

Legal, ethical and counselling issues  
related to HIV testing of children

## Participant's Manual



## Acknowledgements

The development of the guidelines and training tools on the legal, ethical and counseling issues related to HIV testing of children is the culmination of a huge effort by many people over several years. A consultative group of experts, policy makers and practitioners working with children more generally, and in HIV/AIDS specially, shaped the initial ideas and content for these tools. Many from this group gave feedback on the materials at various stages of their development, and participated in workshops piloting the training materials. Thato Chidarikire from the Department of Health and Thato Farirai from the Centers for Disease Control have been staunch champions and active participants in this process from the start. We are grateful for their support and look forward to ongoing assistance in making sure the tools get into the hands of health care workers working with children in HIV/AIDS. Several dedicated, passionate and committed individuals took the responsibility for drafting these tools: Kitty Grant, Ray Lazarus, Ann Strode, Marnie Vujovic and Heidi van Rooyen deserve our heartfelt thanks. The tools have been made possible by the generous support from the Bill and Melinda Gates Foundation. The Foundation provided these funds to support the South African government in the implementation of the counselling and testing goals of the 2007-2011 National Strategic Plan.

Project management: Jive Media Africa

Design, layout and typesetting: John Bertram, Tangerine Design

Cover design and illustrations: Maja Sereda

Editors: Sharon Dell and Angela Hough-Maxwell

Produced by



Jive Media Africa

P O Box 22106, Mayor's Walk, 3208

Tel: +27 (0)33 342 9382

admin@jivemedia.co.za

www.jivemedia.co.za

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Human Sciences Research Council

P.O Box 90, Msunduzi, 3231, South Africa

Phone: +27 (0)33 324 5009 | Cell: +27 (0)82 338 2071 | Skype: heidivanrooyen

Fax: +27 (0)33 324 1131

Email: hvanrooyen@hsrc.ac.za

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# **Legal, ethical and counselling issues related to HIV testing of children**

## **PARTICIPANT'S MANUAL**

**Developed by:**

Kitty Grant, Ray Lazarus, Ann Strode, Heidi van Rooyen and Marnie Vujovic

**For this training you will receive a Participant's Manual together with a Resource CD.**

The **PARTICIPANT'S MANUAL** is for the participants of the training. It contains course material and exercises. It also gives you space to record ideas and your own thoughts or experiences.

The **Resource CD** will be given to you at the start of the training. It includes copies of powerpoint presentations used in the training as well as course handouts. The Resource CD also includes a scenario library that contains all the case studies used in the training, as well as some additional ones that may be useful in future. Finally, the CD contains copies of the following guidelines:

- a) HIV counselling and testing of children: Implementation guidelines; and
- b) HIV testing of children: Legal guidelines.

We hope that you enjoy the course and the materials on the resource CD.

Thank you for participating in this course.



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## Glossary of Terms:

AIDS	Auto-immune deficiency syndrome
CG	Caregiver (here including parents and other caregivers)
CICT	Client-initiated Counselling and Testing
HIV	Human immune deficiency virus
HCT	HIV Counselling and Testing
PEP	Post exposure prophylaxis
PICT	Provider-initiated Counselling and Testing
PMTCT	Prevention of mother-to-child transmission
SOP	Standard operating procedure
STI	Sexually transmitted infection
VCT	Voluntary Counselling and Testing

**Abuse:** Deliberate ill-treatment or harm of a child. Abuse can be physical (e.g., beating), sexual (e.g., rape), emotional (e.g., bullying), or can involve exploitation (e.g., underage labour).

**Antibodies:** These are special cells, which fight against particular diseases. Example: “When doctors test for HIV they count the number of antibodies in the blood.” The presence of antibodies indicates the presence of a particular disease.

**Cognitive:** A term used to refer to activities such as thinking and reasoning.

**Concrete:** The opposite of abstract; specific or precise; related to the physical world and to physical actions.

**Confidentiality:** The right to confidentiality means the right to keep information to yourself. People have a right to confidentiality about HIV and AIDS, and others have to respect a person’s right to keep information private.

**Containing:** Able to hold things together. This is from the word “container” which is something that holds something else, like a pot holds water. When we use the word “containing” for people, it means someone who can hold other people in a safe way, emotionally (not physically). So “containing” is used as a metaphor. It is about being held and supported in a safe place, like water could be contained in a water jar. It is used to say that difficult emotions are “contained”, we stop them from exploding and leading to more negative behaviours. Example: “When I was so upset after I lost my husband I found it very containing to go to church.” Or, “She was very containing when I was so angry I wanted revenge. She calmed me down a lot.”



**Disclosure:** In law, disclosure means breaking confidentiality by giving private information to another person or to the general public. Disclosure is allowed in law in defined circumstances, for defined reasons.

**Discrimination:** Discrimination is when a person is treated differently and usually unfairly, because of a certain characteristic they have, e.g., a child is refused schooling because she is living with HIV.

**Immune system:** The immune system is made up of special cells, which protect the body from illnesses. Example: “A healthy diet helps to strengthen the immune system so that the body is able to fight diseases”.

**Incest:** A sexual act between members of a natural or adoptive family.

**Limit setting:** The placement of restrictions such as rules.

**Limits of confidentiality:** Circumstances under which confidentiality cannot be maintained for legal or ethical reasons.

**Mandatory reporting:** The legal obligation to report abuse and neglect of children.

**Neglect of a child:** When a caregiver doesn't meet the child's basic needs, like physical needs (e.g., food), emotional needs (e.g., care), intellectual needs (e.g., school) or social needs (e.g., friends).

**Primary caregiver:** This is the main person who is looking after a child. It is the person who the child is most connected with or bonded to. Example: “Her primary caregiver is her grandmother because her mother died when she was small.” A primary caregiver can be a man or a woman.

**Rape:** Sexual penetration of a boy or girl without his or her consent. Sex with a child under 12 years, even with consent, is always rape. Sex with a child 12-16 years, even with consent, is statutory rape.

**Reasonable grounds:** Reasonable evidence for believing a child is abused or neglected. It does not mean proof beyond a doubt, but it should be persuasive evidence that makes it reasonable to believe something has happened.

**Resilience:** The capacity for a person to prevent, reduce or overcome the damaging effects of an adverse event or events.

**Sexual assault:** Sexual violation (e.g., touching) of a boy or girl without their consent. Sexual violation of a child under 12 years, even with consent, is always sexual assault. Sexual violation of a child 12-16 years, even with consent, is statutory sexual assault.

**Statutory rape:** Sexual penetration of a boy or girl child aged 12-16 years with the child's consent. Even though the child gives consent, the law recognises this as a crime because of the child's age.

**Stigmatisation:** A negative social label that shows prejudice against some people, e.g., children may be stigmatised because a parent is living with HIV.







# DAY 1

## MODULE ONE:

# Introduction and setting the scene

Becoming  
child-centred in  
our work



*This module introduces you to the trainers and to each other. It enables us to get to know each other and our existing knowledge and what to expect from the course. It helps to create a safe learning space that encourages participation. It introduces you to the reasons for which children may be tested for HIV. It gives an understanding of a rights-based approach and principles in HIV counselling and testing of children.*



**Overall total time:** 180 minutes (3 hours)

### **Objectives:**

At the end of this module participants will:

- Understand the aims of counselling
- Identify requirements for working with children and adapting HCT to meet the needs of children of different ages

### **Activities:**

- Small group discussion
- Input and large group discussion
- Complete pre-course assessment questionnaire
- Develop a "job description" in small groups
- Quiz
- Discussion





## KEY POINTS:

- ▶ We encourage and value your participation
- ▶ Share your experience and questions
- ▶ Listen to and respect other people's experience and questions



## Unit 1: Introducing yourself

■ What is your name? \_\_\_\_\_

■ Where do you work and what is your current work role there? \_\_\_\_\_

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■ What kind of contact do you have with children in the course of and outside your work?

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■ What are your expectations of this course? \_\_\_\_\_

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■ What will help you to feel that we have a safe learning space in the group?

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## Unit 2: Setting the scene



• Activity 1: 60 minutes • Activity 2: 20 minutes • Activity 3: 40 minutes

**Total: 120 min (2 hours)**

### Objectives:

At the end of this module participants will:

- Understand the concept of and principles relating to children's rights
- Have discussed the legal framework which regulates HIV testing of children
- Be able to accurately describe the models of HIV counselling and testing (HCT)

### Activities:

- Input and facilitated discussion
- Input
- Quiz

*Our law says that anyone under the age of 18 is a child. Children have in most cases the same rights as adults but they also have some special rights which are only for children.*



### KEY POINTS:

- ▶ Our law says that anyone under the age of 18 is a child. Children have in most cases the same rights as adults but they also have some special rights which are only for children. These "children's rights" aim at protecting them from harm and enabling them to develop and fulfil their potential.
- ▶ Sometimes working with children's rights is challenging as they may threaten our belief systems or cultural values, for example we may think it is immoral to have sex before marriage but children can consent to sex at 16. Respecting the rights of sexually active teenagers may make community workers feel uncomfortable. We need to learn strategies which enable us to protect children's rights and manage our own personal opinions.
- ▶ Children's rights are particularly important in the context of HIV testing as in the past many children have been tested for discriminatory reasons.
- ▶ Today, the Children's Act sets out when and how a child may be tested for HIV and the National Policy on HIV Counselling and Testing (JCT) gives us more detailed guidance on how to apply these principles. *The HIV Testing of Children: Legal Guidelines for Implementers* gives even more advice on applying the principles in the Children's Act and the HCT policy.
- ▶ There are two models or ways in which HIV testing can be offered in our health system, through Voluntary Counselling and Testing (VCT) also sometimes called Client-initiated Testing and Counselling (CITC) and Provider-initiated Counselling and Testing (PICT). Both of these models are ways in which children may be offered HIV testing.



When counselling children, you must remember:

- 1) The Children's Act
- 2) National Policy on HIV Counselling and Testing
- 3) HIV Testing of Children: Legal Guidelines For Implementers.



### **NOTES: Legal regulation of HIV testing of children**

HIV testing of children is regulated by:

- Section 130 of the Children's Act (No. 30 of 2010)
- The National Policy on HIV Counselling and Testing
- HIV Testing of Children: Legal Guidelines for Implementers

The Children's Act describes the circumstances in which a child may be tested for HIV, how such testing should be done and who is able to provide consent for such testing.



*The Children's Act helps us understand when we can test a child for HIV. This handout can be found on the Resource CD in the "Notes" section.*



**The National Policy on HIV Counselling and Testing** describes the circumstances in which lawful HIV testing of children may take place. The requirements in the National Policy are similar to the legal requirements for HIV testing which are set out in the Children's Act. To comply with the law and National Policy, HIV testing should be:

- client- or provider-initiated;
- only carried out in specific circumstances;
- accompanied by voluntary and informed consent;
- authorised by a person with legal capacity (i.e., a person who is regarded in law as being mature enough to make a decision. This could for example be the child themselves);
- with pre-test and post-test counselling; and
- be confidential.

**The National HIV Counselling and Testing Policy** says that HIV testing of children is important in the following circumstances:

- HIV-exposed infants;
- abandoned babies;
- infants younger than 18 months who may be at risk of HIV infection;
- infants older than 18 months who may be at risk of HIV infection;
- breastfed babies of HIV-positive mothers;
- children not identified by PMTCT (prevention of mother-to-child transmission) programmes;
- young persons; or
- child survivors of sexual assaults.

*All HIV testing of persons under the age of 18 should be carried out in accordance with the Framework created by the Children's Act and The National Policy on HIV Counselling and Testing.*





# MODULE TWO: Counselling children

Creating a special  
helping relationship  
for children



*This module deals with understanding what counselling is, the values guiding counselling and counselling with children. This includes understanding their different developmental needs.*



**Overall total time:** 175 minutes (2 hours, 55 minutes)

### Objectives:

At the end of this module participants will:

- Understand the aims of counselling
- Identify requirements for working with children
- Understand the need to adapt HCT to meet the needs of children of different ages
- Understand the influence of personal attitudes and values on our work

### Activities:

- Small group discussion
- Large group discussion
- Develop a "job description" (in small groups)
- Discussion
- Values exercise
- Large group discussion



# Unit 1: Counselling: General definition of counselling and working with children



## KEY CONCEPTS IN COUNSELLING DEFINITIONS:

There are many definitions of counselling, however the **Guidelines for HIV Counselling and Testing of Children**, gives the following definition:

*“...A facilitative process in which the counsellor, working within the framework of a special helping relationship, uses specific skills to assist children and young people to help themselves more effectively. This involves helping the person to cope with their emotions and feelings as well helping them to make positive choices and decisions” (Gillis, 1994).*

The various definitions of counselling generally share common aims. Examples of words/concepts in definitions of counselling include that counselling:

- ▶ Is an interactive, helping relationship
- ▶ Provides a framework for positive action
- ▶ Provides support
- ▶ Creates opportunities for education
- ▶ Is empowering
- ▶ Strengthens emotional well-being
- ▶ Creates a safe space for exploring feelings and attitudes
- ▶ Provides opportunities for problem exploration
- ▶ Helps people manage difficulties
- ▶ Helps people to cope
- ▶ Assists in problem solving



## Activity

1. Ask yourself the following questions:

- What do you consider to be the most important concepts in counselling?
- What key words/concepts would you add to the list above?

Make notes:

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2. Write a “job description” for people counselling children:

Make notes and discuss in groups:

*How would you describe a job in counselling children – what qualities, skills, values, attitudes would you think that job requires?*

Write your job description here:

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### **NOTES on ‘job description’ for counselling children:**

The following could be included in the “job description” for counselling children:

#### *Qualifications or training*

- Must have a sound understanding of child development including physical, mental, emotional and social processes that characterise development. This enables the healthcare provider to:
  - Respond accurately to the needs of the child;
  - Engage with the child in ways that are appropriate for his or her level of development, e.g., using puppets or stories with younger children;
  - Undertake a sound and accurate assessment of the child’s capacity to participate in the counselling process;
  - Use language that is appropriate for the child’s level of insight, understanding, education and emotional readiness.
- Must be interested in and prepared to update training to assist in developing competencies.
- Must be prepared to receive mentoring and supervision to ensure implementation of work to an acceptable standard.
- Must be prepared to seek support in dealing with the stressful nature of the work.

#### *Knowledge required*

- Must have up-to-date knowledge of HIV.
- Must have up-to-date knowledge about the range of services available for those that test positive and support services for referral purposes.
- Must be familiar with legal aspects of work with children, e.g., Children’s Act.

#### *Skills*

- Must be able to listen attentively to what the child is saying.
- Must be able to build an environment of trust and safety in a short space of time.
- Must be able to establish a relationship with the child by showing an interest in his/her world.



- Must be able to talk openly about sensitive issues in a way that is appropriate to the culture, educational level and beliefs of the child.
- Must be able to help put the child's feelings into words.

#### *Personal attributes*

- Must be able to discuss sexuality comfortably with children.
- Must be approachable and easy to talk to.
- Must be accepting.
- Must be aware of his/her biases and moral judgements and treat children in a non-judgemental manner i.e., be able to listen without criticism or giving opinions.
- Must respect child's rights to age-appropriate information, participation and involvement in decision-making.
- Must be affirming and respectful of the child's needs, feelings and responses.
- Must be genuine in interactions with children. (Children easily recognise when a person is playing a role.)

*Adapted from: Integrating HIV voluntary counselling and testing services into reproductive health settings (2004) UNFPA.*

## **Unit 2: Understanding children at different ages**

### **1. Introduction to child development**

In implementing HCT with children, healthcare providers will work with children across a wide range of ages. It is therefore necessary to have some understanding of how children develop, and differences at different ages. This module provides a broad overview which you can supplement by further reading. The following information provides guidance on key aspects of work with children:



*Children of different ages are counselled differently. There are four stages of childhood development that are useful to understand.*

#### **• Stages of childhood**

In HCT with children, healthcare workers will work primarily with children in the following stages:

- Early childhood (roughly 3-6 years)
- Middle childhood (roughly 6-10 years)
- Early adolescence (about 10-14 years)
- Late adolescence (older than 14 years)

In the case of infants and children younger than about three years, HCT will generally not directly involve the children themselves, but rather will be directed at their parents/caregivers, including how they could make the experience as comfortable as possible for their children. In this section, therefore, the focus is on children who are a little older – those in early childhood and more particularly middle childhood and adolescence.





## KEY CONCEPTS IN CHILD DEVELOPMENT:

**Detailed knowledge of child development is less important than the healthcare providers always keeping in mind the following points:**

- ▶ Children change and develop with age
- ▶ Different children develop at different rates
- ▶ Children have different needs at different ages
- ▶ A child's cognitive, emotional and social capacities may develop at different rates
- ▶ Development can be promoted or held back by circumstances affecting the child
- ▶ Children are resilient and have the capacity to survive difficult circumstances given appropriate support.

### • Factors affecting child development

These include:

- Genetic factors
- Nutrition
- Good health/illness (affecting body/brain and opportunities for play/learning)
- Feeling safe and protected, having a sense of trust in caregivers
- Stable caring relationships
- Caregivers who are sensitive and responsive to the child's needs
- Illness/depression in the caregiver that interferes with the relationship with the child
- Expectations that are appropriate for the child's developmental level (cognitive, emotional)
- Consistent patterns of limit-setting by caregivers
- Access to opportunities for play and learning
- Cultural and religious beliefs and practices of caregivers
- Good enough vs. difficult circumstances (e.g., sufficient food, protection vs. poverty, abuse).

