How the

Rest of their Lives Affects Pregnancies

of Pacific Islanders and African Americans in Utah

April Young Bennett, Principal Investigator

2012 Birth Certificate Analysis by Laurie Baksh

UTAH DEPARTMENT OF HEALTH

Office of Health Disparities

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Executive Summary

Pacific Islander and African American women in Utah have a history of poor pregnancy outcomes, including high infant mortality rates and high rates of preterm birth. In 2012, compared with Non-Hispanic White mothers, both Pacific Islander and African American mothers had higher rates of obesity and overweight, gestational diabetes, chronic hypertension, preterm birth history, short birth intervals and lack of first trimester prenatal care.

The Utah Department of Health (UDOH), Office of Health Disparities (OHD) sought to learn more about the social determinants of health leading to poor birth outcomes among these minority groups by interviewing Utah Pacific Islander and African American mothers who experienced an infant mortality, fetal death or preterm birth during the time period from January-August 2013.

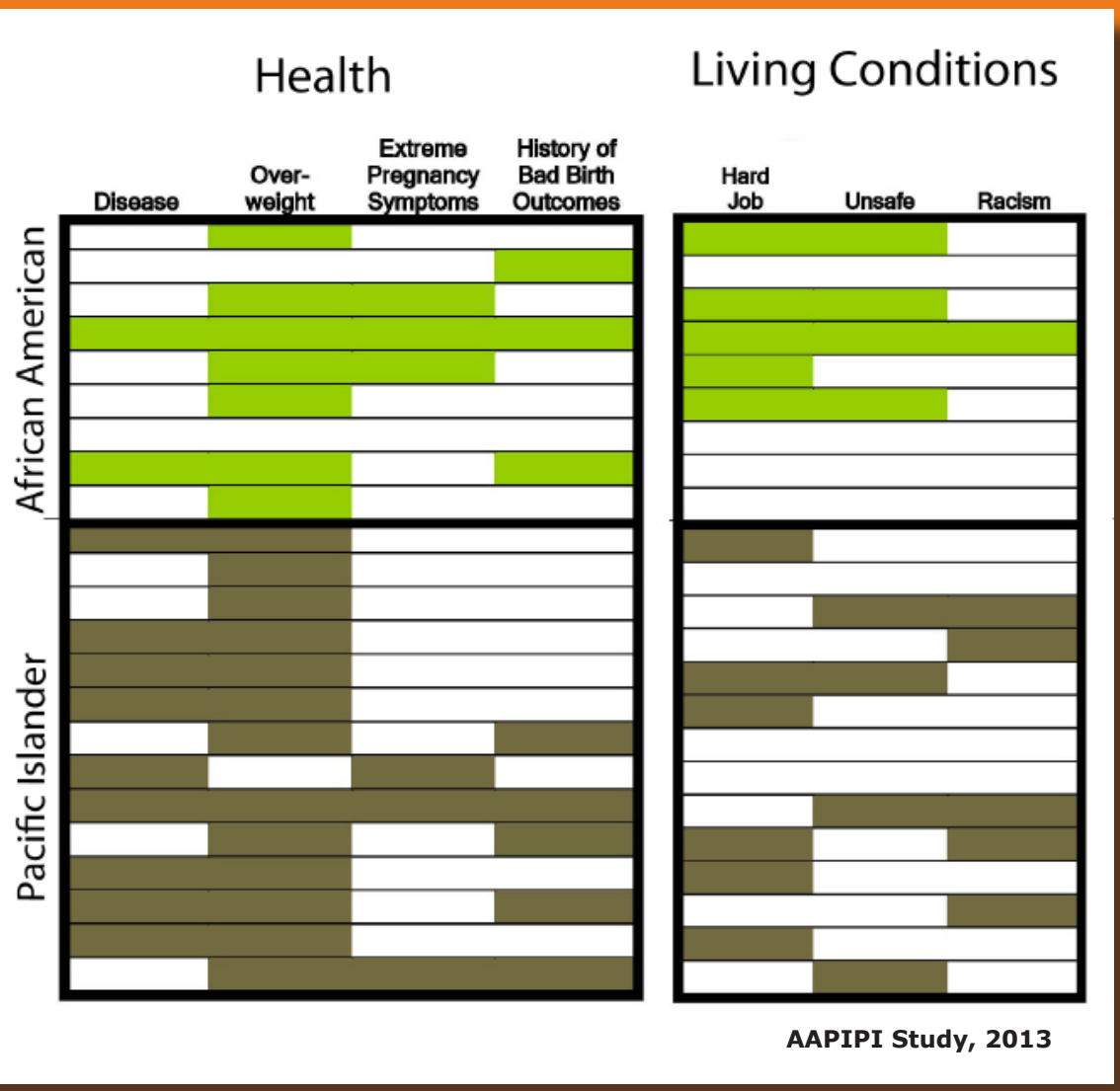
The investigators compared prevalance data from 2012 Utah birth certificates of infants born to White, Pacific Islander and African American women. They collected and analyzed data from all of the birth, death and fetal death certificates of Utah Pacific Islander and African American mothers who experienced a poor birth outcome such as an infant mortality, fetal death or preterm birth from January-August 2013 and contacted all of the women in this cohort 4-8 months later to request written surveys and detailed interviews about the circumstances surrounding the women during the year before the adverse birth outcome took place, such as work and income, living conditions, social support, important life events and access to health care. The women were also asked for their personal perspectives on how their pregnancy experience could have been improved.

African American and Pacific Islander Postnatal Interview Study (AAPIPI) participants described conditions in their lives during the year before the birth, stillbirth or infant mortality such as unsafe living conditions, problems with finances, relationship problems, encounters with racism and other stressors. High proportions of these mothers were obese, did not take folic acid, and had unplanned pregnancies.

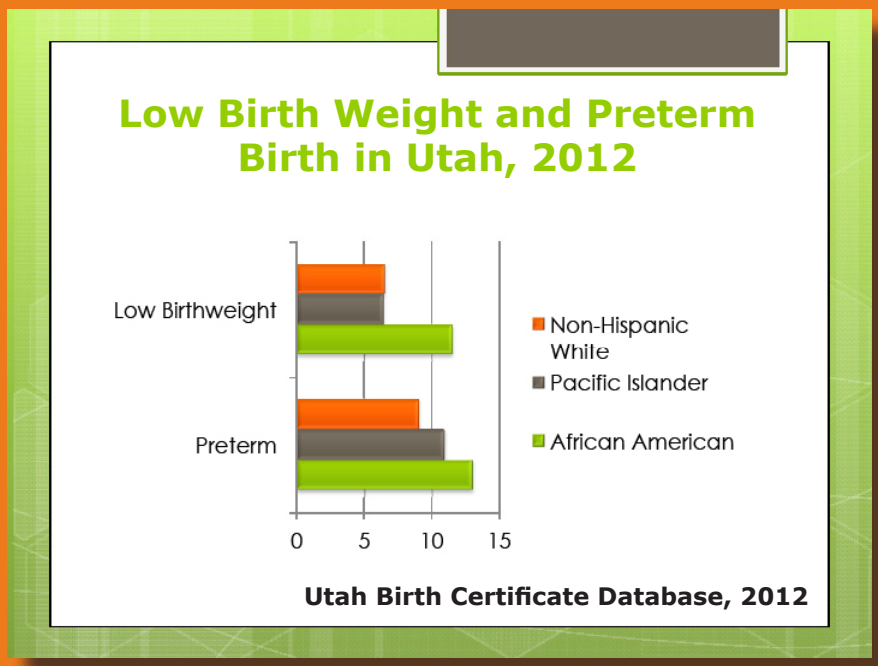
Study recommendations include supporting the whole woman instead of focusing unilaterally on health, concentrating health promotion efforts before and between pregnancies, and explaining and offering resources thoroughly and frequently.

Each row on the chart represents one of the study participants and the problems and stressors she experienced during the year prior to the poor birth outcome. Most of the women in the cohort were overweight or obese prior to pregnancy. Other common problems included chronic illnesses such as hypertension or diabetes, a history of poor birth outcomes, physically hard or emotionally stressful jobs, unsafe working or living conditions, poverty, financial problems such as inability to pay bills, compromised access to social support, and relationship problems.

