SAT SHARE SERIES

Children and Home-Based Care

Integrating support for children affected by HIV and AIDS into home-based care programmes

Southern African AIDS Trust

SHARE SERIES

SHAPING HIV AND AIDS RESPONSES

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Southern African AIDS Trust

SAT and the SHARE series

The Southern African AIDS Trust (SAT)

SAT is a regional initiative that supports community responses to HIV and AIDS through in-depth partnerships with community groups in southern Africa. It also supports wider networking, skills exchange, and lesson learning throughout the region and internationally. The organisation's overall goal is to build the competence of communities to develop and manage effective, appropriate, and sustainable responses to HIV and AIDS.

SAT was established in 1990 as 'The Southern African AIDS Training Programme', a project of the Canadian International Development Agency (CIDA) implemented by the Canadian Public Health Association (CPHA). In 2003, SAT became an independent regional organisation, and was re-named the 'Southern African AIDS Trust'.

SAT believes that most of the information and inspiration needed to increase the scale, speed and quality of the response to HIV and AIDS in southern Africa already exists within the region. It is the role of SAT and other similar organisations to facilitate the process of learning, and sharing those resources.

The SAT SHARE series

This is a document of the SAT SHARE (**S**haping **H**IV and **A**IDS **Re**sponses) series. The series aims to document practical experiences, identify lessons learned, and advocate effective strategies and policies. As part of SAT's Good Practice Strategy, the series seeks to inspire, inform, and improve the evolving community response to HIV and AIDS in southern Africa.

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Executive summary

When increasing numbers of people in southern Africa began to experience HIV-related illnesses in the late 1980s, public health services were soon overwhelmed and as a result a range of home-based care (HBC) initiatives were developed. Though many programmes were initiated by local health workers, they varied both in the way they were organised and in the services that were provided. At the same time, support programmes for children affected by HIV and AIDS (CABA) were developed. These built upon the traditional caring and coping practices of families and communities.

Today, there are many programmes in place that cater separately for people needing home-based care, and children affected by HIV and AIDS. Such divisions, however, make little sense for families and communities trying to provide care for both groups. This has led to a growing interest in integrating responses in order to create more holistic and comprehensive programmes that address all these people's needs.

This report, which draws on the rich experiences of organisations working in the field, focuses on this growing trend to integrate home-based care initiatives with those serving children affected by HIV and AIDS. It advocates for integration, and looks at the challenges as well as the benefits of doing so.

The main advantage of integrating CABA initiatives into home-based care is that it increases the ability of organisations to meet the needs and concerns of sick adults, affected children and their carers. Importantly, this approach recognises that children are affected by HIV and AIDS long before their parent dies, and that HBC carers are in a position to understand these children's complex needs. Children also benefit from maintaining the close and trusting relationship with HBC carers after the parent has died. Integrated programmes also facilitate family counselling, which improves communication between adults and children, and helps both generations to cope. Finally, integrated programmes could also prove more cost-effective, as providers of HBC services may be able to make better use of scarce resources by integrating child support into their work.

Organisations seeking to integrate HBC and CABA services face a number of practical challenges. Central to these is the fact that sick adults and their children may have different needs, problems, and fears that vary over time. Integration can also put serious strain on the skills, time, and resources of carers, and pose significant organisational challenges to community-based organisations (CBOs) and non-governmental organisations (NGOs).

This report looks in detail at the processes necessary to integrate CABA services into HBC. There are a number of options that will be determined by the specific nature of the existing programmes, and the aspirations of the organisation(s) concerned. Some options for integration are described as:

- Creating new services for CABA or merging existing programmes
- Radically redesigning HBC and CABA programmes or changing them with minimal disruption
- Using separate or shared volunteer groups
- Crisis interventions or programmes that support affected people over a long time frame
- Programmes with a narrow medical focus or those that are more holistic in outlook.

CBO/NGO support providers have a role to play in the integration of HBC and CABA responses. They may catalyse and facilitate integration by supporting their partners in research, planning, and training. They may also provide financial support and advocacy for integration. Effective information and advocacy work is also needed at community level, among implementing CBOs/NGOs and at the government and donor levels.

In the past, issues of care, support, prevention, treatment, and income-generation were often compartmentalised as 'vertical' projects operating in the same community. Now, the need to develop more of a comprehensive response to HIV and AIDS is becoming increasingly clear. This is mainly because an integrated response mirrors a community's natural coping mechanisms and also encourages local participation and ownership. As the pandemic continues to pose the severest challenge to communities across southern Africa, the time has come for all stakeholders to renew their commitment to the development of more comprehensive responses at community level. This publication focuses on one way to make such a response a reality.

1 Introduction

In many countries, projects providing home-based care for people living with HIV and AIDS, and those providing support for children affected by HIV and AIDS, have developed separately. This publication aims to present the experiences of organisations that have tried to combine these activities, and to advocate for the benefits of such integration.

This report targets implementing organisations, policy-makers, and those who have a strategic role in encouraging and facilitating more comprehensive responses to HIV and AIDS at community level. This includes governments, donors, and SAT's peers, i.e. CBO/NGO support providers. Though focused on southern Africa, the report may also be of use to similar actors in other parts of the world.

The main source of information for this report was a regional workshop held in Harare, Zimbabwe, in July 2003. The workshop brought together representatives of CBOs and NGOs responding to HIV and AIDS in Malawi, Mozambique, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe (see Appendix 1 for list of participants), with many of them being partners of SAT. All participating organisations had practical experience of integrating support for children affected by HIV and AIDS with home-based care responses.

2 Context and background

Sub-Saharan Africa continues to be the part of the world most heavily affected by HIV and AIDS. This region accounts for the majority of all people living with HIV and AIDS (PLWHA) and the majority of AIDS-related deaths across the globe. This is true of both adults and children.

Within sub-Saharan Africa, some countries are more severely affected by HIV and AIDS than others. SAT and its partners work in some of those hardest hit, i.e. Malawi, Mozambique, South Africa, Tanzania, Zambia, and Zimbabwe.

Across the region, CBOs and NGOs play a leading role in responding to the needs of individuals, families, and communities affected by HIV and AIDS.

2.1 Home-based care (HBC)

In the mid to late 1980s, across southern Africa, significant numbers of people started to experience HIV-related illnesses. At that time, public health services were unable to cope with the increasing demands for care and treatment, and also often discriminated against PLWHA.

To meet the escalating needs for both medical and social support, a large number of HBC initiatives were developed. Many of these were started by health workers, and were based in the facilities where they worked, i.e. hospitals and clinics.

