

Trust Talks Episode #6: Overcoming Vaccine Hesitancy

Anna Lee: My name is Anna Lee, and I'm the senior director of community impact here at The Chicago Community Trust, the region's community foundation. We have a 10-year goal of closing the racial and ethnic wealth gap. I oversee the changemaking activities in Addressing Critical Needs, which looks to respond to the region's most urgent needs.

Currently, there is nothing more urgent than COVID-19 and its impact on our community. With us today are Jackie Jacobs from Sinai Urban Health Institute. Karen Tamley from Access Living, Lee Edwards from Free Spirit Media, and James Rudyk from Northwest Center. I would love to begin the conversation with you by introducing yourselves.

Karen Tamley: I'm the president and CEO of Access Living. We are a Chicago-based nonprofit organization committed to advancing the independence of people with disabilities. We do that through direct services, advocacy, policy reform, and peer support. We're an organization governed by a majority of people with disabilities. I myself was born with a disability, and I've used a wheelchair all of my life. Access Living is a very grateful grant recipient of The Chicago Community Trust. In a past role, I served for many years on the Disability Fund at the Trust.

Lee Edwards: I am the manager of the Real Chi at Free Spirit Media, a learning newsroom program. Our connection to the Trust is we've hosted On the Table discussions with community members from Chicago's greater West Side, particularly the North Lawndale community.

James Rudyk: I'm the executive director at the Northwest Center, a nonprofit community-based organization located in and focusing on the Belmont Cragin community. Belmont Cragin is one of the neighborhoods in Chicago and is unique because it's largely been an Eastern European Polish neighborhood. Over the last 20 years, it has become the fastest-growing Latinx community in Chicago, largely due to the displacement of Latinx folks from surrounding communities.

The mission of Northwest Center is to identify and respond to the needs of the community. We're connected with the Trust because we've been a long-time grant recipient of their housing work. In addition to that, we've been partnering with Anna and her team on the vaccine work the Trust has done as well, as well as the Chicago Community [Response] Fund activities the Trust has participated in. We'll talk more about it, but I'm excited to share some of the learnings and what we've seen related to vaccine equity here in Chicago.

Jackie Jacobs: I'm the director of evaluation at the Sinai Urban Health Institute. We are the community engagement research arm of Sinai Chicago and have been doing research and evaluation with the community for more than 20 years.

We are currently working with the Trust as the data and evaluation lead for Chicago's Equity First Vaccine initiative, and we are evaluating the Chicagoland Vaccine Partnership.

AL: We talk so much about being data-driven and recognizing that data can be both qualitative and quantitative. I'd love for you to frame the conversation and talk a little bit about the objectives of this initiative.

JJ: The Chicagoland Vaccine Partnership is a network of individuals and organizations that have come together to address the COVID-19 pandemic, focusing on the communities with some of the highest case rates but the lowest vaccination rates. The network is made up of individuals, community-based organizations, government, philanthropy, policy and advocacy experts, and beyond. The initiative was launched to support equitable and culturally responsive vaccine access and public health workforce capacity building at a hyperlocal level here in Chicago. The objectives are to increase vaccine education opportunities, support coordination of COVID relief efforts and vaccination response from a community-engaged lens and decrease barriers to vaccination. It is also a hub for documenting the shared learnings and innovative approaches that we're hearing from our community partners around community education.

There's a learning community, a space for dynamic problem sharing and finding additional partners to work with out in the community, and a space for policy advocacy policy partners to work together to make sure we are building a platform where folks across Chicago can access what they need.

AL: All of us on this call address the social determinants of health, whether that's communication, mobilizing the community, or using an equity lens in the work that we do addressing housing, barriers for people with disabilities, or aging adults.

COVID has really uncovered the fractures of public health. I feel like this is an opportunity to think about both the short and long-term. Could you talk just a little bit about why it's important to think about both?

JJ: Our evaluation is doing just that, looking both at the immediate needs in Chicagoland and how those are being addressed. Things like the number of people accessing a vaccine or the number of culturally and linguistically appropriate services to support folks. But we're also thinking, like you said, long-term: anticipating and measuring what's going to happen in a year, two years, five years.

