



# **Advancing Health Equity Science, Practice & Outcomes**

# A Culture of Health Program Listening Workshop: Community Perspectives

# Stakeholder Webinar Series #3 Key Takeaways

On December 8-10, the National Academy of Medicine (NAM), in partnership with the Robert Wood Johnson Foundation (RWJF), hosted a public meeting to discuss barriers, models, and opportunities to using community knowledge and strength to drive health equity policy and research. The objectives of the meeting were to:

- Examine and understand the current landscape for community-driven efforts to advance health equity, especially in communities most affected by inequity (Black/African American, Latinx, and Indigenous populations), and center the voices of the young people in those communities
- Identify and discuss the barriers and gaps experienced by communities and organizations supporting communities working to advance health equity
- Examine promising models of community-driven efforts to change or enact policy that advances health equity, and identify strategies to address root causes of inequity that can inform the work of other communities
- Identify the priorities for community-driven efforts to advance health equity, and opportunities to use community knowledge, strengths, and resiliency to inform the way forward, especially in a world affected by COVID-19 and increased calls for racial equity

In advance of the meeting, the program asked public participants:

"What ground rules or principles are useful in your community to support open and honest conversations?" Based on the more than 300 responses submitted, NAM staff compiled the following 10 principles to guide the meeting's discussions. <u>*Click to view all public participants' responses.*</u>

- 1. Respect and honor all voices, embracing diversity and all worldviews.
- 2. Listen without interruption and participate actively.
- 3. If you're someone who tends to speak a lot, consider leaning back. If you're someone who tends to be quiet, consider leaning forward.
- 4. Be open to hearing about perspectives and experiences that differ from your own or that challenge you.
- 5. Entering the community valuing unknowing and with the recognition that we are all here to learn and grow.
- 6. Acknowledge when a comment is difficult to share and take the risk.
- 7. Give space for thought.
- 8. Speak from your own perspective instead of speaking for others. You are an expert of your own lived experiences.
- 9. Offer advice only when it is welcome or asked for.
- 10. Assume best intent, but own your impact.

Below are key takeaways from the meeting.

# **Day 1: The History and Persistence of Inequities**

### Audience Poll: What makes you proud of your community?

In opening remarks, meeting participants were asked: "What makes you proud of your community?" Responses are below.

Resilience	Dedication to education		The community members
Love	Neighbors helping neighbors		A growing desire to do practical things to address inequity
Resources	Active in many health related initiatives		
Family			The response to support one another
Cohesiveness	Civic work on behalf of community sense of belonging		
Beautiful Parks			Determination
Accepting	Collaboration		Perseverance
Commitment	Culture	Diversity	Diversity of thought
Passion	Bold	Unity	Caring for each other

### She's Hungry: Resiliency and Grit



Melody Phillips, Director of Operations, The Warehouse

Ms. Phillips shared her personal story growing up in the under resourced area of Riverside in Wilmington, Delaware. Many Riverside residents experienced poorer quality health care compared to white communities and drug addiction was a significant problem, factors which negatively impacted Ms. Phillips' mental health

and education. Ms. Phillips shared how the influence of a mentor helped her develop resilience and a strong desire to not only succeed, but to serve her community and mentor other youth to bring about change in their own communities. <u>Click to</u> <u>watch the recording</u>.

"My experience being mentored allowed me to mentor other [young women] coming after me to show them that they don't have to be a product of their environment or the circumstances they grew up in."

# Why Do Inequities Persist in Communities?

Speakers examined the historical and current landscape affecting their work to advance health equity. *Click to watch the recording.* 

Lautaro Diaz, Vice President, Housing & Financial Empowerment, UnidosUS

Mr. Diaz examined several historical markers of inequitable treatment toward Latino populations, especially related to migration, and identified underlying causes that continue to perpetuate the inequities seen in the United States today.

