

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



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FOREWORD

The *National Strategic Plan on HIV, STIs and TB, 2012- 2016* (NSP) identified several goals in response to the intertwined HIV and TB epidemics in South Africa. These include:

- Halving the number of new HIV infections;
- Ensuring at least 80% of people eligible for antiretroviral treatment (ART) receive medication;
- Halving the number of new tuberculosis (TB) infections and TB related deaths;
- Ensuring that the rights of people living with HIV are protected; and
- Halving HIV and TB related stigma.

The NSP calls for a comprehensive approach to HIV care and treatment, which highlights the World Health Organisation's (WHO) definition of health as complete state of physical, mental and social well-being. The provision of psychosocial support (PSS) is integral to achieving the health of South Africans and meeting the goals of the NSP and hence, is gaining increasing importance to improve the quality of the lives of all South Africans, especially those living with and affected by HIV.

While the provision of PSS has had a significant and positive impact on people's health and health seeking behavior, the PSS needs of children and adolescents are often overlooked. This support is especially important for children and adolescents who are infected and affected by HIV as they are particularly vulnerable to psychological and social stressors which negatively affect their development and wellbeing. This may be partially due to health care providers (HCPs), who have reported feeling ill- equipped and not very confident in their ability to assist in this regard.

This booklet, *Psychosocial Support for Children and Adolescents Infected and Affected by HIV*, has been developed especially for HCPs to provide a basic understanding of PSS interventions within clinical settings. There are some wonderful examples of excellent support from HCPs, as well as clinical sites doing exceptional work and channelling efforts in this direction. These examples been highlighted in this booklet.

We hope that this booklet provides an opportunity for HCPs to familiarise themselves with or refresh their understanding of principles guiding the provision of PSS to children and adolescents, and especially those who are most vulnerable due to the effects of the HIV epidemic in the country.

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
APS	Adherence and Psychosocial Support
ARV	Antiretroviral (drugs)
ART	Antiretroviral Therapy
CBO	Community-Based Organisation
CCMT	Comprehensive HIV and AIDS Care, Management and Treatment
EPI	Expanded Programme on Immunisation
FBO	Faith-Based Organisation
HIV	Human Immunodeficiency Virus
HCP	Health Care Provider
IMCI	Integrated Management of Childhood Illness
MDT	Multi-Disciplinary Team
NGO	Non-Governmental Organisation
NIMART	Nurse-Initiated Management of Antiretroviral Therapy
PHC	Primary Health Care
PLHIV	People Living With HIV
PMTCT	Prevention of Mother-to-Child Transmission
PSS	Psychosocial Support
YFS	Youth Friendly Service

INTRODUCTION

This PSS booklet has been developed for health care providers. It will help to raise awareness and highlight the need for the inclusion and integration of PSS in the Comprehensive HIV and AIDS Care, Management and Treatment (CCMT) of children and adolescents. This booklet emphasizes that PSS can happen at any level, including community or health-care settings, and that PSS is not limited to specialised professionals.

This booklet aims to:

- Introduce key concepts and terms; and
- Provides basic concepts of PSS that can be used in health care settings; and
- Provides examples of PSS activities and interventions that could be used in health care settings.

1

CONTEXTUAL ANALYSIS OF THE SOUTH AFRICAN SITUATION

HIV and the Psycho-Social Needs of Children and Adolescents

The detection of HIV in the early 1980s, and the steady growth of the pandemic in sub-Saharan Africa, and particularly in South Africa, has resulted in additional burdens and many challenges in the health care system. The comprehensive treatment and management of those infected and affected by HIV is particularly challenging.

For a long time, the focus was on finding ways to manage HIV and its numerous challenges among adults. Many believed that since HIV was primarily sexually transmitted, it affected adults only, and children were largely ignored. Recently, with the successful roll-out of prevention of mother-to-child transmission (PMTCT) and paediatric HIV programmes in South Africa, we realise that the needs of children and adolescents affected by HIV must be prioritised and addressed.

