

# **PSYCHOSOCIAL SUPPORT (PSS) FOR CHILDREN AND ADOLESCENTS INFECTED AND AFFECTED BY HIV AND AIDS**



**health**

Department:  
Health  
REPUBLIC OF SOUTH AFRICA



## BACKGROUND INFORMATION

The National Strategic Plan (NSP) on HIV, STIs and TB 2012- 2016 identified a number of goals including halving the number of new infections; ensuring at least 80% of people eligible for treatment, receive ARV medication; halving the number of new TB infections and TB related deaths; ensuring that the rights of people living with HIV are protected, and halving HIV and TB related stigma. This Plan calls for a more holistic and comprehensive approach to HIV Care and Treatment, taking into account the World Health Organization's definition of health, which encompasses the notion that health is a state of complete physical, mental and social well-being. The provision of psychosocial support is integral to achieving this definition of health & meeting the goals of the NSP and hence, is gaining increasing importance in order to improve the quality of the lives of all South Africans, especially those living with infected and affected by HIV and AIDS.

While the provision of psychosocial support has been acknowledged to have a significant and positive impact on people's health and health seeking behavior, the PSS needs of children and adolescents are often overlooked when providing services to them and their caregivers. The focus on psychosocial support is especially critical for children and adolescents infected and affected by HIV and AIDS as they are particularly vulnerable to psychological and social stressors which impact negatively on their development and wellbeing. Unfortunately, in many instances, psychosocial support to children and adolescents has been largely overlooked in the provision of the services that they access. Healthcare providers have reported feeling ill-equipped and not very confident in their ability to assist in this regard.

This Psychosocial Support Booklet has been developed especially for Healthcare providers (HCP) so as to provide a basic understanding of psychosocial support interventions within clinical settings. There are some wonderful examples of individual HCP's as well as clinical sites doing exceptional work and channeling efforts in this direction – some of which have been highlighted in this booklet.

We hope that this PSS Booklet provides an opportunity for HCP's to become familiar with, or to refresh the understandings and principles guiding the provision of psychosocial support to children and adolescents generally, and more specifically in providing support to those children and adolescents who are most vulnerable due to the issues relating to HIV and AIDS.

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# CONTENTS

<b>HOW TO USE THIS BOOKLET:</b>	<b>7</b>
- <i>Who is it aimed at?</i>	
- <i>What are the key objectives for providing this booklet?</i>	
<b>ACRONYMS</b>	<b>8</b>
<b>1. CONTEXTUAL ANALYSIS OF THE SOUTH AFRICAN SITUATION</b>	<b>9</b>
- HIV and AIDS and the Psychosocial Support Needs of Children of and Adolescents	
<b>2. DEFINING PSYCHOSOCIAL WELL-BEING AND PSYCHOSOCIAL SUPPORT (PSS)</b>	<b>10</b>
- What do we mean by psychosocial well-being of children and adolescents?	
- What do we mean by psychosocial support for children and adolescents?	
- What do we mean by psychosocial support in healthcare settings?	
<b>3. WHY THE NEED FOR PSYCHOSOCIAL SUPPORT?</b>	<b>12</b>
- PSS Needs of Children and Adolescents Infected and Affected by HIV and AIDS, and other chronic conditions	
<b>4. A PSYCHOSOCIAL CONCEPTUAL FRAMEWORK</b>	<b>13</b>
- Key Components for Understanding the PSS Needs of Children and Adolescents Infected and Affected by HIV and AIDS	
- Key Principles guiding psychosocial support	
<b>5. SEVEN PRINCIPLES IN PROVIDING PSYCHOSOCIAL SUPPORT TO CHILDREN AND ADOLESCENTS</b>	<b>15</b>
- Psychosocial Support guidelines for working with children and their caregivers.	

<b>6.</b>	<b>WHY THE NEED FOR PSYCHOSOCIAL SUPPORT IN HEALTHCARE?</b>	<b>16</b>
<b>7.</b>	<b>INTRODUCTION TO THE MULTI-DISCIPLINARY TEAM (MDT) APPROACH</b>	<b>17</b>
-	The role of the MDT	
-	Opportunities within PHC programme to strengthen PSS	
<b>8.</b>	<b>LEGAL CONSIDERATIONS REGARDING CHILDREN AND ADOLESCENTS ACCESSING HIV TREATMENT AND CARE</b>	<b>19</b>
<b>9.</b>	<b>PRIMARY ACTIVITIES FOR PSYCHOSOCIAL SUPPORT IN CLINICAL SETTINGS</b>	<b>22</b>
-	Psychosocial Support Activities that occur in healthcare settings for children and adolescents	
-	Peer Education Groups which benefit young children	
-	Peer Educators which benefit youth and adolescents	
-	Community Based Psychosocial Support Initiatives	
<b>10.</b>	<b>PRACTICAL TIPS FOR THE HEALTHCARE WORKER</b>	<b>24</b>
-	How to talk to children	
-	Tips for creating adolescent-friendly spaces	
-	How to talk to adolescents	
	<b>REFERENCES</b>	<b>27</b>
	<b>APPENDIX 1:</b>	<b>28</b>
	TABLE PSS Needs of Children and Adolescents Infected and Affected by HIV and AIDS	

## HOW TO USE THIS BOOKLET:

- This booklet is aimed at HCP's, and serves to raise awareness, and emphasize the need for the inclusion and integration of psychosocial support in the Comprehensive HIV and AIDS Care, Management and Treatment (CCMT) of children and adolescents.
- It also aims to introduce key concepts and terms.
- It provides basic concepts of psychosocial support that could be used in healthcare settings.
- It provides a brief explanation of psychosocial-related activities and interventions that could take place in a healthcare setting.
- The key messages in this booklet aim to address the fact that psychosocial support can happen at any level, for example, community settings and/or healthcare settings, and is not only the responsibility of specialized professionals.

