Protocol for Child Counseling on HIV Testing, Disclosure and Support

Family Health International (FHI)
India Country Office
With Funding from the United States Agency
for International Development (USAID)

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Impact Implementing AIDS Prevention and Care Project
YouthNet

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Acknowledgements

Dr. Jonathan Brakash, FHI consultant nd Ms. Shyamala Nataraj from South India AIDS Action Programme, developed early drafts of the Protocol for Child Counseling on HIV Testing, Disclosure and Support. The photographs on the cover were taken by Anita Khemka for FHI. The National OVC Task Force including the Ministry of Women and Child Development (MoWCD), the National AIDS Control Organisation (NACO), UNICEF and the India HIV/AIDS alliance, reviewed the Protocol and gave valuable comments. The Lawyers Collective HIV/AIDS unit designee, Mr. Vivek Diwan also reviewed the protocol. The staff and children of 30 USAID/FHI projects contributed their time in the development and then pre-testing of the protocol.

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Preface

This protocol has been developed to meet a need for guidance on counseling of children and their parents/guardians about HIV/AIDS in 30 USAID/FHI projects with orphans and vulnerable children (OVC) under the IMPACT project in India. The document follows a holistic approach to counseling considering HIV/AIDS as one among many other issues in a child's life.

Counselors need to be familiar not only with HIV/AIDS counseling issues but also with child development and skilled in communicating with children. This document provides guidance to the counselor on the process to be followed in different situations considering the age of the child, the counseling need and the circumstances. It also discusses the various ethical dilemmas, a counselor faces in dealing with children living with and affected by HIV/AIDS. The guidance on HIV testing has been detailed both for counselors working within and outside a HIV counseling and testing (CT) center.

The document is a product of national and international experience on counseling with expert advice gathered through a two-day national meeting of child psychologists, child psychiatrists and social workers, as well as regional meetings with 30 NGOs working

with children on HIV/AIDS issues. The Ministry of Health and Family Welfare (MOHFW) through the National AIDS Control Organization (NACO) and State AIDS Control Societies (SACS) has participated in various consultation workshops including a national review meeting with the 30 NGOs who pre-tested the protocol. The participation has facilitated the effort to follow the national priorities in addressing the HIV/AIDS prevention and care and support needs of OVC. FHI is thankful to the Ministry and NACO for providing valuable direction.

We appreciate the review undertaken by a number of stakeholders including the Lawyers Collective and the National OVC Task Force consisting of the Ministry of Women and Child Development (MoWCD), the National AIDS Control Organization (NACO), UNICEF, the India HIV/AIDS Alliance and FHI. Our special thanks to the MoWCD for endorsing the protocol with the official logo and message. FHI appreciates the funding support from USAID, the support of different national stakeholders, and the tremendous input of energy, time and commitment from the NGO parents and specialists to the protocol development.

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Message

Counseling has an important role in prevention and care and support of HIV/AIDS. It can provide the necessary psychological support for people who are living with HIV and those who are vulnerable. In case of children living with HIV/AIDS, both children and the parents/guardian need to be counseled. The counselor needs to be equipped with adequate skills for counseling children in different circumstances.

This document describes the different contexts of HIV/AIDS in the lives of children with guidance on the counseling needs and the protocol to be followed. The document also discusses a number of ethical dilemmas which challenge counselors. I am told it can be used both in the community and institutional settings.

The guidance would be useful for counselors working with children on HIV/AIDS.

I commend the efforts of USAID/FHI in developing this guidance.

(Deepa Jain Singh)

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Foreword

An estimated 50,000 children below the age of 15 years are infected with HIV/AIDS in India every year. The present response of care of children infected and affected by HIV/AIDS has little focus on long-term psycho-social support strategies and systems, including child-centered counseling skills. Family Health International (FHI) has taken the initiative to develop a protocol for counseling on HIV testing for children with support from the United States Agency for International Development (USAID). With the proposed expansion of Voluntary Counseling and Testing centers, Prevention of Parent to Child Transmission centers and centers for provision of Anti-Retroviral Therapy (ART) under NACP-3, the protocol will serve as a valuable tool to complement the existing national protocol on HIV/AIDS counseling of adults.

The protocol has been developed through useful contribution from a variety of stakeholders at different stages of its development. Counselors and care givers in 30 sites spread across 6 states found the protocol useful in guiding the emotionally challenging process of counseling children and their families on HIV testing, disclosure and provision of care, support and treatment services for orphans and vulnerable children (OVC). We are thankful to the members of

the National OVC Task Force convened by the National AIDS Control Organization that included UNICEF, the India HIV/AIDS Alliance and Ministry of Women and Child Department for reveiwing the protocols.

I hope this tool will be a contribution towards the efforts in addressing the needs of children infected/affected by HIV/AIDS, a key segment of population and future of this country.

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List of Abbreviations

AIDS	--	Acquired immune deficiency syndrome
ART	--	Antiretroviral therapy
CBO	--	Community-based organization
FHI	--	Family Health International
GOI	-	Government of India
HIV	--	Human immunodeficiency virus
IEC	--	Information, education and communication
IPC	--	Interpersonal communication
LSE	--	Life Skills Education
OGAC	--	The U.S. Office of the Global AIDS Coordinator
OI	--	Opportunistic infection
OVC	--	Orphans and vulnerable children
PLHA	--	People living with HIV/AIDS
STI	--	Sexually transmitted infection
STD	--	Sexually transmitted disease
TB	--	Tuberculosis
USAID	-	U.S. Agency for International Development

Introduction

1. Introduction

Since the first report of HIV infection in India in 1986, the country now has one of the largest number of people living with HIV/AIDS (PLHA) in the world[1]. HIV prevalence varies across the country, with states categorized between highly vulnerable (low prevalence) and highly prevalent. The population of children affected by HIV/AIDS is steadily increasing, either they are themselves infected with HIV or their parent/s and siblings are infected. In either case, children face tremendous challenge for their survival and development in living in distressed families or on the street without parent/guardian. Besides the basic care and support needs of food, shelter, clothing and education, children require psychosocial support to help them cope. A counselor trained to deal with the child-specific impact of issues such as HIV prevention; testing and supportive care, can play an important role in empowering children and parent/guardians to cope with HIV/AIDS.

Contemporary literature from India on counseling children has tended to focus on mental health issues among school-going children with an emphasis on improving attention span, decreasing absenteeism, and increasing academic performance. There is need for guidance on counseling children in the context of HIV/AIDS.

Recognizing the urgent need for culturally appropriate materials that address children, in India, FHI undertook the task of developing counseling protocols for children vulnerable to,

[1]UNAIDS Annual Report, end 2005

affected by, and living with HIV/AIDS, with funding from United States Agency for International Development.

What this document includes:

This document is premised on the human rights framework in the best interests of children (See Annexure I on Rights of a Child). This counseling protocol covers five key areas:

(1) Principles of counseling children;

(2) Life situations of the children in the context of HIV/AIDS;

(3) Protocol for specific areas including prevention counseling, risk assessment, pre-test counseling, informed consent, post-test counseling, disclosure, confidentiality, and supportive counseling;

(4) Counseling guidelines for issues such as abuse, death and stigma; and

(5) Recommendations for operational issues such as training and supervision, referrals, quality assurance and integration.

The challenge has been to remain true to the principles of child-centred counseling, while integrating elements of family and community, which are particularly significant in India.

Who will find this document useful:

This document is primarily addressed to those working in the field of child support and counseling. It is an endeavour to build on an existing knowledge base of counseling and skills related to working with children. The protocols will build the capacity of individuals in dealing with children in the context of HIV/AIDS.

The process for developing this protocol:

A participatory process and an exhaustive literature review

were the key processes in developing protocols for counseling interventions with children in the context of HIV/AIDS. A summary of the literature review was sent to a broad range of practitioners around the country with questions regarding the need for development of a counseling framework for HIV/AIDS infected and affected children.

Five consultative workshops with NGOs working on HIV/AIDS with orphan and vulnerable children (OVC): were held in New Delhi, Pune, Vijayawada, Chennai, and Kolkata, in which nearly 200 representatives of non governmental organizations (NGO) and community-based organizations (CBO) participated. At the one-day workshops, participants agreed on several generic counseling principles and presented actual case situations for discussion.

Collection of first-hand field level information: A total of 22 NGO projects sites across India were visited to observe counseling and care systems, meet caregivers and children, and discuss administrative procedures. These visits highlighted operational issues involved in maintaining confidentiality and access to testing, practical issues around consent and disclosure, and problems associated with referrals.

Consultation with experts: A two-day meeting was held in Bangalore, through which a panel of practicing child psychologists, psychiatrists and social workers from across India suggested the content and structure of the protocol.

Pre-testing the draft protocol: The protocol was pre-tested in different NGO project locations. This was followed by feedback from the counselors.

Development of operational guidelines: Operational guidelines were developed based on feedback received from the counselors after pre-testing, which resulted in a more user-friendly protocol with useful practical tips. The documents were initially developed by South India AIDS Action Programme and international child psychologist, Jonathan Brakash.

Document review: The two documents were reviewed by USAID/IMPACT OVC partners, FHI technical and program staff and experts. The partners provided useful feedback through a series of regional workshops. The protocol was peer reviewed by members of the National OVC task force which included Ministry of Women and child Development, National AIDS Control Organization, UNICEF and India HIV/AIDS Alliance. In addition, the protocol was reviewed by Dr. Vivek Diwan representing the Lawyer's Collective who provided inputs on legal issues.

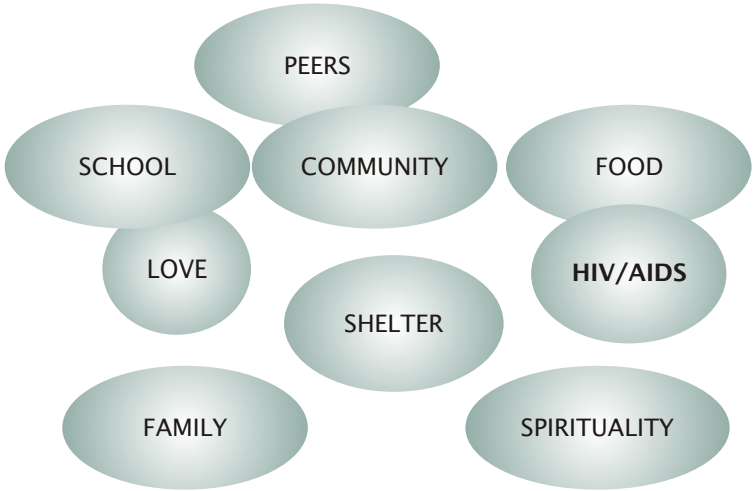
Children and HIV/AIDS

2. Children and HIV/AIDS

The life of a child in the context of HIV/AIDS

HIV/AIDS is but one aspect of the child's life. Whether the child is HIV positive or negative, his/her life still continues. As depicted in the diagram below, an individual's life is full of many experiences and people. Even if one is HIV positive, life is not centered upon the issue of HIV/AIDS alone.

Consequently, it is important to remember that with children and families, an HIV/AIDS counselor is a life counselor. The counselor needs to counsel the person as a whole, with the objective of building the social and emotional resilience of the child and parents/guardians to respond to any crisis. Life counseling focuses on all aspects of life and how



individuals have handled previous crises. The counselor needs to identify aspects of a person's life that provide strength and enjoyment as well as problems and stress.

There are three interlinked domains of children impacted by HIV/AIDS:

- Children vulnerable to HIV/AIDS;
- Children affected by HIV/AIDS; and
- Children living with HIV/AIDS.

2.1. Children Vulnerable to HIV/AIDS

Children vulnerable to HIV infection may fall under one or more of the following categories: street children, working children, children of sex workers, children in sex work, trafficked children, runaway children, abandoned children, sexually abused children, sexually active children, children using substances and orphans.

2.1.1. Context of work

The family background, living environments and personal experiences of these children are very different from those of 'other' children, as explained below in more detail. Understanding these differences will help counselors work more realistically.

Moving from dependence to independence: Children from 'normal[2]' families move into independence gradually and over fairly long periods of time. During the transition, they learn to deal with adult authority figures, sometimes through negotiation and other times through confrontation. At all times, there are clearly defined boundaries and adult

[2] Webster New World Dictionary defines "Normal" as something that conforms to an accepted standard, model or pattern. For purposes of this text, "normal" refers to something that is conventional, usually observed or practiced.

supervision. The child thus learns to express his/her identity in a well-defined framework. For example, a normal adolescent, on being told to cut his hair, might yell at his mother to leave him alone. The reply is confrontational, but non-threatening and allows the child to express his identity.

On the other hand, children outside the home or in fragmented families are forced into a stage of premature independence with no set limits or regular, caring adult supervision. Though the children have enormous freedom, they have very few choices to make.

Identity: An individual's identity is related to self image, self worth, gender, the relationships s/he has, the people and positions s/he is associated with, positions of power, and social and economic status. The way children define themselves as people, and understand themselves in relation to others, forms their identity. People express their identity in terms of their long-term goals, career choices, friendships, gender, sexual experiences, sexual orientation and behavior, and religion. These parameters are often based on conventional value systems.

A child's identity is formed through the opportunities that are available to her/him within the security and boundaries of a 'normal' family. Caring adults as role models, as well as healthy peer relationships, help children deal with negative emotions and support them in making difficult but constructive choices.

Vulnerable children usually do not have the opportunity to live in 'normal' families, and therefore do not learn to define their identities in ways described above. They are unsure about who they are, and what they ought to do in a

given situation. These children usually do not know how to cope with negative emotions, and try to escape dealing with them through the use of drugs, alcohol or sex. Because a majority of the children have had very little education, they have very few career choices available, and lack a sense of future goals and choices.

Intimacy: Children usually learn to be intimate in a relationship that is safe and consistent, such as one available with parents, siblings and friends. When children lose these familiar relationships, they also lose the ability to be intimate and to share their deepest thoughts and emotions with another person. Most vulnerable children tend to live without one or more supportive adults in their lives.

Sexuality: There is early development of sexuality in most vulnerable children as compared to children from 'normal' families. Many children living on the street tend to be sexually active before they have reached the age of fourteen. Since there are few opportunities for safe recreational activities, and sex is easily available, it quickly becomes part of their daily life. Most of it is unsafe and is often accompanied by alcohol, drug use, and violence. Many vulnerable children also tend to develop short-term, pleasure seeking behavior as an escape from problems.

Stigma and discrimination: Stigma and discrimination is a constant factor in the lives of vulnerable children from a very young age. As a result, they have low sense of self-worth, high levels of anger, resentment, and deep mistrust of society.

2.1.2. Intervention needs

The complicated life situations of most vulnerable children put them at high risk of HIV

infection they thus also require complex interventions.

Health care services: As some of the children are sexually active, they tend to suffer from STIs and need access to care and quality treatment facilities.

Information, education and communication (IEC): Depending on their age, children can absorb only a certain amount of new information at any given time. The critical factor is to provide the child with just the amount of information that s/he may need at a particular time and situation. For example, if a child has sought treatment for an STI, it may not be appropriate to discuss HIV infection with him/her until after addressing the need for STI treatment. The child is educated about the absolute necessity of abstinence during the period of treatment. Subsequent sessions can be used to discuss HIV/AIDS in greater detail according to the OGAC guidance on applying the ABC approach to preventing sexually transmitted HIV infections. (Please refer to Annexure II for details).

Condoms: Condoms may be a priority, along with skills for negotiating use. (Please refer to Annexure II, for guidance on ABC approach of HIV prevention).

Advocacy with police and justice systems: Because many children are abused, and violence by the police is common, interventions must sensitise police on the need to help these children live safer lives. If children report abuse, offenders can be prosecuted under Section 377 of the Indian Penal Code (IPC).

Halfway homes/shelters: These temporary homes are critical in helping children reintegrate with families.

Life skills training: A life skills approach can improve both

self-esteem and build skills that will help children cope with life outside care homes. Children will feel more capable of finding safer environments and choose to act more safely.

Vocational training and placements: Children can be helped with career choices, options that will give them an opportunity to escape the vulnerable environment in which they live.

2.2. Children Affected by HIV/AIDS

Children affected by HIV/AIDS are those who: have one or both parents/guardian living with HIV/AIDS; have lost one or both parents/guardian to AIDS; live in households fostering children orphaned by AIDS; and those with siblings living with HIV/AIDS.

AIDS orphans are defined as children below 18 years who have lost one or both parents to AIDS. The traditional definition of orphans has been expanded to address the specific vulnerabilities of children orphaned by AIDS and to plan for their care and support.

Unlike other parental diseases, HIV is likely to spread sexually between parents, thus rendering a child more likely to lose a second parent relatively quickly. Experts suggest that orphan hood peaks seven to ten years after peaks in HIV sero-prevalence.

In high HIV prevalence areas in India, many children are either coping with the loss of parent to AIDS, caring for an ill parent, working to support the family, or dealing with AIDS-related illnesses themselves.

2.2.1. Context of work

Caregivers report that many children and adolescents affected by HIV/AIDS come from homes where alcoholism and violence are common. Trauma thus appears to be an

ongoing issue. The entry of HIV/AIDS intensifies the experience of trauma. It also burdens children with other issues that are critical to their physical, mental, emotional and spiritual well-being.

Stigma and discrimination: The discrimination and social exclusion directed at individuals living with HIV/AIDS and at their families affect the child's sense of identity and control. Children experience shame, fear, guilt and self-hate all of which can deeply affect their development and growth into adulthood.

Fragmentation of family and dislocation: For a child, losing one parent, and sometimes both, is devastating beyond description. One of the first consequences is the disintegration of family structures. Children have to leave home and live with relatives or move into care institutions. These events are extremely disturbing, and many children may show signs of a condition called post-traumatic stress disorder. In this situation, child may: persistently relive the traumatic event in thoughts or dreams; avoid people and places linked with the trauma; find it difficult to fall asleep, or concentrate; and easily become angry or irritated.

Loss of educational opportunities: Most children whose parents live with HIV/AIDS find themselves forced to support the family when the father, usually the main wage earner, falls ill and eventually dies. If the mother is infected she is likely to do the same. Thus the child's income becomes crucial to pay for food, care and other necessities. Schooling is disrupted, and children may find it difficult to resume education.

Caring for sick parents: Affected children find themselves caring for sick parents. This reversal of roles and responsibility can be difficult, particularly when parents suffer from diarrhoea, tuberculosis or dementia. Over and above the burdens of care, the child's vulnerability to infections such as tuberculosis is increased. The situation can overwhelm the child and cause anxiety, depression, and a sense of helplessness and hopelessness.

Denial of inheritance rights: There are many instances in India where children who have lost one or both parents to AIDS have been cheated out of their inheritance by members of the extended family. With neither knowledge nor support, the child is dispossessed of both home and income, and usually left in the care of an institution.

Child labour: In India, child labour is common, especially among poorer families. Older children routinely drop-out of school to augment family income. In a situation where a parent is dealing with HIV/AIDS, children will be forced to look for employment much earlier than they are physically or emotionally ready.

Lack of health care: The many demands made on children usually result in poor health with little access to appropriate clinical care or nutrition.

Early marriage and abuse: Children are likely to be severely affected by the illness/death of parents. They will be vulnerable to early marriages and possible abuse, as parents/guardian try to settle their future as quickly as possible. The well-being of children affected by AIDS depends in great part on the capacity of the community to support and raise them. Yet few programs have focused on preparing and supporting

willing guardians to take on additional childcare responsibilities.

2.2.2. Intervention needs

Interventions should include all children affected by HIV/AIDS, not just those whose parents have died from AIDS. If organizations wait until children become orphans, it is almost too late[3].

A review of programs to reach AIDS-orphaned children in east and southern Africa concludes that there is an urgent need to reach these children as soon as the parent is known or suspected to be terminally ill[4]. Relatively few programs, however, have instituted this approach or documented program outcomes and experiences. It is likely that psychosocial distress among both HIV positive parents and their children can be reduced by making provisions and plans for the children if they are likely to be orphaned.

The well-being of all children affected by HIV/AIDS depends in great part on the capacity of the community to support and raise them. Yet few programs have focused on preparing and supporting willing guardians to take on additional childcare responsibilities.

Program and policy implications: Interventions should reach all children affected by HIV/AIDS, including orphans and children living with HIV-infected parents. Adult caregivers, both parents and guardians, have needs of their own that must also be addressed to improve and prolong their capacity to care for children affected by HIV/AIDS.

[3] UNAIDS 1999

[4] Reid 1993

Reach children affected by HIV/AIDS before they become orphans: The impact of parental HIV/AIDS on children begins when a parent is diagnosed with HIV or becomes ill. The impact is especially strong for older children, whose education may suffer when they stay home from school to work and care for younger children and sick adults. One way to reach children early is to link programs for children affected by HIV/AIDS with care and support programs for PLHA, which provide a natural group of parent beneficiaries. This link also addresses a priority concern expressed by PLHA: the future welfare of their children.

Increase community awareness and accountability regarding the property rights of women and children: Property rights are especially critical because most surviving parents and guardians are female. Women, who often outlive their husbands, are vulnerable to property snatching. Thus it is important to train men as well as women to write wills, an activity that must be accompanied by efforts to mobilize communities to uphold women's and children's property rights. Community groups and leaders (local government officials, clan/caste leaders and spiritual leaders) should help to enforce property rights. Indian laws for Hindus allow equal share of property for women and/or surviving children. The International Convention on the Rights of the Child, ratified by India, is another useful tool for advocates.

Address the critical health needs of adult caregivers, including guardians: Prolonging adult-child relationships should be a top

priority of programs for children affected by HIV/AIDS. A study[5] from UGANDA demonstrates that guardians, as well as parents, have critical health needs. Life-prolonging care and support services for adults including access to ART may minimize the effects of parental illness on children, improve children's access to school, and delay being orphaned. These services should be extended to guardians to prolong their ability to care for orphans.

