

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

Title:	Not a child and not an adult: What ICAP can do to meet the needs of adolescents
Country	New York
Name/Title:	Nancy Briggs, Clinical Implementation Officer
Session Goal:	To share and understand emerging issues, promising interventions, better practices and technical/program support needs to consider best meet the needs of the adolescents living with HIV
Learning Objectives:	<ol style="list-style-type: none"> 1. Identify challenging issues in HIV care and treatment for adolescents 2. To describe different approaches to address the needs of adolescents 3. Identify approaches which are adaptable 4. To identify areas where ICAP-NY can assist programs in meeting the needs of adolescents.
Instructional Method(s):	<ul style="list-style-type: none"> • Discussion • Brainstorming
Session Description :	<p>0-15 minutes: Values clarification activity Health systems values related questions</p> <ul style="list-style-type: none"> • Adolescents should be hospitalized in a pediatric wards • Adults will never be able to counsel adolescents • Adolescents do not have reproductive health related issues • Disclosure is not an issue for adolescents • We have so few adolescents that we should not direct special services to them • Adolescents are not mature enough to participate in their service plan <p>16-30 minutes: Each participant will describe:</p> <ul style="list-style-type: none"> • their programs challenges in providing care to adolescents • interventions undertaken to address the challenges • outcome of interventions <p>30-60 minutes: Group Work</p> <p align="center">Case Study</p> <p>Yetunde is a 14 y.o. female. It is presumed that her HIV infection is as a result of perinatal infection but it is not clear since she is also sexually active. Both parents died prior to her 10th birthday and she does not know the cause of death and her family only says that they both became very ill.</p> <p>Yetunde only became aware of her status during a hospitalization for malnutrition last year. Subsequent to her hospitalization, she has been started on ARVs and has been doing fairly well. She has missed several appointments in past few months and seems withdrawn when sitting in the waiting room of the clinic. Although there are support groups, she has not participated in any other than those required for initiation of treatment. Yetunde medical care is being provided by Dr. Joseph Ntebele in the adult ART clinic. Yetunde attends clinic on her own since her relatives are busy working and cannot afford transport to the clinic. Yetunde has not told any of her friends about her HIV.</p> <p>Break into 3 groups to:</p> <ul style="list-style-type: none"> • identify challenges in the case • present possible solutions <p>What would have to be present at site level to implement the interventions:</p> <ul style="list-style-type: none"> • Competencies for MDT members: nurses, counselors, doctors, lab techs., etc • What would be the challenges in programs to implement the interventions? • How can ICAP-NY support implementation of interventions

	61-90 minutes: Groups report back
	Participants are requested to reflect on their personal experience of adolescence and come to the session prepared to discuss: <ul style="list-style-type: none"> • Different aspects of adolescence • What if any impact having HIV would have had on their adolescence

Session Notes and Summary

Session name: Not a child not an adult

Note taker name: Stephen Arpadi

Major Discussion Points and/or Conclusions:

A. The major developmental changes during adolescence?

1. Physical body changes
2. Sexual awareness
3. Increased importance of peers
4. Separation from family/growth toward independence
5. Feelings of indestructibility/limited judgment and risk taking behavior
6. Mood changes
7. Time of experimentation with alcohol, drugs, sex

So, adolescence is time of great transition in all spheres: physically, socially, emotionally, and psychologically

B. What effect does HIV have on an adolescent?

1. Physical changes in body can be delayed of “different” due to either disease itself or ARVs
2. Feeling different than peer/ may lack peer/feel apart from peers
3. Sexual development (psychologic) may be impaired due to HIV (exemplified by the following comment made by a father: “Doctor please tell my son that when it comes to sex he’s a loaded gun”)
4. Exaggerated moodiness anger depression related to having HIV
5. Increased risk for psychiatric problems
5. Increased risk for learning disabilities

C. Values exercise for the group and consensus:

1. HIV infected adolescents should be hospitalized in pediatric units
Disagree, ideally if resource provide, adolescents should be provided “adolescent friendly services”
2. Adults can never provide counseling to adolescents
Disagree, adult HCW must become competent and skilled in counseling methods for adolescents.
3. Adolescents do not have reproductive, family planning, sexual health issues
Disagree, adolescents often are in need of these services
4. Disclosure is not really an adolescent issue.
Disagree. Disclosure is critical for this age group and has significant implications for adherence, peer relationship, sexual and reproductive (and public health).

