[INTRO MUSIC]

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Artist: Emmit Fenn

Song Title: Alone

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[EMMA] Maria works with undocumented immigrants at a grassroots organization. But, when COVID hit, her team dropped everything they were working on. Their priorities had changed. Instead of helping immigrants know their rights, they started helping immigrants put food on the table. They started an emergency cash fund. Any eligible family could receive $1200 from Maria and her team – no strings attached. That money could go to rent, groceries, utilities, or whatever essential items the family needed the most.

Maria ran the financial support hotline. She began noticing that getting people on the line was harder than the team expected. It went a little bit like this. Maria would get a phone call from someone who needed help. She would go through the eligibility questionnaire with them; everything would check out. But when she asked for the person's phone number or address, suddenly, the client would clam up. No one wanted to share information that could be used to track them – even with an organization that was trying to help.

[JEFF] Why did Maria's financial support hotline run into problems? Is it a matter of trust? And, how does trust work in a community where revealing the wrong information could get you, or you and your loved ones, deported? And what lessons does this offer to our public health responses, such as contact tracing, in the midst of a global health pandemic?

Welcome to Duke Law's TechTrust, where we explore how to maintain trust in an increasingly digital age. This podcast, we're looking at trust among vulnerable populations in the times of coronavirus.

[THEME MUSIC]

[JEFF] My name is Jeff Ward, and I'm the Director of the Duke Center on Law & Tech at Duke School of Law. Much of the work of our Center aims to ensure that technology empowers and ennobles all people, and here, we look at the important topic of trust. We bring in students, researchers, and experts to discuss how their work in the field can help us understand more about technology, law, and trust in a world where digital tools play increasingly vital roles in shaping our societies, facilitating our exchanges of ideas, allocating our rights and resources, and fueling our economies.

This series looks at how public health data surveillance in the times of COVID affectsundocumented immigrants. To do that, I'm joined by Emma Ritter, a student at Duke Law and Andrea Rojas Rozo, a Fulbright Scholar from Columbia and fellow with the Duke Center on Law & Tech. Both were part of a research team with the Center aimed to better understand the needs of some communities left out of primary public discussions on pandemic response.

Welcome, Emma and Andrea.

[Emma and Andrea] Hi, Jeff! Thanks for having us on TechTrust.

[JEFF] Yeah, absolutely, thanks so much for being here, it's good to have you! So, we're talking undocumented folks and the pandemic. Tell me about how you got involved in this topic.

[ANDREA] Sure. I'm interested in the social impacts of technology generally, and when I joined a research team of Duke Law students and faculty members this summer, our initial goal was to conduct a listening project: we really wanted to hear about viewpoints that the mainstream conversation around COVID and data collection was missing, and then amplify those voices. As university-based researchers, we knew we had a lot of privilege, but we also had some sort of power to use our privilege, stop and listen more carefully. And we wanted to use that power for listening to those we often neglect to listen to.

[JEFF]. I love this idea of a listening project. How wonderful. Stop and listen more carefully. Maybe we should get shirts made with that, that sounds like a good theme. We could use more of that! What prompted this desire to listen?

[EMMA] It turned out that pandemic-specific guidance for undocumented immigrants was either scarce, missing or inaccessible. We wanted to look at how this lack of guidance impacted those vulnerable populations. And, as various proposals to address the pandemic were being discussed, we wanted to understand how undocumented immigrants thought about health data surveillance and digital contact tracing. It seemed like there wasn't much conversation about how these efforts might affect this community, the undocumented community, differently from communities that were already well-represented in the public discussion.

[JEFF] That seems like an astute observation, Emma. Because of my role, I'm part of several groups that—when COVID hit—we began rather urgent discussions about public health data surveillance and contact tracing, especially. For those who might not know, when we talk about contact tracing, we're talking about the various efforts of both public agencies like state departments of health and also of private actors like the combined project of Google and Apple, to use data to track those who have been infected and those with whom they've come in contact, and in turn to provide alerts to individuals that they might want to get tested and provide collective insights to public health authorities about these contacts. It's a public health tool that—with the availability of mobile phones and modern data-collection tools--is made potentially more effective, but also, of course, as you're starting to elude to, potentially more intrusive. Why did the concerns of undocumented immigrants about such efforts stand out to you?

[ANDREA] Well, for a couple of different reasons. For one thing, a lot of the members of these communities are on the front lines. They're often essential workers, still working despite the pandemic, with a real risk of exposure. But, even so, they don't have a lot of influence in public decision making. For example, we heard from one organizer in this state that North Carolina didn't have any public health communications in Spanish until months into the pandemic. So, many on the front lines were the least able to participate in shaping the public responses that affect them.

[EMMA] That's right, Andrea. Undocumented immigrants also don't have the same social safety net that others have. That stimulus check people got in the mail? Citizens only. Same with unemployment benefits. And, so, these support programs did very little to support this

undocumented community and left them very vulnerable to financial instability, housing instability, and employment instability. Plus, without access to affordable health care or access to legal protections, many undocumented workers won't quarantine or seek care even with symptoms or known exposure to the virus, just because of this varying mix of instabilities.

