International HIV/AIDS Alliance

Save the Children

Supporting community action on AIDS in developing countries

Family-centred HIV programming for children

GOOD PRACTICE GUIDE

Good practice guide series

This guide is one in a series of good practice guides produced by the International HIV/AIDS Alliance (the Alliance). This series brings together expertise from our global community-level HIV programming to define and guide good practice in a range of technical areas, including:

- Human rights and GIPA
- Research, evaluation and documentation
- HIV prevention
- Sexual and reproductive health and rights and HIV integration
- HIV and tuberculosis
- HIV programming for children
- HIV and drug use
- Planning

Alliance good practice guides are:

- user-friendly ‘how to’ guides
- targeting HIV programmers working in community settings in developing and transitional countries
- helping to define what is good practice for community-level HIV programmes.

To download Alliance publications, please visit **www.aidsalliance.org/publications**.

How was this guide developed?

This guide to using a family-centred approach to HIV programming for children has been produced collaboratively by the Alliance and Save the Children UK. It draws on the experience and expertise of both organisations. It was developed in consultation with the Alliance and Save the Children staff and partners around the world, as well as other external technical specialists.

Save the Children UK are leaders in the areas of children’s rights, care, protection and participation, with specific organisational capacity in responding in emergency contexts. Save the Children UK is an advocate for family strengthening and family-based alternative care for vulnerable children.

The Alliance has expertise in comprehensive programming for children affected by HIV and AIDS across Asia and Africa. The organisation has developed a wide range of tools for implementing programmes for children, focusing on community action and mobilisation, work with key populations and children in concentrated epidemics. The Alliance has also produced research on the sexual and reproductive health needs of adolescents living with HIV.

Both organisations share a commitment to upholding children’s rights and ensuring their protection. They are also committed to listening to and valuing all children, and to keeping children in their communities and families wherever possible.

First edition published: January 2012

ISBN: 1-905055-96-8

Photos (from the top): Members of the Nyimbwa Multi-Purpose group, Nyimbwa, Uganda. The group works with children affected and infected by HIV and AIDS. © Nell Freeman for the Alliance.

The Mother Theresa children’s support group, set up as part of the CHAHA project, India. © The Alliance.

Outreach worker for sex workers’ association 21 de Septiembre and her son at a brothel in Esmeraldas, Ecuador. © Marcela Nievas for the Alliance.

Alliance good practice HIV programming standards – family-centred HIV programming for children

Each guide in the Alliance good practice series is accompanied by a set of programming standards. Implementing these is one of the ways that the Alliance, our partners and other organisations can define and promote a unified and quality-driven approach to HIV programming.

This good practice guide contains information, strategies and resources to help programme officers meet the good practice standards of our family-centred HIV programming for children. There are seven Alliance standards that guide HIV programming for children. This guide focuses on Standards 6 and 7 that directly relate to implementing family-centred HIV programming. The other five standards are detailed in Appendix 1.

ALLIANCE GOOD PRACTICE HIV PROGRAMMING STANDARDS FOR FAMILY-CENTRED HIV PROGRAMMING FOR CHILDREN	
Good practice standard 6	Our organisation promotes a family-centred approach, reaching children within and through their families and communities.
Good practice standard 7	Our organisation promotes and/or provides integrated family-centred services in health, education and social welfare in order to address the needs and rights of children.

KEY RESOURCE

The full Alliance good practice HIV programming standards for a range of technical areas can be found at:
www.aidsalliance.org/Publicationsdetails.aspx?Id=451

French version
www.aidsalliance.org/Publicationsdetails.aspx?Id=452

Spanish version
www.aidsalliance.org/Publicationsdetails.aspx?Id=453

Acknowledgements

Authors: Ros Kent, Kate Iorpenda and Alice Fay

Project coordinators: Kate Iorpenda and Alice Fay

Copy editor: Kathryn Perry

Final review team: Bill Bell (Save the Children UK), Linda Richter (HSRC/Global Fund), Christine Stegling (Alliance).

Reviewers: Henk van Beers (Save the Children, Cambodia), Annet Biryetega, Kendra Blackett-Dibinga (Save the Children US), Emily Delap (Everychild), Kate Harrison (Comic Relief), Ian Hodgson (independent consultant), B. Keerthi (VMM, India), Pat Lim Ah Ken (UNICEF, US), Ronnie Lovich (Save the Children US), Maxwell Madzikanga (IFRC), Sita Michael Bormann (Save the Children, Denmark), Rita Muyambo (Alliance South Africa), Hannah Newth (Save the Children, Côte d'Ivoire), Caroline Enye (Save the Children, Nigeria), Nina O'Farrell (Christian Aid), Hak Phirath (KHANA, Cambodia), Rebecca Sinclair (VSO), Chea Thira (KHANA, Cambodia), Andrew Tomkins (Institute of Child Health), Maria Zuurmond (LSHTM).

Contributions: Rachel Albone (Help Age International), Olivia Dix (The Princess Diana Memorial Fund), Choolwe Haamujompa (Alliance Zambia), Anne Nolan, Nthabiseng Nkwe (BONELA, Botswana), Lesley Holst (Save the Children Mozambique).

Thanks to the Alliance Best Practice Unit, the publishing and communications team, and the field programmes teams.

ABBREVIATIONS AND ACRONYMS

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
ARV	antiretroviral
CABA	children affected by HIV and AIDS
CBO	community-based organisation
HIV	human immunodeficiency virus
MARYP	most-at-risk young people
NGO	non-governmental organisation
OVC	orphans and other vulnerable children
PEPFAR	President's Emergency Plan for AIDS Relief (USA)
PPTCT	Prevention of parent to child transmission
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	The United Nations Children's Fund
VCT	voluntary counselling and testing
WHO	World Health Organization

Contents

Introduction

This guide is one of a series of good practice guides, and contains information, strategies and resources to help HIV programmers implement family-centred HIV programming for children.

The importance of family in the lives and development of children has long been recognised, as well as the need to strengthen a family's ability to care for their children. However, the HIV response has so far assembled only limited evidence and guidance for family-centred programming for children.

Historically, programmes working to meet the needs of children affected by HIV have targeted individual children to provide direct support, sometimes bypassing their family. Paediatric treatment and services for children have been delivered separately to those for adults. Care and support for ill people at home has not addressed the needs of children, many of whom are involved in caregiving. Recent evidence[1] suggests that outcomes for children affected by HIV could be improved by working with families as well as individual children. Our focus needs to shift towards supporting families to care for children, providing services that consider the needs of the whole family rather than only individuals within it.

This family-centred approach builds on relationships within the family to maximise the services delivered to children. Working with families in this way is the basis of a family-centred approach.

What is this guide for?

This guide aims to:

- increase understanding of the benefits of a family-centred approach to providing care and services for children affected by HIV
- show how a family-centred approach can complement and improve the impact of services such as health, education and social welfare provided directly to children
- assist programmers to apply a family-centred approach in programmes providing services to children affected by HIV
- support advocacy for family-centred approaches to programmes that provide care, support and treatment for children affected by HIV.

The guide will do this by:

- describing what is meant by a family-centred approach (Chapter 1)
- presenting a summary of the research indicating that a family-centred approach can achieve better outcomes for children (Chapter 1)
- describing different types of families, their characteristics and contexts (Chapter 2)
- setting out practical steps to implement family-centred approaches in our programmes working with children affected by HIV (Chapter 4)
- sharing case studies from around the world of programmes already using a family-centred approach (Chapter 4)
- examining some practical considerations for our organisations to help us prepare for family-centred working (Chapter 5)

KEY TO ICONS USED IN THIS GUIDE

🔍 Key resource

👁 Case study

✓ Good practice standard

? Explanation of key terms

---

[1] Joint Learning Initiative on Children and HIV/AIDS: www.jlica.org

- outlining cross-cutting principles that should be applied to ensure good practice when we plan and implement family-centred programmes (Chapter 6)
- describing how a family-centred approach can be more widely applied to programmes that are not primarily targeting children in order to ensure that they are included (Chapter 6).

Who is this guide for?

The guide is for people and organisations that are developing and implementing programmes for children affected by HIV in resource-limited settings. Family-centred programming has many benefits outside of the context of HIV. The guide will also be useful to anyone involved in developing and delivering services for children more generally.

Making it work in practice

This guide is designed as a resource to help our organisations implement a family-centred approach to caring for and protecting children, and providing the services they need. It aims to be useful across a broad range of contexts and cultures, and case studies from a number of countries have been included. We need to apply the principles offered here to our own contexts and adapt the approaches taken in many of the case studies. We do not expect any organisation to provide the full range of interventions described. Rather, organisations can apply the information and principles relevant to their own programmes. However, when we, as programmers, also understand the broad range of interventions that can support families and children using a family-centred approach, we can make better referrals to and create linkages with other services.

The guide is designed as a user-friendly and accessible resource. We provide references and resources for readers who wish to learn more about particular topic areas or interventions, and signposts to related or more in-depth tools and resources.

Language matters

Children affected by HIV

The term ‘children affected by HIV’ is used widely throughout this guide. It includes the following groups:

- children directly affected by HIV – this means children living with HIV and children living with a family member who has HIV
- children vulnerable to the impacts of HIV and AIDS – for example, children who have been orphaned, children living outside of parental care, or children in poor families
- children especially vulnerable to exposure to HIV because of their circumstances – for example, children injecting drugs and abused children who are sexually exploited
- children who are exposed to HIV through maternal infection.

We avoid the use of abbreviations and acronyms commonly used to describe children affected by HIV and AIDS – such as OVC, CABA, MARYP – or descriptions that are inaccurate and often stigmatising such as ‘AIDS orphans’.

This guide is designed to support children and their families who are affected by HIV in different ways. The starting point is our belief that children have the right to be treated with dignity and respect and that children can be an active part of the solution.

HOW OLD IS A ‘CHILD’?

In many countries there are different definitions and age ranges that can make it challenging for programmers. In this guide children are defined as 0–17 years. It is recognised that children go through a process of development between birth and the age of 18, and have varying needs at each key stage of development. These key stages of development are summarised in Appendix 3.

KEY RESOURCE

Sherr, L. et al. (2008), ‘A systematic review on the meaning of the concept ‘AIDS orphan’: confusion over definitions and implications for care’, AIDS Care 20(5): 527–36.

1

What is a family-centred approach?

In this chapter:

- Definition of a family-centred approach
- Why should we apply a family-centred approach to our work with children affected by HIV?
- What is the evidence that a family-centred approach can work in practice?
- Critiques of a family-centred approach

Definition of a family-centred approach

Historically, programmes working to meet the needs of children affected by HIV have targeted individual children to provide direct support, often bypassing the family. Paediatric treatment and services have been delivered separately to those for adults.

A family-centred approach acknowledges that a child's quality of life is interwoven with the life and experience of the family in which they live. Supporting them individually may not be enough to ensure the best possible quality of life for a child affected by HIV. A family-centred approach suggests that without addressing problems that affect the child at home, such as extreme poverty or sickness of family members, the best quality of life for that child will not be achieved.

WHAT IS A FAMILY-CENTRED APPROACH?

A definition of the family-centred approach that is widely used in the area of HIV is: *'A comprehensive coordinated care approach that addresses the needs of both adults and children in a family and attempts to meet their health and social care needs, either directly or indirectly, through strategic partnerships and/or linkages and referrals with other service providers.'*[2]

The above definition highlights two principles that are important in family-centred programming and policy development:

1. Social care and health needs are both addressed, including developmental, cognitive and emotional needs.

   A family-centred approach helps families to care for children within the family. It provides services in a way that is 'family friendly' and recognises the relationships between family members.
2. The holistic needs of the family are met by a number of different groups, so referral and coordination between groups and agencies is needed.

From this definition we can see that in family-centred programmes we need to know where the family of the child is and who the family members are – direct relatives, extended family, or carers in different settings. We need to know how the situation of the family affects the child, their wellbeing and their opportunities for development. The family-centred approach recognises that supporting the family is one of the most effective means of ensuring the best possible quality of life for the child. Supporting and strengthening families so that children can be cared for in a family setting, where possible, rather than in institutions such as orphanages, is key to a family-centred approach.

Family-centred services

As well as strengthening and supporting families, a family-centred approach looks at how services such as health or education can be provided in a way that is supportive and useful to families. Historically, funding for services for people living with HIV has been provided separately for adults and children. In some cases this has fragmented how services have been provided, so they are not offered in a way that is most effective for families.

---

[2] Wakhweya, A. et al. (2008), 'Children thrive in families: family centred models of care and support for orphans and other vulnerable children affected by HIV and AIDS', JLICA.

> “By focusing policy and service provision predominantly on the individual child, we miss the opportunity to draw on and strengthen the structure that is most effective in responding to children’s needs: the family.”[3]

Family-centred services can act as an entry point to support for all family members. To achieve this, those at the point of service delivery should be able to assess the needs of children and families, and link them to appropriate supports and services.

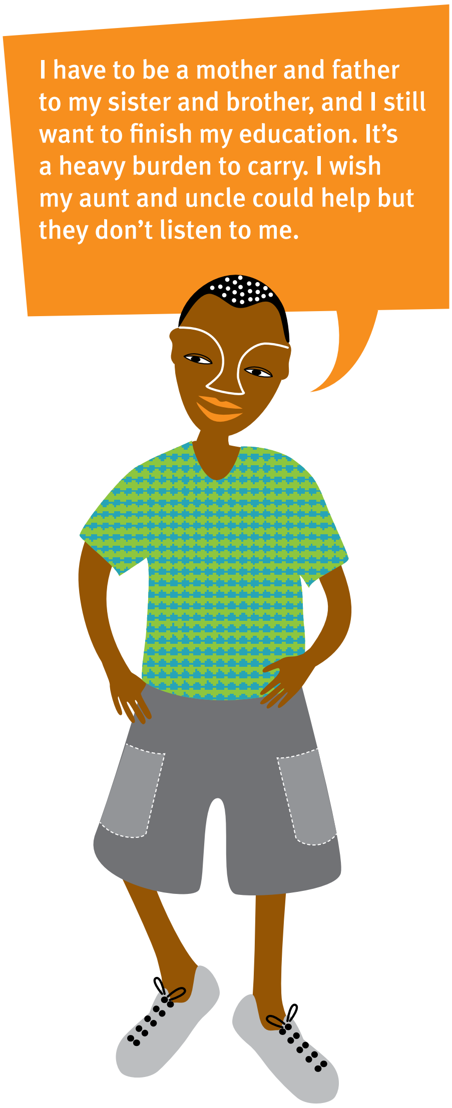
As we can see, the family-centred approach goes beyond providing programmes that are targeted only at children to consider the wider family and its role in supporting and caring for children. It also considers the impact that difficulties within the family have on children. This does not mean that we work only with families as the unit of support and no longer work with children as individuals. We need to assess all the factors that are affecting a child and provide the most appropriate programme.

In practice this may mean complementary programme components at different levels that target:

- children as individuals – for example, individual counselling, supplementary nutrition
- families or households as a unit – for example, access to child grants
- adults within a family to enable them to care for children or reduce the caring responsibilities of children – for example, support and companionship, savings and loans schemes, antiretroviral therapy.

Why should we apply a family-centred approach to our work with children affected by HIV?

There a number of reasons why a family-centred approach makes sense when we are planning and delivering programmes and policy initiatives for children affected by HIV. Many of these reasons will be familiar to us already. Some of the key ones are outlined below.



Families are the primary unit of care for children

Most children are cared for by their families. An estimated 95% of children who have lost one or both of their parents to AIDS live with a surviving parent or extended family members.[4] In most contexts, adult family members are the main providers of love, protection, care and socialisation for children. They have a strong influence on their children’s survival, health and educational achievement. Programmes and services – valuable as they are – tend to be transient, while families are lifelong influences on children. Therefore supporting families and developing their ability to care for their children will mean that the children themselves will benefit, both in the short and longer term.

Within some families in areas of high HIV prevalence children are no longer cared for by adults. Instead, they are the primary carers in the family, taking care of sick and elderly family members or younger children. Child and young adult carers bear a huge burden of responsibility for earning an income and providing physical care for others. Consequently, they are often deprived of opportunities for school, play and emotional support from adults. Providing support to all the family, including sick and vulnerable adults, can remove some of the child’s responsibilities and may enable them to return to school.

Interventions that provide direct support to vulnerable children are usually time limited. But strengthening the economic security and caring capacities of the family will have an impact beyond the life of the programme. Maintaining the

---

[3] JLICA (2009), ‘Home truths: facing the facts on children, AIDS, and poverty. Final report of the Joint Learning Initiative on Children and HIV/AIDS’.

[4] Hosegood, V. et al. (2008), ‘Demographic evidence of family and household changes in response to the effects of HIV/AIDS in Southern Africa: implications for efforts to strengthen families’, JLICA.

health of all family members, particularly adults, through early treatment and improved health care means that children are less likely to be orphaned and families can stay together.

There is evidence that the health, wellbeing and survival of a mother are critically important, particularly for children under the age of six. Research from East Africa shows that maternal survival and HIV status are strong predictors of child survival. The research demonstrates that higher maternal mortality in HIV-positive women compounds the risks of mortality for children, regardless of their HIV status.[5] Further research shows that the health of female carers, particularly mothers and grandmothers, has a significant impact on household welfare, including the nutritional status of children. The deaths of adult women decrease opportunities for children to attend school, while increasing nutritional insecurity and household poverty.[6]

Families provide the best outcome for children

There is also evidence that functional families provide the best outcomes for children. A functional family is one that is able to provide for the material and social needs of the child. It is motivated to care for, nurture and protect the child. Enabling families to function as well as possible in caring for their children will offer the best outcomes for children themselves. This may be achieved by providing economic support, developing the skills of family members, or giving family members companionship and support to meet the needs of their children.

In many contexts the HIV epidemic has resulted in large numbers of children being taken into institutional care even when they have surviving relatives. It is clear from the evidence that institutional care in most cases cannot offer children the same level of consistent love, support and care for their social, physical and cognitive development as they would get in a family setting. Moreover, the cost of institutional care for children can be up to ten times more than family care.[7] There needs to be a reallocation of current investments in orphanages into families and communities so that children can be better cared for within a family setting.

When there is need for residential care, it should be offered only in the short term when there is no family-based alternative such as kinship or foster care. It should always be part of a process of re-uniting children with their families or striving to establish them in permanent family settings.

Save the Children believe that children should be cared for in family settings unless this is impossible or unsafe. Care in institutions should only be used as a last resort. The organisation has a detailed set of resources in the *First Resort* series (www.savethechildren.org.uk/resources/online-library/a-sense-of-belonging-case-studies-in-positive-care-options-for-children) that provides guidance and case studies to help plan programmes to support families to care for children.

KEY RESOURCES

Csáky, C. (2009), 'Keeping children out of harmful institutions: why we should be investing in family-based care', Save the Children.

Doyle, J. (2010), 'Misguided kindness: making the right decision for children in emergencies', Save the Children.

SOS Children's Villages International and ISS (2009), 'Guidelines for the alternative care of children'.
Available at: www.ovcsupport.net/s/library.php?ld=988

Tolfree, D. (2005), 'Facing the crisis: supporting children through positive care options', Save the Children.

Tolfree, D. (2006), 'A sense of belonging: case studies in positive care options for children', Save the Children.

Williamson, J. and Greenberg, A. (2010), 'Families not orphanages', Better Care Network.

---

[5] Zaba, B. et al. (2005), 'HIV and mortality of mothers and children: evidence from cohort studies in Uganda, Tanzania and Malawi', Epidemiology 16(3): 275–80.

Nakiyingi, J.S. et al. (2003), 'Child survival in relation to mother's HIV infection and survival: evidence from a Ugandan cohort study', AIDS 17(12): 1827–34.

Shema, N. et al. (2009), 'HIV-free survival at 9-24 months among children born to HIV infected mothers in the National Program for the prevention of mother-to-child transmission of HIV in Rwanda: a household survey', Epidemiology 16(3): 275–80.

Sherr, L. (2008), 'Strengthening families through HIV/AIDS prevention, treatment, care and support', JLICA.

[6] Zoll, M. (2008), 'Integrated health care delivery systems for families and children impacted by HIV/AIDS: four program case studies from Kenya and Rwanda', JLICA.

[7] Desmond C. et al. (2002), 'Approaches to caring: essential elements for a quality service and cost effectiveness in South Africa', Evaluation and Program Planning 25(4): 447–58.

The United Nations (UN) *Guidelines for the Alternative Care of Children*[8] produced in 2009 also endorse the concept that children should be cared for within families whenever possible. However, while keeping children within a family is usually preferable, not every family is functional, and abuse and neglect within families does occur. Alternative care should be available when children are at risk, but in a family-like setting wherever possible. Many children are placed in alternative care in response to extreme poverty and economic stress rather than abusive or dysfunctional families. Providing support to families can help break this pattern. As well as preventing children being placed in alternative care, it can also allow children who are already in care to return to their families.

HIV within families

HIV can be transmitted within families: sexually between adult partners; through transmission from mother to child; and through sexual abuse between adults and children. If one member of a family is HIV positive it is likely that other members of the family have been exposed, either sexually or through parent-to-child transmission.

This is why it makes sense when an individual is diagnosed with HIV to assess the risk of all the family and offer counselling, testing, treatment for HIV and preventive services as needed. This can result in family members who are HIV positive receiving monitoring and early treatment. New infections can be prevented or reduced between discordant partners by providing voluntary counselling and testing, safer sex counselling, condoms and treatment. Prevention of parent-to-child transmission services (PPTCT) can also help prevent or reduce infections from mothers to subsequent children. Referral of family members for early diagnosis and initiation of treatment can help prevent infection within families.

A similar approach is used in tuberculosis (TB) services,[9] where contacting all of an individual's family members is a priority. However, currently most HIV services in developing countries provide testing and treatment to individuals in separate adult and paediatric clinics. A family-centred approach promotes assessing, testing and treating families as a unit, while acknowledging that services must carefully consider the ethics of confidentiality, consent and disclosure (see Chapter 4).