- Exclusionary government policies in sectors from housing to transportation to financial services, only some of which are explicitly based in race and ethnicity, help create and sustain unstable economic foundations for communities of color.
  - For example, the Social Security Act of 1935 provided a nationwide system of income support, but excluded coverage for agriculture and domestic workers, a large percentage of whom were Latino and Black.
- Research and advocacy around the barriers Latino populations face must be done in partnership with the community and address upstream factors across the social determinants of health.



**Stephanie Russo Carroll,** Assistant Professor of Public Health and Associate Director for Native Nations Institute at the University of Arizona

Dr. Carroll presented on the critical importance of Indigenous peoples' sovereignty in data and research about them, as well as structural barriers to sovereignty rooted in racism and colonialism.

- Indigenous peoples have always been creators, users, and stewards of data, and data sovereignty is the right of self-governance from funding to data collection and storage to use and reuse.
- The ongoing colonization to enforce Western ideas, values, and lifestyles in Indigenous communities have led to epistemicide the suppression and destruction of Indigenous knowledge and data systems and forced many tribes to rely on external sources of information about their communities.
- Tribally-driven data rebuilding requires relationships with other data actors for both stewardship and expertise, led by multiple ways of knowing, Indigenous ingenuity and core values, and promotion of Indigenous scholarship.

"The revitalization of Indigenous knowledge is in the application of Indigenous design to data and research, and is central to Indigenous peoples' capacity to realize their human rights. ... For Indigenous people, shifting discussions from equity to sovereignty reorients conceptions of well-being and community health from deficit and disparity to rights and responsibilities."

Rufus Williams, Former President and CEO, BBF Family Services

Mr. Williams explored barriers to the culture change needed to advance health and racial equity and the deep history that perpetuates structural racism and its effects.

- Inequities are perpetuated by interrelated historical and institutional influences resulting from structural racism, including:
  - Distrust in the health care system stemming from abuses of communities of color





- o A history of disinvestment in the built environment of communities of color
- Lack of access to medical care and health insurance, particularly through an employer
- Unequal educational outcomes
- Persistent and deep-seated stress of surviving poverty
- The pervasive nature of structural racism requires actors across the social determinants of health to interrogate and challenge the policies and norms within systems that perpetuate inequity.

**Youth Response Panel** 

Melody Phillips, Director of Operations at The Warehouse, facilitated a panel with young people committed to serving their communities to explore their perspectives on the persistence of inequity. The below responses have been lightly edited and condensed. <u>*Click to watch the recording.*</u>

#### Aaron Lewis, Teen Employee, The Warehouse

Q: What are barriers to advancing health equity in your community?

A: One challenge being presented by COVID is the need to speak up and protest for racial equity while trying to remain socially distant. Black and brown people, and especially young people, are testing positive at higher rates and continuing to challenge the nation to understand its biases that have led to these disparities.

#### Shavaughna Underwood, Center for Native American

Youth's Champions for Change

Q: How can minority youth shape the discussion of health disparities?

"The intergenerational trauma experienced by Indigenous communities is something that Western medicine cannot heal."

A: We are leading with a powerful and uplifting message that we are not our trauma. We are healing. We are medicine. We

are valuable knowledge. Our traditional healing doesn't have to be validated by the white man – it is valid, and we should be able to bill for traditional healing and alternative coping mechanisms. We are leading by saying we don't need the United States' permission to heal.

#### Andrea Vega, Campaigns Fellow, Voto Latino

*Q: Why have health inequities persisted, though there have been efforts to eliminate them?* A: Not enough attention is being given from the vast majority of elected officials, whether on the state or local level. The region I live in is predominantly Latino and working class. When the COVID lockdown orders first came up in March, community leaders came together to push for a freeze on things like mortgages and rent. But the people who are supposed to protect our best interests, people that we put into power and even campaigned for, just aren't doing that follow through. The community has created solutions, whether rent relief programs or food banks – so we already know what the issues are, we know what we need to help us, we just need those with more power and access to resources to really listen and engage in what we are doing.

