Adherence Counselling for Children at the LAC

National AIDS Control Organization
Session objectives

- List the reasons why CLHIVs require counselling
- Identify children with developmental delays and take appropriate actions
- Demonstrate interactive strategies for working with children and describe appropriate uses for them.
- Discuss age-appropriate ways to handle disclosure of HIV status to children
Issues and challenges faced by CLHIV

- Harm to maturing immune system
- Difficulties in communication
- Physiological changes
- Frequent change of caregivers
- Growth problems
- Dependency on adults for treatment
Paediatric HIV treatment

- Paediatric HIV treatment is specialized ART treatment for children up to the age of 14 years.
- Treatment of paediatric HIV infection is more complicated than that of adults: physical, psychological & family issues.
How counsellors can support children

- Counsel children to cope with their infection and look after their health properly

- Counsel caregivers to support children

- Provide a comfortable and friendly environment at the centre for children and caregivers
Working with children

- Understanding children
  - Growth & Development
  - Perceptions & emotions
- Using effective strategies for communication
  - Drawing, story telling, puppetry.
- Developing personal qualities for working with children
- Making the centre-child friendly
Child-Centred Counselling

- Focus on the child’s issues and concerns from perspective of child as well as caregiver
- Oriented to build capacity of the child to understand and cope with their life situation
### Activity

- Turn to your handouts and fill in the table. Refer to your ICTC Refresher Handouts.

<table>
<thead>
<tr>
<th>Situation</th>
<th>Is this child facing a developmental delay?</th>
<th>When would a &quot;normal child&quot; complete this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ishani is 5 months old. When her grandmother holds her, her head falls to the side.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Afsaana is 2 years old. He can walk without holding the wall.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dhanesh is 18 months old. He has just learned to sit up.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Balbir Kaur was born 6 weeks ago. She delights her family with her new development – smiling.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bhavna is 3 months old. She has begun sliding around and will learn to turn over in a few days.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kamlesh is 6 months old. He is very pleased at his new trick – moving his rattle from one hand to the next.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Developmental milestones

Developmental delay: Expected progress is not present at any specific age

Inform the treating doctor

Smiling  Controlling the head  Rolling over  Transferri ng object from one hand to another hand  Sitting  Walking with help

Birth  6 weeks  10 weeks  14 weeks  6 months  9 months  12 months

Activity

- Turn to your handouts and fill in the table. Match Counselling to the Developmental Milestones Refer to your ICTC Refresher Handouts.

<table>
<thead>
<tr>
<th>Situation</th>
<th>3–6 years</th>
<th>6–9 years</th>
<th>9–12 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICTC Clients</td>
<td>Example given</td>
<td>Example given</td>
<td>Example given</td>
</tr>
<tr>
<td>LAC Clients</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
How to explain about HIV and ART to children?

- **3-6 years**
  
  “You are not well. If you want to play, you should be well and for that you need to take medicine”

- **6-9 years**
  
  “You have got a germ inside your body. That germ is making you fall sick often. To kill that germ you need to take medicine everyday. The germ will become strong when you don’t take medicine”

- **9-12 years**
  
  “There is a germ in your body. It reduces your body’s ability to fight against other infections. We cannot remove it from your body. But we can control it so that you can stay healthy. For that you must take medicines regularly.”
Interactive communication strategies

- Help the child to understand what you are trying to communicate
- Maintain the child’s attention during the session
- Explore sensitive issues
- Create a safe environment to talk

Important slide

You learned about this in ICTC Refresher. You will get an opportunity to practise.
Activity

- Read the table titled “Helping Children to Manage their Emotions” in the ICTC Refresher Handouts.
- Read the situations.
- Identify the emotion and prepare a role-play on how to help the client manage it. The trainer will tell you which type of interactive communication strategy you should use.
- Answer the questions at the end.
- You will have a lot of time to prepare and practise.
Personal qualities for working with children

- Ability to maintain confidentiality
- Ability to understand emotional needs and provide support.
- Non-judgmental attitude
Child-friendly LAC

• What can **YOU** do to make your centre child-friendly?
  - A small blackboard at the child’s level
  - Notice-board with paintings by children
  - Drawing paper and other art material
  - Inexpensive games and toys for children
  - Story books
  - Some festival decorations
  - Coloured pictures from magazines/newspapers of popular sportspersons or animals
Tips for child friendly LAC

Story Books

Posters

Toys
Example of a Child-Friendly Centre

Photographs courtesy Dr. Suresh Shastri, Regional Co-ordinator, Karnataka
Activity

- Instructions for the Quiz on Disclosure. Please read the section on Disclosure in your ICTC Refresher Handouts. There will be a quiz on the same tomorrow.
ADHERENCE
COUNSELLING FOR CHILDREN
Objectives of adherence counselling

Educate child and caregiver about treatment

Prepare child and caregiver for treatment and life-long adherence

Monitor adherence and support to maintain it.

