

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

Title:	Achievements and future directions in pediatric adherence
Country:	New York
Host Name/Title:	Tayla Colton, Consultant
Session Goal:	To apply a developmental, family-focused approach to pediatric adherence counseling and support in care and treatment programs.
Learning Objectives:	By the end of this session participants will be able to: <ol style="list-style-type: none"> 1. Identify the different stages of child development and common characteristics of each stage. 2. Identify the key challenges to pediatric adherence during each stage of childhood development. 3. Describe the role of the family in pediatric adherence and identify ways to support a family-focused approach to adherence counseling. 4. Identify key strategies for improving pediatric adherence in their respective ICAP programs.
Instructional Method(s):	<ul style="list-style-type: none"> • Introductory exercise • Large group brainstorm • Small group work and report back • Summary and wrap-up
Session Description :	<ol style="list-style-type: none"> 1. Introductions (10 minutes): State name, title and one word to describe how you feel/would feel about supporting a child living with HIV (Note: Participants will not need to disclose whether or not they are caring for a child living with HIV). Facilitators to capture the word on flipchart paper and quickly summarize and introduce the session. 2. Session goal and objectives (5 minutes): Write goal and objectives on flipchart paper in advance and present them to the group. Ask if there are any questions or other expectation of the group. If their expectations can't be met in this session but may be a topic in another, direct them to the other sessions. Otherwise, take note of expectations raised by group. Finish by quickly describing the activities for the session. 3. Large group quick brainstorm (10 minutes): Introduce session by acknowledging that adherence to care and treatment is a challenge for all patients, but pediatric patients have particular issues and needs over the course of childhood. In the large group, ask participants to identify key challenges to adherence for adult and pediatric patients (refer to Table 1 of draft ICAP Adherence Monograph and hand out to participants). 4. Small group work (40 minutes): Introduce the small group sessions by stating that we will now examine ways in which adherence challenges are different for pediatric patients, and that they change depending on the developmental stage of the pediatric patient. Also highlight the fact that pediatric adherence involves parents/guardians and other family members. Divide participants into 2-3 small groups of 3-4. Each group should select someone to take notes during the discussion and someone to report back to the large group. Instruct each group to do the following: <ul style="list-style-type: none"> • Step 1 (10 minutes): Define the different developmental stages of childhood. Using flipchart paper, draw a timeline with the starting point being birth and the end point being the end of childhood (as your group defines it). For each stage, identify some of the characteristics – biologic,

	<p>cognitive and social – related to this stage of childhood.</p> <ul style="list-style-type: none"> • Step 2 (15 minutes): Identify key challenges to adherence during each developmental stage, including family barriers/challenges. • Step 3 (15 minutes): Identify key interventions and counseling messages to support adherence during each developmental stage. When possible, highlight strategies that have been developed and tested in ICAP country programs. Also identify tools that may be needed to support adherence at each stage. <p>5. Report back from small groups (20 minutes): Depending on the number of groups, have each group report back on 1-3 developmental stages. For instance, group 1 would report on infancy – toddler, group 2 childhood - adolescence, etc.</p> <p>6. Wrap-up (5 minutes): Summarize small group reports and discussion and conclude by making the following points (prepared in advance on flipchart):</p> <ul style="list-style-type: none"> • As seen in this exercise, adherence support for pediatric patients needs to be adjusted depending on the developmental stage of the child. • Interventions must account for the influence of parents and families on the success or failure of adherence in children throughout the developmental stages. <p>7. Distribution of the following:</p> <ul style="list-style-type: none"> • <i>Table 1 from draft ICAP Adherence Monograph</i> • <i>Kids Count: Children’s ART Adherence Resource Pack</i>
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Session Notes and Summary

Session name: Achievements and future directions in pediatric adherence

Note taker name: Asqual Getaneh

Major Discussion Points and/or Conclusions:

1. The Developmental Approach to Adherence

Children’s developmental stages have discrete and significant impact on adherence to medicines. The children’s cognitive stage, emotional milestones, ability to communicate, and their social milieu dictate the effectiveness of the care-givers’ and health care workers’ (HCWs) ability in achieving adherence to ART. In addition, the care givers comfort level in caring for a sick child, understanding of AIDS, health beliefs, their resolve to deal with societal stigma and discrimination also determine the success of pediatric ART programs. HCWs might not have adequate training in pediatric ART, drug formulations might not be available and might lack time necessary to train care givers on administering medicines to the child and the challenges associated with each age group. HCWs should explore their own feelings, attitude and knowledge on pediatric care and pediatric ART.

