



Countering systemic erasure? Data justice for marginalized communities

“So you keep your people healthy, you keep the economy healthy. And I believe that is something that we need to connect the dots for folks because they don't see that connection.” Dr. Seciah Aquino

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Welcome to Code WACK!, where we shine a light on America's callous healthcare system, how it hurts us and what we can do about it. I'm your host, Brenda Gazzar.

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This time on Code WACK! What is the **Latino Coalition for a Healthy California** doing to advance the health of Latinx and Indigenous communities in the state? What policy solutions are needed to reduce disparities among these vulnerable communities? And what are their hopes and fears of these communities when it comes to their health and the upcoming presidential election? To find out, we recently interviewed **Dr. Seciah Aquino**, the Latino Coalition for a Healthy California's executive director. This is the second episode in a two-part series.

Q: Welcome to Code WACK! Dr. Aquino.

Aquino: Thank you so much

Q: So what are some of the recent wins that the coalition has had related to policy or advocacy?

Aquino: Yeah, so I'll highlight a very exciting campaign that started about two years ago and it began with a very honest conversation with our partners at CIELO, our indigenous community partners and we talked about the Latinidad movement and how it had invisibilized our Indigenous community members. How can we make sure that our indigenous communities are front and center, that they are receiving the resources that they need? And so was born our fight for data justice because for us as a public health advocacy organization, we make data-driven decisions. And guess what? Our Indigenous communities are not represented in the data.

And so we began to explore ways in which we can explore the diversity and the richness within the Latino and Indigenous community through our data and so that the data could give us the trends, the patterns, and delve deeper into those deep health disparities and thus it gives us the opportunity to dig a little bit deeper into the solutions or the resource allocation.

So this bill [Senate Bill] 1016 was born and what we're doing and asking is the [California] Department of Public Health, the CDPH, to collect and disaggregate data at the Latino subgroup level. So if you're Guatemalan, you know, you would be able to indicate that. If you're Hondureño [or] Nicaragüense, you would be able to indicate your country of origin. If you are from an Indigenous nation, you would be able to mark Aztec, Mayan. If you speak an Indigenous language, you would be able to mark Triqui [or] Mam. and ideally collect that data at that level. And then after collection, we're asking for a report on public health trends at that

level for our community, and that report would be provided to the legislature to make sound decisions with data in their hands.

This is something that would dramatically change the way that we see the Latino and Indigenous community in California.

A quick update: Since this interview was conducted with Dr. Seciah Aquino, Governor Gavin Newsom has signed SB 1016 into law.

Q: How would you characterize the disparities affecting Latino and Indigenous communities today? And which issues do you see as the most pressing?

Aquino: Yeah, that is a big question. You know, at LCHC, we pride ourselves in translating community solutions into equitable policy and lasting systemic change. And I would say with our public health framing, we work on addressing the social determinants of health, right? For us, when we talk about health, it's not just health care, we're talking about housing, we're talking about green spaces, we're talking about nutrition, making sure that you have access to education and the right opportunities to keep growing as a person. Honestly, at the end of the day, the biggest issue that is hurting the Latino and Indigenous community is poverty. If we had jobs that provided a dignified salary, that provided opportunities to take care of yourself and your family, if we had educational opportunities where a child that's living on WIC or food stamps to one day be a doctor, if you are able to provide systemically for those families, then we would have a much stronger society, right?

And unfortunately, those opportunities are not provided broadly. There one in a few, and it's a huge privilege to be able to live through something like that. But having lived it myself, I know that it's possible and it's doable. And guess what? The more that you invest in the wellbeing of a community, the more that community will invest back into that community and the more that the economy will continue to grow. And so I could give you rates for different diseases, both acute and chronic, and I think we can spend all day within that space. But I think when we dig down to the root cause of the issues, it's poverty.

So if we were able to address poverty, re-envision a new future, a new reality for our community members, we would be able to affect better, better change and change that would be sustainable and completely transforming those health outcomes.

Q: Great. So thank you for speaking to that. And so tell us what the coalition is doing to address poverty among Latin and Indigenous communities of California?

Aquino: Yeah, well, we have many different solutions and approaches to the work. We just launched a workforce institute for Indigenous and Latine communities. And what we're trying to do here, and the vision is really to transform the health care and public health workforce to be more reflective of what our California population looks like. We make up 40% of the population, but when you go to your clinic, when you go to the emergency room, when you access any kind of safety net program, you're not necessarily being seen by someone that comes from your community that has that cultural perspective.

When we look at rates, right, they're extremely low when it comes to formal roles like a physician, et cetera and so what we're trying to do is invest in our community. So we start training students as early as high school and we move up to college students, grad school students, recent graduates, early professionals and promotoras, community leaders that play a very strong advocacy role, to teach them this public health perspective, giving the social determinants of health framing and the civic engagement part, right?