Problems Reported By Utah African American and Pacific Islander Mothers During the Year Prior to a Preterm Birth, Stillbirth or Infant Mortality



AAPIPI Study, 2013



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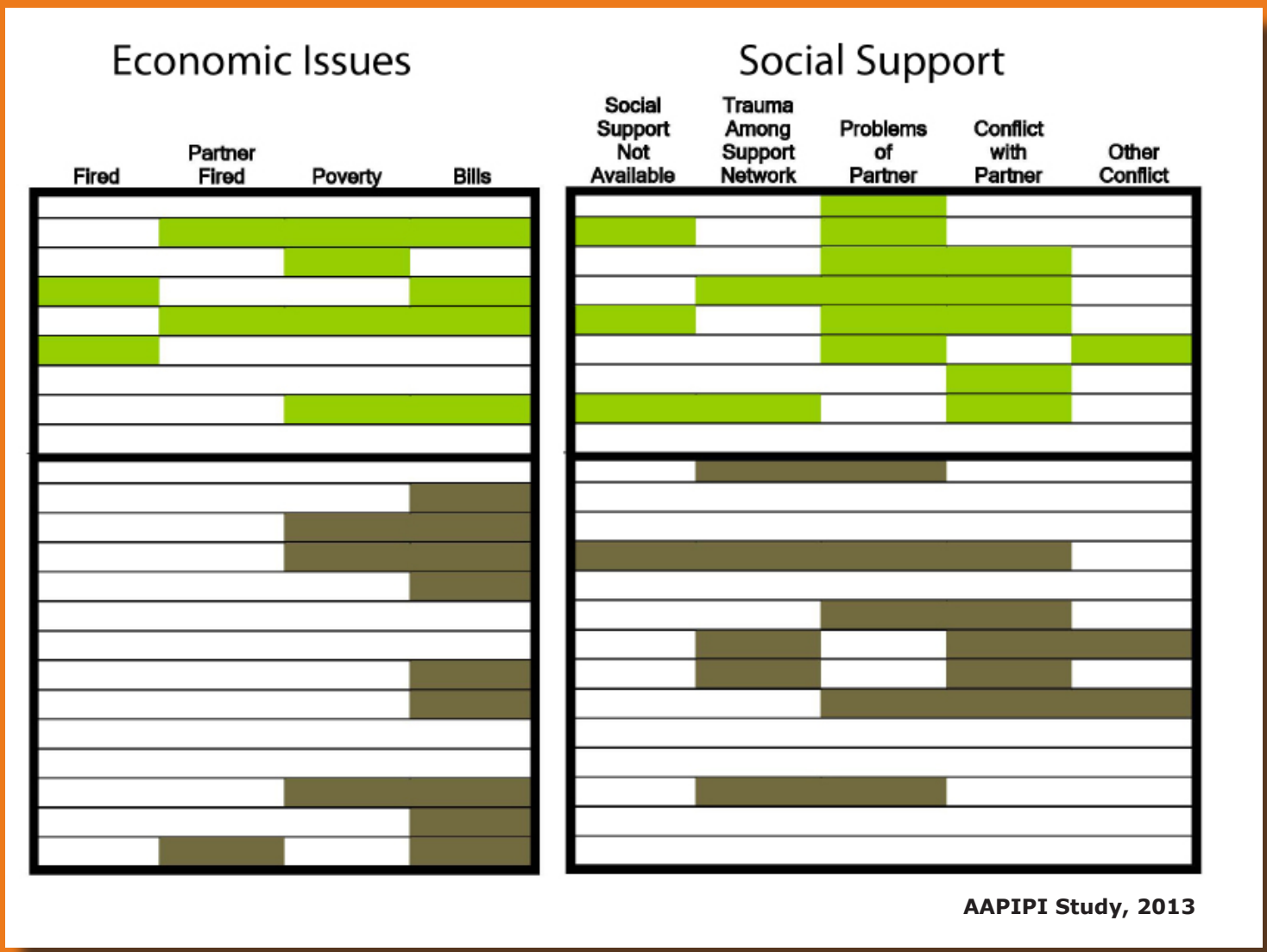
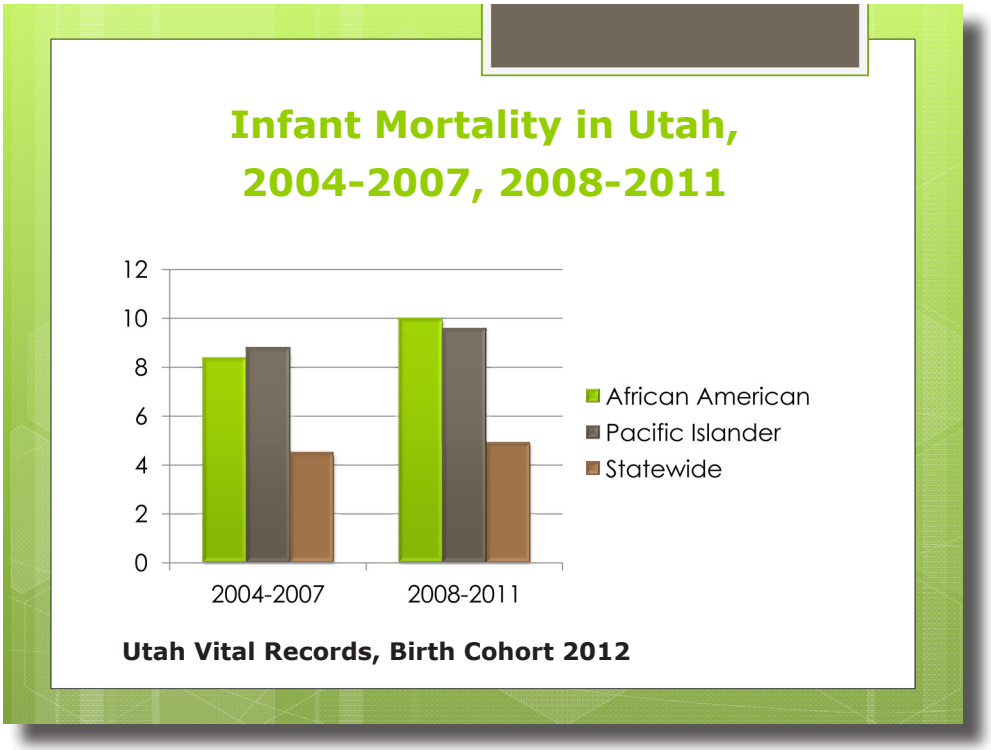


Background

The Utah Department of Health, Office of Health Disparities (OHD) began focusing on birth outcomes among Utah Pacific Islanders[1] and African Americans or Blacks in 2009, after analyzing data that showed that infants of these racial groups were about twice as likely to die within the first year of their birth as other infants statewide.[2]

1 The term "Pacific Islander" as used in this report refers to mothers who reported their race as Native Hawaiian, Tongan, Samoan, Guamian, or other Pacific Islander on their child's birth or fetal death certificate.
2 http://health.utah.gov/disparities/data/disparitiessummary/blackfactsheet.pdf and http://health.utah.gov/disparities/data/disparitiessummary/PacificIslanderFactSheet.pdf



Because Pacific Islanders are such a small racial group in the United States, there was very little information about Pacific Islanders in the literature to inform this effort. Likewise, the Utah Behavioral Risk Factor Surveillance System (BRFSS) did not reach a large enough sample of Pacific Islanders and was not administered in Samoan or Tongan. OHD recruited other Utah Department of Health programs to assist OHD in funding a statewide, multilingual study of Pacific Islander health, the Utah Pacific Islander Survey (UPIS) and involved local Pacific Islander groups to ensure the cultural appropriateness of the study, which may have been the first of its kind addressing Pacific Islanders in the continental United States.[3] A peer-reviewed article about the study, *Developing a Multilingual Questionnaire and Surname List to Sample Utah Pacific Islanders*, by Bennett, Friedrichs, Nickerson and Díez was published in the Journal of Public Health Management and Practice.[4] This article addresses the gap in knowledge about Pacific Islander health in the continental United States and explains methodology that may be useful in other states for sampling a variety of small population groups that aren't reached effectively through the BRFSS.

Locally, the UPIS study results were used to raise awareness of Pacific Islander health issues in the media, improve health promotion

3 http://www.health.utah.gov/disparities/data/PacificIslanderReport2011.pdf
4 http://journals.lww.com/jphmp/Abstract/2013/03000/Developing_a_Multilingual_Questionnaire_and.19.aspx