The short and long-term approach is really important for a couple of reasons. In the short term, we need to know what's happening now. We need to know if the activities and approaches that all of my colleagues

on the call are working on are working. Are there strategies that may need to be adjusted, or do we carry on?

For example, we know that education and engagement sessions, particularly around some of the influxes we've seen in case rates. With the Delta variant and Omicron increasing [cases], around those times, we know that people are seeking out more information or asking more questions.

In the long-term, we want to understand more broadly how shifts in resources and changes in the pandemic and workforce are changing over time. It helps us understand if some of the objectives that I described previously are being met. It also helps us document and understand some of the unintended outcomes of the program.

AL: James, I'd love to hear how your organization is responding to these immediate impacts of COVID.

JR: Our initial COVID-19 mobilization focused on getting resources into the hands of undocumented and mixed-status families. We saw early on in the pandemic that there were racial and xenophobic undertones to how the pandemic response was led at the time, really disproportionately impacting communities of color.

The Latinx community we serve was largely left out of a lot of the stimulus and appropriation. So, we worked with the Trust, United Way, and the Chicago Community [Response] Fund to assemble resources to provide direct cash assistance to families. As an organization, we've never provided direct assistance to families before. But I'm really proud to say that as a result of our joint work, we were able to raise over \$300,000 for a universal basic income pilot that is giving to 50 undocumented families here in the community. We've raised over another \$100,000 that we provided in one-time direct assistance to families. Since the pandemic, we also provided PPE and other support to the community.

In addition to the financial support, we provided over 24,000 masks and sanitizers to the community. That was the first wave of our pandemic support. Then we worked closely with the City of Chicago, Westside United, the Trust, and other funders to be part of the Racial Equity Rapid Response team to respond to the pandemic specifically focused on racial equity as part of that response. As part of that, we became a Protect Chicago community that allowed us to dedicate resources, including testing and vaccinations, to Black and Brown communities.

We focused on making sure that those communities had equitable access first to testing. We were able to open up testing sites at local schools here in our community and at our office and provide drive-through and walk-up testing free of charge six days a week to community members here that were bilingual and bicultural.

Then, we were the first pop-up [vaccine] clinic in the state of Illinois and Belmont Cragin at Steinmetz High School. Beginning in February of 2021, in a partnership with the City of Chicago, we were able to provide 24,910 vaccines total for the community.

We're not a healthcare organization, so we didn't actually provide the vaccine, but we helped do the outreach, registration, staffing, and support the vaccine clinics and efforts through, again, funds from the Trust, the CCRF, and other funders.

We're really proud of that. I just checked the City of Chicago's COVID data. The 60639 Zip code, or Belmont Cragin, has a 92 percent one vaccination rate, and 81 percent have received both doses, which is the highest of any majority non-white Zip code in the city. We believe that's a result of the year-long efforts of the team and all of our partners, funders, and supporters.

AL: While you're not a "health provider," because you are so deeply rooted in the community and trusted by the residents of Belmont Cragin, you leveraged that to provide the education and remove the barriers for people to receive the vaccine. I'd love to hear examples of how you were able to focus on the needs of residents to get vaccinated.

JR: We realized early on that government and even large health institutions, or health systems may not be able to reach folks as hyper-locally as a community-based organization can. So, firstly, we went door to door. We realized a lot of folks weren't necessarily receiving the message—particularly those who are monolingual Spanish speakers. And, if they were receiving the message, sometimes it wasn't always the accurate message, particularly from their social networks, family, friends.

Initially, we went door to door with a simple flyer that had the 10 myths of COVID-19. This is back in early 2020. From there, that evolved to why to get tested, what does testing do, mask usage and wearing (that's when we passed out sanitizer and masks to folks), and then most recently, the vaccine.

