# The new NDOH and NDSD…

# CHILD AND ADOLESCENT DISCLOSURE COUNSELLING (CADC) FLIPCHART

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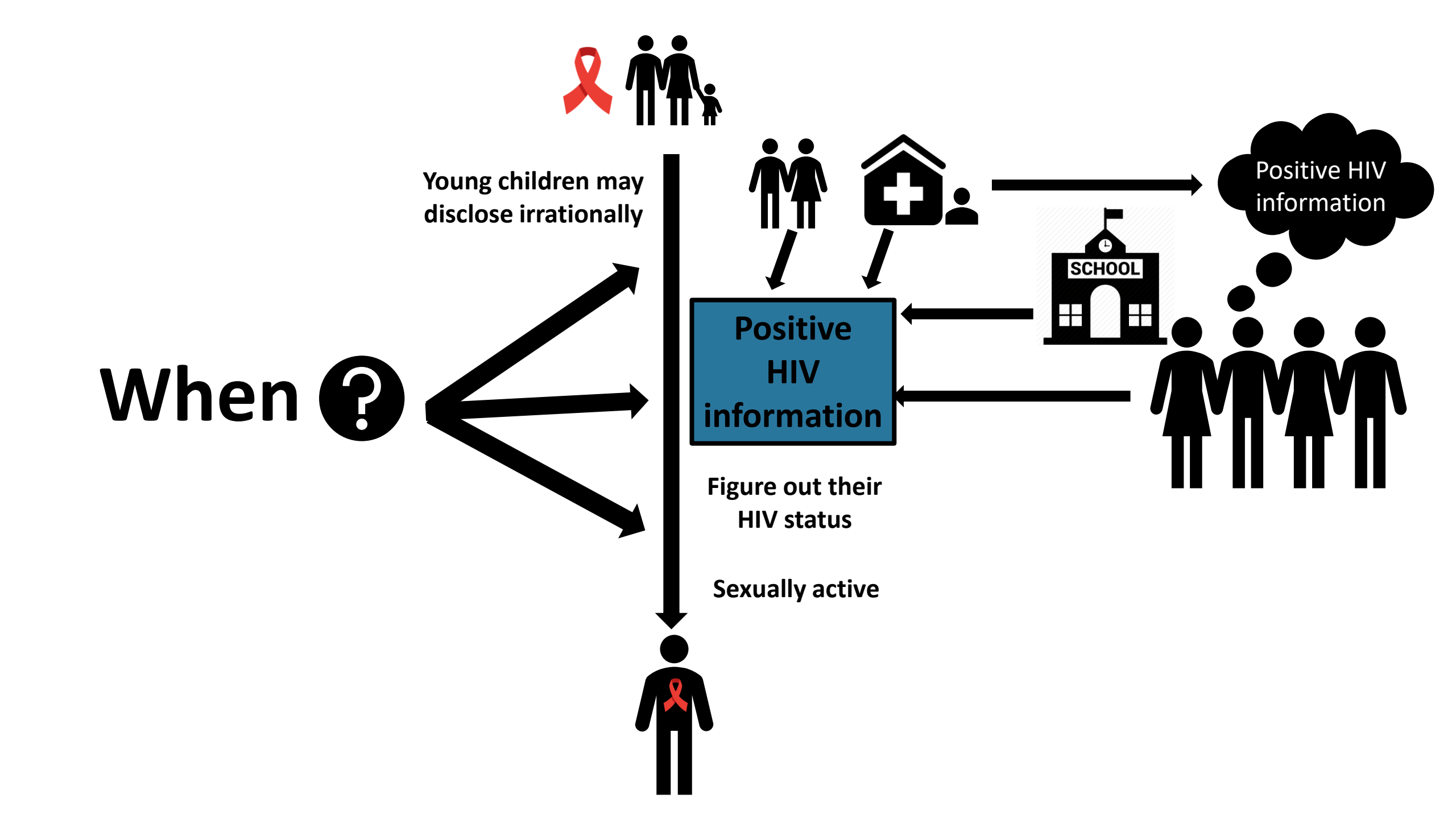
Right to Care NGO

# INTRODUCTION QUIZ

## What is CADC?

- Child and adolescent disclosure counselling
- A gradual process of giving children age-appropriate information regarding their HIV status.
  - Partial disclosure
  - Full disclosure
  - Post disclosure

## When to disclose?


Young children may disclose irrationally
When ?
Positive HIV information
SCHOOL
Positive HIV information
Figure out their HIV status
Sexually active