Identify different barriers to treatment and help to overcome them
Counselling the child

- The information provided to the child should be based on:
  - the age of the child
  - level of understanding of the child
  - disclosure of HIV status
Treatment preparedness counselling: 5As

Assess
- Child’s and caregiver’s understanding
- Child’s knowledge about HIV status
- Potential barriers and social support systems

Assist
- Planning for adherence and treatment

Advise
- Implications of treatment
- Importance of adherence and follow-up visits
- Importance of following the doctor’s instructions

Arrange
- Required investigations
- Referrals

Agree
- Treatment adherence plan
- Disclosure to the child
Preparing caregiver

- Identify **WHO** will administer the medicines
- Explain **WHAT** medicines will be given
- Specify **WHEN** the medicines should be given/taken
- Provide details on **HOW** the medicines will be given/taken
Commencement & Follow-up

- Commencement stage
  - Treatment education
  - Identifying strategies
  - Preparing & agreeing on treatment plan

- Follow-up stage
  - Adherence monitoring
  - Addressing barriers to adherence
  - Monitoring of growth and development
Monitoring children’s adherence

- Pill count
- Report by caregiver
- Refill boxes
- Checking pill charts/calendars/diaries
- Interactive strategy
  - Drawing, story telling, role play
Using ART Calendar/Diary

Don't forget to see me twice a day: Once with sun and once with moon

Dear Child:
- Sun: Colour the box in the morning after taking the dose
- Moon: Colour the box in the evening after taking the dose

Supported by WHO India
Factors affecting the child’s adherence

- Dependency on adults
- Taste, smell and colour of medicine
- Interest in experimenting with treatment
- Emotional factors
- Using medicines to manipulate adults
- Other infections and medications

Knowledge and understanding of HIV/AIDS and treatment
- Misconceptions regarding treatment
- Health beliefs
- Daily routine
- Attitude towards adherence
- Relationship/closeness with the child
Adherence fatigue

I can’t take these medicines

I don’t like the taste of these pills

My friends are not taking it. It is only me taking medicine like this

My head is paining

I feel like vomiting
Adherence fatigue in children

- **Child**
  - Marked change in the confidence level and attitude to treatment.
  - Expression of “feeling bad”.
  - Symptoms of psychological distress
  - Repeated or severe side-effects of medication

- **Caregiver**
  - Feeling tired of administering/supervising medication.
Adherence counselling for children at LAC

First Visit to LAC

Follow-up visits

Session prior to visit to Nodal ART Centre

Adherence Monitoring and Follow-up Counselling
Counselling Checklist

- Building rapport with child and caregiver
  1. Warmly greet the child and caregiver
  2. Ask the caregiver to introduce the child ("May I know whom you have brought with you?")
  3. Ask the child's name and other personal details in a warm way ("May I know your name?", "It is a nice name", "Who all are there in.....'s home?", etc)

  4. Children may like physical closeness. If the child is comfortable, gently touch the child on shoulder or head.
  5. Tell the child that you would like to talk to the caregiver for some time.
  6. Engage the child with some activity and talk to the caregiver.
  7. Obtain the details of the caregiver.
  8. Elicit details about the child's family and the HIV status.

- Address different concerns regarding shift in centre
  9. Ask the child about the experience with the ART Centre. Explain that this is also a similar centre and he/she can be comfortable here.
  10. Inform the caregiver that the services and medicines are the same and all personnel in the centre are trained. Also inform them that the child can return to ART centre, if any illness or side effect develops.

  11. Assure the caregiver about confidentiality. Also inform about the shared confidentiality and who on the LAC team will be informed about the child’s HIV status for treatment purposes.

- Collect details of and child’s and caregiver’s understanding about the treatment
  12. Collect the details of current treatment (You can use the White Card and also ask the caregiver)
    - Drugs and dosages
    - Method of administration
  13. Assess what the child knows and feels about treatment ("What do you understand about going to the clinic/taking medicine?", "Can you tell me how you feel about coming here?")
  14. Assess what the child feels about being sick often ("What do you understand about falling sick often?", "How did you feel when you fell sick last time?")
Counselling during child’s initial visit to the LAC

- Build rapport with the child and the caregiver
- Address shift-related concerns
- Assess child’s awareness about HIV status
- Assess child’s and caregiver’s understanding about treatment
Counselling during child’s follow-up visit to the LAC

- Adherence
- Developmental milestones
- Disclosure
- Diet and nutrition
- Support systems
DISCLOSURE COUNSELLING
Disclosure of HIV status to children

- The process by which a child’s HIV status is shared with the child.
Disclosure counselling

QUIZ TIME

BASED ON YOUR ICTC REFRESHER HANDOUTS
Less than 1 out of 5 Indian children on ART know their HIV status.

True
Is this person eligible for LAC Plus services?

A child who does not know her/his ART status will show better adherence than a child who knows...

False
Say if the statement is true or false

A child client has a right to know their HIV status.

True
Is this person eligible for LAC Plus services?

A counsellor who facilitates disclosure will tell the child client his/her HIV status on his/her own.

False
Is this person eligible for LAC Plus services?

It is best to do disclosure in one session.

False
Is this person eligible for LAC Plus services?

It is sufficient to tell a child once their HIV status for them to understand properly.

False
Is this person eligible for LAC Plus services?

To prepare a caregiver to disclose to the child, it is necessary to use puppets. 

False
Is this person eligible for LAC Plus services?

Providing the child with complete information about HIV status & implications for their health is called partial disclosure.

False
Each group should name one

Barriers that caregivers face to disclosure
Each group should name one

Helpful suggestions to give caregivers about disclosure
Role of counsellor in disclosure

- Check whether child is aware of the status
- Encourage caregiver to disclose
- Enable caregiver through practice sessions
- Disclose to child with the consent of caregiver
When to disclose

- No perfect time
- Determine based on
  - Developmental level
  - Emotional maturity
  - Preparedness of caregiver
How to disclose

- Break down information to the child’s level
- Use interactive communication strategies
- Repeat concepts over time
- Repeatedly initiate health-related conversations
- Be prepared for the child’s reactions
Activity

- Fish-bowl exercise on Disclosure counselling
Activity

- Story Telling Practice