Through the Chicagoland Vaccine Partnership, we were able to provide bilingual health educators and doctors who have come to train our team and talk to the community in their language and answer questions. We've done several customized workshops for youth, parents, and older adults, thinking through what their common concerns and questions may be and answering them in a safe space that centers around spaces that already exist. Whether that's a school group, our older adult community center, our afterschool youth programs, meeting folks where they're at has been really successful. I think our outreach team has been innovative in going to grocery stores and laundromats.

We run our vaccine clinic weekly, still to this day, at the Bricktown Square Mall, which is an outdoor shopping center. We realized that there's so much foot traffic there, through grocery stores and gyms.

That's the place where people in our community are. We've seen upwards of 300 people a day still in January, February of 2022.

In addition to that, we've seen that consistency is important. It's something that we've always shared back. Pop-ups, one-off events, traveling doesn't work. People spread information via word of mouth. So, when we're in the same place, same time, same location every week for over a year, people spread that to their neighbors, their friends, their family, their colleagues, their coworkers. The information just gets out. And it's easier for us because we have one simple flyer that just says every Saturday, 10 to 3 p.m. We're able to use that material and let it spread throughout the community.

We've realized during this time that word of mouth is how these informal networks share things in our community. And lastly, what I'll say is really important is that folks see people who look like them and speak their language.

We strive to make sure that we have bilingual providers. We have bilingual vaccinators. We have bilingual registration folks and folks that are bicultural. We want folks to see people like them getting the vaccine, helping them get the vaccine, talking about the vaccine, so that folks know it's safe and that it's effective. I think there's a lot of counter-messaging to that. We're working hard to make sure that message comes through and breaks through all the other noise that can reach our community. And I think our vaccination numbers show that it's working.

AL: Karen, could you talk about Access Living and share some of the work you've been doing?

KT: First, as you know, the disability community is broad. It's very diverse, it's intersectional, and it requires a multi-layered multifaceted approach.

A lot of the work we've been doing over the last two years has come from the direct services approach and a policy approach. The disability community experienced a lot of anxiety as a result of COVID, a lot of trauma. Our community is one that has been at greater risk of contracting COVID, having more severe symptoms and death. Early in the pandemic, we were closely tracking the numbers of those that were dying or had some form of underlying health condition that would meet the definition of a disability as defined by the ADA and ensuring that the work we're doing is protecting the health, the safety, and the rights of our community.

A lot of our community lives in settings where they rely on close contact with a personal assistant or caregiver. They may live in a congregate living environment, like a group home or even in a nursing home, where COVID was widespread, particularly in the earlier days of the pandemic, all of which have put disabled people at greater risk.

There are also a lot of disability-related barriers, accessibility barriers, that we've seen that we've needed to address from multiple angles to ensure that our community is safe, has received PPE, has equal access to vaccines.

One of the things we did early on was establish a comprehensive COVID relief resources page on our website, covering everything from housing resources for basic human needs to any type of information we felt our community was needing during this pandemic. We were also able to get thousands of dollars in relief funds into the hands of people with disabilities who were impacted by COVID and the pandemic, such as ensuring that PPE was available for personal assistance and caregivers. On the policy front, too, it was important that Access Living had a role in ensuring that we had protection. We worked on two policies with the State of Illinois. One was strengthening the State's guidance on non-discrimination and bias in crisis standards of care. Throughout the pandemic, we saw many instances where our hospital systems were getting overwhelmed. Hospitals, ICU beds, and ventilators were running low, and those are situations where hospitals have to make decisions about who gets treated, what kind of treatment, and who may not. It was absolutely critical that we worked to ensure there was guidance to all hospitals and medical facilities that aimed to eliminate stereotypes and bias in the treatment of people with disabilities.

We also worked closely with the State on guidance providing exceptions to hospital visitor policies because many disabled people who were going in for treatment needed a personal assistant or a sign language interpreter, a family member, to support them while they were in the hospital.

Hospital visitor policy and those restrictions on visitors during the pandemic were preventing a lot of disabled people from getting the access they needed.

