

“We are volunteering”:
**Endogenous community-based responses to the
needs of children made vulnerable by HIV and AIDS**

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Executive Summary

The Child, Youth, Family and Social Development (CYFSD) research programme at the Human Sciences Research Council (HSRC) was commissioned by the Children in Distress (CINDI) Network, through funding from Irish Aid, to conduct a study of endogenous community-based responses to the needs of children affected by HIV and AIDS, and how these might be supported. This research topic was identified by CINDI members in a workshop process because it was considered valuable for enhancing their future practice. This project aimed to explore prevailing endogenous responses to the needs of children made vulnerable by HIV and AIDS in three CINDI-selected sites. Specifically, the aim was to consult with local communities to identify appropriate forms of support for such responses, and to explore mechanisms for integrating community-based responses into government and non-governmental organisation (NGO) programmes.

The report consists of the following sections: introduction, literature review, methodology, results, discussion, conclusion, recommendations and appendices.

HIV and AIDS impact on children in a number of ways. With increasing numbers of children being affected by HIV and AIDS, families and communities have coped through a variety of mechanisms to mitigate the impact of the epidemic on children. Community initiatives, usually emerging spontaneously from within communities themselves, are front-line responses providing material and psychosocial care and support to vulnerable children.

From the literature, it seems there is no commonly accepted definition of community responses, and they tend to be diverse. Community-owned responses are referred to as grassroots or indigenous, homegrown, or endogenous responses. For the purposes of this project, responses initiated and owned by communities themselves are referred to as endogenous community responses. There are a number of common characteristics to endogenous community initiatives responding to children affected by HIV and AIDS. These characteristics are volunteerism, a consultative decision-making approach, community reliance on its own resources, a central role for local leadership, and revitalisation of traditional values. Community initiatives face a number of challenges mainly relating to how they are formed and structured, and their limited access to financial and other material resources. Thus, strategies to strengthen such initiatives should be targeted appropriately.

This project received approval from the HSRC Research Ethics Committee at its September 2006 meeting. Three research sites were purposively selected in KwaZulu Natal in consultation with CINDI. Community entry into the three selected research sites was facilitated by the following CINDI member organisations: Umgeni AIDS Centre, the Community Care Project at Project Gateway, and Umvoti AIDS Centre. The three selected sites reflect a peri-urban setting (Mpophomeni, outside Howick), an urban setting (Imbali, outside Pietermaritzburg), and a rural setting (Ngome, outside Greytown). In each area, organisations assisted with the recruitment of a local person as an interviewer for the duration of the project, and with identifying initiatives providing services to children and potential key informants. All three field-based interviewers received training provided by the lead researcher on adhering to ethical principles during participant recruitment, data collection, and on using interview guides for this study.

To meet the objectives of the study, a multi-method approach was used and it included the following components: stakeholder consultation with CINDI member organisations, site

visits, in-depth interviews with key informants, and focus group discussions. Data collection commenced in mid-November 2006. Using purposive and snowballing techniques, key informants and initiatives of interest were identified. Telephone contact was made with identified key informants and initiatives, and interviews were scheduled to take place at a time and place suitable to them. It was difficult to organise groups to interview and to identify community initiatives in Imbali and Ngome. In Imbali, the services targeting children affected by HIV and AIDS, that the project team was informed about, tended to be provided by individuals rather than groups. At the time of the study, no community initiatives were operating in Ngome, that we could discern. It also became apparent during data collection that some of the identified community responses in Mpophomeni did not have a base or site from which they provided care and support to children. This made it difficult for the research team to document these initiatives as case studies.

Thirty key informants were interviewed across all three sites, and almost all key informants (27 out of 30) were women. Key informants included community members, volunteers such as home-based caregivers and community health workers, an auxiliary social worker, a teacher, a paralegal officer, a church leader, a foster mother, day mothers, and members of community initiatives. A total of 10 focus group discussions, each consisting of 6-7 participants, were conducted across all sites. Focus group discussions were held with members of community-based initiatives, home-based caregivers, community health workers, and women and youth from a local church. Key informant interviews and focus group discussions were conducted using semi-structured interview guides, and were recorded after receiving permission from participants. Data was collected on the following main issues: participants' conceptions of child vulnerability, family responsibility and responses to children in a context of HIV and AIDS, community responses to children made vulnerable by HIV and AIDS, and how community initiatives can be strengthened to better respond to the needs of vulnerable children. Transcribed audio tapes were coded, and codes were organised into primary themes which were guided by the objectives of the study and the literature review. To facilitate data management and coding, data was entered into NVivo. Results are presented by site in the main report.

Although the three study sites represent different geographic and socio-economic contexts, situations which compromise the attainment of children's rights and their needs are common. Situations rendering children vulnerable are at an individual, household and/or community level. These circumstances include parental loss, infection with HIV, neglect and abandonment, living in very poor households, dislocation, living with an elderly caregiver, and living with or caring for an ill adult. Participants' conceptions of child vulnerability reflect a broad understanding of the multiple levels of child vulnerability in communities affected by HIV and AIDS, however loss of a parent is viewed as a primary indicator of child vulnerability.

Family is identified as those sharing common descent, who may co-reside or across a number of households. All families are viewed as having a responsibility to love and care for children, and to provide for their basic needs such as shelter, food, clothing, education and health care. Furthermore, family remains the most important safety net to protect children from the direct and indirect shocks of HIV and AIDS. Factors cited as motivating some families to respond to vulnerable children include the following: traditional values such as

*ubuntu*¹, compassion, a special value placed on children, seeing the devastating impact of the epidemic on children, access to information, and encouragement by external agencies. Child Support and Foster Care Grants were cited as a perverse incentive for child fostering, i.e. a family might foster a child in order to access a grant, which is then not used to meet the needs of a child. This issue of the grants as a perverse incentive was, however, not explored further as part of this project. Constraints to family responses to vulnerable children, in a context of HIV and AIDS, include widespread poverty and unemployment, lack of compassion, lack of or insufficient information, fear of HIV infection, stigma associated with taking in a child whose parents may have died from AIDS-related illnesses, responsibility for own children, and the difficulty of accessing birth registration documents and grants. In the face of these constraints, it is noteworthy that most families nonetheless respond to vulnerable children.

Responses at community level, whether initiated by individuals or groups, offer material and non-material assistance to children and households affected by HIV and AIDS. This assistance includes food and nutrition support, educational support, psychosocial support, household visits and home-based caregiving, treatment support, and child fostering. A community response may not necessarily offer a tangible resource or service, instead it can offer relief to caregivers, companionship, acceptance and solace through prayer to those affected by HIV and AIDS, as well as help to destigmatise HIV and AIDS. Other responses may enable volunteers, who are themselves living with HIV and AIDS, to cope with their own situation. Therefore, responding itself can be a coping mechanism for volunteers directly affected by HIV and AIDS.

Community initiatives, built on a spirit of volunteerism and a willingness to help others in need, are of various types and can be at different stages of development within the same community. No community responses appeared to be operating at Ngome, instead care and support for vulnerable children was embedded within kin and kith. Unlike Mphophomeni and Imbali, Ngome seemed to have a weak sense of community which was characterised by low levels of togetherness, trust and reciprocity. An examination of factors facilitating or hindering responses by a community needs to look at both individual and social factors, because some individuals volunteer despite facing problems such as poverty and unemployment. Social factors hindering community responses may include substance abuse, HIV and AIDS-related stigma, erosion of traditional values such as *ubuntu* and compassion, lack of local leadership, pre-existing political conflicts and divisions, and a sense of helplessness.

That which builds community responses can also threaten their survival. As much as volunteerism is commendable, community responses may be destabilised when volunteers leave or when they die. When volunteers take time off due to ill-health or when they die, including from HIV and AIDS-related illnesses, the quality of services provided and volunteer morale suffer. Furthermore, volunteering can be challenging for volunteers, who may be poor themselves, as it can limit their income-earning opportunities in the short-term. However, volunteers may find themselves in a better position to access formal employment and skills development opportunities in the long-term. Volunteers, mostly women, need to be adequately acknowledged and remunerated, and this can be done in cash or kind.

¹ *Ubuntu* originates from the Zulu expression *umuntu ngumuntu ngabantu*, literally meaning a person is a person through other people. *Ubuntu* is a concept used in reference to the spirit of comradeship and togetherness, and a willingness to help others in need.

Community responses face a number of challenges, the biggest of which is access to financial and material resources. Poorly resourced responses may struggle to compensate and retain volunteers and are limited in the type and scope of services they can offer. Low levels of technical training in areas such as fundraising, planning and project management, and competition for resources present other challenges to community-based responses. In supporting community-responses, however, a number of key elements need attention. These include improving their access to financial and other material resources, involving community leaders, facilitating a reciprocal relationship between initiatives and government services, and facilitating networking and skills sharing opportunities between initiatives. It is also important that government and others create a supportive and enabling legislative and policy environment.

Building AIDS-competent families and communities is one of the key strategies for cushioning children from the current and future shock of HIV and AIDS. While families and communities should be commended for their endogenous responses seeking to address the needs of children made vulnerable by HIV and AIDS, more should be done to enhance their coping capacities. While acknowledging the critical role that organisations such as CINDI, Umgeni AIDS Centre, the Community Care Project at Project Gateway, and Umvoti AIDS Centre continue playing in supporting families and communities respond to vulnerable children in a context of HIV and AIDS, there is an even bigger role for local leadership and government in improving the coping capacities of families and communities affected by HIV and AIDS, and supporting community-based initiatives.

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Acronyms

AIDS – Acquired Immune Deficiency Syndrome
CBO – Community-based organisation
CINDI – Children in Distress Network
CYFSD – Child, Youth, Family and Social Development research programme
FGD – Focus group discussion
HIV – Human Immunodeficiency Virus
HSRC – Human Sciences Research Council
IGA - Income generating activities
NGO – Non-governmental organisation
PLWHA – People living with HIV and AIDS
OVC – Orphaned and other vulnerable children

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1. Introduction

Almost half of South Africa's population is children, with the majority being African children. With HIV prevalence increasing in the economically active population in South Africa, many families and children are being affected by HIV and AIDS. HIV and AIDS impact on the lives of children and make them vulnerable in a variety of ways. Vulnerable children are at an increased risk of experiencing negative life events, such as living in poverty, losing a parent and other significant adults, dropping out of school and being excluded from other social processes (USAID, undated). In the mix of responses required to assist children and families in the face of poverty and HIV and AIDS, community responses play a critical role in averting destitution and crises, retaining children in school, providing psychosocial support, and promoting human and social capital development.

Community-level safety nets provide the major share of assistance given to children and families affected by HIV and AIDS (Foster, 2005b). Community responses to the HIV and AIDS epidemic take various forms including communal land and crop production, grain loan schemes, organised individual or group income generating activities (IGA), often involving small trade selling home-made food or vegetables, communal labour to repair houses and schools, home-based care for ill people and their families, labour sharing to relieve carers and to enable children to attend school, community schools, orphan registration and home visiting programmes to provide relief, food, clothing, and school fees, social groups for vulnerable children, psychosocial activities to address the distress of affected children, and a variety of other efforts that give succour and support to those who are worst affected by the epidemic (Mutangadura, Mukurazita & Jackson, 1999).

Community initiatives are often seen as separate or peripheral in relationship to more formal service delivery mechanisms such as government and the NGO sector, and the significance of their contribution is often not recognised nor given due credit (CINDI, 2006). Since most community-initiated activities are not sufficiently documented, it becomes difficult to assess the reach, range and quality of their services. Their ability for fundraising, networking and expansion is also compromised. Although affected communities are better placed to provide support to vulnerable children than external agencies, their activities are usually not sustainable in the long-term without additional assistance.

Reciprocity and a sense of solidarity are common features of people living together. A strong sense of community and a need to develop localised solutions to a desperate local situation may encourage community members to organise themselves spontaneously into groups. The concept of community in some African contexts extends beyond location and geography to include people who share endogenous characteristics, like religion, language and culture. The way community, family, parenthood and children are conceived may inform community perceptions about when children require care and support. Cultural beliefs about communal responsibility for children may prompt non-kin to contribute to a child's care and support when the extended family cannot fulfill this role. Although the capacity of community-based safety nets to care for and integrate vulnerable children does not appear to have been exhausted, it is undoubtedly stretched due to poverty, unemployment, and HIV and AIDS. Thus, there is a need to explore mechanisms for identifying, supporting and strengthening these initiatives on a sustainable basis. However, scaling up strategies from the outside should guard against undermining community-initiated responses.

2. Literature Review

This section presents an overview of the impact of HIV and AIDS on children, how child vulnerability is conceptualised across contexts, and how families are responding to children made vulnerable by HIV and AIDS. In addition, it outlines the nature, characteristics and types of community-initiated responses, the challenges such initiatives generally face, and a few approaches which can be considered for strengthening community responses.

2.1 Impact of HIV and AIDS on children

The impact of HIV and AIDS on children is not simply through orphaning, there are in addition direct and indirect effects as well. In 2006, it was estimated that 293 549 children were living with HIV in South Africa, with 40% of these children requiring antiretroviral treatment (Day & Gray, 2006). HIV and AIDS also have psychological effects on children. If parents are living with HIV and AIDS, there can be a long and drawn out process of a child caring for the parent before the parent dies, in settings in which the parents cannot provide adequate levels of care. This can have huge psychological impacts on a child (UNICEF, UNAIDS & PEPFAR, 2006). Education is also likely to be affected, if a child's parent dies of an AIDS-related illness. In a multi-country study in Sub-Saharan Africa, it is reported that if a parent dies, a child's education is more likely to be interrupted than if no parent dies (Bicego, Rutstein & Johnson, 2003). Other studies report that there can be increased levels of stigma in a community, particularly directed at orphaned children. Orphaned children report being given different food to the household that is hosting them, being poorly treated by the hosting household and also being excluded from friendship networks at schools (UNICEF *et al.*, 2006).

There are also growing indirect consequences for children. As adults become ill and die due to AIDS-related illnesses, various community institutions and services, which provide for children can become affected. As services, such as education and health systems, become increasingly affected through high levels of mortality, children are likely to receive substandard care and support (UNICEF *et al.*, 2006).

2.2 Conceptions of child vulnerability

A child exists in a context of a family or household and a community. There is a growing recognition that child vulnerability is not simply linked to whether children are orphaned or not (Foster, 2006; Henderson, 2006; Meintjes & Giese, 2006; Skinner, Tsheko, Mtero-Munyati, *et al.*, 2006). Foster (2002) suggests that there is a continuum of vulnerability, and that there are multiple overlapping factors that make children vulnerable in a context of HIV and AIDS. Vulnerability, as well as being linked to whether a child is an orphan, is also linked to questions of household poverty, gender-inequality, and the ability to access services like education and health care. As such, vulnerability needs to be situated within a broader understanding of the factors that compromise the fulfilment of children's rights.

Children living in communities affected by HIV and AIDS find themselves in particularly difficult circumstances. Children affected by HIV and AIDS may themselves be infected with HIV, may have to care for ill adult caregivers and/or other children, may lose their sources of livelihood when their caregivers are no longer able to work due to ill health or upon death, and may be over-exposed to illness and death resulting in psychosocial distress.

There is a shift to expand the definition of vulnerability outwards, to focus on a wider group of children than simply orphans. A recent shift has been to frame vulnerability in terms of child rights. The British NGO Tearfund for instance, in a briefing paper on strengthening community initiatives and motivation to support orphaned and other vulnerable children (OVC), uses a definition suggesting that OVC include all children who “are denied the basic rights to which all children are entitled.” (Tearfund, 2004:3).

This approach is also supported by Skinner *et al.*'s (2006) multi-country study of conceptions of orphanhood and child vulnerability. Drawing on research from Botswana, Zimbabwe and South Africa, they identify that vulnerable children were not only orphans, but also any child that was at risk of having their rights infringed. Importantly, they suggest that vulnerability can be at multiple levels, the individual, the household and the community.

A number of individual factors, such as physical handicap, psychological or emotional problems, are likely to render a child, as an individual, at specific vulnerability. At the family level, focusing on whether a child has a caregiver who wants to, and in addition is able to, provide an adequate level of care can be useful in assessing the vulnerability of a child. The financial resources available at the household level are also a consideration in relation to the vulnerability of children. The final level that Skinner *et al.* (2006) identified was the community context in which children and families were situated. High levels of community poverty and inadequate sanitation and water were other issues identified by participants that made children more likely to be vulnerable.

A broader focus on rights also allows a focus on various external factors which expose children to vulnerability. As Tearfund (2004) highlighted, these include the increasing impact of the HIV and AIDS pandemic which could also render children vulnerable to losing their rights. They highlight the impact of HIV and AIDS on education systems. With high levels of death and illness amongst educators, children may become vulnerable to losing their rights, as education systems may no longer be able to provide adequate levels of education. As can be seen, the definition of vulnerability has moved away substantially from a simple focus on orphanhood, to include an analysis of the specific contexts and situations that a child lives in. This is important as it allows a broader conception of child vulnerability, which further necessitates responses that take account of children's multiple vulnerabilities in families and communities affected by HIV and AIDS.

2.3 Family responses to vulnerable children

A number of authors have started focusing on the role of the family and the extended family in providing care and support for children made vulnerable by HIV and AIDS including orphaned children. There is a debate in the literature, between those who see extended families actively responding *and* coping with the growing demands (e.g. Foster, Shakespeare, Chinemana, *et al.*, 2000), and others who suggest that the extended family is starting to fail and is buckling under the new strain, leading to the collapse of the extended family (e.g. Ntozi, Ahimbisibw, Odwee *et al.*, 1999).

A range of studies have looked at the patterns of fostering that have been employed across Africa in the face of the HIV and AIDS pandemic. Heymann, Earle, Rajaraman *et al.* (2007), using data from Botswana in 2002 of adults caring for orphaned children, suggest that the majority of these children were looked after by the extended family. This study shows that the majority of orphaned children were cared for either by aunts or uncles. In a separate study

around Mutare, in Zimbabwe, Foster *et al.* (2000) show that while the rate of orphaning had doubled in ten years prior to their survey in 1992, no orphaned children were being cared for outside of the extended family unit. They assert this does demonstrate what appears to be the strength of the extended family to cope with increasing numbers of orphaned and vulnerable children.

While there are a number of studies, which commend the ability of the extended family to cope with increased demands on it by the care of vulnerable children, other studies suggest that this is not the case. For instance, Ntozi *et al.* (1999) drawing on data on northern Uganda collected in 1997, argue that the extended family cannot cope anymore, and is shifting the burden of caring onto children – normally one of the older siblings. As Ntozi *et al.* (1999) go on to point, many of the older children doing the caring were often too young to provide the necessary care and support required for their siblings. Grant and Palmiere (2003) in a different study argue that while the extended family is showing great resilience, that certain groups, namely the old and young are starting to be excluded from the extended family network. While they stress the resilience of families to cope, they are concerned that the extended family is starting to breakdown.

In an attempt to resolve the contradictory nature of these studies Foster *et al.* (2000) suggest a number of possible resolutions. Firstly, they suggest that studies have tended to focus on the more extreme examples of the so-called ‘orphan crisis’ in Sub-Saharan Africa, highlighting the failures rather than the successes of the extended family to cope with the increasing number of orphaned and vulnerable children. As such, many of the reports that are published which highlight the failure of the extended family fail to see the whole picture, which generally suggests that the extended family is providing an adequate safety net.

Secondly, these studies argue that HIV and AIDS may well be having the opposite effect of strengthening the family unit, and at the same time reshaping it. What others have identified as being near collapse is what they identify as adaptation. One adaptation that Foster *et al.* (2000) identify is the growing role of the maternal side of the family providing care in Zimbabwe. In their study they saw an increasing proportion of orphaned children being looked after by the maternal family, compared to those fostered by the paternal family. In addition, after the death of a mother most orphaned children are not cared for by their father, but are placed in the extended family. As they point out, in the ‘classic’ sociological and anthropological literature on fostering in Zimbabwe, the emphasis is on the paternal family taking children in. It appears as if this trend is changing as the context is changing. Another study found that a growing number of older caregivers (grandparents) were caring for children, with the middle generation missing (UNICEF *et al.*, 2006). Grandparents, as part of an extended family system, have always played an important role in the upbringing of children (Ntozi *et al.*, 1999). However, grandparents are finding themselves having to resume primary parental responsibilities as they have to care for, provide for, support and supervise their grandchildren as parents die. Where the elderly are not capable of providing adequate care and support due to their limited access to material and psychosocial resources, this may contribute to the vulnerability of children under their care.

