

# DISCLOSURE OF HIV TO PERINATALLY INFECTED CHILDREN AND ADOLESCENTS

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## I. INTRODUCTION

### RECOMMENDATION:

**Clinicians and other members of the multidisciplinary team should collaborate with caregivers of HIV-infected children to disclose the diagnosis of HIV to the child in a developmentally appropriate manner. (AIII)**

One of the most difficult issues that families with HIV-infected children face is when and how to talk about HIV to their children. HIV disclosure to infected children and adolescents should take place in a supportive environment with collaboration and cooperation among caregivers and providers. Disclosure is contingent on the caregiver's acknowledgment of the illness, the readiness to disclose, and the child's cognitive skills and emotional maturity.

Some studies have shown that children who are able to discuss their illness with adults have fewer behavior problems and have improved social functioning, school performance, and adherence to medications<sup>1,2</sup>; however, other studies have shown an increase in behavior problems and stress levels after disclosure.<sup>3,4</sup> Poor adjustment to a chronic illness can be a barrier to adherence and may cause conflict between the child, the caregiver, and the healthcare team. Collaboration among providers and caregivers helps to ensure that a plan is in place to provide support to the child who learns about his or her HIV status. Developmentally appropriate and truthful explanations of the illness, validation of the child's concerns about the disease, clarifications of misconceptions, and ongoing support are the cornerstones for promoting a positive adjustment to living with HIV infection.

### **Key Point:**

Identification of one member of the multidisciplinary team who is trained as the "disclosure specialist" may facilitate the disclosure process. Many multidisciplinary teams include a psychologist or other mental health professional who may be uniquely suited to this role.

This chapter addresses the following:

- Collaboration with caregivers to create a disclosure plan
- Age-specific considerations for disclosure
- Ways in which providers can prepare families for the disclosure discussion
- Considerations for disclosing to adolescents
- Follow-up visits to provide support and to monitor the child's/adolescent's emotional adjustment and understanding of the illness

Issues related to disclosure to schools, other medical professionals, and social services are addressed in *Ambulatory Care of HIV-Infected Children*.

## II. WHEN SHOULD THE DISCLOSURE PROCESS BEGIN?

### RECOMMENDATION:

**Ongoing dialogue between the clinical team and caregivers regarding disclosure of HIV diagnosis and health concepts should occur early in the patient's childhood. (AIII)**

The American Academy of Pediatrics (AAP) encourages the disclosure of HIV infection status to school-aged children.<sup>5</sup> Most children without cognitive deficits have the capacity to understand the diagnosis and concepts about immune systems and health. Disclosure can help children understand the illness and may further a child's willingness to adhere to his/her treatment regimen. A disclosure plan also prevents an accidental disclosure from occurring, such as when the child overhears the caregiver discussing the illness. Children who accidentally learn of their diagnosis may have a more difficult time adjusting to it.<sup>2</sup>

Once the diagnosis has been explained to a child, it needs to be reinforced or regularly discussed as the child develops because many children will not have understood the full implications of the disease or diagnosis at the time of disclosure. For example, preadolescent children can cognitively understand the concepts about the virus but may be less likely to think of the future implications, such as transmission risks and safe sexual practices. As the child ages and matures, he/she will slowly understand and integrate the implications of the diagnosis into his/her life. Children's perception of self, health, illness, and death evolve as they mature through different developmental stages. Knowledge of these different developmental stages (see Table 2 and Appendix B) can help guide clinicians and caregivers when discussing HIV with infected children and non-infected siblings.

### **Key Point:**

Disclosure of HIV status is not a one-time event, but rather a process, involving ongoing discussions about the disease as the child matures cognitively, emotionally, and sexually.

Whenever possible, disclosure should occur at a time when the child is clinically and emotionally stable and the caregiver is ready to disclose. Preferably, disclosure should not take place during an acute illness or family crisis and should not coincide with other events such as birthdays, holidays, or graduations. Disclosure can provide an opportunity for a family to share important information and to focus on health, communication, and relationships.

