

# National Guidelines for the Care and Support of Children Affected HIV and AIDS in Pakistan

2010



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National AIDS Control Programme  
Ministry of Health  
Government of Pakistan





# National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan

To assure and improve the quality of services for the well being, protection and development of children affected by HIV and AIDS in Pakistan

Published by:  
National AIDS Control Programme  
Federal Ministry of Health  
Islamabad  
PAKISTAN  
Telephone: +92 (0) 51 9255367/8  
Website: [www.nacp.gov.pk](http://www.nacp.gov.pk)

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The production of the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan was made possible through technical assistance and support UNICEF and Family Health International and in close collaboration with the National Commission for Child Welfare & Development, Ministry of Social Welfare and Special Education.

Printed in Islamabad, Pakistan



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## **FOREWORD – National AIDS Control Programme**

Around the world, millions of children have lost one or both parents to AIDS, and millions more live with sick and dying family members. Asia has been experiencing concentrated and smaller scale HIV epidemics, however, with 1.2 billion children in Asia i.e. almost four times the child population of sub-Saharan Africa (350 million), even a small increase in prevalence could result in greater absolute numbers of children orphaned by AIDS. In communities around the world, people are rising to the challenge to care for the children affected by HIV and AIDS. Children who have lost their parents to the pandemic need sustained assistance to recover their physical and emotional wellbeing and to realize their full potential. Children cannot wait; they cannot postpone their future.

With the Convention on the Rights of the Child, the international community has reiterated States' accountability for the safeguarding of children's rights, including by providing assistance and support to families and communities, and by ensuring priority attention to the most vulnerable groups. The National AIDS Control Programme recognises the need for safeguarding the rights of the children affected by HIV/AIDS and support initiatives with the National Commission on Child Welfare & Development and UNICEF Pakistan. These guidelines will lead to enhanced programming to ensure that children affected by HIV/AIDS in Pakistan are able to reach their full potential, protect themselves and contribute positively to the development of self, community and society.



**Dr. Hasan Abbas Zaheer**  
National Programme Manager  
National AIDS Control Programme

## **FOREWORD – National Commission for Child Welfare and Development**

The HIV epidemic is emerging as a major threat to social development in many countries including Pakistan which requires urgent attention for undertaking concrete actions while taking into account our realities and specificities. The need for generic guidelines on care and support for children, affected by HIV and AIDS in Pakistan has long been recognized. In this context, the guidelines provided by the Regional Strategic Framework for Protection, Care and Support of Children, Affected by HIV and AIDS have been localized. The National Commission for Child Welfare and Development (NCCWD), National AIDS Control Program, UNICEF and FHI have jointly accomplished this task.

The guidelines are well designed to suit the specific care, support and needs of children, affected by HIV and AIDS which provide line of action for targeted interventions required for care and protection of affected children. The guidelines set forth a framework and identify opportunities for progress that will serve as the foundation for the stakeholders' response to the epidemic in the years ahead. These guidelines also provide understanding and guiding principles for role and responsibilities of various stakeholders. These guidelines are an expression of our commitment and determination to face HIV and AIDS, not only as medical and health problem, but also to address them as cultural, social and economic issues which affect all sectors of our society. It is opportune time to consolidate our efforts and let us ensure that the Guidelines will be followed and translated into concrete, focused and sustained actions.

Ministry of Social Welfare and Special Education has a vital role in translating national commitments for welfare, development, protection and rehabilitation of vulnerable children in collaboration with provincial governments and non-governmental organizations. Treatment of children affected by HIV and AIDS should not be seen in isolation, as it is part of comprehensive care and rehabilitation services. The relevant stakeholders are required to continue their support to the communities and individuals especially children, affected by this disease. The lessons learnt from this exercise will help promote deeper understanding in the society, besides reflection in all plans and programs dealing with HIV and AIDS.

The NCCWD duly acknowledges the endeavours of partners for contributing generously in developing these guidelines.



Muhammad Hassan Mangi  
Director  
National Commission for Child Welfare &  
Development  
Ministry of Social Welfare and Special  
Education



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## ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
AJK	Azad Jammu and Kashmir
ARI	Acute Respiratory Tract Infection
ART	Anti Retroviral Therapy
CBO	Community-Based Organisation
CHABA	Children affected by HIV and AIDS
CRA	Child's Right Act
CRC	Convention on the Rights of the Child
CSI	Child Status Index
CSO	Civil Society Organisation
DCCWD	District Commission for Child Welfare and Development
ECD	Early Childhood Development
FBO	Faith-Based Organisation
FHI	Family Health International
FIDA	International Federation of Women Lawyers
FMOH	Federal Ministry of Health
GFATM	Global Funds to fight AIDS, Tuberculosis and Malaria
HBC	Home-based Care
HCP	Health Care Providers
HES	Household Economic Strengthening
HIV	Human Immunodeficiency Virus
IA	Implementing Agency
IATT	Inter-Agency Task Team
IDUs	Injecting Drug Users
LGA	Local Government Area
MARPs	Most-at-Risk Populations
M&E	Monitoring & Evaluation
NACP	National AIDS Control Programme
NCCWD	National Commission for Child Welfare and Development
NGO	Non Governmental Organisation
NWFP	North West Frontier Province
OVC	Orphans and Vulnerable Children
PACP	Provincial AIDS Control Programme
PCCWD	Provincial Commission for Child Welfare and Development
PC-1	Project Cycle- 1
PLHIV	People Living with HIV
PPTCT	Prevention of Parent-To-Child Transmission
SAARC	South Asian Association for Regional Cooperation
SOP	Standard Operating Procedure/Standard of Practice
TB	Tuberculosis
UN	United Nations
UNICEF	United Nations Children's Fund
USAID	United States Fund for International Development
VCCT	Voluntary Confidential Counselling and Testing



## SECTION 1: INTRODUCTION

The AIDS pandemic has affected millions of children and is placing increasing numbers at risk. AIDS weakens traditional protective mechanisms such as parental care and support, intensifies vulnerability and income poverty, and provokes stigma and discrimination increasing children's risk of exposure to abuse, exploitation and neglect, which in turn increases their vulnerability to HIV.

These Guidelines are meant to be considered in the wider protective environment for children in Pakistan, as elaborated under the Child Protection Policy by the National Commission for Child Welfare and Development, Ministry of Social Welfare and Special Education, Government of Pakistan, Islamabad, March 2009 and in accordance with the Federal Government of Pakistan policies, international instruments and internationally accepted best practices.

### 1.1 Pakistan Country Profile

Pakistan became a sovereign state in 1947 and is made up four provinces divided into Districts, Tehsils and Union Councils and territories [the Islamabad Capital Territory (ICT), the Federally Administered Tribal Areas (FATA)], Azad Jammu and Kashmir (AJK), and Gilgit-Baltistan; spreading over an area of 852,392 sq km. Pakistan is the sixth most populous country in the world with the Population Census Organization putting the population at over 167,000,000 at the end of November 2009<sup>1</sup>. According to the Pakistan Policy for population, the Population Growth Rate (PGR) has declined from over 3 percent in previous decades to its current level of 2.1 percent per annum; which still is high.

Agriculture is the most important sector in the economy and over two-thirds of the total population resides in the rural areas. One fourth of GDP originates from agriculture in Pakistan. The GNI per capita (US\$), 2007 is 870 and the GDP per capita is 8.4%. With an overall literacy rate of 53%, Health expenditure (public sector) is 0.08 % while total health sector investment is 3.9 % of GDP<sup>2</sup>. The religion of the country is predominantly Muslim. Urdu is the National language while multiple regional languages are spoken in the country; however, English is used for most official purposes.

### 1.2 Overview of HIV and AIDS in Pakistan

Following a gradual increase in the number of cases reported in Pakistan from the late 1980s onwards, surveillance data since 2003 provides evidence that the prevalence of HIV is rising rapidly though largely 'concentrated' among most-at-risk populations (MARPs). Currently, it is estimated that a total of 96, 400<sup>3</sup> adults are living with HIV in Pakistan with a prevalence of less than 0.1% in the general population. The number of persons who have died of AIDS-related complications between 1986 and 2007 is estimated at 5, 000<sup>4</sup>.

By 2008, HIV prevalence averaged nearly 21% among injecting drug users (IDU), with variation reported between large urban centres of the two most populated provinces of the country: Sindh and Punjab. Over recent years, rates have also risen among drug injectors in the North West Frontier Province (NWFP) and Baluchistan. Subsequently, an increased risk of infection through

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<sup>1</sup> <http://www.statpak.gov.pk/depts/pco/index.html>.

<sup>2</sup> <http://www.commerce.gov.pk/countryprofile>

<sup>3</sup> Draft estimates by NACP using WHO/UNAIDS Epidemiological Model in 2009

<sup>4</sup> HIV and AIDS Second Generation Integrated Biological and Behavioural Sentinel Surveillance, Round II, 2008.

sexual transmission also exists across the country for spouses and other partners of IDUs and from spouses to their children<sup>5</sup>.

Unprotected sexual contacts also account for a higher rate of HIV infection among populations with multiple partners such as male and transgender sex workers, with an overall prevalence of 6.4% in the latter group but with substantial diversity across urban centres in 2008<sup>6</sup>.

Other populations at increased risk and vulnerability to HIV include prisoners, street children, migrant workers, truck drivers and specific occupational groups. Since the initial cases were reported in the country in the late 1980s, a considerable number included returning migrant workers mostly from the Gulf States. A substantial number of people living with HIV on Antiretroviral Therapy (ARV) are still among those reporting a history of having worked for periods of time abroad or their partners and children. A possible increase in prevalence among such populations does not exclude the potential for wider spread in the general population.

### 1.3 International Commitments for Children in the Context of HIV

#### UN General Assembly Special Session on HIV 2001

Realizing children's right to protection requires systemic action by governments and protective attitudes and practices by all those who have an impact on children. The Declaration of Commitment from the 2001 United Nations General Assembly Special Session on HIV/AIDS explicitly recognizes the role of governments in protecting children affected by AIDS. In it, states pledged to "protect orphans and vulnerable children from all forms of abuse, violence, exploitation, discrimination, trafficking and loss of inheritance"<sup>7</sup>.

#### Convention on the Rights of the Child

The Convention on the Rights of the Child is the principal framework articulating the rights of all children globally. It also provides guidance for actions concerning orphans and other vulnerable children, including children affected by HIV and AIDS. The issue of children and HIV and AIDS is perceived as mainly a medical or health problem, although in reality it involves a much wider range of issues. In this regard the right to health (article 24 of the Convention) is central, however, HIV and AIDS affects all children's rights – civil, political, economic, social and cultural. The rights in the general principles of the Convention – the right to non discrimination (art. 2), the rights of the child to have her/his interest to be a primary consideration (art 3), the right to life, survival and development (art. 6) and the rights to have her/his views respected (article 12) - should therefore be the guiding themes in the consideration of HIV and AIDS at all levels of prevention, treatment, care and support<sup>8</sup>.

In 2003 at the 32<sup>nd</sup> session of the Committee on the Rights of the Child a General Comments paper related to HIV and AIDS was produced<sup>9</sup>.

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<sup>5</sup> HIV and AIDS Second Generation Integrated Biological and Behavioural Sentinel Surveillance, Round II, 2008.

<sup>6</sup> Ibid, 2008.

<sup>7</sup> Child Protection and Children Affected by AIDS: A Companion Paper to the Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV and AIDS, UNICEF, August 2006.

