

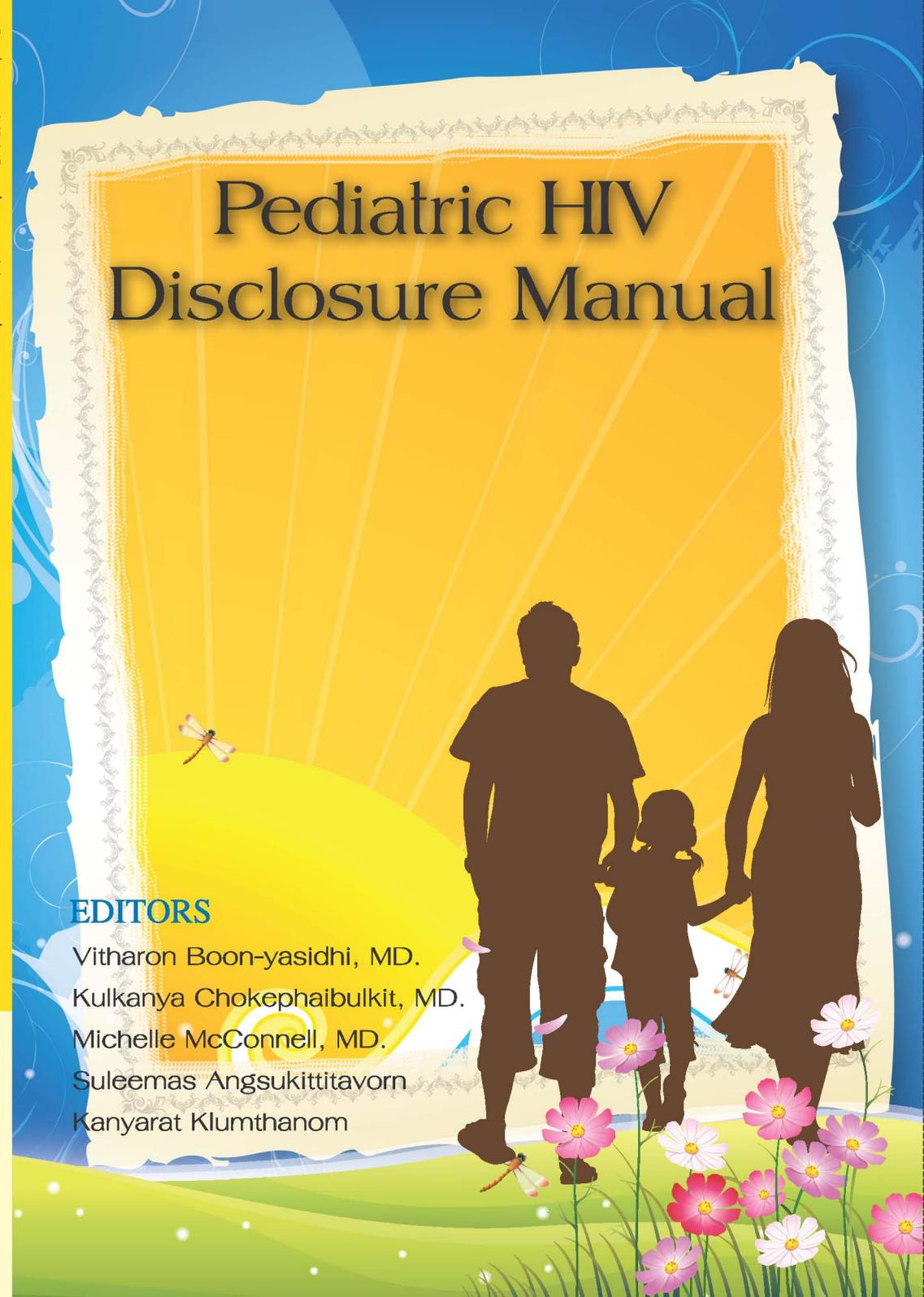
Department of Pediatrics, Faculty of Medicine,
Siriraj Hospital, Mahidol University
Queen Sirikit National Institute of Child Health,
Department of Medical Services,
Thailand Ministry of Public Health

In partnership with the
Thailand MOPH – U.S. CDC Collaboration

Pediatric HIV Disclosure Manual

EDITORS

Vitharon Boon-yasidhi, MD.
Kulkanya Chokephaibulkit, MD.
Michelle McConnell, MD.
Suleemas Angsukittitavorn
Kanyarat Klumthanom



Pediatric HIV Disclosure Manual

EDITORS

Vitharon Boon-yasidhi, MD.

Kulkanya Chokephaibulkit, MD.

Michelle McConnell, MD.

Suleemas Angsukittitavorn

Kanyarat Klumthanom



Pediatric HIV Disclosure Manual

ISBN : 978-974-297-994-2

© Thailand MOPH – U.S. CDC Collaboration

First edition 2010

Written and edited by

Department of Pediatrics, Faculty of Medicine,
Siriraj Hospital, Mahidol University
Queen Sirikit National Institute of Child Health,
Department of Medical Services,
Thailand Ministry of Public Health
Thailand MOPH – U.S. CDC Collaboration

Printed by

Aksorngraphic & Design Publishing House, Thailand.

Thailand Pediatric HIV Disclosure Working Group

Faculty of Medicine, Siriraj Hospital, Mahidol University

Bunnada (Uraporn) Kotrapat	Thanapon Nimsomboon
Karakate Yenikorn	Vitharon Boon-yasidhi, M.D.
Kulkanya Chokephaibulkit, M.D.	Wasana Prasitsuebsai, M.D.
Pornwilai Urajchachairat	Wimon Anansakunwatt
Sirijit Kanakool	Yuitiang Durier

Queen Sirikit National Institute of Child Health

Juree Uthaichalanont	Slunluck Inbumrung
Nawaporn Vimolsarawong	Sujinda Yadech
Parinda Senirattanaprayoon	Siriniran Iamlaor
Pimsiri Leowsrisook	Umaporn Chantbuddhiwet, M.D.

Thailand MOPH – U.S. CDC Collaboration

Chanidapa Yuvaseeve	Suleemas Angsukiattitavorn
Kanyarat Klumthanom	Wipada Nuchanard
Thananda Naiwatanakul	Waraporn Suwannapha
Sujira Jaranchavanapet	

Advisors

Faculty of Medicine, Siriraj Hospital, Mahidol University

Nirun Vanprapar, M.D.	Chief, Dept. of Pediatrics
-----------------------	----------------------------

Queen Sirikit National Institute of Child Health, Ministry of Public Health

Naris Waranawat, M.D.	Physician, Dept. of Pediatrics
Tawee Chotpitayasunondh, M.D.	Senior Consultant

Thailand MOPH – U.S. CDC Collaboration, Global AIDS Program

John Henderson	Editor
Rangsim Lolekha, M.D.	Chief of PMTCT and Pediatric Section
Michelle McConnell, M.D.	Senior Technical Advisor

Preface

In 2005, the Department of Pediatrics, Faculty of Medicine, Siriraj Hospital; Queen Sirikit National Institute of Child Health; and the Thailand MOPH – U.S. CDC Collaboration (TUC) started a project known as “Promotion of Antiretroviral Adherence and Development of an HIV Disclosure Model for HIV-Infected Thai Children Using a Multidisciplinary Approach.” As the name suggests, the objective of this project is to develop and assess an educational model for promoting antiretroviral (ARV) adherence and preparing children and families for HIV disclosure.

There has been growing awareness of the importance of and the need for setting up a plan for disclosing HIV status to HIV-infected children. As these children grow up, they need to learn how to maintain their health, and especially how to take ARV medication correctly, continuously, and regularly. They will not be able to do this well unless they can learn about the status of their illness, their health, and the appropriate method of treatment and care. Because HIV infection and AIDS are often viewed as life crises, many factors must be taken into consideration during the process of HIV disclosure to children. One of these factors is the appropriate age range when children are ready—physically, emotionally and socially. At the same time, the caretakers and families must be ready to work together with healthcare providers to let the children know about their health status.

(A note on the use of “he” and “she” in this book: to be inclusive, the authors consciously use both pronouns. Instead of employing the awkward “s/he,” or “his/her,” sample dialogue balances references to girls and boys in alternating chapters.)

The Pediatric HIV Disclosure Manual is prepared based on clinical experiences and a review of the literature. Counselors may use it to guide counseling services for children and their caretakers to ensure readiness for HIV disclosure. The working group hopes that this manual will serve everyone involved in pediatric HIV/AIDS care.

Pediatric HIV Disclosure Working Group
June 2010

Acknowledgements

This Pediatric HIV Disclosure Manual and the related tools and materials are part of the project known as “Promotion of Antiretroviral Adherence and Development of an HIV Disclosure Model for HIV-Infected Thai Children using a Multidisciplinary Approach.” These resources would never have been produced successfully without the cooperation of the caretakers and HIV-infected children who attended the infectious disease clinics at Siriraj Hospital and Queen Sirikit National Institute of Child Health.

The personnel and project staff at these two hospitals have also made helpful contributions. The Project Working Group is very grateful for the efforts of these people in driving the development and improvement of services over the past three years while this manual and training curriculum were being established and produced.

We would like to thank Ms. Bongkoch Jetsawang and Ms. Chariya Utenpitak, the counselors with the Thailand MOPH – U.S. CDC Collaboration, for reviewing this manual and making suggestions for improving the contents. Also, we would like to thank Ms. Chuenkamon Setthabuttra, a Project Coordinator, and the working group of the Pediatric HIV/AIDS Care Model and Network Development Project (CT2), Bureau of AIDS, TB and STI, Thailand MOPH, for their coordination and financial support of the publication.

 **ontents**

Working Group	III
Preface	IV
Acknowledgements	VI
Chapter 1 : Importance of Pediatric HIV Disclosure	I
Chapter 2 : Service Delivery System for Pediatric HIV Disclosure	7
Chapter 3 : Counseling Principles for Pediatric HIV Disclosure	12
Chapter 4 : Pediatric HIV Disclosure Model	20
Chapter 5 : Identification of Children Who Meet Program Criteria and Proposal of Disclosure Counseling to Caretakers (Disclosure Process Step 1)	25
Chapter 6 : Caretaker and Children's Readiness Assessment and Preparation for Disclosure (Disclosure Process Step 2)	31

Chapter 7 : Disclosing HIV Status to Children in a Counseling Session (Disclosure Process Step 3)	49
Chapter 8 : Post-Disclosure Monitoring and Evaluation of Children and Caretakers (Disclosure Process Step 4)	67
Chapter 9 : Partial Disclosure	74
Appendices	79
A) Basic Knowledge About HIV/AIDS for Counselors Working on Disclosing HIV Status to Children	80
B) Frequently Asked Questions by Children Related to HIV Disclosure	90
References	94

A decorative blue banner with a light blue map of Thailand in the background. The text "Chapter 1" is written in a black, serif font in the center of the banner.An icon consisting of four small circles in a 2x2 grid. The top-left circle is grey, the top-right is blue, the bottom-left is blue, and the bottom-right is grey.

Importance of Pediatric HIV Disclosure

The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated in 2008 that around the world there were two million children under 15 years of age living with HIV/AIDS. In Thailand the number was estimated to be 14,000.¹ At least 6,000 of these were receiving antiretroviral treatment (ART) under the national program. Thanks to improved access to ART, these children are living longer.

Many hospitals taking care of HIV-infected children find that as such children grow up, they become suspicious of their illness. They wonder why they have to come to the clinic, why they have to take medicine and test their blood. Some children are teased about symptoms such as certain skin lesions. Neighbors may ask about their illness because it is known that their parents are AIDS patients.

As pediatric patients start engaging in society there is also the chance that they will learn about their infection by chance, or learn about it inadvertently from the media. Children watching television programs related to HIV may compare a drug shown on TV with their own medicine. Their self-esteem may be damaged by prevention efforts that portray HIV as a frightening disease. Disclosing HIV status to children in a systematic manner plays an important role in helping children to accept their diagnosis and to take an interest in their own health care.

Currently in Bangkok, of 250 cases of HIV-infected children at Siriraj Hospital and 220 cases at Queen Sirikit National Institute of Child Health (QSNICH), more than 30% of those receiving ART are older than 10 years of age. The oldest child who acquired HIV through mother-to-child transmission (MTCT) is now 20 years old. Young people are comparing themselves with friends at such ages, often forming close social or sexual relationships. They need to be educated about their illness before becoming contributing members of society.