# INTRODUCTION QUIZ

## When to disclose?

- No disclosure (0-4 years)
- Partial disclosure (5-9 years)
- Full disclosure (10-15 years)

  Ideally between 10-12 years old if normal cognition and maturity

# ROLES AND RESPONSIBILITIES FOR CHILD AND ADOLESCENT DISCLOSURE

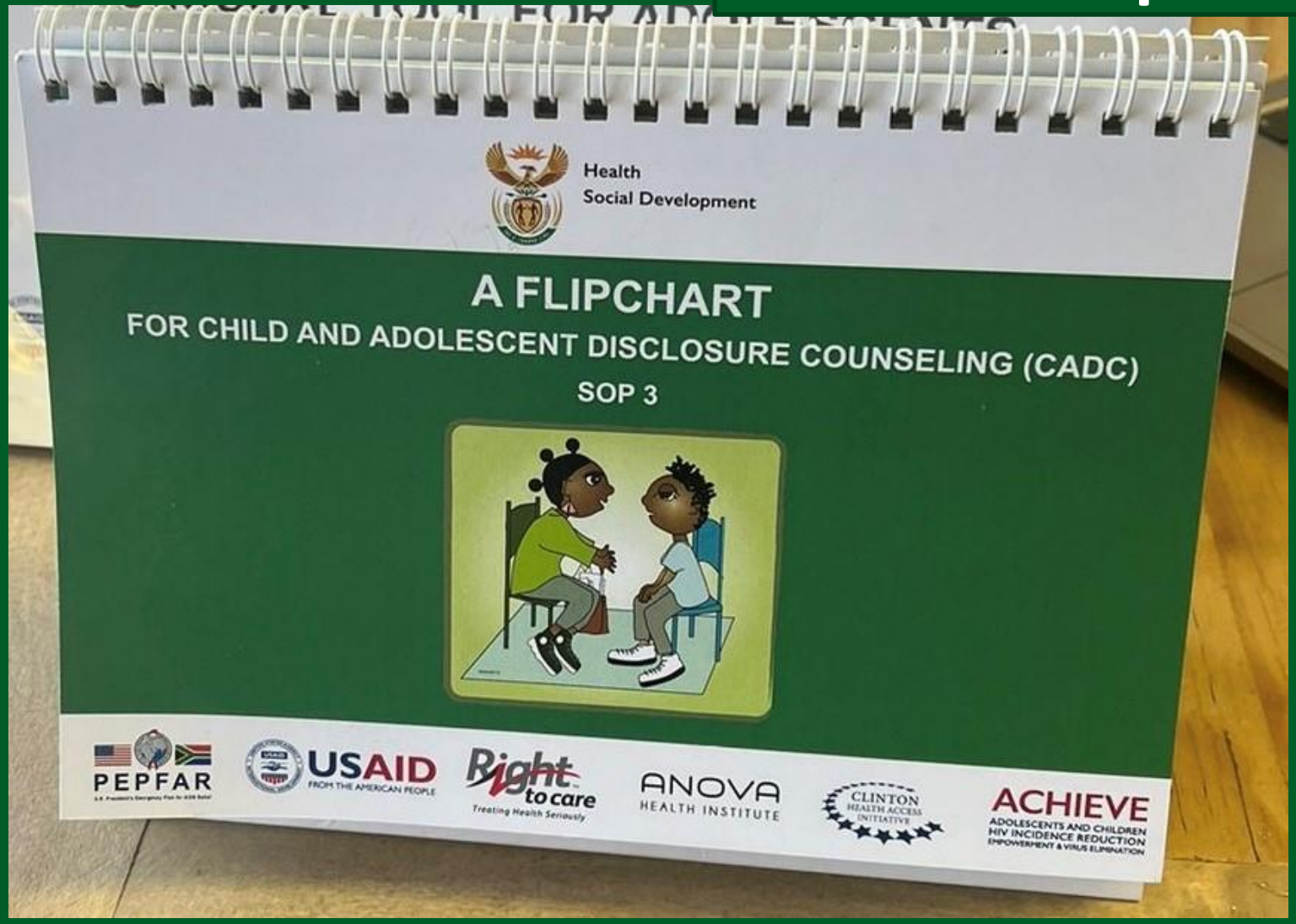
**Clinician/Counsellor/social service provider role:**

Support the caregiver and child with the process of disclosure and refer to other psychosocial services, as necessary. Should be prepared to take any role as requested by the caregiver including doing the whole or part of the disclosure.