<sup>8</sup> Committee on the Rights of the child 32nd session, 13-31 January 2003, General Comment No. 3 (2003): HIV/AIDS and the rights of the child (CRC/GC/2003/1).

<sup>9</sup> Ibid, General Comments, 2003.

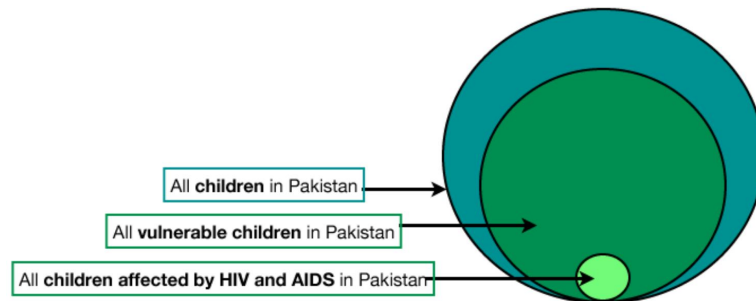
The objectives of the General Comment are:

- a. To strengthen the identification and understanding of all the human rights of children in the context of HIV and AIDS
- b. To promote the realization of human rights of children in the context of HIV/AIDS as guaranteed under the Convention on the Rights of the Child.
- c. To identify measures and good practices to increase the level of implementation by the States of rights related to the prevention of HIV/AIDS and the support, care and protection of children infected with or affected by this pandemic.
- d. To contribute to the formulation and promotion of child oriented Plans of Action, strategies, laws, policies and programs to combat the spread and mitigate the impact of HIV/AIDS at the national and international level.

#### 1.4 Defining Children Affected by HIV and AIDS

In Pakistan children affected by HIV and AIDS (CHABA) are defined by three criteria: 1) Children living in or coming from a family where one or more parents or primary caregivers are HIV positive; 2) Children who have lost one or more parents or primary caregivers due to AIDS; 3) Children (<18 years) who are HIV positive.

Children affected by HIV and AIDS in Pakistan are a subset of orphans and vulnerable children covered in the National Child Protection Policy 2009 (draft) and National Plan of Action and these Guidelines should be seen as complimentary.



Children affected by HIV and AIDS who fall under the categories listed below should be the priority groups when programmes and interventions for the care, support and protection of orphans and vulnerable children are being designed and implemented. There may be overlaps across categories, since a single child can belong to several vulnerable groups due to the composite nature of vulnerability. Some of these children live on their own and are in need of re-integration into a family under the care of a loving adult. Others are already living within a household but the capacity of that family to cope with the child's unique vulnerability needs to be improved.

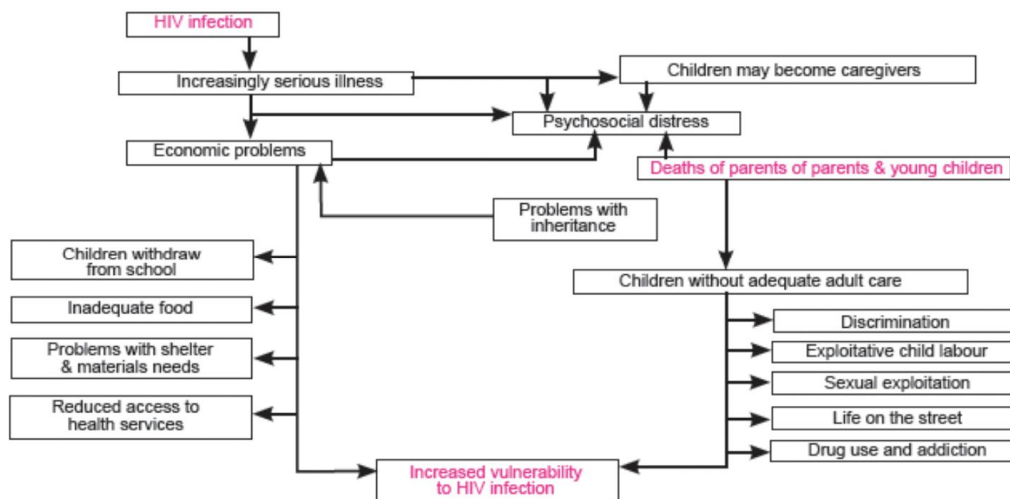
- Children in need of alternative family care (e.g. in child-headed households; homeless or unaccompanied; in institutional care; living with aged grandparents or caregivers; whose parents are dead and are relocated to other poor households; whose parents are alive, but are extremely poor; whose parents are sex workers, drug addicts or in jail; in prison with their mothers)
- Children who are abused or neglected (e.g. are working or exploited; subjected to harmful cultural and religious practices; are sexually abused and exploited; are physically abused or neglected; are child-parents, especially child-mothers)

- Disability related vulnerability (e.g. mental, physical, or other forms of disability or whose parent(s) or caregiver(s) has a disability in a poor setting)
- Children affected by armed conflict (e.g. whose safety, well-being or development is at direct risk by armed conflict; child militia; are abducted; are refugees or internally displaced; whose parent(s) die as a result of conflict)
- Children in need of legal protection (e.g. in conflict with the law; are institutionalized [e.g. in remand homes, rehabilitation centres, babies homes, and children's homes]; are denied their inheritance rights; are forcefully denied access to either of a living parent)

It is important to recognize that there are marked differences in manifestations of vulnerabilities between and within provinces, districts, and communities. Therefore, identifying and responding to children affected by HIV and AIDS should involve local decision-making at the community level (e.g. CBOs) to determine the factors that contribute to child vulnerability and the children and households who are at greatest risk. The criteria for identifying and responding to levels of vulnerability of HIV affected children and their households should be developed and agreed on in consultation with the community, including people living with HIV and AIDS. Intervening as early and effectively as possible without inadvertently undermining the coping capacities of the children and their families should reduce vulnerability.

### 1.5 Problems among Children and Families Affected by HIV

Many factors, such as poverty and conflict, in addition to HIV, contribute to make children and their households vulnerable. However, no single factor has increased the number of vulnerable children and families to unprecedented numbers globally as HIV. The complex and interrelated problems among children and families affected by HIV are illustrated below.



Adapted from J Williamson 2002 in UNAIDS, UNICEF, USAID (2004)

The magnitude of the growing crisis of children orphaned or made vulnerable by HIV and AIDS and other causes requires a multi-sectoral response, as no single organization or tier of government can handle the challenges alone.

### 1.6 National Response for Children affected by HIV and AIDS

There are no official figures for children affected by HIV and AIDS in Pakistan. However, a rough conservative calculation can be made by multiplying the national birth rate (3.5 children)

times half of the estimated 96,000 PLHIV (15-49) in Pakistan. The total would be from 150,000 – 200,000 HIV and AIDS affected children.

Thus far, the response for children affected by HIV and AIDS has been led largely by the National and Provincial AIDS Control Programmes, although much work has been done on the general protection of vulnerable children, including those affected by HIV, by the National Commission for Child Welfare and Development.

Some notable national level responses for children affected by HIV and AIDS include:

<b>Strategic Information</b>	
2007	Assessment of Protection Risks and Failures for Children Vulnerable to and Affected by HIV and AIDS in Pakistan
<b>Policy and Advocacy</b>	
2008	National Consultation on Protecting Children and Adolescents in the Context of HIV
2008	Positive Diaries <sup>2</sup> : Children and Young People Living with and Affected by HIV and AIDS in Pakistan
2006	National Plan of Action for Children
<b>Programming support</b>	
2009	National Care and Support Training of Trainers and Provincial Roll-out Trainings
2008	HIV Testing Criteria for Children affected by HIV and AIDS
2008	National Care and Support Reference Materials for NGOs and Families Living with HIV and AIDS
2008	Inclusion of HIV positive families (including children) in the Government Planning and Costed Documents (PC-1s)
2008	National Strategic Framework for HIV Treatment, Care and Support in Pakistan
2007	National HIV Counselling Guidelines for Children and Adolescents

Pakistan's response for children affected by HIV and AIDS is guided by the SAARC Regional Strategic Framework for Protection, Care and Support of Children Affected by HIV/AIDS (CABA). This Framework was developed by the South Asian Association for Regional Cooperation and UNICEF in 2008.

In view of the current plans to accelerate and scale up the response for children affected by HIV and AIDS through the PC-1s and other funding allocations for the care and support of families, efforts to assure and improve the quality of services provided for the well-being, protection and development of children affected by HIV and AIDS in Pakistan are timely. At the centre of the concept of quality are the needs of HIV affected child, the family and community. The main purpose therefore, is to create an environment where all stakeholders support quality provision of care, support and protection to children affected by HIV and AIDS in compliance with agreed guidelines.

#### 1.7 Goal of the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan

Children affected by HIV and AIDS in Pakistan are protected and their quality of life improved.

#### 1.8 Objectives of the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan



1. Provide guidance for the development and implementation of interventions for the care, support and protection of children affected by HIV and AIDS in Pakistan.
2. Provide minimum standards of practice related to all areas of care, support and protection of children affected by HIV and AIDS that are socially and culturally acceptable.
3. Provide a clear understanding of the guiding principles, and define roles and responsibilities for all stakeholders to enhance collaboration and strategic partnership among stakeholders through effective referral and coordination.

### 1.9 Concepts and Definitions

The following are the definitions of various terms and concepts used in the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan.

- Caregiver: The individual who takes primary responsibility for the physical, mental and emotional needs and well being of a child.
- Child: A person who is below the age of 18 years.
- Community: A group of people, usually living in an identifiable geographical area, who share a common culture, and are arranged in a social structure that allows them to exhibit some awareness of a common identity as a group. When “community” is mentioned in this guideline it can also refer to a community of PLHIV served by a CBO.
- District Commissions for Child Welfare and Development: Government department at District level responsible for ensuring the protection of vulnerable children ensuring timely and appropriate referrals, including for children affected by HIV.
- Duty Bearers: Individuals or institutions that is responsible for the progressive realization of specific rights. Duty bearers acquire duties through designation, position or election. They will include the family, community, national, state and local government.
- Extended family: A collection of a number of households or families of individuals who are related by blood and with social ties and responsibilities towards one another. Most communities especially in the rural area depend on extended families for nutrition, care and support.
- Family: A group consisting of one or more parents and their offspring and close relations that provides a setting for social and economic security, transmission of values, protection and affection for the family members.
- Field Worker: A generic term that refers to the programme staff or community volunteer, paid or unpaid, full-time or part time who has direct contact with children affected by HIV and AIDS and their households (programme beneficiaries).
- Gender: The social relationship between girls and women and boys and men as opposed to biological sex differences.
- Gender mainstreaming: A strategy to ensure that an analysis of the relationship between males and females is used to incorporate the needs of girls and women and boys and men, constraints and potentials into all development policies and strategies and into all stages of planning, implementation and evaluation of development interventions.
- Gender sensitivity: The ability to recognize issues related to the relationship between males and females, and especially the ability to recognize differences in perceptions and interests between males and females arising from their different social position and different gender roles.
- Guardian: Any person caring for a non-biological child.

