Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases

NATIONAL DEPARTMENT OF HEALTH
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Contents

Acronyms 4
Foreword 5
Acknowledgments 6
Introduction 7
Situational Analysis of HIV Disclosure in South Africa 7
Chapter 1: Definitions and Guiding Principles 10
Chapter 2: Legal and Ethical Framework 13
Chapter 3: A Contextual Framework for Disclosure 24
Chapter 4: Holistic Model for Disclosure 30
Chapter 5: Disclosure in the Context of a Child 45
Chapter 6: Disclosure in the Context of the Adolescent 54
Chapter 7: Integrating Disclosure 67
Chapter 8: Monitoring and Evaluation 72
Disclosure Documentation 75
References 80

Acronyms

ACRWC	The African Charter on the Rights and Welfare of the Child
ANC	Antenatal Clinic
ART	Antiretroviral Therapy
AYC	African Youth Charter
CBO	Community-Based Organisation
CDC	Centers for Disease Control and Prevention
CEO	Chief Executive Officer
CFS	Child-Friendly Space
CRC	Convention on the Rights of Children
CRPD	Convention on the Rights of People with Disabilities
C&A	Child(ren) &/or Adolescent(s)
C&AFS	Child & Adolescent-Friendly Space
C&ALHA	Child(ren) &/or Adolescent(s) Living with HIV/ AIDS
DBE	Department of Basic Education
DSD	Department of Social Development
EPI	Expanded Program on Immunisation
FBO	Faith-Based Organisation
FSI	Family Support Intervention
HAST	HIV / AIDS / STI / TB
HCP	Healthcare Providers
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
I ACT	Integrated Access to Care and Treatment
ICCPR	International Covenant on Civil and Political Rights
IMCI	Integrated Management of Childhood Illnesses
ISHP	Integrated School Health Programme
MCWHN	Maternal Child Womens Health and Nutrition
MDG	Millennium Development Goals
NCD	Non Communicable Diseases
NDOH	National Department of Health
NGO	Non-Governmental Organisation
OAU	Organisation of African Unity
OVC	Orphans and Vulnerable Children
PICT	Provider-Initiated Counselling and Testing
PCG	Primary Caregivers
PMTCT	Prevention of Mother-to-Child-Transmission of HIV
SRH	Sexual Reproductive Health
STI	Sexually Transmitted Infection
TB	Tuberculosis
UN	United Nations
WHO	World Health Organisation

Foreword

It gives me a great pleasure to present these new HIV disclosure guidelines for children and adolescents.

The National Development Plan 2030 of South Africa identifies the priority interventions which should lead to a more effective health system and, subsequently, the achievement of improved health outcomes. The key priority interventions are as follows:

1. Address the social determinants that affect health and diseases
2. Strengthen the health system
3. Prevent and reduce the disease burden and promote health

It is the Department of Health's commitment, as indicated in the National Strategic Plan 2015/16 - 2019/20 (NSP), to scale up the number of people on antiretroviral treatment and retain those on treatment over time.

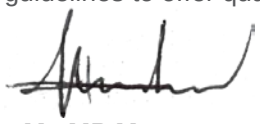
The purpose of the guidelines is to address the four strategic objectives that form the basis of HIV, STI and TB response, as identified by the National Strategic Plan on HIV, STIs and TB, 2012-2016. These are:

- Addressing social and structural barriers to HIV, STI and TB prevention, care and impact
- Preventing new HIV, STI and TB infections
- Sustaining health and wellness
- Increasing the protection of human rights and improving access to justice.

The NSP indicates that social and behavioural change communication is also critical to changing risky behaviour and the social conditions that drive the HIV and TB epidemics, while at the same time supporting a demand for prevention, care and support, and treatment services. The Department has committed to prioritise efforts to support and guide primary caregivers (PCGs) and health care providers (HCPs) through a disclosure approach, ensuring the physical, emotional, cognitive and social well-being of the child and adolescent. This will improve the long term benefits of ART through adherence and retention in care.

I am grateful to all the internal and external stakeholders who actively contributed to the development of these guidelines, despite their demanding schedules.

It is our sincere wish that all clinicians at PHC clinics and community health centres will use these HIV disclosure guidelines to offer quality, comprehensive services to the public.



Ms MP Matsoso
Director General (National Department of Health)
Date: 31/05/2016

Acknowledgments

The National Department of Health would like to thank the individuals and organisations who contributed their efforts to the development of the Disclosure Guidelines for Children and Adolescents in the context of HIV, TB and non-communicable diseases in 2015.

The efforts include strategic leadership and guidance, initiation and management of the process, conceptualisation and writing of sections, reading and editing as well as providing inputs to improve the quality of the document.

National Department of Health Chief Directorates and Directorates

Child, Youth and School Health, Maternal and Woman's Health, HIV and AIDS and STIs, TB Control and Management, Nutrition, Health Information, Evaluation and Research, and Human Resource Development and Management for Health.

Other National Departments

Department of Social Development
Department of Basic Education
Department of Women

Provincial Departments of Health

Partner Organisations

Zoë-Life Innovative Solutions, Centers for Disease Control (CDC), UNICEF, WHO, Programme for Appropriate Technology in Health (PATH), USAID, Regional Psychosocial Support Initiatives (REPSSI), South to South (S2S)-Stellenbosch University, Children's Rights Centre (CRC), Clinton Health Access Initiatives (CHAI), UNAIDS, FHI360, Yezingane Network, United Nations Populations Fund (UNFPA), Rahima Moosa Mother and Child Witwatersrand University, Centre for the Study of AIDS (CSA) – University of Pretoria and NHLS.

Introduction

The national provision of antiretroviral therapy (ART) to children in South Africa means that children infected with HIV now live well into adulthood. A recent survey[1] estimated that in South Africa there were 369 000 children between the ages of 0 and 14 living with HIV in 2012. It is further estimated that of these 369 000 children, 166 000 were on antiretroviral treatment as of mid-2012. The survey found that this age group had the highest exposure to HIV treatment. Children and Adolescents living with HIV (C&ALHA) are now surviving to an age where disclosure of their status is relevant and appropriate. At some stage, these children become aware of the fact that they have a chronic illness, and they experience its impact on their bodies and lives, in either a positive or negative way. This poses a challenge to both primary caregivers (PCG) and health care providers (HCP), who face the stressful process of informing the child or adolescent (C&A) about his or her HIV status, or disclosing to the C&A about the status of their PCG.

Although developmentally-guided disclosure of HIV status is widely recommended, there are few specific frameworks to guide primary caregivers, families, and healthcare providers through this disclosure process[2]. The WHO Disclosure Guidelines on HIV Disclosure Counselling for Children up to 12 years of age (2011) provides strong evidence that disclosure is central to the overall well-being of the child and adolescent. These guidelines confirm the psychological and emotional benefits of disclosure to HIV-positive children and adolescents, dispelling concerns that disclosure may cause harm.

In the absence of contextually appropriate guidelines and tools to facilitate the disclosure process, HCPs in South Africa may not have the skills and knowledge to help C&A through the disclosure process in a safe and healthy manner. These skills would include the provision of appropriate guidance on when, how, by whom and under what conditions C&A should be given information about their own, or their PCG's HIV status. The PCGs of the C&ALHA are equally paralysed by their own fears and misconceptions about the consequences of disclosure, resulting in a double barrier to disclosure. This results in C&ALHA having to navigate a serious and chronic illness without the information, care and support that is promised to them by the South African National Strategic Plan on HIV, STIs and TB (2012 – 2016) and relevant key components of the National Development Plan 2030.

The South African National Department of Health has committed to prioritise efforts to support and guide PCGs and HCPs through a disclosure approach, which ensures the physical, emotional, cognitive and social well-being of the child/adolescent. This will improve the long-term benefits of ART through adherence and retention in care.

Situational Analysis of HIV Disclosure in South Africa

The WHO report on the "Global Update on HIV Treatment 2013"[3] estimated that 151 860 children in South Africa were on antiretroviral therapy (ART) at the end of December 2011. By 2012, this number had increased to 166 000. In a study[4] on the patterns of and demographic factors associated with HIV disclosure among South African children, of the 149 caregivers who were interviewed about their HIV-infected children only 59 children (39.6%) knew of their status. Of these 59 children, 30 children (50.85%) learned of their HIV status between the ages of 11-17 years. Of those who had been disclosed to, 26 children (44.1%) fell between the ages of 6 to 10 and only 3 (5.1%) fell under the age of 6.

There is a clear relationship between age and disclosure, with older children (11-17 years) more likely to know their HIV status4. Research[4,5] indicates that a large number of C&ALHA will only learn of their status when they are in their teens. These delays in disclosure are likely to lead to a delay in access to treatment and/or difficulties related to adherence to treatment[6].

These findings suggest four things:

1. There is a low disclosure rate amongst South African C&A
2. PCGs are likely to delay the disclosure process until the child is over 10 years of age.
3. Delaying the initiation of the disclosure process is likely to make eventual disclosure an increasingly difficult process.
4. Disclosure that takes place during adolescence can result in non-adherence and consequent treatment failure

Reasons for the low disclosure rates in South Africa are as follows:

1. PCG issues:
   - Fear of the emotional impact of disclosure[7,8]
   - Fear of the consequences of disclosure e.g. C&A then discloses to family and community[7,8].
   - Issues of guilt, blame and shame[8]
   - PCGs are, by definition, not always biological parents (see Chapter 1: Definitions and Guiding Principles)
2. HCP issues:
   - Lack of access to policies or guidelines to assist them in the disclosure process[3]
   - HCPs often miss the opportunity to educate PCGs about the importance of disclosure and the disclosure process6.
   - Lack of skills and tools to provide age-appropriate counselling services to children[9]
3. Health systems issues
   - Poor implementation of available policies and protocols (e.g. Integrated Management of Childhood Illness - IMCI, Provider-Initiated Counselling and Testing - PICT) to identify C&ALHA within facilities and communities
   - Lack of Child and Adolencent-Friendly Spaces (C&AFS) to provide appropriate disclosure services10
   - Poor referral and linkage systems to strengthen disclosure processes between facility and community level

Purpose of the Guidelines

These guidelines ultimately aim to assist all stakeholders involved in the disclosure process in empowering and equipping C&A to be actively involved in the management of their chronic disease. Although disclosure is commonly associated with HIV and disclosure of one's status, the principles and processes outlined within these guidelines are applicable to any chronic disease. These include but not limited to, HIV, TB, Diabetes and Mental Illness.

Aim of the Guidelines is to:

1. Provide guidance regarding increased case finding of C&ALHA that have not been diagnosed, or who are diagnosed but have not been disclosed to
2. Provide a support and guidance framework to address the specific needs of PCGs and family members relating to disclosure
3. Provide a framework and model to support HCPs in providing structured disclosure services
4. Provide guidance to support disclosure services to C&A in "C&AFS" with a children's rights-oriented approach

The **intended** outcomes would be the following:

1. The disclosure process starting as early as possible after a child's HIV diagnosis
2. Increased number of C&A who are fully informed about their HIV status and equipped to be actively involved in the management of their illness within an age-appropriate framework.
3. C&ALHA being linked to the most appropriate continuum of care and support.

Target Audience

This document is intended for HCPs and facility and programme managers involved in C&A HIV counselling, testing, treatment, care and support at health care facilities and at community level.

Chapter 1: Definitions and Guiding Principles

For the sake of consistency, the following terminologies, definitions and guiding principles will be used throughout the guidelines.

Definition of the C&A

Newborns	**Birth - 28 days**
Infants	**28 days – < 1 year**
Toddlers	**1 – < 3 years**
Early Childhood	**3 – 5 years**
Middle Childhood	**6 – 9 years**
Early Adolescence	**10 – 14 years**
Late Adolescence	**15 – 19 years**

Health

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO definition, 1946).

Family

These are the face-to-face interactions within the family group, mainly between a C&A and PCG. There is more than one picture of what a family looks like - it is the quality of the relationships and interactions that are important.

Primary caregiver

The parent, legal guardian or person responsible for providing primary care to the C&A.

Health Care Provider

Any trained HCP providing disclosure services within facility or community (nurse, doctor, counsellor, social worker or psychologist).

Child and Adolescent Disclosure

A process whereby a child gains knowledge of his/her HIV status or his/her caregiver's HIV status. A gradual process of giving children age-appropriate information regarding their illness, leading to full disclosure when the child has the cognitive and emotional maturity to process this information.

Levels of Disclosure

Non-Disclosure	The child is unaware of their illness and its effect on their body
Partial Disclosure	The child is made aware of their illness without actually naming HIV
Full Disclosure	The child is made aware of their illness which is named as HIV
Health Promoting Disclosure	The child knows everything about their disease that is appropriate for their age. They are equipped in a supportive manner with skills to take age-appropriate responsibility for their health
Complete Disclosure Process	The child is guided through a process, from the stage of non-disclosure to the stage of health-promoting disclosure within a children's rights framework

Types of Disclosure

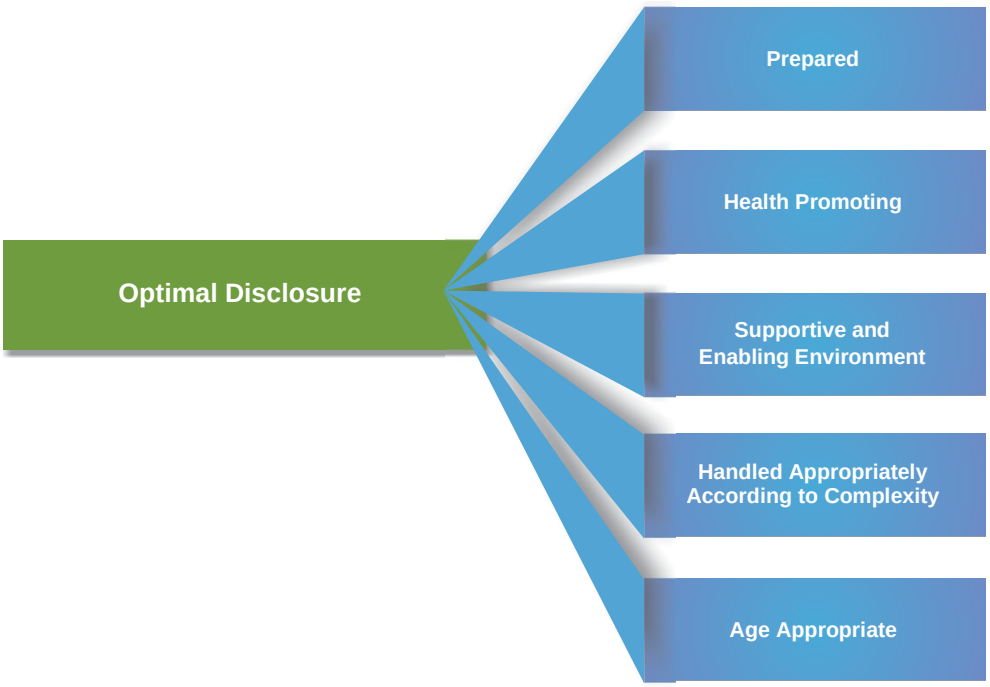
Prepared Disclosure	The HCP, the PCG and the child are fully prepared for the disclosure process
Unprepared Disclosure	Either the health care provider, the primary caregiver or the child are not fully prepared for the disclosure process
Involuntary Disclosure	The primary caregiver is forced into disclosing to the child due to circumstances
Accidental Disclosure	The child becomes aware of their illness purely through an incident that is accidental
Complete Disclosure Process	The child is guided through a process, from the stage of non-disclosure to the stage of health-promoting disclosure within a children's rights framework

Complexity of Disclosure

Uncomplicated Disclosure	"Typical" transmission e.g. Perinatal, or consensual sexual activity for adolescents Not abusive or illegal No current or recent trauma No current or recent crisis Supportive environment
Complex Disclosure	"Atypical" transmission Abusive or illegal Recent or current trauma Current crisis Non-supportive environment Pathological bereavements Child-headed household Vulnerability of caregiver Disability

Optimal Disclosure

Disclosure that is prepared, health-promoting, age-appropriate, takes place within a supportive and enabling environment and is handled according to the complexity of the situation.



Chapter 2: Legal and Ethical Framework

Please Note:

For the purposes of this chapter, the term "child" in reference to Child Rights, refers to children and adolescents, in line with the definition of the Convention of the Right's of Children (CRC), i.e. a child is defined as 0 – 18 years of age.

The HIV counselling and testing (HCT) of children in South Africa is governed by a specific set of laws and ethics. Since disclosure occurs once a C&A has already been tested, this document looks at legalities and ethics specifically related to disclosure.

It is recommended that HCPs, seeking legal guidance on HIV testing and counselling of C&A, refer to the Human Sciences Research Council document, "Legal, ethical and counselling issues related to HIV testing of children: Legal guidelines for implementers".[11] This publication is endorsed by both the National Department of Health (NDOH) and Centers for Disease Control and Prevention (CDC).

A second publication, by the Health Professionals Council of South Africa (HPCSA), "Ethical Guidelines for good practice with regard to HIV – booklet 11" is recommended.

Evidence to Support Legal Framework for Disclosure

South Africa has committed, and is legally obligated, to the following international, national and domestic agreements and laws:

International	South African commitment
Universal Declaration on Human Rights[i] A declaration adopted by the United Nations in 1948. Universally adopted as the fundamental norms of human rights that everyone should adhere to.	1948 – South Africa abstained from voting in favour of the declaration due to Apartheid. 1994 – South Africa readmitted as a member of the United Nations, thus showing commitment to the declaration. The South African Constitution is adopted in 1996 incorporating Human Rights.
International Covenant on Civil and Political Rights (ICCPR)[ii] A declaration adopted by the United Nations in 1966. The covenant expands on civil and political rights freedoms listed in the Universal Declaration on Human Rights.	2002 – South Africa agreed to the declaration (Accession).
United Nations Convention on the Rights of the Child (CRC)[iii] The CRC is the legally-binding international instrument to incorporate the full range of human rights — including civil, cultural, economic, political and social rights. The Convention has achieved near-universal acceptance, having now been ratified by 193 parties – more than belong to the United Nations or have acceded to the Geneva Conventions.	1993 – South Africa Signs. 1995 – South Africa Ratified. South Africa is legally obligated to uphold the rights of its children, as defined by the CRC.

United Nations Millennium Declaration[iv] Adopted by the United Nations in 2000. Delegates collective responsibility to states to uphold human dignity, equality and equity, at a global level.	The child is guided through a process, from the stage of non-disclosure to the stage of health promoting disclosure within a child rights framework.
United Nations Convention on the Rights of Persons with Disabilities (CRPD)[v] Convention that elaborates in detail the rights of persons with disabilities and sets out a code of implementation. Countries that join in the Convention engage themselves to develop and carry out policies, laws and administrative measures for securing the rights recognized in the Convention and abolish laws, regulations, customs and practices that constitute discrimination.	2007 – South Africa Signed and Ratified. South Africa is legally obligated to uphold the rights of disabled children as specified by the CRPD.

