

# SAARC Regional Strategic Framework for Protection,Care and Support of Children Affected by HIV/AIDS (CABA)



Jointly developed by SAARC & UNICEF



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#### SOUTH ASIAN ASSOCIATION FOR REGIONAL COOPERATION SECRETARIAT

#### Preface

The need of facilitating evidence based advocacy and programming for children affected by HIV and AIDS was identified as a key issue in the 'SAARC Regional Strategy on HIV and AIDS (2006-2010)' formulated on the direction of the 12<sup>th</sup> SAARC Summit (Islamabad, January 2004) and its Work Plan endorsed at the 27<sup>th</sup> Session on the Council of Ministers (Dhaka, August 2006). The Strategy articulates the need to "facilitate evidence based advocacy and programming for children affected by HIV and AIDS in the Member Countries and to coordinate the efforts towards developing costed actions plans in all countries through the mechanism of a regional forum". The Regional Consultation on Children Affected by HIV/AIDS in South Asia held in Kathmandu in May 2007 formulated a common strategic approach for policy and programming to protect and support these children and their families, namely, SAARC Regional Strategic Framework for the Protection, Care and Support of Children Affected by HIV/AIDS.

The Framework places children affected by HIV/AIDS within the broader group of children in difficult circumstances, and focuses on delivering an integrated response to children's medical, nutritional, educational, legal and psychosocial needs, in line with the UN Convention on the Rights of the Child. It calls for a universal approach to ensure that children affected by HIV/AIDS have access to the same public and social support systems which are available to other children, rather than being separated or singled out among their peers. This is linked to measures to address the stigma attached to HIV/AIDS, and to intervene on behalf of children who are discriminated against as a result of this stigma.

While The 2008 UNAIDS Global Report on AIDS epidemic estimates adult HIV prevalence among 15-49 years at 0.3 % in South Asia, an estimated 0.2% of young people aged 15-24 in the SAARC region are living with HIV. Moreover, a high proportion of the adult population currently living with HIV infection in the region have children. The impact of the epidemic is therefore felt not only by the infected adults but also their children; having detrimental effects on their well-being and their future. Moreover, within the fast growing number of Children at Risk due to various causes, the subset of Children Affected by HIV is also on the rise. It is therefore, imperative that all stakeholders take necessary action in support of this Framework.

I would like to commend participants from the Member States for their active consultations, which led to development and endorsement of the SAARC Regional Strategic Framework for the Protection, Care and Support of Children Affected by HIV/AIDS. I also wish to place on record sincere gratitude to the UNICEF Regional Office for South Asia (UNICEF ROSA) for being the collaborative partner in developing the Framework.

I am confident that this Framework will go a long way not only towards making a difference in the lives of children and families affected by HIV/AIDS in South Asia but also setting an example for the other parts of the world facing similar challenges.

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### Introduction

The Regional Strategic Framework for the Protection, Care and Support of Children Affected by HIV/AIDS provides guidance to the eight member States of the South Asian Association for Regional Cooperation (SAARC) on a consistent approach across South Asia to the protection, care and support of children affected by HIV/AIDS.

It locates children affected by HIV/AIDS within the broader group of children in difficult circumstances, and focuses on delivering an integrated response to children's medical, nutritional, educational, legal and psychosocial needs, within the context of the UN Convention on the Rights of the Child, which all Member States have ratified.

The Regional Framework promotes a universal approach to ensure children affected by HIV/AIDS have access to the same public and social support systems which are available to other children, rather than being separated or singled out. However, within this universal approach the Regional Framework calls for additional and specific measures in relation to overcoming the stigma that surrounds HIV/AIDS and to intervene on behalf of children who are discriminated against as a result of this stigma.

The Regional Framework recommends that the response be age- and gender-sensitive, take into account the specific situation and location in which affected children live, and that prioritise legal, policy and practical action to reduce the stigma and discrimination around HIV/AIDS. It recognises that many of the threats to the rights of children affected by HIV/AIDS relate to the health and survival of their parents, and in this light encourages action to ensure expanded access to HIV testing and counselling, and to appropriate treatment and care for those infected. The Regional Framework takes into account that many of the children affected by HIV/AIDS are also at risk of HIV infection and some may be HIVpositive, and promotes strong intervention-level linkages to essential HIV/ AIDS prevention and treatment services for children and their families, including prevention of mother-to-child transmission. The Regional strategic framework emphasises that the best method of avoiding paediatric HIV infection is to have in place an effective PPTCT programme especially in countries with high HIV prevalence.

