The Development, Implementation and Evaluation of Interventions for the Care of Orphans and Vulnerable Children in Botswana, South Africa and Zimbabwe

A Literature Review of Evidence-based Interventions for Home-based Child-centred Development

Anna Strebel

HSRC
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Social Aspects of HIV/AIDS and Health Research Programme, Occasional Paper 1
Series Editor: Olive Shisana, Executive Director: Social Aspects of HIV/AIDS and Health Research Programme of the Human Sciences Research Council

Published by HSRC Publishers
Private Bag X9182, Cape Town, 8000, South Africa
www.hsrcpublishers.ac.za

First published 2004

ISSN 1810-5564
ISBN 0 7969 2056 7

Cover by Jenny Young
Production by comPress

Distributed in Africa by Blue Weaver Marketing and Distribution,
PO Box 30370, Tokai, Cape Town, 1966, South Africa.
Tel: +27 +21-701-4477
Fax: +27 +21-701-7302
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Preface

The Social Aspects of HIV/AIDS and Health Research Programme of the Human Sciences Research Council publishes an Occasional Paper series which is designed to offer timely contributions to debates, disseminate research findings and otherwise engage with the broader research community. Authors invite comments and responses from readers.

About the Author

Anna Strebel is currently a Managing Partner at Headways Research Training and Development, Cape Town. She was previously professor in the Psychology Department at the University of the Western Cape. She is both a registered researcher and clinical psychologist and has worked in a number of psychiatric hospitals. She completed her D. Phil in Psychology at UCT on women and AIDS. Her current research interests include STI/HIV/AIDS, gender and sexuality, focusing especially on project evaluations. Comments and suggestions on this paper may be emailed to the author at astrebel@mweb. co.za

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A Literature Review of Evidence-based Interventions for Home-based Child-centred Development

Introduction

There is widespread recognition of the urgency of addressing the problem of orphans and vulnerable children (OVC) within the context of the HIV/AIDS epidemic, especially in sub-Saharan Africa (Hunter & Williamson 2000; Smart 2000; UNAIDS, UNICEF & USAID 2002). Many countries in the region, including South Africa, in collaboration with development agencies and non-governmental organisations (NGOs), have outlined policy guidelines and identified models of intervention (Family Health International 2001; Kalemba 1998; Loening-Vosey & Wilson 2001; Schneider & Russell 2000; UNAIDS 2002; UNICEF 1999: USAID & the Synergy Project 2001; Wilson, Giese, Meintjies, Croke & Chamberlain 2002). As a result, a considerable number of programmes targeting OVC have been implemented in the past few years. However, there are very few which have been independently evaluated in

order to establish sustainable best practice models, which can confidently be recommended for replication and scaling up to meet the rapidly growing need with regard to OVC.

This review of recent literature aims to provide an overview of interventions for OVC that focus on providing home-based services (where possible those which have been evaluated in some manner). A number of examples of projects in various African countries are presented in some detail, following which some common principles of best practice that emerge from an assessment of these projects are highlighted.

Community- and home-based interventions for OVC

Regarding OVC programmes, there is acknowledgement of the need for a range of interventions. However, most guidelines and models stress the central role of mobilising community-based projects to keep affected children within the extended family. There are many examples of such programmes in the region, a few of which are described below.

Nsutebu, Walley, Mataka and Simon (2001) discuss the need to scale up HIV and tuberculosis (TB) home-based care in Zambia, with greater government involvement. Rutayuga (1992) outlines a project in rural parts of East Africa which draws on family/kinship traditions and locally available resources in order to provide a long-term, cost-effective approach; and Sayson and Meya (2001) describe a project in Uganda, which aims to provide spiritual and educational services by strengthening existing structures and using a community-focused approach. In Malawi, Kalemba (1998) describes government/NGO collaborations which demonstrate the willingness of communities to address the problems of orphans if they are supported. What was notable about these programmes was the pooling of labour by villagers to develop community gardens, the improvement of productivity following technical assistance, the need to access other resources and the role of village orphan committees. In Botswana, an