The data from Thailand and overseas reveal that most HIV-infected children did not know their HIV status prior to disclosure. In some studies, only 30-60% of older children were informed about their HIV status.²⁻⁴ The main reasons that healthcare providers and caretakers do not disclose HIV status to children include fear that disclosure will cause psychological harm to children, belief that the children are too young to understand the diagnosis, fear of social segregation, and fear that the children cannot keep their HIV status secret. Some caretakers' feelings of guilt

and sadness about having played a role in their children's disease status are reasons they avoid disclosing HIV status to their children. However, 70% of caretakers have a plan to disclose HIV status to their children in the future.⁴⁻⁶

One study reported that 85% of caretakers and 97% of the children felt more comfortable after disclosure.⁷ Furthermore, several studies found that HIV disclosure helped the children improve self-esteem and develop closer relationships with family members. The caretakers felt relieved that they didn't have to keep the diagnosis secret any longer. Children became more responsible about taking antiretroviral (ARV) medicines and children and caretakers increased their knowledge about HIV.^{8,9}

Some undesirable effects after disclosure were also reported, including anger, denial, and depression among children, and feelings of guilt among parents when the children were infected through perinatal transmission.^{4,6} Based on preliminary data, the possible advantages and disadvantages of pediatric HIV disclosure are summarized below.

Disclosure	No disclosure
<p>Advantages:</p> <ul style="list-style-type: none"> • Better adherence to medication • Prevention of transmission • Better self care • Potentially fewer complications of HIV • Improved attitudes and quality of life • Strengthened relationships and communication within family • Less secrecy about child's illness <p>Disadvantages (these occur only in settings with inappropriate disclosure process or timing):</p> <ul style="list-style-type: none"> • Emotional reactions such as depression and anxiety • Potential negative impact on behavior and self-care • Potential negative impact on family relationships • Inadvertent disclosure to other people 	<p>Advantages:</p> <ul style="list-style-type: none"> • Protection of children against distressing feelings after knowing HIV diagnosis • No need for caretakers to deal with emotional reactions and negative impacts that might occur after disclosure • Less chance of children disclosing to others outside family <p>Disadvantages:</p> <ul style="list-style-type: none"> • Caretakers' discomfort with keeping the diagnosis secret and difficulty communicating with children • Risk of children accidentally learning their HIV status, possibly causing severe emotional reactions and poor relationships with caretakers (especially in adolescents) • Lack of cooperation from children in taking medication because they don't know why they have to take it • Risk of transmitting the virus to others by engaging in risky sexual behavior • Children's worry about their illness, with no opportunity to discuss it or to be reassured appropriately because diagnosis has been kept secret

Overall, the advantages of HIV disclosure outweigh the disadvantages, as shown above. Many of the potential disadvantages of disclosure can be avoided through proper techniques. If the proper disclosure process is followed, children will accept their HIV status, develop a positive attitude toward chronic disease, and eliminate risky behavior.

The important thing is that children receive correct and clear information in a stress-free environment. It is not necessary to tell them everything at once. A few subjects that should be emphasized early include clearing up any of the children's misconceptions about HIV disease, and reinforcing the importance of ARV adherence. A positive attitude toward the disease and good ARV adherence lead to the most desirable outcomes for HIV-infected people. These outcomes include good family relationships and a long life span.

Involving healthcare providers in the disclosure process serves as a way to ensure correct knowledge about HIV after the children learn their status. Health professionals can provide additional information, and provide follow-up and assistance according to the needs of children and their families. According to a prior study at Siriraj Hospital, most children say they want to receive information about HIV status from their caretaker or a person close to them, while most caretakers prefer to have a healthcare provider disclose their children's HIV status.¹⁰

When should disclosure happen? It depends on several individual factors: family characteristics, caretaker readiness, and the child's level of development. The American Academy of Pediatrics recommends

that HIV-infected children of school age should be informed about their HIV status.⁹ In Thailand, the average age at which HIV status was disclosed to children was 9.6 years.⁶

Children whose HIV diagnosis is disclosed to them too late—for example, after they have reached puberty—may have already engaged in risk behaviors. They may also be less likely to trust adults if they feel that caretakers have kept the secret and not told them the truth. Disclosing too early, when the child is too young, may lead to misunderstanding or feelings of depression in children, or inadvertent disclosure to other people.

Regardless of when HIV disclosure takes place, it should follow a systematic process. This manual, developed by Siriraj Hospital staff, in cooperation with the Queen Sirikit National Institute of Child Health and the Thailand MOPH–U.S. CDC Collaboration, offers an approach and guidelines for ensuring systematic and appropriate pediatric HIV disclosure. The procedure consists of four steps:

1. Identify children for disclosure who meet program criteria and propose disclosure counseling to caretakers
2. Assess the readiness of caretakers and children and prepare them for disclosure
3. Disclose to children their HIV status in a counseling session
4. Monitor and evaluate children and caretakers after HIV disclosure

A decorative blue banner with a light blue map of the United States in the background. The text "Chapter 2" is written in a black, serif font in the center of the banner.

Chapter 2

A small icon consisting of three circles: a grey one on the left, a blue one in the middle, and a grey one on the right.

Service Delivery System for Pediatric HIV Disclosure

Pediatric HIV disclosure as outlined in this manual employs counseling techniques that aim to build relationships and feelings of trust between healthcare providers, HIV-infected children, and their caretakers. The techniques also will help caretakers disclose the children's HIV status to the children in a supportive way. The disclosure counseling process emphasizes educating the children about their HIV diagnosis, facilitating communication between the caretaker and the children, and assessing and managing the impact of the disclosure. The delivery of such services involves two important parties; the healthcare provider team and the caretakers.

Healthcare Provider Team

The healthcare provider team may include physicians, nurses, pharmacists, social workers, and other personnel, depending on the treatment setting. Any of these personnel can function as counselors in the disclosure counseling process. The major key roles of the healthcare provider team are as follows:

Treatment

- Provide medical treatment and antiretroviral therapy
- Provide information on health status of children to children and caretakers
- Screen for and assess the necessity of the HIV disclosure process in children
- Work together with the rest of the multidisciplinary team to review and monitor the progress of the HIV disclosure process

Pediatric HIV disclosure counseling

- Assess the necessity of beginning the HIV disclosure process for children
- Ensure the preparedness of caretakers to disclose HIV status to children in terms of their knowledge and understanding of the disease, childcare, child development, and how to provide assistance to children when they need it after disclosure
- Ensure the preparation of children
- Collect data from children and caretakers for a case conference with the multidisciplinary team

- Disclose HIV status to the children, or provide assistance to the caretakers so they can disclose HIV status to their children by themselves
- Assess children's understanding, knowledge, and self-adjustment immediately after disclosure
- Monitor the children's understanding, knowledge, and self-adjustment again by paying a home visit to children who seem not to be adjusting well after disclosure
- Provide additional information to children who lack information or who do not understand information about self-care
- Refer children who need additional assistance and give instructions to caretakers on how to access additional services if needed

Medication counseling

- Assess adherence of the children to ARV medication
- Provide information and increase understanding about drug administration and side effects of the medicines
- Report to the multidisciplinary team about drug adherence problems

Psychosocial services

- Monitor and assess how children and their caretakers are taking care of themselves
- Identify health-related problems of children, caretakers, and their environments, using a holistic approach
- Provide information or refer for social assistance when needed

Caretakers

The success of the pediatric HIV disclosure process cannot be achieved without good coordination between the healthcare provider team and a caretaker (in other words, a father, mother, relative, or foster parent who takes care of children and brings them to the hospital). Note that caretakers may feel anxious due to HIV, the responsibility of bringing children to the hospital, economic problems, and their concern about the children's future. Most of them have kept the HIV diagnosis secret for a long time.¹¹ Mothers especially may be apprehensive about their children's reaction.

Caretakers are the ones who will make the decision about HIV disclosure to children. Their roles are as follows:

- Provide information to healthcare providers about the children, the home environment, and the situation of children and families
- Receive counseling to prepare themselves for disclosing HIV status to children
- Work with the healthcare providers to determine a suitable time for disclosing HIV status to children
- Make decisions about who will disclose the HIV status to children—counselor, doctor, nurse, psychologist, social worker, or the caretakers themselves
- Observe the impact of disclosure and self-adjustment of the children after disclosure

- Support the children emotionally and psychologically and take them to counseling services on a continuing basis as needed
- Report to the healthcare provider team about the self-adjustment of the children

Venue Arrangement

The venue is important and can help increase the effectiveness of the counseling. The venue should be as follows:

- A counseling room or a space should be set up specifically for counseling. The environment should be quiet and peaceful without any noise or passersby that may interfere with the discussion.
- A place for children to do some activities while their caretakers are talking with the healthcare provider. This way, the caretakers will not have to worry about their children during the discussion.

Chapter 3 Counseling Principles for Pediatric HIV Disclosure

The process of pediatric HIV disclosure starts with the readiness of families and children. From beginning to end, healthcare providers should consider children as individuals, emphasizing client-and family-centered principles. Caretakers should select a timeline and process that best fits their children and families.

Counseling is an important part of this sensitive process. Often caretakers are confused about whether and when to disclose HIV status to their children, fearing the children's reactions, and having feelings of guilt themselves. Counselors must assess the relationships between the caretakers and the children, the caretakers' attitudes toward HIV, and the likely impact of disclosure on both caretakers and children.

Other qualifications of counselors include basic counseling skills, experience with pediatric patients, knowledge of child development, and respect for the decision-making abilities of the caretakers.^{12, 13}

Principles of Communicating with Caretakers

The disclosure counseling process may include assisting caretakers with problem solving, assessing caretakers' readiness to disclose HIV status to children, and helping caretakers with decisions on whether or not to disclose. Counselors should use the following principles and skills:

Rapport building

- Build trust and cooperation by respecting caretakers' and children's ideas, even when the ideas differ from the counselors' own
- Remain friendly, attentive, flexible, and sincere when discussing problems and decisions

Listening and responding¹⁴

- Use and observe body language: maintain eye contact, nod to indicate understanding, lean toward the speaker
- Empower and encourage caretakers to express their feelings
- Rephrase final sentences to be sure that everyone understands the same things and encourage caretakers to elaborate

Sample dialogue:

Caretaker: "My child asked me if her illness is AIDS, but I never said yes or no, because I'm afraid she* won't accept it."

Counselor: "You fear your child won't accept it when she knows the facts."

- Request clarification of information or problems

Counselor: "You said your child misbehaves. Say more about that. What do you mean?"

- Summarize main points in a way that shows sympathy for caretakers

Caretaker: "I worry about everything: she may not take the medicine, she may feel sad. I think I'll cry when I see her face."

Counselor: "I know you are confused and sad. But you don't know how either of you will deal with this."

*A note on the use of "he" and "she" in this book: To be inclusive, the authors consciously use both pronouns. Instead of employing the awkward "s/he," or "his/her," sample dialogue balances references to girls and boys in alternating chapters.

Questioning techniques

- Ask clear questions that follow naturally from previous topics
- Avoid blaming or forcing answers
- Ask open-ended questions that let caretakers feel free to give information

Counselor: "After your child knows her diagnosis, what are you most concerned about?"

- When rechecking or confirming understanding, ask close-ended questions

Counselor: "Are you afraid your daughter will hate you when she knows she received HIV from you?"

- Probe for more details with in-depth questions
- Give caretakers enough time to think about their answers
- Be careful not to lead caretakers into expected answers
- Avoid asking too many questions at a time
- Choose questions that help caretakers come to their own conclusions and gain self-understanding

Principles of communicating with children

Communicating about health with children aims to achieve the following goals:

- Strengthen relationships between healthcare providers and children
- Assess children's understanding and perception of their health status
- Assess the psychosocial status of children
- Identify problems children encounter
- Provide information, according to the needs and readiness of children

Communication may be most effective if healthcare providers and caretakers keep in mind the developmental characteristics of different age groups:

Children under age five know that they are ill and have symptoms but do not know the cause. They want to recover but they are not responsible for their own care. Despite frequent illness, lack of strength, and a wish for someone to take care of them, they do not want to see the doctor. These children know they have some restrictions about food and play. They may become irritable or fearful. They imitate the behavior of other people and can be taught to take care of themselves up to a certain level. They do not understand the meaning of death as permanent and may ask whether or not people die. They do not understand the future and don't yet have serious aspirations.

Children aged 5-12 years realize that they are sick and feel that getting ill is something shameful. They ask more questions and really want answers. They are tired of illness and of going to the doctor. They know that they must practice self-care. They may fault themselves for being ill and becoming a burden to others.

Children older than 12 may be able to find answers themselves. They know the cause of their illness and accept it. They may feel shy or afraid of being disliked and need someone from whom they can seek advice. They can find self-care information by themselves and eagerly seek treatment. If they receive good advice on how to live life, they may become more introspective. They are imaginative and may have dreams for the future. Some think about how long they will be able to stay alive to achieve their aspirations. Others may feel discouraged, confused, and hopeless and have a difficult time deciding whether or not to struggle on with life. Children this age understand that death is permanent and may feel depressed after knowing that they will die. They fear the process of dying and are afraid of being dead, though these fears may be eased if they receive good advice on how to face death.

