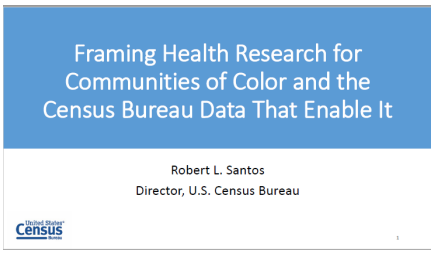
Illinois Minority Health Conference

Director's remarks as prepared for delivery

December 4, 2023

"Framing Health Research for Communities of Color and the Census Bureau Data That Enable It"



- Good morning, everyone. It's an honor to be here in my role as director of the U.S. Census Bureau.
- I really appreciate opportunities like this to speak to anyone who seeks a better understanding of health and health disparities among people of color.
- So…what I like to do is tell stories that I hope enable people to think a little differently about how we frame health research.
- And in the process, I'll then point to data resources we produce at the Census Bureau that can be used to spark new insights.

- Now, please indulge me a moment. I'd like to start by sharing a quick snippet from my childhood growing up in the barrios of San Antonio, Texas.
- It's a cuentito—a story—about a mouse, a pecan branch, and a little boy.
- I'll circle back to this story at my conclusion to tie it all together when I wrap up…OK?
- Well…as a child, when I was about 6 years old, my family lived in a wooden bungalow home, where even in fall, the house seemed cold because heat always seemed to pour out.
- That was pretty common back in the late 50s and early 60s.
- One cold night I was all warm and comfy in my bed, in a deep sleep lying on my back under the covers.
- And wouldn't you know it—we had mice in the house.
- They liked the inside warmth, too, what little remained, anyway.

- Well, that night one of those mice decided to check me out.
- It climbed the bedpost at my feet, proceeded to run alongside me on the bed moving towards my head.
- I awoke suddenly to the sound of the pitter-patter, in short spurts.
- I froze in place hoping it would reverse course.
- But instead, it ascended and ran clear across my chest, and then it head back down the other side.
- This was too much to bear for a kid.
- I shrieked loudly, flew out of bed and barreled to the other end of the house.
- And in the process, I scared the heck out of my brother who I shared a room with, and I awoke the entire family.
- It was quite a debacle.
- I was rattled…and I remained that way for days.
- I simply refused to go to bed at night, fearing a repeat performance.
- But a few days later, my *abuelita*—my grandmother—came to the house for a special visit.
- She arrived, looked me over, and proceeded to head outside to the backyard. She walked up to a pecan tree and broke off a small branch.
- She came back to me and had me lie on my bed with my eyes closed.
- I then felt the branch brushing across my body, and I heard the whispers of a prayer.
- She was administering what we in Mexican culture call the *asusto* blessing.
- And guess what? Afterwards, I actually felt better. I was cured.
- And no, she wasn't a *curandera*.
- She was just living the culture and traditions she learned where she was raised in Paras, Coahuila.
- She was bringing her whole self to the table, leveraging her culture, her values, and her life experience to help her family.
- And now I too, live the culture and traditions of what I learned growing up as a Mexican-American in San Antonio.
- My own life experiences, culture, and values have proved profoundly formative to who I am as a professional…as a leader…and as a human being.
- In fact, I draw upon them daily to help make me be a better researcher, a better scientist, and a better Census Bureau director.
- So that's my opening story.
- It lays the groundwork for the rest of my remarks today.
- I'll offer some lessons I've learned over a 40-plus year career that relate to health research for communities of color.
- I hope you find them useful.
- I'll start with a little more context.
- As a generic statistician, I've worked the vast landscape of policy research. And I've used an array of methodological approaches—both qualitative and quantitative.
- I've been fortunate to play in everyone's backyard.
- That includes health research, election exit polls, education, housing discrimination, employment, immigration, firefighter safety, travel behavior, justice policy, pollution, hunger—I could go on, but I won't.
- The same is true of research methods, but I won't list them.
- So, I haven't "seen it all," but I've seen plenty, all up close and personal.