Regional	South African commitment
African Charter on the Rights & Welfare of the Child (ACRWC)[vi] Adopted by the Organisation of African Unity (OAU) in 1990. Drafted to give the CRC specific application in an African Setting. First regional treaty on the human rights of children.	1997 – South Africa Signed. 2000 – South Africa Ratified. South Africa is legally obliged to uphold and advance the rights of children as specified by the ACRWC. This charter is built on the same principles of the CRC but highlights issues of special importance in the African context.
African Youth Charter (AYC)[vii] A strategic framework for the development of youth policy at national and regional levels.	2009 – South Africa Ratified. South Africa is legally obliged to uphold and advance the rights of children as specified by the AYC. This charter aims to strengthen, reinforce and consolidate efforts to empower young people through meaningful youth participation and equal partnership in achieving Africa's development agenda[12].

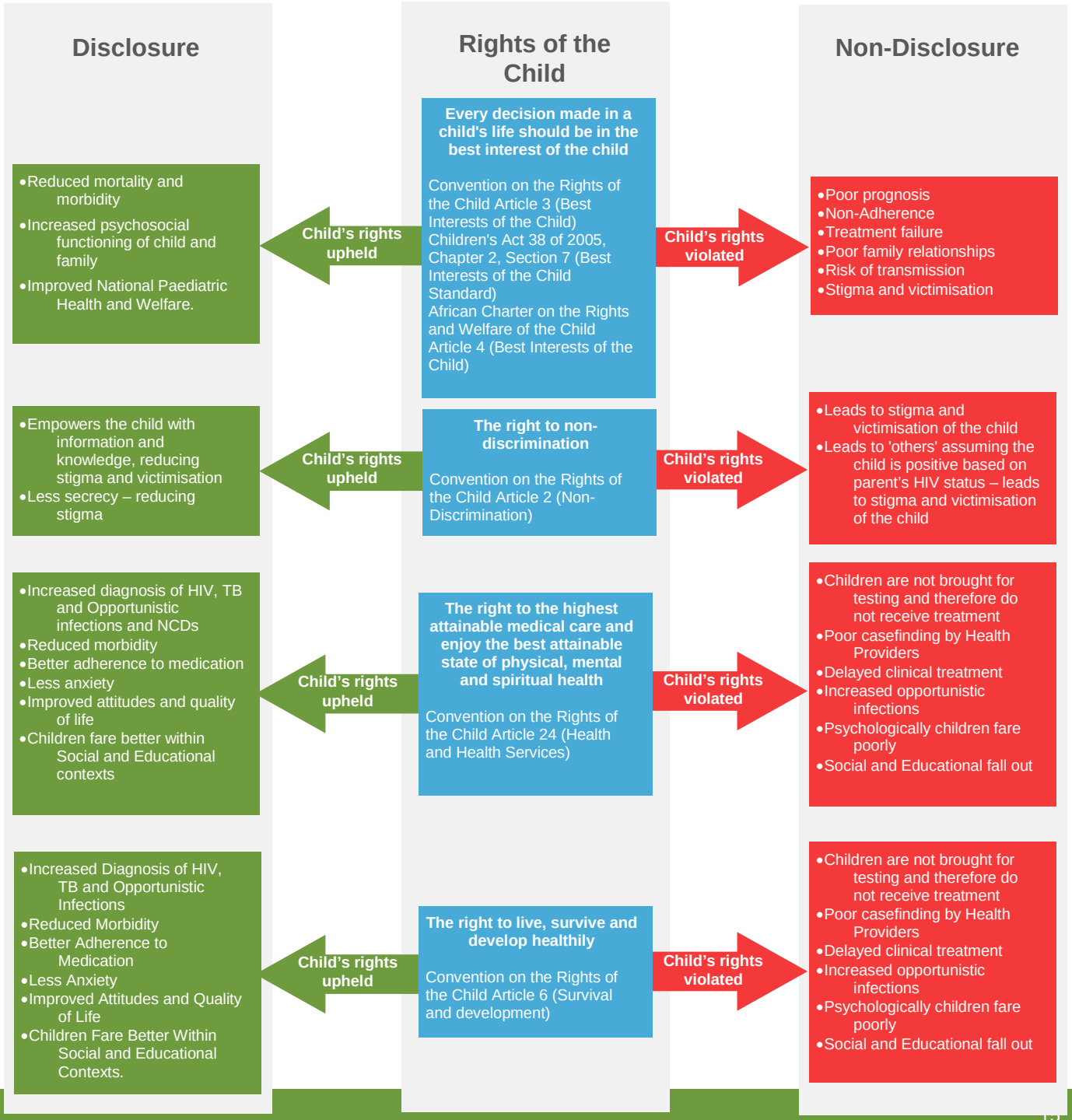
Domestic legislation	Relevance to Guideline
South African Constitution (ACT 108 OF 1996)[viii] Chapter 2, Section 28: Children's Rights, outlines the rights of children. The rights relevant to these guidelines are found in the table labelled "Human rights of children in the context of disclosure."	The Constitution provides the legal foundation for the existence of the Republic of South Africa, sets out the rights and duties of its citizens, and defines the structure of the government.

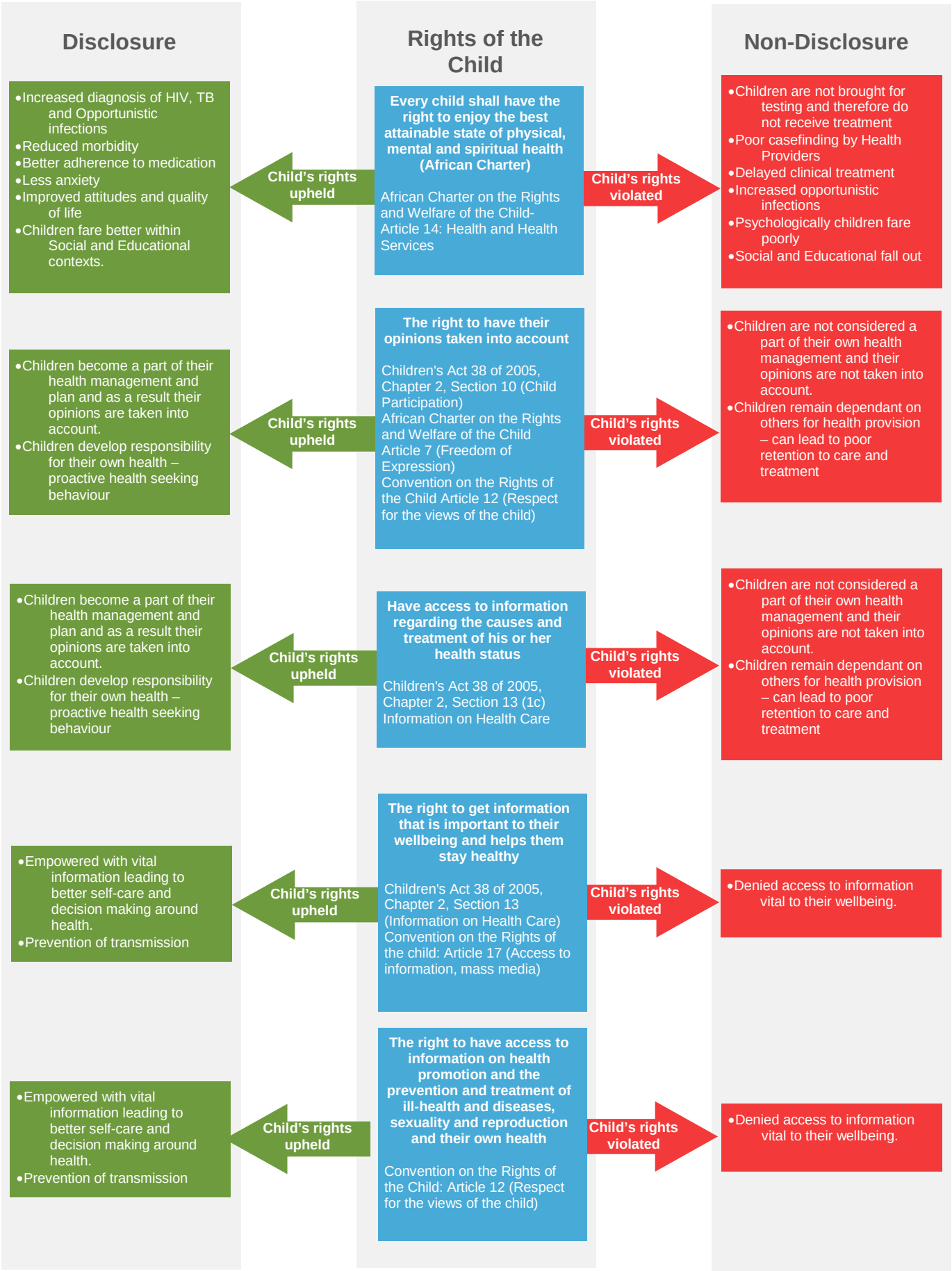
Children's Act (No. 38 of 2005) as amended by children's Amendment Act (No. 41 of 2007)[ix, x] Part 3: Protective measures relating to the health of children, informs rights relative to HIV. These are found in the table labelled "Human rights of children in the context of disclosure."	This act gives effect to the rights of children, as outlined in the constitution.

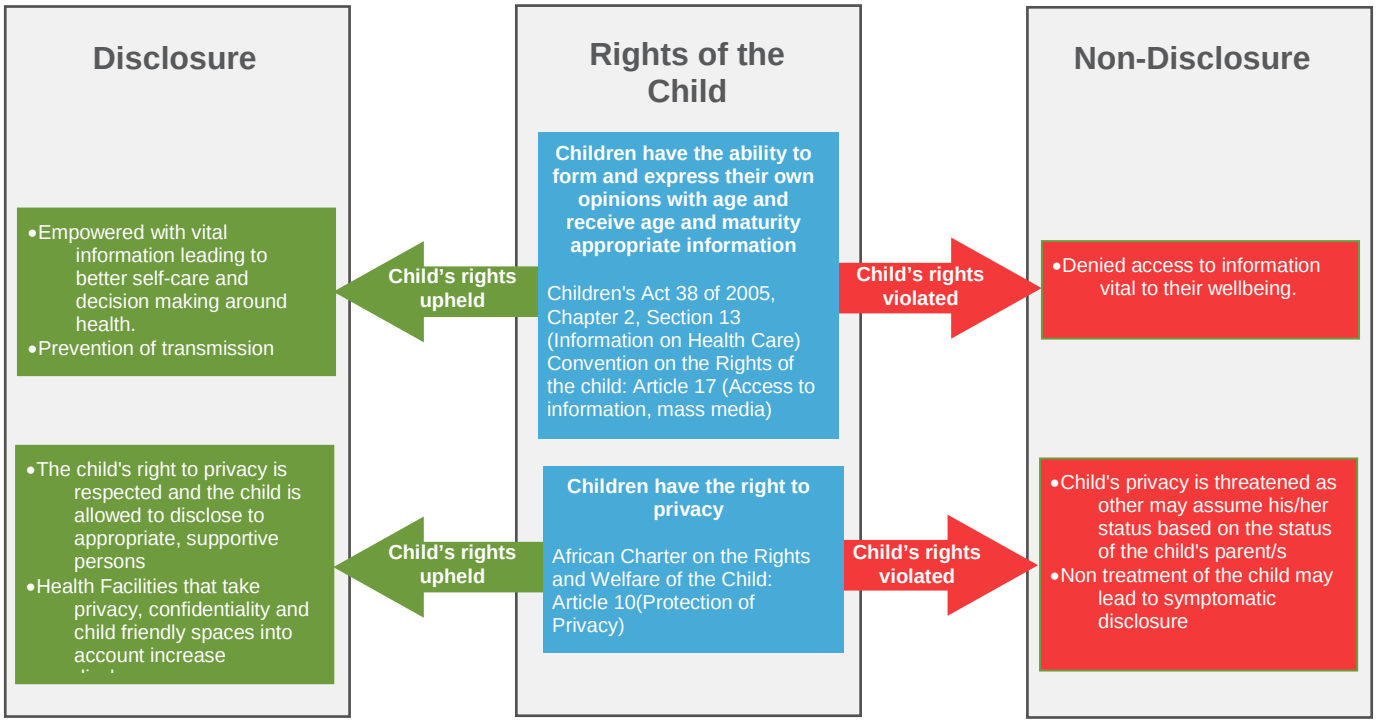
The Rights of the Child in the Context of Disclosure:

As evidenced from the literature review, South Africa is legally obligated to ensure that appropriate disclosure becomes an integrated component of comprehensive C&A HIV management. C&A disclosure impacts on numerous children's rights, and by choosing not to disclose to C&A, the rights of those children are violated rather than upheld. Below is a summary diagram of the rights of the child, appropriate to disclosure. The diagram illustrates the relevant right, how appropriate disclosure upholds the right and how non-disclosure is a direct violation of the right.

Human rights of children in the context of disclosure:



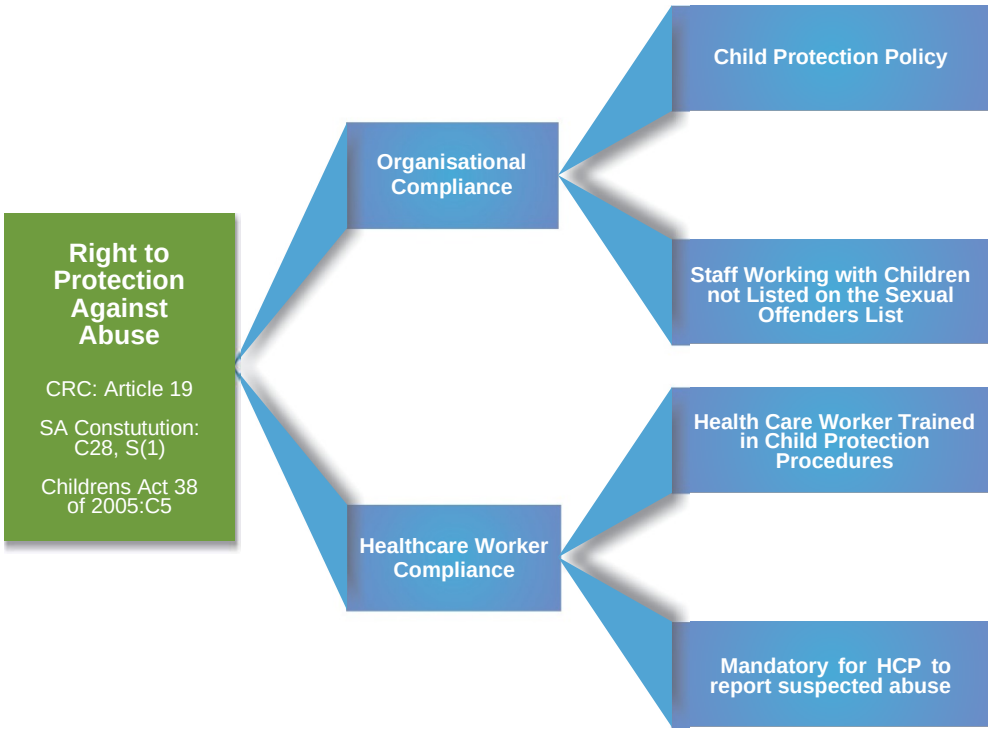

Disclosure
Rights of the Child
Non-Disclosure
•Increased diagnosis of HIV, TB and Opportunistic infections
•Reduced morbidity
•Better adherence to medication
•Less anxiety
•Improved attitudes and quality of life
•Children fare better within Social and Educational contexts.
Child's rights upheld
Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health (African Charter)
African Charter on the Rights and Welfare of the Child- Article 14: Health and Health Services
Child's rights violated
•Children are not brought for testing and therefore do not receive treatment
•Poor casefinding by Health Providers
•Delayed clinical treatment
•Increased opportunistic infections
•Psychologically children fare poorly
•Social and Educational fall out
•Children become a part of their health management and plan and as a result their opinions are taken into account.
•Children develop responsibility for their own health – proactive health seeking behaviour
Child's rights upheld
The right to have their opinions taken into account
Children's Act 38 of 2005, Chapter 2, Section 10 (Child Participation)
African Charter on the Rights and Welfare of the Child Article 7 (Freedom of Expression)
Convention on the Rights of the Child Article 12 (Respect for the views of the child)
Child's rights violated
•Children are not considered a part of their own health management and their opinions are not taken into account.
•Children remain dependant on others for health provision – can lead to poor retention to care and treatment
•Children become a part of their health management and plan and as a result their opinions are taken into account.
•Children develop responsibility for their own health – proactive health seeking behaviour
Child's rights upheld
Have access to information regarding the causes and treatment of his or her health status
Children's Act 38 of 2005, Chapter 2, Section 13 (1c) Information on Health Care
Child's rights violated
•Children are not considered a part of their own health management and their opinions are not taken into account.
•Children remain dependant on others for health provision – can lead to poor retention to care and treatment
•Empowered with vital information leading to better self-care and decision making around health.
•Prevention of transmission
Child's rights upheld
The right to get information that is important to their wellbeing and helps them stay healthy
Children's Act 38 of 2005, Chapter 2, Section 13 (Information on Health Care)
Convention on the Rights of the child: Article 17 (Access to information, mass media)
Child's rights violated
•Denied access to information vital to their wellbeing.
•Empowered with vital information leading to better self-care and decision making around health.
•Prevention of transmission
Child's rights upheld
The right to have access to information on health promotion and the prevention and treatment of ill-health and diseases, sexuality and reproduction and their own health
Convention on the Rights of the Child: Article 12 (Respect for the views of the child)
Child's rights violated
•Denied access to information vital to their wellbeing.