The disclosure process should not be rushed; however, the timing of disclosure becomes more pressing as the child nears adolescence, a time when the potential to engage in sexual and substance-using behavior may emerge (see Section VI: *Considerations for Disclosure to Perinatally Infected Adolescents*).

### III. COLLABORATING WITH FAMILIES TO DEVELOP A DISCLOSURE PLAN

#### RECOMMENDATIONS:

#### Clinicians or a member of the multidisciplinary healthcare team should:

- Assess, early in the patient's childhood, the readiness of caregivers to disclose HIV diagnosis to their infected child (AIII)
- Work with caregivers to develop a disclosure plan that meets the individualized needs of the family and the child (AIII)

#### Clinicians or a member of the multidisciplinary healthcare team should discuss the following with caregivers of HIV-infected children on an ongoing basis:

- Caregivers' concerns about disclosure (AIII)
- The importance of ongoing communication with the child regarding health issues (AIII)
- Benefits and risks of disclosing the diagnosis of HIV infection to the child (BIII)
- The potential harm that can result from long-term nondisclosure (BIII)

These discussions should be documented in the child's medical record.

When caregivers are reluctant to develop a disclosure plan, clinicians should ask about their concerns and attempt to develop a plan that addresses those concerns (see Section IV: *Individualizing the Disclosure Plan*). Referrals for counseling and additional assistance regarding disclosure issues may be necessary. (AIII)

#### **Key Point:**

Caregivers who are HIV-infected can provide a positive model of healthy behaviors for their children by tending to their own health needs, such as medication adherence and medical appointments.

Preparing caregivers to disclose HIV status to the infected child may take several months or even years.<sup>1</sup> Many caregivers with HIV infection have difficulty accepting the illness, either their own or their child's, and struggle with whether or not to disclose the diagnosis of HIV infection. The following are common reasons why caregivers are reluctant to disclose HIV to their children<sup>6</sup>:

- Fear that the infected child will inappropriately disclose his/her HIV status, especially in families in which the diagnosis remains closely guarded
- Fear of stigma, rejection, and loss of support by the family/community
- Desire to protect the child from worrying about his/her future
- The possibility that the burden of learning of his/her HIV status will lead to depression or other mental health issues
- Feelings of guilt and shame may prevent HIV-infected caregivers from disclosing their own infection to their child

Clinicians should respect caregivers' reasons for fearing or resisting disclosure and should attempt to understand the factors associated with the reluctance to disclose. Validation of caregivers' concerns can foster a partnership and prevent the development of an adversarial relationship between the members of the healthcare team and caregivers. Appendix A provides strategies that can be used to alleviate caregivers' concerns regarding disclosure.

Motivational interviewing may be useful for facilitating discussions with caregivers who are not ready to disclose HIV to their child.<sup>7</sup> In a motivational interviewing framework, clinicians adjust the tenor of their discussions to fit the caregivers' current readiness and encourage caregivers to discuss *all* of their feelings and concerns about disclosure (both pros and cons), as well as their long-term goals for the physical and emotional well-being of their child. The motivation to disclose is then framed in the context of the caregivers' values, and the caregivers gain confidence in their ability to create a disclosure plan that supports their child's best interests. More resources on motivational interviewing are available at [www.motivationalinterview.org](http://www.motivationalinterview.org)

*Partial disclosure* may be an effective strategy to use to help caregivers who are not ready to use the terms "HIV" or "AIDS." Partial disclosure involves teaching a child about his/her body and how the immune system works before using the actual words "HIV" or "AIDS." Partial disclosure is useful for building a context in which HIV disclosure can be more meaningful for children. Within these parameters, clinicians can be honest with their patients without forcing disclosure before the caregivers are ready. Clinicians need to remain truthful in their communications with children about their illnesses so that they do not undermine the therapeutic relationship. Collusion with caregivers who are not truthful can be detrimental for some children because they may ultimately feel betrayed by the adults they trusted.

In some cases, caregivers and providers may require additional support to inform children/adolescents of their HIV status. In these cases, referral to a "disclosure specialist" or mental health professional who is experienced with discussing disclosure issues should be considered.