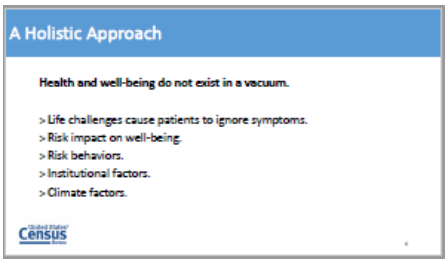
- I've come to the conclusion that our research training, and indeed our research enterprise, has two features of note.
- First, statisticians and researchers tend to emulate the thinking and the methods that have been taught to us.
- And why not? Such teachings are supposed to be best practice.
- Yet, sometimes…adherence to conventional approaches to research may become self-propagating and unnecessarily constraining.
- What is seldom taught is the creativity and critical thinking that can lead to new ways to view a problem…and new methods to collect and analyze data which then can lead to novel solutions.
- That's why I think it's critical to bring one's "whole self" to the table when doing research.
- I'll talk more about what that means in a moment.
- The other phenomenon I've seen is a bit is more obvious, but we don't always understand its importance to research design and methods.
- The policy research we conduct tends to be specialized, right?
- Cancer researchers study cancer. Education researchers study education. Labor economists study—yup—they study the labor market.
- For the most part, we tend to seek scientific knowledge from our substantive silos.
- And this can lead to siloed solutions.
- Are you homeless? Go to this shelter for a few days.
- Your family has nothing to eat? Visit this food pantry.
- You're not taking your meds the way they are prescribed? Here's some counseling on how to correct that.
- Make no mistake: These types of solutions are helpful—indeed necessary—for short-term relief.
- But short-term solutions often fail to address the underlying root cause of the symptoms being treated.
- Sustainable solutions can benefit from starting with a broader, more holistic perspective and framing.
- We need to take our siloed blinders off.
- We need the benefit of different perspectives that are informed by culture, values, and life experience.
- Otherwise, we risk solutions that treat symptoms rather that the root causes.

- This brings me to my next story, one that illustrates how we can use our culture and life experience to think differently about a research problem.
- Back in the late 1990s, I served on a health services research grant review committee where I was the only statistician as well as the sole person of color.
- We'd meet periodically to review and score grant application for funding. You know the setting.
- At these review sessions, everyone would be allocated a few grant applications for a primary review, but we were obliged to assess the whole lot.
- There was this one session I attended where a specific proposal not assigned to me happened to pique my interest.
- It featured a rigorous randomized control trial to test an inexpensive, alternative health care treatment specifically aimed at uninsured patients suffering from chronic pain.
- It involved the use of transcendental meditation to mitigate pain.
- The experimental treatment was novel because it avoided the standard, expensive pharmaceutical therapy.
- This was before passage of the Affordable Care Act, so the idea was to mitigate the cost burden of the health care industry while providing care to indigent patients.
- The solution was posed as win-win…reduce cost yet still provide care for the uninsured.
- The solution had an exceptional experimental design, randomizing uninsured patients to usual treatment or the alternative option.
- Everything about this grant application appeared to be academically and technically superb—the lit review, conceptual framework, the design and statistical analytic plan, etc.
- In fact, the proposal was well-received for its innovation and superb scientific, rigorous design.
- And everyone loved it…except for me, the sole person of color in a room full of decision-makers.
- With all these renowned health researchers sitting around the table ready to vote affirmatively, I—a generic statistician—dared to raise my hand and speak.
- I saw what no one else there saw.
- To me it was obvious.
- I expressed as sincerely as I could that this project should not be funded as proposed.
- You see, because of my lived experience growing up as a Mexican-American in a lower income barrio, I believed that no one deserved a lower quality of health care as a matter of protocol.
- I didn't want my *abuelita* or *tio* to be forced into a potentially lower standard of health care than the more privileged among us.
- I stated that if this study was approved as proposed, it would only serve to reinforce a two-tiered health care system.
- If you are insured, then step over to door number 1 and receive conventional, high-quality care.
- But—wait—if you are uninsured, then step over to door number 2 where you would be relegated to a cheaper, potentially less-effective alternative.
- I voiced this concern…and I strongly suggested that the proposal be declined.
- I suggested that the application be revised and resubmitted so that the alternative therapy was offered to all patients with the chronic condition, regardless of insurance status.

- If the therapy is effective, why shouldn't it be available to everyone?
- After all, many insured people would gladly avoid prescription drugs if an alternative was available, even if it proved somewhat less effective than standard care.
- To my relief, the review committee agreed.
- Turns out my perspective simply had not occurred to them.
- My inclusion in this group and my diverse voice led to what I believe was better science, one that advanced equity.
- Had I restricted myself to a statistical assessment of the design, I would've had no qualms—it was scientifically sound.
- But what's the use of implementing a rigorous scientific study if the framing of the research question is flawed?
- This experience and others like it reinforced in me the value that comes when project team members use their "whole self"—not only their technical expertise but their life experience, culture, and critical thinking—in their research practice.
- This promotes research excellence that can transcend a siloed approach that stubbornly adheres to conventional practice.