In South Africa, the impact of HIV 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 made in increasing access to HIV medical treatment and care for adults and children the emotional impact HIV has been neglected. Collective efforts are needed to provide comprehensive services, including PSS that are relevant to individual needs, and with particular attention given to children and adolescents. . As children and adolescents present at health care facilities, HCPs 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 socially, psychologically, economically and emotionally affected by the virus. These children have unique PSS needs. They are particularly vulnerable to distress caused by a multitude of reasons, including the illness itself, loss of loved ones and fear of rejection and isolation as a result of stigma and discrimination. We are therefore compelled to consider how HCPs should include PSS to children, adolescents and their caregivers as part of the CCMT programme.

2

DEFINING PSYCHOSOCIAL WELL-BEING AND SUPPORT FOR CHILDREN

What is Psychosocial Well-Being?

Firstly, it is very important to understand that children and adolescents have different needs because of varying ages and developmental needs. A child is defined as an individual younger than 12 years, while an adolescent is a person older than 12 years. This distinction is important as there are many legal and ethical issues regarding individuals older than 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 and spiritual factors; while the social aspect refers 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 antiretroviral treatment (ART) particularly with reference to adherence or disclosure issues.

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

What is PSS for Children and Adolescents?

PSS is interventions that helps the child and adolescent live and cope with life and its stressors. It helps build resilience. It is an on-going process within the family circle and the community, and the care and support offered by caregivers, family members, friends, neighbours, teachers, HCPs and community members, as well as support offered by specialised psychological and social services. PSS is about day-to-day consistent care and support through family and community interaction.

What is PSS in Health Care Settings?

PSS is important to children and adolescents – and their caregivers -- infected and affected by HIV and other diseases. Some children and adolescents may be caring for sick adults within their household. They may be cared for by disabled or mentally handicapped primary caregivers that may result in them being victims of conflict or violence, sexual and emotional abuse, deprivation and neglect.

PSS in health care settings focuses on the following factors affecting children and adolescents and their primary caregivers:

PsychoSocial Support is ...

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

- Emotional factors such as HIV-related issues like disclosure, adherence and treatment literacy;
- Social factors including stigma and discrimination;
- Physical health;
- Mental health and well-being; and
- Spiritual experiences.

Considering all these factors assists to minimise the negative effects of HIV through adequate healthcare provision. It requires the creation of a supportive environment at health care facilities for children, adolescents and their families. PSS should facilitate participation of all these individuals in their own health care. PSS 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 HIV disclosure. Sometimes, in child- or youth-headed households the HCP might need to work directly with the child and adolescent. It is important to acknowledge that some HCPs are already incorporating aspects of PSS into their daily work even though they do not call such efforts “PSS”. The process of disclosure, counselling, social support grants, foster care for children or adolescent are some examples of PSS in the health care setting.

Often HCPs complain that they do not have enough time to manage heavy patient loads not counting the additional work load of PSS. It is therefore useful for the HCP to understand that any simple interaction with the child or adolescent and their primary caregiver should include some aspects of PSS. For example, **ensuring confidentiality** and building a rapport with the patient or finding out more about their support structures is an aspect of providing PSS. Referrals to specialised services can also be seen as another example of PSS. For example, close working relationships with organisations such as Mother-to-Mother’s peer educators who provide PMTCT support is an essential bridge between the clinical setting and the community. (Please refer to Section 9 for more ideas.)

3

WHY DO WE NEED PSYCHOSOCIAL SUPPORT?

Children and adolescents, infected and affected by HIV may experience psychological and social distress due to the following factors:

- Unmet basic needs (including shelter and food)
- Unmet needs for basic protection and safety
- Inconsistent or no day-to-day care by a primary caregiver
- No positive child-caregiver interaction activities
- Lack of encouragement and affirmation
- 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
- Inability to participate in the management of one's own health care¹

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

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

Children and adolescents infected and affected by HIV often share common problems and concerns, but also experience unique challenges that are highlighted in Appendix 1. It is crucial that HCPs, primary caregivers, teachers, community organisations and policy-makers bear this in mind when developing and implementing to address their psychosocial needs.