- **Household:** A group of people who normally live and eat together in one spatial unit and share domestic functions and activities. Although a household is similar to a family, the two are not identical. A household may be a family living in the same house or compound. A household may consist of one or more parents, children, and often includes extended family and friends.
- **Human Rights:** Human rights are the rights people have simply because they are human beings, regardless of their nationality, ethnicity, gender, language, race or other status. They are the basic standards without which people cannot live in dignity. They are held by all persons equally, and forever. Human rights are universal, interdependent, inalienable and indivisible, and are based on equality, human dignity, non-discrimination and responsibility.
- **Marginalized:** A term used to refer to persons who are deprived of opportunities for living a respectable and reasonable life that is regarded as normal by the community to which they belong.
- **Minimum Package of Services and Rights:** Proposed priority interventions that have been selected through a national consultative process that should provide a supportive environment for children affected by HIV and AIDS to live to their full potential.
- **Orphan:** A child who has lost one parent [maternal/paternal orphan] or both parents [double-orphan].
- **Poverty:** The inability of an individual, family or community to attain a minimum standard of living, as defined in the millennium development goals. This is evidenced by the lack of basic needs and services such as food, clothing, bedding, shelter, basic health care, roads, markets, education, information and communication<sup>10</sup>.
- **Vulnerable Child:** A child who because of circumstances of birth or immediate environment, is prone to abuse or deprivation of basic needs, care and protection, and thus disadvantaged relative to his or her peers. Many children in Pakistan can be considered vulnerable (see *National Child Protection Policy, 2009*), including those affected by HIV and AIDS.
- **Vulnerability:** A state of being or likely to be in a risky situation, where a person may suffer significant physical, emotional or mental harm that could result in their human rights not being fulfilled. There are many factors that make a child vulnerable (See *Vulnerable Child*)<sup>11</sup>.

#### 1.10 Intended Use of the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan

The Guidelines are meant to facilitate a policy and programming response for children affected by HIV and AIDS.

The Guidelines can be used:

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<sup>10</sup> In preparation for the PRSP, the Government has deliberated on the analytic of poverty. The Planning Commission has adopted an official poverty line based on a caloric norm of 2350 calories per adult equivalent per day and minimum non-food requirements. This poverty line approximates Rs. 673.54 per month per equivalent adult in 1998-99, rising to RS. 748.56 in 2000-01.

<sup>11</sup> The monitoring and Evaluation Indicators for the SAARC Framework for HIV Affected Children call for National definitions of vulnerability in line with definition for all vulnerable children and note: "A limitation to this indicator is the difficulty in defining vulnerability. The concept of a vulnerable child is a social construct and varies from one cultural and socio-economic context to another. Also, the term takes on various definitions that can be contradictory, depending on whether the term was developed for the purpose of gathering and presenting quantitative data or for developing and implementing policies and programmes. It is important to make a clear distinction between definitions developed for these two purposes."

- At provincial and district levels to develop plans of action to apply the Child Status Index, define packages of support, and create referral linkages between services, including treatment care and support for children infected with HIV.
- At National and Provincial levels to engage ministries and line departments in the response for children affected by HIV and AIDS, including resource allocation and joint programming.
- At National and Provincial levels to engage Parliamentarians, National Assembly Members and other policy makers in the response for children affected by HIV and AIDS, including development of protective laws and policies for vulnerable children, including those affected by HIV and AIDS, as well as specific laws and policies for HIV infected children.

The Guideline is meant for all stakeholders related to children affected by HIV and AIDS, especially:

- Government line ministries and agencies
- Development partners and donor organizations
- Programme managers and staff of implementing agencies – NGOs, faith-based organisations (FBOs), CBOs, and private sector organizations
- People living with HIV (PLHIV)

#### 1.11 Development of the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan

The National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan were developed from existing global guidelines and best practices, contextualised for Pakistan, and refined through a steering group comprising of Government, donors, INGOs, NGOs and PLHIV CBOs.

## **SECTION 2: PRINCIPLES AND APPROACHES**

### 2.1 Guiding Principles

The guidelines and standards of practice outlined in this document are aligned with the guiding principles outlined in the National Child Protection Policy, 2009. The Government of Pakistan has the duty to ensure the following principles for action underpin these Guidelines are followed:

- Children affected by HIV and AIDS 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.
- Children affected by HIV and AIDS 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, including nutritional support for mothers and children who need it.
- Service providers do not discriminate against children affected by HIV and AIDS.
- Families affected by HIV and AIDS are encouraged and assisted 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 and AIDS, and ensure that institutions are not used as a substitute for family care.
- Provide comprehensive clinical care, including ART, for HIV positive children.

### 2.2 Eight Strategic Approaches for Children Affected by HIV and AIDS

The following eight strategic approaches are drawn from the SAARC Regional Strategic Framework for Protection, Care and Support of Children Affected by HIV/AIDS, and the International Framework for the Protection, Care and Support of Orphans and Vulnerable Children Living in a World with HIV/AIDS, 2004. These approaches are recommended for guiding Key Elements of Programmatic Action for HIV Affected Children:

1. A rights-based approach, which focuses on reaching all children and affected by HIV and AIDS. Programmes should mobilise efforts and direct services children in those communities which are most affected by HIV and AIDS.
2. An integrated and inclusive approach, which ensures access for children affected by HIV and AIDS to the same social services as other children, including health, education, birth registration, social welfare, protection and psychosocial support.
3. Family capacity strengthening to protect and care for children affected by HIV and AIDS by ensuring access to economic assistance, social security, psycho-social support, information on appropriate care practices, and to HIV and AIDS treatment and clinical care for infected adults and children.
4. Mobilise and support community-based responses to both identify the needs of HIV affected children and their families, and for their involvement in the development of the most appropriate interventions.

5. 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 and AIDS and their families.
6. Build public awareness and mobilize society at all levels, including community, business and faith-based leaders, to create a supportive and non-discriminatory environment for children and families affected by HIV and AIDS.
7. Link efforts to mitigate the impact of HIV and AIDS on children through 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 and AIDS. To further reduce gender-related 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.

## SECTION 3: PROGRAMME DESIGN

### 3.1 Identification of Children Affected by HIV and AIDS

The first step in programming for HIV affected children and integrating them into general development and social services is to identify them. Children who require care and support will often be identified through household surveys in communities, and/or via self or community-based referral, referral from VCCT services, treatment care and support centres, PPTCT sites, support groups of PLHIV, schools, FBOs, orphanages/children's homes, NGOs working with street children, or prisons (for children born to convicted mothers). All such children need to be assessed based on an agreed-upon definition of vulnerability<sup>12</sup>. The Child Status Index is a globally accepted scoring tool for assessing the well-being of orphans and vulnerable children.

The CSI provides an easy-to-use tool to assess the current needs of a child, monitor improvements in specific dimensions of child well-being, and identify areas of concern that can served by program interventions. The index gathers information in the following 6 areas:

1. *Food/nutrition*: Does the child have sufficient and nutritious food at all times to grow well and to have an active and healthy life?
2. *Shelter and care*: Does the child have shelter that is adequate, dry and safe? Is there at least one adult who provides consistent love and support?
3. *Protection*: Is the child safe from abuse, neglect or exploitation? Is there adequate legal protection for the child?
4. *Health care*: Is the child healthy? Does he/she have access to preventive and treatment health services?
5. *Psychosocial*: Is the child happy and does he/she have hope for a good life? Does the child enjoy good relationships with other children and adults?
6. *Education*: Is the child performing well at home, school, job training or work and developing age appropriate knowledge and skills? Is the child receiving the education or training he/she needs to develop knowledge and skills?

The 6 areas of the Index and their sub-areas are graded on four levels of well being with the higher score indicating better well-being of the child. The scoring categories are defined as follows:

**4 = Good** The child's status or situation is good; there are no concerns and no apparent risk for this factor.

**3 = Fair** The child's status or situation is generally acceptable, but there are some concerns on the part of the caregiver or field worker.

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<sup>12</sup> The Monitoring Indicators for the SAARC Regional Strategic Framework for Protection, Care and Support of Children Affected by HIV/AIDS (CABA) define vulnerability, but programmes may further breakdown the definition to include household income, prioritised expenditures, etc.

**2 = Bad** There is concern that the child's status or situation on this factor is not good. Additional resources or services are needed.

**1 = Very bad** The child is at serious risk on this factor. Urgent attention to the child or the situation may be needed.

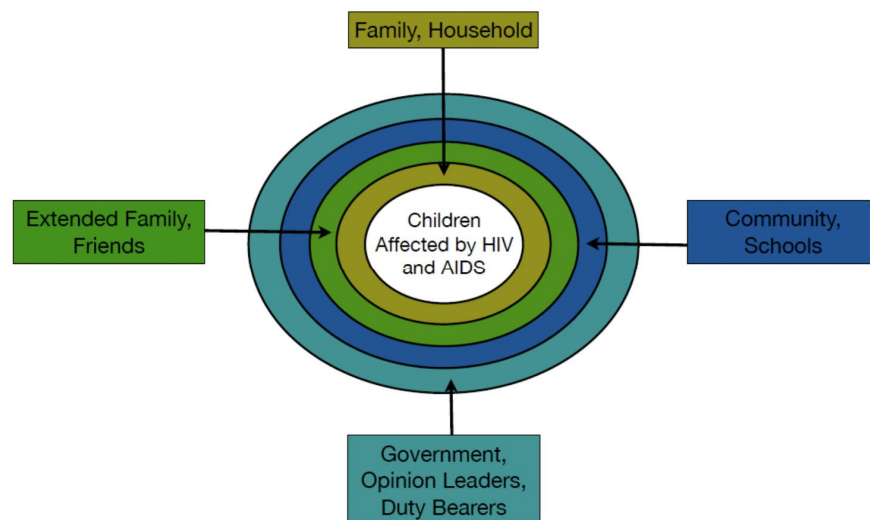
The level of response to an individual child's score, or the package provided, should be defined in collaboration with communities and should be implemented consistently to ensure children affected by HIV receive appropriate support corresponding to how they score on the index – not all children affected by HIV and AIDS have the same vulnerabilities.

One-on-one discussion with the child(ren), should occur wherever feasible and acceptable when implementing the Child Status Index. Children affected by HIV identified outside of NGOs or CBOs should be referred to and have the option to join an NGO or CBO.

Sample Questions to ask for the Child Status Index can be found in Annex C.

### 3.2 Levels of intervention

In order to provide sustainable and holistic care for children affected by HIV and AIDS, it is imperative that different segments of society are involved so that a wider range of services can be offered to these children. The needs of the children should be identified and assessed with meaningful participation of the children, their caregivers and the communities. The first level of intervention for an HIV affected child is the child himself or herself, and the family, including the extended family. Where the family cannot cope, they should be empowered and supported by the community. CBOs and NGOs can serve as intermediaries to strengthen responses and in the care and support of the affected children. Government at all levels should have the political commitment to use existing structures, resources and networking capabilities to promote appropriate interventions for children affected by HIV and AIDS.



### 3.3 Minimum Package of Services<sup>13</sup>

A minimum package of services are the services that must be provided to HIV affected children in need or scoring low on the Child Index. These services can either be included under one area e.g. Health, or can be designed to cut across areas e.g. health and shelter. All needs of children need to be assessed and best addressed given resources in the community. It is not expected that any one programme will be able to directly provide all these services. Therefore, programmes should ensure timely referrals and linkages with other organizations and service providers, to enable the children and their households receive the recommended minimum package of services, fulfilling their rights<sup>14</sup>.