## ACRONYMS

<b>APS</b>	Adherence and Psychosocial Support
<b>ARV</b>	Anti-Retroviral Medication
<b>CBO's</b>	Community-Based Organizations
<b>CCMT</b>	Comprehensive HIV and AIDS Care, Management and Treatment
<b>EPI</b>	Expanded Programme on Immunization
<b>FBO's</b>	Faith-Based Organizations
<b>HCP's</b>	Health Care Providers
<b>IMCI</b>	Integrated Management of Childhood Illness
<b>MDT</b>	Multi-Disciplinary Team
<b>NGO's</b>	Non-Governmental Organizations
<b>NIMART</b>	Nurse Initiated Management of Antiretroviral Therapy
<b>PHC</b>	Primary Health Care
<b>PLHIV</b>	People Living With HIV
<b>PMTCT</b>	Prevention of Mother to Child Transmission
<b>PSS</b>	Psychosocial Support
<b>YFS</b>	Youth Friendly Services



# 1. CONTEXTUAL ANALYSIS OF THE SOUTH AFRICAN SITUATION

## **HIV and AIDS and the PSS of children and adolescents**

The detection of HIV in the early 1980's, and the steady growth of the pandemic in sub-Saharan Africa, more specifically, South Africa, has resulted in many challenges in the healthcare system. The comprehensive treatment and management of those infected, and affected by HIV and AIDS, is particularly challenging.

For a long time, the focus was on finding ways to manage HIV, and its numerous challenges amongst adults. We believed that HIV was an adult illness, affecting adults only. Recently, with the successful roll-out of PMTCT and Paediatric HIV programmes in South Africa, we have realized that the needs of children and adolescents regarding HIV and AIDS need to be prioritized and addressed.

In South Africa, the impact of HIV and AIDS has been increased by other social challenges such as poverty, and the socio-economic imbalances that already exist in diverse communities. These challenges have increased the physical and emotional vulnerability of women and children.

While great strides have been achieved in increasing access to HIV medical treatment and care for both adults and children, there has been an absence of acknowledging the impact of HIV and AIDS on the emotional well-being of the individual. Collective efforts are needed to holistically address the individual's, particularly children and adolescents, wellbeing, including, psychosocial needs. As children and adolescents present at healthcare facilities, HCP's are expected to address their psychosocial needs as part of CCMT.

In South Africa, approximately 1.3 million children and adolescents are infected with HIV, and even more are affected. These children have very different psychosocial support needs. They are also particularly vulnerable to distress caused by a multitude of sources, including the illness itself, loss of loved ones, as well as fear of rejection and isolation, as a result of stigma and discrimination. We are therefore, compelled to start thinking about how HCP's should include psychosocial support to children, adolescents and their caregivers, as part of the comprehensive HIV and AIDS Management treatment.

## 2. DEFINING PSYCHOSOCIAL WELL-BEING FOR CHILDREN AND PSYCHOSOCIAL SUPPORT

### What do we mean by the psychosocial well-being of children and adolescents?

Firstly, it is very important to understand that children and adolescents have different needs because of varying ages and developmental needs. A child is usually seen as an individual under the age of 12 years old, while an adolescent is someone older than 12 years. It is important to understand this as there are many legal and ethical issues regarding individuals over the age of 12 years.

Psychosocial well-being refers to the social and emotional well-being of an individual, and the ability to fulfill his/her potential as a human being. It includes many areas of the individual's life: the psychological aspects, including, emotional, cognitive, mental health and spiritual issues; while the social aspects refer to relationships with others, the environment, and society. These aspects of well-being also influence physical health, and how the patient engages in his/her own treatment, adherence or disclosure issues.

Children and adolescents also have unique psychosocial needs that should be considered when providing healthcare services.

### What do we mean by psychosocial support for children and adolescents?

- It helps build resiliency
- It is an on-going process within the family circle, and the community
- It is about day to day, consistent care and support, through family and community interaction

#### PSS

..is the **on-going care** and **support** of children and adolescents to meet their age-appropriate and identified emotional, spiritual, cognitive, social and physical needs, through interactions with their surroundings and the people who care for them.....

### What do we mean by psychosocial support in health care settings?

Psychosocial support in health care settings is important to children and adolescents infected and affected by HIV and AIDS and other diseases, and their primary caregivers. Some may be caring for sick adults within their household. They might be cared for by disabled or mentally disturbed primary caregivers, and may also be victims of conflict or violence, sexual and emotional abuse, or deprivation and neglect.

PSS in healthcare focuses on the emotional (regarding HIV and AIDS-related issues like disclosure, adherence and treatment literacy), social (stigma and discrimination), physical, mental, and spiritual experiences of children, adolescents and their families, to minimize the negative effects of HIV, through adequate healthcare provision. It requires the creation, of a supportive environment at healthcare facilities, for children, adolescents and their families, to facilitate participation in their own healthcare. Psychosocial support therefore, should be included in all aspects of treatment, care and management of all patients.

Often when providing PSS to children and adolescents, the HCP will work with the primary caregiver. This is particularly important when dealing with, and facilitating issues such as disclosure. Sometimes, in child or youth-headed households the HCP might need to work directly with the child and adolescent. Currently, it is important to acknowledge that some HCP's are already incorporating aspects of psychosocial support into their daily work, although not calling such efforts "PSS". The process of disclosure, counseling, social support groups, foster care for children or adolescent are some examples.

