



**Trust and Health Equity**  
**A conversation between African American Religious Leaders and Health Care Leaders**

**Background**

Over the past four years, the Centers for Disease Control and Prevention has partnered with the Interfaith Health Program at Emory University to provide grant support for 10 faith-based projects to prevent flu disparities by partnering with faith-based entities as trusted agents to deliver flu vaccine and prevention information. Chicago has been one of the 10 sites participating. The Center for Faith and Community Health Transformation has led the Chicago initiatives, along with the Chicago Area Immunization Campaign, the health departments for Chicago and Cook, Lake, and DuPage Counties, the Illinois Department of Public Health, the American Respiratory Association, and Walgreens. Our projects have included setting up flu clinics in congregations, building our own knowledge about faith-based resources for refugees and vulnerable immigrants, creating faith-rooted educational materials, and linking congregations with Walgreens-staffed clinics.

Our partner group decided this year to focus on addressing the vaccination rate for African Americans in metropolitan Chicago. African Americans consistently have the lowest rates of immunization and disparities in flu incidence. Trust seems to be a core issue in whether or not people access vaccination resources and we wondered if there was an important conversation to be had about trust, not only as it relates to disparities in flu incidence, but as it connects to other health resources, as well. African Americans are less likely to avail themselves of health resources that are available, such as clinical trials, mammograms, HIV testing. While this does not account for the presence of health disparities, it is one factor in higher mortality and morbidity in the population. All of these things form barriers that have significant implications for the health of African Americans.

This project created a space for what we hoped would be a deep and spirited conversation among African American religious and health care leaders about trust and how it affects how and whether African Americans interact with the health care system. This is a complex conversation. We know that much of what shapes our health is socially determined. Our economic status, the amount of power and control in our day to day lives, the cohesion and stability of our communities, etc. are all at the root of our health status. For African Americans, the chronic stress of racism and real issues around access, quality of care, and a history of abuse by government and health care (e.g. Tuskegee) play a critical factor in creating serious and seemingly intractable health disparities and in whether or not African Americans receive the health services they need.

In the search for solutions, one of the strategies government, academic and health care organizations turn to is the idea of the “trusted messenger” to bring health information into communities where there



are barriers to receiving care. Pastors and religious leaders are one of these trusted messengers. We prepare sermon points, ask pastors to get their flu shot on a Sunday morning, prepare bulletin inserts, and set up clinics for screenings and education in church buildings. But what does it mean to be a “trusted messenger” and is this the best possible partnership between faith communities and organizations promoting health?

Is there more that we might learn about how to address the real experiences underneath the barriers if we paused and spent time sitting with the issues in a prayerful, conscious, open way? Are there more effective ways in which these critical barriers might be addressed by both the health care system and the African American community? How might pastors and faith leaders be a resource in that process? How might the faith community shape what it means to be a “trusted messenger” on its own terms? This project brought together African American clergy, religious leaders, and health leaders to prayerfully consider the deeper dimensions of these trust issues and to explore how these issues can be addressed creatively and proactively to ensure the well-being of the community.

### **Method**

We held a meeting of 15 distinguished faith and health care leaders from the metropolitan Chicago area to address this question. Many of those in attendance wore both faith and health hats—a researcher who leads the health ministry at his church, a pastor who leads in HIV/AIDS prevention, a public health director who is a leader in her congregation, a physician who leads in his church, etc. The meeting was professionally facilitated by Rev. Penny Willis (see attached bio). The process raised key questions and used small group discussion circles to explore the questions. The proceedings were recorded and we also took detailed notes of the conversation. We also engaged a group of approximately 20 Apostolic pastors in a conversation on similar questions. We were invited to conduct this dialogue as an agenda item on their standing monthly meeting. Information from this meeting was recorded through note taking. Finally, we conducted an in-depth interview with the director of the Evanston Health Department regarding experiences and research conducted during the H1N1 outbreak.

Participants discussed trust issues and formulated recommendations to present to the Centers for Disease Control and Prevention and other federal partners when the 10 funded sites gather to share the outcomes of their projects. In addition, their recommendations will also be shared with the Chicago organizational partners and will inform on-going faith-based outreach on flu and other health issues. Outcomes from the meeting will inform the future development of programs and approaches of The Center and our partners. This gathering also provided a venue for relationship building among faith and health care leaders, which may continue to bear fruit in the future.

### **Key Themes**

Following are the central themes that emerged across all of the conversations. There was a remarkable synergy in the responses and opinions of participants. Without prompting or knowing what the other group had talked about, they reached many of the same conclusions. Direct quotes from the conversations are indented within the narrative below. Specific recommendations for action are noted in a separate document.

