- Disclosure should ideally be a gradual process over many years, advancing from partial disclosure to full disclosure, post-disclosure, and ongoing support.
- Ideally full disclosure should take place between 10 and 14 years old if the child is of normal cognition and maturity, making sure that it is done before sexual debut.
- The parent or caregiver (PCG) should be prepared for disclosure and supported through each step by the healthcare worker (HCW). PCGs should decide what role the HCW should play.
- The HCW/PCG should make sure to use age-appropriate language, pictures where possible, excellent counselling skills, be aware of emotions, use a private space, and refer to psychologists and social workers when necessary.

Failure of full disclosure by early teenage years can lead to:

- Poor adherence
- Emotional difficulties
- Poor school performance
- HIV transmission if sexually active
- The adolescent finding out their HIV status through other mechanisms
- Psychological issues if disclosure is not sensitively done

No disclosure yet (0 — 4 Years)

- Conduct the consultation with the child present (but do not mention the word HIV if the child can understand the conversation)
- The child is too young for direct information about HIV but explanations to the caregiver about how HIV can affect the child remain important.
- Provide ideas to help the caregiver support the child taking medicine. Congratulate the child on taking their medicines well.
- Address the caregiver's anxieties and inform them that in time you will support them through the partial and full disclosure process as outlined below.
- Provide a safe and welcoming clinic and build a relationship with the child through play/singing.
- Warn the PCG that when the child starts asking questions about why they must take medicine, they should give the information described under partial disclosure below. They should try not to lie and name other illnesses as the reason for needing medication.

Partial Disclosure (5-9 years)

- The child needs to learn about illness and why they must take medicine but not HIV by name yet.
- Introduce the concepts of good and bad health. Talk about how good health can be promoted by eating healthy food, keeping clean, exercising, looking after teeth etc. Explain that medicines help to keep a body healthy and strong.
- Introduce infections as 'germs' that can damage the body/make you sick and (white) blood cells as the part of the body that look for and kill germs.
- Explain that some germs hide, and you need to take medicines to help fight the germs or explain that they were born without enough white blood cells so they need to take medicine every day to make their white blood cells increase so that they can stay healthy and are able to fight the germs
- Advise PCG that they can start teaching their child about HIV and other illnesses without telling them that they have HIV, so that the child learns correct information about HIV and not the negative myths (see the 5 points in the red box below)

Before Full Disclosure:

- Assess the adolescent's cognitive and emotional maturity (if they are passing school at the appropriate level for their age, they can be assumed to be of normal cognitive maturity)
- Prepare the PCG for full disclosure
- Get consent to disclose the adolescent's (and PCG's) HIV status. It is preferable to disclose the PCG's status as well, but not essential if the PCG requests not to.
- Find out what the adolescent knows about HIV already before disclosing to them.
- Educate them about HIV and dispel the negative myths:

Children and adolescents living with HIV (C/ALWH) often learn negative myths about HIV from their community, their friends and school, such as "HIV kills", "people with HIV are promiscuous or bad" and "people with HIV can't live a normal life". It is therefore extremely important to educate C/ALWH and dispel all of these myths before you tell them they have HIV. Different ways of educating them include teaching them about a few different illnesses, holding education sessions in the clinic or telling their parents to teach them about HIV at home from a young age. Five important things for them to understand include:

1. These days we have very good treatment for HIV, so people living with HIV (PLHIV) can remain perfectly healthy and never get AIDS.
2. PLHIV can live as long as people without HIV if they take their treatment every day.
3. Anyone can have HIV and it does not make them different/bad. Many people around you have HIV and you do not know because they are just as healthy as those without HIV.
4. PLHIV can have relationships and have children, and if they are taking their treatment and have a suppressed viral load, they will not transmit HIV to their sexual partner or children.
5. Living with HIV does not prevent people from living a completely normal life and following any career they want.

Full disclosure:
Ensure they first understand points 1- 5 in the box above before you explain that:

- They were born with a germ/virus called HIV, which can kill their white blood cells so they can't protect their body from other germs.
- The medicine they receive works very well at making the HIV virus sleep so that it can't kill white blood cells. That way the body is well protected from other germs and you won't get sick.
- If you don't take your medicines every day the HIV virus can get stronger and prevent the medicines from working
- They need to understand their responsibility for not transmitting HIV e.g. safer sex, and family planning

Once the adolescent has been disclosed to it is very important to offer for them to join a support club, answer any questions they have, let them express their emotions, and make sure they understand the following things:

- Repeat the 5 points mentioned in the red box above, now relating to the adolescent themselves.
- It is not their mother's fault that the adolescent got HIV. When their mother was pregnant we did not have such good medicine, so many babies got HIV from their mothers, but nowadays we have very good medicine so if an adolescent wants to have a baby one day the medicine will be able to prevent their baby from getting HIV.
- It is not their parents' fault they have HIV: millions and millions of people in the world have HIV and they did nothing wrong and they are no different to anyone else. You can't tell who has HIV by looking at them because they will be healthy when they are taking their medication.
- They are allowed to keep their HIV status a secret, and are allowed to lie about it if their friends or strangers ask, because some people don't know enough about HIV and might treat them differently or think that it means they are going to be very sick. It is up to them and their PCG to decide who they think deserves to know.
- When they are ready to have a boyfriend/girlfriend or become sexually active they can come to the clinic to discuss how or when they would like to tell their partner about their HIV status.
- They should know how much their PCG loves them and be grateful for all the effort they put in over the years to make sure that they took their treatment every day to keep them healthy. This is a good opportunity for the child to thank the PCG and for them to tell each other how much they love them and give each other a hug.
- They must feel free to come into the clinic any time to ask any questions they have or discuss anything they are struggling with.

Post Disclosure (10-19 years)

- During follow up visits after full disclosure the information mentioned under "Full Disclosure" will need to be repeat many times as the C/ALHIV will not remember everything, might be in denial, might have since heard conflicting information, and will develop a deeper understanding of the information as they get older.
- They must feel free to ask any questions they might have.
- It is very important to assess their mental health and how they are coping with the information and with adolescence in general.
- Discuss whether they have or would like to disclose their status to friends or partners.
- Ask (privately) if they are sexually active or are thinking of becoming sexually active. Educate about safe sex, condom use, and family planning.
- Repeat information about the importance of taking medication every day to stay healthy and avoid development of drug-resistant HIV.

For more details on disclosure, please refer to the Differentiated Care Models Standard Operating Procedures 2023 SOP 3: Child and Adolescent Disclosure Counselling or contact the Right to Care Helpline on 082 352 6642