Often HCP's complain that they do not have enough time to manage heavy patient loads, as well as provide psychosocial support. It is, therefore useful for the HCP to understand that a simple interaction with the child or adolescent, and their primary caregiver, should include some aspects of psychosocial support. For example, **ensuring confidentiality** and building a rapport with the patient and finding out more about their support structures, is an aspect of providing psychosocial support. Referrals are also an example of PSS. For example, closer working relationships with organizations such as Mother-to-Mother's peer educators, who provide support to mothers on PMTCT programmes, is essential and seen as a bridge between the clinical setting and the community. (Please also refer to section 9 for more ideas.

### 3. WHY THE NEED FOR PSYCHOSOCIAL SUPPORT?

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#### **PSS needs for children and adolescents infected and affected by HIV and AIDS, and other chronic conditions**

Children and adolescents, infected and/or affected, or orphaned, may experience psychological and social distress due to the following factors:

- unmet basic needs
- food insecurity
- unmet needs for basic protection and safety
- no consistent day-to-day caring by a primary caregiver
- no positive child-caregiver interaction activities
- lack of encouragement and affirmation
- the unfulfilled need for a sense of belonging in the family
- unequal sharing of resources within the family resulting in neglect
- exposure to stigma, discrimination and bullying
- social isolation and rejection by the community
- the need for participation in own healthcare management

In other words, children and adolescents do not only need material support, healthcare and education, but also emotionally responsive relationships, for optimal growth and well-being.

*(Adapted from: Dept. of Social Development (2010.) A Conceptual Framework for Psychosocial Care of Orphans and Vulnerable Children)*

Psychosocial support includes rebuilding and strengthening relationships which are vital to human development. It has been argued that the most powerful and important form of psychosocial support is everyday care and support provided by families, households, friends, teachers, community members and significant others and it is this premise that guides psychosocial interventions at healthcare facilities.

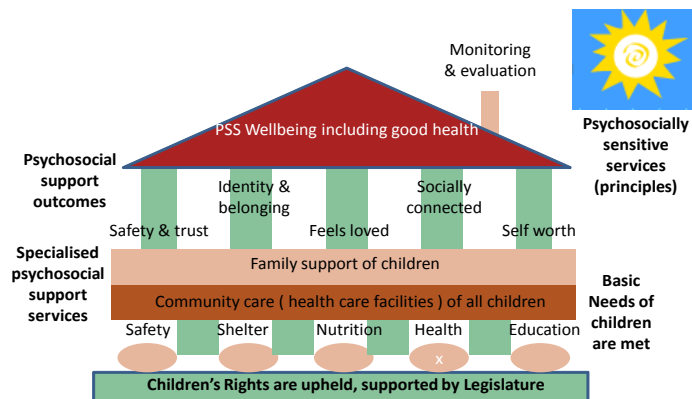
Children and adolescents infected and affected by HIV/AIDS, often share common problems and concerns, but also experience unique challenges that are highlighted in this table below. It is crucial that HCP's, primary caregivers, teachers, community organizations, and policy-makers, bear this in mind when dealing with children and adolescents, and when creating interventions to address their psychosocial needs. (see Table: Appendix 1)

## 4. A PSYCHOSOCIAL CONCEPTUAL FRAMEWORK

### KEY COMPONENTS FOR UNDERSTANDING THE PSYCHOSOCIAL SUPPORT NEEDS OF CHILDREN AND ADOLESCENTS INFECTED AND AFFECTED BY HIV AND AIDS

Adapted from REPSSI (2008)

- Children and adolescent's psychosocial support rests on having legislation and policies which protects the rights of the child, and offers guidance regarding the different needs of the child. HCP's should be familiar with the legislation and policies relevant to psychosocial support for children and adolescents in healthcare setting. (see the section 8)



- PSS support includes: meeting their basic needs such as safety, shelter, nutrition, health and education which are the building blocks for their well-being. The family, community members, and the MDT in the healthcare setting are seen as important members of society, responsible for ensuring that these basic needs are met.
- Families and communities are at the frontline of providing basic needs, and psychosocial care and support to their children and adolescents.
- Where there are gaps in psychosocial support offered by families and communities, specialized psychosocial services may be introduced, to assist families and communities to provide better day-to-day care and support, for their children and adolescents.
- The services and the manner in which support is offered to children, adolescents and their families, may then contribute to positive psychosocial support outcomes, thereby enhancing the overall psychosocial well-being of the child.

### KEY PRINCIPLES GUIDING PSYCHOSOCIAL SUPPORT

The core principles that underpin psychosocial care, and enhance the psychosocial well-being of children, include the following:

- A child rights perspective
- Protection from harm
- A developmental perspective
- Sustainability of services
- Dignity and respect
- Trust and stability
- The best interests of the child

- Child participation
- Family-based care
- Culturally appropriate psychosocial support services
- Inter-Sectoral collaboration
- Prevention as opposed to reaction
- Gender sensitivity
- Age and developmentally appropriate services

## 5. SEVEN PRINCIPLES IN PROVIDING PSYCHOSOCIAL SUPPORT TO CHILDREN AND ADOLESCENTS

There are several principles that guide the provision of psychosocial support to children and adolescents.

The seven guiding principles are:

### SEVEN PRINCIPLES IN PROVIDING PSYCHOSOCIAL SUPPORT TO CHILDREN AND ADOLESCENTS

- **Work ethically:**

Working ethically means respecting the rights and dignity of every individual. Health services and practices are embedded in a legal and ethical framework – be familiar with these legal guidelines.

