

PACIFIC ISLANDERS' POINT OF VIEW

Perspectives and perceived
control about addressing
infant mortality disparities

JULY 2018



UTAH DEPARTMENT OF
HEALTH
Office of Health Disparities

Utah Office of Health Disparities

Organizational description

Guiding Principle

Health equity is the principle underlying our commitment to reduce and, ultimately, eliminate health disparities by addressing its determinants. Pursuing health equity means striving for the highest possible standard of health for all people and giving special attention to the needs of those communities at greatest risk for health disparities.

Health disparities are differences in health outcomes that are closely linked to economic, socio-cultural, environmental, and geographic disadvantage.

Mission

Our mission is to advance health equity and reduce health disparities in Utah.

Vision

Our vision is 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, and social mobility.

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Background

Utah's Pacific Islander communities experience a higher rate of infant mortality when compared with Utah overall. This health disparity is accompanied by other birth outcomes disparities such as high rates of maternal obesity, gestational diabetes, unintended pregnancy, poor rates of folic acid consumption, continued breastfeeding, birth spacing, and early prenatal care.¹

For more than five years, the Utah Office of Health Disparities (OHD) has been working with Utah's Pacific Islander communities to begin addressing these birth outcomes disparities. In spring 2015, OHD, in collaboration with the MAHINA (Maternal Health & Infant Advocates) Task Force, conducted a pilot project, the first of its kind in the nation, specifically created for Pacific Islanders to educate and raise awareness about birth outcomes disparities and maternal and infant health.

After evaluating the pilot project, OHD instituted a Native Hawaiian/Pacific Islander (NHPI) Birth Outcomes Advisory Committee to revise and expand the pilot project. In spring 2016, the first phase of *It Takes a Village: Giving our babies the best chance* (ITAV) project was implemented in NHPI communities across the Wasatch Front.

Project Overview

After evaluating the first phase of the ITAV project, OHD began a second phase of the project focused on refining the curriculum delivery method and developing a promising practice. In order to inform these changes and develop a more strategic approach for the project, OHD sought to better understand attitudes, behaviors, and outside support related to infant mortality and how to address this issue in the Pacific Islander community. Focus groups were held in March 2017.

Methods

The original project design included four 90-minute focus groups among; (1) Samoan community members, (2) Tongan community members, (3) mixed Pacific Islander community members, and (4) Pacific Islander community leaders. Each group was intended for 8-12 participants of varied gender, age, educational status, city of residence, and religious affiliation. Because of scheduling, no-shows, and deadlines, only three groups were actually held and the Samoan and Tongan community member focus groups were combined.

Two facilitators lead the focus groups: one for the community groups and one for the community leaders group. The focus groups started with an engagement question for discussion and then proceeded to exploratory questions, which included a worksheet with scenarios to be filled out individually and then discussed as a group. There was also a final question about outside support. The focus groups then concluded with an exit questionnaire. Focus group materials can be found in the appendix. OHD staff members were present at each focus groups to record notes.

Data analysis included reviewing notes for each section of the focus group to develop common group themes and shared commentary. Data from the worksheets was compiled by recording all the notes, developing category themes, categorizing the data, and looking for categorical trends.

Findings

Group Demographics:

All 27 participants from three focus groups completed the exit questionnaire: Samoan and Tongan community (12), mixed Pacific Islander community (8), and Pacific Islander community leaders (7). Participants included Tongans (10), Samoans (8), Native Hawaiians (5), Fijians (2), Marshallese (1), and Pohnpeian (1). A majority of participants were female (63%), married (74%), and had some college but no degree (30%); more than half (52%) of participants were between the ages of 30 and 34 years old.

Engagement Question:

1. Describe in a few sentences how you feel when you learn of the death of a baby before his/her first birthday in your family or in your community?

Common Group Themes:

- Feelings of sadness and devastation
- Questioning what went wrong
- Wondering if it could have been prevented or avoided
- Desire to provide support and consolation

Shared Commentary:

- This is a private matter for the family and is not openly discussed
- There is a sense of blame and shame associated with the loss

Exploratory Questions:

2. First scenario: Imagine that YOU or YOUR PARTNER lost a baby. Describe three things that YOU think YOU could have done to help avoid this loss.

Common Group Themes:

- Visiting the doctor for the best medical care
- Having a support system or being the support system
- Doing all you can to be prepared (physically, financially, mentally, emotionally, etc.)