Other Legal Considerations:

Whilst the literature review has revealed that a C&A has the right to disclosure, there are other legalities that govern working with C&ALHA. Organisations and HCPs need to ensure that there is compliance with the following:

The child's right to protection against abuse

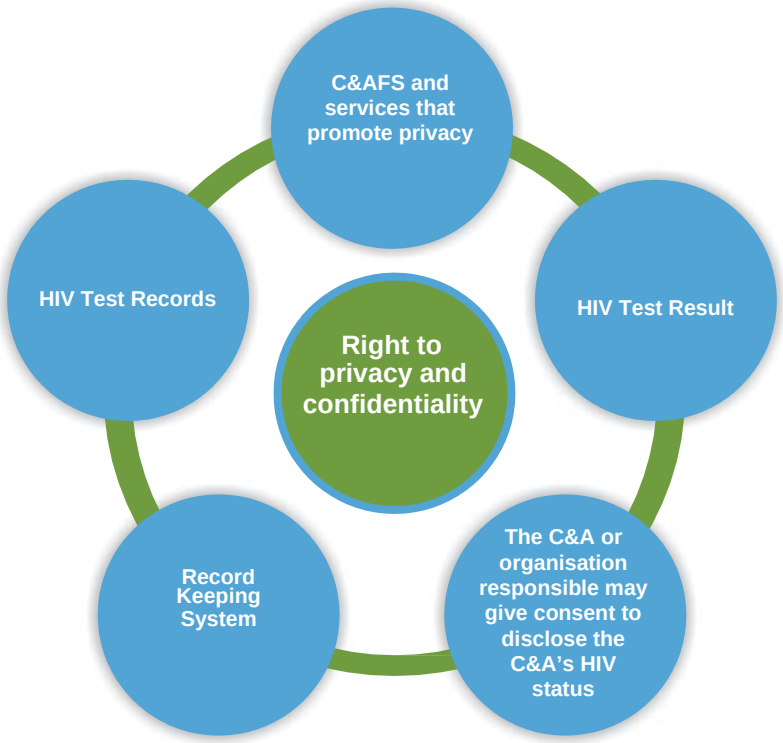


1. The child's right to confidentiality, privacy and child-sensitive health services

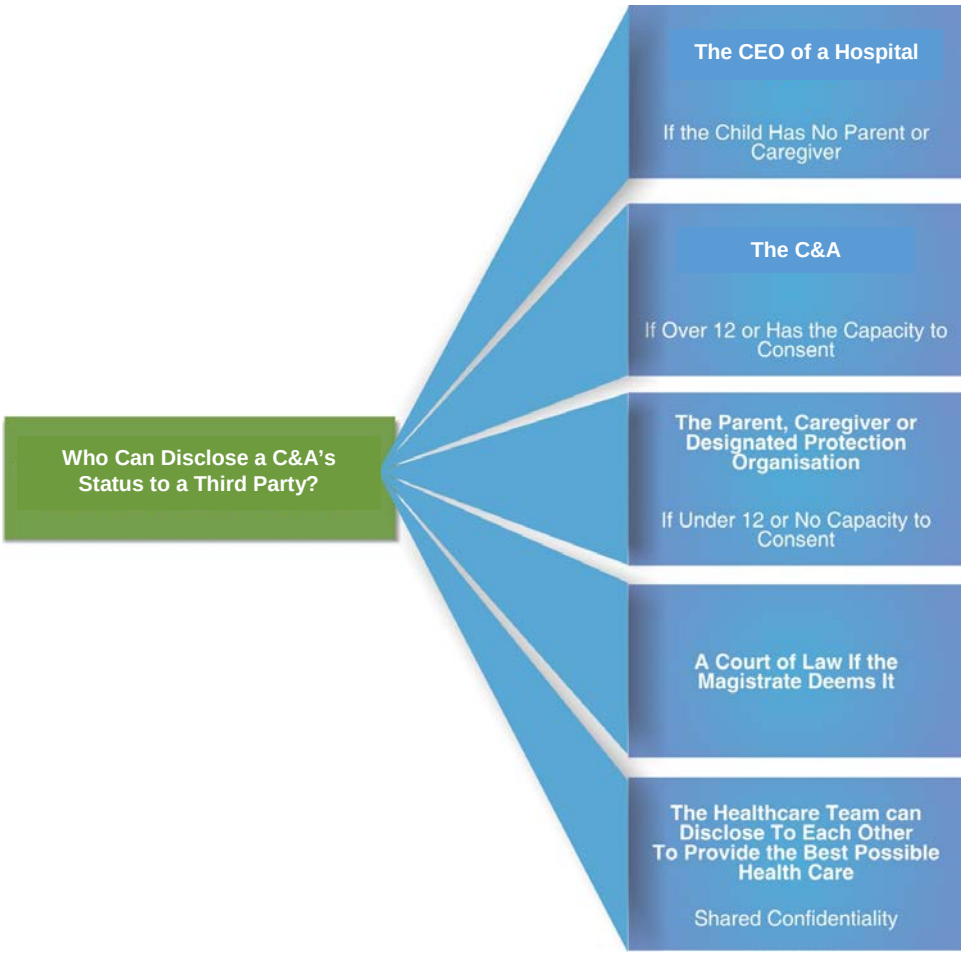
All children have the right to have their HIV status kept confidential.

The NDOH HCT Policy further emphasises confidentiality and specifies:

> **Note:** In the case of an adolescent >12 years who is living with AIDS and engaging in consensual sexual activity, the HCP has an ethical obligation to disclose the adolescent's HIV status to the partner if it is deemed that the life of an identifiable partner is at risk. In this situation, the HCP is encouraged to counsel the adolescent to disclose their status. However, should the adolescent refuse after numberous counselling opportunities, the HCP should, under the supervision of a multidisciplinary team, disclose to the partner at risk. The HCP should follow the guidelines provided by the HPCSA, which clearly outline the responsibilities of the HCP in terms of a rights-centred approach to both parties concerned, as well as the steps that should be followed before the disclosure is made.



The South African Children's Act states that the following people may consent to disclose a child's HIV status to a third party (e.g. to a teacher or doctor) when this is in the best interest of the child.



According to the Children's Act you may not disclose a C&A's HIV status without the proper consent, unless the C&A is being tested because there is a suspicion that a HCP may have contracted HIV through contact with the C&A. It is the only instant in the Act, where the "best interest of the child" does not come first. There are consequences contained in the Act for disclosing a C&A's status without permission.

In the case of a medical emergency the medical team should do what is required to prevent death or disability. In all other cases consent can be obtained from the Department of Social Development (DSD) who can overrule the C&A/parent or caregiver where necessary.

2. The rights of C&A with disabilities within the disclosure context

C&A with disabilities have the same fundamental human and freedom rights as other C&A (CRC article 7). However, C&A with disabilities are more vulnerable, can be exploited and may sometimes have reduced capacity with regards to decision making and cognitive capacity to receive and process information.

The following rights specific to C&A with disabilities should be taken into consideration:

<table>
<tr><th colspan="2">Rights of Children with Disabilities</th></tr>
<tr><td>All children with disabilities shall enjoy the same fundamental human and freedom rights as other children.

CRPD Article 7: Children with Disabilities.</td><td>Children with disabilities should access HIV treatment and other related services.

Community care givers should identify children with disabilities at community level and refer them for appropriate health care services.

Facilities must ensure that disabled children access all services relating to HIV and disclosure.</td></tr>
<tr><td>In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

CRPD Article 7: Children with Disabilities.</td><td rowspan="3">Children with physical disabilities but with normal cognitive or emotional development should receive disclosure services within the normal facility setting and processes. Children with cognitive or emotional problems relating to their disability should be referred to a social worker, psychologist or specialist service for disclosure and ongoing support.</td></tr>
<tr><td>Children with disabilities should be allowed to express their views freely on all matters affecting them.

CRPD Article 7: Children with Disabilities.</td></tr>
<tr><td>The views of a child with disabilities must be given due weight in accordance with their age and maturity.</td></tr>
</table>

An Ethical Framework for Disclosure

Ethics is the rule that should guide HCPs on what is “a principle of right or good conduct”.

HCPs dealing with disclosure are likely to come across many situations in which they are unsure of the correct ethical path to take. Ethical decision making is a complex process. In order to guide HCPs, it is necessary to include a framework on ethical decision making. The framework will ensure that the HCP has a set of ethical principles to work within as well as a systematic approach to decision making, which are essential to competent practice[13].

An Ethical Consideration in the South African Context

Protecting C&A or a culture of covering up the truth?

Our individual attitudes towards C&A are linked to culture and other broader social factors. For example, the common view that children are innocent and need to be protected from harm reflects a positive value, one that is beneficial to a community and society. However, sometimes parents or PCGs hold false ideas of what protects the child. A parent who wants to protect a child from being stigmatised at school may decide to hide the truth about the circumstances surrounding the child’s illness or a family member’s death. Therefore, half-truths or made-up stories are used in the family to keep the child “safe” from the truth and its consequences. Unfortunately covering up the truth comes to be seen as a normal, perhaps even a “good thing”. This does not mean that the parent or family is bad.

This covering up has become accepted as a normal practice and perceived as child protection by parents, but it eventually does more harm than good. It breaks relationships at family level, fragmenting communities and compromising useful cultural values such as Ubuntu.

Guiding Ethical Principles for HCPs14

Ethical principle	What does this mean?	In the Context of Disclosure
Autonomy	Every individual is entitled to receive information about their condition and the treatment options in order for them to make an 'informed' decision.	C&A that need more information about their illness are entitled to know.
Justice	Every decision made regarding an individual's healthcare must uphold the existing legislation and be fair and justifiable.	Decision-making processes around disclosure must be documented to show how the decision was justified.
Beneficence	All decision-making should be aimed at the "best intent" of the client. HCPs should ensure best care for their clients.	Documentation should reflect how decisions were made in the best interest of the C&A.
Non-maleficence	A HCP must not do anything that will hurt, cause emotional, physical or psychological pain to the child.	The short term effects of disclosure should be well managed to minimise harm to the C&A. Long-term follow up is required to ensure benefit to the C&A.
Integrity	A HCP must handle themselves professionally, demonstrating trustworthiness and reliability.	HCP must be trained in the correct procedures and skills.

Systematic Approach to Ethical Decision Making for HCPs[13]

When facing a difficult ethical problem the following systematic approach to decision making should be followed:

1. **Identify the conflicting ethical issue**
   Identify all contributing factors and conflicts. These should be discussed with the client and be recorded.

2. **Identify all role-players who will be affected by the decision**
   Include:
   - HCP
   - Client
   - Family
   - Community

3. **Thoroughly identify consequences of the decision to all role-players**
   Identify benefits and risks of the decision. These should be discussed with the client and recorded.

4. **Explore possible options and outcomes with the client**
   Guide the client in this process, but simultaneously allow the client to come up with their own possible outcomes.

5. **Consult with the multidisciplinary team**
   Seek advice from other professionals regarding the decision, always taking into account client confidentiality.

6. **Take the decision and document the process**
   Document decision-making steps to show evidence of the HCP's prudence and professionalism.
   At all times, discuss the decision with the client before proceeding. Include specific time frames.

7. **Monitor, evaluate and document the decision**
   Continually monitor the short and long-term consequences of the decisions taken and address related challenges as they arise.

Best Practice Recommendations:

Based on the legal and ethical framework provided, the following are best practice recommendations for disclosure:

The organisation should:

- Provide the family with C&AFS and services.
- Have adequate record-keeping systems, in order to document the disclosure journey of the C&A. Disclosure should be recorded in the National Paediatric and Adolescent Clinical Stationery at facilities.
- Have a C&A Protection Policy that is adhered to.
- Screen HCPs to ensure that they are not listed on the sexual offenders listing, before being permitted to work with C&A.

The process:

- Disclosure should be a process, and not a once-off event or conversation.
- HCPs should include follow up visits to support and to monitor the C&A's emotional adjustment and understanding of the illness.
- Disclosure should be based on a systematic, developmental approach, using the age of the child as a guide. Assessment of the child's cognitive ability is key to disclosure.
- Disclosure should be done in a team with appropriate stakeholders, based on the best interests of the C&A.

HCPs should

- Be equipped with the necessary knowledge and skills in order to facilitate the disclosure process.
- Adequately prepare PCGs for the disclosure process.
- Work together with primary caregivers to disclose to the C&A.
- Be trained on the Child Protection Policy relevant to their organisation.

The family and community

- PCGs and family members should be adequately prepared for the disclosure process and the consequences thereof.

The child and adolescent

- It is in the best interest of a C&A to be told their own HIV status and that of their parents, as long as it is done in the correct manner.
- The PCG of the C&A should be guided, with the support of the HCPs, by the principal of "the best interests of the child". Each C&A's case should be independently assessed before this decision is made.

All HCPs and child care workers engaged in the process of disclosure need to be familiar with the overarching principles of these agreements, legal and ethical principles.

These are in place to ensure that best practices are embedded into our systems and that the Rights of the Child are upheld.

Chapter 3: A Contextual Framework for Disclosure

In order for disclosure to take place successfully, it is essential that the HCP understand four elements:

1. What defines a **successful** disclosure?
2. What is the **context** of disclosure: What is the bigger picture in which disclosure takes place?
3. **Age appropriate** disclosure: What is appropriate to disclose at which age?
4. What is the **process** of disclosure: Understanding how disclosure unfolds over time?

By understanding these four elements, we are able to structure a **model** for **disclosure** that will be defined in the next chapter.

Successful Disclosure

Based on research, best practice, and international recommendations, a successful disclosure is one in which a C&A is made fully aware of his or her own illness and its consequences. This is handled in a manner that is sensitive, yet equips the C&A to deal with the emotional and practical issues related to living with HIV.

What is successful disclosure?

1. **Intentional and not accidental**
2. **Timely, starting as early as possible**
3. **Truthful, all stakeholders must be prepared to tell the truth to the C&A**
4. **Family centred, include all persons that play a significant role in the C&A's life**
5. **Prepared**
   - Primary caregiver and other family members are well prepared
   - Health care provider is trained and knowledgeable
   - There is a C&AFS in which the disclosure process will take place
6. **Age / Development appropriate**
   - Tools and languages are developmentally appropriate
   - Information shared about transmission is appropriate
   - Counselling skills are appropriate
   - Health promoting messages are relevant
7. **Linked to appropriate support**
   - PCG and family prepared with appropriate tools to support C&A
   - Linkages and referrals for complex disclosures are available.
   - Return to services scheduled for ongoing psychosocial support and health information

Disclosure in Context

Unlike other clinical interventions, such as taking blood, disclosure is not an event that takes place between a HCP and a C&A. It is a complex process.

Disclosure is a long term process of:

Understanding a disease, its progress, its origins, its name, its consequences, and its management.

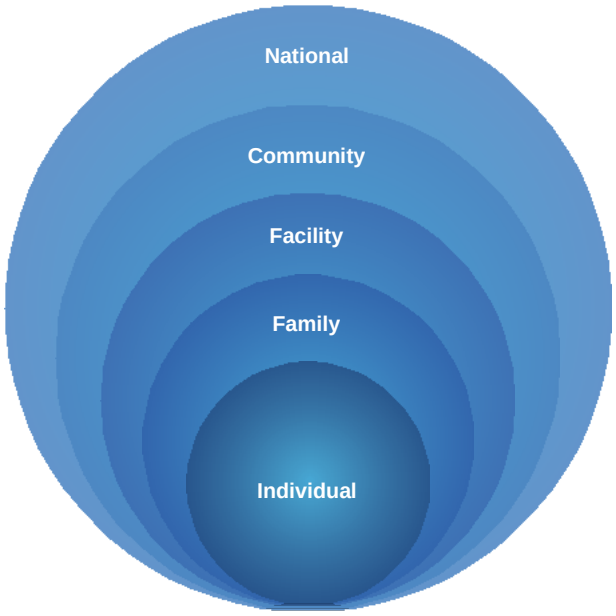
Disclosure is a series of answers to a long list of questions which can take place over a period of time.

Answers, and the manner in which they are given, will play a huge role in assisting the C&A to take responsibility for their health, and in providing the emotional and social guidance that is required.

Some of these questions should and will be answered by the PCG. Some are better answered by a HCP. Some will be answered by the community and some will have to be discovered by the C&A themselves.

The ecological development framework

It is a way of seeing people and their environments as connected systems rather than as separate units. All people relate to others within five interconnected levels namely: Individual, Family, Facility, Community and National levels. Disclosing to a C&A will impact on their family, their school life and their social life. By influencing as much of the C&A's larger environment as possible, a successful disclosure can be supported.



Using this approach, we can see that disclosure is:

1. **Relational:** levels influence each other

Culturally sensitive

2. **Contextual:** people experience disclosure in a particular context, which is different for everyone
3. **Time relative:** disclosure is an ongoing process, with different elements needing to be highlighted at different points.
4. **Multi-faceted:** disclosure requires multiple stakeholders and a multidisciplinary team approach.

Supporting successful disclosure within the ecological framework

From national level down to individual level, it is possible to create an enabling environment in which disclosure can take place. The following are examples of roles that are played at various levels to support disclosure:

Level	Disclosure Considerations	Roles To Support Disclosure
National	Develops policies and guidelines that govern HIV disclosure processes in a C&A-friendly manner and within the best interest of the C&A.	Disclosure guidelines within a children's rights framework and South African Children's legislation. National culture of truth telling.
Community	A **community** is made up of diverse people, groups and structures, in complex relationships with each other. All play an important role in influencing how a C&A experiences their reality as they grow up. For example, a C&A lives with its parents, goes to school, participates in a sports club and attends church. All of the relationships that this C&A will form can have a positive effect and influence on the disclosure process. **Culture** plays a part in prescribing decision-making roles in families, attitudes and beliefs around C&A behaviour. The community's cultural views about a child's age and their levels of maturity need to be considered in relation to stigmatisation following disclosure.	Community based case finding through community based structures such as: • Schools through the Integrated School Health Programme (ISHP) activities, churches • Active support networks • C&A's support groups • C&A Drop in Centres • Youth Centres/clubs
Facility	Implementation of HIV management policies which include HIV disclosure.	Truthful conversations about health. Skilled health care professionals. C&AFS. Age-appropriate services and tools. Tools to mitigate stigma.
Family	Face-to-face interactions within the family group, mainly between a C&A and PCG, or between a C&A and peers at school or home. It is important to note the level of emotional support and what boundaries a child feels they are receiving at home or school.	Prepared and supported PCGs. Family-level, age-appropriate services and tools. Long-term disclosure plans.
Individual	Personal factors such as age, physical health, and personality of the individual, must be considered. For example: does the C&A consistently perform poorly at school, or what are the implications of an C&A who has an angry and violent temperament.	Access to information, counselling, and support. Individual responsibility to use available support systems to adhere to care and treatment plans.

Age-appropriate Disclosure

There are different ways of understanding a child's development journey into adolescence, as well as adulthood. As a child grows into adolescence and adulthood they are able to think, feel and relate to others in more complex ways. Childhood development is thus seen as a process of gaining increasing abilities within physical, cognitive, social and emotional areas that lead to meaningful participation in family and society[15].

There are many layers of information that C&A will require, each with corresponding health promoting and adherence tasks.

Practical examples:

- A 5-year-old child will learn of their infectious illness (a germ) with a related task of taking medication daily (partial disclosure).
- A 10-year-old child, who is able to read names of his or her medication, will learn how ART works, and how he/she can participate in his own adherence to medication (full disclosure).
- A 12-year-old adolescent, who is entering adolescence will need to know that he or she has HIV, and that condom use or delay of sexual debut is recommended if exploring sexual activities. An individual at this stage of adolescence will also need to understand the legal implications of infecting an HIV negative person (full disclosure).

