

UNIVERSITY OF KANSAS SCHOOL OF LAW “POST-
PANDEMIC PRIVACY” SYMPOSIUM:

ROUNDTABLE DISCUSSION ON THE DISPROPORTIONATE
IMPACT OF THE PANDEMIC IN RACIALLY MARGINALIZED
COMMUNITIES*

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I. QUESTION 1

The COVID-19 pandemic has brought social and racial injustice and inequity to the forefront of public health. One of the most disturbing aspects of the COVID-19 pandemic is that it has disproportionately affected racial and ethnic minority groups, with high rates of death in African American, Native American, Latin American, and Alaskan Native communities. Can you please discuss why the pandemic has had a disproportionate impact in racially marginalized communities?

A. *Answer of Professor Teri Dobbins Baxter*

I think one of the things that we've recognized is that these racial health disparities existed before the pandemic. And so, it's not as though the pandemic came along and created racial disparities. Instead, it exacerbated existing disparities. And I want to point out that a lot of these health disparities can be traced back to legal frameworks, laws, historic racism, historic segregation, all of these factors that have led to some of these disparities. And, in fact, we, I think, tend to blame people for their own poor health. We tend to believe it's all because of poor choices: if we just ate better; if we took better care of ourselves; if people in these communities behaved as they should they wouldn't have these disparities. But, in fact, there's a lot of research that has shown that much of those disparities aren't related to behavior, but instead to structural conditions—including racism, including the stress of perceived racism. So, people who live in communities, or who in their daily interactions, perceive that they're being discriminated against have higher rates of stress, have higher rates of many illnesses. And that's even if you control for things like education—for other factors that tend to have an insulating effect for other populations.

Several people talked about the higher rates of maternal and infant mortality, and there's research that shows that those rates don't correlate with poverty or lack of insurance—that they're higher even for people with advanced degrees, with higher income, and things like that. So, I think that the first step is "Why were there pre-existing racial disparities?" And a lot of that has to do with historic racism, historic discrimination, and the ongoing reality of dealing with a community that often still discriminates in ways that are harmful to health, including in the health care system. There are still persistent misperceptions about particularly Black people, you know, that we don't feel pain the same way, that we have thicker skin. These are attitudes that they found among medical students in recent years. Some of these perceptions are leading to health disparities before the pandemic. And then, after the pandemic, because of already higher rates of illness and lack of access to health care, when the pandemic came along, they tended to hit, as several of the panelists have talked about, people who are in lower-income jobs, people who have to travel through public transportation, people who can't socially distance. And then, once we have the higher rates of illness, the higher rates of death, that also contributes to higher stress which contributes to higher rates of

illness. And so, the disparities that we've seen since the beginning of the pandemic are building on disparities that have existed for a much, much longer time.

II. QUESTION 2

How might community rights to privacy overtake, or at least become equivalent to, individual rights to privacy in the era of big data? Does the way data is collected, stored, and used in health care require a redefinition of the substantive and normative construction of privacy? As a corollary, are there areas and contexts in which removing some components of privacy might be necessary to meaningfully highlight inequities and achieve greater equity? Whether structurally or individually. And if so, how do we approach that discourse?

A. *Answer of Professor Thomas Williams*

I think through the course of the day, I've been thinking a lot about how dynamic privacy is. Whereas we often talk about it, and think about it, as quite flat and static, but that it really is like your privacy rights and interests. And the way that you view them is really dependent both on your position in some of the intersectional components that we heard Dean Mutcherson talk about. And that this means things may shift. And so, when I, in the course of the day, I was thinking a lot about the incursion of privacy rights but thinking, too, about: Who those incursions serve? Who is collecting data? And for what purposes? And that if you have different answers to those questions, it can really realign the way that you think about privacy and who should be surveilling, and how they should be surveilling, and why.

In hearing Professor Baxter's comments, I was also thinking about the idea that stress is also linked to being surveilled. That surveillance based upon living in a Black body is the thing that is causing the problems that then become relevant in thinking about health care. If we're surveilling folks within health care structures to actually provide them benefit, to return something to them in the structure of the research we're doing—rather than to serve other populations, to create treatments that they don't have access to—then we need to be having a really different conversation from one in which we're simply usurping from communities' data and information in efforts to not only perhaps not serve them but also to relegate them and to reinforce norms that exist.

I think, over time, one of the dynamics of privacy is that it has to shift with technology, with technological change, with the insights that come from that. I was really taken by, and thinking about, Professor Elberg's comments around the idea that part of physician oversight, and fraud, and abuse requires patients to allow some incursion into privacy and how we might relate that to thinking about health disparities and monitoring of care as an incursion that also reflects and shifts privacy rights of patients and understanding their care. But that may be really focused on understanding what is happening in the

dynamics that they experience with providers and attempts to serve them.