### **Regional Situation**

Between 2.3 and 3.7 million people in the SAARC region are estimated to be HIV positive. UNAIDS and UNICEF estimated that in 2004 there were nearly 1.3 million children who have lost one or both parents to AIDS in South Asia. A significantly larger number of children – estimated up to 10 million - are living in families where one or both parents is HIV positive. Whilst these numbers are large, the children affected by HIV/AIDS are still a small proportion of the large number of children who are living in vulnerable households where their rights are not protected.

HIV/AIDS affects children in all parts of the SAARC region, however, children in different countries are not necessarily affected in the same way. How children are affected depends on a range of considerations including epidemiological factors like HIV prevalence, risks and vulnerabilities amongst certain populations: cultural factors such as child care practices and orphan uptake and care: family factors including poverty levels and child care capacity; community factors like community resilience and coherence to deal with increasing numbers of vulnerable children; and the existing and potential response capacity provided by community groups, NGOs and Governments.

Recent research in the SAARC region shows a consistent pattern of exclusion and abuse of those who are, or who are presumed to be, associated with HIV/AIDS. The discrimination takes place within the family, the community, in schools, health centres and in other public and private services. Once infection is recognised or even suspected, many people living with HIV are disowned by their own families and excluded from services offered by their communities and governments.

Misconceptions and lack of full and correct knowledge about HIV/AIDS is at the core of the stigma and discrimination. In much of the region, it is widely assumed that children with HIV-positive parents are themselves infected, and that they are likely to infect other children. The fact that these assumptions are wrong makes no difference to those children, many of whom are excluded from school, routine medical services and important social rituals. Research is showing that it is often the most educated members of those communities the teachers, doctors and community leaders - who are the instruments of this exclusion. The effect on these children is often extreme and irreversible.

There is also evidence of the socio-economic impact of HIV/AIDS in the region which indicates that the households of AIDS widows are economically and socially worse off than other households in terms of income, expenditure, borrowings and liquidation of assets. In addition, in many parts of the region the loss of income due to the death or absence of a male may be compounded by an inability for women and children to inherit property. A more enduring source of vulnerability is likely to be the exclusion of affected children from essential services.

Across the region, the strong welfareoriented approach which influences policy development and the practices is manifested in a number of Member States by an approach of long-term institutionalisation of children outside parental care. This is contrary to international experience on how to respond effectively to the social impact of increased household vulnerability, which clearly highlights that the most important lesson is that children need to be raised by their own parents or extended family, within their own communities. The UN Convention on the Right of the Child (CRC), which every SAARC Member State has ratified, provides an important framework to guide any response to HIV/ AIDS prevention, care and support of children. It states that children shall be protected from discrimination; that the "the best interests of the child shall be a primary consideration"; and it obliges governments to offer children, in accordance with their maturity, an increasing role in decisions that affect them. The CRC affirms "the right of the child to the enjoyment of the highest attainable standard of health."<sup>1,2</sup>

The Millennium Development Goals (MDGs) adopted by 189 nations-and signed by 147 heads of state and governments in September 2000 commits to "*halt and begin to reverse the spread of HIV/ AIDS*" (MDG Target number 7).

The United Nations General Assembly Special Session on HIV/AIDS adopted a Declaration of Commitment in June 2001 which binds members – including SAARC Member States – by 2005 to: The need to facilitate evidence based advocacy and programming for children affected by HIV/AIDS was identified as a kev issue in the SAARC Regional Strategy on HIV and AIDS 2006-2010, formulated at the 12th SAARC Summit (Islamabad, January 2004) and in terms of the Work Plan endorsed at the 27th Session of the SAARC Council of Ministers (Dhaka, August 2006). This Strategy also called for Member States to coordinate efforts for these children through the mechanism of a regional forum. The Regional Framework builds on and compliments the SAARC Convention on the Regional Arrangements for Child Welfare in South Asia (January 2002). Article III on guiding principles in the Convention reaffirms the right of the child to eniov all rights and freedom guaranteed by the national laws and regionally and internationally binding instruments; and to consider the UN Convention on the Rights of the Child as a comprehensive international instrument concerning the rights and wellbeing of the child and shall, therefore. reiterate their commitment to implement it.

build and strengthen governmental, family, and community capacities to provide a supportive environment for orphans and girls and boys infected and affected by HIV/AIDS, including by providing appropriate counselling and psychosocial support; ensuring their enrolment in school and access to shelter, good nutrition, health and social services on an equal basis with other children; to protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance.