In a similar argument, Chirwa (2002) looking at Malawi, argues that extended families are learning to adapt to the broader changes that they are facing, and are not collapsing. The family collapse literature, according to Chirwa (2002) sees the situation as one of social rupture – the HIV and AIDS pandemic stops the nuclear family from working effectively and

therefore the wider extended family. Rather, he argues that a large number of factors shape the way the extended family copes with a given situation and there is no one correct way.

A further problem with the thesis that the extended family is collapsing under the pressure of HIV and AIDS is that it relies, to a great extent, on the idea that the extended family is a fixed idea (Madhavan, 2004). Indeed many studies show that the extended family is under constant pressure and evolution. In her study of the extended family in South Africa, Madhavan (2004) argues that one of the effects of apartheid was to disrupt the extended family and create a broad need for fostering within the black community. As such, with the increasing demands of the HIV and AIDS pandemic, it becomes difficult to look back to an ideal situation, rather the focus needs to be on how families are actively coping and changing. Recognizing that the extended family is constantly changing, forces a look at the nature of the relationships that are important in fostering arrangements. Verhoef (2005) in a study of fostering in Cameroon, emphasizes that the intimate relationships between the biological parents and the foster parents generally have a strong impact on where a child is placed. There is no direct placement in a household, rather it is carefully negotiated.

It is important to remember, however, that households are also situated in specific situations. While the extended family may be adapting and evolving to cope, the burden is not equally distributed throughout a society. As Foster *et al.* (2000:4) state “Poorer communities may be in double jeopardy with regard to the requirement to care for orphans. Firstly, they may be least able to take measures to avoid HIV infection so that the absolute numbers of children becoming orphans may be higher in poorer than in more affluent communities. Secondly, these communities are less able to provide support to orphans due to their limited economic resources.”

Therefore, it becomes apparent that assumptions that the extended family is not coping need to be contextualised and placed within a broader framework of change and evolution. As a large number of studies concur, “The extended family as a safety net is still by far the most effective community response to the AIDS crisis.” (Grant & Palmiere, 2003:233). Change is probably a more likely scenario than collapse, at the present time.

2.4 Description of community responses

A proliferating number of studies around the impact of HIV and AIDS in African countries demonstrate that the major share of assistance to families affected by HIV and AIDS – cash and support – is given by the extended family and the immediate community (Foster, 2005b; Mutangadura, Mukurazita & Jackson, 1999; Urassa, Boerma & Ng’weshemi *et al.*, 1997).

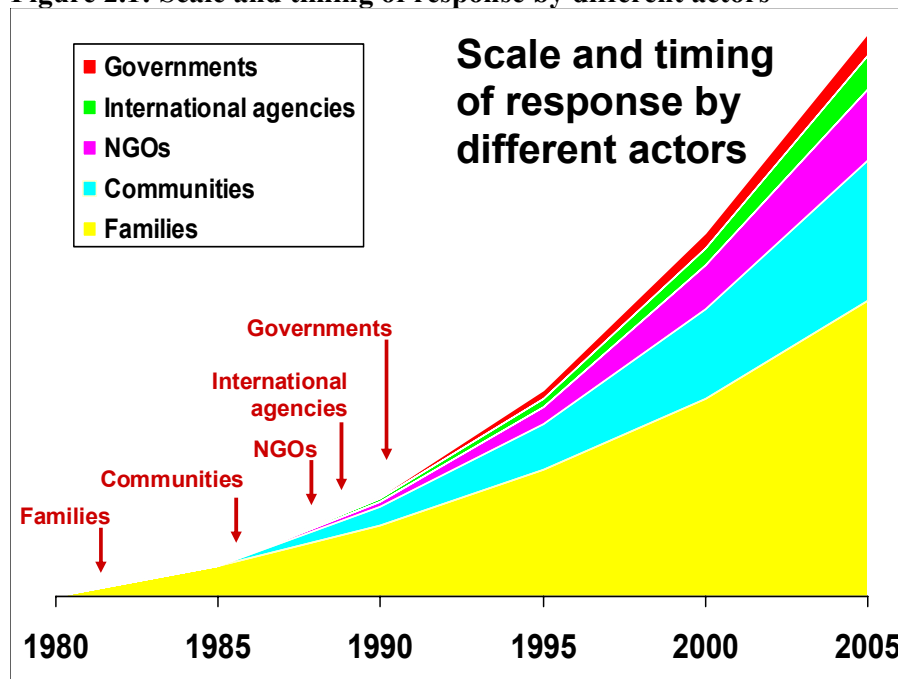
A World Bank study of households in Kagera, Tanzania, reports that up to 90% of assistance to families is provided through family and community groups, while only 10% comes through the government or NGOs (in Mutangadura *et al.*, 1999). Another study in rural Zimbabwe emphasised that only 2% of needy households received the government support that they were entitled to (Drew *et al.*, 1996 in Foster, 2005b). Leatt, Meintjes and Berry (2005) estimate that 67% of the 8.8 million children eligible to receive the Child Support Grant, in South Africa, have access to this form of financial assistance.

There are many reasons for poor access to government assistance, e.g. structural adjustment programmes in the 1980s and early 1990s, emphasised the removal of social security grants and support (Foster, 2005b). In addition, social welfare departments often lack the necessary

human resources and capacity to effectively cover rural areas (Foster, 2005b). In South Africa, some of the reasons cited for delayed uptake of the Child Support Grant are that caregivers struggle to get the right documentation and do not always have the necessary knowledge about this grant (de Koker, de Waal & Vorster, 2006). In effect, for the majority of people across Sub-Saharan Africa, while the state plays a large role in their life, it may not be as large as is expected.

In addition, governments and NGOs have been relatively slow to respond to children and caregivers affected by HIV and AIDS. It is therefore apparent that household and community responses still remain the main providers of material, psychosocial and spiritual support (as indicated in a figure designed by Foster and Williamson).

Figure 2.1: Scale and timing of response by different actors



Source: Foster & Williamson

Community-initiated responses are as much about the strength of communities to react to the demands that are placed on them, as they are about the failure of governments and NGOs, to respond to the increasing demands of vulnerable children in Africa. Community-based responses to the impact of the HIV and AIDS pandemic are diverse (Foster, 2005b). Some of the responses that are seen across Africa build on existing ‘traditions’ that are reworked to provide a framework for an effective response. Others, while drawing in some way on community ‘traditions’ are new and offer alternative ways of responding to the pandemic. These alternative ways emerge from the interactions of communities as they identify a problem.

The key link between these responses is that they are community responses, initiated from within a community and in general, working without external inputs in the forms of ideas, funding or support. As such, these community-initiated responses draw on local knowledge and resources and are referred to as indigenous or grassroots responses by Mutangadura *et al.* (1999), homegrown safety nets by Foster (undated) and as endogenous networks by De

Weerdt (2002). This is in opposition to external responses that are introduced to communities, whether by NGOs, international organisations, or government.

Community-initiated responses may be preferable to externally introduced responses. “Community initiatives that build upon traditional systems are more efficient as they typically require less training and input from external sources, more relevant as they are readily understood and accepted by community members, and more sustainable as people are quicker to identify with, adopt and take ownership of such initiatives.” OSSA (2003:7).

In addition to the sustainability of the activity in the long-run, community-initiated responses are also, it is argued, more likely to be able to identify the children who are most vulnerable, and therefore needing support (OSSA, 2003). Importantly, being located in the environment they serve, community-initiated responses generally have a solid understanding of local issues, needs, and dynamics. Thus, they have the potential to provide appropriate support and deal with complex social issues of children affected by HIV and AIDS than external agencies (Foster, 2005b).

2.5 Characteristics of community responses

For Foster (2002:11), community-initiated responses to the needs of vulnerable children can be described by a number of principles, which are often in stark contrast to externally introduced projects. Foster (2002) identifies five principles that cut-across the community responses, in a context of HIV and AIDS, he has studied:

- *Voluntarism* – as Foster (2002:12) puts it - “is the cornerstone for community support initiatives.” Because of the limited resources that are available to communities, most people are volunteers. Volunteers are driven by a variety of reasons, ranging from altruism, empathy towards those less fortunate than themselves, through to a sense of community and a realisation that one’s own survival is dependent on the goodwill of others. Community ties tend to be a strong predictor of volunteering. Religious commitment has also been identified as central to many people’s desire to respond to the needs of the community. Because faith-based groups already convene regularly they are often in a strong position to respond. It is important though to recognise that it is predominantly women who are volunteers in community-initiated responses (UNAIDS, 2000).
- *Consensus-based decision making* – community-initiated responses often take years to become established, as the norms and politics of the community are negotiated. Foster argues that they are likely to be sustainable because of their slow emergence from within a community. This is in contrast to externally introduced projects, with their short time frames and targets that need to be achieved.
- *Self-reliance* – resources are mobilized from within the community, rather than being provided from outside organisations. Individuals provide labour, time and financial inputs. This is as much a product of the limited support governments and NGOs are providing to the majority of the population, as it is a decision by community-initiated responses to be self-reliant.
- *Local leadership* – while community-initiated responses might occur without direct support of local leadership, where local leaders do give their support, both verbal and material, this can profoundly strengthen and shape the nature and extent of community responses. Furthermore, local leadership can mobilise broader support for a response within a community, rather than being limited to one group of people.

- *Innovation* – is also a feature of the community-initiated responses. Responses often rework ‘traditional’ community forums to allow them to respond to HIV and AIDS more effectively. In Swaziland and Zimbabwe, a number of examples of this have appeared, where land is donated to orphaned children and is worked by community members (UNAIDS, 2006). This draws on pre-existing ideas of community that have fallen out of use. They are revived in innovate ways to overcome some of the challenges that are faced in providing adequate care and support to vulnerable children.

An important point Foster (2005b) makes is that studies of community-initiated responses to HIV and AIDS often omit a lot of what is happening within a community. As such, they do not capture the complexity and subtlety of how community safety nets and responses to HIV and AIDS, actually work. Despite positive features, there is recognition that the impact of the HIV and AIDS pandemic is putting strain on community-initiated responses.

2.5.1 Low cost and efficient

An additional benefit of community-based responses may be that they are more efficient than externally imposed responses to vulnerable children (Foster, 2005b). It is argued that they have a better understanding of local situations and are therefore more likely to be able to target children who are vulnerable and create support structures that are locally appropriate. Externally introduced responses are more inclined to be based on a ‘one-size fits all’ model, and inappropriate for individual contexts. CARE International is one example of an international NGO that has stopped using its own criteria for identifying orphaned and vulnerable children in Rwanda. It now supports a process of community consultation and participatory mapping, through which the local community can identify children they deem in need of additional care and support (CARE, undated).

For many organisations looking to support community-initiated responses, a key strength is that they are relatively low cost compared to externally driven programmes. The low costs result from the largely voluntary nature of the work that is done, and the fact that they generate a substantial proportion of their own material resources. In addition, they reflect a better local understanding of the issues faced by vulnerable children and also the identification of these children. However, poor communities are expected to shoulder the burden of caring for children without adequate support?

2.5.2 Broader impacts

An issue which is commented on only in passing, is the fact that community-initiated responses to children’s needs often have ‘spill-over’ effects into the wider community. A number of reports highlight the potential routes that this can take. In one instance, the local response was to provide land, which the community would farm and give the produce to vulnerable children. As well as providing for the child, it also encouraged members of the community to work together and allowed a space for the transfer of agricultural skills and knowledge across the community (UNAIDS, 2006).

Another example of this is seen in Democratic Republic of Congo. It is reported that a project to support families with additional children, saw adults starting to talk about sex to the children they cared for – something that had not been planned for in the community-initiated response (Christian AID, undated). In Swaziland, the establishment of Neighbourhood Care

Points for OVC, has “also brought together communities in other ways: some have also established adult literacy classes that meet in the afternoon.” (UNAIDS, 2006:21).

As well as these relatively ‘tangible’ outcomes, community-based responses can also increase ‘intangible’ outcomes, such as a sense of empowerment in the community, especially in situations of high levels of poverty, unemployment and HIV and AIDS. Community-initiated responses are not solely beneficial for the children to whom they provide additional support and care, but have the potential to provide positive spill-over effects in the wider community.

2.6 Types of community responses

There are a number of responses that are initiated in seeking to alleviate the plight of children made vulnerable by HIV and AIDS in communities. Below is an outline of some of the approaches used, such as food support, material support, care for caregivers, psychosocial responses, education and informal transfers.

2.6.1 Food support

In Zimbabwe and Swaziland, similar practices have been documented of a Chief providing land for the community to farm and the food generated being used to feed orphaned and vulnerable children (UNAIDS, 2006; Foster, 2005b). This draws on ‘traditional’ notions that have been reshaped and re-appropriated to meet modern social issues. As UNAIDS reports, “traditionally, any stranger to the community or person in need would go to the *Imphakatsi* or chieftdom to be fed and accommodated, but in modern times this tradition had largely died away. The growing numbers of orphans and destitute children, combined with the desire to keep these children in the community, has led to the revival of the traditional practice of *Indlunkhulu* fields.” (UNIADS, 2006:24). *Indlunkhulu* fields is the term used in Swaziland to describe land donated by a Chief for the community to farm, and produce food which may be used to feed vulnerable children and households.

The provision of food more generally, not only self-grown food, is also frequently part of the responses to vulnerable children in Africa. Again in Swaziland, food has been distributed through community run centres, called *KaGogo* Social Centres or grandmother’s houses. The *KaGogo* Social Centres, draw on the traditional ideas of the grandmother’s house being a place of refuge. These houses have been built to coordinate the response to the growing numbers of vulnerable children. Initially food was handed out to children who took it home to prepare and cook, but it was soon realised that the youngest or weakest child would be excluded from such food distribution. Consequently, there has been a shift to preparing the food at the *KaGogo* Social Centres, and thus ensuring a more equitable distribution of food (UNAIDS, 2006).

2.6.2 Financial support

The provision of financial support is also noted in many community responses. Christian Aid (undated) have documented instances of this and more specifically the introduction of loans, either to child-only households or to families with vulnerable children. One example highlighted by Christian Aid (undated) is from Rwanda, which has a high proportion of orphaned children, because of the genocide and the impact of the HIV and AIDS pandemic. *Giving Hope*, a small community-based organisation, has helped form support groups for child-only households. Out of these has emerged a savings scheme, whereby each household

puts a small amount of cash into a central pool. Households can apply for emergency loans, such as to pay for school fees. This allows the households to have some form of insurance and a safety net in times of need.

A similar scheme is also reported in the Democratic Republic of Congo, but this time aimed at poor households that have taken additional children in. Loans allow households to start small businesses, or cover immediate costs that are imposed on the family or to increase the level of care that the additional child can have (Christian Aid, undated).

2.6.3 Care for the caregivers

The impact of caring for vulnerable children (and their families) has been recognised by a number of organisations (UNAIDS, 2000). They recognise that it is not only the children who are placed in a distressing situation, but there are also demands on those who choose to be volunteers and respond to the needs of these children. A number of organisations have specifically incorporated supporting caregivers into their work. One such example is a small organisation called *Kondwa* Day Care Centre, based in Zambia, which provides day care for vulnerable children. The aim of this is not only to provide additional support and care for the children, but also to give the caregivers of these children a break, allowing them to recover and to do tasks that they cannot do with children around (Christian Aid, undated). Support for caregivers is a crucial area of work that can be done to support community-initiated responses.

2.6.4 Psycho-social support

The impact on children of caring for an ill parent as they die, under conditions where providing adequate care might not be possible, can create situations whereby psychological and emotional support is required by children. For many community-initiated responses, a central pillar has been providing psychosocial support for both orphaned and children on the verge of orphaning. Such responses include the Farm Orphans Support Trust (FOST) in Zimbabwe, and the *Kondwa* Day Care Centre in Zambia which are outlined below.

FOST is a community-based organisation that works with orphaned and other vulnerable children on commercial farms. The aim is to support farm communities to provide care and support to children. One of the components of the project is the Community Project Clubs, which are often run at schools and provide a space for all children to get together, talk about pertinent issues and start projects such as drama clubs. These Clubs provide psychosocial support by creating a safe and caring space which children can easily access and feel supported in (UNAIDS, 2001).

The *Kondwa* Day Care Centre has been working to develop a range of ‘memory approaches’ to help children and guardians deal with the loss and grief that is suffered, when a parent dies. “Parents are encouraged to make ‘memory books’ or ‘memory boxes’, which allow them to pass on important information about their family history and their hopes for their children’s future.” (Christian Aid, undated:28). Creating memories and a space in which death can be dealt with, is important to supporting vulnerable children.

2.6.5 Education

Studies show that children whose families are affected by HIV and AIDS are more likely to drop out of school and to provide care to a person living with HIV and AIDS (PLWHA). This situation may result because a child might no longer be able to afford the costs of attending school. Education is often a high priority for community-initiated responses. While some pay fees and try and get children to return to school, others recognise this might not be possible and provide different forums for education. This might include providing direct education to children rather than supporting them to attend schools. The range of support covered paying for school fees, through to providing uniforms and books for children (Foster, 2005b). One mainly religious group, which does this, is a congregational group from St. Joseph's in Mutare, in Zimbabwe. They identified that their community had some 300 orphaned children, a number of which could not pay for education. They organised for their congregation to pay for school fees for a number of these vulnerable children (AIDS Alliance, 2002).

2.6.6 Informal transfers

Informal transfers can take many forms, including rotational savings clubs, burial societies and direct transfers from one family to another. They can include cash and other material transfers or services such as childcare and cooking. They can be classified as a "subset of coping strategies that involve drawing on support from other households during periods of particular livelihood hardship." (Devereux, 1999:5). Transfers can either be horizontal – between households of similar wealth and situation – or vertical – between a richer benefactor household and a poorer household (Platteau, 1997). A number of other factors influence the type and range of transfers that an individual household will receive and give. De Weerd (2002), in a study of informal transfers in Tanzania, found that a wide range of factors influenced informal transfers including, geographical proximity, kinship, religious affiliation and wealth.

Informal transfers constitute safety nets, and they are an attempt to overcome the lack of formal safety nets such as welfare payments or insurance found in many poorer communities. As the study by Arnall *et al.* (2004) demonstrates, in South Africa, for many households informal transfers are highly valued and needed. Furthermore, they force a sense of reciprocity, which binds households together. In times of great and generalised distress, they provide a cushioning for households as they cope with day-to-day life. The impact of HIV and AIDS on informal transfers is unclear, some suggest that they are providing a collective mechanism for absorbing the shock (Arrehag, Durevall, Sjoblom *et al.*, 2006), while others argue that informal networks are struggling and starting to show signs of strain (Mtika, 2000).

2.7 Challenges faced by community responses

While community-initiated responses are there to meet the needs of vulnerable children, there are also a number of systemic challenges that are faced by these responses. A range of these will be highlighted, particularly the financial challenges, the fact that they predominantly draw on unpaid female labour and the broader context in which they are located (OSSA, 2003; Mutangadura *et al.*, 1999; Lundberg, Over, & Mujinja, 2000; Foster, 2005b).

2.7.1 Financial

While community-initiated responses provide a huge level of care and support across a range of different issues, there is an emerging recognition that they cannot provide for all the needs of the children they support. This is because, being community-initiated responses, they are not linked, in general, into any sources of formal financial support. For example, they draw on their own financial resources and cannot therefore generate the necessary levels required to buy drugs and other treatments necessary to provide comprehensive care to children affected by HIV and AIDS (Mutangadura *et al.*, 1999).

Broad structural issues have been identified as one of the main reasons that community initiatives struggle to systematically receive the funding from national and international sources that they require to provide comprehensive care. Foster (2005a) identified these as ‘bottlenecks’ within the funding system. Four bottlenecks were identified in the report as blocking funding from reaching the community organisations it was directed towards. The first bottleneck identified was the low priority of care and support for children on donors and national decision making bodies.