So, what do those consent structures look like? And what are we thinking about? I'm really taken with thinking about the dynamics of privacy—to which I think about Professor Fowler's comments: It can really be lost in the narratives that we create around privacy and how they are reinforced. I think there's a lot there to think about how we align privacy and "does it serve individuals versus groups?"

III. QUESTION 3

Is surveillance a predicate to creating meaningful arguments for, and access to, the social safety nets required in a pandemic era? If so, what does it mean about the connotation of surveillance and the structure of systems and collection of data not required of those with more robust financial means?

A. *Answer of Professor Thomas Williams*

I think this follows up on Professor Landers' comments and her work—which is that we've made it predicate. But I don't think it's necessary at all. We can provide safety nets that don't require the heavy surveillance that we have created—which has included drug testing, has included proving that you're trying to find work, all these systemic kinds of components of surveillance that folks have been led to believe is a necessary component. And so, I think that is one of the broken pieces. At the same time, I was really taken with one of the early questions in the first panel around the idea that perhaps Native Americans and Alaska Natives are really quite overlooked. And that, at some level, surveillance serves these communities to reinforce the anecdotal evidence they have around how the world works. And how systems, especially in health care systems which we are talking about today, are filled with bias that we may not easily identify but that we can find if we decide to. But to actually add credence, and kind of bona fides, to the complaints of those communities that will be overlooked when it is anecdotal.

IV. QUESTION 4

We all have a part in helping to prevent the spread of COVID-19 and promoting fair access to health. As professionals in the legal field, what steps can we take to fight racial injustice and inequity, promote fair access to health, and address racial health disparities?

A. *Answer of Professor Teri Dobbins Baxter*

I think one of the things that I found in talking to students is, particularly as a law professor, there's a role that I can play in educating them about how the law has functioned to create some of these disparities, and perpetuate, and sustain the disparities. Because, I think, otherwise we all go in with our own biases based on our own experiences or lack of experiences—particularly with communities of color. And so often, what students come in with is stereotypes,

right? Or stories or anecdotes about how other people behave. And I think it's very easy to, like I said in my initial comments, blame people for their own health disparities and say, "well this is just about personal choice." And so, "if we give people better access," "if people would just get better educated," "if they would just get better jobs," that'll fix the problem. And they don't take into account the role that the law has played in creating these disparities, and perpetuating, and sustaining them.

Part of what I think we can do, as a legal profession, is a better job of educating people about the law in all its complexities and understanding that the laws don't exist and aren't created in a vacuum; and they don't function in a vacuum; they affect people in different ways; and that the legal structures have contributed to problems in ways that we probably don't understand; and, as lawyers, we don't see the research from public health authorities that talk about the fact that these disparities are not necessarily linked to these indicators like behavior, like economic status, like education. And so, doing a better job of, I think Professor Landers talked about it, science and health literacy, right? And some of that, I think, also needs to be passed on to our law students, and to lawyers, and to educators so that when we make these decisions and we push for, and advocate for, policies and for laws, we're doing so with a better understanding of their effects and the problem that we're actually trying to solve.

B. Answer of Professor Thomas Williams

I think that we have roles, especially as law professors, to think about how we create advocates, how we train them to look at problems. I think you know from my seat, especially connected to the Masters in Bioethics, to think about how we can approach problems in an interdisciplinary way. And the ways in which lawyers actually absolutely need to be engaged with their colleagues in the sciences, in the humanities, in the social sciences to inform their work and their approaches. And that can be, I'll say, simple, but it's not simple at all, science communication and how we message, and how we think about our audience. But also, I think there's room for all of us to be advocating for better baseline educational systems so that folks understand and are able to engage in the world in meaningful ways and so that we don't have wide disparities in understanding, in folks' ability to understand an informed consent document or a contract of adhesion that you click through when you go onto a website, and so you can actually educate yourself about what is happening with your data, so that you're making informed choices around it, so that you understand the regulatory regimes in which you operate, and have a sense of how you can navigate that world, not just as a lawyer, but for everyone who is trying to figure out how to live in the world and understand privacy.

C. Answer of Professor Jacob Elberg

I think it's critically important to be teaching about issues of disparities when we're talking about these specific issues. But I think there's also

important work to be done more broadly when you think about the health care system. I think about a lot of folks who are well-intentioned and well-meaning and who don't intend to be perpetuating problems. But where folks, I think, have gotten better and better at where they've learned about a disparity and where they've been educated about a disparity saying, "Okay I've learned about that. I care about that. I'm going to try to do something about that." But it only is within that where they've been educated about that.