Improve adult-to-child communication and provide counseling on such difficult issues as parental illness, parental death, and sex education: Parents and guardians say they need support with, and advice about, discussing difficult issues with children. Older children benefit from disclosure and honesty about parental illness. Memory books like albums with photos, anecdotes, and other family memorabilia, provide a good medium for disclosure and planning for the future. Other means for developing communication skills among parents, guardians, teachers, and community leaders should be explored, including skills in educating youth about AIDS and reproductive and sexual health.

Address the material needs of HIV/AIDS-affected households, including those headed by HIV positive parents and guardians: whether in the form of income-generation projects, vocational training, food, clothing, home repairs, or school fees, HIV-positive parents and guardians need material support to provide for their dependents.

[5] Making a difference for children affected by AIDS: Horizons Program, Washington, DC, USA; Makerere University, Department of Sociology, Kampala, Uganda

Improve the morale of children affected by HIV/AIDS by keeping children in school and offering sports and recreational activities: Since adult illness can cause children to drop out, program workers should tell families and guardians about the role of consistent schooling in sustaining children's morale through difficult transitions. Primary and secondary education is free in government schools. However, school uniforms and supplies should be subsidized, a critical need to mitigate the educational and psychosocial impact of HIV/AIDS on children. Sports and recreation are other inexpensive, but often overlooked, activities that help to integrate children with their peers and maintain psychosocial well being.

Address stigmatization of and discrimination against HIV/AIDS-affected adults and children: Fear of disclosure limits parents' ability to appoint guardians and take other steps to secure their children's future. To reduce the stigma of AIDS, social service agencies should work to increase the sensitivity of community members, including children, to the needs of AIDS-affected children and their families. This should include community-based efforts to monitor and reduce discrimination of these children, such as teasing, neglect, and physical and sexual abuse.

Involve future guardians in intervention efforts: Program workers should engage future guardians and schedule special events whenever they are likely to visit[6].

[6] Making a Difference for Children Affected by AIDS; Horizons Program, Washington, DC, USA; Makerere University, Department of Sociology, Kampala, Uganda

2.3. Children Living with HIV/AIDS

By the end of 2004, UNAIDS estimated 220,000 children below the age of 15 years as infected by HIV in India[7]. Caregivers in India attest that over 95% of children under the age of 15 have acquired the infection from their parents, either through vertical transmission (during pregnancy or child birth) or through breast milk.

Though Indian law classifies a person less than 18 years of age as a minor, official statistics for HIV/AIDS include adolescents between 15 and 18 years under the category of adults. Thus, there is no clear indication of the number of children above 15 years living with HIV/AIDS. It is also assumed that most children between 15 and 18 have acquired HIV through sexual transmission unsafe blood transfusion and/or sharing infected needles/syringes.

2.3.1. Context of work

In addition to issues of displacement, loss of family, and stigma and discrimination; children living with HIV/AIDS need to cope with the following issues that are unique to their situation.

Illness: Children living with HIV/AIDS often have the same health problems as other children, but these may occur in a more severe form with which the child is unable to cope. Children with moderate to severe HIV disease manifest several signs and symptoms. These include daily fevers, night sweats, fatigue and weakness, weight loss, diarrhoea, oral thrush, and various skin conditions such as rashes and herpes zoster

[7] UNICEF India– HIV/AIDS http://www.unicef.org/india/hiv_aids_1539.htm

infection. HIV/AIDS can also affect the heart, causing shortness of breath, chest pain and fatigue. Enlarged lymph nodes and an enlarged liver are common. Childhood illnesses could be categorized into the following:

- *Delayed developmental milestones:* Development milestones mark the stages that children normally attain at different ages in terms of their, physical, cognitive, emotional, sexual and social development from infancy through adolescence. Because children living with HIV/AIDS fall ill often, they sometimes experience delays in reaching developmental milestones. There may be delay in language development, difficulties in expression, and disorders of voice, articulation and language fluency. If there is visual or hearing loss, children may show learning disabilities;
- *Mental health disorders:* Children may have short-term memory deficits and reduced concentration. Behavioral problems can range from social withdrawal and apathy, to impatience, irritable mania and even psychosis. Some show learning disabilities – difficulties in reading and writing, solving mathematical problems, and spelling; and
- *Sensory disorders:* Children can be affected by visual loss due to infection of the retina or hearing loss, depending upon the location of damage in the ear.

Death and dying: Although the Government of India (GOI) has rolled out a free ART program through select health facilities in the country (Please refer Annexure III for list of ART

centers), it currently only reaches a small section of the population. Often PLHA are forced to depend on their own resources; the majority is not able to support medication costs. As a result, most children with HIV/AIDS die before they reach adulthood. Since the source of infection is often the parents, they undergo the trauma of watching parents, and often one or more siblings, fall sick and die. In care institutions, watching a friend fall ill and die is a common experience. Death and dying issues are a fundamental and intense concern in the lives of young children.

Ignorance of HIV status: Most children living with HIV/AIDS in India are unaware of their status because they do not have access to testing services. Even when HIV positive status is confirmed, many parents and institutional caregivers believe that non-disclosure protects the child, as s/he is less likely to unknowingly reveal the status. The decision not to tell the child of her/his HIV status is also rooted in poor accessibility of anti-retroviral therapy in the country. Some caregivers believe that non-disclosure also protects children from fear and depression.

However, other parents and caregivers believe that children must be aware of their status to help them deal with the implications of living with HIV/AIDS. They emphasise that the decision to disclose should be based on the child's emotional and intellectual maturity. Often the child is aware that there is a problem from hearing others talk about it, or from observing reactions. This can make her/him very anxious, particularly if the parents are unwell. In general, parents feel that they must be involved in the process of

disclosure. If the guardian is a relative, the experience is that the news of HIV infection is better conveyed by a doctor/social worker/counselor, especially if they have been involved in the care.

Denial: Sometimes parents may be in denial about the positive test result of a child because they want to protect the child from stigma, or because they are unable to accept that the child may become ill and die.

Blame: Often people in India tend to see HIV/AIDS as a result of 'karma' the result of one's past actions, or as a curse, and blame neighbours or relatives. Their initial responses may be to seek the help of traditional or spiritual healers which may help address HIV/AIDS more openly.

Guilt: Children who know they have HIV/AIDS may feel that they have done something wrong and are responsible for the situation. Parents too are weighed down by guilt for having been the cause of HIV infection in their child.

Anger: Adolescents often respond with anger to the knowledge that they have HIV/AIDS. This can be self-destructive and can express itself in increased acts of unsafe sex, alcohol or drug use. All these factors lead to a near complete erosion of self-esteem.

Stigma and discrimination: Children living with HIV/AIDS face continued discrimination in India. Health care, education, and property rights are commonly denied or grudgingly offered. While families are largely caring and supportive, orphaned children who also have HIV/AIDS are usually abandoned, or handed over to institutions by relatives.

2.3.2. Intervention needs

In addition to counseling, children living with HIV/AIDS require the following services:

Medical care is a primary requirement. Important components include treatment for opportunistic infections (OIs), pain management, and antiretroviral therapy (ART), where necessary and available. (Please refer to the list of Government ART centers in the Annexure III).

Meeting developmental needs of children is particularly important for those living with HIV/AIDS. These include psychological support, education, nutrition, socio-economic and legal services. Periodic assessment by a specialist and access to peers, schools and other educational facilities can help children live productive and fuller lives. (Please refer to the Annexure IV for details on child development stages and needs).

Recreational needs of children living with HIV/AIDS are important but often overlooked, as children tend to fall ill more often and experience other stress factors. Simple outings to parks or beaches, excursions and picnics, or visits to a temple, movie theatre or art exhibition, can assist in their health and well-being.

Placements, temporary as well as permanent, within the family or in other settings, may need to be an integral part of intervention, because one or both parents may be ill, or may have died of AIDS. Research has shown that children usually do better in extended family or community placement situations than in institutions. Other options include placements with relatives or with a person in the community caring for a small number of children with support from the community or from an NGO. Institutional care must be

considered only as the last option.

Support from PLHA networks in the area will help children feel 'they are not alone', and teach them to live life positively.

Sexual and reproductive health services will assume greater importance as children start living longer, healthier lives with ART. Sexuality and relationship issues become crucial as the child grows older. For children, particularly those living with HIV/AIDS, these issues are particularly difficult, both in terms of accepting their HIV status, as well as learning to negotiate relationships. Children must be helped to understand that the desire for sexual and other intimate relationships is healthy, and can be negotiated in-spite of difficulties or rejections along the way.

Please refer to Annexure V for details on the prevention and support service needs at different points of HIV progression.

The Child Counseling Protocol

3. The Child Counseling Protocol

3.1. The Basic Principles and Skills of Child Counseling[8]

The protocol for child counseling is based on the following three principles:

- This protocol addresses both the child and family members, as everyone is affected by the results of an HIV test, either positive or negative;
- The cognitive and emotional development stage of the child is central. The counseling process is adjusted according to the age of the child. What is said and how it is said changes according to the child's age; and
- The protocol takes a holistic approach to counseling and care, addressing all aspects of a person's life. HIV/AIDS is one aspect of a person's life.

3.1.1. Consent

Most people understand consent as related to HIV testing. Before that stage, consent must be obtained from the child/children and the parents/guardians to initiate the counseling process; in case of children living on the street without parents/ guardian, counseling can begin with the child's consent. This stage occurs at the very beginning of the counseling relationship. This is different from the processes associated with decisions to take the HIV test and disclosure procedures.

Consent is defined as “to agree (to do something) to give

[8] For detailed understanding of Counseling theories and approaches refer Annexure VI

permission, approval or assent (to something proposed or requested) in opinion''[9]. Consent implies compliance with something proposed or requested, stressing an act of will. The opposite of consent is to dissent, refuse or deny.

Key principles include:

Understanding: Children, when possible, along with parents/guardians must understand the objectives and processes involved in the counseling intervention. With the child, this can be achieved simply by saying that if the child wishes, the counselor can spend time with her/him every week/month, and that they could do things together that will help the child be happier.

Giving consent: This can be explicit or implicit. For example, the counselor can say, "Daddy has sent you to meet me. While you are here we can talk, we can play, or you can draw or tell a story. Would you like to stay?" The child may either answer directly, or provide enough cues, for the counselor to interpret consent or refusal.

Refusing consent: Children, where possible, and parents/guardian must know and be able to use their right to withhold consent if they are not comfortable with the process. This too can be explicit or implicit, and counselors must be sensitive enough to recognize when consent is being withheld.

Withdrawing consent: Children, where possible, and parents/guardian, must also be aware that they have a right to withdraw from the counseling process even after it has begun. This is an important empowering tool for children

[9] Webster's New World College Dictionary, New Millennium Fourth Edition

who might simply say, "I do not feel like talking now", or indicate through behavior and/or body language that they do not wish to continue with the session.

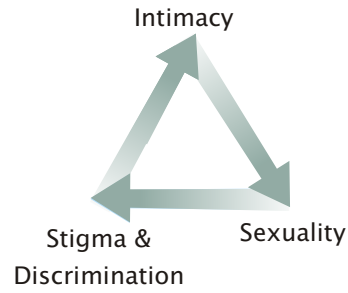
Contracting: This refers to an agreement between the counselor and the child, wherever possible, and the parents/guardian, on the objectives, time and the processes involved in a counseling session. The steps described earlier are part of a process of contracting, which is critical to the success or failure of the entire counseling intervention.

Note: If children are too young to understand, the parents/guardian should decide whether the child should undertake counseling; in case of children living on the street without parents/ guardian, the counselor can take this decision. If children want to have an adult present, the counselor needs to explain to the person that s/he should remain an observer, as far as possible, and not participate actively in the session.

Explain to the parents/ guardian, and to the child, if s/he is old enough, how s/he will benefit from the counseling. Children will work hard in a situation that they perceive to be entirely focussed on meeting their needs.

3.1.2. Areas to focus in counseling children in the context of HIV/ AIDS

Despite the many obvious intervention needs that vulnerable children have, the primary areas that counselors must focus attention on are:



- Helping the child establish intimacy in relationships;
- Helping the child explore and understand sexuality issues, feelings, and concerns; and
- Exploring and addressing issues of stigma and discrimination.

As counselors work deeper and deeper in these areas, the child will be able to regain the lost ability to trust, make appropriate choices, and deal with anger and other negative emotions. This in turn will help a more positive self to emerge.

3.1.3. Issues to be considered during counseling

- Working from a positive angle and with respect for the child;
- Identifying one supportive adult in the child's life who will constitute her/his secure base;
- Dealing with sexuality issues feelings, knowledge and behaviours;
- Helping the child to develop a sense of owning the consequences of an action or choice rather than ascribing it to external causes (e.g. If I had been born in a rich family, I would not have started smoking). This process is called an internal locus of control;
- Providing medical and psychological information that a child can understand and relate to;
- Linking with appropriate services;
- Helping the child build a sense of future goals;
- Arranging to meet the developmental needs of the child. (See Annexure IV on Developmental needs);
- Building skills to deal with emotions and behaviors, rather than just providing information;
- Maintaining the child in school;

- Planning for the child's relaxation and recreation; and
- Working with support systems, both within the child to build problem solving and negotiation skills; and with the family, the peer group, school, neighbourhood and the police and justice departments.

The counselor's role is essentially to facilitate children's thinking and talking about the above issues. The session must not become a question and answer exercise, where the child is a passive provider of information. Counselors should be able to raise issues of sex and sexuality and must be comfortable discussing them.

3.1.4. Important considerations for a counseling session

Key norms in conducting a counseling session:

- Establish rapport with the child;
- Respect the child's viewpoint and choices;
- Listen actively for the 'inner voice';
- Use age appropriate language. The use of colloquial language may help the children express themselves better;
- Work with the child using methods of participatory exploration and clarification;
- Be non-judgemental;
- Stay calm and unhurried;
- Establish a feeling of permissiveness; and
- Set boundaries for the session.

3.1.5. Attitude of a counselor

This encompasses the four basic pillars:

Respect: What the child or any family member says is treated

as a valued contribution to the dialogue of understanding in which the counselor and client(s) engage.

Acceptance: Whatever the child says is accepted by the counselor both verbally and non-verbally. The counselor accepts who the child is and how s/he lives.

Non Judgemental: Listening without criticizing or expressing opinions about how the client is living his/her life.

Empathy: In a counseling session, the counselor attempts to understand the client's experience; experiences the client's feelings; understands both the content of what the client says and feelings associated; and finally summarizes them for the client.

3.1.6. Essentials of counseling

- Allow your client time to think;
- Allow your clients the time to express their emotions; and
- Maintain contact with your client over an extended period of time.

3.1.7. The process of building rapport with children

To counsel children, you must form a relationship with them. To establish a relationship, you need to find a way to attract the child's interest and then involve them in an activity or conversation of interest to them.

For children five years and below do any of the following:

- Physically, get down to their level. If they are sitting on the floor, then you should do the same;
- Comment positively on their appearance;
- Show them several toys or objects that look interesting; and

- Find a simple game to play together e.g. rolling a ball, clapping hands.

For children 6 to 12 years do any of the following:

- Physically, get down to their level;
- Find out what activities or sports they like to play;
- Find out their hobbies or other interests;
- Look through an interesting magazine together; and
- Children of this age like to show adults what they can do. Ask them if they can do mildly challenging tasks such as balancing on one foot for a length of time, touching their nose and hopping.

For children 13 to 18 years of age, do any of the following:

- Comment positively on their appearance;
- Share an object of interest and discuss it, e.g. a beautiful rock or an object from another country; and
- Look through a magazine or newspaper together. Discuss their likes and dislikes on general issues like fashion, strength of the men, which sports figures they would like to be.

3.1.8. Tips to prepare for a counseling session

Before the parent/guardian or the child client enters the counseling session, a counselor must prepare in the following ways:

- Know how much time you have for the session;
- Be presentable;
- If you have seen your client previously, review your notes (The same counselor should see the client for both the pre and post-test sessions);

- Prepare any materials that you might need during the session well in advance;
- Assess your state of mind. If there are personal problems or concerns that might interfere when counseling your client, tell yourself you will deal with them after the session;
- Remove or turn off anything that might disturb you, eg: radios, phone, and computers;
- Arrange the chairs so that you and the client(s) can see each other easily. Keep the seating relaxed and informal, at a comfortable distance. Do not put a desk between yourself and your client;
- If you will be taking notes, ensure that pen and paper are ready; and
- Have other relevant items or materials easily accessible like toys, tissues and drinking water.

3.1.9. Tips for creating a child friendly environment

- Create boundaries of safety;
- You can give an approximate time to the child about how long the session will last;
- If the parents/guardians are not in the room, inform the child exactly where the parents/guardians will be. Show the child where they are sitting;
- Let the child know that whatever s/he wants to say, s/he can. A counselor should inform the child that s/he will not discuss anything with the child's parents without permission. Also, the counselor must add that the only time that the rule changes is if the child hurts him or herself, or

tells the counselor that s/he wants to commit suicide, and then the counselor will speak to the child's parents in order to help;

- The child is informed that this is “a safe place”. That this is a place where the child can relax, talk, and play. For the counselor, the rule is that the counselor cannot hurt the child, and the child cannot hurt the counsellor;
- Focus on the child. Show an interest in their life and their daily activities. Be curious. Appreciate who they are. Find the uniqueness in each child. Find out what is interesting or special about each child that you see;
- Have toys and objects that the child likes and that are age appropriate. (See Annexure VII for a sample playroom). Have toys and objects that will help you illustrate your discussion about HIV and what will happen during an HIV test;
- Use age appropriate language;
- Be calm and unhurried. Follow the child's lead. What they want to talk about and do encourage it, as long as it is not destructive or dangerous. Then you can bring them back to the main topic if they are not talking about it or showing it in their play.

3.1.10. Tips for ending a counseling session

- Summarize what has been discussed;
- Review your client's action plan or health plan;
- Discuss with your client(s) what will be talked about when you next meet;

- Acknowledge your client's contribution to the session;
- Ask your client(s) how they felt about the session;
- Ask your client(s) if they have any further questions;
- Set a date for the next counseling appointment;
- If appropriate, make any necessary referrals that were discussed in the session; and
- Accompany your client to the door.

3.1.11. Participatory methods for assessing the risk of HIV infection

There are several participatory methods to assess a child's risks for HIV infection.

The 10-seed exercise evolved in Tamil Nadu in South India, where women and children commonly use the seeds of the tamarind fruit as playing counters for board games drawn in the sand. Examples of other local materials that can be used include twigs, stones, bottle caps and coins.

This method can be used as a risk-ranking exercise among small groups of older children (13-18 years) who have already had an opportunity to talk about issues around HIV/AIDS, sexual behavior and alcohol and drug use. It works best when the facilitator is familiar enough for the children to feel comfortable, yet not so familiar as to embarrass them or use information against them.

Children work in small clusters of eight to ten and list out environmental and behavioral factors that make them vulnerable to HIV infection. The ranking is according to the numbers of seeds/counters they assign to the different factors. More important than

[10] The exercise has been refined by Dr Ravi Jayakaran, World Vision

the precision of the results is the discussion it provokes among children, providing the counselor important insights into their situations and responses. It also serves as a pointer to work with individual children for a more specific assessment.

Play therapy: Many professional counselors use the medium of play, especially with younger children who are unable to express their problems with words. Play is a natural and non-threatening outlet through which children express their inner struggles. In the play therapy environment, the child is the director of her/his play. The counselor gives constructive interventions and feedback to help the child overcome negative feelings, trauma, and struggles which may have left them feeling unbalanced.

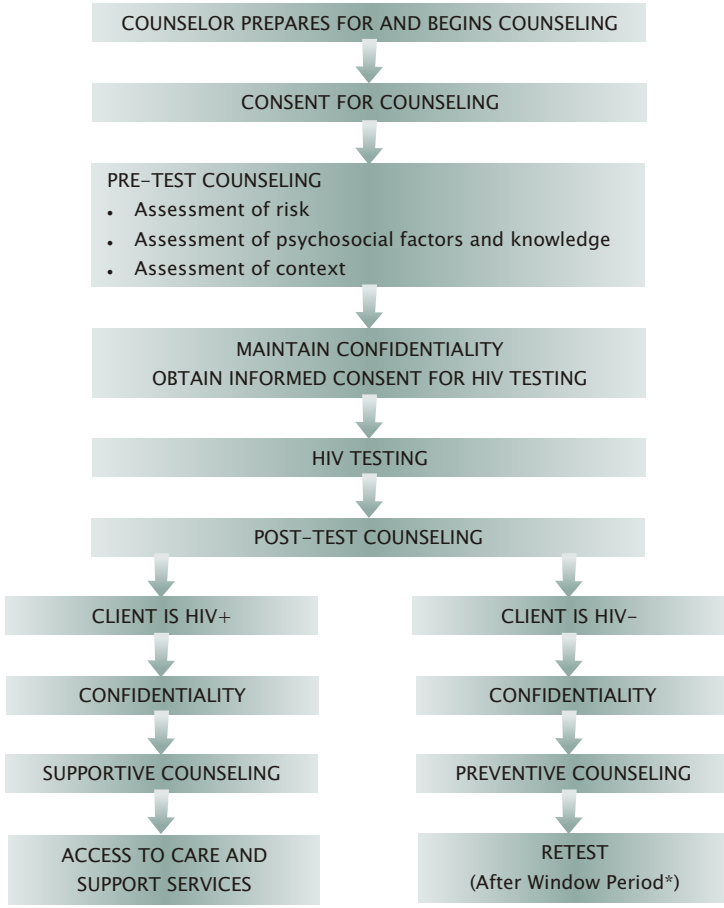
Play therapy can be used as a participatory risk assessment tool by observing the child and exploring specific actions. For example, a sexually abused child may act out the event through play with a set of dolls. Gentle and skilful probing by the counselor can help him understand the child's environment, specific events and the likely degree of risk for HIV infection. (Please see the Annexure VII for further details on Play Therapy).

Structured questionnaires though relatively non-participatory, can be controlled by children (if old enough and literate), if the counselor asks them to fill them out on their own, seeking clarifications or help only if they want.

3.2. Counseling in the Context of HIV Testing

HIV testing is an important part of the counseling continuum and counselors must be aware of the HIV testing method and possible test results *(Please see Annexure VIII for details)*.