The following table summarizes the thoughts of the participants from the session.

Age	0-1yr	>1-2yrs	3-5yrs	6-9yrs	10-12yrs	13+
Developmental stage	Completely dependent on care giver Non verbal communication	Dependent on care giver but tries to be independent Rudimentary verbal communication Has temper tantrums Sense of separation are magnified	Growing independence But tries to be independent Can separate from care giver Can express self verbally Magical thinking Preschool-school	Independent in many areas of self care Verbal communication and concrete reasoning	Able to take care of self Wide range of expressions and verbal communication Peer centered Interest in exploring sexuality	Abstract thinking Still needs support of care giver Engages in experimentations Sexual, drugs Peer pressure -conformity Rejection of authority Identity separation from care givers conflict with care-givers Also acquires more household responsibilities
Challenges	Dependent on care giver Difficulty administering medicine- lack of appropriate formulations Frequency of infant illness Other medical visits-immunization Care providers' discomfort with giving drugs to children Lack of adequate	Completely dependent on care giver Difficulty administering medicine- lack of appropriate formulations Frequency of childhood illness Other medical visits-immunization Care providers' discomfort with giving drugs to children	Still dependent on care giver Does not completely understand illness but gets distressed Disclosure concerns (how much and when) School related issues- Stigma and lack of adequate knowledge re medicines loss of a parent ,	Concrete reasoning School related challenges Disclosure concerns Children can be cruel- Loss, grief, depression Illness of a parent and the child may take responsibility Increasing focus on peers	Disclosure concerns Loss, grief and depression Illness of a parent Child-household heads	Disclosure concerns Loss, grief and depression Rejection of medical care Medication fatigue Peer influence Concern over appearance Drug and alcohol influence Economic concerns More family responsibilities for younger siblings and ill parents

	<p>knowledge-care providers Poor counseling Cultural beliefs about taking children out of the house</p>	<p>Lack of adequate knowledge-care providers Poor counseling Cultural beliefs about taking children out of the house</p>	<p>not understanding death illness of a parent</p>			
<p>Strategies/ solutions</p>	<p>HCW and care givers education on medication administering- syrups, syringes, masking bad taste of medicine Color coding medicine Help care giver deal with childhood illness Feeding difficulties</p>	<p>HCW and care givers education on medication administering Helping the child take medicine- providing treats Masking taste</p>	<p>HCW and care givers education on medication administering Helping the child take medicine- providing treats Understanding side effects Taste of medicine still an issue so helping the children be involved in how they want to take the medicine Taking tablets Setting up routines Educating teachers and involving them in the care of the child Helping the children understanding their</p>	<p>HCW and care givers education on medication administering Helping the child take medicine supervised but independently, Understanding side effects Can take tablets Setting up routines Educating teachers and involving them in the care of the child Helping the children understanding their illness and other's reaction</p>	<p>Educating parents on the child's need for independence, peer influence, school related concerns Enable care givers to help children be actively involved in their care, give them choices Help children in disclosure Involve teacher/schools Help children Help care givers understands sexual developmental stage and start</p>	<p>Pre-ART evaluation of adherence risk, social and home challenges Clear explanation of ART and involving the adolescent on timing of initiation of treatment Educating parents on the child's need for independence, peer influence, school related concerns Enable care givers to help the adolescent be actively involved in their care, understand the developmental stage, deal with difficult behavior, rejection, risk taking behavior that may lead to non adherence Help adolescents with disclosure Involve teacher/schools Help adolescents in making life choices that may impact adherence-drug/alcohol Educate the adolescent on side</p>

			illness and other's reaction		discussing sexuality	effects of medicines and Discuss sexuality need for contraception, and condom use
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