Family relationships affect the health choices of individuals

Family relationships and power dynamics within families can affect the uptake of information, advice or services of individual members. Women living with HIV may not feel able to act on health advice about exclusive breastfeeding and appropriate infant feeding if it is contrary to local norms or cultural practices. Family pressure and stigma from partners, in-laws and mothers to do things differently can stop women from acting upon the advice they have received. Health is influenced by a set of social relationships, cultural norms and practices. Using a family-centred approach can help us to assess the impact of family relationships and influences. We can then address them sensitively, finding information, advice and approaches that work within the family setting.

Impacts of HIV are experienced within families

When a person is diagnosed with HIV the impacts go beyond the individual themselves and affect other family members. The cost of treatment, travelling to medical appointments and the loss of income when they are unable to work

---

[8] UN (2009), 'Guidelines for the alternative care of children 64/142'. Resolution adopted by the General Assembly, 24 February 2010.

[9] International HIV/AIDS Alliance, 'Good Practice Guide: TB/HIV integration' (forthcoming).

reduces the money available within the family for essentials like food and school fees. Illness or death of the adult breadwinner may mean children need to leave school in order to work. Young girls may have to engage in sex work, or families may split when members migrate to find work and others stay behind.

Increased expenses and reduced income are likely to result in inadequate food, leading to malnutrition. The vulnerability of the whole family may be increased and their coping mechanisms eroded. On a social level, stigma and discrimination can extend to the whole family in areas where people with HIV are still stigmatised. This will affect social relations, work and educational opportunities, causing emotional distress and isolation. A family-centred approach recognises how HIV affects the whole family, and develops policies and programmes that increase the resources and resilience of the family as a whole.

What is the evidence that a family-centred approach can work in practice?

In 2004 and 2008 two global initiatives were set up to identify strategies that would lead to the greatest improvement to the quality of life for children affected by HIV. These were:

- **The Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS (an interagency consensus document produced by UNICEF)**[10]
- **The Joint Learning Initiative on Children and HIV/AIDS (JLICA)**[11]

KEY RESOURCE

DeGennaro, V. and Zeitz, P. (2009), 'Embracing a family-centred response to the HIV/AIDS epidemic for the elimination of pediatric AIDS', Global Public Health 4(4): 386–401.

Experts, researchers, implementers, activists, policymakers and people living with HIV from different parts of the world collaborated over a number of years to come up with a set of recommendations. Following an extensive analysis of research and evidence, and drawing on their professional and personal experience, both groups strongly recommended working with families in order to provide the greatest benefits for children affected by HIV.

Both groups have since produced a range of additional documents and resources. A companion document to the 2004 framework was launched in

A SUMMARY OF THE RECOMMENDATIONS OF GLOBAL INITIATIVES TO IDENTIFY STRATEGIES TO IMPROVE THE LIVES OF CHILDREN AFFECTED BY HIV

Support children through families.

Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support, especially access to social protection such as cash transfers.

Mobilise and strengthen communities to support families.

Ensure access for orphans and vulnerable children to essential and integrated services, including education, health care and birth registration.

Ensure that governments protect the most vulnerable children through policy and legislation, and channelling resources to families and communities.

Raise awareness at all levels through advocacy and social mobilisation to create a supportive environment for children and families affected by HIV.

---

[10] UNICEF (2004), 'The framework for protection, care and support for orphans and vulnerable children living in a world with HIV and AIDS'.

[11] JLICA (2009), 'Home truths: facing the facts on children, AIDS, and poverty. Final report of the Joint Learning Initiative on Children and HIV/AIDS'.

2011.[12] Building on the principles and approaches of the 2004 framework, this brings in new evidence and experience of:

- child vulnerability in the context of HIV
- the importance of child-sensitive social protection
- the importance of protecting the most marginalised children
- data on programmes for children
- how resources are reaching children and families.

The new guidance also recognises the advances in international thinking around alternative care for children presented in the Guidelines for the Alternative Care of Children,[13] and recent developments in child-sensitive social protection. It offers national-level guidance, and this good practice guide will complement it by applying the framework at the programme level.

Both UNICEF and JLICA recommend supporting children in and through families. They emphasise the importance of children having access to essential services. Both groups also prioritise targeting interventions at family, community service and policy levels. This is to ensure joined-up working, and sustainable services and support for children and families affected by HIV (see Chapter 2).

Evidence of the effectiveness of family-centred interventions

Research that directly compares programmes using family-centred approaches to those that focus on individual children would be difficult to conduct. However, there is evidence demonstrating the effectiveness of family-centred approaches in specific family-centred interventions for HIV. For example, family-centred PPTCT programmes have shown an increased uptake of services.[14] There is also a growing evidence base to support the effectiveness of social protection measures such as cash transfers in improving outcomes for children.[15] Further evidence for specific interventions is included in Chapter 4.

In order to validate and contribute to this emerging evidence base, it is important that we use it in conjunction with international guidance and our own experience to develop mechanisms to evaluate our family-centred programmes.

Critiques of a family-centred approach

Looking at current critiques of a family-centered approach allows us to effectively evaluate our own contexts and how this approach will be most successful. A number of criticisms have been raised.

Families do not always prioritise the needs of children

The success of family-centered approaches depends on families acting as functional units and adults prioritising the wellbeing of their children. It assumes that if resources are targeted towards families, adults will use these resources effectively to benefit their children. But we know this is not always the case. In many cultures men have the final say on how resources are used. They may prioritise activities outside of the family over providing food, paying for treatment or school fees for children. There may also be issues around the allocation of household resources related to the gender or age of children, and whether they are biological or extended family members.

---

12. UNICEF (2011), 'Taking evidence to impact: making a difference for vulnerable children living in a world with HIV and AIDS'.

13. UN/ISS/SOS (2010), 'Guidelines for the alternative care of children: a United Nations framework'.

14. Aluisio, A. et al. (2009), 'Male partner HIV-1 testing and antenatal clinical attendance associated with reduced infant HIV-1 acquisition and mortality'. 5th IAS Conference on HIV Treatment, Pathogenesis and Prevention, Cape Town, abstract TUC105. Available at: www.ias2009.org/pag/Abstracts.aspx?AID=1530

15. Adato, M. and Bassett, L. (2009), 'Social protection to support vulnerable children and families: the potential of cash transfers to protect education, health and nutrition', AIDS Care 21(1): 60–75.

Families are not always functional and supportive of one another's needs

Family-centred testing and treatment approaches may work well in functional families but can have negative consequences in families where there are abusive power relations that are not addressed or where parenting is compromised. In some contexts, disclosure of HIV within the family can result in violence or individuals being thrown out of the family group. Understanding family dynamics is important to assessing the effectiveness and safety of providing family-centred services.

Ethical issues

Ethical issues around the specific intervention of families and couples testing and attending health services have also been raised. Unless appropriate care is taken, couples and families attending services together may lead to compromised patient confidentiality and denial of individual rights. It is also crucial that family testing considers the life long commitment that is required by family members within treatment initiation and that children are aware of their options and have adequate follow up support.

Cost implications

There can be concerns that a family-centred approach will be more expensive to implement in certain types of programme, limiting the ability to take such programmes to scale. For example, the need for multi-disciplinary teams to provide family-centred case management may require additional training for health and social work staff, and could result in increased costs. However, having a number of services located in one place may have cost benefits, such as reduced infrastructure costs, and reduced transport and time costs for families. Costs may be higher in the short term as family-centred services are established, but lead to efficiencies in the long run.

There has been little work done to analyse the cost of different types of family-centred programmes. This needs to be researched and documented systematically, with evaluation of the benefits in terms of health outcomes for children and families in relation to costs. However, some exploratory work has been carried out using a methodology called social return on investment (see case study below).

WHAT IS 'SOCIAL RETURN ON INVESTMENT'?

Social return on investment is a way of measuring the value created by a programme, or series of initiatives. It is of particular relevance to programmes where there is no way of allocating a monetary value to outputs. It is a community-led approach, where progamme beneficiaries define the financial value to represent the impact of social, health and economic outcomes.

CASE STUDY: MEASURING THE SOCIAL RETURN ON INVESTMENT IN INDIA

Alliance India has been adapting and piloting a method to measure the social return on investment (SROI). A study in Maharastra and Andhra Pradesh, India, in 2010 calculated a SROI of US$6.97 for every US$1 invested in the CHAHA programme for children affected by HIV and their families.

Children aged over 10, and their parents and carers, were asked to assign values to the outcomes from nutritional and educational support, support in household emergencies, income-generating projects, and support to access antiretroviral therapy. As a result, CHAHA has been able to identify which activities generate the most value for beneficiaries. These include work on increasing household income through income-generating projects, and linkages to nutritional support, ration cards and under-five feeding centres. These activities have lessened economic strain on households by reducing hospital visits and transport costs, and have improved educational attainment. The study found less value in the more welfare-based assistance, such as household emergency grants.

This methodology is still being tested, and there is more work needed to develop other tools to measure the value of different inputs for families and their outcomes for children. However, SROI could be useful as a tool to begin to focus on programme activities that have most 'outcome value' in order to compare interventions and maximise outcomes for beneficiaries.

CHAHA is funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria and is implemented by Alliance India and its partners.

2 What do we need to know about families?

In this chapter:

- Definitions of family
- Common ‘shapes’ of families
- What characteristics of families are relevant to designing programmes?
- Contexts in which families live
- Who are the people and what are the places that support families?

In order to work effectively with families we need to understand what we mean by 'family'. We need to understand how families function, what influences them, and the places and people from which they receive support.

Definitions of family

The word 'family' has different meanings to different people around the world. There is no clear definition of family that is universally accepted. Diverse family structures exist in various parts of the world, with the nature of relationships and the power dynamics between men and women and adults and children varying across countries and cultures. New variants on traditional family structures have emerged in response to conflict, crisis and social change. Specifically, HIV has caused new forms of family to appear as a result of multiple deaths within traditional family units. As a result, new broader definitions of family have emerged.

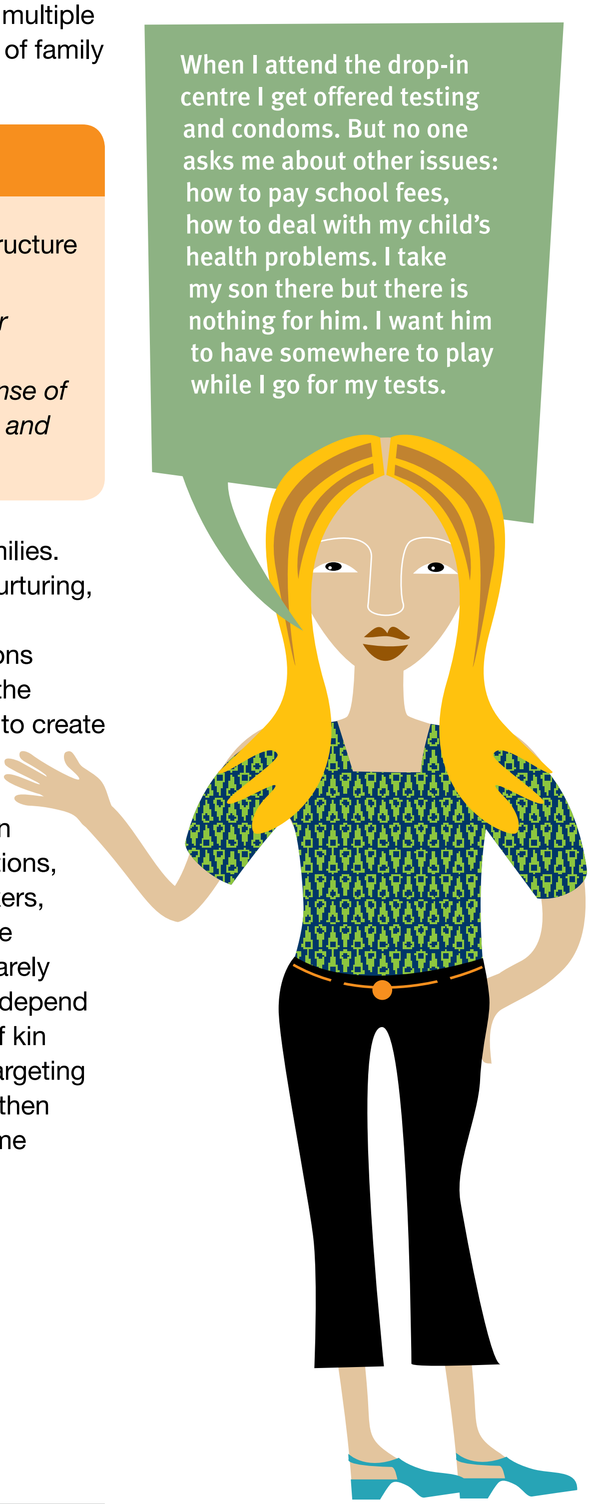
WHAT IS A 'FAMILY'?

This guide uses the following definition of family, which refers to the structure of the family and the roles and relationships of its members:

'Families are social groups connected by kinship, marriage, adoption or choice. Family members have clearly defined relationships, long-term commitments, mutual obligations and responsibilities, and a shared sense of togetherness. Families are the primary providers of protection, support and socialisation for children and youth.'[16]

From this definition we can see that there are many different types of families. While the structure of families may vary, their functions with respect to nurturing, rearing and protecting children remains constant. Throughout this guide, where we use the word 'family' we acknowledge the different compositions of families, from birth families to extended families. This is illustrated by the following examples of real family groups. We have used these examples to create characters who will speak throughout the guide.

These characters help us to see that families can take many forms. When thinking about families it is important to remember people in key populations, such as men who have sex with men, people who inject drugs, sex workers, migrants and refugees. These groups are often targeted through separate programmes. They are assumed to be isolated from family life, and are rarely asked about their partners or children. But people in these groups often depend on their biological families and, like others, form new families made up of kin and friends. A family-centred approach can be applied in programmes targeting key populations to assess the needs of each individual's children. It can then incorporate supports and services to meet their needs into the programme design.



---

[16] JLICA (2009), 'Home truths: facing the facts on children, AIDS, and poverty: final report of the Joint Learning Initiative on Children and HIV/AIDS'.

My name is Shilpal. I am a 65-year-old grandmother from South India. I have been sole carer for my two grandchildren, Amar (11) and Smita (9), since their parents died seven years ago. Both children are HIV positive and are receiving treatment.

My name is Innocent. I am 17 years old, I look after my sister who is 12 and my brothers who are 9 and 7 since my parents died. I try to go to school most days, but sometimes I have to work to find money for food.

My name is Marie-Angela. I make a living as a sex worker. I have a son but he mostly lives with my mother outside Buenos Aires. I would like him to stay with me but I have no one to look after him at night when I am working. I visit him as often as I can.

My name is Grace. I work for an international non-governmental organisation in Lusaka, Zambia. I have two children, Comfort and David, and I also care for my sister's four children and two of my brother's children. My sister and brother have both passed away.

My name is Ferdinando. I live in Beira in Mozambique. I am HIV positive. I lost my wife last year and now I look after my two daughters. I lost my job when I was sick and now I can't afford to send my kids to school. My youngest daughter is also living with HIV.

My name is Alexi. I live in Kiev in Ukraine. I left home when I was 12. I have lived on the streets for three years. Twelve of us live together and look after each other.

Common 'shapes' of families

There are a number of 'shapes' of families commonly found in the context of HIV. We will look here at some of those we work with in our programmes.

Child-headed households

Some families have no surviving adult and are headed by children. A synthesis of reviews[17] of national household-level surveys and Demographic Surveillance Systems data in Sub-Saharan Africa demonstrated that less than 1% of children live in child-headed households. Children may head households for temporary periods related to the migration or death of an adult, or during the time before orphaned children are taken into extended families or community care. Often these child-headed households receive support from extended family or community members.

However, many young people are still required to make decisions alone about the care of their siblings. They deal with the daily burden of finding food and materials for the family. And while being responsible for younger children, they may also be dealing with their own trauma and stress of bereavement. These children often miss school because of their caring roles, and can feel stigmatised and isolated. Their experiences vary due to age, gender and the amount of external support they receive,[18] and we must consider these different influences and stages of transition in our responses.

Households headed by grandparents or vulnerable adults

Many children live in households with older carers such as grandparents or young adults. Studies in South Africa and Uganda found that approximately 40% of orphaned children are living with their grandparents, and in Zimbabwe more than half.[19] In many countries HIV has led to a lost 'middle generation' of adults, leaving grandparents and grandchildren together as a family unit to provide care and support for one another. Older adults are often among the poorest in communities, and have fewer opportunities to earn an income for the household. Consequently, children in families headed by older adults often have to undertake caring and earning responsibilities. This means they are frequently withdrawn from school,[20] and miss out on playing and interacting with other children of the same age.

Providing care has a major impact on grandparents' lives. As people age, their ability to earn an income reduces. They may also be trying to cope with declining health related to ageing. Looking after children is both physically and emotionally demanding, especially when the grandparents are already grieving for the loss of their own children. Caring for grandchildren also brings additional costs: school fees and uniforms, and providing food, shelter and health care. Grandparents may have to sell assets like land in order to get by. Of course, the role may also bring great rewards.

Children and young adults in AIDS-affected households often take on significant caring roles for sick or older carers. Research is building a picture of the positive

KEY RESOURCES

Clacherty, G. (2009), 'Participatory child-led research with children who are carers in Kafanchan Town, Kaduna State, Nigeria: a case study', Save the Children.

Save the Children (2010), 'Child carers: child-led research with children who are carers. Case studies from Angola, Nigeria, Uganda and Zimbabwe'.

Available at: www.savethechildren.org.uk/en/54_12080.htm

Young Carers Project South Africa is a collaboration between the University of Oxford, the South African National Government and three South African universities.

Available at: http://youngcarers.org.za/

> "The children give me a lot of happiness. Seeing them in front of me is like a mirror to my life. Everything bad that has happened to me in the past seems worthwhile when I see them healthy and happy and going to school."
>
> Grandmother from Sudan[21]

---

[17] Hosegood, V. et al. (2008), 'Demographic evidence of family and household changes in response to the effects of HIV/AIDS in Southern Africa: implications for efforts to strengthen families', JLICA.

[18] Evans, R. (2010), 'The experiences and priorities of young people who care for their siblings in Tanzania and Uganda', Research Report, School of Human and Environmental Sciences, University of Reading.

Save the Children (2010), 'Child carers: child-led research with children who are carers. Four case studies; Angola, Nigeria, Uganda and Zimbabwe'. Available at: www.savethechildren.org.uk/en/54_12080.htm

[19] HelpAge International/International HIV/AIDS Alliance (2003), 'Forgotten families: older people as carers for orphans and vulnerable children'.

[20] Cluver, L. (2010), Research presented at Orphans and Vulnerable Children conference, South Africa, November 2010. Available at: www.plusnews.org/Report.aspx?ReportId=90988

[21] HelpAge International (2011), Presentation by Rachel Albone at Positively Caring Event, 22 March 2011. Available at: www.everychild.org.uk/positively_caring

potential of these roles.[22] As well as developing resilience and coping skills, children report added benefits of closer relationships with siblings and older carers, and community recognition for their caring work.

A number of reports have called for the specific needs of older-headed households,[23] child carers[24] and households headed by young adults[25] to be taken into account in the formulation of policy and programme interventions. For example, when planning interventions to strengthen the economic security of the family, the ability of older people to engage in income-generating activities needs to be assessed alongside the specific economic vulnerability of young adults who are sole carers for children. Social protection interventions have to be effective for supporting older-headed families with no adult who is able to earn an income, as well as families with child carers. These interventions should include grants and pensions that alleviate financial burdens and enable children to stay in school. They also need to help older carers to access services for themselves, and provide support around legal and inheritance issues.

What characteristics of families are relevant to designing programmes?

Change over time

It is important to remember that families do not always stay the same. Over time, changes occur in the family group and the roles that members play within it. This may be as a consequence of the death of an adult, resulting in children leaving school to earn an income or be absorbed into a new family unit. Sometimes family roles may change with the absence of a parent who has migrated for work, leaving children in caring roles. These changes can also affect the economic situation of the family and its ability to care for children and other family members. As families undergo so much change, it is important to regularly reassess their capacity to cope and thrive throughout the programme life.

Power dynamics and gender

Gender and power play an important role in the dynamics of families. They affect the interactions between members and the expectations of individuals. They also affect the socialisation of boys and girls, and the subsequent roles they play. Gender and power influence decision-making within families, especially around the allocation of resources or access to economic and educational opportunities.

Age, gender and family position can attribute power, and the misuse of power can lead to unequal decision-making and distribution of resources within a household. An illustration of this is the burden of care placed on women and girls for family members and household chores – specifically the care of people living with HIV. Girls are more likely to be removed from school to take on caring roles, and in economically deprived households resources for education are more likely to be allocated to boys. The impact of social norms around gender can mean that women and girls have limited participation and influence in community decision-making. It can also mean they are more vulnerable to violence and abuse within the family. This has a direct impact on their ability to make informed decisions around their health care, including if, when and where to test for HIV and access.

---

22. Skovdal, M. et al. (2009), 'Young carers as social actors: coping strategies of children caring for ailing or ageing guardians in Western Kenya', Social Science and Medicine 69(4): 587–95.

The International Network for Caregiving Children: www.caregivingchildren.org/academic-literature.html

23. HelpAge, International/International HIV/AIDS Alliance (2003), 'Forgotten families: older people as carers for orphans and vulnerable children'.

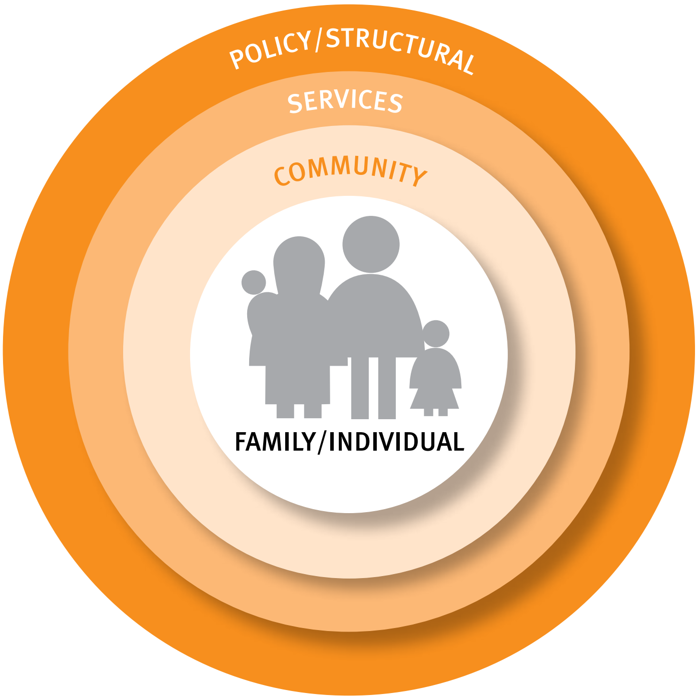
24. Save the Children (2010), 'Child carers: child-led research with children who are carers. Four case studies; Angola, Nigeria, Uganda and Zimbabwe'. Available at: www.savethechildren.org.uk/en/54_12080.htm

25. Richter, L. and Desmond, C. (2008), 'Targeting AIDS orphans and child-headed households? A perspective from national surveys in South Africa 1995-2005', AIDS Care 20(9) 1019–28.