Counselors may find the following principles useful when communicating with children of all ages:¹⁶

Accept and respect

All children want other people to accept and respect what they say and feel. Children may express this desire differently than adults.

Understand developmental stages

Children of different ages have different abilities to communicate about illness, death, hope, and the future.

Use simple language, body language, and illustrations

In trying to develop trust, use body language that implies attentiveness, acceptance, and understanding. This body language must be sincere. Children sense when it is not real. Do not rush communication with children. Proceed slowly, and always pay attention to the children's feelings and emotions. Some issues require time to be resolved, though the passing of time doesn't always help and may even make some children feel more pain.

Listen in silence

Listen attentively. Reflect what you have just heard to ensure that you understand correctly. When you are silent, remain attentive.

Keep their secrets

Keeping children's confidences will help build the relationship and show your respect for their privacy.

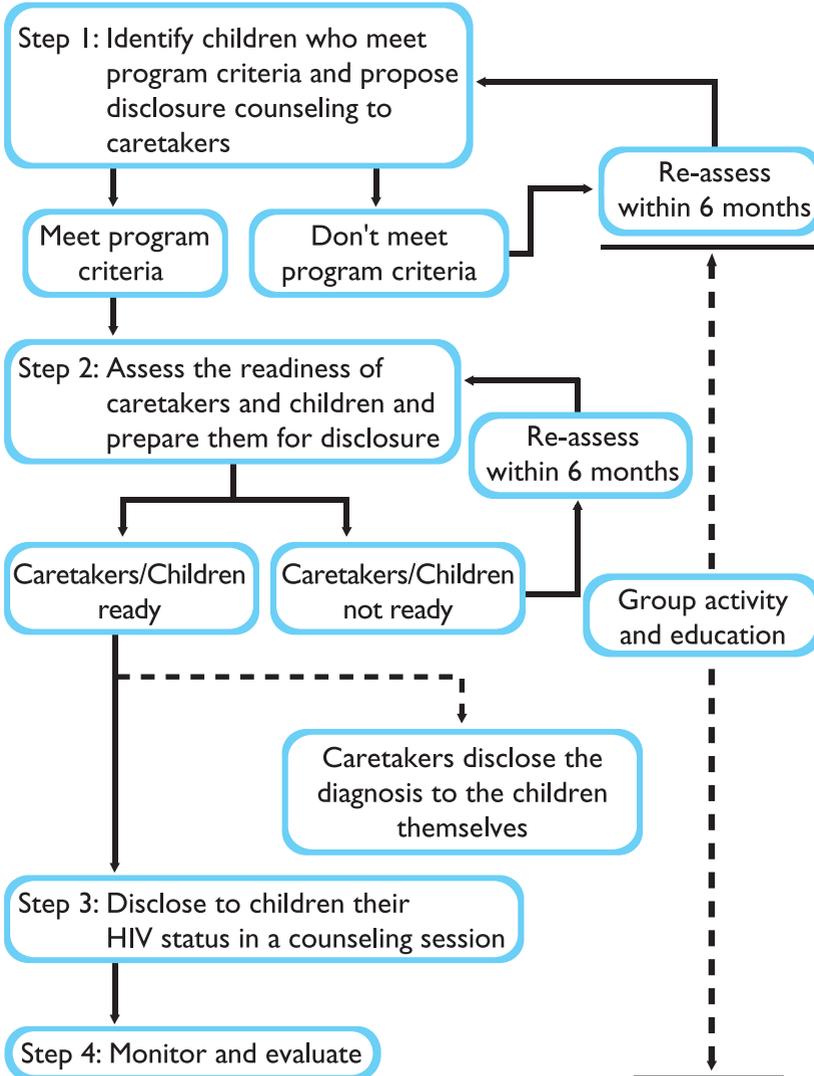
Tell the truth

If you don't tell the truth or if you provide incorrect information, children will guess and they may be wrong. Some children will not trust or respect adults any longer if they aren't told the truth.

Don't think or make decisions for the children

Encourage positive attitudes about HIV infection and living with the disease

Pediatric HIV Disclosure Model



A decorative blue graphic with a scalloped border containing the text "Chapter 4" in a black serif font.A small icon consisting of three circles: a blue one on top, a grey one on the left, and a white one on the right.

Pediatric HIV Disclosure Model

Disclosing HIV status to HIV-infected children involves more than just telling children their diagnosis. The process requires good preparation, good communication techniques, and appropriate counseling for each individual. Below is an overview of four steps in the pediatric HIV disclosure process. These steps will be detailed further in the chapters that follow.

A small icon consisting of three circles: a blue one on top, a grey one on the left, and a white one on the right.

Step 1: Identify children who meet program criteria for disclosure and propose disclosure counseling to caretakers

Providers identify children who meet program criteria (which are defined according to the context of each setting), and then offer to provide the disclosure counseling service to caretakers whose children are eligible.

Step 2: Assess the readiness of caretakers and children and prepare them for disclosure

After caretakers consent to receive the disclosure counseling service, counselors assess the readiness of caretakers and children through counseling. This preparation for the disclosure step can be divided into two sub-processes.

a) Assessing the readiness of the caretakers and children and preparing caretakers

Counselors assess the readiness of caretakers by exploring any concerns or fears the caretakers might have about disclosure. While discussing whether or not to proceed with disclosure at this time, counselors help caretakers explore advantages and disadvantages of disclosure, and prepare them to respond to any disadvantages. Counselors and caretakers jointly determine the readiness of children by reviewing the children's ability to understand their illness and cope with stress, as well as their ability to maintain confidentiality. Counselors also prepare caretakers for disclosure, including how and what to discuss with children, and how to support children's emotions after disclosure.

b) Preparing children

In this step, counselors build relationships with the children and strengthen their communication and stress management skills.

These two sub-processes can proceed simultaneously or separately depending on the situation and setting. For example, you may start by assessing the caretakers and later prepare the children. Alternatively, you may prepare the children first so that you can obtain information that will be useful for counseling caretakers. Avoid discussing or assessing children's perceptions of their diagnosis in this step; this prevents unintentionally disclosing the HIV diagnosis to children whose caretakers are not yet ready.

In some cases, it may take more than one visit to assess readiness. If the caretakers or the children are not ready for disclosure, counselors should counsel the caretakers and assess their readiness periodically.

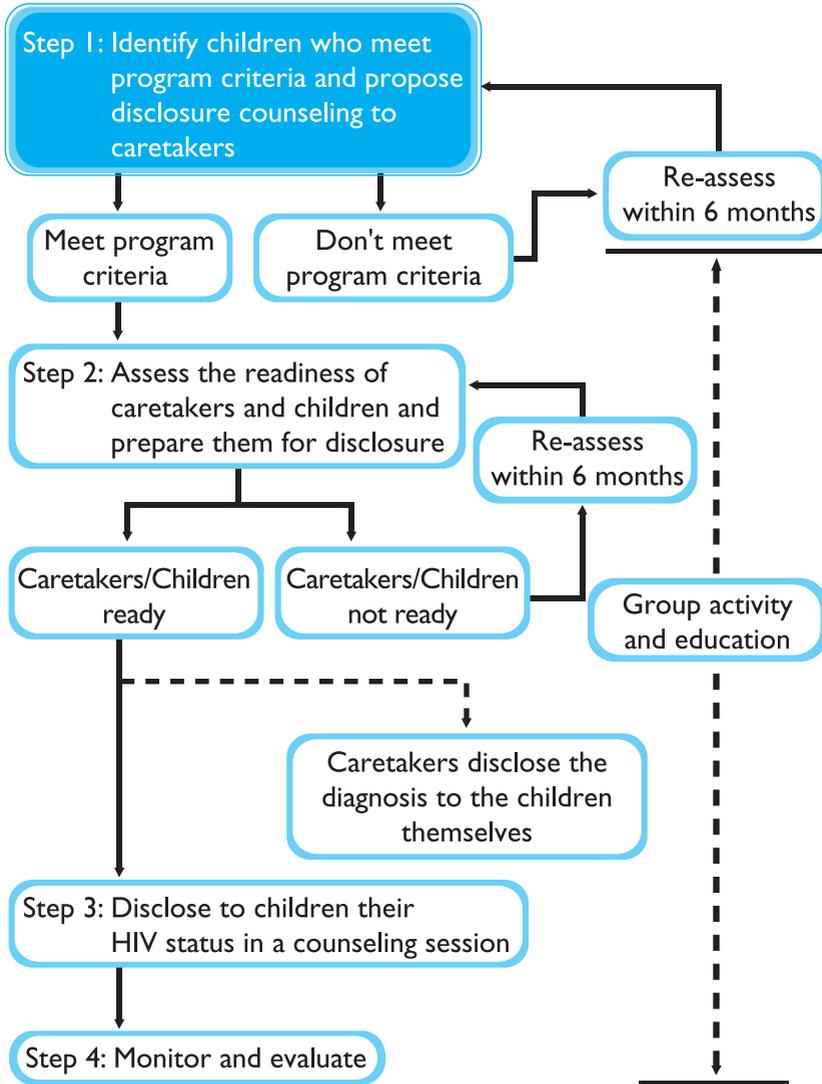
Step 3: Disclose to children their HIV status in a counseling session

After the caretakers and children are determined to be ready and are prepared for disclosure, the caretakers may decide to disclose HIV status to the children by themselves at home. Alternatively, they may want the disclosure to occur in the hospital, where they can either disclose the status to the children themselves with assistance from a counselor or have the counselor disclose to the children. No matter which scenario they choose, a counseling session should be arranged. The purpose of this session is threefold: disclosing HIV status to the children (if it hasn't already been done); providing correct information about HIV and self-care practices; and assessing and supporting the children's emotional reactions.

Step 4: Monitor and evaluate children and caretakers after HIV disclosure

After disclosing HIV status to children, both short-term and long-term assessment should be conducted. The objectives of this assessment are to explore changes in the children and caretakers after disclosure, to explore the children's understanding of their health status and self-care practices, and to identify an approach for providing assistance to children and caretakers after disclosure.

Pediatric HIV Disclosure Model



Chapter 5 Identification of Children Who Meet Program Criteria and Proposal of Disclosure Counseling to Caretakers (Disclosure Process Step 1)

In this chapter, identifying children who meet program criteria and proposing the disclosure counseling service to caretakers (Disclosure Process Step 1) is discussed in detail.

Establish program's criteria

Counselors can determine eligibility by using the criteria agreed upon by the team of healthcare providers, as appropriate for each setting. (For example, “The criteria used at our site are as follows: Children older than seven with a confirmed diagnosis of HIV; neither caretaker nor child is in a severe stage of illness or in need of a hospitalization; and the child does not have suicidal ideas or severe mental retardation.”)

Regardless of the setting's specific eligibility criteria, the following approaches may be useful when counselors look for eligible cases and provide information about the service to caretakers.

Build rapport

The counselor introduces himself or herself and asks some basic questions in order to establish the relationship and feelings of trust.

"Hi, I am _____. I'd like to ask about (name of the child).
How is his health? So far, has he ever asked you about his illness? Have you ever talked to him about his HIV status?"

Provide information

The counselor offers the service for help in disclosing HIV status to children and gives caretakers an opportunity to ask questions.

"The hospital has set up a counseling service for caretakers to help them prepare to disclose HIV status to children. The staff here will talk with the children about their HIV status only when the caretakers are ready and give us permission to do so. Do you think you might like to make use of this counseling service?"

Ask questions

Counselors should ask questions to assess the current circumstances of caretakers and children. It is important to assess each family's situation, the attitude of the caretaker, and the caretaker's need for facts. Through this assessment, the counselor will be able to uncover problems that may help to determine the best time to begin the HIV disclosure process. Disclosure is urgent if any of the following circumstances apply:

- Children more than usually suspicious about their health diagnosis
- Children learned of their HIV status unintentionally and were unprepared
- Children do not want to take medication
- They are teenagers and may engage in sexual risk behaviors
- Caretakers want to disclose children's HIV status because they find it stressful to keep the secret

"Do you have any severe health problems?"

"In your opinion, does the child have any problems that would make it unwise to disclose his HIV status to him? Is he now in a depressed mood, or feeling so sad that he talks about wanting to die?"

"Is anyone else in the family infected with HIV?"

"Who in the family knows about the child's HIV status?"

"What makes you hesitate to tell the child about his HIV status now?"

"In your opinion, what would be the advantages of disclosing the child's HIV status to him? What would be the disadvantages?"

"Does the child have any problems taking ARV medication?"