¹ Adapted from: Dept. of Social Development (2010.) A Conceptual Framework for Psychosocial Care of Orphans and Vulnerable Children

4

PSYCHOSOCIAL CONCEPTUAL FRAMEWORK

Key Components for Understanding the PSS Needs of Children and Adolescents Infected and Affected by HIV

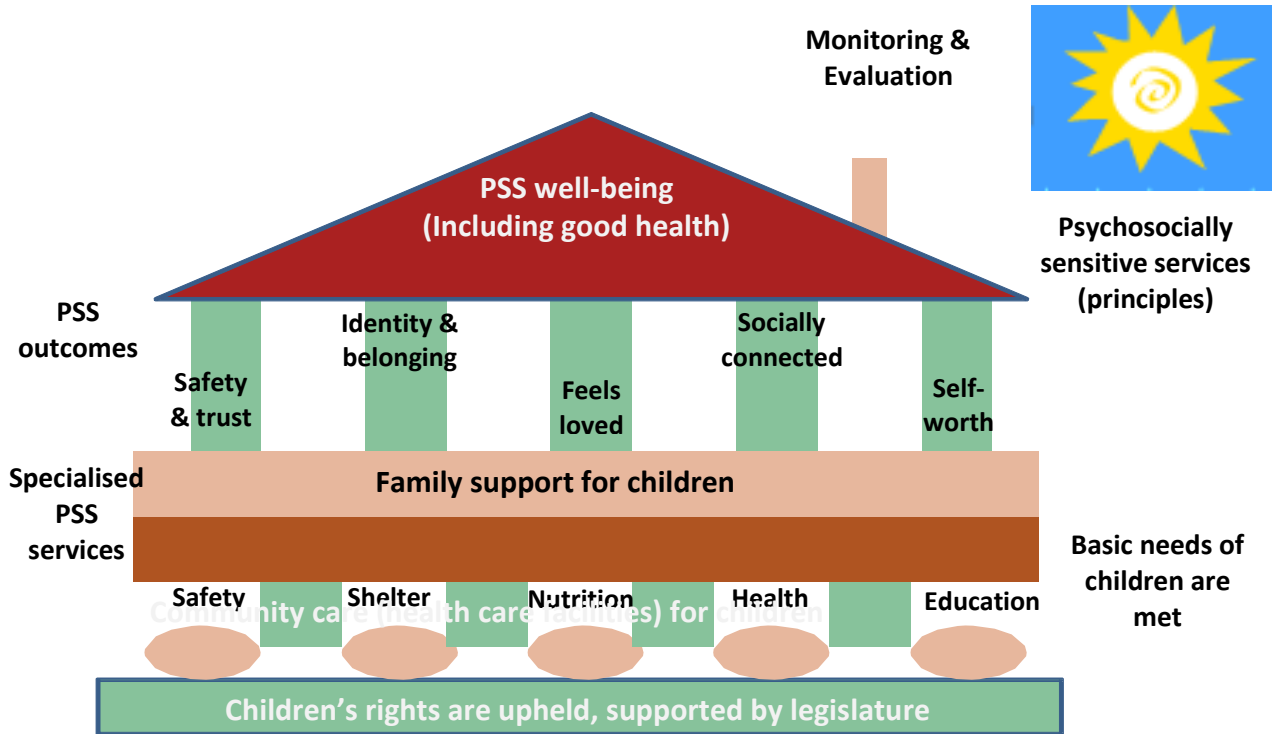


Figure 1 Principles of PSS for Children and Adolescents (Adapted from REPSSI (2008))

Figure 1 shows the fundamental PSS principles that are required to ensure the complete state of health and well-being of children and adolescents.

The health, well-being and the PSS provided to a child and an adolescent rests on having legislation and policies that protect their rights. These should also provide guidance on the unique and different needs. HCPs should be familiar with the legislation and polices relevant to PSS for children and adolescents in the health care setting.

PSS includes meeting basic needs such as safety, shelter, nutrition, health and education. These are all the building blocks for growth, development and well-being. The family, community members, and the multi-disciplinary team (MDT) in the health care setting are important members of society and are responsible for ensuring that these basic needs are met. (The MDT is described in full in Section7.)