Contexts in which families live

In order to design effective programmes and policy initiatives, we need to understand the context in which families exist and what influences them. We also need to understand the places from which families access support.

Across the world families rarely exist in isolation. In almost all circumstances families are based within a wider community and society, with its structures, policies, social norms and attitudes, systems and services. The context in which families exist can be represented in the simple diagram on the right.

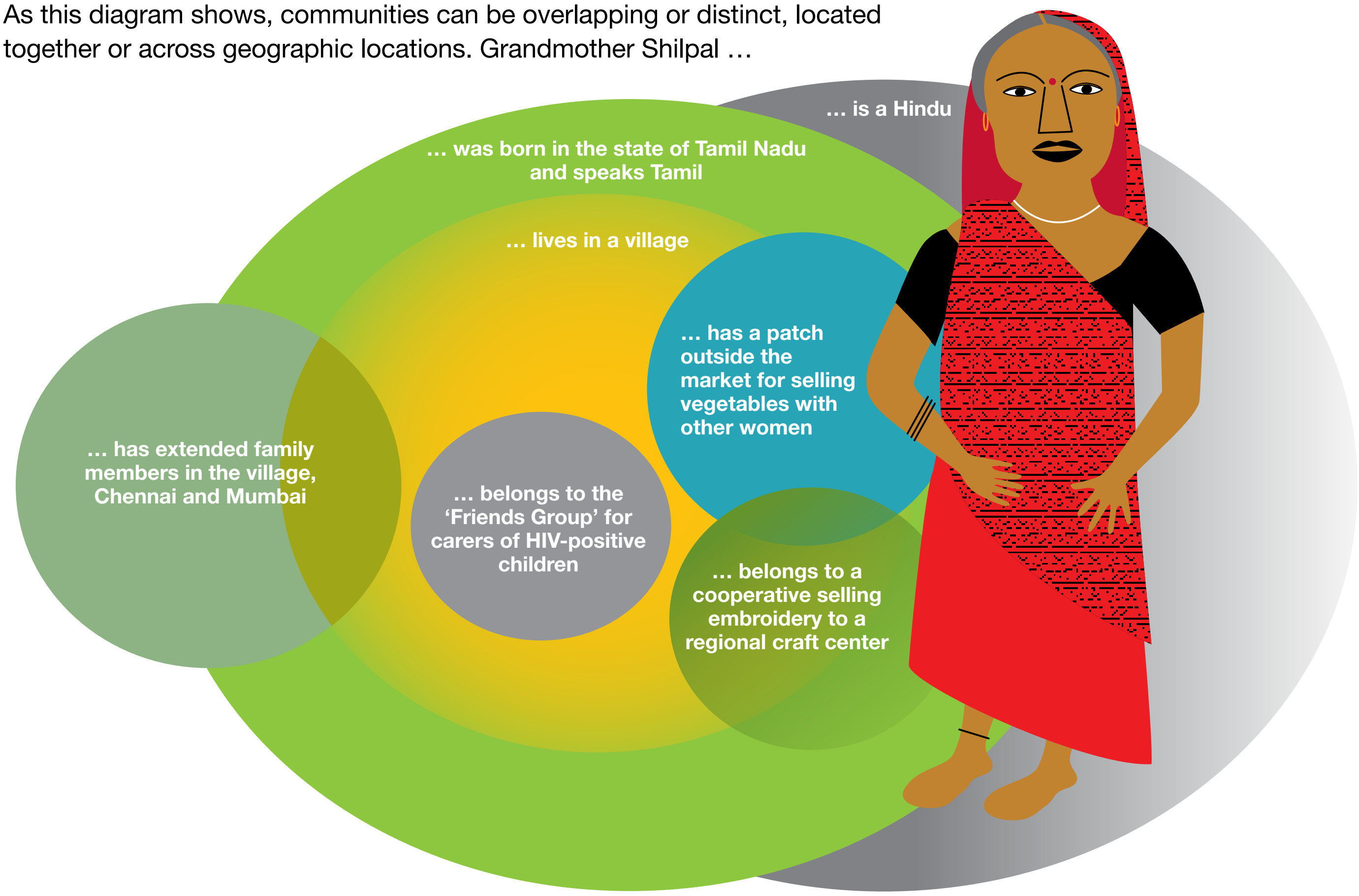


Who are the people and what are the places that support families?

WHAT IS A 'COMMUNITY'?

As with 'family', there is no universally accepted definition of 'community'. Community is often taken to mean the people living in a particular geographical area, such as a village or neighbourhood. However, community can also mean people united by a common background, language or culture, such as a group of refugees from one country. It can mean people united by a common faith or interest, or by occupation, such as a community of sex workers living together. In this sense, families may be part of more than one community.

As this diagram shows, communities can be overlapping or distinct, located together or across geographic locations. Grandmother Shilpal …



The communities to which a family belongs may have positive or negative effects on that family. Positive effects may be in the form of providing families with material or practical help, through mentoring child-headed families or child carers, or providing emotional support. Negative impacts may be in the form of stigma and discrimination, and isolation of marginalised groups. Looking at the positive support a community may provide to children and families affected by HIV, a number of community responses are common:

- informal financial or in-kind support provided by extended families, friends or other community members
- community-based groups with specific roles, such as health committees, child welfare committees, youth groups, peer support groups, savings and loans groups
- pre-existing groups, such as faith groups or schools, with programmes to provide support to families – for example, school feeding programmes and church-based family outreach.

Negative effects might include excluding children and their families from community activities because they are stigmatised due to their HIV status. HIV positive people may not be allowed to participate in church, and children from affected households may be unable to play with neighbours or even attend school. The children of sex workers can be excluded from support programmes for children affected by HIV because of stigma, and children may be ‘rescued’ from poor families for a better life . Children may also be forcibly removed from criminalised groups such as people who use drugs and those in conflict with the law, based on preconceived ideas about their ability to parent.

It is important to assess these effects when we plan programmes so that we can build on the positive supports and minimise the negative impacts, as well as help families to cope with them. As we saw in Chapter 1, JLICA and UNICEF recognise the potential of communities to provide support to families affected by HIV. Both emphasise the importance of strengthening the systems in communities that provide services, protection and support. We look at how we can engage community groups in our programme in Chapter 4.

The family and the community exist within a wider society, usually a country. The quality and availability of health, education and welfare services provided by the government, and the laws and policies it implements, will have a significant impact on the ability of families to function and care for their children affected by HIV.

Services

Families usually have access to certain types of services that help them care for children affected by HIV or support them to function as a family. We need to assess the accessibility, availability and quality of services that are available to the families we are working with especially for those most marginalised. This will enable us to create referral pathways and link families to all available supports they need. The availability and quality of essential services such as social welfare and health will have a dramatic impact on the ability of families to care for children. Families can better support their children in countries where national social protection systems provide social welfare benefits and economic support, and where health systems provide antiretroviral therapy, than families in places where these services do not exist.

WHAT IS ‘SOCIAL WELFARE’?

Social welfare is the provision of benefits and services by government, civil society and other actors to help people meet basic needs, to alleviate poverty, and to improve the wellbeing of individuals, families and communities.

Social welfare systems

A strong social welfare system acts as a critical safety net for vulnerable children and their families. When the system functions well, families can access a range of services, such as pensions, grants, insurance, care facilities and early childhood education. However, in many countries these services are non-existent or weakened through lack of investment, training and supervision. International attention is now focused on strengthening systems for social welfare[26] to build up the workforce and professionalise it. This will support family-strengthening interventions and child protection systems, and promote their sustainability. Similarly, health services are often weak, under-resourced and under-staffed. In response, there has been major global focus on helping countries to improve their health services through a process known as 'health systems strengthening'.

Families, structures and policy

When planning family-centred programmes, we need to think about the policies and laws within a country that can either make it easier or more difficult for families to care for their children affected by HIV.

Laws and policies that will help families care for children affected by HIV include:

- laws that promote the rights of children and women through social protection interventions such as birth registration, inheritance and property rights that respect women as equal partners and their children as beneficiaries
- policies that target resources to family-based care, and see institutional care for children as a last resort
- social protection policies that provide pensions and grants to support vulnerable families
- policies that ensure the rights of families to be involved in the health and wellbeing of their children, and ensure that children receive services in the context of their families.

Laws and policies that may make it more difficult for families to care for children affected by HIV include:

- laws that discriminate against populations such as people who use drugs and remove children from their care
- laws that prohibit sex work, which can mean that when sex workers are put in prison their children are left alone or in the care of others
- laws on birth registration that require a father's name on the certificate before issue, which discriminate against women with no partners
- policies that exclude HIV-positive children from schools
- laws that criminalise HIV transmission.

Broader attitudes within society also impact on families. Certain groups may not be criminalised or excluded by policies but by attitudes. Discrimination around sexuality, ethnicity or HIV status can also result in exclusion.

KEY RESOURCES

Child protection system mapping and assessment toolkit:
Available at: www.unicef.org/protection/57929_58020.html

Ministry of Gender Equality and Child Welfare Directorate of Child Welfare (2007), 'A human resources and capacity gap analysis: "Improving child welfare services"'.

Social Welfare Strengthening Conference 2010 resources: www.ovcsupport.net/s/index.php?c=99

USAID (2009), 'Human capacity within child welfare systems: the social work workforce in Africa'.

Wulczyn, F. et al. (2010), 'Adapting a systems approach to child protection: key concepts and considerations', UNICEF.

---

[26] www.ovcsupport.net/s/index.php?c=103

3

How do we design a family-centred programme?

In this chapter:

- Principles in planning and design

Principles in planning and design

The Alliance good practice guide on planning can help with the overall development of our programmes, but below are some suggestions on how to make our approach more family centred.[27]

When developing programmes for children, we need to assess:

- Who are the key people caring for the children? What are their personal, social and economic resources?
- Do any of the children provide care?
- What does the child do within the family?
- What is the impact of HIV on the child and how does it affect their development?

The assessment should focus on the capacities and needs of all family members rather than looking only at the needs of individual children. It should assess:

- the capacities and resources available within the community to support the family, and any negative influences of the community in which the family lives, such as exclusion and stigma
- whether treatment programmes map family members, and the need for counselling and testing, prevention and treatment for other family members
- the availability of services
- barriers to accessing services, such as missing identity documents like birth certificates
- the impact of national laws and policies on the family, and the support available.

Our programme design should:

- support family-centred care of children and reinforce families' capacities to stay together
- build the capacity of communities to assist in the care and support of children affected by HIV
- acknowledge that within many communities people will have their own prejudices or misconceptions about who is vulnerable or which families are entitled to support. Therefore evidence for targeting should be gathered in different ways
- recognise and reinforce the linkages between the supports and services provided at each level
- promote the delivery of national-level family-centred services such as antiretroviral therapy clinics on the same site for adults and children
- promote the implementation of policies and legal frameworks that support families to care for children, and optimise the access to and quality of services for people living with HIV
- integrate and combine services for adults and children in common geographic locations with family services such as voluntary counselling and testing, antenatal care, PPTCT, and treatment programmes that consider children and how to reach them
- build in plans for evaluation from the outset to enable the effectiveness of family-centred working to be evaluated

KEY RESOURCES

DiPrete Brown, L. (2008), 'Establishing service standards for improving quality of OVC services: a facilitator's guide 3', Pact and University Research Co, LLC for the United States Agency for International Development.

Available at: www.pactworld.org/galleries/resource-center/Facilitator_Guide_OVC_Standards_Nov08.pdf

MEASURE (2009), 'Child status index: a tool for assessing the well-being of orphans and vulnerable children.

Available at: www.cpc.unc.edu/measure/tools/child-health/child-status-index

---

[27] International HIV/AIDS Alliance, 'Good Practice Guide: Results-based planning' (forthcoming).

- develop indicators of inputs at the family level and the related impacts for the wellbeing of children. Global indicators focus on broad indicators such as ‘households received free basic external support in caring for the child’,[28] which tells us very little about the outcomes for children in terms of health or access to education[29]
- recognise that tools such as the Child Status Index[30] or the orphans and vulnerable children wellbeing tool[31] focus on the outcomes for children from the child’s perspective but are limited in capturing their broader family context. Our programmes need to include measures of household food security, wealth, the attendance and attainment in school of all children, and the health and wellbeing of all family members.

As we plan the implementation of our family-centred programmes, we should think about the interventions needed at different levels – with families; in communities; with service providers; and to influence policies impacting children and families affected by HIV – to ensure families are able to access the supports and services they need.

---

[28] UNAIDS (2009), ‘Monitoring the Declaration of Commitment on HIV/AIDS: guidelines on construction of core indicators: 2010 reporting’.

[29] Schenk, K. (2008), ‘What have we learnt? A review of evaluation evidence on community interventions providing care and support to children who have been orphaned and rendered vulnerable’, JLICA.

[30] MEASURE (2009), ‘Child status index: a tool for assessing the well-being of orphans and vulnerable children’. Available at: www.cpc.unc.edu/measure/tools/child-health/child-status-index

[31] Senefeld, S. et al. (2009), ‘Orphans and vulnerable children wellbeing tool‘, Catholic Relief Services.

The diagram below gives examples of interventions that can be developed at these four levels. However, it is likely that our organisations may not have the capacity or technical expertise to implement all of the interventions needed. If that is the case, we can work in collaboration with other agencies linking to existing services, or ask another organisation with a particular expertise to take on the intervention.

A SUMMARY OF INTERVENTIONS AT ALL LEVELS

FAMILY LEVEL

- Comprehensive health information
- Family home-based care
- Early childhood development
- Food aid for family and nutritional support
- Disclosure of HIV status within families
- Family counselling
- Parenting support
- Family reunification
- Family treatment adherence support
- Legal support – inheritance, property
- Infant feeding support and information to household

COMMUNITY LEVEL

- Community systems strengthening (community groups, voluntary support health and child protection committees etc)
- Local advocacy on child rights and protection
- Support child welfare committees
- Promote children's groups and networks
- Establish community watchdogs
- Community structures – leaders, peer/age groups
- Community savings for family strengthening
- Introduce community referral agents
- Support for community health workers in case management (including traditional birth attendants), community care coalitions

SERVICE LEVEL

- Family clinics at health facilities
- Training health workers in family-centred care
- Linking and referral of children through different services – voluntary counselling and testing, PPTCT, maternal and children health, sexual and reproductive health, TB
- Early childhood development services
- Primary and secondary schooling, vocational training, youth employment
- Childcare facilities
- Integrating HIV issues into education system
- Integrated family services and continuum of care approach
- Co-located service for adults and children
- Child protection and legal services for families
- Work with police and judiciary on child rights and protection

POLICY AND STRUCTURAL LEVEL

- Laws and policies – children's policies, inheritance and property rights
- Legal support
- Orphans and vulnerable children national plans for action
- Implementation of the Convention on the Rights of the Child and rights-based approach
- Birth and civil registration
- Decriminalisation of sex work and drug use, decriminalisation of HIV transmission
- Policies on alternative care, deinstitutionalisation of children
- Policies on PPTCT, paediatric antiretroviral treatment, rapid infant testing and diagnostics availability
- Social welfare entitlements – widows pensions, child grants, ration cards, poverty certificates
- Social protection mechanisms – state health insurance, child protection systems

4

Family-centred programmes in practice

In this chapter:

- Health
- Economic strengthening
- Food and nutrition
- Education and early childhood development
- Care and protection
- Emotional and psychological support

How do we go about implementing a family-centred programme, or adapting our current programmes to be more family centred? In order to look practically at this, we need to consider six common sectors in which interventions are provided for children and their families. In each sector we offer ideas about how to implement programmes in a more family-centred way, and illustrate these with case studies of programmes that have started using family-centred approaches.

The sectors are:

- Health
- Economic strengthening
- Food and nutrition
- Education and early childhood development
- Care and protection
- Emotional and psychological support

Health

In this section we focus on how health services for children living with and affected by HIV can be delivered in a way that is most useful and supportive to families. We look at how a number of services can be delivered together in an integrated way, and how services such as PPTCT, antiretroviral therapy, and home-based and palliative care can be provided in a way that helps identify children in need of care and supports them within their family network.

Providing health services for family members together in one place

Recent work looking at how health services in developing countries can be delivered in a family-centred way has suggested a number of different models. A recent systematic review of published papers and abstracts documenting programmes currently delivering family-centred treatment models for children has demonstrated their diversity. The programmes differ in types of services available to family members, method of enrolment of patients into the programme, site of delivery of family-centred services, and the qualifications of the staff delivering the programme.[32]

Case management is a key principle of family-centred HIV services.[34] It uses the family as the basis of the consultation, with family members receiving monitoring and treatment together in the same clinic. Case management means that community-based health workers or home-based care workers can identify children through their contact with the whole family. They can then address the children's needs within the context of their family and home.

Family-centred case management requires understanding the relationships and power dynamics within the family. It means taking into account the different needs of adults and children. It also means ensuring that responses deliver the best outcomes for children by strengthening and using family support to the greatest effect.

Programmes should consider:

- promoting access to both adult and paediatric specialist health workers to meet the different needs of adults and children in one location (in resource-

KEY RESOURCES

Harrison, K. (2009), 'Building hope: supporting work with children affected by HIV and AIDS', Macmillan/International HIV/AIDS Alliance.

International HIV/AIDS Alliance (2003), 'Building blocks: Africa-wide briefing notes. Resources for communities working with orphans and vulnerable children'.

Available at: www.aidsalliance.org/publicationsdetails.aspx?id=106

Steinitz, L. (2009), 'The way we care: a guide for managers of programs serving vulnerable children and youth', Family Health International.

> "Family-centred care, which offers HIV/AIDS prevention, testing, care, and treatment to the whole family at one location, has been shown to increase case-finding of women and children, and also increases treatment service uptake."[33]

---

32. Leeper, S.C. et al. (2010), 'Lessons learned from family-centred models of treatment for children living with HIV: current approach and future directions', Journal of the International AIDS Society 13(Suppl2).

33. DeGennaro, V. and Zeitz, P. (2009), 'Embracing a family-centred response to the HIV/AIDS epidemic for the elimination of pediatric AIDS', Global Public Health 4(4): 386–401.

34. Leeper, S.C. et al. (2010), 'Lessons learned from family-centred models of treatment for children living with HIV: current approach and future directions', Journal of the International AIDS Society 13(Suppl2).

limited settings this may mean additional training so health workers can respond to the specific needs of children and communicate effectively with different age groups)

- creating linkages and referrals between departments and service areas, where case management is not possible, to ensure that all family members can access the range of services they need
- providing services together to improve care to families and reduce the time and cost of travelling to separate service providers
- adapting individual health interventions using a family-centred approach so they have a greater impact for families and children; for example, encouraging men to accompany their partners for PPTCT, and referring siblings for testing through PPTCT interventions.

CASE STUDY: PROVIDING COMMUNITY-BASED CARE FOR ALL THE FAMILY IN ZAMBIA

Bwafwano Community Based Care Organisation is providing a comprehensive range of integrated services for a community of around 50,000 people just outside Lusaka, Zambia – including over 16,000 children. The services are managing to reach where state providers currently cannot: the most deprived people in Zambia.

Bwafwano ('Helping one another') was created in 1996 and has grown to provide services for HIV, TB and other diseases, together with treatment, care and support for children. Bwafwano specialises in community-based care, with all the services provided in the same place: laboratory work, counselling, testing and PPTCT services.

Whenever an individual or family is assessed at home or in the Bwafwano clinic for HIV, TB or other diseases, a wider assessment by one of the organisation's 500 community carers also takes place. This includes assessing the social, psychosocial, economic and livelihood prospects of all family members. When pregnant women who are living with HIV receive treatment and counselling, their partners are also invited to receive it. Then when the baby is born, the baby receives treatment too, including follow up from a paediatrician and psychological support if needed. The organisation also offers counselling, income support and skills training for single mothers and children who have extra responsibilities at home.

Bwafwano also provides a sexual and reproductive health education programme, and maternal and child health services. There is disease screening for children, a home-based care programme to provide nutrition for children, and a paediatric antiretroviral therapy programme, as well as an education programme that includes access to grants for school fees and materials.

CASE STUDY: USING A CASE MANAGEMENT APPROACH TO CARE FOR PARENTS WITH HIV IN VIETNAM

Family Health International, in partnership with Vietnam's Ministry of Health and district health centres, established seven continuum-of-care sites with a focus on care and treatment for parents with HIV. The aim was to reduce orphaning and support those who were orphaned to remain within their extended families.

Using a case management approach, Family Health International established a system of linked services: inpatient care and services for children affected by HIV, as well as an outpatient clinic; TB/HIV linkages; support groups for people living with HIV; and home-based care teams. Each site also had a committee responsible for coordinating HIV services and improving referrals. The committees were made up of community leaders, service providers, affected families and individuals, and representatives of organisations responsible for the welfare of children.

Family-centred care coordinators were also based in the clinics as case managers. They assessed needs, helped to develop a family care plan, and linked families to services. The coordinators worked closely with home-based care teams, who provided follow-up and family care in the home, including support to access schooling, food and essential child health services. The teams also helped families plan for the future and identify guardians. In many continuum-of-care sites, care coordinators and home-based care teams ran playgroups for children, and organised family days that included life skills discussions and fun activities.

During family clinic days, outpatient staff provided care for entire families and assessed HIV-positive children and their carers together. The family then saw an adherence counsellor and visited the family-centred care coordinator.