It also got us as an organization to think about and strategically plan for those disparities that were amplified as a result of the pandemic. We rebooted our strategic plan to address everything we were seeing, the digital divide that was affecting our community. And we're looking at addressing poverty and wealth building in the disability community, mental health, and greater access to health care because we know there are so many barriers our community still faces in getting equal access to healthcare.

Lastly, I would say it is important for us to be playing a role in thinking about those that are becoming disabled as a result of long COVID. We are seeing many people have long-term, permanent disabilities as a result of COVID. So much so that on July 26, on the ADA anniversary, President Biden talked about those with long COVID with permanent disabilities meeting the definition of the Americans with Disabilities Act and therefore being protected by various disability laws and able to benefit from services and support programs.

AL: Lee, given your work with media, talk a bit about the disinformation that's spreading about COVID-19 and the vaccine and how your strategy is to promote trusted messengers. Who are those messengers, and what are some of these hyperlocal campaigns?

LE: Our reporters and editors for the Real Chi are emerging journalists from the greater Chicagoland area. Also, some of them are from university institutions outside of Chicago. Our major campaign right now is making sure everyone is trained and understands misinformation versus disinformation information and how to combat these sorts of elements as they present themselves, both in the professional setting as reporters and journalists and in interpersonal situations with family and friends. One of the things that stands out about COVID, as well as any number of stories or issues that may arise, is that when it comes to combating them, it's a simple thing as 'Well, my mom saw this information there, or I heard this at some point.' Without proper channels, particularly hyperlocal channels to combat that, those sorts of ideas spread, and that's how misinformation, at least in part, can continue and thrive in different communities throughout the city and across the nation.

It's important to make sure that reporters are not just reporting information in terms of the masses but also feeling comfortable and equipped with the tools to challenge misinformation even in their own direct friend groups.

AL: When I think about the specific populations you work with, your key stakeholders, how have you seen them lead the work of being a trusted messenger to combat some of the disinformation you're seeing?

LE: We primarily work with the greater West Side of Chicago. We are housed right now in the North Lawndale community as we have been for a number of years. The ways in which the community has addressed that is trusting the local officials, like Ald. Michael Scott, Jr., of the 24th ward, as well as other community organizations like the North Lawndale Community Coordinating Council and other similar groups beyond North Lawndale, whether that be in East or West Garfield park, the Little Village community, or Austin, to take ownership of this communication, take ownership of this information through their own channels, through churches, community groups, community stakeholders, to let people know what the situation is with COVID, with testing, and all those related details and to make sure that whatever choice they are making, they are making with the full information that is available at the time.

KT: I think the trusted messenger piece is critical. What was talked about earlier with this local response to both the pandemic and vaccines, that's been an important role we've played.

Because we are a trusted organization in the disability community, and we put out information in an accessible manner so that any information we put out digitally is going to be accessible. We're thinking about information that includes captioning and sign language interpreters. We've also been a source early in the vaccine rollout to help people with disabilities access appointments. We were able to book over 200

people with disabilities in just 48 hours for vaccine appointments. Many people were coming to us because they were having trouble figuring it out. They may have had a cognitive or intellectual disability. The digital divide was a barrier for many, and transportation getting to vaccine sites. When you talk about having that trusted community member, messenger, and organization that truly knows the barriers the community faces, that's a critical point in making sure we're doing everything we can to protect the health of our own communities throughout the city.

AL: Jackie, do you want to say anything about what you're seeing with regards to the need for research and evaluation? You've been doing this for a long time. Have you seen a hunger that has grown?

JJ: We have. I think the partners we have in Chicago are eager for the data.

A lot of them understand the value like those on the call today and are using the data to drive action, to change strategy, and the data is getting better. If folks remember the beginning of the pandemic, we knew case rates. Was it reliable? Was it not? I think there are still some challenges with home testing, that a lot of the positives from home tests are not being reported to the health department, so the health department only knows what they know. When it comes to vaccinations, case rates, and how people are accessing vaccines, it is getting a lot better. Transparency is really important, making sure the information gets back to community organizations, residents, and we're learning from it.