Listen and respond

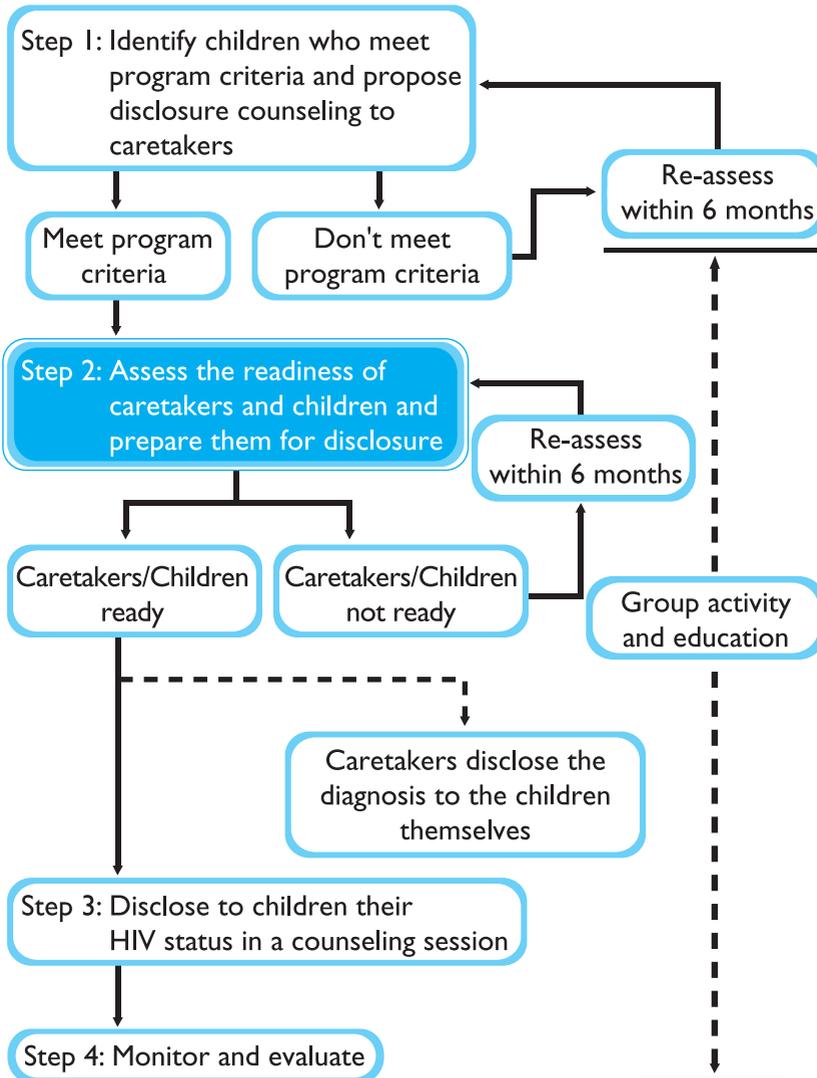
Pay attention. Listen to what caretakers say. Respond in ways that encourage caretakers to explain their circumstances in detail. Careful listening will allow counselors to offer information that best addresses caretakers' needs. By asking questions, the counselor can determine the most appropriate time to offer the following information:

- The most appropriate time to disclose HIV status depends on the readiness of caretakers and children.
- The children of school age (7 years or older) are mostly able to understand the disease and keep the secret, and therefore this period is suggested for disclosure.¹⁰
- All HIV-infected children should be told of their health status before reaching puberty or engaging in risk behaviors.

Summarize

Review the topics that have been discussed and the decisions that the caretakers have made. Then make an appointment for proceeding to the next step. Proceed right away if the caretakers want to receive the service and are ready to do so on the same day. If the caretakers decide not to receive the counseling service, the counselor should ask about the reasons and assess the concerns of the caretakers. The counselor may address the problem in a team conference to plan follow-up service to the family within six months.

Pediatric HIV Disclosure Model



Chapter 6

Caretakers and Children's Readiness Assessment and Preparation for Disclosure (Disclosure Process Step 2)

Once caretakers have decided to receive the disclosure counseling service, the next step is for the counselor to explore and understand the caretakers' opinions and the children's psychosocial status. Information from the caretaker will help to prepare both children and caretakers for disclosure and to predict the impact of disclosure. This preparation may take time if caretakers or children are not ready. Counselors should not force caretakers to disclose, but should help them move towards readiness using the guidelines detailed below.



Readiness Assessment and Preparation for Caretakers

Build rapport

Create a relaxed and friendly atmosphere. This is important at each counseling session.

Provide information

Ask caretakers to review the points previously discussed so that they can receive new information in a way that builds on the previous sessions. Help the caretakers to review their own attitudes. Offer them an opportunity to correct any misunderstandings.

"At your last visit, we discussed disclosing HIV status to your child. May I ask you to review what you thought that day?"

After reviewing the previous session, the counselor can offer new information, building upon the caretakers' needs and their understanding of HIV/AIDS. The following are suggested topics to cover:

- HIV is a kind of virus that will destroy white blood cells known as CD4 cells. These white blood cells play an important role in the immune system to protect the body from pathogens. HIV can cause Acquired Immune Deficiency Syndrome (AIDS) if an infected person does not receive treatment and the disease progresses to an advanced stage.
- To avoid the development of AIDS and the spread of HIV, infected people should take ARV drugs, practice self-care, and avoid risk behaviors.
- HIV is a chronic disease much like diabetes or heart disease. With proper treatment and the use of antiretroviral drugs, people with HIV can control the disease and live normal lives.

- HIV is not transmitted through regular activities. The disease is transmitted one of four ways: through unsafe sex; through direct contact with patient blood, discharge, or secretion; through sharing needles while injecting intravenous narcotics ; or through mother-to-child transmission in pregnancy, delivery, or breast-feeding.

Question, listen, and respond

Asking questions is an important way to explore the caretakers' emotions and attitudes about the children's illness, as well as to identify emotions, behaviors, and perceptions within the context of the larger family. Observing body language is helpful in this step.

Caretakers should be encouraged to discuss:

- Relationships within the family
- How family members can help and share
- Problems and barriers to communication with the HIV-infected child and the with the larger family

These discussions provide the preliminary information for the medical team, and will be useful for making a plan for service delivery.

"How many people are in the family at the moment?
Who are they?"

"In the family, who is the primary caretaker?
Who is the person closest to the child?"

"At home, whom does the child talk to most often?"

"Who currently knows about the HIV status of the child?"
(At home, in the family, in the community, at school.)

"Who knows about your own HIV status?"
(In cases where the caretaker is also infected.)

Assess what the children know about their illness. How do they behave? How would the caretakers describe the children's characters and personalities? What are the children's problem-solving skills? How able are they to cope with problems or stress?

"How would you describe your child's personality?"

"How does she act when she feels stressed or unhappy?"

"How do you know when she feels dissatisfied?"

"What does she do when she has questions or doesn't understand something?"

Assess the children's self-care habits. Do they adhere to an ARV drug regimen? How do they take care of themselves? What are their risk behaviors?

"Does the child have any problems taking ARV medication?
If so, what are those problems?"

"Who normally takes the child to the clinic for appointments?
Who takes care of her medication?"

"How is the child's health recently?"

"How does she know that it's time for taking medication?"

"Has the child complained or appeared to be getting tired of
taking the medication? If so, what has she said or done?"

Discuss the communication that has taken place with the children about their health status. Recall and review events or interactions between the caretakers and the children. How do the children perceive their illness? How urgent is it to disclose the children's HIV status?

"Do you think the child knows her HIV status? If so, how?"

"Are there any events or questions that suggest that the child suspects she is infected?"

"Have family members ever talked to the child about her illness? If so, what has been said?"

"Do you think the child is now ready to learn about her HIV status? What barriers might make it hard to talk with her?"

"Are you concerned about anything that would prevent the child from being ready?"

Assess the children's development and social patterns. What is their level of education? How effectively do they communicate? Are they able to keep a secret?

"What grade is the child in at school? How is her academic performance?"

"Does she have any concerns about her academic performance? Does she have other problems at school? If so, what are they?"

"What does the child's teacher report about her behavior?"

"Has the child ever mentioned any concerns about school?"

Explore the caretakers' attitudes, knowledge and worries about HIV/AIDS and childcare. Assess the decision-making abilities and expectations of the caretakers.

"Are you worried about taking care of the child? If so, what are your concerns?"

"What affects your confidence in taking care of the child?"

"How do you feel about your child's HIV infection?"

"Do you think that HIV infection is different from AIDS?
If so, how?"

"What do you know about the ways that HIV is transmitted?"

"Do you need any more information about your child's health?"

Review the advantages and disadvantages of HIV disclosure with the caretakers. Explore their expectations and decisions. Help make a plan for taking care of the children in the future.

"In your opinion, what are the advantages of disclosing her HIV status to the child?"

"What would be the disadvantages to the child?"

"Do you think the child can keep her HIV status secret? If so, how will she manage that?"

"How do you plan to disclose her HIV status to the child?"

"What essential information would you tell the child on the first day that you disclosed this information to her?"

"Are you ready to disclose HIV status to the child? Is there anything else that you're still worried about?"

The counselor may also want to discuss ways the caretaker could prepare to deal with children's tears, silence, denial, or aggression, any of which may occur during the disclosure process.

Sometimes caretakers may appreciate a direct question that encourages them to express a difficult feeling. Counselors should ask questions that guide caretakers toward problem solving.

"Some parents worry that their child will be angry with them or even attempt suicide when they learn about the HIV status. Have you ever worried about that?"

"Are you worried about your child not keeping her HIV status a secret?"

"After you tell your child, she may cry. In the past when your child felt sad, how did you respond to her?"

Before the close of the session, the counselor should give caretakers the opportunity to ask additional questions. An appointment for the next visit should then be scheduled.

If caretakers are not yet ready to disclose the children's HIV status, do not pressure them to do so. Assist caretakers by making an appointment for another conversation. Help them to get more information from other sources such as books, pamphlets, or a health education class in the clinic. Encourage them to return for periodic conversations until they are ready.

The counselor is not the one who determines whether or not caretakers or children are ready. That decision belongs to the caretakers themselves. The counselor only helps reflect and clarify the different perspectives to help caretakers make an appropriate decision.

Preparation for Children Prior to HIV Disclosure

After caretakers are ready, it is time to consider how to prepare the children so that they too are ready for disclosure. When talking with children, avoid unintentional disclosure. Don't raise the children's suspicions or worries. Avoid questions about their health status, HIV infection, and the reasons they take medication.

Counselors should work with the caretakers and children to develop trust. The guidelines below will help resolve problems, establish closer relationships with the children, and allow counselors to prepare children emotionally and psychologically before their HIV status is disclosed to them.

Build rapport

The counselor should communicate with the children in a friendly manner and accept their opinions without judging whether such opinions are right or wrong. Counselors should make the children feel relaxed and not interrogate them. The counselor may start with an activity that the children like, such as drawing and painting. Remember that the interests of primary school-age children and adolescents are very different.

"I'm so glad to have a chance to talk to you today."

"How old are you now?"

"Can you tell me what your favorite TV shows are?"

"What kinds of things you enjoy doing most?"

Discuss general ways of handling change and stress

Counselors can assess children’s readiness and empower them to cope with stress by bringing up experiences with family, school, or physical health in general. Counselors also encourage children to verbalize their thoughts and help them feel more comfortable in talking about difficult issues.

"Can you tell me how your school has been?
How do you handle problems that come up there?"

"You say your friends sometimes tease you.
What do you do when that happens? Does it work?"

"When you feel worried about something, whom do you turn to?"

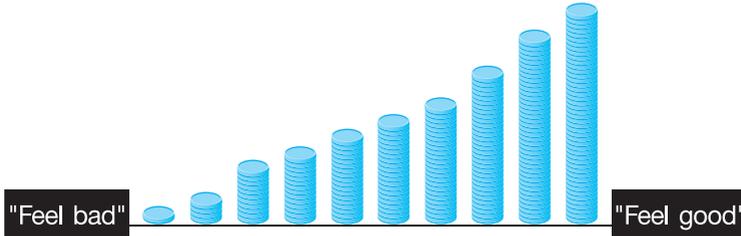
"When you have questions about your health, how
comfortable do you feel asking your (caretaker)?"

"As you are growing up now, which kinds of important things
do you discuss with your (caretaker)? For instance, how much
have you talked about becoming a teenager or about going
on dates?"

Question, listen, and respond

Ask children questions that are clear, uncomplicated, direct, and related to them. Observe expressions and body language when it comes to topics that make the children feel uneasy, or when the children find a topic difficult to talk about. To facilitate children talking about their feelings, counselors may use scales, pictures, or direct questions, as shown on the next page.

Afraid	1	2	3	4	5	6	7	8	9	10	Confident
--------	---	---	---	---	---	---	---	---	---	----	-----------



Feel very bad



OK/So-So



Feel very good

"Can you tell me what kind of work you are asked to do at home?"