Flow Chart: Steps involved in Pre and Post Test Counseling of Children



* Window period is the time between the entry of HIV virus in the human body and the formation of antibodies against it. This is usually between six to 12 weeks. The routinely conducted HIV test detects HIV antibodies, hence it remains negative during the window period. Thus someone can have a definite positive or negative result through the routine HIV test only three months after their last exposure to HIV. During this period, the virus can be transmitted to another person.

The counselor must also ensure that they refer the child for testing at a centre where the following conditions are ensured:

- Respect for the client;
- Quality of the test;
- Expertise of healthcare personnel;
- Availability of trained counselor;
- Accuracy of results;
- Confidentiality of result; and
- Availability of result within a reasonable time period (preferably one to three days).

3.2.1. Pre-test counseling

This is the first step in the process of HIV testing. Issues related to testing are complex, and people may want to discuss it with others before taking a decision. Counselors may need to allow for the pre-test counseling process to be spread over two or three sessions.

Objectives of pre-test counseling:

- The assessment of risk includes the child's personal history and risk of having been exposed to the HIV infection;
- Assessment of psycho-social factors and knowledge includes the childs' and parents/ guardians' understanding of HIV/AIDS, the testing procedure, and their support network for dealing with difficult issues such as HIV positive status; and
- The assessment of the context includes discussion on the social, economic, government policy and cultural factors that might influence the client's reasons for HIV testing. Does the family have the resources or

access to the resources to improve the child's life, especially a child who is diagnosed as HIV positive.

Exploring the reason for HIV testing

Before going in depth in the counseling session, the counselor must find out the reasons leading to the test: These could be:

- The child has been sexually abused and penetrative sex has occurred;
- The child had sexual exposure unrelated to sexual abuse;
- The child is sharing infected syringes and needles;
- The child shows symptoms suggestive of AIDS related illness;
- The child expresses the desire to have the test;
- If one/both the parents have HIV infection and have a young child;
- The child is pregnant;
- A child is at risk due to exposure to unsafe blood (through untested blood transfusion) or un-sterilized needles; and
- For purposes of placement in institutional child care, fostering or adoption.

Testing should not be mandatory in the above situations. The major question to be asked is what will be gained by testing the child? How will it improve the child's life? Protection of the caregiver is not an acceptable reason for HIV testing. Testing in these circumstances should be carried out only if the counselor, the child and parents/guardian feel that it is in the best interests of the child.

Criteria to help the counselor, parents and child decide if HIV testing would be in the best interests of the child

- Is the child presently showing any symptoms of HIV/AIDS related illness?

- Will the test results enable the child to obtain medical treatment that was not easily available (e.g. ART)?
- Will the test results reduce the child's anxiety about health?

If the answer is "YES" to at least two of these questions, then the test maybe in the best interests of the child.

Procedure to be followed with children of different ages:

Children up to five years old:

- First meet the parents/ guardians to discuss the reason for wishing to test the child;
- Discuss with parents/ guardian to determine how they wish to proceed with their child. To what extent do they wish the child to be involved and informed about the test procedure;
- If the parent requests that their child be tested without discussing the matter with him/her, explore their reluctance to inform the child about the nature of the test;
- If the parent/guardian requests the counselor to explore the testing issue with the child, ask the parent/guardian how they would feel if the child refused the test or accepted the test;
- Find out how much the parents/guardians know about HIV/AIDS and how much they would like their children to know;
- Take a medical history from the parents/ guardians to determine if the child may have been exposed to the HIV virus previously. For example, through vertical transmission, unsafe sex, or exposure to unsterilized needles or unsafe blood transfusion;

- Discuss with the parents/guardian how the implications of a positive or negative test result might affect them. The child's HIV sero-status might imply that the parents are infected as well;
- If the parent/guardian wants the child to have an HIV test, then invite the child in. If possible, have the parents talk to the child about their concerns first and encourage a dialogue between the parents and the child;
- Create a friendly and playful environment. Introduce the child to some toys (see Annexure VII on play therapy);
- Take time to get to know the child and their interests and find out more about what the child enjoys doing;
- Find out about the child's understanding and knowledge of HIV/AIDS as well as his or her feelings about having HIV test:
  - Can you tell me what you have heard about HIV/AIDS?
  - Is there anything that you want to know about HIV/AIDS?
- Answer the child's questions accurately and honestly. The information provided must be appropriate to the child's level of development and age;[11]
- Explain the testing procedure accurately and calmly. Do not try to

[11] Suggested Response: This is a test for HIV and not for AIDS. Having the HIV virus means that the virus is present in one's body and that the person is capable of infecting others. It is like having a flu virus. The virus can stay in a person's body for a long time and they still remain healthy. If we know that the virus is in your body we can find ways to weaken it and you will stay strong.

protect the child, such as by promising the blood test will not hurt. Give the child the facts in a way they can understand. You might want to explain using dolls or relevant objects *(see Annexure VII on play therapy)*;[12]

- Ask the child how s/he feels about having this type of test;
- If the child is alone, seek his/her permission to discuss their feelings with the parents/guardian;
- According to what has been agreed, obtain consent from the parents/guardians for the HIV test; and
- If the child does not seem ready for the HIV test or asks for more time, provide the child with as many pre-test sessions as they need. Encourage the support person -"the secure base" to come as well.

Children from 6 to 12 years old:

- Meet with parents/ guardian first to discuss what is their reason for wanting to test the child;
- Discuss how they wish the child to be involved and informed about the test procedure;
- If the parent requests that their child be tested without discussing the matter with him/her, explore their reluctance to inform the child about the nature of the test;
- If the parent/guardian requests the counselor to explore the testing issue with the child, ask the

[12] Suggested Response: This is a test to see if one is healthy. We will go like this (take a syringe without a needle and press it into the child's arm). It will feel like a fast bee sting. You try it into my arm. (Allow the child to press fairly hard)

parent/guardian how they would feel if the child refused the test or accepted the test;

- Find out how much the parents/guardians know about HIV/AIDS and how much they would like their children to know;
- Take a medical history from the parents/guardians to determine if the child may have been exposed to the HIV virus previously. For example, through vertical transmission, unsafe sex or unsterilized needles or blood transfusion;
- Discuss with the parents/guardian how the implications of a positive or negative test result might affect them. The child's HIV sero-status might imply that the parents are infected as well;
- If the parent/guardian wants the child to have an HIV test, then invite the child into the room. If possible, have the parents talk to the child about their concerns and encourage a dialogue between the parents and the child. If the parents cannot do this, then the counselor can summarize the part of the discussion that directly concerns the child (For example "You have been sick quite often lately and your parents want to help you to feel better");
- Create a friend and playful environment. Introduce the child to some toys (see Annexure VII on play therapy);
- Take time to get to know the child and his/her interests;
- Evaluate how comfortable the child is with you and if

the child could be separated from their parents without becoming upset. The older the child the easier this will be. You can simply ask the child if the two of you can play and talk while the parents wait outside. If the child looks upset with this request, the parents should remain with the child and the session continues;

- Find out the extent of the child's understanding and knowledge of HIV/AIDS:
  - Can you tell me what you know or what you have heard about HIV/AIDS?
  - Do you know anyone who has been HIV positive?
  - Do you know anyone who has had AIDS? What happened to them?
  - Is there anything that you want to know about HIV/AIDS?
  - Answer the child's questions accurately and honestly. The information provided must be appropriate to the child's level of development and age;[13]
- Explain the testing procedure[14] accurately and calmly. Do not try to protect the child, such as by promising the blood test will not hurt. Give the child the facts in a way they can understand. You might want to explain using dolls or relevant objects;

[13] Suggested Response: AIDS is the final stage of the HIV infection when the virus has seriously weakened the body's defences against the disease. The person will then become ill with a life threatening illness."

[14] Suggested Response: This is a test to see if you are healthy. We will go like this (take a syringe without a needle and press it into the child's arm). It will feel like a fast bee sting. You try it into my arm. (Allow the child to press fairly hard).

- Ask the child how s/he feels about having this type of test;
- If the child is alone seek his/her permission to discuss their feelings with the parents/guardian;
- According to what has been agreed, obtain consent from the parents/guardians for the HIV test; and
- If the child does not seem ready for a HIV test or asks for more time, provide the child with as many pre-test sessions as they need. Encourage the support person ("the secure base") to come as well.

Children from 13 to 18 years:

- Meet with parents/ guardian first to discuss what is their reason for wanting to test the child;
- Discuss how they wish the child to be involved and informed about the test procedure;
- If the parent requests that their child be tested without discussing the matter with him/her, explore their reluctance to inform the child about the nature of the test;
- If the parent/guardian requests the counselor to explore the testing issue with the child, ask the parent/guardian how they would feel if the child refused the test or accepted the test;
- Find out how much the parents/guardians know about HIV and how much they would like their children to know;
- Take a medical history from the parents/ guardians to determine if the child may have been exposed to the HIV virus previously. For example, through vertical transmission, unsafe sex or unsterilized needles or unsafe blood transfusion;

- Discuss with the parents/guardian how the implications of a positive or negative test result might affect them. The child's HIV sero-status might imply that the parents are infected as well;
- If the parent/guardian wants the child to have an HIV test, then invite the child into the room. If possible, have the parents talk to the child about their concerns and encourage a dialogue between the parents and the child. If the parents cannot do this, then the counselor can summarize the part of the discussion that directly concerns the child (e.g. "You have been sick quite often lately and your parents want to help you to feel better");
- Take time to get to know the child and their interests;
- Ask the adolescent if the two of you can talk while the parents wait outside. If the adolescent looks upset with this request, the parents should remain with their child and the session continues;
- Find out what the child's understanding and knowledge is of HIV/AIDS:
  - Can you tell me what you know or what you have heard about HIV/AIDS?
  - Do you know anyone who has been HIV positive?
  - Do you know anyone who has had HIV/AIDS? What happened to them?
  - Is there anything that you want to know about HIV/AIDS;
- Answer the child's questions accurately and

honestly. The information provided must be appropriate to the child's level of development and age;

- Explain the testing procedure accurately and calmly. Do not try to protect the adolescent, such as by promising the blood test will not hurt. Give the adolescent the facts in a way they can understand. You might want to explain using animal or human figures or relevant objects;
- Ask the child how s/he feels about having this type of test? Discuss with the child alone, if the child prefers, or with the parents and child together the advantages and disadvantages of testing for HIV; and
- According to what has been agreed, obtain consent from the parents/ guardians for the HIV test.

Guidelines for counselors:

- The parent/guardian should be given pre-test counseling before they can decide if they want their child/ward to undergo a test for HIV. Children must be reassured about the presence/ availability of a supportive adult through the process;
- It is necessary to prepare a child for the test. Generally, children above the age of 11 or 12 years are considered old enough to understand simple explanations about HIV. Questions must be answered simply, but honestly;
- The counselor must explain the benefits and possible disadvantages of knowing the status of the child, and facilitate the

ability of the parents/ guardian to make a choice in the matter. Children must feel comfortable to ask questions and communicate concerns;

- HIV infection must be projected as a medical condition that can be dealt with;
- Children must be reassured that a positive result is not shameful, wrong, or their fault;
- If old enough to understand, children must be empowered to refuse the test, if they so wish;
- If no parent/guardian is available, the counselor must identify an adult who can act as a secure base for the child.

Some Ethical Dilemmas the Counselor may have to deal with

- *What should the counselor do if the parent wants the child to test for HIV to provide better care?*
- *What if the parent wants the child to "test as a proxy" i.e in order to establish her/his own status?*
- *What if the child wants to have the test and the parent/guardian does not consent?*
- *What if the child does not want to test and the parent/guardian wants her/him to?*

These dilemmas are best handled by assessing if the test is in the best interests of the child. The bottom line is that the counselor should play the role of an advocate for the child, and should assess if knowledge of the child's HIV status will benefit her/him in any concrete way. 'Testing by proxy' is dangerous and the counselor must help the parent see that it is not really an option. It threatens the emotional well-being of the child, and exploits the child's innocence and ignorance. Besides, it can be misleading because a child testing positive for HIV need not mean that the parent/s is/are also positive, though it is very often the case, and child testing HIV negative does not mean that the parents are negative.

3.2.2. Informed consent

Informed consent refers to the process of informing the parents/guardian, and where applicable, the child, of the implications of having an HIV test; assessing existing knowledge, attitudes and beliefs about HIV/AIDS; exploring the advantages and the risks involved; and receiving explicit written permission to go ahead with the HIV test.

Young children may be unable to give consent for a test. Similarly, adolescents are usually referred for testing by a parent/guardian, or an institution. Testing in these circumstances should be carried out only if the counselor feels that it is in the best interests of the child/children to do so.

Under Indian law, consent given by children and adolescents under the age of 18 is not valid, and must be given by the parents/guardian. If an institution is the guardian of the child in its care, consent can legally be given by the institution. In case of a child living on the street without parent/ guardian, this would mean the child first needs to interact with staff of an agency working on HIV/AIDS and then the agency can act as de facto guardian of the child.

The concept of consent has three distinct but equally important aspects. First, consent is valid only if a person giving it is competent to do so. Second, consent must be properly informed. Third, consent must be voluntary.

Guidelines for counselors

- The counselor should explore the reason for HIV testing and go ahead only after being satisfied that the test is being done in the best interest of the child. In general, testing children for HIV can be considered only if:

- Child is sexually active;
- Child has been sexually abused;
- Child is a substance user;
- Child is symptomatic;
- Child expresses the desire to have the test; and
- One/both the parents have HIV infection.

- Counselors must emphasise that help is available, regardless of the results of the test or the child's circumstances;
- Where a child has no parents/guardian, the individual identified as the secure base[15] must also act as the child's legal advocate and explore options for action;
- If there is a possibility of the child being in the window period, counselors must advise appropriate precautions. These mainly include safer sex practices, abstaining from sex with more than one partner, not sharing needles, and testing and treatments for STI, if necessary.

The blood sample for HIV testing is drawn after pre test counseling and informed consent. *See Annex XIV for sample consent from.*

3.2.3. Post-test counseling

In India most children living with HIV acquire the infection from their parents; a child testing positive for HIV usually indicate that one or both the parent/s are likely to be HIV positive also. The counseling needs of the family as a whole

[15] The "secure base" refers to an adult in the child's life whom the counselor assesses as trustworthy, consistently available, and caring of the child's best interests. Ideally, this will be a parent, but can also be a family member, a neighbour or even a social worker.

becomes important while addressing the specific needs of the child. Even where parents do not test HIV positive, a diagnosis of HIV in their child can be devastating. Helping them cope will help ensure the well-being of the child.

Objectives of post-test counseling:

- Exploring the readiness of the parents/guardian/child to receive the test results;
- Sharing the result of the HIV test;
- Ensuring that the parents/child understood the meaning of the test result;
- Helping parents/guardian/child cope with the impact of a positive, negative, or an indeterminate result, and plan for risk reduction or coping;
- Providing relevant information and referrals for treatment, care and support;
- Planning for appropriate legal and educational services;
- Identifying support systems in the family/community;
- Exploring issues of confidentiality and disclosure; and
- Exploring need for succession planning and ensuring appropriate actions.

Procedure to be followed with children of different ages

Children up to five years old:

- First share the result with parents/guardians and discuss one more time with them the extent to which they wished the child to be involved and informed of the test result;
- With parents/guardians' consent, plan the ongoing counseling sessions to prepare the child for

disclosure (it can take up to six months);

- Explain the procedures to the parents/guardians; and
- Plan with parents/ guardians' for their own supportive counseling sessions to address psychological and other issues related to HIV/AIDS.

Children from 6 to 12 years old:

- First share the result with parents/guardians and discuss one more time with them the extent to which they wish the child to be involved and informed of the test result;
- With parents/guardians' consent, plan the ongoing counseling sessions to prepare the child for disclosure (it can take up to six months depending on the child' age);
- Explain the procedures to the parents/guardians;
- Speak to the child alone;
- Plan with parents/ guardians for their own supportive counseling sessions to address psychological and other issues related to HIV/AIDS; and
- Bring the parents and children together to summarize what has been discussed without violating the confidentiality of either the parents or child if needed.

Children from 13 to 18 years old:

- Share the result to parents/guardians or child as identified during the pre-test counseling session;
- Meet with the second party;
- Bring them together if needed;
- With the consent of both parties, plan the

supportive counseling sessions to help the child and parents/guardians cope with the test result;

- Explain the procedures to them;
- Then speak to the child alone and ask if s/he wants to be alone or with parents his/her parents for the counseling sessions;
- If possible, have the parents talk to the child about their concerns first and encourage a dialogue between the parents and the child; and
- Discuss with them again separately to address their psychological issues if needed.

Guidelines for counselors:

- Plan for more than one post-test session, especially if the child has been diagnosed with HIV;
- Give the result if the child, parent/guardian seems ready to receive it;
- Allow parents/guardian and the child, if appropriate, enough time to deal with a positive result, before discussing plans, referrals;
- Encourage the parents/guardian, and/or the child to speak about their feelings, concerns and needs;
- Help parents/guardian/children deal with feelings of shame and guilt associated with testing positive for HIV;
- Project HIV infection as a medical condition that can be treated;
- Assess need for, and ensuring access to appropriate referral services for the child and the family, where

applicable (including specialised counseling, medical services, support groups, abuse and domestic violence services, drug and alcohol services, legal and financial services, helping with spiritual well-being);

- Identify an adult who can function as a secure base for the child;
- Explore issues around disclosure (to whom, how much, with what consequences);
- Plan for risk reduction and care as appropriate including ART, nutritional support, home care, and treatment for opportunistic infections prophylaxis;
- In case of a negative result, helping parents/guardians, and the child, where appropriate, ensure that s/he remains negative;
- Refer the family/guardian/ child to a support group in the area, as early as possible;
- Identify support systems and services for the family (including institutional care);
- Plan for ongoing support as appropriate including anti retroviral therapy, nutritional support, home care, and treatment for opportunistic infections;
- Assure availability and ongoing support, if needed; and
- Plan for the next session, if appropriate.

Points to consider:

When a child is HIV negative or the result is indeterminate:

- After meeting with the parents/guardians, invite the child into the room;
- Explain to the parents/ guardian and the child that the test results are negative or indeterminate.

If less than twelve weeks had elapsed since the child was exposed to the HIV virus and tested, the child should be encouraged to come for retesting after 12 weeks (after window period);

- The parents/guardians and child should be encouraged to take the necessary precautions to prevent HIV infection in the future. (Please refer Annexure IX for details on prevention counseling); and
- If the child has the potential to be at risk for HIV infection, then discuss with parents and the child whether they can maintain these precautions and what obstacles they might face.

When a child is HIV positive

- Discuss with the parents/ guardians about how they wish the child to be involved and informed about the test results;
- Plan with the parents/ guardians for ongoing counseling sessions to prepare the child for disclosure. (This process can require from one week to six months);
- Explain the procedures for disclosure (see following section on disclosure);
- Plan with the parents/ guardians for their own supportive counseling sessions to address the various issues related to HIV/AIDS;
- Talk to the parents/ guardian and child to identify the adult(s) and children who can provide emotional support (the secure base) for the child and the family members when needed;
- Assess what help the child and family might need at

this time. Identify support systems and services for the family; and

- Plan for risk reduction and care. Discuss with the family what services they might need.

These services might be:

  - Medical services–ART, treatment of opportunistic infections;
  - Home based care;
  - Institutional care;
  - Specialized counseling (child or marital counseling);
  - Counseling and legal guidance for sexual abuse and domestic violence;
  - Drug and alcohol abuse counseling;
  - Legal and financial guidance;
  - Nutritional counseling;
  - Positive living; and
  - Spiritual support;

- Plan for ongoing support where needed. The counselor needs to follow-up to ensure that the services are being provided to the client. These would include:

  - ART;
  - Nutritional support (Please refer to Annexure X on nutritional needs of an HIV infected child);
  - Home based care; and
  - Treatment for opportunistic infections;

- How is the health of the surviving parent? Is there a need for succession planning? Make the appropriate referral or work with the parent(s) on this issue;
- What are the advantages and disadvantages of disclosure? Discuss with

parents (see section 7 on disclosure below)

- Disclosure to whom?
- How much to disclose?
- With what consequences?

- Discuss issues of confidentiality.
- Discuss support groups and PLHA networks.
- Arrange for the next session, if necessary.

(For further details on HIV testing please refer to the Annexure VIII)

3.2.4. Disclosure of HIV status

"Disclosure" refers to the process of letting somebody know about their own, or another person's, HIV positive status. Essentially it is a sharing of an HIV positive result of the child with a person other than the parents/guardian. Disclosure is voluntary when the HIV positive individual herself/himself talks about it or gives consent to another for the information to be disclosed. It is involuntary when the status is revealed by another person without the permission of the concerned individual.

There are contradictory viewpoints about disclosure of an HIV positive result of a parent/self to the child. While some people believe that children must be told that their parents/self have HIV, others believe it may be dangerous to do so, and risk breach of confidentiality. Disclosure can have a number of implications depending upon who is disclosing, how much information is disclosed, whom the status is disclosed to, when the status is disclosed, and how the status is disclosed.

Advantages of disclosure:

- It is easier for children to get involved with their medical treatment;

- It can facilitate children to understand the difference between themselves and other children;
- It can reduce the stress undergone by a child, who may be suspicious about her/his parent's status, but not be able to ask outright;
- The child may be aware of her/his own illness; and
- Identification of peers/close friends for feedback/follow-up.

Disadvantages of disclosure:

- Children may not fully understand what a HIV positive result means;
- Children may be depressed and not know how to seek help;
- Children may experience high levels of anger and resentment;
- Children may unwittingly talk about the result with others, leading to stigma and discrimination; and
- The emphasis on secrecy can result in feelings of guilt and shame which are harmful to self -esteem.