**Caregiver's role:**

Caregiver supported by the counsellor chooses what role they wish to play, from doing the full disclosure to letting the counsellor /clinician do the full disclosure

# The Flipchart

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## Overview

- This disclosure tool is a desktop tool to be used while conducting partial, full and post-disclosure with children and adolescents living with HIV (C/ALHIV)
- It is intended to be used by either the health care provider (HCP) or social service practitioner (SSP) or the parent or caregiver (PCG). For the rest of the tool the abbreviation "HCP/SSP/PCG" will be used to refer to either of the three.
- The tool engages young people with illustrations (which should face the C/ALHIV), while the other side guides the HCP/SSP/PCG on what to say.
- The speech bubbles indicate the sections that should be said by the HCP/SSP/PCG
- The PCG should be given the option to choose whether they would like to either:
  1) do the whole process,
  2) do the whole "full disclosure" process,
  3) only do the actual disclosure section on page 27 and page 29 in which the PCG answers the C/ALHIV's question about whether or not they have HIV, or
  4) do none at all.
- If the PCG chooses to do the whole "full disclosure" process they should refer to the solid yellow blocks on page 25, 27,29 and 33, in which they refer to themselves in the first person.
- Where possible this tool was made to align with Annexure 7 of the NDOH ART Clinical Guideline, as well as the Child and Adolescent Disclosure Counselling (CADC) SOP3 in the Adherence Guideline.

# GUIDANCE FOR ALL SESSIONS

## BEFORE EACH SESSION:

- Prepare the parent/caregiver
- Familiarise yourself with the content of the session
- Conduct readiness assessment and get consent before full disclosure

## DURING EACH SESSION

- Prepare a warm friendly and conducive environment to conduct a disclosure session, establish language preference and assure caregiver and child of confidentiality.
- Build rapport with caregiver and child by introducing yourself and ensure the child is comfortable.
- Use age-appropriate simple, clear language.
- Do not use a tone of voice that makes the child think that living with HIV is a terrible thing
- Listen, respond and allow the child to express emotions.
- Discuss immediate concerns and help caregiver and child decide who in their social network may be available to provide immediate support.
- Provide information on care and support, adherence, treatment and prevention services. (do not mention the word HIV until after full disclosure)
- Encourage and provide time for the caregiver and child to ask questions
- Accept and normalise feelings, contain reactions with empathy and allow space for personal expression

## AT THE END OF EACH SESSION:

- Ask the caregiver and the child if they have any questions or concerns.
- Ensure ongoing assessment of the child's wellbeing.
- Refer for psychosocial support such as social worker, psychologist, support group for both child and caregiver.
- Schedule and confirm the follow up visit after determining a suitable date and time with the caregiver (ideally align with treatment supply appointment dates).
- Document sessions in the disclosure records.
- Leave IEC materials with the patient after making sure that the patient understands information on IEC material in their language. (do not share anything with the word HIV with a child who has not finished full disclosure)
- Provide hope and encouragement to caregiver and child.
- Encourage the PCG to create an environment in which the young person feels comfortable asking questions and expressing emotions.

# READINESS ASSESSMENT AND CONSENT

| | Partial disclosure | Full disclosure |
|---|---|---|
| Readiness assessment | Age over 5 years, and ask the caregiver if the child is of normal maturity for age (if they are in the correct grade for their age) | Within DOH: HCW to check the following:<br>Age > 10 years old<br>• Normal maturity for their age (for example, they are in the correct grade for their age. If not, and they are not sexually active, suggest delaying for a year or two.)<br>• Child agree that they want to know the name of their illness<br>• Ensure adequate family/peer/social support or refer to SSP if necessary<br>• Caregiver has been through preparation session, chosen their role and given consent. |
| Consent | Verbal consent<br>(and write in the file of the client) | Written or verbal consent (and write in the file of the client for example "I _____, parent/caregiver of _____ give consent for full disclosure. Signed _____ Date_____", and ask the caregiver to sign. If caregiver cannot sign, 2x HCW/SSP can sign as witness). |

# Partial Disclosure for children 5-9 years

# PARTIAL DISCLOSURE CONTENT TO BE COVERED WITH THE CAREGIVER

- **Ask what the caregiver has told the child so far about the reason for coming to the clinic and taking treatment.**

**Explain partial disclosure as follows:**

The disclosure process is like a journey with many stops. At each stop, we will explain a little more to the child. At the end of the journey, when it is the right time for the child, the child will understand HIV and the treatment the child is taking. we will be explaining to your child exactly why they need to take their meds but we will not give them the name of the sickness (HIV).