#### ***Relationship building is the most important thing a provider or government can invest in.***

In both sessions relationship building emerged as a foundational element for trust. That treating people well—courtesy, respect, kindness—creates trust seems like a basic learning, but it is a lesson that is not being lived out in many encounters between providers (health care, public health, government) and communities.

*Brusque or impolite treatment creates distrust. If I don't feel honored, I won't engage in that relationship.*

Participants see this kind of insensitive relating at both the individual and systemic level—doctors with individual patients, and large organizations, public health or government with whole communities or with congregations. Time is a critical piece of this. The investment of time, being there for the long haul, continuing to show up and participate in what is important to the community goes a long way in creating trust.

*Relationships are a critical vehicle for trust. So much of our medical care is time constrained and rushed. TIME is a core value here. You have to commit to developing relationships over time.*

*Relationships take TIME. We need to foster a culture that acknowledges the time it takes to create and sustain relationships.*

Respectful treatment and showing commitment over time are so critical that they can outweigh the importance of whether or not the provider or organization is of the same ethnicity as the person or community. A study by one of the conversation participants showed that...

*for African Americans, if the doctor "looks like me" was not critical. For African Americans, the critical piece was "I'm not trusting you until you give me a reason to trust." You can't be a product coming into the community trying to sell something. You have to show your commitment and concern.*

The same principles apply to relationships with faith communities, many of which feel used by "partners" that gather information from congregations or fulfill grant requirements by bringing a program or information into the church, but that do not enter into a longer-term relationship.

*In relation to the question of the connection between church and government...It's a partnership—not a hierarchy but it's a linear partnership with mutual accountability to one another.*

*Approach the church before you need the church. BUILD A RELATIONSHIP. If already have a relationship, it's easier to talk about epidemics, pandemics when they happen. Eg. H1N1—if relationship already exists, easier to go and say "this is something important and urgent" and get buy in and get information out.*

***The onus is on providers and government to cultivate the relationship and accommodate the community, rather than the other way around.***

Again, both groups emphasized that the responsibility for setting the tone and cultivating the relationship is on the provider, organization or governmental body. This includes things like making sure the language used is appropriate for that community, ensuring the cultural competency of staff, investing in the development of leaders from within the community

*Health literacy should not just be people in the community learning medical language. Providers should learn the language of the community and create materials and resources in that language.*

*Identify and align agendas. Public health should follow the agenda of the community or church.*

*Translate the findings of the efforts into a format that congregations can understand and use. Come back to the congregation to provide follow up on the findings. Be honest. If the intervention didn't work, say that and continue to explore opportunities.*

*The CDC should allocate resources to train African American public health workers. When Dr. Satcher apologized for Tuskegee, there was money given to start an Institute focusing on health and ethics, but Tuskegee does not have a school of public health. Provide funding for historical black colleges to fund schools of public health.*

*Cultural competency of medical staff will also help. Health care providers may not come from the community or look like the people they treat, so need more training on competency for health care providers. Greater insight about the community providers are serving may help diminish treatment bias. In a 10 minute appointment, preconceived ideas can quickly kick in and the provider may treat the person relative to what they already perceive about the person, not what is really true about the person.*

*Increase the number of health care providers. Obamacare is great, but it doesn't really help if you don't have enough doctors to serve all the people who need care. We have 444 patients per doctor in this country. So doctors only have about 10 minutes to see patients. So we need more medical schools, especially that recruit people that look like our communities. Increase the capacity of providers, like nurses, who often have strong relationships with patients.*

Public health leaders need to be more integrated into the community. It can be difficult for public health to build relationships because so much of the work is behind the scenes and because they tend to work in the 9-5 realm, which can be a conflict when trying to bring messaging into faith communities on evenings and weekends.

*The public health and medical systems have different issues around trust. Public health doesn't have the on-going relationship with people like medical providers do. Good public health work is behind the scenes keeping people healthy and protected in ways that they cannot see, so there is little awareness of the public health system.*

There was also a sense that programs from the federal government need to be more in touch with the realities of local communities and the organizations and faith-based communities serving those communities.

*The CDC needs to come out of their separate silos. They to give their policies to local people to execute them, but that doesn't work well. They need to come into the community to be more available. This points to the disconnect between the public health field and the community.*

*Does the CDC have a community and/or faith advisory board that guides them when they are creating the programs they are trying to implement in the community? Some of the things they ask for are unrealistic. So CDC, HRSA—all big granting agencies should have community advisory boards*

***The most pressing issue is not trust, but poverty and social stress.***

In both conversations, this issue came up immediately. Distrust exists and is an issue, but the main reason why people don't get immunized or get screened or seek preventive care is because they are busy trying to meet the basic needs of their families for food, shelter and safety.