"For the first time, much of the rest of America seems to be accepting a permanent underclass as a fact of life."

# **Takeaways and Facilitated Audience Q&A**

Cherie Collins Sims, Chief Strategy and Innovation Officer, Prosperity Now

Dr. Collins Sims provided high-level takeaways from the day's presentations and remarks:

- The nation is at a pivotal moment to address many root causes of inequities, which requires new thinking that includes all social institutions and does not continue to simply mitigate or even perpetuate structural barriers.
- Effective action must be founded in meaningful partnership between networks of power and resources many of which historically helped to create existing barriers and are therefore often distrusted by communities and communities showing resiliency and innovation to address inequities. Solutions should be developed with communities, building on how they are talking about and solving for inequities.
- Partnerships are built by listening to the voices of those who are impacted by inequities, shifting the narrative to center lived experience, and making the places where decisions are made accessible and welcoming to different perspectives and ways of knowing.

Dr. Collins Sims facilitated speakers' responses to select questions from the audience. Below are highlights from the conversation. <u>*Click to watch the recording.*</u>

*Q*: What are the state-level accountability mechanisms to ensure that elected officials support anti-racist policies and that policies are in place, funded, and implemented effectively?

**Ms. Vega** encouraged communities to contact their local or state officials whose legislation and votes on bills contradict their campaign platforms. **Mr. Williams** emphasized that politicians who do not serve the needs of communities can be voted out and urged communities to be clear on their expectations and use the power of their vote.

*Q*: What are the implications of Indigenous data sovereignty for other communities, especially other marginalized and minority communities?



**Dr. Russo Carroll** reflected on the application of the principles for Indigenous sovereignty to all communities through the creation of mechanisms that normalize respect of different rights of collectives, consultation with affected groups before and during research efforts, and community groups leading and driving research.



Carroll, SC, Garba, J, Figueroa-Rodríguez, OL, Holbrook, J, Lovett, R, Materechera, S, Parsons, M, Raseroka, K, Rodríguez-Lonebear, D, Rowe, R, Sara, R, Walker, JD, Anderson, J and Hudson, M. 2020. The CARE Principles for Indigenous Data Governance. Data Science Journal, 19: 43, pp. 1–12. DOI: https://doi.org/10.5334/dsi-2020-043

*Q*: How can adults and youth create shared leadership opportunities that bring forth bold solutions to health inequities, particularly in disadvantaged communities?

**Ms. Phillips** highlighted The Warehouse's "for teens, by teens" model of operation and leadership, where the youth work alongside the adults to influence the design, structure, and development of its programs. As more teens are active at the table and aware of their power, collective youth-adult partnerships are increasingly possible and effective.

# Day 2: Promising Models for Community-Driven Efforts to Advance Health Equity

### **Fireside Chat with the President**



Culture of Health Program Director Ivory Clarke hosted a conversation with National Academy of Medicine President Dr. Victor Dzau to discuss his priorities to advance health equity and the perspectives he brings to the work. <u>*Click to watch the recording.*</u>

"Lived experience is so important because you can't talk about theory without having actually experienced it and knowing what it's like and what needs to be done. NAM is the voice of medicine and science, the advisor to the nation, but how can we advise policymakers or the public if we don't understand what it is we're advising? ... We have to understand what it takes to make the right recommendation from the community and, importantly, work with them, and then be able to convince policymakers to make the right decision."

# **Promising Models: How Do We Define and Measure Success?**

Presenters shared promising models of community-driven efforts to change or enact policies that advance health equity. <u>*Click to watch the recording.*</u>

#### Model: Indians Into Medicine and Master of Public Health Programs, University of North Dakota



**Donald Warne,** Associate Dean of Diversity, Equity and Inclusion; Director of the Indians Into Medicine (INMED) and Master of Public Health Programs; Professor of Family and Community Medicine at the School of Medicine and Health Sciences, University of North Dakota

**Petra Harmon One Hawk**, Director of the Title VI: Nutrition for the Elderly/Caregiver Support, Standing Rock Sioux Tribe



Dr. Warne and Ms. Harmon One Hawk highlighted the need for intentional efforts to increase representation of American Indians and Alaska Natives (AI-AN) and INMED's approach to eliminating barriers perpetuating disparities in the physician workforce.