## 2. Child development and HCT with children

### • Implications for HCT with children

- Counselling must be adapted to the developmental level and capacities of the individual child.
- Children need to be involved in HCT to the extent possible in line with their developing capacities.
- With very young children, the focus of HCT is generally on the caregivers. However, even then, the particular child and his/her specific needs and capacities need to be kept in mind.
- The older the child, the better the child's understanding and capacity to express himself/herself. However, because of differences between children HCT must always be adapted to the needs and capacities of the particular child.
- It is necessary to assess the child's developmental level (including level of understanding and capacity to express him/herself), emotional well-being and relationships with others to decide whether the child has the capacity to give informed consent.



- Be alert to circumstances that could possibly be affecting or could have affected the child's development, well-being, relationships and thus capacity to give informed consent.



## KEY AREAS OF DIFFERENCE RELEVANT TO HCT

In working with children in HCT, healthcare providers need to have some sense of the differences between children of different stages with regard to how they:

- ▶ make sense of or understand information and reason (e.g., needing simple, concrete explanations, or being able to understand and follow more abstract ideas);
- ▶ use language (understand what is said to them and express themselves);
- ▶ experience, express and cope with feelings;
- ▶ relate to others and the significant people in their lives (e.g., dependent/independent, range of relationships);
- ▶ manage in terms of self-care (seeing to their own daily needs);
- ▶ understand illness (causes, effects on body, prevention, treatment);
- ▶ express themselves sexually (e.g., through pleasure in bodily sensations, sexual exploration in games, romantic involvement, becoming sexually active).

### • Communication with children

To remind yourself to think about a child's level of development, always make a point of asking or checking a child's age at the beginning of a session. Then, as you interact with the child, or hear reports about the child, think about how this compares with what might be expected at that age and adapt your approach accordingly.

Make space for a child to ask questions and be guided by them as to how and what to say in response. Don't give a long lecture – rather answer the question and wait for more questions to guide what you need to say.

Be aware of how a child responds to you and what you say. If the child fidgets or looks bored, perhaps this means that you're saying too much, or talking in too abstract a way, or that you've lost the child's interest. Try a new tack, or move on.

## 3. Typical characteristics at different stages of development

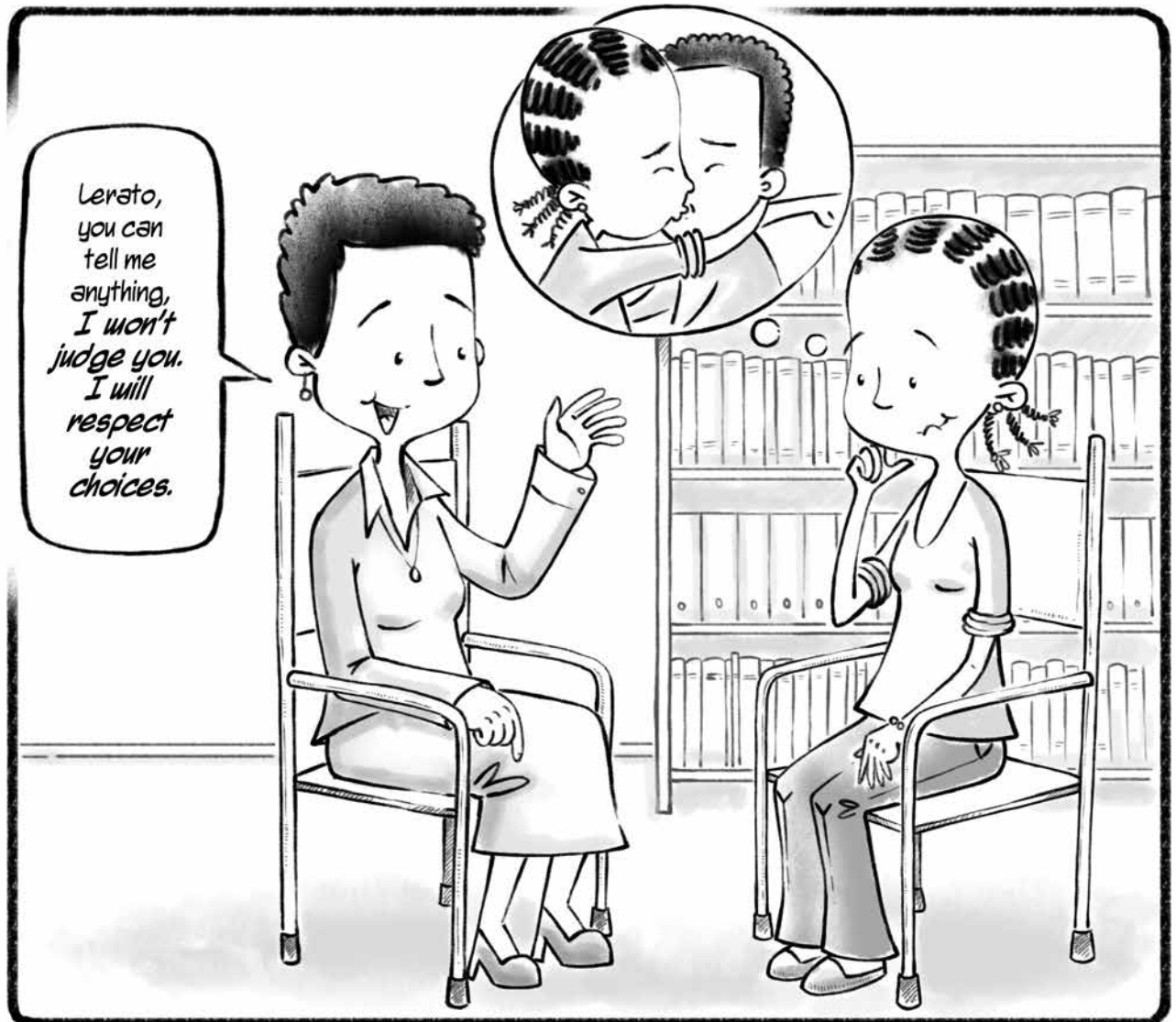
It is important to think about how the differences between children of different ages might affect the implementation of HCT with children. A detailed guide to different phases of development will be provided to you.

*In the "Notes" section of the Resource CD is a very useful detailed guide to the different phases of development!*



## Unit 3: Values and attitudes

The values and attitudes that a person has can influence the way in which he or she responds to others. Healthcare providers have an important role to play in helping children and adolescents to feel supported and understood and can help children, young people and their caregivers or parents to build a positive relationship with the healthcare system.



Think about how values and attitudes might shape the way in which healthcare providers perceive and respond to a situation. Stereotyping is an example of an attitude that is damaging to certain groups. For instance, adolescents are often stereotyped as difficult and rebellious.

When an individual is aware of his or her attitudes and values and is open to new information, it is possible to change or manage these. Consider how you might respond to the following statements:

- Young men don't like using condoms.
- Talking to an adolescent about sex might encourage him or her to try it.
- Adolescence is a time of "storm and stress" caused by hormonal changes.
- Parents are unimportant to adolescents.
- Children need discipline and a good slap now and then isn't a bad thing.

- Women put themselves at risk of HIV because they sleep around.
- Young children can't express themselves.
- Some girls fall pregnant just to get a grant.



## Activity

Make notes after the above exercise: \_\_\_\_\_

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Think about and then write down what values you would want someone who is counselling children to have:

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Value Statement	Additional Information
Young men don't like using condoms	A survey conducted by the HSRC shows that a substantial proportion of the population reported using a condom at last sex. This was particularly high amongst 15-24 year-olds, with an increase amongst males from 57% in 2002 to 87% in 2008. <a href="http://www.southafrica.info/about/health/hiv-150609.htm">http://www.southafrica.info/about/health/hiv-150609.htm</a>
Talking to an adolescent about sex might encourage them to try it	There is a large body of research which shows that talking to adolescents about sex will not hurt children or encourage them to experiment, but it does help to protect them. A Ugandan study showed that the failure of parents to provide guidance and advice and demonstrate concern for their daughters was considered an important reason for girls engaging in risky behaviour and falling pregnant (Sekiwunga & Whyte, 2007). <a href="http://www.community.nsw.gov.au/docswr/_assets/main/documents/parsex.pdf">http://www.community.nsw.gov.au/docswr/_assets/main/documents/parsex.pdf</a>
Adolescence is a time of "storm and stress" caused by hormonal changes	The idea that adolescence is a period of "storm and stress" was popularised in 1921 by a man named G. Stanley Hall and was reinforced by others who believed that hormonal changes were the primary cause of aggression, mood swings and other problems. More recently research suggests that adolescent development is the result of biological, environmental and social factors. Biological influences represent only one aspect of adolescent development. Many adolescents navigate adolescence without "storm and stress".



Value Statement	Additional Information
Parents are unimportant to adolescents	Studies suggest that parents are an important source of support for adolescents. Whilst separation might be a goal, the young person is also concerned with remaining connected. Adolescents need to feel that they are part of a family. Research has found that at critical moments in the decision-making process, it is likely that parental help will be sought. The importance of the parent-adolescent relationship has been demonstrated in South Africa. One study found that parents were ranked as being more significant than the peer group for many black adolescents (Haasbroek in Vujovic, 2008).
Children need discipline and a good slap now and then isn't a bad thing.	Research has shown that there is a link between corporal punishment in childhood and aggressive or violent behaviour in the teen and adult years. Children learn from their parents and physical punishment gives the message that it is alright to hit a person. Physical punishment may also interfere with the bond between parent and child. It is difficult to feel love towards a person who hurts or harms us. <a href="http://www.naturalchild.org/jan_hunt/tenreasons.html">http://www.naturalchild.org/jan_hunt/tenreasons.html</a>
Women put themselves at risk of HIV because they sleep around	AIDS-related stigma and discrimination refer to negative attitudes towards people who are HIV and AIDS infected. In sub-Saharan Africa where heterosexual contact is the most common form of transmission, stigma is focused on promiscuity. In societies where women are culturally or socially disadvantaged the behaviour of men is often excused and women are blamed for transmission of the disease. Biologically women are more than twice as likely to contract HIV through unprotected sex. One reason is that HIV-infected semen has a higher concentration of the HIV virus than vaginal secretions. Another is that women have a much bigger area of skin and tissue that is exposed to the secretions (semen) of their partner. <a href="http://www.hivinfosource.org/hivis/hivbasics/women/">http://www.hivinfosource.org/hivis/hivbasics/women/</a>
Young children can't express themselves	Children communicate from infancy. For example, they express themselves in vocalisations such as "cooing" sounds and through their body movements. Children also express themselves in their play and through their drawings. Healthcare professionals who work with young children (3-5 years) often use the drawings that are produced by young children as a way of tuning into their needs.
Some girls fall pregnant just to get a grant	In a survey of 1 500 girls aged 15-24 only 2% cited the child-care grant as an incentive to fall pregnant. Evidence suggests that teenage pregnancy is driven by factors such as sexual coercion, forced sex, social pressures that prevent condom usage and healthcare provider attitudes towards teenagers seeking contraception. <a href="http://www.irinnews.org/Report.aspx?ReportId=70538">http://www.irinnews.org/Report.aspx?ReportId=70538</a>







# DAY 2

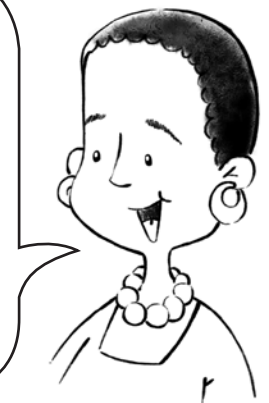
## MODULE THREE:

# When can children be tested for HIV? Circumstances, best interests and capacity

Assessing the individual needs of each child



*Sometimes children are tested because it is hoped that knowledge of their HIV status will benefit them, i.e., for access to treatment and care. We need to know how to assess when a test is in a child's best interests, and how to assist in the informed consent process. A child may need to be tested because this information is wanted for the benefit of another person, such as a nurse, who may be infected due to exposure to the child's body fluids. Then no informed consent is required. However it is still important to be respectful and explain what is happening. This module gives us that information.*



This module has four units:

**Unit 1: Circumstances in which a child may be tested for HIV**

**Unit 2: Informed consent**

**Unit 3: Assessing the best interests of a child: guidelines**

**Unit 4: Assessing the best interests of a child: application in counselling.**





**Overall time:** 360 minutes (6 hours)

**Objectives:**

At the end of this module participants will:

- Have an understanding of the circumstances in which a child may be tested for HIV (UNIT 1)
- Be aware of when children can consent to an HIV test and what to do if it is refused (UNIT 2)
- Understand the key elements and process of assessment of a child’s best interests and capacity to give informed consent (UNIT 3)
- Have an opportunity to apply guidelines on assessment of a child’s best interests and capacity to give informed consent (UNIT 4)

**Activities:**

- Input and small group work
- Input, role-play and group work
- Review and discussion
- Paired and group discussion
- Group discussion
- Paired discussion

**Scenarios:**

- Nomonde, Belinda, Tshepo, Aaron (Scenarios section of Resource CD)

## Unit 1: Circumstances in which a child may be tested for HIV



### KEY POINTS:

**The Children’s Act says that children may only be tested for HIV in two circumstances:**

- ▶ (a) If it is in the best interests of the child and consent has been given by the child or an adult caring for the child;
- ▶ (b) If a healthcare worker or another person has been exposed to HIV when working with a child. Testing here does not need to be in the child’s best interests and consent is not needed.

The concept of HIV testing only taking place when it is in the child’s best interests means that we have to look at a range of factors such as the impact the test will have on the child, why it is being done, the support or treatment that can be provided to the child, etc., and then decide if the test will promote the child’s welfare.



### Activity

**Complete the following table in pairs by:**

- (a) Placing a cross in the column to indicate if testing is in the best interests of the child or if it is testing to establish the child’s HIV status for a third party;
- (b) Writing yes or no in the column asking whether consent is required; and
- (c) Writing yes or no in the column asking whether a court order is required to authorise the HIV testing.



<b>Scenario</b>	<b>Test is in the best interests of the child</b>	<b>Test is to establish the child's HIV status for a third party</b>	<b>Consent is required: Yes/No</b>	<b>Court order is required before testing may be done: Yes/No</b>
A child has fallen and is bleeding. A pre-school teacher is exposed to the child's blood after she carries the child from the playground to the neighbouring clinic				
A young mother (16) brings her 18-month-old child to the local clinic for his vaccinations				
A 17-year-old girl is brought to the clinic for Post exposure prophylaxis (PEP) after being raped				
Social workers take an abandoned baby (seven hours old) to the clinic for treatment				
Lindiwe, a 15-year-old, sexually active adolescent comes into the clinic for VCT				
A baby who is born to an HIV-positive mother				
A nurse incurs a needle stick injury on herself after drawing blood from an eight-year-old girl				
A doctor recommends PICT for a five-year-old child with TB				





## Activity

### In your groups complete the following tasks:

- Identify and list on post-it stickers the factors that would be relevant to a best interests analysis in this case. Place all the post-it stickers onto a piece of flipchart paper marked "Factors".
- Decide which groups of factors are the most important in this context. Move them to the bottom half of the flipchart paper under the heading of, "Most important factors to take into account".
- On a new piece of flipchart paper draw two columns. On the left side head the column, "Factors in favour of testing" and on the right side write, "Factors against testing". Move the factors that you consider to be the most important to the new columns.
- Conclude your group work with a discussion in which you weigh and balance the factors in favour of and against Ms XM having an HIV test and decide if it is in her best interests to have an HIV test at this point. Write your brief answer up on the flipchart.

## Unit 2: Informed consent



### NOTES: Informed consent to medical treatment including HIV testing

**Informed consent to medical treatment rests on a recognition of the rights of individuals to act as autonomous agents and make their own decisions.**

The purpose of consent to medical treatment is to:

- Ensure that a patient's right to self-determination and freedom of choice are respected; and
- Encourage rational decision-making by a patient through enabling them to weigh and balance the various options available to them.

### The criteria for valid informed consent

Consent is only legally valid if the following exist:

- The patient must have knowledge of the nature of the treatment or test*

Consent will only be valid if it is based on knowledge of the nature and effect of the act being consented to. Healthcare workers must inform the patient of any relevant information regarding the procedure. The National Health Act also says that healthcare providers must, where possible, give information to the patient in a language that they understand and in a way that takes into account their level of literacy. The Act also says that even if the patient does not have the capacity to consent to medical treatment themselves (i.e., they are too young) they must still be given information on their diagnosis and treatment.

### If we apply this to HIV testing it means:

- Information must be provided on the HIV test, why it is important and the implications of a negative or positive result;
- The information on the HIV test may be provided in a group counselling session;
- A person undergoing HIV testing should be offered the opportunity of asking any questions;
- If the child is being assisted by an adult, the information must be provided to the adult, but where possible, the child should be involved and concepts should be explained to them so that they understand why the HIV test is being done.

