



# Amplifying the Voices and Experiences of Parents Living with HIV Around Breast/Chestfeeding

**Authors:** Ciarra Covin, Allison Agwu, Jenna Conley, Olivia G. Ford, Krista Martel

## BACKGROUND

Breast/chestfeeding is considered both the healthiest option for infant feeding for the general population and the standard of care for women and other birthing parents living with HIV in resource-limited settings. Limited research on breastfeeding and HIV in high-resource settings such as the United States and Canada, however, has resulted in a lack of education and clinical standards for providers in these areas to enable them to support informed infant-feeding decision-making among women living with HIV. Currently, the elimination of any risk of HIV transmission is often the only factor considered in counseling women in these settings about infant-feeding decisions. This ignores challenges related to health disparities and family, cultural, and economic values, as well as the potential benefits and advantages of breastfeeding.

## DESCRIPTION

The Well Project, a nonprofit whose mission is to change the course of the HIV pandemic through a unique and comprehensive focus on women and girls, is committed to ensuring that women and other parents living with HIV have access to the information, support, and tools necessary to make informed infant-feeding decisions. The Well Project is executing these efforts in response to the demonstrated need for programming that advances research, policy, and education around breast/chestfeeding for women and other parents living with HIV and the providers who support them. The core of this programming elevates the experiences of women living with HIV to improve knowledge among healthcare providers and policy makers while building leadership capacity. Specific programming about breast/chestfeeding includes webinars, live-streaming events/videos, and fact sheets. To assess interest in breast/chestfeeding and HIV, we measured views of the resources.

## Language matters:

**At The Well Project, we use “breastfeeding” and “breast/chestfeeding.” The Well Project focuses on cis and trans women living with and vulnerable to HIV and strives to be inclusive of trans men, nonbinary individuals, and all others living with HIV who wish to explore these options.**



## LESSONS LEARNED

The Well Project’s 2020 survey of expert stakeholders in the US and Canada (n=21) investigated the most important priorities for infant feeding among women living with HIV and the biggest challenges to achieving them.

### Priorities and Challenges Affecting Breast/Chestfeeding among Women Living with HIV

TOP PRIORITIES		TOP CHALLENGES	
76%	More research to understand HIV transmission through breast milk among women living with HIV with sustained viral suppression	48%	Disregard for the bodily autonomy and decision-making ability of people living with HIV and parents
57%	Increased/improved provider education addressing research, risks and benefits, ethical issues, and harm reduction strategies for and among women living with HIV	43%	Inadequate resources for providers to support the infant-feeding decisions of women living with HIV and lack of knowledge around harm reduction strategies
48%	Increased/improved education for women living with HIV addressing research, risks and benefits, ethical issues, and harm reduction strategies for and among women living with HIV	38%	Lack of understanding among providers of existing breastfeeding research, its implications, and limitations
		33%	Criminalization, including HIV criminalization and criminalization of pregnant people, especially Black and Brown parents

The Well Project [created a series of resources](#) (including, but not limited to those listed below) that aimed to address the profound educational needs around infant-feeding for women living with HIV, while providing leadership development opportunities for women living with HIV.

RESOURCES	REACH	TIMEFRAME
English fact sheet on infant-feeding choices	44,000	3 years
Spanish fact sheet on infant-feeding choices	30,000	2 years
Webinar featuring two women living with HIV who breastfed	27,000	3 years
4 live streamed events describing different aspects of infant feeding experiences for women living with HIV, featuring women living with HIV in exchanges with other thoughtleaders, including healthcare providers and legal experts	5,200	7 months
Webinar featuring community leaders focused on expanding breastfeeding resources for women living with HIV	1,000	4 months
Provider roundtable including co-presentations by women living with HIV and providers with expertise in infant feeding	295	One day

The demand for these resources made evident the need for more education and advocacy tools. The Well Project responded to that need with the December 2021 launch of [BEEBAH \(Building Equity, Ethics, and Education on Breastfeeding and HIV\)](#), a comprehensive, multi-tiered project that expands upon our efforts to increase knowledge around breast/chestfeeding and HIV across the HIV community, including healthcare providers, policymakers, legal experts, researchers, and women and other birthing parents living with HIV. Through educational resource creation, leadership development, and collaborative efforts, BEEBAH strives to ensure that women living with HIV can experience their fundamental right to make informed, supported, uncoerced infant-feeding decisions.

## CONCLUSION

There is a significant appetite for content about breast/chestfeeding and HIV that centers the experiences of women and other birthing parents living with HIV. Endeavors in this field are strengthened when providers and other stakeholders work in partnership with parents living with HIV to address their infant-feeding desires and concerns, recognize their bodily autonomy, and trust that they will make well-informed decisions. This work must also recognize the conditions of structural racism, colonization, assimilation, anti-Blackness and anti-Indigenous bias, gender inequity, and economic injustice in which it takes place. Centering the voices of women and other birthing parents living with HIV in the development and execution of this programming ensures that those most impacted by these issues can experience their fundamental right to make informed, uncoerced infant-feeding decisions, while also developing their capacity as leaders.