Transcript

Greetings, everyone.

My name is Brittney Okada and I work for the Utah Department of Health, the Office of Health Disparities.

I work as the Health Equity Epidemiology and Evaluation Manager, and I am very grateful to be with you today and share with you about a project that is very dear to me.

It takes a village giving our babies the best chance. And I want to spend time specifically talking about how data, community and culture combine in this project to advance health equity, build identity and address birth outcomes, disparities in Utah among our Native Hawaiian Pacific Islander populations.

Also, just a quick note and invitation.

I think this presentation and project have a special significance in the context of this year's conference theme, reflecting on our past, shaping our future.

I really invite you to think about the theme throughout the presentation and take note of and critically think about the unique ways this project and approach brings this theme to life.

And that is the theme of reflecting on our past, shaping our future, So what is it takes A Village? is a promising practice and injects and innovation station and a community educational engagement series which is grounded in Pacific Islander cultural beliefs and practices.

It really raises awareness and educates about maternal and infant health. This is a project that we built from the ground up, and I really wanted to take a moment to acknowledge our funders that supported that.

So the federal Office of Minority Health through the State Partnership Grant to improve minority health and also the state maternal and child health care all through the Maternal and Child Health Services Block Grant I want to give you an insider's view onto the project. I'll do that by introducing our office, explaining about the state of data disaggregation, introducing the project talking about community and culture and pathways to help, and also sharing the curriculum and some of the project outcomes. At this point, I want to extend another invitation for you to really think about this project like a blueprint or a template that really can be used for any type of health disparity or any community. And I invite you to look for practices, processes and principles for application to the work you do in public health, help, health care, and also for the community that you specifically serve.

So the

Office of Health Disparities, is part of the Utah Department of Health's Executive Director's Office, we will actually soon be the Office of Health Equity and the Utah Department of Health and Human Services, because we are currently going through a merger of the two agencies. But even with the merger, our mission remains the same, which is to advance health equity and reduce health disparities in Utah, which really does fit into a larger vision for all people to have a fair opportunity at reaching their highest health potential, given that health is crucial for well-being, longevity and economic stability. So part of the reason I share who we are is to clarify that we are a state government.

Sometimes our partners in this project and other projects really can't believe that we're government because they share that they don't typically trust or work with government. We had one community leader, particularly from our Pacific Islander community, that shows that she wakes up every day comforted knowing that someone in the state government is thinking about and working for her community. It really does take an incredible amount of effort in a government agency to do this work with the community but it pays off so much and community trust and partnership to work to address health disparities.

So one of our roles as Office of Health Disparities is to be the Utah Office of Minority Health.

Accordingly, we monitor and report on racial and ethnic health disparities. One report that we produced is the Utah Health Status by race and Ethnicity, which we do every five years.

We actually just publish the 2021 report.

So this report looks at several different health indicators or outcomes by race and ethnicity.

So you can see here a profile on life expectancy at birth and infant mortality.

It really is quite comprehensive in its approach. So in our 2005 report, we had Asian and Pacific Islander.

The infant mortality rate was combined for the populations And you can see it was 4.6 per 1000 births, which was actually lower than Utah overall. And then you can see in 2010 we were able to disagree.

The data for Asians and Pacific Islanders and you see the Pacific Islander infant mortality rate jump to 8.8 which was significantly higher than Utah overall and almost double the overall rate. Essentially what was happening is the healthier status of Asian communities in Utah was masking the struggles of NHP communities. Disaggregated data really unveiled significant health disparities and infant mortality and many other health indicators for Pacific Islanders. So I can't emphasize enough how important it is to collect disaggregated data and that you should work closely with your surveillance systems in your state to do so.

In 1997, the federal OMB revised standards for collecting race ethnicity data and in 1999 Utah adopted those standards and started to collect data separately for Asian and Pacific Islanders, which really was the foundation of our work. I know that that's not the case in every state across the nation, but Utah's data disaggregation practices and our subsequent projects which followed like it takes a village, we're actually cited as examples in California.