Shared Commentary:

- Many do not have access to resources or support

3. Second scenario: Imagine that **SOMEONE IN YOUR FAMILY** lost a baby. Describe three things that **YOU** think **YOU** could have done to help avoid this loss.

Common Group Themes:

- Encouraging and helping them see a doctor
- Offering all types of support

Shared Commentary:

- Family members will not ask for help if they are struggling and need help
- Older siblings are expected to bear burdens and provide support and younger siblings are expected to reach out for help

4. Third scenario: Imagine that **SOMEONE IN YOUR COMMUNITY** lost a baby. Describe three things that **YOU** think **YOU** could have done to help avoid this loss.

Common Group Themes:

- Providing any type of support (physically, mentally, emotionally, financially)
- Becoming educated and sharing resources in the community
- Being aware of who needs help in the community

5. What type of outside support do you think your community needs to solve this problem?

Common Group Themes:

- Making information and resources easy to access
- Working through community members and leaders to provide education

Shared Commentary:

- Some people are more open to their own people and some are not
- The community is reactive and not proactive

Common Themes Throughout:

- Those new to Utah need help finding resources and seeking help
- Pride impedes community members from accepting help
- Communication about the subject is challenging because of privacy and gender norms
- Community members do not want to pry into other community members' lives
- Blame and shame are often connected to the loss

Worksheets:

Twenty-five individuals completed and turned in the scenario worksheet. Almost all participants (96%) knew someone who had lost a baby. Of those who knew someone, five indicated that it was themselves or their partner, 21 said it was someone in their family, and 16 said it was someone in their community.

First scenario: Imagine that YOU or YOUR PARTNER lost a baby. Describe three things that YOU think YOU could have done to help avoid this loss.

Common Group Themes:

- Being healthy
- Setting up an appointment with a doctor

Additional Themes:

- Educating self
- Prenatal care
- Limiting stressors

Distinctive Comments:

- Allowing others to help you or your partner emotionally and spiritually
- Becoming aware of the challenging role of parenthood, and don't have a child
- Self-evaluating their quality of life
- Avoiding activities or environments that can affect the health of baby and mom
- Somethings are out of one's control

Second scenario: Imagine that SOMEONE IN YOUR FAMILY lost a baby. Describe three things that YOU think YOU could have done to help avoid this loss.

Common Group Themes:

- Supporting them physically (healthy eating, taking prenatal vitamins, exercising, sensitive to body, etc.)
- Communicating with families about how to seek help from a physician regarding prenatal care
- Providing health resources to families

Additional Themes:

- Educating family members about having a healthy baby
- Supporting families emotionally
- Protecting the family

Distinctive Comments:

- Being influential in taking care of their health
- Eating healthy

Third scenario: Imagine that SOMEONE IN YOUR COMMUNITY lost a baby. Describe three things that YOU think YOU could have done to help avoid this loss.

Common Group Themes:

- Supporting them physically (house work, family obligations, nutrition, transportation, financially)
- Communicating about prenatal care and other health resources

Additional Themes:

- Supporting them emotionally and spiritually
- Educating about prenatal care
- Supporting organizations that advocate and educate about prenatal/postnatal care
- Donating to organizations that support expectant moms and healthy babies
- Advocating health awareness in the community

Distinctive Comments:

- Nothing to offer
- “Me Time”
- Preparing for the death prevention of infants

Educational Format and Project:

When asked how likely it would be for community members to participate in an online educational session, a higher percentage of participants selected “Probable” and “Highly Probable” when given the option of interacting with other community members versus not having the option of interacting with other community members (93% vs 78%). This indicated that if online education sessions were used the community would still prefer them to include community interaction.

However, when asked how likely it would be for them to participate in face-to-face educational sessions with other community members, the percentage of participants selecting “Highly Probable” increased substantially when compared with the average of people who chose the option of online educational sessions (67% vs. 36%). This demonstrates that community members highly favor face-to-face educational sessions compared with online educational sessions.

Furthermore, when asked how likely it would be for participants to develop a project, a much higher percentage selected “Highly Probable” when given the option of developing a project with other members of their community (44%) versus by themselves (15%).