orphans trust has been contracted to deliver essential government services to OVC. Community volunteers and local extension staff identify and register orphans, screen for assistance, identify providers of material resources, refer cases to local social welfare and development services, liaise with local councils concerning child protection laws and conduct training (UNICEF 1999). In Abidjan in Cote d'Ivoire, two NGOs – one of which is a network of people with AIDS (PWAs) – provide material (including payment of school fees), medical, and skills-training support for poor families with AIDS orphans. Results indicate that orphans benefit from staying within the extended family, families have become more independent through income generating activities (IGAs) and that the PWAs experience ownership of the project, which is due to be replicated elsewhere.

There is evidence of the valuable role faith-based organisations are playing in community responses to OVC. In Zimbabwe, an interdenominational community-based orphan care network works to revitalise existing traditional coping mechanisms within the family, through a process of sharing resources and experiences (Siwela & Germann 1996). Drew (1996) describes the introduction of participatory methods of HIV/AIDS education into youth groups of local churches, and the training of church volunteers to support homecare and orphan visiting programmes.

While many projects develop in response to perceived needs in communities, there are some initiatives that aim to develop programmes on the basis of research findings. One such undertaking is described by Khan, Muia and Leonard (1996), who outline a collaboration between a government agency and pharmaceutical company, which is carrying out action research interventions based on previous research to identify key problem areas. A programme of participatory planning was conducted to address, among other identified needs, skills training for AIDS orphans in Zambia, and assistance to a women's organisation in Tanzania to improve

organisation and management structures. There is another example of a study conducted to investigate the performance of NGOs offering credit/grants to PWA, widows, orphans and HIV/AIDS-affected families in Uganda. Results indicated that only about 40 per cent of money granted reached beneficiaries, recovery levels of credit were very low, and the costs of dealing with AIDS for families and communities outstrip profits generated. Thus participation of beneficiaries in grant programmes, project management training and project monitoring are essential. In Uganda, two international agencies and a local university are collaborating on an evaluation of two orphan interventions. Firstly they are assessing the impact of an orphan support programme on the physical, educational and emotional well-being of the children. Secondly they are studying a succession planning programme, which includes helping parents promote the long-term well-being of their children through writing wills, appointing guardians, creating 'memory books', etc. (Gilborn, Nyonyintono, Kabumbuli & Jagwe-Wadda 2001).

Evidence-based community and family interventions for OVC

There are also examples of large-scale, multi-sectoral collaborative projects, which have been evaluated and found to demonstrate sustainable and replicable models of good practice in community-based care for OVC. A number of these are discussed in some detail below.

In Malawi, Community-based Options for Protection and Empowerment (COPE) is a project implemented by Save the Children Federation of the United States (SC-US), which utilises a systematic approach to mobilising community-based responses to the needs of orphans and others vulnerable to the impact of HIV/AIDS (Donahue & Williamson 1998). USAID and the Displaced Children and Orphans Fund (DCOF) initially undertook funding in 1995 and then extended this to

2001. The funders evaluated the project in 1996, 1998 and 2000 (Williamson & Donahue 2000).

The project works with local residents to form or reform and mobilise district, community and village AIDS committees, each of which includes a focus on orphans, in order to facilitate sustainable community action to prevent the spread and mitigate the impact of HIV/AIDS. This is done through community-care coalitions made up of representatives from state departments, NGOs, religious organisations, businesses and other interested people, who were already being brought together by the government in collaboration with UNICEF (Hasewinkel 1999; UNICEF 1999).

