TAKING EVIDENCE TO IMPACT:

MAKING A DIFFERENCE FOR VULNERABLE CHILDREN LIVING IN A WORLD WITH HIV AND AIDS

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INTRODUCTION

The purpose of this document is to inform the development of appropriate responses for children affected by HIV and AIDS. It builds on the principles and approaches from the 2004 *Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS*, bringing in new evidence from academic analysis and programmatic experience, and translating evidence into normative guidance for policymakers and programmers. The guidance in this document is relevant for a range of implementing partners within governments, the United Nations and civil society organizations, including those working on HIV and AIDS, child protection, social policy and social justice.

The term 'children affected by HIV and AIDS' (CABA) refers to children living with HIV, as well as those whose well-being or development is threatened by HIV because they live in HIV-affected households and communities. The term is used throughout this report because it serves to highlight the specific ways that HIV and AIDS impact children. It is used for clarity, and readers should not interpret its use as an attempt to promote action that exclusively targets children and families affected by HIV and AIDS where this does not make sense.

This document does not seek to replicate the numerous CABA guidelines and 'how to' notes developed in recent years, although it does point readers to specific guidelines, where they exist, through **web links** at the end of each chapter. It also lays out **new programmatic directions** to increase CABA's access to critical health and other social services, highlighting the importance of better context-specific **vulnerability analysis** to guide programming and targeting, as well the need to enable children and young people to participate more actively in planning and programming. The report also illustrates how **child- and HIV-sensitive social protection approaches –** when delivered through government and non-governmental agencies – can help address household and community economic and social deprivation. Finally, it highlights the importance of increased investments in **national and community social welfare and child protection systems** to improve the quality and coverage of support for CABA, their families, and their households.

Orphan: A child under 18 years old whose mother died (maternal orphan), whose father died (paternal orphan), or whose parents both died (double orphan).

Orphans and vulnerable children (OVC): Orphanhood, both single and double orphans, or the presence of a chronically ill adult in the household. National Plans of Action often extend OVC to include children in poor families, street children and children with disabilities, among others.

Most-at-risk adolescents (MARA): Refers to those at heightened risk of HIV infection associated with their risk behaviour.

Children affected by HIV and AIDS (CABA): Children living with HIV, as well as those whose well-being or development is threatened by HIV and AIDS in their families or communities.

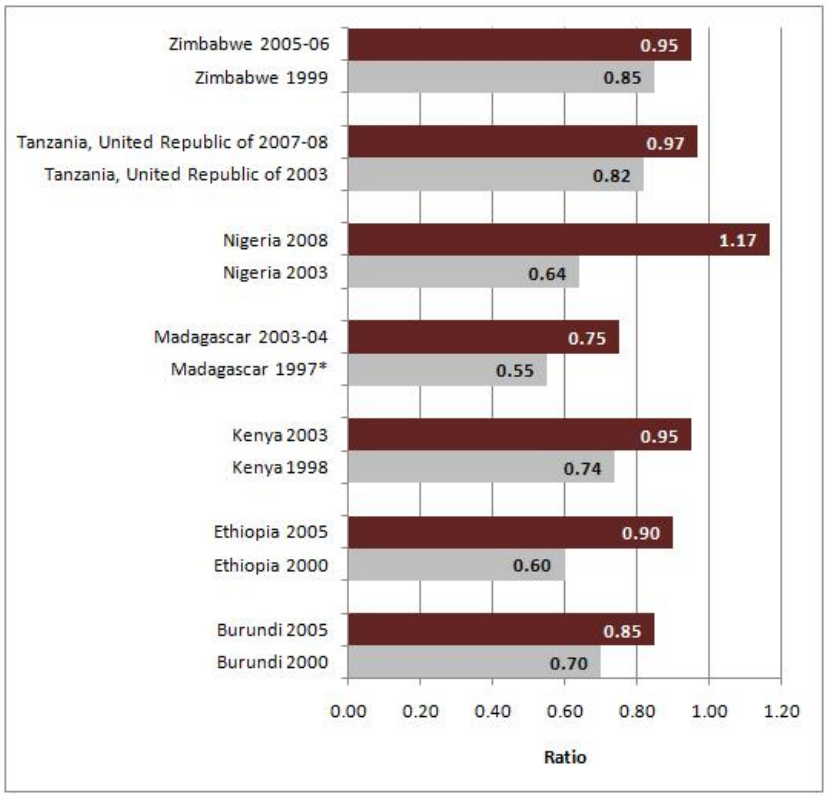
Much of the recent scientific and programming evidence – which is available to a large extent as a result of the Joint Learning Initiative on Children and HIV/AIDS[1]– shows how the needs of CABA are intertwined with the needs of all vulnerable children. Increasingly, this is leading to an environment where HIV responses are integrated within broader development and child protection efforts. In this context, some readers may sense a tension in producing guidance specifically for CABA.

While this report recognizes that CABA have particular needs as a result of loss of parental care, HIV-related stigma and exclusion and coping with the disease itself, it also recognizes that **HIV-sensitive – rather than HIV-specific –** approaches are more appropriate in most HIV-impacted environments. For example, programming to improve access to education or livelihoods for children and households more broadly can be an effective way of scaling up support for CABA, particularly in contexts with high HIV prevalence. In all contexts, a combination of HIV-sensitive and HIV-specific approaches is required.

HIV and AIDS responses have motivated many innovative and scalable approaches that promote **equitable outcomes** for children more generally. In the past decade, national plans of action (NPAs) for orphans and vulnerable children (OVC) have catalysed policies and programmes to improve development outcomes for a wide range of vulnerable children. NPAs have also supported a process by which sustainable livelihoods for poor HIV-affected households have been achieved, access to education for excluded children has been promoted, legislation to uphold the rights of vulnerable children has been strengthened, and gender inequalities that fuel HIV's spread have been addressed. Sector-wide approaches (SWAps) that aim at supporting entire sectors – such as education or social welfare – rather than projects have also helped donors move towards more holistic approaches.

These approaches are starting to yield benefits for children and families. For example, most countries in sub-Saharan Africa have made significant progress towards parity in school attendance for orphans and non-orphans 10–14 years old *Figure 1*. Data from Demographic Health Surveys (DHS) in 27 out of 31 countries in sub-Saharan Africa indicate that the rate of school attendance among children who lost both parents has increased.[2]

FIGURE 1: TRENDS IN ORPHAN AND NON-ORPHAN SCHOOL ATTENDANCE RATIOSIN SELECTED COUNTRIES, 1997–2008

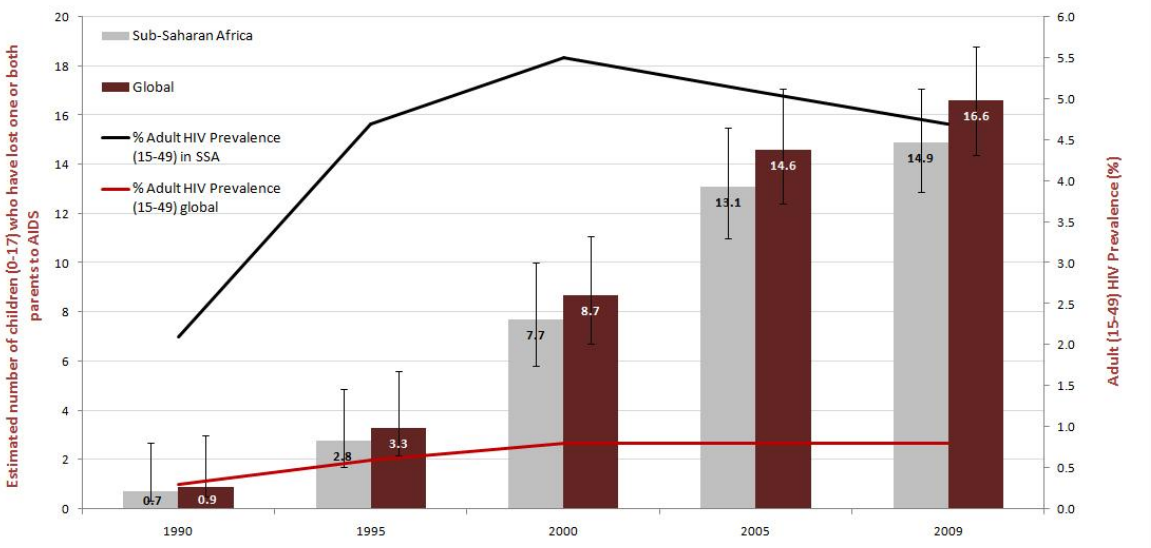


Source: AIDS Indicator Survey, Demographic Health Survey, Multiple Indicator Cluster Survey, 1997–2008.

In addition to progress in school attendance, recent evaluations of social protection programmes in high prevalence countries such as Kenya and Malawi show how cash transfers are improving food security, nutrition, education and health outcomes in some of the poorest and most vulnerable households, including those affected by HIV and AIDS.

Another area where there has been notable progress is paediatric treatment. The increasing effectiveness and availability of antiretroviral therapy (ART) means that thousands of children born with HIV are surviving into adolescence. This good news is accompanied by the emergence of new challenges, including how to best assist adolescents living with HIV regarding disclosure, emerging sexuality and transition to adult treatment programmes. Although there has been a scale-up of people on treatment, including through the prevention of vertical transmission from mothers to children, as of 2011 this has not yet translated into a decline in the numbers of children who have lost parents to AIDS as *Figure 2* illustrates. Scaling up responses for CABA remains a high priority, building on the notable successes in programming efforts throughout the past 10 years.

FIGURE 2: ESTIMATED NUMBER OF CHILDREN (0-17) WHO HAVE LOST ONE OR BOTH PARENTS DUE TO AIDS AND ADULT (15-49) HIV PREVALENCE INSUB-SAHARAN AFRICA AND GLOBALLY, 1990-2009



SOURCE: JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS, *REPORT ON THE GLOBAL AIDS EPIDEMIC*, 2010.

At the end of 2010, an estimated **16.6 million children lost one or both parents to AIDS – 14.9 million of these in sub-Saharan Africa**. Despite the millions of dollars invested in OVC programmes, it is estimated that only about 11 per cent of households caring for OVC receive any form of external care and support.[3] Many HIV-affected children continue to face enormous challenges, including the burden of care for sick relatives, trauma from the loss of parents, economic distress due to declining incomes and high health costs, and the risk of early sexual debut and abuse,[4] which in turn can make children – particularly girls – more susceptible to HIV infection. In settings where epidemics are still relatively concentrated, HIV-affected children often have parents who are highly marginalized and stigmatized, and they may be highly vulnerable to HIV themselves.

Another key challenge is that CABA needs continue to outstrip available resources. The financial crisis led to a levelling in HIV expenditure and strong focus on treatment and prevention. As a result, the agencies working on care, protection and support for CABA find it hard to maintain, let alone increase, funding levels. Along with advocating for increased financing for care and support, programmers need to be more innovative in how they use existing resources and more concrete in demonstrating impact. This document highlights the importance of aid effectiveness and looks at maximizing the impact of CABA investments through better use of evidence, harmonization of effort, and targeting of resources to ensure they reach those most in need.

Significant opportunities have emerged since the original *Framework* document was published in 2004. In particular, treatment availability has increased the importance of care, protection and support, rather than diminished it. With people living longer on treatment, HIV has become a chronic condition for many. This requires not only health sector responses but also the involvement of other sectors that can impact social protection and child protection outcomes for families, as well as improve children's treatment and health outcomes. *Taking Evidence to Impact* examines opportunities to strengthen linkages between social care and health systems to ensure effective and comprehensive responses for CABA.

This document aims to translate evidence into broad practice. Chapter 1 summarizes the main conceptual shifts in the approach to CABA's protection, care and support. Chapter 2 reviews what is known about the importance of family centred approaches to HIV and AIDS. Chapter 3 summarizes major developments in the dedicated HIV-specific services that many CABA need, while Chapter 4 highlights relevant guidance on essential services that all vulnerable children require, including those affected by HIV and AIDS. Chapter 5 explores ways to improve the effectiveness and efficiency of national responses for CABA, and Chapter 6 provides guidance for programmers on the need for quality strategic information and how it can be used for more effective programming. Each chapter includes a number of programmatic recommendations.

1

NEW PROGRAMMATIC APPROACHES TO THE CARE, PROTECTION AND SUPPORT OF CHILDREN AFFECTED BY HIV AND AIDS

The 2004 Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS is still relevant today; its impact will be strengthened by recognizing important experiences that have informed implementation since its publication. These include improved understanding of vulnerability, helping the focus shift from the particular needs of children orphaned by AIDS to all vulnerable children; and increasing recognition of the importance of family and community centred care, which has helped the move from providing materials and services to individual children to strengthening the families and households that care for them. Finally, increased mobilization around social protection has helped shift support from an emergency response to one that is tackling longer-term issues of economic and social exclusion.

The watershed 2004 *Framework* led to intensified action and national responses. This chapter addresses that experience to provide background for the discussion in subsequent chapters, specifically:

1. The central tenets of the 2004 *Framework;*
2. New evidence on child vulnerability in the context of HIV and implications for programming;
3. How child-sensitive social protection can broaden coverage and sustain responses for CABA (and how CABA responses can strengthen responses for all vulnerable children).

THE FRAMEWORK: FIVE STRATEGIES THAT TRANSFORMED THE LANDSCAPE FOR HIV-AFFECTED CHILDREN

The *Framework* strategies form the basis for *Taking Evidence to Impact*. The *Framework* still serves as a common agenda for the broad range of civil society, donor and international partners that contributed to its development. It outlines five key strategies intended to assist policymakers and programmers in ensuring comprehensive, rights-based programming for HIV-affected children, recognizing that the specific mix of activities will vary depending on the needs and capacities in a given context.

Each strategy is briefly summarized below:

1. **Strengthen the capacity of families to protect and care for OVC by prolonging the lives of parents and providing economic, psychosocial and other support.** The *Framework* calls for support for improved child-care practices, prolonging parents' lives with ART, succession planning, and providing life skills to children in HIV-affected families.

2. **Mobilize and support community-based responses**. The *Framework's* second core strategy calls for the engagement of local leaders, who have a duty to respond to the needs of vulnerable members of their communities, as well as for efforts to promote openness about HIV and combat stigma by facilitating activities where community members can discuss HIV and AIDS. It also promotes community-based care for children without family support.

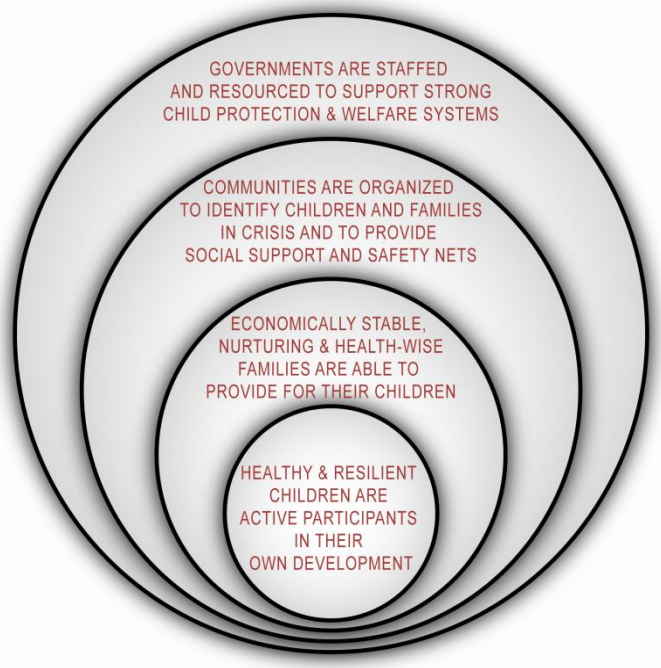
3. **Ensure OVC access to essential services, including education, health care, birth registration, ART for them and their caregivers, child-friendly justice and other services**. The *Framework* also calls for participatory local needs assessments and comprehensive local action plans in the context of decentralized government structures.

4. **Ensure that governments protect the most vulnerable children through improved policy and legislation and by channelling resources to families and communities**. The *Framework* notes that governments have the ultimate responsibility for ensuring the rights of their citizens. To this end, it calls for national policies,

strategies and action plans; investments in enhancing government capacity; and focused efforts to ensure that resources actually reach communities. Supportive legal frameworks include protection against discrimination and child labour, property inheritance rights, alternative care, and other legal and community protections for OVC.

5. **Raise awareness at all levels through advocacy and social mobilization to create a supportive environment for children and families affected by HIV and AIDS**. The *Framework* calls for data collection using situation analyses to generate awareness, and for using the data to rally opinion leaders to combat stigma and discrimination and to work with community-based organizations to mobilize communities to advocate for greater support and protection for OVC.

FIGURE 3:SUPPORTING FAMILIES AND CHILDREN AFFECTED BY HIV AND AIDS, BUILDING ON THE FRAMEWORK STRATEGIES



Source: UNICEF 2011 adapted from G. Bachman.

The *Framework* also sets out shared **principles** to underpin international responses:

- Interventions are focused on the **best interests of the child**, are **age sensitive,** and enable **meaningful and effective participation** of children in the development of responses consistent with the Convention on the Rights of the Child

- **Stigma and discrimination** do not deter people from accessing information and services.

- **Gender inequalities** do not differentially influence boys' and girls' vulnerability to HIV infection and their ability to access prevention, treatment and care services.

- All children should have access to services, which means paying greater attention to **marginalized and excluded** children. This may include children with disabilities, those living in remote areas or on the streets, migrant children living outside of their country, boys who have sex with other boys or men, or children who are part of communities who use drugs or are involved in sex work, factors which often make them more vulnerable to abuse and exploitation and therefore less able to access services.