**Explain the advantages of disclosure:**

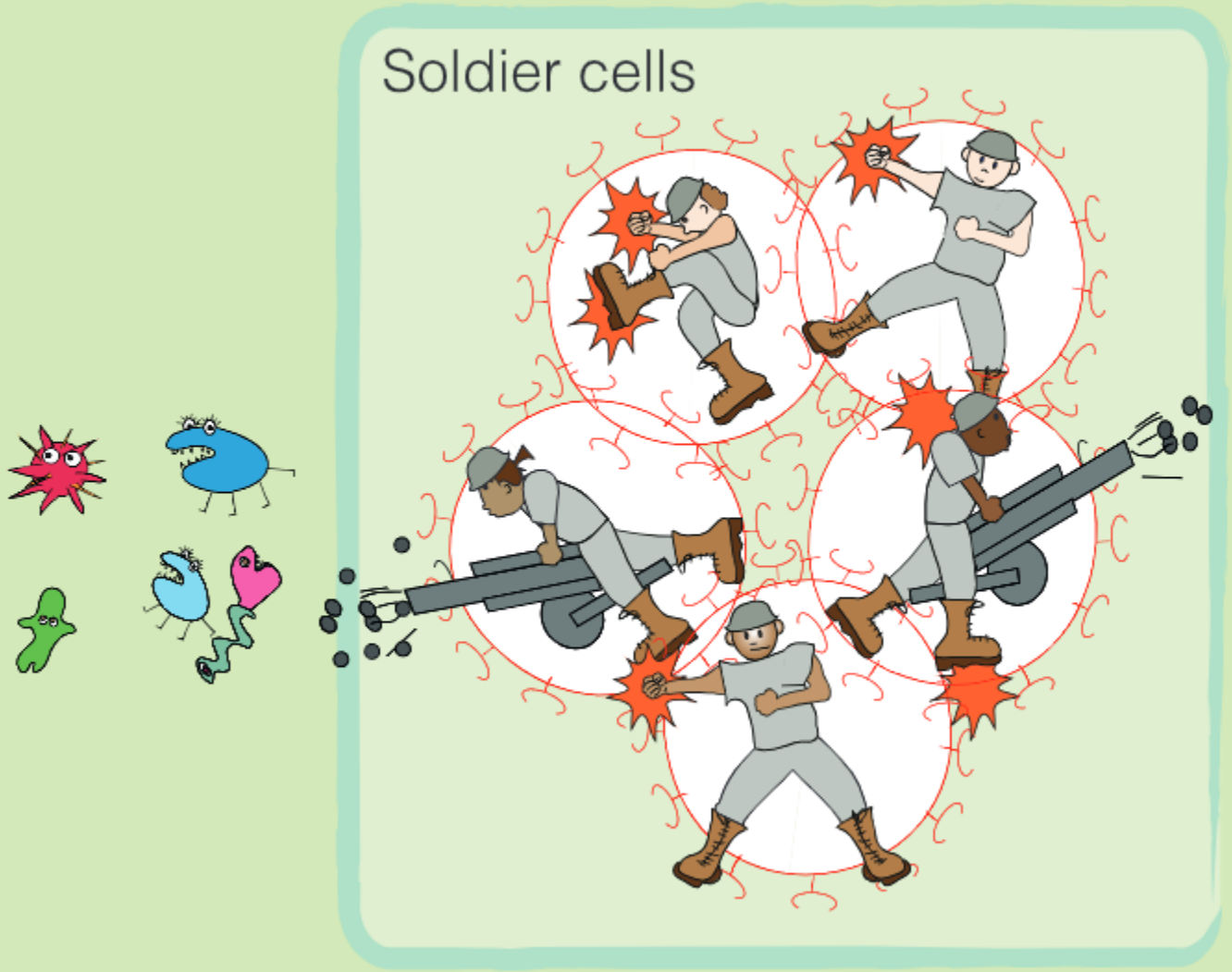
Children who know their status take their medicine better because they understand why they must take the treatment. Children often know that something is wrong. Hearing about HIV from you rather than anyone else will help the child to accept the situation.