Prevention of parent-to-child transmission

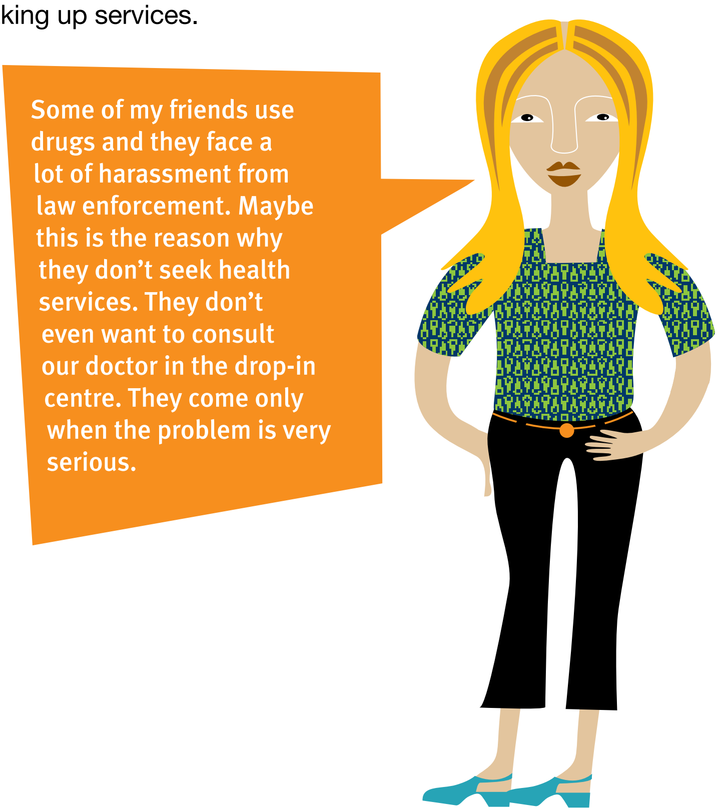
Programmes to prevent vertical transmission of HIV from parent to child were the focus of much of the early thinking around developing family-centred services for people living with HIV. Historically, PPTCT programmes focused on interventions that directly reduce the risk of transmission of HIV from the mother to her baby during pregnancy, delivery or via breastfeeding. Family-centred PPTCT models have expanded this approach to consider the broader health needs of the family, particularly those of the mother and child and across the four prongs of PPTCT (see table on page 30).

This approach draws on evidence of the long-term outcomes for children being improved by good-quality antenatal care and healthy mothers who are able to access HIV treatment, as well as linking mother and baby pairs to broader child health programmes. More recently, integrating early childhood development and care and support services for children into the PPTCT model has been recommended. This is sometimes referred to as PMTCT-Plus.[35]

The table on page 30 summarises the key components of family-centred PPTCT services from the time of identification of the pregnant woman until early childhood. The components in **bold** can be included into PPTCT programmes to achieve a more integrated service that is family centred. This entails providing services to other family members beyond the mother and newborn child.

Globally, there has been significant progress in reducing transmission of HIV from mothers to their babies. However, there are many countries and communities where there is still limited coverage of PPTCT services and where babies continue to acquire HIV through vertical transmission.

For many communities, stigma, discrimination and criminalisation mean that mothers and their babies will continue to be prevented from accessing prevention interventions, family planning support and PPTCT services unless we challenge the attitudes, laws and policies that stand in the way of the most vulnerable families taking up services.



KEY RESOURCES

UNAIDS (2011), Countdown to zero: global plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive'.

UNAIDS (2011), 'Promising practices in community engagement for the elimination of new HIV infections in children by 2015 and keeping their mothers alive'.

WHO (2010), 'PMTCT strategic vision 2010–2015: preventing mother-to-child transmission of HIV to reach the UNGASS and Millennium Development Goals'.

---

[35] Betancourt, T.S. et al. (2010), 'Family-centred approaches to the prevention of mother to child transmission of HIV', Journal of the International AIDS Society 13(Suppl2).

KEY COMPONENTS OF FAMILY-CENTRED PREVENTION OF PARENT-TO-CHILD TRANSMISSION

PRONG 1	HIV prevention among women and men of reproductive age provided through community structures and within reproductive health services such as antenatal, postpartum and postnatal care, and at other health and HIV service delivery points. Address structural drivers of HIV through peer to peer education led by people living with HIV, working with most affected groups.			
PRONG 2	Counselling, support, and contraceptives provided to women and men living with HIV to meet their needs for family planning and spacing of births, and to optimise their health outcomes and those of their children. Referrals from family planning services to other health services.			
PRONG 3	Work with communities to promote early antenatal care attendance. HIV testing and counselling provided to pregnant women living with HIV and their partners, together with access to the antiretroviral drugs needed to prevent HIV infection from being passed on to their babies during pregnancy, delivery and breastfeeding.			
PRONG 4	**BEFORE BIRTH**	**DURING/AFTER BIRTH**	**WEEKS AFTER**	**LONG-TERM**
	CD4 test, treatment for HIV-positive mother. Antenatal care. **Early childhood development counselling.** **Assessment of additional household vulnerability (food insecurity).** Social worker, **community health worker or nurse for early childhood development.** Referral for nutrition. Counsel on PPTCT. **Father involvement.** **Stigma reduction and disclosure support.**	Delivery assisted by skilled birth attendant. Caesarean section available. Risk assessment available. Antiretrovirals for mother and child **and others in family as needed.** Counselling on feeding. **Parenting and communication support.** **Increase family engagement with new baby.**	Assess mother's physical and mental wellbeing. Feeding and counselling. Immunisations begin. HIV testing for infants. Referrals to support programmes. Child health worker home visits, **include early childhood development activities.** **Involvement of other family members in early childhood development content.**	Child health workers assess and monitor child growth and development. **Ongoing early childhood development activities with family.** **Pre-school access.** **Carers mental and physical health.** Nutrition, social contexts, **economic opportunity.** Follow-up: general and specialised paediatric care. **Family planning.**

Adapted from Betancourt, T. and Smith Fawzi, M.K. (2009), 'Family-centered approaches to the integration of PMTCT + ECD: LG3: expanding access to services and protecting human rights'. Available at: www.ccaba.org/resources_nairobi.html

CASE STUDY: PROMOTING FAMILY-CENTRED PPTCT SERVICES

The MTCT-Plus Initiative is known internationally as a model programme for family-based care, and early diagnosis and care of infants exposed and infected with HIV. A core belief of the Initiative is that HIV is a family health issue, and that all members of the family should be included in care and treatment. This is why the Initiative makes sure that all HIV services, including antiretroviral therapy, are extended to every mother's children living with HIV, partners and other family members.

The services are designed to be comprehensive, with a focus on keeping each member of the family healthy and engaged in long-term care. In addition to antiretroviral therapy for those who are eligible, a variety of HIV-related and primary health care services are also provided. These include opportunistic infection prophylaxis; screening and treatment for other diseases, particularly tuberculosis; nutritional evaluation and support; access to family planning; and clinical and immunologic monitoring. Psychological support and adherence counselling by counsellors or peers are considered critical components of the MTCT-Plus Initiative.

Paediatric care is an essential part of family-focused services. All HIV-exposed infants are monitored until HIV infection can be definitively diagnosed or excluded. Each site has access to early virological tests to provide timely diagnosis of HIV infection during the first months of life. All children have regular assessments of growth, developmental status and CD4 counts while receiving opportunistic infection prophylaxis and antiretroviral therapy, if eligible.

The MTCT-Plus model of care has been implemented through 14 clinical programmes based in nine countries throughout sub-Saharan Africa and Asia. After eight years, it has provided life-saving care and treatment to more than 16,000 adults and children, and has made valuable contributions toward increasing community awareness and preserving families.

Since the early 2000s the Initiative has been an entry point for reaching family members with comprehensive care services for families affected by HIV. The programme goes beyond prevention of vertical transmission to include safe delivery, antiretroviral therapy, early childhood development, breastfeeding and nutritional advice, antibiotic prophylaxis, family testing, TB care, vaccinations, and sexual and reproductive health and psychosocial support. There have been positive results in the enrolment of HIV-positive pregnant women into the programme, but enrolment of children has been less successful.
A number of suggestions have been made about the remaining barriers for families that need to be addressed, such as family disclosure, stigma, gender inequity and social exclusion.

See http://cumc.columbia.edu/dept/icap/whatwedo/mtctplus/who.html

CASE STUDY: GETTING MEN INVOLVED IN PPTCT IN KENYA

Zingatia Maisha ('Carefully consider life') is an Elizabeth Glaser Paediatric AIDS Foundation programme in western Kenya. Its aim is to get men more involved in PPTCT. To this end, the programme has been establishing exclusively male clinics because existing clinics can be off-putting for men since they tend to be dominated by female staff and patients.

At these men-only health centres HIV-positive men form support groups, and both HIV-positive and negative men are counselled on the importance of accompanying their partners for antenatal visits. The men also receive education on issues that are usually taboo for men, such as the importance of exclusive breastfeeding for HIV-positive mothers.

The programme has adapted antenatal clinics to make them more attractive for men to attend, by giving priority to women who attend with men and to men who bring their children. Over 15,000 men have enrolled in the project since 2005. One man commented: *"I am taught about breastfeeding and nutrition for me, my wife and our child. When my wife isn't well I just take the child to the clinic... I never thought I would go to the clinic like a woman."*

"We not only escort [treatment] defaulters to the clinic, but we also try to reach out to the others who are missing out and we tell them: 'We are men as you are and we are in this and our spouses and children are benefiting.' We explain to them the benefits and we have seen converts." – Pastor Joseph Muhemberi, support group leader

See www.irinnews.org/report.aspx?reportid=90847

CASE STUDY: SUPPORTING MOTHERS AT RISK OF ABANDONING THEIR NEWBORN CHILDREN IN UKRAINE, RUSSIA AND VIETNAM

The MAMA+ project focuses on preventing children born to women living with HIV and using drugs from being abandoned. HealthRight International establishes partnerships with maternity hospitals, AIDS centres and other local organisations, who refer HIV-positive pregnant women at risk of abandoning their children to the MAMA+ project.

The case management team provides counselling, comprehensive HIV information, and a long-term plan for women who choose to participate in the programme. This includes PPTCT services, referral for harm reduction and treatment services, psychosocial support to mothers, and parenting support. This combination is designed to help mothers care confidently for their newborn infants and therefore reduce the risk of abandonment.

Through MAMA+ centres, women are also able to access other social services. Infant day care enables mothers to attend vocational training, job interviews, legal appointments or access other services. The MAMA+ team provides support to HIV-positive mothers and their families through counselling and family visits. In addition, referral networks with public and non-governmental agencies help families to access welfare support, education and job placement. They also provide care for children, such as nutritional support and medicine. Previously up 20% of children born to HIV-positive mothers were abandoned in maternity hospitals. The project has led to significant reductions in this outcome.

See www.healthright.org/where-we-work/ukraine/ukraine-mama

HIV counselling and testing

Family-centred counselling and testing recognises that HIV transmission occurs mostly within families, from parent to child and between partners and spouses. It also recognises that diagnosis, disclosure, treatment initiation and adherence can be positively supported by families. Taking a family-centred approach to testing has the potential to increase the focus on paediatric testing and treatment. It can help identify untested children and promote early identification through infant testing as part of PPTCT.

Programmes should consider:

- making early contact with families, especially through PPTCT, to increase early infant diagnosis, initiation of co-trimoxazole[39] prophylaxis and testing of young children who may otherwise remain untested
- taking testing into the home as an effective way of reaching people previously untested, and supporting family disclosure (while recognising that maintaining individual informed consent and confidentiality may be difficult in families where some members have authority or power over others and may coerce them into testing or sharing their results)
- recognising the possibility of negative impacts of a positive test, such as rejection or domestic violence, and ensuring they are addressed within the family as well as the resulting need for support to parents
- recognising the specific considerations around testing children and their right to be involved in decisions that affect their lives as well as the lifelong commitment required of family members to a child's HIV treatment and care
- ensuring that tests are done in the best interests of the child, and that parents' decision about when to test and disclose results is done in their child's best interests
- ensuring that when testing children there is consent for the counselling as well as the testing process
- ensuring that children know that they can withdraw at any time
- ensuring that counsellors support children to understand the implications of tests and next steps, depending on the result.

KEY RESOURCES

Family Health International India (2007), 'Protocol for child counseling on HIV testing, disclosure and support'.

Human Rights Watch (2003), 'Just die quietly: domestic violence and women's vulnerability to HIV in Uganda'.

Maman, S. et al. (2001), 'HIV and partner violence – implications for HIV voluntary counseling and testing programs in Dar es Salaam, Tanzania', Population Council.

---

[39] Co-trimoxazxole is a very cost-effective antibiotic that has been proven to significantly reduce the rate of illness and death among HIV-exposed infants and HIV-positive children.

Disclosure

Families play an important role in telling a child that they are HIV positive. Often the focus of programmatic interventions is on training clinical staff to give the diagnosis to children. However, families can help children in the longer term to understand their diagnosis, adapt positively and plan for the future.

Parents may be reluctant to disclose to a child for fear of the consequences. They may have concerns about the age to tell them or how to actually talk about it. An HIV diagnosis for a child may also mean that parents need to tell the child for the first time that they themselves have HIV. The parents may need support to do this and respond to the child's feelings. Many parents experience fear and guilt if their child is diagnosed with HIV.

Children who acquire HIV as infants have different needs to those those who become HIV-positive in adolescence, and it is important that programmes recognise this. Children infected perinatally are likely to know their diagnosis, and their status is usually acknowledged within the family. But on reaching adolescence they face new challenges about who to disclose to, especially when entering early sexual relationships.

Programmes need to consider:

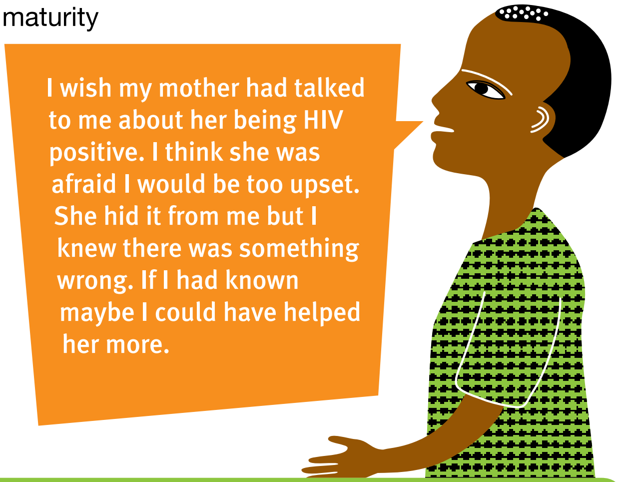
- supporting parents to disclose to their children, and helping them understand the process of disclosure and acceptance, and the different stages and emotions a child may go through depending on their age and maturity
- recognising that adolescents face specific challenges in sharing their HIV status with their families and peers, and adapting to their diagnosis
- addressing the different psychosocial impacts on parents, adolescents and children of a positive diagnosis, and tailoring responses accordingly
- developing psychological support to families over the long term as well as at the time of diagnosis
- promoting among clinical staff the value of engaging with families and supporting them to carry out disclosure.

KEY RESOURCES

Domek, G. (2010), 'Debunking common barriers to paediatric HIV disclosure', Journal of Tropical Pediatrics 56(6): 440–42.

International HIV/AIDS Alliance (2011), 'Needs, challenges & opportunities: adolescents and young people living with HIV in Zambia', Briefing Paper.
Available at: www.aidsalliance.org/includes/Publication/ZambiaStudy.pdf

WHO (2011), 'Guideline on HIV disclosure counselling for children up to 12 years of age'. World Health Organization.



CASE STUDY: UNDERSTANDING CHILDREN'S NEEDS AROUND DISCLOSURE IN ZAMBIA

Too often health providers and families fail to share a child's HIV diagnosis because they want to protect the child from the psychological impacts. They may also be unclear about the most appropriate time and way to do this. Elizabeth Glaser Paediatric AIDS Foundation in Zambia has tried to address this by carrying out training for 121 counsellors, nurses and doctors to ensure that children's needs around disclosure and the psychosocial impacts are properly considered in the treatment support given to them and their families.

Using a Catholic Relief Service/AIDS Relief/African Network for Care of Children Affected by HIV/AIDS training curriculum*, Elizabeth Glaser has supported frontline health staff to better understand the processes for disclosure, the importance of family counselling, and the psychosocial impacts of disclosure on children and their carers.
The training has drawn on evidence of the positive impacts of early disclosure to children in terms of treatment adherence, self-esteem, psychosocial wellbeing, family relationships and communication. It has also supported greater understanding of family dynamics, and processes for follow-up after diagnosis. As a result, there has been an increased retention of children in treatment services.

See www.pedaids.org/What-We-re-Doing/Foundation-Blog/August-2010/Talking-to-Kids-About-the-Hard-Stuff-Disclosing-H

* Catholic Relief Services (2009), 'Psychosocial care and counseling for HIV-infected children and adolescents: a training curriculum'.

Treatment and adherence

There is significant evidence of the positive role that families play in supporting adherence for children and adolescents. A study in South Africa[40] demonstrated high rates of adherence for children on treatment when cared for by HIV-positive carers in the home. Family-centred adherence programmes recognise that even where a family is heavily impacted by HIV and has more than one person living with HIV, this can translate into positive outcomes in adherence.

Treatment services located together also have the potential to reduce costs for families and build on the unifying features of the family in treatment adherence.

Programmes should consider:

- tackling common barriers to adherence with the whole family, including costs of treatment, transport to clinics, nutrition and other health issues
- promoting mutual support between family members, which can improve adherence
- providing nutritional support and guidance to the whole family, alongside treatment support
- recognising that adherence issues change with the age of the child, related to their understanding of treatment, growing independence and ability to take personal responsibility for their own treatment.

KEY RESOURCES

Knodel, J. et al. (2009), 'The role of parents and family members in ART treatment adherence: evidence from Thailand', Population Studies Center Research Report 09-686.

Muller, A. et al. (2011), 'Predictors of adherence to antiretroviral treatment and therapeutic success among children in South Africa', AIDS Care 23(2): 129–38.

Williams, P. et al. (2006), 'Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection', PEDIATRICS 118(6): 1745–57.

CASE STUDY: FAMILY-CENTRED ADHERENCE COUNSELLING IN BURKINA FASO

Initiative Privée et Communautaire de lutte contre le VIH/SIDA (IPC) runs a programme in Burkina Faso supporting families affected by HIV. Children are identified through interventions such as voluntary counselling and testing, antenatal care and PPTCT services, and referred for care and support.

One aim of the programmes is to improve treatment adherence. To this end, the programme has trained 30 community carers in paediatric adherence and adherence support. They work with the family to support disclosure and build understanding around treatment and adherence. Children and families are supported through home visits and family meetings at Centre Oasis.

The centre provides community meals, and health staff are available to monitor and support clients. The centre also facilitates support groups to help provide solidarity and problem-solving to improve adherence. Patients lost to follow-up are visited at home.

A greater sense of solidarity has been reported not only among the adults but also among the children living with HIV. The project coordinator commented: *"Between themselves, the children know who is adherent and who isn't. It's really true. If I take the example of Clement, he is not adherent and the other children have realised this. In the mornings, because their houses are not far from one another, the children go to Clement's house to make him take his medication, or in the evening after school (Clement dawdles so he doesn't have to go home) – even at 6pm when they are having fun – when it's time, they accompany Clement to his house to take his medication."*

---

[40] Williams, P. L. (2006), 'Predictors of adherence to antiretroviral medications in children and adolescents with HIV infection', Pediatrics 118(6): e1745–57.

Home-based and palliative care

Too often programmes cater separately for people needing home-based and palliative care, and children affected by HIV and AIDS. This can make it difficult for families and communities to provide adequate care for both groups. Family-centred home-based care integrates the interventions to provide a range of supports to an entire household affected by HIV. It recognises that children are affected by HIV long before they become orphans. It also acknowledges that home-based carers are in a unique position in the home to respond to the specific challenges children face, whether they are infected or affected by HIV.

In the same way, palliative care programmes cover a comprehensive set of supports that address physical, psychosocial and spiritual needs of individuals and families who are dealing with life-threatening illness. Programmes recognise whether it is adults or children who are faced with the impacts of life-threatening illness. They also acknowledge that family members play a key role in decision-making and management of treatment, pain management, end-of-life care, psychological support for bereavement, and planning for the future.

Programmes should consider:

- training home-based carers to provide physical and emotional care in the home for adults who are unwell, and to assess all the family and identify the needs of children and other vulnerable adults in the household
- making referrals for children, with the family's consent, to other services as needed
- home-based carers providing training and support to children who are caring for adult family members in order to address gaps in their knowledge, which can be a significant source of anxiety for them[41]
- addressing the specific needs of children in dealing with grief, bereavement and end-of-life decisions
- supporting families in succession planning, dealing with property and land inheritance, care options and death registration
- providing practical advice about burial and legal processes on the death of a family member, and including children in the decision-making process.

KEY RESOURCES

Bunn, M. (2010), 'No secrets: helping families and carers talk to children about life limiting illness', Diana Princess of Wales Memorial Fund.

Amery, J. (ed.) (2010), 'Children's palliative care in Africa', Oxford.

Available at: www.icpcn.org.uk/survey_page.asp?section=000100010021&sectionTitle=Textbook+for+Children%27s+Palliative+Care+in+Africa%3A+The+comprehensive+new+textbook

CASE STUDY: PROMOTING PALLIATIVE CARE IN THE HOME IN KENYA

Kitovu Mobile Palliative Care Service is based in Masaka, on the shores of Lake Victoria. The palliative care team visits patients and their families in their homes and liaises closely with the community home-based care programme. This provides a holistic programme of clinical, psychological and spiritual support within the community, and social contact for the patient and family. The programme also works closely with other agencies and the community to support schooling, housing, food and other needs.

Visiting patients in their homes is central to them being treated as people leading their lives among their families and household activities, rather than as people with a disease. Carers feel that they too are being supported and that the difficulties they experience are recognised. They feel less isolated, receiving not only practical support but social and financial support as well.