The second was that the existing funding arrangements – the structures of applying for and receiving grants – hindered successful applications for funding from community organisations. Many local community organisations often did not have the skills or abilities to access the information and undertake applications for external funding. This was exacerbated by the fact that the procedures to apply for funding were complicated. In a study in Malawi of 15 churches applying for national funding, it was found that the process was time consuming and that it had been extremely difficult to apply for funding, with many community organisations giving up because of the lack of response from the national body (Foster, 2005a). The structures of applying for funding effectively prohibited community organisations from even being able to organise and submit an application.

Thirdly, because donors were not used to funding community-based organisations (CBOs), they found it hard to deal with organisations that did not have the necessary level of reporting structures that they stipulated. This made monitoring and evaluation and impact assessment of the grants difficult to achieve. Funders also felt that community organisations did not have the capacity to absorb funding, so it was better not to target them.

The final bottleneck was that there was little data around government spending on HIV and AIDS especially on OVC. Not only did this make it difficult for organisations to hold the government accountable, it also meant that donors were unsure where gaps were and so could not easily identify what areas were under-funded. In essence, the structural constraints on funding community organisations meant that it was difficult for small organisations to receive money to scale-up or deepen their responses to vulnerable children.

2.7.2 Women volunteers

A central challenge faced by many of these community responses to the needs of children in communities affected by HIV and AIDS, is that they are voluntary and that it is women who do most of the volunteering. Volunteering with little reward in situations of often dire poverty and hardship is demanding. Many of the volunteers may be ill as well. In *Caring for the Caregivers* (UNAIDS, 2000), it is reported that volunteers suffer multiple causes of stress, while providing care for PLWHA. Not only is it that the work of caring for someone who is

dying is psychologically and physically draining, there are other demands on the volunteers' time, nonetheless, from their own family, the demands of poverty and the lack of resources, volunteers have to provide adequate care. This is especially true for elderly caregivers, who may have thought that their caring days were long gone (Ntozi *et al.*, 1999; Christian Aid, undated). This can lead to frustration and burnout in volunteers, if these tensions are not handled sensitively. Eventually, without proper structures in place to provide support for the volunteers, the volunteers may themselves withdraw from the work that they are doing (UNAIDS, 2000).

Another critical issue identified by volunteers in poorer communities is the impact volunteering has on incomes. A number of studies have identified that being a volunteer has a negative impact on income levels (UNAIDS, 2000). This translates into reduced consumption of food. A study in Uganda demonstrated that providing care for an orphaned child had a negative impact on food consumed by a household and that this was most pronounced for poorer families (Deininger, Crommelynck & Kempaka, 2005).

Volunteers in community responses, especially around the provision of care and support are predominantly women (UNAIDS, 2000). The reason is because it is impossible to separate community responses from the broader social and economic context that they are set in (OSSA, 2003). Due to the gendered division of labour, women are seen as care providers, while men are seen as workers. This has a number of implications for community responses. Firstly, women volunteers have a double-burden of caring, as not only do they have to care for people within their own household, but they are also volunteers providing care and support for people in the wider community (Population Council, 2004). Female volunteers may therefore be thought of as double-carers.

Second, the lack of involvement of men, limits the resources, in terms of labour and skills that a local initiative can harness. Without the involvement of men, fifty percent of the possible workforce is excluded particularly a group that has extensive networks and can better access material and social support. Finally, because of the nature of patriarchal societies, men tend to be in positions of authority in communities. Without drawing community leaders into the project, they can effectively block the expansion of a project and stop additional support being given in the community (OSSA, 2003).

It is therefore apparent that a major challenge for many community-initiated responses is the nature of voluntary work and the fact that most of this work is carried out by women. The lack of community leadership support for a project can be crucial in shaping the possibilities and future that it has.

2.7.3 Unintended exclusion of the poorest from responses

While many of the reports that are written about community responses to children correctly applaud the work that they do, they can also be naive about it. Studies of informal transfers between households in vulnerable communities are often seen as a central response, allowing for the transfer of assets between households. However, some studies are a lot more sceptical of them. A number of studies suggest that transfers between households are not equal and that richer households receive greater transfers than poorer households, given the death of an adult (Lundberg *et al.*, 2000, Arnall *et al.*, 2004). This is because it is assumed that a richer household will be able to reciprocate help at a later stage.

Another factor contributing to exclusion may be the stigma of a person in the household dying of an AIDS-related illness, which may exclude that family from social networks of support (Bryceson, Fonseca & Kadzandira, 2004). The crucial point to derive from this is that while social networks may well provide a positive endogenous response to the needs of households that have vulnerable children in them, they can also serve to exclude the poorest and therefore the most vulnerable households and children as they have fewer resources to maintain support networks (Warwick, Bharat, Castro *et al.*, 1998). As the HIV and AIDS pandemic deepens, there may be a rationing even further of resources that leads to the social networks becoming even less encompassing, with more people excluded from them.

2.7.4 Environmental factors

It is important to remember that community-initiated responses often occur in situations where the broader social and economic contexts are not conducive to supporting such responses (OSSA, 2003). There are different factors, which may shape this. In an overview of some of the more successful and scaled-up community responses to children in Swaziland, UNAIDS (2006) point to the initial success of *Indlunkhulu* fields which were undermined over time because of the drought that hit the region. The broader context of drought in which the response to child hunger occurred, was essentially impossible to overcome.

The government environment might well shape the possibilities of local community responses - lack of adequate financing from government has already been highlighted above. However, the lack of other services is also important. In Zimbabwe, in a response referred to as the Chief's Field, there was a great need for agricultural inputs such as fertilizer. However, because the area was rural and under-serviced, government agricultural extension workers did not come often enough and the project effectively collapsed (Foster, 2005b).

The main context that all of these community responses share, is the growing impact of the HIV and AIDS pandemic – this has many repercussions and challenges for initiatives that are attempting to respond. While on the one hand it has galvanized them into action, on the other, it threatens to undermine them. The overwhelming nature of the pandemic can undermine the possibilities of collective action (OSSA, 2003). In addition, it is likely that a number of people volunteering their time and skills may well be living with HIV and AIDS. This threatens community responses, through the death of volunteers – not only decreasing the skills base that a local response has to draw on, but also further undermining members' morale, as they see their comrades dying.

It is therefore important to recognise that the same issues that generate these community responses to children affected by HIV and AIDS can also be central in limiting their responses.

2.7.5 Technical issues

Although many community organisations may be responsive to local needs and understand the context better than external organisations, some of internal 'technical' procedures may be factors hindering their work. Often, because of low levels of literacy and inadequate structures of reporting, it can be unclear about the number of children that an organisation is serving. This can make it difficult to assess the reach and quality of the services they offer. It can also lead to children being missed, because checks cannot be adequately done to ensure the inclusion of all vulnerable children.

Linked to internal technical issues is the low level of training that many of the people in community responses have had. Not only does inadequate training frustrate volunteers, who wish to give the highest level of care that they can in any situation (UNAIDS, 2000), it can also make it difficult to monitor and understand the care activities. As these responses are often very localised and ‘below the radar’ (Foster, 2005b), lack of adequate and appropriate training can hamper the support and care provided to children.

Finally, another ‘technical’ problem that many community-based responses face is that there are few well-documented studies of such responses. This limits the sharing of good practices and innovative ideas. Notwithstanding dissemination challenges such as distribution of written materials, language and literacy, documentation of good practice responses can allow for good practices to be shared amongst other communities and for people to further develop their responses.

2.8 Approaches for strengthening community responses

Strengthening community-based responses has been identified as one of the key strategies for assisting children made vulnerable by HIV and AIDS (Richter, Manegold & Pather, 2004). This however requires a shift in approach from traditional development work of providing direct support to facilitating community-owned responses. Engaging local leadership, providing financial and other material support, capacity building, exploring mechanisms for linking community responses with other community initiatives, and government and NGO programmes are other important considerations.

2.8.1 Move to facilitation

The shift to facilitation of local responses emphasises the need to build on what already exists. Crucially, ownership of the response by the community is central to its sustainability in the long-run. As such, building on pre-existing structures and forms makes it more likely that ownership is retained within the community, rather than the project being seen as imposed from the outside. Foster (undated:14) states that “homegrown approaches based around community priorities are the most appropriate and sustainable responses” to the HIV and AIDS epidemic. As Phiri, Foster & Nzima (2001:46) emphasise “NGOs and CBOs can greatly increase the effects of their resources by facilitating and strengthening the autonomous AIDS responses of communities, rather than attempting direct provision of services...The change agent should build on existing responses to the crisis, seeking to strengthen and not to replace or eliminate initiatives already underway.”

Foster (2002) gives an example of the problems of external organisations coming in and undermining community structures that were coping with the issue of vulnerable children. He relates the story of how a local organisation in a rural area of Zimbabwe “established and then expanded a program that successfully mobilized volunteers to support vulnerable children. Without contacting or acknowledging the local organisation, an international agency based outside the area invited volunteers from the existing community-based program to attend its training workshops and provided them with substantial payments.” (Foster, 2002:22). He goes on to say that the actions of the international agency undermined the local organisation, by removing a sense of ownership from the community and creating tensions around some volunteers being paid, while others were not.

An example of a facilitating approach to developing a community-initiated response is the work of Campbell, Nair, Maimane *et al.* (2005) in rural KwaZulu-Natal. After spending a year documenting community responses to HIV and AIDS, they identified that the strongest response was amongst home-based caregivers. Rather than imposing their own agenda on this group, the project used facilitation – workshops, focus groups and community meetings to discuss what support was needed for the home-based carers and then went about ensuring this was provided. Engaging communities in this manner meant that the response was more likely to be owned by the local community, and thus sustainable in the long term.

2.8.2 Involving leaders in the community

Engagement of community leaders in a community initiative is important when seeking to strengthen and scale-up that initiative. Leaders can mobilise additional resources and provide much needed public appreciation for the work that volunteers are doing. Phiri *et al.* (2001) make the point that it is particularly useful to engage religious leaders if possible in community responses. As they point out, not only do they have a captive audience to mobilise, they also are often held in high respect in the wider community and so may hold authority to make change happen more easily.

Engaging leaders may mean that resources can be accessed more easily. In the district of Dedza, Malawi, the chief became involved in the local vulnerability assessment committee. As the chief, she offered her own land to the committee, so that it could be worked for the benefit of orphaned children. Not only did she offer her land, but also she worked the land, saying it was because leaders needed to set an example (Phiri *et al.*, 2001).

Failure to involve local community leaders can lead to community-initiated responses being stopped. It is therefore a crucial component of attempts to scale-up and support existing responses that leaders are brought on board, and that they give tacit support to such responses, even if they do not become involved further.

2.8.3 Providing funding

Lack of funding for scaling-up or scaling-out community responses is often highlighted as a key constraint (Foster, 2005a; OSSA, 2003). However, effective forms of funding are necessary to ensure that support for community responses is sustainable. There has been a shift from focusing on larger inputs of money to what has been termed ‘drip-feeding’. The metaphor of ‘drip-feeding’ is based on the assumption that CBOs require long-term funding that is “continuous, steady, small amounts of resources to ensure that communities can sustain their responses and improve the quality of life...for children.” (Foster, 2005a:2). By focusing on small and long-term funding, it is hoped that the problems of swamping organisations with too much money which they struggle to absorb, may be overcome.

There are few examples of effective financial support for CBOs, from groups hoping to scale these projects upwards (Chapman & Grellier, undated). One such example is the Firelight Foundation (FLF). This US based organisation provides ‘risk’ grants to small NGOs and CBOs, in 12 countries across Africa. These risk grants are around US\$5000 or less for one year and are aimed at organisations, which have had little or no funding from external sources. After one year, the grants are assessed and those which are deemed successful can be

re-granted. The risk grants have been successful in general, strengthening organisational capacity to respond and increasing community participation (Save the Children, 2007).

2.8.4 Capacity building and skills training

Effective strengthening by external organisations is often in the form of capacity building and skills training for small community organisations (Phiri *et al.*, 2001). The AIDS Foundation of South Africa (AFSA) has developed a longer-term approach to capacity building and tries to work with individual CBOs for up to three years at a time. Over this period, it works on building capacity and technical capabilities of the CBOs through a variety of methods. These include the ‘coaching’ of key members of the CBOs and building a close relationship between AFSA and the CBO. In so doing, it has been reported that organisations have increased their ability to manage projects, evaluate their programmes and work more effectively (Save the Children, 2007).

2.8.5 Motivating volunteers

A major barrier to success, mentioned earlier, was the over-reliance on volunteers to sustain community-initiated responses (AIDS Alliance, 2000). One possible solution is creating structured incentives to keep volunteers motivated and alleviate a number of problems that they face by undertaking this additional work. Psychological and emotional support for volunteers is an important aspect of developing a stronger response. In Uganda, The AIDS Support Organisation (TASO) has deliberately built the capacity of counsellors within its programme, who provide support for other carers and families with whom it works. In so doing, it has managed to alleviate stress that volunteers are placed under (UNAIDS, 2000).

In addition to the psychological impacts and needs of volunteers, the impact voluntary work has on incomes has been recognised and a number of alternative solutions have been used. In South Africa, this has been done through the government’s Expanded Public Works Programme, which pays a nominal stipend of R1 000 a month to people who undertake home-based care. This programme is currently limited in scope, however it is a productive way of remunerating women’s labour.

Other organisations have reduced the loss of income by using the community organisation as a basis for income generation. World Vision, in supporting a home-based care project in Uganda, developed income-generating projects alongside its other work, as a method of increasing volunteer carers’ incomes (UNAIDS, 2000). It has been suggested that paying volunteers can be one of the best ways of motivating them and this has the additional benefit of allowing more effective management of workers, though this approach may not be the most cost effective route for delivering services (Finger, 1999).

Incentives do not only need to be monetary, but can be in the form of smaller donations such as food or merely the recognition of the work that volunteers are doing. Importantly training in the skills that volunteers need to perform their work can be a huge incentive. As already noted, many volunteers are frustrated because they lack skills, which suggests that training would be a way to overcome this. In addition to providing skills, training can also boost volunteers’ sense of worth and more broadly have a positive impact in the community, when community members realise that volunteering is worthwhile. This is seen in Campbell *et al.*’s (2005) support of home-based carers in KwaZulu-Natal, South Africa. Here training and t-shirts were provided for the volunteers, as well as building their technical skills in providing

home-based care, there were also spill-over effects. Home-based carers reported that the community respected them more and they were more confident in the work that they were doing.

2.8.6. Creating links to other community responses

A relatively simple method of strengthening community responses that a number of studies identify is facilitating networking amongst community organisations, with the hope that this will lead to collaboration. AIDS Alliance (2000) suggests that the main benefits of collaboration between community organisations is that this will increase the impact of any actions that organisations may want to take. Furthermore, it will also allow the development of a continuum of care, with different local responses referring people from one to another. In addition to this, it also allows for the better use of limited resources which will reduce duplication and overlapping of services (OSSA, 2003). Dialogue between organisations will more broadly create a more positive environment, with support being shared and morale being boosted.

Creating links, and importantly people sharing their ideas and experiences across different communities, can lead to other communities starting similar projects. In Zimbabwe, the Family AIDS Caring Trust (FACT) had its first replication of one of its projects, Family, Orphans and Children Under Stress (FOCUS), through a Methodist Minister. The Minister worked in the area that the FOCUS programme operated and on a visit to his home province told the local pastor about it. This pastor approached FACT for assistance in setting up a similar initiative in a new area. The project has successfully replicated itself and is now a stand-alone project in this new area (Phiri *et al.*, 2003).

2.8.7 Creating links to government

Another important aspect of strengthening community-initiated responses is linking them into and developing reciprocal relations with government systems (Phiri *et al.*, 1999). There are a number of positive outcomes of linking communities more closely to government. At one level, it is hoped that this will allow government to provide additional resources to the community to support the response – a key constraint as noted above. It is also assumed that closer government engagement will increase the quality and responsiveness of service delivery to communities (Goetz & Gaventa, 2001). This can be a particularly productive route to improving local community responses.

The Bethany Project, in Zimbabwe, is one example of closer working with the government to support the community response. This has been particularly the case with the Social Welfare Department, where lack of transport has made it difficult for the Department to reach rural areas. Workers from the Social Welfare Department frequently accompany the Bethany Project, allowing government workers to target vulnerable children more easily and making government more responsive (Foster, 2002). Save the Children (2007) report that in Ethiopia and South Africa some community-based groups working with children, that Save the Children support, have regular monthly meetings with local government personnel. Not only do they share what they do, but “it is also a useful way of raising issues that are of importance to the local community and starting a dialogue with local service providers.” (Save the Children, 2007:34). Engaging the government in dialogue is important for expanding and sustaining community-initiated responses.

A different approach was taken by Save the Children in Phofung, South Africa. Here they worked with the government to convince them of the benefits of working more closely with Child Care Forums. This has been at the municipality and provincial levels. The results have been positive, with some government departments setting aside money in their budgets for the Child Care Forums and the municipality dedicating a Community Development Practitioner to supporting the Child Care Forums (Save the Children, 2007). The increased dialogue between community organisations and the government can also defuse tensions where government officers feel that such organisations undermine their role, and community organisations are frustrated with the lack of support that the government provides (OSSA, 2003).

One example of excellent government responsiveness to local community's needs, was documented in Swaziland (UNAIDS, 2006). While creating *KaGogo* Social Centres in various villages, the lack of adequate road access was raised. The Swaziland government diverted equipment from other tasks to create access roads, which meant deliveries could reach the Social Centres more easily. A supportive and enabling government can create positive synergies between local community responses and itself. In addition, it is necessary for governments to start providing an enabling framework of legislation and responses for vulnerable children broadly. In so doing it makes co-ordination of activities between different organisations simpler and creates a collective space from which to work from (AIDS Alliance, 2000).

What has become prominent in the literature on supporting community-based responses to vulnerable children is that there is no 'one-size fits all' approach. Rather support from external organisations needs to be tailored to fit each specific context that is being worked in, and the needs of the community initiatives have to be identified by the community rather than by an external organisation. This is highlighted in the shift in terminology to facilitation of development, with the emphasis being on community initiative and ownership.

3. Methodology

This is an in-depth qualitative study seeking to understand how communities are responding to the needs of children made vulnerable by HIV and AIDS in three purposively selected research sites. A multi-method approach was used and it includes the following components: stakeholder consultation, site visits, in-depth interviews with key informants, and focus group discussions.

- Stakeholder consultation enables the participation of interested groups in the research process and facilitates research ‘with’ rather than ‘on’ selected communities. Three CINDI member organisations were consulted at the start of the project. These are the Community Care Project at Project Gateway, Umgeni AIDS Centre, and Umvoti AIDS Centre. The three organisations facilitated community entry, respectively into Imbali (an urban research site), Mpophomeni (a peri-urban site) and Ngome (a rural site). Through these three CINDI member organisations, a field-based interviewer was recruited in each area, who remained in the site for the duration of the study. Stakeholders also assisted the research team in identifying community initiatives. However, the research team ensured that stakeholders did not play the role of gatekeepers by sharing with them the importance of an open research process. This reduced the possibility of stakeholders dictating which initiatives were included in this study and/or identifying initiatives to which they were partisan.
- In-depth interviews with key informants, using a semi-structured interview guide, were conducted by a field-based interviewer who was assisted by a field supervisor from the HSRC. These interviews investigated conceptions of child vulnerability, family and community responses to vulnerable children, factors that motivate or hinder such responses, and how family and community initiatives can be supported and strengthened. Key informants, i.e. information-rich individuals, were purposively sampled in order to get an understanding of family and community-based initiatives. Key informants included community members, volunteers such as home-based caregivers and community health workers, an auxiliary social worker, a teacher, a paralegal officer, a church leader, a foster mother, day mothers, and members of community initiatives. Informants were sampled using purposive and snowball approaches.
- Focus group discussions were held with selected community members and members of community initiatives to explore their conceptions of child vulnerability, family and community responses to children, and how such responses can be strengthened. Each focus group discussion was co-facilitated by a member of the research team from the HSRC and a field-based interviewer who had been recruited from the local community.
- In Mpophomeni, three site visits were conducted by a field-based interviewer and the lead researcher from the HSRC. However, it proved difficult for the research team to collect comprehensive information about some of the initiatives and to describe them in context. This partly resulted from the fact that they did not have a base from which they provided services. Also, the nature of services provided prescribed that these services were taken to the people in need of care and support rather than people coming to a central point for services. It was not possible for the research team to accompany some of the caregivers on their home visits.

