention within PEPFAR-funded programmes reaching an estimated 4.5 million children per year. The studies have also been used to inform PEPFAR's programming for South Africa in particular - see PEPFAR-USAID Southern Africa's SA Government Capacity Development and Support Activity (1 citation) and were an important contribution in their focus on promoting psychological support for HIV+ adolescents, as shown in the PEPFAR-USAID Technical Brief 'Transitioning of care for adolescents living with HIV in Sub-Saharan Africa' [C8] (4 citations). An entire module of the training for USAID Peace Corps volunteers working with orphaned and vulnerable children (around 2000 volunteers per year, working in all sub-Saharan African countries) is based directly on the research findings (9 citations).

To summarise, this research has had considerable impact both in terms of reach and significance. This is evidenced by a comment from a Regional HIV and AIDS Advisor at Save the Children: 'By sharing rigorous evidence on how children affected by HIV faced increased vulnerabilities over time, Dr Cluver has engaged major policy makers, donors and program implementers in critically "rethinking" and redesigning programs with an emphasis on effectively measuring results. Based on Dr Cluver's research, UNICEF, PEPFAR have launched new technical guidance (UNICEF: From Evidence to Impact; PEPFAR: OVC Guidance: 2012) for program implementers. Her work is a testimony of how rigorous research is the foundation for effective programming...a clear example how a true partnership between researchers, policy makers and implementers can result in programs that actually make a difference in children's lives.' [C9] A senior advisor for PEPFAR also stated: 'I have quoted Dr Cluver's data more than any other research to support our work and also to justify and set policy for our global portfolio. All of the data presented from these studies has been influential, however of particular influence has been the data discussed in Cluver [et al] (2011) [R2] and 2012.' [C10]

5. Sources to corroborate the impact

This is a representative sample of a much greater body of corroborating evidence

(* = not in public domain or not online: copies can be provided on request)

[C1] Chief Director HIV/AIDS, National Department of Social Development, Government of South Africa – confirms the utilization of the research in development of policy guidelines and National Action Plans for children affected by HIV and AIDS.

[C2] *The South African National Action Plan for children infected and affected by HIV/AIDS 2012-2016. Government of South Africa.

[C3] National Department of Social Development, Government of South Africa: Psychosocial Support for Orphans and other Children made Vulnerable by HIV and AIDS.

http://www.dsd.gov.za/Nacca1/index2.php?option=com_docman&task=doc_view&gid=217&Itemid=39.

[C4] Save the Children 2012: 'Child Protection in the Context of HIV and AIDS'.

<http://resourcecentre.savethechildren.se/sites/default/files/documents/6008.pdf>

[C5] UNICEF 2012 Report on HIV-sensitive Social Protection. <http://knowledge-gateway.org/?c2a3palq>

[C6] *The Regional Psychosocial Support Initiative 'Programme guidelines for households in which young people are caring for other household members'.

http://www.reppsi.org/index.php?option=com_content&view=article&id=134&Itemid=37

[C7] PEPFAR-USAID Guidance for Orphans and Vulnerable Children Programming 2012.

<http://www.pepfar.gov/documents/organization/195702.pdf>

[C8] PEPFAR-USAID 'Transitioning of care and other services for adolescents living with HIV in sub-Saharan Africa- Technical Brief'. http://www.aidstar-one.com/sites/default/files/AIDSTAR-One_TechnicalBrief_ALHIV_Transition.pdf

[C9] Personal email from a Regional HIV and AIDS Advisor at Save the Children – confirms the role of this research in engaging major policymakers, donors and program implementers to "rethink" and redesign programs with an emphasis on effectively measuring results.

[C10] Senior Orphans and Vulnerable Children Advisor, Office of the Global AIDS Coordinator, PEPFAR – confirms the extensive engagement and value of the research in planning PEPFAR-USAID programming guidance, and informing ongoing policies.