TRANSLATING POLICY INTO PRACTICE: EFFECTIVE CHILD PARTICIPATION IN THE CONTEXT OF HIV

Meaningful child participation is a child's right, allowing them to play an active part in their communities and increasing programming effectiveness. A review of child participation in Eastern and Southern Africa found a gap between policy regarding child participation and its practice, despite the sense of urgency about effective CABA responses. To improve child participation in the region, the reviewers recommended:

- *Institutional structures that often hinder child and youth participation need to change in order to include children and youth more fully and effectively.*

- *Efforts are needed to break down the silos that tend to form between organizations working on children's, youth, and older people's rights that hinder joint planning and implementation between age groups, preventing the involvement of children in activities with other age groups.*

- *Stakeholders need to be better informed about how to access funds for child and youth participation.*

Source: Regional Inter Agency Task Team on Children and AIDS in Eastern and Southern Africa **(**RIATT-ESA),2010.

These principles are fundamental to promoting equity in development outcomes.

IMPROVED UNDERSTANDING OF VULNERABILITY IS ESSENTIAL TO CABA PROGRAMMING

In recent years, there has been an important shift in how policymakers conceptualize child vulnerability in the context of HIV and AIDS.[5] While there is still widespread agreement that HIV and AIDS have increased children's vulnerability, there is growing understanding that HIV must be viewed as one of many stresses faced by children and may not be the main driver of vulnerability.

Children may be exposed to multiple shocks as they grow, including conflict, natural disaster, family disruption, and disease including HIV. The relative impact of HIV's shock on children differs according to epidemic contexts and income settings. But typically, parents' illness and death negatively affect households, families and children through

increasing economic hardship, psychosocial distress and HIV-related stigma and discrimination, along with reduced access to services and adequate nutrition. Equity analysis shows that the poorest households are often least resilient to the impacts of HIV, and that HIV is in itself impoverishing. The subsequent chapters describe approaches to strengthening family and individual resilience, and to helping vulnerable people and families cope with the potentially devastating impacts of HIV and AIDS.

There is no doubt that HIV and AIDS increase vulnerability and negatively affect food security, health-care access, and abuse, exploitation and neglect.[6] Maternal orphanhood – the loss of a mother – has also been associated with higher likelihood of transactional sex and higher rates of pregnancy, sexually transmitted infections and HIV prevalence in adolescent girls.[7] Studies show that a child does not have to be infected with HIV to be seriously impacted by the disease: Children whose mothers are living with HIV are approximately three times more likely to die by age 5 than children whose mothers are not, regardless of the child's own HIV status.[8]

Global analysis of commonly used definitions of HIV-related vulnerability show that **being a single or double orphan is <u>not</u> consistently a useful predictor of child vulnerability**[9]. Analysis of household data shows that orphaning alone is a poor predictor of other outcomes, including nutritional status and sexual debut, although double orphans (who lost both parents) usually have worse educational attendance than non-orphans. The same analysis shows that poverty intensifies the impact of HIV and AIDS on children's lives and that vulnerability is shaped by many factors, such as age and gender. Non-residence with living parents may have a similar negative impact as orphaning in some settings.[10]

UNDERSTANDING VULNERABILITY IN DIFFERING EPIDEMICS

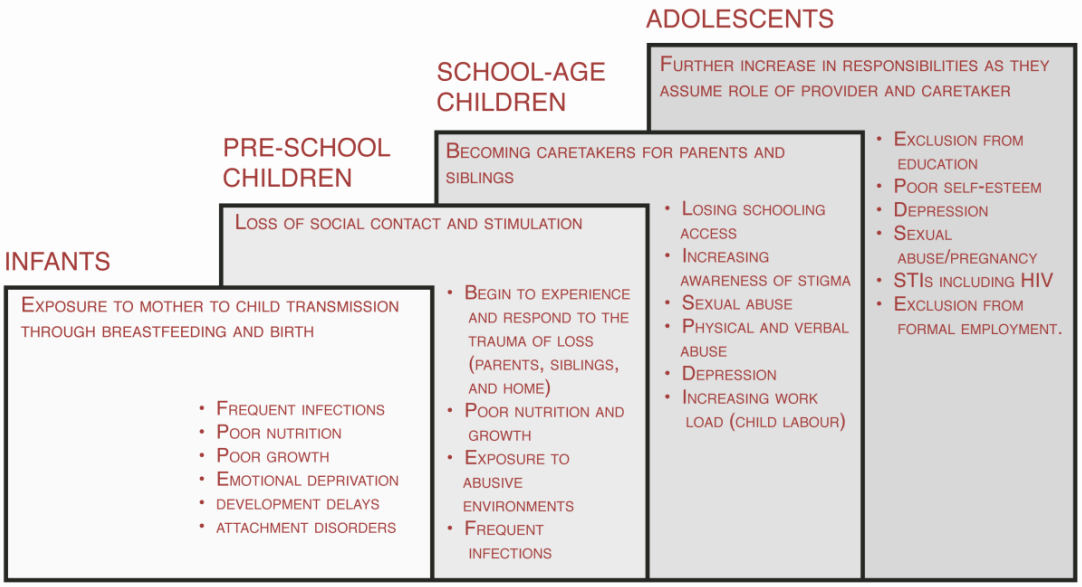
In concentrated epidemic settings, HIV clusters in key populations at higher risk of HIV infection, such as sex workers, people who use drugs, and men who have sex with men. Children living among key population groups may be excluded from education, health and other social services due to their parents' or their own marginalized and often illegal status. The term 'most-at-risk adolescents' (MARA) includes people who use drugs – especially injectable drugs – men who have sex with men, and children who are exploited in sex work. Other categories of adolescents at high risk of infection are defined based on patterns of HIV incidence or vulnerability to exploitation. They include adolescent girls, young people working in potentially exploitative situations (e.g., domestic workers), and those living and working in communities of sex workers or on the street.

As policymakers and programmers increasingly approach HIV as one of many dimensions of vulnerability, they seek to ensure that services for vulnerable children – including child protection, education, health, social protection, psychosocial support and legal protection – are inclusive of vulnerable CABA. This approach is often described as **HIV-sensitive rather than HIV-specific programming**.

USING A LIFE CYCLE APPROACH TO IDENTIFY PRIORITIES

There are critical periods in a child's life cycle for intervention, which, if missed, can have severe and irreversible consequences. *Figure 4* shows the HIV-related risks by age group and highlights the need for gender-sensitive approaches.[11]

FIGURE 4: HOW HIV AND AIDS CAN AFFECT CHILDREN ACROSS THE LIFE CYCLE



Source: UNICEF 2011 adapted from Makhweya, A. 2003 and Robbins, D. 2003.

VULNERABILITY ANALYSIS RECOMMENDATIONS

- ✓ Targeting orphans or CABA in isolation of other vulnerable children can exacerbate HIV-related stigma and discrimination and overlook children most in need of assistance. For many interventions, an HIV-sensitive approach that is inclusive of CABA, rather than an HIV-specific approach that focuses exclusively on them, will be more effective.

- ✓ National responses need to analyse sources of vulnerability to improve understanding of which children are vulnerable, what they are vulnerable to, and why. For targeting, a combination of variables should be used to identify and reach vulnerable children. These can include sex, household wealth, orphan status, if children reside with parents or grandparents, and education level in the household.

- ✓ In all epidemic contexts, attention should be given to the drivers of social exclusion (e.g., disability, displacement, ethnicity, punitive laws, stigma and discrimination) that make children additionally vulnerable.

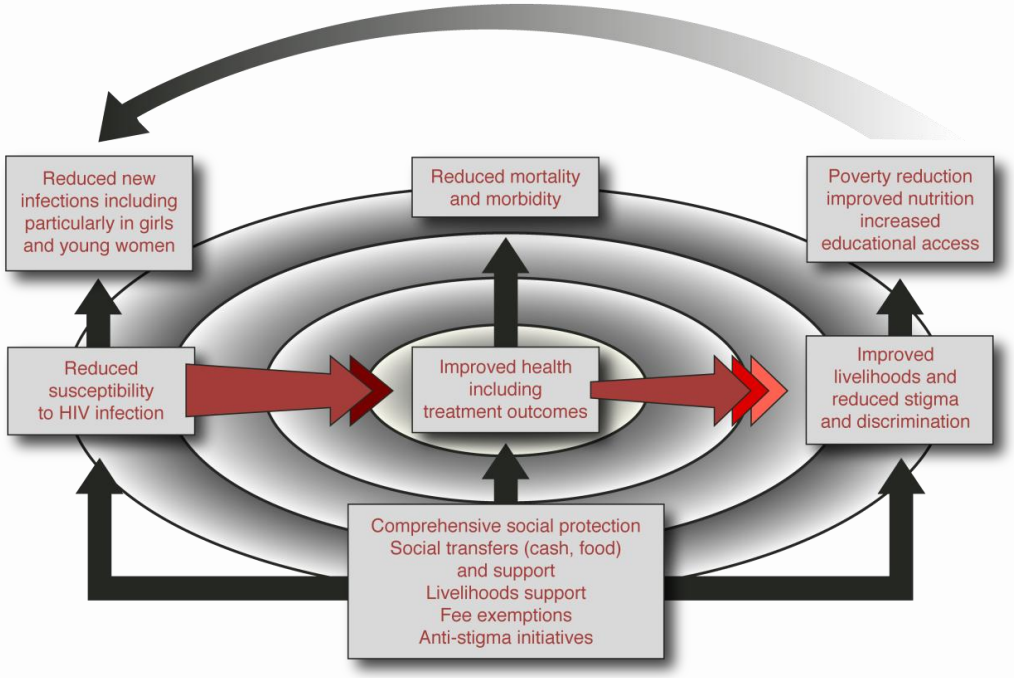
- ✓ Age and gender analysis need to be integrated into vulnerability assessments and inform a life cycle approach to programming.

STRENGTHENING CHILD-SENSITIVE SOCIAL PROTECTION TO SUPPORT VULNERABLE FAMILIES AND CABA

Another key shift since the 2004 *Framework* is the increasing attention to social protection. While there are numerous definitions of social protection, a widely accepted one describes *'a set of public and private initiatives that provide income or consumption transfers to the poor, protect the vulnerable against livelihood risks, and enhance the social status and rights of the marginalized*."[12]

Social protection programmes can accelerate progress towards the Millennium Development Goals (MDGs) by increasing access to health, education, nutrition and child protection, including for children and families affected by HIV and AIDS.[13] When it is HIV-sensitive, social protection can help prevent susceptibility and reduce vulnerability to HIV, while also reducing barriers to HIV treatment, prevention, protection and support.[14]*Figure 5* shows how social protection can help mitigate the downstream impacts of HIV and AIDS on households by increasing resilience to illness and death at the household level and reducing stress to families and individuals.[15] There is also growing evidence on how investments in impact mitigation, such as keeping girls in school, supporting economic strengthening of households and empowering vulnerable groups can feed back into reduced HIV infection risk.[16]

FIGURE 5: IMPACT OF SOCIAL PROTECTION IN IMPROVING HIV PREVENTION, TREATMENT, CARE AND SUPPORT OUTCOMES



Source: Adapted from Edstrom, J., UNAIDS/UNICEF/IDS workshop on Social Protection, HIV and AIDS, 2010.

To address the needs of CABA, social protection approaches also need to become child-sensitive, responding to the patterns of children's poverty and vulnerability and recognizing the long-term developmental benefits of

investing in children. When sensitive to children, social protection can address both the economic and social aspects of deprivation. The key elements of child-sensitive social protection are:[17]

- Social transfers (e.g., cash and food)
- Programmes to ensure effective access to health, education and other services
  Social support services (e.g., family strengthening services)
- Legislation and policies to ensure equity and non-discrimination in access to services and employment/livelihoods (e.g., abolition of school fees)

As set out in Chapter 2, there is compelling evidence that predictable social transfers, such as cash grants to ultra-poor, HIV-affected households, enhance children's nutritional status, improve human capital, and even increase lifetime earnings.[18] Such **interventions do not have to target children directly to benefit them;** a large portion of old-age pensions in Namibia, for example, is spent on children's education.[19]

Cash transfers should also be part of broader national systems. This requires investments in strengthening government leadership and national capacity to deliver the components of child-sensitive social protection and supporting inter-sectoral coordination. Gaps in the social welfare workforce also need greater attention.[20] A number of countries in Asia, Latin America and sub-Saharan Africa have social protection systems that are in place or emerging, which integrate economic support and social care, but research on the impact of integrated approaches is rare.

Child-sensitive social protection emphasizes the role of governments and civil society as duty bearers to ensure the care, support and protection of all vulnerable children. This paradigm shift emphasizes the role of governments in providing leadership and oversight on service delivery, coordination, and monitoring of policies and programmes for vulnerable children. This includes integrating the needs of vulnerable children in poverty reduction strategies and associated social protection strategies. It also stresses working with civil society to ensure that all children can access basic services and support.

INCREASED FOCUS ON SYSTEMS STRENGTHENING

The increasing momentum on social protection accompanies another important conceptual shift in CABA programming: an increased focus on systems strengthening. This is consistent with recognition that short-term emergency responses to HIV need to move to nationally owned, sustainable responses. **Given that the impacts of HIV and AIDS will be felt for generations, strong, sustained responses for all vulnerable children are required.**

A functioning social welfare system – typically inclusive of social protection and child protection services – is a vital safety net for children and families made vulnerable by HIV and AIDS as well as other risks. When the system is functioning well, families and children have access to an array of quality services that promote well-being and protect them from harm. Services can include family support and early intervention, protection to address abuse and neglect, and alternative care for children separated from their families.

In the following chapters, the conceptual shifts on vulnerability, social protection and systems strengthening inform the discussion of programmatic approaches to family support and increasing service access. The chapters will also demonstrate how these approaches can improve the quality and coverage of the global HIV response and ensure that CABA can enjoy their rights along with other children.

CHAPTER 1 WEB RESOURCES AND GUIDANCE

1. HRBA (human rights-based approach) Portal: UN Practitioner's Portal on HRBA Programming, <http://hrbaportal.org>.

2. Regional Inter Agency Task Team on Children and AIDS in Eastern and Southern Africa, Child and Youth Participation in East and Southern Africa: Taking stock and moving forward – An analytical review of the literature and five case studies on child and youth participation in East and Southern Africa, Johannesburg, 2010, <www.riattesa.org/c/document_library/get_file?p_l_id=219005&folderId=121411&name=DLFE-2401.pdf>.

3. Inter-agency Working Group on Children's Participation, Children's Participation in Decision-Making: Why do it, When to do it, How to do it, Bangkok, 2007, <www.iawgcp.org/download/wwh.pdf>.

4. Child Rights Foundation, Save the Children, Adults First! An organizational training on children's participation, 2004, <http://seap.savethechildren.se/upload/scs/SEAP/publication/publication%20pdf/child%20participation/Adults%20first!.pdf>.

5. Joint United Nations Programme on HIV/AIDS, HIV Prevention Toolkit, Know Your Epidemic, Geneva, 2008, <http://hivpreventiontoolkit.unaids.org/Knowledge_Epidemic.aspx>.

6. Joint United Nations Programme on HIV/AIDS, Agenda for Accelerated Country Action for Women, Girls, Gender Equality and HIV: Operational plan for the UNAIDS action framework – Addressing women, girls, gender equality and HIV, Geneva, 2010, <www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2010/20100226_jc1794_agenda_for_accelerated_country_action_en.pdf>.

7. Interagency Gender Working Group,<www.igwg.org>.

SUPPORTING FAMILIES TO PROTECT AND CARE FOR CHILDREN AFFECTED BY HIV AND AIDS

2

HIV is a disease that clusters within families, requiring a family centred response; using the family as the unit of analysis rather than the individual can improve the impact of HIV-related programming. Family strengthening is essential to keeping the most vulnerable families together and able to care for children. Social protection approaches can play an important role in strengthening families using comprehensive programming with social transfers and complementary social welfare services.

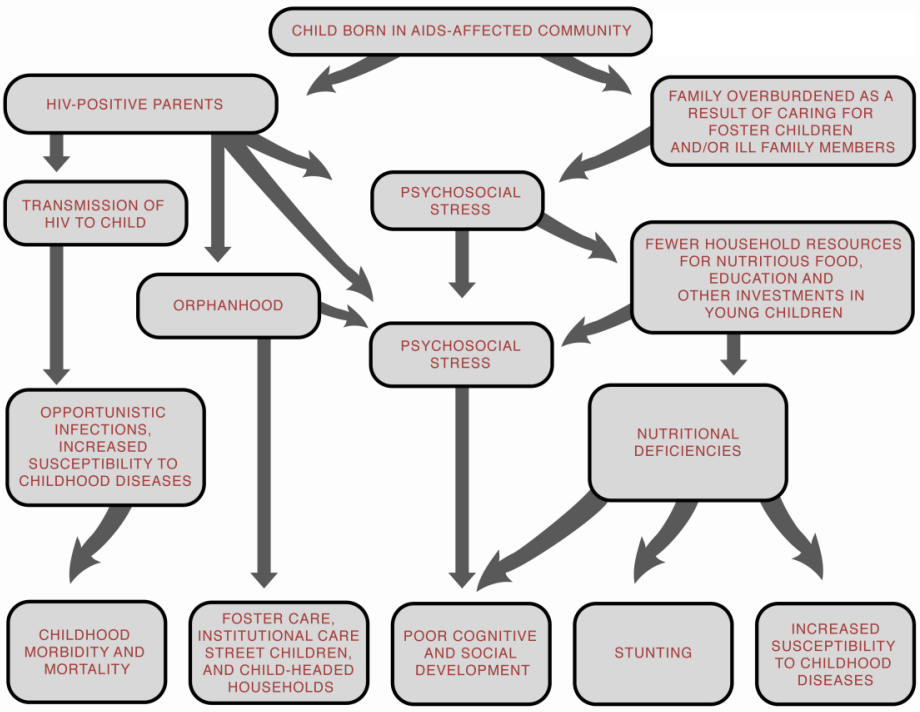
While services are intermittent, families are forever. This makes strengthening families a critical intervention for CABA. The 2004 *Framework* recognized the importance of families and the lifelong care they provide for children, emphasizing that services need to reinforce family care. This chapter covers:

- Why we need family centred approaches to HIV, treatment and support;
- The importance of keeping children within a supportive family environment;
- Social protection to strengthen affected families.