Since then, HBC initiatives in the region have evolved and grown. Now, they are very varied in terms of both the way they are organised and the types of care and support that they provide. Some mainly focus on providing social, spiritual, and support services, together with some basic nursing care, such as bathing and treating sores. Other initiatives provide more comprehensive medical services, including the dispensing of antiretrovirals and other drugs to treat and prevent opportunistic infections.

2.2 Children affected by HIV and AIDS (CABA)

As the epidemic has continued to impact upon communities, a substantial number of children have been orphaned. Many NGOs and CBOs, particularly those that are faith-based, have responded by developing orphan support programmes. The best of these have built upon and supported the traditional caring and coping practices of families and communities.

More recently, it has, however, become clear that a much wider group of children is being affected by HIV and AIDS. In this report, we use the term 'children affected by HIV and AIDS' (CABA) to cover the diversity of children whose lives have been affected, slightly or significantly, by HIV and AIDS. This includes children who have lost one or more parent, family member or carer, or are living in a household or community where other children or adults are experiencing HIV-related illnesses. It also includes children who are HIV-positive.

2.3 The development of separate HBC and CABA responses

Understanding why projects developed the way they did may help us to understand the barriers to addressing HBC and CABA together, and to identify the best way to integrate them.

Historically, HBC and CABA initiatives tended to develop separately. There is a danger in oversimplifying the history of HBC and CABA projects and their current ways of working. However, it is clear that most initiatives emerged with a strong focus on either sick adults or orphaned children. There were two main reasons for this:

- **Different mandates** – The initial driving force for developing HBC programmes came from health professionals who were largely motivated by the desire to solve the problem of the growing numbers of PLWHA needing medical and nursing care. Early HBC programmes often operated from a health facility and were formed around small, mobile, professional teams. In many cases, the programmes then became interested in issues affecting children, largely through their contact with the children of very sick or deceased clients. In contrast, projects focusing on orphans were often started by faith-based CBOs/NGOs that were concerned about the growing numbers of local children losing one or both parents as a result of AIDS
- **A project-based approach** – In order to carry out new activities, organisations needed to mobilise additional resources, a process that usually required them to 'package' their work as projects. In practice, these projects tended to be framed either towards HBC *or* CABA. This occurred for many reasons. For example, organisations had different mandates, concerns about children and HBC arose at different times, and donors had clear rules about how funds could be spent.

The outcome is that in many communities there are 'vertical' programmes in operation, i.e. separate programmes for HBC and for CABA.

2.4 The push for more comprehensive community responses

Today, many vertical programmes remain in place and do good work. However, there is growing recognition that families and communities usually do not approach care and support in that way. This has led to a growing interest in integrating responses for PLWHA and affected children in order to create more comprehensive programmes and more 'organic' responses. As discussed in the following pages, this presents different opportunities and challenges for those running existing projects and those planning new ones.

This report explores the processes that have been used to integrate HBC and CABA activities and overcome the challenges involved. In particular, it focuses on the way that organisations already providing HBC can integrate new activities to meet the needs of children. As such, the report takes the form of a 'gap analysis'. This involves taking a starting point of an existing HBC programme and the desired end point of a more comprehensive programme that meets the needs of sick adult as well as the children of the family or household to which the adult belongs.

3 Integrating a focus on children into HBC responses

3.1 What are the benefits?

There are many benefits to integrating HBC and CABA activities. Some of these are:

People receiving HBC worry about the well-being and future of others, particularly their spouses and children. Meeting the needs of PLWHA requires us to also think about the needs of the affected person's wider family and their carers.

Family carers are usually very concerned, not just about the sick adult but also for the children of the household. Meeting the needs of carers requires us to also think about the needs of children.

Children are severely affected by the illness of a parent. They need care and support throughout this time, not only if and when the parent is bed-ridden or dies.

- **Meeting the concerns of adults living with HIV and AIDS** – Although people receiving HBC have many needs and worries relating to their own illness, their thoughts are often dominated by concerns about their family, and their children in particular. Knowing that their children are being cared for can help PLWHA regain their health and strength more quickly. Knowing that their children will be looked after adequately can also allow a person to die in peace
- **Meeting the carer's concerns about children** – As well as carrying a heavy load of concern about the sick person's health and future, carers often worry about the future of the family as a whole. In devoting so much time, energy, and emotion to the care of the sick adult, carers (especially spouses) often feel that they are unable to give the sick person's children enough attention, love, and guidance
- **Meeting the needs of affected children before their parent dies** – Many projects providing care and support for CABA started by focusing on children orphaned by AIDS. However, it quickly became clear that children were affected by HIV and AIDS much earlier on, i.e. when their parent's illness began having a severe effect on their lives (see Appendix 2). At this stage, children are often confused about what is happening to their family and are fearful of the future. Their attempts to understand the situation are often met with silence, denial, or even despair by adults. Involving children in HBC programmes may help them to prepare for, and thus cope with, their parent's death
- **Providing continuity** – An integrated programme allows children to maintain the strong, trusting relationship they may have developed with their parent's carer. It may be very traumatic for a child to suddenly lose this personal contact when their parent dies
- **Using the expertise of carers** – HBC volunteers tend to know families well and, as such, can identify the needs of individual children early on. An integrated programme can build on this expertise
- **Building on traditional ways of caring and coping** – Many communities have traditional ways of caring for community members in need. These are rarely incorporated into vertical projects, each targeting a specific group of people or issue. By contrast, developing an integrated approach mirrors the traditional way of working
- **Facilitating improved planning** – This can lead to the better care of children after the death of their parent(s). Among the benefits of this is the possible reduction of child-headed households, and

children falling into exploitation and additionally vulnerable circumstances, such as sex work and/or life on the streets