#### IV. INDIVIDUALIZING THE DISCLOSURE PLAN

##### **RECOMMENDATION:**

**Clinicians should work with caregivers to develop an individualized disclosure plan that addresses each family's unique circumstances** (see Table 1). (AIII)

Table 1 provides a list of factors that should be discussed with the caregiver when developing an individualized disclosure plan. Circumstances that may require additional consideration and support include adopted children who do not yet know their adoptive status and children with non-infected siblings (see Sections A and B).

<b>TABLE 1</b>	
<b>FACTORS TO CONSIDER WHEN DEVELOPING AN INDIVIDUALIZED DISCLOSURE PLAN</b>	
<b>Factors to Consider</b>	<b>Effect on Disclosure Plan</b>
<b>Child's age, cognitive ability, and developmental understanding of illness and mortality</b>	<ul style="list-style-type: none"> <li>Developmentally appropriate words and explanations should be used to maximize the child's understanding of the disease and diagnosis (see Table 2)</li> </ul>
<b>What the child has already been told and what the child already knows about medications or doctor visits</b>	<ul style="list-style-type: none"> <li>Provides a starting point for the disclosure discussion. Some older children may already know or suspect they are HIV-infected</li> </ul>
<b>Clinical status of child</b>	<ul style="list-style-type: none"> <li>Symptomatic and asymptomatic children usually have a different understanding of the disease</li> </ul>
<b>Other disclosures that may need to be made, such as adoptive status, paternity issues, or parental HIV diagnosis</b>	<ul style="list-style-type: none"> <li>Child may need additional time and support to cope with these factors before HIV disclosure is made</li> </ul>
<b>Caregivers' thoughts about disclosure</b>	<ul style="list-style-type: none"> <li>Caregivers' readiness to disclose may affect the timing of disclosure and will guide caregiver-clinician discussions regarding disclosure</li> </ul>
<b>Cultural influences</b>	<ul style="list-style-type: none"> <li>Cultural beliefs regarding child rearing, health, illness, and death should be discussed and respected to encourage a supportive partnership</li> </ul>
<b>Family/social circumstances</b>	<ul style="list-style-type: none"> <li>Factors such as whether child is adopted or in foster care, whether there are siblings, and if siblings are HIV-infected may affect the approach to disclosure</li> </ul>
<b>Anticipated response of the child when learning his/her diagnosis</b>	<ul style="list-style-type: none"> <li>Children who are emotionally unstable or who have poor coping skills may require closer post-disclosure follow-up and additional support</li> </ul>
<b>Types of support available to the child and family once disclosure occurs, such as counseling and peer support groups</b>	<ul style="list-style-type: none"> <li>A post-disclosure plan for assessment and support should be in place before disclosure occurs</li> </ul>

### **A. Disclosing Both Adoptive Status and HIV Diagnosis**

#### **RECOMMENDATION:**

**Consultation with or referral to a mental health professional should be considered when working with caregivers who are disclosing both adoptive status and HIV diagnosis to the child. (BIII)**

Providers and caregivers may need to address different issues with HIV-infected children who are in foster care or are adopted. Some of these children may not understand why they are infected but their caregivers are not. Before disclosing HIV diagnosis to these children, they need to know that 1) they were adopted, and 2) how HIV transmission occurs.

Children who have experienced the death of one or both biological parents need time to grieve and adapt to their adoptive caregivers before disclosure takes place. The healthcare team should recognize that for these children there may be an absence of stable, consistent, and supportive relationships with adults.

## **B. Effects of Disclosure on Siblings**

### **RECOMMENDATION:**

**Clinicians or a member of the healthcare team should collaborate with caregivers about the timing and effect of disclosure on both HIV-infected and non-HIV-infected siblings. (BIII)**

As part of the disclosure plan, the clinician or member of the healthcare team should collaborate with the caregiver to discuss disclosure of a child's HIV status to non-infected and infected siblings in a developmentally appropriate manner. Ideally, the disclosure process will lead to greater support for the HIV-infected child within his/her family.