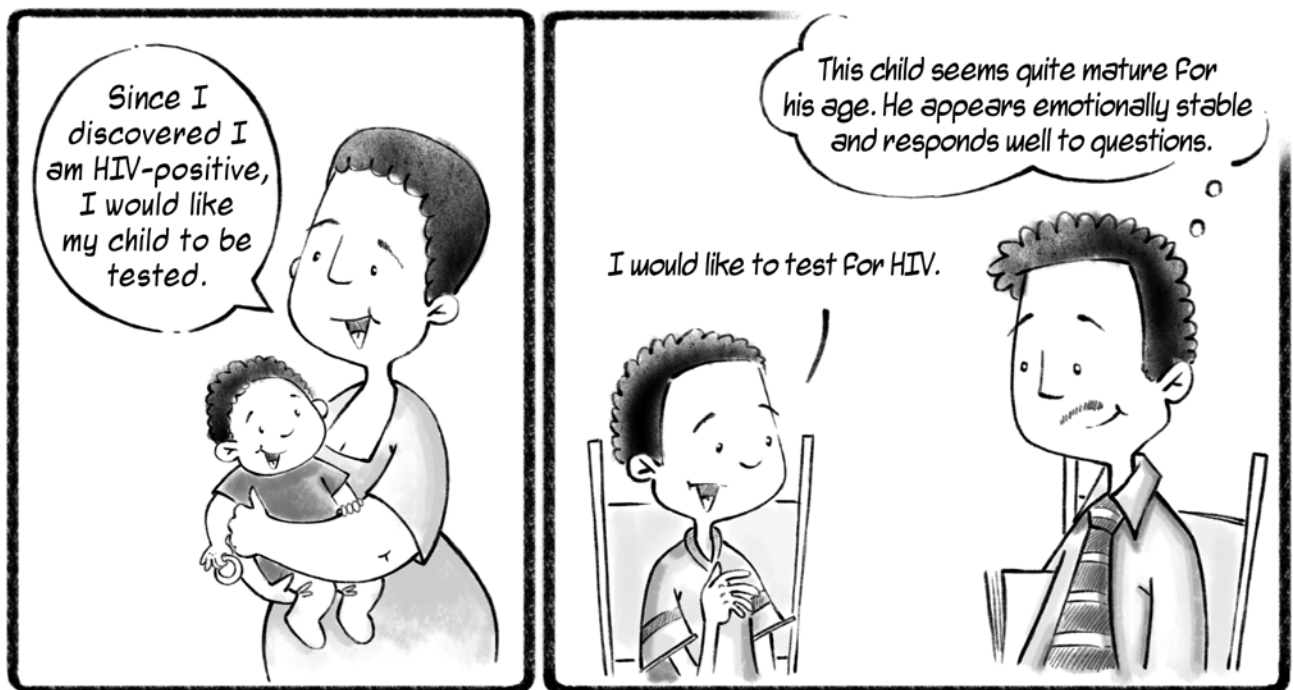


ii. *The patient must understand the nature of the medical treatment or test*

The patient must understand and accept the information given. In other words, the patient must not only be given information, but healthcare workers must make sure that they understand the information. There is not much guidance in our law on how to know whether a patient has understood the information. It has been suggested however that when trying to see if a child has understood the information the following factors should be taken into account: the child's age, their knowledge of their test or treatment and their ability to show that they are able to make choices. The child's circumstances at the time are also important, for example, are they living away from their parents? Have they always had to act independently, etc?

**If we apply this to HIV testing it means:**

- Counsellors and healthcare workers must ensure that a child who is consenting independently to HIV testing understands all the information on the test and its implications;
- Testing a child's understanding of the information can be done informally by asking them questions so as to ensure that they understand the implications of the test.



iii. *The patient's consent to the medical treatment or test*

Consent must be given either expressly (by signing a consent form) or tacitly (i.e., through conduct). Consent must be given freely and voluntarily. Consent may not be obtained through fear, force, threats, fraud, undue influence, or financial gain.

**If we apply this to HIV testing it means:**

Consent to VCT must be given in writing whilst consent to PICT can be given verbally as long as this is noted in the patient's file (National Policy on HIV Counselling and Testing).

iv. *Capacity*

Consent must be given by a person who is legally capable of consenting to medical treatment. The Children's Act says that a child may give independent informed consent to an HIV test if he or she is 12 years or older, or if he or she is under the age of 12 and of "sufficient maturity to understand the benefits, risks and social implications of such a test".



The Children's Act therefore assumes that children have the capacity to consent to an HIV test independently from the age of 12. However, if a child over the age of 12 appears to not have the capacity (ability) to absorb the information regarding an HIV test, understand it and give agreement to it then consent should be obtained from one of the listed persons below. The types of circumstances in which a child would appear to not have the capacity to consent even though they are over the age of 12 include when they are:

- Unaware of the key concepts of HIV testing and its implications for their future health;
- Not able to grasp or understand the key concepts regarding the nature of HIV testing and its implications for their future health;
- Intoxicated or under the influence of drugs;
- Unable to act independently in making the choice regarding whether to test or not.

The Children's Act allows children under the age of 12 to consent independently to an HIV test if they have the necessary capacity. In such a case a detailed assessment of capacity should be done.

If the child cannot consent themselves, consent may be given by:

- the parent, guardian or caregiver of the child;
- the Provincial Head of the Department of Social Development; or
- a designated child protection organisation arranging placement for the child.

A caregiver is defined in the Children's Act as any person other than a parent or guardian, who actually cares for a child and includes –

- (a) a foster parent;
- (b) a person who cares for a child with the implied or express consent of a parent or guardian of the child;
- (c) a person who cares for a child whilst the child is in temporary safe care;
- (d) the person at the head of a child and youth care centre where a child has been placed;
- (e) the person at the head of a shelter;
- (f) a child and youth care worker who cares for a child who is without appropriate family care in the community; and
- (g) the child at the head of a child-headed household.

Where there is no parent, caregiver or child protection organisation, informed consent may be provided by a superintendent or person in charge of a hospital. The Children's Act does not provide for the head of a clinic to consent to the HIV test and in such a case the child would have to be referred to the closest hospital.

## Common questions about consent to HIV testing

*What should a counsellor do if the child, parent or caregiver withholds consent to HIV testing?*



Where those listed above don't want to or can't give consent, the Children's Court may consent to an HIV test on the child, if the testing is in the best interests of the child. The table below explains this principle by looking at various scenarios.



Scenario	Legal position	Responsibilities on the counsellor
<p>Child under 12 and doesn't have capacity to consent independently, parent or another person refuses to consent</p>	<p>Consent can be given by the Children's Court if a parent or another person who is able to consent "unreasonably refuses" to give such consent (S 130(2) (f), Children's Act No. 38 of 2010).</p>	<p>If the counsellor believes that refusal to consent is unreasonable they need to contact the clerk of the Children's Court for advice on how to get consent from the Children's Court.</p> <p>The court will have to consider the best interests of the child in deciding whether to override the parent's decision.</p>
<p>Child under 12 and the parent or another person gives consent but the child refuses to submit to the test</p>	<p>The Children's Act doesn't deal with this in the section on HIV testing. However, S 10 says that "every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration".</p> <p>It can be argued that consideration should be given to the child's refusal. This should only be overridden if it is in the best interests of the child. For example, a child who has been raped may need to take PEP. If they refuse to test for HIV they will not be able to access this treatment and could face the risk of being infected with HIV. In such a case it is possible that the child's wishes could be overridden but in most cases the views of children should be respected.</p>	<p>Obtain further information on why the child is refusing to test and ensure that the parent or person who is consenting gives due consideration to such views.</p>
<p>Child over the age of 12 refuses to consent</p>	<p>The right to consent to an HIV test is coupled with the right to refuse such a test.</p> <p>However the Children's Act provides that if a child unreasonably refuses to consent the Children's Court may be approached to give consent (S 130(2) (f), Children's Act No. 38 of 2010).</p>	<p>If the counsellor believes that refusal to consent is unreasonable they need to contact the clerk of the Children's Court for advice on how to get consent from the Children's Court in this instance.</p> <p>The court will have to consider the best interests of the child in deciding whether to override the child's decision.</p>





Who can consent for HIV testing on a child living in a child-headed household?

The Children’s Act says a child who is between the ages of 16 and 18 who is acting as the head of a child-headed household is a caregiver of the younger children. This means that the child acting as head of the child-headed household can consent to HIV testing on the younger children as long as they are over 16 themselves.

### Unit 3:

## Assessing best interests and capacity to consent: Guidelines



### NOTES:

#### 1. Key requirements for an HIV test

The key requirements for an HIV test are as follows:

- It must be in the best interests of the child (regardless of age);
- There must be voluntary and informed consent by a person who has the capacity to consent (i.e., understands the risks, benefits and social implications of testing);
- A child of 12 years or older can consent independently;
- A child younger than 12 years can give consent, provided the child understands the risks, benefits and social implications of testing;
- In the case of other (younger) children, consent must be given by a parent or caregiver or other designated persons;
- A child can be tested without the above consents if a healthcare worker or any other person has been exposed to their blood or body fluids (subject to a court order in the case of any other person).



### Activity

#### Discuss in your group:

- When (under what circumstances) would HIV testing be in a child’s best interests and what factors could justify refusal to test on the grounds that testing is not in the child’s best interests?

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- What are the risks, benefits and social implications of HIV testing that a child needs to understand in order to give informed consent? What factors would justify refusal to test on the grounds the child does not have capacity to give informed consent?

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## NOTES:

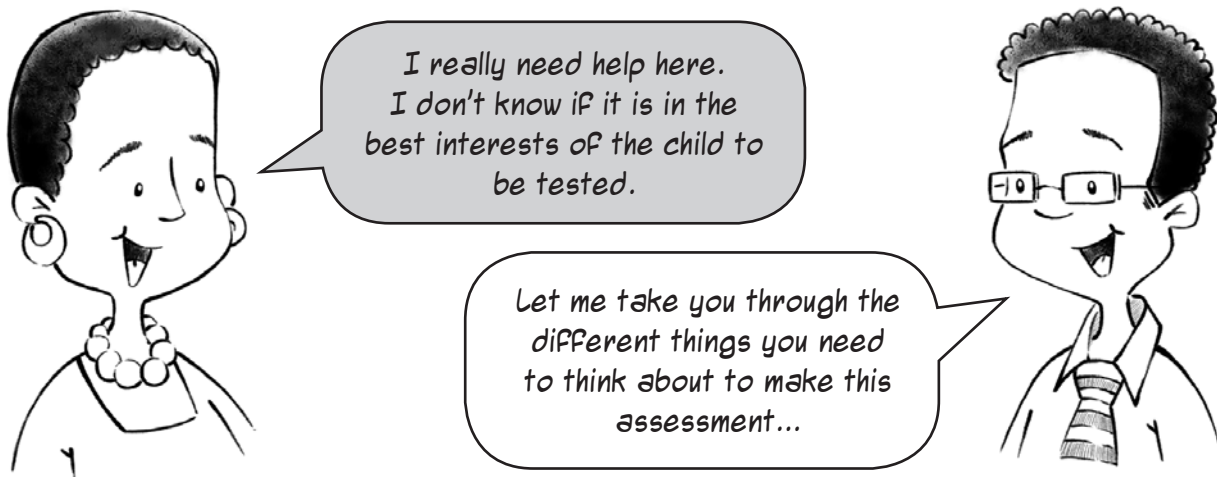
### 2. Assessing best interests and capacity to give informed consent

HIV testing of children aged 12 years or older (or even a child younger than 12 years) is governed by the Children's Act (Section 130 and 132) and the National Health Act (Section 7). This legislation allows children to give informed consent for HIV testing without the assistance of parents or caregivers, subject to the following important conditions:

- Testing is in the *best interests* of the child.
- The child has *knowledge of the nature of the test*.
- The child is of "*sufficient maturity to understand the benefits, risks and social implications of such a test*".

#### ► *Best interests:*

The condition of best interests is a primary requirement. Mostly it is assumed that testing will be in the child's best interests (because it will allow him/her to access treatment if s/he tests positive). However, if the child's circumstances are such that testing is thought not in his/her best interests at this time (e.g., there is no effective support should the child test positive), then testing can be refused at that point in time, even if the child has the capacity to consent.



#### ► *Child must understand potential harms and benefits:*

The other conditions say that the child must have *sufficient* knowledge of and *sufficiently understand* any harm or risk of the test itself, but also the benefits, risks and social implications of the test.

In other words, the child must understand the possible outcomes and implications of the test in order to provide consent. Therefore he/she needs enough cognitive maturity, but also emotional stability and willingness to accept support to be able to cope with results, especially if they are positive.

Therefore they imply that, in certain circumstances, a child who requests HIV testing may be refused on the grounds that:

- s/he is not at least 12 years of age; and/or
- does not have sufficient knowledge, understanding or appreciation of the implications of testing.

In such a case the child will require the assistance of an adult who can assist them by providing consent.



► *Assessment of best interests:*

Assessment of best interests and sufficient capacity to consent requires paying attention to a number of indicators (see below). These need to be assessed in an interaction with the child or their caregiver. Assessment is not based on a single aspect of the interaction (e.g., a specific question), but on an overall judgement based on the whole observation and assessment process. The assessor should try to identify consistent patterns that suggest whether testing is in the child's best interests at the time, taking into account his/her particular circumstances, and whether the child has the capacity to consent.

The outcome of the assessment may be a decision to refuse the child testing at this time. Such a decision should be taken with care, bearing in mind the following:

- the need to respect and promote the child's sense of agency and control;
- the barriers that the child will have had to overcome in coming for testing;
- the likelihood of the child having been exposed to risk (and possibly of continuing HIV exposure);
- the fact that refusing testing will block access to treatment if required.

Note that a healthcare provider's overall judgement relates only to the assessment **at that time** and may differ at another time, even quite soon after a previous negative assessment. For example, a child may on a particular day not show capacity to consent due to the influence of drugs (e.g., inhalants), or significant distress due to recent emotional trauma, but be sufficiently recovered to be able to do so later in the day, or the following day.

**Who should do the assessment?**



*Assessment should be undertaken by an appropriately trained person, that is, someone who has training and experience in VCT and in working with children and who has been trained or has practised assessment in simulated situations.*

*To encourage careful and consistent decisions, assessments should, if possible, be discussed with a colleague before the child is informed of the outcome. Difficult cases and decisions to refuse testing should **ALWAYS** be discussed with a senior colleague (preferably a registered professional colleague such as a social worker or nurse) before the child is informed of the outcome.*



**Recording consent**

If a child is assessed as having capacity to consent, it is necessary, after pre-test counselling, to check that the child still wishes to test – i.e., to obtain consent to test. According to the HCT policy (2010), consent may be given either verbally or in writing for VCT and for PICT it may be verbal. It may depend on the policy of the facility which approach is adopted. It is always necessary to document consent in some way and, in the case of children it may be advisable to have written consent in case of subsequent queries.



## Indicators of best interests and sufficient capacity to give informed consent:



The checklists below are a useful tool to help you assess if a child has sufficient capacity to make an informed decision about testing. Let's go through each of these areas that you need to assess.

### ► Age/developmental level

**Based on the child's self-report, and documentation (ID or other). If there is any doubt regarding the child being 12 years or older, make a judgement based on:**

- Behaviour and responses during assessment process;
  - Growth and physical development (though children may show stunted growth due to e.g., malnutrition, HIV infection through MTCT);
  - Mental and cognitive development;
  - Emotional and social maturity.
- .....

### ► Behaviour and mental state

**Extent to which child engages with interviewer (even if hesitant initially or needing encouragement throughout)**

- Speaks reasonably fluently (in own language);
  - Speech not slurred or very rapid and difficult to follow;
  - Does not appear drowsy;
  - Not excessively restless (can remain seated for five or more minutes at a time);
  - Pays attention to what is being said, does not appear distracted (occasional lapses acceptable);
  - Is able to respond to most questions without having them repeated/re-stated;
  - Follows through a train of thought (does not jump from one topic to another);
  - Gives reasonably complete answers to questions (not just single word responses);
  - Responses not long, rambling, incoherent or irrelevant to question or topic;
  - Can give own name, where s/he is today (e.g., NGO name, clinic, hospital), whether morning or afternoon, name of area/suburb/town/city where s/he lives.
- .....

### ► Views

**The views or opinions of the child on the HIV test and whether they believe that it is in their best interests**

- Child has a view or an opinion on the test;
- Child is able to express their views on the test;



- Child is able to explain how the test will benefit them and is aware of any negative consequences that may flow from it.

.....

► *Emotional state*

**Emotional state not so intense or overwhelming that s/he cannot maintain/regain sufficient control to be able to engage in interview**

Children may well express some emotion in response to the opportunity to share their concerns during the assessment. This should not be a reason to refuse testing if the child is able to regain control of his/her emotions within a reasonable time during the assessment, or after a longer postponement and then resuming the assessment. However, in cases where any of the following are severe or persistent or where a child is not able to regain control of his/her emotions, the assessment should be stopped and the child should be referred to a professional colleague (e.g., social worker):

- Agitated (e.g., shaking, very distracted, not able to sit still);
- Distressed (e.g., crying);
- Withdrawn (e.g., does not respond to questions or needs a lot of prompting, no eye-contact);
- May express suicidal ideas (“kill self”), but when probed, are not firm and well-thought-out plans.

.....

► *Responsiveness*

**Extent to which responses are appropriate, rather than whether they are correct**

- Responds appropriately to introductory greetings (e.g., greets, takes seat);
- Responds appropriately to identifying questions (e.g., gives name, age);
- Can give account of self (e.g., living situation, schooling, friends, out-of-school activities);
- Gives appropriate reason for coming to service/wanting to test (e.g., to find out status, may have been infected);
- Attempts some sort of explanation in response to question, “What do you know about HIV?”.

.....

► *Knowledge*

**Extent to which child has or can acquire and then communicate facts and implications related to HIV and testing**

- May be shown either through initial responses or if child’s initial response is incorrect or insufficient, in response to question being repeated after giving further information (e.g., that’s not quite right ... [give information] ... I hope that’s clearer now – could you tell me again [e.g., how someone can get HIV]...);
- Child should not be unnecessarily penalised for difficulty in conveying his/her knowledge, but if after explanation child still cannot give acceptable response (see criteria as per Indicator Check in Assessment Tool below), this should be taken into account in making final assessment;
- Can explain basic facts relevant to implications of testing (nature of test; HIV transmission; course; treatment but no cure; resources; potential stigmatisation);
- Can explain meaning of negative result (i.e., provisional if recently exposed; does not mean immune in future) and implications (ways to protect self in future);
- Can describe implications of positive result (possibility of transmission to others) and possible social implications (need for support, possible stigmatisation).



► Reasoning

**Extent to which child is able to reason logically**

- Can indicate understanding of confidentiality and raise any concerns;
  - Can respond to request to consider possible events (e.g., if test positive, then what? if test negative...);
  - Has or can construct a plan of what to do and where to access support in the event of positive result.
- .....