Field-based interviewers used purposive and snowball sampling approaches to identify key informants and community-based initiatives of interest. Key informants and representatives of initiatives identified through the stakeholder consultation process were asked if they were aware of other individuals and groups that were providing services to children in their communities.

Data collection tools were developed and translated into IsiZulu. They are included as appendices.

3.1 Aims of the study

The current project aims to:

- Explore prevailing endogenous responses to the needs of children made vulnerable by HIV and AIDS in three different environments – peri-urban, urban and rural.
- Explore factors motivating or hindering endogenous community-based responses to the needs of children made vulnerable by HIV and AIDS.
- Consult with local communities to identify appropriate forms of support for such community-based responses.
- Explore the potential for supporting, collaborating with and/or integrating community-based responses to vulnerable children into general practice of CINDI members.

3.2 Key questions

Some of the key questions this project aimed to answer include the following:

- How is child vulnerability conceived?
- How is the family and its responsibility towards children conceived?
- What activities occur within selected communities?
- Which factors motivate or hinder family and community responses?
- What do participants understand by endogenous, what makes an initiative endogenous?
- How can community responses be strengthened?
- How can community responses be linked to government services, NGO and other externally supported programmes?

3.3 Sample

A total of 30 key informant interviews were conducted across all three research sites. Table 3.1 below provides a breakdown by site. These key informants included community members, volunteers such as home-based caregivers and community health workers, an auxiliary social worker, a teacher, a paralegal officer, a church leader, a foster mother, day mothers, and members of community initiatives. Almost all key informants, 27 out of 30, were women.

Table 3.1: Breakdown of the number of key informant interviews and focus group discussions by site

	Imbali	Mpophomeni	Ngome
Key Informant Interviews	7	11	12
Focus Group Discussions	2	6	2

In total, 10 focus group discussions were conducted across the three study sites. Focus group discussions were held with members of community-based initiatives, home-based caregivers, community health workers, women from a local church, and youth from a local church. Each

group consisted of between 6-7 participants. Key informant interviews and focus group discussions were tape-recorded after obtaining permission from all study participants.

3.4 Data collection process

On 3rd August 2006, CINDI facilitated a meeting whereby all researchers receiving grants from Irish Aid introduced their research to selected CINDI member organisations. Thereafter, the lead researcher held follow-up meetings with the Community Care Project at Project Gateway on 12th September, Umvoti AIDS Centre on 14th September, and Umgeni AIDS Centre on 4th October. Respectively, follow-up meetings took place in Pietermaritzburg, Greytown and Mphophomeni. Each CINDI organisation was an entry point in each community, assisted the researcher with recruiting a locally-based interviewer and identifying grassroots responses to vulnerable children.

Field-based interviewers, one per site, were local women working as volunteers within the selected organisations. Interviewers were trained by the project team on the basics of research, including the importance of informing participants of the risks and benefits of participating in the study, obtaining informed consent, ensuring audio privacy during interviews, and administering the interview guides. Each interviewer was supported by the lead researcher and a fieldwork supervisor² during the initial stages of data collection and in selecting participants and initiatives for inclusion in the study.

Data collection took place across all three sites from November 2006 to January 2007. After scrutinising the data, additional interviews were conducted at the end of May in Mphophomeni, and at the end of June in Ngome. It was not possible to conduct additional interviews in Imbali, as the interviewer initially recruited for the project was doing other work which did not allow her to assist the project team. Attempts were made to compile background information on each area. Information collected as part of this exercise will be presented in the results section below. This information is not as complete as was anticipated, due to field-based interviewers not accessing sufficient information from their local municipal offices.

3.4.1 Mphophomeni

In Mphophomeni, initiatives which were identified are the following: Friends for Life, Stay Together, Hlanganani, Isibani, Masibumbane, Sakhisizwe, Zenzeleni, and Zibambeleni³. It should be noted here that most of these initiatives do not have a base or site from which they provide services to children. Most of them hold their meetings at the offices of the Umgeni AIDS Centre where they discuss their current activities, plan their future activities and write their reports. Although these initiatives are very active within the community of Mphophomeni, it proved difficult to conduct site visits and to document some of the initiatives as case studies as originally planned. Therefore, members of the identified initiatives were interviewed as key informants and/or as a group. Key informant interviews were conducted with 5 volunteers, 3 community members, a Manager of an initiative, a Project Facilitator, and a teacher. Three FGDs, each consisting of 6-7 participants, were conducted. FGD

² A graduate in the social sciences, with fieldwork experience, was appointed for the duration of the study, and was based at the HSRC.

³ Hlanganani means Get together, Isibani: A lamp, Masibumbane: Let us unite, Sakhisizwe: Building a nation, Thuthukani: Develop, Vukuza: Make an attempt, Zenzeleni: Do it for yourself, Zibambeleni: Take it upon yourself.

participants were members of a support group, youth from a local church and a Citizen's Club. In seeking to collect data on specific initiatives, group interviews were conducted on-site with three of the initiatives mentioned above. These initiatives are referred to as Initiatives 1-3 in the results section.

3.4.2 Imbali

Contact was made with potential participants in different wards in Imbali, however identifying community initiatives was found to be difficult. In Imbali, most volunteers seemed to be working individually with some having been previously attached to organisations like Thandanani. Where contact was made with faith-linked initiatives, it proved difficult to schedule interviews. This was as a result of some of these groups providing services to children on an *ad hoc* basis and their tendency to meet on Sundays as a group. Key informant interviews were conducted with 2 day mothers, a foster mother, a home-based caregiver, a church leader, a volunteer at Initiative 1, and a manager of Initiative 2. Two focus group discussions, each consisting of 6 participants, were conducted with women and youth from local churches.

3.4.3 Ngome

It should be noted that, at the time of the study, no endogenous community-based initiatives were identified or were operating in Ngome. It emerged that home-based caregivers providing services to children and families in this area are all affiliated to Umvoti AIDS Centre in Greytown. Community health workers in the area are attached to the Department of Health. It was generally difficult to organise focus group discussions in Ngome, due to the distances between homesteads and a lack of a communal meeting place. This may be considered as part of the reason why community members have not yet organised themselves into groups to alleviate the double burden of poverty and HIV and AIDS on children. Key informant interviews were conducted with 7 community members, 4 volunteers – 1 volunteer at the Centre, 1 community health worker, and 2 home based caregivers, and an Auxiliary Social Worker. A focus group discussion was held with home-based caregivers and community health workers, and another with members of a Granny Club.

3.5 Data analysis

Audio tapes were transcribed, and transcripts were translated from IsiZulu into English. Transcripts were coded, and codes were grouped into primary themes which were informed by the objectives of the study and the literature review. These primary themes – conceptions of child vulnerability, family responsibility and responses, community responses, challenges faced by community responses, and approaches for strengthening community responses - informed the presentation of the results section below. Coded data from key informant interviews and focus group discussions was entered into NVivo. Where appropriate, frequencies are presented, and statements made by participants are quoted verbatim in the results section below. Although results are quite similar across sites, they are presented individually by site.

3.6 Ethics

The research proposal and data collection tools including participant information leaflets, informed consent forms, and interview guides were submitted to the HSRC Research Ethics Committee. The study received ethics approval on 20th September 2006.

Only participants who gave written informed consent to being interviewed and tape-recorded were included in the study. All participants were informed of their right to withdraw from the study without adverse consequence to themselves or their organisation. Also, they were assured of the safe keeping of audio materials and anonymity when the results of study are published. Although none of the questions posed any risks to participants, interviews were conducted in venues which provided audio privacy.

4. Results

In this section, data from the three research sites (Mpophomeni, Imbali and Ngome) are presented individually by site. The section provides a brief description of each study area and study participants, outlines conceptions of child vulnerability, family responsibility to children and responses to vulnerable children, and community responses to the needs of children made vulnerable by HIV and AIDS, and how such initiatives can be strengthened. Data from focus group discussions are presented in tandem with data from key informant interviews, due to the limited number of focus group discussions conducted in Imbali and Ngome.

Section A: Mpophomeni

Section A presents findings from Mpophomeni, and is structured as per the outline described above.

A1. Brief description of Mpophomeni and study participants

Mpophomeni, meaning *home of the falls*, is a township located outside Howick. It was established in 1972⁴ in order to provide housing for people who were moved from the areas of Howick West, Cedara, Merrivale, Zenzele Location, Tweedie, Lion's River and Lidgetton. There was unhappiness about the move, which was a result of the segregationist *Apartheid* policies at the time. In 1984, there was a massive strike to protest low wages of workers employed in factories located in neighbouring Howick. More than a hundred people died from the resultant violence.

Mpophomeni, a peri-urban area falling under the Umgeni Municipality, had a population of about 200 000 in 2005⁵. The rate of unemployment is speculated to be high; those in formal employment work in Howick, Pietermaritzburg and Durban. Access to services is described as good. There is a clinic, a community hall, a library and a number of schools. The supply of housing has seemingly not kept up with population growth and the resulting demand for housing. Roads are not tarred, but access to electricity and water is good. There are, however, certain parts of the township still dependent on communal taps. Mpophomeni, marketed as part of the sought after 'Zulu tourism experience', is surrounded by waterfalls and is close to the Midmar Dam⁶. HIV prevalence is high, and this is largely attributed to oscillatory migratory labour patterns.

To collect data, a total of 11 key informant interviews were conducted in Mpophomeni. Nine (out of 11) key informants were women, 9 were unmarried, and 9 were involved in local churches. Key informant interviews were conducted with 5 volunteers – 3 of whom were associated with two initiatives, 3 community members, a manager of an initiative, a project facilitator and a teacher. A total of 3 FGDs were conducted with members of a support group, youth from a local church and a Citizen's Club. In seeking to collect data on specific initiatives, group interviews were conducted on-site with three of the initiatives mentioned in the methodology section above. Hereafter, these initiatives are referred to as Initiatives 1, 2 and 3.

⁴ <http://mpophomeni.kzn.org.za/mpophomeni/index.html>

⁵ http://www.tac.org.za/news/ns04_04_2005.htm

⁶ <http://www.africastay.co.za/zulu-mpophomeni-tourism-experience.html>

A2. Conceptions of child vulnerability in Mpophomeni

Factors contributing to a healthy child development and those rendering children vulnerable were explored with key informants and focus groups. Children primarily need love in order to develop well. Provisioning for their basic needs such as clothing, shelter, food, and education is also important. Adult support and supervision, and the teaching of basic values, such as respect, give children a firm grounding in preparation for growing up. Below are statements made by participants in relation to what they consider as important for healthy child development.

“A child needs love. You may think a child is hungry and make him/her food and buy things but see that the child is just not happy. A child needs love, to be cared for and for his/her needs to be met. Then comes food.” Volunteer 1.

“Nothing is more important than love by parents and being cared for adequately.”
Programme Manager.

“Love ...patience ... guidance just to be taught maybe respect ... and to be shown love and care by a parent and other people in the community.” Volunteer 5.

“A child needs clothing, shelter, food. A child will not grow up well without these three basic things. Then comes education...” Volunteer 3.

“You need to spend time with a child and to talk to him/her.” Participant 6, FGD 3.

“To be taught values and to be provided for.” Participant 4, Initiative 1.

The needs of children made vulnerable by HIV and AIDS are not considered different from those of other children in that they also need to be loved and cared for, and for their basic needs to be met. It is in cases where a child has been exposed to a particularly difficult circumstance, e.g. directly caring for a sick adult without any form of external support, that a child is considered particularly vulnerable and requiring special attention.

Table A1 below suggests a broad understanding and multiple overlapping causes of perceived child vulnerability. Factors contributing to the vulnerability of children are at multiple levels. That is, they can be at the individual (e.g. a child’s age), household (e.g. parental illness or death) and community (e.g. widespread poverty and unemployment) levels. However, loss of a parent is a main contributor to perceived child vulnerability. In this context, the word orphan is used in reference to a child who has no one to care for him/her after the death of biological parents or primary caregivers. Other conditions which put children at risk include a child’s age, living with an unemployed caregiver, being disabled, and being directly affected by HIV and AIDS.

Table A1: Situations rendering children vulnerable in Mpophomeni⁷

Situation contributing to child vulnerability	Number of responses
Loss of parent	8
Abandonment	3
Abuse	2
Age	1
Caregiver unemployment	1
Disability	1
HIV and AIDS	1
Homelessness	1
Living in a child-only household	1
Living with an elderly caregiver	1

A direct impact of HIV and AIDS on children is the loss of parents which may leave children at the risk for neglect and other abuses like rape. Younger children may also be at risk for abuse because they are not yet able to protect themselves from physical harm and cannot yet partake in decision making involving their immediate situation.

A3. Family responsibility and responses to children made vulnerable by HIV and AIDS in Mpophomeni

Family includes a group of individuals, usually co-residing, who can trace common descent. A family can be nuclear in nature, i.e. a couple with or without children, or extended, maybe consisting of several households or abodes. Family is also indicative of a home which is expected to provide love, warmth and the support children need. On whether families were fulfilling their primary obligation towards children, i.e. loving and caring for them, some families were fulfilling this obligation while others were not. Other responsibilities of families are basic provisioning, support and supervision, and imparting values, mores and traditions. Within families, women including mothers, grandmothers, and aunts play the main role of caregiver and nurturer.

The way families respond to and treat children made vulnerable by HIV and AIDS differs across families and circumstances (see statements made by focus group participants in the box below). Some families do something about the situation of children by taking them in, giving them food, making sure they stay in school, and providing adult support and supervision.

“Some families treat children well while others cannot care for them. A child may end up on the streets because of poor treatment at home.” Participant 2, FGD 3.

“Families differ. Some families quickly absorb them⁸ while other families do not. You may find that in other families, it is relatives who stigmatise a child and that neighbours open their door to that child, feed the child and take care of the child ...” Participant 6, Initiative 1.

⁷ These situations are presented individually rather than as categories, as mentioned by key informants..

⁸ That is, children affected by HIV and AIDS.

A critical issue is what makes the difference between families that respond and those that do not. Social problems in families such as substance abuse and pre-existing conflicts between family members are potential reasons for some families' failure to respond to vulnerable children.

A3.1 Factors motivating responses by the family in Mpophomeni

Factors motivating or hindering families to respond to the needs of children affected by HIV and AIDS were explored. Access to information, traditional values of *ubuntu*, and access to a foster care grant are some of the factors motivating families to respond to vulnerable children. See statements made by participants in the box below in this regard.

"I think it is mostly information. When a person does not have information, that person does not know how to respond to needs or maybe a person is willing but cannot act because he/she does not know what is right and what is wrong." Project Facilitator.

"I think in each and every family no one wants to see a child suffer or even homeless ... It is ubuntu which makes us care for children." Programme Manager.

"The grant, they are after the grant. Sometimes those who receive the grant use it to buy alcohol and not for what it is intended." Volunteer 1.

Access to information is enabling to a family's willingness and capacity to respond to a child made vulnerable by HIV and AIDS. Although some families are driven by the spirit of *ubuntu*, other families are perceived to be persuaded by less than altruistic motives. That is, a family may take in a child in order to access the foster care grant. It should be noted that the issue of the grant as a perverse incentive for child fostering was not explored in-depth by the study.

A3.2 Barriers to responses by the family in Mpophomeni

Constraints to family responses addressing the needs of vulnerable children include the following: lack of or insufficient information, fear of infection, difficulties in applying for birth registration documents and grants, the death of compassion, and poverty. Looking at these constraints mentioned in the box below, it is however possible that when a family is not informed about the basics of HIV transmission and prevention, that family is likely to be overly concerned about infection through casual contact. Such misinformation may curb a family's willingness to assist a child in distress.

"I think my point above about information also applies here... maybe families need to be educated so that they know exactly how to respond to a vulnerable child when that time comes." Project Facilitator.

"Most people think that because a child is affected by HIV and AIDS ... Maybe they think they will be infected as well... Then they do not want anything to do with that child." Volunteer 5.

"Sometimes after a child's parent has died and the child stays with a relative ... the problem is that when they want to apply for a welfare child grant and there is no certificate, the person has to start the application process from scratch." Community

member.

“Some families would like to help children but do not have the means to do so.”
Participant 1, FGD 1.

“I do not know what is really going on or whether compassion has died in people or is it because maybe people are poor. Poverty levels are quite high in this community.”
Volunteer 3.

Furthermore, people in resource-constrained households may find it difficult to consider fostering ‘an additional mouth to feed’ when they are struggling to meet their own basic needs. They may not be sure what that child’s material and health requirements are. It thus seems social education on HIV transmission and prevention and on the ‘special’ needs, if any, of children affected by HIV and AIDS is an area requiring attention. Social education coupled with improving the economic capacity of families may go a long way towards addressing the fear of stigma associated with fostering children in communities affected by HIV and AIDS.

A4. Community responses in Mpophomeni

The impact of HIV and AIDS is not limited to children and their families, but it is also far reaching in affected communities. As adult caregivers become ill, are no longer able to work, and cannot adequately care for their children, the community is expected to assist. In African communities, according to African cultural values, a community is required to look out for children finding themselves in difficult circumstances for various reasons. This might be in the event of caregiver death, abandonment or neglect, caregiver unemployment, living in a very poor household, living with an elderly caregiver, and being exposed to abuse.

It is noteworthy that the community of Mpophomeni is described as having a strong sense of community. A project facilitator put his view as follows: *“Yes, I think when you talk about a community you mean a collective, which means an injury to one is an injury to all.”* This strong sense of community is characterised by togetherness (i.e. a communal identity and purpose), trust (i.e. reliance on others), and reciprocity (i.e. helping others with the hope they will return the favour). See participants’ responses in Table A2 below regarding their perceptions of whether there is a sense of togetherness, trust and reciprocity in this community.

Table A2: Participants’ perceptions of togetherness, trust and reciprocity in Mpophomeni

Participant	Togetherness		Trust		Reciprocity	
	Yes	No	Yes	No	Yes	No
Community member 1	√			√	√	
Community member 2	√			√	√	
Community member 3	√		√		√	
Volunteer 1		√		√		√
Volunteer 2	√		√		√	
Volunteer 3	√	√		√		√
Volunteer 4		√	√		√	
Volunteer 5	√		√		√	
Programme Manager	√		√		√	
Project Facilitator	√		√		√	√
Teacher	√		Don't know		√	
TOTAL	9	3	6	4	9	3

Table A2 above shows that togetherness and reciprocity were each mentioned by 9 out of 11 participants, and 6 participants felt community members still trust one another. Although some participants doubted levels of togetherness and trust within their community, and the willingness of community members to help those less fortunate than themselves, it seems children and families are generally assured of assistance and support in times of distress.

At community level, factors urging community members to respond to vulnerable children include the following: seeing the impact of HIV and AIDS, a high value placed on children, a communal responsibility for children, *ubuntu*, compassion, the ability to do something about another’s situation, and personal experience of HIV and AIDS. See statements in the box below. Furthermore, providing care and support to vulnerable children comes from the heart. That is, those providing care and support to others are driven by love. Volunteers, by doing something for children, may also be coping with the impact of HIV and AIDS on their families and communities.

“It means they see the situation that children are being affected in this way. That makes them do something... I have seen how death is ravaging my community. I do not like to see my community being ravaged by death when there is something I can do with the skills that I have...” Volunteer 3.

“It is the value of a child. As I said earlier, as a people, it is our culture we have ubuntu.” Programme Manager.

“Where there is no parent, we the community are there. We have to see to it that we help that child.” Participant 1, Initiative 3.

“It is wrong to see someone suffering when you have the skills to help ... when you see that in that house they are poor, you have to lend a helping hand even if not materially.” Community member 1.

“For me, it comes from within. I love the work I do. It does not matter even when you visit people and find them not feeling well and irritable. But if it does not come from love,

you would not be able to do it because you would give up. When it comes from within, you can tolerate people.” Participant 5, Initiative 1.