Families and communities are at the frontline of providing basic needs as well as psychosocial care and support to their children and adolescents. Where there are gaps in PSS offered by families and

communities specialised 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 contribute to positive PSS 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 PSS services.
- Inter-sectoral collaboration.
- Proactive prevention as opposed to reaction.
- Gender sensitivity.
- Age and developmentally appropriate services.

5 SEVEN PRINCIPLES IN PROVIDING PSS TO CHILDREN AND ADOLESCENTS

There are several principles that guide the provision of PSS to children and adolescents. The seven guiding principles² are:

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

Various and different environmental issues must 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 or adolescent as a unique individual

Each child and adolescent is an individual and should be viewed and treated as more than the disease or circumstances surrounding the disease. They all have their strengths and limitations and this might influence how HCPs engage with them.

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

Resources may include a whole range of factors including support from other groups such as faith-based and other community-based organisations.

Establish approaches and objectives

HCPs must understand and be familiar with children and adolescents. This includes clear and appropriate communication.

Work within local norms and practices

Always consider the local cultural and value systems within which the child and adolescent operates. This could facilitate improved support and well-being.

Evaluate the effectiveness of the plan or the intervention

HCPs must check whether their plan/intervention is working, what the positive effects are and what can be done if it is not working.

² Adapted: REPSI Psychosocial Support and Care for Children and Infants (2008)

6

WHY DO WE NEED PSS IN THE HEALTH CARE SETTING?

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, while 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 (REPSI, 2007). Holistic care requires collaborative, inter-sectoral networking and the development of partnerships with other organizations, programmes and service providers to enhance capacity.

PSS has a much more significant impact when coming from the child or adolescent's immediate family. Health care interventions and programmes should therefore have a family-centered approach and prioritise 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

All HCPs interacting with children and adolescents need to be sensitive to their psychosocial needs. According to the Southern African Development Community's *Regional Conceptual Framework for PsychoSocial Support for Orphans and other Vulnerable Children and Youth* published in December 2010³ (2010), calls for a multilayered and multidisciplinary team (MDT).

The Department of Health's role in the provision of PSS is to:

- Provide primary health care.
- Provide the Road-to-Health booklet.
- Assist in the application of birth certificates.
- Provide HIV counseling and testing,
- Raise awareness of and advocate for the rights of children and families (social mobilisation)
- Identify and refer children in need of care and support.
- provide specialised support (e.g., social workers and psychologists offering trauma counseling, respite care and hospice services).
- Promote healthy lifestyles, thereby reducing risky behavior among adolescents.

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

The MDT could provide PSS by:

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

Opportunities within Primary Health Care Programmes to Strengthen PSS

Several programmes within the primary health care system can contribute to strengthening PSS. These include:

³ Available online at http://www.repssi.org/presentations/SADC_PSS_Framework.pdf (accessed October, 2012)

- PMTCT
- CCMT
- Nurse-Initiated Management of ART (NIMART)
- Integrated Management of Childhood Illness (IMCI)
- Expanded Programme on Immunisation (EPI)
- Integrated School Health Services
- Youth and Adolescent Health
- Reproductive Health
- Maternal and Women's Health
- Mental Health
- Care and Support activities (e.g., 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 counselling and testing
- Disclosure of HIV status
- On-going counselling 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 ART
- Access to services meeting basic needs

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

8

LEGAL CONSIDERATIONS REGARDING CHILDREN AND ADOLESCENTS ACCESSING CCMT

One of the most challenging areas identified by HCPs are the multiple legal and ethical implications and considerations in the process of paediatric and adolescent disclosure of HIV status.

On 1 April 2010, the *Children's Act 38 of 2008* (as amended by the Children's Amendment Act 41 of 2007) was passed into law. This Act guarantees the child's rights to participate in health treatment decisions. In this Act new principles relating to the role of children, primary caregivers and HCPs in making decisions about health care 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 that can assist in providing care and protection for children.