*For the poor, there are worse things happening than getting flu. Vaccination is a distraction. People have to worry about housing, food, safety.*

*People will get immunized if they get paid for it. Financial incentives work. Some worry about whether this approach is "coercion," but financial incentives need to take into consideration people's real economic needs. Stipends should take into consideration that people who work hourly may not get time off from work, people's travel and child care costs, etc.*

For the poor or for those with little social influence, there is power in being able to say yes and no, in making choices for oneself. Refusing the flu is a way to assert oneself in relation to authority. There is an interplay between personal choice and trust. Trust may be an underlying factor, but people still exercise their own decision-making capacity.

*Trust is a factor for both Interventions and Prevention. People are more likely to pursue and accept treatments when they are ill and need an intervention. But people are less likely to pursue and accept preventive treatments. So **both personal choice and trust are factors.** People make their own decisions even if trust is an issue for them.*

Poverty can also create a kind of inertia. Even when you give people information and access to services, when people are poor, uneducated, struggling with addiction, it is difficult for them to take steps on their own behalf.

*In the teachings of the Beatitudes and in the Catholic tradition there is the concept of the preferential option for the poor. If you feel so impoverished, whether that impoverishment is based on a spiritual deficit, based on material deficits, based on that you are not in relationship or communion with that faith community, you're never going to have the opportunity to develop trust because you feel that you are going to be cast out before you can even be in.*

***Culture and worldviews of distrust can have a powerful affect, but a variety of strategic trusted messengers may be helpful.***

Most often when we talk about distrust in health care in the African American community, we often point to the Tuskegee experiments, but this may not be as great a factor as we think in creating and supporting this world view, especially for younger people. People have heard about it but they may not even really understand what happened and what the consequences were.

In one participant's research to find out why people didn't receive cancer screenings, Tuskegee did not come up at all. The researcher had to prompt participants to get them to talk about it. When people did talk about it, they had inaccurate information about it. Stories are transmitted through an oral tradition, so the story gets told and interpreted differently. So while a lot of power is given to the Tuskegee example, it may not have the level of influence that we think.

Consistent with good relational practice, participants felt it was critical for health care and government to be honest about shortcomings and transparent about agendas so the community knows that the information they are getting is correct.

*Public health needs to acknowledge the past and not skirt around it. Acknowledge what was done and the consequences. Use a process like the truth and reconciliation process in South Africa as a model.*

*Translate the findings of the efforts into a format that congregations can understand and use. Come back to the congregation to provide follow up on the findings. Be honest. If the intervention didn't work, say that and continue to explore opportunities..*

Trust can be very much of a “gut” sense. For example, at a gut level we know we can trust our families or good friends. People may trust or not trust based on a feeling or a worldview, versus on empirical or objective reasons. In some worldviews there is a sense of suspicion around intentions and of the efficacy and legitimacy of what is offered by government or other agencies. Poverty can also create a fabric of distrust—a them versus us mentality.

*We need to make a distinction between race and culture. Race is socially constructed, so race isn't the core issue. Culture is what drives behavior, so when we are talking about barriers and trust in the African American community, we are really talking about culture.*

*Class affects how health providers perceive and treat people. It's not necessarily race. Race is integrated with gender, sexual orientation, class. One of the ways to build trust is to outreach. Building trust is necessary across all these areas.*

#### *An example*

During H1N1, in a suburb of Chicago, the health department set up mass clinics that were public and open to anyone. They also set up clinics in schools. **People of color** (not just African Americans, but also Latinos and Asians), **both poor and affluent, did not get immunized**. In a follow up study conducted by the health department to find out why people had or hadn't gotten the flu, they found that the same reasons that whites gave **for getting vaccinated** were the same reasons that people of color gave **for not getting vaccinated**.

The vaccine was made too fast

Whites—so we better hurry up and get it before it runs out

People of Color—so it's not safe

The vaccine was free

Whites—it's convenient and easy to get

People of Color—there must be something wrong with it

Trusted source of advice about the vaccine was influential in whether or not someone was vaccinated

Whites sought the opinion of their health care provider. When the provider encouraged them to get it and to go to the established clinics it created a sense of urgency—my provider doesn't have it and encouraged me to get it

People of Color—Family and friends encouraged them NOT to get the vaccine. There was even a report cited of a public health worker discouraging her own family and friends from getting the vaccine.

