Episode: Ethics Talk – Building Trustworthiness and Ethical Public Health Practice

Guests: Alicia Best, PhD, MPH; Faith Fletcher, PhD, MA

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Access the video and podcast here

[bright theme music]

TIM HOFF: Welcome to *Ethics Talk*, the *American Medical Association Journal of Ethics* podcast on ethics in health and health care. I'm your host, Tim Hoff. This episode is an audio version of a video interview conducted by the Journal's Editor in Chief, Dr Audiey Kao, with Dr Alicia Best, an Assistant Professor in the College of Public Health at the University of South Florida, and Dr Faith Fletcher, an Assistant Professor in the Center for Medical Ethics and Health Policy at Baylor College of Medicine in Houston, Texas. They joined us to talk about building trustworthiness by advancing equity and inclusion in bioethics and public health. To watch the full video interview, head to our site, <u>Journalof Ethics.org</u>, or check out our <u>YouTube channel</u>.

DR AUDIEY KAO: Drs Best and Fletcher, thank you for being guests on *Ethics Talk* today. [music fades out]

DR ALICIA BEST: Thank you for having us.

DR FAITH FLETCHER: Thank you for having us.

KAO: So, to start, can you please distinguish between mistrust, distrust, and trustworthiness, and why this distinction is important?

BEST: So, I think the importance of this distinction is that one places the blame on the individual that may be impacted by a certain health issue, whereas the other one focuses on the institutions or systems that are responsible for protecting the public's health. And this is critical as we shift this paradigm so that we can focus our strategies on fixing broken systems rather than inappropriately labeling populations as inherently mistrustful. And I feel like this is the way forward in order for us to use this perspective to make sure that individuals aren't being labeled, but we are fixing the issues that the systems have created.

FLETCHER: And just to add a little more to that response, in terms of decades of medical, biomedical, bioethics, and public health research, we have documented the ways that systems harm and the ways that systems are structurally violent towards communities of color. We still lack interventions that really address institutional untrustworthiness as well as structural violence. So, the importance of really distinguishing between mistrust and trustworthiness is that we have an ethical obligation in our profession to really think about the ways that we use framing, the way that we use words. And some examples include characterizing participants as vaccine hesitant, as risky, as hard to reach, because these frames are harmful. And they're harmful for a number of reasons. And I'll point out one: They compromise and can compromise funding as well as policy decisions. They influence the way that we engage participants in our research endeavors or the way that we engage

patients as medical providers. The development of research questions are influenced by our frames and also the ways that we choose to answer those questions, as Dr Best suggested, from a structural or systemic perspective versus an individual level perspective.

KAO: So, given what you both said, what should we understand about relationships among institutional distrust, transgenerational oppression, and individuals' cumulative risk exacerbated by racism?

BEST: These are what we call in public health longitudinal or life course perspectives. And what these perspectives do is they provide evidence for the fact that these instances of trauma don't just impact us one at a time, but they can accumulate over time. And so, an individual may not have been impacted by a certain, may not have experienced something directly, but the trauma that is associated with that experience could be passed down throughout generations, either subconsciously or consciously. Therefore, these perspectives help us to put this in the appropriate context, that these instances aren't just one and done. But they can accumulate over time, and they can be passed down through generations.

FLETCHER: So, in addition to the conversation about ongoing stressors and trauma, this supports Dr Best, her statement about racism as a chronic stressor. Recently, the director of the Centers for Disease Control and Prevention declared racism as a serious threat to the public's health. So, we've known again, there is document. We have evidence that suggests that racism is a chronic stressor. It has lifelong effects as Dr Best stated: It impacts our mental, physical, emotional health. And this is not new. Scholars of color and other scholars and activists have long challenged the scientific community and other communities to really characterize racism as a social determinant of health, and not race. So, this is something that as we move towards promoting health equity amongst all individuals in our society, we really have to think about addressing racism in multiple systems. This includes health care systems as well as research systems, which is why this conversation is so important today, as people who do social and behavioral research.