Central objectives were to: strengthen community capacities; mitigate the impact of HIV/AIDS; identify, assist and protect orphans and other vulnerable children; increase economic opportunities and resources to especially vulnerable households; strengthen the capacity of government and community organisations to sustain effective responses to the needs of HIV/AIDS affected families; and advocate policy change at national, district and local levels. In line with these objectives, village AIDS committees (VACs) received training to mobilise their internal resources, were helped to gain access to external resources, and were assisted in undertaking initiatives, based on a thorough needs analysis, designed to benefit orphans and their families (USAID 2002). Some of the projects which have been undertaken include the identification, monitoring, assistance and protection of orphans and other vulnerable children; advocating with guardians and schools for OVC to attend school; home-based care training for caregivers of the ill and elderly; community fundraising for emergency assistance funds; income-generating gardening; organisation of youth clubs to promote HIV intervention and care; structured recreation activities to promote vulnerable children's healthy psychosocial development; and community-based child care, which is linked with health care programmes, to free guardians of orphans for other work

(Hasewinkel 1999). As a result, over 350 VACs have been mobilised, which provide care and support (including food, clothes, and school fees) to over 15 000 OVC; nurseries and communal gardens have been established; youth have been participating in youth clubs; and money has been raised through local fundraising (USAID 2002).

Thus COPE has activated low-cost, multi-sectoral efforts by communities affected by HIV/AIDS, including home-based care, community resource mobilisation to increase income and food security, psychosocial support, and community-wide education on HIV/AIDS. Community ownership is recognised as an essential element in the COPE approach, and the focus on mobilisation and capacity building has resulted in higher levels of social capital in HIV/AIDS-affected villages. COPE has also been successful in playing a linking role between district and village levels. However, it recognises the need in the future to focus more on the creation and maintenance of community safety nets by generating resources locally, and to provide effective micro-enterprise services for families (Serpell & Williamson 1999). In addition, COPE needs to intensify HIV/AIDS prevention messages and activities.

Evaluators concluded that the structure of the district AIDS co-ordinating committees, community AIDS committees and VACs is a good model, which has the potential to provide a package of services needed by HIV/AIDS-affected families and communities (Serpell & Williamson 1999). Lessons learned include that there needs to be greater involvement of the Malawi government, and improved liaison and collaboration with other development agencies. It was also recognised that COPE should guard against becoming a service-delivery programme. In addition, interventions need to be addressed in families and communities before they become destitute. Moreover, providing quality home-based care requires hands-on training and monitoring by qualified people (Williamson & Donahue 2000).

In Zambia, the Strengthening Community Partnerships for Empowerment of Orphans and Vulnerable Children (SCOPE)

project, implemented by CARE International, works in 12 districts to mitigate the impact of HIV/AIDS by strengthening community capacity to address the needs of orphans and other vulnerable children. The project aims to strengthen and expand district and community committees and programmes that address the needs of OVC, and to provide technical support to such structures. The objective is to establish a multi-sectoral process of community consultation, involvement and commitment, as well as initiatives to address household economic security (Family Health International 2001).

Key accomplishments of the project thus far include: the establishment of 12 OVC district committees and nearly 50 community OVC committees which meet regularly; links being made with key institutions; the disbursement of grants and ongoing capacity-building training for organisations and communities; conducting a baseline household survey and the subsequent development of a psychosocial support strategy for OVC and caregivers; expanded collaboration with government and other implementing agencies, as well as media sensitisation; and the development of a number of training guides, manuals and newsletters. In 2001 about 90 000 OVC were reached, over a third of whom received educational support (USAID 2002).

Project Concern International (PCI) is another project which has been evaluated in Zambia. Its fundamental strategies involve strengthening capacities of two primary social safety nets, namely the family and community. The project emphasises community mobilisation as its central strategy, and uses Participatory Learning and Action (PLA) to increase community awareness, concern and commitment for OVC, and to plan and organise concrete action. The evaluation by the DCOF found that the project had performed acceptably in the period under review (1996–9), that it had made considerable progress, shown significant immediate results, and demonstrated the ability to learn quickly and apply lessons. Community mobilisation showed good promise as a cost-effective and sustainable community-owned and managed approach; and PLA was an

effective methodology for participatory research, community awareness raising, organisation and action. Thus the approach needed to be scaled up, with national co-ordination. Interestingly, OVC initiatives were regarded as possible mechanisms for mobilising communities around HIV/AIDS issues more broadly (USAID 1999).

