

Reproductive Justice for the Deaf Community

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Almost half of all pregnancies each year in the United States are mistimed or unwanted and associated with adverse health outcomes. Deaf women are as likely to be pregnant as their hearing counterparts but are 67% more likely to experience unintended pregnancy. Although there are limited data on the sexual health behaviors of deaf individuals, research has shown that deaf people are more likely than the general population to rely on withdrawal and condoms to prevent pregnancy. Further, health resources and communication with physicians are often not fully accessible, with the former often in spoken or written English and the latter when sign language interpreters are not present. The combination of use of less-effective methods of contraception and inaccessible health resources puts deaf women at heightened risk for unintended pregnancy. Deaf women are denied reproductive justice when they are inadequately equipped to practice bodily autonomy and prevent unintended pregnancies. In this commentary, I present literature to illustrate the disparity deaf women face compared with hearing women and to make the case for the association among unintended pregnancy, its adverse effects, and reproductive injustice for deaf women. As a medically trained deaf woman conducting reproductive health research, I leverage my lived experience and

accrued knowledge to elucidate the shortcomings and strategies to use. As public health researchers and health care professionals, we can alleviate this injustice with inclusive research methodology, representation on research and health care teams, and ensuring access to health information with time given and accommodations provided.

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Reproductive autonomy is guaranteed only with full access to reproductive health resources, contraception, and contraceptive counseling. Yet, deaf women are consistently denied reproductive autonomy, which is a core tenet of reproductive justice. Although the term and original framework conceived by the Women of African Descent for Reproductive Justice in 1994 centered around women of color,¹ the human rights issues they raised can apply to another marginalized, albeit oppressed in different ways, population. Sexual health literacy and behaviors in the Deaf community are limited by society due to inaccessible information and limits on access to physician-mediated contraception, the result of which is that deaf women are 67% more likely to become pregnant unintentionally than the general population.² As a medically trained deaf woman conducting reproductive health research, I am uniquely positioned to bring this issue to light based on my lived experience and accumulated personal and professional knowledge. In this commentary, I bring together the knowledge I have gained over the years. Although there are significant gaps in the literature on reproductive health outcomes for deaf women, my identities allow me to propose critical connections, the need for further exploration, and solutions we can all pursue to promote reproductive justice for deaf women.

In 2012, the National Health Interview Survey identified 6.8 million American adults between age 18 and 44 years with some trouble hearing.³ Adjusting for national population statistics that claim that

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women comprise roughly 51% of the workforce-aged population, there are approximately 3.4 million deaf or hard-of-hearing women (henceforth, deaf) of reproductive age.

Deaf people have been found to have inadequate health literacy—the ability to find, understand, and apply health information—particularly around sexual health topics, such as contraception use and sexually transmitted infections.^{4–7} Studies show that, as a result of limited sexual health literacy, deaf college-aged individuals rely on less-effective contraception methods such as condoms and withdrawal.^{4,8,9} The limitations on sexual health literacy are compounded by the fact that deaf women encounter significant communication barriers to receiving appropriate reproductive health care services.¹⁰ These factors put deaf women at risk for unintended pregnancy and short interpregnancy intervals (IPIs), which can lead to negative health consequences, including delays in or lack of prenatal care, maternal postpartum depression, intimate partner violence (IPV) during pregnancy, and lower rates of breastfeeding.^{11–13} Deaf women are more likely to have fewer prenatal visits and are frequently less satisfied with the prenatal care they receive than their hearing counterparts.^{14,15} Without a reliable screening scale administered in the primary language of deaf women, there are no data on maternal postpartum depression in this population.¹⁶ However, research has shown a higher prevalence of behavioral health disparities, including depression, in this population.^{17–19} Pregnancy status aside, there is a higher prevalence of IPV in the Deaf community; when compared with hearing women, college-aged deaf women are twice as likely to have experienced IPV in the past year.^{20–23} Although characteristics of Deaf culture support breastfeeding success, deaf women are more likely to have shorter breastfeeding duration if their health care professionals do not offer access in their native language.¹⁵

The risk for adverse reproductive outcomes for deaf women transcends pregnancy intention, because unintended pregnancies often occur with short IPIs of less than 18 months. Short IPIs have been associated with adverse events such as preterm birth, placental abruption, and low birth weight.^{24,25} A woman who has experienced IPV is at risk for poorer pregnancy outcomes, including the same events associated with short IPIs: preterm birth, placental abruption, and low birth weight.^{26,27} A population-based examination of deaf women in the United States identified that they are at increased risk of experiencing these same adverse birth outcomes (preterm birth, placental abruption, or low birth weight) compared with

hearing women.^{28,29} However, the study did not assess pregnancy intention, IPI, or IPV. Adverse events that are common among women who experience an unintended pregnancy (with or without a short IPI), IPV during pregnancy, and women who are deaf are shown in Figure 1 to illustrate this point.