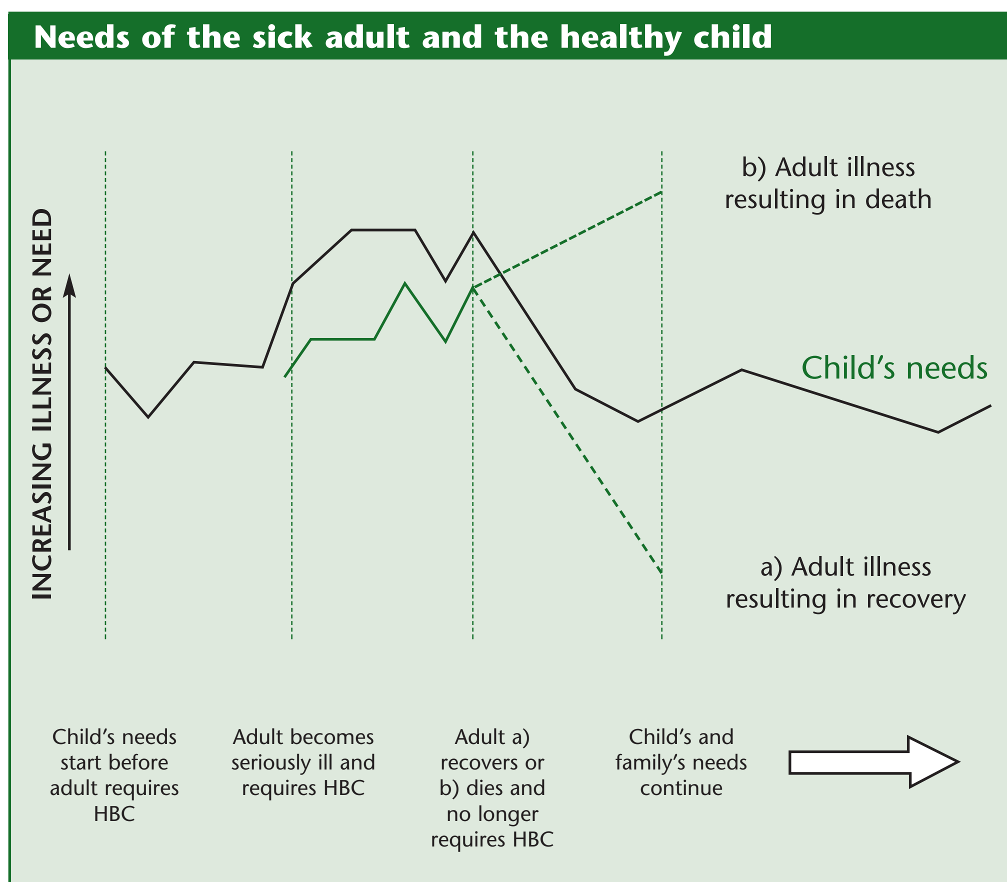
- **Facilitating counselling** – An integrated approach might, for example, enable a parent to disclose their HIV status to their children and have open discussions about related issues. This improves communication between adults and children
- **Giving children skills** – These skills could include knowledge of how to perform domestic tasks or care-giving skills, which may help children to contribute to the livelihood of their household during their parent's illness and after their recovery or death
- **Improving cost-effectiveness** – Providers of HBC services might be able to make better use of their scarce resources by integrating CABA responses into their work.

3.2 What are the challenges?

CBOs and NGOs seeking to develop integrated services face a number of potential challenges. These include:

The needs of adults and children can follow quite different courses. Community responses must be tuned into these differences and be flexible enough to respond to each in the right way and at the right time.

- **Different needs of beneficiaries** – Sick adults and their children have different needs, worries, problems, and fears, all of which can vary over time and may not coincide. For example, children's needs often begin before a parent becomes ill enough to need HBC and continue after the parent has recovered or died



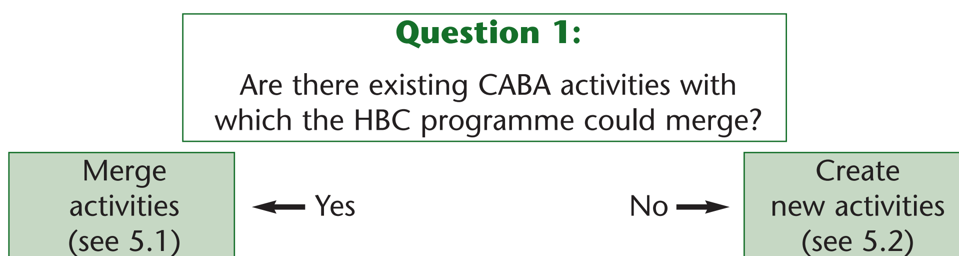
- **Different interests and motivations of staff or volunteers –** The staff or volunteers of HBC or CABA support programmes might not wish to work more closely together, or share care roles for adults and children alike
- **Integration requires investment –** Successful integration requires that organisations and individuals make significant investments in the process, i.e. of time, energy, enthusiasm, and often financial resources. These resources – particularly time and financial resources - are often in short supply
- **Misunderstanding of the change process –** Without significant investment in consultation and information-sharing, the integration process can be easily misinterpreted. This may result in resistance to change among staff and volunteers, but can also cause fear and/or confusion among beneficiaries
- **Changing resource mobilisation strategies –** A shift towards integrated programming will typically require consultations and renegotiations with existing donors, and often demand new resource mobilisation efforts by the CBO/NGO
- **Re-thinking organisational management issues –** To successfully shift to more integrated approaches, it will often be necessary for CBOs/NGOs to review and revise their organisational structures and systems, for example to re-structure in order to cope with greater coverage, or with the creation and supervision of new volunteer teams
- **Re-thinking programming issues –** For many home-care programmes, the process of integration will require adjustments and changes to programme delivery. For example, the CBO/NGO may need to undertake reassignment and/or recruitment of volunteers, make alterations to catchment areas, or revise their criteria and/or processes for identifying beneficiaries in greatest need
- **Capacity development –** Skills training for volunteers and staff is an essential component of most options explored below. Capacity development opportunities for staff and volunteers can be costly and time-consuming to organise.

4 Choosing the right approach – five questions

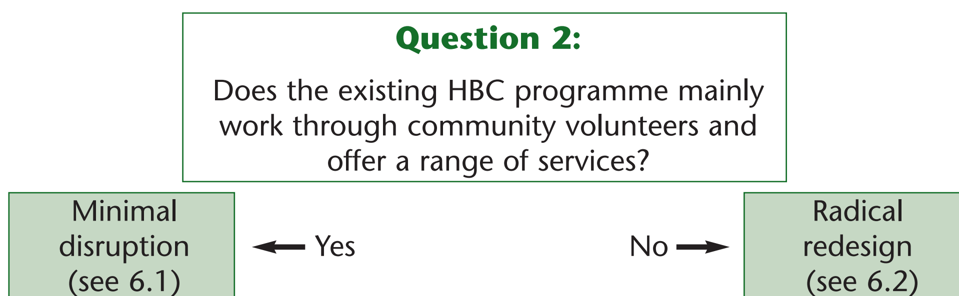
Support for children affected by HIV and AIDS can be integrated into HBC programmes in many different ways. This section provides those organisations with HBC programmes that would like to address the needs of CABA (or CBO/NGO support organisations working in partnership with such organisations) with assistance to analyse their options. It does this by taking organisations through a decision-making journey, based upon five key questions.

These five questions are introduced below and then explored in more detail, each in turn, in the next five sections of the report.

To start with, an organisation with a HBC programme needs to identify whether there are existing CABA initiatives with which they could merge their home care activities. This is more likely to be possible if the two sets of activities are being implemented by the same organisation. However, if there are community-level projects being carried out by another organisation, it might also be possible to merge with them – although this brings with it new and different administrative and organisational challenges.

