

TAKING EVIDENCE TO IMPACT

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



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20 THINGS YOU SHOULD KNOW

unite for children



Introduction

This brief lays out the rationale for investing in social protection, care, and support for children affected by HIV and AIDS. It demonstrates how investing in these initiatives not only improves the resilience of HIV affected households but can also enhance HIV prevention and treatment outcomes. HIV-affected children are benefitting from expanding treatment coverage however, as ever-greater amounts of HIV resources go into health systems and health responses, complementary investments are needed to maximize the impact of health expenditure. It is essential to recognize the key development synergies between social welfare, protection, health, education, and community system strengthening in order to ensure equitable access to quality prevention, treatment, care, and support for HIV-affected children and their families.

The brief draws key messages from UNICEF's *Taking Evidence to Impact: Making a Difference for Vulnerable Children Living in a World with HIV and AIDS*, (which brings together evidence from research and experience and proposes programmatic responses for children affected by HIV and AIDS). This brief is useful for policymakers and programmers engaged in children and AIDS work.

HIV continues to make millions of children vulnerable care and support is as important as ever

1. By 2009, 16.6 million children lost one or both parents to AIDS.¹
2. HIV and AIDS continue to impoverish families, threaten children's schooling, nutrition and mental health, and increase children's risk of abuse and exploitation.
3. Families and communities carry most of the burden of HIV's impact on children with very little external support reaching them.

Despite increased access to treatment, numbers of orphans due to AIDS will continue to increase, particularly in parts of sub-Saharan Africa.² Research from South Africa shows that children affected by HIV and AIDS, including orphaned children and those living with a parent with AIDS, face greater risks of emotional and physical abuse and sexual exploitation than other children.³ Children who have lost one or both parents are also at greater risk of dropping out of school than non-orphaned children.⁴

The number of orphans is a fraction of the much larger number of children whose vulnerability has increased because of HIV and AIDS. For example, in some countries children living with or affected by HIV are more likely to be placed in institutional care⁵. HIV puts stress on families which in turn affect children's health, nutrition, mental health, and education; in some cases, children have to do

1. Range of 14.4 – 18.8 million. UNICEF (2010), Children and AIDS: Fifth stocktaking report, New York.
2. Belsey, M. & L. Sherr (2011). The definition of true orphan prevalence: Trends, contexts and implications for policies and programmes. *Vulnerable Children & Youth Studies*, 6:3.
3. Cluver, L. Orkin, M. et al. (2011) Transactional sex amongst AIDS orphaned and AIDS affected adolescents predicted by abuse and extreme poverty, *Journal of Acquired Immune Deficiency Syndromes*.
4. UNICEF (2012, Forthcoming).
5. EveryChild, Maestral and UNICEF (2012), Children living with and affected by HIV and AIDS in residential care.

arduous or exploitative work to help meet basic needs. Children may also experience HIV-related stigma and discrimination, keeping them from school, groups of friends, and health services.

HIV increases children's vulnerability in multiple ways

4. Being a single or double orphan is a factor that can negatively affect outcomes for children but needs to be seen as one of many factors making children vulnerable.
5. Poverty, living arrangements, education of household head, gender and age all shape the impact of HIV and AIDS on children.
6. Children at risk of HIV exposure need a continuum of care including testing treatment, nutritional and psychosocial support.
7. To promote equity, decrease stigma and improve sustainability, programmes to strengthen household resilience should be inclusive of HIV affected children rather than exclusively reaching children affected by AIDS. This approach is often called HIV-Sensitive programming.

Rich and poor households alike can face hardships such as stigma, discrimination, and psychosocial distress due to HIV and AIDS. But the poorest households are the least resilient to HIV's economic consequences and least able to cope with rising health costs and lost household earnings. Attention needs to be paid to children who do not live with one or both parents as they are more likely to be out of school and experience early marriage⁶. Children affected by HIV outside of family care e.g. living in institutional care are in particular danger of not receiving adequate services, care, and support.



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HIV and AIDS exacerbate the vulnerability of children in key population groups such as people who use drugs, boys and men who have sex with men, migrants, and sex workers. Across all settings and population groups, gender mediates HIV's impact on children, with differing consequences for affected boys and girls. For example adolescent girls may face increased risk of dropping out of school, early sex or sexual violence.

Country level analysis of bottlenecks and barriers to accessing services should determine which children are excluded from which services and why. This will help determine who to target with what support in different epidemic contexts. For example, in some cases HIV-related stigma and discrimination may be the most significant barrier to accessing health or education, requiring greater investments in changing social norms than establishing economic assistance initiatives. Many countries are shifting away from stand-alone projects targeting orphaned children and HIV-

6. UNICEF (2012, forthcoming).

affected families to HIV-sensitive approaches, for example ensuring that child grants and widows' pensions are reaching eligible HIV-affected households instead of establishing separate grants mechanisms for HIV-affected children alone, which may be unsustainable in the long term.