Guidelines for counselors:

When a child is HIV positive:

- The decision to disclose or not to disclose the results of the test to the child rests with the parents/ guardian. This decision also depends on the awareness and involvement of the child. If the child has been fully involved up to the stage of testing, s/he will need to know the result. Not knowing will make the child feel tremendously anxious, fearful and confused. The counselor has a duty to explain and explore the advantages and disadvantages of disclosure;

- Disclosure may be partial. This means telling the child that s/he has a medical condition that requires specific care, but not naming HIV/AIDS as the condition;
- Ideally, parents, or the primary caregivers, should be the ones to reveal the HIV test result. However, this may not always be appropriate, especially in cases of abuse, or where there is family discord or violence;
- The time to disclose the HIV status to a child should be determined by the child's level of development and emotional maturity, combined with the readiness and comfort of the parents/guardian to talk about such a sensitive topic. It is generally thought that the best time to tell a child her/his sero-status is ten to eleven years, though children as young as five or six years can understand, and cope with living with HIV/AIDS. By the age of 10 or 11, children are able to think about abstract issues, plan ahead and organise tasks independently. At this point they also begin to have opinions on social issues;
- The counselor must assess the probable post-disclosure reaction of the child, and tailor information appropriately;
- The best place to disclose the status is at home. However the counselor must assess if the parents/guardian is the best source of support, or if it should be some other individual;
- The child must be taught to keep the result a secret between herself/himself and the parents; and

- Explanations must be simple and questions must be answered simply but honestly.

When a parent/sibling is HIV positive:

- The decision to disclose rests with the parents/ guardian;
- If the parent/sibling is ill, it can be explained that s/he has a disease that is making her/him sick, but all possible care is being given to make her/him feel better;
- If the child is older (above 10 years), and the sibling is aware of her/his own positive status, it might be advisable to tell the child about the HIV diagnosis;
- Reassure the child that having HIV is not bad or wrong. It is an infection like any other, and can be medically treated;
- The child should be cautioned not to discuss the issue with anybody other than the parents and the counselors. S/he may be told that people do not understand this disease and are likely to treat the family badly, if they come to know;
- Help the child explore ways in which s/he can relate positively with the parent/ sibling; and
- Encourage the child to express her/his love and affection for the parent/ sibling to them.

Disclosure at school

There is very little evidence that other children have ever acquired HIV from a HIV positive child at school. It is not legally required to inform school authorities about the HIV-positive status of a child. However, people working with

HIV-positive children over a period of time recommend that school authorities be informed. They can be requested not to share the information, except with one or two people who may be primarily involved with the child. Most caregivers report positive experiences with disclosing to school authorities. There have been a few instances where children have been harassed or thrown out of school after disclosure.

The decision to disclose to the school should be made keeping in mind the possible impact of such a step on the child and should only be done to serve the best interests of the child. The school may need to help the child in adhering to medication, make allowances for her/his absences due to illness, and protect the child's confidentiality.

Disclosure to health care provider (HCP)

HIV-positive people report that health care personnel are the largest source of stigma and discrimination of people with HIV/AIDS in India. It is legally not required to inform a HCP of a child's positive status. However, if disclosure is found beneficial to serve the best interests of the child and to provide the most appropriate and efficacious care and treatment, counselors may advise the parents/guardian to disclose. In most health care institutions in India, confidentiality is poorly maintained. Counselors must discuss the importance of maintaining proper confidentiality with the institution before going ahead with disclosure.

Supportive Counseling

4. Supportive Counseling

This is a term used to describe the processes involved in reducing the impact of HIV/AIDS on children and their families.

Objectives of supportive counseling:

- Help the child, the family and peers, where appropriate, to accept and cope with the realities of HIV/AIDS;
- Increase knowledge and understanding of HIV/AIDS;
- Increase access to medical and other appropriate services;
- Assist the child to deal with specific physical and psychological issues; and
- Encourage linkages with other available support systems in the area.

4.1. Stages in Supportive Counseling

To assist the child and parents/guardians to cope with HIV/AIDS, there are several aspects of supportive counseling. These can be divided into three stages which are part of a cycle of support. Each of these stages may be revisited throughout the child's life.

Stage 1: Coping with HIV positive status

The issues to be addressed during this stage are:

- Coping with a HIV positive diagnosis;
- Identifying a secure base;
- Linkages with HIV prevention, treatment, care, support and treatment services;

- Working with the family; and
- Maintaining social integration.

When? Stage one of supportive counseling begins immediately after the child is found HIV positive.

Who does the counseling? The responsibility for counseling does not fall entirely upon the counselor. The counselor is most active in this stage of supportive counseling but the counselor's role decreases in stages two and three. In stage one the counselor involves family members, people with close relationships to the child ("the secure base"), and professionals who provide treatment, care, and support services.

How? The counselor listens to the feelings of the family regarding the HIV status of the child. The HIV positive status of the child might impact upon many different levels of the familys' life: the relationship between parent and child; the marital relationship; parents' relationship with adult peers; and the child's relationship with peers and adults such as teachers. The counselor addresses the life issues that arise. The counselor provides additional information where necessary about HIV/AIDS and links to treatment, care, and support services if the child is ill. Importantly, the counselor supports maintaining social integration of the child and the family. The child and the family should remain socially involved in all activities of the community (school and religious activities). Coping with a child's HIV positive status, is an issue that is frequently experienced by both the child and family members.

Stage 2: Skill building for Positive Living

The issues to be addressed during this stage are:

- Providing for the child's developmental needs;
- Building self-esteem;
- Coping with illness and bereavement; and
- Identifying future goals.

When? Stage Two starts when the family has made attempts to cope with the implication of their child's HIV positive status, has maintained social integration and kept the child in school, and made necessary linkages to treatment, care and support services.

Who provides the counseling? The counselor includes the qualified professional and lay persons - CBO/NGOs working with children, peers, religious groups, and all others with whom the child come into contact (family members, extended family, school staff, traditional leaders and counselors, neighbours). The professional counsellor orients and provides ongoing support to the lay counsellors on the issues to be dealt with.

How? The objectives of this stage are to strengthen the child's self esteem, support the child's developmental needs (physical, emotional, social, spiritual and mental), achievement of developmental milestones, assist the child in moving forward in life (future goals), and help the child cope with his/her own illness or illness of parents/guardians. The counsellor supports the child to express his/her feelings; the child may be encouraged to attend the Life Skills Education (LSE) sessions. The counsellor guides the home-based care staff to follow "Holistic Care Checklist" to ensure that the psychological and social needs of the child and the family are addressed *(see Holistic Care Checklist in Annexure XI)*.

Stage 3: Support systems and environments

The issues to be addressed during this stage are:

- Building peer relationships;
- Identifying support networks of CBOs/NGOs working with children;
- Maintaining spiritual well-being;
- Building supportive environment.

When? Stage one deals with the shock and immediate emotions that the child or family may experience. Stage two helps to strengthen the child psychologically. Stage three creates supportive environments around the child and family.

Who provides the counseling? The professional counselor and lay counselors

How? Child support systems need to be understood and strengthened. Think of the child as surrounded by "circles of caring". These are people in the child and family's life who care and support the child and the family on a daily basis. These support systems also support the counselor in knowing that there are also others who can help the child.

Guidelines for counselors

- Work with a positive attitude and communicate a sense of reassurance and optimism;
- Try to facilitate provision of holistic care (Refer to Annexure XI for the checklist on holistic care);
- Create an atmosphere of safety and trust for the child;
- Acknowledge that the child has suffered/is suffering a traumatic experience;
- Encourage the child to share feelings and

thoughts about the situation;

- Protect the child's privacy and confidentiality;
- Work closely with an adult, who can act as a secure base for the child;
- Prepare the child for separation/loss and bereavement, if necessary;
- Involve the family/guardian in the process;
- Encourage children to participate in planning for care of selves/families/ siblings;
- Provide information about available and approved treatments;
- Emphasise the concepts and methods of positive living;
- Link with support, services/networks of positive people, and CBOs/NGOs working with children;
- Refer to specialised care, where appropriate; and
- Seek help for oneself, if overwhelmed.

Confidentiality

5. Confidentiality

Maintaining confidentiality regarding the HIV status of children within an institution is one of the most difficult tasks. "Does confidentiality need to be maintained at all, especially if the institution only caters to HIV positive children?" is a common question. Though there is no explicit legal requirement on maintaining confidentiality, all Indian citizens have the right to non-discrimination, education, access to health care, dignity, employment and self-respect. Any action that threatens these rights can be challenged in a court of law. Thus breach of confidentiality that leads to violation of any of the basic rights of citizens can be legally challenged.

Each organisation must have a documented policy on confidentiality. A discussion on the issue among key staff and some positive people in the institution, if appropriate, keeping the following questions in mind, can be the first step in this process.

- What are the benefits and limitations of maintaining confidentiality for the child?
- What are the benefits and limitations of maintaining confidentiality for the institution?
- What is the usual method of receiving information regarding the status of the child?
- Who in the institution receives this information?
- Which other people in the institution also have access to the information?
- Where is the information kept? Is it secure?

- What are the possible sources of leak of information?
- Under what circumstances should the information be shared, and with whom?
- What exactly should be said? (write down sentences).
- Who should disclose the information?
- Where should the disclosure happen – at the hospital or in the institution itself?
- What steps can be taken in case confidentiality has been broken?

Once the policy is finalised, staff must have an opportunity to seek clarifications, understand how the policy works, and what their own responsibilities are in maintaining confidentiality. This is best done by organising a half-day session to which all staff and guardians of HIV positive children (if appropriate) are invited. Confidentiality measures should be applied to all staff, including receptionists and guards; all should be included in the training. The policy implications would depend on the nature of the institution, the confidentiality guarantees need to be more stringent in an institute catering to both HIV positive and negative children compared to only HIV positive children.

5.1. Key Questions on Confidentiality to be discussed with the Child and Parents

Pre-test Phase

- Who knows that you have come to discuss HIV testing?
- Whom do you want to tell that you have come for testing?

- Whom do you want to tell about your test results, if you decide to be tested?
- If your test results are negative, who would you like to tell?
- If your test results are positive, who would you like to tell?

Post-test Phase

- Now that the results are known, how do you want this information to be shared? (By letter, face to face contact);
- Now that the results are known to you, do you want this information to be shared with anyone else?
- With whom do you want to share this information;
- How much information do you want to share with each of these people?

5.2. Shared Confidentiality

In India, counselors often find that the notion of 'shared confidentiality', i.e., keeping the information confidential among a set of people (usually family or institution) is practiced. Culturally, this seems appropriate given the importance that families play in providing emotional and other support. However disadvantages of shared confidentiality in the context of prevailing fear and stigma around HIV/AIDS will have to be discussed, as such information rarely remains private. The other members who are party to the information must also be sensitive to maintaining confidentiality among an identified set of people.

Children may wish to keep information about themselves confidential. Under such circumstances, counselors are bound to respect their wishes.

India has ratified the UN Convention on the Rights of the Child (CRC). This implies that breach of confidentiality cannot be done at the cost of denying the rights of the child as defined in the Convention. (See Annexure I for details).

Guidelines for counselors

Counselors must help caregivers consider the following issues with respect to confidentiality.

- Who should have access to the information;
- Under what circumstances can be it shared;
- How much and with whom;
- Who should share the information;
- What security exists for the information;
- What steps will be taken in case confidentiality is breached;
- Indian law generally recognizes the position that person below 18 years of age are incapable of giving consent in the medical context; therefore in such case, it is the parent/ guardian who acts on behalf of the child and with whom the child's medical information should be shared; this also applies to disclosure of HIV status of a child. If the de facto guardian is an institution, the test result must be disclosed to the institution. However, the parent/guardian/institution must take care to see that the result remains confidential, and is not disclosed, except in the best interests of the child;
- HIV-related information can be released to an adoption agency. Due to the seriousness of the commitment involved, prospective adopters

should be given full information about the HIV status of the child. However, the decision to do so rests with the parents/guardian; the information to the adoption agency should be provided by the parent/guardian.

- Information should be revealed to healthcare personnel only if it helps them to provide better quality of care for the child. It should be confidential between the doctor and the immediate team;
- In a medical setting, the rule of thumb is to share information with only people who need to know, and as few people as possible;
- If children are aware of their status, they must be prepared before the status is shared with others. They can be told that other people need to know their secret for important reasons, but it will still be a secret shared among only a few people;
- Children find it hard to not talk about things and may unwittingly disclose their own HIV status. The parents/guardians should be the ones to decide when the child should be told about her/his positive status. The child must also be told to not talk about the result with others because of the possible negative reactions. The counselor must explain that having HIV/AIDS does not make the child bad or dangerous, but that many people are ignorant about the facts, and are afraid of people with HIV/AIDS;

Counselors must explain to the parents/guardian and the child, the circumstances under which confidentiality may need to be broken, such as in life threatening situations or those affecting the child's welfare.

Ethical Principles for Counselors

6. Ethical Principles for Counselors

Ethics is defined as a system of values conforming to the standards of conduct of a group or professional body. A code of ethics for counselors should include the following:

- The primary obligation of counselors is to respect the integrity and promote the welfare of the child, whether the child is assisted individually or in a group;
- The counseling relationship and information resulting from it should remain confidential, consistent with the legal obligations of the counselor. In a group counseling setting, the counselor sets a norm of confidentiality regarding the disclosures of all children;
- Counselors know and take into account the traditions and practices of other professional groups with whom they work, and cooperate fully with such groups;
- When a child's condition indicates that there is a clear and imminent danger to him/her, the counselor must take reasonable personal action or inform responsible authorities;
- Records of the counseling relationship, including notes, test data, correspondence, audio or visual tape recordings, electronic data storage, and other documents are to be considered professional information for use in counseling. They should not be considered a part of the records of the

institution or agency in which the counselor is employed, unless specified by law or regulations;

- Revelation to others of counseling records must occur only upon the expressed consent of the parents/guardian; counselors must make provisions for maintaining confidentiality in the storage and disposal of records. The data must be accessible only to appropriate staff members involved in the provision of services;
- Data derived from the counseling relationship for use in counselor training or research must be confined to content that can be disguised to ensure full protection of the child's identity. Information must be obtained with informed consent;
- Counselors must inform children/parents/guardian before, or at the time the counseling relationship commences, of the purposes, goals, techniques, rules, procedures, and limitations that may affect the relationship;
- Counselors must have updated information about HIV/AIDS issues and referral resources to ensure an effective referral can be initiated;
- Counselors must discuss professional values with their organisations so that there is no conflict; and
- Counselors may choose to consult with any other professional competent persons, senior counselors, peers, or supervisors about the child.
- Counselors should maintain an appropriate professional distance, and should nor get emotionally or physically involved with the child.

Special Issues

7. Special Issues

7.1. Role of Counselor in Anti-retroviral therapy (ART)

What is ART? ART is a combination of antiviral drugs prescribed for a person living with HIV/AIDS depending on the immune status and clinical symptoms and signs. The therapy prevents multiplication of the virus in the human body, resulting in strengthening of the immune system and prevention of opportunistic infections.

The following issues need to be considered before initiating ART:

Proper health care and services: ART drugs must be taken in proper combinations and dosage for a life long period. The therapy may also result in failure of drug response and sometimes serious side effects. The decision to initiate the therapy and provide a proper follow-up system is crucial. This can be best done by a physician trained in ART provision with access to adequate infrastructure. GOI initiated free ART program in April 2004 through select health centers in six states of India. *(Please refer to Annexure III for a listing of centers*. Currently there are sround 60,000 PLHA on ART in India. Physicians trained on ART are now available in most states of the country both in government and private sectors.

Cost: The simplest first line of ART combination costs around 1,200 Indian rupees per month. Combined with costs of investigations and transportation, the total may reach around Rs. 3,000 per month. The GOI program bears the cost for the drugs and subsidized investigation costs. However, medicines once started need to

be taken lifelong without any interruption as suggested by physician. Under NACP-3, NACO is expanding the number of ART centre and hopes to cover 300,000 PLHA with ART by 2011.

Psychosocial Support: Emotional support for clients on ART remains a cornerstone of care. Continuous drug information and counseling is essential for drug adherence. Issues of when, how, and to whom, to disclose HIV status need to be carefully planned.

Issues specific to children: Maternal HIV antibodies clear from the child's body in 18 months. Since the routine HIV test detects presence of HIV antibodies in the body, it would give a confirmatory diagnosis for the child only after 18 months of age. If there are symptoms and signs of HIV in a child before 18 months, a more sophisticated test (PCR) detecting HIV antigen can be utilized for diagnosis. This test is expensive (approximately Rs.3000/) and only available in a few major Indian cities. Further, paediatric formulations (liquid and tablets) of ART are not easily available. The Pediatric initiative that was launched in November 2006 has made available ART in pediatric formulations and dosages.

Guidelines for counselors

- The counselor should have information on the nearest available doctor and health facility qualified for ART and develop a rapport for referral.
- Counselors should encourage parent/ guardians who are HIV positive to visit the ART centre. Counselors should encourage parents to take their children who are living with HIV to attend the nearest ART centre for

screening and enrolment on ART.

- The counselor should also discuss the realities of ART, particularly that while it helps to a great extent; it is not a cure or a preventive tool.
- After a physician has suggested ART based on clinical examination and test, the counselor can play a crucial role in decision making to initiate the therapy. S/he should counsel on strict drug adherence and follow-up needs in depth with the parent/guardian.
- The counselor should provide ongoing psychosocial support for drug adherence, side effects, drug failures and other issues with the child and parent/guardian. Hence close coordination with the physician is critical.

7.2. Abuse

Abuse is described as an act that endangers or impairs a child's physical or emotional health and development. Abuse can be physical, emotional or sexual, as explained below.

Physical abuse occurs when a child is deliberately hurt, causing cuts, bruises and fractures through excessive beating.

Emotional abuse is the failure to provide the care necessary for a child's physical and emotional growth. It can include constant criticism, looking down upon a child, neglect, withholding praise and love, or verbally abusing the child.

Sexual Abuse Child sexual abuse occurs when a child is used for the sexual gratification of an adolescent, peer, or adult. It involves the exposure of a child to sexual contact, activity or behavior and may include invitation to sexual touching, intercourse, or other forms of

exploitation such as juvenile prostitution or pornography. Common indicators that a child may have been sexually abused can include excessive crying, an increase in irritability or temper tantrums, fears of a particular person or object, disrespectful behavior, poor school performance, bedwetting or soiling of pants, knowing more about sexual behavior than what is expected of a child of that age, sexualised play (e.g. trying to have sex with other children), and unexpected changes in behavior. Physical indicators can include unexplained pain, swelling, bleeding or irritation of the mouth, genital or anal area; sores, discharge or frequent itching of the genitals, pregnancy, unexplained difficulty in walking, or increase in headaches or stomach aches.

Guidelines for counselors

Disclosure of abuse may be a difficult process for children. However, if abuse has been reported, counselors must encourage the child to talk about it. In addition, counselors may need to work closely with the parents/guardians of the child. This may not always be appropriate, because in a majority of cases, the family itself may be the source of the abuse. Thus counselors need to assess whom to involve. The "secure base" for the child may be one good option. The "secure base" refers to an adult in the child's life whom the counselor assesses as trustworthy, consistently available, and caring of the child's best interests. Ideally, this will be a parent, but can also be a family member, a neighbour or even a social worker. One adult may function as a Secure Base for a group of 8 to 10 children. In India, there may be several individuals who may act as a Secure Base as the presence and participation of an adult in the child's life even

when s/he is older is an integral part of cultures and lifestyles of most people. It is important to explain to the person identified as Secure Base what is expected of them, and to allow them an opportunity to accept or refuse the role.

In general, there are five important messages that counselors must convey to a child who has disclosed abuse:

- I believe you;
- I am glad you have told me;
- I am sorry this has happened to you;
- It is not your fault; and
- I need to speak to other adults in order to help you and to try and make sure this does not happen to you again.

The following specific requirements must be addressed by the counselors:

Medical care: A sexually abused child will need a medical examination as soon as possible, both for treatment and for evidence. This examination must be conducted with parental/guardian consent. Ideally, a doctor trained in the area of child sexual abuse should examine the child. It is important to retain any evidence, such as stained underwear or clothes that can be sent for a forensic analysis to confirm abuse.

Medical examinations may evoke powerful reactions from a child. Before the medical examination, it is important to explain to the child that the purpose of the examination is to check for signs and symptoms of sexual abuse. It is also important to explain to the child that there may not be any visible signs of abuse, and that this does not mean that anyone thinks that s/he has lied. The results of the medical examination should always be discussed with the person who

cares for the child, and, where appropriate, the child.

Legal services: The law in India recognizes the crime of child sexual abuse, albeit not adequately and clearly under section 377 of the Indian Penal Code (IPC); counselors can advise parents/ guardians to file a complaint under this provision. If the child needs to be interviewed as part of a legal process, counselors should try and arrange for the interview in private, and in the presence of a person with whom the child feels comfortable.

Very often, police can be insulting, abusive or refuse outright to register cases of abuse. In such a situation, counselors should advise parents/guardians to file a copy of the complaint with the Human Rights Commissions as well as the State Commission for Women (SCW), which have the authority to enquire into the issue. Each state has also established a Child Welfare Committee (CWC) who can be approached for intervention.

Testing for STI and HIV: If a child has been sexually abused, s/he may be vulnerable to acquiring STI or HIV infection, especially when penetration has occurred. Testing and treatment for STIs must be initiated immediately with the permission of the parents/ guardian.

Note: An important issue to recognise is that counselors themselves may be vulnerable to emotional, physical or verbal abuse from the child/children they work with and must be aware of this possibility. Symptoms can include feelings of exploitation, emotional blackmail, fatigue, and resentment towards the child.

7.3. Succession Planning

Counselors need to help families plan ongoing care for the child, particularly if one or

both parents have HIV/AIDS. It is better to be prepared for placement of the child early on, and not wait until the parent/s are severely ill. Often, the burden of caring for sick parents fall on the child.

In India, if a child is to be placed for adoption, s/he must be relinquished to the care of an organization before the parent dies. Parents must state in their will that the child needs to be adopted. Children can be placed with the extended family, and an organization must make every reasonable effort to trace relatives. Another option for placement is a substitute or a foster care family. A variation of this is to place children with paid foster mothers living together with small groups of children. Institutional care is normally advised as a last resort.

