Lack of Information is a Weapon of Oppression

March 02, 2021

If you are in a position to influence or block policy solutions and do not have the information you need, cede your power to someone who does. Unfortunately, this essay arises from our experience with professionals who have insisted that they cannot support a particular policy solution, or even need to block policy change, due to *a lack of information*. **This is unacceptable.** It is especially unacceptable when the policy solutions are being advanced by people who are directly impacted. There will always be someone whose life experience required them to find, understand, process and take a stand based on the available information, and those life experiences make them well-suited to policy change. Those life experiences are *information* that can and should be translated into policy solutions.

Lacking information is unacceptable since there is plenty of information freely and widely available.[i] From time to time a specific data point may be lacking. But in these situations, it is not just possible, but responsible and necessary, to make sense of missing data. Missing data *is information,* and information about which policy decisions can be made.

When it comes to maternal health[ii] policy, "lack of information" is additionally unacceptable because the information is there and the time for action is now. Whole generations of professionals encountering this "lack of information" in maternal health have dedicated their lives to both gathering information and making sense of missing data. Those dedicated researchers took the "lack of information" claim as an earnest assessment, and not "delay and denial" on the part of policymakers willfully blocking needed change to the status quo. But it is worth examining "lack of information" as both earnest, and as a pattern of delay or denial that has dire maternal health consequences.

"When researchers have analyzed maternal deaths and near-deaths to understand what went wrong, one element they have noted time and again is what some experts have

dubbed "delay and denial" — the failure of doctors and nurses to recognize a woman's distress signals and other worrisome symptoms, both during childbirth and the often risky period that follows."[iii] Though more removed from the clinical setting, delay and denial happens in policymaking too, and the consequences are just as dire. Lacking information is part of a dangerous pattern in perinatal health care.

Providers fail to listen to their patients, people who have critical information, and this leads to poor care. This was put starkly by Susan Goodhue when she told USA Today, "The staff, by not knowing, and not listening and not taking precautions, almost killed us."[iv] Indeed, not listening guarantees a lack of information. It is worse for Black, Indigenous and other women of color, as Pat Loftman aptly described to ProPublica, "If you are a poor black woman, you don't have access to quality OBGYN care, and if you are a wealthy black wom[a]n, like Serena Williams, you get providers who don't listen to you when you say you can't breathe,"[v] referring to Serena Williams' high profile experience with providers who initially ignored her when she told them she was having a pulmonary embolism after giving birth.

As midwife Demetra Seriki points out in this 9News Interview, "Being heard is a life-saving conversation that every Black person needs to have with their provider. And if they're not getting it with this provider they need to get it somewhere else."[vi] The same is true when it comes to policymaking, we can no longer countenance providers who fail to listen and then stand in the way of necessary change. The stakes are too high.

Whether it be the voice of patients, or experts, researchers, and advocates too much critical information is being dismissed by people in a position to save lives. "Failure to listen to Black women" is such a common problem across industries that it is Googleable, and it is unconscionable every time. Lacking information about maternal health, in this day and age, means you have either failed to make gathering information a priority, or you have dismissed certain information as illegitimate. The egregious inequities in perinatal outcomes by race alone should give you pause and make you look closely at how and to what extent you are contributing to those inequities; how and to what extent you are missing distress signals, how and to what extent your lack of information is part of the problem.

Lack of information has been a persistent excuse for obstetric racism both at the individual and structural levels from the beginning; it was designed that way. Individual distress signals are delegitimized among providers, and expert, researcher, and advocate distress signals are delegitimized among policymakers. Many, many people had information about obstetric racism before the information was prioritized or legitimized. [vii] This antipathy to information in maternal health has costs and must be urgently addressed.

The antidote is simple: make it a priority to gather information and listen more. Interrogate whether your lack of information is actually a failure to receive the available information; listening can be impeded by bias. It is part of the structure of white supremacy and other systems to categorize the voices of people of color, women, the queer, disabled, incarcerated etc, as illegitimate or *not information.* There is a long history of denying the information that Black and Indigenous people have (and need), denying the information that communities of color have (and need), denying the information that all kinds of marginalized people have (and need). *"*Lack of information" from people in power, when there is a cacophony of information being delegitimized, is a weapon of oppression.

Of course, it's possible that when people say they lack information what they actually mean is that processing the information requires them to take a stand; perhaps a stand against white supremacy or some other powerful system. This too should give us pause. At whose expense and for whose benefit can you afford *not to take a stand?* At whose expense and for whose benefit can you afford *not to listen*? This is a good question in general and particularly acute when it comes to maternal health.

It is irresponsible to be in a policymaking position without the capacity to process information and the courage to take a stand. People who have been marginalized figure out how to process information and take the associated risks because they must as a matter of survival. Cede your power to them. Whether it is a lack of prioritization, a lack of legitimization, or a lack of willingness to take a stand, there is no excuse for showing up to influence policy *without information*. Come to the table ready or cede your power to those who are.

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[i] Though there are other places to start, consider the 1925 White House Conference on Child Health and Protection that determined "untrained midwives approach, and trained midwives surpass, the record of physicians in normal deliveries." *See*

Judith Pence Rooks, Midwifery and Childbirth in America (Temple University Press 1997).

[ii] Using the term "maternal health" here, though the people who need health care for pregnancy and birth are not just moms, because there is a field of inquiry referred to in this way where there is a bounty of information.

[iii] Katherine Ellison and Nina Martin, "Severe Complications for Women During Childbirth Are Skyrocketing — and Could Often Be Prevented," ProPublica, December 22, 2017.

[iv] Alison Young and Alison Young, "Hospitals know how to protect mothers. They just aren't doing it." USA Today, Jul. 26, 2018. See also this video:

https://twitter.com/USATODAY/status/1022535120237080581

[v] Annie Waldman, "New York City Launches Initiative to Eliminate Racial Disparities in Maternal Death," ProPublica, July 30, 2018. Available at:

https://www.propublica.org/article/new-york-city-launches-initiative-to-eliminate-racial-disparities-in-maternal-death And speaking of not breathing, *see also* Rachel Hardeman, et. al., "Stolen Breaths," N. Engl. J. Med. July 16, 2020. Available at: https://www.nejm.org/doi/full/10.1056/NEJMp2021072

[vi] 9News.com, February 25, 2021. Available at: https://9news.com/embeds/video/73-33122767-fea2-44b7-a0aa-2ae9b40fd925/iframe?jwsource=cl

[vii] Not just in recent history, but for decades and decades and even hundreds of years. Every person whose reproduction has been politicized, through slavery or colonization just to name two broad examples, has information about inequities in health

outcomes. The problem is not a lack of information but a characterization of some information as *not information*. There are so many citations for this, but to reinforce the point check out this Executive Summary from 2015.