An older sibling who is also HIV-infected may be able to provide extra support to the younger infected child by discussing his/her own thoughts, emotions, and experiences as someone living with HIV. More mature non-infected siblings who know the serostatus of the infected child may become additional sources of support for both the infected sibling and other family members. However, some non-infected siblings may feel neglected or become jealous of their HIV-infected sibling because of the attention that the "sick" child receives. Non-infected siblings need ongoing support and validation to meet their own emotional needs and may require referral to mental health services.

## **V. PREPARING FOR THE DISCLOSURE DISCUSSION**

### **RECOMMENDATIONS:**

**Clinicians should educate caregivers about using developmentally appropriate words and language when disclosing HIV diagnosis to an infected child (see Table 2). (AIII)**

**Prior to disclosure, the clinician or a member of the healthcare team should assess the child's coping skills, family and peer support, school/work functioning, and interests. (AIII)**

Caregivers should be able to choose the disclosure strategies that suit them best, such as whether they want to disclose the diagnosis independently or together with a member(s) of the healthcare team. If caregivers want the healthcare team to participate in the disclosure discussion, a separate appointment devoted only to disclosure may provide the opportunity for a more thorough and honest discussion with the infected child. Follow-up appointments and calls are necessary to help assess the need for additional support and to continue the disclosure process over time (see Section VII: *Post-Disclosure Assessments*).

When helping families disclose HIV diagnosis to the infected child, the clinician or a member of the healthcare team should explain that the use of developmentally appropriate words and explanations is the most effective and comprehensible approach to the child's understanding of

the disease and diagnosis (see Table 2). The words and terms that are used can gradually evolve into more HIV-specific language and concepts about immune status or health. Clear and developmentally appropriate explanations of the diagnosis and disease need to be reinforced and repeated as the child matures.

TABLE 2 STRATEGIES FOR DISCLOSING BASED ON DEVELOPMENTAL STAGE OF CHILD		
Stage	Illness Explanation	Strategies for Disclosing
<b>Preoperational</b> (~2 to 6 years old)	<ul style="list-style-type: none"> <li>• Symbolic thought develops and ability to use language increases.</li> <li>• Child provides illness explanations based on <u>association</u>, i.e., any object, event, person, or cause that s/he perceives to be related to it.</li> <li>• Child may still be unable to explain the link between the cause and the illness.</li> </ul>	<ul style="list-style-type: none"> <li>• Use visual aids such as drawings or puppets in addition to stories to illustrate concepts</li> <li>• Use of play can be helpful in demonstrating concepts</li> <li>• Use associations to concrete observations (e.g., “<i>When mommy stays in bed, she is feeling sick</i>” or “<i>When your tummy hurts you don’t feel like eating, but some medicine can help</i>” or “<i>There are pills that can help your body grow bigger and stronger.</i>”)</li> <li>• Avoid having to explain too many concepts at this age and focus on concrete examples</li> </ul>
<b>Concrete operational</b> (~7 to 10 years old)	<ul style="list-style-type: none"> <li>• Child provides illness explanations based on <u>sequence</u>.</li> <li>• Child’s illness descriptions progress from the belief that disease is transferred through contact, to an understanding that disease carriers can be internalized through swallowing or inhaling.</li> </ul>	<ul style="list-style-type: none"> <li>• Use visual aids such as drawings or media to show concepts</li> <li>• Use of play and more language-based communication can be more effective with age</li> <li>• Use examples such as, “<i>Your soldier T helper cells protect your body from enemy germs. Your pills help protect your soldier T cells to fight the enemy germs. When your soldier T helper cells kill more germs, then your body can get healthier and stronger.</i>”</li> <li>• Emphasize the concepts of health, wellness, and body</li> <li>• Discuss issues related to privacy, stigma, and confidentiality in an age-appropriate manner</li> </ul>
<b>Formal operational</b> (~11 years and older)	<ul style="list-style-type: none"> <li>• Abstract thinking and reasoning develops.</li> <li>• Child begins to view body as a system and provides illness explanations based on <u>interaction</u> of a number of factors.</li> <li>• Child’s illness understanding develops from the belief that it is caused by internal organ malfunctioning to his/her ability to explain its cause as a complex interaction between host and agent.</li> </ul>	<ul style="list-style-type: none"> <li>• Use visual aids such as books or websites to demonstrate the key concepts in HIV, the immune system, and illness</li> <li>• Use slightly more complex language to convey the interactions between health, illness, and treatment</li> <li>• Use examples such as, “<i>Your body has different parts and your immune system helps to protect your body from infections. HIV virus is a type of infection that destroys your immune system’s T helper cells. Your medications can help to stop the HIV virus from hurting your T helper cells and immune system.</i>”</li> </ul>