1 UN. (2002) Declaration of commitment on HIV/AIDS

2 UN. (1989) Convention on the rights of the child

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### SAARC Regional Strategic Framework ("Regional Framework")

## Definition of Children Affected by HIV/AIDS

The terms "children affected by HIV/AIDS" and "affected children" refer to:

- Children living in or coming from a family where one or more parents or caregivers are HIV positive;
- Children who have lost one or both parents or primary caregiver/s due to AIDS;
- Children and young people under 18 years of age who are HIV positive.

### **Principles for Action**

Five principles for action underpin the Regional Framework.

Children affected by HIV/AIDS in the SAARC region:

- Have the same rights as other children, including the right to the care of their parents and extended families, to health, education, legal services, social security and protection against abuse and neglect;
- Pose no threat to others, and as such should have access to the same social service facilities and providers as other children, including schools, hospitals, health clinics and welfare services.

Governments in the SAARC region have a duty to:

- Ensure that service providers do not discriminate against children affected by HIV/AIDS;
- Encourage and assist families including those affected by HIV/AIDS – to raise their children by ensuring they are

aware of their rights and entitlements to public services, and by providing safeguards if those rights are not met;

- Promote family- and community-based alternative care for children affected by HIV/AIDS, and ensure that institutions are not used as a substitute for family care, or used to gain access to education and other essential services.
- Provide ART for HIV positive children.

### **Strategic Approaches**

The Regional Framework endorses the five key strategies from the Global Framework as applicable and appropriate in the SAARC region:

- Strengthen the capacity of families to protect and care for orphans and vulnerable children by prolonging the lives of parents and providing economic, psychosocial and other support
- Mobilise and support community-based responses to provide both immediate and long- term assistance to vulnerable households
- Ensure access for orphans and vulnerable children to essential services, including education, health care, birth registration and others
- Ensure that governments protect the most vulnerable children through improved policy and legislation and by channelling resources to communities
- Raise awareness at all levels through advocacy and social mobilisation to create a supportive environment for children affected by HIV/AIDS.

The Regional Framework builds upon these five broad global strategies and recommends eight strategic approaches to guide interventions for children affected by HIV/AIDS in the SAARC region:

- A rights-based approach, which focuses on reaching all children and families at risk, not only children affected by HIV/AIDS. Programmes should not single out or target individuals affected by HIV/AIDS but should mobilise efforts and direct services towards all children in those communities which are most affected by HIV/AIDS.
- 2. An integrated and inclusive approach, which ensures access for children affected by HIV/AIDS to the same social services as other children, including health, education, birth registration, social welfare, protection and psychosocial support. Instead of providing separate services for children affected by HIV/AIDS, resources should be used to strengthen existing services for all children.
- Family capacity strengthening to protect and care for children, including those affected by HIV/AIDS, by ensuring access to economic assistance, social security, psycho-social support, information on appropriate care practices, and to HIV/AIDS treatment and clinical care for infected adults and children.
- 4. Mobilise and support community-based responses to both identify the needs of affected children and their families, and for their involvement in the development of the most appropriate interventions.
- Improve policy and legislation, and its administration and enforcement, to protect and ensure the fulfilment of the rights of children including those affected by HIV/AIDS and their families.

- Build public awareness and mobilise society at all levels, including community, business and faith-based leaders, to create a supportive and nondiscriminatory environment for children and families affected by HIV/AIDS.
- Link efforts to mitigate the impact of HIV/ AIDS on children to prevention and treatment programmes, to reduce the incidence of infection among parents and children and to improve the health and survival of those already infected.
- 8. Focus particular attention to the roles of boys and girls, men and women, and to gender-based discrimination, Addressing social exclusion and gender-based discrimination and violence should guide programming for children affected by HIV/AIDS. To further reduce genderrelated vulnerability, the demand side of child abuse and exploitation must also be addressed, including norms about male sexuality, gender inequity, and the sexual exploitation of children and youth.