- **Be aware of environmental factors:**

Different environmental issues need to be considered when working with children and adolescents. This includes, thinking about their living situation, support and the factors that might hinder or facilitate their well-being.

- **Regard each child/adolescent as a unique individual**

Each child and adolescent is an individual, and is more than the disease, or circumstances surrounding the disease. They all have their strengths and limitations, and this might influence how HCP's engage with them.

- **Explore and develop the actual and potential resources that exist in children and adolescents, families, communities, and society**

These resources may include support from others such as faith-based organizations, relevant groups in the community, etc.

- **Establish approaches and objectives**

HCP's need to understand and be familiar with children and adolescents as well as, how to communicate clearly and appropriately with them.

- **Work within local norms and practices**

Always consider the cultural, and value system, within which the child and adolescent operates, as such practices could sometimes facilitate improved well-being.

- **Evaluate the effectiveness of the plan or the intervention**

HCP's need to check whether their plan/intervention is working or not, what the positive effects are, and what can be done if it is not working.

***Adapted: REPSSI Psychosocial Support and Care for Children and Infants (2008)***

## **6. WHY THE NEED FOR PSYCHOSOCIAL SUPPORT IN HEALTHCARE?**

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Disease affects all dimensions of a person's life, namely, the physical, psychological, social and spiritual. It has been a common practice in the past to only concentrate on an individual's physical problems and challenges, whilst completely neglecting their psychological, social and spiritual concerns.

It has become increasingly obvious that the mind and body cannot be separated, and that psychosocial interventions can help individuals and their primary caregivers, cope more effectively with their illness. There is increasing agreement that psychosocial well-being depends on holistic access to children's rights, including access to safety, shelter, nutrition, healthcare, education and psychosocial care (REPSSI, 2007). Holistic care requires collaborative, inter-sectoral networking and the development of partnerships with other organizations, programmes and service providers to enhance capacity.

Psychosocial support has a much more significant impact when coming from the child or adolescent's immediate family. Health interventions and programmes should therefore, have a family-centered approach and prioritize the strengthening of families and existing community-based systems of care.



## 7. INTRODUCTION TO THE MULTI DISCIPLINARY TEAM (MDT) APPROACH

### THE ROLE OF THE MDT

NB! All HCPs interacting with children and adolescents need to be sensitive to their psychosocial needs.

According to the Conceptual Framework for Psycho-Social Support for Orphans and Vulnerable Children (2010), a MDT approach needs to be considered when providing psychosocial support.

The Department of Health has been identified as having the following role amongst others:

- To provide Primary Healthcare
- To provide the Road to Health booklet
- To assist in the application of Birth Certificates
- To provide HIV Counseling and Testing
- To raise awareness of and advocate for, the rights of children and families (social mobilization)
- To identify and refer children in need of care and support
- To provide specialized support (for example, social workers/psychologists, offering trauma counseling, as well as, respite care, and hospice services)
- To promote healthy lifestyles, thereby reducing risky behavior amongst adolescents

The MDT in healthcare settings is therefore encouraged to incorporate this understanding in the holistic management of children and adolescent's health, and should also be clear about their different roles within the MDT, in their respective healthcare facilities.

The MDT could provide psychosocial support by:

- Assisting in coping with HIV and AIDS issues, including, adherence, disclosure, stigma and discrimination, etc.
- Assisting to build resilience
- Assisting families to provide for the needs of their children and adolescents
- Assisting in dealing with the traumatic events that children and adolescents may experience, such as illness, the death of a parent, or caregiver, disclosing their HIV status
- Assisting in providing respite care/hospice services, to children and adolescents burdened by caring for a sick primary caregiver, or relative

### **Opportunities within PHC programmes to strengthen PSS**

- PMTCT
- CCMT
- NIMART
- IMCI
- EPI
- Integrated School Health services
- Youth and Adolescent Health
- Reproductive Health
- Maternal and Women's Health
- Mental Health
- Care and Support Activities (for example, support groups)
- Chronic Care Services
- Nutritional Care Services
- Emergency Care

**Some PSS interventions** that have a positive impact on children and adolescents lives are:

- HIV Counseling and Testing
- Disclosure
- On-going Counseling and Support
- ARV Initiation
- Good Nutrition and Healthy Eating
- Adherence to Treatment and Care Plan
- Routine follow-up Care of children and adolescents initiated on ARV's
- Access to Services meeting Basic Needs

Every member of the MDT, therefore has a contribution to make in ensuring that the psychosocial needs of children and adolescents.

## 8. LEGAL CONSIDERATIONS REGARDING CHILDREN AND ADOLESCENTS ACCESSING CCMT

One of the most challenging areas identified by HCPs, the legal and ethical implications and considerations in the process of paediatric and adolescent disclosure, and the multiple issues related to it.

On the 1 April 2010, the Children's Act 38 of 2008 (as amended by the Children's Amendment Act 41 of 2007) came into being, aiming to give effect to children's rights to participate in health treatment decisions. In this Act, new principles relating to the role of children, primary caregivers and HCP's in making decisions about healthcare services for children and adolescents, have been developed.

The act also makes provision for structures, services and means for promoting and monitoring the sound physical, psychological, intellectual, emotional and social well-being, and development of children. This includes, developing community structures which can assist in providing care and protection for children.

While this act aims to provide legal and ethical guidance to the HCP's in providing health treatment to children, it also highlights the professional obligation to report suspected cases of abuse, and deliberate neglect.