Suggested domains of response under the Child Index categories include:

- 1) Food and nutrition: a) food security and b) nutrition and growth (such as food rations, supplemental foods)
- 2) Shelter and care: a) shelter and b) care (such as house repair, clothes, bedding and caregiver received training or support, child placed with family)
- 3) Protection: a) abuse and exploitation and b) legal (education on abuse provided to child or caregiver and birth registration, legal services, succession plans prepared)
- 4) Health: a) wellness and b) health and care services (such as vaccinations, medicine, ARV, fees waived, HIV and AIDS education)
- 5) Psychosocial: a) emotional health and b) social behaviour (clubs, group support, individual counselling)
- 6) Economic and skills training: a) performance and b) education and work (vocational training, micro-finance opportunities for family etc. and fees waived; provision of uniforms, school supplies, tutorials, other)

### 3.4 Social Protection<sup>15</sup>

Social protection for the most vulnerable and marginalized, is gaining momentum as a development priority. Social protection describes all 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 marginalised; with the objective of reducing the economic and social vulnerability of poor, vulnerable and marginalised groups. Families affected by HIV and AIDS should be addressed within this framework of support and not exceptionalised based on HIV status.

For children affected by HIV and AIDS, the risks of poverty and loss of livelihood are compounded by the risk of losing family care - their first line of protection. While cash transfers alone are not the solution, they can be an important element of an overall care package for children.<sup>3</sup> Social protection measures – including social transfers (cash, in-kind [food] or vouchers), family support services, and alternative care – can help mitigate the impact of HIV and AIDS by reducing poverty and family separation. Integrated social protection, in line with the SAARC Regional Strategic Framework for Protection, Care and Support of Children Affected by HIV/AIDS (CABA), can contribute to better health, education and protection outcomes.<sup>4</sup>

Cash transfers are gaining increased support as a means to mitigate the impact of HIV and

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<sup>13</sup> As mentioned under section 2.2 Eight Strategic Approaches for Children Affected by HIV and AIDS, a rights-based approach guarantees access to services for HIV affected children.

<sup>14</sup> Children affected by HIV with multiple vulnerabilities may need additional services.

<sup>15</sup> Inter-Agency Task Team (IATT) on Children and HIV and AIDS Working Group on Social Protection, October 2007.



AIDS on children, and potentially decrease their risk of HIV infection. Regular and predictable cash transfers can provide a consistent income and help reduce the burden of care for households with children.

Evidence gathered from existing and emerging cash transfer programmes shows that:

1. Regular, predictable cash transfers can have a long-term positive impact on children affected by HIV and AIDS, their families and carers, but do not need to specifically target children affected by HIV and AIDS to effectively reach them.
2. Cash transfers alone are not enough to fully transform the lives of children affected by HIV and AIDS, they must be part of a comprehensive system of social protection and accompanied by investment in accessible basic services such as healthcare, education, and water and sanitation.
3. Cash transfer programmes must be context specific and nationally supported.
4. Cash transfers are a vital element of ensuring children's right to social security as outlined in the Convention on the Rights of the Child.

The Government of Pakistan has developed a comprehensive Social Protection Strategy with the support of donors. The types of social protection available in Pakistan include:

- a. Social Assistance/Safety Nets: Cash transfers; food related programs; price and other subsidies; public works programs
- b. Social Security:
  - i. Social insurance: unemployment insurance; health insurance; funeral assistance and disaster insurance
  - ii. Labour market interventions: establishing minimum wage; abolition of child labour; elimination of forced labour; changes and implementation of labour legislation
- c. Human Development and Child Protection Measures: targeted fee waivers and exemptions, and life line tariffs; school feeding programs; child care and child nutrition; micro-nutrient supplementation programs; and, child support grants.
- d. Microfinance: micro-credit, savings, micro- insurance Income and consumption smoothening, protection against shocks

In addition to the traditional cash transfer systems of zakat and bait ul mal, Government of Pakistan has implemented new cash transfer initiatives including the Benazir Income Support Program (BISP), a cash transfer program intended to smoothen the impact of the food and fuel crises for the poor; and the Child Support Programme (CSP), implemented through the existing Food Support Programme (FSP). This Programme provides additional funds to Pakistan Bait-ul-Mal beneficiaries who are currently enrolled in FSP. Families affected by HIV and AIDS should be facilitated at district and provincial level to access these social protection benefits.

Social protection initiatives, especially cash transfers, hold the potential to make a considerable difference to the lives of children affected by HIV and AIDS. However, like any other intervention intending to benefit children, transfers need to be long-term, regular and predictable and linked with other services.

### 3.5 Standards in Programme Design

- Interventions should be in line with the National and Provincial AIDS Control Programme *National Strategic Framework II* and the National and Provincial Child Protection Programmes, as well as current best practices and programmes that are globally acceptable.
- Proposed interventions must directly benefit children made vulnerable as a result of HIV.

- Programmes should adopt a holistic approach in providing care, support, and protection for children affected by HIV and AIDS in communities.
- Service providers should be appropriately trained to respond to HIV affected children.
- Resources for the support of children affected by HIV and AIDS should, wherever possible, be channelled through existing systems, and structures, to the target beneficiaries.
- Communities, including children, should actively participate in the design, implementation, monitoring and evaluation of programmes and services.
- Organisations should provide care, support and protection within their proven expertise. Where such expertise does not already exist, they should (i) collaborate with and/or refer to other organizations with comparative advantage to provide such services; or (ii) develop a structured plan that will help build capacity in the identified area. The referral system for services should include monitoring and feedback for all referrals.
- P/DCCWDs, in collaboration with local NGOs/CBOs, should be strengthened to:
  - Identify children affected by HIV and AIDS
  - Link children affected by HIV and AIDS to essential services
  - Identify locally available resources
- To avoid stigma, programme interventions should include community sensitisation meetings and use community terminology in addressing children.
- Individuals and agencies working directly with children must adhere to accepted ethical standards in working with children<sup>16</sup>.
- Services should be child friendly.
- Institutional care should be the last resort.

### 3.6 Resource allocation

- Resources must preferably be allocated to households rather than individual children within the household, as direct allocation of support to a child can attract undue attention jealousy and stigma.
- The right balance must be found in each situation, as the child or children who are HIV affected may not be the only children vulnerable or in need in the household. Resources need to be shared.

### 3.7 Sustainability

To ensure sustainability, programmes should:

- Prioritise the identification of locally determined solutions and resources in an effort to increase sustainability, reduce dependency and empower communities. These solutions should improve, not replace or duplicate existing government strategies. For instance, barriers to accessing Basic Education should be identified, and locally determined solutions found. Individual scholarship should be the last resort.
- Ensure a plan to sustain in whole or part the support to children affected by HIV and AIDS and their households beyond the life span of the programme, including strategies to identify alternative sources of funding, for example public-private partnerships, etc.

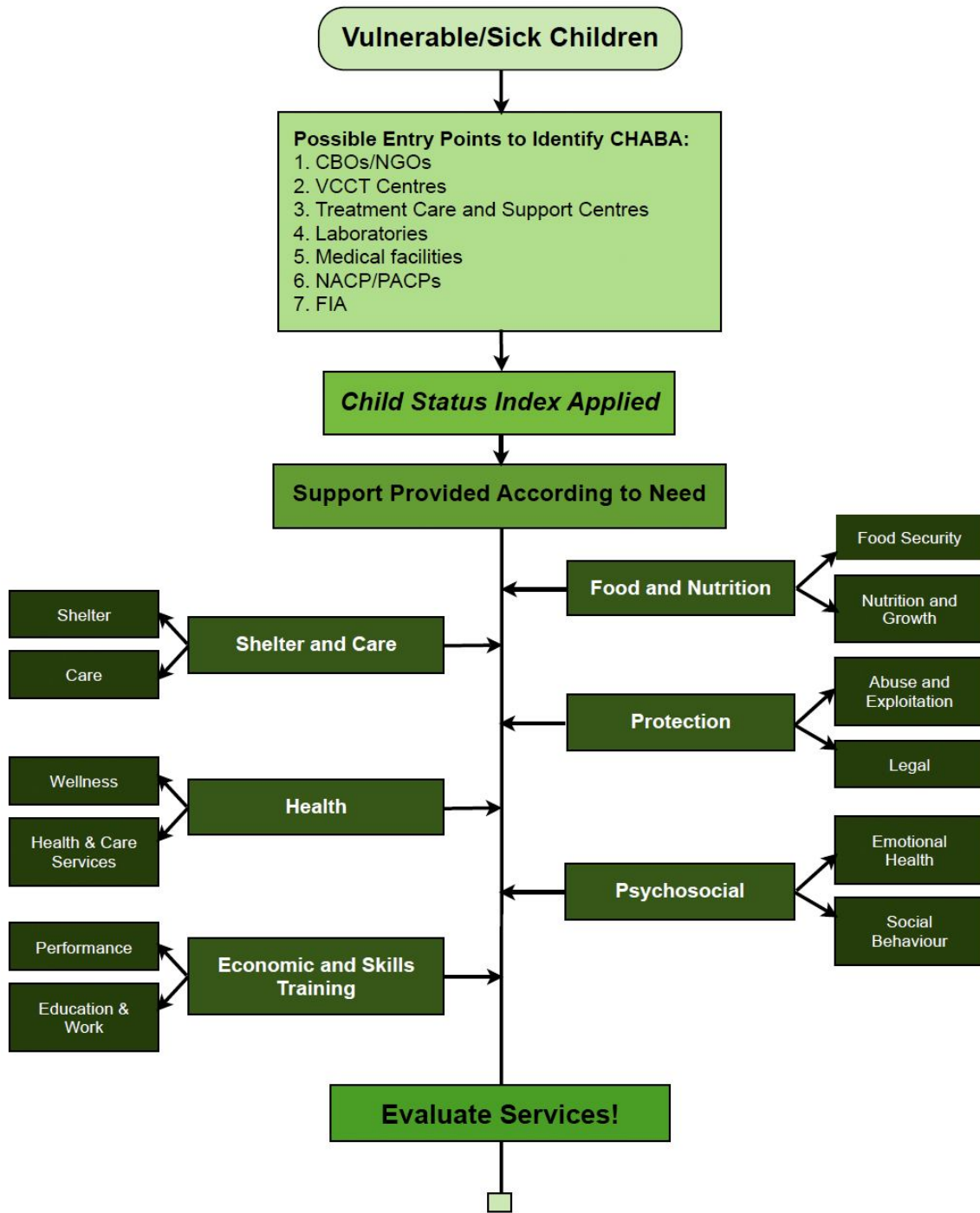
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<sup>16</sup> Resource include: *Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources*; Schenk, Katie and Jan Williamson, 2005, Population Council. ([www.popcouncil.org/pdfs/horizons/childrenethics.pdf](http://www.popcouncil.org/pdfs/horizons/childrenethics.pdf)). World Health Organization resources for HIV-Treatment and Care in children and infants: [http://www.who.int/hiv/topics/vct/toolkit/additional\\_resources/children/en/index1.html](http://www.who.int/hiv/topics/vct/toolkit/additional_resources/children/en/index1.html)

### 3.8 Monitoring

- Indicators for monitoring children affected by HIV and AIDS programmes are evolving a great deal. Programme staff will therefore, be required to adapt and adjust their work accordingly. Broad monitoring indicators for children affected by HIV and AIDS can be found in the *SAARC Guide to Monitoring & Evaluation of National Responses for Children Affected by HIV/AIDS* (see Annex G), a companion to the *SAARC Regional Strategic Framework for Children Affected by HIV and AIDS*, however programmes will have to develop output and outcome indicators (see Annex E - Monitoring of Programmes for Children Affected by HIV).
- Children, households and the wider community (or CBOs) should be involved in monitoring and assessing the impact of programmes.
- Protocols and an effective monitoring system must exist or be established to ensure that programmes protect the confidentiality of any information regarding the identification by name, place of residence, and or HIV or AIDS status of any HIV affected child or household being assisted.
- Guidelines and protocols must exist or be established by programmes that clearly outline staff ethical responsibilities towards children affected by HIV and AIDS.
- Careful advance planning is crucial for data collection from children. Investigators need to think through the consequences, both intentional and unintentional, of the information gathering activity on children and their households. If appropriate safeguards cannot be put in place, the activity should not proceed.