FAMILY CENTRED APPROACHES TO HIV TREATMENT, CARE AND SUPPORT

HIV affects entire families; in high-prevalence settings, infection is mainly transmitted by cohabiting partners and mother-to-child transmission is the mode of transmission for more than 90 per cent of children under 15 years old.[21]In communities affected by HIV and AIDS, families bear 90 per cent of the costs of responding to the impact of HIV and AIDS on children, but they often lack adequate knowledge, skills or resources, which can harm children.[22] For example, the health of female caregivers has a significant impact on children's nutritional status, and the death of adult women in particular decreases opportunities for children to attend school, while increasing household poverty.[23] *Figure 6* summarizes how HIV can impact families, hamper caregivers' abilities to care for children, and disrupt children's growth and development.

FIGURE 6: CHILDREN BORN INTO HIV-AFFECTED COMMUNITIES



Source: UNAIDS, UNICEF, World Bank, *Operational Guidelines for Supporting Early, Childhood Development (ECD) in multi-sectoral HIV/AIDS programmes in Africa*, 2009

Community-based organizations can play an important role in identifying and supporting families in need. For example, trained community assistants selected and/or elected from villages in Cambodia provide regular home visits to children and families. They accompany beneficiaries to schools and health services, distribute food and commodities, follow up on child protection cases, provide referrals to vocational and income generation activities, and provide psychosocial support. These assistants work closely with local health-centre staff to do home-based care activities, following up with people living with HIV who miss monthly doctors' appointments and ensuring that those who are sick get prompt medical attention. They also organize monthly children's playgroups, parenting clubs and community education sessions on stigma and discrimination.

Source: Family Health International, 2010.

Keeping parents alive is key to maintaining strong families and protecting children. Yet despite strong evidence on the prevention, treatment and care benefits of involving the whole family, HIV-related services continue to target individuals.[24]PMTCT services, for example, target pregnant women but not always their partners and/or other children, while paediatric treatment targets children but not siblings or parents.[25]

A package of HIV-related services for the entire family within a continuum of care is missing. Family centred practices tend to be overlooked, such as those involving men in PMTCT and infant-feeding counselling or risk assessments for intimate partner violence. These additional services could have a positive impact on PMTCT and the wider family, as in Swaziland, where an MTCT-Plus community-based treatment project reported lower transmission rates to infants when male partners were involved and participated in a support group.[26] Couples counselling and testing to facilitate early detection of serodiscordance in partners and prevention of HIV transmission are other promising family based approaches.[27]

Another priority for people for living with HIV and their caregivers and children is comprehensive HIV care and support, including psychosocial, physical, socio-economic, nutritional and legal services that can benefit entire families. Care and support services are needed from diagnosis throughout the course of HIV-related illness, regardless of ability to access ART. Compared with prevention and treatment, however, it is widely recognized as being a relatively overlooked and under-resourced component of the global response, despite its demonstrated cost-effectiveness.[28] The relative neglect of care and support critical for children, especially those who are caring for sick adults and siblings, is a particularly ignored issue.[29]

Home-based care is a central element of care and support, and often goes beyond services to individuals to serve entire families, as well as serving as an entry point for improving clinical outcomes and keeping parents alive as described in the box above. Home-based carers (who are predominantly women and girls) have important roles in assisting individuals, families and households. Home-based care programmes support pain management and the psychosocial well-being of patients and caregivers, but also need to consider the needs of children, especially those serving as caregivers themselves.

One of the most neglected areas in the care and support response has been palliative care. Where such strategies exist, they often overlook the palliative needs of children who have different clinical, psychosocial and support needs from adults. Home-based care providers may also help to improve economic support to households, such as by linking families to social benefits, including social protection services in some settings.[30]

In many contexts, home-based care providers are volunteers, which can lead to high levels of burnout and attrition, risking the quality and continuity of care. South Africa has taken an innovative approach to supporting home-based carers by including home-based care as one of the options in its expanded national public works programme. There is a need to identify other such financing strategies to ensure a well-trained and motivated workforce.[31]

FAMILY CENTRED PROGRAMMING RECOMMENDATIONS

- ✓ Investments in prevention, treatment and care and support should focus on families, which necessitates shifting HIV interventions from individual targets and looking at the needs of whole families. It also requires providing clinical and social interventions through family based support.

- ✓ Evidence-based models of family centred approaches are needed, including home-based HIV voluntary counselling and testing, family antiretroviral (ARV) treatment services and adherence promotion, and child nutrition and education components of adult ARV programmes.

- ✓ Promoting male involvement is also a priority, which involves employing approaches such as couples counselling and HIV testing; support for safe and voluntary disclosure; and engaging men in family planning decisions, maternal health and care and support activities.

- ✓ There are opportunities for partners working with CABA to link systematically to broader care and support agendas. There is a need to collectively advocate for the expansion of essential care and support services on the ground, including psychosocial, physical, socio-economic, nutritional and legal and human rights services to people living with HIV and their caregivers, many of whom are children.

THE IMPORTANCE OF KEEPING CHILDREN IN A SUPPORTIVE FAMILY ENVIRONMENT

Families are the first line of protection and support for children and are crucial throughout their development. The way a young child develops can affect his or her confidence, self-esteem and social skills later in life. Young children's family environments are major predictors of cognitive and socio-emotional abilities, as well as of a variety of outcomes such as crime and health.[32]

Young children develop the most rapidly during the first few years of their life; family care can enhance that emotional, intellectual and social development with physical affection, providing a safe environment to explore, as well as stimulation. As children grow older, parents and caregivers are best placed to meet their changing learning needs through the phases of development – and they have a responsibility to do so. Apart from having a family, children need consistent caregivers, safe home environments, adequate attention and quality care.[33]

Health, education, social welfare and legal services can be family centred when they recognize the primary and long-term role that families have in children's lives. **Strengthening family centred approaches to child care can benefit children's cognitive, physical, emotional and mental development**.[34] Investments in parenting and child-care practices, including hygiene practices, can improve children's nutritional status. Similarly, providing poor families with cash transfers typically enables them to send children to school, while psychosocial support for family members can help detect early signs of abuse and neglect, improve parenting practices, as well as help to overcome children's trauma resulting from parental illness and death.

Unfortunately, not all families provide children with adequate care; neglect and abuse occur in families at an alarming rate.[35] If interventions cannot improve a family situation when this occurs, children need alternative care, recognizing that placement in residential care is not considered the best environment for them.[36] Chapter 4 provides more information on alternative care for children.

FAMILY STRENGTHENING RECOMMENDATIONS

- ✓ Greater recognition is needed that families have a responsibility – and are best placed – to provide care for children. HIV and AIDS can hamper their ability to do so, and programmatic responses are needed to strengthen families and enable them to provide the best possible care for their children.
- ✓ Specific family strengthening measures are part of a strategy for preventing family separation, but if these cannot improve a situation in which there is serious neglect or abuse, children should be removed and placed in a nurturing family setting.
- ✓ At the community level, existing opportunities to strengthen families should be identified and supported, such as by using early childhood development centres to assist parents, or child protection committees and community care workers to help support families.

SOCIAL PROTECTION TO STRENGTHEN AFFECTED FAMILIES

A strong evidence base is emerging on the role of child-sensitive social protection in mitigating the impact of the epidemic and in reducing poverty and inequalities that place individuals at risk of HIV infection. Some CABA interventions mitigate the economic cost of the epidemic on families with social transfers, livelihoods support and other economic empowerment activities. As mentioned in Chapter 1, cash transfers, in particular, can improve outcomes for children by increasing access to education and health care and decreasing household food insecurity, poverty and reliance on child labour.[37]

Transfer programmes must reach intended beneficiaries to achieve these outcomes. It is important to regularly monitor if transfers are actually reaching the poorest and most vulnerable families and children– such as those in the bottom wealth quintile and without parental care – to ensure that the most-stressed families are benefitting. From an HIV perspective, it is also important to consider the potential impact on HIV vulnerability, for example, by reaching girls at high risk of HIV infection. Combining transfer schemes with social work and child protective services can reduce exclusion (and inclusion) errors and expand coverage to those commonly excluded, including key populations at higher risk of HIV infection. The *box* below shows how South Africa is scaling up a comprehensive approach, including through activities to address the ways that gender exacerbates the impact of HIV.

AN INTEGRATED, GENDER-SENSITIVE COMMUNITY CHILD-PROTECTION SYSTEM KEEPS FAMILIES TOGETHER IN SOUTH AFRICA

In South Africa, the National Association of Child Care Workers' Isibindi Project is a community-based model for reaching vulnerable children. The association partners with local community-based organizations that identify, train and provide ongoing support to volunteers who are unemployed community members – largely younger women – who would otherwise struggle to enter the formal labour market. The volunteers provide practical support to households containing vulnerable children. Gender-related aspects include: training and structured career path for volunteers; a Girl Child Programme in which girls and young women heading households receive an intensive programme of self-development, skills development training and work opportunities in their communities; a caregiver support programme in recognition of the burdens that volunteers face, especially when also being principal caregivers at home; and responses to sexual abuse.

UNICEF supported a costing review of the project, which built evidence to advocate for national scale-up of the model. The cost evidence, along with UNICEF advocacy and support for the association's involvement in national OVC planning processes, led to the Isibindi model's acceptance as a model of good community-based practice in the new OVC national plan of action. The model is already implemented in eight of the nine provinces, with more than 40 local partner organizations.

Source: International Center for Research on Women, 'Building a Gender Response: A synthesis of findings and recommendations from gender reviews of UNICEF CARI and HIV Programs in Southern Africa', ICRW, Washington, D.C., 2010.

Expanding ART coverage is increasing the labour availability in HIV-affected households, thereby heightening the relevance of programmes that promote household production. **Different social-protection approaches make sense for different groups** (e.g., labour-constrained households) may need cash transfers, while poor or marginalized families with untapped labour potential may benefit more from income-generating programmes. Livelihood programmes such as public works, income-generating activities, and microcredit have the potential to reduce the economic impact of HIV, as well as other shocks. Households that are labour-constrained due to AIDS, as well as ultra-poor households, may not always be appropriate targets for livelihood programmes that involve starting small businesses in light of the economic risks associated with income-generating activities.[38]

Broader policy and legislative initiatives also are needed to expand and sustain the impact of family based approaches. Legislative measures to reduce stigma and protect the rights of people living with HIV help them access services. Legislation can reduce disinheritance by widows and affected children. Both are important ways to promote the resilience and rights of HIV-affected families. Social protection as a mechanism to increase families' access to services is discussed in Chapter 3.

SOCIAL PROTECTION PROGRAMMING RECOMMENDATIONS

- ✓ Regular, predictable cash transfer programming can have a long-term positive impact on CABA, their families and caregivers, even when not specifically targeting CABA. Planners should ensure that targeting is inclusive of HIV-affected children and families in need.
- ✓ Cash transfers alone are insufficient to transform CABA's lives. They must be part of a comprehensive system of social protection and complemented by family based care, access to social services and progressive legislation to reduce social exclusion.
- ✓ The degree to which social protection approaches are HIV-sensitive should be monitored by tracking their impact for vulnerable HIV-affected families and households without targeting benefits exclusively to them.
- ✓ Governments and international partners should strengthen the capacity of ministries responsible for delivering social protection programmes, both at national and decentralized levels, including investments in administrative systems.

1. OVC Support net: A global hub for the exchange of experience, practice and tools on policy and programming about children and HIV, <www.ovcsupport.net>.

2. Better Care Network: facilitating global exchange about children without adequate parental care, <www.crin.org/bcn>.

3. Inter-Agency Task Team on Children Affected by AIDS, <www.iattcaba.org/web/guest/home>.

4. Joint Learning Initiative on Children andHIV/AIDS, <www.jlica.org>.

5. International HIV/AIDS Alliance, 'Young Children and HIV: Strengthening family and community support – Building Blocks Africa-wide briefing notes', International HIV/AIDS Alliance, Brighton, United Kingdom, 2006, <www.aidsalliance.org/includes/Publication/young_children_and_HIV_FINAL_300107.pdf>.

3

INCREASING ACCESS TO HIV-SPECIFIC SERVICES FOR CHILDREN AND FAMILIES AFFECTED BY HIV AND AIDS

Most CABA and their families require HIV-specific services, such as issues of disclosure and PMTCT and paediatric treatment. HIV-exposed children need a continuum of care, including testing, treatment and nutritional and psychosocial support. Communities have an important role in reducing potential barriers. Stigma and discrimination are particularly harmful where legal and social barriers prevent children in key populations at higher risk of HIV infection from accessing essential services. Best practices are not widely adopted in countries most affected. Many of the HIV-specific services are more effectively accessed when linked to existing community-based networks and structures, such as early childhood development and child protection.

Globally agreed universal access goals for HIV prevention, treatment, care and support will only be met through scaling up interventions that are "equitable, accessible, affordable, comprehensive and sustainable over the long term."[39] Universal access calls for and depends on increasing equity between those who currently access essential services and those who don't. This chapter considers the access of children and families to HIV-specific services, including:

- PMTCT;
- Assistance for HIV-exposed children;
- Psychosocial support; and nutrition.

The chapter also examines how to reach children and families who are not reached by these services, including tackling HIV stigma and discrimination. It also addresses the critical need to understanding the barriers to service uptake, recognizing that not enough is known about specific access barriers as they pertain to children.

ENHANCING ACCESS TO COMPREHENSIVE PMTCT PROGRAMMES

The importance of using PMTCT programming as an entry point for family centred services is detailed in Chapter 2; this chapter addresses PMTCT as a key strategy for reducing the impact of HIV on children and explores how community-based programming can improve access to and uptake of PMTCT and other clinical services.

Invigorated efforts towards elimination of mother-to-child transmission by 2015 provide an important opportunity to reduce the burden of HIV in children and their families. Global guidance on scaling up comprehensive PMTCT services includes four prongs: primary HIV prevention; prevention of unintended pregnancies among women living with HIV; HIV testing and ART access for pregnant women living with HIV; and, most relevant here, integration of HIV care, treatment and support for women living with HIV and their families.

ADDRESSING LOW UPTAKE OF HIV TESTING AMONG PREGNANT WOMEN: CAMEROON BAPTIST CONVENTION HEALTH BOARD

The Cameroon Baptist Convention Health Board's PMTCT programme successfully integrated PMTCT into routine prenatal care services provided by the board's outreach branch. Before initiating the PMTCT component, board staff obtained village health committee buy-in. Beginning in 2002, the staff trained traditional birth attendants – who had previously been trained to assess obstetric risk and perform low-risk deliveries – in confidential HIV counselling and testing using oral HIV tests.

Typical initial prenatal visits include group education sessions on HIV testing and ARV prophylaxis, pre-test counselling, a prenatal exam with a midwife while awaiting results, and then post-test counselling with the same provider when results come in.

In four years, the programme expanded to 115 health facilities in six provinces, including large hospitals and remote clinics, training nearly 700 health workers and testing more than 68,500 women. Important factors contributing to its success include: offering HIV testing and PMTCT as part of routine prenatal care; well-trained educators, nurses and traditional birth attendants; same-day HIV test results; decentralized and sustainable prenatal services; community support and awareness; and intensive follow-up, quality assurance and supervision.

Source: *Yong, Jim Kim, et al., 'Expanding Access to Services and Protecting Human Rights,'Joint Learning Initiative on Children and HIV/AIDS, Geneva, December 2008.*

Community systems have an essential role to play in the fourth PMTCT prong, as they are frequently connected and complementary to health systems and services. Community and health systems both deliver health services and, to varying degrees, support communities for access to and effective use of services. In addition, community systems have unique advantages in advocacy, community mobilization, demand creation, and linking families and individuals to services, including ensuring follow-up for people with HIV and AIDS. Community systems also play important supportive roles in increasing community literacy on testing and diagnosis, treatment literacy and adherence support, and monitoring and evaluation of service quality.[40]

Strengthening referral systems between community-based outreach and health services can increase PMTCT uptake as well as paediatric treatment and nutrition support. Similarly, when health services are linked with community systems, they can improve care and support by referring patients and their families to support, such as psychosocial services and health-based care.

Eliminating mother-to-child transmission requires reaching the hardest-to-reach families, yet evidence about the factors hampering access to PMTCT services is insufficient. The poorest typically have the least access to mother and child health services, while HIV-related stigma, discrimination, and even fear of violence may exacerbate coverage and highlight disparities, especially in concentrated and low-prevalence settings and among marginalized groups. In particular, violence and the threat of violence can hamper women's ability to assert healthy decision-making.[41] These factors can amplify the impacts of HIV on children in vulnerable families.