		<ul style="list-style-type: none"> <li>• Discuss and explore issues regarding HIV transmission using examples of age-appropriate behaviors</li> <li>• Discuss issues related to privacy, stigma, and confidentiality</li> <li>• Explore normal sexual development and education</li> </ul>
<p>Modified from Reference 6.  <u>Note:</u> underlined words are categories of developmental stages from Walsh ME, Bibace R. Children's conception of AIDS: A developmental analysis. <i>J Pediatr Psychol</i> 1991;16:273-285.</p>		

Table 3 includes general principles that may be used when disclosing HIV diagnosis to the infected child.

<b>TABLE 3</b> <b>GENERAL PRINCIPLES FOR DISCLOSING HIV STATUS*</b>
<ul style="list-style-type: none"> <li>• Date of disclosure should not coincide with other events such as birthdays, holidays, graduation, etc.</li> <li>• Use clear and developmentally appropriate explanations of the disease/diagnosis</li> <li>• Share the diagnosis quickly, do not delay or stall</li> <li>• Promote sharing of feelings, but also accept silence</li> <li>• Always allow the child to ask questions</li> <li>• Give developmentally appropriate educational materials</li> <li>• Both the healthcare team and caregivers should be involved throughout the process</li> </ul>
<p>* From Reference 2.</p>

Pre-disclosure assessment of the following areas of the child's or adolescent's functioning will provide a baseline from which the impact of the disclosure can be monitored post-disclosure:

- The child's school functioning
- Family and peer relationships and support
- Interests and activities
- Mood and behavior



## VI. CONSIDERATIONS FOR DISCLOSURE TO PERINATALLY INFECTED ADOLESCENTS

### RECOMMENDATIONS:

#### Clinicians should:

- **Strive to ensure that, within a reasonable time frame, HIV-infected adolescents are fully informed of their HIV status (AIII)**
- **Assess what adolescents understand about their health/illness and use that information to guide future discussions and the disclosure process (AIII)**
- **Give adolescents the opportunity to discuss their health/illness and ask questions independent of caregivers (AIII)**
- **Help the adolescent identify a supportive person to whom he/she can safely disclose and discuss HIV-related issues (BIII)**
- **Incorporate discussions about disclosure and understanding of the illness into routine ongoing care (AIII)**
- **Counsel about sexuality and risk-reduction behaviors (see *Prevention of HIV Transmission*) (AIII)**

**Caregivers who object to disclosing an adolescent's HIV diagnosis should receive intensive support and services from the clinical team to address their concerns. (AIII)**

**Decisions regarding disclosure to adolescents with significant cognitive deficits need to be individualized. Specific strategies should be undertaken based on the developmental stage of the child (see Table 2). (AIII)**

Disclosure and knowledge of HIV status are essential components in the care of perinatally infected adolescents. Nondisclosure of HIV status reinforces stigma, fosters secrecy, and prevents the individual from assuming responsibility for their own health care and well-being. Nondisclosure also places adolescents who are sexually active at risk for unknowingly exposing others to HIV. Because of the significant consequences that nondisclosure may have for perinatally infected adolescents, this Committee feels that disclosure should occur before adolescence and supports the AAP recommendation that:

Adolescents should know their HIV status. They should be fully informed to appreciate consequences for many aspects of their health, including sexual behavior. Adolescents also should be informed of their HIV status to make appropriate decisions about treatment and participation in clinical treatment trials. Physicians should also encourage adolescents to involve their parents in their care.<sup>5</sup>

In New York State, caregiver consent is required for clinicians to treat minors for HIV/AIDS (exceptions, including minors who are married and minors who are pregnant or parenting, have been described elsewhere<sup>8,9</sup>); however, adolescents should actively participate in their own care and treatment decisions. Without knowing their HIV status, adolescents are unable to make informed decisions. Knowledge of HIV status will likely affect medication adherence and how the clinician counsels the patient about sexuality and risk-reduction.