This case study seems to point to a cultural dynamic that is fundamentally distrustful of the dominant culture. With this grounding of distrust, it doesn't take many rumors or much misinformation to derail efforts to engage the community in immunization or other disease prevention/health promotion campaigns.

*We need to make a distinction between distrust and fear. It may be **fear** versus distrust—a desire to “not know.”*

*We may avoid going to the doctor because we’re afraid of what they may tell us. We’re afraid that we might be held accountable for the things we’ve been putting into our bodies and they way we’ve been living, so we avoid it—If I don’t know that something is wrong, then I won’t have to worry about it.*

We can combat fear with facts. Fear is built on inconsistencies in information. Fear is built on what people do not know about illness and treatments. If we give people facts about disease and illness, it will help them manage their fear. Trusted messengers are important for conveying facts, but it may not necessarily be the pastor or religious leader. Others in the congregation may be as important, if not more important, for getting out messages and information—e.g the usher who has a passion for the topic; Chair of Trustee Board; First Lady; Church clerk. Each church is unique and you need to find the key people that make things work in the church.

Other messengers are important, too, if they are perceived as a trusted individual. However, they need to be able to be diverse enough that they can speak to the target audience’s different world views. For example, one campaign, the celebrity spokesperson (Toni Braxton and Holly Robinson Peet—on autism), spoke to each person in the group differently:

- One heard the spokesperson as a mother
- One heard the person as a celebrity
- One heard the person as a youth/generational connector
- One heard the person as the wife of a sports figure.

*The message needs to be “sexy” and speak to a desired lifestyle. This is one of the biggest gaps that public health suffers from. We do cartoons and try to push that out to get people to change their behavior. For example, with tobacco cessation. We use little drawings and tobacco companies use the sexiest things in the world to tell people why they should smoke a cigarette. We need to start speaking to lifestyles. Marketing of other products shows that this works—tobacco, alcohol. Sexy sells.*

One example of an effective faith-based public health campaign is the Balm in Gilead model for HIV prevention. The campaign used:

- Positive messages in sermons. Even changing just a few words in a sermon can create behavioral change in the congregation—can shift the tone from negative and judging to positive
- Sex dialogue in the church—pushing the system to provide sex education
- Graphic images and stories to show the real impact
- Active listening—not there to “coach” or give opinions. Sat back and absorbed information from congregation
- Strategic approaches to engagement. They used age-specific, generational groupings to be able to have candid conversations about topics relevant to each group
- Asset mapping—identifying where the resources exist and helping people navigate the systems

*Early childhood education provides a great opportunity to provide services—immunizations, infant mortality. Start with messaging when people are young and repeat the messages over time. Repetition over time is key. Many faith communities house day care and preschool programs, and*

*even grammar and high schools. These can provide a good platform for early and on-going health education and messaging.*

Finally, there was a sizable sub-group among participants who refuse flu vaccine, not because of fear or mistrust, but as part of a larger wholistic health regimen. These participants tend not to put foreign substances into their bodies, preferring to promote health through a healthy diet, exercise, stress moderation, and spiritual practice. This also represents a cultural perspective, but participants felt this was a positive orientation.

In all of our flu prevention projects, The Center and CAIC have emphasized this very perspective in our educational materials. Our message has been—it is important to get immunized, but it is just as important to practice good health promotion behaviors. We believe that this is also an important message for “trusted messengers” to convey.

***Systemic distrust within the health care system must be addressed.***

Distrust exists not only between the community and health providers, but also across organizations:

- Between public health and health providers
- Between public health and faith leaders
- Between faith communities
- Within our own organizations and congregations

This can fundamentally impact the quality and coordination of services to the community. We have to address our own relationships and trust issues if we want to address trust as a core issue for the community.

*An example*

In one health department, during H1N1, health care providers were anxious because there was not enough vaccine. They wanted the health department to give them the vaccine because they thought they could be more effective than the health department in delivering it since the health department tends to be seen as a resource for the poor. While the health department did share vaccine with the providers, there was on-going challenge to the health department around availability of the vaccine and enforcement of standards for distribution.

***The relationship between faith communities and government/public health needs to be more nuanced.***

Participants in both groups shared a similar analysis of the potential for partnership between faith communities and organizational partners (health care, public health, government.) In an era when membership in religious organizations is declining, organizational partners cannot rely on congregations to deliver numbers. Instead, faith communities can be understood as organic webs of relationship in which each member is a portal to other networks and systems.

