

DISCUSSING DISCLOSURE DECISIONS WITH CAREGIVERS

GUIDELINES FOR STUDY STAFF

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The new SMARTT Stigma and Disclosure surveys are an important step in helping PHACS better understand caregivers' decisions around disclosing their HIV status to their children, as well as their experiences with HIV stigma. Thank you for being such an integral part of helping us gather this information so that we can improve how we approach these topics at our sites.

After you administer these surveys, there is an opportunity for you to open up a conversation about stigma and disclosure with the caregiver you are interviewing. As you read through this guide, please note that we use the term "caregiver" throughout to include parents (biological and non-biological) and other types of caretakers and guardians; please simply fill in the appropriate term for each specific conversation you have. For some staff and caregivers, it may feel comfortable and natural to have an open-ended discussion about these topics, and for others, it may feel uncomfortable, difficult, or tiring to do so. All of these feelings are normal ones to have.

The goal of the conversation

The goal of this conversation is to provide an open, nonjudgmental space for caregivers to discuss their current thoughts and feelings on the topic of disclosure, if they choose to do so. It may be an opportunity for them to request resources or additional information about disclosure. It can be an opportunity for site staff to help explain maternal disclosure in the context of the child's HIV- and ARV-exposed status being part of their medical record. Most of all, it's a chance for you to support them in their decision-making process and offer education and perspective where appropriate.

Deciding whether, when and how to disclose one's HIV status to a child is a personal decision, and we recognize that disclosure may not be the right decision for a family at a particular point in time, or maybe even ever. Some caregivers decide to disclose their status, some decide to give partial information, and others decide not to disclose at all. A caregiver may feel ready to tell one child, but not another. Each caregiver's situation is unique and should be treated as such. Because disclosure is a process, it will take time. It may involve multiple conversations and different levels of information and support provided for a child over time. This means that even if a caregiver has already disclosed their status to their child(ren), they may still need additional assistance from you or others as they have ongoing conversations with their child(ren). As you guide the discussion, it may be helpful to ask the caregiver to discuss their feelings about disclosure for each individual child, if they feel comfortable, so that you can gain the best understanding of their situation and offer more targeted support.

Tips from PHACS caregivers

For recommendations and insight from other PHACS caregivers regarding disclosure decisions, please read through the HIV Disclosure Caregiver's Guide here: www.tinyurl.com/PHACSGuide. This guide was developed with dozens of caregivers from across the U.S. While each caregiver's situation is unique, the guide should be helpful in enhancing your understanding of how best to approach the topic of disclosure with caregivers at your site.

Tips from other study staff

- If possible, the staff person with the most rapport with the caregiver should administer the surveys and start this conversation.
- It is important to communicate early with caregivers in SMARTT about the eligibility criteria for young adults wishing to continue in the study at age 18 or older. They should know that disclosure is one of those criteria, but this information should be shared in a way that does not pressure them to disclose.
- One reason the caregiver might consider disclosure is that HIV and ARV exposure is part of their child's medical history. Their child is part of a study looking at potential long-term effects of ARV exposure, and many would suggest that their child may have a need, and also has a right, to know this information because it may affect their health. If the timing feels appropriate, this conversation can be an opportunity for the staff person to remind the caregiver of this important factor in their decision and potentially to refer them to some of the lay summaries of our published research on the PHACS website. Start having conversations with caregivers about disclosure as early as possible, to help them understand that disclosure is a process, starting with open communication within a family and helping children understand basic health information. Let the caregiver know that they can start talking to their children about health and even HIV without disclosing. Discussing these topics early can help lay the groundwork for future disclosure conversations.
- In some cases, caregivers who were adamantly against disclosure change their minds if they have consistent support for wherever they are at in the process. In other cases, caregivers may never choose to disclose.
- As much as possible, normalize and validate whatever the caregiver is feeling about disclosure. Wherever they are on the spectrum, reiterate that it is completely normal and common to feel that way.
- Caregivers should not be pressured to disclose their status if they don't want to. However, we do want to offer information appropriate for them and specific to their situation. In some cases, this might push them slightly out of their comfort zone as they consider new information, but ultimately towards a decision they feel most comfortable with.
- Be aware of cultural differences in attitudes towards HIV and disclosure. What works for one person's context may be inappropriate for another's circumstances.
- In rare circumstances, some caregivers may benefit from talking to a mental health professional after completing the surveys and having this conversation. Create a plan for a mental health professional on your team to be available if needed (you can refer to your site's PHACS Emergency Response Protocol for guidance).
- We have heard from site staff and CAB members that peer support is a powerful support tool for caregivers as they make decisions about disclosure. Offering to connect the caregiver with a CAB member can be very helpful.