AL: I'd love to hear what you think is the biggest opportunity, what things we cannot afford not to do, or what we must do. I'd also be curious to hear what continues to give you hope.

LE: I think one of the things that we should continue to do is remain hopeful. It's important to recognize that though the statistics may not always bear it out, there are people every day who are learning more about COVID, making sure their friends and family are up to date with information, and making the decision to be vaccinated. Or if not, consistently test and care not only about themselves but about others.

I think that's a key element that Karen spoke to as well as others. Just because you are unconcerned about the vaccine or COVID or other elements that other people may be encountering, it's important to care about other people as well. Their wellbeing and the wellbeing of your community are paramount. Everyone can lend a hand and make it safer for everybody.

AL: Jackie has been conducting pulse surveys with many community organizations. One of the things I hear again and again is the importance of trust and recognizing that what we are seeing now with COVID and some of the disparities is because there has been a lot of distrust. The way we're going to close those disparities is to leverage those trusted relationships. James and Karen, Jackie, do you have anything to add there?

JR: For me, a lot of our work has centered on continued advocacy to ensure we don't lose the support we've seen over the pandemic. One of our fears, but also our hopes, is that we are operating in a new way than we have before. The philanthropic community, the city government, and the state government have changed some of their requirements and how they give resources out to communities.

We're trying to preserve that and preserve this moment to really focus on equity, and particularly racial equity, in all that we do in a different and new way. I think the universal basic income work we're doing and the financial assistance work we're hoping are here to stay. Just being able to give people resources in a way that in our 18-year history we never did. And continuing to vaccinate folks. We're seeing that our vaccine clinics are increasing in terms of who's going to them. We're pushing the city, the state, and our healthcare providers to continue to provide that level of vaccination support into 2022, even as COVID continues to change around us.

What makes me hopeful is now, a year later, seeing folks that we vaccinated in February of 2021 coming back for their booster in February of 2022 and seeing the same families in our clinic. That continued care and service shows we formed relationships that are long-lasting and that work and that we're here to stay to support our community.

KT: For me, this pandemic has allowed us to bring our mission into sharper focus, to learn from everything this pandemic has taught us. Take these disparities that we have seen every single day in our work and use them as an opportunity to recommit ourselves and make the world better for our community.

For me, that's what this is about, and I am really hopeful. There's been a lot to show that we have reason to be hopeful because of what this pandemic has taught us and the things that we can accomplish to reverse longstanding barriers that have prevented equity in each of our communities.

That's what I feel is the silver lining and the thing that's driving me every day to do this work.

JJ: I'll just say, as the data person here, I think that while data can be burdensome if done well and meaningfully, it can teach us a lot, and we can make it actionable.

Anna, you mentioned this at the beginning. It's so important to get both qualitative and quantitative data. So, the numbers as well as the stories, and that's how we're going to see action. What gives me hope is seeing the data play out and seeing the change.

We know that a lot of people, both vaccinated and unvaccinated, trust their doctors and providers, and that helps us strategize. It helps us encourage people to talk to those that they trust. And then I also love hearing the stories. The organizations that have shared with us about the one patient that they talk to and talk to, and that person changed their mind, and they became comfortable getting vaccinated. Hearing

about those stories and triangulating them with some of the quantitative data gives me hope because I am seeing the change happen. All the important work that James, Karen Lee, and their teams are doing, it's working, it's playing out. So that's exciting to me.

AL: I think it's so appropriate that as we think about a public health crisis like COVID, which has been generations in the making, not just the virus but the impacts we're seeing, that recovery is an economic one. It makes a lot of sense to me because we are all using this opportunity to think about what does justice look like? If we were to realize more justice and get to the other side of COVID, we have to dismantle and disrupt that. I'm so grateful to all of you for being positive disruptors and making sure you're asking all of the right, hard questions. It gives me so much hope.

Thank you for all that you do for the community. I truly do believe that all of you are adding to the resilience of our incredible city. And with that, thanks so much for being with us today.