The new legislation, therefore, fully recognizes the rights of children to participate in decisions affecting their healthcare, clarify their right to privacy in respect of disclosure of HIV status, it lowers the age of consent to promote access to healthcare services, and allows primary caregivers (for example, grannies and aunts) to consent to healthcare treatment to children in their care.

### Definition of Caregiver:

A 'caregiver' is anyone who primarily cares for a child and includes:

- Grandmothers, aunts and other relatives
- A foster parent
- The head of a Child and Youth Care Centre
- A Child and Youth Care Worker supporting children in the community without family care
- A child (16yrs and older) heading a household (child-headed household).

Source: Adapted from: Mahery, Proudlock & Jamieson. 2010. 'A Guide to the Children's Act for Health Professions'. Children's Institute, University of Cape Town.

It is critical that HCP's become more familiar with the legislation affecting children's health issues.

### CONSENT TO HIV TESTING IN CHILDREN

The Children's Act states that a child may consent independently to HIV testing if he/she is:

- 12 years of age or older, or

- Under the age of 12 years, and of 'sufficient maturity' to understand the benefits, risks, and social implications of such a test
- For children less than 12 years old, with insufficient maturity to understand the risks and benefits of an HIV test, the primary caregiver needs to consent to the HIV test on the child's behalf.

If there are no caregivers, other people who can give consent for a child under 12, who is not "sufficiently mature" to understand the benefits, risks, and social implications of an HIV test, include:

- The Provincial Head of Social Development
- A designated Child Protection Organization arranging the placement of the child (e.g. Child Welfare)
- The superintendent or person in charge of a hospital, if the child has no parent, guardian, or caregiver, and there is no designated child protection organization arranging the placement of the child
- A Children's Court, if consent is unreasonably withheld by the above, including the child, or the parent, guardian, or caregiver of the child is incapable of giving consent.

### **What is meant by "sufficiently mature"**

A child is considered to be "sufficiently mature" if he/she can demonstrate that they understand information on HIV testing, and can act in accordance with that appreciation.

In deciding whether a child is sufficiently mature, the factors that should be taken into account include:

#### **Age**

The older the child, the more likely that he/ she will have sufficient maturity.

#### **Knowledge**

Children with knowledge around issues of HIV and AIDS, and its implications are more likely to understand its consequences.

#### **Views**

Children who are able to articulate their views on HIV testing, and whether it is in their best interests, are likely to meet the maturity requirements.

#### **Personal Circumstances**

An assessment of the child's personal situation, and his/ her motivation for HIV testing, may help in assessing their maturity.

### **Special considerations for testing children:**

A child may also be tested in the following circumstances:

- If during the course of a medical procedure, a healthcare worker has had contact with any substance from the child's body that may transmit HIV, and there is a suspicion that the healthcare worker may have contracted HIV due to contact.
- If any other person may have contracted HIV due to contact with any substance from the child's body that may transmit HIV, provided the test has been authorized by a court (for example, if the child is accused of sexually assaulting another person, and a compulsory HIV test, under the Sexual Offences Act, has been authorized by the court)

### **Pre- and Post-Test Counseling**

The Children's Act states that:

- HIV testing may only be done, after proper counseling by an appropriately trained person, has been done.
- The parent, guardian, or caregiver, must also be counseled, if they have knowledge of the test, or have consented on the child's behalf.

## Confidentiality

- Section 133 of the Children's Act provides that information regarding a child's HIV status must be kept confidential.
- Breaching confidentiality without consent, is an offence, with a penalty or a fine, or imprisonment for up to 10 years (certain exceptions apply).
- Healthcare workers, however, need to encourage, and assist parents, guardians, or caregivers, with the process of disclosure to their child.
- Although Section 133 provides that information a child's HIV status must be kept confidential, problems can arise where a child under 12 years, can consent to take an HIV test, and the results are positive. A child under 12 years cannot consent to treatment, but can refuse to disclose the results to the parent, guardian, or caregiver. In this case, the healthcare worker should encourage and assist the child to disclose to the parent, guardian, or caregiver.

### The right to confidentiality:

- Information on the child's health status, or the health status of the child's parent, caregiver or family member, must be kept confidential, except when maintaining such confidentiality is not in the best interest of the child.
- If the healthcare worker decides that it is in the best interests to breach confidentiality, he/she should talk to the child before breaching confidentiality, and explain why doing so is in the best interest of the child.
- This is particularly relevant when working with older children and adolescents, and efforts should also focus on strategies that could encourage disclosure.

If all attempts to persuade the child to disclose his/her status to the parents, guardian, or caregiver fail, the HCP has two options:

- Either approach a court if the child is unreasonably withholding consent, and disclosure is in the best interest of the child, or
- The superintendent of the hospital can consent to treatment, if the need for the treatment is so urgent, that it cannot be deferred for the purpose of obtaining consent.

(There is no case law, or definitive ruling on such a case, however, and HCP's are advised to approach such matters with extreme caution and consult with other professionals.)

Source: Adapted from: Mahery, Proudlock & Jamieson. 2010. 'A Guide to the Children's Act for Health Professions'. Children's Institute, University of Cape Town.

## 9. PRIMARY ACTIVITIES FOR PSYCHOSOCIAL SUPPORT IN CLINICAL SETTINGS

The common understanding is that PSS activities are held and managed within the community. In this case there is an increased awareness that:

- PSS activities happen at healthcare facilities as well
- PSS activities within the family and community are very important linkages to ensuring more effective healthcare outcomes
- Such activities form a bridge between the clinic and the community

There are good examples of local PSS programmes and activities:

### PSS ACTIVITIES THAT OCCUR IN HEALTH CARE SETTINGS FOR CHILDREN AND ADOLESCENTS

- **Support group activities**
- **Individual counseling sessions**
- **Life skills coaching**
- **Spiritual guidance**
- **Physical therapy**
- **Income-generating projects**

#### Peer Educators which benefit youth and adolescents

The use of peer educators in HIV and AIDS programmes provides an opportunity for the meaningful involvement of PLHIV, in the provision of HIV services. Peer educators, are usually a group of HIV-positive people, trained to provide various activities at healthcare facilities and communities. Sometimes the educator might not be living with HIV, but shares common experiences with the patient.