Criteria for Disclosure in children and adolescents

Care givers and all children from age of 3 years should start being prepared for disclosure as follows:

Non-Disclosure (under 2 years)

Partial Disclosure (3-9 years)

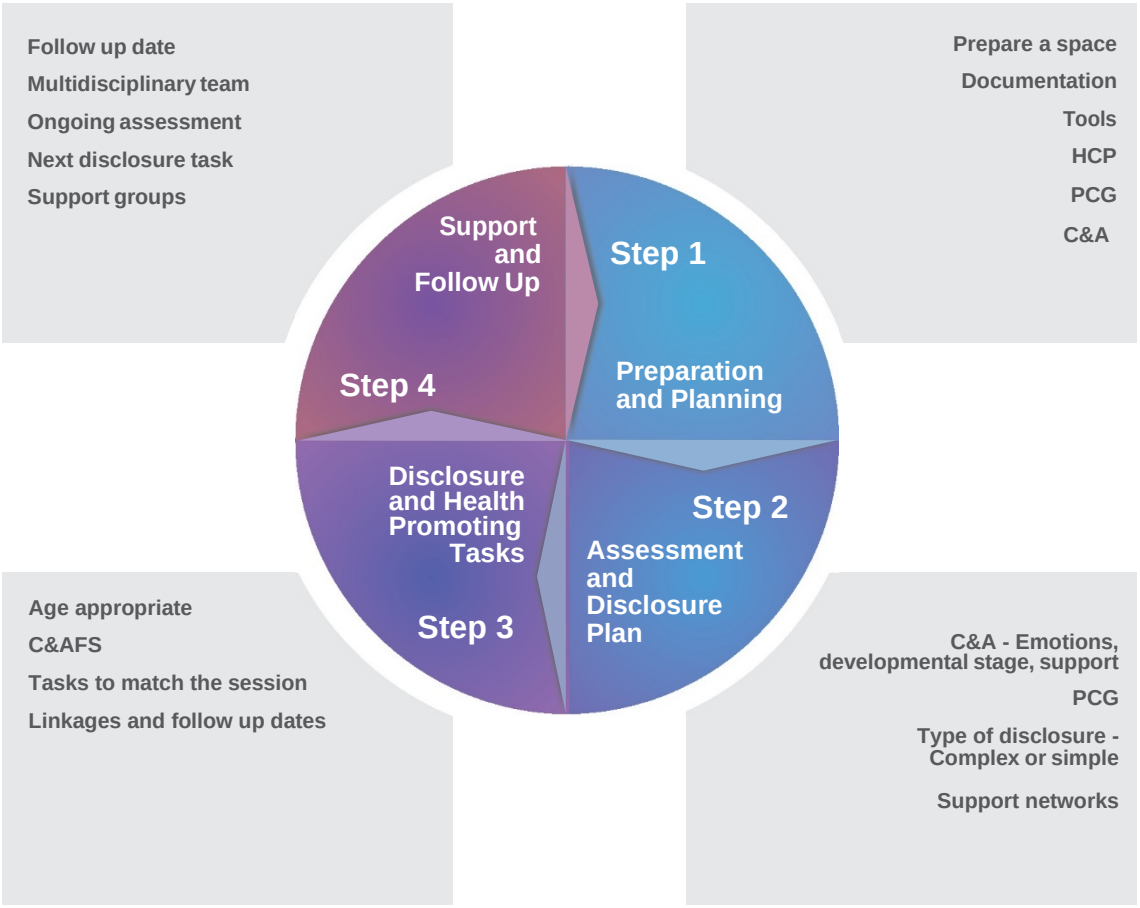
Full Disclosure (from 10 years), legal and ethical principles.

Process of Disclosure

Disclosure should follow a plan or process. Disclosure does not have a rapidly-reached end point, therefore disclosure should be handled as a cyclical process, which gets repeated as new information is shared with the C&A.

For each cycle, there are 4 steps in the process, shown in the diagram below, namely:

- **Step 1:** Preparation and Planning
- **Step 2:** Assessment and Disclosure Plan
- **Step 3:** Disclosure and Health Promoting Tasks
- **Step 4:** Support and Follow up



The detail of this process will be unpacked in the following chapters.

Overcoming Barriers to Disclosure

In order for disclosure to be successful, a conducive environment needs to be created. In this environment, we need to maximise **Facilitators** and overcome **Barriers**.

Facilitators are anything that supports the process of disclosure: Skilled HCPs, C&AFS and age-appropriate tools.

Barriers are anything that could prevent disclosure. Currently there are more barriers than facilitators. Such barriers stand between the C&A and a healthy response to a chronic manageable disease. The table below outlines the barriers that occur within health facilities and relating to HCPs and PCGs:

It is clear from the table below that the biggest barriers are fears and issues related to the **PCGs**.

It is vital that enough time and energy is spent preparing and supporting PCGs to commit to long-term disclosure work with their children

Barriers to disclosure

Health Facility	Health Care Provider	Primary Caregiver
Negative attitudes of HCPs who are known to be unfriendly by patients or PCGs[16].	Limited knowledge and skills to handle and encourage disclosure process[16].	Little knowledge regarding disclosure issues, therefore do not feel prepared[17].
Absence of guidelines and policies on the HIV disclosure process.	HCPs believe that children are too young to be disclosed to[17].	Fear the parent/PCG- child relationship may be negatively affected by disclosure[18]
Unavailability of HIV disclosure services for children and adolescents.	Lack of confidence to engage in disclosure process involving children and adolescents due to lack of required knowledge and skills.	Caregiver fears that the C&A will disclose their status to other people in the community once they know their own status, and they will, as a result, experience stigma and discrimination.
Poor HIV testing in C&A	Poor implementation of HCT or PICT policy during child and adolescent health care services.	Some PCGs are reluctant to sign for consent to an HIV test for their children.
Lack of C&AFS to maintain privacy and confidentiality during the disclosure process.	Unresolved issues relating to their own HIV status and disclosure experiences in some cases[19,20].	Caregivers that do not feel prepared to answer questions the C&A may have regarding disclosure[17]. Caregivers have not come to terms with their own shock and/or grief associated to their own HIV-positive status[17]. In contexts of poverty, PCGs may have concerns about the financial implications once a child's HIV-positive status is known, which may prevent testing and disclosing[16].

Chapter 4: Holistic Model for Disclosure

Step 1 - Preparation and Planning

The aims of the Preparation and Planning phase are to ensure that the:

1. Health care facility is equipped with the correct policies, tools, documentation and referral networks.
2. HCP is equipped with the skills, tools and language to assist both the C&A and the PCG.
3. PCG is fully engaged to understand the benefits of disclosure, and is equipped with a plan and language to share with the C&A.
4. C&A receives a disclosure service with a prepared PCG in a C&AFS from a qualified HCP.

A. Preparing the Health Facility:

Health facilities should facilitate the disclosure process by creating an enabling environment.

Policies, guidelines and other related documents

Systems and patient pathways within the health facility need to support case finding of C&A that require HIV disclosure services.

Facility management must ensure access to required resources and in-service training on:

- HCT policy and related guidelines such as IMCI
- Disclosure guidelines
- C&A protection policy and procedures

Health facility structures

The health facility should be C&A friendly and have space for a private, confidential and safe environment conducive to disclosure.

Adapting service delivery

- HIV treatment, care and support services for C&A and their PCGs should be accessible at any time
- More flexible service times must be adopted in health facilities and organisations
- Opportunities must be used, such as using school holidays to conduct Wellness Days and intensify HIV case finding and disclosure services for children and adolescents

HIV care and support services for children, adolescents and their PCGs must be strengthened, by collaborating and linking with community-based services.

Other facilities with C&AFS

It is important to consider where the process of disclosure of a C&A's HIV positive status takes place. Some community structures such as NGOs and faith-based organisations (FBO) with C&AFS may also be used for the disclosure process. Partnerships between facilities and community- based structures is key.

What is a child-friendly space?

> "A place where children and/or youth meet other children to play, learn competencies to deal with the risks they face, are involved in some educational activities, and can relax in a safe place. It gives children a sense of security, structure and continuity that provides support amidst overwhelming experiences.'" (World Vision definition).

In the context of disclosure, this is a confidential and private place where C&A can receive a disclosure service in an enabling environment that is age appropriate and consistent.

Why do facilities need a child and adolescent-friendly space (C&AFS)?

- It encourages positive interaction between the family and the clinic staff, which is vital for successful disclosure.
- It establishes a positive routine for the C&A, which diminishes the anxiety related to change.
- It provides a conducive environment for ongoing evaluations, such as psychosocial and cognitive (developmental milestone) assessments.
- It provides an environment for ongoing health education.
- It opens up the door for simple skills development such as life skills.
- It provides a safe place for C&A to express their feelings.
- It helps in strengthening privacy.
- It creates an environment where the C&A can feel safe and comfortable.
- As a common space for all C&A, it reduces stigma.
- It releases PCGs to attend to their needs (clinical and psychosocial) undisturbed whilst the C&A are cared for.

Creating C&AFS in space constrained facilities[21]

A C&AFS does not need to take up a lot of physical space. It can be in a small corner of a room, a converted store room, or an outside room or container. Some facilities use a gazebo during dry weather, in an open space near the facility. But it must be a place where C&A feel safe. If possible, a separate area should be created for adolescents.

General ideas regarding C&AFS[21]:

- The spaces should be colourful, but not so much as to distract the child's attention.
- The C&A has to feel comfortable and safe at all times.
- The room should be as soundproof as possible.
- The child's feet should touch the floor, so use low tables and chairs. Sitting on the floor with the child and being at the child's level helps communication.
- Certain items can be stored in higher cupboards, out of children's reach.
- Bulky cushions/Bean bags are comforting.
- Furniture and other items can be very basic and still provide a lot of fun, creating a warm, inviting atmosphere
- The space should be informal enough to enable the C&A to feel happy and inspired
- Appropriate tools should be kept in the C&AFS to assist the counsellor in using C&A-friendly and applicable play material e.g. board games

Planning for post disclosure:

- Following a disclosure session, documentation must be completed in the Paediatric & Adolescent Clinical Stationery, with any additional notes filed along with the patient file. The file must be stored in a confidential manner.
- A written referral must be available, particularly relating to child protection or complex disclosure issues. For complex disclosures, a social worker or a psychologist should be accessible.
- Children, Adolescents and their PCGs should be referred to a support structure using tools that are nationally endorsed such as, Family Support intervention (FSI) for PCGs, Kidz I ACT and Adolescent I ACT.

System documentation and guidelines
HCT policy guidelines
Disclosure guidelines
Child protection policy.
Staff trained in above guidelines and policies
Staff trained in HCT and disclosure to children and adolescents (clinical and psychosocial)
HCT and disclosure tools available to HCP
Family Support Intervention (FSI) tool
Written referral pathways and linkages developed and available to all staff
Case finding system in place and protocols followed
Documentation and monitoring and evaluation available for each child in locked cupboard
Child & adolescent-friendly space
Child-friendly space
Adolescent-friendly space
Post-disclosure planning
Written referral pathway functional
Support groups running using NDOH endorsed resources e.g .Kidz I Act and Adolescent I ACT
FSI established at facility

B. Preparing the Health Care Providers

Evidence to support HCP training in disclosure

Currently HCPs are not trained on HIV disclosure for C&A and lack the necessary skills and language to help facilitate the disclosure between the PCG and the C&A. This could result in either disclosing in a harmful way or avoiding disclosure altogether.

There are six key tasks for HCPs, namely:

1. Case finding:
   a. C&A living with HIV that have not yet been diagnosed
   b. C&A living with HIV and / or on ART that have not been disclosed to
   c. C&A with incomplete disclosure e.g. a C&A is on ART but is told they are taking TB medication.
2. Counselling PCGs for the benefits of disclosure
3. Preparing PCGs for disclosure
4. Facilitating the process of disclosure together with the PCGs
5. Ensuring the legal documentation of disclosure sessions are adhered to
6. Facilitating ongoing linkages and support

To accomplish these tasks all HCPs need:

- Training and experience in:
  - the disclosure process, to enable them to provide a supportive and non-discriminatory disclosure service
  - other related issues, such as topics related to sex, sexuality and sexual health[16]
- Support to explore their own fears and concerns related to the disclosure process
- Tools and resources to facilitate the process of disclosure to different age groups

HIV-positive HCPs need counselling and support to ensure that they have dealt with their own unresolved emotional and psychological issues so that these do not act as a barrier to disclosure.

A training and mentorship package regarding disclosure for HCPs is provided. It includes:

- Information on preparing and counselling PCGs
- Foundational principles of working with children and adolescents
- Guidance on counselling and testing C&A using age-appropriate techniques
- Guidance on disclosure to young children and adolescents

Mentorship with supervision enables HCPs to embed disclosure services within the health system and to gain experience under supervision.

C. Preparing Primary Caregivers

Parents or PCGs retain primary responsibility for disclosure, with HCPs functioning in a supportive role.

Supporting PCG preparation

Disclosure depends on the readiness of the caregiver to disclose and it occurs more often amongst PCGs who have discussed disclosure with a HCP.

- HCPs should provide the primary PCGs the opportunity to discuss disclosure[5] to prepare them for the disclosure process
- Many PCGs often choose to disclose to a C&A when the C&A:
  - starts to ask questions about their deceased biological parents who died of AIDS
  - starts to ask questions about their medication or does not adhere to their treatment

These questions from the C&A can lead to impulsive or accidental disclosure by PCGs[4], with psychologically damaging consequences for the C&A and/or the caregiver.

Caregiver preparation and support should be given the appropriate time and resources, which will ensure a lasting relationship with the health service, and provide long-term benefits to the C&A.

What preparation do PCGs need?

It is important to provide the following to support caregivers before disclosure:

- Do not force disclosure until the PCG is ready
- Provide an HIV-positive caregiver who has not come to terms with their own HIV-positive status with counselling and support
- Provide caregivers with education about HIV and its psychosocial impacts so that they feel equipped to answer questions about HIV/AIDS once the C&A has been disclosed to
- Provide caregivers with education about the development of C&A so that they understand what is appropriate for C&A at specific ages
- Provide caregivers with the opportunity to discuss the disclosure process with a HCP so that they feel more confident about the process
- Provide caregivers with the option of disclosing themselves or with the support of a HCP
- Provide caregivers with knowledge and skills that will equip them in the ongoing disclosure process
- Link caregivers with necessary support services within the government sector and community to ensure ongoing social, psychological and economical support (for example, social grants)

How to prepare and support a PCG

A package has been developed for PCGs and family members, known as the **Family Support Intevention (FSI).** A trained HCP should use knowledge and skills from the FSI to prepare and support the PCG and other significant family members before disclosure to a C&A takes place.

The Family Support Intervention entails:

1. Assessing the current knowledge and beliefs about disclosure
2. Assisting the PCG to process their own HIV status, grief, anger, guilt and shame
3. Sharing the advantages and disadvantages of disclosure, with the aim to promote disclosure to be part of long-term health and psychological benefit
4. Developing a plan to disclose to the C&A that deals with the fears of self disclosure, child disclosure and community disclosure, including plans to mitigate the risks of accidental community disclosure
5. Preparing wording and tools with the PCG to facilitate a caregiver-led process wherever possible

The FSI can be offered as:

- Group sessions within facilities or communities (support group style, 4-6 sessions)
- Early morning health promotion talks
- One-on-one counselling sessions

Training for FSI is included in the training package.

D. Preparing the Child and/or Adolescent for Disclosure

All members of the team can assist in preparing the C&A for a successful disclosure session by:

1. Ensuring that the system within the facility is supportive and C&A-friendly
2. Ensuring that the C&AFS is ready
3. PCGs can assist by not letting the C&A notice their anxiety
4. PCGs can bring a snack to the facility so that the C&A is not over hungry
5. HCPs need to be friendly to create a relaxed environment

Summary

A. Health Facility	B. Health Care Provider	C. Primary Caregiver and Family	D. Child and Adolescent
Guidelines, policies and documents	Training (KidzAlive)	FSI	Bring a snack during waiting times
System of case finding	Overcome fears and misconceptions	Deal with own HIV	PCGs to be aware of projected anxiety
C&AFS	Resources and tools	Overcome fears	HCP to be warm and relaxed
Skilled staff	Mentoring	Disclosure plan	C&AFS ready and welcoming

Step 2 – Pre-Disclosure Assessment and a Disclosure Plan

A pre-disclosure assessment explores how the C&A is functioning emotionally, cognitively, socially and economically. It is important to assess whether a C&A is ready to be disclosed to and/or the extent to which the disclosure is important[22]. The assessment should take place in discussion with the PCG and other family members where possible.

The aim of the assessment is to:

1. Ascertain whether the disclosure will be an 'uncomplicated' or 'complex' disclosure
   a. Uncomplicated disclosures can be conducted by a trained HCP.
   b. Complex disclosures should be handled by social workers or psychologists
2. Gain insight into the family and community setting to provide a context for the disclosure
3. Gain insight into the developmental level, challenges and context of the C&A

It is important that the Predisclosure Assessment is not conducted in front of the child or adolescent

C&A process information very differently from adults, and they often misunderstand and misinterpret information. Whilst the assessment is being conducted, the child should be occupied in the child-friendly space with drawing or other activities. If the disclosure involves an adolescent, the HCP will still need to speak to the PCG alone, prior to the disclosure taking place. In this case the age of the adolescent will determine which activities are appropriate.

Following the assessment, the HCP and the PCG should discuss the disclosure plan, based on the information provided.

Promoting Disclosure to unsure PCGs

If the caregiver is still not convinced that disclosure is the right thing to do, it is useful to share the **advantages and disadvantages of disclosure** and non-disclosure with him or her.

These advantages and disadvantages should have been thoroughly dealt with during the caregiver preparation session, or during FSI groups. A list of advantages and disadvantages are contained in the Disclosure Toolkit for HCPs to discuss with the PCGs. HCPs should facilitate a discussion in which PCGs think about these advantages and disadvantages themselves, rather than the HCP merely providing them with the list.

Pre-disclosure Assessment Tool

This form should be completed by the HCP (see Disclosure Documentation).

Developing the Disclosure Plan with the PCG

Once the assessment has been completed, and the PCG understands the need to, and the benefits of, disclosure, the HCP should work on a disclosure plan with the PCG. This should include:

1. Setting a date and time for the disclosure to take place.
2. Deciding on who will disclose to the C&A (the PCG, together with the HCP, is recommended).
3. Explaining age-appropriate disclosure.
4. Previewing tools and material that will be used.
5. Discussing whether the disclosure is likely to include naming the disease (recommended for children who ask for the name, or for children older than 10 years).
6. Introducing the "Hand of Safety" or age appropriate tool to assist – (a tool which will assist the caregiver to identify potential people to whom the child may want to disclose, and to contain other disclosures).

Deciding when to disclose

Disclosure should not be delayed unless[22]:

- The C&A's family or caregiver is experiencing a family crisis.
- It will coincide with other significant events like birthdays or graduations.
- The C&A is ill.

Refer C&A for appropriate psychosocial interventions before they are disclosed to when this is appropriate; for example, a C&A who has experienced a trauma like sexual abuse should be given the opportunity to deal with this trauma prior to HIV disclosure.

Deciding who should disclose to the C&A

Research indicates that the C&A's PCG is considered to be the best person to disclose to the C&A. However, in some cases PCGs would like to disclose in partnership with a HCP or would like the HCP to lead the disclosure process[17]. This should be decided when preparing the disclosure plan.