A lot of our work as an advocacy organization is just providing and opening up the doors into the advocacy space because it can be such a reserved and exclusive space. So we're saying, 'no, this is what it is meant to do – to center the voices of community members.' And we believe that every community member is strong and powerful and has all the expertise they need to create change. And so we're just opening up the doors and the opportunities for community members to share their stories. And so our goal in this very specific program is to bring those community solutions that can then be implemented into policy and hopefully all these students that were training and the promotoras – whatever field they go into, supposedly become an architect or you know, a businessman, whatever field

they decide to go into, they will be carrying that social determinants of health perspective. They will be carrying that public health framing with them into any space that they go into. So for us, it's almost public health Trojan horses, right? We are bursting the systems from the inside out so that more of our community members can have access and can continue to build up their wealth and their health.

Q: That's wonderful. So what policy solutions do you think are needed to reduce disparities among Latine and Indigenous communities?

Aquino: That's a good and very broad question. Actually. Right now we're bringing together over 20 different Latina and Indigenous serving organizations across the state in our regional power hubs to think through that specifically. And so we'll be co-creating a policy agenda, a health equity agenda, looking across the social determinants of health. In addition to that, the way that we guide our work internally right now is through three specific policy focus. First access to health care for all building healthy communities, which is a social determinant of health perspective, and then our health as a fundamental human, right? So when we look at the different policy solutions that we're seeking that year or that we're supportive of that year, we are putting them through that frame to see what we need to move forward with in each and each year provide a different opportunity and different policy windows that can be activated or leveraged to drive change.

Q: So it sounds like you might support single-payer Medicare for All based on the criteria that you gave. Is that right?

Aquino: I think it depends. When we think about transforming our current system, there's a ton more that needs to happen. I think when we talk about single payer, I think there are very specific thought leaders or specific frameworks that come to mind. So I don't want to, you know, sign up to anyone specifically, but I will support the fact that we need a better system that centers the patient and that centers the community member and we get away from this basically disease treatment into actual health treatment, right? How do we make sure that

we keep families healthy and we are not just treating disease and maintaining someone in disease. So I do think we need some powerful transformation, but it involves actually a complete cultural shift in the way that we see [public health.]

Q: Right, right. So not as, not so much as disease management, but kind of more whole person care.

Aquino: Exactly.

And preventative care.

Aquino: Exactly.

With equal access to everyone.

Aquino: Oh, a hundred percent.

Q: Right. Wonderful. So as the nation faces what some say is the most consequential presidential election in decades, what are your greatest hopes and fears for Latino communities? Whoever wins?

Aquino: Yeah, I think the opportunities are huge, right? I think we know that representation matters. We know that whoever sits in the very privileged role, formal leadership role of the presidency plays a very large role in the narrative that gets played out across the nation. And you know, in the United States, our states have a lot of ownership over the way that they implement policy or the way that they guide their systems within the state. But there is an overall narrative that the president drives, and I think we've seen it play out both positively and negatively, right? When there is a president sitting in office that is anti-immigrant, you see levels of violence rise against immigrants across the nation. You see actual policy changes that affect immigrants and other disenfranchised groups.

And so I think if we can have someone in office that really a) has the expertise, <laugh>, right? Coming from being a vice president herself, right, to the lived experience in being and coming from community, to having a vision to support families, working families, families that may be living in poverty and already coming with an idea for policy changes that need to be affected to provide more opportunities both for health and the economy, it'll create a huge change in the way that our nation honestly is able to thrive – that during not just our presidency, but thereafter. So I think the opportunities are huge. Of course, there is a level of fear, right? We've already seen how hurtful a Trump presidency can be for communities of color and how much it can set us back from the amazing growth that we have been able to establish and see. And unfortunately with what we're hearing in terms of Project 2025 to the narrative that continues to be a negative one, it's unfortunate that it's even a possibility again.

And that it can have very real health outcomes and can affect our health negatively. Not just our mental health being, you know, aware of what's happening, but also just decreasing access to healthcare services, decreasing opportunities to be well. And I think many times public health is a hard topic to be able to talk about because it takes many years to see change, right? It's not something where you see the outcomes right away. These are investments that are almost intangible for the time that you are making those investments. And it's only decades and years later that you can see that fruit grow, right? And so I think public health is on the ballot this year, just the way that it has been every time.

And there's this theory of human capital. It's an economist [who] came up with this theory and it says, 'if you keep your people healthy, your people will show up to work. Your people will show up to school, your people will feed back into the economy.' So you keep your people healthy, you keep the economy healthy. And I believe that is something that we need to connect the dots for folks, because they don't see that connection. But if we did [that], we are such an amazing nation. Our diversity makes us beautiful. And I think if we're able to own the power that we do hold as the United States of America, we would be able to better the lives of so many here and have a positive impact across the world.

Thank you Dr. Seciah Aquino of the Latino Coalition for a Healthy California.

Do you have a personal story you'd like to share about our wack healthcare system? Contact us through our website at heal-ca.org.

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Code WACK!'s powered by HEAL California, uplifting the voices of those fighting for healthcare reform around the country. I'm Brenda Gazzar.