Although we cannot establish causal relationships, it may be appropriate to infer that, in addition to being at increased risk for unintended pregnancy, deaf women may be at increased risk for short IPIs and the associated negative health consequences. However, they are missing or hidden in the sexual health literature because research methods may preclude their involvement. Reasons for their exclusion include data collection through telephone survey before the advent of video relay services, lack of investigator knowledge about video services or concerns about research integrity with interpreters on the calls, spoken English language as an inclusion criterion, no research budget for professional sign language interpreting services, and lack of representation of deaf members on research teams. Even when deaf people are able to participate in research, they may still be hidden in the data if survey questions do not identify them as deaf or if deafness is not distinguished from other types of disabilities. This last situation may (understandably) occur when the sample size of deaf participants is small or when hearing loss is viewed as a sensory disability and is collapsed into a category that includes vision loss or other physical disabilities.^{30–33}

The Deaf community should be viewed as a linguistic and sociocultural minority; they are disabled in the sense that society places limitations on their access to language, which in turn defines their health care experience. To assert that people with intellectual disabilities, those with vision loss, and those who are deaf are less knowledgeable about contraception falsely implies that the root cause is the same. The majority of deaf women do not have additional disabilities, and their limited knowledge of contraception is not due to limitations in mental capacity but to systemic barriers and gaps in full language access. Research that ignores deaf people or categorizes them with people who have other types of disabilities disenfranchises the Deaf community.

To obtain quality data to inform reproductive justice work, research protocols need to be broadened to include greater numbers of deaf participants. Instead of asking binary questions about a respondent's difficulty hearing (or, eg, seeing or moving) or omitting the question entirely, surveys should include at least one nuanced question to identify participants

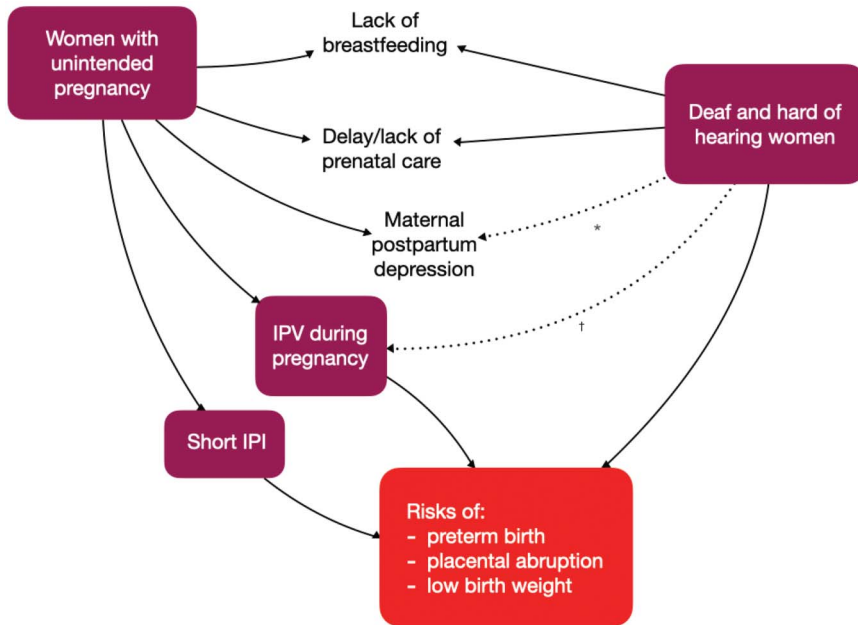


Fig. 1. Adverse events in common between women who experience unintended pregnancy, short interpregnancy intervals (IPI), intimate partner violence (IPV), and being deaf. *No reliable postpartum depression screening scale for deaf and hard of hearing women, but higher prevalence of depression in this population. †Outside of pregnancy status, higher prevalence of IPV in deaf and hard of hearing women.

