

# DISCLOSURE

A MINI WORKSHOP

# DISCLOSURE

## **Mini-workshop**

- Experiential
- Interactive

## **Overview**

- Legal aspects
- Policies, frameworks and guidelines
- Tools and resources

# LEGAL ASPECTS

- In groups discuss the scenario given to you



# POLICIES, FRAMEWORKS & GUIDELINES

Guidelines on HIV Disclosure Counselling for Children up to 12 years of age (World Health Organisation, 2011)

- Lack of disclosure affects well-being
- Cognitively ready for disclosure 8-11 years
- Cognitively and emotionally mature children of school going age should know their status
- Younger children should be told incrementally
- Adopt a process orientated and developmental approach

# POLICIES, FRAMEWORKS & GUIDELINES

National Guidelines on HIV Disclosure for Children and Adolescents (in draft)

- Children and adolescents 12-18 years
- National framework offers a model for disclosure
- Facilitates a structured approach
- Emphasises child participation, family, age and stage appropriate interventions, rights of the child (S.A Constitution)
- Reinforces NSP goal of psychosocial support

# TOOLS AND RESOURCES

## Children's Rights Centre Clearing House on HIV and AIDS Disclosure for Children

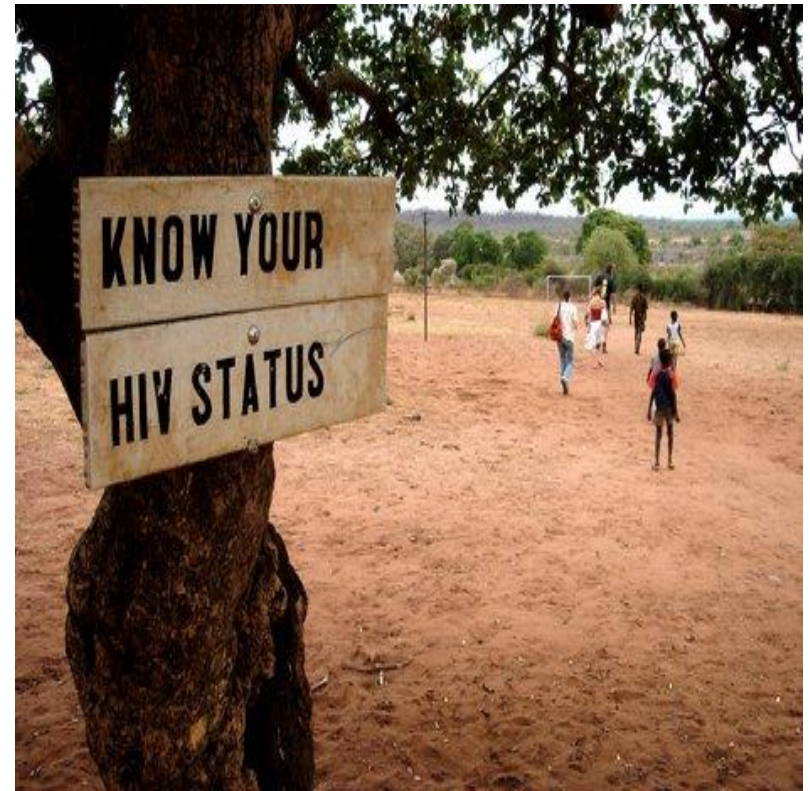
- Worldwide resource centre
- Contains examples of tools that illustrate useful practices
- Offers links to websites
- Information on issues related to disclosure
- [www.hivaidsdisclosure.co.za](http://www.hivaidsdisclosure.co.za)

# TOWARDS DISCLOSURE

- A bit of background
- Working with the caregiver or parent
- Working with the child or adolescent
- Disclosure of parental HIV status to a child
- When not to disclose

# BACKGROUND

- Highest number of children with HIV globally
- Mainly perinatally infected
- 460 000 children below 15 years living with the virus (NDoH,2011)
- An estimated 125 000 children on ART (NDoH, 2011)





# BACKGROUND

## 12 Reasons to disclose

- Promotes treatment adherence
- Improves psychological adjustment
- Control over disclosure
- Improves relationships
- Communicates respect for the child



# BACKGROUND

- Children get the right information
- Take responsibility for own healthcare (transition)
- Recognises rights of child
- Builds self-esteem
- Decision making in adolescence
- Access psychosocial support



# WORKING WITH CAREGIVERS



- Discuss the vignette with your partner
- Think about the questions that are underlined in the scenario

# WORKING WITH CAREGIVERS

Why is disclosure avoided?