In Zimbabwe, the Family AIDS Caring Trust (FACT) was established in 1987 as a Christian-based AIDS service organisation based in Mutare. Their Families, Orphans and Children Under Stress programme (FOCUS) started in 1993. It is community-based and delivered by local community-based organisations (CBOs), using volunteers recruited through local churches (Drew 1996; Drew, Mafuka & Foster 1998). The volunteers are trained to identify, prioritise and support orphan households in their immediate surroundings. Visits focus on supporting carers, assessing material needs and small-scale distribution of material assistance (food and seeds). Volunteer supervisors provide local support and monitoring, while FACT provides training and support, funding for school fees and overall management (Hasewinkel 1999; Lee 1999). The intention is to identify ways to support orphans that complement existing mechanisms, as well as encouraging the more influential members of communities to become involved (Foster 2000).

FOCUS was evaluated in 1999, using a participatory self-evaluation methodology to analyse issues of programme effectiveness, short-term impact on children, degree of community ownership, and future strategy. The research involved three components, namely in-house assessment, stakeholder interviews, and community workshops with orphaned children, volunteer caregivers and community members. By mid-1999, FOCUS extended to nine project sites (eight of them rural), with 180 community volunteers making over 56 000 visits in support of nearly 3 000 orphan households with roughly 9 000 children in need of care. In addition, nearly 1 000 children received support in the form of school fees (Lee 1999). With regard to programme costs, FOCUS has reduced

programme unit costs over the three years and continues to incur a majority of programme spending at the community level, on items such as volunteer allowances, uniforms and training. Thus FOCUS is regarded as an inexpensive form of community orphan support (Lee 1999).

Although FOCUS aims to enhance and support existing community coping mechanisms and thus to augment the work of community-based carers (Hasewinkel 1999) – so that it does not directly provide care and material support – the impact on children and their carers was found to be considerable. Moreover, feedback from the evaluation revealed a number of important areas that need to be addressed: sexual abuse is widespread; stigmatisation and discrimination occur in families, schools and the wider community; there has been insufficient participation by children in the programme; FOCUS needs to shift its focus from an orphan household visiting programme to one which also visits children themselves; while there is an urgent need to scale up OVC support, FOCUS aims to increase its focus on capacity building rather than direct intervention (Drew, Mafuka & Foster 1998; Lee 1999).

Overall, the project can be regarded as a cost-effective, targeted and replicable form of community-based orphan care, with committed volunteers providing a valuable and sustainable service (Foster, Mafuka, Drew, Kambeu & Saurombe 1996; Lee 1999).

Given the high percentage of the population living on farms in Zimbabwe, and the particular problems that HIV/AIDS raises for those on commercial farms, the Farm Orphan Support Trust (FOST) was established by FACT in 1986 as a community response, which aims to keep sibling orphans in a familiar environment. It operates foster schemes on farms using farm development committees to train caregivers, provides orphan registration, household visits and awareness raising among farm owners, as well as establishing channels to monitor care on farms (Foster 2000; Hasewinkel 1999; UNICEF 1999). Collaboration with district authorities has significantly

improved the capacity of farm communities to deal with OVC, with a district team training caregivers in childcare, IGAs and providing psychological support to orphans and their guardians (UNICEF 1999). FOST promotes five levels of orphan care: ideally within the extended family; alternatively within substitute or foster care; within a family-type group looked after by a carefully trained foster mother; adolescent-headed household with siblings remaining together with community support; and lastly, in temporary care in an orphanage (Hasewinkel 1999; UNICEF 1999).