Key Findings and Recommendations

- Infant mortality is recognized as something tragic in this community. Although attitudes and behaviors are mostly reactive, there is some sense that the issue could be prevented.
- Work should be done to support and grow attitudes and behaviors related to preventing infant mortality.
- Community members are able to identify specific actions related to preventing infant mortality when prompted, meaning that the community feels something can be done to prevent infant mortality, instead of feeling as if nothing can be done.
- Community members need to be supported in preventive actions they perceive to be within their control. These actions vary by relationship (individual, family, and community) and are impacted by socio-cultural norms.
- While community members identify support and resources as necessary to preventing infant mortality, they acknowledge barriers to access exist.
- Work needs to be done to increase access to support and resources for this community. This needs to be strategic and account for cultural considerations and other social determinants of health to be effective.
- Community members prefer to interact with each other face-to-face rather than online. However, if educational workshops were to be held online, they would still need to include an interactive component.
- Activities to address infant mortality need to encourage community members to work collectively because community members prefer to work together on projects rather than by themselves.

Moving Forward

OHD plans to use the findings from these focus groups to inform curriculum revisions for the second phase of the ITAV project. Revisions will include:

- Continue providing face-to-face educational workshops instead of online sessions
- Refocusing the intent and direction of the curriculum to engage the community in education and empowerment.
- Shift the target audience to focus on working with community members who can act as resources for other community members and instigate change in the community.
- Create specific activities to promote open communication, teach resource navigation, and encourage information dissemination.
- Develop a final group project to invite participants to work together to implement activities in their community.

Acknowledgements

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The City Library: Day-Riverside Branch

The Doty Family Education Center

Sorenson Unity Center

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Appendix

- Consent Form
- Facilitator Guide
- Scenarios Worksheet
- Exit Questionnaire



CONSENT TO PARTICIPATE IN FOCUS GROUPS FORM

You are invited to participate in the "It Takes a Village: Giving Our Babies the Best Chance" focus group being conducted today. We are asking you to participate in this focus group because we would like to learn from your experience as a Pacific Islander in Utah. You will be one of approximately 36 people participating in focus groups along the Wasatch Front.

Opinions from these focus groups will be gathered, summarized, and used to develop and implement an educational curriculum that will contribute to reduce poor birth outcomes and infant mortality among Pacific Islanders/Native Hawaiians in Utah.

The group discussion will last about 90-120 minutes. In the group meeting, we will be audiotape recording and taking notes to make an accurate record of the discussion, including your comments. There are no right or wrong answers to the questions that will be asked in the group; the important thing is for you to share your opinions as a member of the Pacific Islander/Native Hawaiian community in Utah.

Our notes and the information you share during this discussion will be kept confidential. Only the staff involved in this project will have access to the information we collect. This information will be kept in a locked place. No one else will see your responses. We will only report summarized results, so your identity will be unknown. We will not disclose any information that can be identified with you, nor connect your name to any information we present.

Your decision whether or not to participate will not affect any services you now receive or will receive from the Utah Department of Health or any other health service provider. If you decide to participate, you are free to discontinue participation at any time. We want you to feel comfortable while participating. Please let us know if you are uncomfortable; you do not have to answer any question that feels uncomfortable, and you can leave the group if you need a break at any time.

If you have any questions, feel free to contact Dulce Díez at 801 538 6773 or Brittney Okada 801 538 6779. Your signature indicates that you have read the information provided above and have decided to participate. Your signature also indicates that you have given permission to be audiotape recorded during the focus group. You can keep a copy of this form.

For attending this discussion, you will receive a \$25.00 gift card.

Name of participant (in capital letters) _____

Signature _____

Date _____

Facilitator Guide
FOCUS GROUP QUESTIONS
It Takes a Village – Phase II
March-April 2017

Project Introduction and Signing of Consent Form (*10 minutes*)

You are invited today to participate today in this focus group organized by the Utah Department of Health, Office of Health Disparities. We are asking you to participate in this focus group because we would like to learn from your experience as a Pacific Islander/Native Hawaiian in Utah. You will be one of approximately 36 people participating in four focus groups along the Wasatch Front.

The group discussion will last about 1 hour and 45 minutes. In the group meetings, we will be audiotape recording and taking notes to make an accurate record of the discussion, including your comments. There are no right or wrong answers to the questions that will be asked in the group; the important thing is for you to share your opinions. If you do not feel comfortable sharing some of your opinions with the group, you will have a chance to write those ideas on paper.

Opinions from these focus groups will be gathered, summarized and, in combination with other data, used to develop and implement an educational curriculum that will contribute to reduce adverse birth outcomes and infant mortality among Pacific Islanders/Native Hawaiians.