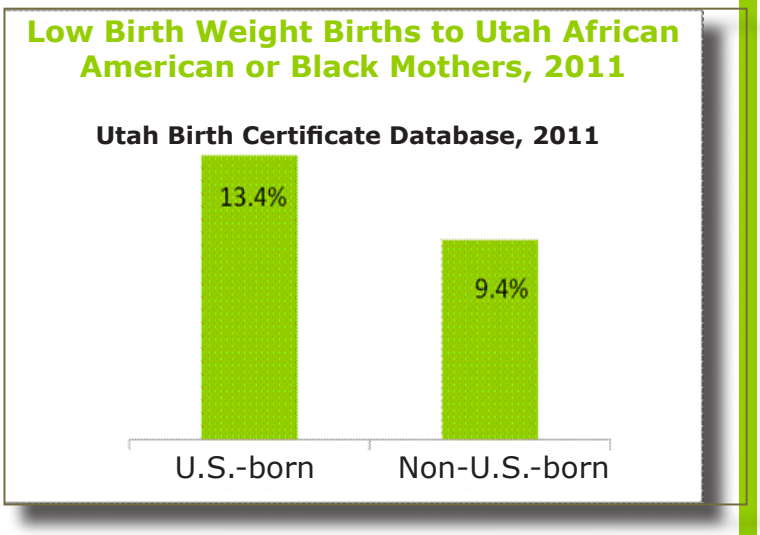
materials such as health videos, develop outreach programs for preventive care clinics and government health programs such as Medicaid, and plan statewide policy changes to reduce preterm birth in cooperation with the March of Dimes Prematurity Summit. Five Pacific Islander employees were hired by UDOH to work on this study and these employees continued employment after its completion, increasing Utah's institutional capacity to serve Pacific Islanders in the future. In collaboration with UT OHD, several Utah Pacific Islander community-based organizations, faith-based organizations and networks organized to improve outreach to the Utah Pacific Islander community. The Utah Pacific Islander community is organized within community organizations, cultural centers and churches that have become mobilized around the issue of infant mortality. These community groups have amplified OHD efforts by distributing OHD videos, reports and materials and increasing participation in OHD coalitions and events. During the years that followed, OHD and its community partners were successful at increasing Utah Pacific Islander rates of folic acid consumption and early prenatal care increased while rates of obesity during pregnancy decreased.[5]

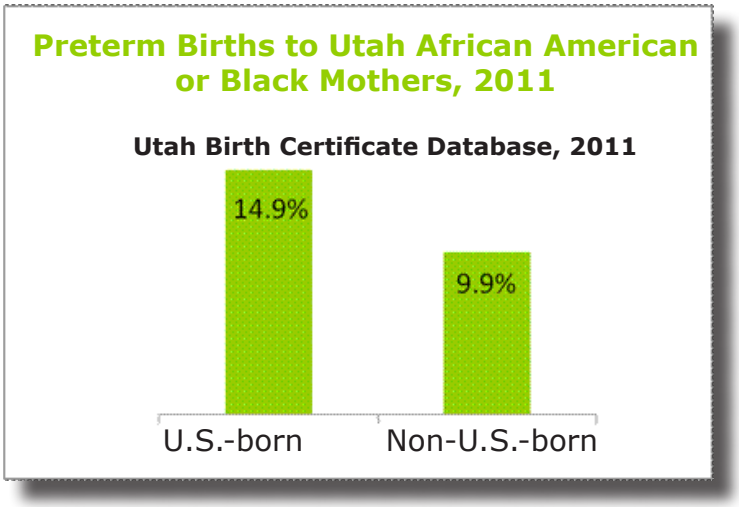
Similar outreach efforts were conducted among Utah African Americans or Blacks, but these efforts did not include a local study of the magnitude of the Utah Pacific Islander Survey. A surname-based study is not a feasible option for African Americans because they commonly have Anglo surnames.

Further investigation clarified that the low birth weight and preterm birth problems among African Americans or Blacks were actually concentrated among U.S.-born African American women. Preterm birth affected 14.9% of infants born to U.S.-born African Americans or Blacks, compared to 9.9% of Non-U.S.-born African Americans or Blacks and low birth weight affected 13.4% of infants born to U.S.-born African Americans or Blacks, compared to 9.4% of Non-U.S.-born African Americans or Blacks in 2009-2011.[6] This report will focus solely on U.S.-born African Americans or Blacks, referred to henceforth simply as "African Americans."

5 http://health.utah.gov/disparities/AboutCMH/2012legislativereport.pdf

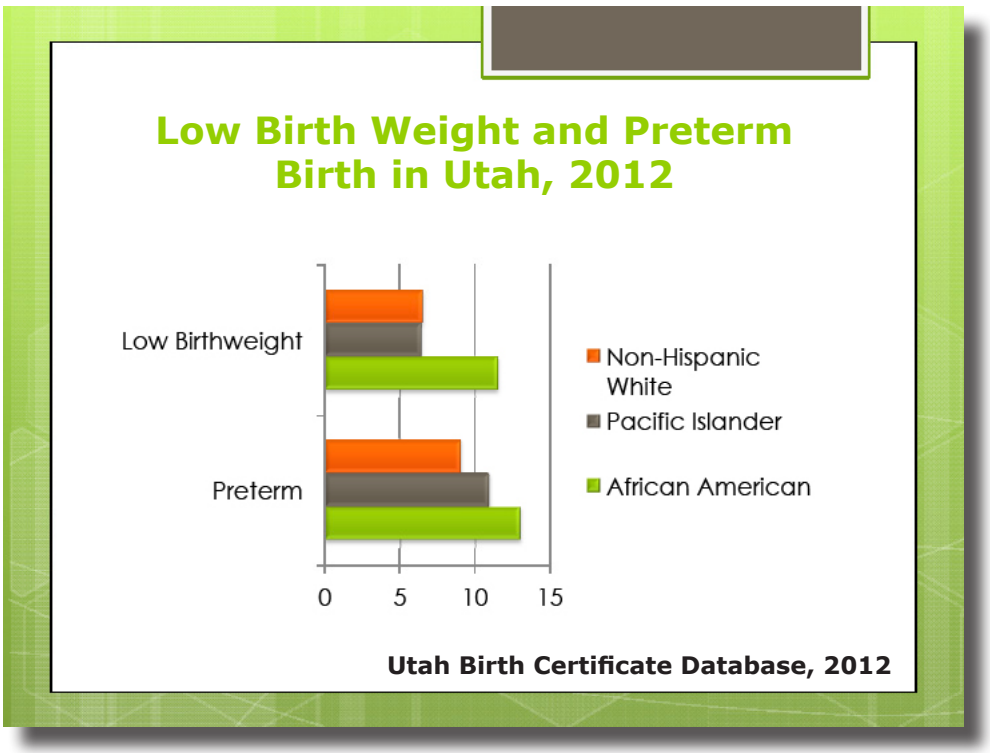
6 Utah Birth Certificate Database 2006-2011, Utah Department of Health.





Examination of 2012 Utah birth certificate data showed that 11.5% of infants born to African American mothers in Utah were preterm, significantly higher than the rate of preterm births among Non-Hispanic Whites, which was 9.0%. Utah African Americans also had a higher rate of low birth weight (11.5%) compared to Non-Hispanic White infants (6.5%).

In an effort to address the infant mortality problem among Utah Pacific Islanders and African Americans, OHD conducted the African American and Pacific Islander Postnatal Interview Study (AAPIPI) to learn more about the social determinants of health affecting mothers in Utah of these racial/ethnic groups who experience poor birth outcomes.



The World Health Organization defines social determinants of health as follows: "The social determinants of health are the conditions in which people are born, grow, live, work, and age, including the health system. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status."[7]

7 http://www.who.int/social_determinants/en/

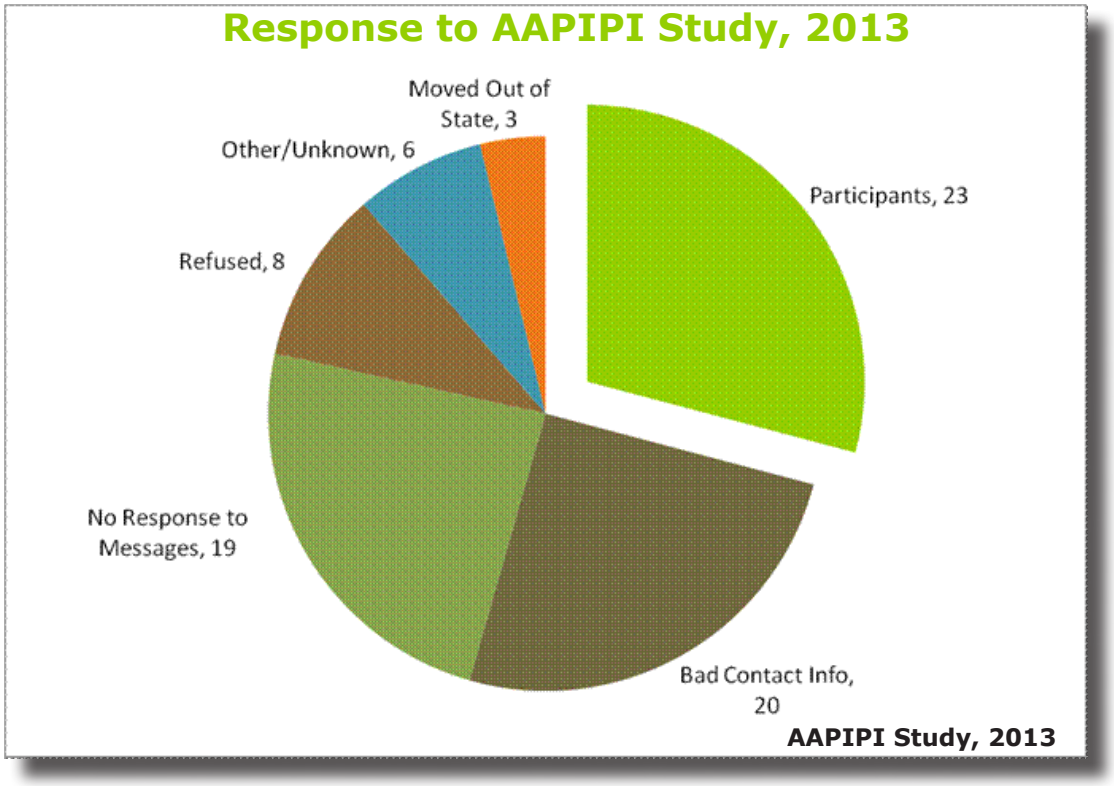
Methods

Using vital records to identify eligible study participants, OHD attempted to contact all women who met the following criteria:

- Delivered a stillborn infant after 24 weeks gestation, delivered a living infant between 24 and 36 weeks gestation, or whose infant died due to perinatal conditions within one year of its birth.
- Identified themselves on the birth or fetal death certificate as Black/African American and indicated a birthplace within the United States of America or identified themselves as Pacific Islander (any bithplace).
- Experienced this adverse event at least four months prior to the interview but no more than eight months prior to the interview. This cohort included Pacific Islander or African American women who experienced an adverse event from January to August of 2013.