Governor Brown's signing of a health data disaggregation bill in September 2016 which empowered the California Department of Health to separate

Pacific Islander group data from broader Asian Pacific Category Sometimes when we

start disaggregating data, it can make for small numbers in communities. So another practice that is really good and important to do is aggregating data over the years.

Particularly three to five years.

And this is to decrease the standard error, improve and improve the reliability of the estimate. So Utah has a smaller population, but we do have about 38,000 Native Hawaiian Pacific Islanders.

One in four Tongan Americans actually lives in Utah and Salt Lake City. Our Salt Lake County has one of the greatest overall proportions of any HPI of any city or county in the continental US.

And so I can't emphasize enough that the focus on separating data for Asian Pacific Islanders really was the foundation of the work that I'm going to share a little bit later.

So when we are able to have this data and take it to a broad set of stakeholders, we started getting involved with other programs, maternal and child health organizations, community based organizations, state agencies, local health departments and health care organizations. We formed a diverse partnership to be able to really think about the health disparities that we were seeing.

And this led to say, stakeholders wanting to learn more.

So we're able to do an oversampling survey of Pacific Islanders in Utah that was modeled after the virus.

It was the first statewide health survey which was conducted and someone Tongan and English.

And what we did is we developed a unique survey sampling methodology using a surname list And so we you we worked with Utah Pacific Islanders in all stages of the development and implementation.

And this really did increase the reliability of a lot of estimates. And what we saw was there were differences in health status and behaviors by language. And so it was really important to do this over sampling to better understand our Pacific Islander communities. This led to more studies to really talk with the community and figure out contributing factors

We did an online survey and focus groups on awareness of the different guidelines on maternal and child health, breastfeeding, health care preferences. We also did a study where we surveyed and interviewed mothers who had had a recent infant loss. And we looked at work and income, living conditions, social support, important life events, and access to health care. So after this understanding and work with HPI communities and other stakeholders, there really was a desire to do something, to do an intervention.

And so that's where it takes a village came into place. What we learned is from community experts that there was an unequivocal community silence that really surrounded the topics of birth outcomes, disparities.

And so the need was to begin raising awareness. We looked locally, nationally and even internationally for a health promotion intervention tailored to Pacific Islanders to address birth outcomes, disparities.

And we couldn't find one.

And so we worked with partners to develop one. We did a pilot project in 2015 and two additional phases of cohorts from 2016 to 2018.

And all of those efforts really culminated in the final product that I'm going to share more with you today.

It takes a village giving our babies the best chance project

So when we're creating the project, we really knew that this needed to be really tailored to our Pacific Islander communities because we understand that this is not just a personal, physical, medical type of issue, but really involves community, involves family, involves culture.

And so community, family and culture are all pathways to help So all of our efforts were really grounded in principles of community based participatory research.

The project development and implementation was done in collaboration with Pacific Islander staff that we hired on community and advisory boards that we developed, Pacific Islander community based organizations that we contracted and then worked with NHP,

WS and community members.

And so the key was that we really value community perspective and acknowledge that they are experts.

And this is when community really becomes a pathway to help.

It is really this approach where we view the input of public health professionals or health care professionals and community members as equally important. And that has allowed us to create a product that really marries health and culture and a very balanced and reciprocal way.

And I think this really manifests well in our project So the project is really four workshops, each with different topics and activities.

We talk about maternal infant health topics, cultural concepts, videos,

We have PowerPoint presentations, group activities, and of course, homework assignments.

The workshops typically last one and a half to 2 hours.

And our facilitator by community members like Kathy here from our Fijian community, who have been trained to lead a workshop of six to 12 participants and the community facilitators really do the recruitment for the participants so that that relationship is intact and are there. We really invite all genders, generation marital statuses to participate.

We encourage it to be a family and community centered effort, which may be very different from typical maternal child health interventions.

We often got the question of can only pregnant women attend or only women attend?

And we said no, we wanted everyone because we wanted to stay true to our community approach, going back to community and relationships, because this is what is most important to the community. And so we really wanted to focus on providing education and support to the whole community.