3.9 Diagram of Support Services for Children Affected by HIV and AIDS (CHABA)



## SECTION 4: KEY ELEMENTS OF PROGRAMME ACTION

The SAARC Regional Strategic Framework for Protection, Care and Support of Children Affected by HIV/AIDS proposes six areas of programmatic action for the Pakistan Government in relation to children affected by HIV and AIDS<sup>17</sup>:

1. Inclusion and integration of children affected by HIV and AIDS into general development and social services:
  - Children affected by HIV and 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 and AIDS then additional measures should be integrated into those services, rather than creating separate services. Service providers must have accurate information on the HIV and 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 and AIDS related 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 and AIDS.
  - Families affected by HIV and 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 and AIDS, must be overcome by amending and implementing legislation, making the process of inheritance easier, sensitizing 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 and AIDS.
  - Institutional care should be used only as a last resort for all children, including those affected

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<sup>17</sup> These Key Elements of Programme Action are drawn from the SAARC Regional Strategic Framework for Protection, Care and Support of Children Affected by HIV/AIDS.

by HIV and AIDS, and then only when all alternative forms of family and 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 and 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 HIV-positive 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 and AIDS in order to inform programme design and improve responses.
- Monitoring and evaluation systems, including a database, 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 affected by HIV and AIDS.
- Ensure that children affected by HIV and AIDS and the social impact of HIV and AIDS on children and families are appropriately included in national plans, including National Development Plans, National Strategic Plans on HIV and 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 and 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.

## **SECTION 5: SUGGESTED ROLES FOR KEY STAKEHOLDERS**

### 5.1 National/Provincial AIDS Control Programmes (N/PACPs):

The National/Provincial AIDS Control Programmes at National/Provincial levels respectively are responsible for providing the overall leadership in coordinating the planning, implementation and monitoring of programmes and interventions for children affected by HIV and AIDS in Pakistan, in close consultation with all relevant staff at national and provincial levels. NACP/PACPs will:

- Develop a co-ordination mechanism on Children and AIDS (including HIV affected children) that has a defined mandate and reporting processes with a Task Force that supports program implementers.
- Publicize, interpret, advocate and popularize the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan among the various duty bearers.
- Sensitize and train leaders and technical persons at state and local government levels in provision of services to ensure that children affected by HIV and AIDS benefit appropriately
- Build capacity of service providers and key actors in programme implementation, monitoring and evaluation of children affected by HIV and their families
- Monitor and assess the effectiveness and cost of interventions intended to benefit children affected by HIV and their families.
- Carry out research and disseminate findings on best practices and lessons learned for increasing programme planning and implementation effectiveness
- Mobilize collaborative action involving Government bodies, NGOs/CBOs and other development partners to ensure effective and efficient resource allocation and use in conformity with government policies and strategies.
- Demonstrate and encourage all duty bearers to institute a level of transparency regarding information, intervention methodologies (including a review of what works and what does not), resources, costs of interventions, numbers of beneficiaries of interventions, feasibility of implementing and sustaining interventions at scale.
- Ensure that children affected by HIV and AIDS, and their caregivers participate substantively in the planning, development, implementation, monitoring and assessment of interventions intended to benefit them.

The N/PACPs will undertake these activities in collaboration with the National/Provincial Commission on Child Welfare and Development (N/PCCWD), Ministry of Social Welfare and Special Education.

### 5.2 The National/Provincial/District Commission on Child Welfare and Development, Ministry of Social Welfare and Special Education (N/PCCWD):

The National and Provincial Commissions on Child Welfare and Development are responsible for providing the overall leadership in coordinating, planning, implementation and monitoring of child protection programmes, which may include interventions for children affected by HIV and AIDS. In close consultation with relevant staff at national, provincial and district levels, N/PCCWD will:

- Ensure relevant SAARC monitoring indicators for HIV affected children are integrated into overall child protection information management system.
- Publicize, interpret, advocate and popularize the National for the Care and Support of Children Affected by HIV and AIDS in Pakistan among the various duty bearers.
- Sensitize and train leaders and technical persons at state and local government levels in provision of services to ensure that children affected by HIV and AIDS benefit appropriately as part of orphans and other vulnerable children.
- Build capacity of service providers and key actors working for orphans and vulnerable children

- on additional programme implementation, monitoring and evaluation for HIV affected children.
- Mobilize collaborative action involving Government bodies, CSOs and other development partners to ensure effective and efficient resource allocation and use in conformity with government policies and strategies, especially inclusion of HIV affected families into social protection/inclusion programmes.

The N/PCCWD will undertake these activities in collaboration with the National and Provincial AIDS Control Programmes (N/PACP).

### 5.3 Other Government Ministries, Agencies and Departments:

Ministries or Government agencies that may have some responsibility – direct or peripheral - for child care, support and protection, education, health, psychosocial support, or socio-economic security should ensure HIV affected children are addressed in their respective sectors, in accordance with the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan. Their roles include to:

- Develop sectoral implementation guidelines
- Build capacities in the respective sectors
- Integrate children affected by HIV and AIDS concerns in sectoral policies, program

### 5.4 Local Government:

Local Government authorities have the responsibility to:

- Incorporate concerns relevant to the safety, well-being and the fulfilment of the rights of children affected by HIV and AIDS in District Government work plans and budgets.
- Ensure access to essential and social services for most needy HIV affected children as part of service provision to orphans and vulnerable children.
- Ensure data on children affected by HIV and AIDS and their circumstances are collected, collated and disseminated for improved targeting and service delivery.
- Actively promote information sharing and collaboration in relation to the implementation of children affected by HIV programmes in accordance with the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan among duty bearers in their areas.
- Monitor the action of all local duty bearers relevant to the fulfilment of the rights of children affected by HIV and AIDS.
- Ensure that children affected by HIV and AIDS, and their caregivers participate substantively in the planning, development, implementation, monitoring and assessment of interventions intended to benefit them.
- Participate in the identification of children affected by HIV and AIDS, in partnership with NGOs/CBOs and communities.

### 5.5 Development partners:

- Provide financial, material and technical support to facilitate the effective adoption of the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan.
- Build the capacity of service providers and program managers to deliver quality care to children.
- Collaborate with each other for more equitable national program planning for HIV affected children.
- Monitor and advise government and other partners on concerns relevant to the safety, well being and development of children affected by HIV and AIDS within their areas of operation.



#### 5.6 Parents and other caregivers:

- Protect, care and support children affected by HIV and AIDS by providing for their safety and basic needs.
- Provide the love; guidance and attention children need to develop in healthy ways and to become active members of their family and community.
- Plan for the welfare of the children, including succession planning, including will writing.
- Participate in the review and/or formulation of national and international policies that promote the rights of children affected by HIV and AIDS.
- Ensure births and deaths within the household are registered with the appropriate local authorities.

#### 5.7 Civil Society Organizations (including FBOs, CBOs, NGOs):

- Lobby and advocate on issues and concerns related to HIV affected children.
- Develop and implement interventions to benefit children affected by HIV and AIDS that are consistent with the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan.
- Promote awareness, understanding and use of these National Guidelines.
- Build the capacity of relevant service providers.
- Build partnerships with government and other agencies in support of HIV affected children.
- Promote and facilitate networking and collaboration among service providers.
- Give primary emphasis to mobilizing community action and building community capacity.
- Facilitate supervision, monitoring and evaluation of interventions to benefit children affected by HIV and AIDS by relevant government bodies.
- Advocate and support succession planning, including will writing.

#### 5.8 Community (local councils, traditional, cultural, religious and opinion leaders):

- Organize/strengthen social support networks to protect and promote the well-being and development of children affected by HIV and AIDS and their households.
- Identify appropriate strategies and interventions in keeping with the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan and, so far as possible, implement and monitor these using local capacities and resources.
- Link service providers with children affected by HIV and AIDS.
- Protect property rights of children affected by HIV and AIDS and widows.
- Facilitate succession planning, including will writing.
- Mobilize local resources and use any external resources available to improve the care and support of children affected by HIV and AIDS.
- Encourage a communal responsibility for the protection and care of orphans and vulnerable children in keeping with the traditional value that each child is everyone's child.
- Encourage families to register all births and deaths.
- Encourage community discussion to identify and change cultural and religious norms and practices that negatively affect children affected by HIV and AIDS, especially girls.
- Actively seek external resources to reinforce community efforts.

#### 5.9 Children:

- Participate in identifying the factors that cause the most vulnerability among children affected by HIV and AIDS.
- Participate in identifying and planning action to improve the safety, well being and development of children affected by HIV and AIDS in the community.
- Participate in implementing and monitoring the results of interventions intended to benefit

children, especially children affected by HIV and AIDS.

5.10 The Private sector:

- Participate in, and undertake initiatives for improved protection and care of children affected by HIV and AIDS.
- Contribute resources and opportunities for the care, support and protection of children affected by HIV and AIDS.
- Develop work policies that protect children affected by HIV and AIDS from exploitation and abuse, and ensure that workers living with HIV have access to treatment, including ART and PPTCT.
- Provide health, social insurance and other social security schemes for their workers and their families.
- Collaborate with government and NGOs/CBOs to support development and delivery of social services
- Publicize and advocate for the implementation programmes for HIV affected children in accordance with the National Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan.

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## **ANNEX B: Steps to Operationalise Guidelines**

Various stakeholders will ensure that children affected by HIV and AIDS, and their caregivers participate substantively in the planning, development, implementation, monitoring and assessment of interventions intended to benefit them.

1. Constitute National and Provincial Working Groups for HIV Affected Children to ensure institutional arrangements for the implementation of the Guidelines and a coordinated response down to local level.
2. Mobilize resources and monitor their allocation and use, including man, money material from all possible sources, eg. Public /private sector and local philanthropy.
3. Sensitise Government, Community and non-Governmental stakeholders on the *Guidelines for the Care and Support of Children Affected by HIV and AIDS in Pakistan* through advocacy events, e.g. seminars, media, religious leaders.
4. Develop Monitoring Framework for implementation of Guidelines at District, Provincial and National levels (to be developed/ implemented by N/PACP, N/PCCWD and UNICEF). Framework should be in line with UNGASS and other international commitments.
5. Train Government, Community and non-Governmental stakeholders at Provincial and/or District level on the Guidelines in provision of services that target children affected by HIV and AIDS. Orient and train implementing partners at Government, Community and Non Governmental sectors at provincial and district levels. eg. Health Care Providers (HCP) and Community field workers/ volunteers

## **ANNEX C: Sample Questions for Child Status Index**

### **1. Food and Nutrition**

a) Food security: According to existing research on children affected by HIV and AIDS, food security and nutrition is an area of significant vulnerability. Increased risk for poor health and malnutrition among CHABA is stressed.

- What does the family/child eat?
- How does this household/institution get the food?
- Tell me about times when there is no food.
- Does this child complain of hunger?

b) Nutrition and growth: Growth is an important marker of child well-being. Improving the nutritional status of infants and children is associated with improved mental and motor development as well as growth.

- How is the child growing?
- Does he/she seem to be growing like other children that age?
- Are you worried about this child's growth? Weight? Height?