While the Children's Act provides legal and ethical guidance to the HCPs 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 recognises the rights of children to participate in decisions affecting their health care and to clarify their right to privacy in respect of disclosure of HIV status. It also lowers the age of consent to promote access to health care services and allows primary caregivers (e.g., grannies and aunts) to consent to health care treatment to children in their care⁴.

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 (16 years and older) heading a household (child-headed household).

It is critical that HCPs 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:

⁴ Source: Adapted from: Mahery, Proudlock & Jamieson. 2010. A Guide to the Children's Act for Health Professions. Children's Institute, University of Cape Town.

- 12 years of age or older, or
- Younger than 12 years and of ‘sufficient maturity’ to understand the benefits, risks and social implications of such a test

If the child is younger than 12 years and is insufficiently mature 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 or other people who can give consent for a child younger than 12 years and who is not “sufficiently mature” to understand the benefits, risks, and social implications of an HIV test, include:

- The provincial head of the Department of Social Development;
- A designated child protection organisation 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 organisation arranging the placement of the child; or
- A Children’s Court if consent is unreasonably withheld by the above, including the child or the parent, guardian or caregiver if the child is incapable of giving consent.

Special Considerations for Testing Children

A child may also be tested in the following circumstances:

- If, during the course of a medical procedure, a HCP has had contact with any substance from the child’s body that may transmit HIV and there is a suspicion that the HCP may have contracted HIV due to contact; or
- 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 authorised by a court (e.g., if the child is accused of sexually assaulting another person and a compulsory HIV test, under the *Sexual Offences Act*, has been authorised by the court).

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 of HIV 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.

Pre- and Post-Test Counselling

The *Children's Act* states that HIV testing may only be done after proper counselling by an appropriately trained person, has been done. The parent, guardian, or caregiver, must also be counselled if they know that the test will be done 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 punishable by a penalty or fine or imprisonment for up to 10 years. (Certain exceptions apply.) HCPs, however, must encourage and assist parents, guardians or caregivers with the process of disclosure to their child.

Although Section 133 provides that information on a child's HIV status must be kept confidential problems can arise, especially where a child younger than 12 years consents to take an HIV test and the results are positive. A child younger than 12 years cannot consent to treatment but can refuse to disclose the results to the parent, guardian or caregiver. In this case, the HCP should encourage and assist the child to disclose to the parent, guardian or caregiver.

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
- Contact the superintendent of the hospital who can consent to treatment especially 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 HCPs are advised to approach such matters with extreme caution and consult with other professionals⁵.

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.

⁵ 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 PSS IN HEALTH CARE SETTINGS

Usually PSS activities are held and managed within the community, but they can happen at health care facilities as well. PSS activities within the family and community are very important linkages to ensuring more effective health care outcomes. These activities form a bridge between the clinic and the community.

There are several good examples of local PSS programmes and activities, including the Mothers-to-Mothers' peer education programme.

PSS Activities for Children and Adolescents in Health Care Settings

There are several PSS activities for children and adolescents in health care settings. Some of the most important include:

- Support groups
- Individual counselling sessions
- Life skills coaching
- Spiritual guidance
- Physical therapy
- Income-generating projects
- Peer educator programmes

Peer Educators

The use of peer educators in HIV programmes provides an opportunity for the meaningful involvement of people living with HIV (PLHIV) in the provision of HIV services. Peer educators are usually a group of people who share the same characteristics of the target audience, like age, gender, HIV status, language or cultural and community traits. They are trained to provide various supportive activities at health care facilities and within communities. Often peer educators can relate to groups because they share the same experiences.

Mothers-to-Mothers, a national, non-governmental organisation (NGO) plays a very important role in providing PSS to pregnant women in communities. This initiative is based on peer education where a mother who is living with HIV and has been through the PMTCT programme, provides PSS 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 and promotes adherence to treatment plans. The latter includes taking the child to the clinic for other follow-up care (e.g., PCR testing, immunisation etc.) after the child is born.

A good example of a peer education programme in South Africa is the LOVELIFE Groundbreakers. The Groundbreakers are peer educators working with adolescents on issues of HIV prevention, care and treatment. Sometimes these youth groups meet at community centres or they meet at health care facilities.