This cohort included records from 79 women, including 32 African Americans and 47 Pacific Islanders. Of these, three had moved out of state, current contact information could not be found for 20, messages were left for 19 with no response (working numbers were called, but whether the women were still at those numbers is unknown), and eight chose not to participate in the study. Utah OHD successfully attained supplementary information via written survey and/or verbal interview from 23 women (29%), including nine African Americans (28%) and 14 Pacific Islanders (30%).

Data were collected by examining the women's birth certificates and through written, quantitative surveys followed by qualitative, in-person interviews at the woman's home or location of her choice. Women who did not complete the written survey prior to the in-person interview received the quantitative questions verbally from the interviewer.



All Pacific Islander study participants were interviewed by Pacific Islander interviewers and all African American study participants were interviewed by African American interviewers. Interviews were electronically recorded and transcribed.

Interview and survey questions were based on the National Fetal and Infant Mortality Review (NFIMR) by American College of Obstetricians and Gynecologists and the Maternal and Child Health Bureau of the Health Resources and Services Administration, the Pregnancy Risk Assessment Monitoring System (PRAMS) of the Centers for Disease Control and Prevention and the Utah Pacific Islander Survey (UPIS) conducted by the Utah Department of Health, Office of Health Disparities in 2011.

The Utah Department of Health Internal Review Board approved this study.

Interviewers were unable to reach about half of the women in the cohort because they did not respond to messages or have a working phone number. These populations appear to be highly mobile, with many of the participants having moved since the qualifying event 4 to 8 months prior.

Mothers were asked about virtually every aspect of their lives in the year leading up to a poor birth outcome. The study took an inductive reasoning approach, looking for patterns among the variety of experiences the women reported.[1] However, it should be noted that every pregnancy is different and every woman is different. While we did find some patterns and similarities, each woman also had unique experiences. Consider how these two African American mothers summarized their pregnancies:

"It was a perfect pregnancy. I didn't have any problems. …That's why this is a mystery." –African American mother

"I'm just glad it's over. It was hard. It was the hardest nine months. It was hard." –African American mother

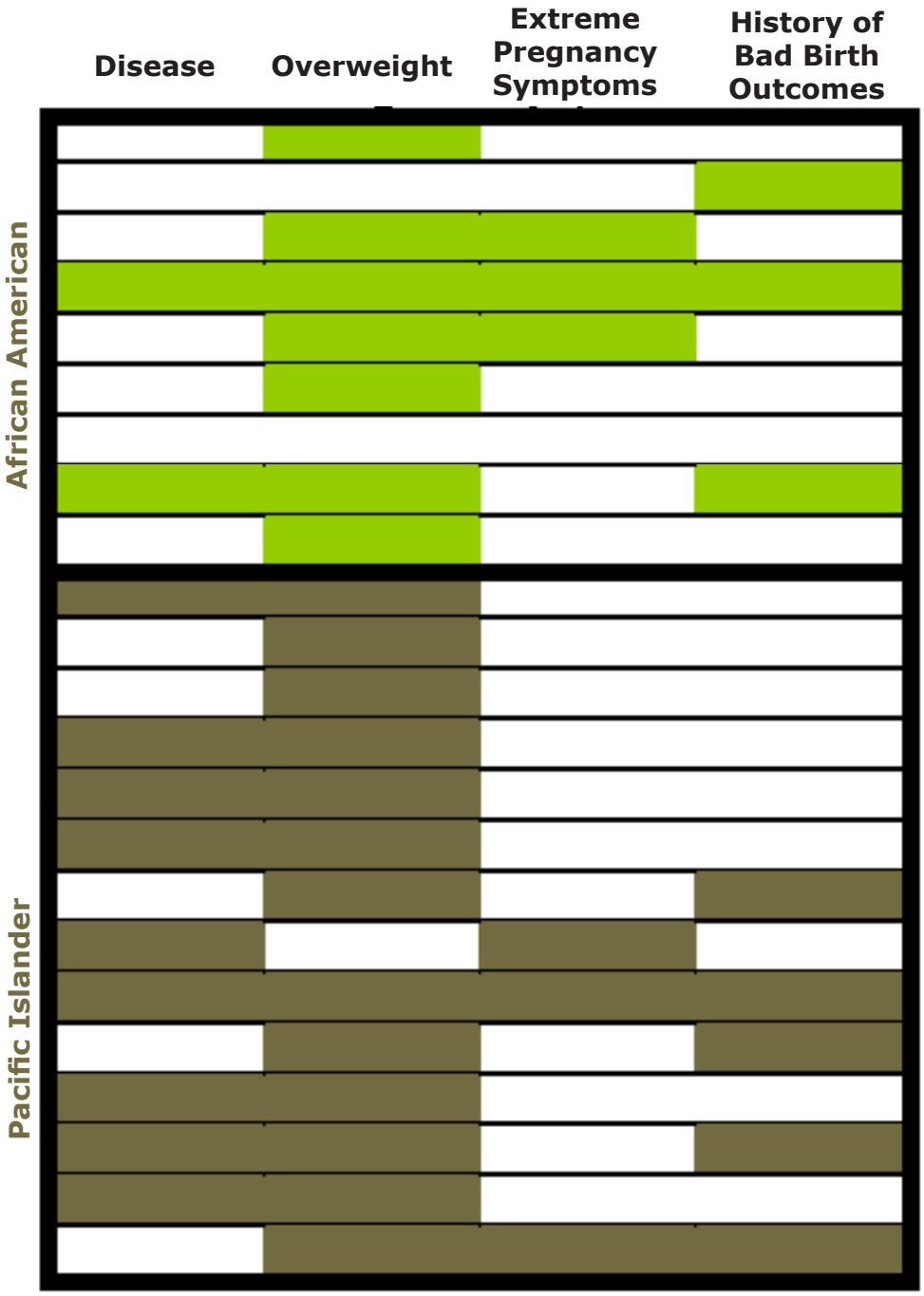
1 http://www.socialresearchmethods.net/kb/dedind.php

Mother's Health

Each row of this table represents a study participant, with African American participants on the upper rows in green and Pacific Islanders in the lower rows in brown. Data from the women's birth certificates, quantitative surveys, and qualitative interviews were collated to complete the table. If a problem was found in any of these sources, it was marked in color on the table.

The most common problem among the study participants was being overweight or obese at the time they became pregnant. Several participants also had other health

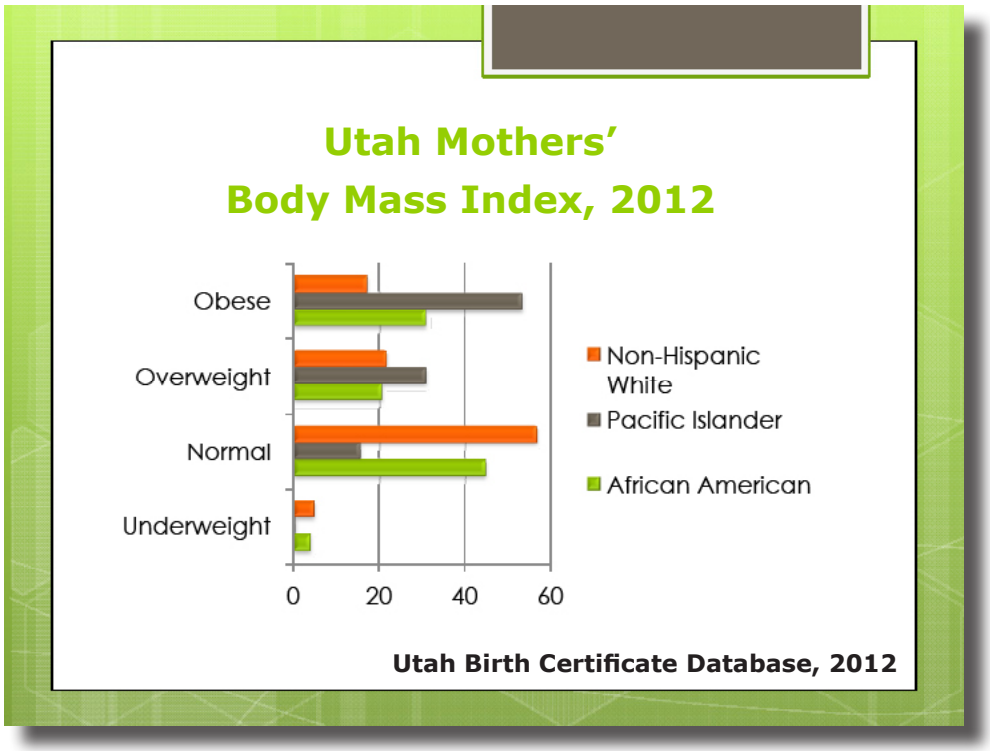
Problems Reported By Utah African American and Pacific Islander Mothers During the Year Prior to a Preterm Birth, Stillbirth or Infant Mortality.