Family structures within the communities are varied and sometimes complicated, with different roles being assigned to family members. Working within the home, palliative care workers can assess and support family members in their different roles, and address misunderstandings and barriers to the care of patients.

The workers also extend their reach into the community, promoting awareness of palliative care together with the family and community supports needed to build the resilience of families. In addition to the programme's clinical and personal care and pain management support, they have a school fees programme and they work with community on referrals for services. They also have links to the micro-enterprise and skills programmes run by the community home-based care service and other non-governmental organisations.

See www.theworkcontinues.org/page.asp?id=1505

---

[41] Save the Children (2010), 'Child carers: child-led research with children who are carers. Four case studies; Angola, Nigeria, Uganda and Zimbabwe', Save the Children.

CASE STUDY: TRAINING HOME-BASED CARERS TO MEET CHILDREN'S NEEDS IN MOZAMBIQUE

Save the Children in Mozambique has transformed the organisation's approach to home-based care so that it addresses the needs of children as well as adults. An evaluation of a previous programme showed that the children of home-based care patients were often overlooked. In response, Save the Children developed a training programme for home-based care providers known as 'activists' to equip them with the knowledge and skills to integrate child-focused care and support into their work.

During the training, home-based care activists learn how to:

- create an open and trusting environment during home visits
- communicate with children
- understand and promote child rights and child protection
- recognise signs of physical, sexual and emotional abuse and neglect
- understand how chronic illness or death of a loved one affects children
- help families to understand reasons for changes in the behaviour of children
- help carers talk openly to children about sickness and death
- counsel families to maintain a healthy, safe and pleasant atmosphere in the home.

When home-based care activists visit a patient, they talk to the children to find out if they are attending school, how they are feeling and if they have any health problems. They also talk to carers to see if the family has birth certificates and access to adequate food. The home-based care activist is able to assess the needs of each child, identify issues of concern and take appropriate action. This might be referral of the child to a health centre for treatment, or referral to the orphans and vulnerable children committee. The committee provides or facilitates access to psychosocial, educational and nutritional support, and appropriate shelter and livelihoods support depending on the needs of the child.

Key lessons identified by the project are:

- Knowing that children are being taken care of brings great relief to the sick carers and allows them to focus on their own health and recovery.
- Home-based care activists are well placed to gain the trust of children and their carers, and conduct ongoing assessments of the needs and wellbeing of children. This is because they visit the households of their patients twice a week and build close relationships with the families.
- Extending care and support to the children in a household, in addition to the patient, has been very rewarding. Home-based care activists do not see it as an extra burden.

Sexual and reproductive health and rights, and HIV prevention

Families play a key role in the sexual and reproductive health of children and adolescents, and have significant influence on the behaviours of young people. However, many HIV prevention and sexual and reproductive health and rights programmes targeting children and young people are carried out in schools, with little involvement of families.

Family and social networks are critical to behaviour change. Families can hinder the prevention of HIV infection among adolescents, and family conflict, violence and separation can trigger or accelerate risk-taking among young people. Poor relationships with parents and other family members, compounded by structural issues such as unemployment, poverty, crime and marginalisation, can increase risk, with young people turning to drugs and sex work as a means of coping or escape.

Programmes should consider:

- ensuring that children and young people are supported with comprehensive sexual and reproductive health information and access to services
- addressing the barriers to information and services that adults create through fear of 'corrupting' children or encouraging 'promiscuity'
- helping parents to talk with their children about sex and sexuality
- supporting families to offer emotional support to young people in decisions around their sexuality, sexual behaviour and relationships

KEY RESOURCES

International HIV/AIDS Alliance (2010), 'Good Practice Guide: Integration of HIV and sexual and reproductive health and rights'.

Available at: www.aidsalliance.org/publicationsdetails.aspx?id=507

International HIV/AIDS Alliance, 'Good Practice Guide: Prevention' (forthcoming).

- addressing practices that can make young people more susceptible to HIV infection; for example, intergenerational sex, early marriage, female genital mutilation, early sexual debut, laws on inheritance, dowry and bride price
- supporting young people to take responsibility, and overcome peer pressure and harmful gender norms
- strengthening the capacity of families to care for children through access to welfare support, counselling, harm reduction services, parenting support and legal assistance in order to reduce the likelihood of a child leaving family care and becoming more susceptible to risk.

CASE STUDY: YOUNG PEOPLE'S SEXUAL AND REPRODUCTIVE HEALTH IN SWAZILAND AND ZAMBIA

Family Life Association Swaziland and Alliance Zambia are implementing the 'Happy and Healthy' sexual and reproductive health, rights and HIV prevention programme for young people. It aims to create environments where young people can protect themselves, while enjoying happy and healthy relationships and expressing their sexuality safely. This includes access to comprehensive sexual and reproductive health services, such as education and counselling, life skills education, access to treatment, and psychosocial support. A particular aim of the project is to address the barriers young people face in accessing sexual and reproductive health and HIV information and services because of the attitudes of adults in communities.

A key part of the programme is the facilitated interaction between parents and children and other community members. The programme promotes communication in families to support young people to have healthy and positive sexual lives. It also encourages participatory learning to help young people understand the risks they face, and enable adults to support them.

The programme, which has reached 29,174 young people to date, is mobilising communities and empowering young people. In the process it is increasing respect and communication between young people and adults, and reducing harmful cultural practices. It is also increasing gender equality and respect for young people's rights to sexual and reproductive health and HIV prevention.

"Indaba [consultative forum] was the best platform for the pupils to bring out critical issues that negatively affect the development of children… Solutions were discussed by parents and pupils together. They identified problems, and parents promised to play an active role to ensure that their children grow up happy, healthy and safe… Teachers, health centre management and parents agreed to work together effectively with the support of Young, Happy, Healthy and Safe."
Indaba participant

CASE STUDY: SUPPORTING CHILDREN ON THE STREETS IN UKRAINE

Odessa Charity Foundation Ukraine reaches over 420 of the 600 children thought to be living on the streets of Odessa. The charity has also supported over 10,000 children and families with social rehabilitation and interventions to prevent homelessness and neglect. Through mobile outreach services and social rehabilitation programmes, homeless or neglected adolescents can be supported to achieve their potential in society – and for some, a return to family life.

The Way Home programme offers shelter for children identified on the streets of Odessa by social patrols that go out during the night. Programme staff work with the young people to resolve family conflicts and address risk behaviors, such as selling sex and drug use, in order to start the process of reintegration with families where possible.

The Way Home also works with vulnerable families to prevent family breakdown. It offers counselling, conflict resolution services, access to health care and harm reduction services for drug use. It also helps to address violence in families.

The programme supports individuals and families to register for and access social welfare benefits. It also helps with education and employment, and provides food, clothes, personal hygiene requirements and medicines in order to alleviate economic pressures in their lives. This comprehensive and family-centred approach aims to strengthen the resilience of families and prevent the crisis situations that can lead to children moving onto the streets.

Economic strengthening

We have seen that evidence supports the care and protection of children within families. It also recommends 'family-strengthening'[42] activities to develop resilience and economic security in families through financial and social support. The aim of these interventions is to provide sustainable improvement to families' economic situations. This is so they are better able to access services and support for their children and protect the family from economic shocks associated with the impacts of HIV. There is growing evidence that economic strengthening through grants to families can increase educational attainments and the nutritional status of children.[43]

There are a range of interventions that can help families continue to care for children at home and avoid family separation and the need for institutional care. These include financial transfers, pensions and grants, savings and loans schemes, and insurance.[44] Ideally this support should be provided by the state but in many countries the economic situation means that these interventions are limited. Programmes providing support even in the short term can achieve long term health, social and economic benefits for families.

Programmes should consider:

- using economic strengthening interventions in families of all types, including those headed by children or grandparents (the approach may need to be adapted depending on the family structure)
- supporting families with information and encouragement to learn about and access supports offered by other organisations or the government
- working with community leaders or other community members to promote awareness of entitlements and help people access services
- lobbying for national social protection schemes, including child grants, widows pensions and guaranteed employment or training programmes to help people get employment
- advocating for national social protection to ensure that the needs of the most vulnerable and commonly excluded children are met – for example, children of sex workers, people who use drugs, street and working children
- supporting the creation of laws and policies that protect inheritance and property ownership, and promote will-writing, particularly for women and children
- recognising the role of gender in relation to access to supports and the impact within families and communities.[45]

KEY RESOURCES

Adato, M. and Bassett, L. (2008), 'What is the potential of cash transfers to strengthen families affected by HIV and AIDS? A review of the evidence on impacts and key policy debates', JLICA.

Devereaux S. and Sabates-Wheeler, R. (2004), 'Transformative social protection', Working Paper 232, Institute of Development Studies.

Hofmann, S. et al. (2008), 'Salt, soap and shoes for school: the impact of pensions on the lives of older people and grandchildren in the KwaWazee project in Tanzania's Kagera region', HelpAge International.

Holmes, R. et al. (2009), 'Gender vulnerabilities, food price shocks and social protection responses', ODI.

Save the Children (2007), 'Children and social protection: towards a package that works'.

ODI/UNICEF (2009), 'Child poverty: a role for cash transfers? West and Central Africa'.

Roelen, K. et al. (2011), 'Lessons from the Children and AIDS Regional Initiative (CARI): child- and HIV-sensitive social protection in Eastern and Southern Africa', Institute of Development Studies.

UNICEF (2009), 'Advancing child-sensitive social protection', Joint Statement UNICEF.

Yablonski, J. (2009), 'Lasting benefits: the role of cash transfers in tackling child mortality', Save the Children UK.

---

[42] Richter, L. et al. (2010), 'Strengthening families to support children affected by HIV and AIDS', AIDS Care 21(1): 3–12.

[43] Adato, M. and Basset, L. (2009), 'What is the potential of cash transfers to strengthen families affected by HIV and AIDS? A review of the evidence on impacts and key policy debates', International Food Policy Research Institute/JLICA.

[44] Save the Children (2009), 'Policy brief: family strengthening and support'.

[45] Brady, C. (2011), 'Walking the talk: cash transfers and gender dynamics', Concern Worldwide and Oxfam GB.

CASE STUDY: SHIFTING FROM SERVICE DELIVERY TO LINKAGE AND REFERRALS FOR GOVERNMENT SOCIAL WELFARE IN INDIA

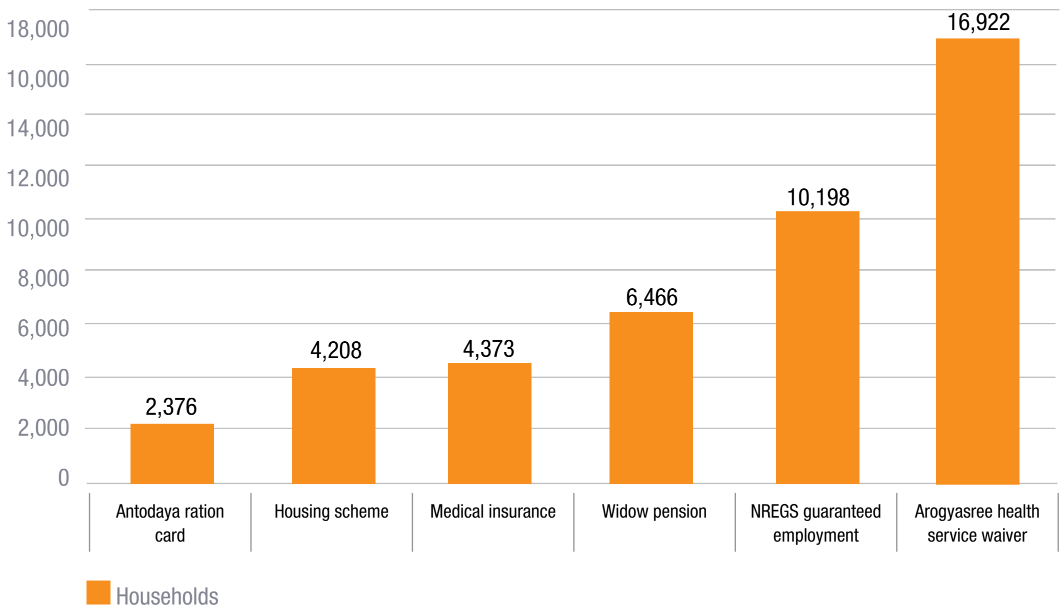
CHAHA is a Global Fund programme implemented by Alliance India in four states. The original programme design focused on developing a service package for children around HIV testing and treatment, education and nutritional support. It aimed to reach 64,000 children.

While the strategy of direct services was successful, it became clear that with growing numbers of children affected by HIV in India, the project had to look at more scalable and sustainable responses. These needed to link families rather than individual children to support and entitlements, and be capable of being integrated into the national government response. As a result, the programme has shifted its emphasis to establishing linkages for families and households to government social welfare support. This includes widows' pensions; ration cards; nutritional services for under-fives within the integrated child development services; income generation support; and guaranteed employment schemes. These types of support are now offered in addition to their support around testing and treatment, and access to education.

Alliance India's experience of referrals to medical services, like antiretroviral therapy and PPTCT, provided valuable learning for building additional linkages and referrals to government social welfare entitlements. The project has now developed a directory of essential services and government schemes. Families are supported to access these by the project's 350 outreach workers, who also help them with registration and grant collection.

Continued advocacy at national, state and district levels ensures a systematic link with government departments around these services and support, addressing remaining barriers such as stigma and discrimination. The programme also advocates for new schemes, and works with communities to generate demand for services. 41,974 households have now been registered in CHAHA, with 99% of households linked to at least one government scheme or entitlement between 2009 and 2011. The table below shows the number of families affected by HIV registered in the programme who are accessing government entitlements.

Number of households accessing government entitlements through CHAHA



CASE STUDY: COORDINATED COMMUNITY TARGETING WITHIN A SOCIAL PROTECTION FRAMEWORK IN ZAMBIA

Alliance Zambia, with support from Irish Aid's Orphans and Vulnerable Children Programme, started supporting six community-based organisations in the Ndola and Masaiti districts of the Copperbelt Province, to coordinate and integrate with the Public Welfare Assistance Scheme (PWAS). PWAS is a government social protection initiative designed to provide support to the poorest communities and those affected by HIV. One of its objectives is to ensure that the most vulnerable children have access to basic needs, including education, health care and good nutrition.

The project aim is to strengthen government and community support systems so that the most vulnerable children and families have adequate livelihood security to meet their basic needs, despite the impacts of HIV, AIDS and poverty. Alliance Zambia conducted training workshops to introduce the partners to the Public Welfare Assistance Scheme, including the beneficiary selection matrix and national child policy. Partners were also trained in social mapping, data collection, documentation, financial management, monitoring and report writing.

The partners then worked with existing community welfare assistance committees in the target communities to identify and select poor households caring for vulnerable children using the beneficiary selection matrix. This approach ensured non-discriminatory selection that is community driven.

Households were supported through transfers of food and materials and various economic strengthening initiatives such as cash grants, agricultural inputs and small livestock. This support improved household food security, as well the nutritional status of children. Some beneficiaries used the cash grant to start small household businesses like buying and reselling food commodities. Supports were complemented with psychosocial activities with children and families, and training on paediatric HIV treatment adherence to optimise treatment success.

In all, 670 households were supported with a comprehensive package. By the end of the project in 2008, 1,535 children were reached with support, and 800 of them were supported to access primary and secondary education. Parents and guardians were supported with economic strengthening initiatives, such as cash grants, agricultural inputs and small livestock. This helped families to improve food security and their children's nutrition. Parents and carers were also trained in paediatric HIV treatment adherence to ensure treatment success. A qualitative research study with parents found that children's sense of self-belief improved, along with school attendance and academic performance.

By taking an integrated family-centred approach, the individual needs of children were met alongside the needs of their families. This approach makes families healthier and stronger. Then they are better able to care for, protect and support their children. Linking families to existing government welfare support meant the project avoided duplication of effort, making it more sustainable in the long term. And because the approach drew on existing welfare support, it meant that greater numbers of families could be reached.

> I have seven children. We had many problems. We did not have regular meals and I was unable to send my children to school. I found out about the scheme from a community welfare assistant committee member. They visited my house and interviewed me. I received a cash grant of 500,000 kwacha [approximately $100], which has enabled me to start up my own business. I have also received food supplements that have assisted me and my children greatly. With the money I make from my business, I can now support my children to attend school and buy food for my family, so we are no longer hungry. To be able to look after my family and be self-sufficient has made me a much happier person.

CASE STUDY: INCREASING FAMILY INCOME WITH A SAVINGS AND LOANS SCHEME IN KENYA, NIGERIA, UGANDA AND ZAMBIA

Christian Aid's community-based orphan care programme is a five-year initiative with an overall goal to improve the quality of life of at least 25,000 orphans and vulnerable children in four African countries.

Households affected by HIV and struggling to support vulnerable children are given help to earn a sustainable income. The type of support varies, from providing tools, seeds and fertilisers for grandparents to increase their crop yield, to being included in savings and loans schemes that help teenagers and young adults start up innovative small business schemes to increase the family's income.

Workshops are held in communities and members are recruited into savings and loans associations, where they develop a plan of action. They agree on an amount of money to contribute per week and receive passbooks to record this in. At each meeting the group makes a decision about which families can be supported with a loan.

Jana Okoye, 24, cares for six children. Jana was 16 when her parents died:

"I have received help from neighbours. They gave me food and money at the time. The eldest two boys and the youngest sister were not able to finish school because we could not afford it. I felt extremely sad. It was very painful and very difficult to care for them. Our parents used to look after us, but it has been very difficult for me to make enough money to care for them all properly.

We don't have enough money to buy food – that is the biggest problem – or medicines when we are sick. We try to eat twice a day; sometimes we have enough to eat three times a day. It has been a very big challenge.

I was able to secure a loan from the group, which I used to buy cooking oil. I buy it in bulk and then sell it on in smaller amounts for a small profit. I took 4,000 Naira for the loan and it takes me about three months to pay it back.

I've learned so much since I joined the group. I've learned how to manage the family better, how to budget our finances and how to talk about HIV.… I've seen a real change in them [the children]. In the mornings they clean themselves, which they didn't used to do. They tell me when people say bad things about HIV, for example, and they criticise them.

I've learned so much from joining the group. I've got a loan, but I've also learned how to manage the family, how to economise, how to talk about HIV and about nutrition. It has made my life a bit easier. The loan has helped me to earn a bit more income – it means that I can earn 600N more a month. It helps with food and a bit towards school fees. I hope to build up and save more so that my brothers and sisters can have a better life."

Food and nutrition

Good nutrition is essential for the physical growth and development of children, and the full development of their immune system. Children's need for good nutrition starts before birth, and nutritional support of HIV-positive women is an important intervention. Certain groups of children – young children, children living with HIV, children living in poverty and children outside of family care – are particularly vulnerable to malnutrition. Food security is also an issue for families affected by HIV where a parent or carer is ill and unable to work. Adequate food and good nutrition is essential for children and adults on antiretroviral therapy to support adherence and ensure that medication is effective.

Family-centred food and nutrition programmes aim to support long-term food security in homes rather than provide food assistance to individual children. They also support family members to understand the importance of good nutrition across different age ranges, together with the specific nutritional needs of children living with HIV.

Programmes should consider:

- promoting the importance of nutrition at the various stages of child development

- providing food and nutritional supplements – malnourished children and pregnant women may require supplementary or therapeutic feeding
- enhancing skills in household agricultural and livestock production to increase the amount of food harvested for the family
- social protection measures such as cash transfers to increase access to food in the household and reduce the need for children to work
- providing guidance to families on food preparation and hygiene
- linking nutrition support programmes with agricultural support for increased food security
- identifying and targeting vulnerable households, and ensuring equitable distribution of food, taking account of household dynamics that affect patterns of food distribution and consumption such as the of age of children, their gender and the biological link
- providing safety nets for vulnerable children through community grain banks, community gardens, livestock management and crop selection, school feeding programmes, and junior farm programmes.

CASE STUDY: IMPROVING CHILDREN'S HEALTH AND NUTRITION IN TANZANIA

Lindi in Tanzania has one of the highest rates of malnutrition in the country, with a stunting rate of an estimated 53.5%. Malnutrition is driven largely by poverty and food insecurity, compounded by inadequate infant and young child feeding practices. Most women, especially in rural villages, are unable to identify signs of malnutrition. Due to lack of access to nutritional and childcare education, they do not know what they can do to ensure that their children are getting the nutrients they need to survive and be healthy.

Save the Children's health programme in Tanzania is tackling this through a community mobilisation campaign. This is bringing together individuals, groups and organisations to share information and carry out activities focused on improving health and the nutritional status of women and children.

Tupendane ("Let's love each other") is one of the groups formed to ensure that all pregnant women and children in their area live and grow healthily. Individuals in the village, including men, came together after recognising the importance of working together to address the health problems in their area. Tupendane group members meet twice a month to plan their community mobilisation activities. These include visiting pregnant women and newborns in the village to provide nutritional and health education and support. Women are taught about what it means to eat a balanced diet and why it is important, especially during pregnancy.

Group members also plan their livelihood activities, including group allotment and rearing poultry to support the most vulnerable families. Women who have received support and advice in the village grow vegetables and grains and keep chickens for eggs and meat, providing valuable protein.

Through community mobilisation activities, messages about healthy nutrition are reaching a broader section of the community. These are reinforcing health behaviours within families, challenging myths around nutrition, pregnancy and infant feeding practices, and providing greater support to food security activities across the community. In other settings this has been reinforced by linking the most vulnerable families to supports such as therapeutic feeding for those who are malnourished, ration cards and welfare supports such as cash transfers or food vouchers.

KEY RESOURCES

Family Health International (2007), 'HIV, nutrition and food: a practical guide for technical staff and clinicians'.

Gillespie, S. (2008), 'Poverty, food insecurity, HIV vulnerability and the impacts of AIDS in sub-Saharan Africa', JLICA.

International HIV/AIDS Alliance (2003), 'Building blocks: Africa-wide briefing notes. Health and nutrition'.