If the child is being placed with a care facility in India, the counselor must advice the family to have the following:

- Birth Certificate of the child;
- Family history;
- Photograph of the child;
- Medical report of the child;
- HIV status of the child. This is mandated by law only when (a) children are being given in adoption, and (b) have been trafficked and rescued;
- Notarized declaration by the parents saying that the institution has all guardianship rights over the child; and
- Documents such as a 'Will' related to property rights or inheritance rights.

In case the parents are not alive, most institutions require a copy of their death certificate, and a written and notarized declaration before death stating that they transfer the

guardianship rights to the institution. There is a need to increase will writing among men, whose participation had been limited but critical to the preservation of familial property. Wills are more effective when the survivors are adults or older children, and far less so when the survivors are young children. It is thus strongly recommended to strengthen community sensitization and to engage local spiritual leaders and government bodies in the maintenance of property rights.

Guidelines for counselors

- Explore the suitability of members in the extended family to provide care for the child.
- Work with other staff to assess facilities and the quality of care available in shelters in the area.
- Encourage the parents/ child to visit the appropriate institutions.
- Encourage parents/ guardians to prepare necessary documentation.
- Prepare the child well in advance for the processes involved in adoption.
- Remain accessible to the child.

7.4. Preparation of a Child for Death and Dying

The main objective of the counseling intervention with respect to issues of death and dying is to ensure the physical and emotional comfort of the child on experiencing death of parent, sibling, friend and self. In all cases, the same counseling principles apply. Children should be helped to view death as part of life, and as an experience which may help them grow and mature. In India, children are usually allowed to stay where death has occurred and are included in the discussion and fears expressed within a family. This inclusion provides the comfort

of shared responsibility and shared mourning; it is gradual preparation for the child as well. Where death is viewed as taboo and discussion of it regarded as morbid, children will have unresolved grief and regard death as a frightening, mysterious, and traumatic experience.

Children below five years of age see death as reversible and are unlikely to understand its full meaning. Explanations should be brief, simple and concrete, such as "When people die they do not breath any more". Children between the age of five and ten years develop an understanding of death as irreversible, unavoidable and universal, though they often resist the idea of their own death. Older children begin to understand the true long-term consequences of death and the facts surrounding it. They experience similar emotions as adults but may find it harder to express them.

Things to be considered in communicating with children on death and dying:

The counselor should first examine her/his own attitude towards illness and death so

The child's view of death at different ages

9-12 months	Baby distinguishes between the presence/absence of a loved person. Can realize when the loved person has disappeared.
1-3 years	Death is reversible a person can be dead and wake up again.
3-5 years	"The magical stage" - Child thinks s/he can prevent death or cause it through certain behaviors. No understanding that they can die.

	Experience death as being abandoned. Little understanding of where a person goes to when they die.
5-8 years	Death is final and irreversible. A person cannot function when they are dead. "Superstitious thinking"-if mother coughed when she died, if I cough I will also die.
8-12 years	Confusion about what happens to a person when they die, especially with their physical body and their spirit.
12-18 years	Curious about physical and philosophical questions regarding death.

that s/he is able to talk about such matters without undue anxiety. This applies both in the case of a child who may be dying as well as a parent/ sibling/friend. If children are asking about the absence of a parent/sibling/ friend who has died, the counselor must tell the child the truth, as simply as possible.

Children who know they are very ill and suspect that they may be dying will have many fears including not knowing what is going to happen at the time of death, dying if they go to sleep, losing bodily functions, worry about what will happen to the body and soul after death, worry about family members left behind, and worry about toys and other possessions.

If a child is old enough to understand, and asking if s/he will die, the counselor can acknowledge that s/he is very ill, while leaving the door open for hope, namely new drugs,

treatments and chances of new techniques. The main thing is to communicate to the child that it is a process they- child, counselor and doctor- are going to share. Such a child will have confidence in the honesty of the counselor, and know that if there is anything that can be done, they will do it together.

7.5. Palliative and Terminal Care for a Dying Child

If the child is dying, talk to her/him, and play music s/he enjoys because hearing is the last sense that the child retains. Conveying care through touch, holding, stroking, hugging, touching can be a great source of comfort. This is often missing if children are in the hospital. The counselor should try to assess if the child is in pain and ensure access to appropriate pain medication. If the child is conscious, the counselor can arrange for people s/he cares for to be present through this process. Encourage them to communicate their love to the child. If a child wishes to talk about approaching death, help them do so. As far as possible, remain available to the child and the family/caregivers.

Guidelines for counselors

- Answer questions about death openly, simply and honestly.
- Encourage the child to talk about her/his fears.
- Allow the child to express sorrow without attempting to cheer her/him up.
- Allow the child to express anger safely without hurting self or others.
- Give the child time to cope with loss. Do not impose expectations of quick recovery.
- Identify a secure base for the child and involve this individual in the process.

- Accept that s/he may engage in searching behavior.
- Prepare to discuss questions relating to the child's religious or cultural beliefs.
- Help to make the loss real for the child by encouraging participation in rituals and keeping reminders of the dead family members around.
- Allow children to plan how they would like themselves to be remembered.
- Encourage children to make a memory book or box.
- Help family members to identify people or organisations who can provide support, such as friends, relatives, health workers, or other organisations.
- Provide family members with information on how to deal with distressing symptoms.
- Help the child with appropriate sources of spiritual support. Praying together, talking about the spirit, and about God, and teaching the child to meditate are good methods.
- Work with health care workers as a bridge between them and the child.

7.6. Gender

Gender is defined as society's expectation of behaviors by males and females. Counselors working with children have reported that there are differences in the needs of male and female children. One important area that counselors must address is the physical aspects of adolescence, including menstruation and accompanying bodily changes. A girl child's increased

vulnerability to rape and sexual abuse, which may sometimes lead to unwanted pregnancy, is associated with these changes.

Even in modern families, girls in India continue to internalise messages of inferiority as compared with boys. They are expected to contribute more to housework, care for younger siblings, and forego their share of food or other resources in favour of their male siblings. In the context of HIV/AIDS, these expectations can translate into caring for sick parents or for siblings, taking on the burden of running households, dropping out of school, and being forced by sick parents to marry early.

While the burden of care falls on the girl, the burden of earning for the family often falls on the boy child. This expectation can mean that the child takes on inappropriate amounts of work, loses relationships with peers, drops out of school and has little opportunity for vocation skill building. In addition, some boys prone to cross dressing and feminised behavior have greater chances of abuse or rape. Counselors have to be alert to issues of gender, and may need special training in this area.

7.7. Stigma and Discrimination

In the context of HIV/AIDS, stigma is the belief that 'people with HIV/AIDS have “done something wrong” and the fear that they will infect others. It often results in their social exclusion, and can lead to acts of discrimination. Children in India suffer from the impact of having a parent, sibling or themselves living with HIV. They are denied admission in schools, denied proper health care, and labeled as “AIDS” in hospitals. These practices are not merely violation of their rights, but are also the biggest barrier to the prevention of HIV

and provision of treatment, care and support. Feelings children associate with stigma include humiliation, anger, and loss of self-esteem, confusion, fear, anxiety and rejection. These should be addressed; otherwise children can turn to alcohol, drug use, violence, or in extreme cases suicide.

Guidelines for counselors

- Acknowledge the fact that stigma and/or discrimination exists.
- Encourage the child to talk about stigmatizing/discriminating behavior they have experienced, and listen to their feelings.
- Help the child build a positive self-image.
- Link the child/family with positive support groups in the area.
- File a complaint against discriminatory practices with local authorities as well as the State and National Human Rights Commission. Complaints should be filed only with the knowledge and consent of the child, wherever possible, and the parents/guardian. Counselors must discuss ways to protect confidentiality in such cases.
- Plan for outreach programs to schools and the community with the help of local support groups, NGOs and networks of PLHAs.

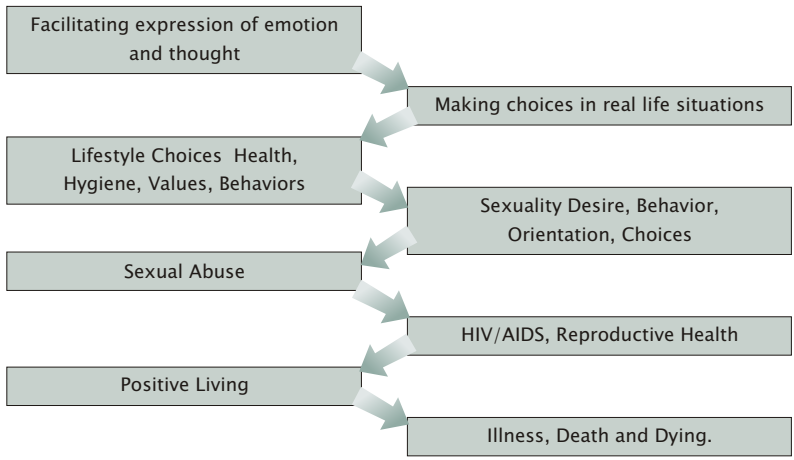
Operational Issues

8. Operational Issues

8.1. Integration with other Children

Integration with other children can be an issue, particularly in institutions caring for both HIV positive and negative children. Common problems reported by caregivers include issues around confidentiality, disclosure, illness and death. One of the most important factors that promote integration is an open discussion among staff and children about mourning and bereavement. This is especially important when older children take care of and interact with younger HIV positive children; they will particularly feel the impact of when children die. Each organisation must evolve a policy that is documented and followed. This process is best conducted through discussions among staff. The discussion questions provided in the section on confidentiality can be used as a guideline.

To facilitate integration, organisations must work with staff and children in the following areas.



Children deal with sensitive issues like sexuality, HIV/AIDS, illness and death much better when they are acknowledged as part of normal life, and discussed together.

8.2. Working with Schools

Schooling is the easiest way to meet many development and relationship needs of children. School allows children to develop cognitive skills, make friends, feel part of a peer group, learn to negotiate, enjoy cooperation and competition, and simply have fun. However, stigma and discrimination around HIV/AIDS can also make attending school difficult.

Freedom Foundation in Hyderabad has developed guidelines, listed below, for childcare organisations to admit and retain children with HIV/AIDS in schools.

- Visit four to five schools in your locality to determine which three principals may be open to change. (Do not talk about HIV/AIDS at this stage).
- Ask the principals if the organisation can conduct education programmes on HIV/AIDS for staff. If the answer is yes, go ahead. If the answer is "no", look for another school.
- Talk about HIV/AIDS with the staff. Explain transmission methods in detail. Leave a lot of time for questions. Work with a small group of about 15 people to encourage a feeling of safety and intimacy. This environment will encourage people to ask questions.
- Invite principals and teachers to meet HIV positive children or a HIV positive child-care facility in your locality.
- Encourage the school faculty to interact and build a rapport with the

children. A monthly visit by a few members of the school faculty would be a good idea. Do not mention admission of positive children.

- Enquire if the school is willing to hold an awareness programme for the school Parent Teacher Association (PTA).
- Once the PTA meeting is held, approach the principal regarding admission of positive children in the school. Emphasise the low risk of HIV transmission from one child to another.
- If your State has passed an order regarding admission of children living with HIV/AIDS in schools, share the order with the principal. For example Andhra Pradesh has passed an order making it compulsory for school authorities to admit HIV positive children.
- If the principal is willing, have a discussion regarding disclosure to other staff. The rule of thumb is to disclose a child's HIV status to as many people as necessary and as few as possible.
- Teach the child to care for her/himself. For example, if the child has a fall, s/he should immediately go to a teacher designated by the school for the purpose.
- Teach the designated teacher how to dress minor wounds and cuts using universal precautions.
- If you fail, try and try again.

8.3. Referrals

Referral is an essential component of care of children vulnerable to, affected by, or living with HIV/AIDS. Referrals include services for specialised counseling, testing, medical care, legal and financial help,

positive support groups, shelters, skills training centres, employment agencies and spiritual carers.

Steps for developing a referral network

Step 1 Maintain a list of appropriate referral services in the area.

Step 2 Ask other users/ organisations about the quality of services provided.

Step 3 Visit the centre/office to assess the nature, availability and quality of services.

Step 4 Check for confidentiality procedures.

Step 5 Check for signs of discriminatory practices.

Step 6 Identify a contact person who can be approached when necessary.

The government counselling and testing counsellors may not be adequately trained to counsel children. It is preferable that the referring NGO counselor having experience of working with children also provides the pre-test counseling. To ensure consent, the counselor should accompany the child to the testing centre, use an assumed name for the child, be present during the counseling session, and help the child clarify doubts after the session. (Refer Annexure XII for list of USAID/FHI supported list of NGO projects for prevention and care and support services to OVC).

A Model of collaboration between NGO and CT centres: The model described herein suggests that NGOs and CTC can complement each others' efforts to ensure that the client receives the best possible services. If CTC staff is limited by the amount of time they can spend with clients, NGO staff

can contribute by meeting with the client to prepare them for the CTC process, as well as provide follow up. There are several ways in which this partnership can operate:

- The NGO staff meets with clients before the CTC procedure and also provides follow-up. They may accompany the client to the CTC;
- The NGO provides staff that can work in the CTC and support the work of the center's staff; and
- The NGO functions as a mobile CTC providing counseling and testing and the CTC provides analysis of the blood samples.

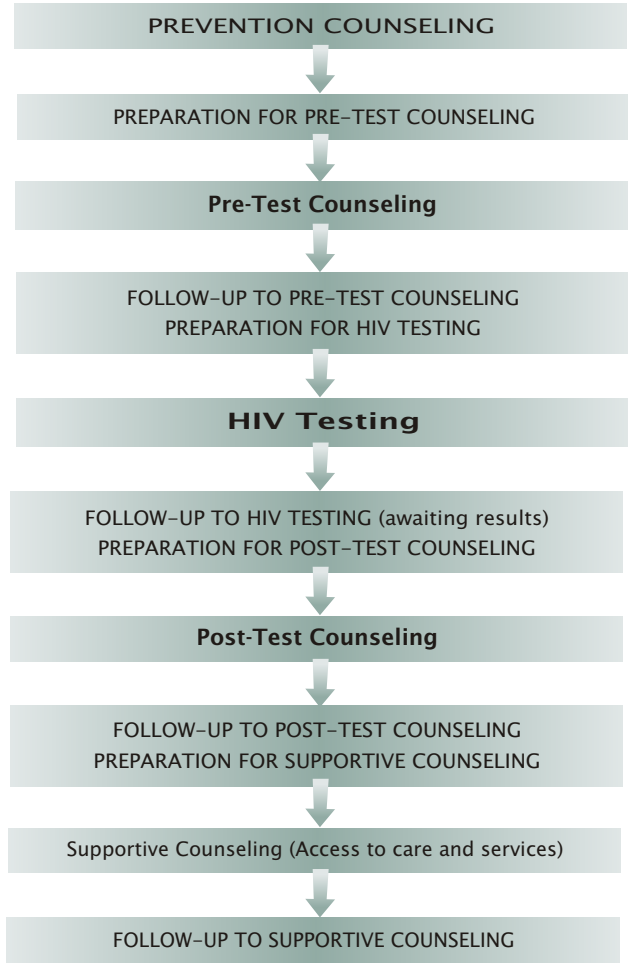
In the flow chart below, a model of Option One is presented wherein the NGO staff meets with clients during all phases of HIV/AIDS counseling, providing preparation and follow-up to the work of the CTC. Because of the pressures of work or lack of staff training, many CTCs require additional support from NGOs. In many areas the CT centers are the only site for HIV testing. The NGOs can provide useful support to by providing in-depth client counseling and developing an ongoing relationship with the client. In order to develop a comprehensive treatment strategy for clients, NGO and CTC staff should work together to determine how each can support the other. NGOs might be well-placed to provide the following counseling support:

- Preparation for pre-test counseling;
- Follow-up of pre-test counseling;
- Preparation for HIV testing (if the client chooses to be tested);
- Follow-up of HIV testing;
- Preparation for post-test counseling; and

- Follow-up of post-test counseling.

If the client's financial resources or inability to access counseling prevent all these steps from being completed, then preparation for pre-test counseling and follow-up of post-test counseling are essential.

Flow Chart



(The steps for the NGO are in regular font, and CTC steps are in bold.)

Training

9. Training

Counselors working with children in the context of HIV/AIDS, require training in many areas, including counseling theory and skills, communication, sexuality, gender, human rights, ethics, reproductive health, HIV/AIDS, alcohol and drug use, abuse, death and dying and advocacy strategies.

Because training in India focuses on knowledge and relies on information provision as the key method, counselors often end up knowing what they need to be doing, but do not know how to do it. A good trainer must have in-depth field experience, skills in participatory training methodologies, and an intellectual ability to collate and present information in a way that trainees can understand. Good training can be expensive: professional organisations usually set aside about 10% of their annual budget under this head.

Guidelines for effective training

- Training must focus on skill building for counselors.
- It must be participatory.
- Resource persons must be trained themselves in using participatory methodologies. Often experts in the field are very good at sharing experiences but have little or no understanding of participatory methodologies.
- Experiential methods that allow trainees to feel and express emotions are very effective in counseling-related training.

- Training must be structured, and over a period of time, allowing trainees to build upon experiences on the field.
- Training and materials must be in the local language.
- A set of handouts/ materials pertaining to each session must be available for distribution at the beginning of the training.

Supervision

10. Supervision

Supervision is a little understood, and often neglected area of work. Traditionally, supervision has been viewed as synonymous with monitoring and evaluation. A more effective interpretation translates the goals of supervision as:

- Encouraging and supporting personal growth and development;
- Assisting improvement of professional knowledge and skills; and
- Overseeing implementation of planned work.

Emphasizing personal growth motivates people to perform better and be more open in their beliefs. Coupled with assistance to improve professional skills and knowledge, supervision can also be vital in self-monitoring quality of services. Management of supervision should be in line with organizational goals, and should ensure effective and timely completion of planned outputs.

Supervision is necessary for all counselors, not as support only for those dealing with excessive stress or not performing effectively. It needs to be provided regularly, about once a month, and consistently. Supervision support should be planned for as part of the activity calendar.

Ideally, supervision should include:

On-site supervision: Supervisor observes the counselor working with a specific child/children, after obtaining consent. This observation is followed by individual or group sessions with the counselors.

One-to-one supervision: Supervisor works with the

counselor to reinforce effective approaches that the counselor uses, and highlights areas that need attention. The significant part of this process is the assistance provided to the counselor to explore her/his motives for using specific approaches/responses. This helps counselors become aware of their own prejudices, fears, beliefs, so that they can be alert the next time.

Group supervision is done with a group of about eight to 12 counselors. It helps in sharing of experiences, as well as promotes personal bonding between counselors and professional development. A combination of exploratory exercises, case discussions, teaching and affirmations are used.

Peer supervision is done by two or more counselors who meet periodically to share experiences and case discussions, challenges, and personal issues in the counseling process. Peer supervision is ideal when there are no/trained supervisors available.

Note: It is preferable that the same supervisor works with a set of counselors over a period of time.

Client Feedback

In addition to training and supervision it is useful to get feedback from children whenever possible, and parents/guardian, about their view of the services. What did the counselor do that they liked, what were the questions asked that they were uncomfortable with, would they come back for more sessions, how did they feel after the session as compared to before are some questions that can be asked. The interviewer may be an external person or another organisation whose services the children/parents/guardian use.

Supervisors must keep record of all sessions, but these records are confidential and require consent of the counselor/supervisee before disclosure to anybody, including the head of the concerned institution. Special circumstances where information can be disclosed must be discussed and agreed upon between the supervisor and the supervisee beforehand. More general reports that do not reveal the counselor's identity, and highlight areas that need attention, can be made available to the organization for reference and to help plan future trainings.

Quality Assurance

11. Quality Assurance

All organisations must have a checklist of quality requirements against which they can assess services. These include the following:

- Organisational policy statements on issues of consent, disclosure and confidentiality;
- Protocols for counseling children. (Please refer to the Annexure XIII for a sample checklist for counselors);
- Privacy requirements;
- Qualifications and training of counselors;
- Supervisory reports;
- External reviews; and
- Exit interviews with clients.

The following strategies can help organisations working with children to ensure quality:

Periodic, ongoing, structured supervision should happen both 'on-site' i.e., while the counselor is with the child, as well as outside of this setting. On-site supervision is easier when the counselor is working with a group of children. The counselor must explain the presence of the supervisor, as an observer who can help the counselor do her/his own work better. The counselor must seek consent and must facilitate children to express concerns, including refusing consent. The supervisor observes the counselor's relationship with the children, and later, gives feedback, explores possible problem areas, and provides guidance. Supervisors must have a written report of the session to monitor the counselor's progress. The reports are also useful when planning trainings.

Case discussions can be an important way to help

counselors, as well as maintain quality. The entire team–caregivers, counselor, outreach worker, and other staff responsible for the children, meet once a week, or fortnight, and discuss progress of specific children, as well as relevant operational issues. A case discussion is a forum that can both critique a counselor's approach as well as offer support. Time must be allocated for case discussions as part of the work calendar.

Diary: Counselors are usually encouraged to maintain a diary that only the supervisor can access. The principal objective of maintaining a diary is to support the counselor's personal growth. Counselors must be encouraged to record their feelings and thoughts, in specific cases, not so much "what they did", but what the session "did to them". Supervisors can help counselors understand the motives behind their responses in specific situations, examine attitudes, concerns and prejudices, and develop more effective ways of working.

Refresher trainings are essential to keep counselors involved with active learning, and expand their skills and areas of knowledge. Ideally, they should be held once every six months.

Exposure visits to, and discussions with other centres working on counseling interventions, including those with children, are a valuable learning exercise and can help improve quality.

Burn-Out

12. Burn-Out

For those working in HIV/AIDS care, and particularly with children, stress is common. Heavy workload, unreasonable demands, intensity of expectations, illness and death of children, and non-availability of adequate care, can cause high levels of stress leading to burn-out. Burn-out is a condition noted among caregivers, usually characterized by emotional and physical exhaustion. The main symptoms of burnout include chronic fatigue, anger at those making demands, self-criticism, cynicism, negativism and irritability, a sense of being besieged, and hair-trigger display of emotions.