In South Africa, the Children in Distress Network (CINDI) was formed in 1996 in response to a summit of concerned stakeholders held in Pietermaritzburg. Four catch nets were identified as providing possible responses to the problems of OVC, ranging from the extended family, through community-based foster care and a 'kibbutz type situation' of adopting orphans, to institutional care. CINDI is a network of about 40 organisations operating in nine communities around Pietermaritzburg, which aims to be a multi-sectoral network of civil society and government agencies implementing diverse, effective sustainable care and prevention programmes for children affected by HIV/AIDS. They base their interventions on the principle of acting in the best interest of the child. Specifically, they focus on prevention (building the capacity of families and communities to care for their OVC), early intervention (to divert vulnerable children to community rather than residential care), and ensuring that children in care get optimum interventions (Hasewinkel 1999; Smart 2000). The CINDI partners operate independently, but collaborate and support each other where appropriate. Two examples of the partner organisations are discussed below.

The Pietermaritzburg Child and Welfare Society (PCW) identifies, recruits and trains cluster foster parents, and places children with special needs with such parents. Their training includes home-based care, management of HIV-positive people, and bereavement, and they receive material and other support from PCW. PCW also runs a short-term place of safety

and an adoption unit for placing HIV-positive children in caring homes (Hasewinkel 1999; Smart 2000).

The Tandanani Association was founded in 1989 with the aim of moving abandoned children out of hospital and into more appropriate forms of care. As the impact of AIDS on communities grew, the AIDS Orphan Project (AOP) was started as a community outreach programme that assists communities in identifying and developing ways in which children affected by the AIDS epidemic might be supported. The broad framework of the project required a shift from a previous 'welfarist' approach to more of a social development focus. The main objectives are to improve awareness about the needs of OVC, to promote the message that the state would be unable to provide for these needs, and to foster a spirit of self-reliance (Harber 2001). AOP facilitated the establishment of childcare committees, which would be trained and supported by the project. The committees identify and register vulnerable children, identify potential substitute families for orphans and abandoned children, and develop ways to provide assistance to families caring for OVC. The project has networked with other agencies to teach income-generating skills and to train the committees in a variety of necessary skills. They also run the Abandoned Children's Hospital Project to respond to children abandoned in public hospitals (Harber 2001; Hasewinkel 1999; Smart 2000).

An evaluation of the project identified a number of problems experienced in the process of trying to implement a development-orientated project (Harber 2001). Most of those who became involved in the AOP were women with very limited access to resources, so there were strong expectations that the project would provide some form of material assistance. Given the relative invisibility and stigma still associated with HIV/AIDS, it also became necessary to widen the target group to include other vulnerable children. In addition, small income-generating projects did not always raise enough funds to support families sufficiently, and so required innovative networking to maximise resources.

Thus the project has come to recognise: the value of networking and collaboration between NGOs and other sectors; the need at times to combine development with direct poverty relief; given the gendered nature of community care, the importance of not overlooking women's needs; the difficulties of the slow pace of development approaches in the face of a rapidly expanding OVC crisis; as well as the problems of mobilising community responses to a still stigmatised problem (Harber 2001; Hasewinkel 1999).

There are a number of documented evaluations of other related projects and approaches to community-based care for OVC in South Africa. For example, Fransman and Hussey (1999) discuss a demonstration paediatric AIDS care model in Cape Town, which aimed to provide effective and integrated community case management through the primary health care approach, and to empower families through home-based care and education. The project was externally evaluated, and found to be a successful collaboration between the NGO and formal health sectors, through interventions at community, clinic and hospital levels, which contributed to community awareness and destigmatisation. Family and children participants in the project also saw it as having a positive impact. Lessons learned were that a comprehensive continuum of care, which is accessible, supportive and sensitive to community needs, is required for families with paediatric AIDS cases (Fransman & Hussey 1999).

The Integrated Community-based Home Care (ICHC) model of the Hospice Association of South Africa has also recently been evaluated (Fox, Fawcett, Kelly & Ntlabati 2002). Although work with OVC has traditionally not been the main focus of hospice work, the model recognises the need for hospice community caregivers to assist with the support of OVC. Some hospices have incorporated such work into regular home-based work, while others have created special palliative care programmes and day-care centres for OVC. Training of caregivers includes bereavement care; play, art and music therapy; and developmental stimulation. Various

activities are included in home-based care programmes to provide psychosocial support, while welfare support includes assistance with grants, and foster/adoptive care. Such initiatives were found to be effective in improving quality of life and providing respite for caregivers. The adaptability and the vocational attitude of staff, notable for their dedication, professionalism and compassionate commitment, were regarded as particular strengths of the hospice model of ICHC (Fox et al. 2002).