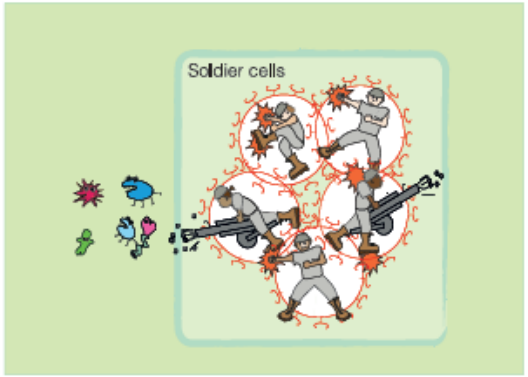
**Explain the timing for disclosure:**

Talking with your child about HIV is not going to happen on just one occasion. You can take opportunities to tell them part of the story, it is good to follow their lead. When children ask questions, find ways to respond with adapted explanations for their age without lying.

**Assess barriers to disclosure:**

How do you feel about us giving information to the child on their condition today without naming HIV. What are your fears about disclosing child's status one day?


Soldier cells




10 Great! You know some things about germs already. **So we can say that a germ is something that makes us sick.**

11 Remember we said white cells are the soldiers that fight germs. **What do you think a soldier cell would do if it found a germ?**

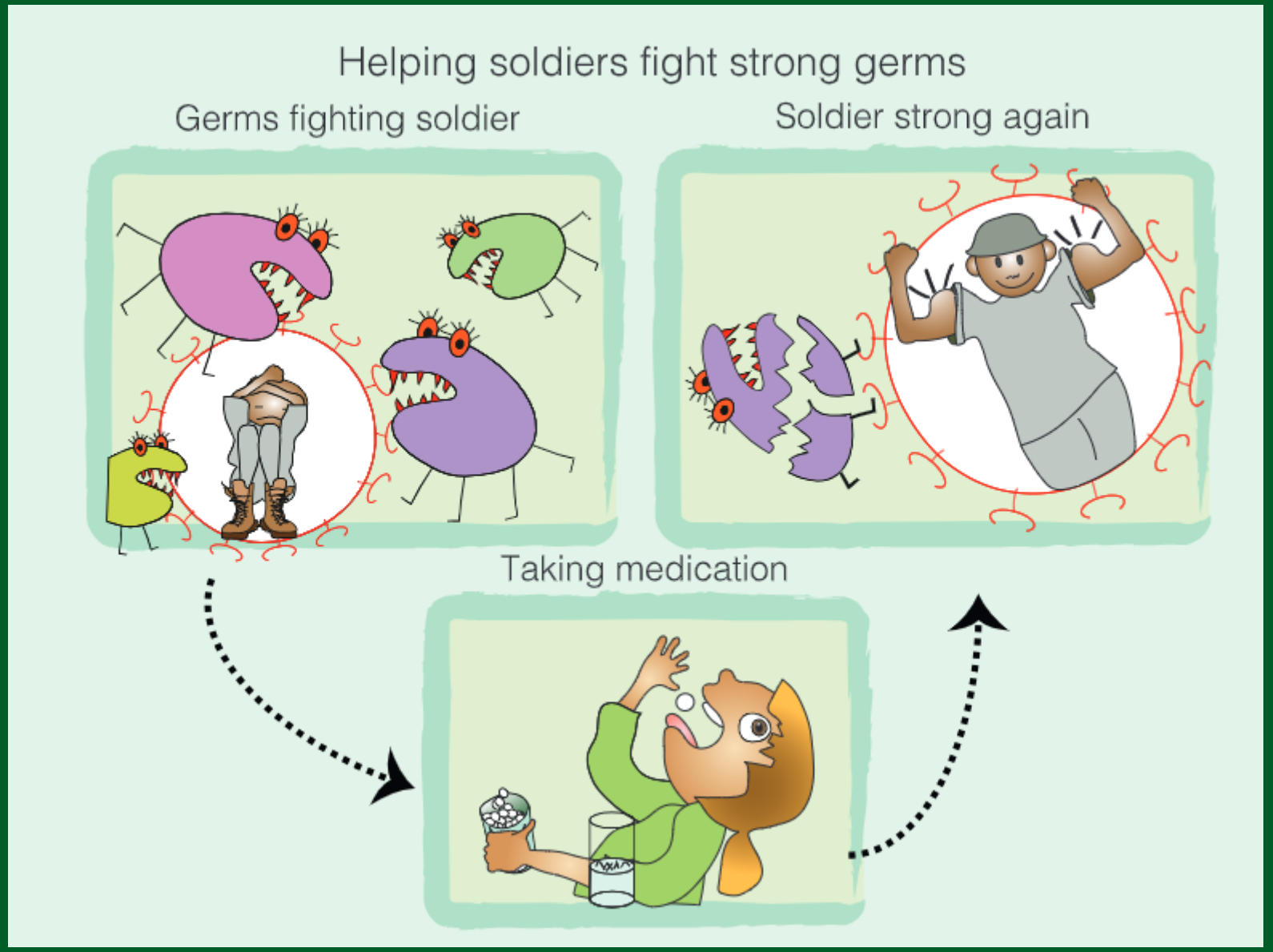
*Encourage the young person to answer.*

12 The **white cells** travel around our bodies in our blood looking for germs. **When they find them they kill them so that we don't get sick.**