#### Peer Education Groups which benefit young children

**Mothers-to-Mothers**, a national, non-governmental organization, plays a very important role in providing psychosocial support to pregnant women in communities, who choose to participate in a PMTCT programme. This initiative is based on peer education, where a mother who is living with HIV, and has been through the PMTCT programme, provides psychosocial support to groups of HIV-infected pregnant women, and new mothers, who have recently entered the PMTCT programme. Young children indirectly benefit from the activities of this programme, since it prevents mother-to-child transmission of HIV, promotes adherence to treatment plans, which include taking the child to the clinic for other follow-up care (e.g. PCR testing, immunization etc.), after the child is born.

A good example in South Africa, is the concept of the **LOVELIFE** Groundbreakers who are peer educators working with adolescents regarding HIV/AIDS prevention, care and treatment. Sometimes these youth groups meet at community centres, or at the healthcare facility.

#### Community –based psychosocial support initiatives

- These initiatives are critical to providing support and relevant information to those who

participate in them.

- They are important in ensuring adequate follow-up of mothers and children, for example, in PMTCT, CCMT, TB, Child Health programmes
- They can reduce stigma within communities
- They carry the potential to provide a bridge between the community member, and the healthcare facility.
- They are particularly beneficial in rural areas where clinics are very far from homes
- Even though the majority of these initiatives are aimed at addressing the psychosocial needs of adults, more attempts are being directed at identifying and accessing more children and adolescents

Some of community-based activities include:

#### **Income Generation Projects**

The Heartfelt project in Moretele, North West Province, consists of a group of local women developing and producing, well-designed, felt objects, for example, brooches, mobiles and hairclips. They work together, and provide support, information and encouragement to each other, especially with regard to their childcare responsibilities and child health. This is an example of a group that has an indirect positive impact on children, through working with the caregivers.

#### **Home Visits**

In South Africa, Community Based- Carers are often based at clinics, and play an important role in tracing patients, and assessing the healthcare needs within the households, supporting and encouraging adherence to treatment.

This intervention is often directed at adults and caregivers, with the indirect beneficiary being the child or adolescent. These visits are a very important approach for follow-up of the entire family, or household, including children infected, and affected by HIV. National programs integrate home visits as a priority intervention for all Primary Health Care programmes.

# 10.

## PRACTICAL TIPS FOR THE HEALTHCARE WORKER

Good communication skills are key when working with patients, including, children, and adolescents. There are some important skills and practices that assist in effective communication, and building relationships, with both children and adolescents.

Some practical tips that could assist when communicating with children and adolescents

### How to talk to children:

- Be relaxed and open
- Think about your body language:
  - Lean towards them
  - Keep your face neutral and friendly
  - Maintain eye contact
  - Sit close by, and on the same side of the desk
- Remember that you are trying to develop a supportive relationship

WHAT WORKS?	WHAT DOESN'T WORK?
<b>Get down to the child's eye level:</b> Let the child see your eyes and read your intentions.	<b>Avoid comparing the child to others:</b> Each child is a person with his or her own individuality.
<b>Speak softly and directly to the child:</b> Children respond better when you address them especially by their names and not only focusing on the caregiver.	<b>Be careful when you touch children:</b> Physical affection is okay, especially as you have to examine the child for medical reasons, but wait until the child is ready.
<b>Smile and play:</b> A smiling face makes a huge difference and will help your interaction with the child, and remember that for young children, play is very important. If they leave laughing, they will look forward to coming back.	<b>Don't forget that the child is in the room:</b> If you are to have a private conversation with the caregiver, do so separately. This is important when discussing issues such as disclosure. Remember children understand more than you think.
<b>Be honest:</b> Telling the child the truth will build confidence for future clinic visits, and develop a relationship based on trust.	<b>Don't pity:</b> Children need love, support, and care, but not pity.
<b>Allow and respect normal emotions:</b> Crying is okay, and so is anger. Be patient with the child.	Treat children appropriately for their age. Older children require a different approach to babies
<b>Start with the least invasive activity:</b> Keep the child on the caregiver's lap as much as possible, and don't start with painful or invasive activities, for example, ear examinations, or blood drawing.	<b>Try not to say, "Be a good girl or boy":</b> Children do the best they can, and making them feel inadequate will not build a good relationship.
<b>Give the child choices:</b> Choices provide a sense of control. Let the child, for example, choose whether you examine the left or the right ear first, or whether to have juice or water with medication.	<b>All children are not raised in the same way:</b> Approaches to child-rearing and discipline are never the same in different families. Don't expect your experience to be the same as someone else's.
<b>Engage the child:</b> Talk about things of interest to him or her, for example, school, friends, or hobbies.	<b>Stop yourself before you threaten the child:</b> Making the child fear you, will not build trust or confidence.



WHAT WORKS?	WHAT DOESN'T WORK?
<b>Support the parent-child relationship:</b> Parents are the experts on their own children, and adolescents also need their parents' supportive adults.	<b>Don't be bad tempered:</b> A positive attitude and humour, is especially effective with children and adolescents. If you are too serious, children will feel depressed about their illness, and their visits to the doctor.