Dealing with Burn-Out

The first thing organisations must do in the case of burn-out is to encourage counselors to seek professional help. However this option may always not be available or even practical. Counselors are usually poor at seeking professional help, often feeling ashamed that they cannot solve their own problems. In such situations, organisations can assist by moving them into a less demanding, and more routine role with less responsibility. Taking time off, developing a hobby, and establishing a social network are some helpful strategies.

Processes to help prevent burn out include:

- Regular staff meetings to discuss and promote communication;
- Regular case review meetings;
- Clear job descriptions for staff;
- Periodic training for staff;
- Supervision of staff;
- Encouraging staff to take regular holidays, and not work beyond office hours; and
- Social outings for staff.

Annex

Annex I: Rights of a Child UN Convention on the Rights of the Child, (CRC), 1993

Rights of the child in the context of HIV/AIDS

The United Nations Convention on the Rights of the Child (CRC) is the human rights instrument that sets out the rights of children and adolescents, taking into account their particular needs for protection, and the opportunities they require for growth and development. According to article 1 of the Convention on the Rights of the Child, a child is every human being below the age of 18 (this includes adolescents) unless, under the law applicable to the child, majority is obtained earlier. The Convention is a vital tool for those who work towards improving the conditions of life for children and adolescents throughout the world.

In the context of HIV/AIDS, the CRC has spelled out principles for reducing children's vulnerability to infection and for protecting children from discrimination because of their real or perceived HIV/AIDS status. This human rights framework can be used by governments to ensure that the best interests of children with regard to HIV/AIDS are promoted and addressed.

- Children's right to life, survival and development should be guaranteed.
- The civil rights and freedoms of children should be respected, with emphasis on removing policies which may result in children being separated from their parents or families.

- Children should have access to HIV/AIDS prevention education, information, and to the means of prevention. Measures should be taken to remove social, cultural, political or religious barriers that block children's access to these.
- Children's right to confidentiality and privacy in regard to their HIV status should be recognized. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved which should be obtained in the context of pre-test counseling. If children's legal guardians are involved, they should pay due regard to the child's view, if the child is of an age or maturity to have such views.
- All children should receive adequate treatment and care for HIV/AIDS, including those children for whom this may require additional costs because of their circumstances, such as orphans.
- States should include HIV/AIDS as a disability, if disability laws exist to strengthen the protection of people living with HIV/AIDS against discrimination.
- Children should have access to health care services and programs, and barriers to access encountered by especially vulnerable groups should be removed.
- Children should have access to social benefits, including social security and social insurance.
- Children should enjoy adequate standards of living.

- Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.
- No discrimination should be suffered by children in leisure, recreational, sport, and cultural activities because of their HIV/AIDS status.

Special measures should be taken by governments to prevent and minimize the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices.

Annex II: Guidance on ABC approach of HIV prevention

Excerpts from "Guidance to US Government In-country staff and Implementing Partners Applying the ABC Approach to preventing Sexually-Transmitted HIV infections within The President's Emergency Plan for AIDS Relief

(From the "Office of the US Global AIDS Coordinator)

Defining the ABC Approach

The ABC approach employs population-specific interventions that emphasize abstinence for youth and other unmarried persons, including delay of sexual debut; mutual faithfulness and partner reduction for sexually active adults; and correct and consistent use of condoms by those whose behavior places them at risk for transmitting or becoming infected with HIV.

Abstinence programs promote the following:

- Abstaining from sexual activity as the most effective and only certain way to avoid HIV infection;
- The development of skills for practicing abstinence;
- The importance of abstinence in eliminating the risk of HIV transmission among unmarried individuals;
- The decisions of unmarried individuals to delay sexual debut until marriage; and
- The adoption of social and community norms that support delaying sex until marriage and that denounce cross-generational sex; transactional sex; and rape, incest, and other forced sexual activity.

Be faithful programs promote the following:

- The elimination of casual sexual partnerships;
- The development of skills for sustaining marital fidelity;
- The importance of mutual faithfulness with an uninfected partner in reducing the transmission of HIV among individuals in long-term sexual partnerships;
- HIV counseling and testing with their partner for those couples that do not know their HIV status;
- The endorsement of social and community norms supportive of refraining from sex outside of marriage, partner reduction, and marital fidelity, by using strategies that respect and respond to local cultural customs and norms; and
- The adoption of social and community norms that denounce cross-generational sex; transactional sex; and rape, incest, and other forced sexual activity.

Condom use programs promote the following:

- The understanding that abstaining from sexual activity is the most effective and only certain way to avoid HIV infection;
- The understanding of how different behavior increase risk of HIV infections;
- The importance of risk reduction and a consistent risk-reduction strategy when risk elimination is not practiced;
- The importance of correctly and consistently using condoms during every sexual encounter with partners known to be HIV-

positive (discordant couples), or partners whose status is unknown;

- The critical role of HIV counseling and testing as a risk-reduction strategy;
- The developments of skills for obtaining and correctly and consistently using condoms, including skills for vulnerable persons; and
- The knowledge that condoms do not protect against all STIs.

Two overarching considerations in implementing the ABC Approach

- Individual programs must be appropriately designed to meet the needs of the target audience
- Information on the correct and consistent use of condom must be coupled with:
  - Information on abstinence as the only 100% effective method of **eliminating the risk** of HIV infection; and
  - Importance of HIV counseling and testing, partner reduction and mutual faithfulness as methods of **risk reduction.**

Age appropriate ABC information for youth

Young people are the most important asset to any community or nation. Protecting them from contracting HIV is unquestionably one of the most important missions of the Emergency Plan. Young people who have had their sexual debut must be encouraged to practice abstinence until they have established a lifetime monogamous relationship. For those youth who have initiated sexual activity, returning to abstinence (secondary abstinence) must be a primary message of prevention

programs. Implementing partners must take great care not to give conflicting message with regard to abstinence by confusing abstinence messages with condom marketing campaigns that appear to encourage sexual activity or appear to present abstinence and condom use as equally viable, alternative choices.

For 10 to 14 year olds, promotion of only AB including:

- Dignity and self-worth;
- The importance of abstinence in reducing the transmission of HIV;
- The importance of delaying sexual debut until marriage; and
- The development of skills for practicing abstinence.

For older youth above age 14, promotion of ABC including:

- Dignity and self worth;
- The importance of abstinence in reducing the transmission of HIV;
- The importance of delaying sexual activity until marriage;
- The development of skills for practicing abstinence, and where appropriate, secondary abstinence;
- The elimination of casual sexual partnerships;
- The importance of marriage and mutual faithfulness in reducing the transmission of HIV among individuals in long-term relationships; and
- The importance of HIV counseling and testing. Provide full and accurate information about correct and consistent condom use as a way to significantly reduce-but not eliminate-the risk of HIV infection for those who engage in risky sexual behaviors.

Integrated ABC program for youth

It must be recognized certain young people will, either by choice or coercion, engage in sexual activity. In these cases an integrated "ABC" approach is necessary.

Such programs should have the following characteristics:

- Be located in communities where youth engaging in high-risk behaviors congregate;
- Be coordinated with school-based abstinence programs so that high-risk in-school youth can be easily referred; and
- Be targeted to specific high-risk individuals or groups (i.e. not involve the marketing of condoms to broad audiences of young people).

Annex III: List of Government ART Centers

List of 100 ART Centers (Source NACO, February 2006)

Existing Centers (50)

S.No.	State	
1.	Andhra Pradesh	Government Medical College, Guntur
2.	Andhra Pradesh	Government Medical College, Vizag.
3.	Andhra Pradesh	Osmania Medical College, Hyderabad
4.	Assam	Medical College, Gauhwati
5.	Chandigarh	PGIMER, Chandigarh
6.	Delhi	AIIMS, New Delhi
7.	Delhi	DDU Hospital, West Delhi
8.	Delhi	GTB Hospital, East Delhi
9.	Delhi	LNJP Hospital, New Delhi
10.	Delhi	LRS Hospital, Delhi
11.	Delhi	RML Hospital, New Delhi
12.	GGH, Pondicherry	GGH, Pondicherry
13.	Goa	Government Medical College, Bambolim
14.	Gujarat	BJ Medical College, Ahmedabad
15.	Himachal Pradesh	IGMC, Shimla
16.	Karnataka	Bowring & Lady Curzon Hosp., Bangalore
17.	Karnataka	KIMS Hubli

18.	Karnataka	Mysore Medical College, Mysore
19.	Karnataka	VIMS, Bellary
20.	Kerala	Medical College, Thiruvantharam
21.	Kerala	Medical College, Thrissur
22.	Madhya Pradesh	Medical College, Indore
23.	Maharashtra	BJ Medical College, Pune
24.	Maharashtra	NARI, Pune
25.	Maharashtra	Government Medical College, Nagpur
26.	Maharashtra	Government Medical College, Sangli
27.	Manipur	Jawaharlal Nehru Hospital, Imphal
28.	Manipur	RIMS, Imphal
29.	Mumbai	Sion Hospital, Mumbai
30.	Mumbai	JJ Hospital, Mumbai
31.	Mumbai	KEM Hospital, Mumbai
32.	Mumbai	Nair Hospital, Mumbai
33.	Nagaland	Naga District Hospital, Kohima
34.	Rajasthan	SMS Hospital, Jaipur
35.	Tamilnadu	Coimbatore Medical College
36.	Tamilnadu	GHTM, Tambram, Chennai
37.	Tamilnadu	Government Hospital, Namakkal
38.	Tamilnadu	Government Medical College, Madurai
39.	Tamilnadu	Kilpouk Medical College, Chennai
40.	Tamilnadu	Madras Medical College, Chennai
41.	Tamilnadu	Medical College, Kanyakumari
42.	Tamilnadu	Medical College, Salem

43.	Tamilnadu	Medical College, Tirunelveli
44.	Tamilnadu	Thanzavur Medical College
45.	Tamilnadu	Theni Medical College
46.	Tamilnadu	Trichy Medical College
47.	Tamilnadu	Vellore Medical College
48.	Uttar Pradesh	Banaras Hindu University, Varanasi
49.	Uttar Pradesh	KGMC, Lucknow
50.	West Bengal	School of Tropical Medicine, Kolkata

New centres to be established (50)

S.No.	State	
1.	Andhra Pradesh	Dist. Hospital, Cuddolre
2.	Andhra Pradesh	Dist. Hospital, Prakasam
3.	Andhra Pradesh	Medical college, Ananthapur
4.	Andhra Pradesh	Medical college, Kakinada
5.	Andhra Pradesh	Medical college, Karnool
6.	Andhra Pradesh	Medical college, Tirupati
7.	Andhra Pradesh	Medical college, Vijayawada
8.	Andhra Pradesh	Medical college, Warangal,
9.	Arunachal Pradesh	General Hospital, Nahar Lagun
10.	Assam	Medical College, Dibrugrah
11.	Bihar	Medical college, Gaya
12.	Bihar	Medical college, Patna
13.	Chhatisgarh	Govt Medical College ,Raipur
14.	Delhi	Safdarjung Hospital
15.	Gujarat	Medical College, Surat

16.	Harayana	Medical College, Rohtak
17.	J & K	Govt Medical College, Jammu
18.	Jharkhand	Govt Medical College, Ranchi
19.	Karnataka	District hospital, Bagalkot
20.	Karnataka	District hospital, Belgaon
21.	Karnataka	District hospital, Bijapur
22.	Karnataka	District hospital, Davangeri
23.	Karnataka	District hospital, Gulburga
24.	Karnataka	District hospital, Kolar
25.	Karnataka	District hospital, Mangalore
26.	Karnataka	District hospital, Raichur
27.	Kerala	Medical college, Calicut
28.	Kerala	Medical college, Kottayam
29.	Madhya Pradesh	Medical College, Jabalpur
30.	Maharashtra	Medical college, Akola
31.	Maharashtra	Medical college, Ambejogai
32.	Maharashtra	Medical college, Aurangabad
33.	Maharashtra	Medical college, Dule
34.	Maharashtra	Medical college, Yawatmal
35.	Manipur	District Hospital , Ukhrul
36.	Manipur	District Hospital ,Churachandpur
37.	Meghalaya	State Hospital, Shillong
38.	Mizoram	Civil Hospital, Aizawal
39.	Nagaland	Civil Hospital , Tuensang
40.	Nagaland	District Hospital, Dimapur

41.	Nagaland	District Hospital, Kohima
42.	Orrisa	SCB Medical College, Behrampur
43.	Pondicherry	JIPMER
44.	Punjab	Civil Hospital, Jallandhar
45.	Punjab	Medical College, Amritsar
46.	Rajasthan	Medical College, Jodhpur
47.	Tripura	G.B. Pant Hospital, Agartala
48.	Uttar Pradesh	Medical College, Merrut
49.	Uttranchal	Doon Hospital, Dehra dun
50.	West Bengal	Medical College, Siliguri

Annex IV: Development Stages in Children

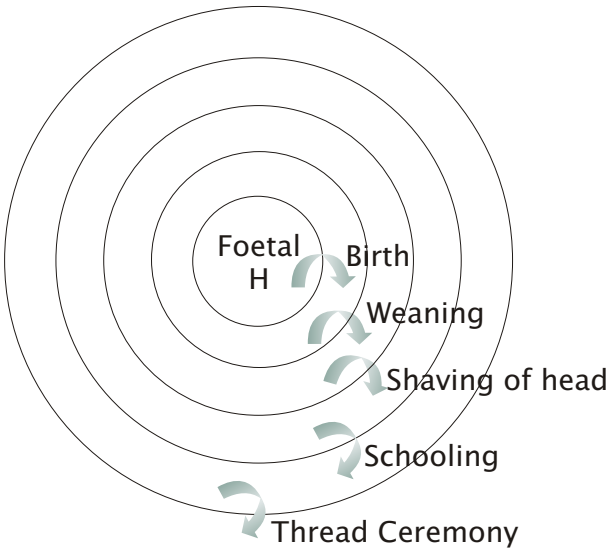
Traditional Indian texts emphasise that a child passes through a series of stages in developing from infancy to adulthood. The period of a child's life up to 16 years is divided into five main stages: (1) Garbha, or the foetal period; (2) Ksheerda (0–6 months), when the infant lives entirely on milk; (3) Ksheerannada (6 months–2 years), the period of early childhood in which weaning takes place; (4) Bala (2–5 years); and (5) Kumara (5–16 years).

Each of these stages is marked by rites of passage or Samskaras in childhood. These are Jatakarma (ceremony at birth), Namakarana (naming ceremony), Nishkramana (outing ceremony), Annaprashana (feeding of solid food), Chudakarana (shaving of head), Karnavedhana (piercing the ears), Vidyarambha (initiation of education), and Upanayana (sacred thread ceremony). The ceremonies of naming, feeding the cereals and piercing the ears are common to boys and girls. The texts do not mention girls in connection with rest of the rites.

These rites are meant primarily to address the child's points of transition from an exclusive relationship with the mother at birth to a gradual integration with the larger world. Each Samskara denotes a progressive expansion of the child's social circle. They not only commemorate the “grand occasions” of birth, marriage, giving birth, and death, they also celebrate many small milestones such as a child's first outing, first hair-cut,

initiation of learning, and a girl's first menstrual period. Psychologically, these can be difficult periods in a child's life as s/he is forced to leave the sanctuary of the primary relationship with the mother, and later, with the immediate family, for an unfamiliar world.

To help the child cope, these transition points are marked by ceremonies and rituals in which the child is placed at the centre, and family and friends participate. They celebrate the child's place and importance in her/his particular family, they reassure the child that s/he belongs, affirm the child's individual identity as a family member, and consolidate the child's and the adult's belief that family ties are the most moral, durable and reliable of all social relations. Thus the Samskaras strengthen the child's sense of belonging as well as personal distinctiveness i.e., they strengthen the child's budding sense of identity.



Western Development Theories

Contemporary western theories broadly classify the stages of development in a child into three phases; childhood, pre-school and early adolescence.

Early childhood – Birth to 2years

Physical development: The child's development starts when it is in the womb. The drugs that the mother takes, her physical condition, infections, and her mental state influence the child's development. In the first few weeks after birth, the infant needs to be physically held, cuddled and stimulated. Children deprived of this care grow up to be emotionally withdrawn.

Emotional development: Emotional expression is very overt at this stage and helps children in pre-speech communication. Physical health can have a direct impact on experience of pleasant and unpleasant emotions. If children experience more pleasant emotions in early childhood, they will be better adjusted later on.

Social development: Children begin to show interest in relating to others. If they have a warm and happy relationship with the parents/guardians, they will want to have a warm and lasting relationship with others.

Sex/Gender development: By the time they are two, children have learnt to refer to themselves as a boy or girl, and correctly label others as belonging to one sex or the other. However until they are about four years old, they do not understand that their sex is a constant and does not change.

Middle phase - Pre-school (2-5 years)

Physical development: Children develop muscle

coordination and begin to feed and dress themselves with greater skill. Most children, by the age of 5-6 years, become good at throwing and catching. They can run, hop, skip, jump and dance, and enjoy using crayons, pencils and paints.

Cognitive development: One of the major developments at this stage is that the child begins to speak, and understands when s/he is spoken to. Children learn skills such as how to solve problems, find hidden objects, and arrange picture puzzles.

Emotional and Social development: Children experience most emotions. Most causes for anger in young children are conflicts over toys, thwarting of wishes, or attacks from other children. The child also experiences jealousy when s/he thinks that parental attention and interest is shifting to someone else. Bed-wetting, pretending to be ill, or being naughty, are all a bid for attention. Curiosity, joy and affection, and grief are other emotions that children begin to experience during this stage. Children also learn to imitate a group or a person they admire. They learn to compete as well as to cooperate with their peers. They learn to form close relationships. Social approval influences the way they view themselves and others.

Gender and sexual development: Pre-school children recognize the anatomical differences between boys and girls. They seek information about body parts and curiously examine their own bodies as well as those of their peers. Talking about sex with their peers when adults are not around, engaging in sex play with peers and masturbating are common. Children also start learning sex-role stereotypes at this time.

Personality development: Early peer attitudes and the attitudes of significant family members influence the self-concept of the child. Once these foundations are laid, they remain stable through adulthood. Labels like 'kind', 'helpful', 'show-off', 'careless', 'stupid' are likely to influence how children perceive themselves.

Middle Years (6-9 years)

Children are increasingly interested in rewards for their efforts, and define their sense of self-worth by their achievements. They need time and opportunity to learn and practice complex skills. The peer group is very important to them.

Physical development: Children experience less rapid physical growth. Their gross and fine motor skills improve and they attempt to master physical activities through practice. They have lots of energy that, at times, can become reckless. They like structured games that have rules, but may need help in learning and interpreting the rules.

Cognitive development: Seven to nine year old children have longer attention spans. They like increasingly complex intellectual challenges, and are now reading to learn, rather than learning to read. They are interested in discovering things for themselves.

Emotional and Social development: Children form close friendships, mostly with same-sex peers. Friendships are more long lasting. They are often guided by the behavior and beliefs of the peer group. They enjoy adult encouragement and like to be acknowledged for their accomplishments. They tend to be self-conscious about their abilities.

Sexual Development: There is greater self-awareness about

sex and sexual differences between boys and girls, as well as increased curiosity about sexual activities.

Pre-and early Adolescence (10-13 Years)

Adolescence is defined as a period beginning with the onset of puberty and ending when individuals assume adult roles. Because of varying rates of growth spurts, there is greater variation among children in this age group than children in the two other age groups. Even within individual children, there may be a great deal of variability in behavior. They may act like teenagers much of the time, but other times, act more like young children. Children are very interested in being independent and having more responsibility. They need lots of time to be with their peers.

Their time with adults is often focused on exploring the adult world or issues of their own identity. They are examining their values, their relationships with family, friends, and with the world. They may begin to worry about social justice issues like the environment, hunger, and homelessness.

Physical development: Young people between the ages of 10 and 13 grow more rapidly than at any time since infancy. They may feel awkward and experience a lack of coordination. Puberty begins: it is a period of rapid change during which children reach maturity and become capable of reproduction. Appetites tend to be big. Hormonal changes can cause moodiness.

Cognitive development: Children develop abstract thinking skills. They begin to think about future life roles and are better able to postpone gratification. They can plan ahead and organize tasks with little or no assistance from adults. They begin to develop

opinions about social issues.

Emotional and Social development: Children tend to be very self-conscious about their bodies and how they look. This is a time of increased psychological vulnerability, particularly for girls who are at risk of developing distorted body images, eating disorders, and depression. All children of this age feel a strong desire to conform to their peer group and often assert their emerging individuality by being critical of others. They tend to be competitive and daring. They form close one-to-one friendships. They need loving, supportive adults, but often hide this need by intense loyalty to a peer group.

Sexual Development: During puberty, external sex organs assume their adult form. Sexual maturation may be early or late, and can influence personality development.. Early maturing boys seem to be more self-assured and popular, while early maturing girls may face unwanted attention from older people.

Late Adolescence (14-19 years)

Cognitive Development: Research indicates that adolescents tend to think more like adults than earlier suggested. Though they tend to engage in high-risk behaviors, ranging from trying tobacco, drugs and alcohol, to sexual activity, they do not think of themselves as vulnerable. Often, they find the rewards associated so pleasurable that they are not put off by the threat of serious consequences. Alternatively, many adolescents may belong to groups whose social norms favour such actions.

Emotional and Social Development: Young people are prone to wide swings in mood, but are not necessarily unhappy or disturbed.

Friendships with members of both sexes are increasingly important. They also experience interest in romantic or sexual relationships. Adolescents also experience intense conflicts with friends and others that can cause serious psychological distress. They are heavily influenced by peers and can acquire both positive as well as negative behavior traits. The quest for personal identity is an important element.

Erik Erikson suggests that all human beings pass through specific stages of development, and that each stage of life is marked by a specific crisis or conflict. Only if individuals negotiate each of these hurdles successfully can they continue to develop in a normal, healthy manner.