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as hearing, deaf, hard of hearing, or something else (some people may choose to identify as DeafBlind, for example), especially given national recruitment. Additional questions should identify preferred language use (American Sign Language, English, both, something else), because this is a rough marker for a person's ability to navigate health information in English, and age at hearing loss (birth, before age 3 years, between age 3 and 18 years, or later in life). Compared with the general population, those who are prelingually deaf (before age 3 years) make fewer physician visits, tending instead to favor the emergency department over primary care, whereas those who are postlingually deaf (after age 3 years) make more physician visits, except in the case of screening mammography.^{34,35}

These recommendations come from my experience as a deaf woman conducting deaf health and reproductive justice research, but, ultimately, inclusion of deaf researchers and working with the Deaf community can identify the appropriate questions to ask. The Research Center on Culture and Language at the National Technical Institute for the Deaf at the Rochester Institute of Technology can be referred to as a model of how to conduct high-quality, deaf-centered research. The Research Center on Culture and Language is the largest deaf-run interdisciplinary research center, with the largest number of deaf faculty, staff, and students in the world; the primary language used for center business is American Sign Language. The Research Center on Culture and Lan-

guage often collaborates with researchers from other universities and has experience working in diverse research teams. Diverse research teams lead to stronger science, not only by strengthening the data collected, but community members may be more willing to participate in research when they see that they have representation on the team. A deaf researcher can find their place on almost any research team, providing insight on inclusive methodology and interpretation of findings. This is especially important when considering that research teams need to be representative of the communities they are researching.

Clinicians' failure to observe communication best practices with deaf patients often results in frustrations and suboptimal health care delivery.^{10,36,37} Deaf women receive less information from their physicians than hearing women and report knowledge gaps about preventive reproductive health care due to communication barriers.^{14,38} When health care professionals do not provide comprehensive counseling about all available contraceptive options, they are effectively acting as information gatekeepers. Deaf patients, like other patients, may not always know what questions to ask and may accept the options they are offered without knowing there are more choices. Additionally, health care professionals' failure to guarantee appropriate communication accommodations (eg, qualified sign language interpreters) not only causes information gaps, but threatens trust and relationship building, which compounds the Deaf community's general mistrust of the medical

community.^{39,40} These are especially important considerations with regard to physician-dependent and invasive methods, such as long-acting reversible contraception. Long-acting reversible contraception is often touted for its effectiveness, yet it may be infrequently prescribed for deaf patients, who primarily use condoms.^{4,8,9}

Better health care delivery demands closer adherence to the Americans with Disability Act, with every effort placed on ensuring that professional sign language interpreters are used. However, language access does not always mean effective communication access. Understanding the cultural and linguistic needs of deaf patients is essential to improving the patient–physician relationship, reducing frustration and, ultimately, leading to better care. One of the most effective ways to understand patients’ cultural and linguistic needs is to ask about them. Learning about Deaf culture and understanding that, due to decreased opportunities for incidental learning, deaf patients may have a limited fund of health knowledge is a great start. Even so, it is important to recognize that each deaf patient is different. Asking deaf patients how to best support communication signals respect and value for the patient–physician relationship. Clinicians should provide deaf patients with every reasonable opportunity to attain in-depth health information. Although not all patients know what they need, all will appreciate earnest efforts. Although the need for more health information and provision of accommodations, such as sign language interpreters, apply to all deaf patients, these are important considerations for facilitating trust-building with patients for sensitive topics.

Deaf women and birthing people are consistently denied reproductive autonomy, which constitutes a major reproductive injustice and requires immediate attention. Only when researchers deploy inclusive methodology, and health care professionals acknowledge the communication needs of their deaf patients, will we produce better data, provide better health care, and guarantee reproductive justice for deaf women and the Deaf community.