“I ... love this work because I also have a child who is positive.” Participant 1, Initiative 2.

“I saw with my child, if I had been properly informed I think my child would still be alive because s/he was growing well and s/he died at age three... After some time I realised that if s/he had accessed treatment early... s/he started treatment and then died after two weeks.” Participant 2, Initiative 2.

Unemployment and poverty are major constraints to responses to the needs of children in communities affected by HIV and AIDS. In addition, secrecy about HIV and AIDS, the difficulty of accessing material support, jealousy, individualism, and accusations of favouritism are other factors which prevent community members from seeking solutions to the problems of children in a context of HIV and AIDS. As can be seen from the last statement in the box below, volunteers are accused of favouring some people – maybe their kin, friends or neighbours - over others, and are questioned about their selection criteria. This makes volunteering difficult, as volunteers may have to justify their selection of beneficiaries to people not yet benefiting from their services.

“Barriers are that our community is poor ... has no money ... the majority are unemployed.” Volunteer 5.

“Sometimes it is that you have a small house so you cannot take in an extra person into your home because your family is overcrowded anyway.” Volunteer 2.

“... What prevents people is that families are secretive about children affected by HIV and AIDS. For example, that a child’s mother died from an AIDS-related illness such that children end up not getting help. Even when a child falls ill, the family still does not tell the truth ... and the child is not helped appropriately.” Participant 4, FGD 3.

“Maybe challenges they experience are that there is no easily accessible support ...in case of emergency ... when a child has an urgent need ...currently available forms of assistance take long to reach the children.” Project Facilitator.

“... Others are just consumed by jealousy ...They always want to be the ones doing things.” Volunteer 1.

“Sometimes you find that community members are individualistic ... when they have things that can help others, they would rather keep it for themselves... People ask us why we are helping other people and not them. We get asked - who gets assistance, who is entitled to assistance? That is a problem we encounter in our community. Even when you try to explain ... the person does not believe you. They accuse us of favouritism and nepotism.” Volunteer 3.

It would seem that environmental factors and the context within which community responses are set up deserve attention. In a context of high unemployment and poverty, it may prove difficult for community members to see beyond meeting their own immediate basic needs. However, there is indication that some community members still subscribe to the spirit of

ubuntu which may be driven by their faith, tradition, sense of community, close-knit kin, history of reliance on each other, or a shared struggle during *Apartheid* days.

A4.1 Description and characteristics of endogenous responses in Mpophomeni

When engaging participants on how they and their community describe endogenous responses which emerge within communities themselves without external influence, it became apparent that participants do not use specific terms to describe such responses. However, endogenous community-based initiatives to children affected by HIV and AIDS are characterised by community members giving of themselves, their time and expertise (i.e. volunteering), the internal mobilisation of human and material resources (i.e. taking matters into their own hands or self reliance), and a community seeking localised solutions to local challenges (i.e. community doing things for themselves or innovation). See statements below made by participants in this regard.

“Our community has taken this into its own hands ... They are able to form organisations ...which go into the community and educate the community about everything ...” Project Facilitator.

“We are volunteers.” Participant, Initiative 3.

“Wake up and do something for yourself, that is what it is called – wake up and do something for yourself. Yes, ... do not expect someone else to help you but look at what you can do for yourself and see if that will not help you survive.” Participant 4, Initiative 1.

Community responses are about a community taking ownership of local issues and capitalising on the traditional values of *ubuntu* and reciprocity. It is becoming apparent that community-based initiatives are as much about an effort to cope as they are to provide assistance to others. The informal transfer of resources and services, through initiatives outlined below, can be considered to be both horizontal and vertical. That is, community members are providing much needed services to other community members who are of similar socio-economic status. However, their membership of the various initiatives facilitates their access to resources and power thus putting them at a slightly improved position. Although organisations should have clear inclusion and exclusion criteria, factors such as kinship may play a role in the selection of aid beneficiaries.

A4.2 Types of community responses in Mpophomeni

A range of responses are providing a variety of services to children made vulnerable by HIV and AIDS. These are psycho-social responses in the form of memory boxes and counselling, education support such as study groups and facilitating fee exemptions for vulnerable children, food support including food parcels and food gardens, informal transfers such as child fostering, home visits and home-based care, treatment support, playing an intermediary role with government departments, and income generating activities like needle work. Some of these initiatives have spill-over effects, that is, they benefit vulnerable caregivers and households rather than being directed to individual children per se. For example, food parcels and proceeds from food gardens feed households thus improve wellbeing and reduce vulnerability at household level, including the wellbeing of children.

Initiatives known, by key informants, to be active in Mpophomeni are Ethembeni, Future Promises, Hospice, Hlanganani, Isibani, Masibumane, Sakhisizwe, and Umgeni AIDS Centre. It should however be noted that participants did not distinguish between initiatives emerging spontaneously within their community, and those that may have been introduced into the area by an external agency. It is noteworthy that a member of one initiative was aware of four other community initiatives. Meanwhile participants in a FGD mentioned five other initiatives which were offering various services to children in Mpophomeni. These are Friends for Life, the Gender and Paralegal Office, Inkanyezi⁹, Stay Together, and Umgeni AIDS Centre. This is suggestive of existing relations between community-based responses, and an opportunity for encouraging and strengthening partnerships, networking, skills sharing and referrals between initiatives. This could also potentially reduce duplication in service provision, and improve children's access to a continuum of care and support.

Although a range of services are currently being provided by initiatives mentioned above, some of the needs of children made vulnerable by HIV and AIDS were unmet (see Table A3 below). Access to basics such as food, education and clothing is a priority that requires more attention, according to participants. Struggling for basics is a situation that is not unique to children affected by HIV and HIV but is an everyday reality for children in poverty-stricken settings. Other unmet needs include availability of information to address HIV-related stigma, home-based care, and a shelter to serve as a day care centre.

Table A3: Vulnerable children's unmet needs in Mpophomeni

Unmet need	Number of responses
Basics (food, education, clothing)	10
HIV information	2
Home-based care	2
A shelter for vulnerable children	1
Poor grant access	1
Poor treatment access	1

Focus group participants mentioned a drop-in centre, facilitation of the grant application process, provision of psycho-social support, and HIV-related information as service gaps. These service gaps suggest that the demand for services is growing as the community sees the difference the initiatives are making in the community. However, there is a danger that some of the initiatives may over-stretch themselves while seeking to meet this increase in demand for services.

A5. Challenges faced by community responses in Mpophomeni

Poor access to financial resources is one of the key challenges facing community responses in Mpophomeni. It also has implications for the proper functioning of initiatives. Without sufficient and consistent financial backing, an initiative may find it difficult to buy or rent an adequate place to be used as a base and/or from which to render its services, to buy seedlings for food gardens, sewing materials for an income generating project and utensils for a soup kitchen. It also makes it difficult to access telecommunication technologies like telephones, computers and the internet. Such technologies can facilitate networking and the sharing of ideas between initiatives as well as access to more resources.

⁹ Meaning: A star.

Low levels of technical training in areas such as planning and project management present another challenge to community-based responses. As such, some activities are planned but do not get off the ground. Lack of networking opportunities, partly resulting from poor access to financial resources and telecommunications, leaves some initiatives without the expertise and support of those doing similar work within their community. It should be noted that as much as initiatives see the value of networking and partnerships, they also find themselves competing for resources which may put a strain on partnerships. In addition, members of one initiative felt an initiative they considered 'successful' was not willing to share information and other success tips with them.

Since Initiative 3 is constituted of young people, adults and even other young people do not take them and their activities seriously. One member related their experience in relation to this as follows:

"... Because we are the youth, sometimes when you encounter an older person ... like when we were advising people on budgeting ... for the grant ... sometimes we are not taken seriously because we are young... Most of the time, even other young people ... do not give us respect." Participant 1, Initiative 3.

It is also particularly concerning that members of an initiative are ridiculed and called names while volunteering their services towards improving the situation of children affected by HIV and AIDS. Below is an interchange between a facilitator and members of Initiative 2 in this regard.

Facilitator: *"As an initiative, what challenges or problems do you come across in the work you do?"*
Participant: *"... It is having fingers pointed at us and being called names"*
Facilitator: *"Uhum."*
Participant: *"That we are nurses who wipe bums"¹⁰.*
Facilitator: *"Uhum."*
Participant: *"Here comes those who have a high heel (iqhoks in IsiZulu, meaning HIV)¹¹."*
Participant: *"And that we are not welcome in some homes."*
Facilitator: *"Uhum."*
Participant: *"People ask how much are we getting paid for bothering ourselves about others and neglecting our own homes."*
Participant: *"Hey even within our families, my husband gets angry ... and says 'why do you bother me and ask for money from me, what does this work of yours do for you because you do not get paid?"*

Volunteering within a context of poverty and unemployment, occasionally on an empty stomach, can be very challenging for volunteers themselves and even difficult to understand for non-volunteers. Women volunteers, some of whom are directly affected by HIV and AIDS, shoulder a double burden of caring for their own families and for children in need

¹⁰ Referring to home-based care.

¹¹ A high heel or *iqhoks* in IsiZulu is a metaphor used for HIV infection. HIV results in weight loss which is equated to the slimness of a high heel. Another hidden implication of the high heel metaphor may be promiscuity, meaning that it is those who aspire to a high life who get HIV. When a person has died from AIDS, it is said that person was hit by a high heel.

within the broader community. A volunteer can find it emotionally draining to give hope to others when his/her immediate environment does not offer hope.

A6. Approaches for strengthening community responses in Mpophomeni

While community-initiated responses are recognised as a critical safety net protecting vulnerable children, there does not seem to be enough done to support them. Most participants were not aware of any kind of support that is currently available or has been extended to such responses. However, some participants acknowledged support they are receiving from CINDI, Umgeni AIDS Centre, and the Department of Social Development. These organisations are providing valuable financial, material and technical support. Below are statements made by members of Initiative 1 about the kind of support they are receiving from CINDI.

Participant 6: *“CINDI helps us quite a lot, particularly ... with programmes relating to children, so we work quite a lot with them. They help us with uniforms ... they do a lot of work ... There is quite a lot they help us with, maybe my colleagues can mention a few programmes.”*

Participant 1: *“They started parties where they give children presents.”*

Participant 6: *“And with training community facilitators like us ... As we come from CBOs, there is a CBO cluster for CBOs and grassroots responses ... They train us by doing workshops on monitoring and evaluation, strategic planning ... They are running many useful programmes ... they are very practical.”*

Providing financial support, organisational development, creating networking and information sharing opportunities, and community mobilisation are mechanisms that can be used to strengthen community responses. Considering that the location of community-based initiatives within a resource-constrained environment puts strain on their functioning, it is not surprising that ‘drip-feeding’ or small amounts of regular financial support is one of the key mechanisms identified for their strengthening.

In relation to who should be providing the required support to community responses, government, at provincial and local levels, is a major role player. Below is a statement made by a member of Initiative 1 in relation to this issue.

“Firstly, ... working closely with the Department¹² and our local municipality. We need the support of our municipality and support of the Department. They are playing a big role but they can play a bigger role so that we can benefit.” Participant 6, Initiative 1.

Table A4 below shows that other stakeholders have a role to play regarding the sustainability and strengthening of community initiatives. Once community responses get off the ground, it is important that they maintain their momentum and keep volunteers motivated.

¹² The Department of Social Development.

Table A4: Views regarding who should provide support to community initiatives in Mpophomeni

Who should provide this support?	Number of responses
Government	11
Donors	3
Private sector	2
NGOs and CBOs	2
Other community responses	2
Anyone willing and able to assist	1

Although community initiatives are an important safety net in settings where vulnerable children and their families have limited coping mechanisms, it is noteworthy that they do not seem to be adequately supported. It is crucial that government, NGOs, CBOs and the private sector interact with community responses in order to identify the nature and extent of support these initiatives require.

Section B: Imbali

This section presents findings from Imbali, and provides a brief outline of the area and study participants. In addition, it outlines conceptions of child vulnerability, family and community responses to children made vulnerable by HIV and AIDS, and how community initiatives can be strengthened to better respond to the needs of vulnerable children in a context of HIV and AIDS.

B1. Brief description of Imbali and study participants

Imbali, meaning *flower*, is a township in the Pietermaritzburg area. It lies on the south bank of the Umsunduzi River. Imbali township, once a hotbed for politically-motivated violence which marred the country's political landscape in the late 1980s and early 1990s, is where former State President Nelson Mandela delivered his last speech prior to his imprisonment on Robben Island¹³.

Imbali, home to about 223 000 people, is sprawling, almost boundaryless - some of the land is owned and let by landlords to informal households. Although Imbali consists of both formal and informal housing types, the four-roomed houses, symbolising township architecture, are predominant. There is fairly good access to services such as water and electricity, health care and education. There are a number of schools, and there are 4 libraries in the area. Health facilities offering primary level services and 24 hour maternity and emergency care are available in the area. Access to tertiary level health and education services is also good, due to Imbali's proximity to Pietermaritzburg. Levels of formal employment are estimated to be low. Most of those in formal employment work in nearby Pietermaritzburg, which is the province's capital city.

In Imbali, a total of 7 key informant interviews were conducted. All key informants are women, 3 are married, and all 7 are associated with local churches. Key informants include 2 day mothers, a church leader, a foster mother, a home-based caregiver, a volunteer at Initiative 1, and a Manager of Initiative 2. Two FGDs were conducted with women and youth from local churches.

B2. Conceptions of child vulnerability in Imbali

Views on what a child needs for healthy development, and what compromises child development and puts children at risk were explored with participants. Their views are similar to those expressed by participants in Mpophomeni. Love and being cared for are the most important requirements for a child to grow up and develop well. This love and care can be provided by biological parents and/or other significant adults. Basic provisioning such as access to shelter, food, clothing and education is also important. Children also need to be guided, i.e. to be disciplined and supervised. Below are statements made by participants in this regard.

"A child mostly needs love, nothing is more important than love, nothing is more important than love." Foster mother.

"A child needs love and parents, even if they are not biological parents as long as they

¹³ http://brabys.com/kzn_new/pmb_info.asp

guide the child.” Manager, Initiative 2.

“A child needs love and to be provided for.” Day mother 1.

“A child needs love and to be cared for.” Day mother 2.

“A child needs a warm home environment, love and to be cared for.” Church leader.

“A child needs a home, food, clothes and education.” Home-based caregiver.

“I say, it is to be taught respect for your elders and education.” Participant 5, FGD 1.

Table B1 indicates that there are a number of situations which contribute to perceived child vulnerability in a context of HIV and AIDS. As such, children are perceived to experience vulnerability at multiple levels. However, circumstances perceived to render children vulnerable are interlinked.

Table B1: Situations rendering children vulnerable in Imbali

Situation contributing to child vulnerability	Number of responses
HIV and AIDS	5
Loss of parent	5
Poverty	5
Homelessness	2
Living with an elderly caregiver	2
Sexual abuse	2
Abandonment	1
Disability	1
Living with ill parents	1

Although participants’ conceptions of child vulnerability are broad, orphaning is considered as rendering children particularly vulnerable because the death of a parent compromises household wellbeing through the loss of livelihood and possibly a home. Parental loss may also cause distress resulting from seeing and/or nursing a parent during illness and death, and may limit a child’s access to food, education and health care. However, one participant considered children to be vulnerable by virtue of being children. Her statement, the last statement in the box below, suggests that perceived child vulnerability rests upon a child’s level of development and maturity.

“Vulnerable children are those who are orphans, those in families affected by HIV and AIDS, and those children infected with HIV.” Volunteer, Initiative 1.

“Children who do not have parents, children whose parents are unemployed or children living in child-only households.” Home-based caregiver.

“Children who do not have parents, those who have been sexually abused and street children.” Church leader.

“Children who do not have parents, those who do not have homes and those who have been abused.” Day mother 2.

“Children need help because they cannot do things for themselves ... when you are not yet capable to do things for yourself, you need the help of others ... so they need help because they cannot do things for themselves and make decisions on their own ...” Foster mother.

Definitions of orphaning are broad (see statements in the box below). These definitions include children who find themselves in situations with less than adequate levels of adult care, support, and supervision. These are children who have no one to care for them as a result of neglect by their biological parents or primary caregivers, and those whose parents have died.

“An orphan is a child who has lost both parents.” Home-based caregiver.

“A child whose parents have died. Sometimes a parent is alive but does not take responsibility for his/her child ... that child is an orphan.” Manager, Initiative 2.

“An orphan is a person who has no one to care for him/her.” Day mother 1.

“An orphan is a person who has nobody, no mother, no father, no sister, no grandfather.” Church leader.

“I hate that word ... I do not like that word. I do not believe that there is a person who should be called an orphan. You might not have parents ... but if there is someone who loves you, who is with you, you are not alone... It does not mean you only have parents when they are your biological parents.” Foster mother.

“When a child has no one to care for him/her, lives on the streets ... the word is used. When a child has lost parents but when that child receives love, the word is no longer used. The word orphan does not quite work if I give a child love and care for him/her.” Day mother 2.

As can be seen from the last two statements in the box above, some participants were uncomfortable with the use of the word ‘orphan’ particularly in reference to children whose parents have died. It seems this discomfort stems from the fact children who have lost parents do not necessarily end up without a family.

B3. Family responsibility and responses to children made vulnerable by HIV and AIDS in Imbali

Family is described broadly to include both kin and kith, that is, blood relatives and social relations. Also, family is an important safety net which helps one cope with life’s daily challenges. See statements made by participants in this regard in the box below.

“A family is two-fold. You can have blood relatives, parents, your mother and father. A family can be people you are not related to by blood. A person who stays with you is your family.” Day mother 1.

“A family consists of a co-residing married couple.” Volunteer, Initiative 1.

“A family is everything because you need your family to survive in life. When you are feeling down, you are sure your family will be there for you.” Foster mother.

“A family to me is something big. If you do not have a family, you are like a person who has nothing in the world.” Participant 4, FGD 1.

It is a family’s responsibility to love and care for a child, to provide for a child’s basic needs including shelter, food, clothing and education, to engender a sense of security and belonging, to mould and guide a child through the different life stages. Thus, loving and caring for a child are important obligations that a family has towards a child. It was reassuring to hear most participants say that the family is meeting its obligations towards children. Meanwhile, 1 participant felt that some families are fulfilling their responsibilities to children while others are failing to do so. One participant felt that some families pretend to be good to children while they are awaiting receipt of the foster care grant. After receipt of the grant, children taken in by these families are neglected.

“They treat the child accordingly because they are after money. They take the child in ... a child who has lost parents. They comfort the child while the person is still after this grant. After receipt of the grant, you notice that the child does not benefit accordingly.” Volunteer.

There was agreement among participants that it is mostly women (mothers, grandmothers, aunts and sisters) who take on the role of caregivers in families (see statement below). This is not surprising as the care and nurturing of children is traditionally women’s work.

“It is mostly women because women have compassion, particularly towards children. Maybe it is because women are the people who actually give birth ... When a child no longer has clothes to wear, it is a woman who notices, when a child is hungry and when a child needs health care.” Church leader.

B3.1 Factors motivating responses by the family in Imbali

Factors motivating families to respond to the needs of children were explored with participants. Compassion, love and seeing the devastating impact of HIV and AIDS on children are some of the factors cited as motivating families to assist (see statements in the box below). Mobilisation by CBOs also contributed to families wanting to do something for children affected by HIV and AIDS in Imbali.

“I think it is compassion and love. When you see a child on the streets ... searching through bins for something to eat you think that if you were to take that child home and care for him/her, he/she would not have to search through bins for food.” Day mother 2.

“I think it is love, just love.” Home-based caregiver.

“Seeing the devastating impact of the epidemic in our families and communities. We have placed our hopes in our children, that they will help us. Some children die even before they start working after completing their training.” Participant 1, FGD 2.

“Families are encouraged by organisations, by us. We go around, encouraging them ...” Volunteer, Initiative 1.