The first stage, which occurs during the first year of life, centres on the crisis of trust versus mistrust. Babies must trust in others to satisfy their needs. If these needs are not met, they fail to develop feelings of trust in others and remain forever suspicious and wary.

The second crisis occurs during the second year of life and involves autonomy versus shame and doubt. During this time, toddlers are learning to regulate their own bodies and to act in independent ways. If they succeed in these tasks, they develop a sense of autonomy. But if they fail, or if they are labelled as somehow inadequate by the persons who care for them, they may experience shame and doubt their abilities to interact effectively with the external world.

The third stage takes place during the preschool years, between the ages of three and five. The crisis then involves initiative versus guilt. At this time, children are acquiring

many new physical and mental skills. Simultaneously, however, they must develop the capacity to control their impulses, some of which lead to unacceptable behavior. If they strike the right balance between feelings of initiative and feelings of guilt, all is well. However, if initiative overwhelms guilt, children may become too unruly for their own good. If guilt overwhelms initiative, they may become too inhibited.

The fourth and final stage of childhood occurs during the early school years, when children are between six and eleven or twelve years of age. This stage involves the crisis of industry versus inferiority. During these years, children learn to make things, use tools, and acquire many of the skills necessary for adult life. Children who successfully acquire these skills form a sense of their own competence. Those who do not may compare themselves unfavourably with others and suffer from low self-esteem.

In adolescence, the crisis is one of identity versus role confusion. Adolescents seek to establish a clear self-identity an understanding of their own unique traits and what is really of central importance to them. If they fail to do so, they may experience confusion over who they really are.

Adolescents adopt many different strategies to help them resolve their own personal identity crisis. They try out many different roles the good girl/boy, the rebel, the dutiful daughter/son, the athlete and join many different social groups. They consider many possible social selves different kinds of persons they might potentially become (Markus and Nurius, 1986). Out of these experiences, they gradually piece together a cognitive framework for

understanding themselves a self-schema. Once formed, this framework remains fairly constant and serves as a guide for adolescents in many different contexts.

Integration with Indian Systems

The most significant element of Indian traditions in child development, regardless of religious background is the attention paid to the stages of transition in a child's life, as it moves from infancy to adulthood.

The important characteristic of Western models is their ability to identify specific development milestones for specific ages of children, making it easy for the caregivers to assess the child's needs.

Counselors may choose to integrate these models by marking similar periods of transition that may have psychological importance to the child, while continuing to assess the child's growth in more conventional ways like milestone. Where families are not available, caregivers/ institutions may wish to play the role of the family. The occasions after birth need not necessarily conform to the stages traditionally described, but can evolve, based on what seems to be important points of transition in the child's life, at present. The nature of the rituals or ceremonies need not conform to traditional practices either. The important thing is to ensure that the child is at the centre of the celebration, and there is participation by the family, relatives, friends, and significant others.

Along with the child, the counselor must attempt to work with the mother, family, or any other person identified as a “secure base" for the child.

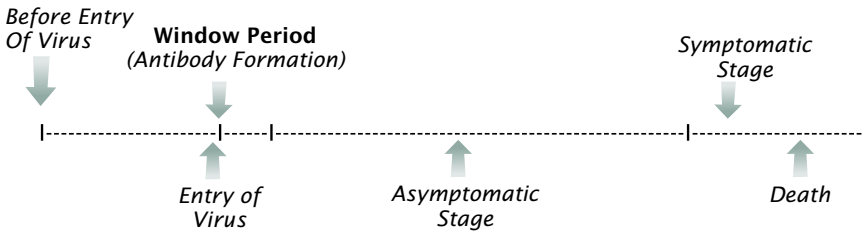
Developmental Tasks and Needs

Age	0-2 years	2-7 years	7-9 years	10-13 yrs	14-19 yrs
Physical	– Crawl, Toddle – Need holding, cuddling, stimulation	– Muscle coordination, – Feed and dress themselves run, hop, skip, jump and dance	– Less rapid growth – Lots of energy, can be reckless – Like structured games	– Rapid physical growth – Hormonal changes – Puberty sets in, girls start menstruation – Body changes in girls and boys	– Complete growth spurt, gain weight, body maturity – Peak motor skills and coordination
Cognitive	Understand language, respond to gestures, grab desired objects	– Speak, and understand when spoken to – Solving skills begin (like puzzles, hidden objects)	– Longer attention spans – Reading to learn – Like discovering things independently	– Abstract thinking skills develop – Plan ahead, organize tasks independently	– Full cognitive development

Age	0-2 years	2-7 years	7-9 years	10-13 yrs	14-19 yrs
		– Literal and concrete thinking in latter half of this stage – Learn through play – Short attention spans – Learning to read, seek instant gratification		– Opinions about social issues	
Emotional/ Social	– Overt expression of emotion – Pleasant emotions influence better	– Experience most emotions intensely – Overt expression of jealousy	– Form longer lasting friendship – Influenced by peer group – Tend to be self–	– Vulnerable to developing distorted body images – Strong need to conform to peer group	– Establish personal identity – Strong and fluctuating emotions – Question

Age	0-2 years	2-7 years	7-9 years	10-13 yrs	14-19 yrs
	– adjustment in later life.	– Seek attention from primary caregiver – Learn to form relationships – Seek peer and adult approval – Stability and routine important	conscious – Need adult encourage-ment	– Form close friendship – Need loving and supportive adult influence	authority and break rule – Need support at home and school
Sexual Gender/Sex	Idea of boy and girl as different	– Recognize anatomical differences between boys and girls – Explore body parts, seek information, discuss sex with peers, begin to masturbate	– Greater self awareness about sex – Recognize sexual differences Increased curiosity about sexual activities	– Interest in the opposite sex – Self conscious about bodies and looks	– Self conscious – Relationships with opposite sex very important – Attention to details about one's body

Annex V: Prevention and Support Service needs at different points of HIV Progression



This information serves as a flexible guideline to the counselor regarding when and what prevention and support services might be useful within the continuum of the progression of HIV. HIV testing can be done at any of the four stages in the progression of the virus as can some of the interventions listed below.

Before Entry of Virus

- Prevention
- Risk Education
- Life Style Education
- Addressing Myths and Misconceptions

Entry of Virus and Window Period (six to twelve weeks)

- Preparation for Pre-test
- Pre-test Counseling
- HIV testing
- Post-test Counseling
- Follow-up to post-test counseling
- Psychosocial support (while waiting for test results)

Asymptomatic Phase

- Prevention of HIV infection
  - To others
  - To self (re-infection)

- Prevention of progression of HIV infection
- Screening for immune status
- Enrolment in ART, if eligible.
- Positive Living
- Family Counseling
- Succession Planning
- Development of Support Systems
- Psychosocial Support

Symptomatic Phase

- Universal Precautions
- Positive Living
- Crisis Counseling
- Family Counseling
- Care and Support Services
- Home Based Care
- ART and adherence counseling
- Coping with Illness
- Stress Management
- Succession Planning
- Preparation of family for death of child (if in terminal stage)
- Responding to stigma and discrimination

Death

- Bereavement Counseling
- For surviving family members, responding to stigma and discrimination

Annex VI: Counseling Theories and Approaches

Counseling Theories

Psychodynamic theories hold that psychological disorders are due to conflicts buried in our unconscious mind, and try to bring these hidden conflicts to light. According to Sigmund Freud, personality consists of three basic parts: id, ego, and super ego which correspond roughly to desire, reason, and conscience. Freud believed that all human beings moved through a series of psychosexual stages during which the id's search for pleasure was focused on different parts of the body. If certain desires were not resolved at each stage, problems developed later in life. Too much or too little gratification at any of the stages could result in psychological disorders.

Humanistic theories hold that while people are affected by their social experiences and conflicts, they possess the ability to overcome their problems and grow as individuals. They emphasise that growth, dignity, and self-determination are largely responsible for developing personality, and emphasize personal responsibility and innate tendencies towards personal growth.

Behavior theories assume that psychological disorders stem from faulty learning. They attempt to change behavior through the use of basic principles of learning. This approach can include use of positive and negative reinforcements, as well as modelling and observation.

Cognitive theories Cognitive therapists assume that psychological disorders are caused by irrational thoughts, and help individuals to recognise and reject them. They also encourage individuals to understand and focus on their positive attitudes.

Interpersonal theories According to practitioners of the interpersonal approach, psychological disturbances are mainly the result of disturbed interpersonal relationships. This is very close to traditional Indian approaches to mental health. Couple therapy and family therapy are commonly used techniques.

Trait theories The trait approach believes that all people possess traits consistent, stable dimensions along which they differ- which describe their personality. Five basic traits are currently recognised, with each person possessing them to a different extent agreeableness, conscientiousness, openness to experience, emotional stability, and extroversion. Jung made a major contribution to the trait approach when he made the distinction between extroverts- people who are sociable, talkative, and open with emotions - and introverts who are often reserved, and quiet.

Counseling Approaches

Traditional Indian Approaches Sudhir Kakkar points out in his book "Shamans, Mystics and Doctors", that India and Japan are among the few ancient cultures which have a tradition of acknowledging and addressing psychological distress. This tradition continues in India, through traditional physicians like the vaids of the Hindu Ayurveda and Siddha systems and the hakims of the Islamic unanai system. In addition, there are palmists, astrologers, herbalists, diviners, sorcerers

and a variety of shamans, who use elements from classical Indian astrology, medicine, alchemy and magic. Then there are the Sadhus, Swamis, Maharajs, Babas, Matas and Bhagwans, who trace their practices to mystical-spiritual traditions and claim to specialise in the restoration of moral and spiritual well-being. In all these systems, the 'Sacred' plays a prominent role. The Sacred can mean the Supreme spirit of the mystics, the Godhead of the devotees, the gods of the rituals, the spirits of ancestors and forests, enchanted beings, and ghosts and demons.

Modern Approaches The main difference between the traditional and the modern or "Western" approach to psychological healing lies in the concept of illness. The former sees illness in metaphysical, psychological and social terms; the latter treats it only as a condition of the body and the mind. Modern Western science sees a person as individual, i.e., indivisible and closed, but Indian theories hold the person to be divisible and made up of relationships. Most Indians tend to rely on the support of family and friends when making decisions or when faced with difficulties. This difference is reflected in the way Indian approaches to the mental health focus on the person's relationships with others, especially the family and the community. The distress suffered by the person is seen as a disorder of these relationships, and thus the aim of therapy is to restore harmony between the person and his group.

Integrated Approaches An important characteristic of Indian healing systems is the involvement and integration of the patient's family in the healing process. The funda-

mental characteristic of the Indian approach with adults, and more so with children, is its directive nature. Individuals are rarely asked what they want, or what they think will be good for them. Approaches are prescriptive, and come from the outside, from the family or a traditional healer. A child's wishes are rarely given importance. Even in such small matters as meals and clothes, the mother usually decides, and the child agrees. This approach continues to be the situation in a majority of Indian homes even today.

Client-centred therapy (CCT)
A key goal of therapy should be to help remove obstacles so that natural growth processes can continue. Using a "client-centred" approach, theorists liken children to plants who, if left to grow in a nurturing environment without too much input or outside influence, would blossom naturally. The idea gained popularity in the United States, where nursery schools began to be called "kindergartens." A non-directive approach to therapy is appealing to many clients because they keep control over the content and pace of the therapy. CCT believes that people tend to move towards growth and healing within their own capacity to find answers. Having accepting and comforting environments, establishing a trusting relationship with the client, and focusing on the counselor's professional development are all keys to successful therapy. In India, the National AIDS Control Organisation (NACO) has recommended the adoption of CCT counseling model for HIV prevention and care.

Annex VII: Play Room and Play Therapy

The Play Room

It is useful to have various objects in your office or meeting room to help illustrate how the HIV virus is transmitted and how the test will be conducted. A suggested list of objects and their uses is provided below:

Paper and crayons: To illustrate how the HIV virus is transmitted and affects the body

Stones: To represent healthy cells or infected cells

Soldiers: cut out of paper, moulded from clay, drawn, or made from plastic. You can use them to show how the body fights back against HIV and can stay healthy for many years.

Ball: made out of newspaper or plastic bags or bought in a store. This can be used to play with to relieve anxiety.

The child can use their imagination to create many things if a collection of various objects and toys is available. This will allow the child to play to relieve anxiety, to show you their current mood, and to convey to you experiences from their life. Almost all of these objects can be found in the home or made at home and do not require great expense.

With the easy to find objects listed below the child will be able to play and listen to you as well as respond to you verbally and through play - String, Clay, Paper, Puppets, Dolls, Piece of Cloth, Marbles/stones, Ball, Animal figures.

A Case Illustration of Play Therapy

MK was a 5-year-old boy from a poor socioeconomic background. His parents reported that he was withdrawn, cried easily, was fearful, and had minimal interaction with peers and preferring to play alone. He had nightmares, almost every night, for the last two years.

The father worked as a part-time driver and coolie. The mother was a housewife. The boy was the older of two siblings, a younger sister being 3-years-old. His interaction with his parents was minimal. The father has been alcohol dependent for the last six years. He frequently beat the children. The mother alone took care of most of their needs. The boy almost never interacted with her younger sister. The teachers reported that he preferred being alone in class did not participate in any of the class activities and cried when called to do so.

Summary of sample therapy sessions with highlights

Session 1

As an introduction to the play situation, the child was asked to accompany the therapist to the playroom. He was extremely reluctant and stood in the classroom unsure of what to do. After persistent coaxing, he agreed to come into the playroom. Again in the playroom, he stood motionless and was led to see the play materials. He looked at the materials and stood to one side. He was asked to sit down and the therapist explained the characteristics of each of the toys and then asked if he would like to play with them. He touched the gun and the crayons, but did nothing else.

Session 2

The child willingly accompanied the therapist to the playroom. He sat down and began playing with the toy buses and a car. He pretended he was on a road

and imitated the sound of, and enacted, an accident. He looked at the therapist, who did not say anything then. He picked up the gun, saw that some sparrows had entered the room and took aim at them. He laughed aloud and looked at the therapist. He then took the gun and began pulling the trigger over and over again. He then picked up the buses and the car and began playing with them. After this he picked up the dolls, examined their clothes and put them back.

Session 3

The child was seen to be crying in the classroom when the therapist went there. But he got up willingly when called and came to the therapy room. He took the gun and then looked at the therapist and smiled. He then examined the gun, tried the trigger and smiled to himself. He took the bus and held it up close to his eyes for inspection. He then pointed to the chairs inside the bus and said 'chairs'. He then placed the bus on the floor, picked up a donkey and put it on the bus. He moved it around the floor for some time.

He then picked up the telephone and took the receiver to his ear and held it for a little while and then kept it down. He then looked at his school bag, picked it up and was ready to go.

He looked at the play materials once again. He then picked up the animals and made them stand. He put the dog in front of the elephant.

C – 'The dog is fighting with the elephant and will kill it'

T – 'You feel the dog will win the fight with the elephant'

C – 'He may be small but he will'.

Session 4

The child accompanied the therapist willingly. He ran into the playroom and picked up the bus. He pointed to it and said 'bus'

C – 'Daddy is sitting here'.

T – 'You feel your father is sitting here'.

C – 'Yes, here is my mother and here I am sitting'.

T – 'It looks to you as if your parents and you are sitting in the bus'.

C – 'Yes'

The child then picked up the animals. He made them all stand next to each other.

He picked up the female doll, pulled off her hair and said, 'See, she is bald' and began laughing. He then spread out all the utensils.

C – 'We will eat, I have cooked a grand lunch'.

T – 'You want me to join you for lunch'.

C – 'Yes'

The child then started filling a plate with sand and water. Abruptly he stopped, picked up the car and began moving it around the room, then stood up and made noises with his mouth and ran with the car in his hands. 'This is a plane,' he said.

Session 5

This child willingly accompanied the therapist to the playroom. He ran in as soon as he saw the door open and sat in front of the play materials. He first picked up a few utensils and placed them in front of the therapist.

C – 'Let's eat first and then play'.

T – 'You would like to eat first and then you would like to play'.

C – 'What shall I play first'

T – 'You cannot decide what to play with first'.

C – 'Yes, I think I will start with this'.

The child says pointing to the feeding bottle. He picked up the feeding bottle and shook it several times, then put it to his mouth, made a face and put it down.

He picked up the dolls, and looked at the therapist.

C – 'I want to keep the dolls leaning against your leg'.

T – 'You would like to keep them here'.

C – 'Yes, I will'.

The child then picked up the dolls in twos and placed them against the leg of the therapist.

He then took each of the animals by turn and made them stand in threes. He put a plate in front of the dog. He hit the dog with another animal and threw it away.

He went to the family of dolls. He picked up the baby doll and said, 'She is so small, like my little sister.'

T – 'She looks as small as your little sister'.

C – 'Yes'.

He then knocked her off and yanked at her hair.

C – 'Yes, I want to hit her'.

T – 'You feel like hitting her'.

C – 'Yes, I do'.

Sessions 6,7 and 8 followed along similar lines.

Session 9

The child came willingly for therapy. He took the feeding bottle and sucked at it for some time. After this, he took the father and mother dolls and kept them side-by-side. He then rode the bus over them. He did not look at the therapist, nor did he say anything.

He then picked up the baby doll and kept her on a car and pushed very hard.

C – 'They are all gone'.

T – 'You feel they are all gone'.

C – 'Yes, my family, I sent them away'.

T – 'You appear angry with them, so much that you sent them away'.

C – 'I am'.

He did not elaborate further.

Session 10

The child repeated what he had done in the previous session, but this time, he took the dolls from under the bus and buried them in the sand.

Session 11

He took the mother and father dolls from under the sand and took care to clean them properly with water.

C – 'Now, they have come back, see. They were dead and now they are back'.

T – 'You feel they have come back from death'.

C – 'Yes, now they will be good people'.

T – 'You feel that now that they have come from the death, they will be good people'.

Session 12

The final session was a re-enactment of the previous session, but the child verbalized more about future goals for the family.

Discussion

The child came to the therapy situation very reluctantly and appeared fearful in the initial two sessions. It can be seen from the description of the sessions that the child felt more comfortable as the sessions progressed. During the course of the sessions the following major points were observed.

Attitude towards play situation

Although negative in the first session and neutral in the next two sessions, the child began to react more favorably in the later sessions, to the extent that he would request the teacher for permission to come to the playroom even at other times.

Amount of time spent in active play

In the initial two sessions, the child would sit and observe the play materials and tentatively touch them. By the fifth session, he would be active most of the time with minimum pauses before switching to different play materials and different activities. By the last session, he would run into the play room and begin playing with no discomfort at all.

Attitude towards therapist

Initially the attitude of the child to the therapist was neutral and the therapist actually did not exist for the child. He would play by himself. By the third session, he had begun speaking to the therapist more and seeking her opinion.

Involvement of the therapist

An indicator of the therapeutic milieu being comfortable and anxiety-free is the child's attempt at involving the therapist both in conversation and in the play activity itself. This child, by the second session itself, had begun involving the therapist in conversation and by the fourth session had begun involving the therapist in the play activity itself, by deciding to cook a meal for the therapist.

Acting out conflicts

Perhaps the best indicator of play therapy having a therapeutic effect is when the conflict situations are played out in the playroom. The child's conflict appeared to center on sibling rivalry, as seen by his

play in the fifth session when he hit the baby doll and pulled off her hair, after having identified the doll as his little sister. He also appeared to have some conflict with his family as seen in the session when he said, "I have sent my family away," and a lot of aggression also came through in the ninth and 10th session when he ran a bus over the mother and father dolls (ninth session) and buried them under the sand (10th session). There was a tendency to regress, as a method of seeking attention, as seen clearly by his sucking at the feeding bottle in three of the sessions. A good deal of the conflict appeared to have been resolved after the playing out, as seen in the 11th session, when he brought the family back from the dead, hoping that "they will be good people" from then on.

Annex VIII: HIV testing

Routinely conducted HIV testing

This test detects presence of HIV antibodies in the body. The first test most commonly used is ELISA, which is 100% sensitive with specificity approaching 99.5%, so that a negative result can be regarded as a definite indicator that the person is not infected, except for tests carried out during the "window period". Correspondingly, a positive result suggests the possibility of HIV infection. The usual procedure then is to retest, again using another antigen specific ELISA test. The results of such supplemental testing can either be positive, strongly indicating HIV infection or negative, indicating no infection. In areas with less than 10% prevalence of HIV infection, to diagnose HIV infection, a third ELISA with a specificity of 100% may be carried out on sera positive with first two ELISA tests. If it is positive, it strongly indicates HIV infection. If it is negative, it is indeterminate. The reasons for indeterminate test result may be as follows:

- The person has developed clinical signs of HIV infection more quickly than might normally be expected;
- A related HIV virus is present; and
- A cross-reaction is occurring with a non-viral protein and the reaction is simulating that associated with the HIV p24 core protein.

[16] Excerpts from National AIDS Control Organization HIV/AIDS Training Manual

The following options are then available:

- Use alternative methods with the aim of obtaining a reliable result, e.g. by using combinations of techniques so as to exclude false-positive results; and
- Carry out repeat test after 3 months. Where the result is indeterminate and either the results of further testing are being awaited or further testing is not possible, it is not possible to say with any degree of assurance that the person is HIV-infected. The counselor should then advise the person to present again after three months for repeat testing.

It is important to remember that, in areas with low levels of HIV infection, the risk of finding a false-positive result is greater than in those where background rates of HIV infection are high. Thus, where there are many people with AIDS in the community, it is more likely that a positive ELISA result is accurate.

Special Tests: These tests detect presence of HIV antigens in the body. One such test is called Polymerase Chain Reaction (PCR). The test is expensive and available only in a few major Indian cities. This test is mostly used for research and conditions where an early diagnosis of infection is required. The antibody-based tests diagnose HIV infection after the window period i.e. formation of antibodies; the period may be 6 to 12 weeks. The antigen-based tests can diagnose within a week of the infection. Common conditions which may require early diagnosis are a symptomatic child below 18 months of age; continuation of medication for post-exposure prophylaxis and monitoring clients on ART.