Reynolds, L. (2009), 'Nutrition in ART programmes', AIDS Map.
Available at: www.aidsmap.com/Nutrition-in-ART-programmes/page/1325010/

UNAIDS (2008), 'HIV, food security and nutrition: policy brief'. Available at: http://data.unaids.org/pub/Manual/2008/jc1515_policy_brief_nutrition_en.pdf

'WHO HIV and infant feeding technical consultation held on behalf of the Inter-agency Task Team (IATT) on prevention of HIV infections in pregnant women, mothers and their infants, Geneva, October 25–27, 2006'.
Available at: www.who.int/hiv/mediacentre/Infantfeedingconsensusstatement.pf.pdf

Education and early childhood development

Children are often withdrawn from education because of financial pressures within the family. If children are carers or heading households, they may find it impossible to attend school as well as care for family members. Family-centred education needs to take into account these pressures. Teachers and other educational professionals have close contact with children, and can identify problems they are experiencing within the family. They also know when children drop out of school. They are well placed to make referrals to community organisations, agencies, services and state supports that can provide assistance to the child and family.

Programmes should consider:

- recognising that education services need to understand the challenges faced by children who have caring roles and many out-of-school responsibilities, and adapt to optimise their ability to access education
- promoting flexible school hours, and offering support with school materials and school feeding to reduce the burden on the family
- advocating school fee exemptions for the poorest families
- addressing maltreatment and exclusion by teachers and other pupils through policies around the behaviour of staff and pupils that promote protection and inclusion
- building family and community trust and value in education, making school a priority for children affected by HIV
- training education professionals to understand the role of schools in supporting families affected by HIV, by planning and adapting services to meet their needs.

KEY RESOURCE

International HIV/AIDS Alliance (2003), 'Building blocks Asia. Education'.

The outreach worker in our suburb encouraged us to come to the drop-in centre for first-aid help and stay for classes. The teacher there is great because she understands the life we have to live.

CASE STUDY: INCREASING ACCESS TO EDUCATION FOR CHILD-HEADED FAMILIES IN SOUTH AFRICA

Heartbeat is a South African organisation, supported by Save the Children, which works with child-headed households to increase their access to education. The programme provides paid childcare workers, who visit families regularly and ensure that the children are in school by negotiating school fee waivers. The workers help children to access government grants, and they provide food. After-school centres give the children help with homework, life skills training and individual counselling. They also provide peer support groups for children heading households, and opportunities for play, drama and music. The children can access a social worker to support them with the challenges of being young carers.

Heartbeat has been supporting a township community in Khutsong, where many adults migrate away for work. Here, support systems for children have been weakened. Through a Heartbeat centre, 196 children in 27 child-headed households have now been supported with school fee waivers. Those not receiving government social grants have been provided with food and materials. As a result, teachers have seen improved attendance and attainment of these children.

Heartbeat has now handed this project over to the local Khutsong community childcare forum and is scaling up their work, providing training and mentoring to community- and faith-based groups who are starting similar programmes with child-headed families.

See Tolfree, D. (2006), 'A sense of belonging: case studies in positive care options for children', Save the Children. Available at: www.savethechildren.org.uk/en/docs/A_Sense_of_Belonging.pdf

CASE STUDY: JOINT SCHOOL AND COMMUNITY INTERVENTIONS IN BOTSWANA, SWAZILAND, NAMIBIA AND SOUTH AFRICA

The Circles of Support initiative was piloted in Botswana, Namibia and Swaziland and is also now operating in South Africa. Its purpose is to enable vulnerable children to remain in or re-enter school and fulfil their development potential. The project has developed an approach to building the capacity of communities to identify vulnerable children. They then use existing resources to support vulnerable families living in the community, with the school as the central support structure.

Using participatory tools, the community- and school-level facilitators are trained to know children's rights, to set up Circles of Support groups that include family and community members, and identify children in need. The facilitators help with local-level interventions, such as support with caring for younger siblings or sick parents, to allow children to attend school. They also help them to access grants or get fee exemptions from school, and provide school uniforms and stationery.

Circles of Support groups are linked with fieldworkers who work directly with families, making household visits and assessments. They explain the programme to families, and talk to children to identify their needs and their problems. They also talk to carers about their household situations, as well as the children's needs and possible solutions. The Circles of Support monitor children who are not registered for or attending school, and home visits allow follow up with children and families to address barriers to attendance. They also enable referral to services for families in need of emergency support for abuse cases and domestic violence.

Through Circles of Support the most vulnerable families and children are supported by their community and school. Their progress is monitored and they are linked to external support systems. The programme has enabled teachers to better understand vulnerability and the home situations of pupils, and support them to achieve their potential.

See Health & Development Africa, 'Circles of support for vulnerable children: a community and schools-based multi-sectoral approach to meeting their needs'. Available at: www.hda.co.za/cos.html

Early childhood development programmes

Critical developments take place in early childhood that affect the health and functioning of a child in later life (see Appendix 3). Good nutrition, stimulation, affection and love are key to helping children develop. Early childhood development programmes are designed to optimise the child's development in this period through parenting education, promoting cognitive development and communication, and nutritional support.

These interventions are delivered through support to families by home-based carers, social workers and health workers. They are also offered in community- and service-level settings, which deliver parenting advice and child development monitoring, and provide childcare facilities.

Programmes should consider:

- targeting early childhood development programmes to all family members who have a caring role, not just mothers
- assessing which family members spend most time with infants
- recognising that relationships with a child are different based on factors such as biological connection, age and family position
- teaching family members, such as fathers, grandparents or siblings, about the key factors and stages in the development of a child and how to provide the best care for the child
- designing parent education initiatives that improve the skills and capacity of parents to care for and communicate with their children, and assisting with referrals to other services or to access entitlements
- recognising that parent education approaches may be especially important for parents experiencing difficulties themselves – for example, mental

KEY RESOURCES

AIDSTAR-One (2011), 'Early childhood development for orphans and vulnerable children: key considerations technical brief', USAID/AIDSTAR-one project.

Bernard van Leer: 'Early childhood matters'.
Available at: www.bernardvanleer.org/English/Home/Our-publications/Browse_by_series.html?ps_page=1&getSeries=4

CARE USA (2006), 'Promoting early childhood development for OVC in resource constrained settings: the 5x5 Model'. CARE/USAID/HACI.

International HIV/AIDS Alliance (2006), 'Building blocks: Africa-wide briefing notes. Young children and HIV'.

health issues, drug use and gender-based violence – and for carers taking on children who are not their own. Parenting support is also crucial for individuals who have had poor or dysfunctional care in their own childhood.

CASE STUDY: EARLY CHILDHOOD DEVELOPMENT IN MOZAMBIQUE

The Consultative Group on Early Childhood Care and Development is a global inter-agency consortium focussed on the development of young children. In responding to the specific developmental needs of children affected by HIV and AIDS, the group has developed the 'Essential Package' a framework for addressing the needs of very young children and caregivers impacted by HIV and AIDS. The package recognises that many children are cared for by elderly relatives some of whom are suffering from acute or chronic illness; and may feel depressed and isolated which can affect their care giving.

The 'Essential Package' provides guidelines and tools for use at the household level, to help carers improve the quality of life and long-term developmental outcomes for children by focussing on their needs in the early years of life.The package highlights that there are different types of caregivers within the context of HIV and targets messages accordingly.

Save the Children has carried out work to validate the package through its programme in Mozambique. Regular volunteer visits to families provide caregivers with tools and support to develop the communication skills, cognitive and physical development of the children they care for.

Alice is a 55-year-old woman who has participated in the programme. She lives alone taking care of seven children and grandchildren. The uncertainty about her future, and that of her children and grandchildren, motivates Alice to provide the children with an education. Although there is no nursery school nearby, Alice makes an effort to stimulate learning at home. Through the home visits Alice has learnt about the use of stories and a visual reference guide to improve communication and interaction with the younger children. Alice sees the guide not only as a book of instructions for both herself and the children to follow, but also as a source of inspiration; stimulating creativity and aspiration.

The relationship that Alice has been able to develop with her children has been strengthened as a result of the volunteer's regular visits. The children have been included in the home visits with the volunteer, and have become more engaged. Alice plans to send the younger children to primary school as soon as possible

The volunteer visits also encouraged Alice to ensure the younger children are vaccinated and reinforced the importance of nutrition and the role of vitamins in a children's physical and cognitive development

The volunteer's visits have enabled Alice to feel less alone and therefore more supported in her efforts to raise the children. *"I am also very happy because I have been visited ... I feel like I am stronger."*

See 'The essential package: an age-appropriate framework for action for young children and caregivers affected by HIV and AIDS'. Available at: www.ovcsupport.net/files/file/CARE%20Hilton%20One%20Pager%20Rev%209%2026%20Web.pdf

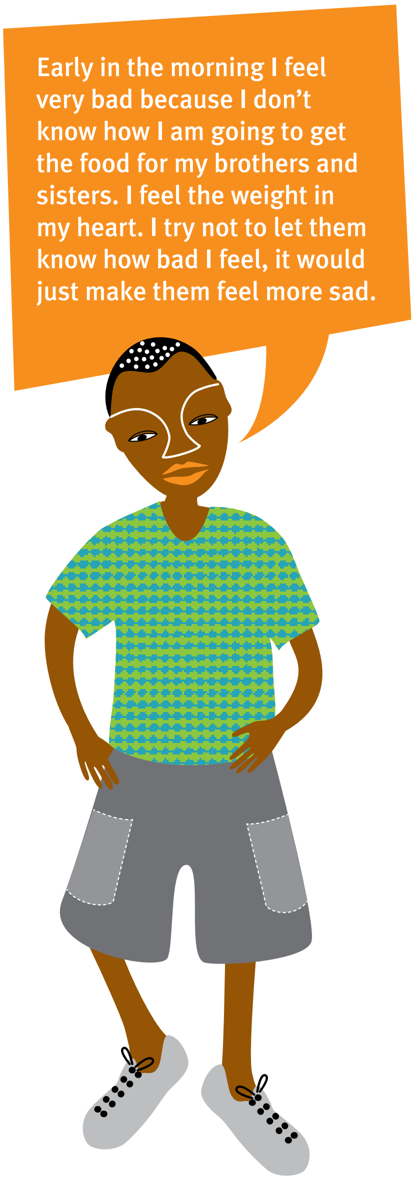
KEY RESOURCES

Global Child Development Group (2011), 'Executive summary of "Child development"', Lancet series on early childhood development.

Available at: www.globalchilddevelopment.org

Pence, A. and Nsamenang, B. (2008), 'A case for early childhood development in sub-Saharan Africa', Working Paper No. 51, Bernard van Leer Foundation.

Zoll, M. (2008), 'Integrated health care delivery systems for families and children impacted by HIV/AIDS: four program case studies from Kenya and Rwanda', JLICA.



CASE STUDY: PARENTING SUPPORT IN CAMBODIA

Korsang was founded in 2004 to work with people who use drugs and provide them with support and harm reduction services. Then in 2010, with support from UNICEF, Korsang established a drop-in centre for women who use drugs.

The centre, managed by a woman who herself had previously used drugs, provides support to women who use drugs, or partners of drug users, to access sexual and reproductive health services, antenatal care, and basic services for their children. Forty women and 23 children, most under the age of two, attend daily, and many more come for the weekly sexually transmitted infection screening and sexual and reproductive health services.

Women also have access to the Korsang doctor, and referrals and financial support for travelling to the clinic for antenatal care and child health services. They are given education and support in basic parenting skills, such as bathing, feeding and managing childhood illness, and advice on how to interact with their babies.

When women first came to the centre they used to leave their babies for hours. Now they are supported to feed, bathe and care for their babies, and shown how to deal with minor illnesses. Most importantly, they learn how to communicate with their babies. Now the women no longer leave their babies alone in the centre but participate in play activities and information sessions, and spend time interacting with and learning from other mothers. Partners are also encouraged to participate in the centre's activities around parenting and childcare.

Care and protection

Protecting and caring for children is a primary responsibility of families. Most families treat the care and protection of their children as a priority. However, the impact of HIV means that some families may be unable to provide all the care and protection that is needed. Their children may then be at risk of neglect and vulnerable to exploitation or abuse. As parents become seriously ill, the caring roles may be reversed, with children taking increasing responsibility for the care of their parents. The death of a parent, or both parents, creates a new situation in which the care and protection of the family's children can be seriously jeopardised.

In many cases the extended family may take on the caring role. But children can also face abandonment or inappropriate placement into an orphanage or other institutional setting. A family-centred approach seeks to ensure that children are placed in an alternative family setting, with the support that ensures the stability of the placement and provides for the children's wellbeing.

Community involvement, and the strengthening of community systems to protect children, is important because national systems rarely reach far into communities and services are often limited. Community-based child protection mechanisms are still relatively untested and they are not systematically documented. But the available evidence is positive in terms of protection outcomes.

Programmes should consider:

- raising awareness within families and communities of children's rights and the risks of neglect and abuse, in order to promote early detection of problems and provide support
- helping families to protect the rights of their children through birth certificates, access to services and entitlements, and inheritance of land or property from parents or other relatives
- supporting communities and the state in their duties of identifying and assisting families facing challenges in their role as primary carers

KEY RESOURCES

Better care network toolkit (2011), 'Care planning and family reunification forms and guidance'.

Available at: http://bettercare-toolkit.org/BCN/toolkit/SubCategory/index.asp?TKsubcatID=110&TKcatID=12

Doyle, J. (2010), 'Misguided kindness: making the right decisions for children in emergencies', Save the Children.

Save the Children (2010), 'Family strengthening and support: a policy brief'.

Wessells, M. (2009), 'What are we learning about community-based child protection mechanisms? An inter-agency review of the evidence from humanitarian and development settings', Save the Children.

UNICEF (2011), 'Policy and programming resource guide for child protection systems strengthening in sub-Saharan Africa'.

Wulczyn, F. et al. (2010), 'Adapting a systems approach to child protection: key concepts and considerations', UNICEF.

- building on existing community-based organisations' response to children and embedding protection systems in existing community structures[46]
- emphasising that child protection systems should prevent family separation, providing the kinds of support that enable families under stress to retain their children and maintain their parenting role
- advocating for government policy that can strengthen the protective environment around a child – for example, parenting education, day care, respite care and counselling[47]
- placing children in family settings wherever possible, and only as a last and temporary resort in institutional settings[48]
- ensuring that children informally placed in the care of their extended family have the same degree of protection as other children, including the right to birth registration and inheritance
- assisting communities to monitor and support children in both informal and formal care in order to identify problems, offer support and seek appropriate external services to help or intervene more directly to protect a child
- advocating for alternative care services to be properly regulated and monitored against a set of minimum standards of quality care. This is an essential step to prevent the unnecessary separation of children from their families and to ensure that children are well cared for in any form of alternative care.

KEY RESOURCES

Long, S. (2010), 'Positively caring: ensuring that positive choices can be made about the care of children affected by HIV', EveryChild.

Olson, K. et. al. (2006), 'From faith to action: strengthening family and community care options for orphans and vulnerable children in sub-Saharan Africa', Firelight Foundation.

Oswald, E. (2009), 'Because we care: programming guidance for children deprived of parental care', World Vision.

CASE STUDY: CHILDCARE FORUMS IN SOUTH AFRICA

As the numbers of HIV-affected children rose in South Africa, many communities developed local responses to orphans and vulnerable children. Almost 240,000 children are now getting some help from community-based childcare forums. These local informal networks play a critical role in identifying orphans and vulnerable children, providing them with psychosocial and other support, and referring them to government services.

The Maluti a Phofung municipality is in the eastern part of the Free State Province. In 2003 the orphans and vulnerable children task team from the municipality, together with the Department of Social Development, Education and Health and Save the Children, began to establish childcare forums made up of 10 to 30 volunteers in all 34 wards of the municipality. The aim was to provide much-needed support and services to vulnerable children in their families. First, the task team met with leaders of religious groups, pre-school teachers and ward councillors to seek support for the forums. The councillors agreed to spearhead them within their wards, and the task team then trained at least five members of each forum for five days.

Right from the start the childcare forums began household surveys to identify vulnerable children in their communities. They help these children to get birth certificates and other identity documents that are critical in South Africa to access government social grants, education and other support. They also help families apply for social grants, and distribute food parcels when these are available. Members visit children in child-headed households, and negotiate with schools to waive fees and allow the children to attend. Some schools have also begun programmes to support vulnerable children, providing meals at school and establishing clothing banks whereby better-off children can share clothes with those who do not have enough. Childcare forums are now established in most wards and work closely with other local organisations, including churches, childcare centres, schools and crèches.

The childcare forum model has demonstrated real potential to assist vulnerable children and their families. It can help families to access social grants and government services, while also directly providing other kinds of support such as home visits, feeding schemes, education support and recreational activities. As a means of mobilising community support to HIV-affected children in their families, they have proved effective in bridging the gap between families and

---

[46] Wessels, M. (2009), 'What are we learning about community-based child protection mechanisms? An inter-agency review of the evidence from humanitarian and development settings', Save the Children.

[47] Save the Children (2010), 'Policy brief: family strengthening and support'.

[48] Williamson, J. and Greenberg, A. (2010), 'Families not orphanages', Better Care Network Working Paper 1.

CASE STUDY: CHILDCARE FORUMS IN SOUTH AFRICA (CONTINUED)

government services, and in providing additional family support services.

The success of these and similar community-based childcare and protection groups is down to:

- community ownership of the group's activities
- building on existing capacities and assets
- support from formal and non-formal leaders
- the participation of children themselves
- efforts to be inclusive and to challenge established social divisions
- linkages with formal systems to mobilise resources and facilitate effective referrals.

However, they are not without their limitations and challenges. These include the extent to which such groups can be made responsible for managing 'sensitive' child protection issues. They also include the risks resulting from inadequate training, and the difficulty of sustaining the involvement of volunteers from the community.

Emotional and psychological support

Psychosocial support is now a standard component of comprehensive programmes for children affected by HIV. However, it is often confused with standalone interventions directed at children in response to trauma, grief or bereavement. For most children it is the everyday love, care and protection that is important, not therapeutic interventions from outside experts. The family is central in achieving the psychosocial wellbeing for so many children, and our approaches need to strengthen children's existing trusted relationships through economic, social and material support to families.

Some children do face extreme psychological and social impacts of HIV, and psychosocial interventions can help children and families to deal with these. Common psychological and emotional challenges faced by children affected by HIV are grief and bereavement, coming to terms with their HIV status, fear about the future, and isolation as a result of stigma. They also have to cope with responsibility for sick family members and a corresponding lack of attention to their own emotional and developmental needs. HIV disclosure or non-disclosure can also be a source of stress and psychological problems for young people. Many children have already realised that they or their parents have HIV before this is officially disclosed to them.

Adults within families can face similar challenges, and relationships may become difficult because of the stress experienced by family members. In these circumstances, tensions can lead to abuse and family breakdown.

Programmes should consider:

- supporting families to maintain good relationships and deal with disclosure, bereavement, stigma and planning their futures together
- using memory work to bring together families affected by HIV in order to address psychosocial issues and plan together for the future. Memory work is especially successful where the entire household, including children, is involved[50]
- using memory work to develop family history documentation so children have information on their family tree and relatives
- integrating memory work into the package of services to families affected by HIV

> **"The most appropriate and sustainable sources of psychosocial wellbeing for young children come from caring relationships in the home, school and community."[49]**

KEY RESOURCES

International HIV/AIDS Alliance and Pact (2007), 'Understanding and challenging HIV stigma: toolkit for action. Module I: children and stigma'.

Richter, L. et al. (2006), 'Where the heart is: meeting the psychosocial needs of young children in the context of HIV/AIDS', Bernard van Leer Foundation.

Williamson, J. and Greenberg, A. (2010), 'Families not orphanages', Better Care Network Working Paper 1.

Healthlink worldwide: International Memory Project.
Available at: www.healthlink.org.uk/projects/hiv/imp_stories.html

REPSSI, 'Memory work manual'.
Available at: www.repssi.org/index.php?option=com_content&view=article&id=75%3Amemory-work-manual-facilitators-guide&catid=37%3Afamily-community-support&Itemid=1

---

[49] Richter, L. et al. (2006), 'Where the heart is: meeting the psychosocial needs of young children in the context of HIV/AIDS', Bernard van Leer Foundation.

[50] 'Memory work: Learning from the Ugandan experience'. Available at: www.kit.nl/net/KIT_Publicaties_output/ShowFile2.aspx?e=1056

- working with all family members to address their different needs and supporting them to take decisions together
- recognising the psychosocial needs of all the family, including carers, and providing them with practical and emotional support in order to be more effective.

CASE STUDY: MAINSTREAMING PSYCHOSOCIAL SUPPORT INTO SERVICES TO FAMILIES

The Regional Psychosocial Support Initiative of Southern Africa (REPSSI) is a capacity-building organisation working across Africa. It advocates for child-related services, programmes and policies that recognise the holistic needs and rights of children. It also integrates psychosocial support into programmes. REPSSI believes that the psychosocial needs of children affected by HIV are best supported and sustained by everyday contact and interactions with parents, carers and communities.

REPSSI has developed a number of tools within services provided to children and their families that support families and carers to work with children.

Weaving Hope for Our Children is a tool that has been developed for community-level health providers such as home-based carers. It helps them to find ways of supporting children and addressing their psychosocial and health needs as they are providing health services to families and communities. There are also tools for families to use with children, such as The Talking Book, which supports carers in disclosing their HIV status to children. REPSSI has produced tracing books for family members to record their physical and emotional responses to HIV infection that can be shared together. In addition, the Tree of Life provides safe spaces for children to deal with their feelings about loss and bereavement.

REPSSI believes strongly that only a few children are in need of individual specialised therapeutic services for extreme trauma. In their experience, psychosocial support is best supported through mainstreamed interventions that are delivered through and with families.

See www.repssi.org

CASE STUDY: PSYCHOSOCIAL SUPPORT FOR CAREGIVERS IN SOUTH AFRICA

When we talk about psychosocial wellbeing we often think only of the children's needs. But the carers of children affected by HIV have their own needs, and often experience stress, fatigue, guilt, fear and grief. Whether young or old, being responsible for the care and protection of others can make it harder to be open about feelings.

The five-year Thogomelo Caregiver Support and Child Protection programme has produced skills development programmes and materials to support the carers of vulnerable children across all nine provinces of South Africa. The project works in collaboration with the South African Department of Social Development, and is implemented in partnership with PATH, Health and Development Africa and the Alliance. At least 500 learners are trained annually.