So, I think there's important and really challenging work to be done to say, "All right, well this is an issue where I don't know anything about there being disparities, but I should give some thought to whether there are. Because it seems likely given what we find when we really look into things that there will be." So, having that be something that people center and think about more frequently—including in areas where it doesn't jump right out at them, where it's not obvious to them that it's an issue—I think, is something that hopefully can be done. For us, that's taken the form of trying not only to have courses that are really focused on and devoted to such issues, but trying in courses where people's initial reaction might be to say, "Hey that's not what this class is about." To say, "All right. Let's do some extra work and figure out if there are issues there and hopefully change people's thinking through that."

D. Answer of Professor Barry R. Furrow

I think it's important as law professors also, in any course you teach, to try to develop in your students and yourself, of course, a sense of empathy. So, I come from blue-collar, working-class background and my aunts and uncles worked in meat packing in South Dakota. So, when I teach torts, I try to give a very strong picture, including YouTube clips, of what it's like to be on the floor of a packing plant. Have you ever killed a chicken? Have you ever gutted a pig? It's a culture that I grew up with. What's it like to be immigrants working in this industry? And how do you feel about what they're going through? You know, a lot of law students come from a privileged backgrounds and I think they need to be shaken sometimes to understand the world of disparities and what it feels like and what the law can do to fix it.

E. Answer of Professor Renée Landers

I remember when my grandfather didn't have indoor plumbing in his house on his farm in central Illinois. But they moved in 1960 and they got indoor plumbing, so it was okay. So, I think that explaining how everyone doesn't come from the same kind of experience growing up is very important. Also, I think what I say to my students is that there's no constitutional right to buy cheap stuff and to make as much money off your business as you can humanly do without any kind of interference or without any societal obligation. Because every cheap pound of chicken that we buy in the grocery store or the vegetables that we eat are at the expense of workers who are not well protected in the current economy. And that should be morally troubling as we go about our lives. To think about how we can make that situation better.

And then the last thing I wanted to say is that, the thing I think that is very important for everybody to recognize is that, there are all of these structures and institutions that we have, the laws that have created these situations we've been talking about today, are choices—they are conscious choices. They are not the only way to go about doing things. We don't have to accept things as they are because there could be other ways of trying to structure our government. You know, have different rules about how the United States Senate operates. I mean, like all of these things that are constraints on progress right now are conscious choices. And we could be activists for enlightening people about how to make different choices about those structures.

F. First Reply of Professor Thomas Williams

I think often in the classroom, I'm somewhat shocked by the failure of imagination to reimagine a system that doesn't hold the defaults that feel familiar. And it's real work to push those boundaries and for students, especially law students who kind of like systems and rules, to step into the possibility that part of their work may be reimagining not simply learning—and creating and structuring new systems that account for far more. And so, there's a lot of work to be done there.

We've all got to be cognizant of the real variety of backgrounds that we bring to the table and provide space for them. I just saw a great New York Times film piece about chicken farming and about, at some level the high cost of cheap chicken.¹ And those folks are lost in the dialogue of thinking about your food. And so, it's about peeling back layers and looking, to Professor Landers' point, at the whole system that results in the chicken in your grocery store.

G. Reply of Professor Teri Dobbins Baxter

I'll just say really quick, that I think it's really easy to get depressed and say that the problems are too big. So, I really like your point about helping them expand their imaginations about what we can do because I talk a lot about what's wrong with the law, but the law can actually change and can fix some of these problems we have to think about and we have to understand. I like the idea of encouraging curiosity as well. If nothing else, if I can convince students that you should go in thinking there's information I don't know and, before you start to come up with solutions, make sure you understand the problem. Because I think that this narrow understanding of the problem leads to ineffective solutions that leave a lot of folks completely out of the conversation.

H. Reply of Professor Renée Landers

Professor Williams mentioned the work requirements for the Medicaid

¹ The New York Times, *See the True Cost of Your Cheap Chicken | NYT Opinion*, YOUTUBE (Feb. 10, 2022), <https://youtu.be/m6xE7rieXU0> [<https://perma.cc/S2G6-YFN9>].

program, for example. There's one recent case which has kind of a good outcome with respect to that. Because when the Arkansas work requirements were challenged, first the U.S. Department of Health and Human Services approved them, and then that approval was challenged. The D.C. Circuit looked at the Medicaid statute and said the statute is about health care for low-income people; it doesn't say anything about encouraging them to work or getting them to work and therefore you can't have work requirements as a part of this program. That's an example of how you can use the law to try to push back at some of these overreaches.

I. Second Reply of Professor Thomas Williams

I think I'll just add that, often, even I assume that the systems in place are forever systems and not created out of like historical anomaly or a specific moment in time. And so, realizing that things have not always been the way they are, I think, is connected to that imagination question. Because it simply is what appears to you and if you don't look under the chicken, then you think that it is as it always has been and there is no room. But we really have had all kinds of tremendous moments of shifts and change and I kind of hold on to the hope that maybe the pandemic, at some level, will be that thing that many of us hope that it was or can be.