Community workers can help to increase uptake and adherence, especially among those hardest to reach.[42]Community-based outreach is particularly important for young mothers who are not accessing services or who are precluded from treatment access due to age-based restrictions.[43]

Evidence on social protection's role in overcoming barriers to health access and other HIV-related services is relevant for keeping parents alive and reducing mother-to-child transmission. For example, the elimination of health user fees and introduction of maternity care vouchers can increase health care and access to maternal health services, including PMTCT.[44] Modest cash transfers to defray transportation costs may be an important strategy to reduce costs and improve treatment outcomes in rural, resource-limited settings.

PMTCT PROGRAMMING RECOMMENDATIONS

- ✓ PMTCT can serve as an entry point for care and support for the whole family, particularly through better integration of couples testing and counselling; HIV treatment, care and support; and linkages with HIV testing and treatment within mother and child health services.
- ✓ Community-based structures hold enormous potential for improving HIV-related clinical benefits. Early childhood development centres, community-based child protection committees and other community systems can serve as referral and entry points for linking vulnerable children and their families to health services.

- ✓ There is a need for greater investments in community-based providers, such as community health, social workers and paraprofessionals, to connect the most vulnerable households and families to PMTCT services.

- ✓ Social protection can help address barriers by reducing user fees and using community-based workers to identify and refer PMTCT-eligible women and families.

- ✓ More evidence is needed on the hardest-to-reach families, what challenges they face in accessing PMTCT services, and how to reach them.

REACHING HIV-EXPOSED CHILDREN

Access to early testing, care and treatment among infants and children exposed to HIV is lagging.[45] With no intervention, approximately half of all infected children die before their second birthday. New guidelines and policy requirements and better methods of infant HIV diagnosis mean that many more children should have the opportunity to commence ART.

As with PMTCT, household and community dynamics can assist or hinder paediatric treatment access. There is some evidence that non-parental caregivers may be less likely than parental caregivers to know their own status and be enrolled in HIV care, which means that care models that rely on reaching children via adults enrolled in HIV care could miss a substantial proportion of children living with HIV residing with non-biological caregivers.[46] Children in residential care may also be at a disadvantage in terms of treatment access where there is no routine HIV testing and staff are unaware of how to access treatment.[47]

HIV-exposed children include those exposed through sex and injection drug use. At the end of 2009, in the seven countries with growing HIV epidemics, HIV was intensifying among injection drug users and sex workers, and among males who have sex with males. Many in these groups are young people, and most of them are marginalized, discriminated against and some deliberately excluded from services and protection.[48] Protecting minors from sexual coercion and from initiating sex work or drug use needs to be part of comprehensive HIV prevention strategies. Young people at high risk for infection who are ultimately infected suffer repeated neglect and violation of their human rights to information, services and often shelter, identity and basic protection.

Early diagnosis is critical to keeping adolescents living with HIV alive. Yet the majority of adolescents living with HIV have not been diagnosed, remain unaware of their status, and are not accessing ART. Under-diagnosis and late diagnosis of HIV infection in adolescents is a significant problem. The opportunity for early detection is missed repeatedly, even when adolescents make contact with the health-care system as the infection and complications advance. The missed opportunity is often the result of limited provider-initiated testing and counselling for adolescents, reluctance among caregivers, and restrictive age-based consent laws that bar adolescents from independently accessing HIV tests.

RECOMMENDATIONS REGARDING PROGRAMMING FOR HIV-EXPOSED CHILDREN

- ✓ Strengthening primary health facilities and communities to provide HIV-related care and support or effective linkages are needed to improve the continuum of care for HIV-exposed and infected children.
- ✓ Investments also are needed to increase communities' capacity to improve the early identification and referral of HIV-exposed children.
- ✓ Early diagnosis of adolescents living with HIV should be a higher priority and significantly more efforts are needed to expand access to testing and complementary support services.

PSYCHOSOCIAL SUPPORT FOR CHILDREN LIVING WITH HIV

The increasing effectiveness and availability of ART means that thousands of children born with HIV survive into adolescence. Whether infected during the neonatal period or during adolescence, young people living with HIV have different needs from young children and adults and require different approaches. For example, a survey of adolescents accessing HIV services in Zimbabwe found that the most common challenges for adolescents were psychosocial in nature and included stigma, difficulty identifying with HIV-negative peers, anxiety about sexual relationships and future planning, and low self-esteem and feelings of hopelessness.[49]

Psychosocial support focuses not just on individuals but on the different social units of which they are part, such as families, friends and wider communities.[50] The types of psychosocial challenges that may arise in paediatric HIV treatment, for example, include children's unwillingness to share their distress due to HIV-related stigma, resulting in a sense of isolation; having questions that are either not answered or answered in an evasive or inappropriate way; or feelings of guilt, anger, sadness and depression that often accompany the death of a parent.

PSYCHOSOCIAL PROGRAMMING RECOMMENDATIONS

- ✓ Psychosocial interventions should be mainstreamed into broader HIV and AIDS programming.
- ✓ Families may need psychosocial support to help them deal with family conflict, trauma and grief related to death.
- ✓ Psychosocial support for adolescents living with HIV should include preparing for and assisting with disclosure to family and friends, addressing feelings of isolation and addressing needs associated with emerging sexuality, including communicating HIV status to partners and avoiding high-risk behaviours.[51]
- ✓ Advocacy for adolescents living with HIV can help to raise awareness, generate political commitment and ensure supportive policies and adequate funds are in place to help them reach their full potential.

NUTRITION FOR FAMILIES AND CHILDREN LIVING WITH HIV AND AIDS

HIV affects populations already experiencing low dietary quality and quantity, which has a particularly serious impact on the poorest and most vulnerable groups, including children and pregnant and lactating women.[52]Good nutrition is important for a strong immune system and healthy living. Food and nutrition interventions can help support ART uptake, adherence and efficacy.

Recently, attention has focused on the causal relationship between HIV, food security and nutrition. Evidence suggests a correlation between children's HIV prevalence and severe malnutrition, as well as mortality risk for children living with HIV.[53] High HIV prevalence in children is associated with severe acute malnutrition in Africa, especially in younger children living with HIV, and severe malnutrition is a marker for predicting mortality. Child malnutrition can be a predictor of not only HIV infection but also disease progression, making nutrition management a critical part of care and treatment of children with HIV.

Community-based responses have achieved good levels of nutritional recovery for children, while also increasing coverage and survival.[54] Community-based case identification of children for therapeutic nutritional intervention brings services closer to households, which results in faster response times and higher coverage than hospital-based programmes. It also provides an opportunity to promote testing for malnourished children with potential undiagnosed HIV infection. At present, however, clinical interventions and household and community-based nutrition interventions tend to operate in isolation from each other.[55]

It is important to ensure that community-based programmes are integrated with hospital and clinic-based carein maternal and child health, PMTCT and paediatric HIV treatment, as well as with food security initiatives. Facility-based case management, increased community-based focus on early identification of at-risk children, and high levels of programme coverage can reduce child mortality.[56] Importantly, these approaches should build on existing community structures.[57]

While severely and moderately malnourished children living with HIV need targeted nutritional interventions, more broad-based nutrition, social protection and livelihood interventions are required for chronically food insecure children affected by HIV in contexts where many children and households face poverty and food insecurity.[58]"

NUTRITION PROGRAMMING RECOMMENDATIONS

- ✓ Links between protection, care and support, and nutrition programmes should be strengthened. Community-based organizations can promote nutrition by screening malnourished children, promoting positive hygiene and feeding practices, and referring children to nutrition programmes.

- ✓ Together with ARVs, breastfeeding should be promoted as the optimal infant and young child feeding practice during the first year of life for HIV-exposed children, along with high-quality complementary feeding when breastfeeding ends.

- ✓ Family support services and home-based caregivers can support nutritional outcomes through monitoring food availability, ensuring that children have routine health and growth monitoring, and promoting health and nutrition messages.

- ✓ Children who have lost their mothers are particularly vulnerable to undernutrition. Linkages to clinics and social services can assure appropriate feeding of maternal orphans, such as formula for the first year of life.

OVERCOMING HIV-RELATED STIGMA AND DISCRIMINATION

HIV-related stigma and discrimination can be barriers to health and other critical services, as well as contribute to psychosocial distress. Stigma can take various forms and may be enacted by communities and institutions – resulting in isolation and denial of rights and services – or by keeping stigmatized people themselves from seeking services and support. Health providers can stigmatize people living with HIV by segregating them, refusing to assist them, or not respecting the confidentiality of their status.[59] Stigma can further prevent health services from reaching populations such as sex workers, men who have sex with men, and people who use drugs, as well as their children.

HIV-related stigma also affects children, either directly or when their parents or caregivers are living with HIV. Children can be excluded from schools, families and communities if others fear infection, which occurs even with children who are not living with HIV themselves but whose parents are.

Laws and legislation are important tools to combat discrimination and stigma. It is equally important to work with communities and societies to address stigma, which functions within the social norms that govern community members' behaviour based on their expectation that others will follow. Changing social norms requires discussion and debate stimulated by information from trusted sources on the harms brought about by stigma, as well as a collective decision to change stigmatizing behaviours.

A COMPREHENSIVE FRAMEWORK TO ADDRESS STIGMA AND DISCRIMINATION

- *Address key underlying drivers, such as root causes and lack of awareness.*
- *Address multiple layers, such as the multiple sources of stigma for vulnerable groups.*
- *Operate at multiple levels, including family, community, institutional and government.*
- *Engage multiple target groups, potential change agents, and marginalized and vulnerable populations.*
- *Employ a range of strategies to prevent and reduce stigma, challenge institutional discrimination and promote human rights.*

Adapted from: International Center for Research on Women and the Department of Public Health and Policy of the London School of Hygiene & Tropical Medicine, 'Scaling up the Response to HIV Stigma and Discrimination', ICRW and DFID, Washington, D.C., and London, May 2010, <www.icrw.org/files/publications/Scaling-Up-the-Response-to-HIV-Stigma-and-Discrimination.pdf>.

- ✓ Successful approaches include building the capacity of stigmatized people and groups through skills-building, network building, counselling, training and income generation.
- ✓ Involve people living with HIV and other key populations, and those at higher risk of HIV infection
- ✓ Use participatory and interactive education, behaviour change communication, such as media campaigns and edutainment programmes.
- ✓ Ensure institutional reform to address discrimination in workplaces, health-care settings, schools and other institutions.
- ✓ Policy dialogue and legal and policy reform with enforcement and mechanisms for redressing rights abuses, especially at local levels.
- ✓ Facilitators working on stigma with CABA should be prepared to deal with grief and disclosure when they arise, including comforting children and turning to existing guidelines on dealing with exploitation or abuse.
- ✓ The 'People Living with HIV Stigma Index' can be an important tool for measuring changing trends in HIV-related stigma and discrimination, including how it relates to affected children.

REACHING ESPECIALLYEXCLUDED CHILDREN AFFECTED BY HIV

Key populations at higher risk of HIV infection are an under-addressed concern everywhere, but particularly so in concentrated epidemic settings. Key populations groups include children as participants and as family members. For example, children are central to the challenge in Eastern Europe and Central Asia, where HIV is driven predominantly by injecting drug use and, more recently, sexual transmission, especially among young people.[60]

The criminalization of sex work and drug use in many countries means that families engaged in these activities are less likely to seek HIV-related services for fear of arrest and imprisonment. This increases the already significant barriers to services for their children, many of whom remain unidentified and unregistered due to their parents' fear that they will be removed from their care.

Many key populations – including children and young people – continue to face obstacles themselves in accessing essential HIV prevention, treatment and care. Emerging evidence on the dynamics of the spread of HIV shows how homophobia and criminalization of same-sex relations and drug use hinder access to testing, treatment, prevention and care.[61]

Stigma and discrimination fuel the marginalization of those most in need, making it difficult to tailor inclusive responses to meet specific needs. Particularly concerning is that most interventions for key populations at higher risk are oriented towards adults, while the needs of children differ. The most common barriers to uptake of services for key populations in Eastern Europe and Central Asia are stigma and discrimination, the threat of arrest and imprisonment, and officials' intolerant attitudes towards behaviour they deem immoral. These result in systems that tend to be punitive rather than restorative environments of equity, trust and care. As a consequence, many marginalized children do not access services but stay on the streets, injecting drugs and engaging in sex work, with the accompanying risks.[62]

RECOMMENDATIONS REGARDING PROGRAMMING FOR ESPECIALLY EXCLUDED CHILDREN

- ✓ When working with populations at higher risk of HIV infection, greater focus is needed on children, both as family members and as participants in risk behaviours, with the accompanying disadvantages of stigma, exclusion and legal barriers.

- ✓ Priorities for children in populations at higher risk of HIV infection are: identifying and overcoming barriers to access to HIV services; building trust among key populations to increase their willingness to access essential services; and understanding how to work with communities to encourage them to include and accept children in key populations, and their families.

- ✓ For males who have sex with other males and transgender people, priorities include improving their human rights situation, building the evidence base and strengthening capacity and partnerships.[63]

- ✓ For children – especially girls – exploited in sex work, priorities include ensuring access to HIV prevention, treatment, care and support; providing protection from exploitation and abuse; building supportive environments; expanding life choices; and reducing their vulnerability by addressing structural issues.

HIV-EXPOSED CHILDREN:

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2. Joint United Nations Programme on HIV/AIDS, United Nations Population Fund, United Nations Children's Fund, World Health Organization, Guidelines on HIV and infant feeding, principles and recommendations for infant feeding in the context of HIV and a summary of evidence, Geneva, 2010, <http://whqlibdoc.who.int/publications/2010/9789241599535_eng.pdf>.

3. WHO, Recommendations on diagnosis of HIV infection in infants and children, Geneva, 2010, <http://whqlibdoc.who.int/publications/2010/9789241599085_eng.pdf>.

4. United Nations Children's Fund, World Health Organization,Policy requirements for HIV testing and counselling of infants and young children in health facilities, Geneva, 2010, <www.unicef.org/aids/files/WHO_UNICEF_Testing_Policy_web.pdf>.

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6. The Regional Psychosocial Support Initiative, Tools for supporting psychosocial wellbeing for children,<www.repssi.net> .

7. World Health Organization, A qualitative review of psychosocial support interventions for young people living with HIV, Geneva, 2009, <http://whqlibdoc.who.int/hq/2009/WHO_FCH_CAH_ADH_09.05_eng.pdf>.

STIGMA AND DISCRIMINATION:

8. International AIDS Alliance & PACT Tanzania, Understanding and challenging HIV stigma, Toolkit for action, Module 1: Children and stigma, 2007, <www.aidsalliance.org/includes/Publication/6_Stigma_I.pdf>.

9. Global Network of People living with HIV, Resources on empowering, engaging and supporting people living with HIV,<www.gnpplus.net/en/resources>.

10. The people living with HIV stigma index, a tool that will measure and detect changing trends in relation to stigma and discrimination experienced by people living with HIV,<www.stigmaindex.org>.

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11. Inter-Agency Task Team on HIV and Young People, Guidance Brief on HIV interventions for most at risk young people, New York, 2008, <www.unfpa.org/hiv/iatt/docs/mostatrisk.pdf>.

12. United Nations Children's Fund, Blame and Banishment, the underground HIV epidemic affecting children in Eastern Europe and Central Asia, UNICEF, New York, 2010,<www.unicef.org/media/files/UNICEF_Blame_and_Banishment.pdf>.

13. Joint United Nations Programme on HIV/AIDS, United Nations Development Programme, Action Framework: Universal access for men who have sex with men and transgender people, Geneva, 2009, <http://data.unaids.org/pub/Report/2009/jc1720_action_framework_msm_en.pdf>.

14. Joint United Nations Programme on HIV/AIDS, Guidance note on HIV and sex work, Geneva ,2009, <http://data.unaids.org/pub/BaseDocument/2009/jc1696_guidance_note_hiv_and_sexwork_en.pdf>.

ENHANCING ACCESS TO HIV-SENSITIVE SOCIAL SERVICES FOR CHILDREN AND FAMILIES AFFECTED BY HIV AND AIDS

4

CABA have equal rights to essential services as non-HIV-affected children, but HIV often threatens their access to services, as it impoverishes families and reduces parental oversight. To achieve equity, efforts to ensure that vulnerable children have access to social services should ensure that services are HIV–sensitive. While we know how to boost CABA's access to – and effective participation in – critical interventions such as education, HIV prevention programming and early childhood development, there is much to learn about how to improve impact and cost-effectiveness using integrated approaches for all vulnerable children. Effective child protection systems are essential to address violence, abuse and exploitation, which are risks that affect CABA. Finally, strengthening community systems can aid progress towards Universal Access goals while boosting community resources for all families in need of external support.

All children, whether HIV-affected or not, require basic social services. HIV programmers increasingly recognize that providing child protection, education, health, social protection, and psychosocial and legal protection for CABA requires a broad response that includes all children. **Targeting only children and families directly affected by HIV and AIDS may not make sense and could even be damaging**.[64] Services, however, should be HIV-sensitive, meaning that they are inclusive and take account of the particular needs of families and children affected by HIV and AIDS. Measures to ensure the inclusion of CABA may be necessary when they face unique barriers that differentiate their prospects from those of other children.

This chapter covers HIV-sensitive approaches for expanding access to:

- Education;
- HIV prevention;
- Early childhood development;
- Child protection services for CABA; and
- Child protection and community systems.