The Thogomelo project aims to help carers reduce their isolation and increase their resilience.
It is developing resources and activities to help carers and their supervisors overcome the challenges they face during their everyday work. The project's belief is that "a well-cared-for caregiver is an effective caregiver". Using activity-based, participatory learning to account for the carers' different backgrounds, the programme also involves classroom and experiential learning and field-work.

The Thogomelo project is providing comprehensive guidance on caregivers' wellbeing. This includes strengthening relationships; self-care; dealing with stress; caring for caregivers; building a caring community; accessing and mobilising resources; responding to child abuse and neglect; understanding child development; maintaining resilience; and increasing HIV and AIDS literacy.

The Thogomelo team is also strengthening the capacity of community carers to identify and respond to violations in child protection within families. This is helping to reduce the anxiety they experience when confronted with child abuse, neglect or exploitation. Community ownership is essential to keeping children safe. That is why Thogomelo is working closely with provincial, district and community stakeholders such as community care forums, community leaders, police officers, community health workers, and Department of Social Development officials.

5

How do we make a family-centred approach work in our organisations?

In this chapter:

- How do we adapt our programmes to a family-centred approach?

We have looked at the benefits of applying a family-centred approach and some examples of how they can be applied in programmes for children affected by HIV. The next step is to think about how to put this into action in our organisations. It may be that some of our current programmes can be adapted without major adjustments. Perhaps as we plan new programmes and develop new proposals for funding we will adopt a family-centred approach, making significant adjustments to our current programme design.

Before moving ahead, it is useful to think about the preparations we may need to make within our organisation and the challenges we may face. Applying a family-centred approach requires a change in the way we think and the way we work. We will need to consider some of the following issues.

HOW DO WE ADAPT OUR PROGRAMMES TO A FAMILY-CENTRED APPROACH?	
BUILDING CAPACITY	■ Adapting programmes to take a family-centred approach is likely to diversify programme activities and hence the skills needed by staff to deliver them. For example, home-based care programmes currently focusing on the needs of adults living with HIV could be broadened to assess and meet the needs of children within the household. ■ In order to do this, the carers would need to be trained so that they are confident communicating with children, aware of child protection issues and understand the services to which the family should be referred. Similarly, programmes that have provided material support through paying school fees or providing school materials may be adjusted to provide a savings scheme or income generation cooperative to provide sustainable family income. Again, staff will need additional skills to implement these programmes successfully. ■ The workload of key staff such as volunteer health workers will also need to be managed so that if they expand their role to care for families, rather than just adults, they may need to support fewer families or cover a smaller geographic area.
COORDINATION AND NETWORKING	■ Few programmes can deliver the full range of services and supports that a family may need. So a strong focus on referrals and linkages to other service providers is needed. ■ This will require assessing available services in the communities where we are working, developing relationships with other service providers, and establishing means of referring families between organisations. ■ We also have a responsibility to assess the quality of the services available before promoting them or making referrals, and a means of monitoring the effectiveness of referrals.
WORKING WITH COMMUNITY GROUPS	■ We may decide to introduce a programme, or programme component, that involves using community groups, networks of people living with HIV, and community child protection committees to mobilise and support families to access resources from government programmes.
LIMITED SERVICES ON THE GROUND	■ Family-centred approaches depend on a range of services and resources being available at different levels. These include national social protection schemes, or access to health services providing key components of family-centred care, such as antenatal care and obstetrics, early infant diagnosis, early childhood development and paediatric antiretroviral therapy. ■ In contexts where few of these exist, it is still possible to ensure that family linkages make the best use and uptake of those that are available, or we can advocate for these services at local or national level.
LACK OF CHILD- AND ADOLESCENT-FRIENDLY AREAS	■ Many health facilities do not have areas that are attractive and user-friendly for adolescents and children, or for seeing families together. However, with a little imagination it may be possible to make changes with limited resources or reorganise available space to achieve a more user-friendly environment.

HOW DO WE ADAPT OUR PROGRAMMES TO A FAMILY-CENTRED APPROACH?	
LIMITED DOCUMENTATION OF APPROACHES IN DIFFERENT CONTEXTS	■ There is currently limited documentation to support promoting and implementing family-centred programmes in different countries and contexts. There are few established programme designs and tools that can be easily transferred from other organisations or programmes. This means that our organisations will need to take the principles of family-centred working and base our programmes on these, together with an assessment of our particular context. ■ We should also document our experience of family-centred working so that it can be shared with others and help develop good practice.
MONITORING AND EVALUATION	■ In order to monitor the impact and effectiveness of family-centred programmes, we will need to develop and adapt tools so they measure factors such as economic security of households, household nutritional levels, attendance and attainment in school of all children, and the wellbeing of all family members.
DONOR FUNDING STRUCTURES	■ Donor funding is often allocated separately for programmes addressing the needs of adults and children. Organisations need to discuss with the donors the value of an integrated response and negotiate to use funds more flexibly. ■ Programmes need to generate evidence of value for money and effectiveness of this approach for these discussions. In the short term, if our organisation only works with children, we may consider applying for grants that will enable us to work more flexibly with families.

6

How do we add quality to our programmes?

In this chapter:

- What are the cross-cutting principles of family-centred care?
- How do we target services and make sure they reach those who need them?

What are the cross-cutting principles of family-centred care?

This chapter outlines cross cutting principles and guidance we should apply when planning family-centred care and services for children. Many of these are important principles for all programmes targeting children. Five of these are based on the Alliance programming standards for children that are referenced in Appendix 1. Links and references are provided for each principle so that we can learn more about each topic and access more information about how practically to apply these in our programmes. The table can be used as checklist to help us ensure we apply all the principles.

PRINCIPLE	WHAT IS IT AND WHY IS IT IMPORTANT IN FAMILY-CENTRED CARE	REFERENCES AND RESOURCES
CHILDREN’S RIGHTS ✓ STANDARD 2	■ Children’s rights were laid out in the UN Convention on the Rights of the Child, which has been agreed by 194 countries. It includes a child’s right to: • life, survival and development • be treated equally and be free from discrimination. • participate in activities and decisions that affect them. ■ All actions should be based on the best interests of the child, in particular the right of a child to participate fully in family life and to be reunited with parents if separated.	■ Child Rights Information Network: www.crin.org ■ Save the Children (2007), *‘Getting it right for children: a practitioners’ guide to child rights programming’.* ■ United Nations General Assembly (1990), *‘Convention on the rights of the child’*, Office of the United Nations High Commissioner for Human Rights. ■ African Union (1999), *‘African charter on the rights and welfare of the child’*. ■ SAARC/UNICEF (2009), *‘Regional strategic framework for protection, care and support of children affected by HIV/AIDS’*.
CHILD PROTECTION ✓ STANDARD 2	■ Children have the right to be protected from abuse, exploitation and neglect. ■ Providing family-strengthening support can reduce stresses within the family and prevent abuse, exploitation and neglect. ■ Means of detecting child abuse and neglect are needed within communities. ■ Alternative care needs to be made available when children are abused.	■ Wessells, M. (2009), *‘What are we learning about community-based child protection mechanisms? An inter-agency review of the evidence from humanitarian and development settings’*, Save the Children. ■ Wulczyn, F. et al. (2009), *‘Adapting a systems approach to child protection: key concepts and considerations’*, UNICEF, UNHCR, Save the Children. ■ UNICEF (2007), *‘Enhanced protection for children affected by AIDS: a companion paper to the framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS’*. ■ Jackson, E. and Wernham, M. (2005), *‘Child protection policies and procedures toolkit: how to create a child-safe organisation’*, ChildHope UK. ■ Save the Children (2008), *‘A common responsibility: the role of community-based child protection groups in protecting children from sexual abuse and exploitation’*. ■ Sheahan, F. (2009), *‘The first line of protection: community-based approaches to promote children’s rights in emergencies in Africa’*, Save the Children Sweden

PRINCIPLE	WHAT IS IT AND WHY IS IT IMPORTANT IN FAMILY-CENTRED CARE	REFERENCES AND RESOURCES
GENDER SENSITIVE	■ Boys and girls should have equal rights and opportunities. ■ Programmes and policies should promote and, as far as possible, ensure equal opportunities and resources for boys and girls, and men and women. They should understand gender norms and recognise when boys are more vulnerable than girls and vice versa. ■ Programmes should also consider relationships between men and women, boys and girls, and how these can affect programmes in positive and negative ways.	■ International HIV/AIDS Alliance (2007), *'Keep the best, change the rest: participatory tools for working with communities on gender and sexuality'*. ■ Strategies for Hope (1995), *'Stepping stones: a training package in HIV/AIDS, communication and relationship skills'.* ■ Save the Children (1999), *'Save the Children's policy on gender equality'.* ■ Promundo/UNFPA/MenEngage (2009), *'Engaging men and boys in gender equality and health: a global toolkit for action'.* ■ Bhana, D. et al. (2006), '*Young children, HIV/AIDS and gender: a summary review'*, Bernard van Leer Foundation.
CHILDREN'S PARTICIPATION ✓ STANDARD 3	■ Participation means that children are actively involved in decisions and plans that affect their lives. ■ Adults may need to be sensitised, as child participation can be seen to challenge traditional roles of adults and children, and power hierarchies. ■ When designing programmes and policy, children need to participate at all stages of the project cycle. ■ Methods to enable children to participate need to take into account age, literacy and other capacities of the child.	■ Save the Children (2005), *'Practice standards in children's participation'.* ■ Inter-Agency Working Group on Children's Participation (2007), *'Children's participation in decision making: why do it, when to do it, how to do it'.* ■ Inter-Agency Working Group on Children's Participation (2007), *'Minimum standards for consulting with children'.* ■ Save the Children (2010), *'Child carers: child-led research with children who are carers. Case studies from Angola, Nigeria, Uganda and Zimbabwe'.* ■ UNICEF (2006), *'Child and youth participation resource guide'*, UNICEF East Asia and Pacific Regional Office.
TARGETING BASED ON VULNERABILITY AND NOT HIV OR ORPHAN STATUS ✓ STANDARD 3	■ Targeting families based on HIV status alone causes stigma and discrimination, and can disrupt relationships in communities. Evidence shows that targeting based on extreme poverty effectively reaches families affected by HIV, and that orphanhood is not a good indicator of vulnerability. ■ New research on developing an indicator related to household wealth is more relevant for identifying who is vulnerable	■ Akwara, P.A. et al. (2010), 'Who is the vulnerable child? Using survey data to identify children at risk in the era of HIV and AIDS', *AIDS Care* 22(9): 1066–85.
INTEGRATION WITH NATIONAL RESPONSES AND PLANS	■ Where feasible, policy and programmes should be planned and delivered to enhance and coordinate with national plans and policy. JLICA found that successful programmes were often delivered by many partners but were government led. ■ Programmes should also have strong links with government agencies at local level.	■ Engle, P. (2009), *'National plans of action for orphans and vulnerable children in sub-Saharan Africa: where are the youngest children?'* Bernard van Leer Foundation. ■ Save the Children (2003), *'National plans of action for children: summary guide for governments'*, Save the Children Alliance.

How do we target services and make sure they reach those who need them?

In addition to these cross-cutting principles, the quality of our programmes will depend on how far they meet the needs of the children and families who need services the most. Quality also depends on programmes being delivered in a way that makes them accessible to the people who need them.

Ensuring services reach those most in need

Marginalised groups are often not reached by programmes or are excluded from services. Programmes and policy should recognise the diversity of families and ensure that programmes are reaching and including the most marginalised children and families. These may be the children of sex workers, drug users, transgender people, men who have sex with men, migrant children, street and working children, children in institutions, and children in conflict with the law.

Ensuring services are accessible

There are many barriers that prevent children and families accessing services. We need to assess the barriers that particular groups face and look at strategies to make services more attractive or easily available to all. Common barriers that relate to the way services are provided are:

- stigma and discrimination
- financial costs of transport or service charges
- registration costs
- pharmacy costs
- time and transport costs of services in different locations for adults and children
- lengthy travel to health services.

Gender norms can also act as a barrier to accessing services. Assessing and addressing the barriers that limit the ability or willingness of boys and girls and men and women to access services should be a key part of programme design. In many areas, particularly rural areas, key services may not be available or of poor quality. Where this is the case, advocating for essential services to be made available to the whole population should be a key policy initiative.

> “When I fell sick the clinic refused to admit me with my daughter. I don’t know who my daughter’s father is ... there was no one to look after her. She is no more ... I will never go for treatment. I am not interested.”
>
> Female injecting drug user (26)[51]

KEY RESOURCES

Beard J. et al. (2010), ‘Children of female sex workers and drug users: a review of vulnerability, resilience and family-centred models of care’, Journal of the International AIDS Society 13(2).

Open Society Institute (2009), ‘Women, harm reduction, and HIV: key findings from Azerbaijan, Georgia, Kyrgyzstan, Russia, and Ukraine’. Assessment in Action Series, Open Society Institute.

Presentations from Coalition for Children Affected by AIDS (CCABA) meeting on family centered care for the most marginalised families.

Available at: www.ccaba.org./resources_geneva.html

---

[51] Oinam, A. (2008), ‘Exploring the links between drug use and sexual vulnerability among young female injecting drug users in Manipur’, Health and Population Innovation Fellowship Working Paper 6, New Delhi: Population Council.

Providing services in an integrated way

JLICA's analysis indicated that services are most effective when delivered in an integrated way. This means providing multiple services, such as health, nutrition, early childhood development and economic support, to families together in one place. Although in Chapter 4 we describe the interventions by sector, many of these services and supports impact on each other and ideally should be delivered together.

Ensuring referrals and linkages between services

While recognising the ideal of providing services in an integrated way from one centre, this may not always be possible – especially in the short term. The different services needed by children and families affected by HIV are often provided by a range of organisations. These may include the government and international non-governmental or community-based organisations. For example, the government may provide treatment, a non-governmental organisation may give nutritional support, and a community-based organisation may offer home-based care or psychosocial support. We need to know what other services are available in our area, and establish and maintain good mechanisms for referral between services.

Government departments at a district level should play a role in collating the service information by provider and service within a geographic location. Within health service provision, different parts of the service may be offered in different centres or parts of a hospital. Smooth referral from one service to another is essential to ensuring that children and families receive all the services they need, and to preventing loss to follow up. For example, women who have received PPTCT should be referred to maternal, neonatal and child health services, or to adult treatment services as needed. Older children receiving paediatric antiretroviral services may need referral for sexual and reproductive health, education or social welfare services. Smooth referral can be facilitated by community members acting as outreach workers or expert patients. They are aware of the range of services available and can help families navigate services. They can help with issues such as lack of information or knowledge of services. They can also provide support for people who are worried about accessing services, whether through lack of experience or fear of stigma or discrimination.

7 Summary


As we work with children affected by HIV, we should be asking ...
... who is the child's family?
... how can all the family members caring for the child be supported?
... what is the situation of all the family members?
... how can the family structure be strengthened?
... who supports us when there is no family?
... what we think!

Programming in the context of HIV has changed. The focus on individuals and their access to treatment has achieved a great deal and people are living longer. Now their ongoing needs are around their families, livelihoods and human rights. Family-centred programming offers an opportunity to focus on strengthening the family unit for more sustainable development.

There is now strong international guidance on family-centred programming, based on growing evidence. But so far, much of the discussion around family-centred approaches has happened at the international level. An important step in the process now is to translate learning and recommendations to the national and local level. We hope this guide will provide programmers with the evidence, examples and ideas to begin this process, and to support advocacy for family-centred programming within our countries.

The guide has looked at the benefits for families and children of a family-centred approach to working with children affected by HIV. Using a family-centred approach, we consider the family in every intervention with children, recognising that supporting the family is one of the most effective means of ensuring the best possible quality of life for the child.

As we work with children affected by HIV, we should be asking:

- Where is the child’s family?
- Who are the family members?
- What is their situation?
- What can be done to strengthen the family structure and ensure its optimal health and functioning?

Throughout the guide we have looked at the family-centred approach through the lens of caring for the child. However, a family-centred approach can also be applied from the perspective of working with adults. When we work with adults we should also be asking:

- Do the adults care for children?
- Are there any other family members?
- Where are they?
- What is their situation?

Programmes focusing on delivering support or treatment to adults can be used as an entry point to consider how interventions can reach children and improve outcomes for families as a whole.

We need to recognise in all HIV programmes that an individual response is limited in what it can achieve. Understanding the contexts in which people live, the social relations and networks they rely on, and ensuring that these families are supported, should also achieve better outcomes for HIV programmes generally.

Implementing a family-centred approach within our HIV programming is an important goal. We can improve the health and wellbeing of vulnerable children by improving the health and wellbeing of their families. A family-centred approach can help us to achieve long-term positive impacts for children in terms of their health, education and social development by acknowledging the inter-related nature of family relationships and their effects on children’s health and wellbeing.

Key challenges remain for organisations in identifying and reaching the most marginalised families and ensuring they are included in family-centred programming. Implementing family-centred programmes and policy requires:

- innovative partnerships between organisations and coordination of services to maximise the opportunities to get a broad range of services to all families
- programmers to think about children within a network of social relations and diverse constructions of family, and develop new ways of working that take a case management approach
- looking at child vulnerability in the context of the family and not just at orphans
- measuring family capacity and resilience in caring for vulnerable children
- strengthening health, social welfare and community systems for safeguarding children
- reallocating resources and training health workers, teachers and other workers who care for children
- developing the evidence base to demonstrate the positive impacts of tracking child wellbeing through a family-centred lens
- an integrated and comprehensive programme of investment to develop a full range of services, such as antenatal care and obstetrics, early infant diagnosis, early childhood development programmes, and paediatric antiretroviral therapy
- detailed cost–benefit analysis of family-centred approaches
- ensuring that national social protection programmes reach the most vulnerable and that they are HIV and child sensitive.

We hope this guide can be a helpful ongoing reference as we design and implement our programmes for children affected by HIV in order to support the best possible outcomes for children.

Appendix 1

HIV programming standards

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
A standard is an agreed-upon level or benchmark of quality. It is measurable and evidence-based	Explanation of the standard and evidence	Suggestions for actions to implement the standard	
STANDARD 1 Our organisation supports children and their families based on defined vulnerabilities, and avoids labels such as OVC and CABA unless they are clearly defined	■ Programmes are most effective when they target children and their families based on an assessment of vulnerability and not based on orphan status. ■ We understand that orphanhood alone is not an effective indicator of vulnerability and that targeting and labelling children with terms such as OVC and CABA can be inaccurate and confusing as well as stigmatising. (See: Sherr et al (2008), '*A systematic review on the meaning of the concept 'AIDS orphan': confusion over definitions and implications for care'*.) ■ When we talk about the children within our programmes we do not label them or group them based on their orphan status, we treat them with dignity and respect and as people. (See: Johnson, J. (2008), '*Who is the vulnerable child? Using data from DHS and MICS to identify children at risk in the era of HIV and AIDS'*.)	■ Conduct assessments to understand the vulnerabilities of children and families in the programme target area. ■ Define the multiple vulnerabilities of children targeted in programme plans. This could include children living with HIV, children in households affected by HIV, children who have lost one or both parents, children vulnerable to HIV infection from living on the streets, and children living outside family care. ■ Use the concepts of children or children and families to define this target group when collecting data or reporting, not 'CABA, or OVCs reached'.	■ Programme plans contain clear definitions of the target group of children and their specific vulnerabilities to HIV within their context. ■ Publications and reports do not use acronyms unless they are accompanied by a detailed definition. ■ Staff do not use terms and labels for children such as OVC and CABA but describe the specific vulnerabilities of the children and their families within the programme.

MATERIALS AND RESOURCES

- Joint Learning Initiative on Children and HIV/AIDS (2009), *'Home truths: facing the facts on children, AIDS, and poverty'*.

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
STANDARD 2 Our organisation respects and promotes the rights of children and their protection from abuse, exploitation and neglect	■ The rights of children should be respected and promoted. Children should be protected from violence, abuse, exploitation and neglect at all times. The best interests of the child must be a primary consideration for actions affecting children. ■ Through our child protection measures we aim to strengthen children's own ability to protect themselves. ■ We strengthen families' ability to protect children by prolonging the lives of parents and enabling them to access basic services. ■ We engage families and communities in identifying harmful practices that put children at risk, making them aware of policies and processes that help in preventing abuse, exploitation and neglect, and providing strategies to responding to a violation of a child's rights. ■ We promote the importance of creating a supportive environment through legislation that gives children and their families legal support to address child protection violations.	■ Implement a child protection policy, and display the policy, develop a staff code of conduct, share guidance on children's participation, and identify focal people in the organisation. ■ Train the staff of children's programmes on children's rights, the child protection policy, staff conduct and on recognising signs of abuse, neglect and exploitation. ■ Promote community awareness and support of child rights, and the rejection of any form of discrimination, abuse, exploitation, or neglect of children. ■ Ensure children and their carers are made aware of policies, systems, procedures and support services that are available to protect children. ■ Formulate a list of materials and services that can be easily accessed should children and families be referred for further support, such as social work, counselling, and the police. ■ Promote and advocate for legislation that protects children at national and international level including child rights act, children's acts, and child protection policies.	■ A child protection policy focal person is identified and is monitoring policy implementation activities. ■ The policy is available in local languages and a child-friendly version is shared with partners, and donors. ■ There is an explicit procedure for reporting incidents available in a range of languages. ■ Staff have a list of service providers and a referral flow chart available to them to support the policy. ■ Staff have received training and can demonstrate an understanding of children's rights and protection, and are clear about expectations of their conduct. ■ There is a clear process for sharing the policy with children and families within the programme. As a result, they know how to take action to highlight protection violations.

MATERIALS AND RESOURCES

- Children's Rights Information Network.
- Jackson, E., Wernham, M. and Child Hope (2005), 'Child protection policies and procedures toolkit: How to create a child-safe organisation', Consortium for Street Children.
- Keeping Children Safe Coalition.
- Save the Children (2007), 'Getting it right for children: a practitioners' guide to child rights programming'.
- Save the Children (2008), 'A common responsibility: the role of community-based child protection groups in protecting children from sexual abuse and exploitation'.
- UNICEF (2007), 'Enhanced protection for children affected by AIDS: a companion paper to the framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS'.
- United Nations General Assembly (1990), 'Convention on the rights of the child', Office of the High Commissioner for Human Rights.