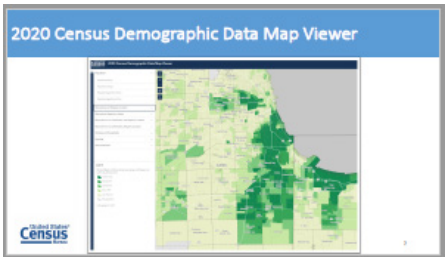
- OK, my next story is also about health services research and the tendency to approach solutions by narrowly focusing on the patient.
- The year was 1995—plus or minus.
- I was casually perusing a newsletter from the National Institutes of Health on program evaluations when I came upon an interesting item.
- There was a short note on a study of Latino health care.
- They found that Spanish-speaking patients had better outcomes when their health care providers spoke even just a little Spanish.
- Now, don't laugh like I did.
- Of course, that should be expected and, indeed, obvious.
- But then I had an epiphany…one that I'll share with you.
- In that moment, it hit me like a ton of bricks.
- I smiled widely.
- I realized that this was the first time I had seen a federal research grant exploring non-English health care delivery.
- This was in the era of "English-only" legislative debates.
- I realized that the *nation's health care industry was acculturating to an increasingly diverse society*.
- People of color and their communities were being recognized as part of our diverse nation.
- Formal research efforts funded by the government were emerging to provide more meaningful health care as a result.
- That was a huge deal…at least to me.

- Going a step further, it made me realize that as our nation becomes more diverse, society will adapt to us.
- After all, *we*—people of color—are an integral part of society.
- Our representation in this country is increasing with time.
- By the way, I also realized the potential missed opportunity coming from an interactive patient-health care industry research lens.
- Yes, patient outcomes flow from their individual behaviors—accessing health care, adhering to prescribed therapy.
- But think about it.
- Health care outcomes are necessarily the net result of an *interaction* between two parties: the health care provider—indeed the health care enterprise—and the person seeking health care.
- So, if the medical provider doesn't adequately acculturate to its increasingly diverse clientele, it will negatively affect health outcomes.
- You see, health care staff operate in the context of their institutional policies.
- And institutional policies are influenced by federal, state, and local policy as well as the health insurance industry itself.
- So patient outcomes not only reflect the patient's behavior, they also reflect the effectiveness of the entire health care enterprise in serving its clientele.

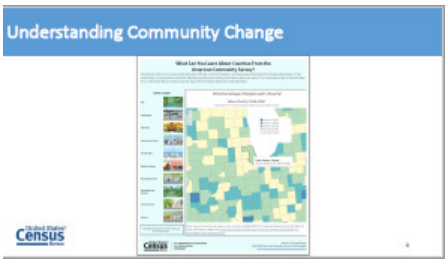


- So how does this relate to my thinking about a tendency for siloed topical research?
- Well, the way I see it, when we look at something like cancer in American Indians and Alaska Natives, it's tempting to focus on cultural and behavioral aspects of a specific group and how one can help individuals from that group who experience morbidity.
- And that's very much necessary.
- But let's not forget that there's another party in the health care room deserving of attention, too: the health care enterprise.
- What research needs to be conducted to explore how players in the health care enterprise can provide more accessible, timely, and relevant health care to American Indians and Alaska Natives?
- And more generally to people of color and communities of color?
- These are the populations who are underserved and experience negative health outcomes.
- Once you start down the path of rethinking health research in a holistic way, a fuller picture emerges.
- We can consider the impact of the environment, in its broadest sense, on health.
- We know cancer risks are affected by air pollution or living downwind from a chemical production plant, living in a neighborhood subject to noxious fumes, occupationally being exposed to pesticides or cleaning aerosols or other carcinogens, or overexposure to ultraviolet rays.
- And the list can go on.
- Such risk factors are wide-ranging.
- We also know that there are many socioeconomic factors that impact health risks.