ACCESS TO QUALITY EDUCATION

Education is a right for all children and, as such, has been prominent in national responses for CABA. HIV works through a number of causal pathways to drive inequitable education outcomes, including reducing household wealth and worsening physical and psychosocial health. Although orphans' school access is improving, as described in the Introduction, several studies show that orphaned children in some countries are still significantly less likely to be enrolled in school than non-orphans, and that they tend to progress more slowly when they are enrolled.[65] CABA, especially older adolescents, may be more frequently absent or drop out of school due to increased economic pressures, caring responsibilities for sick relatives, stigma, lack of permanency in living arrangements and loss of parental guidance.[66] Achievement and outcomes are also at risk due to lowered attention span and perceived irrelevance of curriculum. In order to be HIV-sensitive, the education system must address the cost of schooling, protection and service provision within the school setting, and relevance of curricula to the needs of vulnerable CABA as well as other vulnerable children.[67]

REDUCING THE COST OF SCHOOLING

The realization of commitments on free and universal education is fundamental for increasing vulnerable children's access to education. School fee abolition has a direct impact on the enrolment of vulnerable children, including CABA.[68] But even where education is nominally free, out-of-pocket expenses for learning materials, uniforms and transportation costs can prevent children from attending school. Consequently, many CABA programmes focus on reducing financial barriers to education.

Education subsidies – such as block grants to schools – can exempt the poorest and most vulnerable children from paying fees or development levies. Small, predictable cash transfers targeted at ultra-poor households delivered as part of a comprehensive social protection system can dramatically impact educational access, as discussed in Chapter 2. In particular, cash transfers can be used for educational materials and school fees, compensating for lost income from child labour, and improving children's nutrition for better school performance.[69]

In developing social protection programmes, consideration should be given to the gendered impacts of transfers on boys and girls. A study of a cash transfer programme targeting ultra-poor, labour-constrained households in Zambia found considerable gender differences in impact, with boys' enrolment in school improving significantly more than girls', reinforcing the need for complementary interventions to ensure equitable school access.[70] The *Box* below describes a cash grants research project in Malawi targeting adolescent girls specifically, which improved both education and HIV outcomes.

THE ZOMBA CASH TRANSFER EXPERIMENT FOR ADOLESCENT GIRLS

One of the few experiments from Africa comparing the relative benefits of conditional and non-conditional cash transfers for adolescent girls (using school attendance as the conditionality) substantially increased school attendance among beneficiaries who were currently enrolled in school or had dropped out at baseline. The intervention also led to a significant decline in early marriage, pregnancy and self-reported sexual activity among beneficiaries in both the conditional and non-conditional arms. And importantly, preliminary findings indicate that HIV prevalence among 'baseline schoolgirls' (beneficiaries who were enrolled in school at baseline) was 60 per cent lower than in the control group, although there was no HIV effect among the 'baseline dropouts' (girls who returned to school as a result of receiving cash transfers).

Researchers found that the sexually active beneficiaries reduced their risky behaviour; they did not cease having sex, but rather, with the cash in hand from the transfer, moved away from older partners to peer partners, who were less likely to be HIV-positive. The researchers went on to investigate the relative roles of additional income and increased schooling leading to the positive effect on HIV prevalence.

Source: Baird, et. al., 'The Short-Term Impacts of a Schooling Conditional Cash Transfer Program on the Sexual Behaviour of Young Women', World Bank policy research working paper, World Bank, Washington, D.C., 2009.

The evidence from high HIV prevalence, low-income settings suggests that non-conditional cash transfers are as effective as conditional cash transfers for improving vulnerable children's school access. Imposing conditionalities on cash transfers may help to attract political support for such initiatives, particularly where elites are not convinced the poor will spend the money wisely. Such conditionalities, however, add to the complexity and cost of administering these programmes, as well as necessitating the sufficient supply of services. **Evidence from sub-Saharan Africa shows that poor people use cash transfers wisely, to invest in their children's health, nutrition and education**.

TEACHING AND LEARNING

In addition to cash transfer programmes, other programmatic interventions can help keep CABA and other educationally marginalized children in school and ensure their rights within education. These include, for example, school policies that identify and provide support for vulnerable children, including those HIV-affected; learning environments that are healthy, safe and inclusive; and provision of social, health and nutritional services through schools to vulnerable children.[71] Clubs and activities led by teachers or peers can provide psychosocial support and ensure a supportive learning environment, free of stigma and discrimination. Out-of-school children and adolescents can be served by alternative learning interventions, interactive radio instruction programmes and, in the case of children living on the street, street educators with responsibility for a small number of children.[72]

EDUCATION PROGRAMMING RECOMMENDATIONS

- ✓ Vulnerable children and adolescents may need assistance to exercise their right to schooling, which can help with both protection and HIV prevention objectives – especially critical for adolescent girls.
- ✓ More rigorous evaluations are needed of CABA educational programmes to assess their impact on enrolment and learning – along with better disaggregation of who is being reached (by wealth of household, orphaning status and sex) to assess equity in access.
- ✓ There is the need for more analysis of cost-effectiveness and scalability of education interventions for CABA, including comparisons between individual bursaries, block grants, provision of learning materials and other approaches, in order to ensure that funds are being used in the best possible way and that the maximum number of children access and benefit from schooling.

PRIMARY HIV PREVENTION

All children, especially those in high-prevalence settings, need access to effective HIV prevention programming, including information, education and service. They also need the skills and support to empower them to use this knowledge, and available services to reduce their vulnerability. This need is particularly acute for CABA for at least two reasons: There is evidence from Africa and possibly beyond that orphaned girls are more likely to be sexually active than their non-orphaned peers, placing them at higher infection risk; and those in key population groups at higher risk of HIV infection may be less likely to access protective commodities, services and schooling than other population groups, despite their heightened risk of infection. Yet – of concerning – significant barriers limit adolescents' access to accurate, comprehensive information on HIV and sexuality and access to critical services, commodities, protection and support.

As discussed in Chapter 2, vulnerability to HIV and AIDS – and its effects – cluster within families; children are invariably affected by their parents' illness and mortality. In this way, HIV and AIDS can contribute to intergenerational cycles of poverty and ill health. For example, in Zimbabwe, adolescent girls who lost their mothers at any age and their fathers before age 12 are more likely to be sexually active than those not orphaned, while orphaned girls also are more likely than non-OVCs to have sexually transmitted infections and HIV, and to have been pregnant and be out of school at the secondary level.[73]

Adolescent mothers – especially when younger than 15 years old – and their children face considerable health risks. Childbirth also marks the end of schooling, as well as limits employment options for most adolescent mothers. The combined impact of ill health and poverty on young mothers and their children manifests itself across generations, and can lead to exploitation, neglect and abuse of children, which in turn can lead to HIV infection.[74] Girls are also differentially impacted by the burden of care giving that often falls on them, which can interrupt their schooling and affect their psychosocial well-being.

Boys from HIV-affected families and key population groups may face similar service access, social, schooling and livelihood disadvantages as female CABA. Other risks disproportionately affecting vulnerable boys are increased mobility and exploitative labour, early exposure to criminal justice systems, initiation of alcohol and other drug use, and high levels of violence. Other risks male CABA may face include earlier sexual debut, forced sex, exchange of sex for money, low uptake of HIV testing and treatment, and decreased family protection.[75] For example, a study of adolescents living on the street in the Ukraine found a majority (70 per cent) to be male, and the boys reported an average of nearly five sexual partners each in the year prior to the study.[76]

The barriers preventing access to critical protective services, commodities and support are likely to be particularly acute for adolescents from key population groups at higher risk of HIV infection, such as children exploited through commercial sex, adolescents who inject drugs, adolescent males who have sex with other males, and children and orphans without parental care. Parental consent requirements and age restrictions often inhibit access to essential health services for these adolescents, despite their high risk for HIV infection. Services they may miss include sexual and reproductive health services, HIV testing, and risk and harm reduction counselling – which is often linked to critical commodities such as condoms and clean needles, which may not be accessible to minors or anyone in affected communities.

As discussed in Chapter 3, these children are less likely to benefit from other public services than other children, exacerbating the vulnerability to HIV infection of an already excluded group.

Schooling has a critical role to play in protecting CABA from infection, as schools can provide age-appropriate, gender-sensitive life skills or sexuality education interventions, which are central to equipping students to avoid HIV.[77] Yet the schooling of girls from HIV-affected households and families and key population groups is often jeopardized for social, economic, legal and health reasons. At the same time, schools may be the place where children are most vulnerable to sexual abuse.[78]

Taken together, the evidence indicates that those with the greatest need of protection are most likely to miss it, while at the same time vulnerable children need protection from abuse in schools through rigorous oversight, enforcement of laws and vigilance of teachers and children.

PREVENTION PROGRAMMING RECOMMENDATIONS

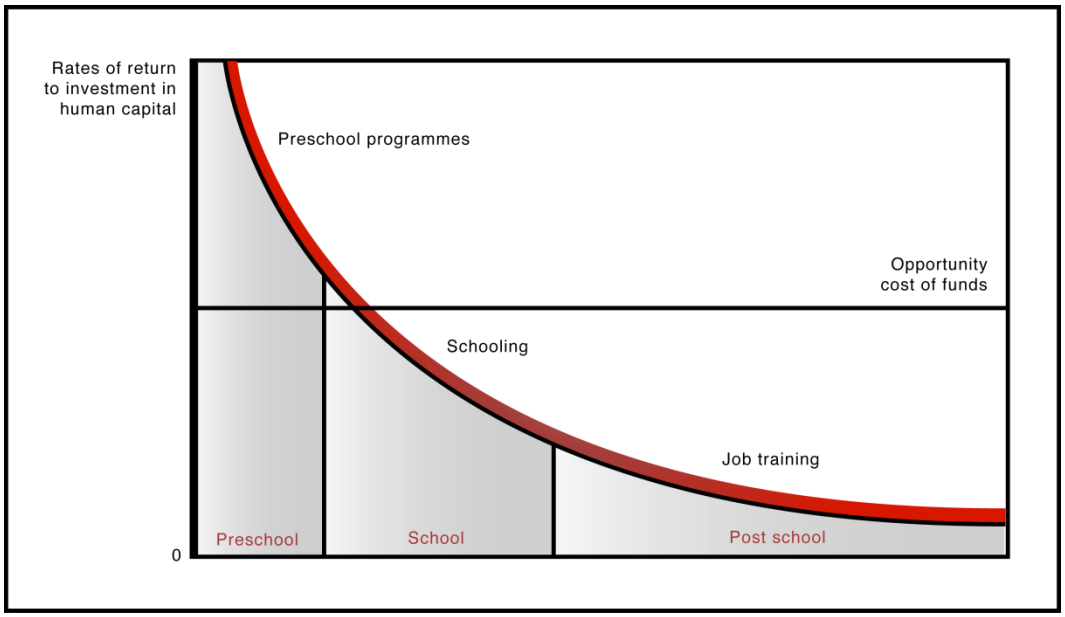
- ✓ The legal, gender, geographic, cultural and other barriers preventing CABA and adolescents at high risk of infection from accessing HIV prevention information, services and commodities must be urgently addressed.
- ✓ Incorporating accurate, culturally appropriate, comprehensive sexuality education into schooling is part of a strategy to equip young people with the information and skills they need to protect themselves against HIV, which must be combined with additional efforts to reach young people out of school.
- ✓ Economic empowerment approaches, when combined with HIV, health and gender education and training, hold promise for girls as a way to promote economic self-sufficiency, reduce gender inequality and empower them to better negotiate sexual relations and reduce their risk of HIV infection.
- ✓ Efforts to transform harmful social norms by working with boys and men to change their behaviour – for themselves and their partners – are also priorities.
- ✓ Child protection measures must be strengthened to prevent vulnerable children and adolescents' exploitation and abuse in all settings, including homes and schools.

EARLY CHILDHOOD DEVELOPMENT

Early childhood development is critical for both cognitive development and early learning, as well as for promoting access to a variety of HIV and other services. For very young children deprived of parental care or in especially vulnerable situations, access to early childhood development services can define the pace of physical and mental development as they grow.[79]

There is good evidence that investments in children's early years can yield impressive returns, e.g., in health, nutritional and cognitive development. The *Figure 7* on the following page demonstrates the economic arguments for investing in young children from a human capital perspective.

FIGURE 7:PRODUCTIVITY ARGUMENT FOR INVESTING IN YOUNG CHILDREN



Source: Heckman, J., and D. Masterov, 'The Productivity Argument for Investing in Young Children', Early Childhood Research Collaborative, *Discussion Paper 104*, 2006.

Community-based early childhood development centres can provide vital support for CABA, along with other vulnerable children. Providing basic services, they: serve as day-care centres, allowing caregivers time for chores and work; act as referral points for other key services, such as child protection, social protection, health, education, and water and sanitation; and follow and monitor children's well-being. These centres enable some of the most disadvantaged children to access important services at a critical age.

EARLY CHILDHOOD DEVELOPMENT PROGRAMMING RECOMMENDATIONS

- ✓ Early childhood development programming for CABA should be integrated with psychosocial, health, nutrition and economic services for children and caretakers to maximize benefits.
- ✓ Early childhood development programmes need to work directly with both caretakers and children and provide sufficient training and supervision for staff.
- ✓ There are significant opportunities to build linkages between early childhood development and clinical services for children infected with HIV, and to promote adherence to treatment through nutritional support.

In Swaziland, neighbourhood care points were set up to respond to CABA and other vulnerable children. The care points are now seen as safe places for eligible children to access food, health services, education and family support. The Ministry of Health and Social Welfare also began Child Health Days at the care points, using centres to deliver immunization, vitamin A, deworming and treatment for illnesses, as well as to monitor the overall health of children. By the end of 2009, an estimated 840 neighbourhood care points were operating, serving approximately 64,000 children.

In Malawi, 3,000 community-based childcare centres were established to provide OVC with a range of services, including cognitive stimulation, early learning, primary health care, school readiness activities, protection, feeding, sanitation and hygiene. Families benefiting from the Malawi cash transfer programme are also referred to the centres, and vice versa.

Source: United Nations Children's Fund, *Early Childhood Development: Real life stories from around the world*, UNICEF, New York, 2010.

CHILD PROTECTION

HIV and AIDS exacerbate child vulnerabilities through reducing household income and the potential loss of parental care, which place children at greater risk of violence, abuse and neglect.[80] This makes child protection a critical component of the CABA response. This section covers legal protection, alternative care and child-protection system strengthening.

While many children in developing countries are involved in some forms of light work, boys and girls from HIV-affected families may be at increased risk of child labour, which is hazardous or prevents them from accessing education. Some of this work, such as sexual exploitation and migrant labour, also can place children at higher risk of HIV infection. Violence and sexual abuse are unfortunate realities for many children, and loss of parental oversight and protection due to orphaning may make these more likely, again placing girls at risk of HIV infection.[81]

All children need legal protection. Widows and children may face the risk of property-grabbing by relatives, and may not be protected under customary law. Birth registration – a component of civil registration – helps facilitate access to basic services as well as inheritance. The official record of a child's birth establishes the existence of the child under law and provides the foundation for safeguarding many of the child's civil, political, economic, social and cultural rights, as well as contributes to efforts to prevent children's economic and sexual exploitation, violation and abuse.

In cases where family disintegration due to HIV or other factors forces children onto the street, their likelihood of coming in conflict with the law increases. Child-friendly justice systems are needed to avoid incarceration of CABA and to ensure that when children come in contact with the law, they are linked with appropriate services and support.

All risk factors associated with HIV are increased for CABA with disabilities. For example, they may be at heightened risk of HIV exposure because children with disabilities may not receive the same information on sexuality and sexual health as their non-disabled peers, while disabled women and girls, particularly those intellectually disabled, are more likely

to be victims of sexual violence and rape than non-disabled women and girls.[82]Children with disabilities who are orphaned, whether they are living with HIV themselves or not, require needs-specific care and special protection against risks of being exploited, neglected, abandoned or placed in residential care facilities.[83]

CHILDREN WHO ARE SEPARATED FROM THEIR FAMILIES

There are many children who are separated from their parents or families, for a variety of reasons, including orphanhood, displacement following natural or man-made disasters, conflict, migration. Many of these children are at higher risk of abuse, exploitation and recruitment into fighting forces than other children.[84] Unaccompanied children have less access to education, health care, livelihoods and basic necessities than peers who are with parents, guardians or customary caregivers. These risks can also render them vulnerable to HIV infection. [85] Such children need immediate attention and alternative care. An estimated 2–8 million children globally live in residential care facilities, and in Eastern Europe alone, an estimated 1.3 million children are deprived of parental care. HIV has added to the large numbers of children in residential care: Up to 10 per cent of children born to women living with HIV in the Russian Federation and Ukraine are abandoned, or taken away from mothers who are deemed unfit, in maternity and paediatric hospitals and residential care facilities.[86]Efforts to strengthen families and prevent family separation are addressed in Chapter 2

Residential care options vary greatly in quality of care, developmental focus and integration with the community. While residential care is often perceived as a 'quick fix' offering immediate emergency care, in many cases long-term residential care can be detrimental for the well-being of children.[87] Evidence shows that this type of care can pose particular risks for the youngest children[88] -especially those under the age of 3 years, who can be particularly affected by under-stimulation and unresponsive caregiving practices which can limit their social competency, cognitive and interactive skills.[89]

The majority of children in residential care facilities have at least one living parent, which points to the need for early family-centred interventions to prevent separation, and to support reintegration where this is in the best interest of the child.[90] Research from Brazil, South Africa and Venezuela suggests that a significant proportion of children in residential care have experienced violence, abuse or neglect prior to their entry into the facilities, which reinforces the need to strengthen child protection services that support family environments where caregiving has been compromised due a number of factors including disability, drug and alcohol misuse, violence, and discrimination against families.

The *Guidelines for the Alternative Care of Children*[91]were adopted by the UN General Assembly in 2010 and provide guidance on the protection and well-being of children who are deprived of parental care or who are at risk of being so. The Guidelines emphasize the importance of preventing family separation in the first place, and, for children who do need alternative care, of helping to determine the most appropriate form of care. The Guidelines also emphasise that alternative care for children under the age of 3 years should be provided in family-based settings.