- Prior to disclosure, some caregivers may find it helpful to consider what information they want their children keep private, and which people are considered safe to talk with about that information. It is important to discuss privacy without reinforcing stigma or shame around HIV. For instance, one site helps parents create a “Star List” of people it’s ok to talk about HIV with.
- Have some resources and/or fact sheets about disclosure ready to share in case the caregiver requests them.
- If there are any interview questions that trigger particular emotions, comments, or questions from the caregiver, listen intently and make note of them. It is helpful to acknowledge their comments, to thank them for sharing (or asking their questions), and to reassure them that you feel it’s very important to address this with them again as soon as the interview is completed. This will help give them an emotional breather, and allow you to continue the interview. Doing so may elicit important information that could be helpful in your post-interview discussion with them when you return to the topic they wanted to discuss earlier.

The role of stigma

Caregivers have shared with us that HIV stigma often plays a large role in their decisions around disclosure. Some caregivers may have encountered stigma and discrimination due to their HIV positive status. This stigma may have been directed from healthcare workers and within the health context, from their family and friends, or from others. As result, many caregivers may be fearful about disclosure of their status. They may also feel stigmatized because of their personal disclosure decisions. It is important to hear and validate these experiences and feelings during the interview process and as they arise during this conversation.

Different attitudes towards disclosure

The spectrum of feelings and attitudes about maternal disclosure is wide, and anywhere people are on that spectrum is normal. Below are some general attitudes caregivers may have about disclosure, though it is important to note that each person’s situation is highly individualized and no two disclosure decisions may be the same.

This section is meant to help you define what your role can be as the person starting the conversation about disclosure.

If the caregiver is firmly against disclosure:

If the caregiver is firmly against disclosure, we respect that. Trying to convince them otherwise at this time could do more harm than good and could lead to feelings of shame, frustration, anger, sadness, guilt, and pressure to make a decision that doesn’t feel right for them. Simply affirm their decision, stating that you understand and respect it. Additionally, make certain that they know how to get in contact with you if they decide they want to talk more about it. If the rapport with the caregiver is solid, you may also want to inform the caregiver that if they are interested at some point in the future, you would be happy to discuss pros and cons of disclosure that other parents have shared.

If the caregiver is considering disclosure but is hesitant:

Even when caregivers are aware of the potential benefits of disclosure, they may be apprehensive to disclose due to fear, anxiety, worry, or a feeling that the process won't go well. They may be thinking about disclosing, but may not want to do it anytime soon. They may want support in exploring the pros and cons of disclosure, including information regarding possible consequences of exposures to HIV and ARVs in their medical history. Some people might find it helpful to hear more scientific facts about each potential decision, or what the experiences of others have been. They may find it helpful to respond to open-ended questions that help them process how each decision may or may not align with values they hold, and what might be challenging or scary about each decision. It may be useful to help them establish a clear vision of what they would like to see happen. It may also be advantageous to help caregivers think about strengths they hold personally or within their family structure that could be factors in their decision about whether to disclose or not.

If the caregiver is considering disclosing soon:

The caregiver may be thinking about disclosing with some sort of a time frame in mind (i.e., this year, in the next 6 months, by the time my child is a certain age, etc.). They have likely identified strong motivators for disclosing, and they may also have already done some problem-solving around overcoming potential barriers. It may be helpful to create a formal disclosure plan with the caregiver with actionable and realistic steps, or to do a role playing activity to help them practice. You can support caregivers to problem-solve in advance by discussing possible issues that could arise before, during, or after disclosure (i.e., feeling nervous, thinking about what questions their child might ask, preparing for a possible negative reaction from their child, etc.). The Caregiver Guide (see "Resources" section) has many tips about this, as well as considerations depending on the maturity level of the child. It may also be helpful to brainstorm with the caregiver to identify small steps they can start to take now to feel more prepared for when they do disclose.