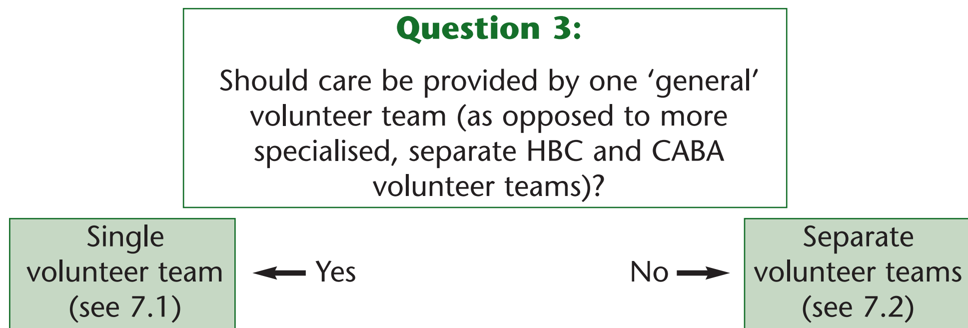


The organisation then needs to decide whether or not their current HBC programme is designed in such a way that they can easily add in activities for CABA, or if it will need radical redesigning. If the HBC programme is mainly operated by a team of health professionals focusing on medical and health care, it is likely to need major redesign before it can provide appropriate services for CABA. However, if the services are mainly provided by community-based volunteers, it may be possible to create a more comprehensive service with only minimal disruption.

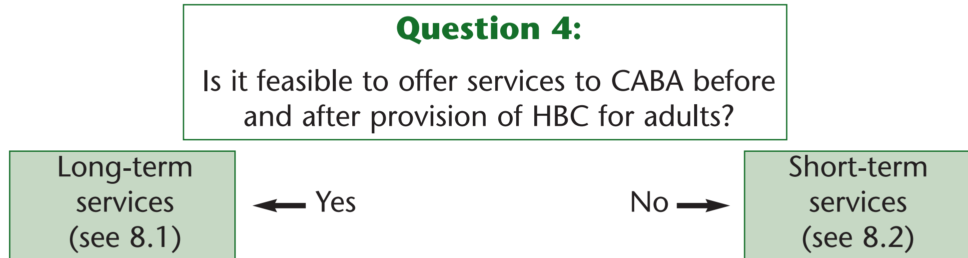


The third step is for the organisation to choose whether to have shared or separate teams of volunteers for the integrated CABA and HBC activities. When deciding, the CBO/NGO should consider issues such as whether there are existing teams of volunteers and, if so, how feasible it would be to merge them, as well as how staff and volunteers might react. A shared team could provide ongoing support for families and children at the time

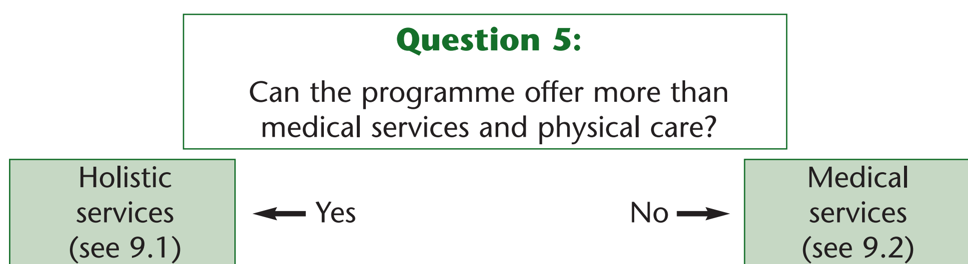
when they need it most, but might require action on workload issues, such as recruiting more volunteers or restricting the catchment area. On the other hand, separate teams could allow more specialised services to be delivered, but might involve considerable management challenges to ensure that they ultimately function as a whole.



CBOs/NGOs also need to decide whether their programme will only provide crisis intervention services to CABA when the parent is receiving HBC, or if services will start before HBC is needed and continue after it is no longer required. Although the longer timeframe is preferable, it can have considerable implications for the organisation's resource requirements and ways of working. For example, rather than relying on HBC volunteers, the programme will need to find other ways to identify vulnerable children in the community before their parent becomes sick. In practice, a programme might start by integrating short-term crisis interventions for CABA and then gradually introduce longer-term services.



Finally, the organisation needs to decide if their integrated programme is going to provide comprehensive services or will focus on particular service areas. Although comprehensive services may seem preferable, they do have considerable resource implications. In practice, it might be better to use available resources to deliver high-quality services with a particular focus rather than trying to meet all of the needs of PLWHA and CABA. On the other hand, if the programme focuses on only one particular area, it might be overlooking the community's priority needs.



5 Are CABA activities pre-existing or new?

5.1 Merging two pre-existing programmes

An existing HBC programme planning to introduce support to children might merge its activities with those of a project already up and running. This is most likely to occur when an organisation has its own 'separate' HBC and CABA initiatives. In reality, such activities are rarely fully independent of each other and may in fact have several informal overlaps. For example, the different groups of volunteers might already meet on a regular basis to share their experiences. There might also be referral mechanisms between the projects, for example with HBC volunteers notifying CABA volunteers when children are orphaned. Now, however, many such organisations are seeking to put these links on a more formal footing.

A merger may be a viable option where HBC and CABA projects are implemented by the same organisation.

If programmes are to be merged effectively, it is important that management discussions and decisions within the organisation are informed by consultations with HBC and CABA staff, volunteers, community members, and donors. The process of programme design will typically involve a needs analysis (to assess the needs of CABA and confirm or revise needs estimates for HBC services), the development (or adaptation) of training materials, training and support for existing volunteers, a reorganisation of the workload and supervision arrangements of current volunteers, developing criteria for selecting clients, and developing or refining monitoring and evaluation tools.

The core motivations of community care and support volunteers are similar, regardless of whether they work with adults or children. However, the specific interests and capacities of individual volunteers may vary.

What might be the benefits?	What might be the challenges?	What might help?
• More equally balanced emphasis on adults and children • New programme, with stronger skills in both HBC and CABA • Greater coverage of clients in need • Less immediate need to expand the number of volunteers or restrict the target area in order to cope with needs/demands • Core motivations of community volunteers are usually similar.	• HBC and CABA volunteers and staff have different interests and skills • The rivalry or 'territory' issues between those working on HBC and CABA • Existing beneficiaries feel their service is diluted • HBC and CABA activities have different donors, and thus different terms and conditions for staff and volunteers, as well as restrictions that hinder integration • Organisational change is always challenging; programme mergers can create uncertainties and fears among staff, volunteers, and clients.	• Peers sharing their skills (e.g. CABA volunteers training HBC volunteers) • Team-building activities to develop a common vision • Strong leadership support from managers • Active consultation with staff and volunteers about merger design • Tapping into the shared motivations of volunteers • Consulting donors to create uniform terms and conditions • Explaining the merger to clients and stakeholders and/or advocating the benefits of more comprehensive responses.