Discussing where disclosure should take place

There is no reason that disclosure should only take place in health facilities. PCGs that prefer to disclose to their children at home, or at a community facility should do so, if this is in the best interest of the child.

If a PCG has been adequately prepared, it may be better for the C&A to be in a less stressful environment. If the PCG prefers more hands-on support, then facility-based disclosure is recommended, within a C&AFS.

Discussing age of disclosure

Research has shown that PCGs and HCPs do not have clear ideas about the right age to start disclosing to a child[16]. They do, however, tend to agree that a child is only ready for HIV-specific disclosure when they are older, that is, older than 10 years[17].

HCPs should take each child's personal background and circumstances into account when making decisions about when that child should be disclosed to and what they are ready to be told.

Recommendations from the field of practice is that:

- Disclosure should start as soon as possible, from as early as age 3, in an age appropriate way[23].
- Each child's personal level of cognitive and emotional preparedness must be taken into account before a decision about when to disclose is made[22].

A child is never "not ready" for some level of disclosure.

Every child has the right to start learning something about their body and health, even small amounts of simple information.

Discussing the level of disclosure with the PCG:

If the HCP or a PCG decides that a C&A is not cognitively and/or emotionally ready to be told that they have HIV, it may be useful to use the strategy of partial disclosure[22]:

- Partial disclosure involves teaching the C&A about their body and illness without actually using the words HIV or AIDS.
- The HCP will guide the PCG over time and in response to cognitive and/or emotional developments, to move towards full disclosure - where the C&A is given more in-depth information about their positive status, including naming the illness as HIV.
- Health-promoting disclosure is the most complete level of disclosure for age, and is defined as disclosure accompanied by health promoting skills and tools to enable the C&A to take responsibility for their health as far as they understand it.

Discussing ongoing disclosure

PCGs need to be assisted to understand that disclosure involves on-going engagement with their HIV-positive C&A, where a range of issues are dealt with as they develop cognitively, emotionally and physically. For example, when a C&A reaches puberty there will be issues around sexuality that will need disclosure and support that was not required at a younger age.

The following are some of the issues that a HCP and PCG may have to deal with at different times during the C&A's development:

- Treatment and adherence.
- Treatment fatigue.
- Fears and concerns related to being HIV positive.
- The disclosure of significant others' HIV positive status.
- Managing intimate and sexual relationships.
- Dealing with stigma and discrimination.

HCPs should make the PCGs aware that the counsellor will see him or her every time he or she brings the C&A to the facility, for ongoing supportive conversations.

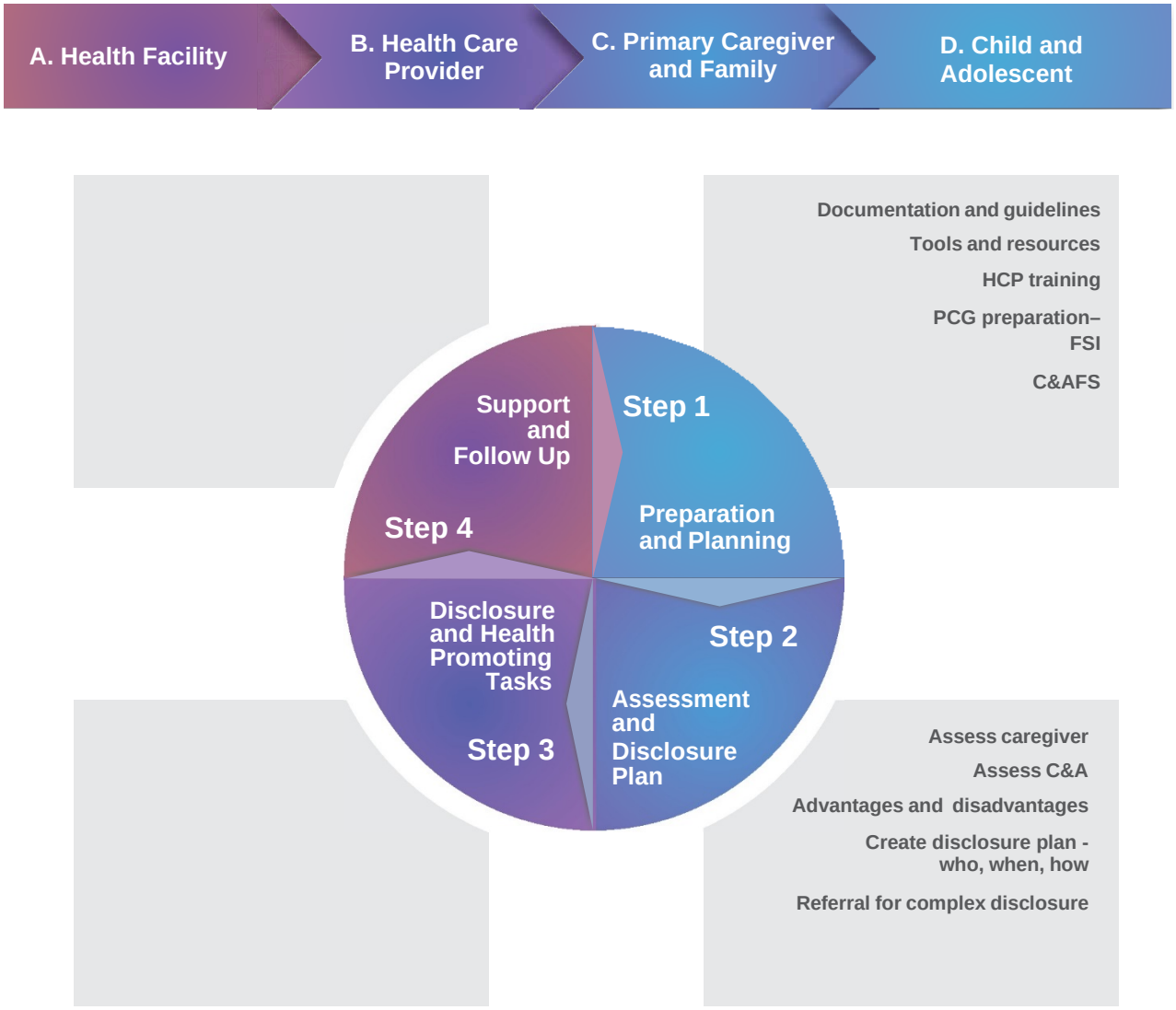
Key information for the PCG before the disclosure process begins:

- HIV, as any other chronic disease, requires a life-long commitment and they should work this into their schedules and routines
- Disclosure should start as early as possible, from the age of 3 years onward
- Disclosure can take place within the home or community, especially if the PCG has tools and has been prepared
- Disclosure of HIV positive status to a C&A is not a once-off event but rather an ongoing process, requiring regular visits to the facility
- The disclosure process needs to be directed by the specific developmental needs of HIV-positive C&A over a period of time
- The process of disclosure will be much longer for some C&A in comparison to others. How long the disclosure process takes will depend on:
  - whether there is a need for multiple disclosures
  - the age of the C&A
  - the cognitive and emotional maturity of the C&A
- Disclosure is not harmful and has many benefits for the C&A
- Disclosure supports long-term adherence, and over time will make the role of the PCG easier, as the C&A becomes more equipped to take on responsibility for their own health

Documenting the disclosure plan

It is good practice to document the disclosure plan (see Disclosure Documentation). It serves as a legal record to support the decision making and consent processes.

Summary: Model for Disclosure: Step 1 and Step 2



Step 3: Disclosure sessions and developing health-promoting tasks

Once the preparation and planning, assessment and disclosure plan have been completed, the next step is the actual disclosure session with the C&A.

The following are key considerations during the session:

1. Ensure privacy and a C&A-friendly environment
2. Whilst the child is busy with an activity, engage the PCG to ensure that the plan is still the same and that no major emotional changes have taken place
3. Start to engage with the C&A, using the skills taught during the training
4. Once the C&A is comfortable and relaxed, use the tools provided to discuss the health of the child, using age-appropriate terminologies.
5. Allow the child to ask questions and answer as truthfully as possible, using pictures and tools to ensure that the child understands
6. Allow the child to express emotions:
    a. Encourage children to express their feelings and to ask questions about why they are being assessed. Children should be provided with honest and developmentally appropriate responses
    b. Be sensitive to the psychological and emotional well-being of the child and understand the child's context and background to ensure any trauma or negative emotions are addressed. (see the pre-and post-disclosure assessment)
    c. Recognise and value the emotions and experiences of the child, no matter how small or insignificant they may be. This is key to the disclosure process, as by diffusing these negative emotions, and pro-actively assisting and supporting the child, the HCP and PCG are contributing to the well-being of the child.

Additional considerations when counselling adolescents

The following table outlines the "5 A's" strategy healthcare workers should be guided by when counselling adolescents. This is an insert from the source document: *Adolescent HIV Care and Treatment: A training curriculum for health workers, Colton T at al. Trainer manual, Module 6. ICAP, New York, 2012.*

The 5 "A's"	More Information	Health Worker Might Say
Assess	• Assess the client's goals for the visit • Assess the client's clinical status, classify/identify relevant treatment, and/or advise and counsel • Assess risk factors • Assess the client's (caregiver's) knowledge, beliefs, concerns, and behaviours • Assess the client's understanding of the care and treatment plan • Assess adherence to care and treatment (see Module 8) • Acknowledge and praise the client's efforts	• What would you like to address today? • Can you tell me about ____? • Tell me about a typical day and how you deal with ____? • Have you ever tried to ____? What was that like for you? • To make sure we have the same understanding, can you tell me about your care and treatment plan, in your own words? • Many people have challenges taking their medicines regularly. How has this been for you?
Advise	• Use neutral and non-judgemental language • Correct any inaccurate knowledge and gaps in the client's understanding • Counsel on risk reduction • Repeat any key information that is needed • Reinforce what the client needs to know to manage his or her care and treatment (for example, recognizing side effects, adherence tips, problem-solving skills, when to come to the clinic, how to monitor one's own care, where to get support in the community, etc.)	• I have some information about ____ that I'd like to share with you • Let's talk about your risk related to ____. What do you think about reducing the risk by _____. • What can I explain better? • What questions do you have about ____?
Agree	• Negotiate WITH the client about the care and treatment plan, including and changes • Plan when the client will return	• We have talked about a lot today, but I think we're agreed that ____. Is this correct? • Let's talk about when you will return to the clinic for _____.
Assist	• Provide take-away information on the plan, including any changes • Provide psychosocial support, as needed • Provide referrals, as needed (to support groups, peer education, etc.) • Address obstacles • Help the client come up with solutions and strategies that work for him or her	• Can you tell me more about any obstacles you're faced with _____ (for example, taking your medicines regularly, seeking support, practicing safer sex)? • How do you think you can overcome this ARRANGE obstacle? • What questions can I answer about ____? • I want to make sure I explained things well – can you tell me in your own words about ___?
Arrange	• Arrange a follow-up appointment • Arrange for the client to participate in a support group or group education sessions, etc. • Record what happened during the visit	• I would like to see you again in ____ for ____. • It's important that you come for this visit or let us know if you need to reschedule. • What day/time would work for you?

Disclosure content

Use the basic content for younger children as covered in the training. For example:

1. How do I stay healthy - What is in my blood?
2. Types of germs in the body
   a. Germs that can be killed (dying germs)
   b. Germs that can only be "put to sleep" (sleeping germs)
3. The body's defence system
4. Healthy living
5. Managing germs with medication
   a. Germs that can be killed – with goodbye medicine
   b. Germs that must be put to sleep – with goodnight medicine
6. Disclosing to others
   a. The hand of safety negotiation with the PCG
   b. Inside and outside stories (explaining confidentiality)
7. Prevention messages

Health promoting tasks

Instead of disclosure being seen only as "giving news", it is an opportunity to build the C&A and caregiver's skills, which will assist them to take responsibility for their own health and engage positively with the health facility and HCPs. During the disclosure, always give age-appropriate task or responsibilities to both the C&A and caregiver, which they should report on at the next session.
For example:

- If a school-going child has been told he has a germ and must take medication daily, set the child a task to mark a calendar with faces each time he remembered to ask for his medication
- Ask younger children to draw pictures of themselves practicing healthy living - eating healthily, playing sport etc
- Ask adolescents to map their social network to see where they can get ongoing support

Working with the child's emotions during a disclosure – a six-step model

This six-step step model will assist the HCP to practically help a C&A who reveals negative emotions such as fear, guilt, blame, worry, denial and anger, which may arise before and after sessions.

This model can be used on children and adolescents but will need to be adapted according to the age of the child. A 4-year-old will need to identify their emotions externally through a picture, whereas a 16- year-old may be able to clearly discuss how they are feeling without the use of pictures. The HCP is encouraged to ask questions, allow the C&A time to respond and talk, be an active listener and not interrupt.

Steps adapted to include adolescents[21]

1. Create or use a picture or diagram with facial expressions of happy, anger, fear/shock, blame, sad, guilt and denial; a piece of paper/ball of clay; a pencil or pen.
2. Ask adolescents how they are feeling.
3. Identify the emotion of the child by allowing the child to point to the face they feel best reflects what they are feeling (use pictures of faces).
4. Ask adolescents to explain their feelings.
5. Make the C&A feel safe by reassuring the child that it is okay to feel that way.
6. Ask further: "What makes you feel…. (happy, sad, nervous)".
7. Transfer the emotions of a child onto an object. Use the child's creativity and insight by transferring the emotions to an object like clay or paper. The child may scratch and scribble over the paper or mould the clay into something that represents their emotions. This serves to diffuse the emotions of anger, fear and sadness.
8. Ask if adolescent has ever experienced this feeling and how they dealt with it, make use of journal/give paper to write on.
9. Develop a plan with the child - what can we do to make this better? Think of ideas together to cope with the situation and empower the child.

When to refer during a disclosure session:

In any circumstances where the C&A is experiencing difficulties beyond what the HCP can handle, the HCP must refer the C&A to a professional (social worker, psychologist). This may include:

- Unresolved bereavement.
- Trauma.
- Sexual abuse.
- Child-headed households.
- Vulnerability of PCGs.
- Disability.
- Emotional immaturity of adolescent.

If the HCP identifies the C&A has been a victim of abuse (physical, verbal, sexual), it is their responsibility to refer the C&A to a professional (social worker) and report the situation.

Completing a disclosure session:

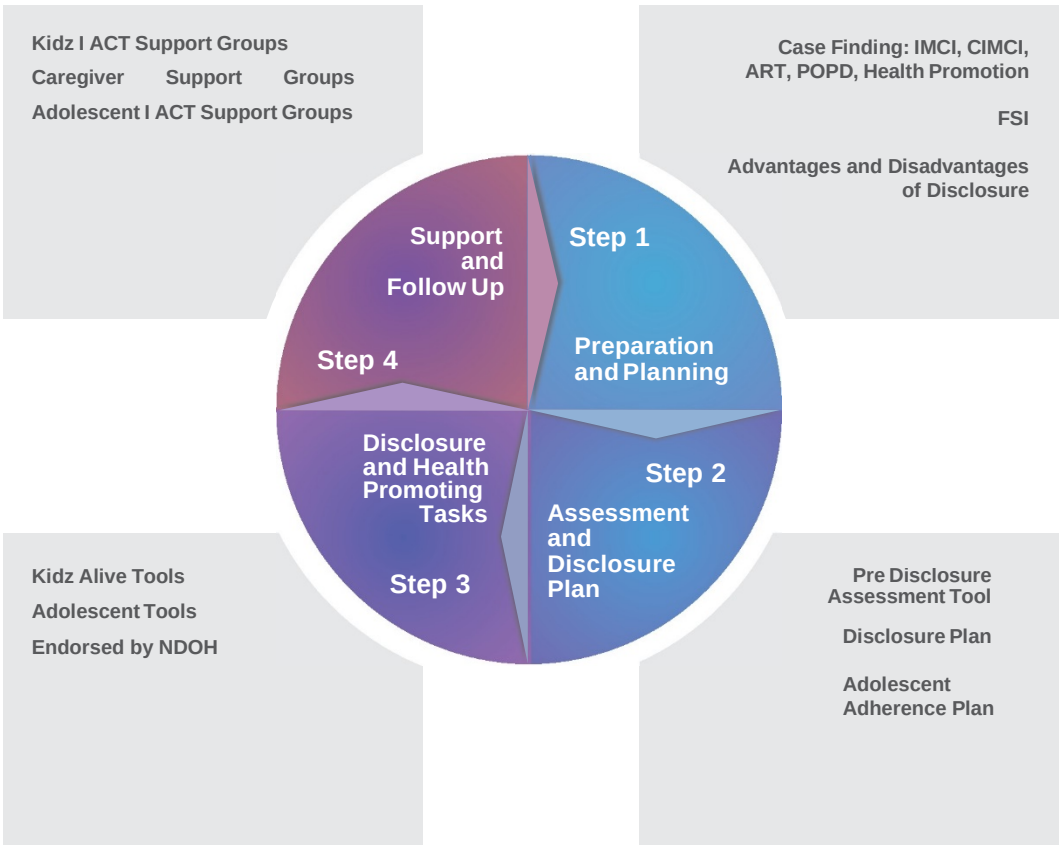
Once a disclosure session is over, the following steps should be taken

1. Remind the C&A of the health-promoting tasks that they have been set, in line with the level of disclosure
2. Encourage the C&A to think about questions that you can answer at the next session
3. Enrol the C&A in a support group
   a. Children < 12 years – Kidz I ACT group
   b. Children > 12 years – Adolescent I ACT group
4. Document the session using the Disclosure Record (see Disclosure Documentation)
   a. C&A and caregiver details
   b. Basic content discussed
   c. Any issues arising
   d. Tasks set for C&A and caregiver
5. Set up a follow-up date with the C&A and caregiver. Wherever possible, this should be on the same day as ART clinic or Kidz I ACT group or Adolescent I Act group.

Step 4: Follow up and support

It is important to assess levels of disclosure and support required at each follow up with the C&A. This can take place informally in clinical follow-up sessions, but if it is evident that the C&A requires more time or has questions, then a referral to a counsellor is recommended, in order to take the disclosure further.

- If the C&A does not initiate questions or issues, then schedule regular follow-up sessions to build the relationship and allow more time
- Always document sessions
- Ensure that the C&A remains in a support group where possible
- Where issues arise, discuss these with the multidisciplinary team



Chapter 5: Disclosure in the Context of a Child

Children make dramatic changes over time, from birth to adulthood, because as they grow, they develop emotionally and begin to learn and understand concepts and the world around them. This happens in stages of childhood and development which is further associated with approximate ages. When working with children HCP should understand and note that children develop differently and at different rates, thus their age is merely a guide[24].

Children think differently from adults, and as we understand their mental, physical and emotional development, we are able to adapt our skills to meet their needs.