13 But what would happen if a person did not have many soldier cells in his/her blood but only very few?

*Encourage the young person to answer and assist if necessary.*

14 A person with very few soldier cells in his/her blood may become sick. You had very few soldier cells when you first started coming to the clinic / hospital.


Helping soldiers fight strong germs
Germs fighting soldier
Soldier strong again
Taking medication

# Full Disclosure for adolescents older than 10 years

# CAREGIVER PREPARATION

**PREPARATION FOR PARTIAL OR FULL DISCLOSURE: CONTENT TO BE COVERED WITH THE CAREGIVER ONLY (WITHOUT THE CHILD).**

If the child has already had partial disclosure you can leave out the discussions about partial disclosure, but if not, then you should talk about both in order to start preparing the PCG for both partial and full disclosure in the future.

1. Ask what the caregiver has told the child so far about the reason for coming to the clinic and taking treatment.
   Explain the disclosure process as follows:

   Adolescent disclosure refers to telling a teenager they have HIV. We recommend that the disclosure process is like a journey with many stops. At each stop, we will explain a little more to the child.

   From 5 years old, we do not tell the child they have HIV but tell them that they need to take medicine to make their soldier cells strong to fight other germs. We call this "partial disclosure".

   At the end of the journey, when it is the right time for the child (around age 10-12 years old), the child will learn that they have HIV. We call this "full disclosure.

2. Explain the advantages of partial disclosure (age 5-9 years):

   It is important to tell the child the truth but without telling them they have HIV. It gives them a reason to take their medicine and builds honesty in the relationship.

3. Explain the advantages of full disclosure (usually 10-12 years old if the child is of normal maturity):

   Usually, adolescents who know their status take their medicine better and take responsibility for their own health. Children often know that something is wrong. They may have fears that are worse than the real thing. Hearing about HIV from you rather than anyone else will help the child to accept the situation. They need to know their HIV status before they are sexually active, and before they figure it out through other mechanisms. Adolescents have the right to know about their own health and don't like to be lied to.

3

Explain that:

Children and adolescents living with HIV (C/ALWH) often learn negative myths about HIV from their community, their friends and school, such as "HIV kills", "people with HIV are promiscuous or bad" and "people with HIV can't live a normal life."

These are not true! It is therefore extremely important to educate C/ALWH and dispel all of these myths **before you tell them they have HIV.** Do you think you would be able to start teaching your child about HIV at home from a young age **(without telling the child that they have HIV)?**

Try to bring it up in normal conversation, and to ask the child what they know about HIV.
**Five important things** for them to understand include:

1. These days we have very good treatment for HIV, so people living with HIV (PLHIV) can remain perfectly healthy and never get AIDS.
2. PLHIV can live as long as people without HIV if they take their treatment every day.
3. Anyone can have HIV and it does not make them different or bad. Many people around you have HIV and you do not know because they are just as healthy as those without HIV.
4. PLHIV can have relationships and have children, and if they are taking their treatment and have a suppressed viral load, they will not transmit HIV to their sexual partner or children.
5. Living with HIV does not prevent people from living a completely normal life and following any career they want.

# Play a Game: Guess the infection

| Name an infection | What do you know about it? | Do you think you have it? |
| --- | --- | --- |
| flu | | |
| TB | | |
| HIV | | |

**NOTE:** You are teaching the child about HIV, but you **HAVE NOT** told them they have HIV yet, so just talk about HIV in general, **do not refer to them having HIV!**

9

"How can people get HIV?"

"People can get HIV through unprotected sex or from blood or it can be passed from a mother to her baby during pregnancy or breastfeeding. You can see in the pictures the ways HIV can be spread and ways it cannot."

Could I (the health care worker) have HIV?

Could your mother have HIV?

Do you think you could also have HIV?

It is important to remember that it wasn't your mother's fault you got HIV

We didn't have such good medicine in those days when she was pregnant with you.