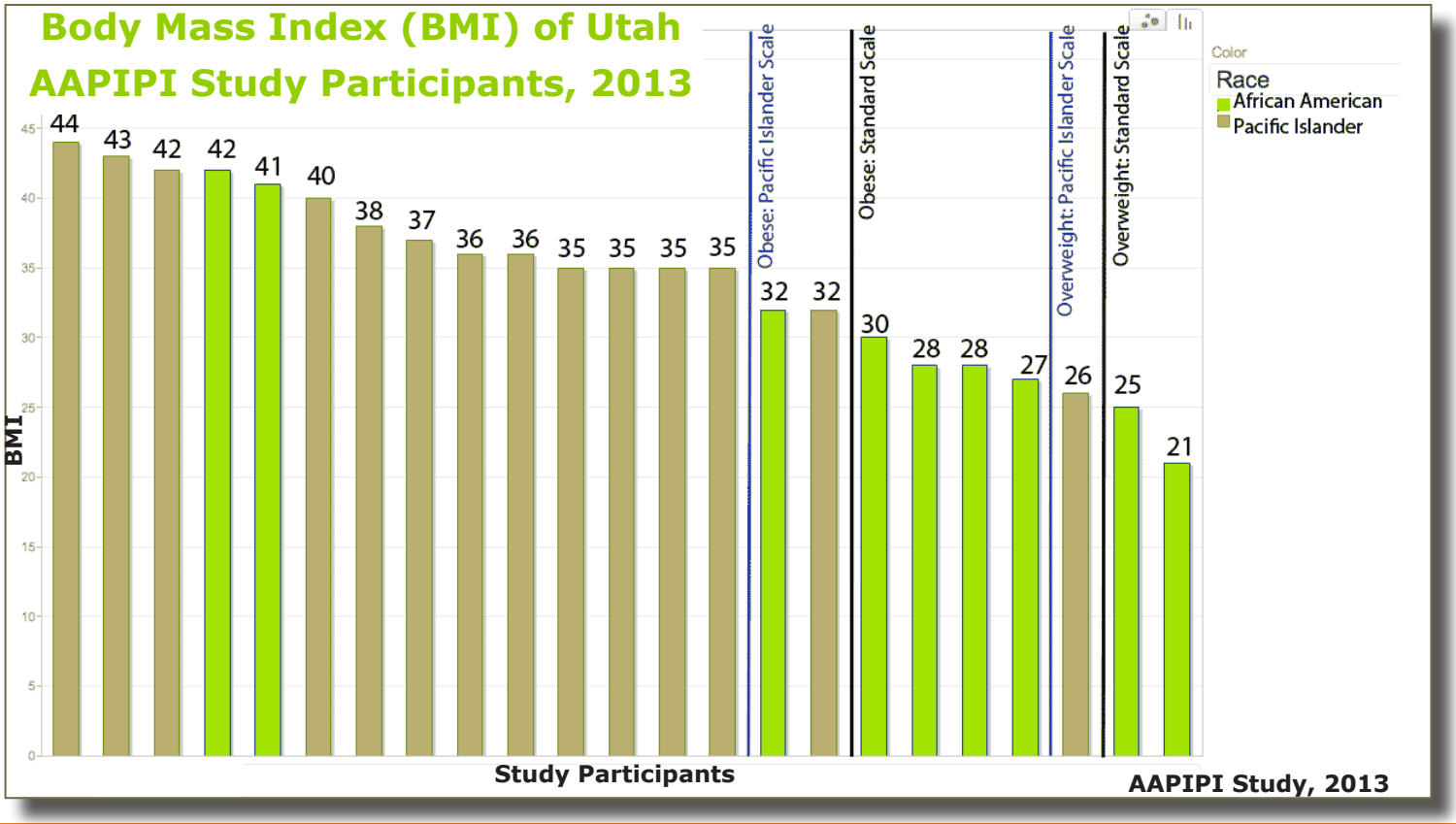


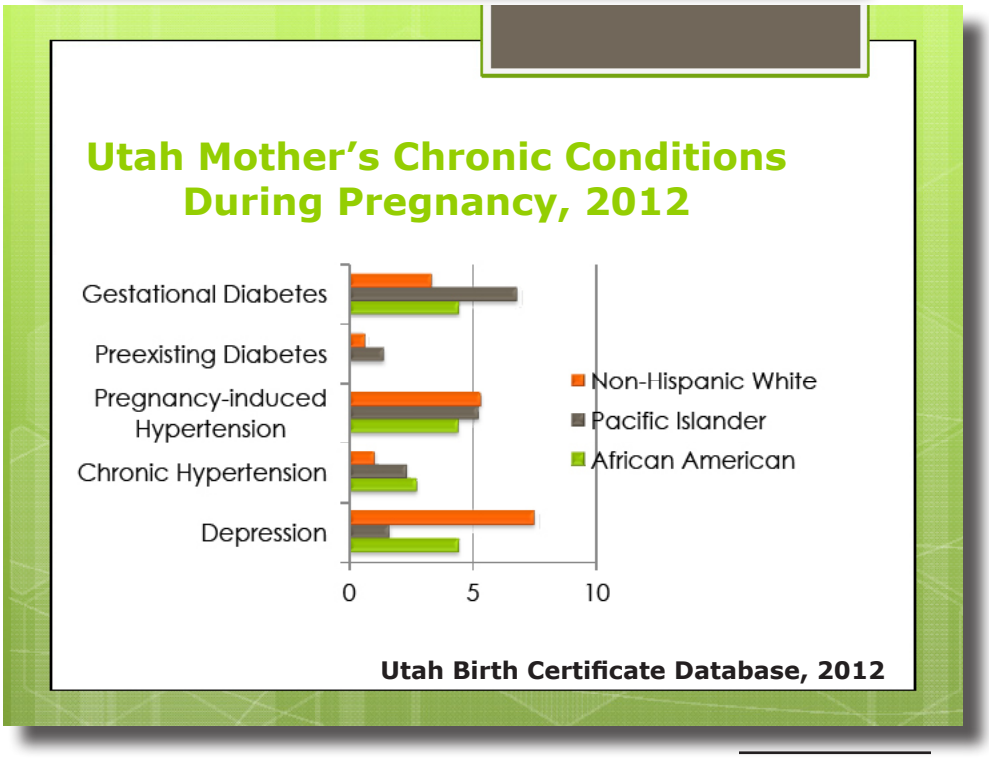
AAPIPI Study, 2013

problems, such as chronic hypertension, gestational diabetes, diabetes, or other chronic illnesses and histories of poor birth outcomes. The category, "Extreme Pregnancy Symptoms," refers to women who reported unusually taxing experiences with morning sickness and other pregnancy symptoms, such as becoming dehydrated and needing emergency room intervention.

Overweight and obesity during pregnancy increase risk of stillbirth, preterm birth, high blood pressure, preeclampsia, gestational diabetes, labor complications, and giving birth to a baby with birth







defects, injuries, and higher risk of infant mortality.[2]

Among the full population of mothers who gave birth in 2012, 30.9% of African American women were obese and 53.3% of Pacific Islander women were obese, compared to 17.0% of Non-Hispanic White women.

Some studies suggest that Pacific Islanders have a body type that can be healthy with a slightly larger Body Mass Index (BMI) than can be tolerated by people of European descent.[3] Researchers have developed a BMI scale specifically for Pacific Islanders. According to the Pacific Islander scale, overweight is a BMI higher than 26, instead of 25, and obese is a BMI higher than 32, instead of 30.[4]

Taking the Pacific-Islander scale into account, only one Pacific Islander study participant was at a healthy BMI, one was overweight, and 12 were obese. Among African American study participants, two were at a healthy BMI, four were overweight, and two were obese.