So the whole community could then turn around and support mothers and infants.

We made sure to involve community members in so many aspects. We actually created videos for each workshop, and participants loved seeing their community members sharing important information and knowledge.

And these are some of the only health promotion videos

featuring all Pacific Islander community members on these topics.

And these are all local to you talk.

So why not just start out by sharing a video and this video is the first one that a participant see when they attend the first meeting. And it's really the introduction to health disparities and it kind of shows our approach to addressing these issues and really sets the tone for the rest of the meeting.

So I'll go ahead and start this now.

My name is Moana ‘Ulu’ave Hafoka..

My husband my name is Mike Hafoka, and I am almost seven months pregnant. And this is our first baby. Being a Tongan woman, married to a Tongan man is an extremely special experience and having the opportunity to raise a Tongan baby is also a beautiful experience that I and my husband are

privileged to have and realizing that that we get to carry on
the legacy of our parents and our grandparents.

I've been extremely blessed with, with such a large extended family and so
has my husband.

He has a huge family himself and the care and the lives that we've had thus far
have been amazing and that the prospect and the opportunity to continue that
line. You come from such a small island with a population of less than 200,000 in
the world and your existence is so minuscule compared to the rest of the world.
And to be a part of the continued legacy, you know, to actually hold a human
being they knew that will continue this legacy is nothing short of a miracle I
guess.

The way that families are viewed in the Pacific Islander worldview is really the
central core of our society.

And children play a very important role in that. The birth of a new child is
celebrated at an epic scale, and all members of the family are engaged.

And so really, the family is the center of our society. And the pride and the joy that we have in
children and babies and seeing them grow and watching them have their own families.

Really, it's central to our culture.

In the islands,, children more than half the children didn't live past one year.

And so it definitely was a life event to have a child.

Because, remember, this is the future.

This is the children that are going to help feed the future of the family. So if you make
it, it was like, okay, this child is going to live and help out the family if they made it to
one years old. So we it is a huge birthday. Everybody there's a big luau. Everybody
cooks pigs and brings gifts for the baby.

My role, I think, is just sharing my story of what happened because I lost I lost twins and I
didn't know why I lost them. And I think if I can do anything to help the next mother I
avoid that from happening. Then that's my two cents into the community to help that.

All right, I wish we could watch the whole video, but we will continue.

So further bringing community into the workshops. We do discussions and group
activities, and each activity is tied back to a cultural concept and health topics.

Which allows participants to share their very personal experiences.

And these are really steeped in Pacific Islander culture.

So we have a communication activity that talks about how he via WhiteHouse.gov, which is using open communication to nurture relationships that connect each other. And so this activity begins to help people feel more confident in being able to openly communicate about infant mortality with the community. The navigation activity talks about nourishing the Fonua, which is the environment in the space in which we live.

And so this activity helps build skills to navigate resources and a Western space as Pacific Islanders master and navigators and a Pacific the connection activity really builds on the (Pacific Island Term) and the practice of sharing wisdom to children and notes that everyone has a responsibility to pass on what they have learned to their kin members and their community through the connections that they have So staying true to our approach culture was also a pathway to help.

Jake says Our culture our community, our history really has a lot to offer us today, and we can find a lot of strength in terms of promoting health by looking back and really remembering and acknowledging the way that our ancestors lived So in public health, many view culture as a barrier to health, and we're not blind to that.

However, we decided intentionally to focus on culture as a pathway to health and focus on the fact that there are traditions, practices and aspects of Pacific Islander culture that support, help and support what we were trying to accomplish in improving community health. I would say our project really actually took this to the extreme, and we have really saturated the project and Pacific Islander culture, and we're really trying to understand and promote Pacific Islander identity and show that really contributes to better health for Pacific Islander mothers, babies and communities.

So this is an thorough anthropological approach.

The name of the project actually was chosen by community members because it mirrors the Pacific way of life.

So we have a cultural framework that the whole project is based on participants.