Basics of counselling children

Development approach[25]

The age of the child is not sufficient to be used as a means to inform how the HCP will disclose to them. The HCP needs to have a thorough understanding of the child's developmental stages in terms of physical, social, emotional and cognitive development to guide the process of disclosure. A child's development is informed by their context, family, access to medical care and their mental, social, and, emotional stimulation.

There are fundamental skills, values and knowledge that a health care provider will need when counselling and building relationship with the child during a healthy disclosure process.
These will be covered in detail in the trainings.

HCP requirements

Attitude - the relatively consistent way that a person thinks and behaves towards different people, objects, situations or issues.

Value – what a person believes to be right or wrong.

Definitions

Attitude/values	Explanation
Passion for working with children	Genuine interest in, and be comfortable with, working with children. Not everyone has the skill or interest required to work with this challenging age group. It is necessary to select HCPs who have this quality.
Honesty	Be honest about what you feel and be in tune with your emotions.
Wisdom	Your life experience as a counsellor develops wisdom, and intelligence to assist the child.
Endurance and patience	You must be able to keep going through a difficult session, be careful not to prematurely end the session and plan what to do next.
Responsible	You need to be responsible for what happens in the session and the direction it is going.
Friendly and natural	Be real with yourself, as children are able to see through pretence.
Calm and open	Be aware of your facial expressions, the way you react and your body posture, as these are all important.
Truthful	When you say you are going to do something, keep to your word. The child must always be able to trust you.
Confidentiality	Don't discuss anything with the child's PCG without informing the child and getting their permission.
Self confidence	Have faith in your abilities, training, your love for children and material you
Warmth and understanding	Remain warm and accepting, even when the child has done something questionable.
Creative	Use your imagination.
Good listener and observant	Don't interrupt but assess what the child is really saying through verbal and non-verbal communication and behaviour.
Energetic	Be full of energy , play and interact with the child.

(Adapted from Zoë-Life KidzAlive: Foundations of working with children, 2013)[21]

Personal Knowledge[26]:

- Knowledge and understanding of counselling content:
  - Extensive knowledge on HIV.
  - Legal aspects of working with children.
  - Stages and characteristics of children.
  - Deep understanding of the disclosure process.
  - Counselling skills in children (e.g. Foundations of Working with Children).
- Clear role of counsellor.
- Identify problems, issues and expectations of child.
- In control of their own feelings, emotions and thoughts.
- Constant growth in:
  - Self-awareness.
  - Self-counselling.
  - Work/life balance.
  - Career and personal focus.
  - Goal setting.

Core counselling skills in children

Core skill	Definition
Play and fun	Children talk using the language of PLAY, rather than the language of words. Using play, and ensuring that the child has fun, as a method of counselling the child are KEY. Laugh with the child. Make appropriate physical contact – touching the arm or hand.
Observation	Observation during play will enable the HCP to pick up the non-verbal messages that the child is sharing during play. This is similar to active listening, except that we are listening to the child by picking up clues through play, drawing and creativity.
Active listening	Using a set of skills to encourage the child to talk and make them feel heard and understood. Called 'active' because the HCP engages intentionally to help the child feel comfortable to talk as well as is attentive to what the child is saying, how they are acting and how they feel.
Questioning	The HCP's ability to probe or question effectively is key to effective counselling. HCP should use open ended questions and closed questions appropriately, based on the information needed. HCP can use drawing, play or puppets to ask questions and receive answers so that the child does not feel intimidated.
Silence	Silence in a session should be recognised as acceptable. The child may need time to process and understand things. Allow them the time.

(Adapted from Zoë-Life Comprehensive guide to HIV and AIDS Counselling and Care, 2011)[23]

The Seven Stages of Counselling a Child

Stage 1: Introduction

Introduce yourself to the child. Break the ice.

Make the child feel comfortable.

Get to know the child.

Stage 2: Build the Relationship and Gain Trust

Place yourself at the same level of the child.
Be and friendly and warm.

Create a sensory awareness for the child.

Explore the child's feelings.
Introduce the tool for play (provide the child with options and let them choose).

Stage 3: Set Specific Limits for the Session

Explore and set the limits for this session.

Stage 4: Let the Child Tell the Story

Introduce the appropriate activity. Let the child tell and invent the story. Assist in identifying options.
Identify and address knowledge.
Give age-appropriate knowledge.

Stage 5: Evaluate the Child's Feelings

Recap what was covered and learned.
Assess child's feelings and assist with processing these identified feelings.

Allow for questions.

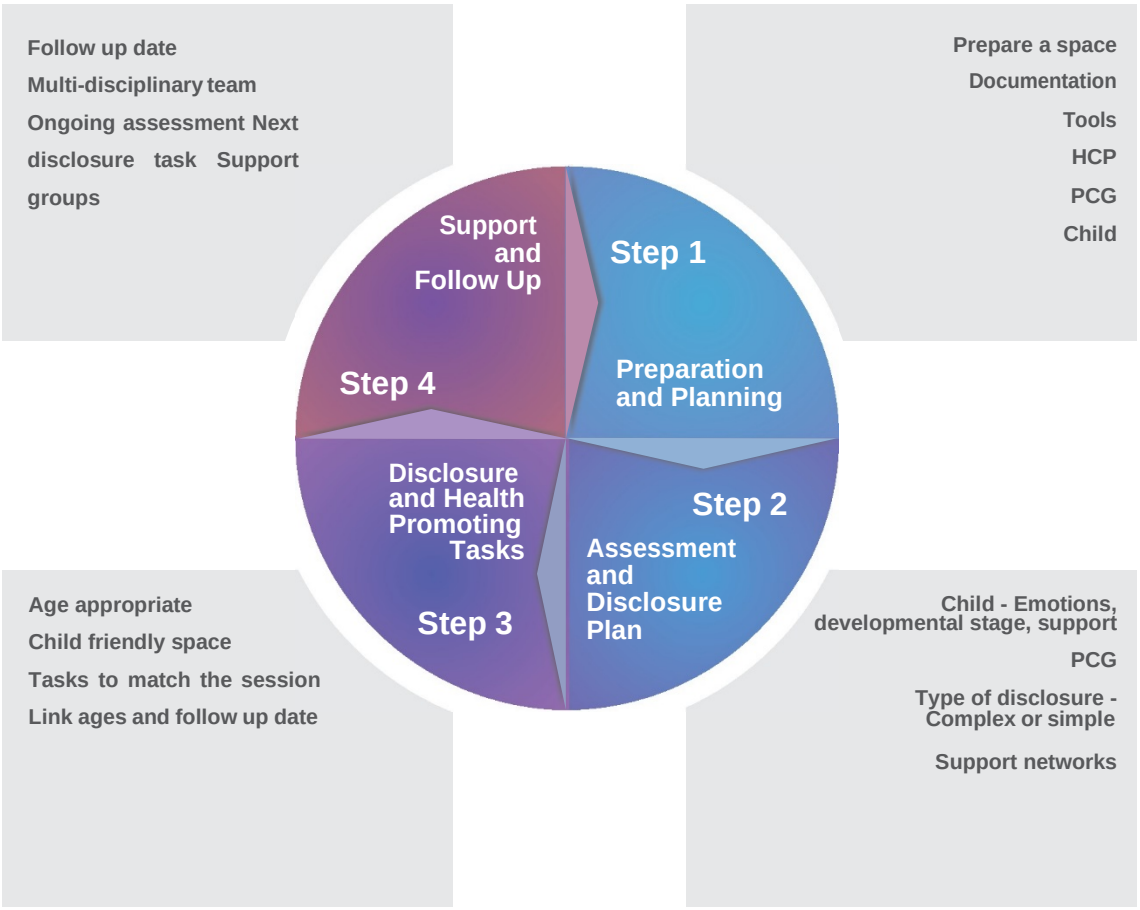
Stage 6: Finding Closure

Close the session appropriately.

Stage 7: Bringing Back

Bring the child back to reality.
Thank the child for their involvement.
Prepare the child for reality.

Using the Holistic Disclosure Model with children



Step 1: Preparation and Planning

1. Health facility planning.
   a. Ensure that HCPs are trained in child counselling skills (e.g. KidzAlive Training).
   b. Are the relevant policies and guidelines in place?
   c. Is there a child-friendly space.
2. HCP preparation.
   It is recommended that HCPs should have attended KidzAlive I ACT training.
3. PCG preparation.
   It is in the best interest of the child for the PCG to be involved in the disclosure of the child.
4. Preparation of the child.
   Assess the child's emotional and psychosocial wellbeing to ensure the disclosure process is in the best interest of the child.

Step 2: Assessment and Preparing a Disclosure Plan

- Use the Disclosure Assessment Tool
- Use this tool every time new levels of disclosure are required, to ensure that the changes taking place in the child and the family are taken into consideration
- Ensure safekeeping of these documents to satisfy legislation

Step 3: Disclosure and Health Promoting Tasks

During the disclosure session with a child, it is vital to understand the developmental stages and how to approach the sessions accordingly, bearing in mind the criteria for disclosure in children & adolescent (p 26)

There are 3 phases of children, each with different stages

1. Toddler (1-<3 years)
2. Early childhood (3-5 years)
3. Middle childhood (6-10 years)

Developmental stages: Toddler (1-3 years)

The toddler, due to their developmental stage, is not fully able to understand or talk sufficiently with the HCP. The focus in this age group will be to work primarily with the caregiver.

It is important to note that the foundation for the relationship between the HCP, facility and child are established from the first time that the child sets foot into the facility. The toddler will need to seek services for the rest of their lives. This period of childhood is an opportunity to establish a firm foundation and positive experiences for the child when it comes to the health facility.

This is also an opportunity to start teaching the primary caregiver how to use play effectively with their child, and to start a relationship with the child based on play. Primary caregivers can be taught how to start showing their toddlers pictures depicting healthy living, healthy foods and other health-related topics.

Once children are comfortable playing and drawing in a facility's child-friendly space, it will be easy to start working with them on disclosure when the time is right.

Developmental stages– Early Childhood (3 - 5 years) [21,22]

Type of development	Age	Characteristics Development Milestones
Mental and Cognitive	**3**	• Can listen attentively to stories • Project feelings easily
	4	• Enjoy stories • Understand routine activities • Can follow 2 and 3 step instructions
	5	• Basic understanding of time and numbers • Ask "why, what, where and when" questions- eager to learn new things
Emotional and Social	**3**	• Impatient • Use fantasy in play • Seek approval of adults • Have imaginary fears
	4	• Friends become more important • Self-confidence grows • Find comfort in PCG's presence • Distinguish between past, present and future
	5	• More independent • Can be without parent for short periods • Better control over emotions • Tend to show off, take charge, argue • Feel ashamed easily • Able to gain a sense of right and wrong
Language	**3 to 5**	• Has simple conversations • Asks and answers simple questions • Can understand concrete explanations (use pictures and symbols) • Language is mainly used to communicate wants
Sexuality	**3 to 5**	• Knowledge of own gender • Explore and touch private parts • Curious and ask questions about their own and other's bodies • Generally not self-conscious but learn to understand idea of privacy

What to expect in the counselling context from early childhood stages:

Questions the early child may ask [25]	Possible answers
Why do I have to go to the clinic?	You are going to go see the nurse and HCP who want to see you to make sure you are healthy.
Why does the nurse take my blood?	The nurse takes your blood to see if you have anything inside of it. If there are any germs in your body she will tell us what to do to make sure you will stay well.
Why do I need to take medicine?	There are germs inside your blood. The medicine can kill the germs or put them to sleep.

Health Promoting Tasks in This Age Group

1. The introduction to partial disclosure is necessary
2. Keep sessions short and structured
3. Use appropriate child focused tools: (Talk Tool, Feeling Faces Tool, Hand of Safety)
4. The focus areas are:
    a. The importance of checking one's health
    b. Your body is valuable and it is good to look after it
    c. The importance of medication and adherence
    d. Reinforce healthy living – eating well, playing outside, drinking clean water

Developmental stages – Middle Childhood (6 – 10 years)[21]

Type of development	Characteristics Development Milestones
Mental and Cognitive	• Become less egocentric- more able to take in other's points of view • Growing interest in the outside world • Concrete reasoning allows some understanding of cause and effect relationships- which can be used to solve everyday problems • Memory for past events begins to extend over longer periods of time, begins to develop expectations (looking ahead to the future) • Enjoys activities that give a chance to control, organise and order things • Able to concentrate for increasing lengths of time within a structured and supervised routine- but still need regular breaks • Children up to 8 still reason in concrete ways and not in abstract ways • They have a stronger sense of right and wrong • Base for future learning is laid at 8 years- at this age, children are very open to life-skills training • From the age of 9 years, children can be spoken to openly about issues like sexuality
Emotional and Social	• Builds sense of identity and self-esteem through experiencing a feeling of mastery and achievement in doing some things well • Proud of success and sensitive to criticism/failure- failure at school or home • Need to develop confidence and feeling of personal value
Language	• Language used as a means to connect with, and influence others; as well as to explore ideas • Not yet able to understand abstract ideas, so needs explanations that are clear and simple with concrete examples • May struggle to express ideas and feelings in words • Vocabulary increases allowing for more conversation
Sexuality	• Strong sense of and concern with gender differences • Desire to know more may result in looking at pictures of naked/semi-naked people • May use slang terms or bad language or tell "dirty" jokes, without fully understanding the meaning • May masturbate, usually in private • May have romantic feelings towards older children/ young people of same/opposite sex • May try out sex roles by playing games ("mommy and daddy", "boyfriend and girlfriend") with peers, sometimes including stimulated sexual behaviour.

What to expect in the counselling context from middle childhood - Talking about HIV, Adherence and Health seeking behaviour [27]

1. **Use The Talk Tool** and **Kidz I ACT Tools** to guide discussions with children.
2. Partial disclosure continues but more information is provided.
3. Age group tools:
   a. Drawing.
   b. Playing with figures.
   c. Use observations like “Your medicine will help fight the germs”.
4. Children need encouragement to persevere.
5. Need to be included in activities such as drawing, group activities (Kidz I ACT groups are ideal).
6. Use their skills to read, colour or write.
7. Give positive feedback and give opportunities to ask questions.
8. Start by giving the child small responsibilities.
9. Talk about friends, respect, and their goals for the future.
10. Set clear rules at this age (6-8 years).

Health promoting tasks in this age group

1. Children this age can do drawings and write stories and poems about wellness, health and being strong and healthy
2. Involve children in reading their medication names, and drawing pictures of how the medicines are strengthening the immune system
3. Involve children in creating adherence calendars
4. Children can be encouraged to make good food choices, and report on these when they return for follow-up visits

Step 4: Follow-up and Support

Children require ongoing support, especially since they will need more information as they develop and are able to handle more information. This period of childhood is about fully preparing the child for a healthy disclosure so that they take responsibility later for their health.

Support group:

Children (through their PCGs) should be enrolled in the Kidz- I ACT support group. In these sessions, children participate in group activities and games that teach them about:

- Taking medicines.
- Eating healthily.
- Listening to their bodies and responding when they need help.
- Understanding how their bodies fight diseases.

During these sessions for children, there are parallel sessions for the PCGs that deal with:

- Encouraging children.
- Adherence issues.
- Building resilience.
- Playing with children to continue ongoing disclosure.

Kidz I ACT groups should be established in both the community and the facility.

Holiday wellness days:

During school holidays, it is possible to use the Kidz I ACT and Wellness tools to run HOLIDAY WELLNESS DAYS. This creates a fun atmosphere at facility and community sites, and children can learn more about their illness in a very non-threatening way, as well as meet other children who are also infected and affected. These are opportunities not only for disclosure support, but also for continued case finding. Wellness days can be organised in conjunction with community caregivers, NGOs and schools for improved networking and linkages.

Routine follow-up at facility

Children should be encouraged (with support from their PCGs) to attend all follow-up sessions, and facility staff need to work with children to create systems and flows that encourage retention in care and treatment.

Chapter 6: Disclosure in the Context of the Adolescent

Adolescence is characterised by a period of transition from childhood into adulthood. There is major growth and development in which important physiological, cognitive, psychological and behavioural changes take place. It is in this period that a strong identity develops and/or needs to be achieved.

Counselling adolescents through a healthy disclosure process is crucial to ensure that the individual learns to cope with and accept their chronic disease, the correct management of their health and the consequences of future choices they may be faced with. Many studies have revealed that adolescents want to be provided with truthful information and to be included as a part of their health management[28].

The following quote was obtained from an interview with an adolescent and reveals the essential need for the HCP to guide the vulnerable adolescent through disclosure[29].

> "Privacy is an issue . . . Not all of us are ready to disclose . . . When we queue at a window [labelled with a sign] 'ARVs' . . . everyone can see that we are HIV-positive and that makes the stigma to be worse. . .My family doesn't know yet . . . Teach us how to discuss [our HIV status] with family."

Basics of counselling adolescents

There are fundamental skills, values and knowledge that a HCP requires when counselling and building relationship with the adolescent during a healthy disclosure process.

HCP requirements

1. Attitudes and values

Attitude/values	Explanation
Passion for working with adolescents	Genuine interest in and being comfortable with working with adolescents. Not everyone has the skill or interest required to work with this age group. It is necessary to select HCPs who have this quality.
Comfortable speaking about sex and sexuality	Sex and sexuality are an uncomfortable subject for most adolescents. It is vital that the counsellor is comfortable speaking to the adolescent around these topics, in order to put the adolescent at ease and ensure that the topics are covered thoroughly.
Non-judgmental attitude towards risk behaviour	In order to assess risky behaviour the adolescent will need to disclose behaviours that might put him/her at risk. If the adolescent feels any judgment, the likelihood of an honest conversation is minimal.
Empathy	The HCP accurately understands the adolescent's thoughts and feelings from their own perspective. When the HCP is willing and able to experience the world from the adolescent's point of view, it shows their perspective has value and they are accepted.
Understanding and warmth (Unconditional positive regard)	Requires that the HCP remain warm and accepting, even when the adolescent has done something that might put them at risk. This may be difficult to sustain especially if the adolescent is making unhealthy choices. The key is to remain positive and non-judgemental but at the same time point out when their actions are harmful to themselves or others.
Respecting human dignity	This is about treating the adolescent as a person of worth and value, regardless of their behaviour or situation. Respect is linked to the adolescent's sense of self-worth and by showing respect, self-worth will increase. At all times individual cultures should be respected. The adolescent has the right to choose their own goals, it is not the HCPs role to choose goals for the adolescent. The role is to guide the adolescent to take responsibility for their own lives and healthcare plans.
Confidentiality	At all times client confidentiality should be upheld, as it forms the basis for building trust within the disclosure process.
Privacy	Adolescents should be offered a private counselling space that is free from interruption and cannot be observed or heard by other people within the facility environment. Furthermore, HIV services should be integrated with all other services, to decrease stigma and ensure privacy of those adolescents receiving the service.