### **2. Shelter and care**

a) Shelter: Adequate housing is associated with a child's social, emotional, physical, and overall well-being and development. Many vulnerable children, especially orphans and children affected by HIV and AIDS, face unique obstacles in this regard.

- Where does the child live?
- Where does he/she sleep?
- Is this house or institution adequate or in need of repairs? What kind of repairs?

b) Care: It is widely acknowledged that a most important aspect of childhood is the physical safety and psychological security provided by the adult or adults who are involved in the child's life.

- Who is the most important adult in this child's life?
- Who takes care of this child?
- How long has he/she been the most important adult in the child's life?
- Does this person plan to care for the child as long as needed?
- When something exciting or fun happens, who does the child tell?
- Who does the child go to when hungry?
- Who does he/she go to if sad?—or talk to about worries?
- Who does he/she go to if they are hurt?

### **3. Protection of Children**

a) Abuse and exploitation: Maltreatment of orphaned children and those affected by HIV is commonplace in high-prevalence HIV areas. Without the safety provided by a loving and committed caregiver, girls in particular are vulnerable to exploitation, such as coercive and commercial sex and unwanted and early marriage and pregnancy.

- Do you have any worries about this child's safety?

- Does anyone hurt this child?
- Do you think the child feels safe and secure?
- How does this child help in the household?
- Does the child work for anyone outside the household?
- Does anyone else who knows the child think he/she is being hurt by someone else? Or sexually abused?

b) Legal: Many children affected by HIV and AIDS lack parental protection and are vulnerable to losing their inheritance, being exploited sexually, and subjected to other forms of abuse. Program, national, and international stakeholders consistently identify legal protection as an important outcome area for children.

- Does this child have birth registration or certificate? Does the family have a will?
- Has he/she been refused any services because of legal status?
- Do you know of any legal problems for this child, such as land grabbing?
- Does this child have an adult who stands up for the child legally?
- Who has the legal responsibility for taking care of this child?
- Does the adult who cares for the child have legal authority to act for the child's best interests?

#### **4. Health**

a) Wellness: Mortality and morbidity have been correlated with poorer nutrition, malnutrition, and an increased prevalence of stunting and wasting among orphans and CHABA. Also, when children are ill, their ability to participate actively in age-appropriate activities is affected. Their well-being in a number of areas, including social relationships and school performance, is impaired.

- Tell me about this child's health.
- Tell me about the last sickness (or sicknesses) the child had.
- Does he/she get sick often?
- Does he/she miss school or work because of illness?

b) Health care services: There is evidence that children of parents with HIV and AIDS and children who have been orphaned by AIDS are less likely to access and use available medical care for prevention and treatment of illnesses, including but not limited to drug therapy for paediatric AIDS.

- What happens when this child falls ill?
- Does he/she see a nurse, doctor or any health professional?
- How does the child get to a doctor or a nurse when he/she needs one?
- When he/she needs medicine, how do you get it?
- Tell me about health services the child needs or needed but did not receive.
- Are the things that make it hard to get what the child needs to be healthy?
- Has the child had vaccinations to prevent illness?
- (For adolescents) Has anyone talked to the child about risks for HIV and how to protect against these risks?

#### **5. Psychosocial**

a) Emotional health: Children affected by HIV and AIDS are vulnerable to emotional health

difficulties that influence their feelings and how they behave. A child with psychosocial distress may show internalized symptoms such as depression, poor self-esteem, anxiety, and frank suicidal thoughts. The grief and loss that children experience related to HIV and AIDS can be acute or chronic and will likely affect multiple aspects of their lives.

- Is this child happy or sad most of the time?
- How can you tell if he/she is happy or unhappy?
- What makes the child sad or worried?
- Do you worry about this child's sadness or grief?
- Have you ever thought the child did not want to live anymore?
- Do you worry he/she might hurt himself/herself?
- Does he/she talk about the parent(s) who died? (If applicable.)
- How is this child doing living here? (When applicable.)

Or, ask the child:

- Tell me about your goals in life.
- Do you think you will have a good life?

b) Social behaviour: Playing well with other children and participating with adults and children in fun activities can indicate psychological adjustment that will extend to becoming a "good" adolescent and adult and this is a construct used frequently by guardians. It is also likely that this child imagines a good future that may include education, marriage, and being a good parent.

- How would you describe the child's behavior towards others?
- What is his/her behavior toward adults? Obedient?
- Does this child need to be punished often?
- Does the child play with other children or have close friends?
- If so, does he/she enjoy playing/being with other children?
- Does he/she fight with other children?
- What do you do if he/she is unruly?
- Do you worry the child will get in trouble at school?
- What do you worry about for this child in the future?

## **6. Economic and skills training**

a) Performance: It is well documented that children orphaned and affected by HIV and AIDS in low-resource countries are more vulnerable for developmental and learning problems, whether their performance is observed in the school or in activities at home.

- Is this child developing as you would expect (younger child)?
- Is this child learning new things, as you would expect of others his/her age (younger child)?
- Do you have any worries about the child's performance or learning?
- Is the child quick to understand and learn?
- Is the young person doing well with work?
- Do teachers report that the child is doing well in school?
- Does he/she do a good job with chores at home, such as work in the garden?
- Tell me about something the child does very well.
- Is the child advancing to the next grade as expected?
- Have you worried that this child does not learn as well as other children?

- Do you think this child is very quick to learn, even a better learner than others?

b) Education and work: In preparation to be a productive member of the community, the child should be enrolled in, attend, and participate in school, a training program, or a learning mentorship. Infants and toddlers should receive developmental stimulation through play and social interactions with household members. In the case of an older, out-of-school child, this domain assesses whether the youth works regularly at an age-appropriate, income-generating job/task, such as maintaining a garden.

- Is the child in (or has he/she completed) primary school?
- Where does he/she go to school?
- Tell me about the child's school or training.
- Who pays school fees and buys uniforms and school materials?
- (If enrolled) does this child attend school regularly?
- How often must the child stay out of school to help out at home?
- How often must the child miss school for any other reason?
- Does he/she go to work regularly?
- Ask the child about his or her play, school, or skills-training activities.



## **ANNEX D: Standards Related to Recommended Support Services**

Programmes providing essential services should, together with children, families, and communities, identify barriers to HIV affected boys' and girls' access to these services. Appropriate interventions to address barriers should be developed based on this disaggregated information.

### 1. Food and Nutrition

Many households caring for children affected by HIV and AIDS often lack access to nutritionally adequate food and have chronic food insecurity (food for survival). Competing needs (food, health and others) may also result in diversion of resources for other purposes. The focus of food security and nutrition interventions should be to:

- Assess nutritional status of the children in the program through a growth-monitoring schedule in line with the Ministry of Health standards.
- Food support through donor organizations should be locally produced foods. Food aid should not be given without a mechanism in place to wean the children, or family off the food aid, and should be complemented with longer-term efforts to increase household and community self-sufficiency.
- Provide nutrient-dense and adequate food to households caring for children affected by HIV and AIDS: at least once a day, in sufficient quantities and adequate quality, with at least three varieties.
- Provide nutritional support for infants born to mothers living with HIV not exclusively breastfeeding.<sup>18</sup>
- Nutrition education should be provided to parents and caregivers and should emphasize locally available and cheap nutrient-dense food.
- Support households with HIV affected children to undertake nutrition gardening, for instance legumes, and poultry, and Improve productivity, quality and storage of food.

### 2. Shelter and Care

Social support is defined to include provision of material support – clothing and shelter in particular - to meet basic physical needs of children affected by HIV and AIDS, their caregivers and communities within a long-term sustainable framework. The provision of social support must not cause stigmatization or promote discrimination of children affected by HIV and AIDS within their communities. The services include provision for basic needs, such as clothing, recreation, and shelter<sup>1</sup>.

Most children affected by HIV and AIDS in Pakistan live in the communities with their extended families. It is recognized that the most appropriate place for their care is within their own families and communities. However, there is increasing strain on these safety nets due to deepening poverty, HIV and urbanisation. This has led to increasing number of children on the streets, and being exposed to hazardous and exploitative situations. In such situations, programmes are left to provide access to alternative form of care, which includes placing children in another family or in residential care. It should be noted that residential care should be seen as the last resort as this living environment impacts negatively on the child's wellbeing. The focus of shelter interventions should be to:

- Strengthen coping capacities of families and communities by providing extra resources and skills to enable them foster or adopt children affected by HIV and AIDS.
- Encourage communal responses from families and communities such as providing land,

building materials and labour for shelter.

- Ensure appropriate standards and rules are put in place for residential care services.
- Institutional care, such as orphanages and rehabilitation homes, should be the last resort, and only as a temporary measure.

### 3. Protection of Children

Child protection entails all initiatives carried out by children, families, communities, CBOs, development partners, government and the private sector that prevent violation of the rights of children in relation to abuse, exploitation and neglect. Children affected by HIV and AIDS need dedicated interventions to protect them from harm, to assist them when affected, and to promote their overall development. The focus of child protection interventions should be to:

- Strengthen the protective systems, networks and other mechanisms that can prevent, address and remedy the harm children face as a result of abuse, neglect and exploitation.
- Strengthen the capacities of children, families and communities to protect and care for children affected by HIV and AIDS - priority should be given to ensuring children remain within the immediate family setting as an increased protection mechanism.
- Address the vulnerability of girls and boys to rape, sexual abuse, exploitation and HIV.
- Build children's resilience and support their participation in their own protection, including child-to-child support and establish/strengthen family and community child protection structures that involve children as a means of implementing child protection services at grassroots level.
- Build the capacity of government to deliver effective care and protection - mainstream sectoral programs and existing services i.e. health, education and social services so that they reach and serve vulnerable children.
- Revitalize/strengthen the registration of all births and deaths in the communities and establish/strengthen family and community mechanisms to prevent loss of inheritance of widows and orphans.
- Increase knowledge, understanding and implementation of child protection laws and statutes by all stakeholders.

*A note on children affected by HIV living with disability: the Convention on the Rights of the Child upholds the rights of children with disability to special protection. In relation to HIV, disabled persons experience a double burden of increased risk of infection due to sexual exploitation, abuse and rape, and reduced access to prevention and care services. Networking between disability and HIV and AIDS organizations should be supported: HIV programme staff should be given with disability awareness training and programmes should develop more age-appropriate and disability-friendly materials about HIV for young people with disability e.g. posters with sign language, produce HIV information on audiocassettes, and HIV education films with sign language and Braille, including for HIV campaigns.*

### Legal Support

Many children and young people in developing countries who have been made vulnerable by HIV face problems when their parents die. They may have their property taken away by relatives. They also face stigma, and violation of their fundamental human rights. Due to limited knowledge or ignorance of the provisions of the law, such as fundamental human rights and inheritance laws, people rarely seek redress when violations occur. Therefore, legal protection must be provided to ensure the protection of rights of orphans and other vulnerable children. The focus of legal support should be to:

- Review and address gaps in the existing laws, especially those that protect the rights of HIV affected children are implemented.

- Ensure access of HIV affected children and their households to legal representation, and other community support organisations - whenever possible, programmes should establish formal linkages with legal support organizations.
- Provide legal education and increase awareness of rights to children affected by HIV, their families, and community members.
- Provide appropriate rehabilitation services to children affected by HIV and AIDS who are in conflict with the law.
- Disinheritance of HIV affected children and widows resulting from HIV and AIDS, must be overcome by amending and implementing legislation, making the process of inheritance easier, sensitizing community leaders to existing laws and promoting public education.
- Interventions related to legal protection may include will writing, inheritance, birth registration, guardianship, and adoption.
- Programmes must establish systems that ensure confidentiality of all information relating the children and their households.