KAO: With that in mind, "centering" is a metaphor used to talk about bringing marginalized perspectives to the center of an important discussion. For those to whom the concept of centering sounds abstract and remote, what are specific practices or behaviors by which centering can happen?

FLETCHER: So, that's an excellent question, and I definitely want to center Black feminist thought and other anti-racism frameworks, as well as justice-oriented frameworks, when we think about this. We don't really want to think about it as metaphoric, but more as praxis, the ways that we engage groups of individuals that have been marginalized and socially, systematically marginalized through society and made vulnerable. So, when we talk about vulnerability, for instance, we want to talk about it in the context of "made vulnerable." Individuals are not inherently vulnerable, just like they're not inherently distrustful. So, it's important to think about this because as, again, social and behavioral sciences, doing work and engaging communities, we want to really think about ways to decenter the dominant voice or culture that generally dictates research practices and shift towards integration, integrating perspectives and preferences of communities of color in research engagement.

BEST: Excellent. I agree with everything that Dr Fletcher just said. And what I will add to that is that centering is not only important in community settings, but it's important in

institutional and academic settings as well. So, researchers of color, African-American researchers specifically, have experienced marginalization in similar ways and in different ways as the communities that we work with. And therefore, our voices should be centered in these conversations as well. And that has to go beyond just having a seat at the table, but it has to shift to actual decision-making power. And we need to share this power not only in the community, but in institutional settings where we are placed in positions where we can lead community-engaged research, and so that our voices are centered as well.

KAO: So, as we near the end of our conversation today, can you share with our audience what public health practices we should focus on to build greater trust among communities of color during the COVID-19 pandemic and beyond?

FLETCHER: Excellent question. Thank you for posing that. As we're having conversations today, it's really important to think about interdisciplinary scholarship and collaboration between bioethicists and public health practitioners as well as researchers. In doing so, it provides a practical lens, as well as a skill set for really addressing concerns and questions that communities may have, for instance, about COVID-19 testing, vaccinations, additional vaccinations that may come on the market. It also provides a lens and a toolset to really think about addressing untrustworthy practices and policies, as we've been discussing today. And finally, it provides the evidence and the expertise to really address health and health care inequities. In order to do this, we have to think about how can we diversify the field of bioethics? And we've really been having a lot of conversations recently about DEI, but we must really demonstrate intentionality around mentoring and training the next generation of bioethicists, especially bioethicists who are trained with the skills to conduct applied as well as empirical research.

And again, in regards to centering, as I've brought up today in this conversation, it's important to especially center Black bioethicists and other bioethicists of color with the lived experiences and really elevate these perspectives as well as their preferences related to scholarship. So, again, thank you for the opportunity to have this conversation, and I think this is ultimately a great model when we think about this interdisciplinary scholarship.

BEST: And I'll just add on to that by saying in order to move the field of public health forward in this area, I think it's really important that we have truthful conversations, but also tangible reconciliation. And so, we started this conversation by saying that there was this distinction between trust and trustworthiness. And in order to move the public towards trust, we have to focus on trustworthiness. We have to restore the public's trust. And in order to do this, we have to openly acknowledge and address the systemic issues and the systemic injustice that these marginalized populations have experienced throughout history. And until we do that, COVID-19 will just be another example of how inequity will persist. So, I would just end by saying truth and reconciliation is key for us moving forward.

KAO: So, with that call for greater inclusivity, truth, and reconciliation, I want to thank Drs Best and Fletcher for sharing their insights and expertise with our audience today. Dr Best, Dr Fletcher, thanks for being guests on *Ethics Talk* today.

FLETCHER: Thank you for having us.

BEST: Thank you. It was a pleasure.

KAO: For more COVID ethics resources, please visit the *AMA Journal of Ethics* at <u>Journal of Ethics.org</u>. Thank you for being with us today. We'll see you next time on *Ethics Talk*. [bright theme music plays]