If the caregiver has already disclosed:

There are many different ways to disclose to a child, and some of the questions in the Stigma and Disclosure instruments should help you understand more about how and when the disclosure happened. Some parents may start with telling their child that they have an illness without mentioning HIV (i.e., "Mommy has a bug/virus."), while others may mention HIV by name and give some additional information about the disease. Some may make a spontaneous decision to disclose, and others may plan their disclosure over a period of time. Because disclosure is a process, it's important to check in with the caregiver to ask how they feel about how the initial disclosure went, and how it may have affected their relationship with their child in positive or negative ways. You can help guide them back to the strengths they possess that have either been reinforced by disclosure, or which they can draw on if they are navigating a difficult situation. As children grow up, they may have different questions and feelings about their mother's status, and the caregiver may want your support in deciding how to continue the conversation with their child.

Guiding questions:

Here are some questions that may help get the conversation started.

- Did answering the questions in the survey bring up any thoughts or feelings for you? If so, what are they?
- What are your current thoughts about disclosure to your child?

Potential scenarios: Below are some potential scenarios and responses. Think about how you might personally feel comfortable responding in each case.

1) *Caregiver: "I never want to disclose to my children, ever, and I don't want to talk about it anymore."*

Some possible responses:

- o I understand you don't feel this is right for you. That's a decision that many caregivers make, and I appreciate your sharing that with me.
- o I understand that disclosure isn't the right choice for your family. I support whatever decision feels right for you. If you ever want to explore the topic of disclosure more, please feel free to reach out to me anytime. I won't ever pressure you to make one decision or the other.
- o I hear from your voice that you feel strongly about your decision, and based on your interview responses, it sounds like you are really concerned about...
- o What are additional ways you might respond?

2) *Caregiver: "I don't want to disclose to my children. I don't see any reason for them to need to know about my status."*

Some possible responses:

- o I understand that disclosure isn't the right choice for your family right now. That's a decision that many caregivers make, and I appreciate your sharing your feelings about it with me.
- o What do you think are some of the reasons you feel that way?
- o If you ever want to explore the topic of disclosure more, please feel free to reach out to me anytime.
- o Would you be interested in hearing about some reasons other caregivers decided to disclose their status?
- o Would you be interested in hearing some of the pros and cons of disclosure from the research?

Lots of people feel the same way; we have heard a whole range of responses, including those who started out feeling that way and then changed their minds. If you ever want to know how they felt after disclosing, let us know – we can share those stories with you, too. What are additional ways you might respond?

3) *Caregiver: "I've thought about disclosing, but I'm really nervous about how my child would react and worry that it would damage our relationship."*

Some possible responses:

- o I understand what you're saying. That's a very normal way to feel when thinking about this decision. Would you like to talk more about those feelings?
- o What do you think would be most challenging about disclosing your status to them?
- o What might be most beneficial or good about disclosing?
- o What aspect of disclosing makes you feel most fearful when you think about disclosing to your child?
- o What are some aspects of your relationship with [child's name] that have helped you get through difficult times before?
- o Would you like to speak with one of our CAB members about how they made the decision that felt right for them?
- o Would you be interested in looking at some resources or tools about disclosure to children? They may help you make a decision that feels right for you.
- o Would you like to hear about some of the typical reactions from children that have been reported in research studies?
- o What are additional ways you might respond?

4) *Caregiver: "I feel like I'm ready to disclose sometime soon, but I'm not sure how to do it."*

- o I understand that. It's a very normal way to feel when thinking about disclosure.
- o Would it be helpful to think through some of the specifics together, and/or to create a plan you can use whenever you feel ready?
- o What specifically would you like to tell your child?
- o What questions do you think you should be prepared for them to ask?
- o Where would you like the conversation to happen?
- o Do you want to use any tools to help explain HIV to them? (i.e., disclosure comics)?
- o Do you want to write out a script of what you might say in advance? This can help some caregivers make sure they don't say more than they're comfortable with in the moment.
- o What is something you can do to help yourself feel as calm as possible before you disclose?
- o It's important to be prepared for any type of reaction your child might have. What are some ways you can be supportive of the range of emotions your child might feel?
- o Would you be interested in looking at some resources or tools about disclosure to children? They may help you as you plan how to talk to your child.
- o What are additional ways you might respond?