This statement, by an obese African American mother, highlights the need to address weight issues prior to pregnancy:

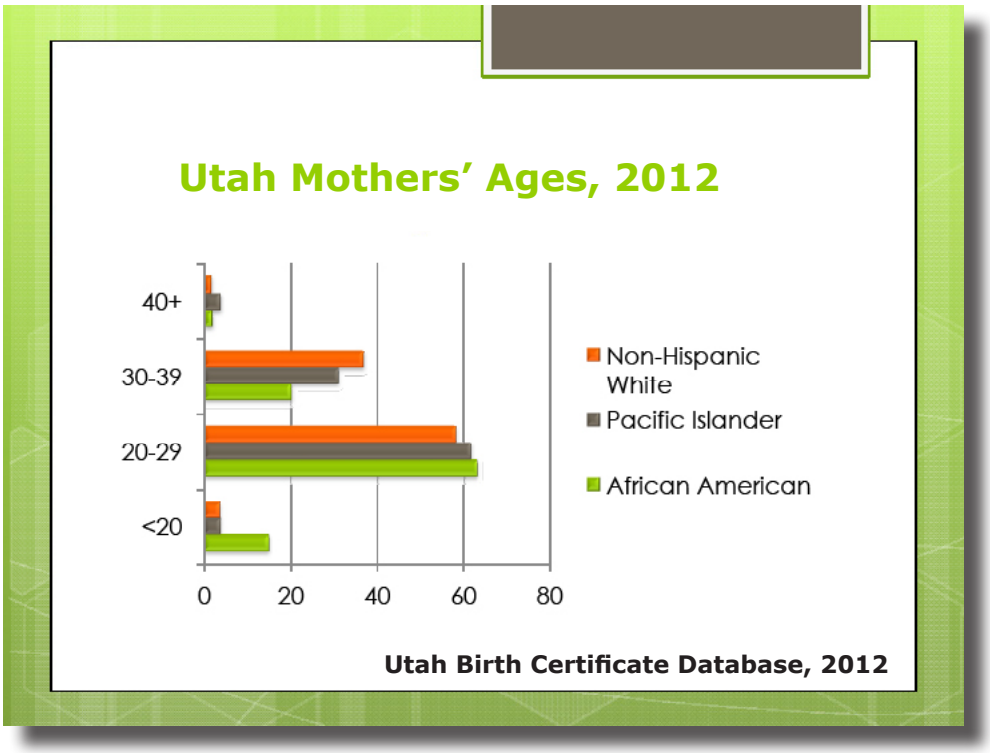
"I didn't exercise at all while

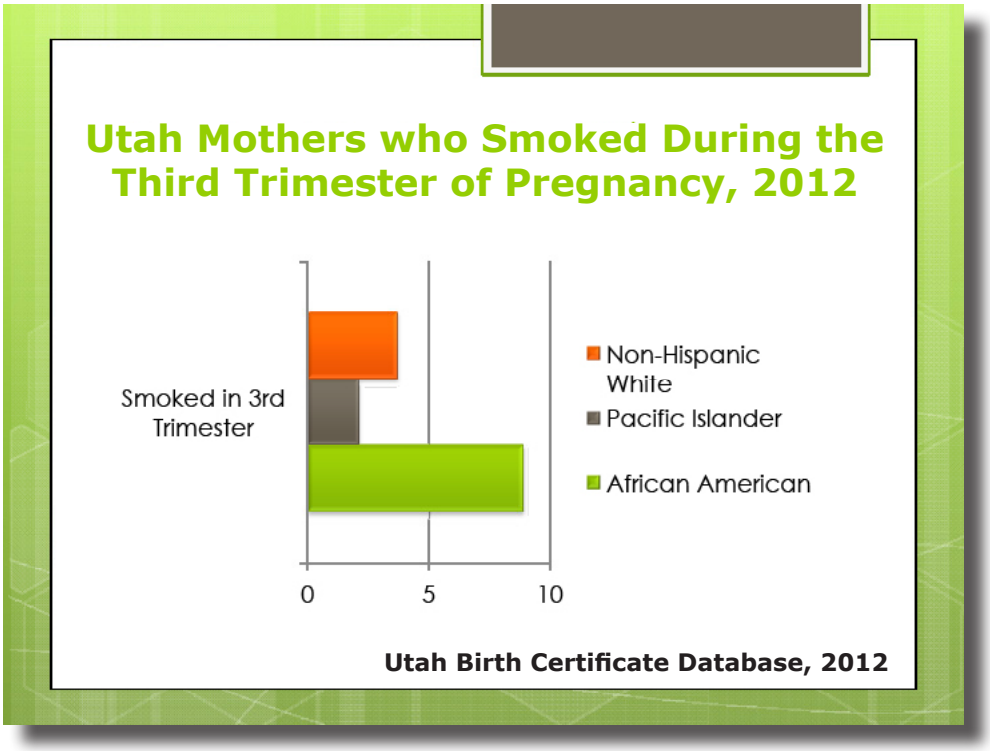
2 http://www.marchofdimes.com/pregnancy/overweight-and-obesity-during-pregnancy.aspx
3 http://apjcn.nhri.org.tw/server/APJCN/18/3/404.pdf and https://researchspace.auckland.ac.nz/bitstream/handle/2292/4675/15608799.pdf?sequence=1
4 http://ajcn.nutrition.org/content/72/5/1067.full.pdf

I was pregnant. I was too scared because I didn't really exercise that much before so I was worried that if I started something bad would happen. So I didn't." –African American mother

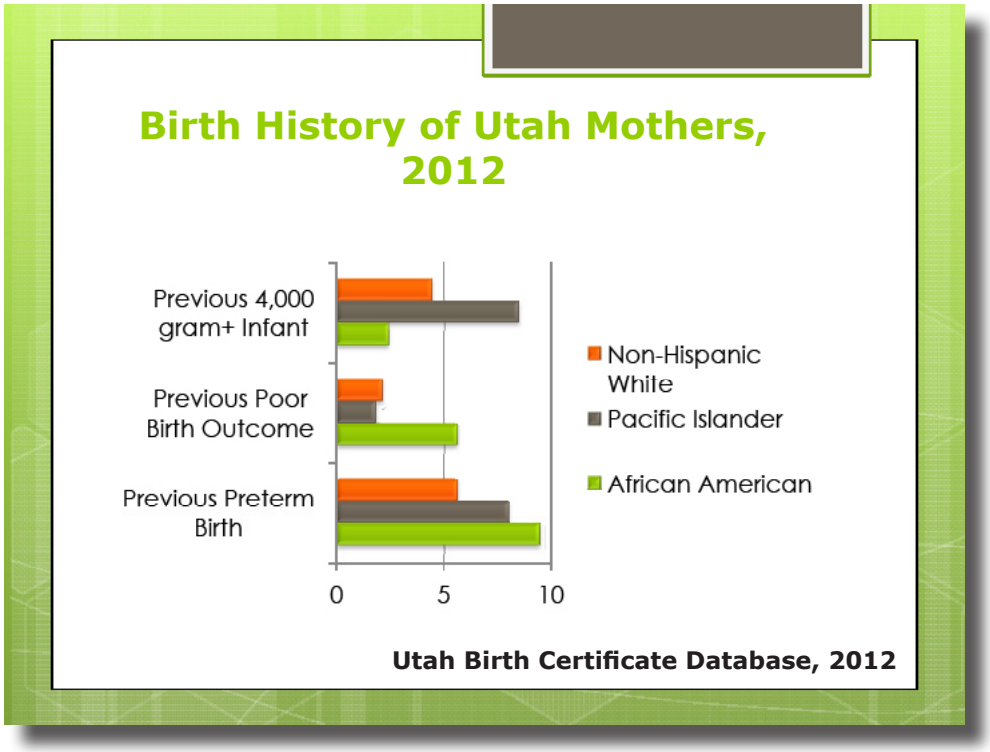
Among the full population of 2012 mothers who gave birth, African Americans and Pacific Islanders had significantly higher rates of chronic hypertension and Pacific Islanders also had higher rates of gestational diabetes. These conditions were common among study participants as well.

African Americans had higher rates of smoking during the third trimester of pregnancy and higher rates of teen pregnancy than Non-Hispanic White and Pacific Islander mothers in 2012. However, by a large majority, most African American mothers did not smoke during the third trimester of pregnancy (91.1%) and most were not teenagers (85.2%). Study participants included one teenager. All other mothers were in their 20's or 30's. Only one of the mothers interviewed smoked during pregnancy.





Pregnancy History & Family Planning



In 2012, 9.5% of African American and 8.0% of Pacific Islander mothers who gave birth in Utah already had a history of preterm birth, significantly more than the Non-Hispanic White population (5.6%). African Americans also had a significantly higher rate of other previous poor birth outcomes (5.6% compared to 2.1% for Non-Hispanic Whites) and Pacific Islanders were also significantly more likely to have a history of having an infant over 4,000 grams in size (8.5% compared to 4.4% for Non-Hispanic Whites).