5. We have so few adolescents we should not direct a lot of resources to them. Disagree, as in an appropriate amount of resources should be apportioned
6. Adolescents are not mature enough to participate in their care and treatment plans. Disagree, there will be considerable variability as to when along the way adolescents can but ultimately the goal is to increasingly involve adolescents in their own care and to foster achieving independence and autonomy.

D. Country reports on status of care services for adolescents:

1. Lesotho: special care services available only at the National Hospital but there has been little experience. Here adolescence can obtain services with good deal of independence and there are legal provisions to permit this.
2. Swaziland: Typically adolescents are treated in adult health care settings including HIV/ART services. There is little activity planning or consideration so far regarding adolescent-specific services.
3. Rwanda: More than 50% of pediatric patients are >5yrs so this needs to become important agenda. Efforts are made when possible to keep children care organized by age group for example during hospitalizations.
4. South Africa: Typically once age 14 yr is reached patients are transferred into adult care settings which are known in some cases to be difficult. There is increasing awareness of the need for developing “adolescent friendly” services and there are some few already in the Cape Town area but not sufficient for need.
5. Nigeria: There are enormous cultural differences related to adolescence in the country. In the North girls are often married at ages 16 or younger. So adolescence is not a very socially relevant concept.
6. Mozambique: There are no adolescent oriented health care services except a few in the large cities. Once age 14 is reached, care switched to adult services.
7. Kenya: There exists independent adolescent oriented family planning and reproductive health services that are available to adolescence but no HIV care and treatment adolescent specific services.
8. Tanzania: Adolescence does have access to reproductive health and STI care and treatment. There is at least one skilled nursing residential type facility “Children of Hope” for HIV infected children and this cohort is growing in age and so has been accommodating services for these aging patients. In their country context there is a defined somewhat overlapping categories of adolescent (age 11=19yrs) and young person (age 15-24).

There was a strong consensus in the group that increasing adolescent services was desirable and necessary.

E. Summary of Case Discussion by 2 breakout groups:

Issues/concerns	Approach	Site competencies	Implementation challenges
Sexually active	Family planning services	Family planning related knowledge and skills	Training , materials and supplies (e.g. condoms) ?medico-legal in some places
Orphaned	Link to services in the community or grants	Able to access/linkages to CBO etc for patients	Such resources may not be available or are very

			limited in nature
Malnutrition	As above	Nutritional assessment and linkages to community resources and support	Limited resources for nutritional support in the community
Withdrawn-concern about depression social isolation	Psychosocial assessment and care and support	Adolescent appropriate skills in counseling assessment support in areas of adherence, disclosure etc, Group support also would be helpful	Staffing training , retention of appropriate health cadre, retention etc
Lack of support/ non-disclosure	As above	As above	Stigma in community and among health providers
Being treated in adult ARV clinic	More' adolescent friendly' care environments	As Above	Limited facilities and financial resource-great cost for few patients

E. Next Steps:

1. Advocacy at National and state and with in community for re: need for services for HIV infected young people and for clarification or develop of supportive laws and policies in health education and other sectors of society
2. Even where resources (or demand) don't permit development of specific adolescent services, short-term goals should include adapting environment for adolescents
 - a. Sensitization increasing awareness of site staff.
3. Developing training approaches and materials for all levels of care cadres to enhance counseling skills and competencies for counseling adolescents (it is recognized that local adaption will be important in virtually all adolescent related areas.)
4. NY should develop adolescent SOC and list of skills competencies and basic training materials to begin instilling these into the pediatric and adult care settings.
5. Psycho-social support for adolescents should be included in training.
6. Develop and disseminate tools for screening for sexual violence and rape
7. A proactive programming approach rather than a reactive approach was advised and that for many at the workshop the opportunity to be forward think and staying "ahead or the curve" in our thinking and programming rather than trying to "catch-up" was enthusiastically embraced.