5.2 Adding new CABA services to an existing HBC programme

New CABA activities will be needed where there are no existing activities with which an HBC programme can merge.

Children should not be the passive recipients of services, but rather be active participants at many different levels. CBOs/NGOs should design appropriate strategies to ensure their greater involvement.

Integration is a process, not an event. It requires careful and participatory planning, as well as proactive consultation with key stakeholders. This can prevent structural problems in programme development.

If an organisation does not have an existing CABA programme, then rather than establishing an entirely new and 'vertical' project, it might choose to integrate new services for children into its existing HBC work.

To add new CABA services into HBC programmes effectively it is important to follow similar steps to those outlined above (section 5.1). In addition, organisations may also find it useful to hold community mobilisation and awareness-raising workshops about the needs of children affected by HIV and AIDS, as well as proactively and explicitly involving children and their families during programme design.

With this option, organisations need to carefully analyse the implications of increased client numbers and increased workload. Unless catchment areas are restricted, this option will necessitate the recruitment of new volunteers, and new supervisory and support staff, as well as additional resource mobilisation.

What might be the benefits?	What might be the challenges?	What might help?
• A more balanced emphasis on children and adults • Builds on the solid foundations of an existing HBC programme • The more explicit recognition of children's needs is a practical way to increase the quality of care and support for families • Can be achieved relatively quickly • Many volunteers will be pleased to meet the needs of CABA more proactively • Community mobilisation and awareness-raising of CABA issues is an important contribution to increasing community support to children.	• HBC volunteers need to develop a new focus, role, and skills • Not all HBC volunteers want to work with CABA • The increased need/demand from wider client group leads to an increased workload for staff, volunteers, and managers • Extra resources needed to sustain a more comprehensive response • Policies and materials for working with CABA need to be developed • Donor demands and restrictions may be a hindrance.	• Training HBC staff and volunteers in relevant skills, (eg. child counselling) • Allowing, or even encouraging, some volunteers to specialise in HBC or CABA • Recruiting and training more volunteers and/or restricting the programme's catchment area • Mobilising resources for CABA • Involving volunteers, staff, and community members in the development of policies and procedures (e.g. criteria for identifying children in greatest need) • Explaining the evolution of the programme to clients and stakeholders and/or advocating the benefits of more comprehensive responses.

6 Does HBC change much as a result of integrating CABA activities?

6.1 Minimal disruption

Activities for children can be introduced without any noticeable change to the way that an organisation delivers its HBC. This is more likely to be possible where the HBC programme extensively uses community volunteers and already has a fairly broad focus. This is also sometimes the preferred option, particularly when an organisation feels that the upheaval associated with radical redesign would not be worthwhile.

Taking this approach forward typically hinges on CABA-related training for staff and volunteers. It also requires some attention to be paid to revising client selection criteria, volunteer deployment, and supervision arrangements, as well as implementing activities to ensure community understanding of the shift in programming emphasis.

Although community care and support volunteers possess certain core skills (counselling, for example), there are specific and different skills needed for effective HBC and CABA work. HBC volunteers typically need training in a wide range of children's issues for programme integration to be successful. This includes areas such as psychosocial support for children, child development, life skills and communication skills for 'joining' with children and building mutual trust.

What might be the benefits?	What might be the challenges?	What might help?
• A more balanced emphasis on children and adults • It builds on the strengths of existing HBC services, including structures and human resources • There is minimal disruption to existing HBC services while new CABA activities are introduced.	• Problems in existing HBC programmes may continue • Activities for CABA may be seen as less important than core HBC services • Staff and volunteers may not want to start activities for CABA.	• Careful pre-assessment of the suitability of an HBC programme for the inclusion of CABA services • Addressing problems gradually • Holding discussions with staff, volunteers, and other stakeholders so as to communicate importance of new activities • Involving staff and volunteers in planning new activities • Advocating the benefits of more comprehensive responses.

6.2 Radical programme redesign

Major programme redesign may be needed where current HBC approaches and structures are poorly suited to CABA activities.

In some cases, starting activities for CABA might lead to considerable changes to the way(s) in which an organisation's home care activities are carried out. Such redesign might involve an increased use of volunteers, changing the roles of staff, and/or broadening the programme's focus by moving away from more narrow medical concerns towards a more holistic appreciation of a client's and/or community's needs. This radical step might be prompted by an organisation's dissatisfaction with its current HBC work, or a desire to develop something new that works in a different way, or both.

Dynamic and strong community support, such as that provided by village caregivers, is a pre-requisite of a successful integrated programme.

To re-design a programme effectively, it is important to follow the good practice steps and activities as outlined above. These include proactive and wide consultation, decisions informed by needs assessments, ensuring appropriate training and support for staff and volunteers, re-organising supervision and management relationships, and adapting monitoring and evaluation tools. Radical re-design also necessitates additional activities such as the development of new structures (e.g. community care teams), the revision of organisational structures, and a deeper level of consultation with resource providers.

What might be the benefits?	What might be the challenges?	What might help?
• A more balanced emphasis on children and adults • Community ownership can be maximised and hence be more sustainable • Problems in existing programmes can be 'designed out' of new ones.	• HBC volunteers need to develop a new focus, role, and skills • Not all HBC volunteers want to work with CABA • Resistance to change among existing staff, volunteers, and community members • Upheaval and disruption to services during the transition period • It may take time to establish meaningful community involvement in, and ownership of, the new initiative.	• Active consultation and participatory planning • Careful planning and mobilisation of extra resources (including staff and volunteers) during the transition phase • Encouraging patience and understanding • Ongoing awareness-raising and community mobilisation activities • Advocating the benefits of more comprehensive responses.

7 Is care provided by a single, general volunteer team or separate, specialised teams?

7.1 Single volunteer team

This option involves creating a single multi-tasking volunteer team to provide more comprehensive care for PLWHA, their families and children. To undertake this extremely broad care and support role, volunteers need to be motivated, skilled, and supported.

A single volunteer team is a radical and potentially more effective yet also more organisationally challenging option, particularly where existing programmes are being merged.

From an administrative point of view, it can appear simpler to have one volunteer team providing support to CABA and PLWHA. However, in practice, this might be difficult to achieve where there are already two teams at work. In addition, it raises issues about how to ensure that volunteers' workloads are manageable. Although separate teams may allow volunteers to develop more specialised skills, particular care will be needed to ensure that the efforts of the teams are truly integrated at community level.