When they join the project, they actually join a village which establishes the communal bond found throughout the Pacific. They then become members of a village council, which is the governing body and the Pacific Islands for important village issues. Finally, they gather in village meetings or phone on, which is the venue in the Pacific for addressing village issues.

So what we have done is we have really borrowed from traditional Pacific systems for resolving community problems in order to appropriately break the silence surrounding infant mortality and other birth outcomes disparities.

So I really feel like this is what differentiates our project from informational workshops or it goes beyond just incorporating some cultural concepts or stories or having it delivered by community members. We really came up with this framework and practices that is built on Pacific Islander traditions and systems that engage community members and a forum to discuss hard topics. And it really builds in a sense of accountability for dissemination of information.

So this framework is the foundation of the project and was carefully constructed to address the sensitivity around the topics we were discussing. So within this framework, we do incorporate incorporate cultural concepts that Pacific Islander wisdom in practices are woven in with current maternal and child health recommendations to really engage and educate new members So this really eases people into talking about difficult topics such as infant mortality, preconception, health and birth spacing, and help make the recommendations help make them more receptive to the recommendations. So all of these topics are difficult for Pacific Islanders to discuss, especially in a community type of setting.

But we were able to pare infant mortality and Vā or that connection, preconception health and formula or Fonua, which is our environment or context and births pacing and Kaliloa or ‘Aliloa.

So I wanted to take you through one of these, which is birth spacing and

Cordillera or Mala.

So birth spacing, as many of you know, as the amount of time between the birth of one baby and the beginning of the next pregnancy. And the recommendation as to wait1 8 months so the body can fully recuperate. This is not necessarily practiced widely by Pacific Islanders in Utah.

37% of Pacific Islander pregnancies are spaced

18 months apart or less, and 11% are actually six months or less, which is three times higher than the rest of Utah. So when first identifying this health disparity and reporting back to the community, the community was very resistant. They view this as a way for government or health care providers to really limit the number of kids Pacific Islanders could have

We could have never guessed that it would have been viewed in that way, nor did we intend for it to be interpreted in that way. Instead, we were we were just trying to promote best practices for a healthy birth,t he birth outcomes.

And so and it takes a village.

We decided to take a different approach We decided to take the approach that birth spacing is actually cultural.

So Pacific Islander ancestors, grandparents, parents and elders practice and valued passing on cultural knowledge and wisdom to their descendants.

This began right after birth where on the mother's forearm, knowledge, teachings and cultural wisdom was passed on to the child through storytelling. In the Pacific wooden headrests called Kali or Ali are used as pillows.

So you can think of like a small wooden bench that you can rest your head on.

And that's what the color is. And there's long ones, long
headdress, which are called Kaliloa or ʻAliloa.

Kaliloa or ʻAliloa is also the word for the mother's forearm or the head for infants, which is long because it continues to support the child throughout the child's life. And so I don't think it's any coincidence that is the same word for the wood plank or the pillow that every family member sleeps on.

That is also the world for the mother's forearm. So breast spacing is definitely cultural and in many ways, but specifically, it gives the mother the opportunity to heal and best quality time with their new baby.

So the more time between births, the more time a mother has with her baby, meaning the baby gets more storytelling time or more time on the lower or I'll be lower and that child will be stronger in regards

to cultural wisdom and knowledge. Also, with birth spacing and gives the opportunity and time for the mother to recover. So that develops and strengthens the Kaliloa or ʻAliloa, where the mother and her forearm. She's healthier, stronger and more capable of passing on that cultural knowledge and wisdom. So demons

trading reciprocity between traditions and current healthy practices really led to increased knowledge and widespread acceptance of the recommendations Many said that this was their absolute favorite topic and the most valuable information that they got from the workshops. They said it also made the most sense This was also heavily supported by older generations, especially mothers who had experienced it. And so we, in doing this approach with that a complete opposite reaction from our first approach, instead of distrust and skepticism, it was widely received and accepted

So I want to now go into some of the development of this project.

How did we actually get to this point?

And so I'm going to provide a context and vision of how it developed and then go through each piece.

So we started with the disaggregation of the data community advisory boards.