Strategic programming priorities

To maximize the impact of programmes for children affected by AIDS it is important to consider how investments in protection, care and support can both improve the resilience of HIV affected children and families and improve treatment and prevention outcomes.⁷

Three broad approaches are proposed. These respond to the ways HIV and AIDS make children vulnerable. Implementing these will maximise the developmental synergies between care and support and other HIV priorities. Programming should always consider children's life cycle, taking account various developmental stages. In particular, the youngest HIV-affected children are the most vulnerable over the long term because of rapid physical and cognitive development during early childhood. Young children need good nutrition, care, and encouragement from stable caregivers, as well as opportunities to learn, they also need preventive health care and protection from harm. Community-based early childhood development activities can provide such support and care and link HIV-affected children to clinical services.



Link HIV care and support, treatment and prevention

8. HIV-affected children need programmes that work across silos; bridging care and support with treatment and prevention programming is especially urgent.
9. Investing in community-based health, social welfare and family centred approaches are critical enablers for HIV treatment and the elimination of mother to child transmission.
10. Integrated care and support is particularly important for adolescents including addressing the social and economic factors which make boys and girls at risk of HIV infection, and can impede access to treatment.

Extending parents' lives through antiretroviral treatment is one of the best ways to provide protection and care for HIV-affected children. However, ensuring parents are on treatment is not sufficient; better linkages between treatment, prevention, care and support can also improve access to and outcomes for HIV-affected children.

Delivering HIV-related programming using a family-centred approach can link different parts of an HIV response. Programmes for children affected by AIDS have typically targeted individual children, bypassing their families and similarly many HIV programmes for adults have bypassed children. Family centred programming ensures the needs of a whole family and not just an

7. Schwartlander B et al. (2011) Towards an improved investment approach for an effective response to HIV/AIDS. The Lancet, 2011, 377:2031–2041.

individual are addressed⁸. For example, programmes targeting children living with HIV should not neglect their carer's health and economic needs, and testing and treatment services for adults should consider needs of their children. These family centred approaches can be facilitated through community-based care workers who are well-positioned to support HIV-affected families by linking adults and children to antiretroviral treatment, legal support, food and nutrition assistance, and social protection entitlements.



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Linking HIV care and support, treatment, and prevention can also improve child and family outcomes by reducing both supply side and demand-side barriers to HIV-related services. This is particularly relevant for the drive towards the elimination of mother to child transmission (EMTCT). For example, community-based organisations, home-based carers, or social workers working with HIV-affected families can be trained to identify and refer pregnant women in their communities to HIV services, as well as providing vouchers to facilitate women's transport to facilities. As more people access lifelong antiretroviral treatment, such integrated support is essential to sustain treatment access. In concentrated epidemic settings, offering legal support alongside HIV services could increase access for key population groups at high risk of HIV infection who otherwise avoid health institutions for fear of being discriminated against.

Linking HIV impact mitigation programmes to prevention programmes can help reduce the number of new HIV infections in adolescent boys and girls. Care and support activities economically can empower girls and boys, address gender inequality and harmful social norms that disadvantage young females thus reducing some of the structural inequalities fuelling the HIV epidemic. Adolescent girls as well as boys need access to comprehensive sexuality education and sexual and reproductive health services; girls also need protection from violence and abuse. Growing numbers of adolescents living with HIV need comprehensive care and support to access and adhere to treatment.



Expand HIV-sensitive social protection

- 11.** Comprehensive social protection, including social transfers, social care services, policies and legislation which promote equity, is a priority for HIV-affected children and families and has proven positive outcomes for children.
- 12.** Effective HIV-sensitive social protection needs to address both economic and social factors which may exclude HIV affected households from services.
- 13.** It is generally more cost-effective and sustainable to adapt national social protection programmes to ensure they are more inclusive of HIV affected children and families than set up small scale pilots exclusively targeting children affected by AIDS.

8. International HIV/AIDS Alliance and Save the Children (2012). Family centred HIV programming for children.

Recent years have seen the expansion of social protection programming in developing countries, in part in response to the limited reach of economic support programmes in communities and countries heavily affected by HIV. Social protection as defined in the box is highly relevant for HIV and AIDS impact mitigation, as well as for enhancing treatment and prevention outcomes. The core components of comprehensive social protection include.

1. social transfers (e.g., cash and food)
2. Programmes to ensure social and economic access to services
3. Social support and care services
4. legislation and policies to ensure equity and non-discrimination in service access and livelihoods

Comprehensive social protection can help mitigate the impacts of HIV and AIDS and enhance the resilience of children and their families. It can also promote access to health, education and nutrition and help keep children stay within the family environment. In Malawi and Kenya, for example, predictable cash transfers improved food security, nutrition, education, and health outcomes for the poorest and most vulnerable, including those affected by HIV and AIDS. Importantly, these programmes achieved an HIV impact without directly targeting HIV-affected households. They also recognised that benefits did not have to target children directly in order to reach them.⁹ A full assessment of feasibility, affordability, sustainability, and appropriateness should precede the development of any cash transfer programme.