- AI-AN medical students disproportionately plan to work in underserved areas but are about 0.2-0.4% of the entire medical school population, resulting in a lack of health providers in tribal communities: one of the significant systemic barriers for Indigenous health.
- INMED was established to increase the pipeline of Al-AN medical students. The



program is led by AI-AN faculty and guided by a tribal advisory board, which also assist with recruitment in the community.

#### Model: The Warehouse



Anaya Patterson, Teen Executive Committee Board Chair, The Warehouse

**Sherry Dorsey Walker**, Delaware State Representative from District 3

Ms. Patterson and Representative Dorsey Walker reflected on the power of teen-led services to address community

priorities and create the cultural shift necessary to build a culture of health.

- The Warehouse is a "for teens, by teens" community center in Wilmington, Delaware. All programming is approved by at least one of the teen staff and falls under five pillars: Recreation, Education, Arts, Career, and Health.
- With the support of the full board, the Teen Executive Committee is responsible for responding to the needs of teen members and overseeing The Warehouse's budget. They also hold communitywide events, including a recent candidate forum with state and local officials which Representative Dorsey Walker noted helped inspire an upcoming initiative in the Delaware state legislature for same-day voter registration.
- The Warehouse supported Ms. Patterson to build confidence and realize her leadership skills, and she actively encourages teens to use their power to make a positive impact on their community.
- Representative Dorsey Walker remarked on how youth have a growing understanding of equity and what is needed to improve their communities. She emphasized bringing youth to the table in discussions on equity as future leaders and decision makers that will impact their communities.

#### **Model: Voto Latino Foundation**

Brianna Carmen, Director of Organizing and Partnerships, Voto Latino Foundation



Dulce Rojas, Campaign Coordinator, Voto Latino Foundation

Ms. Carmen and Ms. Rojas presented on Voto Latino Foundation's (VLF) efforts to encourage participation in the 2020 US Census among the Latino community, identifying barriers to engagement and metrics of success.





- The US Census determines the allocation of more than \$800 billion annually for the next decade, but barriers to engagement in Latino communities perpetuate the inequitable distribution of federal assistance.
- VLF's strategy to increase census engagement included on-the-ground organizing, partnership building from the local to national levels, and in-

#### **Overcoming Census Barriers**

- Unpacking the "Citizenship Question"
- 2016-2020 Administration of "fear"
- History of trauma and roots of oppression
- Using knowledge to organize

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- COVID 19 + Accessibility
- Power in Information and inviting to engage.
- "Speak to, not speak at".

person events to understand and mobilize around the needs of different communities, with an emphasis on peer engagement to build grassroots power that can overcome barriers like access to technology or culturally relevant and translated information.

• One of the biggest challenges in grassroots work, particularly in relationships with funders, is demonstrating community-defined success and impact with data. VLF aims to measure culture shift that increases civic engagement among Latino communities, balancing qualitative and quantitative data to provide information on impact that stays true to the community.

## Analysis: Strategies to Address the Root Causes of Inequity



**Wendy Ellis,** Assistant Professor in Global Health and the Director of the Center for Community Resilience, Milken Institute School of Public Health at George Washington University

Dr. Ellis reflected on the session's presentations and provided several high-level takeaways. *Click to watch the recording.* 

- Dr. Ellis encouraged the audience to consider the intentional and synergistic nature of systems and sectors that influence policies: the pathways to inequity, not just the outcomes.
- Eliminating health disparities requires looking beyond health care to address access to a diverse variety of services that support better social, physical, and economic well-being for all.