#### Key Elements of Programme Action

The Regional Framework proposes six areas of programmatic action for governments in relation to children affected by HIV/AIDS in the SAARC Region:

- 1 Inclusion and integration of children affected by HIV/AIDS into general development and social services:
- Children affected by HIV/AIDS must be provided for and treated the same as any other child, in terms of health, education, social welfare and protection services.
- When existing services do not meet the specific needs of children affected by HIV/AIDS then additional measures should be integrated into those services, rather than creating separate services.

- Service providers must have accurate information on the HIV/AIDS and the lack of significant risks to themselves and other clients, and on their responsibilities toward affected children and their families.
- Social, legal and procedural mechanisms must be in place to prevent, avoid, detect and redress occurrences of HIV/AIDSrelated stigma or discrimination, including exclusion, abuse and violence.
- Maintain confidentiality of all information of children affected by HIV.
- 2 Support for all families in difficult circumstances to keep and raise their children:
- Families and children must be made aware of, enabled and encouraged to access public services and entitlements including social protection, social transfers, educational and economic opportunities, and medical services including HIV testing and treatment.
- Families and children must have access to mechanisms to report and overcome exclusion from public services and entitlements for any reason, including discrimination due to HIV/AIDS.
- Families affected by HIV/AIDS may require specific assistance to keep and raise their children including home-based care, psychosocial and nutritional support, and overcoming externally or self-imposed exclusion from public services, social entitlements and income generating opportunities.
- 3 Legal protection and justice:
- Civil registration systems must be accessible and efficient, and birth registration should be linked to other commonly accessed social services.
- Disinheritance of orphans and widows, especially resulting from HIV/AIDS, must be overcome by amending and implementing legislation, making the process of inheritance easier, sensitising

community leaders to existing laws and promoting public education.

- Child protection services must be developed or strengthened across all appropriate sectors and levels – including within communities – to protect children from abuse, exploitation, child labour and trafficking, and to ensure referral to agencies with the mandate and capacity to respond effectively.
- 4 Appropriate use of alternative care, with institutional care as a last resort:
- There is no need to have special institutions for children affected by HIV/ AIDS.
- Institutional care should be used only as a last resort for all children, including those affected by HIV/AIDS, and then only when all alternative forms of familyand community-based care have failed.
- When children are placed in institutions, the quality and duration of their care must be regulated and monitored to ensure their rights are fully protected.
- Guidelines, standards and regulatory mechanisms must be established and enforced for institutional care, together with procedures for family reunification and social reintegration.
- 5 Strengthen evidence base:
- Governments should ensure accurate. . timely and appropriate information is available to planners, programmers, service providers, parents and children. and the public at large on the HIV/AIDS epidemic - in particular gender and age disaggregated estimates of numbers and trends of children who are HIV-positive, orphaned by AIDS or living with an HIVpositive parent: their geographic location and demographic profile; the availability of diagnosis, counselling and treatment facilities: and the prospects for survival and good health of infected parents and children.

- Periodic assessments must be undertaken of the situation of children and families affected by HIV/AIDS in order to inform programme design and improve responses.
- Monitoring and evaluation systems need to be strengthened to measure the effectiveness of interventions and make mid-course corrections.
- 6 Strengthen coordination and involve all relevant stakeholders:
- Strengthen those ministries at national and sub-national levels that lead and coordinate the delivery of key social services to children and families, including those affected by HIV/AIDS.
- Ensure that children affected by HIV/ AIDS and the social impact of HIV/AIDS on children and families are appropriately included in national plans, including

National Development Plans, National Strategic Plans on HIV/AIDS, Social Welfare and Child Development Plans, and others.

- Ensure the involvement of relevant ministries and stakeholders in the public and private sector at all levels – including people living with HIV/AIDS, children and religious leaders – to develop programme goals, strategies, and reach consensus on roles and responsibilities;
- Governments should take the lead to ensure that all stakeholders are provided with the necessary resources – including information, skills, financial resources and encouragement – to fulfil their responsibilities effectively.
- Systems to ensure stakeholder accountability at all levels must be developed and monitored.

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