Social Protection is...

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.

Devereux, S. & R. Sabates-Wheeler, Transformative Social Protection, Institute of Development Studies Working Paper 232, Brighton, 2004.

Supporting comprehensive programming enables the delivery of tailored approaches which respond to the epidemic context, household productive capacity, poverty levels, and other contextual factors. Beyond social transfers, examples of comprehensive social protection programming include promoting public works and income generating activities for those who can work, and advocating for legal protection, for example to prevent property grabbing from widows and children. Social protection programming also can help promote other HIV-related objectives, in particular, reducing people's risk of HIV infection and removing barriers to services. For example, in prevention terms, cash transfers have increased school enrolment rates amongst adolescent girls, which in turn can help them avoid HIV infection. Emerging evidence also indicates that the removal of user fees, social transfers of cash, food, and transport vouchers can help increase treatment adherence and improve treatment outcomes.

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



Strengthen social welfare and child protection systems

- 14.** Strengthening national social welfare and child protection systems can support the move away from fragmented projects to broad, sustainable programmes that reach children affected by HIV and AIDS.
- 15.** Civil society organisations and community groups are at the forefront of responding to HIV-affected children. As well as service delivery they play a critical role in monitoring the effectiveness and reach of national responses.
- 16.** Systems strengthening includes building the capacity of the lead ministry, the social welfare and child protection workforce and community systems.

In many countries, strengthening social welfare and child protection systems is an important approach to move from small fragmented projects to national comprehensive programmes for children affected by HIV and AIDS. Other government ministries (health, youth, gender, community development, education, national AIDS programmes) have a role to play, but until the mandated lead ministry is capacitated to lead coordinated action, the needs of children affected by HIV and AIDS will continue to overwhelm the response. Systems strengthening activities should include building links to other social sectors. Strategies and programmes must be costed and budgeted, a process through which the cost effectiveness of plans can be assessed. Critically, whilst government systems are being strengthened, programmers must retain their focus on reaching communities and households to ensure response to those most in need.

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Capacity building of those mandated to assist HIV-affected children is critical to systems strengthening. Given the traditionally weak capacity in the social welfare sector, support is required to build institutional capacity to finance, plan, oversee, deliver, and monitor a response at national and decentralised levels. Building up the work-force that delivers care and support to children and families is another aspect of capacity building. This includes social workers and para-professionals, as well as other groups with a key role in supporting HIV-affected children.

Government cannot – nor should not – do it alone. The Government’s core responsibilities should be defined in relation to civil society and communities based organizations on specific mandates, responsibilities, and capacities. At present, community systems have a critical role in responding to HIV affected children for example providing support through child protection committees, networks of people living with HIV, and faith-based organisations. However, limited community capacity, funding and over-reliance on volunteers often hinder coverage and impact, underscoring the need for community systems strengthening and financing. Developing mechanisms to ensure funding reaches civil society organisations and communities is an important complement to strengthening community systems.

All children – including those affected by AIDS – stand to benefit from improved social welfare systems covering oversight, delivery, and regulation of family support, alternative care for children without caregivers, early intervention for children, birth registration, legal and protection against abuse and exploitation, as well as comprehensive social protection.

Using data to improve coverage, effectiveness and value for money

17. The production of national and sub-national level strategic information on the situation of children affected by HIV and AIDS and the state of the response is an urgent priority.
18. Planners should use existing household and specialized survey information to assess programme coverage, geographic gaps and underserved groups.
19. National monitoring and evaluation systems should link to NGO monitoring and evaluation systems to help with coordination and the use of data.
20. Monitoring systems should include baseline measures, comparison groups and robust, quantitative indicators to measure progress and describe impact.



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Programming responses should be based on a full understanding of the situation of children affected by HIV and AIDS in a given context. The three priorities described above – linking care and support to broader HIV responses, social protection, and systems strengthening – rely heavily on quality data to inform effective strategies and ensure they are having the desired impact. Whilst, data availability is often limited, improving the use of existing data can help. Strategic information also should be developed by improving national and community capacity for research, monitoring and evaluation, and the use of data.

Protection, care and support programmes sometimes fail to attract funding due to their inability to demonstrate impact. Monitoring systems should include baseline measures, comparison groups, and quantifiable targets to ensure progress can be measured and impact attributed to the intervention. Context-appropriate indicators should be developed to standardise measurement, including indicators relevant from community-level up to national-level monitoring. Importantly, programmatic monitoring, while essential, should contribute to national monitoring and evaluation systems rather than detracting from them by creating parallel indicators and data collection systems.