• Understanding how cycles of disparities are perpetuated by structural racism and other barriers is foundational for identifying measurements and

"How will we have different outcomes if we don't have the difficult conversations to understand the inequitable impact that these systems have – deliberately, intentionally, and almost predictably – based on the differences in race and income of the communities? This is why ... the community voice is so important."

definitions of success. Efforts to address inequity must build community trust and allow the lived experience of structural barriers to drive sustainable solutions and systems change.

# Day 3: Priorities for Advancing Community-Driven Change

# Audience Poll: How can researchers, policymakers, and community-oriented movements partner to advance health equity?

In opening remarks, meeting participants were asked: "How can researchers, policymakers, and community-oriented movements partner to advance health equity?" Responses are below.

Work directly with communities

Start talking each others' "language"

Listen, and respect community members' reality

Regular forums to connect and discuss

Community collaborative partnerships must be formed.

Save space at the table for community leaders Form a partnership with local and grassroots organizations including the youth, share lived experiences, present at local and state capital meetings to make changes legislatively

By identifying gaps in promoting equity and identifying and bringing in other stakeholders that can fill those gaps. I should have stated that prior to identifying gaps is assembling an entity to maximize efforts.

Transparent, broad range communication efforts.

Researchers, policymakers, and community-oriented movements may partner to advance health equity by collaborating on intervention campaigns from the points of discussion, literature research, notices of funding opportunities, process evaluation, implementation, post evaluation

Ask communities this question and start there.

Through interdisciplinary collaboration that empowers stakeholders and members of the community to be empowered participants in health equity.

Enlarge the table, ask thoughtful questions, and listen intentionally to what people say - especially those who often don't have a voice in decision making	BRIDGE DISCIPLINES. Focus on overlap, rather than difference or competition between disciplines.	Using community-based participatory research (CBPR) principles, form community action boards (CABs)	
Need to have genuine engagement and share goals and understanding	Create policies, tie these policies to money/grants/ rewards	Researchers and research funding organizations woul benefit from input from	
Start with self reflection, define goal, and allow people to bring their full selves to the work	Keep clarity on the final goal, and acknowledge/ credit/recognize FULLY the work of ALL groups -	communities with regard to what they need to know to trust / engage with researchers	
	otherwise will fall into usual silos	Identify common causes an work collaboratively	
Have a common foundational set of language with which to talk about equity.	Prioritize quarterly meetings that engage each stakeholder group at the decision making table	Building bridges to understand each other's perspectives and priorities	

Engagement, understanding, learning from the community	Use data to identify common opportunities	Practice humility and commit to authentic engagement across sectors.
Ground truth, quantitative and qualitative data with community evidence	Facilitate coalitions that include the community	These communities can partner by defining an ideal future state together and taking incremental steps to achieve it.
	Accept and respect the power of our differences up	
Through conversations around achieving the same goals within their community	front	
	Make the commitment to communicate and	Share information and action in language that all stakeholders can understand
Gather community member feedback before designing policies and projects	collaborate to find common goals. It needs to be identified as a priority in decision-making.	with a community impact goal in mind.
		Actively and intentionally implement trust-building activities and retreats
Identify community needs	Find common goals based on data/evidence	

# Shifting Power: Culturally Responsive Evaluation, Research and Policy for Advancing Health Equity



Tracy Hilliard, Director, MPHI Center for Culturally Responsive Engagement

**Tricia Miranda-Hartsuff**, Associate Professor of Public Health, Wayne State University

Drs. Hilliard and Miranda-Hartsuff presented on the importance of community partnership and agency in efforts to advance health equity, particularly through policy and research. <u>*Click to*</u>



watch the recording.

# Culturally Responsive and Racial EquityLens

# "Always place the people who are most impacted at the center of conversations which seek to find solutions to problems affecting them."



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Of the four levels in which racism operates (personal, interpersonal, institutional, and structural), structural racism takes the macro view of the cumulative and compounding effects of longstanding societal factors, including history, culture, ideology, and interactions of institutions and

policies that systematically privilege white people and disadvantage people of color and marginalized identities.