"What do you usually do in school during your lunch break?"

"How did you do at school the past year?"

"What do you do when you don't like something or when you are not satisfied with something?"

"Do you have any concerns you would like to tell me about?"

In addition to listening actively and responding warmly, counselors can give children a chance to review their answers or to elaborate on subjects that may come up, such as stress management, family relationships, self-esteem, or personal responsibility. Counselors should not force answers, but should summarize periodically so both the child and the counselor understand things the same way.

"I notice you're quiet. It's OK to think on your own for a second. Do you mind if I repeat what we've been talking about?"

"If you have other things you want to say about the topics we have discussed, please tell me."

While talking with children, counselors should avoid assessing children's perceptions about their diagnosis or mentioning HIV/AIDS at this point, as it may lead to unintentional disclosure. However, some children may show they are suspicious, or already know about their infection. In such cases, the counselor should probe further to find out how the children have learned about the infection and how they are feeling. If the children have received frightening or negative information about HIV, the counselor should provide the correct information to them. At the same time, the counselor should assess how much they know about their HIV infection and consider disclosing their HIV status to them during that session.

Making a Specific Plan

After the caretakers and the children have been assessed and found to be ready, and the caretakers have decided to disclose the status to the children, the caretakers should prepare for disclosure by making a specific plan. The caretakers are the ones who decide whether they will disclose to the children by themselves or whether they prefer to have someone from the provider team assist or disclose. If the caretakers want the provider team to assist, a planned appointment should be made for the disclosure session.

If the caretakers decide to disclose the HIV status to the children at home, the counselor and caretakers should review and rehearse the message first. Let the caretakers do this repeatedly until they feel confident. The counselor should ask clearly about the specific date and time, the venue, and the plan for disclosure. This way, an appointment for monitoring can be made afterward. The plan should include the following:

- Double check the physical, emotional, and psychological health of the children, caretakers, and the person (if not the caretakers) who will disclose the HIV status.
- Plan the appropriate approach for disclosing to the children, based on their ages and their specific needs. Different media can be used, such as a story or illustrations.
- Prepare the content of the discussion, covering the following points:
 - Tell the children that they have HIV

- Give information about the disease; e.g., the name and characteristics of the virus
 - Explain the difference between HIV infection and AIDS
 - Explain how to care for themselves and how to prevent further transmission
 - Discuss how to keep a secret
 - For adolescents or children at risk for unsafe sex, tell them about sexual relationships and how to practice safe sex
 - Other information according to the age and the interest of the children
- Rehearse the caretakers' answers to anticipated questions from children, especially sensitive questions such as how the children acquired HIV.
 - Consider how the caretakers will respond if children react emotionally at the time of the disclosure. For example, caretakers should know what to do if children become frightened or angry.
 - Provide the caretakers with the counselor's emergency contact number.

"According to your plan, when will you talk to your child?"

"How will you start the conversation with your child?"

"What information do you want or don't want your child to know?"

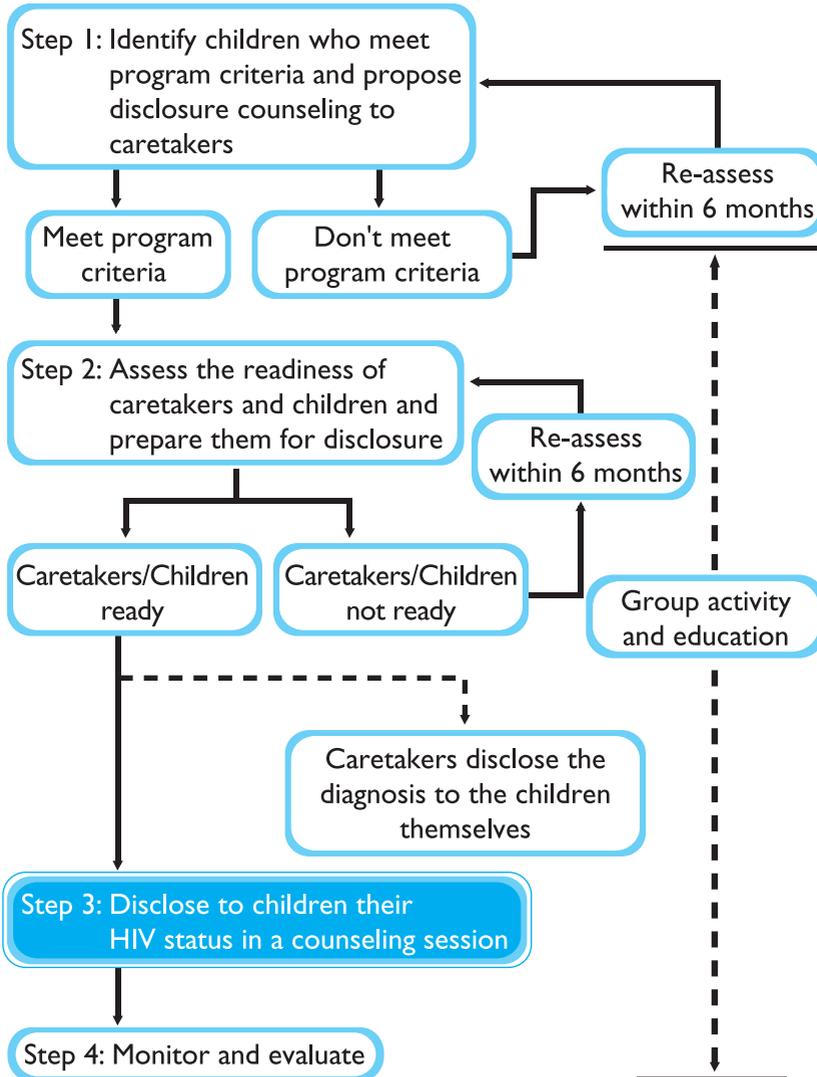
"What will you do if your child becomes sad or starts crying after you tell her the diagnosis?"

"What concerns do you have at the moment?"

"How will you respond if the child asks how she got HIV?"

The counselor should make an appointment for the caretakers and the children to come back and talk with the counselor and the team soon after disclosure at home. This is to ensure that the children have received correct and complete information. The children will also have opportunities to ask questions about things they did not understand well. The counselor should also make a second appointment to monitor the changes of the children and families after disclosure.

Pediatric HIV Disclosure Model



A decorative blue banner with a globe pattern in the background. The text "Chapter 7" is written in a bold, black, serif font in the center of the banner.

Chapter 7

A small icon consisting of three colored dots (blue, grey, blue) arranged in a triangle.

Disclosing HIV Status to Children in a Counseling Session

(Disclosure Process Step 3)

After it is determined that the caretakers and children are ready for disclosure, and the caretakers have made the decision to proceed, the next steps are to disclose to the children their HIV status and to educate them about living with HIV. A counseling session is scheduled at which the children's HIV diagnosis is disclosed to them by a counselor, or by the caretaker with assistance from a counselor. If caretakers choose to disclose to their children by themselves without the presence of a counselor, then a counseling session should be held soon afterward for the counselor to review the children's understanding, as well as to provide education and emotional support to the children after they have learned their status.

In this model, the term disclosure means not only telling children that they are HIV infected, but also helping children understand their disease status in a positive way and providing education on self-care, adherence to medications, and prevention of transmission to others. This step should be well prepared for, and a comfortable place and enough time (at least 30 minutes) should be provided for counseling. In some settings, it may be preferable to make a planned appointment rather than disclose during a routine clinic visit.

The essential components of the counseling process in this step include:

- Assessing children's perceptions, concerns, and attitudes about their disease
- Informing children of their HIV status
- Discussing the meaning of HIV infection, particularly the differences between being HIV infected and having AIDS
- Providing health education about living with HIV, including self-care, the importance of medication adherence, and prevention of HIV transmission
- Assessing and supporting the children's and caretakers' emotional reactions
- Discussing coping strategies, including ways to handle confidentiality
- Encouraging communication between children and caretakers

The above counseling components can be provided in a variety of ways and sequences depending on the clinical situation and developmental level of the child. The following are suggested steps, including sample dialogues, for conducting a counseling session where a counselor assists the caretaker to disclose to a child:

Review previous conversations with the caretaker

If the disclosure step does not happen soon after the caretaker preparation step, the counselor may choose to have another brief meeting with the caretaker prior to meeting the child. This meeting enables the counselor to assess changes that may have occurred since previous meetings and to review again with the caretaker the process of disclosure. Also, caretakers will have a chance to deal with their own emotions and those of the child.

"Since the last time we met, have there been any major changes in the family?"

"Since then, has he ever asked or been told about his* infection?"

"Do you have any concerns, or want to ask about anything, before talking to him?"

"Are you ready to talk with him? It may be difficult but we will help you."

***A note on the use of “he” and “she” in this book:** To be inclusive, the authors consciously use both pronouns. Instead of employing the awkward “s/he,” or “his/her,” sample dialogue balances references to girls and boys in alternating chapters.

Open the discussion with the child

After including the child in the meeting, the counselor should open the discussion and build rapport with the child. The counselor should also facilitate the conversation between caretaker and child.

"Hi, (name of the child). Has (caretaker) told you why we are meeting today?"

"We want to talk to you today because (caretaker) thinks that you are a big child now and that you should understand more about your illness."

(To the caretaker) "Could you tell (the child) how you are proud of him for taking care of himself, and what concerns you have about him growing up."

Assess what children know about their illness

Before informing the child of his HIV diagnosis, the counselor should assess what the child has already learned and understood about his illness. If the child says he does not know his diagnosis, the counselor may ask the child's reactions to what he has previously been told.

"I'd like to know your understanding of your illness. Can you tell me what kind of disease you have that makes you have to take medicine every day?"

"Now that you have grown older, have you ever asked (caretaker) what illness you have? What did she tell you?"

"You might have been suspicious about your illness, or have heard people talking about it. Could you tell me what you think it is?"

"What has the doctor told you about your illness?"

Disclose HIV status to the child

Assessing the child's understanding can serve as a way to open discussion of the child's HIV status before delivering bad news. The counselor should then proceed with telling the child about his HIV infection in a straightforward way. The delivery of this message should not be rushed. It should happen in a supportive way that provides children opportunities to comprehend, ask questions, and express their feelings. The counselor should deliver the information clearly and use language appropriate for the child's developmental level.

If the children already know or suspect that they have HIV, the counselor may tell them their diagnosis directly. Otherwise, the counselor may start with what the children have previously been told, or explain the basics about the immune system, the children's lowered CD4 white blood cells, the virus that causes low white blood cells, and the name of the virus.

"Today, we are going to talk about your illness, and the reason why you need to take medicine. We think you are grown up enough to know this important information so that you know how to take care of yourself. Are you ready for this?"

"You have an illness that decreases your white blood cells, and because of that, you need to take medicine every day."

"The white blood cells known as CD4 cells are like soldiers in your body to fight against bugs and keep you healthy. If you don't have enough of them, you get sick often."

"There is a virus that attacks CD4 white blood cells. You have had this virus since birth and this is why you have low white blood cells. The medicine that you are taking fights against this virus."

"This virus is called HIV. Have you ever heard this name?"

"You are infected with the HIV virus. You have had it since you were born."

The counselor may draw pictures to describe white blood cells and the virus, or use available printed material or story books, such as "The Devimon Virus,"¹⁸ to facilitate the child's understanding of the disease. When the caretaker has chosen to be the person to disclose to the child, the counselor should facilitate the conversation and add necessary information as appropriate.

Allow the children to express their emotions

After children have been told of their HIV infection, the counselor should pause for a moment to allow them to express their emotions. If the child is quiet or does not openly express any emotions, the counselor can help by showing empathy and encouraging the child to ask questions or to share concerns.

"It must be difficult for you to hear this information.
Can you tell us how you feel now?"

"It is normal for anyone to feel afraid, sad, or angry after hearing this kind of news. Your (caretaker) and I want to understand how you feel."

"You may have a lot of questions in your mind.
What do you want to ask?"

The counselor should assess the child's views about HIV/AIDS, as well as any misconceptions that the child may have about HIV/AIDS. The counselor may also encourage caretakers to discuss the children's concerns, in order to facilitate further communication between the children and the caretakers.

"I heard you're afraid that you will die from HIV. I'd like you to think about how you have been taking good care of yourself and how healthy you are now. Although we can't cure the virus, but we have a good treatment for you."

"Your (caretaker) has been worried about your feelings. Do you want to tell her how you feel now or ask her any questions?"

"Do you (caretaker) want to say anything to (name of the child) now?"

Provide education about the HIV virus and about the difference between HIV infection and AIDS

After the children have had a chance to express their emotional reactions and have been supported, the counselor should provide the children with more information about how the virus causes illness and how it can be treated. As the terms “HIV” and “AIDS” may have negative meanings for children, it is advisable to discuss the children’s understandings of these words.