► Voluntariness

**Extent to which child is testing voluntarily and not as a result of pressure from anyone**

- Child has come for testing voluntarily and not as a result of pressure from anyone (e.g., partner, peers, parents, other family members, caregivers, teachers, healthcare providers);
  - If someone else suggested testing, but the child does not indicate (e.g., in response to question “What made you decide to test?”) feeling pressured, it can be taken that the child is testing voluntarily.
- .....

► Support/safety

**Extent to which child has access to resources for support or may be at risk (especially if s/he tests positive)**

- Child can identify or is open to help to access resources (caregiver, peer, teacher, community worker, healthcare provider) that could provide support if s/he tested positive (or in any case);
  - Child does not identify any immediate source of marked risk/threat to safety if s/he tests.
- .....

► Need to promote the child’s well-being

**The HIV test needs to promote the child’s well-being, e.g., it should enhance their health through enabling them to access treatment if needed**

- Child has social support structures and will be able to access further care if needed;
  - Child will be able to draw on the support of trusted adults and friend;
  - Child is able to cope with the test results.
- .....

► Need to protect the child from harm

**The HIV test is not being requested to discriminate against the child or will not in some other way result in the child being harmed by for example, being rejected by their family**

- Child is not being tested in order to discriminate against them;
  - Child will not face negative family consequences that are unmanageable.
- .....

► Impact

**The HIV test should promote the child’s physical and emotional well-being**

- Child will access services as a result of the test;
- Child will be in a better position to manage their health within a supportive environment.



► Overall assessment

Is testing in the best interests of this child at this time, taking into account his/her particular circumstances and does the child have sufficient capacity at this time to give voluntary informed consent for testing?



*After looking at all the criteria, this child has scored very well on all the factors required to consent for their test.*

**Indicators of best interests/sufficient capacity to give informed consent**

The table shown below summarises a set of factors that should be considered in deciding on best interests and capacity to consent and can be used as an aid to decision-making.

Summary assessment table		
<b>Definitely</b> has sufficient capacity to consent	<b>Probably</b> has sufficient capacity to consent	<b>Probably does not have</b> sufficient capacity to consent
<b>Definitely</b> in best interests taking into account his/her circumstances	<b>Probably</b> in best interests taking into account his/her circumstances	<b>Probably not</b> in best interests taking into account his/her circumstances

The healthcare provider needs to draw together his/her observations using the indicators to make a decision as per the Summary table. This is not a simple additive process, but relies on the healthcare provider weighing up observations on all the factors and then making a careful judgement. If in doubt (and always where assessment is tending towards refusal to test) consult with a colleague. Remember that best interests take priority over capacity to consent.



**NOTES:**

**3. Communicating the outcome of the assessment**

**A decision that child may test**

If the outcome is a decision that testing is in the child’s best interests and that the child has capacity or the test may be in the best interests of the child and another adult is able to provide consent, inform child and/or the child and adult and confirm that they wish to continue.

If child or the child and adult agrees, continue with pre-test counselling focusing on any areas that have not been discussed fully (e.g., risk assessment and future protection if negative) or any aspects that need follow-up in more detail (e.g., information on HIV/AIDS and test, feelings, support/safety).



This discussion could take the following form:



Based on what you told me earlier, we could go ahead with testing today if you still want to do that. Would you like to continue?...

I said earlier that we would talk a bit more about testing now. Do you have any questions?... (respond as appropriate)



I'd like to pick up on some of the things we talked about earlier ...

If necessary describe in simple terms the following:

- infection;
- production of antibodies to defend body;
- gradual weakening of immune system;
- becoming ill; and
- the fact that treatment works to destroy HIV and support immune system.

Go on to talk about the test:

- The test does not look for the HIV itself. Rather it looks for the antibodies that the body uses to fight HIV.
- If the test finds antibodies, that means there is HIV in the body – in other words, the test is positive for HIV. To make absolutely sure, we do a second test and if both tests are positive, that would mean you do have HIV.
- If the test does not pick up antibodies, we say that the test is negative. If the time when you could have got HIV is more than three months ago, that would mean you do not have HIV. But if the time is less than three months, it is possible that the test is not showing the HIV yet and you would need to test again when the three months is up to make sure.



Is there anything else you'd like to know or tell me about?  
Do you still want to test?...

Before testing, you need to sign this form. It says that we have talked about the test and what it could mean for you and that you decided on your own to test and that no-one forced you to test.



Now I'll call the sister to prick your finger to take blood for the test. Then we will have to wait about 10-15 minutes before the result is ready.



## A decision that a child may not test at this time

If the outcome is a decision that the child may not test at this time, inform the child and provide reasons (which may reflect a combination of factors). In every case arrangements must be made for follow-up, bearing in mind the possibility of the child's continued exposure to HIV and other risks. (Read Guidelines on HIV Counselling and Testing of Children on *Resource CD*).

The following applies:

- A decision to refuse a child testing must be communicated clearly and in a supportive manner.
- Any decision to refuse a child testing is based on an assessment at a particular moment in time and does not hold beyond that time. Depending on the reasons for refusal and changes in circumstances, the assessment may be repeated quite soon after a refusal.

In the table below are examples of how to communicate reasons for decisions and how to follow up. You could start the conversation this way:

*Based on our discussion, it seems that you are not ready to test today ... (see table for suggestions depending on the reason).*



<b>Age/developmental level</b>	<i>It seems that you are not yet old enough to decide to take the test on your own without having an adult with you. Can we talk about how you would feel about coming back another time with, e.g., parent/caregiver/care-worker? (Work out with child who would be an appropriate person and how to approach them.)</i>
<b>Behaviour/mental state during interview</b>	<i>It seemed difficult for you to talk with me just now – maybe because you were, e.g., high on drugs/tired/upset/scared. Would you like to come back tomorrow/another day and we could talk again?</i>
<b>Views of the child</b>	<i>From what you've said, it seems you've decided you don't want to test after all today, e.g., because you want to think things over some more before testing/you want to talk to a friend before testing.</i>
<b>Emotional state</b>	<i>You seem upset today. It was difficult for you to take part in the discussion or really think through whether you should test. Would you like to come back tomorrow/another day and we could talk again?</i>
<b>Knowledge</b>	<i>You need to understand a bit more about HIV and the test and what it means before you can make a proper decision about whether to take the test or not. Would you like to come back tomorrow/another day and we could talk again?</i>



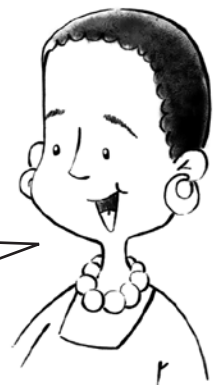


<b>Reasoning</b>	<i>It seems that you don't fully understand what it would mean for you to test and perhaps find out you have HIV. Would you like to come back tomorrow/ another day and we could talk again? (May not be sufficient if reflects significant immaturity – then give age as reason)</i>
<b>Voluntariness</b>	<i>It seems that you came to test because, e.g., X said you must/threatened you and not because it's something you really want to do. We need to find a way to help you with that.</i>
<b>Well-being</b>	<i>If you test positive, there is no-one who could support you. Let's talk about what we can do to help you find the support you need before you test. If you test positive, your situation, e.g., extremely poor living circumstances, lack of support, would make it difficult for you to use health services properly. We need to sort that out before you test.</i>
<b>Protection from harm</b>	<i>It seems that others might make your life very difficult/you could be harmed, if you tested positive today. We need to sort that out before you test.</i>



#### NOTES: 4. Assessment responsibilities

*We as providers have the responsibility to assess if testing is in the best interests of the child. Let's remind ourselves what these are...*



- Regardless of the child's age (i.e., up to the age of 18 years), healthcare providers must always assess whether testing is in the best interests of a child. This factor takes priority over capacity i.e., even if a child has the capacity to consent, testing may be refused because it is deemed not in the child's best interests.
- Assessment of capacity is only important when the child wishes to consent independently to an HIV test. Parliament has set 12 as the average age at which children will have capacity to consent to an HIV test. This means we can presume that children of 12 have the capacity unless the factors listed indicate otherwise. Where children are under 12 the law says that they will only have capacity if they can understand the risks, benefits and social implications of HIV testing.
- Because age is not always a reliable indicator of cognitive and emotional maturity, healthcare providers must be aware of capacity issues and they have a responsibility to ensure that all persons (adults and children) have capacity to give consent.
- In order to give consent any person must have knowledge, understanding and they must provide their express or implied agreement.



- Like a general health assessment, assessment of best interests and capacity cannot be done in a superficial or haphazard way – rather it requires careful and systematic consideration of a number of relevant factors.
- Bearing in mind the potential benefits of testing and barriers to testing (e.g., accessibility, stigma, emotional), a decision to refuse testing should not be taken lightly and should be discussed with a senior colleague.

## Unit 4: Assessing best interests and capacity to consent: Application



### Activity: Making a decision on testing

**In order to make a decision on testing, the healthcare provider has to assess both best interests to test and capacity to consent.**

Refer to the scenario section (on *Resource CD*) and read through the scenario allocated to you. Refer to UNIT 3: Assessing Best Interests and Capacity to Consent: Guidelines (p.28). Use the Indicators/Summary table (Handout I) as a guide in responding to questions related to the scenario you have been given.

- Use the Indicators to assess whether the child has sufficient capacity to give informed consent and whether testing would be in the child's best interests.
- If it is not possible to make a clear determination on any of the indicators, what additional information would you need and how would you go about getting it?
- Based on the information you have, what is your overall assessment (using the summary table)?

Refer to the scenario section (on *Resource CD*).



## MODULE FOUR:

# Pre- and post-test counselling with children



*This module explores how to create a child-friendly environment to facilitate counselling with children (UNIT 1). Then it explores pre-test counselling. We look at the definition of pre-test counselling (how to explain what it is), the guidelines for how to do it, and then apply that learning in some activities (UNIT 2). Lastly we look at post-test counselling. Again we explore the definition, guidelines and application (UNIT 3).*



**Overall time:** 275 minutes (4 hours, 35 minutes)

### Objectives:

At the end of this module participants will:

- Understand how to build rapport with children of different ages (UNIT 1)
- Be aware of appropriate tools and materials in work with children (UNIT 1)
- Define pre-test counselling (UNIT 2)
- Be familiar with pre-test counselling guidelines (UNIT 2)
- Apply pre-test counselling guidelines (UNIT 2)
- Define post-test counselling (UNIT 3)
- Apply post-test counselling guidelines (UNIT 3)
- Understand ways to promote participation of children lacking capacity to consent, or not required to consent (UNIT 4)

### Activities:

- Create an activity in small groups
- Demonstrate activity in the large group
- Large group discussion
- Small group questions
- Role-play in triads
- Discussion and feedback
- Scripted role-plays
- Input and scenario discussion

### Scenarios:

- Nomonde (Scenarios on Resource CD)
- Aaron (Scenarios on Resource CD)



# Unit 1: Creating a child-friendly environment

## 1. Building relationships and establishing rapport with children

It is important that healthcare providers engaged in the provision of HCT for children are able to establish rapport with a child. Building a good relationship with a child includes finding ways to:

- Attract the child's interest by involving him or her in an activity or conversation that is meaningful;
- Ensuring that any approach is appropriate to the age and developmental level of the child.

## 2. Tips for building rapport with children

There are various tools and activities that interest children and which could be used in counselling. The following are some examples of ways to build rapport with children:

- Find out what activity the child likes, e.g., what he or she likes to play;
- Find out what is unique or special about the child;
- Ask the child about his or her hobbies and other interests;
- Ensure that the counselling space is private and quiet. Children need to experience a unique relationship with the counsellor where there is no likelihood of intrusion by others;
- Treat the child appropriately for his or her age;
- Be honest: telling the truth will build confidence and helps to develop a relationship of trust;
- Allow normal emotions: crying is ok and so is anger – be patient with the child;
- Speak softly and directly to the child;
- Make sure you are at eye level with the child. If he or she is sitting on the floor, do the same;
- Younger children like to show adults what they can do, ask them to demonstrate a simple task like hopping, or balancing on one leg;
- Explain to the child that this is a safe place where he or she can relax, talk and play;
- Follow the child's lead. For example if he or she asks about something in the room talk about it and then gently return to the topic;
- Define the nature and limits of confidentiality.

*(Adapted from: The Child-Friendly Clinician, PATA, 2007)*

## 3. Tools and materials for work with children

There are a variety of tools and materials available that can be used in work with children. For example, paper, glue and crayons can be used for many activities, including as a means of illustrating how HIV is transmitted and how it affects the body, and as a way of helping a child to express him or herself. Dolls, storybooks and puppets are also useful.



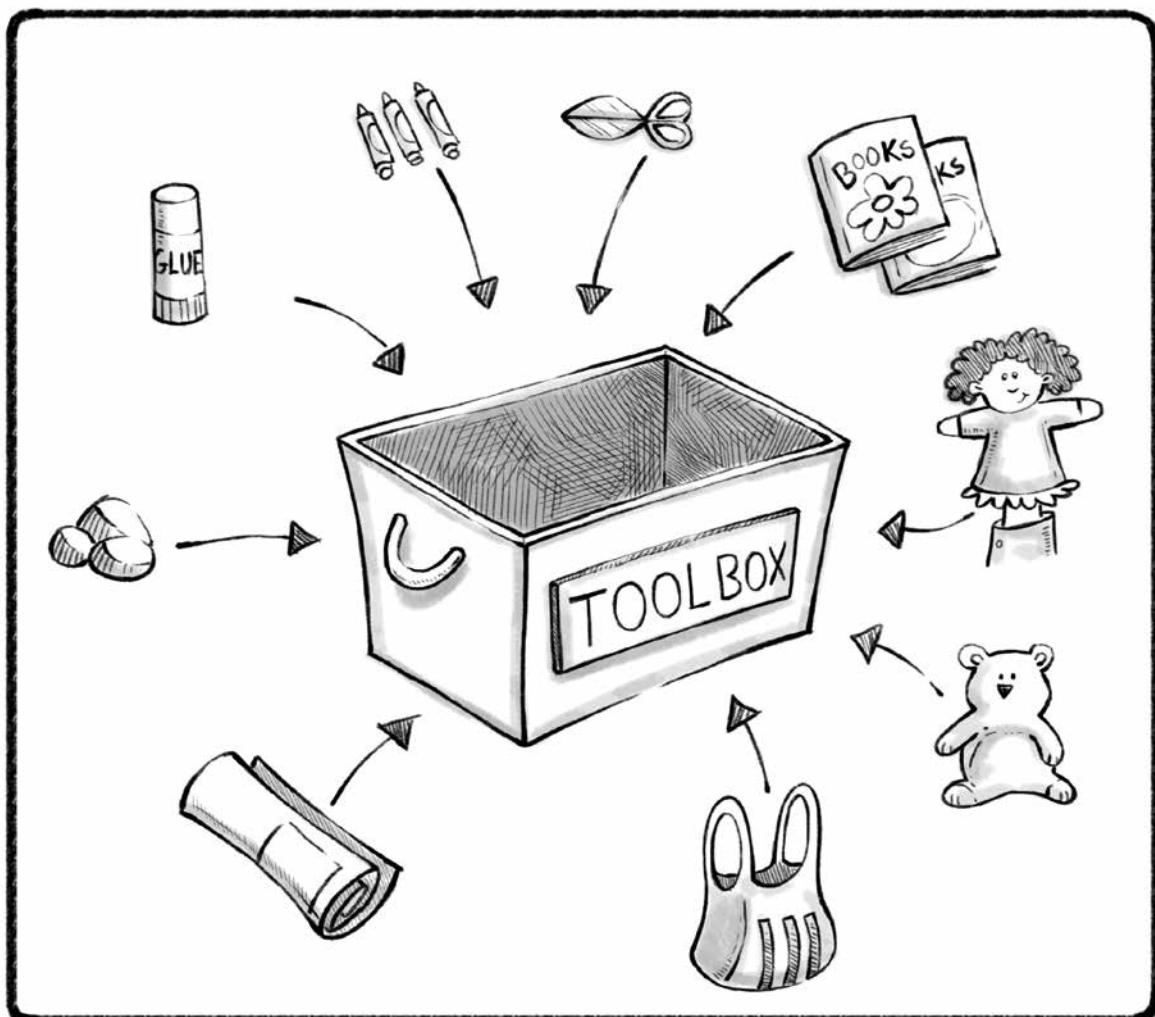
Where materials are not readily available these can often be made inexpensively or obtained from the surrounding environment. For example:

- Stones: can be used to represent healthy or infected cells.
- Newspaper: can be used to make cut-outs of soldiers to show how the body fights HIV.
- Newspaper or plastic bags: can be used to make a ball for playing a game.

**TIP:**

Make yourself a toolbox for your work with children. A useful “toolbox” can include:

- String
- Paper
- Crayons
- Storybooks
- Old magazines
- Glue
- Scissors
- Ice lolly sticks
- Play dough





## Activity

Think of a child-friendly way of explaining the following topics to children in the age group allocated to your group (i.e., early childhood (3-6); middle childhood (6-10); and early (10-14) or late adolescence (14-18).

- HIV and AIDS (3-6 years)
- CD4 count and viral load (7-10 years)
- Prevention (10-14 years)
- Transmission (14-18 years)

## Unit 2: Pre-test counselling:

Regardless of the model of delivery (VCT or PICT) counselling involves as a minimum pre- and post-test counselling. The following definitions incorporate elements that could be considered central in pre-test counselling:



### DEFINING PRE-TEST COUNSELLING:

- ▶ Pre-test counselling is a process where a person undergoes confidential counselling before testing so that he or she can make an informed choice about whether to test in order to learn his or her HIV status. Counselling provides an opportunity for discussion about HIV and AIDS including the risk of infection and means of protection and allows individuals to think about the implications of a negative or positive test result as well as strategies for coping with the test result.