Types of alternative care include (but are not limited to) family-based formal and informal care, foster care, residential care and supervised independent living arrangements. The guidelines urge States to ensure special efforts are made to tackle discrimination, including on the basis of HIV and AIDS, and to support the provision of appropriate care and protection for all vulnerable children, including children living with or affected by HIV and AIDS.

In addition to guidelines, social mobilization and campaigns targeting opinion leaders and community members are needed to combat widely held beliefs that residential care facilities are the best option for children without sufficient care arrangements.

STRENGTHENING CHILD WELFARE CAPACITY IN NAMIBIA

In 2007, Namibia's Ministry of Gender Equality and Child Welfare conducted a detailed Human Resources Gap Analysis with the United States Agency for International Development (USAID) and UNICEF to examine if the Ministry was appropriately resourced to respond to OVC needs. The analysis showed a glaring gap between children's needs and the Ministry's capacity to meet them.

The Ministry used study findings to petition the Government for a substantial staff increase. As a result, 100 new positions were created and the processing of child welfare grants was accelerated. By August 2009, 104,438 children received grants, up from 56,778 in January 2007.

USAID, through its implementing partner Pact, provided further support to the Ministry by assisting the Child Welfare Directorate to develop an OVC data warehouse. Ministry staff, as well as non-governmental organizations (NGOs) and policy consultants, are now able to consult the warehouse for use in programme evaluation, informing policy decisions, adjusting resources and enhancing budget projections. This has facilitated the efficient use of scarce resources and directly improved the quality of services provided to Namibia's most vulnerable children.

Source: Third Annual Report to Congress on Public Law 109-95, the Assistance for Orphans and Other Vulnerable Children in Developing Countries Act of 2005.

STRENGTHENING CHILD PROTECTION SYSTEMS FOR THE PROTECTION AND REFERRAL OF CABA

Earlier child protection efforts traditionally focused on single issues such as child trafficking, street children, OVC and child labour. While these approaches had merits, they often resulted in fragmented systems, both formal and informal. Rather than treating each child safety concern in isolation, a systems approach promotes a holistic view of children and child protection that engages the full range of actors involved in protecting children's rights and a more sustainable government-led response.

HIV strains child protection systems, but at the same time the epidemic has focused attention on the importance of these systems in reaching vulnerable children. **In many cases, HIV resources have catalysed responses in the relevant sectors, which have benefitted all children**. For example, in Angola, Mozambique, Namibia, Swaziland and Zimbabwe – HIV funding has supported strengthening of birth registration systems that benefit a large number of children beyond those affected by HIV.[92]

A functional social welfare workforce is crucial for providing care and protection services to children.[93] This includes recognition of the need to link marginalized children to a broad range of services within the social welfare systems using social workers and paraprofessionals. Social welfare personnel can also enhance the impact of cash transfers by improving targeting and facilitating access to transfers, especially at decentralized levels.[94] Scaling up care, protection and support services requires increased investment to ensure well-trained, motivated, and supervised social welfare personnel at all levels of the system (public and non-governmental, paid and unpaid). Further information on systems strengthening as part of nationally owned responses is covered in Chapter 5.

CHILD PROTECTION PROGRAMMING RECOMMENDATIONS

- ✓ Legal aid can provide training on will writing, guiding widows to navigate legal processes to help protect their assets, and succession planning. Greater priority should also be placed on legal protection, including birth registration, protection from exploitative and abusive work, and child-friendly justice systems.

- ✓ More initiatives can be implemented jointly by the disability sector and those working on HIV using cross-cutting approaches that maximize existing resources and avoid creating segregated environments for people with disabilities.

- ✓ Keeping families together is the priority before considering alternative care options. When needed, the ultimate objective of alternative care is a durable solution for children, either with their own family or with another family.

- ✓ The *Guidelines for the Alternative Care of Children* should be followed for children already separated: Children should be considered on a case-by-case basis and the suitability of care options should be rigorously assessed. Residential care is only recommended when necessary and constructive for the child and on a temporary basis; monitoring of formal care options against national standards and regulations is necessary.

- ✓ Efforts to transform social norms regarding the acceptability of residential care should complement guidelines and policies.

- ✓ In humanitarian settings where many children are separated from their families, it is difficult to determine which children have actually lost parents and which are separated from them. In such cases, family tracing, reunification and child protection for separated children are the first steps to take.

- ✓ Expanding coverage of child protection is best done using a systems approach, building on examples of where the HIV response has catalysed child-protection system strengthening.

- ✓ Greater investments in human resources are needed for quality child and social protection services and for ensuring adequate referrals between systems, including social welfare and health systems.

THE ROLE OF COMMUNITIES IN HIV SERVICE REFERRAL, DELIVERY AND INTEGRATION

A necessary complement to strengthening more formal child protection systems is community systems strengthening, which can improve child protection, health and other outcomes for families. A review of child-focused community groups in 60 countries found that these groups effectively improved protection and well-being in different contexts.[95] Significant outcomes included reduced participation in the worst forms of child labour, reduced trafficking of children, improvement in the psychosocial well-being of orphans and other vulnerable children, and increased realization of children's right to participation, among others. It is worth noting that the study also found that community groups have limitations (e.g., they tend to avoid addressing sensitive issues such as domestic violence).

Strengthening links between communities and formal systems is necessary to improve CABA's access to services and to ensure sustainable HIV responses. Where government structures are decentralized, strengthening local government structures and their links to communities is especially important. District and community-level child protection networks are essential in mobilizing resources and enabling effective referrals, including through the formal protection system with the police and justice systems. Linkages with non-formal systems, such as traditional justice systems and religious groups, are also valuable in engaging local networks, building trust and filling gaps where the government is absent or weak.[96]

Community systems strengthening has been identified as a key strategy for scaling up towards universal access.[97] In 2008, the Global Fund to Fight AIDS, Tuberculosis and Malaria included community systems strengthening in its proposals and guidelines, making this one of the key strategies of an HIV response. For the Global Fund, the goal of community systems strengthening is to "develop the roles of affected populations and communities, community organizations and networks, and public or private sector partners who work with civil society at community level to design, deliver, monitor and evaluate health activities."[98] The approach focuses on capacity building and human and financial resources, with the aim of enabling communities and community actors to play a full and effective role alongside health and social welfare systems.[99]

One challenge to effective community systems strengthening is the lack of predictable financing. While direct donor funding to community-based organizations has increased in recent years, resource flows often fail to reach intended beneficiaries and get caught in complicated delivery mechanisms and intermediaries.[100] An additional challenge is the over-reliance of community-based organizations on volunteers. Community support systems cannot adequately compensate for the lack of government infrastructure and services. Chapter 5 takes up these challenges.

- ✓ Efforts to improve child-focused community groups should always complement national child-protection systems strengthening.
- ✓ Building effective, efficient and sustainable community systems requires capacity building; human and financial resources; and partnerships between community members and health, social welfare, child protection, legal and political systems.[101]
- ✓ Programmers should avoid challenges that frequently arise, such as the excessive targeting of specific groups of children.
- ✓ Multiple, parallel coordination structures should be avoided at the community level and, instead, ways to build on existing structures should be identified – e.g., school development committees or child protection committees.
- ✓ Donor support for communities should cover systematic evaluation on effective, sustainable approaches, and it should avoid the infusion of large sums of money into the community at one time, especially before community ownership has developed.

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5

ENSURING SUSTAINABLE AND EFFECTIVE NATIONAL RESPONSES FOR CHILDREN AFFECTED BY HIV AND AIDS

Programming for children affected by HIV and AIDS needs to be embedded within national plans and policies in order to secure government commitment and accountability, improve cost-effectiveness and sustain impacts for children. Lessons from the development and implementation of NPAs for OVC are illustrative, and point to the need to mainstream CABA issues and action within broader policies and plans for children, HIV, social protection, poverty reduction and other social sector instruments. Challenges of affordability and limited fiscal space must be considered in planning. Alignment of government and civil society action for CABA is essential. Stronger government and community systems, including the human resources needed to oversee and deliver social welfare and child protection services, are fundamental to national responses.

To ensure long-term sustainability of CABA responses and improve outcomes for children, government and civil society ownership of – and commitment to – national policies and programmes are needed. To this end, the shift from addressing HIV as an emergency response to a long-term development challenge, along with widely recognized principles of aid effectiveness (described in the *box* below) can greatly assist with national CABA programming.

At the national level, policies and legislation regarding children, including CABA, are essential not only for establishing and securing government commitment to meeting the needs of vulnerable children, but also for ensuring that government can be held accountable as their duty bearers. Activities to develop, enforce and monitor such policies and regulation are an essential part of creating a supportive and enabling environment for CABA and a necessary complement to the programmatic approaches described in earlier chapters. National policies, laws and legislation need to be fully compatible with international and regional conventions and policies, and need to address vulnerable children and CABA.

This chapter focuses on aspects of designing and managing effective, sustainable national responses including:

- More effective nationally led CABA programmes;
- Improving development partnerships for more effective and efficient responses; and
- Systems strengthening.

KEY PRINCIPLES OF AID EFFECTIVENESS

The Paris Declaration and Accra Agenda for Action lay out widely accepted principles in 2005:

1. country ownership;
2. alignment;
3. aid harmonization;
4. managing for development results; and
5. mutual accountability.

MOVING TO MORE EFFECTIVE, NATIONALLY LED MULTI-SECTORAL PROGRAMMES FOR CABA

Following the 2001 Declaration of the United Nations General Assembly Special Session on HIV and AIDS (UNGASS), countries committed to develop and implement national policies and strategies for the protection and care of OVC. By the end of 2010, 17 countries in Eastern and Southern Africa were in the process of strengthening or developing NPAs to provide a framework for action and support for OVC.[102] While in some cases NPAs succeeded in galvanizing attention and mobilizing resources for programmes, they introduced a number of mainstreaming and coordination challenges. In some settings, they resulted in vertical programmes for OVC that were not aligned with other poverty reduction instruments. These negative experiences are instructive, as they indicate that **countries should consult across sectors to identify the special needs of CABA and help realize their rights by integrating plans to**

address their needs within national strategic plans on HIV and AIDS and other national frameworks on children and poverty reduction.[103]

Countries have embarked on a number of different approaches to planning CABA responses in response to the successes, opportunities and challenges arising from NPA implementation to date. Some have renewed NPAs or extended the time frame of their plans to five years, adapting them to more closely link to other government initiatives. Others are moving from NPAs for OVC to national plans on a broader range of child vulnerabilities, while some have elected to phase out NPAs and mainstream issues affecting vulnerable children – including CABA – into broader legislation and development plans, such as Children's Acts, National Poverty Reduction Plans and sector strategies including social protection strategies and HIV frameworks.

LIMITATIONS OF OVC NPAS IN SOUTHERN AFRICA

Reviews of NPAS in southern Africa have shown that:

- *Most NPAs approach OVCs as relatively homogenous; little or no attention is paid to gender, disability, ethnicity, class and wealth, or to indicators of vulnerability.*
- *Most NPAs do not give sufficient attention to the hardest-to-reach groups (including street children, abandoned and/or institutionalized children, child soldiers, children with disabilities and abused children).*
- *The needs of children of preschool age (0–6 years old) are neglected.*
- *The NPAs lack attention to child and youth participation and leadership development for OVC.*
- *There is limited focus in the NPAs on social protection initiatives or linkages with national social protection frameworks.*
- *There is inadequate focus in the NPAs on reducing vulnerability or on meeting psychosocial needs and developing emotive and psychosocial competencies.*

Sources: Gulaid, Laurie, 'National Responses for Children Affected by AIDS: Review of progress and lessons learned', IATT, 2008; Sabates-Wheeler, R., and L. Pelham, 'Social Protection: How important are the national plans of action for orphans and vulnerable children?', Institute of Development Studies and UNICEF, Brighton, United Kingdom and New York, 2006; and Engle, Patrice L., 'National Plans of Action for Orphans and Vulnerable Children in Sub-Saharan Africa: Where are the youngest children?', Bernard Van Leer Foundation, The Hague, Netherlands, 2008.

IMPROVING BUDGETING AND COSTING OF NATIONAL RESPONSES

A median of 11 per cent of households caring for OVC received any form of external support in countries where coverage surveys had taken place as of 2010.[104] Scaling up coverage and improving the impact of this support is a priority moving forward. Stakeholders must coordinate better to effectively monitor coverage, while at the same time doing more with existing funds to meet CABA's needs. Appropriate gap analysis and use of better vulnerability data (including the use of household datasets, as addressed in Chapter 6) should inform resource mobilization efforts and prevent duplication of services.

In developing CABA programmes, it is important to consider the affordability of taking projects or programmes to scale, and whether pilots have the potential to be scaled up within present and future funding scenarios with domestic and external financing. UNAIDS conducts National AIDS Spending Assessments to calculate the level of external and domestic financing available for social protection, OVC and human resources within the HIV response. These assessments can provide some indication of the fiscal space available for national CABA programmes.

In developing programmatic responses, consideration should be given to the cost per child of delivering an intervention, and if the same impacts can be achieved at lower cost. Costing data is critical to building realistic budgets, but in reality, CABA programmatic cost and impact data is hard to find. Programmers should do more to emphasize:

- Impact evaluation of CABA programmes with well-defined outcome measures;
- Greater analysis of implementation costs and services provided to CABA; and
- Better reporting and coordination of CABA expenditure at the national level.

IMPROVING QUALITY

One of the greatest challenges remains scaling up services for vulnerable children while retaining quality. The US President's Emergency Plan for AIDS (PEPFAR), through USAID, is supporting the Care that Counts quality improvement initiative that defines quality based care as "accessible standards that are delivered in compliance with evidence-based standards and that meet children's needs." The approach is based on four core principles:

1. *Being client-centred: never forgetting that the needs of the children served are the basis for interventions.*
2. *Multidisciplinary team approach.*
3. *Focus on how care is actually provided, examining and modifying the systems and processes use.*
4. *Data-based decision-making*

Their experience indicates that defining service standards through national consensus-building, piloting standards and conducting improvements to achieve standards, and disseminating lessons from the process and outcomes can help with quality improvement. For more information, see <http://www.ovcsupport.net>.

IMPROVED COORDINATION OF MULTI-SECTORAL RESPONSES

Government leadership and national commitment to coordinate, fund, plan and promote interventions for CABA prove important factors for effective outcomes. Since the 2004 *Framework's* publication, experience has demonstrated the need to prioritize programme alignment if capacity to deliver essential services is to be realized and interventions brought to scale.[105]

Whether countries adopt a stand-alone plan or opt to ensure that the needs of CABA are incorporated into national development instruments and HIV strategic plans, the management and coordination of a multi-sectoral response to childhood vulnerability remains a challenge. Because NPAs or other policies for children typically include a broad range of sectoral interventions, implementing the plan is often outside the scope and authority of one ministry, particularly where the line ministry for vulnerable children is not well-resourced or powerful. As an alternative, many governments have constituted coordinating committees involving different ministries to oversee the NPA, often supported by wider technical working groups involving development partners. Support is needed, however, to ensure that national steering committees meet and that participating agencies and ministries are represented by officials who are empowered to make decisions.

To successfully manage and coordinate a stand-alone multi-sectoral NPA or a mainstreamed response covering multiple development instruments, it is advisable to place the responsibility for the response at a sufficiently high level of government to manage and coordinate across sectoral ministries and hold ministries accountable.[106] The example in the *Box* below shows how consideration of political dynamics can improve NPA implementation.

THE VALUE OF SENIOR COMMITMENT TO NPA IMPLEMENTATION

Oversight of the NPA can be provided by a number of different high level bodies such as the Office of the Prime Minister, Vice President, or the National Children's Councils (NCCs), where the NCC has statutory authority to play such a role.

In Swaziland, a decision was made to situate children's issues in the office of the Deputy Prime Minister under a National Children's Coordination Unit. This move is reportedly having a positive impact on NPA implementation, partially due to ongoing capacity building of the Unit and the passionate commitment of the Deputy Prime Minister.

Source: De Bruin, Isabel Cardoso (2010)

MONITORING AND EVALUATING THE RESPONSE

Monitoring and evaluating plans for vulnerable children has been one of the weaknesses in national CABA responses. Many interventions fail to report within national monitoring systems, which results in national authorities not having the necessary information about the scale, scope or impact of various CABA interventions. In addition, most monitoring and evaluation plans are output focused, measuring the volume of services provided. While useful for tracking implementation, they offer little information on impact. Finally, data that many monitoring and evaluation frameworks track is rarely available in a unified data collection and reporting instrument. Some countries have dedicated databases for OVC, but most have yet to grow into nationally owned knowledge management systems. Chapter 6 discusses how to tackle these important challenges.

- ✓ Countries should base decisions about developing a stand-alone NPA or a mainstreamed approach based on an assessment of the HIV epidemiology; political will; infrastructure and children's welfare; and a review of policies and strategies needed to successfully mitigate the impact of HIV and AIDS on children.

- ✓ If a stand-alone plan is preferred, countries should determine an appropriate focus within the country context, as well as whether to maintain a CABA or OVC focus, or increase the focus to broader range of childhood vulnerabilities.

- ✓ Children's meaningful and ongoing participation is essential to supporting the process of implementing national plans for children.

- ✓ Countries replacing a stand-alone plan with a mainstreamed model should review national development plans, poverty reduction strategies, social protection strategies and plans, HIV and AIDS frameworks, and other sectoral policies and plans to ensure they adequately address CABA.