REFERENCES

- Ross L, Solinger R. *Reproductive justice: an introduction*. University of California Press; 2017.
- Horner-Johnson W, Dissanayake M, Wu JP, Caughey AB, Darney BG. Pregnancy intendedness by maternal disability status and type in the United States. *Perspectives on sexual and reproductive health*. 2020;52:31–8. doi: 10.1363/psrh.12130
- Blackwell DL, Lucas JW, Clarke TC. Summary health statistics for US adults: national health interview survey, 2012. *Vital Health Stat* 2014;10:1–161.
- Joseph JM, Sawyer R, Desmond S. Sexual knowledge, behavior and sources of information among deaf and hard of hearing college students. *Am Ann Deaf* 1995;140:338–45. doi: 10.1353/aad.2012.0379
- Sawyer RG, Desmond SM, Joseph JM. A comparison of sexual knowledge, behavior, and sources of health information between deaf and hearing university students. *J Health Educ* 1996;27:144–55. doi: 10.1080/10556699.1996.10603187
- McKee MM, Paasche-Orlow MK, Winters PC, Fiscella K, Zazove P, Sen A et al. Assessing health literacy in deaf American Sign Language users. *J Health Commun* 2015;20:92–100. doi: 10.1080/10810730.2015.1066468
- Tripp AW, Kahn JV. Comparison of the sexual knowledge of hearing impaired and hearing adults. *J Am Deafness Rehabil Assoc* 1986;19:15–8.
- Zodda JJ. Condom use among deaf college students. *JADARA* 2015;49:86–101.
- Heiman E, Haynes S, McKee MM. Sexual health behaviors of deaf American Sign Language (ASL) users. *Disabil Health J* 2015;8:579–85. doi: 10.1016/j.dhjo.2015.06.005
- Bainbridge KE, Wallhagen MI. Hearing loss in an aging American population: extent, impact, and management. *Annu Rev Public Health* 2014;35:139–52. doi: 10.1146/annurev-publ-health-032013-182510
- Kost K, Landry DJ, Darroch JE. Predicting maternal behaviors during pregnancy: does intention status matter? *Fam Plann Perspect* 1998;30:79–88. doi: 10.2307/2991664
- Cheng D, Schwarz EB, Douglas E, Horon I. Unintended pregnancy and associated maternal preconception, prenatal and postpartum behaviors. *Contraception* 2009;79:194–8. doi: 10.1016/j.contraception.2008.09.009
- D’Angelo DV, Gilbert BC, Rochat RW, Santelli JS, Herold JM. Differences between mistimed and unwanted pregnancies among women who have live births. *Perspectives on sexual and reproductive health*. 2004;36:192–7. doi: 10.1363/psrh.36.192.04
- O’Hearn A. Deaf women’s experiences and satisfaction with prenatal care: a comparative study. *Fam Med* 2006;38:712–6.
- Chin NP, Cuculick J, Starr M, Panko T, Widanka H, Dozier A. Deaf mothers and breastfeeding: do unique features of Deaf culture and language support breastfeeding success? *J Hum Lactation* 2013;29:564–71. doi: 10.1177/0890334413476921
- Anderson ML, Craig KS, Hostovsky S, Blich M, Bramande E, Walker K, et al. Creating the capacity to screen deaf women for perinatal depression: a pilot study. *Midwifery* 2021;92:102867. doi: 10.1016/j.midw.2020.102867
- Turner O, Windfuhr K, Kapur N. Suicide in deaf populations: a literature review. *Ann Gen Psychiatry* 2007;6:26. doi: 10.1186/1744-859X-6-26
- Kvam MH, Loeb M, Tambs K. Mental health in deaf adults: symptoms of anxiety and depression among hearing and deaf individuals. *J Deaf Stud Deaf Educ* 2006;12:1–7. doi: 10.1093/deaf/enl015
- Fellinger J, Holzinger D, Pollard R. Mental health of deaf people. *The Lancet* 2012;379:1037–44. doi: 10.1016/S0140-6736(11)61143-4
- Pollard RQ Jr, Sutter E, Cerulli C. Intimate partner violence reported by two samples of deaf adults via a computerized American Sign Language survey. *J Interpers Violence* 2014; 29:948–65. doi: 10.1177/0886260513505703
- Porter J, Williams LM. Intimate violence among underrepresented groups on a college campus. *J Interpers Violence* 2011; 26:3210–24. doi: 10.1177/0886260510393011