Because a minor's caregiver must consent to the minor's HIV care, clinicians should not disclose HIV diagnosis to a minor without the caregiver's consent. Refusal from the caregiver to give such consent may create opposing pressures on the clinician that may result in poor clinical outcomes. Clinicians should be aware of these potential conflicts and should arrange multidisciplinary case conferences to develop a plan for working with these families.

For specific information about decision-making responsibilities of adolescents regarding ARV therapy, see *Antiretroviral Therapy for HIV-Infected Adolescents*.

### **A. Assessing Adolescent Patients' Understanding About Their Health**

The disclosure process for adolescents should start with an assessment of the adolescent's knowledge about his/her illness. Adolescents should be asked about their understanding of their medications, their illness, and reasons for their doctors' visits. The information the adolescent provides should be used to guide future dialogue about both disclosure and the adolescent's health. Some adolescents may already know or suspect they are HIV-infected even though their caregivers and medical team have not referred to HIV by its actual name.

### **B. Providing Opportunities for Adolescents to Discuss HIV Diagnosis**

All HIV-infected adolescents should be given the opportunity to discuss their health with the clinician and healthcare team and should be given the choice of speaking to their providers with or without their caregivers. Some young adolescents may prefer to have their caregiver(s) present during discussions.

Speaking with a member of the healthcare team independent of the caregiver should be encouraged for the following reasons:

- 1) to build a trusting therapeutic relationship between clinician and patient
- 2) to allow adolescents to more easily discuss topics that may be difficult to discuss with a caregiver present
- 3) to develop self-management skills

Open discussion about the disease can provide an opportunity to address false or negative ideas that the adolescent may have about issues such as transmission, treatment, life expectancy, or reproductive options. Such discussions can also serve as opportunities for risk-reduction counseling, including standard precautions and safe-sex responsibilities.

Clinicians should help HIV-infected adolescents identify a supportive person(s) with whom they can safely discuss HIV-related issues. Some may identify a supportive adult family member, a member of the clinical team, or a peer. Peer support groups for HIV-infected adolescents can provide positive experiences that promote a sense of normalcy, lessen anxiety, and improve self-esteem.

Close post-disclosure follow-up is necessary to ensure that the adolescent is receiving the support that he/she may need (see Section VII: *Post-Disclosure Assessments*).

## VII. POST-DISCLOSURE ASSESSMENTS

### RECOMMENDATIONS:

**The clinician or a member of the healthcare team should assess the child/adolescent's emotional well-being and functioning at every visit after disclosure of HIV diagnosis has occurred. The following areas of functioning should be assessed: (AIII)**

- **School functioning**
- **Family and peer relationships and support**
- **Interests and activities**
- **Mood and behavior**

**The clinician should work closely with caregivers to monitor the child for changes in functioning that may signify poor adjustment. (AIII)**

**Clinicians should refer children who demonstrate significant post-disclosure changes in behavior for additional support. (AIII)**

**The healthcare team should provide all disclosed HIV-infected children and their families with ongoing support through the adjustment of learning to live with HIV infection. (AIII)**

Disclosure is a process that does not end with telling an HIV-infected child the name of their illness or diagnosis. After the HIV diagnosis has been disclosed to the infected child, follow-up calls and visits are needed to monitor the child and family's understanding of the illness and their emotional and psychological adjustment. Evaluating the child/adolescent pre- and post-disclosure may help the healthcare team and families identify children who require additional support and services. Some children who learn of their HIV status may experience guilt and shame and may isolate themselves as a result of the stigma and secrecy surrounding the disease. Changes in behavior and school functioning may occur in these children and may be symptoms of depression. Patients and families who have a difficult adjustment to HIV disclosure without progress over time should be referred for mental health services and additional support.