Let us sit down and talk about all the things we need to think about BEFORE we do the HIV test.



## The HOW and WHAT of pre-test counselling

WHAT	HOW
Build a relationship of trust	Be supportive, non-judgemental, respectful, explain role of healthcare provider, stress confidentiality.
Assess knowledge of HIV and explain purpose of HCT	Assess knowledge of acquisition and transmission, give simple explanations and probe to confirm understanding, encourage questions, use teaching aids if available.
Assess likelihood of exposure	Address risk behaviours; provide information on sexual and reproductive health where appropriate.
Explain purpose of testing and procedures	Explain purpose of the test and ensure understanding of test procedure, emphasise need for further testing if result is negative.



WHAT	HOW
Discuss implications of the test	Discuss risks, benefits and social implications of a positive result; discuss strategies for coping with positive/negative result; stress right to confidentiality but draw attention to lawful disclosure intended for the child's own protection, e.g., sexual abuse.
Discuss support systems	Inform of right to test without parental consent; encourage involvement of parents or guardians or identify individuals/organisations who could provide support.
Determine if test is in the child's best interests	Consider child's physical, emotional, moral and spiritual welfare; be prepared to postpone if risk exceeds benefit.
Assess need for further support	Draw attention to services available or refer to services, e.g., sexual and reproductive health.
Discuss availability of services	Stress availability of prevention, treatment, care and support for young people.
Discuss receiving results	Explain when, how and by whom the results will be given; stress privacy including any limits to confidentiality, e.g., other healthcare team members involved in the child's care.
Obtain informed consent	Be prepared to offer the young person more than one visit before s/he decides to test. If consent given obtain verbal and/or written permission to conduct the test.

### Unit 3: Post-test counselling:

*Now that we have your results, let us talk about all we need to think about going forward...*



#### DEFINING POST-TEST COUNSELLING:

- ▶ Post-test counselling: Is provided to help individuals to understand the test result as well as the implications of these results and to consider and plan any follow-up action that is required. It helps children and their parents or caregivers to explore with whom they could share the results and how this might be approached.





## Activity

### **Giving a negative test result: What not to do**

Observe the scripted role-play. A number of problems will become evident in the way in which a negative test result is given. Make a note of the problems you identify in the right-hand column of the observer checklist for post-test counselling of children.

## **Unit 4: Working with children with insufficient capacity or not required to consent**

*This unit focuses on younger children or children with disability who do not have sufficient capacity to consent, as well as children where testing is permitted without consent (primarily, exposure of healthcare providers or others to risk of possible infection).*



### **1. Children's rights to involvement in HCT to the fullest extent possible**

It is a legal requirement to involve children in HCT to the fullest extent possible. This means that the healthcare provider should:

- Respect the child's dignity, treat the child fairly and equitably.
- Facilitate participation (including taking the child's views seriously), specifically in healthcare.
- Ensure confidentiality.
- Inform the child about any action or decision affecting him/her, specifically about how to promote health/prevent illness, his/her health status and causes and treatment of health status.
- Provide information and support participation in a form that is appropriate/adapted to the child's needs and developmental level.
- Not discriminate against children with disability by excluding them from participation; instead provide an enabling environment for them to participate and understand what is happening.
- Consider the child's best interests, taking into account age, maturity, stage of development, gender, background, physical and emotional security, disability.

### **2. Healthcare reasons for child participation**

There are many reasons for encouraging participation that are relevant to promoting health and healthcare. For example, the healthcare provider can:

- Get a better sense of child's capacities.





- Obtain information from the child’s point of view.
- Provide information and answer questions at a level appropriate to the child’s development about the child’s health, health status and investigations/treatment.
- Engage the child with a view to treatment if necessary.
- Provide a positive healthcare experience.
- Empower the child to participate in appropriate ways in his/her own healthcare.
- Model appropriate engagement for the caregiver.

### 3. Definition of assent

Assent “refers to the willingness of a child to be tested, usually expressed verbally to the healthcare provider. It is obtained by explaining in a manner appropriate to the child’s age and stage of development why and how testing will be conducted.” (*Implementation Guidelines*, 5.4).

Obtaining assent is one way to engage a child’s participation where the child lacks capacity to consent or is not required to assent.



#### KEY ELEMENTS in working with children with insufficient capacity or not required to consent:

- ▶ **Attitudes and approach:** Take child’s participation and views seriously, genuine interest and concern, flexibility (e.g., with/without caregiver present), sufficient time, put child at ease.
- ▶ **Factors about the child:** Circumstances that brought child to HCT (e.g., with adult, with friend, on own, related to occupational exposure), age, developmental level, behaviour and mental state (e.g., willingness to separate), emotional state, responsiveness, what child knows/has been told about possibility of testing, extent and quality of support available (similar to indicators used in assessing capacity to consent/best interests).
- ▶ **Explaining why and how of testing:** Start with what child knows; adapt information to child’s age, developmental level, etc.; use simple language, drawings; encourage and answer questions (verbal or implied non-verbally).
- ▶ **Assessing what child understands and whether assenting:** Ask child to say what s/he understands about what is happening; take account of both what child says and body language.
- ▶ **Post-test:** Disclosure of status to child dependent on pre-test assessment and caregiver views.
- ▶ **Reassure if necessary:** The child has done nothing wrong; testing is a good thing because it helps everyone know what to do; any occupational exposure was accidental; treatment is available if necessary.





Note that when working with children less than 12 years, or those who may have an intellectual disability, the Factors used as indicators of capacity to consent/best interests (see Module 3, Unit 3: Assessing capacity and best interests, p.31 and also Handout H) should also be kept in mind, to allow a check on capacity and best interests.



### Activity

**Refer to the scenario allocated to your group by the trainer (Lerato, David, Gloria, Jan or Sipho) and respond to the following questions:**

- Would you see this child on his/her own, or with the caregiver present? Why?
- How would you explain to the caregiver why it is important to counsel this child?
- How would you explain to this child why and how testing will be conducted?
- How would you assess what this child understands and whether s/he is assenting?



# Confidentiality: legal and counselling issue

Respecting  
confidentiality



*This module looks firstly at the counselling aspects of confidentiality and then at the legal aspects of confidentiality.*



**Overall time:** 100 minutes (1 hour, 40 minutes)

**Objectives:**

At the end of this module participants will:

- Understand a child's right to confidentiality
- Discuss why confidentiality is important for HIV testing of children
- Understand the nature and limits of confidentiality

**Activities:**

- Large group exercise
- Large group discussion
- Group Work
- Input and discussion

**Additional resources:**

HIV testing of children: Legal guidelines for implementers: Resource CD (this includes a section on confidentiality)





## COUNSELLING ASPECTS – KEY POINTS:

### 1. The right to confidentiality

- ▶ Every person has rights, including the right to respect. This includes respect of confidential information, which may be considered a key aspect of public health.
- ▶ Adoption of a human rights framework in work with caregivers, parents, children and adolescents ensures that healthcare providers protect rights such as privacy, dignity and respect.
- ▶ Negative feelings such as fear and feelings of vulnerability are greatly decreased when people are made aware of their rights and understand how the law works to help them uphold these rights.

Remember the 3 C's in HCT are *Counselling, Consent and Confidentiality.*



### 2. Confidentiality and disclosure of a child's status

Healthcare providers who adopt a human rights framework provide information that will help caregivers, parents, children and adolescents to understand how and to what extent their rights are safeguarded.

The following information is important with regards to disclosure of a child's status:

- ▶ The decision to disclose a child's status rests entirely with the child if he or she is over 12 years or under 12 years and of sufficient maturity to have consented to testing.
- ▶ Such a child has the legal right to confidentiality about his or her status and disclosure may only take place with his or her consent.
- ▶ Healthcare provider should explain the nature and limits of confidentiality, e.g., situations where a child's physical welfare might be affected.
- ▶ The healthcare provider should explain shared confidentiality, e.g., sharing information with the healthcare team in order to ensure that the best possible care is given.
- ▶ Referral information: referrals should be discussed with the child and/or his or her caregiver and consent obtained prior to information being given to any other party either verbally or in writing.

### 3. Decreasing feelings of vulnerability

- ▶ Every person has rights, including the rights to respect. This includes respect of confidential information, which is a key aspect of public health. Feelings of vulnerability are greatly decreased when people are made aware of their rights and understand how the law works to help them uphold these rights, including the right to privacy.





## LEGAL ASPECTS – KEY POINTS:

- ▶ All people, including children, have the right to medical confidentiality.
- ▶ This means that children have the right to expect that information about their HIV tests, HIV test results, medical and sexual health information and their HIV medication will be kept private.
- ▶ Confidentiality is important because children living with HIV and AIDS still get discriminated against. They need to be able to use HIV testing and counselling services without being afraid that their medical information will be made public.
- ▶ In the case of children who are not capable of consenting to the HIV test themselves (e.g., children below 12 years of age), the adult who consents on their behalf exercises the right to confidentiality. He or she keeps the child's information confidential.
- ▶ Children with capacity to consent to an HIV test themselves (e.g., children above 12 years of age) exercise the right to confidentiality. They may keep their information confidential, and may decide if and when they want to tell their information to others.
- ▶ There are times when a child's confidential medical information can be disclosed.





## NOTES on legal aspects of confidentiality:

**Handout N: McGeary Case Study** tells the story of the *Jansen van Vuuren v Kruger* 1993 court case, the first HIV-related court case heard in South Africa. It was a landmark case because it was the first time the courts were asked to discuss the right to confidentiality in the context of HIV. It took place at a time in South Africa when there was little knowledge, awareness and openness around HIV and AIDS. Yet, the courts nevertheless held that the medical practitioner had no right to disclose Mr McGeary's HIV status without his consent.

*Answers to McGeary case study questions:*

- **The right to confidentiality:** The right to medical confidentiality is the legal right to keep medical information private. The right to privacy applies to many aspects of our life, including to medical information, and it is a long standing rule of our law.
- **The right to confidentiality in relation to HIV:** In this case, Mr McGeary had the right to keep the information about his HIV test, and his HIV status, as well as any other medical information (such as medical visits, medical files, medication, sexual health information), private. He had the right to expect that the doctor would not disclose this information to others without his consent.
- **The importance of the right to confidentiality:** The right to medical confidentiality is important because patients need to be able to access healthcare (like HIV testing) without fear that their private health information will be made public. So, the patient's right to confidentiality helps to encourage people to come for medical testing and treatment without fear. The right to confidentiality is also important because of the high levels of discrimination against people living with HIV or AIDS. Discrimination can have severe consequences for a person's health and well-being.
- **The importance of confidentiality today:** Some people argue that confidentiality is no longer important because there is less HIV-related discrimination today. Others argue that confidentiality doesn't help encourage people to access the various kinds of treatment, care and support available today for people living with HIV. People also argue that sharing information with others may be in a patient's best interests. It is important to remind participants that, while these views may be valuable, medical confidentiality is, and always has been, a legal right. All patients still have the right to confidentiality. Also, our country's national strategic plan on HIV and AIDS reports that HIV-related stigma and discrimination are still widespread, and act as a barrier to effective responses (like encouraging people to test for HIV). Remind participants that disclosure of a patient's HIV status can always be made with the patient's consent, if need be.
- **The importance of confidentiality for children:** Children also have a right to confidentiality regarding their HIV status, and this right is equally important for them. Children are a vulnerable population and experience a lot of HIV-related discrimination. Protecting their right to confidentiality also helps to encourage children (especially older children) to test for HIV, without fear of their information being made public.
- **A child's right to confidentiality:** The right to confidentiality applies equally to children. In the case of younger children (e.g., below 12 years old) who don't have the capacity to consent to an HIV test, the adult who consents to the test exercises the right to confidentiality. The adult keeps the child's HIV status confidential. Older children (e.g., 12 years and older) with the capacity to consent to their own HIV test have the right to keep their own information confidential. There may be times when a child's HIV status can be disclosed (e.g., to promote a child's best interests). This is discussed in Module 6.





*In the case of younger children who don't have the capacity to consent to an HIV test, the adult keeps the child's HIV status confidential.*

*Yes, and older children with the capacity to consent to their own HIV test have the right to keep their own information confidential.*



**NOTE** that during pre- and post-test counselling sessions, a child may reveal information about their home life, their mental and physical well-being, their sexual relationships, possible abuse and neglect, their HIV status or the HIV status of their partners.

All this information should be kept confidential, unless the law requires disclosure.

This will be dealt with in more detail in Module 6.







# DAY 4

## MODULE SIX:

# Disclosure: legal and counselling issues

In the best interests of the child



*This module focuses on legal and counselling aspects of disclosure.*



**Overall time:** 175 minutes (2 hours, 55 minutes)

### Objectives:

At the end of this module participants will:

- Understand when disclosure of a child's HIV status (and other confidential medical information) is lawful
- Apply this learning to different factual situations
- Understand disclosure in the context of HCT with children

### Activities:

- Input
- Group work (poster)
- Input and discussion
- Brainstorm in large group
- Small group preparation activity
- Panel presentations and discussion

### Scenarios:

- Scenarios: Zodwa, Belinda, Lucas on Resource CD
- Handout N – Guidelines for panel discussion





## KEY POINTS:

- ▶ A child's HIV status may be disclosed if:
  - Consent is given for disclosure,
  - Disclosure is required by law.
  
- ▶ The person who has the right to confidentiality, can consent to disclosing a child's HIV status to others.
  - A child of 12 years or older can consent to disclosure.
  - The parent or guardian of a younger child can consent to disclosure.
  
- ▶ Disclosing a child's HIV status may be required by law:
  - The Health Act allows a healthcare worker to disclose in order to carry out their job properly, if it's in the best interests of the child.
  - The Children's Act allows for disclosure of a child's HIV status if it's in the best interests of the child.
  - A court may need or order information about a child's HIV status during legal proceedings.
  
- ▶ A child's best interests depend on his or her circumstances and needs, and is different for different children. It is important to think about each child's circumstances and needs to decide if disclosure is best.



*In this session, you will learn that children have the right to confidentiality in connection with their HIV status, and any other medical information that is part of the HIV counselling and testing process.*

*The general rule is that a counsellor may not disclose a child's HIV status. But confidentiality can be limited in certain circumstances.*



The National Guidelines tell us when a child's confidential medical information (like his or her HIV status) can be disclosed:

- A person who holds the right to confidentiality can give CONSENT for disclosure;
- Disclosure can be authorised by the law in some circumstances (to be discussed by means of examples in more detail, below).

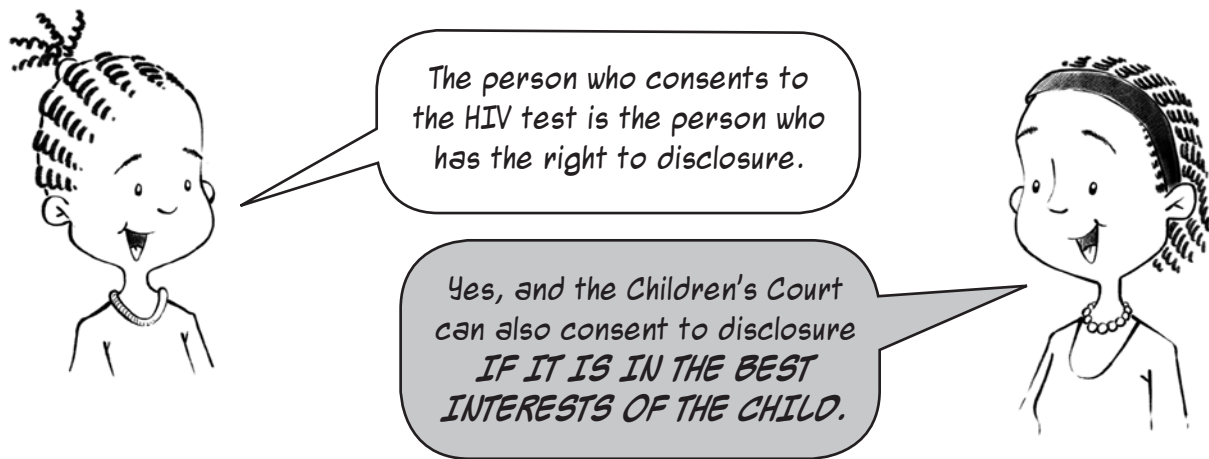
This means that it's important for counsellors to know –

- Who holds the right to consent to disclosure in different circumstances;
- Whether there are other circumstances that require disclosure (without consent, if necessary) in terms of our law;
- Whether disclosure is in the best interests of the child.



## Who can consent to disclosure?

- **A child of 12 years and older:** If a child is 12 years old (or below 12, but with sufficient maturity) they will have provided consent for the HIV test. This means they have the right to consent to disclosure of their HIV status and other medical information relating to the HIV test.
- **Others:** If a child doesn't have the capacity to consent to the HIV test (e.g., they are below 12 years old) the person who gave consent has the right to disclose the child's HIV status. This could be a parent, caregiver or a designated child protection organisation involved in arranging placement for the child. If there are none of these people available, it could be the superintendent or person in charge of a hospital.
- **The Children's Court:** If all those listed above are unwilling or unable to give consent, the court can do so but only IF IT'S IN THE BEST INTERESTS OF THE CHILD.



## When is disclosure in the best interests of the child?

Even where disclosure is required by law, it is still important to determine whether disclosure is in the best interests of the child.

The “best interests of the child” standard is not a “one-size-fits-all” standard. The best interests of the child will be different in each case. While all children have similar developmental needs, the importance of those needs and the impact disclosure will have on their needs may differ from child to child, depending on their different characteristics and circumstances.