Income Generating Projects

Income generating projects are an important part of the PSS intervention. The Heartfelt project in Moretele, North West province, for example, consists of a group of local women developing and producing, well-designed, felt objects like broaches, mobiles and hairclips. They work together, and provide support, information and encouragement to one another especially with regard to their child care responsibilities and child health. This is an example of a group that has an indirect positive impact on children, through working with the caregivers.

Community-Based PSS Initiatives

Community-based initiatives are critical to providing support and relevant information to children and adolescents in need. They are important in ensuring adequate follow-up of mothers and children, for example, in PMTCT, CCMT, tuberculosis and child health programmes. Community-based programmes are especially valuable because they can help to reduce stigma within communities. These programmes are the bridge between the community member and the HCP and health care 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 there is increasing evidence of more efforts being directed at identifying and accessing more children and adolescents.

Home Visits In South Africa community-based caregivers are often located at clinics and play an important role in tracing patients. They also help to assess the health care needs within the households and provide support for and encourage adherence to treatment.

Home visits are all too 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 programmes integrate home visits as a priority intervention for all primary health care programmes.

10 PRACTICAL TIPS FOR THE HEALTH CARE PROVIDER

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.

How to Talk to Children

- Be relaxed and open
- Think about your body language:
 - Lean towards the child or adolescent
 - Keep your facial expression neutral and friendly
 - Maintain eye contact
 - Sit close by the child or adolescent and on the same side of the desk.

Remember that you are trying to develop a supportive relationship.

What Works	What Doesn't Work ⁶
Get down to the child's eye level: Let the child see your eyes and read your intentions.	Avoid comparing the child to others: Each child is a person with his or her own individuality.
Speak softly and directly to the child: Children respond better when you address them directly, especially if you use their names and do not focus solely on the caregiver.	Be careful when you touch children: Physical affection is okay, especially when you have to do a medical examination, but wait until the child is ready.
Smile and play: 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.	Don't forget that the child is in the room: If you do want to have a private conversation with the caregiver, do so separately. This is important when discussing issues such as HIV disclosure. Remember that children understand more than you think.
Be honest: Telling the child the truth will build confidence for future clinic visits and develop a relationship based on trust.	Don't pity: children need love, support and care but not pity.
Allow and respect normal emotions: 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.
Start with the least invasive activity: Keep the child on the caregiver's lap as much as possible and don't start with painful or invasive	Try not to say "Be a good girl or boy": Children do the best they can and making them feel inadequate

⁶ Adapted from: PATA Poster – The Child- Friendly Clinician

What Works	What Doesn't Work ⁶
activities (e.g., ear examinations or drawing blood).	will not build a good relationship.
Give the child choices: Choices provide a sense of control. Let the child, for example, choose whether you examine the left or right ear first, or whether to have juice or water with medication.	All children are not raised in the same way: 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.
Engage the child: Talk about things of interest to him or her, for example, school friends or hobbies.	Stop yourself before you threaten the child: making the child fear you will not build trust or confidence.
Support the parent-child relationship: Parents are the experts on their own children's needs.	Don't be bad tempered: A positive attitude and humour is especially effective with children. If you are too serious, children will feel depressed about their illness, and their visits to the doctor.

Creating an Adolescent-Friendly Environment

There is a growing need worldwide for adolescent-friendly health care services particularly in response to the increase in HIV infections among this group. Once again, these needs differ vastly from those of children and of adults. Adolescent-friendly healthcare services should provide adolescent targeted services (e.g., psychosocial care and support, reproductive health and preventative health care), and HCPs should communicate appropriately with this group. Adolescent-friendly healthcare services should include information and interventions including:

- General health care information and health promotion;
- Sexual and reproductive health (STI information and treatment);
- Management and prevention of pregnancy;
- Sexual identity issues;
- HIV information, testing, treatment, adherence and disclosure)
- Mental health;
- Substance abuse; and
- Counselling on a range of health issues like nutrition, hygiene, substance abuse, high-risk behaviours).