- Sustainability of efforts to address racial equity requires commitment and support at the institutions and structural level.
- Actively shifting power and resources to the community by developing the pipeline of scholars of color and increasing access of

# Culturally Responsive and Racial Equity Engagement Checklist

ldentify racial disparities.

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- Understand racial historical legacy.
- Examine institutional and inter-institutional aspects of structural racism.
- Assess **diversity** of team, service provider, and funder.
- Reflect on **cultural competence** of team.
- Ensure **community voices** are heard and valued.
- Reach out to **community leaders/agents**.



evidence-based strategies and services is critical to undoing processes informed by white dominant culture and sustaining the systems changes needed to advance racial equity.

# **Conversation Across Generations: Priorities for Advancing Community-Driven Change**

**Facilitator: Rebkha Atnafou,** Associate Director, Bunting Neighborhood Leadership Program, Johns Hopkins Urban Health Institute; Affiliated Faculty, Bloomberg American Health Initiative

#### Panelists:



**Monique Brown,** Program Manager, Healthy Neighborhoods Project



**Karina Lopez Zamora,** Student, Johns Hopkins University



**David Garcia**, Director of Quality Improvement & Research, Texas Department of State Health Services



**Rashad Staton,** Youth Engagement Specialist, Baltimore City Public Schools



**Benjamin Yawakie**, Project Coordinator and Intern, University of Minnesota

Panelists discussed the way forward for community-led efforts to advance health equity, including priorities for community engagement, opportunities to implement shared power models, and the importance of valuing the lived experience of community partners. Below are highlights from the conversation. <u>*Click to watch the recording.*</u>

Community engagement is about building trust and respect through relationships and letting
community priorities drive what resources are developed, how they want to engage, and what
outcomes are important. It requires building capacity to do equitable work, creating a space for
partnership, equipping community with the same capacity and professional development skills,
and valuing and compensating those sharing their lived experience to develop solutions.

- Many young people's health, social, and professional trajectories are heavily influenced by
  decisions they make during high school, but families and schools are not always equipped to
  support young people of color to pursue higher education. Community organizations and
  mentors can fill that role to provide needed personal and educational support to increase the
  higher education pipeline for people of color.
- Tribal public health structures have similar capacity as county and state public health departments to respond to COVID-19 and are exercising their sovereignty in innovative ways to protect their communities, despite the government failing to consult with tribal leaders when developing emergency declarations and continuing to contribute to and create barriers to Indigenous sovereignty.

# **Public Response**

In advance of the meeting, the program asked meeting participants if they would like to respond to one of the following questions:

- How can communities harness opportunities to advance health equity presented by COVID-19 and increased calls for racial equity?
- What are you still frustrated about in your work to advance health equity?
- What gives you hope in your work to advance health equity?

<u>Click to view all public response submissions</u>. A selection of public respondents shared remarks during the live public response session on December 10. <u>Click to watch the recording</u>.

# Thank you for your interest in community-driven solutions to advance health equity!

#### The program would like to thank the meeting planning committee:

- Stuart Butler, Senior Fellow, Brookings Institution
- Monique Brown, Program Manager, Healthy Neighborhoods Project
- **Petra Harmon One Hawk**, Director of the Title VI: Nutrition for the Elderly/Caregiver Support, Standing Rock Sioux Tribe
- Logan Herring, CEO, REACH Riverside
- **Tracy Hilliard,** Director, Michigan Public Health Institute's Center for Culturally Responsive Engagement
- **Velma McBride Murry**, University Professor of Peabody College and Vanderbilt University School of Medicine, Department of Health Policy
- Anaya Patterson, Teen Executive Committee Board Chair, The Warehouse

Building a culture of health requires the involvement of many stakeholders. To learn more about the NAM's Culture of Health Program, contact the program director **Ivory Clarke** (<u>iclarke@nas.edu</u>). You can also join our mailing list for program updates.