It wasn't your mother's fault that she got HIV

HIV is so common, anyone can get it

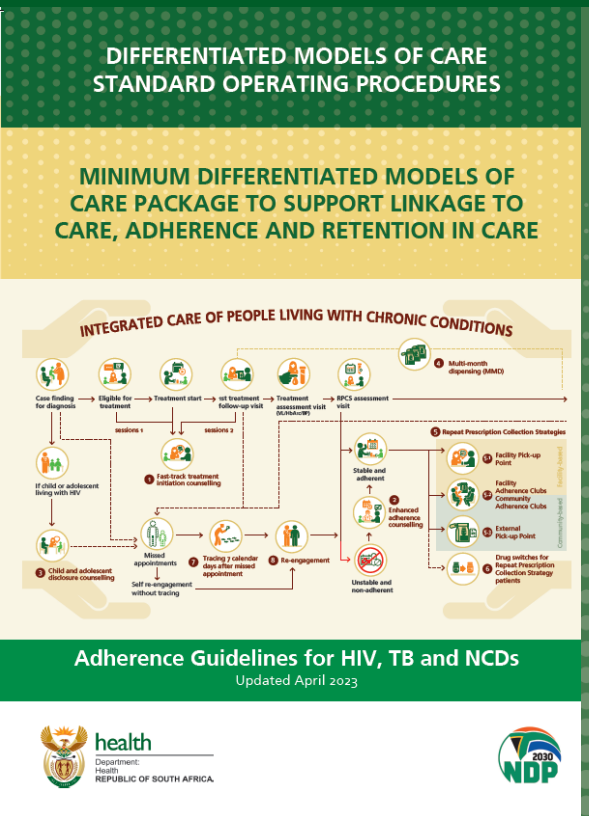
It is important to decide who you should tell that you have HIV or not. Do you think you should tell everyone at school?

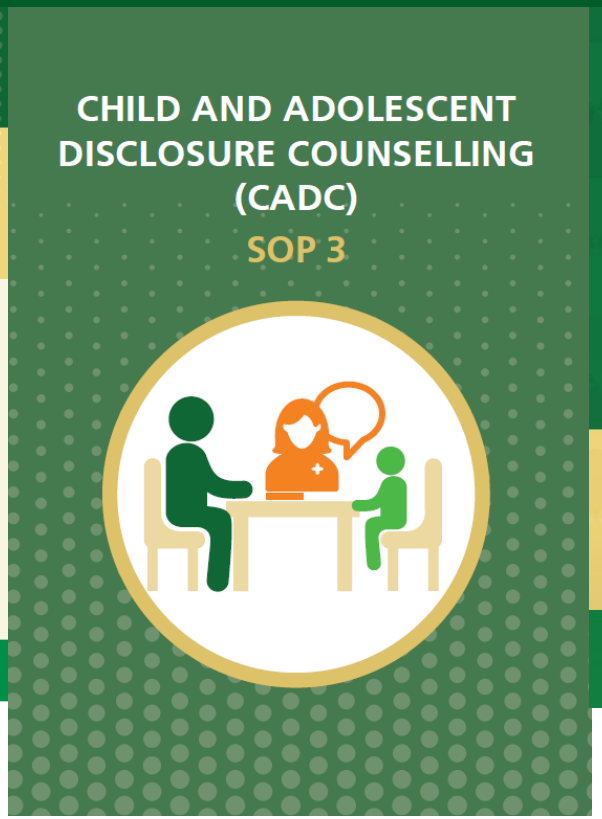
It is probably not a good idea. HIV is a sickness like any other sickness, but some people might treat us differently if they think we have HIV. We call this "stigma". For this reason it might not be a good idea to tell everyone that you have HIV. It is a decision you can make with your parents to decide who you should tell or not. We will discuss this more next session. We can also discuss how and when to tell your boyfriend or girlfriend.