Separate discussions with family members and children may be necessary so that clinicians can address the unique issues of each family member in a safe and supportive environment. Adolescents and their families should be made aware of support resources that are available within their programs or communities.

## VIII. ONLINE DISCLOSURE RESOURCES

Resource for caregivers:

- [www.thewellproject.org/en\\_US/Womens\\_Center/HIV\\_and\\_Disclosure.jsp](http://www.thewellproject.org/en_US/Womens_Center/HIV_and_Disclosure.jsp)

Resources for both caregivers and adolescents:

- [http://aidsinfontet.org/fact\\_sheets/view/204?lang=eng](http://aidsinfontet.org/fact_sheets/view/204?lang=eng)
- [www.treathivnow.com/](http://www.treathivnow.com/)

Books about HIV that can be ordered for children:

- [www.kidstalkaids.org/program/index.html](http://www.kidstalkaids.org/program/index.html)
- <http://j.mp/XBmHH2>

Slide set for provider training:

- [www.hivguidelines.org/wp-content/uploads/disclosure-posted-07-29-2010.ppt](http://www.hivguidelines.org/wp-content/uploads/disclosure-posted-07-29-2010.ppt)

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## FURTHER READING:

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## APPENDIX A. STRATEGIES TO FACILITATE CAREGIVER READINESS TO DISCLOSE

### Strategies to Facilitate Caregiver Readiness to Disclose

Families have many reasons for not disclosing the diagnosis of HIV disease to their children. Caregivers may think they are protecting the child by not telling them about their HIV status. The following table lists common reasons why caregivers may not feel ready to disclose and strategies that may be used to prepare them for disclosure.

<b>TABLE A-1 STRATEGIES TO FACILITATE CAREGIVER READINESS TO DISCLOSE HIV DIAGNOSIS TO THEIR CHILDREN</b>	
<b>Reasons for Not Disclosing</b>	<b>Strategies to Overcome Barriers</b>
Caregiver feels child is too young or emotionally immature to understand disclosure issues	<ul style="list-style-type: none"> <li>Partial disclosure may be used. For example, begin by telling the child that medications help to keep his/her body as healthy as possible. Then, as part of the disclosure plan, caregivers and healthcare team agree to give more information, little by little, as the child matures. Introducing the idea of an immune system, or a part of the body that fights infections, may be helpful.</li> </ul>
Caregiver fears that child will not understand when not to disclose	<ul style="list-style-type: none"> <li>Assess cognitive and emotional ability to understand and maintain confidentiality and discuss assessment with caregiver</li> <li>Offer to create a “contract” that outlines who the child can tell and who the child cannot tell</li> </ul>
Caregiver fears that the child’s reaction will be very difficult	<ul style="list-style-type: none"> <li>Assure the caregiver that the healthcare team will provide support for the family and child before, during, and after the disclosure process, including mental health assessment and treatment if necessary</li> <li>Use developmentally appropriate materials suited to the child’s emotional, cognitive, and psychological level to facilitate education</li> <li>Address false or negative ideas that the child or caregiver has about HIV infection, universal precautions, and safer-sex responsibilities and reproductive options, e.g., the need for safer sex does not equal “being bad” or imply the inability to have children in the future</li> <li>Explain the value of shared feelings and the detrimental psychological effects of repressed emotion</li> </ul>
Guilt from biological parent for transmitting HIV infection	<ul style="list-style-type: none"> <li>Counsel to help alleviate guilt</li> <li>Engage the parent in a more affirming and helpful role with the child to promote empowerment; refer for mental health treatment if necessary</li> </ul>
Caregiver is worried about questions that their child may ask about the caregiver’s sexual behaviors or drug use	<ul style="list-style-type: none"> <li>Use role playing to prepare caregivers to answer embarrassing or painful questions</li> <li>Help caregiver decide how to answer questions that may be asked</li> </ul>