To many children, AIDS is known as a painful disease, accompanied by a frightening appearance. This impression comes from early campaigns when knowledge about HIV disease was limited. Children should be told that being infected with HIV does not mean they will progress to AIDS. Stress that if children are treated properly and take good care of themselves, they can have normal lives and good futures. The counselor may also show the children a graph depicting the CD4 count progression after treatment (see below).

"I'd like to tell you more about the HIV virus. Do you know how it can make people sick?"

"When HIV gets in someone's body, it attaches to CD4 cells and becomes part of those cells. Eventually the HIV destroys the CD4 cells, so the body has fewer CD4 cells to protect against any germs. The lower the CD4 cell count, the more likely it is that the person will get sick."

"You might have heard the word AIDS. Tell me what you know about AIDS."

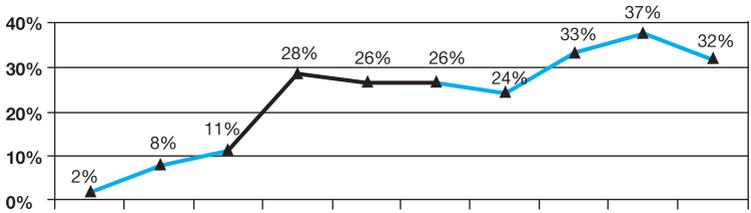
"If someone's number of CD4 cells becomes very low, that person may get sick easily because of a weakened immune system. He might come down with serious infections. In this case, we say that person has 'acquired immunodeficiency syndrome,' or AIDS."

"However, being infected with HIV doesn't mean that you must also get AIDS. If you take your medicines regularly, your CD4 cell count will not be too low and you will not have AIDS."

"This is why you need to take medicine to fight against the virus so that the virus will not destroy your CD4 cells."

"It is important to check your CD4 count regularly to be sure that you are staying healthy and not progressing to AIDS."

"I'd like to show you your CD4 cell count. You can see that your CD4 cells increased after you started taking the medicine and they have been at a good level since then."

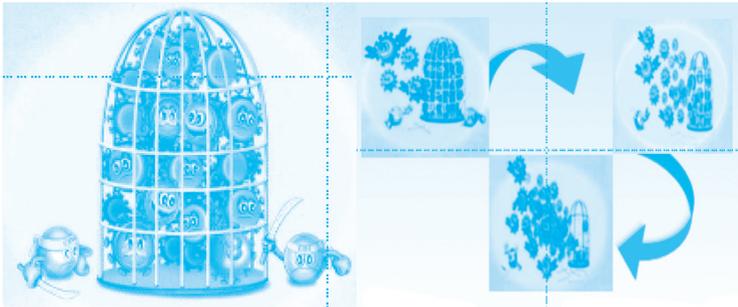


Stress the importance of good ARV adherence

The counselor should help the children understand clearly that while ARV medications are used to kill the virus, they cannot totally get rid of the virus, and that the children need to take them regularly and for life. The counselor may use drawings or pictures (see next page) to help children visualize and understand the concept. Emphasize that strict adherence will not only prevent them from progressing to AIDS, but also from drug resistance and the need to use more difficult drugs. Giving examples of other chronic diseases that also need life-long treatment, such as diabetes or heart disease, may help children cope.

"Although we have medicine to fight against HIV, HIV doesn't go away. People who have HIV must take medicine for the rest of their lives."

"Medicine acts like a cage for HIV. It controls the viruses and prevents it from increasing the amount of virus. If you do not take the medicine regularly and correctly, the viruses can change and escape from the cage, and you will need to take new drugs that may be more difficult to take in order to control the viruses again."



(Drawings courtesy of Department of Disease Control, Thailand Ministry of Public Health)

"It is important to keep the viruses in check, and to control them well all the time. However, even with the best medicine available, we cannot cure the disease. This is because a small amount of the viruses can hide themselves inside your cells so that the drug cannot reach them, waiting to increase their amount and attack you when you stop taking medicine or to miss some doses. This is why it is so important that you need to strictly take your medicine on time every day."

"Not taking medicine regularly may also make the viruses change so that the medicine doesn't work as well anymore. If that happens, it can be difficult to find a new drug that can treat the viruses effectively."

Discuss self-care and prevention of HIV transmission

To cope with a HIV diagnosis, children must be confident about living their lives and about cautions they need to take related to other people. The counselor can start this discussion by asking children what they know about self-care. Then provide new information and correct any misunderstandings children have. It is also important to emphasize prevention of transmission of the virus to others.

"We have talked about you having the virus. At school, perhaps you learned how HIV can be transmitted from one person to another. Can you tell me how HIV can be transmitted?"

"Yes, you're right. There are three ways. The first one is by contacting the blood or body fluids of an HIV-infected person. The second is by sexual contact with an HIV-infected person without using a condom. And the last way is mother-to-child transmission during pregnancy or breast feeding."

"To prevent spreading the virus from your blood, you must clean any wounds you get and cover them well. You must not share needles you have used with anyone. Transmission by sexual intercourse and from mother to child can also be prevented." (Provide details if appropriate.)

(For girls, if appropriate) "When you menstruate, you must learn the right way to manage sanitary napkins."

"Are you afraid that you will spread HIV to the people you live with? No, you won't. There are only three ways that HIV is transmitted, the ways we have already talked about. HIV won't be transmitted through daily activities, hugging, touching, or eating together, as long as there is no contact with blood or wounds."

Counselors may choose to discuss with adolescents, if appropriate, sexual education and prevention of HIV transmission through unsafe sexual activities. Counselors may also encourage caretakers to have conversations about sexual issues with the children.

"We have mentioned that HIV can be transmitted by sexual contact. Can you tell me what you know about sexual contact?"

"Are you worried that you will not be able to have sexual relationships or get married since you have HIV?
(To caretakers) Would you like to tell (name of the child) something about this?"

"Your (caretaker) may have taught that you should wait to be mature enough before having sex. When you are a grown-up, you will be able to have sexual relationships or get married, like other people. The only thing you have to do is to use a condom every time you have sex to prevent giving HIV to your partner (and also to prevent getting other sexually transmitted germs). I suggest you talk more about this with your (caretaker) or with us as you are growing up."

Discuss the way the children became infected

For some children, how they became infected should be discussed, especially when children express suspicion or when caretakers who are biological parents worry about the children's feelings towards them. Even though talking about this subject is not essential, in most cases children and caretakers feel relief after it is openly discussed. If children have strong emotional reactions regarding their acquiring the virus from their parents, the counselor should help the caretakers express their regret, and help the children to understand that the caretakers did not want it to happen.

"Now that we have discussed how HIV is transmitted, do you have any questions or concerns about how you have been infected?"

"Do you want to ask (caretaker) how you got this virus?"

(To the caretaker) "You told me that you were afraid (name of the child) would hate you if he knew that he got the virus. Do you want to ask him if he really has that feeling?"

Discuss confidentiality

As most caretakers are concerned about children's ability to keep their own or their caretakers' HIV status confidential, counselors should encourage discussion about this issue. Bring up who in the family knows the children's HIV status and who they can talk to about their HIV infection. For adolescents, counselors may counsel the children about the pros and cons of disclosing HIV status to their sexual partners.

"If someone asks you about your illness, would you tell them that you have HIV infection?" (To caretakers) What would you like (name of the child) to say if someone asks him that question?"

"You might want to talk about your HIV infection with someone you trust, but you don't have to (and shouldn't) tell everyone. This is your private issue, and you have the right not to allow other people to know about it, not even your friends or your teachers. You can ask your (caretaker), who already knows that you have the virus, whom you can talk to about it."

"You and your (caretaker) should prepare some words to use when you need to answer people's questions about your illness."

"However, when you are grown enough and have a sexual partner, you have to think about how to let your partner know about your HIV infection. We should talk more about this in the future. But the most important thing for you to remember now is that you need to use a condom every time if you have sex with anyone."

Summarize what was discussed and provide encouragement

At the end of the session, counselors should allow an opportunity for the children and the caretakers to ask more questions or express concerns, so that counselors can provide answers and support. Counselors should also summarize the important issues that were discussed and double check that the children have a good understanding of their diagnosis and its implications.

Both the children and caretakers should be complimented for being able to talk about difficult issues and be encouraged to have a positive attitude about living with HIV. Counselors should tell the children and caretakers that it is normal for emotional reactions to emerge a short time after the disclosure, and that they can be given further support if needed. Counselors should encourage continued communication between children and caretakers. Finally, counselors should arrange a follow-up appointment and tell children and caretakers how they can get help in case of emergency.

"Now that we have talked, do you have any more concerns or questions?"

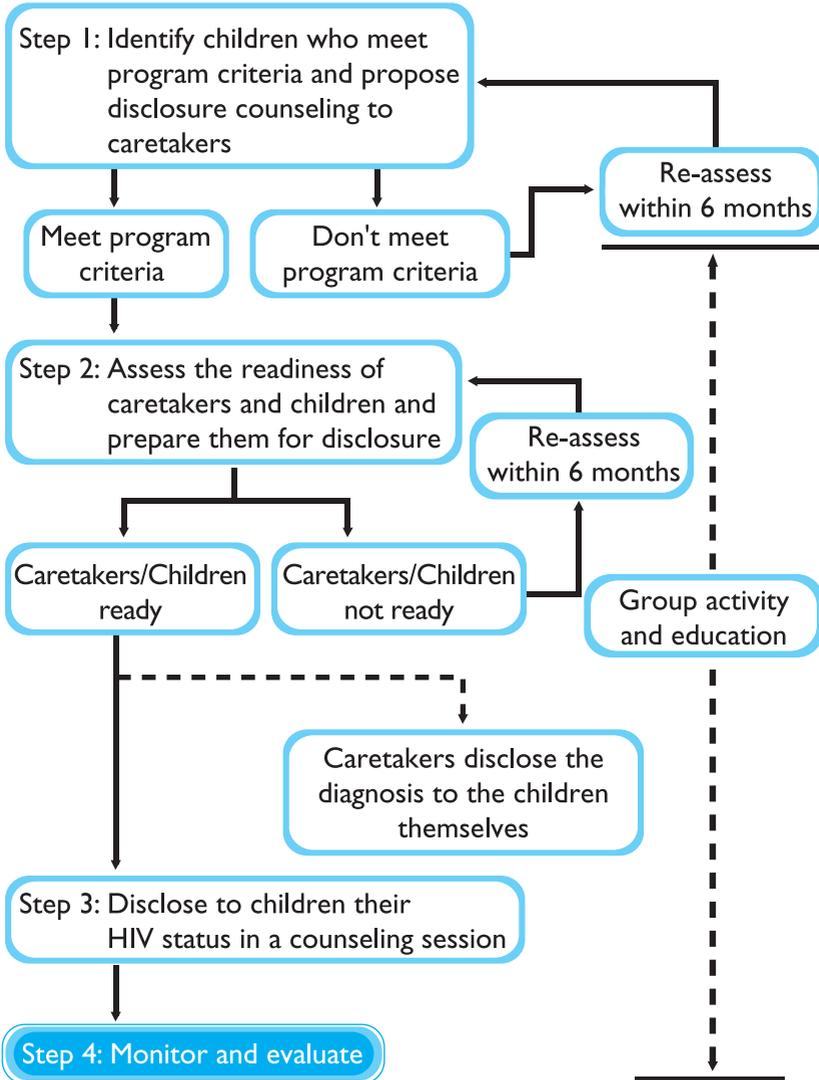
"I'd like us to summarize what we have talked about today. Can you tell me what you need to do to make yourself healthy? What are ways to prevent spreading the virus to other people?"

"Remember that being HIV infected does not mean that you will have AIDS. Taking medicine regularly and strictly will keep you healthy and allow you to live a normal life."

"I'd to acknowledge that both of you (the caretaker and the child) have shown great courage in talking about these really difficult issues. (To the caretaker) You should be proud of (name of the child) for being strong and understanding. Also, you should be proud of yourself for doing such a good job telling (name of the child) about these very important things."

"However, after you go back home or during the next couple of weeks, you may be confused, worried, sad, or angry. I'd like to tell you that emotional reactions like these are very normal. These feelings will lessen overtime. I'd like you to talk to your (caretaker) and ask her if you ever have any questions about your illness. We'll also be happy to support you and talk to you more. We will make an appointment for you to come back in ___ weeks."

Pediatric HIV Disclosure Model



Chapter 8 Post-Disclosure Monitoring and Evaluation of Children and Caretakers
(Disclosure Process Step 4)

Children and caretakers should be followed up after the children have been told their HIV diagnosis. This can be done any time the counselors think is appropriate. Post-disclosure assessment may be conducted at two different time points.

