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# Deaf and Hard-of-Hearing Mothers' Experiences with Pregnancy Care: Explaining Disparities

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(Part 2 of 2 · [read Part 1](#))

*Deaf and hard-of-hearing (DHH) women face numerous disparities compared with other women during pregnancy, childbirth, and beyond, including a higher rate of chronic medical conditions, pregnancy complications, and adverse birth outcomes. Our national survey of DHH women—the first of its kind—heralds a new phase in research on pregnancy and DHH women. Our interviews with DHH women, clinicians, doulas, and interpreters will help researchers more fully understand disparities, as well as DHH women's experiences before, during, and after childbirth.*

Researchers from the Lurie Institute for Disability Policy at Brandeis University and the University of Michigan Medical School have been studying the pregnancy experiences and outcomes of deaf and hard-of-hearing women. Led by co-principal investigators (PIs) Dr. Monika Mitra, director of the Lurie Institute at Brandeis, and Dr. Michael McKee, a deaf practicing physician and researcher at the University of Michigan Medical School, the study is now in its fifth year of funding.

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Our research so far has found notable disparities faced by DHH women, particularly elevated risk for various chronic medical conditions, pregnancy complications, and adverse birth outcomes such as low birth weight.

More unexpectedly, as McKee describes, the study found results he had not previously encountered, namely, higher prevalence of diabetes among DHH women at younger ages. “It’s 2021 and still we’re finding that these disparities are an issue,” observes Mitra.



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**NOTE:** *What's the difference between "Deaf" and "deaf"?*

Deaf and hard-of-hearing people sometimes use the terms “deaf” and “Deaf” to describe themselves. “Deaf” with a capital “D” suggests an identification with Deaf culture, language, and identity, whereas “deaf” with a lowercase “d” is more neutral. For example, a Deaf person may have attended a school for DHH students. Many people use one or the other exclusively, but a person might use “deaf” in one context and “Deaf” in another.

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We are now analyzing data we collected through a national survey of deaf and hard-of-hearing women about their pregnancies, using themes our researchers discovered from in-depth interviews with DHH mothers. Our survey findings from over 475 deaf and hard-of-hearing women will help us learn what DHH women need during pregnancy—and how clinicians can better support them before, during, and after pregnancy.



Importantly, the survey was trilingual—available in ASL, English, and Spanish—and was designed to address the shortcomings of other health surveys. As Mitra points out, although some national health surveys do identify deaf and hard-of-hearing participants and other people with disabilities, these surveys are not always accessible for DHH people—many of whom do not speak English as their first language. Without accessible surveys, fewer DHH people will participate.

To ensure that our survey adequately represents racial and ethnic diversity in the population, our team worked closely with community agencies across Massachusetts and the United States to recruit survey participants from all ethnic and racial backgrounds.

Interviews with clinicians, originally scheduled for 2020, were delayed until spring 2021 because of the COVID-19 crisis. This part of the study is currently underway and aims to understand needs and barriers to pregnancy-related healthcare for deaf and hard-of-hearing women from the perspectives of clinicians, doulas, and interpreters. The study will also assess how clinicians, doulas, and interpreters perceive DHH women’s needs.

This work is part of an overarching “mixed-methods” study, meaning that it uses a variety of different qualitative and quantitative methods. For instance, the study is using interview data, survey data, and secondary analysis of existing administrative data (e.g., hospital discharge records) to gather a wide range of information about deaf and hard-of-hearing women’s experiences.

Administrative data drawn from sources on births in Massachusetts and nationwide gave us important information about birth outcomes. However, administrative data alone are not enough to understand how DHH women experience pregnancy. Mitra notes that the understanding that those data provide is “in some sense superficial.” The study’s mixed-methods design allows researchers to learn directly from DHH women and clinicians, rather than relying solely on facts and figures. This mixed-methods approach will ultimately provide a more complete understanding to answer questions about why we may be observing disparities.

Before releasing our survey, we conducted in-depth interviews with 67 deaf and hard-of-hearing women from across the U.S. The research team is currently analyzing data from the interviews with DHH women using qualitative techniques. Findings will be reported using a variety of methods including journal articles and presentations at scientific conferences.

When researchers study a community, they should consider people’s concerns, perspectives, and experiences. Our advisory board, made up of DHH mothers and clinicians who work with deaf and hard-of-hearing people, helps us do just that: board members review research findings, advise us on recruitment methods, and provide feedback about developing and using research tools.

Adrianna Smart, a Deaf advisory board member with two preteen children, points to the harms of DHH women not having access to information, including information about healthcare rights such as informed consent. The lack of access to information might be unintentional, she adds. Interpreters may not have enough time during an appointment to interpret for patients and providers. Many DHH women may also be unaware of their rights or be reluctant to request all the information they need.

After we combine and analyze our data, we will be able to develop recommendations for both DHH women who may be considering pregnancy and for clinicians. These recommendations should improve DHH women’s pregnancy experiences—and ultimately outcomes.

## Related research publications

Mitra, M., Akobirshoev, I., McKee, M. M., & Iezzoni, L. I. (2016). Birth outcomes among U.S. women with hearing loss. *American Journal of Preventive Medicine*, 51(6), 865–873. <https://doi.org/10.1016/j.amepre.2016.08.001>

Mitra, M., McKee, M. M., Akobirshoev, I., Valentine, A., Ritter, G., Zhang, J., McKee, K., & Iezzoni, L. I. (2020). Pregnancy, birth, and infant outcomes among women who are deaf or hard of hearing. *American Journal of Preventive Medicine*, 58(3), 418–426. <https://doi.org/10.1016/j.amepre.2019.10.012>

Mitra, M., McKee, M. M., Akobirshoev, I., Ritter, G. A., & Valentine, A. M. (2021). Pregnancy and neonatal outcomes among deaf and hard of hearing women: Results from nationally representative data. *Women's Health Issues*, 31(5), 470–477. <https://doi.org/10.1016/j.whi.2021.03.005>

Wu, J. P., Zhang, J., McKee, M., Akobirshoev, I., McKee, K. S., & Mitra, M. (2021). Contraceptive provision and quality care measures for insured individuals in Massachusetts who are deaf or hard of hearing. *Obstetrics & Gynecology*, 138(3), 398–408. <https://doi.org/10.1097/AOG.0000000000004505>

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