

**ICAP Collaborative PMTCT and Pediatric HIV Strategic Planning Workshop
In Partnership with Tygerberg Children's Hospital, South Africa and S2S**

Title:	HIV disclosure throughout the pediatric life stages : Better practices, approaches and tools
Country	New York
Host Name/Title:	Ruby Fayorsey, Pediatric Clinical Advisor Tayla Colton, Consultant
Session Goal:	To understand the complex issues around disclosure of HIV-status to a child, using a developmental approach
Learning Objectives:	<ol style="list-style-type: none"> 1. To examine our own values around childhood, communicating with children, and pediatric disclosure. 2. To define common characteristics of children at different developmental stages and the implications for disclosure of HIV-status. 3. To describe and apply a developmental approach to develop concrete, appropriate approaches/strategies for pediatric disclosure. 4. To practice talking with parents/caretakers and children about disclosure and HIV through role play. 5. To distill key guiding principles on pediatric disclosure. 6. To list key needs of Country Offices, sites, and providers related to pediatric disclosure. 7. To form and describe the tasks of an ICAP Technical Working Group on pediatric disclosure.
Instructional Method(s):	<ul style="list-style-type: none"> • Introductory exercise • Values clarification • Small group work and presentation • Case studies and role play • Brainstorming • Group discussion
Session Description (with times):	<p>0-10 minutes: Introductory exercise</p> <ul style="list-style-type: none"> • Each participant will introduce him/herself, including: <ul style="list-style-type: none"> ○ Name ○ Country office and position ○ Happiest childhood memory <p>10-30 minutes: Values clarification</p> <ul style="list-style-type: none"> • The hosts will post large “Agree” and “Disagree” signs on opposite sides of the room. • Participants will be asked a series of 5 questions related to their own values around children, communication, and disclosure. After each question is posed, participants will move to the “Agree” or “Disagree” sign (or somewhere in the middle), based on their opinion. • Some participants will be asked to share why they agree or disagree with the statements to encourage discussion and reiterate the point that we all hold values and opinions around these issues that can affect our work. <p>30-60 minutes: Small group work</p> <ul style="list-style-type: none"> • Participants will be divided into 3 small groups. Each group will be assigned one of the following stages of childhood development:

- Early childhood/Preschooler/2-5 years
- Late childhood/school aged/6-10 years
- Early adolescence/11-15 years
- The hosts will explain the small group work activity and groups will be asked to assign a facilitator and a rapporteur.
- Each small group will discuss and record the following (on flip chart) for their assigned stage:
 - Key characteristics of children at this stage
 - Implications for disclosure
 - Practical steps /tips/approaches for disclosure at this stage

60-90 minutes: Small group presentations

- Each group will present back a summary of their discussion to the large group (about 5-7 minutes: will be given to each group).
- After each short presentation, the large group will be asked if they have any points of clarification or things to add.

90-135 minutes: Case studies/role play

- Participants will be asked to get back into their small groups (3 in total).
- Each group will be given a pre-prepared case study, highlighting common issues in pediatric disclosure for children of different developmental stages.
- Small groups will assign each member a role (e.g. mother, child, and counselor) and will be given 10 minutes: to prepare a disclosure counseling role play.
- Each group will perform their role play in front of the large group (maximum of 5 minutes: each).
- The large group will comment on/discuss key characteristics of the child and the caretaker, what was done well during the role play, and what suggestions they have for improvement on the disclosure counseling.
- After each role play, the hosts will ask participants to place the characters in the case study along the “path to full disclosure” continuum (displayed on flip chart) and will conclude with a brief description of the stages of readiness.
- The hosts will debrief the exercise by asking how participants felt playing the different roles, what was challenging etc.?

135-160 minutes: Brainstorming

- Participants will be asked to think about what they have learned during this session and to draw upon their personal and professional experiences to brainstorm on the key ICAP guiding principles around pediatric disclosure.
- The hosts will record ideas on flip chart.

160-180 minutes: Discussion of country office needs and next steps

- The hosts will ask participants to brainstorm about the needs of their own office and the sites and providers they mentor related to pediatric disclosure (e.g. guiding principles, tools, job aides, etc.). The hosts will record ideas on flip chart.
- The hosts will present the idea of a Technical Working Group on pediatric disclosure, comprised of NY and Country Office staff.

	<ul style="list-style-type: none"> The group will discuss who will be a part of the TWG and what activities the Group will undertake (e.g. to develop and finalize tools and job aides, to formalize the ICAP guiding principles around pediatric disclosure discussed during the session, and to continuously share information on pediatric disclosure).
--	---

Session Notes and Summary

Session name: Disclosing throughout the pediatric lifestage: better practices, tools, and approaches

Note taker name: Kjersti Schmitz

Small group brainstorming and role plays were presented in large group and *Childhood Development and Disclosure Table (attached) distributed for consideration. Suggestion was to combine ideas below with table to enhance utility, although table was not reviewed or discussed in session.*

Major Discussion Points and/or Conclusions:

1. Groupwork

Group 1: Pre-school Age

Domain	Implication	Practical Tips
Cognitive: Level of thought and understanding limited	Negative Effect	Adapt Message (ie, Bad Germ); Defer full disclosure
Emotional: Strong attachment to immediate caregiver	Caregiver must be first person to start the process	Support caregiver with disclosure
Social: Social relationships still within the family	Caregiver must be first person to start the process	Support caregiver with disclosure
Language: Still evolving	Negative Effect	Simple messages

Group 2: Early School Age (6-10)

Domain	Implication	Practical Tips
Cognitive: Concrete thinking; active fantasy thoughts	Understand explanations of sickness and disease	Use cause and effect; storey telling illustrations for disclosure and HIV discussion
Emotional: Low control of emotions; learning to express; beginning of empathy	Verbal expressions are useful to explain feelings; May relate to parents own status	Encourage articulation of feelings; use alternate mode: drawings, play when feelings cannot be expressed
Social: Social world expanded beyond family to friends, and school in particular	Family is still the reference point but other influences are peer group and other adults like teachers. Concern with acceptance by peers	Family counseling and preparation; Identify key adult collaborators – teachers, friend’s parents; consider peer group in messages and support
Language: Well developed	Ability to articulate thoughts and feelings	Use clear language for majority of communication

Group 3: Early Adolescence (11-15)

Domain	Implication	Practical Tips
Cognitive: Ability to understand complex issues and seek information from various sources	Must tell the truth and be the source of information or they will seek it elsewhere (and it may be wrong)	Give basic information about HIV/AIDS, transmission, types, effects, prevention; Always involve parents in strategy
Emotional: Blame others; emotional expressions and quick tempers	Communication important to understand adolescent; fear judgment	Build confidence; non-judgmental approach; anticipate negative response and denial; have patients
Social: Friends are important	Preference for peer group; peer pressure; threat of stigma and discrimination	Peer support groups and educators

2. Child Readiness / Care giver readiness / Family / Community

Consider the factors of individual child and beyond. One way to think about disclosure based on Stages of Change model used with behavior change interventions:

X (no way)--X (considering disclosure)--X (uncertain how)--X (ready to act)--X (disclosure)--X (maintain /reinforce)

May be useful way to think about where people fall, before deciding how to intervene and support.

3. How to support staff to feel more comfortable with issue, and offer better support to supported providers:

Too much clinical focus, but needs psychosocial aspect.

- Pay attention to staff, time, materials, and funding for psychosocial activities and interventions
- Build capacity on family approach (model)
- Integrate units (NY, country level, etc....MDT approach)
- Interested pediatric and adherence/psychosocial working group members to join together to form disclosure technical working group and address other pediatric psychosocial support
- Develop and share tools to work with children and families
- Utilize WIKI to share information and resources

Remaining Questions/Parking Lot Items:

Continue next steps in open space session

Open Space Session Notes

Why is pediatric disclosure difficult?

1. HIV is a stigmatizing illness in most communities
2. Parents and health care workers are uncomfortable talking about sex to children
3. Parents are afraid of how children will react , perception that children are much better off if they are shielded from “bad news”
4. Parents often feel guilty and feel it is their fault that the child is ill. Parents must be able to handle their own guilt and perceptions

5. Kids may manipulate the situation and take advantage of the caregiver
6. HCW morals and values
7. HCW traditionally have not engaged children in their care. Usually tell parents to tell child what they need to do
8. Parents and care givers often do not know what to say and cannot anticipate questions child might ask. Do not want to look stupid in front of the child
9. Cultural and religious beliefs often play into the emotions
10. Lack of trained counselors to help with preparing families for disclosure
11. Children may ask questions that the parent or caregiver cannot answer

Guiding Principles for Pediatric Disclosure

1. Every child is unique; there is no one approach fits all. Message should be tailored to the child's developmental level
2. There is no ideal age when child is ready for disclosure. It should take into consideration the developmental stage of the child and not just the chronologic age.
3. Waiting too long is not good. Earlier is better. Best to start talking about it as early as possible. It is best to disclose before adolescence with all the added complexities of pubertal development and
4. Effective communication with the child based on their developmental level will make it easier with the harder topics
5. Most often children suspect something is wrong. Follow the child's cues
6. Empower families to help with disclosure
7. Disclosure should be planned with the family, care giver and other support person/s in the family
8. It should not be in the heat of an argument or inadvertent
9. Lies should not be encouraged. It is much harder to undo a lie than to live with the truth.
10. Ideally disclosure should take place in the setting where care giver, family and child are most comfortable
11. Adequate preparation with the caregiver/parent, child and family is important
12. Disclosure is not a onetime event, it is an ongoing process which needs to be reinforced at each subsequent visit
13. Use age appropriate language based on the child's developmental level
14. If a child finds out about their HIV status on their own, they are likely to be hurt, lose trust, become depressed and rebel.
15. Children cope better if they are told by a loving caregiver

How can ICAP help?

1. Training of counselors on talking to kids and families
2. Develop comprehensive pediatric counseling and disclosure training material
3. Develop disclosure material for care givers and children (checklists, easy to use scripts, training material, brochures etc)
4. Job aids/ video material on HIV disclosure