

2018 NERGN Inaugural Meeting Summary of Family Panel Discussion

04/06/18

Multi-Cultural Family Perspectives on Access to Care

Olga Lopez, MA Federation for Children with Special Needs

Virginia Pertillar, Citizens for Quality Sickle Cell Care, Connecticut

Neesu Wushuwunoag, Federation of Aboriginal Nation of America, Rhode Island

Members of the Family Panel were asked to consider these questions:

- What are some of the common cultural barriers members of your ethnic group have experienced in seeking medical care for an individual with a genetic condition?
- When it comes to the provision of medical (or specifically, genetic) care by providers, what do you wish more providers were aware of about your culture?
- What do you think is missing from the array of genetic services made available to families of your heritage?
- Concerns about discrimination, ICE related issues, federal policies impacting decisions to seek care.

Latino communities:

- Not enough information about conditions/diagnoses in Spanish
- Parent to parent connection is important.
- Going out into the communities to establish relationships is a good strategy.
- In Latino community, they need to look at a person face to face (not flyers, videos, etc.)
- Latino families with complex medical conditions often need equipment. If they are not connected to resources, they go without.
- Noted that families need to fight with school system to get services and special accommodations. Schools may not believe parents who don't have documentation.

American Indian communities:

- Latino and Hispanic communities have connection with indigenous people, also need to see people face to face.
- First challenge is lack of relationship. If it's not coming from someone they know, probably not going to go any further.

- Must take into account the history of science and medicine and indigenous people, who were thought to have African heritage.
- Other challenge is that many indigenous people don't know this is something they should be thinking of, or it may cause them to think of ancestry and who qualifies to be designated as Indian
- Before we engage with genetic services, we'd want to know why you want this information? What are you going to do with it if you get it? How will the information be treated and reflect on my community (ex. alcoholism)?
- Doesn't think genetics is on the radar with most, unless there's something happening with you or your family. Because things aren't addressed early, they may become worse and more expensive.
- Whether or not this perception is actually the case, because they believe it, it *is* the case.

African American communities:

- Sickle cell disease is African, in that it came via middle passage on slave ships.
- Common questions and concerns pertaining to sickle cell:
 - Why hasn't this disease been eradicated? Because most people affected by sickle cell are African Americans, there hasn't been the same focus on research. Only two medications, and opioids are common treatment. Adults are frequently labeled as drug-seeker.
 - Why are so many people being born with sickle cell? Many people don't know they are carriers.
 - Why don't people go for treatment? Fear and mistrust. Recall the [Tuskegee Syphilis Study](#).
- People sometimes reluctant to take medication, don't want to take it the rest of their lives.
 - This doesn't account for other things people can sometimes do.
 - May be incentive for drug companies
- Important to see each person with love, open to human connection; if conversation is more about insurance that changes the dynamic.

Discussion:

History of mistreatment and mistrust seems to come back to hurt the communities, in that it is harder for the medical system to help them without enough data.

- Recalled times where data was needed from Latino community and people were given \$10. After that nothing happened. That isn't helping the community.
- Appreciates those comments and is trying to work on this issue with indigenous community. Negative relationship has negative impact on the community, if anything pops up as a problem people may just stop engaging. Encourages us not to look for *the* solution, but *a* solution of many.
- For African American community another source of mistrust is being told things that don't make sense or fit with values (like saying they're going to eliminate a disease). Not knowing how research will be used is also a barrier. Doing research with no follow up is detrimental; it would help just to be told the results.
- How do we move past this? Can we say the information is safe? We shouldn't promise until we are sure.
 - Parent from CT shared that we *all* feel unsafe in this way. Is it possible to guarantee security of information?
 - One example that worked for a Canadian tribe was "data sovereignty" – when the research was done, the tribe took it with them on a thumb drive. They make decisions about it and they own it. People don't want to feel like a check box on someone's grant.

There are many efforts to frame research in such a way that is a partnership, and to use appropriate outreach methods and materials. Is this framework working?

- There are good intentions, but many issues for Latinos with the whole system including education.

- The framework sounds great but indigenous people have heard it all before. What is there to engage me? What is the benefit right now? I want to see ownership, and direct am immediate benefit.
- What's important is the human connection. We need to connect; for African Americans, we haven't done it yet.

If you were at the table from the beginning, what would that look like?

- Acceptance. Respect.
- What would it look like for any target group – that's what it should look like for indigenous people. Ask us, *what are you looking for*, rather than *see what I have*. Listen to our input. Treat us like you would treat your funders. Word travels, so if you do it wrong the community will know.
- Every person would be at the table, because every person matters at every level. Need to realize genetics involves housing, education, etc. Be peaceful and loving.

Wrap up

- NERGN and everyone here wants to do it right. We are asking for your help. We know where the doors are and we just need to go through to the next step.
- *Will you help us in New England?*
 - Neesu – open to helping but cautious. Interested if the partnership is beneficial.
 - Virginia – is willing to be a voice back and forth with her community.
 - Olga – yes, willing to help. She's happy to find families. It's a collaboration.
- Peter Antal and John Moeschler thanked everyone and reiterated that this is a first step.