Adoptive status has not yet been disclosed to child	<ul style="list-style-type: none"> <li>• Explain to foster/adoptive parents the complexity of both disclosure of HIV status and adoption and refer for counseling as needed</li> </ul>
Foster parent and foster agency disagree about disclosure	<ul style="list-style-type: none"> <li>• Arrange for discussion among foster parents, foster agency, and clinical team, including inter-team meetings, to discuss and address disclosure concerns</li> </ul>
Caregivers disagree about disclosing to child	<ul style="list-style-type: none"> <li>• Assess each person's concerns and work together to develop a plan</li> <li>• Counsel and provide mental health/social work support if necessary</li> </ul>

## APPENDIX B. STAGES OF DEVELOPMENT IN CHILDREN

Following is a description of children's perception of their bodies, health, illness, and death at different developmental stages.<sup>1-3</sup>

### • Early Childhood (3-5 years of age):

- Health, illness, and death defined in relation to child's own experiences and ability to participate in peer group activities.
- External body activities are identified; internal functioning is less clear.
- Stress is reduced by considering the child's immediate sensations, experiences, and feelings.
- Illness perceived as something that is "caught."
- The child can follow health and safety rules.
- The child has fears related to his/her own health and safety.
- Death
  - Perceived as separation from loved ones, which is temporary and reversible.
  - Is an altered life state – many normal daily functions are maintained (e.g., sleeping, breathing, and feeling).
  - Often confused with sleeping (adults may describe death as a form of "sleeping", which may cause fear to fall asleep for the child) or a journey (pre-school children may think they can visit the deceased).
  - Is defined literally and in terms of structure and concrete information; death is real; there is separation; the deceased person is immobile.

### • Middle Childhood (6-8 years of age):

- Child has a better understanding of causal relationships; there is a curiosity and excitement about learning.
- Child exposed to ideas and events outside own family.
- Anxiety develops about effects of external events on own life.
- Awareness of differences in people, including those who are very ill, increases.
- Personal privacy becomes important.
- Death
  - Becomes specific and concrete; there are both internal causes (e.g., old age) and external causes (e.g., automobile accident).
  - Starting to be perceived as final and irreversible, but escapable.
  - Is not personally relevant, child believes only the old die.
  - More concerned with pain and mutilation than possible death.
  - Can be personified (e.g., cartoons and fairy tales) and be seen as punishment for bad behavior; personification based on cultural and religious beliefs.
  - Death causes the body to stop functioning and is irreversible.

### • Late Childhood (9-12):

- Child better conceptualizes processes occurring in the body.
- Health influenced by culture, religious beliefs, and personal experiences.
- Peer group a strong influence on behavior and decision-making.
- Independence from family increases as child affiliates with peers and non-family adults.
- Concept of ambiguity better tolerated and reinforces decision-making and assertion skills.
- Increasing curiosity about sexuality and body may involve exposure to sexual activity.
- Secondary sexual characteristics may begin during this phase.
- Awareness of serious illness of family members, other adults, or peers occurs.



- Death
  - Is influenced by child's personal experiences with death and dying.
  - Recognizes that death happens according to certain rules; ideas of universality and permanence are acquired (e.g., the body wears out as does an old car and is no longer able to run).
  - Death is now known as irreversible, and the child may experience some anxiety surrounding death, particularly as it affects loved ones.

• **Preadolescence/Adolescence:**

- Peer group becomes strong influence on behavior and decision-making.
- Physical changes occur, child's own comparison to peers is of great concern.
- Self-consciousness increased in children with chronic illnesses.
- Increased interest in sexual identity and activity; substance use experimentation may occur.
- Increased emotional lability.
- Death
  - Thoughts and speculation about death become more abstract.
  - May have thoughts of indestructibility and immortality; this form of denial may contribute to exacerbations of illness and issues of non-adherence with treatments.
- Adolescents' need for control and autonomy may contribute to non-adherence to medication.
- The art is to acknowledge and accept the adolescent's view of reality and independence while at the same time asserting an adult's view of reality.<sup>4</sup>

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