What might be the benefits?	What might be the challenges?	What might help?
• Enables community volunteers to provide more culturally appropriate types of care and support • Simpler systems for managing, supervising, and training volunteers • A greater sense of unity within the programme and its volunteers.	• Meeting the different training needs of individual volunteers • Monitoring the caseload of each volunteer, in terms of the number and diversity of clients and their needs • Developing strong and integrated approaches to the training and support of volunteers • Changing the mindset of staff and volunteers in order to be able to implement such a comprehensive service.	• Ensuring there is peer-to-peer sharing of existing skills to maximise learning • Giving specific training for volunteers with different existing skill sets • Providing generic, core training for all volunteers • Advocating the benefits of more comprehensive responses.

7.2 Separate volunteer teams

Integrated services can be delivered at community level by separate volunteer teams if there is effective co-ordination.

This option involves integrating HBC and CABA activities at programme level, but not in terms of the volunteers that deliver the services. The result is a more comprehensive service for clients that is delivered by two separate volunteer teams – one focused on HBC and the other on CABA. The key differences between this situation as opposed to operating two purely 'vertical' projects is that the work is managed as one programme at organisational level and provides integrated care and support at community level.

This approach helps to avoid some of the challenges of having a unified volunteer team, such as how to meet the diverse training needs of people with different areas of existing expertise. However, it also poses serious ongoing challenges in relation to volunteer supervision and team co-ordination, such as how to avoid duplication of efforts and how to ensure that information about clients' needs and preferences is shared effectively. Overall, the key challenge is to ensure that volunteers focusing on different client groups operate as a genuine and unified whole, and not as two separate projects.

What might be the benefits?	What might be the challenges?	What might help?
• It allows volunteers to choose whether to specialise in support to PLWHA or CABA • Specialised volunteers might give a higher quality service • Specialisation might reduce volunteer stress and burnout.	• Potential rivalry and miscommunication between volunteer teams • Supervising of volunteers to ensure consistent, co-ordinated activities and approaches • Achieving effective communication and co-ordination so as to avoid services being disjointed and/or duplicated.	• Developing a close working relationship between the supervisors of volunteer teams • Ensuring peer-to-peer sharing of existing skills to promote mutual respect • Using team-building activities to develop a common vision • Providing strong leadership, support, and encouragement through managers • Tapping into the shared, core motivations of community volunteers • Applying uniform policies on volunteer training and incentives • Advocating the benefits of more comprehensive responses.

8 Is support to children long-term or short-term?

8.1 Long-term approach

In practice, as discussed earlier, children's needs begin before a parent starts to receive HBC and also continue after the parent has recovered or died. As a result, programmes might seek to provide services for CABA over a longer timeframe.

Children affected by HIV and AIDS need support that begins before their parent needs externally-supplied care and support (i.e. by a HBC programme) and continues after the parent ceases to need that care (i.e. has recovered or died).

In some cases, the entry point is still the illness of a PLWHA, with activities for affected children commencing with the provision of HBC to an adult in the household. In this case, however, care for CABA continues after the need for HBC comes to an end.

This approach offers a significant and long-term support mechanism for children as they continue to face the challenges associated with growing up in an environment of HIV and AIDS, often without their parents to guide and support them. However, it has wide-reaching implications for the organisation in question – as it implies an ongoing relationship with affected children and their families that extends beyond the bereavement stage.

What might be the benefits?	What might be the challenges?	What might help?
• Provides long-term care and support to CABA • Helps volunteers provide more comprehensive care and support for families • Reduces the concerns of PLWHA about their children's suffering and future • Assists CABA cope with life after the death of their parent(s) and meet emerging challenges, such as stigma, and the risk of abuse or exploitation.	• May still not recognise the needs of CABA before adults become seriously ill • Significant additional volunteer time is required to meet CABA needs on a long-term basis • Since many CABA, especially orphans, need long-term support, the cumulative number of programme clients grows significantly over time.	• Identifying and collaborating with other actors who can meet the longer-term needs of CABA • Facilitating broad community mobilisation and capacity development to ensure the wider community understands, accepts, and is trained in its role in relation to care and support for CABA • Training and supporting families and carers to develop their capacity for longer-term caring and coping • Advocating the benefits of more comprehensive responses.

8.2 Short-term approach

Programmes may not always be able to deliver long-term support for CABA. In such cases, providing some support for CABA at a time of crisis is better than providing nothing at all. This commitment to short-term care and support might also be an interim step, particularly for an organisation that is moving towards delivering services over a longer timeframe.

If activities for CABA are linked to HBC programmes, they might be only provided when an adult relative is receiving support. In other words, CABA activities would start when the adult began to receive HBC, and end when they were no longer receiving the service. This means that such CABA activities would be implemented over a relatively short timeframe – an approach that could be termed 'crisis intervention'. Although this is not as ideal as longer-term support for the child, it is preferable to a situation in which none of the child's needs are met by HBC services. It might also be an interim step, particularly for an organisation that is moving towards providing more long-term solutions.

What might be the benefits?	What might be the challenges?	What might help?
• Provides some time-limited care and support to CABA • Helps volunteers provide more comprehensive care and support for families • Reduces the concerns of PLWHA about their children's suffering and future.	• It does not recognise or meet the needs of CABA prior to adult relatives becoming seriously ill • Care and support for CABA may end when the parent dies, leaving the child in severe crisis • Additional volunteer time is required to meet the needs of CABA.	• Identifying and collaborating with other support-providers who can meet the longer-term needs of CABA • Facilitating broad community mobilisation and capacity development to ensure the wider community understands, accepts, and is trained in its role in relation to care and support for CABA • Training and supporting families and carers to develop their capacity for longer-term caring and coping • Advocating the benefits of more comprehensive responses.

9 Do programmes have a holistic approach or a more narrow medical focus?

9.1 Holistic focus

Many HBC programmes have shaken off their exclusive health focus in order to provide more holistic services for PLWHA, their families, carers, and children. Such initiatives often rely strongly on community-based volunteers and may use them to identify sick people within their catchment area, rather than relying on referrals from health facilities. These programmes are well placed to proactively identify CABA in the community rather than only becoming involved with them when their parents require HBC.

It is clearly ideal to offer comprehensive, holistic services to PLWHA and CABA. However, considerable financial and human resources are needed to do this well, and ensure that the services are of an acceptable standard.