We did more data collection and surveys. We started a pilot project, developed the videos, standardized, and scaled the curriculum. We had a phase two with our different studies and cultural concepts, and then we have been promoting and trying to sustain the project.

And this has been going on since about 2010 up until now.

So over ten years now.

And so let's well walk through each part of the development so you can see how it has evolved and layered on, I strongly believe that it really takes time to cultivate these, and with every step you take forward, you can learn and improve. So our pilot project, we just had an outline for six sessions. We started with the facilitators, the community facilitators program post questionnaires is a really just 90 minute sessions of presentations, discussions, physical activities. And when we started this was really 23 participants in our pilot and they loved it so much and spread word about it that it actually grew to 40 participants. Usually you face attrition, but we just faced a lot of growth, which led us into phase one of it takes a village where we formed an advisory committee to influence the scale and standardization of the project.

This is when we produced the videos featuring local community members.

We standardize and name the curriculum, which ended up being six workshops over six weeks.

That's trained facilitators and 25 participants.

And then we really scaled it to six sites with 80 to 140 participants.

There were a lot of successes. This is when we got in touch with our Fijian community, which we had never really worked before.

People love the videos and the curriculum.

They really and appreciated a venue to discuss these topics. And at the beginning, many of our community partners said, Oh, you cannot come by male and females in the same group. But we really wanted to take a full community approach and ended up working out awesome. And it was actually really empowering to have both males and females and people of all genders all in the same group.

One of the challenges we face was consistent participation for six weeks Just the overwhelming amount of information, the number of individuals in the site and recruiting language and then data for evaluation so this really was we learned so much from this phase one and scaling and sustaining, and it really informed phase two a lot. So we did a quantitative study to look more into infant mortality using birth data.

We did a qualitative study to look at readiness and perceived control about addressing infant mortality. We revised the curriculum with a cultural advisor that we hired on and we took it down to four workshops within a two week period to give more flexibility so that different types of groups could meet

We developed the cultural framework and concepts new activities. We had a participant workbook, and we scaled it back from 25 participants to six to 12 And so our final implementation was in three cohorts, eight different groups with 63 participants So the success of this group was that we began to work with our Native Hawaiian community and also our Micronesian community, which we had never worked with before.

We had good retention rates. People really liked being a part of a village council and felt accountable to each other. We had a better evaluation and we actually really learned about this continuum of acculturation. When we started talking about cultural concepts and some are very familiar with them and some we're just learning about their culture, which was beautiful. Challenges we faced were recruiting and scheduling.

So overall we had 172 participants between phase one and phase two.

We got to involve a variety of communities and a variety of different groups. So now I'll share a little bit about phase two outcomes and the reason I only share phase two is because this is the closest version of the curriculum that was presented, and that is a promising practice. So 63 participants total, we did pre post-test questionnaires and the results really demonstrate changes from the beginning of the intervention to after the intervention.

And so in summary, we really did see increases in all of the areas and awareness and knowledge.

What we saw was interesting that only about half of people at the beginning knew about infant mortality disparities, but that increase to 100% by the end. Other areas where we saw large increases was the definition of infant mortality and also birth spacing.

You can see only 24% knew what birth spacing was before the project and then it went up to 98% We also did self-efficacy or evaluated self-efficacy, which was based on a five point scale to measure how confident the community felt in doing certain practices. And in summary, again, all of these increased, you can see the largest increase.

We're in talking to many members about pregnancy and birth related outcomes, and then also coaching community members and steps that could be taken to have healthy babies.

So they felt confident in being able to share, which I think is linked back to some of our skill building activity. And of course, the one result that I love sharing is that 100% a person said the training was culturally appropriate for Native Hawaiian Pacific Islander communities. So in phase three of the project, we built a website and also updated our website so that it takes a village website, has all of the documents, and our website really goes through some of the processes or the back end work.

So we have our facilitator manual, our participant workbook.

We have recruitment packets.

We have our videos available to everyone.

PowerPoint presentation and our evaluation questionnaires. We also in Phase three, worked on an implementation guide, which really does a readiness assessment checklist. And then below, depending on how you answer it, provides tips and technical assistance in order to implement.