Differences include:

- **Different characteristics of children:** Children of different ages, maturity, stages of development, gender, background, mental and physical abilities and well-being have different vulnerabilities and different needs. The characteristics and circumstances of particular children determine whether disclosure of their HIV status to others is in their best interests. For example, a young child or a child with a chronic illness may need additional protection to make sure their physical and emotional needs are met. Disclosing the child's HIV status to protective caregivers may help the child to get the care he or she needs. An older child may be mature enough to make his or her own decision about disclosures.
- **Different needs of children:** Children have physical, emotional, intellectual, social and cultural needs. Participants can identify a wide range of needs such as food, shelter, love, family, friends, books and faith. Disclosure of a child's HIV status may impact on all of these needs, such as their physical or emotional security, their intellectual, social and cultural development.



- Effect of the decision and need to protect the child from harm: Ultimately we need to weigh up the different characteristics and needs of particular children, to decide what effect disclosure will have on each child's circumstances, and whether disclosure will protect the child (and be in their best interests), or expose the child to further physical and psychological harm.

For example, think about the case of teenage girl child living with HIV who has abusive and neglectful parents, and is afraid of them finding out that she is sexually active. Disclosure of the girl's HIV status to her parents may not be in her best interests if they reject her. If she is thrown out of her home, she is deprived of the shelter, care, food and love she needs to survive.

## When can a child's HIV status be disclosed?

### Consent

The person with the right to confidentiality (e.g., child over 12 years) can decide him or herself to disclose confidential information to another person. Counsellors may encourage (without pressuring) children to share their HIV status with a trusted person who can provide support, and not their sexual partner.



## Required to carry out job

Disclosure of a person's HIV status may be needed to carry out your job properly. For example, the National Health Act says that a healthcare worker can disclose any confidential information if it's necessary to carry out their job properly. It must also be in the patient's interests, e.g., a child needs home-based care for HIV. The healthcare worker discloses the child's HIV status to the home-based care team, to organise care for the child. Ideally, though the healthcare worker should try to discuss this with the child (or caregiver) first, and get their consent for a disclosure.

Our law doesn't say whether a counsellor or healthcare worker should disclose a child's HIV status to their sexual partner. This is something our courts may have to decide if a case comes before them.

The Health Professions Council of SA's ethical guidelines recommend disclosure under very defined circumstances. They stress that great care should be taken, and that the risks to both the patient and sexual partner should be considered. An HIV counsellor who is worried about a child who is not taking protective measures (e.g., using condoms during sex) with their sexual partner should probably refer the matter to a supervisor.

## Required to carry out provision of Children's Act

The Children's Act gives people responsibilities to care for children. There may be times when carrying out those responsibilities requires disclosing a child's HIV status, e.g., the Act requires service providers to report abuse and neglect of children. In some circumstances, a service provider may need to disclose a child's HIV status when reporting abuse or neglect of a child (this is dealt with in more detail in the module on mandatory reporting of abuse).

Slide 6 gives an example from the Children's Act. Section 13 says that a child has the right to confidentiality about their health, except where maintaining confidentiality is not in the best interests of the child. This is another provision in the Act where disclosure of a child's HIV status is lawful.

*The Children's Act gives people responsibilities to care for children. There may be times when carrying out those responsibilities requires disclosing a child's HIV status.*



## Required for legal proceedings or by order of court

A child's HIV status may be important evidence in legal proceedings. A court may order that a child's HIV status be disclosed to the court, e.g., a child is part of a court case relating to HIV discrimination. The child's HIV status may need to be disclosed to the court during the trial. A child's HIV status may also be important if a court is asked to make a protection

order for a child, organise adoption or fostering for a child or consent to medical treatment on behalf of a child.



*A child's HIV status may be important evidence in legal proceedings. A court may order that a child's HIV status be disclosed to the court.*

Slide 7 gives an example from the Sexual Offences Act. In this example, a healthcare worker may be required to disclose a child's HIV status if the child is accused of a sexual offence. Disclosures required for, or by court, are lawful.



## Disclosure (Counselling):



### Activity

**Refer to scenario handed out to your group (i.e., Zodwa, Belinda or Lucas) in order to:**

- Briefly present a case history of each of these people;
- Briefly explain the challenges of the case e.g., young age of child;
- Briefly outline a disclosure approach and explain why this could be considered most appropriate in light of the identified challenges;
- Use the following *supplementary information* for a panel discussion.



### NOTES on disclosure (Counselling):

#### 1. Disclosure in the context of HCT

In the context of HCT disclosure includes:

- Informing the child or adolescent of his or her HIV status;
- Helping the child to disclose his or her HIV status to others;
- Helping the parent/guardian of a child to disclose a child's HIV-positive status to the child;
- Legal disclosure of a child's status.

#### 2. Disclosure of HIV-positive status to the child

The following guidelines are applicable with regard to the disclosure of an HIV-positive status to a child:

- Disclosure is not a “one off” conversation. Once disclosure has taken place further counselling is important to help the child develop strategies for healthy living.
- Disclosure can involve the child on his or her own if the child is over the age of 12, or under the age of 12 but capable of providing informed consent to test.
- Disclosure can involve the parent or caregiver or a designated individual/organisation if the child is under the age of 12 and not capable of providing consent.
- The extent of knowledge and understanding and the emotional responses of the child during pre-test counselling will serve as a guideline for the most appropriate means of disclosing a child's status to him or her in post-test counselling.
- Disclosure strategies differ depending on the age and developmental stage of the child.
- Regardless of the approach, VCT or PICT, a child who tests HIV-positive should be encouraged to disclose his or her HIV status to at least one other person as a means of obtaining support, including for adherence to treatment. Disclosure should therefore be addressed as part of the pre- and post-test counselling process.

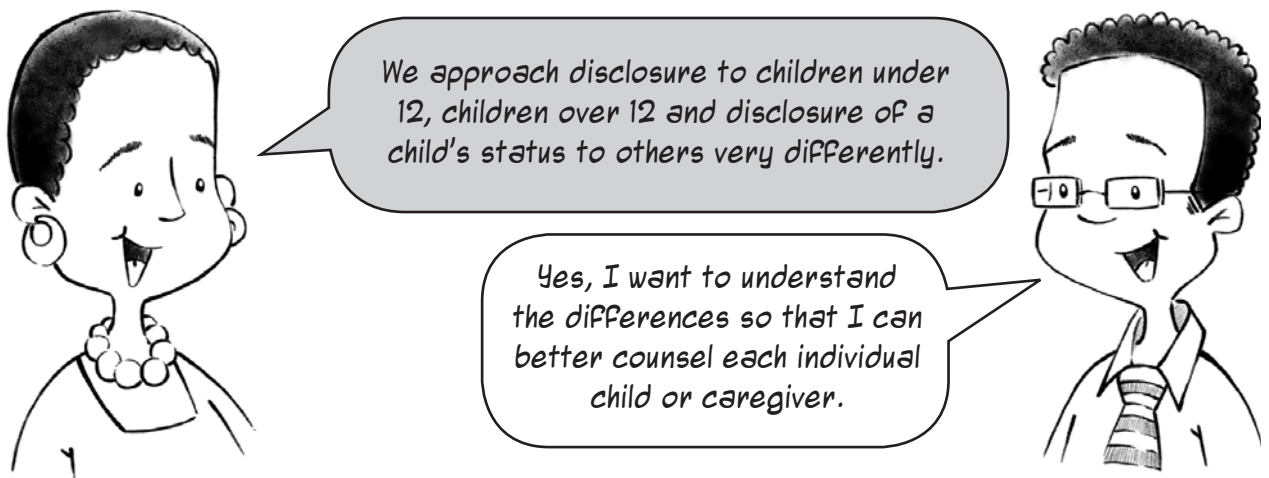


### 3. Different contexts of disclosure

There are a variety of contexts within which disclosure can take place. The healthcare provider should respond accordingly.

#### *Disclosure to pre-school children*

- Consent for children under six is usually obtained from a parent or guardian or other legally designated individual or organisation.
- Such a person has the right to maintain confidentiality or to disclose the child's status including to the child him- or herself.
- Even a very young child can be given simple explanations which can provide a platform for full disclosure later on.



#### *Disclosure to children under 12 or incapable of providing consent (aimed at caregiver/parent)*

- Draw attention to the benefits of disclosure, e.g., treatment adherence, sexual activity.
- Talk about different ways of disclosing to a child.
- Respect decision of parent or caregiver.
- Explore any obstacles that might be making it difficult for the parent/caregiver to begin the disclosure process.
- Talk about the possibility of disclosure to others, e.g., family members, teacher.
- Plan for further counselling to address any concerns that the caregiver might have about disclosure.

#### *Disclosure to children over 12 and children under the age of 12 years capable of consent*

- Disclosure should be relevant and appropriate to the age and information needs of the child.
- Discuss possible disclosure to others including sexual partner.
- Respect the decision of the young person.
- Assure him or her of support and willingness to help when needed.



### *Disclosure of the child's status to others*

- Tailor discussion to the child's age and developmental level.
- Assist the child to express his or her feelings.
- Find out about the child's sources of support.
- Assist the child to think about disclosure to others.
- Discuss the implications of disclosure including the benefits and risks.
- Discuss the implications of disclosure to an inappropriate person or group.
- Ask the child who they think should be told.
- Help the child to think about how and when they should reveal their status.
- Help the child to anticipate and prepare to deal with responses, e.g., role-play in preparation for disclosure.
- Do not put pressure on the child to disclose.
- Arrange follow-up counselling.

### *Lawful disclosure of a child's status to others*

There are instances in the law when disclosure to others is required, with or without consent. The following guidelines are relevant in this situation:

- Address lawful disclosure as part of pre- and post-test counselling discussion about confidentiality;
- Explain reasons for limits of confidentiality: to protect child; to protect others;
- If the context requires lawful disclosure, gently explain reason for this;
- Explain the process, as it applies to the specific context, to the child or caregiver;
- Provide reassurance and arrange follow-up counselling or referral where necessary.

## **4. Developmental stages and strategies for disclosure**







*Strategies for disclosure should be based on the developmental stage of the child. The table below provides guidance.*





## Strategies for disclosure based on the developmental stage of the child

<p><b>Early Childhood</b> (3-6)</p> 	<ul style="list-style-type: none"> <li>• Use visual aids such as drawings or puppets in addition to stories to illustrate concepts</li> <li>• Use of play can be helpful in demonstrating concepts</li> <li>• Use associations to concrete observations, e.g., "There are pills that can help your body to grow bigger and stronger"</li> <li>• Avoid having to explain too many concepts at this age and focus on concrete examples</li> </ul>
<p><b>Middle childhood</b> (6-10)</p> 	<ul style="list-style-type: none"> <li>• Use visual aids such as drawing or media to show concepts</li> <li>• Use of play and more language-based communication can be more effective at this age</li> <li>• Use examples such as, "Your body has soldier cells that protect it from enemy germs. These soldier cells are called helper T cells. Your pills help the soldier helper T cells to fight the enemy germs. When your soldier helper T cells kill lots of germs, then your body gets healthier and stronger"</li> <li>• Emphasise the concept of health, wellness and body</li> <li>• Discuss issues related to privacy, stigma and confidentiality in an age-appropriate manner</li> </ul>
<p><b>Early adolescence</b> (10-14)</p> 	<ul style="list-style-type: none"> <li>• Use visual aids such as books or websites to demonstrate the key concepts in HIV, the immune system and illness</li> <li>• Use slightly more complex language to convey the interactions between health, illness and treatment.</li> <li>• Use examples such as, "The body's immune system is made up of special cells called helper T cells that can help to protect it from germs that cause disease. HIV is a type of infection that can make your immune system very weak by harming your immune system's helper T cells. Medication can help to stop the HIV virus from harming your helper T cells and immune system so they can go on protecting your body and you can stay healthy"</li> <li>• Discuss and explore issues regarding HIV transmission using examples of age-appropriate behaviours</li> <li>• Discuss issues related to privacy, stigma, and confidentiality</li> <li>• Explore normal sexual development and education</li> </ul>
<p><b>Late adolescence</b> (14 upwards)</p> 	<ul style="list-style-type: none"> <li>• Use visual aids such as books or websites to demonstrate the key concepts in HIV, the immune system and illness</li> <li>• Use more complex language to convey the interactions between health, illness and treatment.</li> <li>• Use examples such as, "The body's immune system is made up of helper T cells that help protect it from infection. HIV attacks the helper T cells and weakens the immune system so that it is less able to protect the body against all kinds of infection. Medication can help to stop the HIV virus from attacking the helper T cells and weakening the immune system. This means that the immune system can go on doing the work of protecting the body"</li> <li>• Discuss and explore issues regarding HIV transmission using examples of age-appropriate behaviours</li> <li>• Discuss issues related to privacy, stigma, and confidentiality</li> <li>• Explore normal sexual development and education</li> </ul>





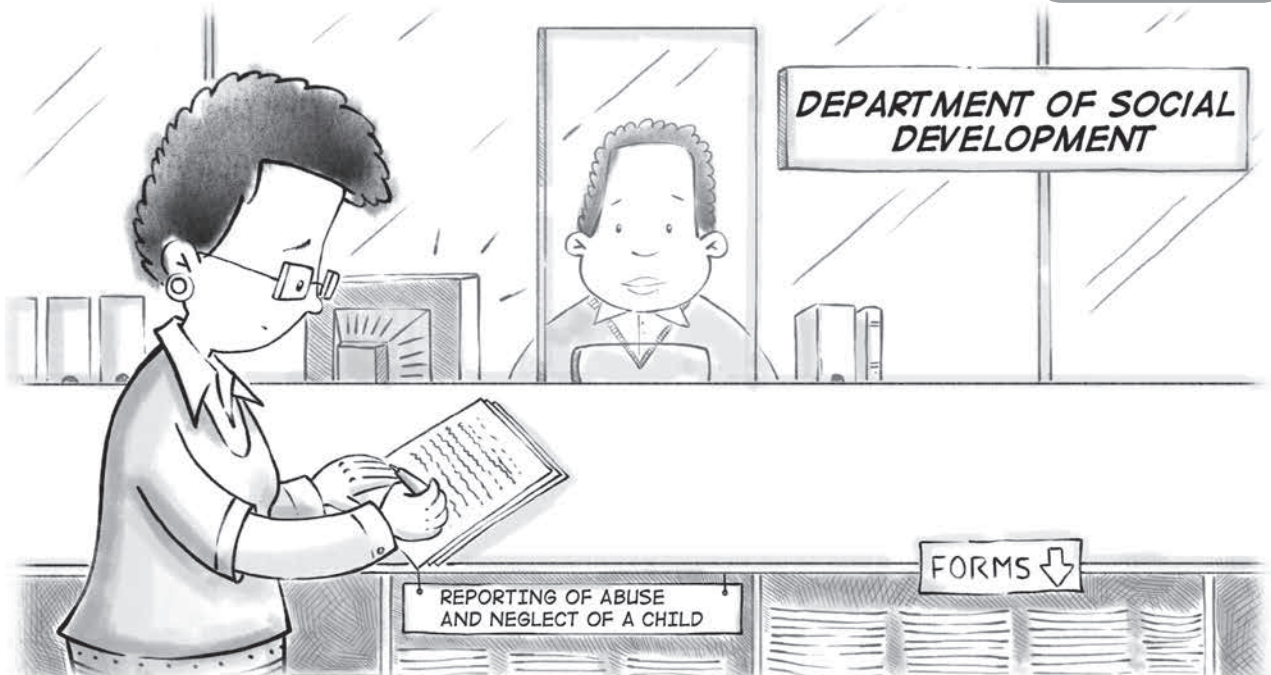
Caregivers are sometimes reluctant to allow a child to disclose for a variety of reasons. The table below details some of the concerns that parents/caregivers might have about disclosure and provides suggestions as to how these concerns might be addressed:

Working with caregivers – Strategies to overcome disclosure concerns	
Caregiver feels child is too young or emotionally immature to understand disclosure issues	<ul style="list-style-type: none"> <li>• Partial disclosure may be used. For example begin by telling the child that medications help to keep his or her body as healthy as possible. Then, as part of the disclosure plan, caregivers and healthcare team agree to give more information little by little as the child matures. Introducing the idea of an immune system, or a part of the body that fights infection might be helpful</li> </ul>
Caregiver fears that child will not understand when not to talk about his or her status.	<ul style="list-style-type: none"> <li>• Assess cognitive and emotional ability to maintain confidentiality and discuss with caregiver</li> <li>• Offer to create a “contract” with the caregiver and child that outlines who can be told and who is best not to tell</li> </ul>
Caregiver fears that child’s reaction will be very difficult for him/her to deal with	<ul style="list-style-type: none"> <li>• Assure the caregiver that the healthcare team will give support for the family during, and after the disclosure process, including mental health assessment and treatment if necessary</li> <li>• Use developmentally appropriate materials suited to the child’s emotional and psychological level to facilitate education</li> <li>• Address false or negative ideas that the child or caregiver has about HIV infection</li> <li>• Explain the value of shared feelings and the detrimental psychological effects of repressed emotion</li> </ul>
Guilt from biological parent for infecting child	<ul style="list-style-type: none"> <li>• Counsel to address guilt</li> <li>• Engage the parent in a more affirming and helpful role with the child to promote empowerment</li> </ul>
Caregiver is worried about being unable to respond to any questions the child might ask	<ul style="list-style-type: none"> <li>• Use role-play to help prepare caregivers to answer difficult, embarrassing or painful questions</li> <li>• Help caregiver to decide how to answer questions that might be asked</li> </ul>

Courtesy of New York State Department of Health, AIDS Institute (2009, November). Disclosure of HIV to perinatally infected children and adolescents



Dealing with special cases sensitively




This module focuses on *working with special cases* including:

- Younger children, children with intellectual disability, or children who lack understanding and don't have sufficient capacity to consent;
- Cases where testing is permitted without consent (mostly when healthcare providers or others are exposed to risk of infection);
- Cases where mandatory reporting of abuse (physical, sexual, emotional) or neglect is required.