B3.2 Barriers to responses by the family in Imbali

Although some families are helping children affected by HIV and AIDS, poverty may be a barrier to the willingness and capacity of other families to respond to the needs of children. For example, a poor household would find it strenuous to take in a child affected by HIV and AIDS or to provide material assistance towards meeting this child's basic needs. Lack of or insufficient information also leaves families unsure about what to do in response to the needs of children affected by HIV and AIDS. Families are left uncertain about the implications of taking in children whose parents have died or those in need. That is, they do not know whether such children have special needs, do they have to give special consideration to fostered children at the expense of their own children, and where they can go for assistance or information? Therefore, families choose not to show interest due to a lack of resources and uncertainty. The box below contains statements made by participants in relation to this.

'What hinders them is poverty ... if a child is infected with HIV, money is surely needed. One needs to be financially stable ... because that child can fall ill at any time ... one needs to have money all the time. That is what is a problem sometimes because most of us are unemployed and we do not have money.' Foster mother.

'Families sometimes have a problem of not knowing where to go for help ... that is what makes it difficult ... they do not know where to go.' Day mother 1.

As the two statements in the box below show, fear of infection may hinder a family from fostering a child made vulnerable by HIV and AIDS. Such a fear may result from a limited understanding of HIV transmission and prevention. It may also be used by a family as a shield for protecting themselves from potential stigmatisation associated with taking in a child whose parents have died from AIDS-related illnesses.

"Others do not like to help because they think if they take in a person infected with HIV, it is easier for them to also get infected." Day mother 2.

"There are families that do not understand what is going on and do not open their homes to people ... because they still think that a child infected with HIV may also infect them if the child is taken in by the family." Church leader.

As is the case at Mpophomeni, social problems at family or household level may have a role to play regarding why some families do not respond, while other families facing similar challenges do. Family livelihoods and access to information are areas requiring attention in order to improve the coping capacities of families and their ability to respond to the needs of children, particularly in a resource-constrained setting like Imbali. Economic strengthening and improved access to information and services will assist families to identify children in need of care, the type of care they require, and how to actually access and/or provide care to them (see statements in the box below).

"Because most families are poor, they cannot meet basic needs. They can be supported primarily with food." Home-based caregiver.

"They can be encouraged by receiving support in the form of a grant from government so that they can ... use the grant to buy food." Church leader.

“The private sector and government should play a role. ... Information is also needed so that people can face up to the problem of HIV and AIDS.” Manager, Initiative 2.

Government, through the provision of grants and other forms of economic relief, and the private sector are key role players in alleviating poverty and uplifting the ability of households to meet children’s basic needs. Stigma and fear of infection, resulting from insufficient information, are also matters that require attention.

B4. Community responses in Imbali

Where and when family responses to vulnerable children are deficient for reasons outlined above, the immediate community is expected to step in in African communities. Most participants (6 out of 7) described their community as being held together by a strong sense of community. Features of this sense of community are community members who feel a sense of togetherness, who trust one another, and help one another in times of crises (see Table B2 below). This finding is similar to that of participants’ perceptions of a sense of community in Mpophomeni.

Table B2: Participants’ perceptions of togetherness, trust and reciprocity in Imbali

Participant	Togetherness		Trust		Reciprocity	
	Yes	No	Yes	No	Yes	No
Church leader	√		√		√	
Day mother 1	√		√		√	
Day mother 2	√		√		√	
Foster mother		√		√		√
Home-based caregiver	√		√		√	
Manager, Initiative 2	√		√		√	
Volunteer, Initiative 1	√	√	√		√	
TOTAL	6	2	6	1	6	1

Statements in the box below indicate the views of some participants who felt a strong sense of togetherness within their immediate community, and reasons why they and other community members are willing to help others. Compassion, love, volunteerism, religion and reciprocity are some of the reasons behind the willingness of community members to help children and others affected by HIV and AIDS.

“Yes, there is a sense of community because ...when someone has died, we go to that person’s home and when someone is ill, we also go there.” Home-based caregiver.

“When you have compassion, you cannot sit by when you have a conscience and compassion ... because when you have compassion, you cannot just look.” Day mother 1.

“I think when you have compassion and love. When you see a child in the streets ... maybe looking particularly on Thursday, they go around looking in rubbish bins for something to eat. Then you think if you were to take that child into your home so that the child can be cared for properly, they will stop scavenging.” Day mother 2.

“When you are a parent or a community member, you want to see all families doing well ... and orphaned children not to feel that they have lost parents. You want to care for them and give them love all the time.” Church leader.

“Being a volunteer is giving oneself ... and trusting in God that if I help someone I will be helped in return some day. Yes, it is giving of oneself... It is religion, we are guided by religion. You cannot do what we do without compassion, it is compassion mostly...” Manager, Initiative 2.

One participant described the community of Imbali as being ‘generally protective’ of children. There was however one participant who felt strongly that her community is unresponsive and individualised – each person is concerned about his/her own immediate situation. This participant saw her community as unconcerned about the general situation of vulnerable children. Therefore, community members have not taken an active interest in the welfare of others less fortunate than themselves as no community member had come forward to help her with the children she was fostering. According to this participant, community members get interested in the welfare of others once they have been directly affected by HIV and AIDS.

“The community is not standing up on its own because everyone has his/her own thing to do. Nobody cares about the situation of these children because nobody is doing anything about their situation ... even to provide clothing ... Here nobody cares about the next person. It is every person for him/herself, until the situation affects him/her directly. It is only then that they understand the other person’s situation and are then willing to help...” Foster mother.

As is the case with families, poverty was perceived as preventing concerned some community members from providing adequate levels of care and support to vulnerable children. In addition, the fear of stigma associated with taking in children affected by HIV and AIDS is also threatening community responses.

“It is because they have nothing to give. You cannot go visit a person everyday with nothing to give, the person ends up despising you.” Home-based caregiver.

“A barrier, the community faces especially in relation to children affected by HIV and AIDS is stigma because such a person is called names and names.” Church leader.

“We encounter problems when looking after children. People are rude and they swear at children, telling their children not to come play with these children.” Foster mother.

For community responses to thrive, the environmental context within which responses find themselves deserves attention. Widespread poverty makes it difficult for community responses to get off the ground and for responses to keep volunteers motivated. Notwithstanding the socio-economic challenges posed by poverty and stigma, it is interesting that some community members are individually or collectively responding to the needs of children affected by HIV and AIDS.

B4.1 Description and characteristics of endogenous responses in Imbali

Participants were engaged on how they describe initiatives started by community members without the support from and/or influence by external agencies. According to participants, endogenous responses capture a spirit of volunteerism which is driving them and other community members to do what they are doing.

“Yes, our community is not sitting down. We are volunteering ... so that we can meet the needs of children affected by HIV and AIDS. The work we are doing, we call it volunteering. Yes, we are volunteers - we are volunteering in our community.” Manager, Initiative 2.

Those who volunteer their time, material resources and expertise in Imbali are offering a variety of services seeking to address the needs and rights of children made vulnerable by HIV and AIDS. Some of the services provided to children are mentioned in the section below.

B4.2 Types of community responses in Imbali

A range of services were provided to vulnerable children by concerned individuals and groups. Services offered are child fostering, home visits and support, treatment support, food and nutrition support, and home-based caregiving. It seems some of the individual and group responses, mentioned below, are about offering children acceptance, solace and companionship.

“I am a foster mother ... I look after children and try to do the important things for them ... so that they know they have a home, a family with a father, grandmother and uncles ... They now feel part of my family ... just to give them a home and love – that is all that matters.” Foster mother.

“There is a lady up there, I know she is fostering children affected by HIV and AIDS. There is another lady who goes from house to house checking how children affected by HIV and AIDS are doing ... I also do go check on children, when I have time, to see how they are doing, whether they have eaten, whether they have taken their treatment ...” Day mother 1.

“Our community has great empathy because ... in the community we have vegetable gardens through which we help vulnerable people to at least get something to eat. We give them spinach, cabbage and other things.” Church leader.

“We have a soup kitchen. We cook for orphaned and abandoned children ... We, the community are cooking for children. We also do home-based care for PLWHA.” Manager, Initiative 2.

Participants were aware of and mentioned specific community responses working with children in their area. These responses were Humpty Dumpty, Sakhimpilo¹⁴, Siyanqoba¹⁵, Sizanani, Zamimpilo, and Zenzeleni¹⁶. Despite a range of services being offered to vulnerable

¹⁴ Meaning: Building a life.

¹⁵ Meaning: We are conquering.

¹⁶ Meaning: Do it for yourselves.

children, there are still some unmet needs. These unmet needs, listed in Table B3 below, point to children’s poor access to welfare and health services, and are indicative of the vulnerabilities being faced by some children in this country.

Table B3: Vulnerable children’s unmet needs in Imbali

Unmet need	Number of responses
Basics (food, health care, education)	6
Poor grant access	1
Love and warmth	1
A shelter for vulnerable children	1
Poor treatment access	1

Also, these unmet needs suggest some of the challenges that community responses face, which are outlined in the next section.

B5. Challenges faced by community responses in Imbali

Challenges faced by initiatives responding to the needs of vulnerable children in a context of HIV and AIDS include poor access to financial and material resources, and the fact that some volunteers are themselves directly affected by HIV and AIDS.

Inadequate access to financial and material resources limits the depth of services offered by initiatives. As the first statement in the box below shows, poor access to resources is making it difficult for Initiative 2, in particular, to provide meals to children on a daily basis. Although Initiative 2 would like to provide children with meals daily, their resources only allow them to do so on certain days of the week.

“A challenge we encounter is that we have not been able to access resources so that we can find adequate shelter. It is our wish to feed children daily but because we have not accessed resources, we skip some days. We eat everyday but there are days when we are not able to feed children because of resource constraints.” Manager, Initiative 2.

“At the moment, everything is dependent upon the availability of funding. We should be having a shelter where vulnerable children, particularly those finding themselves homeless, should be able to live.” Church leader.

While the impact of HIV and AIDS is motivating volunteers to individually or collectively provide care and support to vulnerable children, some volunteers are themselves directly affected by HIV and AIDS. These volunteers may themselves be living with HIV and AIDS and/or may be caring for family members who are living with HIV and AIDS. In the case of the former, as the statement below shows, volunteers die or have to take time off when they are sick. Death of fellow volunteers may adversely affect the morale of those remaining, while time taken off may impact negatively on the quality of services provided to children.

“Some of our volunteers have died, which causes shortages . We ourselves get sick which causes a problem for the children. When children are meant to receive food at 15h00, they instead get it at 16h00 because one of our members is sick.” Manager, Initiative 2.

Furthermore, HIV-related stigma makes it difficult for responses to identify vulnerable children and provide appropriate care and support to vulnerable children. Some families

affected by HIV and AIDS may not be open about the cause of death of a family member which may impede a child's access to antiretroviral treatment, for example.

B6. Approaches for strengthening community responses in Imbali

From statements made by participants in the box below, it seems community responses in Imbali are mostly self-reliant as they have not been able to access any external support. Although endogenous community responses come from the initiative of a community seeking to cushion children from vulnerabilities resulting from HIV and AIDS, they do need support in order to sustain and improve their capacity to respond to children's needs.

"I have not seen anything that has been done, I have not seen anything. I started in 2004 but I have just not seen anything." Day mother 1.

"I have not seen anything in our area, I have not seen anything." Day mother 2.

"There is nothing at the moment, nothing at the moment." Volunteer, Initiative 1.

"There has been no support this side. I have been asking who our councilor is, nobody knows ... and I do not know where to go for help." Foster mother.

It was noteworthy that CINDI was one of the organisations mentioned as providing support to Initiative 2 specifically. CINDI usually extends invitations to relevant workshops to Initiative 2.

"CINDI is one of the big organisations which is helping us. The Department of Health provides us with gloves we need for home-based care and with information on how to provide home-based care to children ..." Manager, Initiative 2.

The Umgungundlovu and Umsunduzi municipalities also provide Initiative 2 with technical support when writing proposals. Volunteers at Initiative 2 have received training on home-based care, and continued to receive food parcels for distribution to beneficiaries from Project Gateway. In recognition of the difficulty community responses face in accessing financial and material resources, their access to resources has to be improved. Thus, community initiatives have to be skilled so that they can identify funding opportunities, apply for funding, and absorb funding.

Considering that community initiatives are providing services to vulnerable children and households, they have to be enabled to meet basic needs such as food and clothing (see statements in the box below). This will partly be addressed through improved access to resources.

"They can be supported maybe with funds, maybe with donations like food and clothing." Home-based caregiver.

"We will be delighted to receive any kind of support. We will not specify that we need this type of support ... One person can donate a container because as I said we do not have adequate space for our soup kitchen. Others can donate funds so that children can have their own centre ..." Manager, Initiative 2.

Table B4 suggests that government has a major role to play in strengthening community-initiated responses. As one participant put it, *“It is actually government’s responsibility to ensure everyone’s basic needs are met.”*

Table B4: Views regarding who should provide support to community initiatives in Imbali

Who should provide this support?	Number of responses
Government	4
Private sector	3
NGOs	2
Anyone willing and able to assist	2
Donors	1

Although government has a major role to play in supporting and strengthening community initiatives, funding sources available within communities themselves should also be explored. For example, the statement below identifies local businesses as having a social responsibility to the community that supports them - that is, local businesses have to plow back some of its profits in that community.

“... It is mainly government and local businesses. The community should approach local business for support, particularly shop owners, ... because that is where the community spends its money. In turn, these businesses should plough back into the community.”
Church leader.

“It is government who should provide this support, government being supported by the private sector and local and international donors.” Church leader.

Since community responses are characterised by innovation, i.e. a community doing something for themselves, continuous community mobilisation is also key to strengthening community responses. This will tap into additional human and material resources, and keep volunteers motivated.

“Every person should assist ... because it is not only about giving money. One can also give time to come and see children and make them happy. Your five minutes giving relief to a caregiver...” Foster mother.

Linking into government programmes and those of NGOs can be facilitated by local councillors and other community leaders. Participants did however stress that the community should proactively approach local councillors in search of information about available programmes rather than wait for councillors to provide such information.

Section C: Ngome

In this section, findings from Ngome are presented, and a brief outline of the area and study participants is provided. The section also outlines conceptions of child vulnerability, family and community responses to vulnerable children in a context of HIV and AIDS, and approaches which can be used to encourage community initiatives in Ngome.

C1. Brief description of Ngome and study participants

Ngome is a rural area located about 25 kilometres from Greytown, and falls under the Umvoti Municipality. It is the birth place of Bhambatha ka Manciza Zondi, who led the Bhambatha Rebellion of 1906. The Bhambatha Rebellion, regarded by some as the beginning of the struggle against *Apartheid*, was waged against a Poll Tax of £1 which was levied on all men over 18 years of age¹⁷. Mbongeni Zondi, a grandson of Bhambatha is the current ruling chief of Ngome.

Ngome is home to about 8 517 people, 42.57% (3 626) of whom are adults and 57.43% (4 891) are children. Literacy levels are low. More than three thousand people (3 208) have no formal education, while only 119 have a tertiary education qualification. Employment rates are also low. It is estimated that only 10% of the adult population is in formal employment, and that a high proportion of the population is dependent on the child support grant for survival.

In terms of services available in Ngome, there are three primary schools and two high schools. There is no health facility in the area, however there is a mobile clinic which visits the area once a month. The nearest hospital is Greytown Provincial Hospital, and it is accessible by public transport. Public transport is limited, and this impacts adversely on the mobility of community members between the scattered households. Access to the welfare system is poor, as there is a shortage of social workers to conduct assessments for foster care grants, for example. Some wards within Ngome have electricity, while most residents still fetch drinking water from the Nyokana River. Described as a 'Cinderella district', by one participant, Ngome seems to have fallen through the cracks of development. It is peculiarly interesting that the Ngome Community Game Reserve, containing a 'lush forest and cascading waterfalls', is located within such a resource-constrained area.

A total of 12 key informant interviews were conducted in Ngome. Eleven out of 12 key informants are women, most (7) are unmarried, and most (9) are affiliated to some of the local churches. Key informants include 7 community members, 4 volunteers (1 volunteer at the Centre, 1 community health worker, and 2 home based caregivers), and an Auxiliary Social Worker. Two FGDs were held with home-based caregivers and community health workers, and another with members of a Granny Club.

C2. Conceptions of child vulnerability in Ngome

When exploring what contributes to the healthy development of children, interestingly basic provisioning came up as the most important contributor for participants in Ngome. It was followed by being loved and cared for. Guidance, i.e. being taught values such as respect,

¹⁷ <http://www.greytown.co.za/bambathastment.htm>

having parents and being allowed to play are other contributors to a child’s healthy growth and development.

“A child needs love, to be provided for basic needs and education.” Community health worker.

“I think a child needs a safe home, love, access to education and all other things a person needs to live.” Home-based caregiver 1.

“In my opinion, I would say a child needs love... needs to play, to be cared for, to have food to eat. Those are all the things a child needs.” Volunteer.

“To be cared for, and to have all basic needs met – food, clothing and education.” Community member 4.

“Love, care and parents.” Auxiliary Social Worker.

The prioritisation of basic provisioning may be indicative of broader socio-economic challenges and the difficulties families are currently facing in fulfilling children’s basic entitlements. Meanwhile, circumstances putting children at risk are multiple and include orphaning, neglect and abandonment, and HIV and AIDS (see Table C1 below).

Table C1: Situations rendering children vulnerable in Ngome

Situation contributing to child vulnerability	Number of responses
Loss of parent	9
Neglect and abandonment	6
HIV and AIDS	4
Age	2
Caregiver unemployment	1
Living in a child-only household	1

Although participants’ conceptions of child vulnerability are broad and suggest multiple conditions, it seems orphaning is considered an important indicator of perceived vulnerability. The box below contains statements made by participants concerning children they consider vulnerable.

“Children who are orphaned because they do not have parents, now the community has to play the parent role.” Community member 1.

“I think vulnerable children are orphaned children, those with unemployed caregivers, children living in child-only households without adult care and supervision, where parents cannot care for their children and they drop out of school, they have no clothes to wear.” Volunteer.

“Vulnerable children are orphaned children like those who have been abandoned by their parents because they are not able to help themselves. They cannot earn a living, they cannot go to school. They are the most vulnerable because they have no one to care for them.” Home-based caregiver 2.

“Those children without parents. Sometimes parents have died or they are alive but they are not able to care for their children due to unemployment.” Community member 6.

There were however 2 participants who were of the view that all children were vulnerable by virtue of being children, below is a statement by a participant in relation to this.

“I think all children are vulnerable, they all need to be taken care of because children are children.” Volunteer.

Although participants did not mention poverty as one of the indicators of perceived vulnerability in children, loss of a parent does compromise household wellbeing and its capacity to provide for a child’s basic needs. It should be noted that orphaning is primarily defined by parental loss, and also by primary caregiver neglect (i.e. a child having no one to care for him or her). The statements in the box below also reflect participants’ unease with labelling a child an ‘orphan’ and point to a potential effect of this on a child.

“You can be an orphan while your parents are still alive. When they have abandoned you, you become an orphan. But this is not a word I like to use because it makes a child grow up with low self-esteem.” Volunteer.

“Actually it is wrong to call a child an orphan because that child may lose self confidence and think that s/he is different from other children now that s/he is called an orphan. If a child’s name is Zodwa, please call that child Zodwa. Because when a child is called an orphan, that child is no longer free and is affected negatively.” Participant 5, FGD 1.

Because all children are members of families, when they experience vulnerabilities in a context of HIV and AIDS, families as a critical safety net are expected to respond.

C3. Family responsibility and responses to children made vulnerable by HIV and AIDS in Ngome

Although families are of various types, they tend to include parents and their children, relatives, and people who care and support one another. One participant used an analogy of a tree in seeking to communicate his understanding of what a family symbolises to him. Common descent is a key characteristic of a family, according to this participant.

“A family to me is like a tree with leaves. A tree has leaves, a trunk, branches, and fruit. A family consists of a group of people – a father, mother, grandparents, children and uncles. It is a group of people who share a surname.” Volunteer.

Another participant’s description of a family is inclusive of both kin and social relations. As long as people co-reside, care about and are loyal to one another, they can be considered a family. Family is also an important safety net which enables its members to navigate life, as indicated by the second statement in the box below.