The success of any adolescent-friendly health care service depends on:

- Full participation of adolescents in health care decisions and interventions affecting them;
- Coordinated peer education and life-skills training;
- Integration with other services and organizations in the communities;
- Comprehensive training of HCPs on adolescent-friendly service approaches, including effective communication, creating safe spaces, privacy and confidentiality; and
- Ongoing 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 counselling and testing. Some tips on talking to adolescents follow:

What Works	What Doesn't Work ⁷
Use simple language and short sentences	Avoid using medical terms or language (e.g., "I will use a <i>rapid test</i> to screen you for HIV infection").
Use non- judgemental language.	Do not label or judge. It blocks communication.
Be aware of the language and slang adolescents use to discuss sexual issues.	Don't use slang or street language if your adolescent client does not understand it.
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.	Do not generalise.
Be encouraging and affirming. Use praise.	Don't judge, as the adolescents may not come back for follow up services.
Use "active listening" by paraphrasing your clients' statements and repeating them. This shows that you understand what your client is saying.	
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.	Don't type on your workstation or do other things while listening.
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.	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.
Make sure young clients understand what you are saying to them.	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.
Rather than giving orders, help youth develop steps they can take to protect themselves.	Do not provide all the answers. Let the adolescent go through the steps themselves.

⁷ Adapted from: PATA Poster – The Child- Friendly Clinician

Be genuine. Admit when you do not know the answer to a client's question, and try to find the answer when you can.

Don't pretend to know it all.

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APPENDIX 1: PSS NEEDS OF CHILDREN AND ADOLESCENTS INFECTED AND AFFECTED BY HIV

PSS Need	Infected Children	Affected Children	Infected Adolescents	Affected Adolescents
Health <ul style="list-style-type: none"> Health care Immunisation Support groups Counselling 	<ul style="list-style-type: none"> Have weaker, developing immune systems Easily become symptomatic Need ART Caregivers must assist with treatment regimens Need access to good nutrition Need preventive and curative child health services 	<ul style="list-style-type: none"> May be deprived of parents and caregivers or lack of parenting skills. Often have to fend for themselves when sick May have neglected health needs Need access to basic needs services for survival (e.g., drop-in centres for care and support, orphanages) 	<ul style="list-style-type: none"> Not always aware of their HIV status May need HIV testing when symptomatic May consent to HIV testing but do not have to disclose to parents, or caregivers Often fear disclosing to their caregivers, are often secretive, which affects treatment adherence Need access to comprehensive adolescent-friendly health care services Need access to good nutrition 	<ul style="list-style-type: none"> Often required to care for sick parents or caregivers and younger siblings. May be responsible for health of others Have a high risk of becoming HIV infected Need access to good nutrition Need access to preventive and curative child health services
Education <ul style="list-style-type: none"> School fees Help with homework 	<ul style="list-style-type: none"> Often miss school due to illness, having to visit the clinic May need to inform their teacher of their illness May drop out of school 	<ul style="list-style-type: none"> May drop out of school because of other responsibilities and caregiver may be too ill to ensure school attendance May have increased adult responsibilities May miss opportunities to learn informal social and life skills due to sick or missing parents or caregivers 	<ul style="list-style-type: none"> Need educational support May often miss school May drop out because of illness or having to go to the clinic May drop out due to fear of rejection or discrimination 	<ul style="list-style-type: none"> Need educational support May often miss school, drop out or experience behavioural problems May have to care for infected family members May have additional stress-related and other psychological problems (e.g., depression, anxiety)
Physical <ul style="list-style-type: none"> Growth and milestones Stimulating environment 	<ul style="list-style-type: none"> May experience cognitive and neurological deficits May have neuro-development delays May have stunted growth May have delays in reaching developmental milestones 	<ul style="list-style-type: none"> Normal childhood illnesses might be overlooked and not receive adequate medical attention 	<ul style="list-style-type: none"> May be very aware of appearance, especially if different to others May feel embarrassed or rejected when symptomatic May experience side effects of the ARVs 	<ul style="list-style-type: none"> Delays in reaching physical milestones because of structural and social factors such as inadequate food or lack of adult care
Support System <ul style="list-style-type: none"> Social support 	<ul style="list-style-type: none"> Need strong support structures to foster emotional well- 	<ul style="list-style-type: none"> May be orphaned May not get support grants 	<ul style="list-style-type: none"> Need strong support structures to foster emotional well-being 	<ul style="list-style-type: none"> Often have to assume parental responsibilities for siblings or

