

HIV and Infant Feeding: Perspectives from National Leaders

2023 Perinatal HIV Roundtable

Summary of breakout room discussions

On June 2, 2023, 216 community members, providers, researchers, program administrators, local and state health department personnel, and funders gathered virtually to listen to seven of our national leaders in the perinatal HIV community discuss the latest [DHHS Perinatal HIV Guidelines](#) update on infant feeding and HIV. This session was co-hosted by The Well Project (thewellproject.org) and the Perinatal HIV Hotline (nccc.ucsf.edu).

We devoted the last 30 minutes of the session to breakout groups to provide an opportunity for attendees to discuss five topics selected during the registration process: prophylaxis for infants of parents with HIV who choose to breast/chestfeed, infant feeding protocols for clinical settings, resources for the healthcare team, resources for parents, and how to hold a shared decision-making conversation as a provider or a parent.

Each breakout was facilitated by a two-person provider-community member team who were given a list of questions to guide the discussion. Below is a summary of those discussions. Resources for both healthcare providers and families/patients are at the bottom of this document.

Breakout room topic: Infant prophylaxis

Participants at the breakout session shared that there is a wide variance in local preparedness to implement the new infant feeding guidelines. Some clinics and hospital systems do not have a local standard or protocol for breast/chestfeeding, including infant prophylaxis protocols; some clinicians are unaware of the change in the guidelines. Some birthing hospitals are separate from infectious disease (ID) clinics so are unaccustomed to serving birthing people with HIV. The existence of care silos – when people with HIV are seen primarily in HIV clinics by HIV specialists - and stigmatization of birthing people by other non-HIV providers mean communication between HIV clinics, birthing hospitals, OB/GYN, and pediatric specialties is critical. However, communication and coordination between these groups is often suboptimal.

There has been a lot of fear of the repercussions of openly breast/chestfeeding. One participant shared the case of a woman whose providers supported her in breastfeeding, but counseled her not to share her decision with the labor and delivery or postpartum team, so that they wouldn't refer her to child protective services. Other people with HIV choose to breast/chestfeed in secret because of the difficulty in securing support from their entire care team.

Clear and consistent communication between all providers, including on-call (e.g., labor & delivery staff) or occasional providers (e.g., lactation consultants) is critical so that people with

HIV are informed of and supported in their infant feeding choices. Also, it is equally important to educate birthing people with HIV, providers, and those who make clinical decisions about the new recommendations.

Best practices that were shared by participants:

- One provider described how they support effective communication between different healthcare teams. Hire one person or team that coordinates care for the pregnant person. Ideally this person or team would know and work closely with local prenatal program(s), ID clinics, and birthing hospitals. The person coordinates holistically with obstetrics, labor & delivery, and newborn nursery to ensure breastfeeding is included in birth plans and supported; visits parent/baby in hospital to make sure all aspects of care are seamlessly coordinated; develops and provides training on the breast/chestfeeding standard of care to various providers who may come into contact with the pregnant or birthing person; ensures mom continues to receive care regardless of decision to breast/chestfeed; hosts perinatal meeting monthly for cases around the state.
- Pediatrician and birthing parent's provider form relationship and communicate with one another.
- Co-locate services for parent and infant.
- For education: Use health department, voices of people with lived experience, regional AIDS Education and Training Centers (AETCs)

Breakout room topic: Protocols

Many groups are working on protocols from different lenses. Some key points to consider when developing protocols:

- A parent with HIV who chooses to breast/chestfeed is **not** engaging in a reportable offense.
- Ensuring doors aren't unintentionally opened to further criminalization. Do not allow protocols to be used as a tool against Black and poor women. Include prohibitions against sharing of medical information with law enforcement outside of context of mandatory reporting.
- Include people with lived experience in protocol development.
- Good communication with child welfare and case management can enable clinicians to intercede on behalf of parents.
- Clinicians and hospital systems want trusted protocols to implement.
- "Keep an eye on our perinatal HIV hotline website for our protocols www.hivpregnancyhotline.org" (Anne Statton, Illinois Perinatal HIV Hotline).

Breakout room topic: Resources for healthcare team

This group discussed challenging situations that have come up or that might come in the care of people with HIV who are considering or choosing breast/chestfeeding. The discussion included the following:

- More information on safety of mixed feeding is needed.

- There was a concern expressed that exclusive breast/chestfeeding is unattainable and others who expressed that it is very do-able, especially with the right support.
- It is important to have early discussions with the patient around infant feeding desires/plans, include their decision in the care plan, and share that plan broadly.
- If a parent does not have the support of their care team, they may choose to breastfeed in secret. Even if a clinician doesn't agree, it's better to provide the patient information so they can make an informed decision.
- There are a lot of providers who are still uncomfortable with the new guidelines. Widely disseminated resources and education are needed.
- There needs to be a champion to educate other providers.
- It's important for lactation consultants to be included in conversations and serve as a resource.