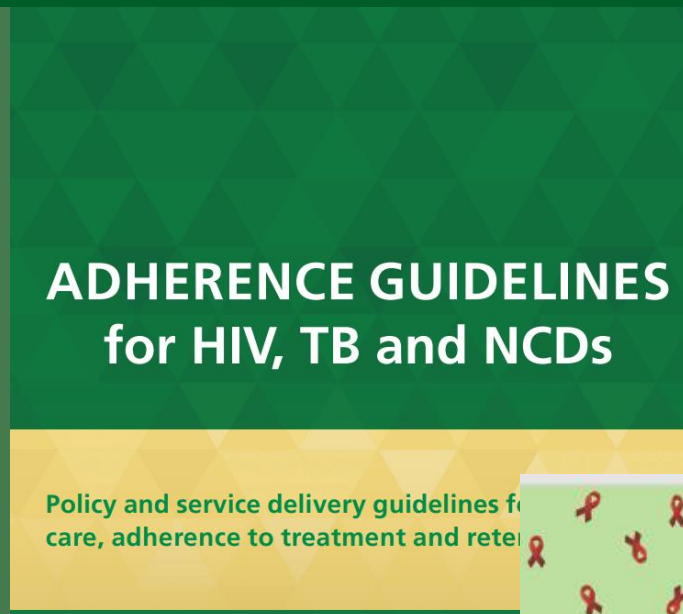
# Post Disclosure
# Ongoing disclosure, follow-up and support

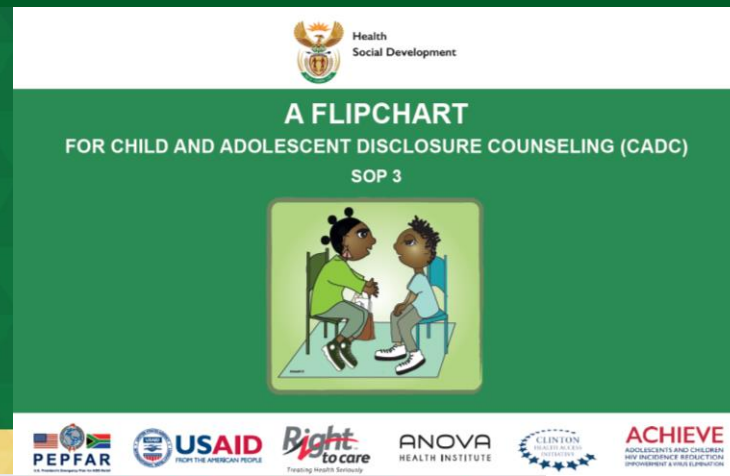
- Explain CD4 count and viral loads
  - Importance of adherence
- U=U and importance of condoms
  - How resistance can develop
- How to decide who to disclose to
  - How to disclose to a partner
  - How to check mental health
  - Support from friends, family
    - Support groups

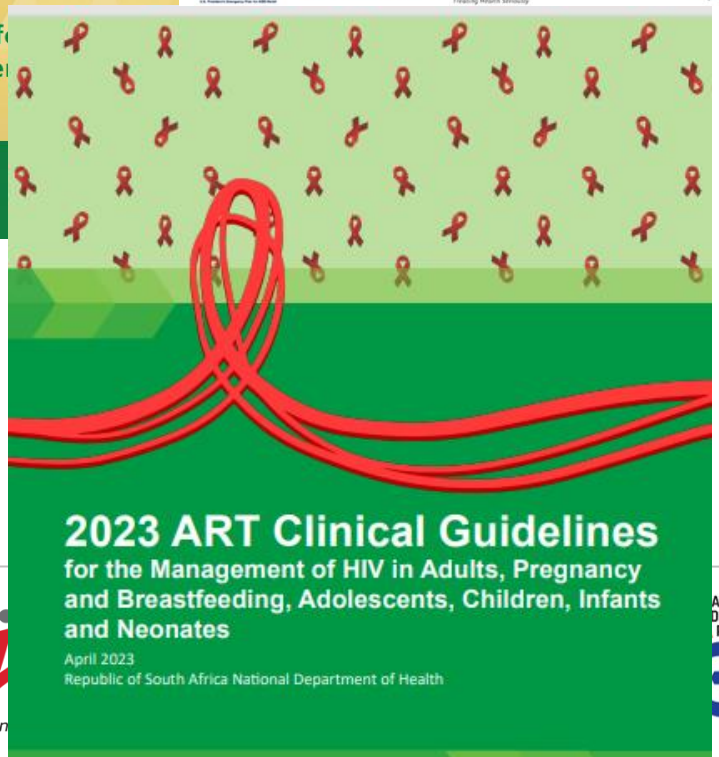
# APPENDIX: APPLICABLE POLICY REFERENCE FOR DISCLOSURE




- [WEB VERSION_South African National Differentiated Models of Care SOPs]
- [2023_FINAL18042023.pdf (health.gov.za)]
- [National ART Clinical Guideline 2023_04_28 signed_0.pdf (health.gov.za)]
- [15 2 16 AGL policy and service delivery guidelines_0.pdf (health.gov.za)]

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# Quiz