- To protect child
- Avoid stigma and discrimination
- Insufficient knowledge & information
- Unresolved issues (loss)
- Family communication patterns

# WORKING WITH CAREGIVERS

- Not knowing how to begin
- Avoidant coping strategies
- Beliefs
- Disclosure of own status
- Guilt (loss)
- Fear of blame

# WORKING WITH CAREGIVERS

Impact on the caregiver:

- Secrets are harmful to health
- Involve stigmatising information about the secret-keeper
- Pre-occupational model of secrecy
- Conceptualised as a physical burden
- Can lead to physical exhaustion

# WORKING WITH CAREGIVERS

Importance of caregiver work:

- Strengthen support
- Respect wishes and views
- Start conversations early
- Educate and provide skills
- List possible outcomes
- Patience: phases of pre-contemplation, contemplation and action



# WORKING WITH CAREGIVERS

- Talk about disclosure to others
- Talk about child's health
- Talk about child's future
- Develop a plan
- How much, where, when and whom?





# WORKING WITH CAREGIVERS

- Expanding pockets of support
- Group work
- Telling the story
- Drawing and painting
- Giving fear a voice, identifying its size and shape
- Building respect for the rights of the child



# WORKING WITH CHILDREN



# WORKING WITH CHILDREN

- Developmentally appropriate
- Child as an individual
- Pre-schoolers
- Early school-age children
- Older school-age children
- Adolescents



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# WORKING WITH CHILDREN

## STAGES OF DISCLOSURE

- Non-disclosure
- Partial disclosure
- Full disclosure
- Post disclosure support



# WORKING WITH CHILDREN

- In groups discuss the scenarios handed out



# WORKING WITH CHILDREN

## YOUNGER CHILDREN

- Use your imagination: drawings, dolls, puppets etc
- Put yourself in the child's shoes
- Use what is available
- Brainstorm approaches with parents or caregivers



# WORKING WITH CHILDREN

## The Cast:

- Healthcare provider
- Mother
- Maria
- Johanna
- Narrator





# WORKING WITH ADOLESCENTS



# WORKING WITH ADOLESCENTS

- What can we expect?
- The challenges of onward disclosure
- How to help:
  - Who do you want to tell and why?
  - What are advantages
  - What are the disadvantages
  - How knowledgeable and confident is the young person



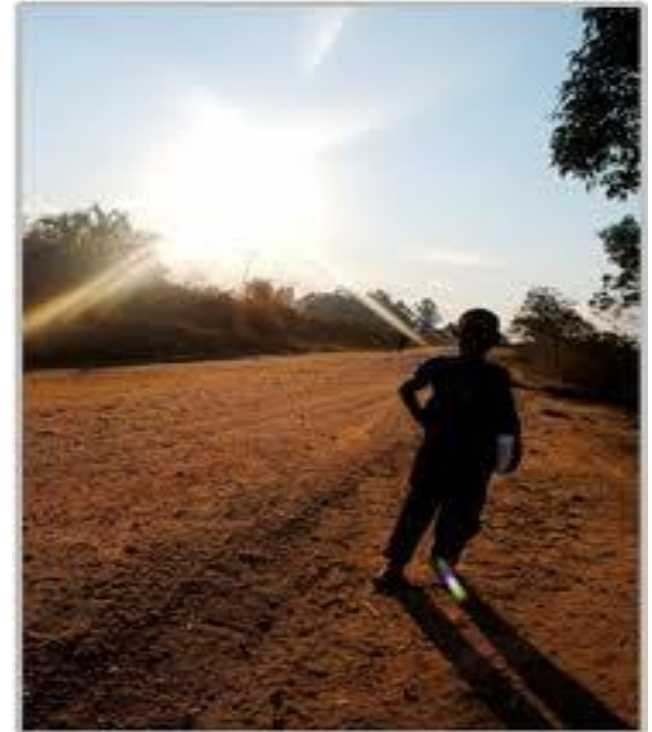
# WORKING WITH ADOLESCENTS

- Support: anyone to talk to or practice with?
- Afterwards: some time to reflect on successes and challenges .
- Staircase activity



# DISCLOSURE OF PARENTAL STATUS

- Will become more common (PMTCT)
- Children as motivators
- Normalise illness
- Importance of timing (health of the caregiver)
- Access to treatment
- Saying only what is necessary (answer questions)



# DISCLOSURE OF PARENTAL STATUS

- Developmental considerations
- Be guided by caregiver (partial or full)
- Younger children more accepting
- Older children tend to worry more
- Importance of access to the caregiver/additional support



# DISCLOSURE AND THE HCP



# DISCLOSURE AND THE HCP

- Often uncertain about counselling children
- Capacity building
- Supervision
- Role of the HCP in disclosure
- Who discloses?



# WHEN TO WAIT

- Very young children
- Children with developmental delay
- Children with severe emotional disturbance
- When a child is dying
- When a child is sick