*Adapted from: PATA Poster – The Child- Friendly Clinician*

### Creating an adolescent – friendly environment

Adolescents have different developmental needs as compared to children, therefore, the manner in which HCP's relate to them should acknowledge this, and age- appropriate communication is encouraged.

There is a growing need worldwide for adolescent-friendly healthcare services particularly, in response to the increase in HIV infections amongst this group. Some of the services that adolescents need, are different to those of children and adults. Adolescent-friendly healthcare services should provide adolescent targeted services e.g. psychosocial care and support, reproductive health, and preventative healthcare.

Adolescent-friendly healthcare services should include information and interventions such as:

- general health care information e.g. health promotion
- sexual and reproductive health (STI information & treatment; management and prevention of
- pregnancy; sexual identity issues; HIV information, testing, treatment, adherence & disclosure)
- mental health
- substance abuse
- counseling on a range of issues, for example, nutrition, hygiene, substance abuse, risky behaviours, HIV etc.

Key features of youth/adolescent-friendly healthcare services include:

- full participation of adolescents in healthcare decisions and interventions affecting them
- peer education and lifeskills training
- integration with other services and organizations in the communities
- Training of HCP's regarding youth/adolescent-friendly service approaches, including effective communication, creating safe spaces, privacy and confidentiality.
- Youth/adolescent support group activities

## How to talk to adolescents

Good communication is the key to positive interactions with your adolescent clients.

This means effectively sharing information, as well as *listening* to the young people who come for counseling and testing. Some tips:

TIP	REMEMBER
<ul style="list-style-type: none"> <li>Use simple language and short sentences.</li> </ul>	Avoid using medical terms or language e.g. I will use a <b>rapid test</b> to screen you for HIV infection.
<ul style="list-style-type: none"> <li>Use non-judgmental language.</li> </ul>	Do not label or judge – it blocks the communication
<ul style="list-style-type: none"> <li>Be aware of the language and slang adolescents use to discuss sexual issues.</li> </ul>	Don't use slang or street language if your youth/adolescent client does not understand it.
<ul style="list-style-type: none"> <li>Be clear in your explanations and make sure your client understands. For instance, when talking about "sex," clarify that sex includes oral, vaginal, and anal sex. Some youth engage in oral or anal sex because they do not consider it "real" sex.</li> </ul>	Do not generalize.
<ul style="list-style-type: none"> <li>Be encouraging and affirming</li> <li>Use praise</li> </ul>	Don't judge as they might not come back for your services
<ul style="list-style-type: none"> <li>Use "active listening" by paraphrasing your clients' statements and repeating them back. This shows that you understand what your client is saying.</li> </ul>	
Ask open-ended questions that will lead to discussion rather "What do you know about protecting yourself from HIV?" rather than, "Do you know how to protect yourself from HIV?"	Don't ask questions that require only 'yes' or 'no' answers.
Use appropriate eye contact, gestures, and verbal responses to show that you are listening	Nod your head or say "go on" to help discussion. Assure young people that they are being heard.
<ul style="list-style-type: none"> <li>Learn to read body language. Be conscious of what your own body language is communicating by the way you stand, sit, or make eye contact.</li> </ul>	If you are frowning and sitting with your arms crossed in front of you, this could seem that you are angry or upset by what your client is telling you.
<ul style="list-style-type: none"> <li>Make sure young clients understand what you are saying to them.</li> </ul>	Do not simply ask, "Do you understand what I have said?" Clients may be too embarrassed to admit they do not. Instead, consider asking questions that will help you determine if the young person understands.
<ul style="list-style-type: none"> <li>Rather than giving orders, help youth develop steps they can take to protect themselves.</li> </ul>	"How do you think you could take care of yourself?"
<ul style="list-style-type: none"> <li>Be genuine. Admit when you do not know the answer to a client's question, and try to find the answer when you can.</li> </ul>	Do ask your colleague to assist with the answer

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**APPENDIX: TABLE: PSS Needs of Children and Adolescents Infected and Affected by HIV and AIDS**