- ✓ A mandated body responsible for CABA should be vested with the authority to manage and coordinate a response across ministries, and to ensure policy compliance, governance and sufficient resources for an effective implementation unit.

- ✓ A multi-sectoral steering committee can provide the strategic guidance, technical leadership, priority setting and quality assurance needed to implement policies and strategic plans for children, be they stand-alone or mainstreamed.

- ✓ Development partners need to ensure their assistance supports national strategies and sustainable systems for vulnerable children including CABA, and also that they within national coordination and monitoring mechanisms and ensure transparency in funding decisions.

IMPROVING PARTNERSHIPS FOR MORE EFFECTIVE AND EFFICIENT RESPONSES

STREAMLINING FUNDING CHANNELS

One of the principle challenges hindering coordinated delivery of national plans for children is the multitude of independent funding streams supporting service delivery. In many countries, CABA funds are channelled outside of government budgets, with typically little government oversight regarding where funds are going and for what purpose. While development partners may be aware of the objectives and priorities of the national plan, frequently no one national agency has a comprehensive picture of how each service delivery stream contributes to the national plan, nor mechanisms to review the combined efforts as a comprehensive response.

Civil society organizations often receive multiple grants and report to multiple donors, which can fragment their ability to provide effective and predictable support for vulnerable children, as well as places heavy administrative burdens on them. More harmonized grant management

mechanisms can help channel more predictable resources from multiple donors to organizations working to achieve the broad objectives of national plans for children[107]. Even when the funding channels are outside of government funding mechanisms, governments need to play a key oversight role in directing funds to areas of greatest need. The *Box* below provides an example of Zimbabwe's effort to streamline processes.

ZIMBABWE'S PROGRAMME OF SUPPORT: LESSONS LEARNED ON AID EFFECTIVENESS

The first phase of the Zimbabwe Programme of Support 2005–2010 was aligned behind the Government's National Action Plan for Orphans and Vulnerable Children and aimed to expand support for OVC, including those affected by HIV. The programme offered a range of services for OVC, such as schooling support, birth registration, psychosocial support, food and nutrition, health care, water and sanitation, child protection and cash transfers (small-scale pilots).

To provide increased and more predictable resource flows for OVC, six donors signed up to a four-year programme of support to be channelled through a pooled funding mechanism managed by UNICEF to more than 180 NGOs and community-based organizations. The increased and pooled funding meant more predictable funding for civil society grant recipients and reduced reporting requirements. UNICEF provided one consolidated report for all six donors. Through the Programme of Support, NGOs and community-based organizations were required to report to the Government of Zimbabwe on an agreed set of indicators, which helped national coordination and enabled the Government to see levels of coverage and gaps. Due to donor funding restrictions, all funding went through civil society organizations.

While the funding mechanism led to scaled-up support and reached more than 480,000 children, as a consequence of the civil society focus, funding was not available for the Ministry of Labour and Social Services. This has resulted in reduced government capacity to deliver on its statutory functions. A capacity assessment of the Ministry systems has subsequently been undertaken to identify key gaps, including in human resources, to inform future development.

Sources: United Nations Children's Fund, Zimbabwe Ministry of Public Service Labour and Social Welfare and Zimbabwe National AIDS Council, 'Zimbabwe's Programme of Support to the National Plan of Action for Orphans and other Vulnerable Children', Harare, 2008; Jitmat Development Consultants, 'Programme of Support for the National Plan of Action for Orphans and Other Vulnerable Children, Impact Assessment', Harare, 2010

PARTNERSHIPS BETWEEN GOVERNMENT AND CIVIL SOCIETY

While donor coordination can improve the alignment of varied funding streams, strengthening government and civil society partnerships remains a critical challenge. Civil society organizations continue to have a major role in national responses to CABA. They have effectively participated in designing and developing national responses for vulnerable children and HIV, as well as delivering services and material support. Increasingly, civil society organizations, particularly community-based ones, are involved in community mobilization, technical support and systems strengthening initiatives.

The role of civil societies in supporting and empowering citizens and community groups to campaign for basic service improvements or women's and children's rights are essential elements of community system strengthening, as discussed in Chapter 4. Communities can also be empowered to engage in local advocacy for the care and protection of CABA, including addressing the underlying causes of vulnerability, such as cultural attitudes that underpin violence, abuse, exploitation, exclusion and discrimination. The following *Box* describes how child participation improved advocacy and communication regarding the situation of CABA.

CHILDREN DOING ADVOCACY

The Abaqophibakwa Zisize Abakhanyayo children's radio project in South Africa stemmed from concern that negative myths about CABA appeared to be shaping funding, policy, interventions and even national law. For the project, groups of children produce radio programmes ranging from personal diaries to commentaries, audio profiles, and current affairs and documentaries. They also present a regular slot on the local radio station. The project has had multiple benefits, including increasing participants' literacy and communication skills, emotional healing, and the creation of opportunities for communication between children and carers. The creation of the programmes and their contents also influenced the way CABA are perceived in the community and beyond:

"In initiating the children's radio project, the team intended to give children in Ingwavuma the opportunity to depict their lives for a broader audience. It was anticipated that the audio packages they produced would provide more nuanced representations of children's experiences than those produced by many adult researchers and journalists and ... therefore contribute to improving public insight into the experiences of children growing up in the context of HIV and AIDS in South Africa."

Source: Regional Inter Agency Task Team on Children and AIDS in Eastern and Southern Africa 'Child and Youth Participation in East and Southern Africa: Taking stock and moving forward – An analytical review of the literature and five case studies on child and youth participation in East and Southern Africa', RIATT-ESA, Ferndale, South Africa, 2010.

UNBLOCKING BOTTLENECKS TO INCREASE FUNDING FOR COMMUNITY-BASED RESPONSES

With the need for greater returns from constant budgets, funding agencies are trying to ensure that a greater proportion of funding reaches intended beneficiaries. Donors have to balance the requirement to get funds to individuals with meeting their organizational financial management requirements. In some instances, this means passing funds through large international contractors – who can fulfill financial and grant management requirements – who then sub-grant support for interventions to NGOs and community-based organizations. While these approaches have merits, cascade models also introduce the risk that multiple levels of overheads erode funding for programming.

In Kenya and Peru, for example, a few NGOs receive the overwhelming majority of funds, while a large number of NGOs and community-based organizations receive extremely limited funding. Moreover, large national NGOs tend to be the main beneficiaries of international aid, while community-based organizations tend to rely more on national funding sources[108].

This reinforces the continuing need to find ways to ensure capacity building of indigenous civil society organizations for a more sustainable response. Increasing the pool of eligible grantees can also serve to increase innovation and improve quality of service delivery.[109]

RECOMMENDATIONS FOR IMPROVING PARTNERSHIPS

✓ Strong partnerships between government, civil society and donors are critical for effective and sustainable national responses. These can be strengthened through joint design and planning of the national response, as well as common programmatic reporting through a single national monitoring and evaluation system.

- ✓ Development partners should inform governments on financial commitments and expenditures on CABA to improve the ability of governments to identify gaps and direct their own resources effectively.

- ✓ Increased, predictable funding for civil society partners can foster more sustainable and scaled-up responses. Harmonized civil-society granting mechanisms can assist by improving coordination and removing funding bottlenecks.

- ✓ A greater focus is needed on channelling resources to community-based organizations and indigenous NGOs, building on a number of documented good practices in this area. Decentralizing calls for proposals to the district level and using national community-based networks can help indigenous civil society organizations to access funding.

SYSTEMS STRENGTHENING TO IMPROVE AND SUSTAIN NATIONAL CABA RESPONSES

Health systems strengthening has been essential to ensure access to HIV services, but is not sufficient to ensure equity nor to meet the wider needs of CABA. Chapter 1 describes the growing interest in directing HIV investments to community, social protection and child protection systems strengthening.[110] This is based on the recognition that strengthened social-care systems will not only mitigate the impact of the epidemic, but will also contribute to more equitable outcomes for children, facilitate timely referrals to HIV services, including testing and treatment programmes, as well as promoting access to life skills, broader education and other essential services.

In its broadest sense, systems strengthening refers to efforts to improve the functioning of systems for better outcomes, including increased access, coverage, quality and efficiency.[111] It recognizes that a system includes individual components that work together towards shared objectives and that the individual components interact. From an aid effectiveness perspective, systems strengthening is important to ensure sustainability, particularly through capacity building of government and civil society partners.

Whilst considerable HIV investments focus on health and community systems, sustainable investments in social welfare systems have been missing.[112] Strengthening social welfare systems is a priority for social protection, recognizing that the movement from pilots to sustainable national programmes can only be achieved when the relevant government ministries are capacitated, equipped and financed to oversee service delivery and track impacts. Increasing coverage and quality of services for CABA also requires greater investment in decentralized social welfare and child protection services delivered through government and civil society. Strengthening welfare to promote social assistance for ultra-poor households and child protection with social welfare workers can help with

the provision of quality care, protection and support for children, and can also enhance aid effectiveness.[113]

WHICH SYSTEMS NEED STRENGTHENING?

No single system for CABA exists, and it would not make sense to construct one. Rather, the child protection and social care that CABA and their families need are typically delivered through social welfare (or similar) systems. In addition, CABA need programming that is comprehensive, meaning that social welfare systems need to work through strong links with mainstream social services (e.g., education), HIV-specific services (e.g., nutritional support and PMTCT) and community-based systems.

At the level of the national government, ministries responsible for vulnerable children (e.g., Social Welfare, Social Development, and Community Development) often lack the human, technical, financial and structural resources necessary to fulfil their mandates. In addition, they are rarely substantively engaged in the national HIV response, and thus are not positioned to ensure that children's issues are reflected in key planning processes (e.g., the development of proposals for the Global Fund). These factors hamper their ability to plan, lead and oversee national action for CABA. This is recognized in NPA reviews, and a key recommendation for improving implementation is to include capacity assessments and plans to address capacity gaps within NPA development processes.

As described in Chapter 4, part of community systems strengthening is building civil society capacity to strengthen civil society engagement in the response to CABA. Network organizations in particular can play a critical role in community systems strengthening by giving civil society a needed voice, building the capacity of community and district level partners, and coordinating and harmonizing the civil society response.[114]

Many of the policies, plans and services that CABA and their families need cut across multiple sectors and service delivery channels. Consequently, investments in strengthening one system – e.g., social welfare – can benefit another – e.g., education – by helping to expand the reach of schools and reduce financial barriers. Similarly, family strengthening using trained social workers can bolster health system efforts to reach excluded families with PMTCT and other essential health services. Recognition of the potential for synergies between systems can help make the case for funding comprehensive multi-sectoral responses with a significant systems strengthening component.

HUMAN RESOURCES

The social welfare workforce plays a critical role within social welfare systems, including in provision of direct services, administration of government agencies policy development, research, workforce education and advocacy.[115] The importance of a social welfare workforce for providing care and protection to children is gaining increasing attention. This includes recognition of the need to link marginalized children to a broad range of services within the social welfare systems using social workers and paraprofessionals. Social welfare personnel can also enhance the impact of cash transfers by improving targeting and facilitating access to transfers and other child protection services, especially at decentralized levels.[116]

While global initiatives exist to address human resources for health, similar efforts in social welfare settings are just beginning to gain momentum. Lessons from initiatives to increase human resources for health have relevance for CABA. Attracting migrants home, increasing output from training facilities, developing reciprocal agreements with richer or oversupplied countries, while maximizing existing in-country resources, are some of the relevant strategies that countries have deployed in recent years. In South Africa, when applications for the Foster Care Grant overwhelmed the Department of Social Development due to a shortage of social work staffing, the Government enacted a retention strategy, including bursaries and scholarships, to encourage take-up of social work training, with significant salary increments awarded to government-employed social work staff.[117]

SYSTEMS STRENGTHENING RECOMMENDATIONS

- ✓ Investments in social welfare systems are essential for nationally owned, sustainable responses to CABA and other vulnerable children.
- ✓ Scaling up care, protection and support services requires increased investment to ensure well-trained, motivated and supervised social welfare personnel at all levels of the system (public and non-governmental).
- ✓ Investment in district and sub-district social welfare systems (both governmental and non-governmental) is essential for strengthening referrals between community-based care and support systems and clinical HIV services.
- ✓ Families and communities must be central to the effort to improve health and social welfare systems. People living with HIV, community health workers and local leaders should be empowered and supported to undertake the responsibility of caring for members of their communities affected by HIV.

CHAPTER 5 WEB RESOURCES & GUIDANCE

1. The Paris Declaration on Aid Effectiveness (2005)and Accra Agenda for Action (2008),<www.oecd.org/dataoecd/11/41/34428351.pdf>.
2. Joint United Nations Programme on HIV/AIDS and the World Bank, AIDS Strategy and Action Plan, HIV/AIDS Costing Model, Washington, D.C., 2008, <http://siteresources.worldbank.org/INTHIVAIDS/Resources/375798-1151090631807/ASAPHIVAIDSCostingModelUserManualv1.2.pdf>.
3. Boston University Centre for Global Health and Development, Orphans and Vulnerable Children Comprehensive Action Research (OVC-CARE), <www.bu.edu/cghd/projects/ovc-care>.
4. Family Health International, Quality Improvement Guidelines for Care and Support Programs for OVC,Durham, 2008,<www.ovcsupport.net/s/library.php?Id=780>.

USING DATA TO BETTER SUPPORT CHILDREN AFFECTED BY HIV AND AIDS

6

Much more attention to data needs, use and capacity is required in order to scale up and sustain effective national responses for CABA. The steps to address this challenge include identifying what information is required and by whom, and agreeing on indicators to use for measurement. Information from national household and specialized surveys should be used for strategic planning, ensuring the use of both qualitative and quantitative information. Programme improvements, as well as accountability enforcement, rely on monitoring coverage in relation to overall need and impact evaluation to determine if activities are achieving desired objectives. Evaluations are most effective when using a robust design that includes baseline measures and a control group. National systems for monitoring and evaluation also need strengthening for oversight, coherence and the effective use of resources to achieve sustained impacts for children.

National governments, donors and service delivery organizations confront difficult decisions in allocating limited economic and human resources to meet CABA needs. Stakeholders need an informed understanding of what is best for targeting, programming and resource allocation to make sound decisions. While much CABA data has been collected, it is often insufficient or inadequate for programme planning, monitoring or advocacy.

This chapter provides an overview of how to better create and use data to support CABA programming, as well as how monitoring and evaluation system strengthening is essential to scale up and sustain improvements. The chapter contents follow the process of data creation to its effective use, covering:

- Clarifying what data are needed;
- Types of data and methods of collection;
- Managing and using data; and
- Strengthening systems for monitoring and evaluation.

The need to harmonize monitoring and evaluation and data systems is endorsed through the 'Three Ones' principle, which was developed to enhance effective and efficient use of resources to ensure rapid action and results-based management. **The 'Three Ones' include one agreed-upon, country-led monitoring and evaluation system**.[118]

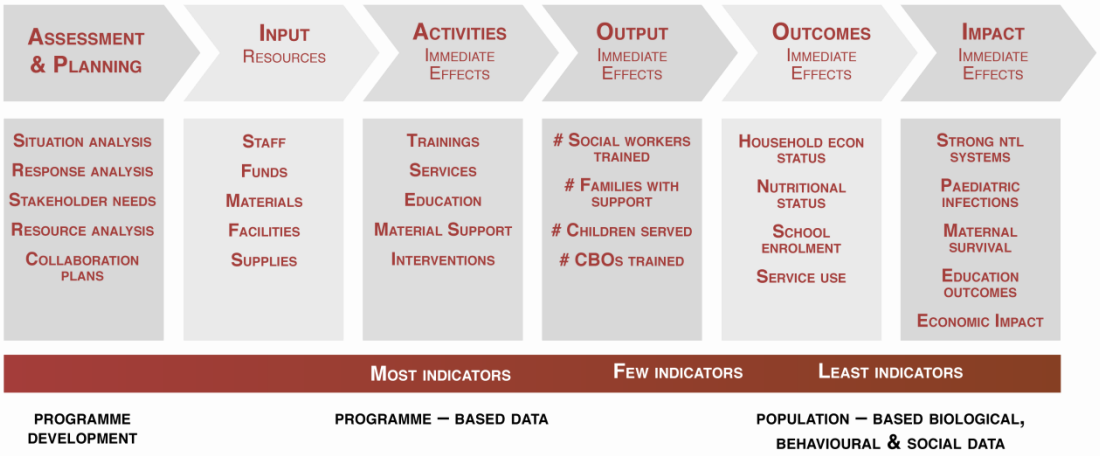
CLARIFYING WHAT DATA ARE NEEDED

Clarifying what data are needed, as well as by whom and for what purpose, is the first step in gathering the right information. Data needs differ depending on the audience for the data and at what level data are required (national/sub-national or community/programme). The primary uses of data on CABA are: for **strategic planning** (at national and programme levels), including establishing where the needs are greatest and what the most appropriate responses are within available resources; **to monitor progress and measure impact;** to hold programmes **accountable** for funds and efforts; and for **advocacy.**

THE USE OF INDICATORS IN DATA COLLECTION

Indicators measure change in a phenomenon or process and help assess the degree to which objectives are being achieved. *Figure 8* provides a useful framework for identifying indicators to be used at each stage of the activity cycle.

FIGURE 8: GLOBAL AIDS MONITORING AND EVALUATION FRAMEWORK AND ILLUSTRATIVE DATA TYPES



Source: Adapted from Rugg et al., Global Advances in HIV/AIDS Monitoring and Evaluation: New Directions for Evaluation, Wiley Periodicals, Hoboken, NJ, 2004.