5) Caregiver: *"I already told my child when they were 6. We haven't really talked about it much since then – it's just normal for us. Now they are 15 and they seem fine with it."*

- o Thank you for sharing that. Many other caregivers are in the same situation.
 - o Tell me more about how it went when you told them when they were 6. What questions did they have then? Have you discussed it with them at all since then?
 - o Do you think telling your child about your status changed your relationship with them in any way? If so, how?
 - o Some caregivers who disclosed when their child was young choose to have follow-up conversations as their children get older, because their children's understanding of HIV may have been very different then. Are you interested in considering another conversation? If so, what questions do you think your child might have now that they're the age they are now?
 - o Is there anything that feels challenging about talking about HIV with your child at this point? If so, what?
 - o What would you like your child to know about HIV now?
 - o What are additional ways you might respond?
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6) Caregiver: *"I told my son and he isn't taking it well. He hasn't spoken to me since then, and I am not sure what to do. It makes me really afraid to tell my other child."*

- o That sounds so difficult. I can understand why you feel the way you do. What are some of the things you're feeling about it right now?
 - o What do you think feels hardest about the situation?
 - o What do you think are the strengths you drew on to disclose to him in the first place? What are the strengths that you're drawing on now?
 - o What do you think might be different or the same about telling your other child?
 - o What are your child's typical ways of coping when s/he is dealing with something difficult? (i.e. do they need time/space, do they need to talk it through more, do they need to hear from others/peers)?
 - o Do you think you would benefit from talking with a professional or a close, disclosed friend of the family who can help your son/daughter work through this information?
 - o Are there other ways that you sometimes communicate with your son/daughter, like texting, sending an email, or writing a letter? Sometimes that gives kids a little space from the emotion, but still allows them to say what they need to say or ask.
 - o Would you be interested in speaking with other CAB members who have disclosed to their children?
 - o What are additional ways you might respond?
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7) Caregiver: "I found out my daughter was having sex, and I ended up telling her my status in the heat of the moment as a warning to her."

- o How are you feeling about the way it happened and the fact that she knows now?
 - o What was her reaction when you told her?
 - o Has the topic come up since then? Would you like to discuss it with her again?
 - o If so, would it help to brainstorm together about how you'd like the next conversation to go?
 - o When do you think would be a good time to re-open the conversation? What about a good location?
 - o What would you like to be different about this conversation compared to last time?
 - o What do you want her to know about what you said last time you talked about it?
 - o What questions do you think you should be prepared for them to ask?
 - o Do you want to write out a script of what you might say in advance? This can help some caregivers make sure they don't say more than they're comfortable with in the moment.
 - o What are additional ways you might respond?
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8) Sometimes disclosure happens inadvertently or accidentally. *For example: My daughter was looking through my medicine drawer and found out when she Googled my medication. Or: During a play date, my son overheard another mom I know from the clinic on the phone talking about my status. Or: My daughter Googled the clinic we come to for study and asked me if I have HIV.*

- o It sounds like this really took you by surprise. How are you feeling about the way it happened and the fact that he/she knows now?
 - o How did your son/daughter seem to react to finding out (if known)?
 - o Have you discussed it with them since then? What was that conversation like?
 - o If you haven't yet discussed it with them, do you feel ready to have a conversation with your child about this?
 - o Were there any questions your child asked that you didn't feel prepared to answer in the moment, but that you'd like to revisit with them in another conversation? Would it help to talk through some of them now?
 - o What are your child's typical ways of coping when s/he is dealing with something difficult? (i.e. do they need time/space, do they need to talk it through more, do they need to hear from others/peers)?
 - o Do you think you would benefit from talking with a professional or a close, disclosed friend of the family who can help your son/daughter work through this information?
 - o What are additional ways you might respond?
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Resources

Some site staff find it helpful to keep resources in a binder (with extra copies in the sleeve of the binder), which is kept in an accessible place, such as the “family room” or testing room. This should ideally be kept in a place that is accessible enough that it can be easily shared with the caregiver, but not necessarily in the open where others may see it or where it could lead to questions.

- HIV Disclosure Comic Books and Caregiver Guide: These comics and caregiver guide were developed by health educators and CAB members in PHACS specifically for caregivers thinking about parental disclosure and whether it’s right for them. The comics can be used to educate children about HIV and stigma even if the caregiver isn’t ready to disclose. The Caregiver Guide is full of insights and tips from caregivers who have faced this decision before. The comics can be used with children of any age; so far, they have been used successfully with youth ranging from age 7 to age 17.

Find it here: www.tinyurl.com/PHACSComics

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