[JEFF] That makes sense to me. We've seen many, many people affected by not only the health consequences of COVID but also the economic disruption that you describe. Even those with some financial means – I know relatives, neighbors, and others - have faced financial hardship and needed that kind of assistance. The community you chose to listen to – it sounds like they are on especially shaky ground in terms of financial stability, and we certainly couldn't blame them for prioritizing work even in the face of potential negative health consequences. With that, talking about the financial background, where does the data collection come in? Why is that a concern?

[ANDREA] Data collection can feel especially threatening. On top of increased exposure to the disease and financial and employment uncertainty, undocumented immigrants face the threat of detention, deportation, and family separation on a daily basis. Some of them are even afraid to seek healthcare because some piece of identifying information might slip.

[JEFF] Hm. So you're saying, in terms of vulnerability, it sounds like a triple-threat going on here: there's increased exposure because of frontline workers, that's a term we've used a lot and you've used, Andrea. They are on the frontlines, oftentimes being exposed, they have limited access to assistance, financial and otherwise, so fewer options to keep away from those environments. And potentially severe consequences to data sharing of any sort. So, you decide to focus on amplifying the voices of undocumented immigrants, partly because of that triple threat. How did you go about doing that?

[EMMA] We ended up interviewing organizations that serve undocumented immigrants in North Carolina. We focused on the Triangle area. For those outside of North Carolina, that's an area in the middle of the state made up of Raleigh, Durham, and Chapel Hill. It also happens to be the same place where Duke is located. Basically, we sought to hear the experiences of organizations who serve undocumented members of our own community.

[JEFF] So, in terms of process and method, Emma, you chose to focus on organizations that *serve* undocumented immigrants. Given what I know of how closely such organizations work with their constituents and how committed they are to serving them really well, I would bet this offered tremendous insights. But I want to ask, were there reasons you didn't focus on undocumented immigrants directly?

[EMMA] You know, this project was focused on privacy, and so we wanted to make sure that what information we collected information was the most confidential possible, that we were collecting it in the most confidential way. We also knew that even anonymized data can be reidentified. So, we decided to err on the side of caution: we'd talk to organizers rather than immigrants themselves. That way, we could still get roughly the same stories, but we were protecting the privacy of these individuals.

[JEFF] Ok. That sounds wise to me. So let's dig a bit more into what you found substantively. As you know, today we're focusing on one key aspect of your findings, which is trust. Let's go back to the story you told about Maria, and even there, just so listeners know, we've changed names and details to protect our interviewee's confidentiality. How did trust play a role there, in the Maria situation?

[ANDREA] Well, Maria's story really emphasizes how careful the undocumented community has to be when they share information. A phone number, an address – those can be used by immigration authorities to track someone down. Undocumented immigrants are much more receptive if a community member or a trusted organization can vouch for someone. Maria said she's learned how to say who referred her to contact a family when she does outreach, for example, and to ask the families to refer her to other families. It lets them know that she's not a threat – she's on their side, and she's trying to help.

[JEFF] That makes sense, and Maria told you that. Did other organizations echo this concern?

[ANDREA] You know, they did. This referral idea came up a lot – trust wasn't just a one to one relationship with someone, it became a one to many system as someone's trustworthiness spread within the community.

[JEFF] OK. This idea of trusted referral brings up a couple of questions for me. First, this notion of a trusted referral and reliance on a community member or organization they can trust—what does that mean for public health efforts during a pandemic? Is there a lesson there?

[ANDREA] Yes. A lot of those grassroots organizations have had to work overtime to let people know where to get their information – who to trust. It didn't help that the state's public health guidelines are not provided in native languages or have not been vetted and communicated through trusted organizations. If you don´t have information you can trust, you go back to what you rely on: home remedies, such as ginger tea – all because public communications weren't accessible to them, or if they were, they didn't trust the messenger enough to believe in it.

[EMMA] That's right, Andrea. And sometimes people trust sources you wouldn't think about. We heard from one organizer about a problem she saw in her own grocery store. The store is popular with some immigrants because they stock things you can't get at a more mainstream shot. But, this particular chain was not enforcing social distancing. It made a lot of people think, well, if my own grocery store isn't doing it, it must not be that important.

[JEFF] That's really interesting. I'd bet that many of us—certainly myself included, but also probably our public policy makers—wouldn't immediately think about the signaling function at a grocery store as an important source of public health information. I mean, I think that anecdote really highlights your point about there being a disjunct between the public health policy, best practices, etc., on the one hand, and the way it is shared with all communities, on the other hand. That gap that you're discussing – I can see how it undermines trust. But, that leads me to the other question, maybe a more difficult question. There are likely some who ask: why the heck does this trust gap matter? It sounds callous, but we know that some might see this as an issue of prettily little concern to them.