Thank you! Let's start.

Engagement Question (*20 minutes, approximately 2 or 2:30 minutes per person*)

- 1- Describe in a few sentences how do you feel when you hear of the death of a baby before his/her first birthday in your family or in your community? Please do not share names (individuals, hospitals, providers, etc).

Exploratory Questions (*60 minutes*)

- *4 minutes for facilitator to explain*
- *10 minutes for participants to write*
- *12 minutes to discuss first scenario*
- *12 minutes to discuss second scenario*
- *12 minutes to discuss third scenario*
- *10 minutes to discuss question # 6*

Now, I will give you three scenarios, and you have 10 minutes to come up with ideas and describe what you would do in each case. After that, I will ask you to share those ideas with the group. If you do not feel comfortable sharing some of your ideas with the group, you will not have to.

2- First scenario:

Imagine that YOU or YOUR PARTNER lost a baby (or if YOU or YOUR PARTNER have lost a baby think of your most recent loss), describe three things that YOU think YOU could have done to help avoid this loss.

3- Second scenario:

Imagine that SOMEONE IN YOUR FAMILY lost a baby (or if SOMEONE IN YOUR FAMILY has lost a baby think of the most recent loss), describe three things that YOU think YOU could have done to help avoid this loss.

4- Third scenario:

Imagine that SOMEONE IN YOUR COMMUNITY lost a baby (or if SOMEONE IN YOUR COMMUNITY has lost a baby think of the most recent loss), describe three things that YOU think YOU could have done to help avoid this loss.

5. Follow up questions for each scenario.

First scenario: Participants will share and elaborate about their ideas, after each idea the facilitator will ask:

5a. Who else in the group had the same idea?

Second scenario: Participants will share and elaborate about their ideas, after each idea the facilitator will ask:

5b. Who else in the group had the same idea?

Third scenario: Participants will share and elaborate about their ideas, after each idea the facilitator will ask:

5c. Who else in the group had the same idea?

6. What type of outside support do you think your community needs to solve this problem?

Fill out “Exit Questionnaire” (5 minutes)

SCENARIOS

Do you know someone who has lost a baby?

- Yes
- No

If yes, who was that person? Check all that apply

- Myself or my partner
- Someone in my family
- Someone in my community

First Scenario: Imagine that YOU or YOUR PARTNER lost a baby (or if YOU or YOUR PARTNER have lost a baby think of your most recent loss), describe three things that YOU think YOU could have done to help avoid this loss

1 st Thing* I could have done	2 nd Thing* I could have done	3 rd Thing* I could have done

Second Scenario: Imagine that SOMEONE IN YOUR FAMILY lost a baby (or if SOMEONE IN YOUR FAMILY has lost a baby think of the most recent loss), describe three things that YOU think YOU could have done to help avoid this loss.

1 st Thing* I could have done	2 nd Thing* I could have done	3 rd Thing* I could have done

Third Scenario: Imagine that SOMEONE IN YOUR COMMUNITY lost a baby (or if SOMEONE IN YOUR COMMUNITY has lost a baby think of the most recent loss), describe three things that YOU think YOU could have done to help avoid this loss.

1 st Thing* I could have done	2 nd Thing* I could have done	3 rd Thing* I could have done

*If can be anything that YOU could have done before pregnancy, during pregnancy, or after the baby was born.

EXIT QUESTIONNAIRE

Are you?

- Male
- Female
- Other

Are you? (Check only one box)

- Fijian
- Guamanian or Chamorro
- Marshallese
- Maori
- Native Hawaiian
- Samoan
- Tongan
- Other (specify)

Are you?

- Single
- Married
- Divorced
- Widowed

How old are you?

- Between 18 and 29 years old
- Between 30 and 45 years old
- 46 or older

What is your education?

- Less than high school
- High school or GED
- Some college but no degree
- Associate degree
- Bachelor's degree
- Master or doctoral degree

How probable is for you to participate in (check one box per row)?

	Highly Probable	Probable	Not Probable
Online educational sessions without the option of interacting with other community members			
Online educational sessions with the option of interacting with other community members			
Face to face educational sessions with other community members			
Develop a project by myself			
Develop a project with other members of my community			

Is there is anything that you would like to add that you did not feel comfortable sharing with the group today. Please use the back of this sheet to write it down. We will keep this information anonymous and confidential. Thanks!