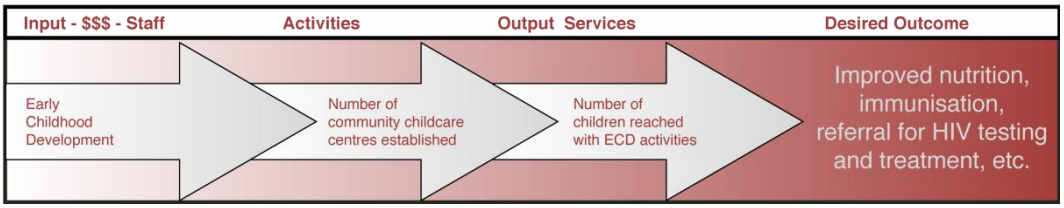
National-level indicators: Understanding the country context and generating shared perspectives on critical needs and national priorities are prerequisites for an effective monitoring and evaluation system. Key stakeholders including government staff, decentralized authorities, civil society (including community-based organizations, faith-based organizations and people living with HIV) and, importantly, caregivers and children, should be involved in the early stages of programme design. Fortunately, in many countries, there is growing recognition of the need to develop consensus among stakeholders on core indicators, as well as of the need to strengthen the capacity of national monitoring and evaluation systems, to reduce CABA data gaps.[119]

Developing the right indicators requires clarity on the desired outputs and outcomes. To track progress for CABA at the international level, global OVC indicators have been developed (see UNGASS indicators in the Annex). Use of the global core indicators, however, should not preclude the addition of other indicators at the national or sub-national levels. National planners will have to prioritize the most feasible indicators in the context of their own monitoring and evaluation capacity.

Community-level indicators: Most information available at the community level is collected via routine monitoring against indicators – that is, collecting and analysing data to track programme processes. Sub-national data are necessary to understand service coverage and access, including who is being reached and who is being left behind (e.g., gender disparities, access by poorest and hard-to-reach groups such as children with disabilities). Community-level indicators can establish levels of social support and behaviour change at the community level. In addition, community-level monitoring can help monitor the reach and effectiveness of broader social services (health, education and social welfare) and the impact on HIV-affected families and children. Wherever possible, **programme and project monitoring should include indicators that can feed into national monitoring and evaluation systems.**

While monitoring is generally conducted on the input/output level, outcome data also are needed to monitor children's well-being and determine if activities are actually having the desired impact. *Figure 9* illustrates the relationship between different categories of indicators and how they relate to each other.

FIGURE 9: DO CABA ACTIVITIES LEAD TO DESIRED OUTCOMES?



Source: Adapted from the United States Agency for International Development, Health Care Improvement Project, 'Care that Counts: Improving Quality of Services to Reach the Most Children', 2008.

Programmes may benefit from using tools such as the Child Status Index, which provides a condensed assessment of a child's comprehensive needs, making it an efficient, user-friendly tool for direct service providers at the community level.[120] Continual monitoring of child well-being with these sorts of tools can help programming respond to changing needs as children grow.

TYPES OF DATA AND METHODS OF COLLECTION

After decisions are made about data needs and indicators, the next step is identifying which types of data and methods of collection are required. Data need to be collected at different levels and from different sources in order to develop a comprehensive understanding of CABA. CABA data are commonly collected through routine monitoring, situational analysis, population-based surveys, targeted special studies, evaluation and operational research.

POPULATION-BASED SURVEYS

Data for developing NPAs are usually drawn from national needs assessments or situation analyses, programme service data, and population-based national surveys typically based on household questionnaires such as DHS, Multi-Indicator Cluster Surveys (MICS), AIDS Indicator Surveys and Living Standards Measurement Studies. These instruments include data on HIV prevalence and other sources of child vulnerability such as orphanhood, non-co-residence with parents, poverty, not being in school or at grade level. Population-level data can assist with prioritizing areas for additional services by showing which sub-national areas have the greatest rates and numbers of children in need of support.

When determining what information is needed to inform targeting, it is important to note that poverty is usually a greater predictor of child deprivation than orphaning, as discussed in Chapter 1. Identifying the distribution of poverty across countries and within districts and communities is therefore important for targeting. Household wealth data

can provide a sharper understanding of child vulnerability in the context of HIV.

SPECIALIZED SURVEYS

While national household surveys are a primary means of collecting data for strategic planning, they are unlikely to be sufficient for establishing priorities for a national response to vulnerable children on their own. For example, household surveys miss children outside of family environments. For such children, including those on the street or in residential care as well as migrant and displaced children, special surveys are needed to ascertain the magnitude of their needs. It is also important to measure how CABA's well-being and access to basic services compare with that of other children. In all cases, gender and age disaggregation of data is critical to fully understanding the specific needs of boys and girls across the life cycle.

MANAGING AND USING DATA

While methods of data collection on CABA have improved, use of data for decision-making is evolving. This section covers data management and usage in a CABA programme cycle, which includes planning, implementation and advocacy.

Broadly stated, management information systems organize and store data. Many countries have information management systems for collecting and organizing data on vulnerable children, as well as national computerized data systems. Their experiences can provide important lessons for others seeking to improve national information systems. One innovation with potential is using cell phones for data collection, which can easily be transmitted to central databases.

Moving from data management to use, a key element is increased awareness of available data through better dissemination to programme staff, who can put the information to use, and to policymakers, who can translate knowledge into policy. Web-based hubs of CABA knowledge, along with locally and nationally collected data, provide critical information for programme planning, improvement, accountability and advocacy.

USING DATA TO INFORM PLANNING IN WEST AFRICA

With the support of PEFPAR, Côte d'Ivoire's national database system and software were developed and installed in decentralized social centres run by the Ministry of Women, Family and Social Affairs. Monitoring and evaluation staff at social centreswere trained in data-quality issues and the use of the database. Data are reported to the central division responsible for OVC services, the National Programme for Orphans and Vulnerable Children, where analysis contributes to regular meetings with implementing partners and donors. Trends and challenges are discussed through the national working group and coordination body, CEROS.

Data from partner quarterly reports are compiled by service level, sex, and age range for analysis. This information forms the basis of recommendations for the Ministry and CEROS on filling programme gaps. National maps of OVC implementing partner sites help coordinate coverage. The national programme has also implemented a series of protocol-based situation analyses in larger cities and is analysing trends to inform resource allocation and focus of support within the Ministry and among partners.

***Source**: Côte D'Ivoire PEPFAR team.*

USING DATA FOR PLANNING

At the national level, data are used to inform the development of strategies and to oversee and monitor their implementation. This requires clear understanding of the extent of the need, identity and location of those most in need (targeting), and what they need most (types of need, service gaps). To address CABA needs in particular, HIV prevalence rates for different areas and identification of those most affected by the epidemic are important. This may include identifying behaviours and social conditions most associated with transmission in each country and how affected children may be impacted, noting the role of poverty in mediating the impact of HIV on children, families and communities.

Many countries have completed situation analyses to guide their planning, which often draw on national records on education, health, sanitation and other measures of socio-economic status. Several countries aggregate and analyse programme-level data for use at the national level, aided by harmonized indicators and data collection against a national plan. For example, at the national level, Uganda is compiling data from service providers at local and district levels. This system will provide ongoing information on the needs of vulnerable children and their households through household surveys. The information will include organizations that are responding to needs, the extent and location of coverage, and current and changing gaps.[121]

Illustrating data visually, particularly at the national level, can help with analysis of complex information from multiple sources. Geographic Information Systems can play a valuable role in linking multiple datasets using geographic identifiers and providing linkages across domains of the data infrastructure. Such systems also can help to identify data quality issues by facilitating mapping and analysis.

Data for programme planning can come from routine data collection; information that is helpful in creating budgets and projecting staffing needs will come primarily from the actual records of community-based organizations and NGOs. National-level data can be distributed to assist planning at local levels. Data on coverage and gaps can also be used to mobilize action by communities and civil society organizations.

USING A COMMUNITY-LEVEL STUDY TO UNDERSTAND THE SITUATION OF CABA IN INDIA

A qualitative, community-level study was undertaken to identify the needs of CABA. India has relatively broad government public services for children, particularly in the areas of health, nutrition and education. However, the study generated evidence that many vulnerable children are effectively excluded from these services by social factors such as gender, caste, parental expectations and, most recently, HIV and AIDS. The key issue that emerged from the study was that HIV-related stigma restricted children'saccess to these essential services. From a programming, monitoring and evaluation perspective, this study pointed to the critical need to ensure that families and children affected by HIV and AIDS are not excluded, whether by officials, communities, or their own fear or lack of information.

Source:United Nations Children's Fund, *Developing and Operationalizing a National Monitoring and Evaluation System for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS Guidance Document*',UNICEF, New York, 2009.

A life cycle and gendered approach to needs assessment and planning is critical, as children's vulnerabilities vary by age and gender. As discussed earlier, household income level, disability and ethnicity are among the factors that can increase vulnerability. Qualitative and participatory methods of data collection, including consulting with boys and girls of different ages, are important to substantiate quantitative data and to provide a more rounded perspective on the needs and priorities of vulnerable children. Such analysis may reveal critical factors such as social barriers to access and discrimination.

USING DATA TO MEASURE IMPACT AND IMPROVE PROGRAMMING

Generating and using data to improve programmes is a crucial but often-missed opportunity. At a programming and national level, it is essential to know to what extent programmes reach those most in need. Monitoring coverage is key and relies on solid information on the number of children and households receiving support relative to those in need. Data on the number of children receiving support typically are available, since this is the most common indicator used by implementers for accountability. A significant challenge, however, is that data on the size of the target population (the denominator) needed to compare the number of children who are being reached with the number who are not yet being served are often not available. In the absence of reliable numbers, statistical modelling has been used to estimate the number of orphans, and complementary efforts are underway to define and measure the number of 'vulnerable children'.[122]

Many programmatic and national systems focus on coverage of services but fail to measure outcomes and the impact of services on children. Although the overarching goal of CABA stakeholders is to improve the well-being of children and their households, data efforts are rarely designed and used to achieve that goal. Programmatic and national monitoring and evaluation systems also need to track how particular interventions contribute to broader national development goals such as health, education, psychosocial and poverty outcomes.

PROGRAMMATIC EVALUATION

Evaluation is the overall assessment of the degree to which a programme achieved its intended outcomes or impacts. Evaluation data usually include results of routine monitoring, as well as additional information, such as project history and situational context. Evaluations with a methodology rigorous enough to link interventions with their effect on beneficiaries can contribute to the general knowledge base available to inform CABA programming and thereby improve well-being, at the same time as providing information to improve specific programmes. A weakness of many CABA interventions is the lack of robust impact assessment on the degree to which interventions make a difference in outcomes.

Although randomized control trials – often considered the gold standard for research – may not be possible due to ethical considerations and resource constraints, other types of experimental design can produce robust evaluations.[123]

Quality evaluations should include the collection of baseline data that describe the target population before the activity begins and a control or comparison group, such as children who do not receive the intervention but whose characteristics are determined at the beginning and end of the activity. Baseline data and a comparison group can help to demonstrate that the change in outcomes can be attributed to programme inputs, an important step in describing impact.[124]

One of the limitations of many evaluations is an inability to demonstrate the **'counterfactual' – in other words, what would have happened in the absence of the specific intervention**. While it may be possible to establish a counterfactual by measuring differences between recipients and non-recipients of assistance, there may be ethical problems with withholding benefits from an equally needy group. In these cases, it is possible to use future beneficiaries as a control group who will benefit from a later phase of the project.

The use of mixed qualitative and quantitative methods can strengthen evaluations. Achieving an adequate sample size, particularly when conducting research involving young children and children living on the street, is a further challenge. Qualitative research, including focus group discussions and in-depth interviews, can confirm quantitative findings and help programmers understand the causal pathways for change. Operational research into the constraints and enabling factors for scale-up are an important component of evaluation. Involving children in conducting research can improve relevance and broaden research results, as described in the following *Box*.

CHILDREN DOING RESEARCH

In Central Uganda, child-led research was conducted on children caring for sick adults, elderly grandparents and younger siblings. The child researchers identified research questions and, using tape recorders and disposable cameras, interviewed child caregivers. The photographs formed the basis of discussion with adult researchers. The use of the cameras enabled the collection of intimate, detailed information that adult outsiders could not access, such as learning about the multiple, repeated caring roles children undertook; how children found money and food; relationship dynamics in the households; and learning that boy caregivers faced cultural and other challenges. This information was used to pilot improvements in Save the Children's OVC programming in Uganda, as well as for broader advocacy.

Source: Save the Children, 2010."

USING DATA FOR ACCOUNTABILITY AND ADVOCACY

Programmes are responsible to the children, families and communities they serve. Indeed, accountability is the primary purpose of the data systems required by most national governments and donors. Data can be used to measure the progress made in national plans in order to hold governments accountable for their commitments to children, while transparency in reporting on activities of community-based organizations in local communities should also be the norm.

The availability of credible data is also important for advocacy. Data have been used to enhance children's visibility and programming efforts at global, national and local levels, even when data collection is initiated for other purposes. Implementers may use monitoring and evaluation data to garner additional support from donors.

STRENGTHENING NATIONAL MONITORING AND EVALUATION SYSTEMS

Where national monitoring and evaluation systems are weak, establishing parallel systems de-linked from national systems will further weaken the ability of national authorities to plan and coordinate national efforts. Hence, as part of the growing awareness that systems strengthening is key to more sustainable responses, many development partners recognize the strategic importance of investing in national monitoring and evaluation systems. Guidance is available to help address weaknesses in CABA monitoring and evaluation systems, setting out key principles, including the need to ensure that programme monitoring and evaluation activities – often responding to donor needs – are harmonized with broader national monitoring and evaluation plans rather than running in parallel.

The following should be considered when developing monitoring and evaluation plans:

- Monitoring and evaluation is a central feature of project design and project cycle management that should be considered from the start of the project cycle.
- The 'Three Ones' principle points to the need to harmonize the monitoring and evaluation of systems to increase effectiveness and efficient use of resources.
- Reaching a common understanding of a problem, the target, relevant national policies, proposed intervention mechanisms and available capacity are fundamental to developing a good monitoring and evaluation system, and wide consultation is necessary to avoid unrealistic expectations.
- Planners should identify what is already in place for monitoring and evaluating CABA programmes, particularly regarding social welfare and child protection. Where National AIDS Councils exist, their advice should be sought on monitoring and evaluation coordinating mechanisms, data collection and core indicators in the context of national strategic plans.
- Planners should also determine what national surveys (MICS/DHS) are planned, and if they include key indicators on CABA and other vulnerable children.
- CABA programme monitoring plans should adhere to national reporting requirements, even when the execution takes place outside of the public sector.

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ANNEX1:
INDICATORS FOR MONITORING AND EVALUATING OF THE NATIONAL RESPONSE FOR CHILDREN ORPHANED AND MADE VULNERABLE BY HIV AND AIDS

Indicator	Age disaggregation	Key domains	Measurement tools
Strengthen the capacity of families to protect and care for OVC by prolonging the lives of parents and providing economic, psychosocial and other support			
C1. Ratio of orphaned and vulnerable children (OVC) versus non-OVC who have three minimum basic material needs for personal care	5–17	Family capacity	Population-based survey
C2. Ratio of the proportion of OVC compared with non-OVC who are malnourished (underweight)	0–4	Food security and nutrition	Population-based survey
C3. Ratio of the proportion of OVC compared with non-OVC aged 15–17 who had sex before age 15	15–17	Health	Population-based survey
A1. Ratio of food insecure households with OVC compared with households without OVC	NA	Food security and nutrition	Population-based survey
A2. Ratio of OVC versus non-OVC aged 12–17 with an adequate score for psychological health.	12–17	Psychological	Population-based survey
A3. Ratio of the proportion of OVC versus non-OVC aged 12–17 who have a positive connection with the adult they live with most of the time	12–17	Psychological	Population-based survey
A4. Percentage of mothers or primary caregivers who report having identified a standby guardian who will take care of the child in the event that she/he is not able to do so	NA	Protection	Population-based survey
Mobilizing and strengthening community-based responses			
C4. Proportion of all children aged 0–17 living outside of family care	0–17	Residential care and shelter	Street children survey and residential care facility survey

Indicator	Age disaggregation	Key domains	Measurement tools
C5.[a] Proportion of eligible households who received economic support in the past three months	NA	Community capacity	Population-based survey
A5. Percentage of orphans who are not living in the same household with all their siblings under the age of 18	0–17	Community capacity	Population-based survey
Ensure OVC access to essential services including education, health care, birth registration, ART for them and their caregivers, child-friendly justice and others			
C6.[a] Ratio of orphaned children compared with non-orphaned children who are currently attending school	10–14 Primary school age, secondary age	Education	Population-based survey
C7. Proportion of children aged 0–4 whose births are reported registered	0–4	Protection	Population-based survey
Ensure that governments protect the most vulnerable children through improved policy and legislation and by channelling resources to families and communities			
C8. National Policy and Planning Effort Index score for orphaned and vulnerable children	NA	Policies/strategies, resources and resource mobilization	Key informant interviews
A6. Percentage of widows who have experienced property dispossession	15–49	Protection	Population-based survey
Raise awareness at all levels through advocacy and social mobilisation to create a supportive environment for children and families affected by HIV and AIDS			
C9. Percentage of children under 18 whose mother, father or both parents have died	0–17	Policies/strategies	Population-based survey
C10. Percentage of children under 18 who are vulnerable according to the national definition	0–17	Policies/strategies	Population-based survey
A7. Stigma and discrimination (being developed?)			

*C: Core indicators A: Additional indicators [a] Revised UNGASS indicators

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