PSS NEED	Infected Children	Affected Children	Infected Adolescents	Affected Adolescents
<b>Health</b> <b>e.g. Health care</b> <b>-immunization</b> <b>-support groups</b> <b>- Counselling</b>	<p>They have weaker, developing immune systems. Easily become symptomatic.</p> <p>Need to receive ARV treatment, and caregivers need to assist with treatment regimens.</p> <p>Need access to good nutrition. Access to preventive and curative child health services</p>	<p>Due to their caregiver's ill health, children may be deprived from their parents/ caregiver's parenting skills.</p> <p>They may have to fend for themselves when sick. Their health is often neglected.</p> <p>They need access to meet basic needs for survival, e.g. drop-in centres for care and support, orphanage homes.</p>	<p>Are not always aware of their HIV status</p> <p>May need HIV testing when symptomatic. Might consent to HIV testing, but do not have to disclose to parents, or caregivers.</p> <p>Often fear disclosing to their caregivers, They are often secretive. This affects treatment adherence.</p> <p>Need access to comprehensive, child and adolescent-friendly healthcare services.</p> <p>Need access to good nutrition.</p>	<p>Usually need to care for the sick parents/ caregivers, and younger siblings.</p> <p>Might be responsible for health of others. High risk of becoming infected</p> <p>Need access to good nutrition. Access to preventive and curative child health services</p>
<b>Educational</b> <b>-school fees</b> <b>-help with homework</b>	<p>Often miss school due to illness, or having to visit the clinic.</p> <p>They may need to inform their teacher of their illness.</p> <p>May drop out of school</p>	<p>Drop out of school because of other responsibilities</p> <p>Caregiver might be too ill to ensure school attendance Increased adult responsibilities</p> <p>Miss opportunities to learn informal and life skills since parents are too sick to teach them</p>	<p>Need educational support.</p> <p>They often miss school, or drop-out, due to being ill, having to go to the clinic, or fear of rejection and discrimination.</p>	<p>Need educational support. They often miss school drop-out, or experience behavioral problems.</p> <p>Takes care of infected family members. Could have additional stress and other psychological problems, e.g. depression, anxiety.</p>
<b>Physical</b> <b>- Physical Growth and milestones</b> <b>-stimulating environment</b>	<p>Infected children may experience cognitive and neurological deficits.</p> <p>Neurodevelopment delays possible</p> <p>Their growth may also be stunted,</p> <p>Delayed developmental milestones</p>	<p>Normal childhood illnesses might be overlooked and not receive adequate medical attention</p>	<p>Very aware of their appearance, especially if they are different to others.</p> <p>May feel embarrassed or rejected when symptomatic, or experience side-effects of the ARV's</p>	<p>May have physical delays because of other factors such as inadequate food, lack of adult care</p>
<b>Support System</b> <b>-Social support</b> <b>-strong family structure</b> <b>-social interaction</b>	<p>Need strong support structures to foster emotional well-being, and encourage adherence to treatment regimens.</p>	<p>Many are orphaned, as their parents, siblings, or relatives pass away from AIDS</p> <p>-Do not get support grants</p> <p>.They survive in child headed household</p>	<p>Need strong support structures to foster emotional well-being, and cope with their diagnosis. Often find support from peers</p> <p>May also find support at various adolescent-friendly organizations, or at faith-based initiatives.</p>	<p>Often they have to assume parental responsibilities for siblings or other family members, as their parents or caregivers are ill, or deceased.</p> <p>Youth headed house holds</p>

PSS NEED	Infected Children	Affected Children	Infected Adolescents	Affected Adolescents
<b>Emotional support</b> <b>-Ongoing day-to-day love and care</b> <b>-family structure</b> <b>-social interaction</b>	<p>Lack of disclosure of child's status by caregivers</p> <p>Frustration at having to take medication daily, for having to regularly visit the clinic, and for being different to siblings, or peers.</p> <p>Need bereavement counseling, targeted to specific cultural backgrounds, to deal with loss of parents, caregivers, relatives, or siblings. Therefore, need access to comprehensive, culturally-sensitive, mental health services.</p>	<p>Lack of disclosure to children by parents regarding their (parent) status.</p> <p>May experience anxiety as to parent's failing health, and, therefore, who will look after them in the future.</p> <p>Need bereavement counseling, targeted to specific cultural backgrounds, to deal with loss of parents, caregivers, relatives, or siblings. Therefore, need access to comprehensive, culturally-sensitive, mental health services.</p>	<p>Fear of disclosing to parents, friends, or community.</p> <p>Experience mental health problems, for example, depression, anxiety, adjustment issues, lack of self-esteem, due to experiences at home, loss of parents or family members, Concern about future, stigmatization, and/or caring for the infected.</p> <p>At risk for developmental and behavioral problems.</p> <p>Need bereavement counseling, targeted to specific cultural backgrounds, to deal with loss of parents, caregivers, relatives, or siblings.</p>	<p>Fear of disclosing their parents, or other family members' HIV status to relatives, friends, or community.</p> <p>Experience mental health problems, for example, depression, anxiety, adjustment issues, lack of self-esteem, due to experiences at home, loss of parents or family members, Concern about future, stigmatization, and/or caring for the infected.</p> <p>At risk for developmental and behavioral problems.</p> <p>Need bereavement counseling, targeted to specific cultural backgrounds, to deal with loss of parents, caregivers, relatives, or siblings.</p>
<b>Sexuality</b>			<p>At risk for engaging in high risk behaviors, for example, substance abuse, and/or sexual promiscuity, increasing chances of HIV contraction.</p> <p>Need information regarding safe sex practices, family planning, and HIV treatment.</p> <p>May be having sexual identity problems.</p>	<p>At risk for engaging in high risk behaviors, for example, substance abuse, and/or sexual promiscuity, increasing chances of HIV contraction.</p> <p>Need information regarding safe sex practices, family planning, and HIV treatment.</p>
<b>Financial</b>	<p>Might impact on the level of treatment and care received</p>	<p>Financial circumstances often difficult as one, or both parents are unable to work, due to ill health,</p> <p>Orphans, or child-headed households, need financial assistance from the government, and/or other organizations, when there is no-one to care for them.</p>	<p>Might impact on the level of treatment and care received</p> <p>Additional risk of school drop out Lack of resources, result in poor nutrition, poor adherence</p>	<p>Financial circumstances often difficult as one, or both parents are unable to work, due to ill health,</p> <p>Orphans, or child-headed households, need financial assistance from the government, and/or other organizations, when there is no-one to care for them.</p>

<b>PSS NEED</b>	<b>Infected Children</b>	<b>Affected Children</b>	<b>Infected Adolescents</b>	<b>Affected Adolescents</b>
<b>Legal</b>	Need to be over 12, or under 12, but sufficiently mature, to consent to HIV testing.	Need assistance with legal issues, or accessing documents, for example, identity documents etc., if parents deceased.	May be tested for HIV if 12 or older, and do not have to disclose results to parents or caregivers. May consent to treatment without consent from parents or caregivers, too.	Need assistance with legal issues, or accessing documents, for example, identity documents etc., if parents deceased.



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