The first suggested period is within two weeks after disclosure, especially for cases who do not appear to be adapting well to knowing their status. These children may have cried or stayed especially quiet during the disclosure session. For children who seem to have adapted well to the diagnosis, the first follow-up assessment might take place as late as two months after disclosure.

The second suggested time point for assessment is after six months, to review the children's understanding of their own health status, and to explore any changes that have taken place for the children and caretakers after the disclosure. At this time counselors should repeat the discussion about good health practices that are consistent with the children's age. For children and caretakers who are negatively affected by the disclosure, the provider team needs to explore ways to provide help and support. After this point, some children may need support and guidance as they become adolescents.

Procedures for Post-Disclosure Assessment of Children

Counselors should start the post-disclosure assessment conversation by using the same counseling techniques as those used in the previous steps.

Build rapport

The counselor should state objectives and obtain agreement from the children before starting the assessment.

"The last time we met, we talked a lot about your health. The appointment today is to review all the things we talked about at your last visit."

"There are some questions or subjects that you may not want to talk about. However, we have to make sure that we all see things in a similar way and can communicate clearly about them. You may feel more comfortable pointing to some of these words on the paper instead of saying the words out loud."

"We may need to spend about 15-20 minutes talking. If you are ready, we will start the conversation now."

Provide information

All topics discussed at the previous visit will be reviewed at this stage. Depending on the children's needs or questions, information may be revised, or additional information provided.

Ask questions

Below are suggested areas to cover as counselors question, listen, and respond.

Assess the children's understanding of their illness.

"Please tell me what we discussed at the last visit."

"Please tell me what you understand about why you have to see the doctor and take your medication regularly."

"What do you think about your health today?"

"Is there anything you are worried about?"

Assess children's knowledge and understanding of HIV/AIDS by discussing modes of HIV transmission, prevention methods, and healthcare practice.

"Is HIV the same as or different from AIDS? How?"

"How can HIV be transmitted?"

"How can we prevent the transmission of HIV?"

"What do you do to maintain good health?"

Assess how the children disclose their health information to others, and how they keep secrets.

"After we talked about your diagnosis, did you tell anybody?"

"What would you say if someone asked you about your illness or why you miss class so often / have to take medicine/ see the doctor frequently?"

"If she is a very close friend, would you tell her?"

Assess behavioral changes and adaptations in physical, emotional, and social health, including any changes to ARV medication.

"After learning about your diagnosis, have you made any changes in health care practices from what you practiced before the disclosure?"

"How do you feel about yourself, the persons in your family, and your friends?"

"How do you feel about being told your diagnosis and about how you should take care of yourself? How does knowing your diagnosis affect your healthcare practices? How have your feelings changed since knowing your diagnosis?"

Procedures for Post-Disclosure Assessment of Caretakers

Caretakers need to be interviewed in addition to the children. Data obtained from an interview will help ensure correct, appropriate, and continuous treatment and care services. Because the caretakers live with the children, they can provide information on what changes have occurred since disclosure. Interviews with the caretakers should include an assessment of children from the caretakers' perspectives and assessment of changes in the caretakers themselves.

Assessment of children from the caretakers' perspectives should cover healthcare, ARV medication, emotional and social wellbeing, and any concern or worries.

"What changes have you seen in your child since the last time we talked, in terms of self-care, emotions, and feelings/relationships with family members and friends?"

Assessment of caretakers should cover the caretakers' worries and fears about the children; relationships between the children, caretakers, and other family members; and the development of future plans for the children.

"How do you feel since the last time you talked with your child? Is there anything you are still worried about?"

"Are there any changes in the family that have occurred since we disclosed this diagnosis to her?"

"Now that she has learned her diagnosis, she may be able to take better care of herself. However, she still needs care and motivation from you. This is very important. When she grows up, especially when she is in her teens, she will go through both physical and emotional changes. Can you tell me what changes you expect to see as she grows up?"

By the time of the six-month assessment, children should have been able to accept their diagnosis to some extent. Counselors should motivate children, provide additional information, and answer questions from children or caretakers. Counselors may also encourage children and caretakers to plan together for the children's futures. This plan should include education, occupation, health practice, adult healthcare facilities, associating with friends of the opposite sex, and taking responsibility for themselves.

If children or caretakers need additional information, an appointment can be made for them to come for a group meeting with other caretakers or other children who have been informed about their HIV status and are in need of similar information. They can also be scheduled for an individual discussion.

A decorative blue banner with a white border and a light blue map of the United States in the background. The text "Chapter 9" is written in a white, serif font in the center of the banner.A small icon consisting of three circles: a grey one on the left, a blue one in the middle, and a grey one on the right.

Partial Disclosure

Very young children, less than six years old, may not be able to understand in-depth information. However, they usually understand illness. Even though such children may not have had problems from not knowing their diagnosis, they may nevertheless be urgent cases for HIV disclosure. For example, they may have become suspicious of their illness, been discriminated against, or not want to take their medication.

To disclose HIV status to these children, the counselor does not need to mention the name of the disease or give detailed information about the disease to the children. Instead, counselors may follow a process known as “partial disclosure.” The goal is to help children adhere to their required treatment and care without telling the children that they have HIV/AIDS. Partial disclosure objectives include:

- Helping children understand the importance of treatment and good adherence to their health
- Reducing concern or misunderstandings among children and caretakers about the illness
- Promoting love in family relationships

Partial disclosure is a good stepping stone for future full disclosure. It has many advantages for very young children and for children who are not ready for full disclosure. Also, in this way the caretaker can give important information needed for self-care but continue to keep the diagnosis secret, which is often an important consideration.²¹ However, the information given must be clear and true.

Before the disclosure session, the counselor should prepare caretakers and children, distinguishing necessary information from information that can be discussed later. Partial disclosure uses the same principles and counseling techniques as the full disclosure process. The readiness of children should be monitored periodically so that a more complete discussion can be organized when they are old enough.

The partial disclosure process consists of three steps, which can normally be completed in a single visit.

●● Step 1a—Assessing and preparing (caretaker)

Build rapport

Greet the caretakers and build a comfortable atmosphere.

The important thing is agreeing that the disclosure discussion itself will concentrate on good self-care and on reducing the children's concerns or misunderstandings. Caretakers should be reassured that the actual HIV diagnosis will not be shared with the children.

Provide information

Counselors should explain to caretakers which information will be given to the children. In addition, the counselor should provide the expected results from partial disclosure. For example, if children have poor adherence, partial disclosure may be helpful to improve adherence.

Question, listen, and respond

Caretakers should be asked open-ended questions about the children's behaviors and problems found, such as caretakers not being present for each dose of medicine or finding many pills still in the cabinet. Counselors should also assess family relationships, the children's ability to solve their own problems, and the sources of information children are most likely to use.

●● Step 1b—Assessing and preparing (child)

The counselor should assess the children's communication skills to prepare for the discussion and to assess what might be causing adherence problems in the children.

Step 2—Partial disclosure

The session consists primarily of providing information about the illness without telling its name. In addition, techniques for maintaining good health should also be covered, along with the following topics:

- Disease characteristics—chronic, not curable, but controllable
- Good self-care—strict adherence to medication, otherwise you will become sick
- Transmission—not through normal daily activities, except through some activities related to blood flow or wounds

"You have a chronic illness. You have had it since birth. The level of white blood cells is lower than it should be, which means your immunity is also lower."

"The illness doesn't have a cure, but it can be controlled by medicines that must be taken strictly every day. If you can take care of yourself that way, you'll grow up beautifully. Also, taking your medication will mean you'll be protecting your own and other's good health."

"Right now, your illness will be controlled by the medicine. But if you don't take it on time or skip it, you will become ill easily and finally may need to be hospitalized. Your medicine may even stop working because the disease will be resistant to it."

"In addition to taking your medicine regularly and coming to appointments, you should get exercise, take enough time to rest, and eat good foods that promote your health."

●● Step 3—Follow-up after partial disclosure

After the partial disclosure, counselors should assess whether or not the goals have been achieved. Also, evaluate the readiness of caretakers and children to move forward with a more complete disclosure. Between the time of the partial disclosure and a full disclosure, the counselor can advise the caretaker about talking with children using words that are related to HIV, such as “immune,” and “CD4 white blood cell.” In this way children will recognize the concepts when a more complete discussion occurs later.

In short, partial disclosure is a good choice for both caretakers and health care providers when caretakers are uncomfortable disclosing full information, or when children are not ready but have problems that could benefit from disclosure. The partial disclosure process is a way for children to learn about their illness step by step, in accordance with their development. Meanwhile, caretakers have time to prepare themselves for a complete disclosure in the future.

Appendices

- | | |
|---|----|
| A) Basic Knowledge About HIV/AIDS for Counselors Working on Disclosing HIV Status to Children | 80 |
| B) Frequently Asked Questions by Children Related to HIV Disclosure | 90 |



Appendix A

●● Basic Knowledge about HIV/AIDS for Counselors
Working on Disclosing HIV Status to Children

●● **What is HIV?**

HIV is a virus that can cause Acquired Immune Deficiency Syndrome (AIDS). This disease develops only in humans. HIV can destroy CD4 cells, a kind of white blood cell that plays an important role in the immune system that protects the body from pathogens.

●● **What is the difference between HIV infection and AIDS?**

In early stages of HIV infection, an adult can live normally for several years without any symptoms. In children who acquire HIV from their mothers, the disease progression is often faster than in adults. After HIV enters the body, it can take several years before the number of CD4 cells becomes very low, resulting in poor immunity and an inability to fight against pathogens. This late stage of immune impairment often

involves a person being susceptible to opportunistic infections, which are generally not found in a person with normal immunity. Only in this stage is the person said to have Acquired Immune Deficiency Syndrome, or AIDS.

HIV infection will not result in AIDS if the person has received antiretroviral therapy appropriately. The perception among the general population is that AIDS is a deadly disease, associated with scary images of skin problems and severe wasting. However, a person may be HIV infected and stay healthy. Such people should not be stigmatized by being called “AIDS patients.”

What are the modes of HIV transmission?

HIV can be found in the blood, semen, vaginal fluid, and breast milk of infected persons. Therefore, if the mucous membranes or lacerated skin of a person is exposed to these infectious fluids, the person is at risk of HIV infection. Generally, HIV dies easily when it stays outside the human body. It is not transmitted from one person to another through routine activities, such as shaking hands, hugging, or having dinner with others. HIV is not transmitted through vectors like mosquitoes or other insects.

There are three main modes of transmission:

1. Sexual intercourse with an HIV-infected person without using a condom. This is the most common and important mode of transmission.
2. Blood-borne transmission: by sharing a needle and syringe for injection with an HIV-infected person, or by receiving a blood transfusion from an HIV-infected person.

3. Mother-to-child transmission during pregnancy, during delivery, and through breast-feeding.

Currently, donated blood is screened for HIV. The chances of acquiring HIV from a blood transfusion are extremely small. Furthermore, in many places around the world, HIV-infected pregnant women are provided with prophylactic treatment that has decreased the chance of infections in newborns.

How can we know whether children have HIV?

Children infected with HIV may develop the following signs:

- Mild symptoms—Enlarged liver and spleen, dermatitis (inflammation of the skin), frequent occurrence of illnesses
- Moderate symptoms—Chronic diarrhea, oral hairy leukoplakia or oral candidiasis (white patches in the mouth due to fungal infection)
- Severe symptoms—Fungal infection of the lungs, fungal meningitis, wasting syndrome (a very emaciated appearance), delayed development

In some cases, HIV-infected persons may not have any symptoms and can stay healthy for several years. Therefore, blood testing for HIV is the only method that can definitely detect HIV and confirm the diagnosis. Patients with symptoms or with exposure should have a blood test.

●● How to prevent HIV transmission?

- Use a new condom every time you have sexual intercourse.
- Avoid having sex with people whose HIV status is unknown, or people with a high risk of HIV infection, such as injecting drug users, people with a history of having unsafe sex, people who have had homosexual or bisexual relationships, and sex workers.
- Avoid risk behaviors that can lead to casual or unsafe sex without a condom. For example, avoid drinking alcohol or using narcotics.
- People with sexually transmitted infections such as syphilis, gonorrhea, or genital ulcers should seek treatment right away because these diseases increase the risk of HIV infection.
- Do not use narcotics, especially those that are injected intravenously. People who need to get an injection of medicine should not share needles or syringes with others.
- Do not share shaving razor blades, toothbrushes, or nail clippers with HIV-infected persons.
- Pregnant woman (or women who wish to get pregnant) should take a test for HIV. If they are HIV-positive, then taking ARVs during pregnancy, providing ARVs to the newborn at birth, and refraining from breast-feeding can significantly reduce the rate of mother-to-child transmission of HIV.