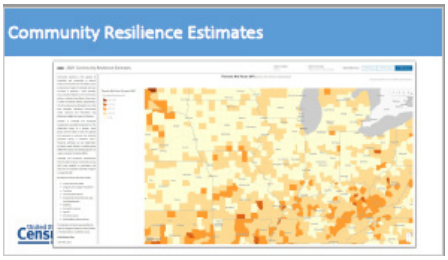
- For instance, patients may have limited access to health care facilities, or an employer that doesn't allow time off for doctor's visits, or they lack broadband access to make appointments.
- Remember when COVID vaccine appointments were almost exclusively available only through the internet?
- All too often in my previous work I heard of economic challenges where families were forced to choose between paying rent or utilities before buying food or medicine.
- As you know, that's why some people fail to follow their pharmaceutical regimens.
- It's not a lack of understanding…it's a lack of resources.
- And why are they in this situation?
- Perhaps they can't find a job with a living wage.
- Or they have no access to transportation. Or no child care.
- Or have an untreated mental health condition.
- Or the suffer the stigma of being an exoffender after paying their dues to society, so no one will hire them.
- Health issues do not occur in a vacuum.
- Many factors directly and indirectly affect the incidence of disease and chronic conditions.
- Researchers have referred to the collection of these and other related factors—such as poverty, education, employment, housing stability, and so on—as "social determinants of health," and there's a deep literature on this topic.
- These factors provide useful context in understanding the health status of people of color.
- These factors also inform programs to help address health care issues in communities of color.
- And such context is especially important if one adopts a more holistic approach for framing minority health research issues.
- But context requires data. So let's talk about that.
- As the director of the Census Bureau, I'm pleased to report that we have publicly available data that can assist in characterizing communities of color.
- Combined with environmental data, one can identify neighborhoods that could be subject to different types and levels of environmental exposures.



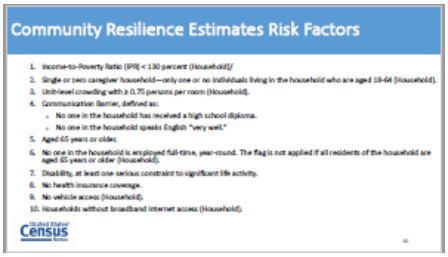
- For instance, the 2020 Census Demographic Data Map Viewer is online now and can identify various demographic characteristics down to the census tract level.



- Data from our American Community Survey provides a variety of important community factors down to the tract and block group levels.
- We include things like poverty rates, employment, internet access, public transportation access, and many other measures.
- I've said many times, the ACS is a national treasure because of the richness of the data available to the public, including communities of color.
- The Census Bureau also creates indices that may be useful in your research.



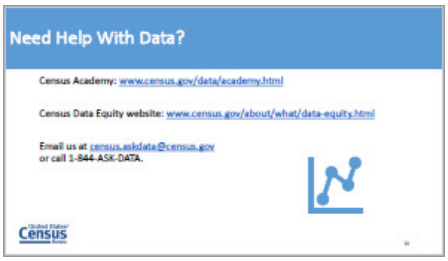
- Data from our **Community Resilience Estimates for Equity** reflect the capacity of individuals and households to absorb the external stresses of natural disasters such as hurricanes, wild fires, floods, other storms, and the COVID-19 pandemic.
- Measures from the 5-year American Community Survey were used to develop ten risk indexes, each acting as its own distinct indicator of vulnerability.



- The risk factors include such characteristics as lack of vehicle access, no health insurance, and absence of broadband internet access.
- And the level of geography goes down to the census tract level.
- There are many other datasets and data tools are available.
- I've only mentioned a few this morning.

- To give you a better idea, here's a sampling of other data sources that include visualizations and mapping capabilities at different levels of geographies.
- Just do an internet search on the words "Data Equity Visualizations," and look for the census-dot-gov (census.gov) link.

- Now, a major part of the Census Bureau's mission is to inform people on our data and how to use them.
- We seek to empower data users—you!—with understandable, accurate, and timely information and the knowledge to put it to work.
- We have so many resources for you, including our online Census Academy, our Data Equity Library, and we have staff called Data Dissemination Specialists whose job it is to answer your questions about Census Bureau data.
- You're invited to partake of these rich data assets for your own research.



- Well, I hope that I've given you some food for thought as you move forward in your work.
- And please think about how you might approach your research using on your own life experiences, values, and cultures.

- Diverse voices can help us to innovate, to enhance creativity and critical thinking.
- People with different lived experiences and cultures do offer powerful insights.
- But they can do so only when we give them a chance to be included and to have their voices heard.
- And under a holistic approach, we can also gain insights by including in our research the health care industry, itself.
- Remember that patient outcomes are the result of interactions between health care workers and the people seeking health care services.
- And by the way, note that diverse voices include those of our research subjects and their communities.
- Community engagement is critical for understanding root causes of problems and developing culturally relevant solutions.
- And that brings me back to my first story about my grandmother and my furry intruder.
- Perhaps we should listen a little more closely the next time a child tells us they feel better because their *abuelita* bestowed the *asusto* blessing using a pecan branch.
- So, let's enhance our research by drawing upon our life experience, our culture, our values, and technical expertise.
- You'll create your own unique insights in a way that no one else can.
- Thank you so much for having me.
- It's been a pleasure to be with you at this conference and to share my thoughts with you on this special day.