What might be the benefits?	What might be the challenges?	What might help?
• Provides long-term proactive and reactive care and support to CABA and PLWHA • Helps volunteers provide more comprehensive care and support to families • Reduces the concerns of PLWHA about their children's suffering and future • Assists families and children build their life skills and support structures prior to an adult becoming ill or dying.	• Needs sensitive and transparent procedures for identifying households and CABA • Can create very high demands on volunteers' time • The risk that the programme might try to meet all the needs and in so doing fail to provide quality services for any of them.	• Identifying and collaborating with other service-providers who can meet the longer-term needs of CABA • Facilitating broad community mobilisation and capacity development to ensure the wider community understands, accepts, and is trained in its role in relation to care and support for CABA • Training and supporting families and carers to develop their capacity for longer-term caring and coping • Advocating the benefits of more comprehensive responses.

9.2 Medical focus

Efforts with a narrow medical focus are more likely to be able to provide quality services in their specific area, but do risk overlooking other major areas of need that might be more important to the families concerned.

Many HBC programmes were established with a relatively narrow medical focus. They were often started and managed by health workers and emphasised areas such as nursing services and the provision of medicines. In some situations, this approach continues. Most of these programmes have no activities for CABA; those that do have activities for CABA tend to focus on limited services addressing children's physical and medical needs. Again, although this is not as ideal as a more holistic approach, it is preferable to a situation in which none of the child's needs are met by HBC services.

What might be the benefits?	What might be the challenges?	What might help?
• Staff and volunteers often have considerable expertise in their specific area of focus • High quality services might be provided in the area of focus, such as nursing and medicines for PLWHA, and physical support for CABA.	• A narrow focus can lead to important areas, such as the psychosocial needs of CABA or food security for households affected by HIV and AIDS, being overlooked • Shorter-term, crisis intervention approach • A strong focus on the quality of services might limit the programme's coverage.	• Identifying and collaborating with other service-providers who can meet the longer-term needs of children • Facilitating broad community mobilisation and capacity development to ensure the wider community understands, accepts, and is trained in its role in relation to care and support for CABA • Training and supporting families and carers to develop their capacity for longer-term caring and coping • Advocating the benefits of more comprehensive responses.

10 Supporting the process

10.1 Information and advocacy for integration

Effective information and advocacy work is needed to encourage and support the process of integrating HBC and CABA services and the development of more comprehensive responses to HIV and AIDS at community level. This involves sensitising and informing key stakeholders at different levels, including:

- **Community-level decision-makers** (such as chiefs, religious leaders, and clinic workers) – and the wider community, who influence the way in which families provide care and support to PLWHA and children. It is important to encourage community ownership of and involvement in the response to HIV and AIDS, and support CBOs/NGOs that are trying to provide a more comprehensive response
- **Implementing CBOs/NGOs** – which provide care and support, are in a position to carry out more integrated and comprehensive responses. These organisations need to understand that community support for CABA is vital for both the well-being of children and their parents' and other adults' peace of mind. They can be encouraged by the fact that integration can be achieved through a variety of different methods, and each can produce good results if it is done well. Many similar CBOs/NGOs have gone through integration and have valuable lessons to share, so they need not feel unsupported. Also, comprehensive responses are more attractive to some donors than vertical programmes
- **CBO/NGO support providers** – who can encourage, facilitate, and resource the integration process. These organisations can encourage and support their partners to work with their communities to conduct needs assessments, provide access to training if new skills are required, and act as a clearing house for information and lessons to support the process of integration. Many CBO/NGO support organisations, including SAT, are committed to encouraging and facilitating the development of more comprehensive responses at community level
- **Government** – which can, at all levels, create and sustain an enabling environment for more integrated and comprehensive community-level responses. A key role for government is to make a multi-sectoral response a reality; this includes emphasising that it is appropriate for communities to care for and support themselves, whilst supporting and increasing the impact of these efforts through the actions and facilities of public health and social welfare services.
- **Donors and other resource providers** – who are important providers of financial and other resources and hold considerable leverage in terms of shaping the direction of community responses. Donors should know that integrating CABA and HBC activities is a practical and proven way of achieving more comprehensive community-level responses.

10.2 The role of CBO/NGO support providers

CBO/NGO support providers such as SAT have a crucial role to play in supporting community groups to develop more comprehensive responses to HIV and AIDS. This support is characterised by a long-term relationship that tends to combine financial resources, technical and programmatic capacity-building, and organisational development.

CBO/NGO support providers are well placed to encourage, facilitate and support groups to integrate HBC and CABA activities and thus achieve more comprehensive programmes. They can do this in many ways, including by:

- Facilitating structured study visits and mentoring relationships between organisations that have completed integration and those that are starting it
- Supporting partners in reassessing their programmes and understanding the rationale and steps involved in integration
- Encouraging participatory monitoring and evaluation processes – to help mobilise communities to change, and help CBOs/NGOs to track the progress and impact of integration
- Providing financial support to encourage integration
- Building skills in core aspects of community care and support, such as counselling, as well as skills in specialised areas of HBC and CABA activities, such as counselling for children who have been sexually abused
- Developing participatory training manuals and other resource materials to support the integration process
- Documenting, testing, and disseminating lessons learned from CBO/NGO experiences of integration
- Advocating and mobilising support for more comprehensive approaches at community level.

10.3 Supporting the development of comprehensive community responses

The need to develop more comprehensive responses to HIV and AIDS at community level is becoming ever clearer. In the past, issues of care, support, prevention, treatment, and income generation were often compartmentalised in 'vertical' projects operating in the same community. It has now been shown that this approach is less effective than one that is more integrated. This is partly because it does not mirror communities' natural ways of coping and caring and, as such, does not encourage local participation and ownership.

As the HIV and AIDS pandemic continues to pose the severest challenges to communities across southern Africa and other parts of the world, the time has come for all stakeholders to renew their commitment to the development of more comprehensive responses at community level. This publication has focused on one practical way in which this can be done.