[EMMA] Yes, that's a really good question. We think this trust gap matters both because 1) excluding identifiable communities from public health efforts puts them directly at risk and 2) because excluding them undermines the effectiveness of public health efforts as a whole, so it puts all of us at risk. If we had one primary takeaway from our listening exercise, it's this: Pandemics are indifferent to immigration status, and our responses should be, too.

[JEFF] That's intriguing. You said, pandemics are indifferent to immigration status, and so our responses should be, too. It sounds like you're offering both altruistic reasons and—for those who might not be prone to altruism--pragmatic reasons for addressing the needs of vulnerable populations like undocumented immigrants.

[EMMA] That's right. Let's start with the altruistic. If undocumented immigrants don't trust contact tracing efforts, it puts them directly at risk. And without the ability to know that that contact tracing won't undermine their employment or threaten their family, contact tracing efforts and the data that contact tracing requires won't be trusted. But put that aside- forget about the health data – that's bad enough, but the basic demographic tracking information they ask for is actually the bigger issue. An address can put you and others at risk. We heard a story about ICE entering a trailer park to arrest one undocumented immigrant because of his immigration status. When but ICE couldn't find him, they just kept knocking on doors until they found other undocumented immigrants and took them into detention instead.

[ANDREA] Then you have recent locations or recent contacts. Those can also put those at risk of deportation. We heard a story about how ICE used to hang around a Latinx church on Sundays, because they knew undocumented immigrants would be coming out after the service. Or they went to a high school in Durham that had a high Hispanic population and hung out near the bus stop. Telling a contact tracer you frequent those locations could expose you to that same risk.

[JEFF] You can certainly see why Maria had those she was trying to help actually hang up on her! So what should contact tracers do? If that information is obviously important to their efforts, what should they do to get it and help prevent the spread of the virus?

[EMMA] It really comes back to trust, you know that's what we heard over and over again. Trust in data privacy, use and governance AND—relatedly—trust that employment won't be lost. Undocumented immigrants need assurances from public health officials that any data collected will not be shared with law enforcement and won't be shared with immigration officers. Until then, they just won't trust the system enough to participate. And to go back to where we started, you know, we also found that any group excluded from our social safety nets will often be forced to choose work—even at the risk of exposure or exposing others—over participation in public health protocol. This is the kind of trust we have to build if we want to be able to respond to pandemics with meaningful participation in our public health measures.

[ANDREA] And—to emphasize the point—if they're not participating, that affects everyone in the community—the virus doesn't care about immigration status. This is the pragmatic concern. Measures such as contact tracing depend on participation. To exclude a certain group—especially a group known to constitute a disproportionate percentage of front-line workers—undermines this essential participation. Leaving an essential part of our community out of our public health measures means they won't be as effective.

[Jeff] On that pragmatic concern, Andrea, would it be fair and simple to say, "If we exclude some, we risk all"?

[ANDREA] Exactly, Jeff. As we focused on communities in North Carolina, we found that failure to care for the state's undocumented immigrants endangers everyone in the state.

[JEFF] These are a lot of really important and actionable insights, Emma and Andrea. I want to a little bit of a summary. It certainly gives us, our listeners, and policymakers a lot to think about. We often hear the term "pandemic response" and—I think— we tend to conceive of our public health measures as both responsive to a disease after it arrives – ex-post, after the fact, and focused on medical and health issues. It sounds like your really productive listening exercise offers some challenges to that. The kind of trust you describe, to me, evidently has to exist *before* the pandemic hits. It's not something that can be built after, or urgently, it has to exist before. And it's not a matter of medicine. As we depend on data collection to deploy these kinds of public health efforts like contact tracing, we see that work, employment matters. That's not something we usually think about as a tool to effectively deploy our health measures, but work really matters. Undocumented immigrants may find economic/employment concerns to be way more urgent than the risk of contracting COVID-19. And you have also pointed out, through this listening exercise, that trusted networks, even outside of our traditional government or healthcare realms, are really essential. It sounds like undocumented immigrants are more receptive to public health guidance when a trusted community member does it than even when, say, a government office or agency provides it, and they need somebody to vouch for the information. And that even, I love that anecdote, I think it's really telling, as you noted— that even the signaling at grocery stores must be considered. You noted as an example that—at least early on—guidance was not initially available in native languages such as Spanish, and therefore seemed inconsistent, unclear, or uncertain coming from the authorities. That inconsistency or absence can really undermine or exacerbate distrust in the authorities. Is that a fair summary?

[EMMA] Absolutely. We certainly heard that better community engagement that takes into account the particular needs of undocumented immigrants—around work, around data, referral networks, etc.—that's necessary to enhance trust in public health efforts. Without closing that trust gap for the most vulnerable, a gap in public health efforts will remain for all.

[JEFF] Nicely put. Well, thank you so much Emma and Andrea. I think our listeners learned much from the listening that you've done.

[EMMA] Of course, Jeff! Thanks for having me.

[ANDREA] Thanks for having us.

[JEFF] And to our listeners, from the Duke Center on Law & Tech, thanks for joining us on TechTrust!

[OUTRO MUSIC]

YouTube Audio Library

Artist: Riot

Song Title: Bomber (Sting)

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