22. Anderson ML, Leigh IW. Intimate partner violence against deaf female college students. *Violence Against Women* 2011; 17:822–34. doi: 10.1177/1077801211412544
23. Barnett S, Klein JD, Jr PRQ, Samar V, Schlehofer D, Starr M et al. Community participatory research with deaf sign language users to identify health inequities. *Am J Public Health* 2011;101:2235–8. doi: 10.2105/AJPH.2011.300247
24. Conde-Agudelo A, Rosas-Bermúdez A, Kafury-Goeta A. Birth spacing and risk of adverse perinatal outcomes: a meta-analysis. *JAMA* 2006;295:1809–23. doi: 10.1001/jama.295.15.1809
25. Blumenfeld YJ, Baer RJ, Druzin ML, El-Sayed YY, Lyell DJ, Faucett AM, et al. Association between maternal characteristics, abnormal serum aneuploidy analytes, and placental abruption. *Am J Obstet Gynecol* 2014;211:144.e1–9. doi: 10.1016/j.ajog.2014.03.027
26. Campbell J, Torres S, Ryan J, King C, Campbell DW, Stallings RY, et al. Physical and nonphysical partner abuse and other risk factors for low birth weight among full term and preterm babies: a multiethnic case-control study. *Am J Epidemiol* 1999;150:714–26. doi: 10.1093/oxfordjournals.aje.a010074
27. Leone JM, Lane SD, Koumans EH, DeMott K, Wojtowycz MA, Jensen J, et al. Effects of intimate partner violence on pregnancy trauma and placental abruption. *J Womens Health (Larchmt)* 2010;19:1501–9. doi: 10.1089/jwh.2009.1716
28. Mitra M, Akobirshoev I, McKee MM, Iezzoni LI. Birth outcomes among US women with hearing loss. *Am J Prev Med* 2016;51:865–73. doi: 10.1016/j.amepre.2016.08.001
29. Mitra M, McKee MM, Akobirshoev I, Valentine A, Ritter G, Zhang J, et al. Pregnancy, birth, and infant outcomes among women who are deaf or hard of hearing. *Am J Prev Med* 2020; 58:418–26. doi: 10.1016/j.amepre.2019.10.012
30. Wu JP, McKee KS, McKee MM, Meade MA, Plegue MA, Sen A. Use of reversible contraceptive methods among US women with physical or sensory disabilities. *Perspect Sex Reprod Health* 2017;49:141–7. doi: 10.1363/psrh.12031
31. Wu JP, McKee MM, McKee KS, Meade MA, Plegue M, Sen A. Female sterilization is more common among women with physical and/or sensory disabilities than women without disabilities in the United States. *Disabil Health J* 2017;10:400–5. doi: 10.1016/j.dhjo.2016.12.020
32. Choquet M, Fediaevsky LDP, Manfredi R. Sexual behavior among adolescents reporting chronic conditions: a French national survey. *J Adolesc Health* 1997;20:62–7. doi: 10.1016/S1054-139X(96)00091-2
33. Mosher W, Bloom T, Hughes R, Horton L, Mojtabai R, Alhusen JL. Disparities in receipt of family planning services by disability status: new estimates from the National Survey of Family Growth. *Disabil Health J* 2017;10:394–9. doi: 10.1016/j.dhjo.2017.03.014
34. Barnett S, Franks P. Health care utilization and adults who are deaf: relationship with age at onset of deafness. *Health Serv Res* 2002;37:105–20.
35. McKee MM, Barnett SL, Block RC, Pearson TA. Impact of communication on preventive services among deaf American Sign Language users. *Am J Prev Med* 2011;41:75–9. doi: 10.1016/j.amepre.2011.03.004
36. McEwen E, Anton-Culver H. The medical communication of deaf patients. *J Fam Pract* 1988;26:289–91.
37. McKee MM, Moreland C, Atcherson S, Zazove P. Hearing loss: communicating with the patient who is deaf or hard of hearing. *FP Essent* 2015;434:24–8.
38. Steinberg AG, Wiggins EA, Barmada CH, Sullivan VJ. Deaf women: experiences and perceptions of healthcare system access. *J Womens Health (Larchmt)* 2002;11:729–41. doi: 10.1089/15409990260363689
39. Steinberg AG, Barnett S, Meador HE, Wiggins EA, Zazove P. Health care system accessibility. *J Gen Intern Med* 2006;21: 260–6. doi: 10.1111/j.1525-1497.2006.00340.x
40. McKee M, Schlehofer D, Thew D. Ethical issues in conducting research with deaf populations. *Am J Public Health* 2013;103: 2174–8. doi: 10.2105/AJPH.2013.301343

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