#### 4. Health Care:

Children infected with HIV (or at high risk either peri-natally or otherwise) need access to healthcare as other children, along with specialised services for HIV detection, treatment care and support provided by the Pakistan Government and NGOs.

The focus of health specific care interventions should be to:

- Enable families' and caregivers' access to preventive and promotive health care as other children, and specifically HIV prevention, including voluntary HIV counselling and testing (VCT), and prevention of parent-to-child HIV transmission (PPTCT).
- Ensure access to appropriate child-focused home-based care (HBC) for children living with HIV.
- Increase awareness about conditions related to AIDS such as failure to thrive, chronic skin diseases, chronic cough chronic diarrhoea and make referrals to available services e.g. antiretroviral therapy (ART), HBC, PPTCT, VCT and tuberculosis (TB) services.
- Programmes should provide caregivers and children with treatment education i.e. home-based care for persons living with HIV and AIDS; adherence training, and so on.
- Promote the reduction of stigma and discrimination against HIV-infected children and adults.
- Ensure access to cotrimoxazole prophylaxis to all children known to be living with HIV, and to those born to HIV mothers until their status is known.
- Link HIV positive mothers and children to facilities where they can access ART treatment.
- Build the capacity of health care providers on communicating with children, especially on child-focused treatment education.
- Provide access for adolescents living with HIV to appropriate reproductive health information and services to encourage positive living.

#### 5. Psychosocial Support

Psychosocial support involves all action that enables children affected by HIV and AIDS to live meaningful and positive lives. It is an ongoing process of meeting the physical, social, emotional, mental and spiritual needs of children, all of which are essential elements for meaningful and positive human development. The primary actors in children's psychosocial support are the children themselves, their families and communities, including their schools. Since psychosocial effects are both psychological and social, interventions must address the relationship between the individual and his/her social environment. Fulfilment of these inherent human needs (or the failure to fulfil them) has long-term impacts on the development of the child. Psychosocial issues are crosscutting and are a critical component of all aspects of

prevention, care and support and should therefore be addressed in all sectors. The focus of psychosocial support interventions should be to:

- Provide emotional support for children fearing or grieving the loss of a parent and/ or ensure referral for children who may need specialized care that is beyond their capacity.
- Build and strengthen the capacity of programmes, communities, support groups of persons living with HIV, children, and care givers to provide quality counselling and other psychosocial support to children affected by HIV and AIDS and their caregivers. Support and care services targeted at the children should be child-focused and family- and community-centred. Interventions should be socially and culturally appropriate to the needs of the children.
- Address emotional issues faced by orphans and vulnerable children and their parents/guardians such as: a) status disclosure between parent/caregiver and child; b) grief counselling; c) living with HIV; d) living with an HIV positive family member; e) treatment education; f) adherence counselling; f) stress management.
- Mitigate the impact of, and reduce stigma and discrimination against orphans and vulnerable children and their households.
- Promote succession planning (e.g. will writing, appointing guardians) with and for children with an HIV positive or terminally ill parent.
- Develop community-based recreational activities
- Build resilience of children affected by HIV and AIDS through the development of life skills to reduce vulnerability
- Research and document lessons learnt from psychosocial interventions
- Child-to-child support activities should also be supported by programmes

*A note on recreation: Recreation is an important part of psychosocial development and well-being. Under the UN Convention on the Rights of the Child, children have the right to play, activities and to participate in cultural and artistic life. Play is crucial for many aspects of children's development, from the acquisition of social skills, experimentation and the confrontation and resolution of emotional crises, to moral understanding, and cognitive skills such as language and comprehension. This vital component of their total development is being compromised by the HIV and AIDS crisis in two ways: 1) Leisure-time reduced: the burden of care and responsibility born by children and young people will increase and reduce the time and energy they have for recreation; and 2) Strained resources: as the economic burden of HIV and AIDS increases so the resources for non-essential items such as related to recreation arts or culture will be reduced, at all levels from the family budget to national finances.*

#### 6. Economic and Skills Training:

Education, including skills training, is an important requirement for the complete development of a child. Schools can provide children with opportunities for emotional support, interaction with other children and the development of social networks. Education can also reduce vulnerability to poverty and HIV through increasing knowledge, awareness, skills and opportunities. Many children affected by HIV and AIDS are not accessing or effectively participating in education due to poverty, caring for sick parents, lack of educational materials, cultural and traditional practices and lack of/low political commitment. This is especially true for the girl child whose right to education is affected by issues such as early marriage, boy child preference, sexual harassment and heavy burden of domestic chores.

The focus of education interventions should be to:

- Ensure access to education and retention of all children affected by HIV and AIDS in school.  
The education activities must be arranged to cater for the following age ranges/categories:
  - 0-5 Early childhood and learning stimulation

- 6-17 in school for either primary or secondary education support
- 15-17 out of school for vocational skills training support
- Life skills education for all children especially age 10 and upwards
- Where formal education is not possible, access to functional literacy should be provided.
- For vocational skills training, the time allocated for the course must be sufficient to allow for skill acquisition. There must be an arrangement for the children to receive start-up support for skill utilization once the training is over. Before providing vocational skill training, the market for such services in the community should be considered, to ensure that available clientele in the communities is sufficient to support the service providers. Programmes could also link children affected by HIV and their families to markets for their services or products.
- Where possible, link children of university age to sources of financial/educational support.
- Protect and care for children affected by HIV and AIDS in school and ensure their integration with other students.
- Improve the literacy of older children affected by HIV and AIDS through links with organizations providing non-formal education.
- Increase inter-sectoral collaboration and co-ordination, particularly among the Ministries of Education, N/PACP, N/PCCWD, and other relevant agencies.
- Programmes should work with necessary education authorities to facilitate the return of adolescent wives and mothers back to school.

## **ANNEX E: Monitoring of Programmes for Children Affected by HIV**

The provision of support to children affected by HIV and AIDS requires a number of systems, guidelines, and materials to be in place. If some of these elements are lacking or do not function properly, then the support will not be provided to the desired standard. Programmes for children affected by HIV and AIDS require regular monitoring and support from Government and implementing organisations to ensure that these elements are in place and work well; that the services are of high quality; and that they meet the needs of the children and their households; while at the same time contribute to the attainment of goals and targets of implementing organisations.

The main objectives of monitoring visits include to:

- Monitor activities and check the quality of services
- Obtain feedback from staff on project activities
- Resolve observed challenges and problems
- Follow up on recommendations from previous monitoring visits
- Mentor and support project staff

The Child Status Index can be used to assess programming. How often the CSI is used depends on how the information will be used, the capacity of the organization or community conducting the assessment, and what other M&E procedures are being used. For example, the CSI can be used to:

- Assess needs at the start of an OVC initiative to select children for programs and/or to design individual care plans for them.
- Compare baseline and end-of-project data for a program for children affected by HIV and AIDS.
- Regularly and periodically monitor the needs, services provided, and progress of child wellbeing, such as every six, 12, or 24 months.
- Collect periodic (e.g., annual or biannual) data for program evaluation research in order to assess the collective needs and well-being of children in a community, region or country.

## **ANNEX F: Focus of Gender Sensitive Interventions**

Gender norms and inequalities influence the vulnerability of boys and girls to HIV, as well as impact of HIV and AIDS, and ability to access prevention, treatment and care and support services and information in different ways. Women and young girls are disproportionately vulnerable to HIV. Their physiological susceptibility is greater than men's, and is fuelled by poverty, their low status, unequal economic rights, and educational opportunities, which place young girls at more risk of sexual exploitation, trafficking and abuse. Gender norms that encourage young boys to engage in early, risky or abusive sexual behaviour also increase the vulnerability of both boys and girls to infection.

The focus of gender-sensitive interventions should be to:

- Programmes should aspire to move along the gender continuum from accommodating inequitable gender differences to seeking to transform gender relations that will promote equity.
- All programme data should be disaggregated by sex.
- As a minimum, initiatives should not worsen or reinforce exploitative gender stereotypes that focus on male dominant decision-making power, or male macho image.
- Programmes should focus on guaranteeing equitable access of children affected by HIV and AIDS to essential services such as health and education based on an analysis of girls and boys differential barriers.
- Programmes should provide adolescents, especially the most marginalized, with gender sensitive knowledge, skills and services to protect themselves from HIV through use of appropriate methodologies.
- Programme activities should address the vulnerability of girls and boys to rape, sexual abuse, exploitation and HIV.
- Initiatives should address the inequitable burden of care on women and girls to assume responsibility of heading HIV affected households by providing them with the appropriate resources and support to fulfil this role.
- Interventions should ensure men and boys share in the responsibility for the care and support of vulnerable children and members of the household living with HIV and AIDS.
- Programmes should recognize and address the differential impact of the loss of a father and the loss of a mother on children.
- Initiatives should strengthen inheritance and property rights of women, girls and boys.

## **ANNEX G: SAARC Monitoring Indicators**

Below are summary descriptions of Core Indicators from the *SAARC Guide to Monitoring & Evaluation of National Responses for Children Affected by HIV/AIDS*. Extended descriptions including numerator, denominator, suggestions for disaggregation and additional strengths and limitations can be found in the original document.

### **Core Indicator 1: Country Policy and Planning Effort Index**

**Definition:** Set of national policy and planning-related criteria to be met.

**Purpose:** To establish the level of national level commitment to address issues facing children affected by HIV and AIDS.

**What it measures:** This indicator measures a country's commitment to address issues facing children affected by HIV and AIDS.

**Measurement tool:** Key Informant Interviews; Document review

**Frequency:** Yearly

**How to measure it:** A periodic assessment conducted by an independent agency that examines the national effort, across multiple sectors, to develop policy and establish planning for programmes addressing children affected by HIV and AIDS. The assessment asks key stakeholders to complete a questionnaire with ten main areas covered by 18 questions.

**Strengths and limitations:** The indicator is simple to assess and is designed to complement other existing indices. Its simple quantitative nature means that it does not give information on the effectiveness of national policies and strategies, only whether they exist or not. However, the outcome depends on the choice of key stakeholders to complete the assessment; the choice will likely change.

### **Core Indicator 2: Country Policy and Planning Effort Index**

**Definition:** Country has national policies and plans on child protection that address children affected by HIV and AIDS.

**Purpose:** This indicator measures the level to which a country's current response at the national level to protect children is inclusive of children affected by HIV and AIDS. It will identify particular strengths, weaknesses, and gaps in policy and planning efforts.

**What it measures:** Government level commitment and effort to address issues facing children as a whole.

**Measurement tool:** Key Informant Interviews; Document review

**Frequency:** Yearly

**How to measure it:** A periodic assessment is conducted by external agency reporting to the appropriate national governmental body. The assessment asks key stakeholders to complete a questionnaire with four main questions. The indicator is based on a score of 1–4, with 4 being the best score and 1 the lowest.

**Strengths and limitations:** This indicator provides a composite score of a country's efforts to address issues facing children in general. Additional strengths and limitations are similar to those presented for Indicator 1.

### **Core Indicator 3: Percentage of children who are orphans**

**Definition:** Proportion of children under 18 years (0-17) whose mother, father or both parents have died of any cause.

**Purpose:** To monitor the levels of orphan-hood in a country.



**What it measures:** This indicator measures the levels of orphan-hood due to all causes among children less than 18 years (0-17), in the country.