It takes a village in a community or in a different place. And so this guide actually I think can be used for many different communities and many different topics.

And this is why we became a promising practice.

We have an article here from Amped Up, a Pulse article, and then we actually, during the pandemic I got to do or is it during the pandemic?

But in 2020 I was able to do a podcast for PBS more than half and you get to hear from Nia, who is our cultural advisor, and Tim a who was participant and then also facilitator and actually came to work from her office and their unique perspectives as specific women and working in this project.

So I hope we encourage you to go check that out. So moving forward, we have been pursuing a best practice in trying to do replication projects, fidelity assessments and publication Much of that has been put on hold due to COVID 19, but we also have been working on community ownership and then also one of the best things moving forward as we try to design the projects so that those who attend or facilitated can continue to apply the knowledge and skills for much longer than the project. And then all Simon conversations with the health care system right now to see if we can integrate some principles and practices of it takes a village into home visiting program

We also are doing a research study right now. It's a randomized controlled trial, which is about maternal mortality and diabetes. And we've been able to take practices and principles from it takes a village and really apply that to the focus of this study. And we've been able to learn about Pacific Heritage Arts and really link that to self-care, nutrition, exercise.

It's been really beautiful in this study as Embrace is the name of it. And we there's actually another presentation that we do for this conference.

So I encourage you to go watch that as this has been really a beautiful development All right.

So in our final moments, I just want to review some key principles, review that this probably did all start with data disaggregation It was foundational to really uncovering these health disparities and initiating this work.

Too often, disparate communities are swallowed up in larger groups, and we even see that within Pacific Islander groups themselves. And specifically, we saw it with Utah's Pacific Islander and Asian communities when those were combined Another principle is flexibility and responsiveness.

Goodness gracious.

Traditional public health approaches are often very prescriptive programs. And not designed for disparate communities, more designed for general population, which can sometimes lead to alienation instead of assistance. So we really tried to not start out with a solution in mind when we saw these health disparities and wanted to work with the community over many years to really tailor products to meet their needs and wants.

So third was to focus on community strengths.

So identifying and addressing barriers is important, but it's not the whole story

really focusing on community and culture as a strength instead of a barrier. This mindset really led to the efforts and the products that resonated with community members and really seamlessly integrated

into their lifestyles.

Another is to build champions.

We really hired a lot of Pacific Islander staff and funded a lot of community based organizations to work on the projects and involve community members.

In many ways, One of our champions out of this is Thomas, who was a participant and then facilitator, now wants to carry on this project.

And there's nothing like a community champion

Another is just a shared commitment to communities.

And I'm going to go over that in this next slide.

You can see that from 20, ten to now.

So over ten years we have been invested in this community and that actually comes through several different funding sources. It wasn't like we've had ten years of funding just from one place to work on this project.

We had to be creative and I give kudos to my director. You always saw it for funding and advocate it so that we could continue to work with this community and find ways to support this community.

I was actually in a conversation with a community member earlier last week.

We were talking about how sometimes data can be stigmatizing or really hard for new members to hear because sometimes it's negative. But she felt like it's okay to hear from us and identifying the health disparities because that would be followed up by action and a long term commitment. And so if you're going to this aggregate data for these communities, be prepared to be with them for a while and learn with them.

And something beautiful will come out of that. So we have really come to understand the importance of continuing family legacies and the best preservation of culture and legacy as children if infant mortality.

Not all children have the opportunity to carry on their
legacies

So I really do love this project and love the cultural concepts that are integrated into health topics and activities.

And I really do feel the whole project is very deep and symbolic. It is an effort to preserve Pacific Islander culture in so many ways, but in an ultimate way of preserving it through children and passing on that legacy, because the focus is really to reduce infant mortality and to help Pacific Islander women have the healthiest pregnancies possible.

So thank you for your time.

Here is my contact information and links to the different websites. And I hope that you can learn and grow from what was shared today.

And remember the theme of reflecting on our past, shaping our future.

Thank you.