The module offers legal guidelines and suggestions for handling counselling situations.



 <b>Overall time:</b> 230 minutes (3 hours, 50 minutes)	
<p><b>Objectives:</b> At the end of this module participants will:</p> <ul style="list-style-type: none"> <li>• Understand when mandatory reporting of child abuse is required (UNIT 1)</li> <li>• Discuss different forms of abuse and neglect of children (UNIT 1)</li> <li>• Discuss mandatory reporting of consensual sex between children (UNIT 1)</li> <li>• Understand the counselling implications of mandatory reporting (UNIT 2)</li> </ul>	<p><b>Activities:</b></p> <ul style="list-style-type: none"> <li>• Input and discussion</li> <li>• Group work and discussion</li> <li>• Input and discussion</li> <li>• Group work</li> </ul> <p><b>Scenarios (Resource CD):</b></p> <ul style="list-style-type: none"> <li>• UNIT 2: Lerato, David, Gloria, Jan, Sipho</li> <li>• UNIT 3: Londi and Lindi, Belinda, Tshepo, Tintswalo</li> </ul>





## NOTES on mandatory reporting of abuse:

**Presentation 9** tells about the legal requirement to report abuse and neglect of children. Healthcare providers need to report abuse and neglect of children based on information that becomes available during pre-test and post-test or any subsequent counselling. It is important to understand the following:

- There is a legal obligation to report abuse and neglect of children;
- The obligation to report is an exception to the general rule of confidentiality;
- This obligation is based on a child's vulnerability and need for protection from harm;
- Our criminal law says that all people have to report sexual offences to the police if they have knowledge of the offence;
- Our children's law also says that certain service providers have to report neglect and abuse (including sexual abuse) to a designated child protection organisation or the Department of Social Development if they have reasonable grounds to believe a child is abused or neglected.

*What is abuse and neglect?*

- Physical abuse (e.g., beating);
- Emotional abuse (e.g., bullying);
- Sexual abuse (e.g., sexual assault);
- Failure to provide for physical needs (e.g., food, shelter);
- Failure to provide for emotional needs (e.g., love);
- Failure to provide for intellectual needs (e.g., schooling);
- Failure to provide for social needs (e.g., friendships).

*What are reasonable reasons for believing a child is abused or neglected?*

Reasonable evidence may include:

- Verbal evidence (e.g., the child tells you she is being beaten)
- Medical evidence (e.g., the child has a history of repeated sexually transmitted infections)
- Documentary evidence (e.g., the child's school reports indicate absenteeism)
- Physical evidence (e.g., the child is bruised)
- Behavioural evidence (e.g., the child is afraid of his caregiver)
- Other evidence (e.g., the child lives on the street)

Reasonable evidence is not evidence beyond doubt. But it should be persuasive, based on a counsellor's knowledge, skills and expertise, and should lead them to believe a child is being abused or neglected.





### **Reporting consensual underage sex**

Mandatory reporting of sexual offences, especially consensual underage sex, is a difficult issue for counsellors. You may have strong feelings about it, one way or another, and the way it impacts on your work.

### **How does mandatory reporting of sexual offences help children?**

Mandatory reporting may help to protect children from harm:

- Mandatory reporting may help to reduce the risk of HIV infection in children. If a child is being raped or sexually abused, he or she is at risk of HIV.
- Sexual abuse impacts on children's mental and physical health in other ways. An abused child may be in need of emotional support, or even in need of alternative family care.

### **How does mandatory reporting of sexual offences harm children?**

Children may be afraid of mandatory reporting for various reasons:

- Older children in consensual sexual relationships with their peers may be happy with their relationships. They may not want to be reported.
- Children may fear the stigmatisation attached to being sexually abused.



- Children may fear the actions of abusive parents or guardians.
- Children may want to avoid the stress of criminal court cases
- These fears can discourage children from using HIV testing and counselling services. This prevents children from getting the prevention, treatment, care and support services they need.

**What does this mean for counsellors?**

The mandatory reporting requirements put counsellors in a difficult situation. Your position as HIV counsellors means that you are likely to receive information about sexual offences, including consensual underage sex. In law, you may be required to report this information. You may feel that mandatory reporting requirements will destroy any possibility of building a relationship of trust with teenage children. You may be reluctant to report in cases where you don't believe the sexual relationship is abusive. You may argue that you will waste hours of time reporting many children unnecessarily. You may find that mandatory reporting requirements discourage children from testing for HIV.

**What would you do?**

You should consider:

- There may be times when a child is clearly being abused, and counsellors should be alert for clear cases that need reporting. Reporting in these instances is important.
- The National Director of Public Prosecutions has to authorise any criminal prosecutions of statutory rape. This authorisation is meant to reduce unnecessary criminal cases.
- If there is less than two years' age difference between children, it can be raised as a defence to statutory rape. In this case, it won't be a crime and reporting is unnecessary.
- The law is currently being challenged so there may be changes to come.

Counsellors should ask for guidance from their institution on how to manage this. Some institutions have set out their own guidelines on circumstances when they believe mandatory reporting should be done, and how to protect children in the process, e.g., some research institutions have developed guidelines for researchers doing HIV research with young people. In this case, the institution (rather than the individual) takes responsibility for the decision.



**Activity: Questions for discussion**

1. How do you think mandatory reporting of sexual offences can help children?

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2. How do you think mandatory reporting of sexual offences can harm children?

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3. How does mandatory reporting of sexual offences affect you as a counsellor?

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4. What would you do when dealing with teenagers having underage sex?

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### **The Criminal Law (Sexual Offences) Amendment Act**

The Criminal Law (Sexual Offences) Amendment Act tells us which sexual acts are crimes. It is important to understand that:

- A sexual act with a child without their consent, is a crime;
- Even WITH CONSENT, sexual acts with children under 12 years will always be a crime, and sexual acts with children 12-16 years may also be crimes;
- Sexual offences against children should be reported to the police, a child protection organisation or the provincial Department of Social Development;
- Form 22 is used to report sexual offences against children. It asks for a lot of information. Counsellors using the form may not be able to fill in all of the information. They do not need to give the name of the person who told them about the sexual offence. They should try to fill in as much as they can, especially:
  - The child's name, age and ID number
  - A contact person who the child trusts
  - The child's parent or guardian
  - The details of the abuser
  - The details of the abuse, including any evidence
  - Their details as the person reporting the offence.

*You can read more about reporting of abuse in Handout 0: Form 22: Reporting of Abuse, which is found on the Resource CD.*



## Mandatory reporting: counselling issues

Mandatory reporting is required where it is known or a child reveals during counselling that s/he has been involved in consensual penetrative sex with another child under 16 years, or has been sexually abused or raped, or there is evidence or a strong presumption of physical neglect or abuse.



### KEY DEFINITIONS:

In order to more fully appreciate the key counselling issues in relation to consensual sex, sexual abuse, or physical neglect/abuse the following definitions are relevant:

- ▶ **Consensual sex:** In terms of our law, if a child or the child's partner is aged 12-16 years, consensual sex is regarded as a crime. However if there is less than two years' age difference between the children involved in a consensual sexual relationship it could be raised as a defence to the charge of statutory rape.
- ▶ **Sexual abuse:** Sexual abuse is the sexual violation of a girl or boy child without his or her consent, e.g., rape.
- ▶ **Physical/emotional abuse or neglect:** Abuse refers to any form of harm or ill-treatment that is deliberately inflicted on a child, and includes deliberately hurting a child, e.g., beatings and subjecting a child to psychological or emotionally harmful behaviour. Neglect is the failure to provide for a child's basic needs, for example food, shelter, love and care.



### KEY COUNSELLING ISSUES:

The following are important issues to take into account when counselling children where mandatory reporting is required:

- ▶ Age and developmental stage
- ▶ Implications for confidentiality
- ▶ Services to be offered
- ▶ Whether and how to involve parents/caregivers

## Age and developmental stage

The child's age and developmental stage is generally a key determinant as to how the child understands and reacts to what has happened.

### ▶ Consensual sex

Even young children engage in exploration of each others' bodies, with gradually increasing interest and experimentation in sexual activity over the course of childhood and into adolescence. Whether this activity is open or hidden and whether it includes full sexual intercourse depends to a large extent on the values that caregivers communicate to their children, how they react when they observe their children showing signs of sexual interest or





activity and what sort of supervision or alternative activities are available to children. However, early sexual debut is not uncommon, with on average 6% of girls and 12% of boys reporting sexual debut before the age of 15 years (SADHS, 2003). Children may be unaware of the legal implications and unprepared for the legal consequences of what they consider to be consensual sex.

### ► Sexual abuse

The younger the child, the less likely it is that s/he will appreciate the meaning and possible outcomes of a sexual encounter or relationship. As the child develops and acquires more advanced cognitive abilities, the ways in which s/he makes sense of sexual abuse will change. This influences the impact of the abuse on the child, e.g., a younger child may find it difficult to trust adults whilst an older child could feel responsible for the abuse and may grapple with feelings of guilt. The impact of sexual abuse on a child is also significantly affected by the nature of adult reactions and support, including those of healthcare providers.

### ► Physical/emotional abuse or neglect

Children who have been physically or emotionally abused or have experienced deliberate neglect amounting to abuse (e.g., when children are malnourished and dressed in rags, as a result of being last in line for food or clothing, despite caregivers receiving child care grants) are generally wary of adults. They may not want to risk adverse reactions or further abuse from their caregivers. They may be unwilling to share information about their circumstances and resist any action that they fear may make their situation worse.

## Implications for confidentiality

- The law requires healthcare providers to report sexual offences (including sexual abuse, as well as consensual sex that amounts to a sexual offence in children under the age of 16 years) to the police, and any physical abuse or neglect of a child to a designated child protection organisation or provincial department of social welfare. These requirements imply the need to breach confidentiality, with or without child's consent. The possibility of breaching confidentiality if the child is at risk of harm and in terms of the law should always be raised during initial contracting with the child. You could say something like:

*What you tell me will be confidential – between us and other staff who are involved in caring for you. But if you tell me something that shows there is some risk of harm to you, I may have to tell others who could help to keep you safe. The law also says that I have to report any sexual offences (e.g., rape) against you. But I would not do this without talking to you first.*



- In cases where consensual sex, sexual abuse, or physical/emotional abuse or neglect is reported, the need to breach confidentiality needs to be discussed in more detail in later discussion with the child.
- The healthcare provider needs to ensure that the child understands that reporting is intended to ensure the child's safety and protection and what will happen in the course of and after reporting. Information to assist participants in this regard is provided in the resource pack.



## Services to be offered

### ► Consensual sex

- Children over the age of 12 years who have engaged in consensual sex should receive age-appropriate counselling about the legal and other implications for themselves and their partners. There may be legal implications in the case of consensual sex where the child or the child's partner is below 16 years of age.
- Options with respect to future consensual sex (e.g., alternatives to penetrative sex, use of condoms if they continue to be sexually active) should be explored.
- They should be offered PEP if within the 72 hour cut-off limit and if they test HIV-negative.
- In the case of a positive result, post-test counselling should be accompanied by referral to the appropriate healthcare services for management and support.
- They will also need to be referred for psychosocial follow-up (possibly including counselling by an experienced healthcare practitioner or social worker) and support through any subsequent legal processes.



### ► Sexual abuse (regardless of age)

- All child survivors of sexual abuse should receive age-appropriate counselling at the time the abuse is identified and will need to be supported through procedures such as a medical examination.
- All child survivors of sexual abuse must be offered PEP if within the 72 hour cut-off limit and if they test HIV-negative.
- In the case of a positive result, post-test counselling should be accompanied by referral to the appropriate healthcare services for management and support.
- They will also need to be referred for psychosocial follow-up (if at all possible including counselling by an experienced healthcare practitioner or social worker) and support through any subsequent legal processes.

### ► Physical abuse or neglect

- All child survivors of physical abuse or deliberate neglect should receive age-appropriate counselling at the time the abuse/neglect is identified and may need to be supported through procedures such as a medical examination.
- In the case of a positive result, post-test counselling should be accompanied by referral to the appropriate healthcare services for management and support.
- They will also need to be referred for psychosocial follow-up (preferably including counselling by an experienced healthcare practitioner or social worker) and support through any subsequent legal and placement processes.



## Whether and how to involve parents/caregivers

- It is desirable where possible to assist the child to identify a trusted adult (not necessarily a parent/caregiver) who can give support in the event the child tests positive.
- In cases involving sexual abuse or physical/emotional neglect or abuse:
  - Discuss with the child whether and how to approach a parent/caregiver and whether to arrange separate and/or conjoint sessions with the child and his/her parent/caregiver.
  - Where the alleged perpetrator of sexual or physical abuse or neglect is a parent/caregiver or family member, discuss with the child whether or not to involve another parent/caregiver.
  - Children with sufficient maturity to test can, if they wish, involve a parent/caregiver in or following testing, but may require assistance and support to do so.
  - In the case of children who are not sufficiently mature to give consent for testing this must be sought from the parents first, if they are still available. The child's views in the matter should be taken into account and the child should be informed in advance, reasons given, the process outlined, and implications discussed.

## Guidelines on counselling children who have been sexually abused

*Read the **Guidelines on HCT Counselling and Testing of Children**, 8.1. These provide a comprehensive overview on counselling children who have been sexually abused.*

*Many of these principles are also applicable in cases of consensual sex, or physical neglect/abuse. The following is a summary of guidelines on counselling children who have been sexually abused:*



- Believe the child, children do not usually lie about sexual abuse;
- Do not be judgemental;
- Do not respond with shock;
- Avoid asking too many questions and probing for details;
- Let the child tell his/her story using terms that he/she is familiar with;
- Tell the child that it is not his/her fault that the abuse occurred (children are often afraid that they may be blamed, disbelieved or rejected as a result of their disclosure);
- Talk to the child about who else will need to be told and ask who he/she thinks should know;
- Without scaring the child, discuss what will happen as regards reporting the abuse;
- Tell the child what kinds of protection and support (e.g., in relation to the perpetrator, or engaging with the family, or finding alternative accommodation) will be available to him/her, including through referral.



## Support for the healthcare provider

- Because of the complexity of and stress of working with cases involving sexual abuse, or physical neglect or abuse, it is preferable that an experienced counsellor deals with these cases.
- Where the issue only becomes apparent in the course of HCT, the healthcare provider should consult with and seek support from a more experienced counsellor in making a determination to break confidentiality in order to report to the relevant authority, and on whether and how to involve parents/caregivers.
- Counsellors and other healthcare providers working on such cases should be afforded the opportunity to debrief and receive support as soon as possible and on an ongoing basis if engaged in follow-up work with the child.



### Activity: Mandatory reporting

**Refer to the relevant scenario that is handed to you by the trainer. Note the following about each of the cases:**

- Lindi and Londi (Handout Q): a case of consensual sex; one of the partners is over 16 years
- Belinda: a case of consensual sex, both partners are under 16 years
- Tshepo: physical/emotional abuse/neglect and sexual abuse/rape; for this exercise assume that there was no NGO involved in the case
- Tintswalo: sexual abuse/rape

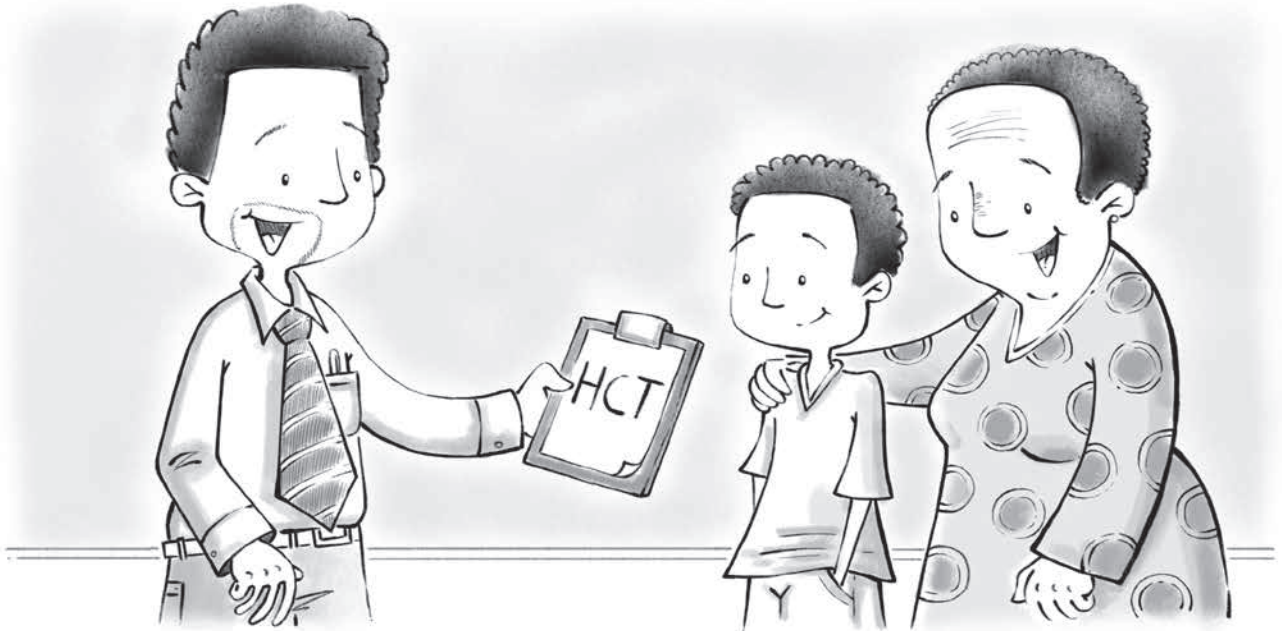


# DAY 5

## MODULE EIGHT:

# Working with caregivers

Caring for the Caregivers



*This module looks at how we work respectfully with caregivers in pre- and post-test counselling and gives some opportunities to practice this.*



**Overall time:** 150 minutes (2 hours, 30 minutes)

### Objectives:

At the end of this module participants will:

- Understand issues confronting parents/caregivers in HCT (UNIT 1)
- Understand essential elements of pre- and post-test counselling of parents/caregivers (UNIT 2)
- Experience the practical application of pre- and post-test counselling of parents/caregivers (UNIT 3)

### Activities:

- Group discussion and feedback
- Discussion
- Group discussion
- Input and discussion
- Scripted role-plays and discussion
- Role-plays and discussion



# Unit 1: Working with parents/caregivers in general



## Activity: Group discussion

**Discuss the following in four small groups. Each group will discuss one statement.**

1. The HCT process may go against common beliefs about the rights of parents and children to make certain decisions. How could a counsellor explain these concepts to a parent/caregiver, so as to maximise support for the child in the HCT process?
  - *a child with capacity has the right to decide whether or not to test without getting parental consent (group 1)*
  - *children must be involved in age-appropriate ways in the HCT process, even when they do not have capacity to consent (group 2)*
  - *even when a parent requests HIV testing of their child, testing may be refused where it does not seem to be in the best interests of the child at that time (group 3)*

2. A parent/caregiver may refuse to give consent to test a child. What could be the reasons for this? How could a counsellor respond? (group 4)

3. Answer the following questions in your groups.

Imagine a parent/caregiver who becomes involved as a result of provider-initiated counselling and testing, or when a child is involved in an occupational exposure event, or when a child asks for assistance/support with VCT:

- *what ideas or opinions about testing and specifically, testing their child, might the parent/caregiver bring to the HCT process?*
- *what questions might the parent/caregiver have?*
- *what feelings might the parent/caregiver have (towards the child, the healthcare provider and about him/herself?)*
- *what might the needs of the parent/caregiver be?*



## NOTES:

### 1. Definition of a parent or caregiver

The following is the definition of a parent or caregiver in the Children's Act, 2005:

**“Caregiver”** means any person other than a parent or guardian, who factually cares for a child and includes –

- a foster parent;
- a person who cares for a child with the implied or express consent of a parent or guardian of the child;
- a person who cares for a child whilst the child is in temporary safe care;
- the person at the head of a child and youth care centre where a child has been placed;
- the person at the head of a shelter;
- a child and youth care worker who cares for a child who is without appropriate family care in the community; and
- the child at the head of a child-headed household.