*As the church declines in numbers, especially among young people, is engaging with faith communities a smart outreach strategy? This is where outreach and engagement become important. For the church not to be defined by the four walls, but to go back to their original definition as a community pillar—in the community and not bound by their four walls.*

In addition, faith communities can do more than just deliver health promotion messages. They can also speak to the larger justice and root cause issues that impact people’s lives.



*But in terms of what it would look like in terms of messages from the faith community, we talked about the public health emphasis on the determinants of health—housing, poverty, education, lifestyle practices. I think the church could be good at incorporating messages like that—into sermons, bible study, church school or whatever they might have. They could almost sound like a public health message because it's very consistent. The reason why Jesus healed people...he was showing us a glimpse of the Beloved Community. In the Beloved Community there is no sickness, so that's what you're trying to get to in the church. You're trying to get to the Beloved Community. So you've got to deal with these issues.*

Finally, working with faith communities should no longer be seen as working with “them,” but people of faith should become more visible *where they are* as integral members of health and government organizations and systems.

*It is important that there is space and safety for people of faith to bring their voice into the public health and health care sphere. It is critical to have people of faith VISIBLE at the table, not just institutions. Church and government are not separate. We need to be more engaged with each other. In fact, there are many people of faith working within government/public health.*

*Faith is already at the table and has always been there. Faith integration happens because people of faith are there. We just don't recognize it. People of faith often have to leave their faith hat outside the door, so it doesn't get into the dialogue.”*

*Wherever I go, the church goes. My church doesn't have to go to Howard Brown, because they may not want to go there, but when I'm at Howard Brown, my church is at Howard Brown. When I'm at The Center on Halsted, there's a faith response at The Center on Halsted. And I think changing the definition of what the church is and how the church goes to where they go will be that solution for why the CDC needs to continue to give us funding because our arm and our reach is beyond the four walls.”*

*Embedded in the question (should faith communities act as trusted messengers on behalf of government?) is the concept of siloism. Is this the work of the church versus is this the work of the government? As faith based individuals or institutions, we are part of society, as is the government, so I don't think one should be mutually exclusive from the other. Just as we approach the health of the individual holistically—mind, body and soul—we need to take that same approach to community, looking at the holistic health of the community, which means that we need to be engaged in government and government needs to be informed by us. There's a duality and mutuality that needs to take place and not looking at it as this is the silo of faith and this is the silo of government.*

*Often there are people of faith in the room, but they don't have their faith hat on. While we are people of faith, we put that hat in our briefcase and be the public health person or the HIV activist. I think that's something we need to challenge people of faith to do. If we are people of faith everywhere we go, then that should be a part of the dialogue and we should be seen as that when we are coming to the table.*

### ***Honor what already exists.***

Faith communities (and communities in general) already have existing assets and capacities that should be recognized and credited. Congregations already have existing programs and structures that carry out the functions that public health calls for. Recognize and build on these strengths.

*In a lot of the black churches, when there's a death, you have a bereavement group that goes out and ministers to that family. CDC calls it public health nursing home visitation. There are groups that pray for people called intercessors...and CDC may call it community outreach workers, so I think I want to encourage CDC to come back to the basic foundation of what already exists. Maybe we need to go back to what we call it. We call it visiting the sick and shut in but CDC calls it home visitation. So if we go back to the foundation of what already exists, then maybe faith will be respected in a different kind of way.*

Give credence and credit to what churches are already doing and have done for centuries.

*Ideas generated in the community are often taken by academics or government and shaped into a program or initiative without the original community idea ever being acknowledged. Academic ideas get lifted up, but community ideas are not considered valid.*

### **Summary**

This project pulled together faith and health leaders to talk about how trust and distrust may impact the care and quality of services received in a community and whether or not individuals make use of services that are available to them. Across the two groups there was remarkable alignment in analysis and recommendations:

- The importance of respectful relationships at all levels of intervention and engagement
- Root causes of poverty and social stress are more important to deal with than trust
- Providers and government need to bend and accommodate the community's culture and needs
- Culture and worldview are powerful, so the need for strategic, effective message carriers is critical
- Systemic distrust across the health care system must be addressed.
- The relationship between faith communities and government/public health needs to be more nuanced.
- Honor what already exists.

We are so grateful for the time, passion and input of this extraordinary group of leaders. This was a rich and productive conversation and we look forward to what will come from it on behalf of those who are most vulnerable in our communities.

The Center for Faith and Community Health Partnerships is a joint initiative of Advocate Health Care and the Office for Community Engagement and Neighborhood Health Partnerships at the University of Illinois of Chicago. The Center advances health equity by building community, nurturing leaders and connecting with the unique spirit power of faith communities to promote social justice and abundant life for families, neighborhoods and communities.