(Adapted from Zoë-Life Comprehensive guide to HIV and AIDS Counselling and Care, 2011)[23]

2. Personal knowledge[26]:

- Knowledge and understanding of counselling content:
  - Extensive knowledge on HIV, TB and NCDs.
  - Stages and characteristics of adolescence.
  - Deep understanding of the disclosure process.
  - Counselling skills.
- Clear role of counsellor.
- Identify problems, issues and expectations of client.
- In control of their own feelings, emotions and thoughts.
- Constant growth in:
  - Self-awareness.
  - Self-counselling.
  - Work/life balance.
  - Career and personal focus.
  - Goal setting.

3. Core counselling skills[26]

Core skill	Definitions
Active listening	Using a set of skills to encourage the adolescent to talk and make them feel heard and understood. Called "active" because the HCP does things intentionally to help the client feel able to talk, and because there is engagement with all attention on what the adolescent is saying, how they are acting and how they feel.
Questioning	The HCP's ability to probe or question effectively is key to effective counselling. HCP should use open ended questions and closed questions appropriately, based on the information needed.
Paraphrasing	Simply restating the adolescent's message in your own words to check that you have understood what they have said.
Clarification	Regularly checking to see that you have understood what the adolescent is saying and feeling.
Reflecting	Requires the HCP to mirror the adolescent's feelings.
Summarising	Similar to paraphrasing but covers a longer time span and more information.

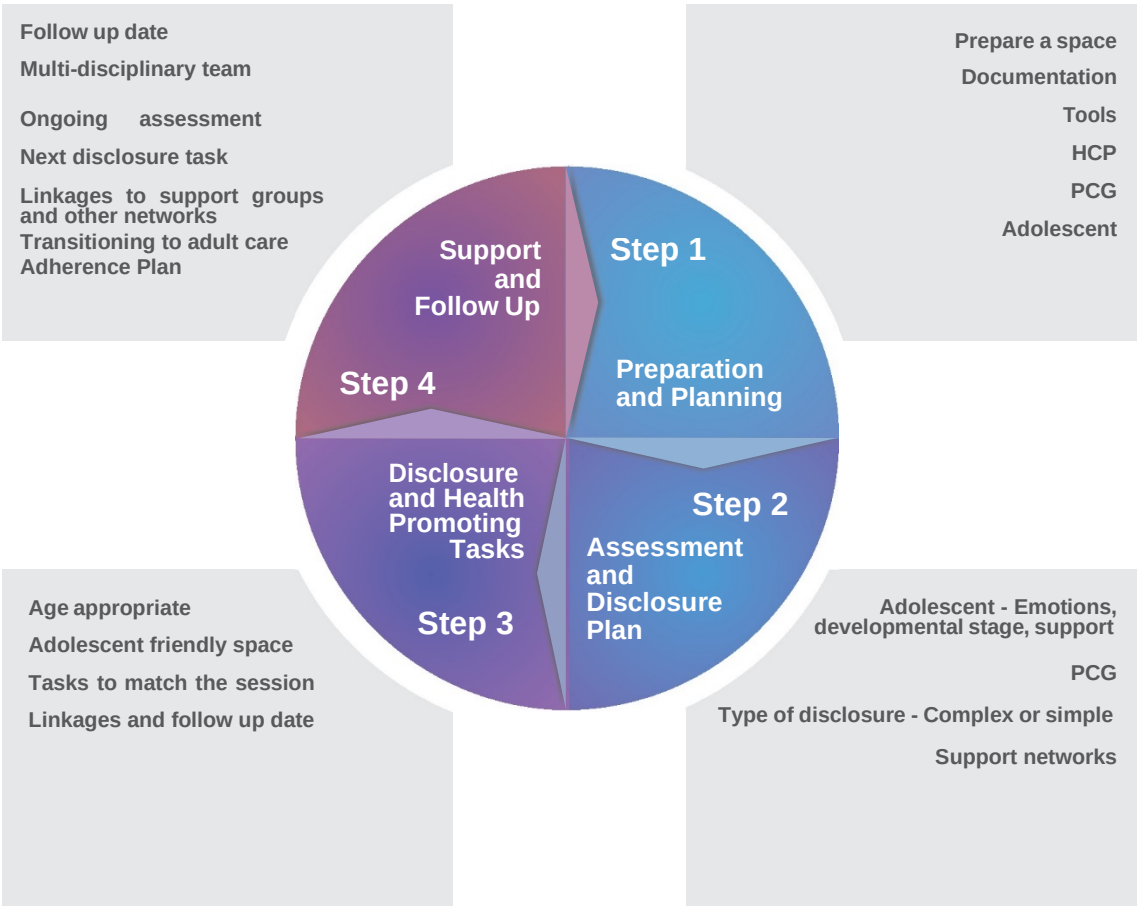
4. Counselling models[26]

There are numerous counselling models that can be used to guide a HCP through a healthy disclosure process with the adolescent. Best practices and guidelines recommend the use of The Egan Model, The TASO Model or the Four Phases of counselling. HCPs should choose the model that best suits them.

These models have the same outcomes, which are:

- A relationship is built with the client
- The client is helped to tell the story
- The client is helped to identify problems and explore options and solutions
- The client is helped to make a concrete plan of action

Using the Holistic Disclosure Model with Adolescents



Whilst the basic model remains the same, there are some specific differences when disclosing to an adolescent.

Step 1: Preparation and Planning

1. Health facility planning

- Ensure that Healthcare providers are trained in adolescent skills.
- Ensure that relevant policies and guidelines are in place.
- Create an adolescent/youth-friendly space.

What is an adolescent/youth-friendly space?

The NDOH has embarked on a process of creating adolescent/youth -friendly clinics. The following are required:

Priority:

Confidentiality and privacy are key, especially in adolescents, to reduce stigma. (WHO 1999, IPPF 2008, Oxfam 2007, Rogstad et al 2002).

Privacy means auditory and visual (Oxfam 2007).

Recommendations (MIET Africa, 2011):

- Partitioning of rooms or adding doors
- Minimal disruptions during consultations

Nice to have:

"Chill out" rooms – a separate space where young people can meet. Peer educators conduct educational activities in these rooms

These have:

- Brightly painted walls
- Video and music equipment
- Information materials

2. HCP preparation

Should have received training on how to age appropriately counsel an adolescent

3. PCG preparation

- It is best for the PCG to be involved in disclosure to adolescents. If the adolescent is resistant to this, the general principle is to continue working with the adolescent to encourage PCG participation. If at any point, the non-participation of the PCG is resulting in the deterioration of the adolescent, either physically or psychosocially, then, in the best interest of the adolescent, disclosure should take place to the caregiver of the HIV-infected adolescent. This needs to be done in consultation with the adolescent, with the multidisciplinary team and with clear and extensive documentation.
- The PCG and HCP should expect resistance from the adolescent as this is a normal developmental behaviour.

4. **Preparation of the adolescent**

- **For adolescents who have a new HIV diagnosis:** some adolescents will self-present for an HIV test, and some will be accompanied by a PCG. Adolescents will need more discussion around the disclosure process, such as who will be with them in the session to receive their results. They may choose to receive results with a PCG or with a friend or other significant person. They may want to be alone. They have the right to choose any of these options. However, they will need to hear the advantages of having a PCG or supporter involved.
- **For adolescents who have had HIV for a long time** and have been on ART, but have not been told the truth about their illness: it is very important to prepare the PCG for this disclosure as the adolescent will present with anger and extreme emotions.
- **For adolescents who know they have HIV**, but want help to disclose this to someone else: these adolescents can be assisted to prepare a disclosure plan with words and terminologies and potential scenarios.

Step 2: Assessment and Preparing a Disclosure Plan:

Use the same assessment tool as for younger children. Focus on emotional and cognitive state, and on what support is available to the adolescent.

- **For adolescents who have a new HIV diagnosis:** spend time preparing the adolescent for the potential of a positive or negative result, and who they would invite to be with them during disclosure. If they want to be alone during disclosure, it is important to have a support plan in place, such as enrolment to an adolescent I ACT group, or structured and frequent follow up, as required.
- **For adolescents who have had HIV for a long time** and have been on ART, but have not been told the truth about their illness: it is very important to have a clear disclosure plan, including a plan which takes extreme responses into account. This may include the adolescent stopping treatment altogether. This plan should be developed in conjunction with the clinical and psychosocial team to ensure that the emotional reaction does not jeopardise good clinical care and follow up.
- **For adolescents who know they have HIV**, but want help to disclose this to someone else: The HCP may be faced with an adolescent who will want to disclose to a third party. Whilst this is the prerogative of the adolescent, they should be adequately prepared to ensure that it is not a spontaneous disclosure and that all consequences, risks and benefits have carefully been thought through, before the disclosure takes place.

Step 3: Disclosure and Health-promoting tasks

During the disclosure session with an adolescent, it is vital to understand the developmental stages and how to approach the session accordingly:

There are 3 phases of adolescence, each with different stages:

- Early adolescence (10-14 years)
- Middle adolescence (15-19 years)
- Late adolescence (20-24 years)

Developmental stages– Early adolescence[30,31]

Type of development	Characteristics/developmental milestones
Physiological development	• Puberty begins (secondary sexual characteristics) • Rapid growth phase – with gains in height and weight • Growth of pubic/underarm hair • Increased perspiration and oil production of hair and skin • Girls: Develop breasts and menstruation begins • Boys: Growth of testicles and penis, nocturnal emissions, deepening of voice, facial hair
Intellectual, cognitive development	• Thoughts dominated by the "here and now" • Action- consequence relationships under-developed • Reactions are based on emotion rather than logic, when under stress
Emotional development	• Feelings of "am I normal?" • Day dreaming is common • Goals change frequently • Strong desire for privacy • Own value system begins to develop • Own problems are magnified – "no one understands" • Challenges authority and family • Loneliness • Argumentative and disobedient
Sexual development	• Shyness and blushing common in girls • Showing off common in boys • Sexual feelings and exploration begin to develop • Experimenting with body - masturbation
Identity development	• Developing identity very influenced by external influences • Moodiness • Ability to express oneself (linked to improved speech) • Expression of feelings is more likely to occur by actions rather than words • Deeper friendships begin to form • Less interest in parents – can be perceived as rude • Realisation that parents are not perfect • Peer influences are strong

What to expect from the early adolescent in the counselling context:

When talking about HIV, adherence and health seeking behaviour (including prevention with sexual partners)

Talking about sex and their bodies:

- Build trust before discussing sexual matters – even if it is within the same counselling session. Start with subjects that the adolescent will be comfortable with, allow them to relax and then approach more difficult subjects.
- Handle talking about sex and their bodies sensitively. Gauge how they are handling the information and centre your approach on their responses.
- Give them as much information that they can handle at a time.
- The HCP will need to be very comfortable with themselves about talking about sex and the body. The more comfortable the HCP, the more comfortable the adolescent will be.
- Answer any questions honestly.
- Encourage delaying of sexual activity – abstinence should always be the first option.
- If abstinence is not a possibility, discuss and encourage safer sex options, including:
  - Self-masturbation
  - Mutual masturbation
  - Oral sex
  - Condom use

Working with their PCG(s)

- It may be difficult for this age group to understand the importance of including their parents/ PCG into their health plan.
- Be patient – this may take time. Do not force the issue, rather carefully allow the adolescent to see the benefits of family support themselves. Allow them to draw up the pros and cons.
- Remember this age group's strong desire for privacy. Respect that and help them come up with solutions that will allow privacy, but gain the support of family. This can be done by encouraging the family and adolescent (in a safe space) to say what it is that they need from the relationship. These points can be noted and discussed until a reasonable compromise is reached and agreed upon, where the adolescent remains independent or gains independence and the family feels included.

Seeing their own long-term health plans

- This age group lives in the now. It is difficult for them to plan ahead. There is also a feeling of being invincible. Help them to see how the health plan can benefit them **Now**.
- Action and consequence relationships are under-developed in this age group.
- Be clear and accurate about the information you provide. Continuously reinforce messaging around long-term plans and consequences of the choices they make.
- This information will need to be repeated at every consultation, but in a non-judgemental manner, that does not appear to be lecturing.
- It is preferable to start conversations with the aim of allowing the early adolescent to provide you with the information and consequences of their actions themselves.
- Always reinforce missing information so that at all times they are able to make informed decisions.

Peer pressure

- This age group are very vulnerable to peer pressure and there is a need for conformity – HIV may make them feel 'abnormal'.
- Always ask how they are feeling, providing them with constant reassurance that HIV, TB and NCDs are a chronic, manageable disease.
- Work closely with strategies to reduce their own internal stigma.

Health-promoting tasks in this age group

1. Use of poems, pictures or letters to help them express their feelings about their diagnosis.
2. Draw up pros and cons of involving PCGs in healthcare.
3. Start to create their own adherence strategies.
4. Make a list of the ways that adhering to care and support will make their current life better.
5. Encourage them to participate in adolescent I Act groups or an alternative support structure.

Developmental stages – Middle adolescence[30,31]

Type of development	Characteristics/developmental milestones
Physiological development	• Secondary sexual characteristics. • 95% of adult height reached.
Intellectual, cognitive development	• Growth in abstract thought – reverts to concrete if under stress. • Action- consequence relationships better understood. • Very self-absorbed.
Emotional development	• Conflict with family related to own emerging identity. • Experimental – sex, drugs, friends, risk-taking behaviour.
Sexual development	• Concerns about sexual attractiveness. • Frequently changing relationships. • More clearly defined sexual orientation. • Internal conflict if feelings of same sex attraction are experienced. • Tenderness and fears showed to opposite sex. • Feelings of love and passion.
Identity development	• Self-involvement. • Alternating between unrealistically high expectations and fear of failure. • Annoyed by parents' interference in personal identity. • Feelings of strangeness about self and body. • Lowered opinion and withdrawal from parents. • Strong effort to make new friends. • Feelings of sadness as the psychological loss of parents takes place. • Examination of inner experiences (may begin journaling).

What to expect from the middle adolescent in the counselling context: Talking about HIV, adherence and health-seeking behaviour

- Managing risks is important as they are taking risks – for example, prevention with positives and condom use.
- Journaling may be a good idea for adherence and also understanding the consequences and implications of the illness.

Talking about sex and their bodies

- Adolescents at this age are very vulnerable, as they are obsessed with sexuality. It is normal that they will be experimenting with sex or sexual acts.
- A great risk for this age group is the fact that they do not have the emotional capacity to form deep relationships with the opposite sex. There is a tendency to feel deeply connected for a short period of time, with frequently-changing relationships. There is great risk of transmission of HIV in this period of adolescence.
- Developing a healthy body image is key to the middle adolescent – characterised by a great concern for their physical image. The HCP has an opportunity in this phase to work with the adolescent to understand that body image is not only linked to the physical but also to their sexuality. Encourage the concept of self-value placed on their bodies and sexuality.
- Provide information, and discuss consequences of multiple sexual partners, both physical and emotional.
- Encourage abstinence and delayed sexual activity, but if this is not possible explore safer sexual practices (as listed earlier).
- It is necessary to discuss prevention with positives and disclosure to sexual partners, with this age group. The content is covered in the I ACT Adolescent training.

Working with their PCG(s)

- This stage of adolescence experiences the most difficulty around relationships with their PCGs. It is characterised by conflict, as a result of trying to gain independence.
- The HCP should use similar techniques to the ones in early adolescence, but should be aware that there may be more resistance from the middle adolescent.
- The risks at this point are that conflict with family may cause problems with adherence in care and treatment and the adolescent may need to find other ways to get to the facility.

Seeing their own long-term health plans

- Still a strong sense of being invincible. This may cause engagement in risky behaviours. Risks may include experimentation with alcohol, drugs, sex and smoking.
- Their capacity to recognise action and consequence is better developed. The HCP will need to discuss action and consequences around each risky behaviour, guiding them toward recognising their own healthy choices. Risk management assists in helping the adolescent to put strategies in place to manage their risk e.g. condom use.
- There is better use of speech in this age group, so they are better able to express themselves. Allow them adequate space and time to do so. Journaling and writing before a session may be helpful for both the adolescent and the HCP.
- The HCP must be aware that adolescents may use “slang”. The HCP must clarify with the adolescent to ensure common understanding.

Peer pressure

- There is increased ability to control impulses, resolve conflict and say no to peer pressure, but this age group is still vulnerable. If guided carefully by the HCP and family, this age group can be taught to resist the peer pressure that may have a negative impact on their health.

Health-promoting tasks in this age group

1. Journaling: their feelings and emotions about their disclosure, the experience of being HIV -infected and their health care plans and experiences
2. Risk management: identifying, listing risks and how to manage these risks to avoid harm
3. Relationship management: finding creative ways to prevent transmission to sexual partners, carefully navigating disclosure to friends or partners
4. Finding creative ways to manage stigma and adherence issues
5. Prevention with positives (Positive Health, Dignity and Prevention - PHDP)
6. Participate in Adolescent I ACT

Developmental stages – Late adolescence[30]

Type of development	Characteristics/developmental milestones
Physiological development	• Physical maturity and reproductive growth levelling off and ending
Intellectual, cognitive development	• Abstract thought established • Able to understand, plan and pursue long range goals • May tend to be idealistic
Emotional development	• More stable emotionally • Able to recognise and identify emotions and causes • More self-aware
Sexual developments	• Concerned with serious relationships • Clear sexual identity • Capacity for tender and sensual love
Identity development	• Firmer identity • Ability to delay gratification • Ability to think through ideas • Can express ideas in words • Better developed sense of humour • Can make independent decisions • Ability to compromise • Greater concern for others

Talking about sex and their bodies

- This age group are far more comfortable with their bodies and sexuality. Their ability to delay gratification is more developed. Reasoning with them is easier.
- Deeper meaningful relationships with the opposite sex begin in this stage.
- The HCP will need to discuss disclosure with their partners, and guide the late adolescent through this process.

Working with their PCG(s)

- The value of family support is more recognised. There is less conflict with family, as the individual's sense of identity is not threatened by seeking their family's advice and help.
- The opportunity should be taken to strengthen family support and relationships.

Seeing their own long-term health plans

- There is a realisation about their mortality and they begin to worry about their future.
- Fear may emerge as a dominant emotion. Allow them the opportunity to express this fear, guiding them into formulating a plan that minimise risks to their health.

Peer pressure

- The peer group is less influential and individual friendships become more valued.
- Encourage friendships that benefit and influence the individual positively, allowing them to realise the negatives and positives of these friendships

Health-promoting tasks in this age group

- Journaling: their feelings and emotions about their disclosure, the experience of being HIV infected and their health care plans and experiences
- Risk management: identifying, listing risks and how to manage these risks to avoid harm
- Relationship management: finding creative ways to prevent transmission to sexual partners, carefully navigating disclosure to friends or partners
- Finding creative ways to manage stigma and adherence issues
- Prevention with positives (PHDP)
- Adherence Planning
- Participate in Adolscent I-ACT groups
- Services for sexually active adolescents (SRH)

Possible challenges in the disclosure process include:

1. Disclosing to an adolescent who has not been told the truth about their diagnosis.
2. An adolescent experiencing recent bereavement as a result of late disclosure (after age 12) through sexual activity.
3. Non-adherence.
4. Disclosing to an adolescent with a new HIV infection.
5. Disclosing to an adolescent who has been sexually abused.