How does the Children's Act define a *parent, guardian* or a *caregiver*?



“**Guardian**” means a parent or other person who has guardianship of a child.

“**Parent**”, in relation to a child, includes the adoptive parent of a child.

Couples who are married, or were married at some point during the pregnancy or after birth, are the joint guardians of their children.

Where couples are unmarried and have never been married:

- Women are automatically the child’s legal guardian.
- Men will only have guardianship over the child if at the time of the child’s birth he was living with the mother in a permanent life partnership or he has consented to being identified as the child’s father or has paid damages in terms of customary law, has contributed to or attempted to contribute towards the child’s upbringing and expenses.

## 2. Caregiver involvement in HCT

Caregivers may be involved in HCT related to their children in various ways:

- *Consent* – when the child doesn’t have the capacity to consent on their own;
- *Support* – when the child requests the parent or caregiver be involved in the test (VCT/CICT) or on the recommendation of a healthcare provider and with the consent of the child if they are over 12 (PICT);
- *Assistance* – where the child needs to be tested following occupational exposure.

The following circumstances where parents/caregivers are involved in HCT of their children are relevant:

Children, especially those under the age of 12 years attending a health facility are generally accompanied by a parent/caregiver. Healthcare providers should routinely suggest HIV testing to parents and caregivers and recommend HIV testing of children where there is reason for concern. For example:

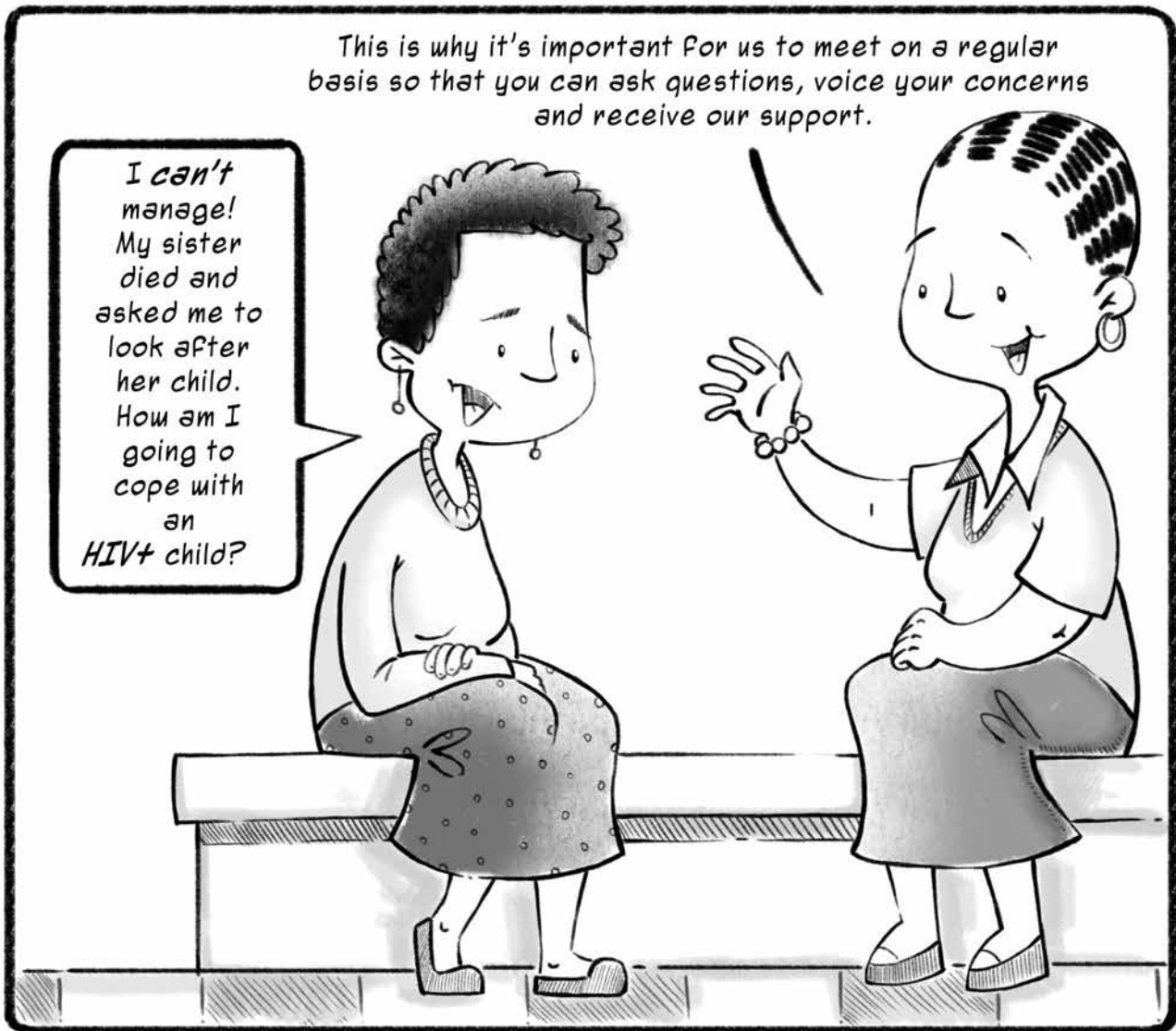
- Exposure in pregnancy, labour or breastfeeding
- A child showing signs and symptoms of HIV illness
- A child showing signs and symptoms of an STI
- A child who is below average in height or weight or appears malnourished
- A child with developmental delay
- A child who is known to have lost one or both parents to AIDS
- A parent/parents known to be HIV-positive
- HIV-exposed infants
- Abandoned babies
- Infants younger than 18 months who may be at risk of HIV infection
- Infants older than 18 months who may be at risk of HIV infection
- Breastfed babies of HIV-positive mothers
- Children not identified by PMTCT (prevention of mother-to-child transmission programmes)
- Young persons
- Child survivors of sexual assault

Parents/caregivers, especially those who are affected or infected, may themselves seek testing for their child related to the above, or related to other concerns, e.g., if they are thought to be sexually active.



### 3. Taking account of the perceptions, feelings and needs of caregivers

An important general principle is that, “in order to encourage appropriate support for the child, [counselling] should take into account the perceptions, feelings and needs of the parent or caregiver”. (Read the Guidelines on HCT Counselling and Testing of Children, 6).



Parents/caregivers may be well-informed about HIV, testing and treatment, or they may be misinformed. Particularly if they themselves have not been tested, they may have many questions about the process. They may have many conflicting feelings about their children being tested, e.g., anxiety, fear, anger, disappointment (in the child or themselves as parents/caregivers), love and concern. Thus, healthcare providers have to respond to a mixture of needs, each unique to the particular parent/caregiver.

Taking into account the need for child participation in the HCT process, the healthcare provider should explain the process of HIV counselling and testing to the parent/caregiver as well as to the child. The important role of the parent/caregiver in HIV counselling and testing should be acknowledged. However, parents/caregivers should be helped to understand that the child will also receive pre- and post-test counselling and that there will be an assessment of whether testing is in the best interests of the child and whether he or she has sufficient maturity to give informed consent for an HIV test.





## 4. Declining to give consent

A parent/caregiver may decline to give consent to test a child. In these circumstances this decision must be respected by the healthcare provider. In the case of refusal, counselling should always be undertaken with the parent/caregiver in order to ascertain and respond to any fears, concerns or beliefs that might be an obstacle to the provision of consent. Where it appears that a parent/caregiver is withholding consent unreasonably and against the best interests of the child, an application may be made to the Children’s Court for consent.

A healthcare provider may decide on the basis of an assessment that it is not in a child’s best interests to test at that time. In these circumstances, the parent/caregiver and the child should receive counselling, appropriate referrals should be made and a new date given for HCT.

## Unit 2:

### Pre- and post-test counselling of parents/caregivers: Guidelines

#### 1. Pre-test counselling: adaptations in counselling parents/ caregivers

*There are both similarities and differences in counselling parents/caregivers as opposed to children.*



Pre-test counselling: adaptations in case of counselling parents/caregivers	
Build a relationship of trust	Important to enlist caregiver’s co-operation in testing and follow-up; basis for dealing with caregiver’s feelings about reasons for testing child
Allow time	Information and emotional needs relate not only to self, but also child and possibly others
Assess knowledge of HIV and explain purpose of HCT	May involve more complicated set of questions, especially if caregiver has not tested/is not HIV-positive
Assess likelihood of exposure	May be complicated by caregiver’s own situation (see previous item) and nature of relationship with child
Explain purpose of testing and procedures	May be particular concerns about child fearing or experiencing pain
Discuss implications of the test	Whether positive or negative, more complicated set of questions about future prevention or treatment, disclosure (child, family, school)



<b>Pre-test counselling: adaptations in case of counselling parents/caregivers</b>	
Discuss support systems	Involvement of others sharing child care or supervision necessary, but may be difficult
Determine if test is in the child's best interests	Implies questions about caregiver's capacity to support, right to decide – may be sensitive
Assess need for further support	For child <i>and</i> self
Discuss availability of services	Caregiver likely to be key agent in accessing services – should be clear about what is required
Discuss receiving results	Key: whether/how to disclose to child
Obtain informed consent	Ensure that caregiver has properly thought through implications, rather than responding based mainly on emotion If caregiver declines consent, explore reasons and follow up appropriately

## 2. General guidelines for pre-test counselling of parents/caregivers

- Tailor the counselling approach to accommodate considerations such as the person's relationship to the child (e.g., parent, caregiver, sibling) and his or her level of education.
- Build a positive relationship with the parent or caregiver and establish a counselling contract (including reference to confidentiality, best interests, informed consent and child participation).
- Provide information on the purpose of counselling and testing including the risks, benefits and social implications of testing:
  - Establish what the parent or caregiver knows about HIV and testing and provide further information as needed (including that knowing the status of a child who may have been exposed to HIV will promote optimal management of the child's health and, in the case of infants, may enhance the chances of survival).
  - Discuss the implications of a positive or negative result for the child and significant others in the child's life, (including the implications of a positive result for a parent whose own HIV status is unknown).
  - Raise awareness of HIV related prevention (including PMTCT), treatment, care and support services either within the facility or through referrals.
  - Emphasise confidentiality of the test results.
  - Outline the HIV test procedure (including the role of the parent/caregiver during testing, especially in the case of infants and very young children).
  - Discuss possible involvement of the child in counselling for purposes of assent, or to prepare the child for testing.
  - Address any concerns that the parent/caregiver might have related to the test.
- Give emotional support and discuss how the parent or caregiver will cope in case of a positive result.
- Advise the caregiver or parent of his or her right to decline to have the child tested.



- Give assurance that declining the test will not affect the child’s access to healthcare services but may affect a child’s long-term health if they are at risk of being HIV-positive.
- Obtain consent to test verbally or in writing, using the prescribed form.

### 3. General guidelines on post-test counselling of parents/caregivers

- Build on knowledge and relationship established in pre-test counselling.
- Convey the result of the test accurately and sensitively.
- Address the feelings arising from the results.
- Give adequate time to understand and talk about the results.
- Give information in a way that is understandable.
- Provide an opportunity for the parent or caregiver to ask questions.
- Give emotional support and, in the case of a positive result, discuss how the parent or caregiver will cope.
- Identify sources of support.
- Talk about the possibility of sharing the test results with someone and disclosure to the child and help the parent or caregiver work through any concerns or fears.
- Discuss treatment, care and support for the child (including prevention).
- Identify any difficulties or problems that the parent or caregiver foresees and discuss means of dealing with these.
- Identify community-based resources and refer as appropriate.
- Discuss social transfers (e.g., child support grant) for which child may be eligible.
- Recommend testing for parent/s and siblings of the child, especially in the case of a positive result.
- Encourage/plan for parent or caregiver to come back for further session (follow-up confidentially if necessary).
- Provide appropriate literature according to needs.

## Unit 3:

### Pre- and post-test counselling of parents/caregivers: Application



#### Activity: Pre-test counselling of parents/caregivers: What not to do

Observe the scripted role-play. A number of problems will become evident in the way in which pre-test counselling of parents/caregivers is conducted.

Make a note of the problems you observe in the right-hand column of the checklist for pre-test counselling of parents/caregivers (Handout S).








*This final module focuses on follow-up, including follow-up counselling, and referral of the child to other services when it is needed.*



 <b>Overall time:</b> 75 minutes	
<b>Objectives:</b> At the end of this module participants will: <ul style="list-style-type: none"><li>• Understand the importance of follow-up and referrals (UNIT 1)</li><li>• Give feedback to trainers (UNIT 2)</li></ul>	<b>Activities:</b> <ul style="list-style-type: none"><li>• Discussion</li><li>• Individual course evaluation</li><li>• Post-course assessment</li></ul>



# Unit 1: Follow-up and referrals

## 1. Circumstances where follow-up is particularly necessary:

Healthcare providers have a responsibility to ensure effective follow-up of children. This is particularly important in the case of:

- Children who test positive and lack support;
- Children who test negative and appear at high risk;
- Children in child-headed households;
- Children caring for ill parents;
- Children who are living in extreme poverty;
- Street-children;
- Children who have been abused.

### ► Follow-up counselling

Follow-up counselling is required:

- To address concerns or issues of child or parent/caregiver that have emerged during counselling (e.g., whether/how to involve parents/caregivers; whether/how to disclose to other family members);
- To motivate referrals where necessary and assist with their uptake in order for the individual to benefit from available care and support services, especially when these are not provided by the facility concerned;
- When the child appears at risk of being infected and the child or parent/caregiver declines testing, despite exploration of reasons at the time and attempts to respond to any fears, concerns or beliefs blocking consent;
- When testing is refused because of temporary lack of capacity (e.g., child or parent/caregiver under the influence of drugs), or because testing at that time appears not to be in the best interests of the child.

Time constraints or limited expertise or experience may mean that some of the above require referral for professional counselling.

### ► Other forms of follow-up commonly required:

- medical evaluation, care and treatment, particularly in the case of an HIV-positive result;
- reproductive health services including STI screening and care;
- nutritional advice;
- age-specific support groups, if available;
- support in dealing with the school system;
- mental health/psychological services (e.g., where a child is having difficulty adjusting to a positive result);
- services for the treatment of drug and alcohol abuse;
- bereavement support;
- spiritual counselling;
- social services or NGOs to assist with grant applications and other material/financial support;



- legal assistance (e.g., maintenance, discrimination);
- employment issues (e.g., time off work for parents/caregivers, claiming benefits).



## 2. Individual factors affecting uptake:

The following individual factors affect uptake:

- age and developmental level of the child;
- stated needs of an individual;
- language;
- culture;
- accessibility of resources.

### 3. Confidentiality in referrals and follow-up

- Referrals should be discussed with the individual and consent obtained prior to information being given to any other party either verbally or in writing.
- Particularly in the case of a child, it is important to ascertain whether the individual has accessed the recommended service and if not, follow up. However, in doing so, it is essential to maintain confidentiality.

**NOTE:** It is advisable for healthcare providers to develop and regularly update a list of local referral resources (including contact details and procedures) and devise a simple referral letter, which can be given to parents/caregivers to facilitate their receiving relevant services.

## Unit 2: Wrap-up and closure

Thank you for your participation in this training.

Please complete a post-course assessment (Handout U) and a course evaluation (Handout T) and return to us. Your opinion is valuable.







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