**Measurement tool:** Population-based survey or census

**Frequency:** Every 3-5 years

**How to measure it:** In a household survey, respondents are asked the ages of all children residing in the household. For each child, respondents are asked whether the biological mothers and fathers are alive. Those children currently under the age of 18 whose mother, father, or both are no longer alive form the numerator of this indicator. All the children, whether orphaned or not, under the age of 18 years, form the denominator.

**Strengths and limitations:** Households with AIDS-related deaths often completely disintegrate following the death of a household head, and children are sent to live with relatives in the same or another area. Using a household survey and asking about whether the parents are still alive will provide information about caring practices and identify opportunities to alleviate the primary household disintegration problem.

#### **Core Indicator 4: Percentage of children who are AIDS orphans**

**Definition:** Percentage of orphans under age 18 (0-17) who have lost one or more biological parents due to AIDS.

**Purpose:** To monitor the levels of orphan-hood due to HIV and AIDS in the country.

**What it measures:** Statistical modelling using Spectrum or other modelling approaches.

**Measurement tool:** Population-based survey or census

**Frequency:** Every 2 years

**How to measure it:** Use various demographic assumptions in Spectrum statistical modelling to arrive at the estimated number of orphans due to AIDS. Further details on the methodology can be found on the UNAIDS website ([www.unaids.org](http://www.unaids.org)).

**Strengths and limitations:** This indicator is important for the assessment of the situation regarding orphans and other children affected by AIDS in a country. *Countries facing a localized or concentrated epidemic may employ different statistical modelling strategies to reflect the local situation. For example, the estimation might be done focusing in regions most affected by AIDS rather than the country as a whole.*

#### **Core Indicator 5: Percentage of children who are vulnerable**

**Definition:** Proportion of all children under 18 (0-17) years who are vulnerable, based on national definition of vulnerable.

**Purpose:** To monitor the proportion of children living in vulnerable circumstances. The indicator provides a view of the overall situation of children in a particular country.

**What it measures:** This indicator measures the overall proportion of children under age 18 who are considered vulnerable from all causes, based on the national definitions of vulnerability for children, out of the total number of children under age 18 years in the population.

**Measurement tool:** Population-based surveys or statistical modelling

**Frequency:** Every 3-5 years

**How to measure it:** In a household survey, respondents are asked the ages of all children in the household and for each child. For each child, the following is determined:

- Whether the mother and the father are alive.
- Whether the child meets the country-specific definition of vulnerability

Those children who are currently under the age of 18 (0-17 years), whose mother or father or both are dead, or who are otherwise considered vulnerable form the basis of this indicator. Children who are both orphans and vulnerable should only be counted once.

**Strengths and limitations:** The country-driven definitions of vulnerability enhance this indicator's sensitivity to children's vulnerability across countries. A limitation to this indicator is the difficulty in defining vulnerability. The concept of a vulnerable child is a social construct and varies from one cultural and socio-economic context to another. Also, the term takes on various definitions that can be contradictory, depending on whether the term was developed for the purpose of gathering and presenting quantitative data or for developing and implementing policies and programmes. It is important to make a clear distinction between definitions developed for these two purposes. Children living on the streets or in institutions should also be categorized as vulnerable. These children are not covered in household surveys

### **Core Indicator 6: Percentage of children affected by AIDS (CABA)**

**Definition:** Proportion of vulnerable children under 18 years (0-17 years) who are affected by AIDS.

**Purpose:** This indicator measures the proportion of children affected by HIV and AIDS who potentially have special needs, out of all children who are vulnerable in a country. Many orphans also have characteristics that would categorize them as vulnerable, so the two proportions cannot simply be summed. The percentage of children who are vulnerable taken alone or in combination with the percentage of orphans can be used to create awareness of the scope of the problem and the impact of an AIDS epidemic on society.

**Measurement tool:** Household surveys; Statistical modelling

**Frequency:** Every 3-5 years for household surveys; Every 2 years for statistical modelling

**What it measures:** This indicator assesses the number of children who have been affected by the HIV and AIDS epidemic in relation to the total number of children who have been orphaned or live in vulnerable circumstances in a particular country. It is a measure of the burden of children's vulnerability caused by the HIV and AIDS epidemic.

**How to measure it:** Population-based surveys, including household surveys, can be used for this. Questions need to identify what children are vulnerable, according to national definitions, and determine, for each of the children, whether or not they are affected by AIDS. Alternately, statistical modelling may be undertaken, using estimates of the adult burden of HIV and AIDS along with family size and other socio-cultural characteristics to estimate the size of the numerator. Further details on the methodology can be found on the UNAIDS website ([www.unaids.org](http://www.unaids.org).)

**Strengths and limitations:** If measured consistently over time, this indicator is a proxy measure of the trends in numbers of children in need of services and support as a result of the AIDS epidemic.

### **Core Indicator 7: Children living with HIV infection**

**Definition:** Estimated number of children living with HIV infection (0-14 years).

**Purpose:** This indicator captures the number of children under the age of 15 years (0-14) who are living with HIV infection. This is a core indicator for UNAIDS reporting.

**Measurement tool:** Statistical modelling

**Frequency:** Bi-Yearly

**What it measures:** This indicator assesses the number of children (age 0-14 years) who are currently living with HIV infection in the country.

**How to measure it:** Use various demographic assumptions in Spectrum statistical modelling to arrive at the estimated number of orphans due to AIDS. Further details on the methodology can be found on the UNAIDS website ([www.unaids.org](http://www.unaids.org)).

**Strengths and limitations:** If measured consistently over time, this indicator is a proxy measure of the trends in numbers of children in need of medical care as a direct result of HIV infection.

### **Core Indicator 8: External support for children affected by AIDS**

**Definition:** The percentage of CABA whose households received any free external support.

**Purpose:** To assess the support provided to CABA (or to those caring for CABA)

**Measurement tool:** Household surveys

**Frequency:** Every 3-5 years

**What it measures:** This indicator measures the support that is given free of charge to CABA (or households caring for CABA). The foundation of an effective strategy is the reinforcement of the capacity of families and communities to provide protection and care for vulnerable children. Increases in this indicator over time could mean that national efforts are improving their reach to families and communities.

**How to measure it:** For each child less than 18 years (0-17) in the household, begin by asking a series of questions to determine whether the child is affected by AIDS. Then, a series of questions would be asked for each affected child in the household about the types of support received for the child, the frequency of support, and the primary source of support. External support is defined as free help coming from a source other than friends, family or neighbours, unless they are working for a community-based group or organization. *Available external support for CABA needs to be defined by each country.*

**Strengths and limitations:** This indicator does not measure the breadth nor quality of services, only that there were services provided. Separate monitoring could be conducted on a periodic basis to ensure that the quality and breadth of services provided meet national standards of service.

### **Core Indicator 9: Children affected by AIDS receiving a minimum package of external support according to national definition**

**Definition:** Percentage of children affected by AIDS receiving a minimum package of external support services (according to national definition of minimum package of external support services).

**Purpose:** This indicator identifies the met and unmet basic support needs of children affected by AIDS. The minimum package of external support services needs to be defined by each member state and may differ from country to country.

**Measurement tool:** Household surveys

**Frequency:** Every 3-5 years

**What it measures:** This indicator measures the quantity of support that is given either free of charge or else subsidized to CABA (or households caring for CABA). The foundation of an effective strategy is to reinforce the capacity of families and communities providing protection and care for vulnerable children. Increases in this indicator over time could mean that national efforts are improving their reach to families and communities.

**How to measure it:** For each child under 18 years (0-17) in the household, begin by asking a series of questions to determine whether the child is affected by AIDS, according to the SAARC definition. Then, a series of questions would be asked for each affected child in the household about the types of support received for the child, the frequency of support, and the primary source of support. External support is defined as free help coming from a source other than friends, family or neighbours, unless they are working for a community-based group or organization. The minimal essential package of services needs to be identified by each country.

**Strengths and limitations:** Information from this indicator will allow countries and the region to assess whether CABA (or their households) are receiving the minimum package of services as defined by each country. Because the essential services will be defined by each country, the indicator cannot be interpreted to mean that all children are receiving equal types of services, only that they are receiving a nationally-defined essential package.

### **Core Indicator 10: Percentage of service organizations that provide care and support to children affected by AIDS**

**Definition:** The percentage of organizations (public, private, faith-based, other) that provide free care and support services to families and children affected by HIV and AIDS.

**Purpose:** To assess the availability of services to children and families affected by HIV and AIDS.

**Measurement tool:** Institutional surveys

**Frequency:** Every 2 years

**What it measures:** This indicator obtains a count of organizations that state they provide services to children and families affected by HIV and AIDS.

**How to measure it:** Periodic national survey of organizations providing services to children, in general. The survey would determine the types of services provided, and for each service provided, whether children affected by AIDS are (1) eligible for the service and (2) currently recipients of the service. Organizations to be assessed include those providing services to all children as well as those providing services only to CABA.

**Strengths and limitations:** By disaggregating the services provided, the data can help determine

- what services are available
  - the degree to which CABA have been integrated in to services being provided to children as a whole
- This indicator does not provide any information about the breadth nor the quality of services being provided, which would be of interest.

### **Core Indicator 11: Percentage of people expressing accepting attitudes towards people living with HIV**

**Definition:** Percentage of people ages 15-49 years expressing accepting attitudes towards people living with HIV, of all people surveyed 15-49 years of age.

**Purpose:** To measure the level of acceptance of people living with HIV and AIDS in society.

**Measurement tool:** Population-based surveys

**Frequency:** Every 3-5 years

**What it measures:** This indicator measures the levels of stigma in the community towards people living with HIV and AIDS.

**How to measure it:** Respondents are asked this series of questions about people with HIV:

- If a member of your family became ill with the AIDS virus, would you be willing to care for him or her in your household?
- If you knew that a shopkeeper or food seller had the AIDS virus, would you buy fresh vegetables from him or her?
- If a teacher (male or female) has the AIDS virus but is not ill, should s/he be allowed to continue teaching in school?
- If a member of your family became infected with the AIDS virus, would you want it to remain a secret?

Only the number of individuals who respond "yes" to all of the questions in the series will be counted in the numerator.

**Strengths and limitations:** This indicator measures accepting attitudes, but does not measure the additional stigma dimensions of shame and blame. In addition, the measure assesses acceptance of people living with HIV infection but not necessarily the stigma associated with being a child affected by HIV and AIDS. However, children affected by AIDS are affected by the stigma and discrimination against people living with HIV.

### **Core Indicator 12: Proportion of children living outside of family care**

**Definition:** Percentage of children under 18 years who are not living in a family environment.

**Purpose:** To measure the proportion of children who have fallen outside of family-based care.

**Measurement tool:** Survey of children living on the streets, and survey of children living in institutions

**Frequency:** Every 3-5 years

**What it measures:** This indicator assesses the proportion of children living outside of traditional households, such as homeless children and children living in institutions. National surveys such as the DHS and MICS do not normally capture these children as they exclude structures not considered to be households from their sampling.

**How to measure it:** Additional surveys are necessary. See the UNICEF/UNAIDS *Guide to Monitoring and Evaluation of the National Response for Children Orphaned and Made Vulnerable by HIV/AIDS* for details.

**Strengths and limitations:** Children under formal care in household-like institutions, such as community homes with appointed guardians, risk being counted as children under family care. Locating children living on the streets requires going to sites where they congregate, visit frequently, or sleep. This might be challenging if the sampling areas are not safe for interviewers to enter.

## **ANNEX H: List of contributors**

The following people generously gave their time to contribute to the development of the Guidelines.

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