Step 4: Follow-up and Support

Adolescents require ongoing support, but they will often not enjoy traditional or conventional types of support.

Support groups:

Some adolescents will agree to become part of a support group, such as I ACT for Adolescents. These groups should be run by young, youth-friendly facilitators who understand the world of an adolescent. Adolescents will often not want to be seen at a health facility, so support groups may need to be held in more neutral and confidential places. Request ideas from the adolescents themselves on where these groups should be held.

Mobile technology support:

Mobile or technology driven support systems are very appealing to adolescents. An example is YOUNG AFRICA LIVE, where adolescents can join a mobile phone SMS chat room, B-WISE (mobiapp for adolescents and youth in South Africa)

> Requires: A mobile platform that is entertainment-oriented, fun, interactive, and provocative. A platform that would not simply state the facts and "lecture" young people about the do's and don'ts, but rather creates a space where young South Africans could talk about hot topics that affect their daily lives for example love, sex, relationships, gender and cultural issues, as well as HIV/AIDS

Follow up

Adolescents should be encouraged to attend all routine follow up sessions, and facility staff need to work with adolescents to create systems that encourage retention to care and treatment.

Chapter 7: Integrating Disclosure

Disclosure should be a service provided according to these guidelines in multiple settings, these include:

- Health programmes/units.
- Programmes offered by DSD and Orphans and Vulnerable Chidren (OVC) service providers.
- NGOs and Community Based Organisations (CBO) with appropriate skills and support.
- The Department of Basic Education (DBE) within ISHP.

There are two main activities within a facility that must take place before accessing the C&A for disclosure

1. The first step towards disclosure is case finding
2. The second step is engaging with and preparing the PCGs of these C&A

Only once these activities have been achieved can one actually disclose to the C&A

1. Case finding

Case finding is a continuous activity which must be built into reportable targets. Without actively seeking out C&A that require disclosure, they will not be reached. Services such as the Expanded Programme on Immunisation (EPI), IMCI and SRH should be used as entry points for case finding.

Many times, the only way to find a C&A is through the PCG. The following groups of people need to be actively sought out in facilities:

Finding the C&A			
HIV infected parents that have not tested their children	Parents that won't disclose to their children	C&ALHA that have not been tested yet	C&ALHA who are on ART that still need disclosure

Where do we find these groups of people?

a. In the Health system
b. In the social system and the community

a. Case finding in the health system

The following programmes provide continuous opportunities for case finding:

Maternal, Child and Women's Health and Nutrition Department (MCWHN)

Antenatal Clinic (ANC) / Prevention of Mother to Child Transmission (PMTCT)	IMCI	EPI	SRH
• All pregnant women in PMTCT - preparation can take place for their unborn children. • Women in PMTCT may have older children who may not have been tested.	• All children with failure to thrive, nutritional issues, developmental delays or any indications as per IMCI guidelines. • Any child that has not returned for PCR results.	• Routine testing at immunisation. • Education of parents bringing children for immunisations - these parents may have older children that need testing.	• All women who are seeking SRH services may have children.

Adult PCGs recruited from these programmes should be referred to **FSI** for disclosure preparation

HIV/AIDS/STI/TB (HAST)

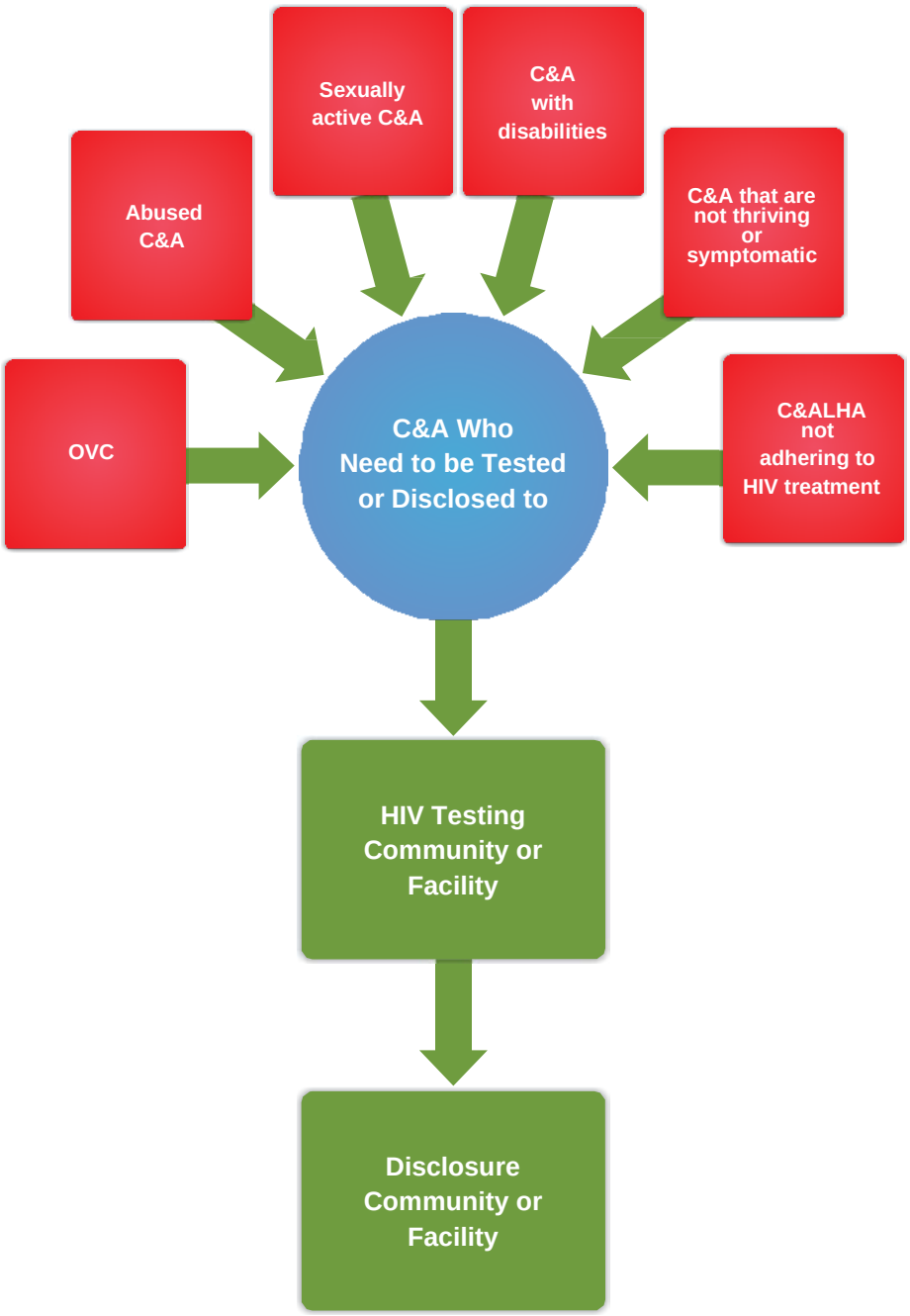
Adult ART Programme	Sexual and Reproductive Health Services	Paediatric ART Programmes
• All adults with HIV should be screened for untested children. • Adults who are enrolled in ART programmes should be screened for untested children. • All adults attending the I ACT programme should be screened for untested children.	• Adolescents attending family planning or STI clinics should be tested for HIV. • Adults who repeatedly present with STIs may have undiagnosed HIV - these adults should be tested and screened for untested children. • Adolescents seeking Termination of Pregnancy services should be tested for HIV (via the PICT services).	• Routine testing at immunisation. • Education of parents bringing children for immunisations - these parents may have older children that need testing.

b. Case Finding In the social system and community

Within the community, the DSD work with children at risk of HIV, and OVCs. Many of these C&A may not have been tested for HIV.

All HCPs including community health workers need to actively advocate for HIV testing in C&A and the resultant disclosure from the following sources:

Case finding via social system and community



2. Caregiver engagement

Once C&A who need testing, or C&ALHA without disclosure have been identified, the PCGs need to be prepared for disclosure.

This entails the **FSI** (support group style intervention in the community or facility)

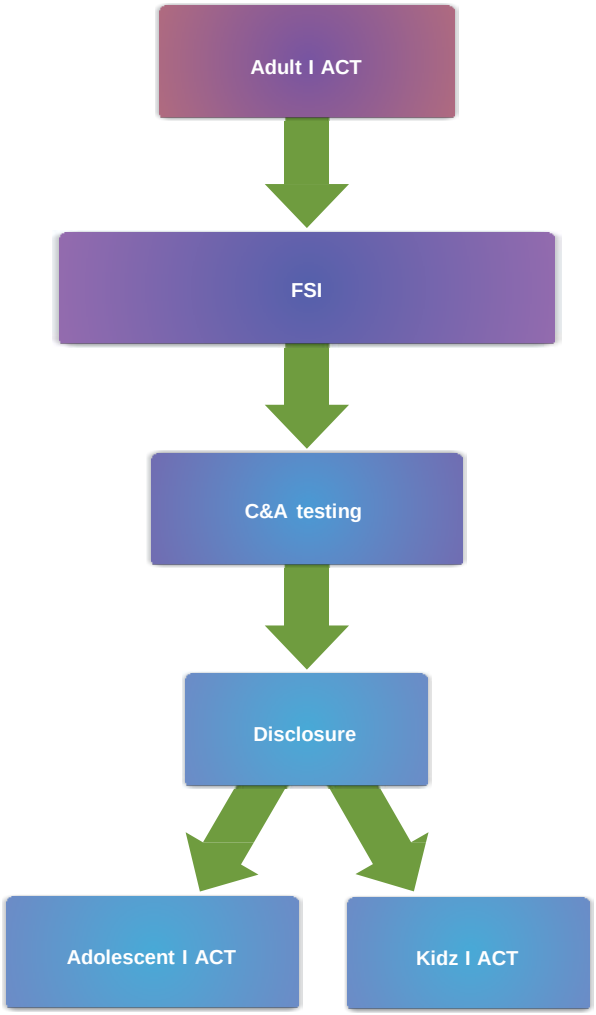
It is recommended that the FSI be implemented via the Adult I ACT programme wherever possible.

Adult I ACT - This targets all HIV infected adults in a 6 session support group style programme to provide information, support and treatment readiness.

Once adults have completed the Adult I ACT groups, they will be invited to attend the FSI if they have C&A. This is to prepare them to bring their C&A in for testing, or to disclose to their C&A.

Following the FSI, C&A will be brought for testing, and the disclosure process begins.

Once the C&A has started the disclosure process, they will be referred the KIDZ-I ACT support group or the Adolescent I ACT support group



Disclosure to C&A within health and social systems

Using the disclosure guidelines, disclosure can take place within either community or facility settings, as long as the guidelines are adhered to.

Disclosure within the educational system

Disclosure of a C&A's status to a teacher is allowed by law if it is in the best interest of the C&A according to the following guidance:

> Permission given by PCG, court, legal organisation, by child > 12 years who has capacity to consent or children on ART if in the best interest of the child.

Chapter 8: Monitoring and Evaluation

Monitoring and evaluating disclosure is a complex discussion as disclosure is not a once-off event that can be measured in the same way as a diagnostic test or visit to the clinic.

Monitoring of disclosure should answer the following questions:

What are the National levels of disclosure to C&ALHA?

1. Are disclosure services being provided at facilities as stipulated in the guidelines?
2. Is the quality of disclosure services of a good standard?
3. How many C&ALHA have not started a disclosure process?
4. How many C&ALHA have completed a disclosure process?
5. Are the individual disclosure sessions being recorded for legal and case management purposes?

Monitoring of disclosure should take place at facility level, where the following can be assessed:

1. Facility compliance to disclosure guidelines.
2. Quality of disclosure services.
3. Individual client disclosure documentation.

Facility compliance to disclosure guidelines

The **Facility Preparation Checklist** can be used as a measure of compliance to the guidelines. District level monitoring can report on number of facilities compliant with disclosure guidelines.

SYSTEM, DOCUMENTATION AND GUIDELINES	Completed
HCT Policy	✓
National Consolidated Guidelines for PMTCT, Management of HIV in children, adolescents and adults	✓
IMCI guidelines for children less than 5 years	✓
Disclosure guidelines	✓
Child protection policy	✓
Staff trained in above guidelines and policies	✓
Staff trained in HCT and disclosure to children and adolescents (Clinical and Psychosocial)	✓
HCT and Disclosure tools available to HCP	✓
Written referral pathways and linkages developed and available to all staff	✓
Case finding system in place and protocols followed	✓
Documentation and monitoring and evaluation available for each C&A in locked cupboard	✓
C&AFS available	✓
Written Referral pathway available in C&AFS	✓
KID	✓
Adolescent- I ACT groups functional	✓
FSI established at facility	✓
Adherence guideines	✓
Adherence and disclosure plans in adolescent and adult files	✓

Post training mentorship and supervision provided after the National Training Programme includes a quality assessment of disclosure services.

HCPs will be mentored at regular intervals. Mentorship and quality assurance tools will be covered in the training.

Individual documentation of disclosure sessions

It is essential to keep records of each interaction with a C&A, both clinical and psychosocial, and anything relating to disclosure and adherence to care and treatment.

Reasons for keeping records [32]

Ethical reasons
The HPCSA, a professional body that oversees the practice of counsellors and many HCPs who register with it, require this.
Disciplinary and legal reasons
If a HCP faces a disciplinary inquiry or a legal case relating to how they handled a particular client's case, notes will act as a "memory" for the counsellor or HCP. A court may also order these notes to be available to a client.
As valuable information for later interventions
Keeping notes provides a history that can assist HCPs in making decisions about future interventions for particular clients.
As a way of sharing information in a network
Where more than one HCP may be involved in the management of a particular client, notes become a way of communicating between the different team members and ensuring that everyone is fully informed about the facts. In this case, clients should be told that notes will be recorded and that these notes will be made available to other HCPs involved in the management of their case.

Practical guidelines for keeping records [32]

Always keep in mind that someone else could read these notes

- Write clearly.
- Keep them to the point.
- Make sure that you record what actually happened during the consultation.
- Do not write anything offensive about a client.

Keep notes secure

Ensure that notes are kept in a secure place where they will not be available to anyone who is not directly involved in the client's management.

Make progress notes

- Make your notes as soon as possible after a session.
- These notes should be factual and objective – what actually happened or what was done during a session.
- These notes are the important notes that will communicate information to other team members involved in the management of the case.
- These are legal notes and form part of a client's official record.

Make brief process notes

- These notes deal with the client's feelings and experiences.
- These notes may also reflect what the HCPs might be thinking or observing about the client.
- These are not considered legal, although would have to be submitted if part of the client's official record and were asked for during a disciplinary hearing or legal case.
- Keep these notes to a minimum.

Include the following in the progress notes

- Date, time and place and who was present.
- A description of activities undertaken in the session (e.g. evaluations).
- Stage of disclosure reached.
- Other relevant information, for example, a sibling was mentioned that may need to be included in the process.
- Referrals made, feedback and recommendations made by others.

Disclosure Documentation

Documents should be stored confidentially and shared only with the multidisciplinary team. The following records are recommended in order to comply with legislation and good practice[33]: a) disclosure plan, b) disclosure assessment and c) disclosure record.

1. DISCLOSURE ASSESSMENT *(to be filled out by Healthcare Provider)*

Name of Child/Adolescent:	
Patient File #:	
DOB: / /	**Gender:** M / F
Name of Healthcare Provider	Date:

CHILD/ADOLESCENT – Circumstances around the child's HIV transmission		
Mother to Child Transmission	☐ Yes ☐ No ☐ Unknown	*If yes, proceed to facility level disclosure.* *If no, refer and follow up to continue disclosure process.*
Possible sexual abuse or other complex disclosure • **Abusive or illegal (sex was under the** • **legal age of consent)** • **Traumatic** • **Current crisis** • **Non-supportive environment** • **Extended and unresolved bereavement** • **Child-headed household** • **Vulnerability of caregiver** • **Disability**	☐ Yes ☐ No	*If yes, refer to social worker or psychologist for follow up to continue disclosure process.* *Any suspected abuse (physical, verbal, Sexual/must be reported according to Child Protection policy.*
Sexual transmission following consensual sex.	☐ Yes ☐ No	*If yes, prepare for expanded counselling relating to Sexual Reproductive Health (SRH)*
Does the child/adolescent already know about his health / illness?	☐ Yes ☐ No	
If on ART already, has the child/adolescent been told about the reason for being on ART?	☐ Yes ☐ No	
Has the child/adolescent previously received disclosure information?	☐ Yes ☐ No	*If yes, was it appropriate for the child/adolescent's developmental stage?* *If no, refer and follow up to continue disclosure process.*
What is the child/adolescent's current emotional state?	☐ Stable ☐ Emotional Issues	*If stable, proceed to facility level disclosure.* *If emotional issues are present, refer and follow up to continue disclosure process.*
Is the child/adolescent performing well at school?	☐ Yes ☐ No	*If yes, proceed to facility level disclosure.* *If no, refer and follow up to continue disclosure process.*
Has performance at school changed recently?	☐ Yes ☐ No	*If no, proceed to facility level disclosure.* *If yes, refer and follow up to continue disclosure process.*
Is the child/adolescent coping socially? Same level as peers?	☐ Yes ☐ No	*If yes, proceed to facility level disclosure.* *If no, refer and follow up to continue disclosure process.*
Does the child/adolescent have family or community support?	☐ Yes ☐ No	*If yes, proceed to facility level disclosure.* *If no, refer and follow up to continue disclosure process.*
Does the child/adolescent present with a negative mood and behaviour?	☐ Yes ☐ No	*If no, proceed to facility level disclosure.* *If yes, refer and follow up to continue disclosure process.*
Any family or social conflict?	☐ Yes ☐ No	*If no, proceed to facility level disclosure.* *If yes, refer and follow up to continue disclosure process.*
Does the child/adolescent show interest and get involved with activities?	☐ Yes ☐ No	*If yes, proceed to facility level disclosure.* *If no, refer and follow up to continue disclosure process.*

SUMMARY OF ASSESSMENT
Readiness of the caregiver:
Considerations for the Child/Adolescent:

2. DISCLOSURE PLAN

PLAN DETAILS			
Date of proposed disclosure:		**Age/ Developmental stage:**	
Who will disclose?	☐ Caregiver ☐ Healthcare Provider ☐ Other, specify: _____		
Who are the people the child/adolescent may disclose to? (Hand of Safety):			
Any other considerations?			

3. DISCLOSURE SESSION RECORD

Name of Client:	
Patient File #:	
Name of Healthcare Provider	Date:

SESSION DETAILS
History leading up to disclosure:
Disclosure topics covered?
Information given to child/adolescent (Include what tools or words were used):
Child/adolescent's response and questions:
Health promoting tasks given to child/adolescent and caregiver:
Follow up plan and linkages :

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