Several of the study participants had a history of prior poor birth outcomes. Despite these previous experiences, some reported that they still felt uninformed and unprepared when they experienced pregnancy and birth complications again.

"I kind of wish that we would have had more information before, especially where I had had a previous pregnancy that was preterm. I wish that we maybe could have had more information at the beginning of my pregnancy about like this is what is going to happen if, more of like a game plan in place just in case this should happen again. Because

it felt, even though we had been through it before it still felt like a lot of it was kind of just happening right before our eyes before we had anything to say or do about it." –African American mother

When births are spaced 2½-3 years apart there is less risk of infant mortality and health complications for the mother.[5] In 2012, Utah African Americans and Pacific Islanders were more likely than Non-Hispanic White mothers to give birth to a child that was conceived before their previous child had reached its first birthday, with 25.8% of African American mothers and 37.4% of Pacific Islander mothers having a pregnancy interval of one year or less compared to 15.9% of Non-Hispanic Whites mothers.

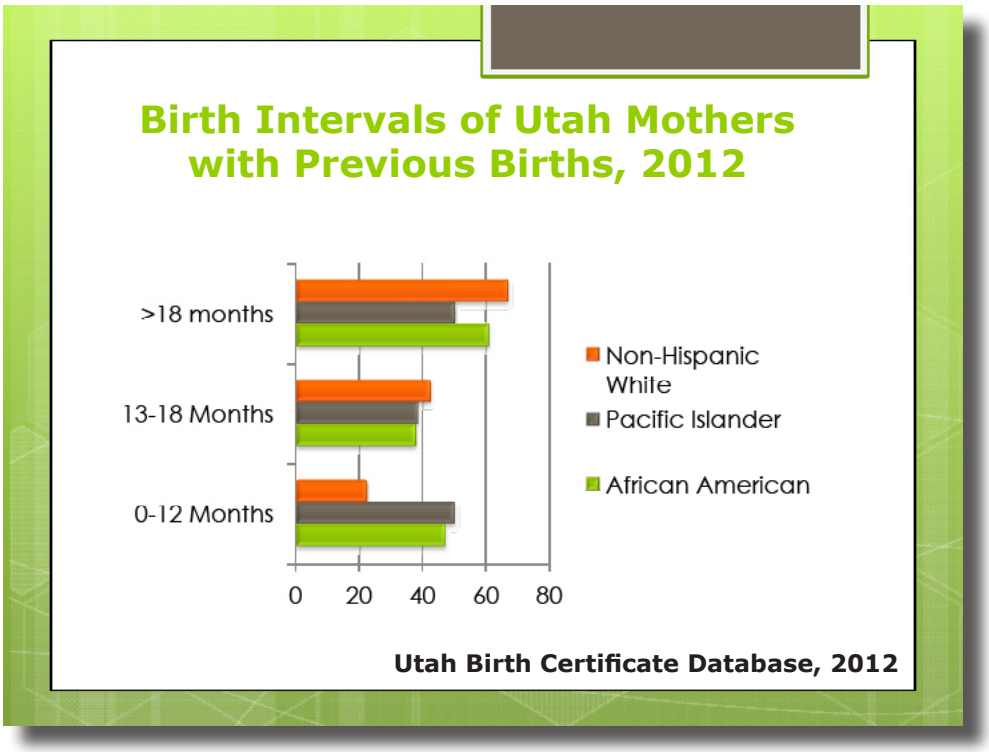
We asked study participants how they felt about becoming pregnant. A large proportion of the mothers had not wanted to become pregnant at that time or at all. If mothers were not planning a pregnancy nor doing anything to prevent a pregnancy at the time they became pregnant, we asked them why they weren't doing anything to keep from getting pregnant. Several mothers expressed ambivalence about family planning.

"I don't know. We were married and it just seemed like we had it under control." –African American mother

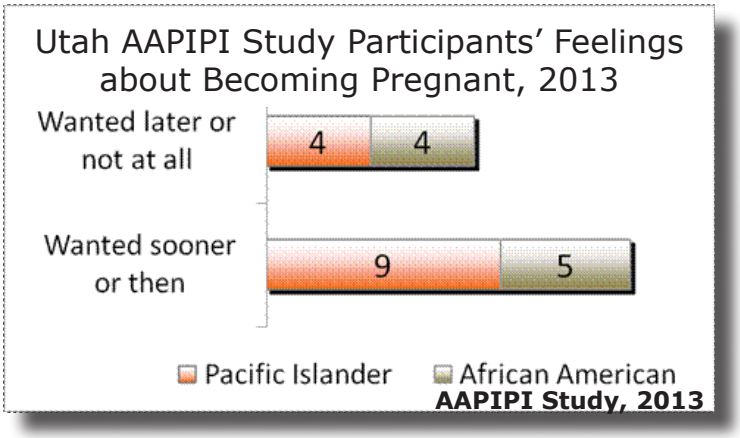
"We just didn't want to." –Pacific Islander mother

"I'm not a birth control believer. Birth control is not my thing. I never wanted it since I was a teenager so why plan now when I'm a mother and a wife. …It is more like I believe in the Tongan tradition. You know he is a family of nine. I'm a family of nine. You know, big families." –Pacific Islander mother

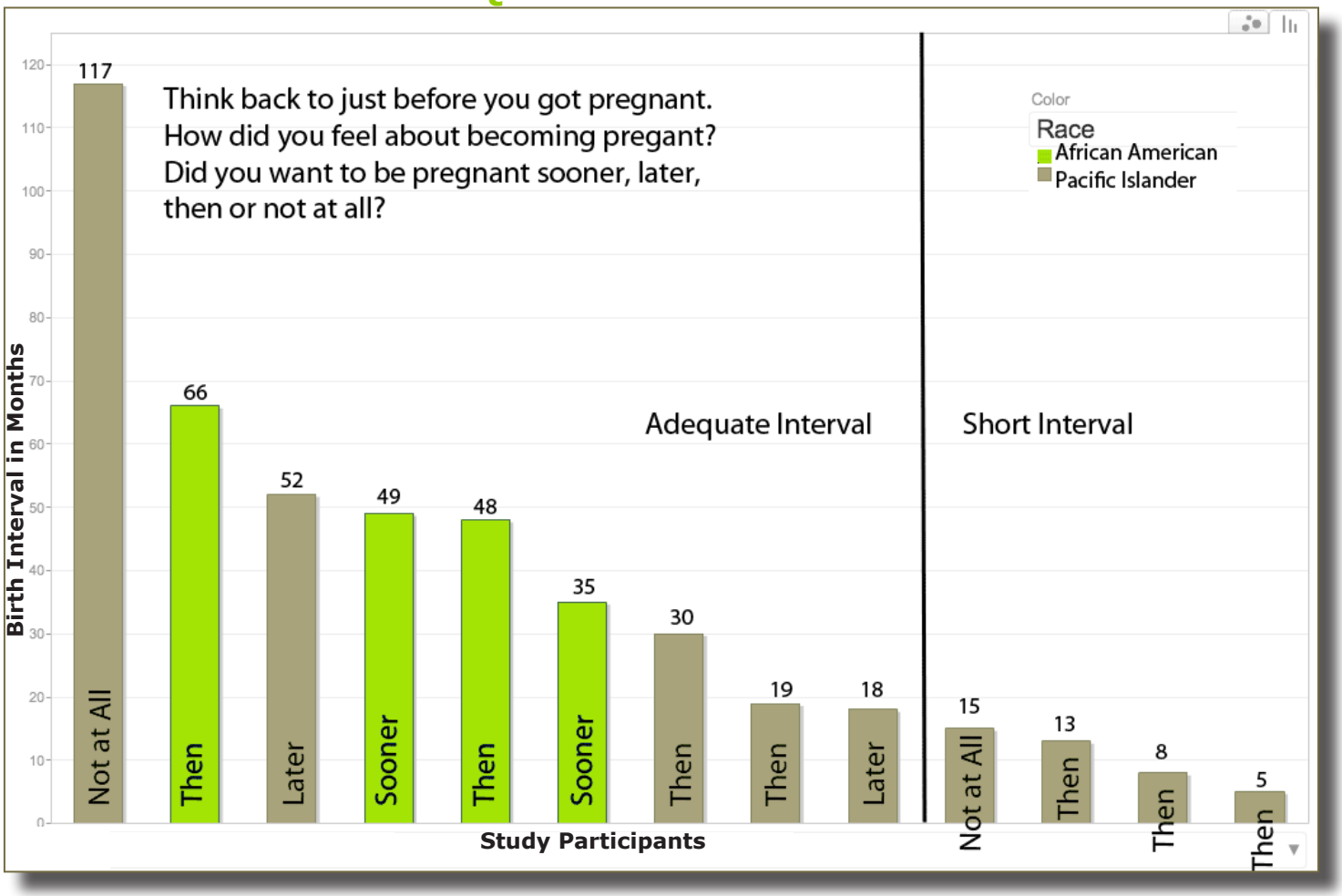
5 http://health.utah.gov/mihp/pregnancy/preged/afterpreg/Pregnancy_Spacing.htm



Among study participants who had already had a previous birth, there were four Pacific Islander women who had a pregnancy interval under 18 months. Interestingly, three of these women reported that they wanted a pregnancy at that time.