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
STANDARD 3 Our organisation promotes children’s participation in processes that are inclusive and age appropriate	■ Participation is a basic human right that children are entitled to. ■ Participation refers to the active involvement of children in the decisions, processes, programmes and policies that affect their lives. ■ In order to respond to the needs of children effectively we understand that programmes must involve the participation of children and their families in all stages of the project cycle. ■ Children are the only ones who can describe issues from their perspective. ■ Participation of children in our programmes aims to build their self-esteem and confidence. It allows them to develop important communication skills and it also raises awareness of the needs of children to the broader community.	■ Actively involve children in developing and designing interventions and in the evaluation and review of programmes that address their rights and needs. ■ Ensure that the activities they are involved in are tailored to their age group. ■ Ensure processes empower children to make decisions about their care and the design of services that are for them. ■ Support families and communities to understand the value of children’s participation and provide opportunities for them to explore the processes within their own context. ■ Consider carefully who within a family takes part and demonstrate awareness of the possible impact on families, other siblings and excluded children.	■ Staff demonstrate an understanding of the value and importance of children’s participation. ■ Organisations can demonstrate children are participating in programme development and implementation and are influencing programme design and evaluation. ■ Programme plans include clear processes for the participation of children that consider the influence of gender and power in the selection and inclusion of children. ■ Programme documentation demonstrates that the views of both boys and girls are heard and used within the programme.

MATERIALS AND RESOURCES

- Inter-Agency Working Group on Children’s Participation (2007), *‘Children’s participation in decision making: why do it, when to do it, how to do it’.*
- International HIV/AIDS Alliance (2004), *‘A parrot on your shoulder: a guide for people starting to work with orphans and vulnerable children’.*
- Lansdown, G. (2001), *‘Promoting children’s participation in democratic decision-making’*, UNICEF.
- Save the Children (2005), *‘Practice standards in children’s participation’.*

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
STANDARD 4 Our organisation promotes and/ or provides programmes for children that are HIV sensitive not HIV specific	■ Evidence demonstrates that interventions targeting the poorest and most vulnerable families using targeting criteria such as extreme poverty will effectively reach those affected by HIV, and at the same time will not stigmatize and label. ■ We understand that when targeting children and families, selecting only beneficiaries directly affected by HIV can result in resentment among other equally poor families, and can increase stigma and undermine the effectiveness of programmes. (See: UNICEF (2007), '*Impact of social transfers on children affected by HIV and AIDS*'.)	■ Assess the factors that make children vulnerable to HIV infection and the impacts of HIV within a specific context. ■ Programmes target children according to agreed criteria around vulnerability not 'orphan' status.	■ An assessment has been completed and the factors that make children vulnerable within the programme context have been identified. ■ A programme plan has been developed to address factors identified in the assessment. Direct links can be seen. ■ Criteria for targeting are explicit and are based on the vulnerability of children and their families, not the HIV status of child or family members alone.

MATERIALS AND RESOURCES

- Joint Learning Initiative on Children and HIV/AIDS (2009), *'Home truths: facing the facts on children, AIDS, and poverty'.*

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
STANDARD 5 Our organisation has policies and programmes to address stigma and discrimination that act as a barrier to children and families accessing programmes	■ Children affected by HIV, especially those living with HIV and children who are highly marginalised, are often stigmatised and discriminated against and excluded from programmes and services. ■ We address stigma at the family and community level so that children can exercise their rights to support and services. ■ We positively promote access to services for all children through the creation of policies on school admission, birth registration, and de-criminalisation of sex work, for example.	■ Conduct participatory learning sessions to enable children and families to understand their rights and respond to discrimination and its consequences. ■ Monitor discrimination and respond to the findings. ■ Train and mobilise communities to ensure community members and service providers understand and address stigma and discrimination. ■ Foster partnerships with human rights institutions, legal services and unions to promote and protect the rights of children and their families, for example to encourage birth registrations. ■ Conduct advocacy and lobbying activities on the rights of marginalised and vulnerable children affected by HIV and their families.	■ An assessment of the factors that lead to stigmatisation of children and their families has been undertaken. ■ Guides and tools for interactive sessions on stigma and discrimination are available for programme staff to use. ■ Staff are trained to facilitate learning sessions with children and families on relevant topics such as developing child-friendly services, self-esteem, and advocacy skills for children. ■ A stigma and discrimination monitoring format is available and up-to-date.

MATERIALS AND RESOURCES

- International HIV/AIDS Alliance and PACT Tanzania (2007), *‘Understanding and challenging HIV stigma: toolkit for action. Module I: children and stigma’.*

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
STANDARD 6 Our organisation promotes a family-centered approach reaching children within and through their families and community	■ Family can be defined as 'social groups connected by kinship, marriage, adoption or choice' (JLICA 2009). Children thrive in families. They develop better cognitively, physically, educationally and socially. (See: UNICEF (2007), '*AIDS, public policy and child well-being'*.) ■ We recognise that economically and socially strong families are better able to provide care and nurture children. We therefore promote social protection measures such as cash transfers, social grants and pensions and child protection legislation as the best approach for securing and strengthening families and communities. ■ Our programmes do not target individual children or measure only individual impacts but understand that children affected by HIV are best reached and supported through interventions that target the family and the community that cares for children. ■ We understand the importance of strengthening family health, because children are better able to cope with their vulnerabilities when their adult caregiver is healthy and able to provide love and cognitive stimulation. ■ Evidence suggests that many children in institutional care have surviving parents. The cost of this care is significantly more than what is needed by families to care for their own children. We therefore strive to keep children with their families whenever possible. (See: Desmond C., et al (2002), Approaches to caring, essential elements for a quality service and cost effectiveness in South Africa'. *Evaluation and Program Planning* 25: 447–458.)	■ Plan programmes that are framed around family-centred care of children. For children outside the family or community setting, the focus should be on family reunification and the de-institutionalisation of children. ■ Reinforce families' capacities to stay together and provide long-term care, through social protection measures such as grants, cash transfers, child protection policies, basic health services for all family members, and access to education. ■ Recognise the diversity of families and ensure that programmes are reaching and including the most marginalised children and families such as children of sex workers, drug users, transgenders and men who have sex with men, migrant children, street and working children, children in institutions, and children in conflict with the law. ■ Analyse and address the additional barriers faced by the most marginalised children and families in accessing support. These include stigma, discrimination, and criminalisation. ■ Implement family-centred services that integrate health, education, and social support for children and their families. ■ Build the capacity of communities to assist in the care and support of children, supporting additional child care facilities, parenting training, and access to welfare assistance.	■ Programme documentation reflects an understanding of the diversity of families and their differing capacities. ■ Communities are involved in the identification of vulnerable children and families. ■ Programmes can demonstrate the inclusion of the most marginalised families. ■ Programme plans demonstrate a family-centred approach to the care of children by using families as the unit for interventions. ■ Programmes can demonstrate communities' involvement in deciding how resources for children are allocated and used. ■ Advocacy activities are taking place that promote social protection measures to support children and their families. ■ Ongoing advocacy activities are promoting the de-institutionalisation of children by strengthening families and supporting family and community fostering.

MATERIALS AND RESOURCES

- Better Care Network: www.crin.org/bcn
- Joint Learning Initiative on Children and HIV/AIDS (2009), *'Home truths: facing the facts on children, AIDS, and poverty'.*
- Meintjes, H., Moses, S., Berry, L. and Mampane, R. (2007), *'Home truths: the phenomenon of residential care for children in a time of AIDS'*, Cape Town: Children's Institute, University of Cape Town and Centre for the study of AIDS, University of Pretoria.
- Richter, L. (2008), 'No small issue: children and families. Universal action now. Plenary presentation at the XVII International AIDS Conference "Universal action now", Mexico City, Mexico, 6 August 2008', Online Outreach Paper 3, The Hague: Bernard van Leer Foundation.
- Save the Children (2003), *'A last resort: the growing concern about children in residential care'.*
- UNICEF and ODI (2009), *'Promoting synergies between child protection and social protection'.*
- Wakhweya, A., Dirks, R. and Yeboah, K. (2008), *'Children thrive in families: family-centred models of care and support for orphans and other vulnerable children affected by HIV and AIDS'*, FHI and JLICA.

STANDARD	DESCRIPTION	IMPLEMENTATION ACTIONS	MARKERS OF PROGRESS
STANDARD 7 Our organisation promotes and/or provides integrated, family-centred services in health, education and social welfare in order to address the needs and rights of all children	■ Integrated, family-centred services are comprehensive, coordinated care services that address the needs of both adults and children in a family, and attempt to meet their health and social care needs either directly or indirectly through strategic partnerships, linkages and referrals with other service providers. ■ Where services for families affected by HIV are integrated with other health and social welfare services there are greater opportunities to reach more people with a more comprehensive range of support. ■ We understand that children and their families need to receive comprehensive services that are harmonised and coordinated, not stand alone services. ■ Children not only need support with health but also psychosocial support, educational support especially in early childhood, and basic material needs. ■ We understand that interventions that only target one individual area miss critical opportunities to reach siblings, family members and carers. For example, treatment for parents living with HIV can significantly improve the survival of children. ■ Social protection measures can strengthen the ability of families to access services themselves.	■ Collaborate with other organisations, institutions and government service providers to ensure services are joined up and their value enhanced by linkages and referrals to other services and programmes. Programmes are actively identifying where there are gaps in service provision for children and their families. ■ Incorporate children's needs and rights into the development of essential health, social welfare and education services. ■ Ensure that children can access appropriate services in key areas such as health, education, shelter, psychosocial support, food and nutrition, protection, economic strengthening, and family and community care. ■ Services target different levels including children, family, community, service and structural/policy levels. ■ Develop programmes that reflect an understanding of the different contexts children live in and the gender relations that influence their ability to benefit from a programme (girls access to school, for example).	■ Programmes demonstrate links and promote the integration of children's issues within other services such as health, education, and social welfare, increasing the number of children and families reached. ■ Services provided to families demonstrate that they are age specific and gender balanced. ■ Programmes are designed to address specific needs, for example the needs of children with disabilities, street and working children, and children of drug users and sex workers. Needs assessments have been carried out and programmatic responses developed.

MATERIALS AND RESOURCES

- Gillespie, S. (2008), *'Poverty, food insecurity, HIV vulnerability and the impacts of AIDS in sub-Saharan Africa'*, JLICA.
- International HIV/AIDS Alliance (2003), *'Building blocks: Africa-wide briefing notes: resources for communities working with orphans and vulnerable children'.*
- Jukes, M., Simmons, S., Smith Fawzi, M.C. and Bundy, D. (2008), *'Educational access and HIV prevention: Making the case for education as a health priority in sub-Saharan Africa'*, JLICA.
- Pence, A. and Nsamenang, B. (2008) 'A case for early childhood development in sub-Saharan Africa', Working paper No. 51, The Hague: Bernard van Leer Foundation.
- Richter, L., Foster, G. and Sherr, L. (2006), *'Where the heart is: meeting the psychosocial needs of young children in the context of HIV/AIDS'*, Bernard van Leer Foundation.
- Yong Kim, J. et al (2008), *'Integration and expansion of PMTCT of HIV and early childhood intervention services'*, JLICA/Harvard School of Public Health.
- Zaveri, S. (2008), *'Economic strengthening and children affected by HIV/AIDS in Asia: role of communities'*, JLICA.
- Zoll, M (2008), *'Integrated health care delivery systems for families and children impacted by HIV/AIDS: four program case studies from Kenya and Rwanda'*, JLICA.

Appendix 2

Glossary

Advocacy is a process aimed at changing the attitudes, policies, laws and practices of influential individuals, groups and institutions for the betterment of people affected by the issue.

Community means a group of people linked and interacting in some way; for example, by location (living in a village), kinship (family and tribe), occupation (peer educators) or by having a common problem (HIV). People may belong to several different communities at any one stage of their lives.

Child-sensitive social protection is an evidence-based approach that aims to maximize opportunities and developmental outcomes for children by considering different dimensions of children's wellbeing. It focuses on addressing the inherent social disadvantages, risks and vulnerabilities children may be born into, as well as those acquired later in childhood due to external shocks, and addressing them through social protection interventions that are child focused.

Culture describes what we learn, think, feel and do as individuals and what our society considers important. Our culture reflects our history and is based on our social, economic and environmental situation. It is learned from our family and society, who provide us with guidelines on how to behave as men and women, how to raise children and how to live. Messages from different sources also influence our culture. All societies change to take account of new knowledge and situations. We can belong to many different sub-cultures.

Development is the process and mission aimed at raising standards of living and quality of life for people around the world.

Discordant partners are those where one partner is HIV positive and the other is HIV negative.

Discrimination is when, in the absence of objective justification, a distinction is made against a person that results in them being treated unfairly or unjustly on the basis of belonging, or being perceived to belong, to a particular group.

Early childhood development is the most important phase for overall development throughout the lifespan of a human being. Brain and biological development during the first years of life is highly influenced by an infant's environment, and a child's early experiences determine health, education and economic outcomes for the rest of life. Families and carers play a key role in ensuring optimal child development.

Evaluation is the periodic assessment of the relevance, performance, efficiency, results and impact of work in relation to its stated objectives.

Gender refers to the socially constructed roles, behaviours, activities and attributes that a society considers appropriate for men and women. It dictates the status of men and women, and who has more power. Gender varies from place to place and can change over time and between generations.

Human rights are universal legal guarantees for all human beings, set out in international standards, protecting human dignity and fundamental freedoms and privileges. Human rights cannot be waived or taken away.

Impact refers to the longer-term effects produced by a development intervention, directly or indirectly. For example, it may refer to a rise or fall in incidence and/or prevalence of HIV.

Indicators are markers used to measure the results of an intervention, project or programme.

Integration refers to different kinds of sexual and reproductive health and HIV interventions and services that can be joined together to enhance outcomes. For example, this could involve referrals. It is based on the need to offer comprehensive services.

Intervention is an action aimed at changing or interrupting a specific aspect of a problem; for example, a behavioural intervention aimed at changing people's adoption and use of condoms.

Key populations are groups at higher risk of being infected or affected by HIV. They play a key role in how HIV spreads, and their involvement is vital for an effective and sustainable response to HIV. Key populations vary according to the local context, but include vulnerable and marginalised groups such as people living with HIV, their partners and families; people who sell or buy sex; men who have sex with men; people who use drugs; orphans and other vulnerable children; migrants and displaced people; and prisoners.

Linkages are the policy, programmatic, services and advocacy synergies between sexual and reproductive health and HIV. It refers to a broader human rights approach, of which integrated services are one component. Linkages can happen between core HIV interventions and core sexual and reproductive health interventions. Linkages also involve addressing the social and structural issues that make people vulnerable to sexual and reproductive ill-health and HIV.

Monitoring is the systematic and continuous assessment of the progress of an activity or programme over time, which checks that things are going to plan and enables us to make adjustments in a well-thought-out way.

Most-affected people are those who experience high risk of exposure to HIV or sexual and reproductive ill-health and have limited ability to reduce their vulnerability to that risk. They may be referred to as 'key populations' or 'most-at-risk groups'. For example, where same-sex practice is illegal, men who have sex with men have limited access to information or services on safer sex. The involvement of the most-affected people is key to the response to these problems.

Outcomes are the results of an intervention. Outcomes may include increased service coverage and utilisation, or behavioural changes.

Outputs are the results of programme activities; the direct products, services, capital goods or deliverables, such as the number of counselling sessions completed, people reached and materials distributed.

Outreach services connect sexual and reproductive health and HIV prevention, support and treatment services to individuals or communities who may have problems accessing them by normal means. This includes meeting individuals with information and services, follow-up visits and education activities in remote villages.

Participatory approaches refer to the active involvement of people affected by a problem, together with those who are concerned about it, in assessing, planning, implementing and evaluating programmes. They help to empower marginalised groups within the wider society. They also contribute to projects tailored to local needs and resources, and a sense of ownership that increases their chance of success.

Post-partum care refers to the services a child needs during the risky period immediately after a woman has given birth – typically for about six weeks. HIV-related post-partum services include interventions to reduce the possibility of HIV infecting the child through breast milk. It is also a good opportunity to talk about family planning.

Poverty is where basic human needs are not met. These include lack of access to food, water, nutrition, healthcare and clothing. The World Bank defines extreme poverty as a person subsisting on less than US$1 a day.

Programme refers to an overarching national or sub-national systematic response to a development problem, and may include a number of projects and interventions.

Project is a particular endeavour with a beginning and an end. It is aimed at achieving specific measurable objectives that are part of an overall programme objective.

Project cycle refers to the stages that a project goes through while it is active. It includes assessment, planning, implementation, monitoring, evaluation and adjustment and/or scaling up.

Prophylaxis is a public health intervention designed to prevent a person becoming infected with a disease. Co-trimoxazole is an antibiotic used as prophylaxis against opportunistic infections. Antiretroviral therapy can have a prophylactic effect by reducing an individual's viral load, lessening the chance of HIV transmission.

Risk refers to activities that put a person at risk of HIV or sexually transmitted infection, unintended pregnancy or other harm; for example, unprotected sexual intercourse.

Sensitisation refers to efforts to change attitudes within a society by providing information designed to increase people's understanding of a problem.

Sexual and reproductive health refers to physical, emotional, social and spiritual wellbeing in those areas of life concerned with sexuality and having children. It includes our feelings and desires, sexual relationships and activities, having children, protecting ourselves from infection, and making choices about our sexual and reproductive lives.

Social norms are the values, beliefs, attitudes and behaviours expected and approved of by society.

Social protection comprises interventions that offer social assistance; for example, cash grants and benefits; social insurance, such as pensions; and social justice, addressing root causes of poverty and vulnerability.

Stakeholders are people with an interest in a project. They include those who will be affected by a project, work on it and fund it.

Stigma is the identification that a social group creates of a person (or group of people) based on some physical, behavioural or social trait perceived as diverging from group norms.

Vertical transmission refers to the transmission of HIV from parent-to-child during pregnancy, delivery or breastfeeding. Efforts to prevent vertical transmission are commonly called prevention of mother-to-child transmission or prevention of parent-to-child transmission. Prevention of parent-to-child is preferable because it acknowledges the responsibility of both parents to reduce the risk of transmission. It is also less stigmatising to women.

Vulnerability is a measure of an individual's or community's inability to control their risk of infection or ill-health.

Appendix 3

Stages of development

AGE	DEVELOPMENT	NEEDS
FIRST STAGE: BIRTH TO 1 YEAR	Normally the baby is held close to their mother or carer most of the time. The baby learns to trust that at least one person will respond to their basic needs for food, contact (touch) and comfort. The mother or carer learns to recognise the baby's cry of hunger, discomfort or loneliness. If the mother or carer does not respond, the baby will not learn to trust and may develop a strong sense of fear.	■ Protection from physical danger. ■ Adequate nutrition and introduction of supplementary foods (exclusive breastfeeding is best). ■ Adequate health care. ■ Safe opportunities to explore the world. ■ Appropriate language stimulation. ■ Loving affection.
SECOND STAGE: 1 TO 2 YEARS	The child is learning to have some control over the body: walking, talking, dressing and controlling their bowels. If the child is frustrated, laughed at or punished harshly during this stage they can develop anger against adults.	■ Immunisation, nutrition, protection. ■ Opportunities to acquire new motor, language and thinking skills. ■ Opportunities to develop independence. ■ Help in learning to control their behaviour. ■ Opportunities to begin to learn to care for themselves. ■ Opportunities to play and explore.
THIRD STAGE: 3 TO 5 YEARS	A time of exploration and experimentation for the child. It is important that the child is encouraged to take initiative and not be punished or blamed when they make mistakes. This can block the child's initiative.	In addition to the above, opportunities to: ■ make choices ■ be creative ■ learn to live within the guidelines of the family.
FOURTH STAGE: 6 TO 12 YEARS	Most children are learning to cooperate with others (at school or home) and carry out tasks. The child needs constant encouragement as they learn. If the child begins to feel like a failure at this point they turn this feeling into blame and guilt.	In addition to the above: ■ encouragement to explore ■ opportunities for learning about living within the guidelines of family, school, community ■ praise rather than criticism ■ honest answers to questions ■ encouragement to express feelings, including negative feelings like anger and disappointment, but in an acceptable way ■ opportunities to participate – to speak, share and learn.
FIFTH STAGE: 13 TO 18 YEARS	This is the time for discovery of identity as a young woman or man. Independence from parents begins. If a child has developed anxiety and guilt at earlier stages they will find this time more difficult. They may feel shy, unloved or uncertain. These feelings can last for many years.	In addition to the above: ■ privacy ■ listening ■ support for understanding sexual development, sexuality, and sexual and reproductive health information ■ support for valuing human relationships – care and love, consideration and respect.

Adapted from REPSSI (2007) 'Psychosocial care and support for young children and infants in the time of HIV and AIDS: A resource for programming' and Eriksson's stages of human development from International HIV/AIDS Alliance and Pact (2007) 'Understanding and challenging HIV stigma: Toolkit for action. Module 1 Children and stigma.'

A global partnership:
International HIV/AIDS Alliance
Supporting community action on AIDS in developing countries

GOOD PRACTICE GUIDE

International HIV/AIDS Alliance
(International secretariat)
Preece House
91-101 Davigdor Road
Hove, BN3 1RE
UK

Telephone: +44(0)1273 718900
Fax: +44(0)1273 718901
mail@aidsalliance.org
Registered charity number:
1038860

Established in 1993, the **International HIV/AIDS Alliance** (the Alliance) is a global alliance of nationally-based organisations working to support community action on AIDS in developing countries. To date we have provided support to organisations from more than 40 developing countries for over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to HIV treatment.

The Alliance's national members help local community groups and other NGOs to take action on HIV, and are supported by technical expertise, policy work, knowledge sharing and fundraising carried out across the Alliance. In addition, the Alliance has extensive regional programmes, representative offices in the USA and Brussels, and works on a range of international activities such as support for South-South cooperation, operations research, training and good practice programme development, as well as policy analysis and advocacy.

www.aidsalliance.org

Design and illustration: www.janeshepherd.com