“I take a family as someone I reside with, who knows what I need and do not need, what I like and do not like. A family can be someone related to me or not related to me. As long as we are close and the person understands what my needs are, that person is my family.” Auxiliary Social Worker.

“Family to me is something very important because I do not see myself surviving without them because they are a great support to me.” Home-based caregiver 2.

As a safety net, families are expected to love and care for children, provide for their basic needs, and to support them. A majority of responses (11) indicate that families are responding to the needs of children made vulnerable by HIV and AIDS. On the other hand, 6 responses suggest that some families are not cushioning children from the impact of HIV and AIDS. It should be noted that 6 participants said some families were providing a safety net for children affected by HIV and AIDS while others were not.

C3.1 Factors motivating responses by the family in Ngome

Families in Ngome generally take in children, provide for them and love them. There were however participants who expressed concern about the way some families were treating children affected by HIV and AIDS. Factors motivating or hindering family responses were explored with participants. It seems community health workers and home-based caregivers encourage family to respond to the needs of vulnerable children. The last two statements in the box below also allude to grants as a perverse incentive for child fostering, an issue which also came up in the other two sites. It should be noted that this issue was not explored as part of this study. Seeing the situation of children affected by HIV and AIDS, and compassion are other motivators of responses by the family.

“It is usually community health workers who encourage families.” Auxiliary Social Worker.

“I think it is community health workers.” Community member 2.

“It is just seeing the situation of children and then maybe they try to do something ...” Community member 6.

“I am not very sure. Sometimes it is home-based caregivers who can encourage a family, because a child is orphaned, to apply for a birth certificate so that a child can get an orphan grant. The orphan grant does encourage them because it is what they are after sometimes ... Money encourages them.” Home-based caregiver 2.

“Others are encouraged by the grant, which they use to meet their own needs and not those of the child. There are also those who are motivated by compassion, wanting to help a grandchild who is in need.” Participant 3, FGD 1.

C3.2 Barriers to responses by the family in Ngome

Poverty and unemployment are some of the barriers to family responses, as indicated by statements in the box below. Other barriers are having own children, lack of or insufficient information about children’s needs and rights, and lack of birth registration documents. A caregiver with his/her own children, in a resource-constrained household, would find it difficult to take in another child as that may affect the material wellbeing of his/her own children. Poor availability of information on children and their needs, in a context of HIV and AIDS, can also result in families being unsure about what to do exactly when fostering a vulnerable child. Delays in the processing of registration documents may dampen willingness

to respond, as a family may anticipate difficulties in the application process and its ability to provide for the needs of a child they have taken in.

“Most families are themselves poor. They are not able to provide for themselves and care for other children on the side because they are poor themselves.” Home-based caregiver 1.

“It is difficult for many families ... to help because there are no jobs. There is very little they can help children with, because they themselves have nothing to eat.” Community member 7.

“Maybe it is because they have their own children, so they cannot help ..., and they can barely make ends meet...” Community member 4.

“I think it is not having information, they are not informed enough.” Community member 2.

“What hinders families from helping a child is, you find that a child was living in Johannesburg with his/her mother and comes back without a birth certificate. While the mother is sick or after the mother’s death, when you try to apply for a child’s birth certificate, Home Affairs asks for details you do not have. Then you end up not helping the child ...” Volunteer.

Regarding how families can be supported in order to enhance their coping capacities, strengthening the economic capacities of families is primary. For example, participating in income generating projects would enable families in a resource-constrained setting like Ngome to better provide for the needs of children and adults within those families. Information about children, their needs and rights, and on how families can meet their obligations towards children would strengthen the family as a safety net. Social problems, at family and community levels, preventing some families from responding to vulnerable children also deserve attention.

C4. Community responses in Ngome

As mentioned earlier in the method section, no community level responses were identified or were operating in Ngome at the time of the study. Participants unanimously agreed that the community had not yet initiated any responses. Instead responses to children made vulnerable by HIV and AIDS were embedded within kin and social networks, and services provided by community health workers and home-based caregivers who are linked to external agencies like the Department of Health and Umvoti AIDS Centre.

“There are no community responses. It is home-based caregivers from different organisations who are doing something.” Home-based caregiver 1.

“No, in my area I have not heard anything other than home-based caregivers who help children with different things. When children need clothes, they give the clothes. When children need food, they can give them food. But in my community, I have not heard what it is planning to do about orphaned children.” Home-based caregiver 2.

“No, there is nothing at the moment. There are no responses ... no one is doing anything

in my community ...My community is not responding to the needs of children ... it is only home-based caregivers ... who come and give children whatever they can ...
Community member 3.

“There are no community responses in this area.” Participant 4, FGD 1.

It is noteworthy that the community of Ngome does not seem to have a strong sense of community, which may limit responses to crises at community level.. Table C2 below shows that some participants are not sure about whether a sense of togetherness exists, whether community members trust one another and whether they can count on the community as a safety net in times of distress. In such a setting, one would expect a limited transfer of services and materials between households and a dependence on external agencies like Umvoti AIDS Centre. It should however be noted here that no children were identified as being on the streets.

Table C2: Participants’ perceptions of togetherness, trust and reciprocity in Ngome

Participant	Togetherness		Trust		Reciprocity	
	Yes	No	Yes	No	Yes	No
Auxiliary Social Worker	√		√		√	
Community health worker		√		√		√
Community member 1		√		√		√
Community member 2	√		√		√	
Community member 3	√		√		√	
Community member 4	√		√	√	√	√
Community member 5	√		√		√	
Community member 6	√		√			√
Community member 7		√		√		√
Home-based caregiver 1		√		√		√
Home-based caregiver 2		√		√		√
Volunteer	√	√	√	√	√	√
TOTAL	7	6	7	7	6	8

One participant struggled to find reasons for the community’s unresponsiveness towards the needs of children, while another saw pre-existing community divisions as hindering community efforts (see statements in the box below). Such divisions may result from political feuds, from community members being resented for not regularly attending funerals due to employment elsewhere, and from traditionalists blaming the scourge of HIV and AIDS on those seen as aspiring to a modern lifestyle.

“It is difficult to describe my community. There is no water when the community should be starting small food gardens to protect them from hunger ... Even when they want to sew uniforms, they do not have sewing machines and they do not have a place where they can meet.” Community health worker.

“Here there are divisions between old and new residents. Old residents do not trust new residents and they always expect new residents to initiate things. There is no togetherness ... when they try to form a CBO, divisions show even before they start,” Home-based caregiver 1.

Although the community appears to be not doing enough for children affected by HIV and AIDS, one participant was of the view the community is *“doing as much as their financial capacity can cope with.”* She went on to say the community *“is so busy coping with life”* that they have little energy left for anything else. It is apparent that the care and support of children made vulnerable by HIV and AIDS is shouldered by kin and kith, and by community health workers and home-based caregivers. The next section outlines factors hindering community-initiated responses in Ngome.

C5. Barriers to responses by the community in Ngome

In looking at community-initiated responses, it is imperative to consider the broader environment within which community members find themselves. HIV and AIDS, in the case of Ngome, seem to be burdening a community that is already experiencing widespread poverty and unemployment. The anomaly, within an African context, of a community weakening as a safety net for children affected by HIV and AIDS indicates that this may be a vulnerable community.

However, statements in the box below suggest that it may be unrealistic to expect community members to take on an additional financial responsibility brought on by fostering vulnerable children, as this will impact on their own survival and wellbeing. From the last statement in the box below, it also seems secrecy surrounding HIV and AIDS is preventing community members from establishing the extent of the problem.

“The community is burdened because children have to be fed while they do not have anything to wear ... They worry that if they say something, the child will end up being their sole responsibility ...” Community health worker.

“It is that many of us in this community are unemployed so we cannot provide for the needs of children affected by HIV and AIDS.” Community member 2.

“Sometimes you want to take vulnerable children in but are prevented by the fact that you are unemployed. You do not have money, you are burdened by your own children ... The community fears taking in these children because they will have problems ... When they try the welfare route, it does not work then they do not know how to support these children.” Participant 4, FGD 1.

“There are barriers because the fact that children are affected by this disease is still kept a secret, and is talked about in hushed tones. A barrier is that people have not yet come out to talk about it so that everybody is made aware about the situation.” Community member 3.

Although community health workers and home-based caregivers interviewed in this study are associated with external organisations, it would have been interesting to explore in-depth factors which motivated (and continue to motivate) them to volunteer in their community. The research team established that some of the volunteers are receiving stipends. Although volunteers’ motivation may not necessarily be driven by monetary gains, it should be acknowledged that volunteering does improve one’s employability potential and access to training opportunities.

C6. Encouraging endogenous community-based responses in Ngome

Access to information regarding the nature of child vulnerabilities in a context of HIV and AIDS is an area that requires urgent attention. Community mobilisation, with emphasis on the critical role of the chief, needs to be coupled with broad community development efforts, since this is a community that is struggling with accessing basics such as water and electricity.

“Information, about where to go when needing what, has to be made available to the community ... The community is in the dark, now they all need to be made aware.”
Community member 5.

“Education only, to be informed about the severity of the problem and that community members need to help. The community needs to be supported with information.”
Community member 7.

While it is understandable that Ngome represents a severely resource-constrained setting, it is suggested that community members use their poor access to basic services as a rallying point. Such action may have spill-over effects such as strengthening the community’s response to issues facing children in the community, including the impact of HIV and AIDS on children.

5. Discussion

This study describes community-initiated responses in Mphophomeni and Imbali, and it proposes approaches that can be considered for strengthening such responses. Also, it particularly outlines factors hindering community members from initiating responses in Ngome. The three study sites reflect different geographic settings and possibly different social, economic, cultural, and political landscapes. All three study sites have a vibrant socio-political history, which has informed current development activities (or lack thereof) in each area. It should however be noted that the study does not attempt to compare the three geographic settings but rather outlines factors facilitating or hindering family and community responses in each setting. The study shows the importance of context, and that responses cannot be expected to emerge and function everywhere in the same way. While acknowledging that the study approach and sample size present some limitations, the study provides a snapshot of current initiatives in two sites, where such initiatives existed at the time of the study.

Findings show that while community responses offer various and much needed direct and indirect services in Mpophomeni and Imbali, they are also about communities trying to cope with and make sense of the epidemic. Responses found in Mpophomeni include direct food and nutrition support in the form of food parcels and food gardens, ensuring children stay in school by facilitating fee exemptions, assisting with homework and organising study groups, providing psychosocial support at household level through memory boxes, and child fostering. Some responses do not necessarily offer a tangible resource or service, they are about a community organising itself to offer relief to caregivers, companionship and acceptance to those affected by HIV and AIDS, and to destigmatise HIV and AIDS. A community response, in any form, should also be regarded as a coping mechanism.

In Imbali, individual and collective responses are an indication that vulnerable children receive care and support in times of distress. Individuals and groups, in Imbali, provide some of the following resources and services to children: child fostering, household visits and home-based caregiving, treatment support, and direct food and nutrition support. The individual nature of some of these responses may be pointing to a slow erosion of trust and of the value of *ubuntu* at community level, brought on by the demands of modern living and the politics of the past. Social problems such as substance abuse may also hinder some community members and families from responding to vulnerable children, and this is applicable to all sites.

Conceptions of child vulnerability, which are broad, are similar across the three study sites. With HIV and AIDS impacting on children directly and indirectly, children, families and communities are finding their wellbeing and livelihoods compromised. Some children are themselves infected with HIV, while others experience distressing levels of adult morbidity and mortality at family and community levels. Parental loss either from death or neglect is considered a key indicator of child vulnerability in the three study sites. Loss of a parent seems to contribute to a worsening of child wellbeing, particularly where it is coupled with widespread poverty at household and community levels. This is in support of research findings by Foster (2002) in Zimbabwe, by Henderson (2006) in South Africa, and by Skinner *et al.*, (2006) in Botswana, Zimbabwe and South Africa.

In all three sites, family is identified as people who trace common ancestry, and remains a crucial traditional safety net which responds to children made vulnerable by HIV and AIDS.

Therefore, when children find themselves in particularly difficult conditions as a result of HIV and AIDS, the family is usually the first to respond. The primary responsibility of a family to a child is to provide love, warmth and security. Basic provisioning in the form of facilitating and ensuring a child's access to shelter, clothing, food, education and health care is also primary. Providing for children's basic needs is crucial in Ngome, which may highlight the broader social and economic challenges experienced in that area. It should be noted that the family was not specifically identified as a protector of children. This is concerning, considering that some children are exposed to abuses within their families and communities.

In most African communities, childcare arrangements have always been shared by both kin and kith even while biological parents are still alive and after they die. In the three study sites, family responses to children made vulnerable by HIV and AIDS range from families providing children with support and supervision through visits while they remain in their parental home, giving them food, making sure they stay in school, taking them to a local clinic when they are unwell, to families taking children in. This is in line with findings by Foster *et al.* (2000) in Zimbabwe, Chirwa (2002) in Malawi, Madhavan (2004) in South Africa, and Verhoef (2005) in Cameroon.

Factors motivating families to respond to the needs of children include seeing the devastating impact of HIV and AIDS on children, compassion, adhering to values of *ubuntu*, a high value placed on children, love for children, ability and willingness to do something, and religion. There are however concerns about some families not fulfilling their obligations to children generally, especially in relation to basic provisioning. This can partly be attributed to poverty and unemployment, which are prevalent in all three study sites. While this study did not explore the social rupture or family collapse thesis (Chirwa, 2002), it seems some families in economically strained settings like Mpophomeni, Imbali and Ngome respond to the needs of vulnerable children while others do not. It is acknowledged that a family without a source of income may find it difficult to inherit additional financial and material responsibilities, brought on by fostering children, when it is struggling to meet the basic needs of its existing members. Meanwhile, some poor families facing these challenges do take in children. This compels one to examine contextual issues which may be hindering other families from responding. Pre-existing conflicts resulting from abandonment by a family member, and estrangement and resentment brought on by long periods of absence may be other reasons for families deciding not to respond.

Furthermore, families in the three study sites seem to have concerns about the possibility of HIV infection through casual contact with a child whose parents may have died from AIDS-related illnesses. The stigma associated with taking in children is also a concern for families. Access to information on HIV transmission and prevention, on the needs and rights of children, services available to support families fostering children, for example, is an area requiring attention. An issue clearly coming out is that families are somehow expected to intuitively know what to do with or how to relate to a child made vulnerable by HIV and AIDS. An assumption is made that affected families will know what type of support a vulnerable child requires, and will make a plan and cope with the resultant challenges, without this being accompanied by broader institutional supports. There are blockages in the welfare grant application process. This further highlights the important intermediary role that organisations like the Community Care Project at Project Gateway, Umgeni AIDS Centre and Umvoti AIDS Centre continue to play in facilitating grant access. As the HIV and AIDS

epidemic continues to test the coping capacity of families, the role of responses at community level becomes apparent.

Endogenous community responses are about members of a community, whether individually or collectively, taking ownership of challenges they are facing, and developing localised solutions to these challenges. Community initiatives draw on the traditional values of *ubuntu* and reciprocity, amass locally available resources in the form of time, money and skills, and rely on women volunteers. The community of Mpophomeni in particular, is characterised by a strong sense of community and togetherness. Unsurprisingly, community members have initiated a number of responses seeking to address the needs of children affected by HIV and AIDS. Services provided by some of these initiatives in Mpophomeni range from direct food support, to the transfer of intangible services like assistance with household chores and with homework. A sense of togetherness, trust and the willingness of community members to help children in distress is also high in Imbali. It was interesting that some of the services currently being provided to children are provided by individuals, rather than by members of community responses. Still, it is reassuring that community members are prepared to assist children made vulnerable by HIV and AIDS, individually and/or as part of a group.

Rural communities are usually thought of in terms of their sense of cohesiveness, and reciprocity is an established norm in such settings. It was surprising that the rural community of Ngome is demonstrating weak community ties. While recognising that it takes time and resources to start a response, it seems the community of Ngome is struggling to get anything off the ground. Volunteers providing services to children affected by HIV and AIDS in the area are attached to external agencies. It would be interesting to find out why these community members started volunteering while others have not. Is Ngome reflective of a rural community struggling to cushion children from the vulnerabilities of HIV and AIDS? A point to note here is that if the present research had engaged participants on community level responses only, one would have gotten the impression that children affected by HIV and AIDS are potentially neglected in this community. What emerges from this research, however, is that responses are not formalised or identified outside of kin and kith. Future research is needed to explore what informs volunteerism, particularly in resource-constrained settings. That is, why some people volunteer while others do not.

When looking at community responses or at why a particular community is not responding, one has to keep in mind the broader social, economic and political constraints a community is facing. It seems a subtle helplessness may emerge in resource-constrained conditions, mainly resulting from widespread poverty and unemployment. The community of Ngome, for example, has to guard against such helplessness engulfing them into inaction and undermining their provision as a safety net for vulnerable children. It should be noted that Ngome is a small rural community with very limited access to services such as water, electricity, and health care, and to print and electronic media. The community also does not have a community hall which makes organising community meetings over weekends, for example, particularly difficult. Inactive leadership, distances between homesteads and poor availability of public transport are also not very encouraging to concerned members considering initiating a response. Future research needs to explore concepts such as coping, coping strategies and resilience at family and community levels, before a conclusion is drawn about the failure of families and a community to respond to the needs of vulnerable children. It would also be worthwhile to look at what communities need in order to actively cope with and adapt to challenges resulting from HIV and AIDS and to fully become 'AIDS competent communities' (Campbell *et al.*, 2005).

Community responses are as much about the cohesiveness of affected communities as they are about the limited ability of government to respond to the needs of children made vulnerable by HIV and AIDS. Community responses in Mpophomeni and Imbali are currently offering a variety of much needed services to vulnerable children. Although community initiatives should not be expected to meet all the needs of children affected by HIV and AIDS, it is noteworthy that children's access to basic services is still compromised. This is indicative of the broader socio-economic contexts within which community initiatives are located. For example, it becomes difficult for an initiative to provide school uniforms when children do not have anything to eat. Community responses should take cognisance of the broader socio-economic realities of affected children. Most importantly, household livelihoods need strengthening. This can be done through facilitating IGAs like food gardens, which would improve household access to food while enabling those participating in these activities to earn a living. Increasing grants, improving access to the Expanded Public Works Programme, and facilitating youth skills acquisition and employment are other schemes that can be considered.

While community responses are considered low cost (Foster, 2005b), they may be high cost for volunteers. Volunteerism is a backbone of endogenous community responses, nevertheless volunteering can be quite challenging (and even unrealistic at times) in a context of dire poverty. Firstly, volunteers may be poor themselves with very little to give other than their time and caring. Although it is difficult to volunteer on an empty stomach, a point to note is that, volunteering is not only about the transfer of tangibles like money and food. A volunteer can also pray with or relieve caregivers (or assist children) with household tasks like cleaning and cooking. This confirms the horizontal and vertical nature of informal transfers between households reported by Platteau (1997). Secondly, women volunteers may carry a double burden of care due to the gendered nature of caring responsibilities. Women volunteers may be caring for their own children and also for vulnerable children in their community. Thirdly, multiple demands on volunteers' time may limit their opportunities to search for paid employment which will impact on their livelihoods. Thus, approaches for volunteer acknowledgement, recognition and remuneration should be identified. Public acknowledgement by local leadership of the work being done by volunteers, paying volunteers a monthly stipend, giving them time off, and creating skills development and networking opportunities are some of the approaches that can be considered in seeking to keep volunteers motivated. It should also be acknowledged that volunteers find themselves in a better position to qualify for formal employment opportunities.

That which builds community responses can also threaten their sustainability. While volunteerism is commendable, community responses can be destabilised when volunteers leave or when they die. Because some volunteers are themselves living with HIV and AIDS, their illnesses or death may reduce the number of skilled volunteers and also weaken volunteer morale. This is an issue of particular concern for community initiatives, in which some of their caregivers are living with HIV and AIDS. In addition, caregivers may be stigmatised because they are known to be living with HIV and AIDS and/or are caring for PLWHA. Caregivers need care and support, i.e. debriefing sessions, in order to deal with their own condition and the challenges they face while providing care and support to others. Furthermore, community-wide interventions addressing stigma and discrimination against PLWHA should be considered.