Annex IX: Prevention Counseling

The term is used to describe processes aiming to prevent HIV infection in a child or adult.

Prevention counseling for children has four main objectives

1. Explore life situations and behaviours that increase children's vulnerability to HIV infection;
2. Increase awareness and understanding of HIV issues;
3. Help develop beliefs, attitudes and behaviours that reduce vulnerability to HIV infection;
4. Link with supportive networks of people and services.

Together, these objectives aim to understand the context of the child's life that can influence vulnerabilities; the beliefs and the attitudes of the individual child; and the environment that can help the child become less vulnerable to HIV infection. The important components of prevention counseling can broadly be classified into three sets of linkages over different periods of the counseling relationship.

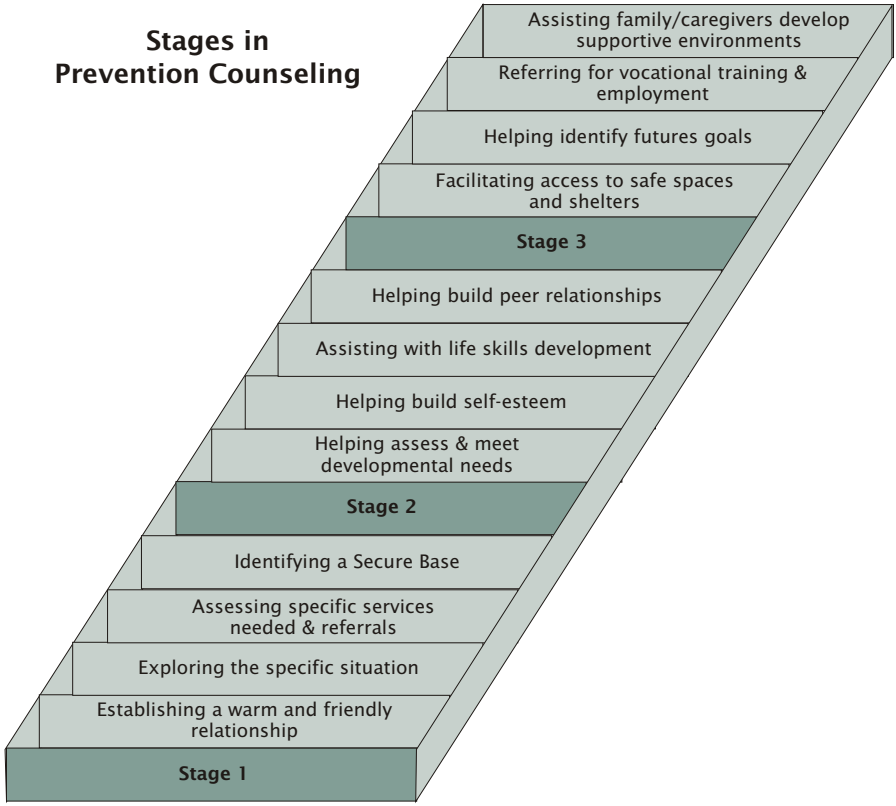
Stage 1: Exploration and Referrals

i) Establishing a warm and friendly relationship;

ii) Exploring the specific situation within the context of the child's life and environment;

iii) Assessing specific services needed and making appropriate referrals;

iv) Identifying a 'secure base'.



Stage 2: Skill Building

i) Helping assess and meet the child developmental needs;

ii) Helping the child build self-esteem;

iii) Helping the child identify future goals;

iv) Assisting the child with life skills development;

v) Helping the child build peer relationships.

Stage 3: Support systems and environments

i) Facilitating access to safe spaces and shelters;

ii) Referring the child for vocational training and employment;

iii) Assisting family/caregivers to develop supportive environments;

v) Advocacy for the child.

Guidelines for Counselors

Prevention counseling and supportive counseling (Section 10) are closely related. Often, the support offered by the counselor/others allows children to deal with the threat, or the real presence of HIV in their lives. Most often, children especially those vulnerable to HIV and those affected by HIV, need prevention as well as support services. Thus there is an overlap in many of the interventions required by children especially these vulnerable to HIV infection, children affected by HIV infection, and children living with HIV infection.

The differences in prevention counseling and supportive counseling largely depends on the regard of priority (what may be needed earlier), and appropriateness (as in the case of coping with illness, positive living and treatment for HIV positive children).

With children, many of these processes can be conducted in group discussions of up to 8 to 10 children. Counselors can facilitate discussions and sharing through role-plays, exercises and games that can lead to insightful learning both for the children and the counselor.

Annex X: Nutritional Needs in HIV infection[17]

Nutritional assessment and education based on the needs of the individual is a critical component of any HIV/AIDS treatment program. Nutrients provide the support necessary for the immune system to mount an immune response. HIV initiated disease process and the opportunistic infections restrict intake of food leading to malnutrition. The nutritional deficiencies also occur in asymptomatic HIV positive individuals. There is an increased need for calories, protein, vitamins (A, C, E, B12, B6, carotenes, choline 2) and minerals (zinc and selenium). Protein needs are highest when there is an acute infection. However, it needs to be remembered that nutrition is not a "magic bullet". Even the best nutritional care cannot prevent the eventual progression of the disease or restore immune function. But it can make clients feel better by increasing their sense of well-being and control over some aspects of their lives. Furthermore, maintaining weight and nutrient levels in the body appears to decrease the number and length of hospital stays by decreasing susceptibility to infections.

With the advent of anti-retroviral therapy, either nutritional problems could occur. A recognized complication is change in body shape called "lipodystrophy" or "fat redistribution syndrome". There

[17] Excerpts from "Nutritional Education for HIV/AIDS patients" by Dale Ames Kline; www.todaysdietitian.com/archives/td_1204p12.shtml

are also some metabolic changes–hypertriglyceridemia, insulin resistance and increased serum cholesterol.

Guidance for all children below 18 months of age

There will be uncertainty about the HIV status of children less than 18 months of age (as ELISA test is not specific) unless the child has access to Polymerase Chain Reaction (PCR) test. If the mother is known to have HIV, she is advised on the safe options of feeding. During the first six months, exclusive breast feeding is the best option for a family without having adequate resources for alternate feed. In case, mother chooses alternate feed she needs to be oriented to the safer method of milk preparation and feeding. It should be ensured, there is no mixed feeding (both breast milk and alternate feed). Mixed feeding is more risky for HIV transmission to the child compared to exclusive breast feeding (no intake of any solid or liquid other than breast milk). After six months, the child needs to be rapidly weaned and put on food appropriate for the age.

Body weight needs to be monitored routinely as per the paediatric growth chart and take advise of the doctor whenever required.

Guidance for children living with HIV infection and not on ART

Children above 18 months, born of HIV infected mother should be tested as soon as possible for deciding appropriate treatment and care. The child should receive adequate nutrition to maintain body weight and prevent nutritional deficiencies of protein, vitamins and minerals.

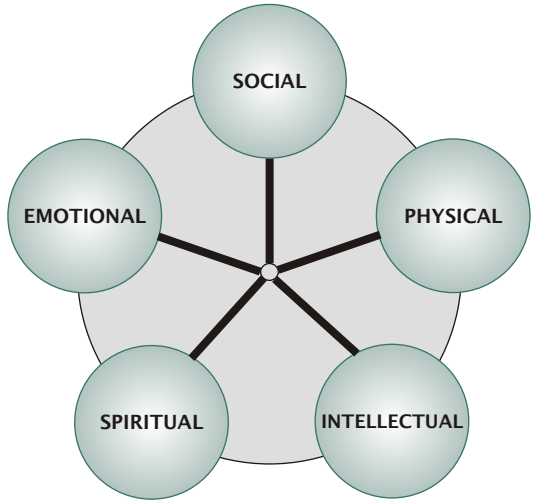
Guidance for children living with HIV infection and on ART

In addition to the above, children on ART also need to be monitored for the blood metabolic changes – triglycerides, cholesterol and sugar. Nutritional advice would need to be modulated accordingly.

Annex XI: The Holistic Care Checklist

Children and adults have five needs. In providing adequate care for children and adults, the home-based care team, teachers, counselors, or anyone who interacts with the child or their family should take the following needs into account.

The Wheel of Needs



Ask yourself, if the child and the other family members are meeting their needs for the following. If not, provide for these needs or find other people who can.

EMOTIONAL

- Love;
- Protection;
- Fulfilment of ambition;
- Resolution of grieving;

- Self-confidence/Faith in one's own abilities;
- Intimacy-close emotional relationship with others.

SOCIAL

- Attending school;
- Has friends;
- Opportunities to play;
- Interaction with family members;
- Interaction with and support by neighbours;
- Attendance at social functions (family and religious).

INTELLECTUAL

- Able to learn in school;
- Involvement in the fine arts (dance, singing and drawing);
- Religious studies.

PHYSICAL

- Food;
- Clothing;
- Shelter;
- Exercise;
- Health and Hygiene.

SPIRITUAL

- Devotion: A path to God;
- Yoga: The physical path;
- Religious studies: The intellectual path;

Community Prayer Meetings: The social path (belonging to a larger social group sharing the same beliefs).

Annex XII: USAID/IMPACT NGO Projects for Prevention Care and Support Services to OVC

ANDHRA PRADESH

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Email: sanjay@crshyd.org

Damian Leprosy Centre Sr. Bridget, Director, Gopalapalem Post, Eluru-534450; Ph: 08812-230465;
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Freedom Foundation Dr Troy Cunningham, No. 7, LIC Colony, Sikh Village, Secunderabad 500 009; Ph: 040 23830310;
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Krishna District Lorry Owners Association (KDLOA) Mr Veera Eswara Rao, President KDLOA; Dr Rama Rao, Project Coordinator, Surakshith Yatra Project, Door Number 29-14-26, 100 Feet Road, Second Cross Lane, Auto Nagar, Vijayawada-520007;
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Social Educational Economic Development Society (SEEDS)
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St. Ann's Health Centre, Sr. Theresa, Director, Sneha sadan, Nunna, Vijayawada-5212128; Ph: 0866-2852231(O) 9440105203 (M); Email: snehasadan@sancharnet.in

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World Vision Guntur ADP Dr. Ch. Israel, ADP Manager, 12-27-104/A, Seelamvari Street, Kothapet, GUNTUR 522001; Ph: 0863-23226087, 9866222842; Email: Arpana_India_ADP@wvi.org

World Vision, Vijayawada Urban ADP Mr. Alexander, ADP Manager, D.No.27-16-75, 4th Floor, Adilaxmi Estate, Beasent Road, Vijaywada 28; Ph: 0866-2570854, 9440674300; Email: Vijayawada_Urban_India_ADP@wvi.org

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Naz Foundation (I) Trust Ms Anjali Gopalan, Executive Director; Mr Irfan Khan, Program Manager, A 86 East of Kailash, New Delhi 110065; Ph: 9811008374 (Anjali); 011- 26910499, 2693 2916; Email: nazindia@bol.net.in, nazcare@rediffmail.com

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Sharan. Mr Luke Samson, Director; Ms Edlin Jash, Program Manager, W 127,GK-II, New Delhi - 110048; Ph: 011-51642311;
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Aussi-CODES Sister Leena, Project Director, 96 B, R. S New Colony, Amba Samudram – 627 401; Ph: 04634 252982;
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Centre For Peoples Education (CPE), Care and Support Project Mr Nadesan, Project Director, 1/74 Kadayam Main Road, Keela Kadayam-627415, Tirunelveli district; Ph: 04633- 250661;
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Annex XIII: Protocol Checklist for Counselors

Date	:	
Name of the Agency	:	
Name of the Counselor (person doing the counseling)	:	
Type of client	:	Infected/Affected/Vulnerable child
Age of client	:	
Educational status	:	
Person Accompanying	:	Parent/Guardian/Foster Parent/ Agency Worker/Other (please specify)
Objective of the session	:	

Describe the stage (for example, the child has been treated for an STI and now needs to be considered for pre-test counseling or follow up for adherence to treatment):

Please use this space to provide comments/ suggestions

Establishing rapport			
i) Did you feel you could trust the child/client?	Yes	No	Do not know
ii) Would you like to change the child from what s/he is?	Yes	No	
iii) Will you share information about the child with colleagues/others if required?	Yes	No	
iv) If yes, is it possible to ask the child's permission to do so?	Yes	May be	Not practical
Identifying a Secure Base			
i) Have you identified a 'secure Base' for the child?	Yes	No	Do not know
Ii) If yes, the person identified is: • Parent • Guardian • Other (specify)			
iii) The person identified as secure Base			
• Can be trusted	Yes	No	Do not know
• Is always available to the child	Yes	No	Do not know
• Has shown to be acting in the child's best interest	Yes	No	Do not know
• Any other reason for identification (Specify)			

Development Needs			
l) Using the child development chart, indicate the areas where the child may need help.			
ii) Have you made a referral to a specialist for management	Yes	No	
iii) If yes, give details • Who? • What was the result?			
Future Goals			
i) Did you explore future goals with the child/parent/ guardian?	Yes	No	
ii) If yes, briefly describe them If no, give reasons			
Supportive Environments			
i) Is the environment around the child supportive?	Yes	No	Do not know
ii) If yes, briefly describe type of support			
iii) If no, did you explore how this could be improved in the short-term?			
iv) If yes, briefly describe discussion.			

Dealing with Sexuality				
i)	I think talking about sexual issues with a child is not appropriate	Yes	No	Not Applicable
ii)	I feel moral education for children is very important to deal with sexuality issues	Yes	No	Do not know
iii)	I am comfortable discussing sexual issues with the child	Yes	No	
iv)	I discussed sexual issues with the child	Yes	No	
v)	If yes, briefly describe Discussion			
vi)	Did you identify any specific incidences and/or behaviors that can increase the child's vulnerability to HIV infection	Yes	No	
vii)	If yes, briefly list them			
Locus of Control				
i)	Whom does the child hold responsible for her/his situation? Specify.			
ii)	Did you explore the issue of locus of control? If yes briefly describe how?	Yes	No	

Allowing Choices			
i) During your sessions, did you discuss possible choices of action with the child?	Yes	No	
ii) If yes, describe briefly how you helped the child to make a choice If no, briefly describe why			
Coping with Illness			
i) The illness is faced by • child • Family member • Both	Yes	No	
ii) If family member, please specify the relationship			
iii) Did you address the issue of illness with the child and/ or family?	Yes	No	
iv) If yes, how did you help the child and/or family members cope?			

Referrals to Support Groups			
i) Was any referral made to a support group/network?	Yes	No	
ii) If yes, please indicate • PLHA network • Child support group • Parents/caregivers support group • NGO			
• Other (specify) **Planning for future needs**			
i) Did you discuss future needs with child/ family/ guardians?	Yes	No	
ii) If yes, which issues were discussed • Health care • Illness • Death • Sexuality/sex education • Abuse • Material needs – nutrition – transport – clothing			

– other (Please specify) ● Legal needs – inheritance/property – wills – guardianship/adoption ● Financial needs – income and expenses ● Schooling – helping child in school – fees – books – uniforms – transport – food ● Support – family – relatives – friends – neighbours – employment – other (specify)			

Spiritual Well-being			
i) Have you addressed the issue of spiritual well-being with the child and/or family?	Yes	No	
ii) Which of the following issues required spiritual counseling? - Trauma - Illness - Death and dying - Sexuality - Bereavement and loss - Grief - Separation - Other (specify)			
iii) Briefly describe the methods used in spiritual counseling			
Risk Assessment			
i) Did you conduct a risk assessment of the child?	Yes	No	
ii) If yes, how would you rate the child's vulnerability to HIV infection?	Low	Medium	High

iii) List areas you think increase the child's vulnerability to HIV infection • Born to a mother who is living with HIV/AIDS • Sexual abuse • Selling sex • Voluntary sex partner • Drug use (Injection) • Alcohol use • Any other (specify)			
Helping parents/guardian/child understand vulnerabilities to HIV/AIDS			
i) What issues were discussed? • Basic information • Transmission routes • Vulnerability factors • Prevention methods • Referrals for resources • Testing • Other (specify)			
ii) Was the 'window period' discussed	Yes	No	

iii) If yes, briefly describe the response of the parent/ guardian/child where appropriate			
iv) How were these issues discussed? ● Discussion ● Play ● Story telling ● Puppet ● IEC material ● Art ● Other			
Testing			
i) Was pre-test counseling offered?	Yes	No	
ii) If yes, with whom? ● Parents ● Guardian ● Child ● Teachers ● Others (specify)			
iii) Who referred the child for testing? (please specify)			

Iv) Briefly describe why.			
v) What do you think is the need for the test? ● Parent has HIV/AIDS ● Child may have been exposed to HIV ● Vulnerability factors (specify)			
vi) Does the child require any specific support before deciding on the need for testing? ● Referrals (specify) ● Counseling ● Emotional support of Family/school/ neighbourhood ● Secure Base ● Social support of any agency ● Any other (specify)			
vii) In your assessment briefly list the advantages of the child having the test			

viii) Briefly list the disadvantages of the child having the test.			
Confidentiality			
i) Was confidentiality discussed in the session?	Yes	No	
ii) If yes, with whom? • Parent • Guardian • Child • Teacher • Social worker • Other (specify)			
iii) Briefly describe what course of action was discussed to maintain confidentiality of results?			
iv) Do you foresee any possibility of confidentiality being breached in this situation?	Yes	No	Do not know
v) If yes, was this discussed in the session?	Yes	No	
vi) If yes, briefly describe the steps that will be taken in case of breach of confidentiality?			

Disclosure			
i) With whom was the result shared? • Parent/Guardian/Child • Teacher • Health care worker/ Social worker • Other (specify)			
ii) In your assessment why was it important for the specific individual/s to know the status?			
iii) Specify how disclosure was carried out • Orally • Report • Referral letter • Other (specify situation)			
iv) Briefly describe when disclosure was done			
V) In whose presence?			

Referrals			
i) Has the child been referred to any of the following services? • Medical services • Legal services • Psychiatric support • School placements • Shelter • Support groups • Vocational training • Employment • ART • Other (specify)			
ii) If yes/no, briefly explain why.			
Support system			
i) In your assessment does the child/family face stigma and/or discrimination	Yes	No	
ii) If yes, specify • Family • Neighbourhood • School • Medical care facility • Other (specify)			

iii)	Did you explore possible sources of support in the context of stigma and/or discrimination?	Yes	No	
iv)	If yes, please list a few examples			

Ethical Principles

1. Our agency has a written/ verbally understood code of ethics or policy for working with vulnerable / infected / affected children

Yes No Do not Know

If yes, please describe the salient features of the agency's ethics policy for working with children

2. In counseling children in the context of HIV/AIDS, the primary obligation of the counselor in our agency is to promote the welfare of the family.

Yes No Do not know

3. The Counselor working with children in the context of HIV/AIDS has only a legal obligation as far as the counseling process is concerned.

Yes No Do not know

4. The records of counseling sessions are accessible to most of the staff members in my organization.

Yes No

Please list the position of staff members that have access to the counseling records. Also let us know against each position as to why it was felt important to disclose to the concerned person.

Briefly describe the process of taking consent for this child for counseling

Annex XIV: HIV Testing Written Consent Form

I, _____, hereby request and give consent to having a HIV test done on a voluntary basis. I understand that the result will be discussed with me after it is available and kept confidential. I have received counseling and the counselor has answered all my questions regarding HIV testing including implications of test result and has given me complete information on HIV/AIDS issues.

I understand that:

HIV is the virus that causes AIDS. I understand how it is spread and how it can be prevented;

The only way to know if I have HIV is to be tested. I understand the limitations of the testing kits and the results; and

HIV testing is voluntary. Consent can be withdrawn at any time.

All this has been explained to me in the language that I understand.

I hereby give my consent so that my blood sample may be tested for HIV.

Signature/thumb impression Date: / /

_____

I, _____, have come on the date: / / to collect my daughter/son/ward's HIV test result. I have been explained the significance of the HIV test result to my satisfaction in the language that I can understand.

Signature Date: / /

Annex XV: Suggested Readings

- *On Death and Dying, Publisher: Simon and Schuster, Author: Elisabeth Kubler-Ross; 1977.*
- *Play Therapy. Publisher: Ballantine Books, Author: Virginia M. Axline; 1993.*
- *Counseling Skills for Professional Helpers, Publisher: Central School of Counseling and Therapy John Pratt.; 1994.*
- *Counseling – A Comprehensive Profession (1988), Second Edition. Compiled by: Samuel T. Gladding and Maxwell Macmillan; 1998.*
- *Healing the Spirit: Counseling children living with cancer (Abstract), Authors: Honore France, University of Victoria. Available at: www.educ.uvic.ca/faculty/ hfrance/spirit.htm*
- *Guidelines for counseling children infected or affected by HIV/AIDS, Author; SAT Programme. Published by: Southern African AIDS Training Programme, Harare, Zimbabwe; 2002.*
- *Youth Incentives Fact Sheet Draft, Authors: Annemaire Oomans and Sara Massaut; 2002*
- *Services for Children and Teens. Available at: www.aremiscounselingservic.supersites.ca/homepage2.*
- *Fact Sheet 5, Care of HIV infected and affected children, available at: www.who.int/whosis/factsheets_hiv*
- *Responding to Family Separation: An Analysis of Children's Talk in Counseling, Author: Dr. Ian Hutchby, Dept. of Human Sciences, Brunel University, Uxbridge. Available at: www.brunel.ac.uk/depts/hs/ian/ESRCPROJ.HTM*

- *Needing the Doe People with HIV, Confidentiality and the Courts, Author: Catherine Hanssens, Esq. Lambda Legal Defense and Education Fund; 1996. Available at: www.thebody.com/hanssens/feb96.html*
- *The Right Balance 'Positive' 'Prevent', Source: Youth Incentives; 2002.*
- *Disclosure of Illness Status to Children and Adolescents with HIV Infection (RE9827), Source: American Academy of Pediatrics Policy Statement; 1999. Available at: www.aap.org/policy/re9827.html*
- *Counseling guidelines on disclosure of HIV status. Authored by: SAT Programme. Publisher: Southern African AIDS Training Programme, First Edition; 2000*

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