●● Can AIDS and HIV infection be cured?

Currently there are antiretroviral medicines (ARVs) that can help reduce the amount of HIV inside the body so that HIV-infected patients are as physically strong as uninfected persons. However, there is no way to completely cure HIV, and HIV-infected patients must take ARVs indefinitely. The time to start ARV treatment is a complex decision requiring consultation with an experienced physician.

It is very important to take ARV medication regularly and on time. By doing so, the level of ARVs in the bloodstream will be consistent, and the ARVs will be able to effectively reduce the amount of HIV. Any conditions that lower the amount of medicine in the bloodstream (e.g., missing a dose, failing to take medicines on time, or declining to take medicines according to doctor's instructions) may result in HIV replicating rapidly, followed by decreasing CD4 levels and opportunistic infections. Reducing the level of HIV in the body as much as possible is very important. Doing so will help prevent progression to AIDS or death.

Moreover, taking ARV medication regularly will help prevent the development of resistance to ARVs. Once drug resistance develops, there are fewer effective ARV regimens available to the patient. Taking ARVs regularly will ensure greater treatment success in the long run.

It is possible for a person to develop side effects from ARV treatment. Because ARVs can interact with other kinds of the medicines, patients should not take over-the-counter medicines without notifying the doctor.

Apart from ARV medication, a patient may also need to take other medicines to prevent opportunistic infections. Whether or not to take these depends on a patient's CD4 level.

The importance of treatment follow-up

The doctor will make an appointment for patients on ARV treatment to come for regular follow-up visits to assess physical symptoms and any side effects of the medicine. The visit will include a medical history and physical examination. In pediatric cases, growth and development will also be monitored. Blood samples may be taken for laboratory testing to monitor medication side effects and disease progression. These tests include CD4 count and HIV viral load, which help monitor the response to treatment. The goal of ARVs is to have a normal CD4 level and undetectable HIV viral load in the bloodstream.

ARV treatment failure occurs when, after a period of time, the amount of HIV in the blood increases or cannot be reduced to a satisfactory level. The CD4 count decreases subsequently and symptoms of opportunistic infections or immunodeficiency will then appear. Regular follow-up is an effective method for observing any signs of treatment failure and for adjusting the treatment plan.

●● How can HIV-infected persons maintain good health?

- Take medicines strictly according to instructions.
- Come for regular follow-up with the doctor.
- Consult a doctor every time when feeling ill.
- Eat healthy, well-cooked, clean, and hygienic foods.
- Exercise regularly.
- Get enough rest and sleep.
- Purify the mind. Meditate and say a prayer.
- Avoid narcotics and other risk behaviors that may lead to drug use and unprotected sex.
- Avoid acquiring new strains of HIV. Use a new condom every time during sexual intercourse, regardless of the sexual partner's HIV status. Do not share a toothbrush or a shaving razor blade with others.
- When there is an ulcer or laceration, wash it well and cover it with a band-aid or a piece of gauze.

●● How can we take care of HIV-infected children?

HIV-infected children need love, care, and attention, just as normal children do. They should receive age-appropriate healthy foods and be encouraged to stay active and to exercise as appropriate. They should go to school. Do not restrict them in playing or participating in activities with other children. However, they should take a few precautions:

- Drink boiled and clean water, eat well-cooked and clean foods.

- Wash hands before meals, and preserve a clean environment and good personal hygiene.
- Avoid having pets that have contact with young children and become sources of infection.
- Toys should be plastic, should not have any pointed or sharp angles, and should be washable.
- Take the children to the doctor when they are ill. Notify the doctor when someone in the family has a communicable disease or when the children are exposed to a disease that may be harmful, such as chickenpox, measles, or TB.
- Take the children to the doctor for regular check-ups and vaccinations.
- When the children have an ulcer or laceration, or menstruate for the first time, teach them how to take care of, to clean, and to cover the affected site.
- Avoid using bare hands to directly touch children's blood, body fluids, and nasal discharge. Use a barrier such as gloves, plastic bags, a piece of cloth, or tissue paper.

Disclosing HIV status of HIV-infected children

HIV-infected children will not normally transmit HIV to people around them. Therefore, their infection shouldn't be a barrier to daily activities or to participating in group activities. Most healthcare professionals suggest that it is not necessary to disclose the HIV status of children to other people except in cases involving direct contact with blood or body fluids, such as when children bite each other.

In most cases, young children infected with HIV do not know their HIV status. When they grow up, they should receive information about their diagnosis and know how to practice proper self-care. This should help them adjust to having a chronic illness, develop a positive attitude towards their disease, and see the importance of medication adherence. As a result, they will be disciplined about taking their medicines.

HIV disclosure should be conducted before the children become adolescents and start having sexual relationships. This is to prevent them from acquiring additional strains of HIV and from spreading HIV to other people. However, the appropriate time for disclosure should be determined on a case-by-case basis based on the readiness of the children and their families.

The process of disclosing HIV status to children should proceed carefully. It requires the caretaker's and the children's readiness, as well as preparation of the healthcare provider. It cannot be done completely and successfully at one counseling session or one visit. After disclosure, children and families should be monitored.

Do HIV-infected children have any restrictions or prohibitions in self-care practice, compared to those of other children?

Generally HIV-infected children do not have any restrictions or prohibitions in their daily activities. HIV-infected children can attend a childcare center, go to school, and participate in activities as

appropriate. For games and sports, they should avoid games and sports in which players crash into each other, such as boxing, wrestling, or rugby, as these may cause them to have open wounds or for others to be directly exposed to blood.

How should caretakers prepare for HIV-infected children becoming adolescents?

Adolescence involves physical and emotional changes. Adolescents should be educated about sanitary and hygienic practices. Any used sanitary napkins or materials stained with blood or semen should be wrapped and thrown into a covered bin. Children should be advised not to prematurely enter into a sexual relationship. Those who are having sex should be reminded to use a new condom every time they have intercourse.

Children who suffer a chronic disease may have problems related to their behavior, adherence to medication, or self-confidence. Caretakers should observe them closely and be their advocates and mentors. Caretakers may also guide them in choosing a vocation or career.

Generally there are no career restrictions for HIV-infected persons, except occupations that might put them at risk of direct contact with blood. For example, in some countries they may not be able to work as physicians or nurses in the operating room.

A decorative blue graphic with a scalloped border containing the text "Appendix B" in a black serif font.A small icon consisting of two overlapping circles, one light blue and one light grey.

Frequently Asked Questions by Children Related to HIV Disclosure

HIV diagnosis disclosure to children is a process of communication between a counselor, children, and caretakers. Many basic communication skills are essential such as listening, asking, and responsiveness. Non-verbal communication or body language such as holding hands and nodding to express active listening are good techniques to use. Drawing pictures is helpful in explaining difficult information. The counselor should select appropriate language for communicating with children depending on individual perception, ability to understand, and maturity.

Below are common questions found during the disclosure process, along with possible answers:

How long do I need to take the meds?

“You have to continue taking your meds for life, just as you have to eat three meals a day.”

What is a sexual relationship?

“A sexual relationship is the way that adults show their love to each other when they may want to have a child together.”

How did I get the HIV virus?

“You may have gotten it from your mother when you were in her womb or at birth. Your mother might not have known that she had it at the time she was pregnant. In the past we did not have drugs that prevented this virus from passing to a child but now we do. Right now we also have drugs that can keep you healthy.”

How long will I live?

“No one can tell at this point. But you can be sure that if you take your meds regularly and take good care of yourself, you can grow up to be adult and be healthy.”

Can this disease be cured?

“Right now we do not have way to cure it. But your medicines can control the virus and the virus will not harm you. You can live with it. HIV is controlled differently than many other diseases, such as cancer or diabetes. Cancer is harmful to life, and is sometimes treated with radiation. Diabetes patients must receive frequent insulin injections. HIV can be controlled by strictly taking medications.”

Will other people hate or be afraid of me?

“Many people do not have a good understanding and have negative ideas about this disease and they do not have chance to talk with HIV doctors like you do. Thus, some people might be afraid or may not like you if they know that you have HIV. It is not necessary to tell others. You can be in the community as usual. Except by having sex, sharing needles or syringes, or giving your blood to others, you will not pass this germ to others.”

Am I dying?

“In fact, everyone is going to die some day. People who have HIV will not die very soon if they take good care of themselves and take their medications regularly. They can still live normally and choose their own way to live.”

Can I have a boyfriend/girlfriend or get married?

“Yes, you can have a boyfriend/girlfriend or get married when you are an adult and ready. The foundation of a couple’s life together is understanding and trusting each other. Your own and your partner’s health should be discussed. We can help you to prepare for talking about this with the person you choose.”

Is it necessary that I should be boyfriend/girlfriend, or married, only with a HIV-positive person?

“No, it is not. But you need to use appropriate protection, which we can advise you about when you need it. Your life as a couple will require understanding and safe practices. The doctor will give you good directions.”

References

1. Joint United Nations Program on HIV/AIDS (UNAIDS) and World Health Organization (WHO). **AIDS epidemic update:** Dec. 2006, Geneva, UNAIDS, WHO, Dec. 2006
2. Thorne C, Newell M-L, Peckham CS. **Disclosure of diagnosis and planning for the future in HIV-affected families in Europe.** *Child: Care, Health and Development.* 2000; 26(1): 29-40.
3. Brady MT, Clark C, Weedy C. **Disclosure of HIV diagnosis to children in ACTG clinical trials (ACTG219).** XI International Conference on AIDS, Vancouver. Abstracts, 2, WeD131.
4. Oberdorfer P. **Barriers of disclosure of HIV/AIDS status to Thai children.** *Thai Journal of Pediatrics.* 2005; 44: 176-81.
5. Wiener L, Battles H, Heilman N, et al. **Factors associated with disclosure of diagnosis to children with HIV/AIDS.** *Pediatric AIDS and HIV Infection: Fetus and Adolescent.* 1996; 7: 310-324.
6. Boon-yasidhi V, Kottapat U, Durier Y, et al. **Diagnostic disclosure status of HIV-infected Thai children.** *J Med Assoc Thai.* 2005; 88 (Suppl 8): S100-5.

7. Blasini I, Chantry C, Cruz C, et al. **Disclosure model for pediatric patients living with HIV in Puerto Rico: design, implementation and evaluation.** *Journal of Developmental and Behavioral Pediatrics.* 2004; 25(3): 181-189.
8. American Academy of Pediatrics. Committee on Pediatric AIDS. **Disclosure of illness status to children and adolescents with HIV infection.** *Pediatrics.* 1999; 103(1): 164-166.
9. American Academy of Pediatrics website: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;103/1/164>
10. Chokephaibulkit K. **Pediatric HIV/AIDS infection.** Bangkok: Department of Pediatrics, Faculty of Medicine, Siriraj Hospital, Mahidol University.
11. Lester P, Chesney M, Cooke M, Whalley P, Peres B, Petru A, et al. **Diagnostic disclosure to HIV-infected children: How parents decide when and what to tell.** *Clin Child Psycho Psychiatry.* 2002; 7: 85-89.
12. Nystul MS. **Introduction to counseling: an art and science perspective.** Needham Heights, MA: Allyn and Bacon, 1999.
13. Inskipp F. **Generic skills.** In: Feltham C, Horton I. **The SAGE handbook of counseling and psychotherapy, 2nd ed** London: SAGE Publication, 2006: 73-86.
14. Lloyd M, Bor R. **Communication skills for medicine, 2nd ed.** Edinburgh. Churchill Livingstone, 2004.
15. UNICEF-Thailand. **Care of the children affected by AIDS.** Bangkok: AIDS Network Development Foundation-Northeastern Office. 2003.

16. Lester P, Chesney M, Cooke M, et al. **When the time comes to talk about HIV: Factors associated with diagnostic disclosure and emotional distress in HIV-infected children.** *J Acquir Immune Defic Syndr.* 2002; 31: 309-317.
17. Waugh S. **Parental views on disclosure of diagnosis to their HIV-positive children.** *AIDS Care.* 2003; 15: 169-176.
18. Ounchit N. **A tale for building up understanding about HIV: Virus Devimon. MSF-B (Thailand).** Amarin Printing. 2002.
19. Bureau of AIDS, TB and STI, Department of Disease Control, Thailand Ministry of Public Health. **Taking ARV medication continuously and regularly.** 2004.
20. Wiener LS, Battles HB, Heilman N, Sigelman CK, Pizzo PA. **Factors associated with disclosure of diagnosis to children with HIV/AIDS.** *Pediatric AIDS HIV Infect.* 1996; 7(5): 310-24.
21. Wiener L. **Disclosure.** In: Zeichner S, Read J, eds. **Textbook of pediatric HIV care.** Cambridge: Cambridge University Press. 2005: 661-665.