Community responses are hindered by a number of challenges, with poor access to financial and material resources being the biggest challenge in Mpophomeni and Imbali. In supporting community-responses, however, a number of key elements can be identified – improving access to financial and other material resources, engaging community leaders in the work, linking community initiatives to formal services, linking community initiatives together, not only to provide each other with support, but also to create a platform for advocacy and skills sharing. Developing a supportive and enabling environment in conjunction with the government is also crucial – especially if this can involve greater government support for community-responses, since this can ensure sustainability of work that occurs.

Access to resources determines whether an initiative functions or not, and how well it functions. Drip-feeding is one of the key approaches that can be used to strengthen community responses. A steady and continuous in-flow of funding would enable a response to sustain, improve and possibly upscale its projects. As more children find themselves vulnerable in a community affected by HIV and AIDS and poverty, the demand for a range of services provided by community-based responses has to be met by an adequate supply of such services. This will partly be enabled by improved access to financial and other material resources by community responses. However, some informal or individual responses may not be in a position to directly apply for or qualify for funding from external agencies. Informal or individual responses, qualifying for funding, would need to approach and be supported by intermediary organisations.

One of the bottlenecks affecting access to financial resources by community responses is a lack of technical expertise in the area of fundraising particularly (Foster, 2005a). Some community responses in Mpophomeni, for example, lack the technical capacity required to identify funding opportunities available locally and internationally, and to complete grant applications. In addition, limited access to resources restricts the ability of an initiative to network and share skills and experiences with other initiatives. This was highlighted by Initiative 3 in Mpophomeni. While acknowledging the impact of competition for resources on the ability of responses to build partnerships, the benefits of networking for skills sharing and improved service provision should rather be emphasised.

Involvement of local leadership is central to initiating and/or strengthening community responses. In all three sites, local leadership does not seem to be playing an active role in community level efforts targeted at children affected by HIV and AIDS. Since community members in Ngome are struggling to initiate responses at community level, there is a clear role for local leadership to get community members interested in the plight of children. The Chief should mobilise the community into action along non-political lines, and consider availing some of his land for communal food gardens as has been done in Swaziland through the *Indlunkhulu* fields. Mobilising the community on issues relating to children will have spill-over effects. Groups set up to advocate for the needs of children may find themselves addressing other issues affecting the community broadly. For example, advocating for better access to water considering that the area houses the Ngome Community Game Reserve. Where community initiatives are up and running, as in the case of Mpophomeni and Imbali, local leaders can be tasked with looking out for potential funding opportunities for initiatives. Also, local leaders can visibly support community responses, which would raise their profile, and their ability to attract financial and human resources.

Overall organisational development, particularly the structuring and functioning of responses, and their technical capacity in the areas of planning, management, fundraising, report writing

is another area that can be targeted for improvement. The support that initiatives receive from organisation like CINDI, Project Gateway, and Umgeni AIDS Centre and from government departments is duly acknowledged. In addition, responses require capacity in the following areas: identifying vulnerable children, responding adequately to the needs of these children, networking and partnership building, and volunteer management and support. Where initiatives do not or cannot provide care to their volunteers at the risk for burnout, for example, such care should be easily accessible.

Another approach for strengthening community responses is by creating awareness of programmes within government departments which community responses can latch onto, as and when necessary. This may be for financial and material support, technical support, and skills development. Some initiatives are not aware of how they can go about applying for funding, particularly from the Department of Social Development, and if such funding is indeed available. In instances where responses need sites for their operations, they are not sure about the kind of support they can expect and/or access through their local municipality.

Community responses do not necessarily see government taking over, but they see different government departments playing a facilitation role. One important function of government is the development of an enabling legislative and policy environment for the care and support of vulnerable children. In addition, government departments can facilitate training on the following: the Children's Act, the national policy framework on OVC, the rights of children, and the responsibilities of duty bearers. Government departments can also alert community responses to potential funding opportunities, assisting them with writing funding proposals and project reports, and providing materials for some of their projects. Initiatives 2 and 3 in Mpophomeni highlighted their difficulty with writing their constitutions and getting themselves registered, which then impacts negatively on their ability to apply for funding from government. Chiefs, local councillors and social workers should be in a position to inform community responses about the types of government programmes and services available, and when and how to access these.

Building AIDS-competent families and communities is one of the key strategies for cushioning children from the current and future shock of HIV and AIDS. While families and communities should be commended for their spontaneous responses seeking to address the needs of children made vulnerable by HIV and AIDS, more should be done to enhance their coping capacities.

6. Conclusion

With children experiencing vulnerability at the individual, household and community levels in a context of HIV and AIDS, it falls to families and communities to protect children from the direct and indirect effects of HIV and AIDS. A major share of care and support for children made vulnerable by HIV and AIDS is still provided within households and families. While some families are responding to vulnerable children, other families are not. Families and communities, being essential safety nets, are motivated by traditional values such as *ubuntu* and compassion to volunteer their time, money and expertise. These values also define what it means to be a family and a community, in an African context, and how families and communities respond to the needs of children.

Community responses are of various types – offering a variety of material and non-material resources and services to those affected by HIV and AIDS. Community activity can be initiated by an individual or a group, can offer support to others affected by HIV and AIDS, and can help a volunteer cope with his/her own HIV status and related difficulties. It is apparent that some community responses are better networked than others, which enhances their ability to access external support and resources, and to link with formal education, health and welfare services. Poorly networked responses, usually without external funding support, tend to be time-limited. Acknowledging that community activity varies, the nature of external support provided should also vary. Some responses will be ready to receive external financial assistance, while others will not. For responses not yet qualifying for or able to absorb external assistance, stipends for volunteers and improving their links with government and NGO services and programmes should be considered.

Volunteerism, at an individual or group level, is the backbone of community responses. Volunteerism is the biggest resource in the response to children affected by HIV and AIDS, and should be used optimally and sustainably. Volunteers, largely women, sometimes carry a double burden of care. They deserve proper acknowledgement and remuneration. Support to family and community responses should seek to revitalise values binding families and communities together, while not ignoring contextual issues hindering individuals, families and communities from responding. External agencies have to take a more transformative approach to development, which seeks to engage local leadership and is premised on listening to what communities need in order to better respond to children made vulnerable by HIV and AIDS.

7. Recommendations

Recommendations outlined below highlight the critical role that CINDI, Umgeni AIDS Centre, the Community Care Project at Project Gateway, and Umvoti AIDS Centre can continue to play in supporting family and community respond to vulnerable children in a context of HIV and AIDS. However, they also point to an even bigger and integral role that should be played by local leadership and government in improving the coping capacities of families and communities, and supporting community-based initiatives.

- Since care and support for children made vulnerable by HIV and AIDS largely occurs within the household and family contexts, **everyday practices taking place within these contexts should be reinforced**. Caregivers should be encouraged to continue being affectionate, attentive, and nurturing to children. Furthermore, coping capacities of households and families need strengthening. This can be done through **facilitating income generating activities like food gardens, facilitating and improving grant access, increasing grants, improving access to the Expanded Public Works Programme, and creating opportunities for labour market participation**.
- It should be acknowledged that children experience multiple realities and vulnerabilities in a context of HIV and AIDS. Also, there is not a uniform response across communities, as communities themselves are diverse. Community responses, where other services are limited, should be supported as they are a critical resource cushioning children from the devastating impact of HIV and AIDS. **Assistance should be packaged appropriately** so that community responses at different stages of development and with different needs can access the type of assistance they require. A well-established response, with a stable funding source, may need financial and project management skills more than fundraising skills. Meanwhile, an emerging response may need a small start-up grant and support with developing project and funding proposals. External agencies should be prepared to listen, and to support in a way unique to context and community initiatives.
- **Community initiatives should be mentored on various aspects of organisational development and management. Initiatives have to be encouraged to identify diverse sources of support**, rather than to rely on a single source of support. It is noted that funding sources are limited and that community initiatives compete for resources. However, initiatives can be alerted to funding and other development opportunities, and how they can access such resources. This can be done through regular telephone updates, meetings, electronic or print bulletins, and word of mouth. Community newspapers, where available, can be used for such communication. Responses should also be encouraged to explore resources available locally, such as approaching local businesses for donations.
- **A register of child programmes and services, and of community responses operating within an area should be compiled**. In Mpophomeni, a paralegal office has started putting together a list of initiatives and CBOs providing services to children in the area. Such a list can improve children's access and referral to services, networking between responses, and identification of initiatives and CBOs for funding by outside agencies. Local government should compile such registers.

- **Links to education, health and welfare services available locally should be strengthened.** The relationship between government and community responses can be reciprocal, with government providing financial and technical support to responses, and responses implementing government programmes in return. In Mpophomeni, Initiative 3 worked closely with their local clinic, and through it they were able to identify children requiring care and support. Some people working in Mpophomeni were trained by professional health workers in home-based care and treatment support, while those without a base used the local clinic and the offices of the Umgeni AIDS Centre for their meetings. Schools can also be used as venues for meetings in Ngome, for example.
- **Acknowledgement, compensation, retention and support of volunteers** are some of the key elements for the survival of endogenous community responses. The work that volunteers do needs to be recognised. Volunteers can be compensated in cash or in kind - through monthly stipends, food parcels, training and networking opportunities. Training opportunities, enabling the attainment of accredited qualifications, can assist in the retention of skilled volunteers, while psychosocial support can boost volunteer morale. Intermediaries need to explore ways of improving and facilitating community groups' access to the Expanded Public Works Programme, the Youth Service Programme and other opportunities. Information can be made available to community initiatives regarding what these schemes are about, and which groups or volunteers qualify for such a scheme.
- Rather than assuming that families and communities will know intuitively how to respond to children affected by HIV and AIDS, they may have to be provided with basic **information on the rights and needs of children generally, needs of children affected by HIV and AIDS, programmes and services available within and outside communities, and how to access these programmes and services.** Social education, addressing the basics of HIV transmission and prevention, and stigma and discrimination against PLWHA, some of whom are volunteers, should be provided. Local leadership, intermediaries such as Umvoti AIDS Centre, the Community Care Project at Project Gateway, and Umgeni AIDS Centre have a crucial role to play in facilitating access to information, resources and services within communities. However, intermediaries need financial support so that they can continue to bridge the gap between external agencies and community responses.
- **Traditional values such as *ubuntu* and reciprocity, motivating community members to respond to vulnerable children in communities affected by HIV and AIDS, should be revitalised.** Engaging local leadership, e.g. chiefs, councillors, and faith leaders, is vital as they can raise the issue of children in community gatherings, publicly acknowledge and legitimise the work being done by volunteers, and encourage the formation of self-help groups. CBOs such as Umvoti AIDS Centre, the Community Care Project at Project Gateway, and Umgeni AIDS Centre can actively encourage the involvement of leadership, men and youth in community responses to vulnerable children.
- **Social problems hindering a community from responding should be acknowledged,** and local leadership engaged on how some of these problems can be addressed. Umvoti AIDS Centre has established good relations with leadership in Ngome. Community leaders should be engaged on how the community can cope with the situation of children affected by HIV and AIDS, and other pressing problems facing the community.

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Appendix 1A: Participant Information Sheet (Key Informant)¹⁸



Endogenous community-based responses

Who are we?

We are from the Human Sciences Research Council (HSRC), a national research organisation that works with universities, hospitals, and community organisations on research projects throughout South Africa.

Why are we here?

The Human Sciences Research Council has been asked by the Children in Distress (CINDI) Network to conduct research on cultural beliefs and community-based responses to the needs of families and children affected by HIV and AIDS. We are doing this to help CINDI identify ways that formal services and non-governmental organisations can better support local community responses to meeting the needs of children affected by HIV and AIDS.

Why is this important?

We know that many families in South Africa are being affected by HIV and AIDS, and that HIV and AIDS can make children vulnerable in many ways, such as being poor, not having enough to eat, not being able to get health care, or dropping out of school. We also know that, most often, assistance given to children and families affected by AIDS is provided by families and communities themselves. Family and community members are often the first to respond to children and caregivers affected by HIV and AIDS and continue to remain the main providers of support and care over time. This study is important because it seeks to better understand the different ways community members assist each other as well as vulnerable children in the context of the HIV and AIDS epidemic. We believe that communities have much to teach us about how to improve services to meet their needs and support existing community initiatives of care.

What is involved in this study?

We want to better understand the cultural beliefs and values that shape community responses to families and children affected by HIV and AIDS. We will ask you questions about the different ways members of your community have responded to meeting the needs of vulnerable children and which factors help or hinder community initiatives. We will also ask questions about what it means for a child in your community to be vulnerable and how decisions are made about providing assistance and care. The interview will last about one hour and a half. If need be, we would like to interview you a second time to follow-up.

What will happen to the information collected?

We will use the information that we gather to write case studies about some of the initiatives we visit. We will also make recommendations for how CINDI partners and other non-governmental organisations can support community responses to providing care for families and children affected by HIV and AIDS.

¹⁸ Information sheets, consent forms and interview guides were modified for focus group discussions and site visits, and were translated into IsiZulu.

Benefits

Participating in this project may help you to think about and better understand how your community is responding to the needs of families and children affected by HIV and AIDS. There will be no direct benefit to you as an individual for participating in this research.

Risks

We realize that it may be hard to talk about how HIV and AIDS are affecting your community. You may have yourself lost a family member to HIV and AIDS. You may feel better after speaking with us or you may also feel sad and upset. If I ask you a question which makes you feel sad or upset, we can always stop and talk about it. If you need to speak with anyone after I have left, you can call Vuyiswa Mathambo at 031-242-5618.

What if I do not want to participate?

Please understand that your participation is voluntary and you are not being forced to take part in this project. The choice of whether to participate or not, is yours alone. However, we would really appreciate it if you do participate and share your thoughts with us. If you choose not to take part in this project, you will not be prejudiced in any way whatsoever. If you agree to participate and you do not want to continue, you can stop at any time.

If you have any further queries, please do not hesitate to contact Vuyiswa Mathambo at 031-242-5618. If you were harmed in any way during the course of research or have any concerns about what happened during the research, you can also contact Jurina Botha from our Ethics Committee for assistance and guidance. Jurina Botha can be reached at 012-302-2009.

Appendix 1B: Consent Form (Key Informant)

Endogenous community-based responses



Hello, I am ---. I am from the Human Sciences Research Council.

The Human Sciences Research Council is a national research organisation, and we are conducting research on cultural beliefs and community-based responses to the needs of families and children affected by HIV and AIDS. We are doing this in order to identify ways that formal services and non-governmental organisations can better support local community responses to meeting the needs of children affected by HIV and AIDS.

Please understand that your participation is voluntary and you are not being forced to take part in this study. The choice of whether to participate or not, is yours alone. However, we would really appreciate it if you do share your thoughts with us. If you choose not take part in answering these questions, you will not be prejudiced in any way whatsoever. If you agree to participate, you may stop me at any time and tell me that you do not want to go on with the interview.

I will not be writing your name down anywhere during the interview and no one will be able to link you to the answers you give. Only the researchers will have access to the unlinked information. The information will remain confidential.

The interview will take about an hour and a half. We may request a second follow-up interview, if we need more time. I will be asking you questions and request that you are as open and honest as possible in answering these questions. I will also be asking some questions that you may not have thought about before, and which also involves thinking about the past or the future. We know that you cannot be absolutely certain about the answers to these questions but we ask that you try to think about them. When it comes to answering these questions, there are no right and wrong answers.

I would like to request your permission to use a tape recorder. Tapes and transcripts from this interview will be kept under lock and key. Transcripts will not contain your name.

If I ask you a question which makes you feel frustrated or upset, we can stop and talk about it. If you need to speak with anyone after I have left, you can contact Vuyiswa Mathambo at 031-242-5618.

The HSRC will report back to your community the general findings once we have completed our study.

CONSENT

I hereby agree to participate in research on cultural beliefs and community-based responses to the needs of families and children affected by HIV and AIDS. I understand that I am participating freely. I also understand that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

I understand that this is a research project whose purpose is not necessarily to benefit me personally. I understand that this consent form will not be linked to the interview.

I have received the telephone number of a person to contact should I need to speak about any issues which may arise in this interview.

I understand that general feedback will be given to my community on the results of the completed research, which will not identify any individual's answers.

.....
Signature of participant

.....
Date

.....
Signature of translator (if applicable)

.....
Date

CONSENT TO AUDIO TAPE

In addition to the above, I hereby agree to the audio recording of this interview for the purpose of data capture. I understand that no personally identifying information or a recording concerning me will be released in any form. I understand that these recordings will be kept securely in a locked environment, and that tapes will be destroyed after 5 years.

I understand that this interview will be recorded and transcribed and I consent to this. I understand that the transcripts will be available to the researchers in this study. I also understand that my name will not be recorded on the transcript and that my identity will be kept confidential.

.....
Signature of participant

.....
Date

.....
Signature of translator (if applicable)

.....
Date



Appendix 1C: Key Informant Interview Guide

Endogenous community-based responses

Introduction: I will ask you questions about your understanding of children, child vulnerability, communal responsibility to vulnerable children, community responses to the needs of children affected by HIV and AIDS, and how such responses can be strengthened.

- Can you please tell me about yourself?
 - Age
 - Gender
 - Marital status
 - Religious affiliation
 - Occupation

I will ask you questions about your conceptions of children & child vulnerability.

- What is your understanding of a child?
- Which child do you consider vulnerable?
 - Which child does this community consider vulnerable?
- What renders a child vulnerable, in your view?
 - Which groups of children are considered vulnerable in this community?
- What does the term orphan mean to you?
 - What does the term orphan mean to this community?
- What defines orphanhood?
 - What should define orphanhood?
- In your view, what does a child need in order to grow up properly?

I will now ask you questions about the family.

- What is a family to you?
- What do you see as the primary role of a family in relation to a child?
 - Is the family playing this role?
 - How has the family responded to needs of children affected by HIV and AIDS?
 - How has the extended family responded to the needs of children made vulnerable by HIV and AIDS?
- How would you characterize the family's response to vulnerable children, particularly those affected by HIV and AIDS?
 - Why do you say that?
- How do families in this community treat children who have lost parents?
 - Children who are poor
 - Children who are destitute
- Within families, who would you say takes primary responsibility for vulnerable children?
- What do you think enhances family responses to the needs of children affected by HIV and AIDS?
- What do you think hinders family responses to the needs of children made vulnerable by HIV and AIDS?

- How can the family – in its various formations - be strengthened to better respond to the needs of children affected by HIV and AIDS?

I will now ask you questions about the community and its responses.

- Can you tell me about how this community is being affected by HIV and AIDS?
- How would you say children in this community are being affected by HIV and AIDS?
- What activities occur in response to children affected by HIV and AIDS?
 - Who does what? Please explain.
 - How are the roles of various actors conceived?
 - How are the roles of the various actors coordinated?
- How does the community support children who have lost parents
 - Children who are poor
 - Children who are destitute
- What would you say informs these community responses?
 - What would you say motivates community members to respond to the needs of children affected by HIV and AIDS?
 - What would you say motivates community members to respond to the needs of other children?
 - Within this community, who would you say takes responsibility for vulnerable children?
- How would you say assistance targeted at children is prioritized?
 - How are children included and excluded?
 - How are children prioritized?
 - What informs such prioritization in this community?
- Where would you say the gaps are in responses to the needs of children affected by HIV and AIDS?
 - Which needs are currently not being met?
 - Why do you think that these needs are not being met?
- How would you characterize community initiatives targeted at vulnerable children?
 - What is your understanding of endogenous?
 - What makes an initiative endogenous? Please explain.
- How can this community be strengthened to better respond to the needs of children affected by HIV and AIDS?
 - Who should provide this support?
- How can this community be strengthened to better respond to the needs of other children?

I will now ask you questions about how community initiatives can be supported.

- How would you describe your community?
 - Sense of community (look out for one another)
 - Neighbourliness (visit & look out for one another)
 - Trust (people can be trusted)
 - Reciprocity (help one another)
- What problems do you think community initiatives face when providing services to children affected by HIV and AIDS?
- What has been done to support community responses?
- How can community responses be assisted / sustained / strengthened?
 - Who should provide this assistance / support?

- How can community responses be linked to government services?
- How can community responses be linked to non-governmental programmes?

Thank you.