A further relevant issue in the provision of community-based care for OVC is the cost-effectiveness of such approaches. Johnson, Modiba, Monnakgotla, Muirhead and Schneider (2001) recently evaluated four home-based care programmes to estimate their costs. They found that home-based care costs, as a proportion of provincial budgets, fall within the parameters of affordability. They recognise that the approach does not provide a quick fix, but rather a key component in a continuum of care that provides appropriate, affordable and good quality services for people with HIV/AIDS (Johnson et al. 2001).

An aspect of OVC interventions which is often mentioned as crucial, but which does not appear to receive much concrete attention in documented projects, is that of psychosocial support. One such study into the psychosocial needs of children affected by HIV/AIDS, conducted in Zimbabwe, Tanzania and South Africa, identified a number of complex issues in this regard: the difficulty of decisions regarding disclosure of HIV status or cause of death of parents; emotional consequences of orphanhood; and the loss of childhood as a result of the responsibilities of child-headed households. Suggestions for addressing such dilemmas include involving children in all stages of decisions and programmes, and providing opportunities for them to express emotions and experiences with other children in similar circumstances (Fox 2002).

Lessons from community-based OVC care programmes

A range of key issues in the implementation of community-based interventions for OVC emerged from this review of such projects and programmes in countries in sub-Saharan Africa. The concerns that recurred across programmes are highlighted below:

- While a comprehensive response to the needs of OVC requires a spectrum of options, including institutional care, there is widespread agreement that the intervention of choice (wherever possible) should be home-based community-supported care.
- While there are strong traditions in the region of extended family support, the HIV/AIDS epidemic has exacerbated the poverty of many households, so that effective support of families and communities in responding to OVC is essential.
- Multi-sectoral collaborations between national and local government, NGOs and community structures appear to provide the most effective services.
- There needs to be a shift from a 'welfarist' approach to a more long-term developmental approach to work in this field. However, models need to be flexible, with a blend of capacity building/empowerment together with material support.
- The importance of a human rights framework for OVC work needs to be emphasised.
- Orphan care should be seen, not in isolation, but within the context of a range of community services. This allows for using the issue of OVC to tackle community mobilisation more broadly.
- The strong stigma still associated with HIV/AIDS, especially in South Africa, must be recognised in devising community-based interventions.
- Thus the focus should be on all vulnerable children and not just those who are affected by AIDS. Communities

need to develop their own criteria for identifying those children in need of support.

- The gendered nature of development work and community care needs to be recognised so that intervention programmes should incorporate addressing the needs of women as well.
- While IGAs are an essential part of developing sustainable community responses, they need careful implementation and monitoring to ensure viability.
- Interventions for OVC need to be linked to and include efforts that deal with AIDS prevention.
- Responses to the problems encountered by AIDS-affected children should begin before parents die, so that early identification is crucial.
- Children themselves need to be involved in all stages of the development and implementation of OVC programmes.
- Strategies to tackle the psychosocial and developmental needs of OVC need greater attention in programmes, and counselling training for caregivers is essential.
- For agencies implementing programmes, issues of scaling down and phasing out are important if goals of sustainability, community empowerment and replication of best practice models are to be realised.

Conclusions

It was evident from this literature review that there has been considerable work undertaken into the development of national policy, guidelines and models of intervention for OVC in many countries in the region. A considerable number of intervention programmes have also been implemented and described. However, there is far less documented work that reports on evaluation of projects or the development of programmes on the basis of research. There is clearly a need for the development of such evidence-based programmes,

which incorporate ongoing evaluation, in order to optimise resource utilisation on the scale required to respond effectively to the growing problem of OVC.

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