PSS Need	Infected Children	Affected Children	Infected Adolescents	Affected Adolescents
<ul style="list-style-type: none"> Strong family structure Social interaction 	<ul style="list-style-type: none"> Being Need support to encourage adherence to treatment regimens 	<ul style="list-style-type: none"> May survive in child-headed households 	<ul style="list-style-type: none"> and cope with diagnosis May often get support from peers May also find support at various adolescent-friendly organisations or faith-based initiatives 	<ul style="list-style-type: none"> other family members May survive in youth-headed households
Emotional Support <ul style="list-style-type: none"> Ongoing day-to-day love and care Family structure Social interaction 	<ul style="list-style-type: none"> May suffer from lack of disclosure of child's status by caregivers May be frustrated at having to take medication daily, having to visit the clinic regularly, and for being different to siblings or peers May need bereavement counselling targeted to specific cultures to deal with loss of parents, caregivers, relatives, or siblings. Need access to comprehensive, culturally-sensitive, mental health services 	<ul style="list-style-type: none"> May struggle with lack of disclosure to children by parents regarding their (parental) HIV status May experience anxiety with parent's failing health and concerns about who will care for them in the future May need bereavement counselling targeted to specific cultures to deal with loss of parents, caregivers, relatives, or siblings. Need access to comprehensive, culturally-sensitive, mental health services. 	<ul style="list-style-type: none"> Fear of disclosing to parents, friends, or community 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 caring for HIV-infected family At risk for developmental and behavioural problems Need bereavement counselling, targeted to specific cultures to deal with loss of parents, caregivers, relatives, or siblings 	<ul style="list-style-type: none"> Fear of disclosing their parents, or other family members' HIV status to relatives, friends, or community 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 stigmatisation and caring for HIV-infected family At risk for developmental and behavioural problems Need bereavement counseling, targeted to specific cultures to deal with loss of parents, caregivers, relatives, or siblings
Sexuality			<ul style="list-style-type: none"> At risk for engaging in high risk behaviours (e.g., substance abuse, sexual promiscuity) increasing chances of HIV infection Need information on safe sex, family planning and ART May have sexual identity issues 	<ul style="list-style-type: none"> At risk for engaging in high risk behaviours (e.g., substance abuse, sexual promiscuity) increasing chances of HIV infection Need information on safe sex, family planning and ART May have sexual identity issues
Financial	<ul style="list-style-type: none"> Financial restraints may affect level of treatment and care 	<ul style="list-style-type: none"> Financial circumstances often difficult as one or both parents are unable to work due to ill health Orphans or child-headed 	<ul style="list-style-type: none"> Financial restraints may affect level of treatment and care Additional risk of school drop out Lack of resources result in poor nutrition or poor adherence 	<ul style="list-style-type: none"> Financial circumstances often difficult as one or both parents are unable to work due to ill health Orphans or child-headed

PSS Need	Infected Children	Affected Children	Infected Adolescents	Affected Adolescents
		households need financial assistance from government or other organisations		households need financial assistance from government or other organisations
Legal	<ul style="list-style-type: none"> Must be older than 12 years or younger than 12 years but sufficiently mature to consent to HIV testing 	<ul style="list-style-type: none"> Need assistance with legal issues or accessing documents (e.g., identity documents if parents deceased) 	<ul style="list-style-type: none"> May be tested for HIV if 12 years or older, Do not have to disclose results to parents or caregivers May consent to treatment without consent from parents or caregivers 	<ul style="list-style-type: none"> Need assistance with legal issues or accessing documents (e.g., identity documents if parents deceased)

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