APPENDIX 1: Workshop participants

Name	Position, organisation, and location
Mubondo Barabona	Executive Officer, WAMATA, Dar es Salaam, Tanzania
Sr O. Cunniffe	Co-ordinator, Dananai Centre, Murambinda, Zimbabwe
Eduardo Paulo Jacobo	Home Care Provider, Kubatsirana, Chimoio, Mozambique
Sauso Kapindu	Project Officer, Edzi Kumuzi Association, Nathanje, Lilongwe, Malawi
Phiriel Kiwia	Programme Co-ordinator, Kimara Peer Educators, Dar es Salaam, Tanzania
Cathy Maddan	Training Manager, Sinosizo, Durban, South Africa
Sr Caroline Mafuta	Home-Based Care Co-ordinator, Katondwe Mission Hospital, Zambia
Gift Moyo	Programme Co-ordinator, Tshelanyemba Hospital, Maphisa, Zimbabwe
Alex Mugume	Projects Co-ordinator, TASO, Kampala, Uganda
Victor Mulimila	Training Co-ordinator, Faraja Trust Fund, Morogoro, Tanzania
Gladys Mwanza	Orphan Care Co-ordinator, Nkotakota AIDS Support, Nkota Kota, Malawi
Steve Ndiwo	Programme Manager, Reford, Thuchila, Mulanje, Malawi
Ben Njovu	Manager, AIDS Management and Training Programme, Chikankata, Zambia
Arlindo Novele	Project Co-ordinator, Association Khanimambo, Maputo, Mozambique
Daniel Simbeya	AIDS Co-ordinator, St Francis Katete AIDS Care and Prevention Project, Zambia
Sandie Simwinga	HIV/AIDS Programme Officer, Churches Health Association Zambia, Zambia
Nonia Temberere	Acting Programme Manager, FACT Rusape, Rusape, Zimbabwe
Amon Tisibele	Home-Based Care/Orphans and Vulnerable Children Co-ordinator, Batsirai Group, Chinhoyi, Zimbabwe
Tim Lee	SAT Executive Director
Benneta Mabvira	SAT Programme Assistant: Communications and Publications
Elisha Maricho	SAT Programme Officer: School Without Walls

APPENDIX 2: Effects of HIV and AIDS on children's lives

Economic effects:

- Sick family members cannot work and family savings are used for medicines. As a result, household income is reduced, nutrition worsens, and homes are poorly maintained
- Family members, including children, look for other sources of income, such as sex work, early marriage, and living on the streets
- If affected children are moved to their extended family, the financial stability of those households is reduced.

Educational effects:

- The extra responsibilities and burdens may cause children to drop out of school
- Traditional skills die with parents before they can be taught to children
- Orphans are stigmatised by other children, even at school.

Social effects:

- Death is not discussed, so children do not understand what is happening until their parent dies
- Greedy relatives disregard wills and leave nothing for the children of the deceased
- Children and elderly people become the head of households
- Poor families become forever impoverished, moving from poverty to destitution.

Psychological effects:

- Signs of damage, such as depression, aggression, and malnutrition, can arise at any time, from days to years, after a person or child has been affected by HIV and AIDS
- Loss of consistent nurture and guidance may cause serious developmental problems and lead to difficulties in maturing and integrating with society
- Children worry about where they will go and who will care for them
- Children may not understand the situation and thus be unable to express their grief effectively. Moreover, even if they want to, there may be no one to listen to them.

(Adapted from: *Investing in Our Future: Psychological Support for Children Affected by HIV/AIDS, a case study in Zimbabwe and The United Republic of Tanzania,* UNAIDS (2001), pp.19-20.)

APPENDIX 3: Summary of lessons learnt

This report highlights a number of key lessons learnt by CBOs/NGOs that are integrating HBC and CABA activities in southern Africa. These lessons are:

- Understanding why projects developed the way they did may help us to understand the barriers to addressing HBC and CABA together, and to identify the best way to integrate them.
- People receiving HBC worry about the well-being and future of others, particularly their spouses and children. Meeting the needs of PLWHA requires us to also think about the needs of the affected person's wider family and their carers.
- Family carers are usually very concerned, not just about the sick adult but also for the children of the household. Meeting the needs of carers requires us to also think about the needs of children.
- Children are severely affected by the illness of a parent. They need care and support throughout this time, not only if and when the parent is bed-ridden or dies.
- The needs of adults and children can follow quite different courses. Community responses must be tuned into these differences and be flexible enough to respond to each in the right way and at the right time.
- A merger may be a viable option where HBC and CABA projects are implemented by the same organisation.
- The core motivations of community care and support volunteers are similar, regardless of whether they work with adults or children. Motivating factors include feelings of compassion, commitment, community service, and/or religious duty. However, the specific interests and capacities of individual volunteers may vary. For example, an HBC volunteer might not automatically be comfortable or willing to provide support to affected children.
- New CABA activities will be needed where there are no existing activities with which an HBC programme can merge.
- Children should not be the passive recipients of services, but rather be active participants at many different levels. CBOs/NGOs should design appropriate strategies to ensure their greater involvement.
- Integration is a process, not an event. It requires careful and participatory planning, as well as proactive consultation with key stakeholders. This can prevent structural problems in programme development.
- Although community care and support volunteers possess certain core skills (counselling, for example), there are specific and different skills needed for effective HBC and CABA work. HBC volunteers typically need training in a wide range of children's issues for programme integration to be successful. This includes areas such as psychosocial support for children, child development, life skills and communication skills for 'joining' with children and building mutual trust.
- Major programme redesign may be needed where current HBC approaches and structures are poorly suited to CABA activities.
- Dynamic and strong community support, such as that provided by village caregivers, is a pre-requisite of a successful integrated programme.

- A single volunteer team is a radical and potentially more effective yet also more organisationally challenging option, particularly where existing programmes are being merged.
- Integrated services can be delivered at community level by separate volunteer teams if there is effective co-ordination.
- Children affected by HIV and AIDS need support that begins before their parent needs externally-supplied care and support (i.e. by a HBC programme) and continues after the parent ceases to need that care (i.e. has recovered or died).
- Programmes may not always be able to deliver long-term support for CABA. In such cases, providing some support for CABA at a time of crisis is better than providing nothing at all. This commitment to short-term care and support might also be an interim step, particularly for an organisation that is moving towards delivering services over a longer timeframe.
- It is clearly ideal to offer comprehensive, holistic services to PLWHA and CABA. However, considerable financial and human resources are needed to do this well, and ensure that the services are of an acceptable standard.
- Efforts with a narrow medical focus are more likely to be able to provide quality services in their specific area, but do risk overlooking other major areas of need that might be more important to the families concerned.

When increasing numbers of people in Southern Africa began to experience HIV-related illnesses in the late 1980s, public health services were soon overwhelmed and as a result a range of home-based care (HBC) initiatives were developed. Though many programmes were initiated by local health workers, they varied both in the way they were organised and in the services that were provided. At the same time, support programmes for children affected by HIV and AIDS (CABA) were developed. These built upon the traditional caring and coping practices of families and communities.

Today, there are many programmes in place that cater separately for people needing home-based care, and affected children. Such divisions, however, make little sense at the local level, where families and communities are trying to provide care for both groups. This has led to a growing interest in integrating responses in order to create more holistic and comprehensive programmes that address all these people's needs.

This report, which draws on the rich experiences of organisations working in the field, focuses on this growing trend to integrate home-based care initiatives with those serving children affected by HIV and AIDS. It provides a convincing rationale for integration and looks at the challenges as well as the benefits of doing so.

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