Breakout room topic: Resources for parents

This group discussed ways that pregnant and postpartum people with HIV can access support in their infant feeding decisions and along their new parenting journey. One participant stated: *"Parents shouldn't feel guilty to bring life into the world."* **If there's any national website where changes are not reflected, please contact Lealah Pollock at lealah.pollock@ucsf.edu.**

Here were some major points from the discussion:

- The guideline change is becoming more widely disseminated. Now when you google HIV+ breastfeeding shared decision making is the message that comes up.
- The DHHS Perinatal HIV Guidelines have made a positive impact in having breast/chestfeeding as a choice providers can support but not everyone is familiar with the Guidelines, especially non-HIV specialists.
 - People living with HIV are asking for referrals to HIV specialist pediatricians to learn more about their options.
 - Providers are still using their hospital policy to not follow the perinatal guidelines
 - Academy of Breastfeeding Medicine needs to also update their guidelines to support implementation of perinatal guidelines.
- We need to continue to push for recommendations and guidelines to be updated across the board so that different disciplines under different professional boards have updated information. The team supporting the parent is critical:
 - Having multi-disciplinary support is extremely helpful.
 - Having a supportive case manager is very helpful.
 - It is important to find ways to engage with lactation consultants and pediatricians. One participant noted that pediatricians might be the most likely to make CPS reports - important to engage them. Another participant said that lactation specialists have also been trained that breastfeeding while living with HIV is a reason to report to CPO.
 - If providers are saying no, other advocates (including lactation consultants) continue to support parent by reminding them it's their choice.

Community still needs to support parents in advocating for themselves when providers are not supportive.

- The Perinatal HIV Hotline is helpful for providers who are not infectious disease specialists who might not know enough about HIV (pediatricians, OBGYN).
 - A challenge is that not all providers call and not all providers know about the Perinatal HIV Hotline.
 - There have been efforts to promote the perinatal HIV hotline to all clinicians who support pregnant and birthing people, but it is a challenge to disseminate outside of HIV specific providers.
- Where can parents email to ask questions? beeebah@thewellproject.org
 - A hotline for parents would be helpful - hotline shouldn't just be for providers.
- Patient-facing educational materials are valuable.
 - Material reviews are essential to ensure that patient questions are answered.

Breakout room topic: Shared decision making

Participants discussed what providers need in order to engage in shared decision making about infant feeding. They also talked about what providers need in order to support a parent's decision to breast/chestfeed. Major discussion points were as follows:

- It is important to open the door to honest conversations so that breast/chestfeeding can come out of the shadows. Previously felt like don't ask/don't tell.
- Breast/chestfeeding can be difficult to establish, especially without lactation support. Support from a multidisciplinary team including lactation support is important.
- Breast/chestfeeding is also a really hard choice to make. It's hard to sit with the knowledge that there is a possibility, however small, of transmitting HIV to your baby.
- Shared decision-making is important, as is having a welcoming medical community that does not make people with HIV feel ashamed of their choices. Clinicians often need education and to be better listeners. It has been built into the provider culture to "prescribe". Participants noted that some clinicians have learned so much from their patients who educated them as a provider.
- The stigma in some communities where breast/chestfeeding is the norm is so high. Parents would indicate they needed to breast/chestfeed because otherwise it would be a red flag to the community that the parent is living with HIV.
- Signed agreements were a controversial topic:
 - Some felt that these may not allow for the possibility of maintaining a humanistic experience.
 - Others said that signed agreements feel punitive or controlling.
 - One participant stated that as a patient, they would be okay signing if the provider also included their own responsibilities/obligations. If the document indicates we are working as a team, that feels like a more supportive arrangement.
 - Another participant shared that they had one parent use the signed agreement after a CPS report as proof that their actions were being conducted with the knowledge, approval, and support of their provider.

Resources:

- Perinatal HIV Hotline: (888) 448-8765; nccc.ucsf.edu
- ReproID HIV listserv: contact hoa.su@ucsf.edu to be added.
- The Well Project: www.thewellproject.org
- Compilations of all The Well Project resources: <https://bit.ly/TWPBfingHIV>

Resources for providers:

- [Listening to Women: Supporting Informed Decision-Making on Infant Feeding and HIV](#)
- For providers to add their information: [List of US-Based Providers who Support Informed Infant Feeding Choices for Parents with HIV](#)
- Infant Feeding and HIV Listserv: Email oford@thewellproject.org
- [Updates to the Perinatal HIV Clinical Guidelines!](#)
- [The Big Picture: Health Implications and Bioethical Considerations of Breastfeeding and HIV](#)
- [Breastfeeding and HIV: Viewpoints from an Adult and Pediatric Provider](#)
- [It's Time to Embrace Breastfeeding/Chestfeeding for US People With HIV](#)