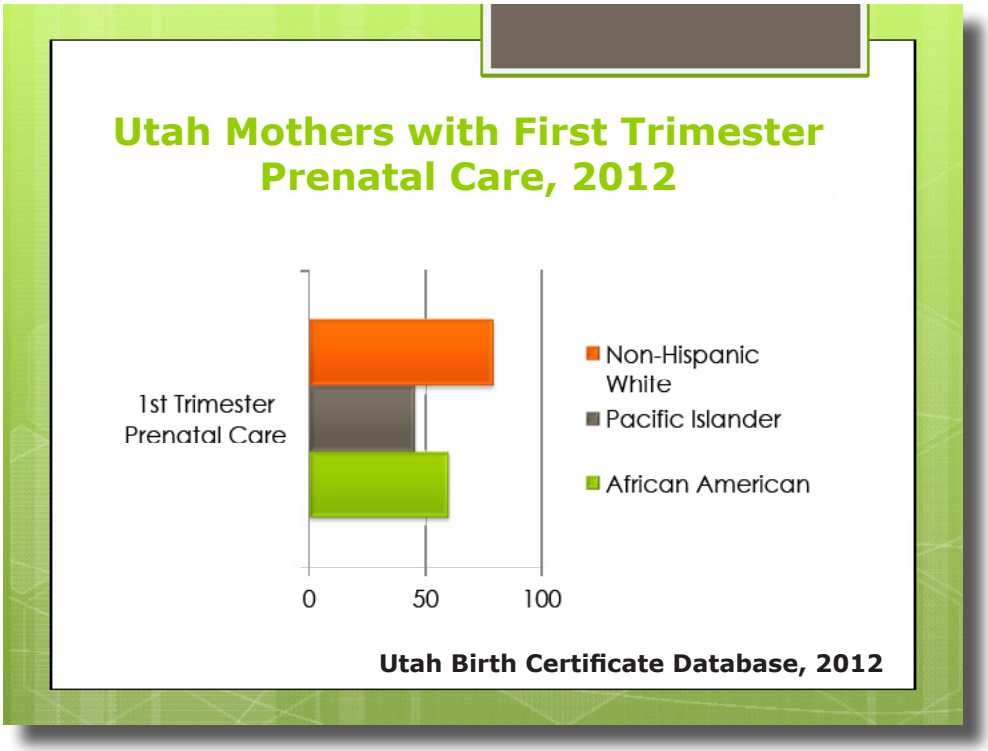


Birth Intervals of Utah AAPIPI Study Participants with Previous Births, 2013, and Their Answer to the Question:



AAPIPI Study, 2013

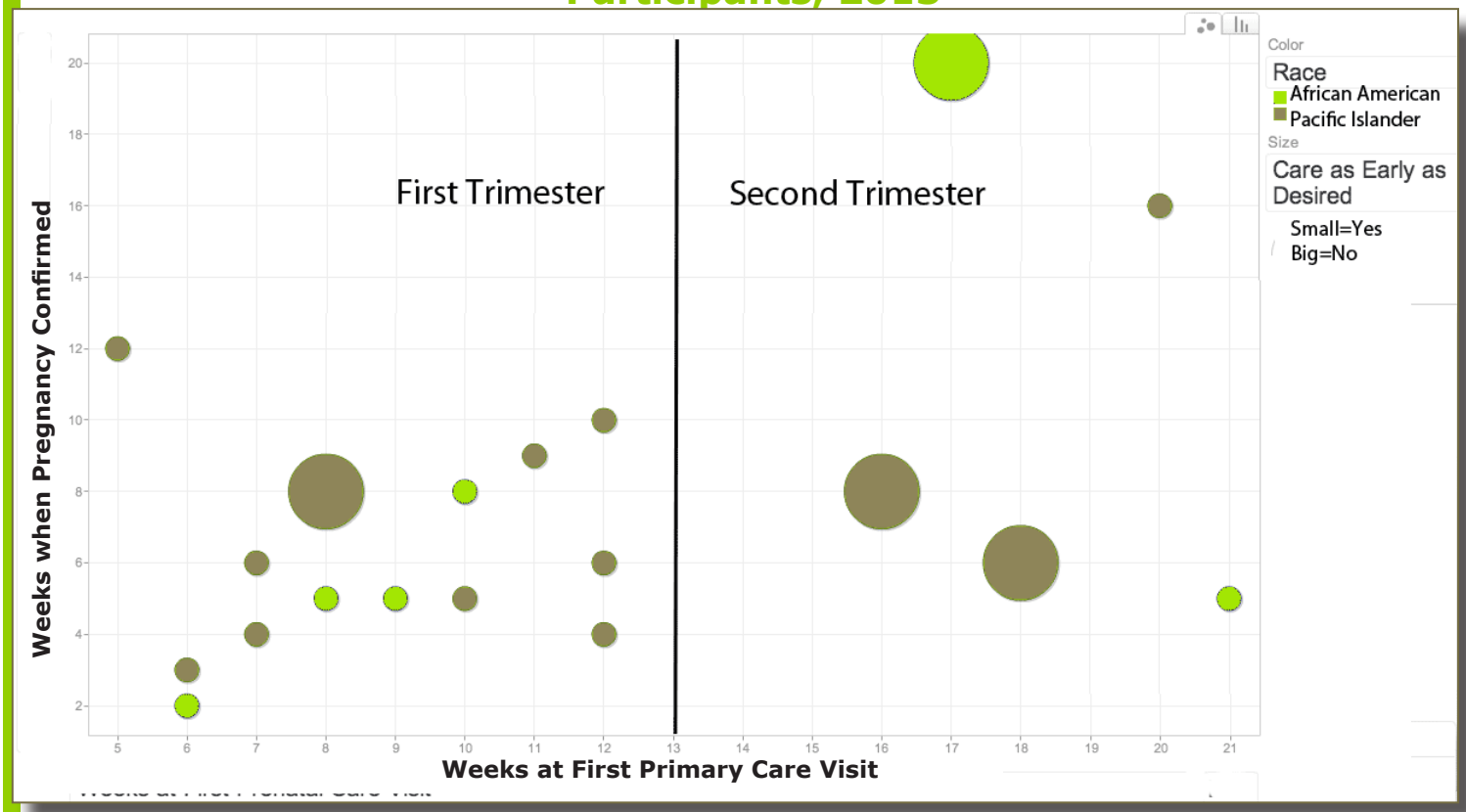
Prenatal Care



In spite of the fact that all of the participants in the study had poor birth outcomes, almost all participants expressed satisfaction with their prenatal care.

However, according to 2012 Utah birth certificate data, both Pacific Islanders and African Americans are significantly less likely to receive prenatal care in the first trimester than Non-Hispanic Whites, with 59.8% of African American mothers receiving first trimester care and 45.4%

Weeks When Pregnancy Confirmed, Weeks at First Prenatal Care Visit, and Satisfaction with Timing of Care of AAPIPI Study Participants, 2013



AAPIPI Study, 2013

of Pacific Islander mothers receiving first trimester care compared to 78.8% of Non-Hispanic White mothers in 2012.

Five study participants did not receive first trimester prenatal care.

"I went to the doctor and they're like you're five months pregnant, almost six months. ...So then I was scared to tell my parents because I was like they are gonna be so mad at me and, I don't know, they are probably gonna kick me out. But they were like no, they were mad for a long time—the whole time I was pregnant they were mad—but they were like we are here for you, to support you in whatever you want to do." –African American mother

Two of the women who received late prenatal care reported that they received prenatal care as soon as they wanted it.

"I think it is so funny because me and my cousins we do the same. Like, we'll find out we are pregnant but we won't go to the doctor. You know what I mean. They wait and then they wait and then they will go...And then you get this guilt trip from the nurses and the doctor and the look of, 'Well, do you do drugs? Well, are you on drugs? Well, why wouldn't you come in?' There's a list of questions you get." –Pacific Islander mother

One woman discussed how confusing Baby Your Baby requirements were a barrier to prenatal care. Fortunately, these requirements have been simplified as of January 2014.[6]

"The lady, when I went to the clinic to take my pregnancy test, she told me to call this number and Baby Your Baby can help me

6 http://www.babyyourbaby.org/financial-help/qualifications.php

with my prenatal care and so I called the number and the lady told me I had to sign up on something. ...It was confusing, the guidelines. ...It says, 'Okay get on this website, find a doctor, schedule your first appointment, go in there, tell them you're Baby Your Baby, go to this place, get the actual approval that you are pregnant.'" –Pacific Islander mother

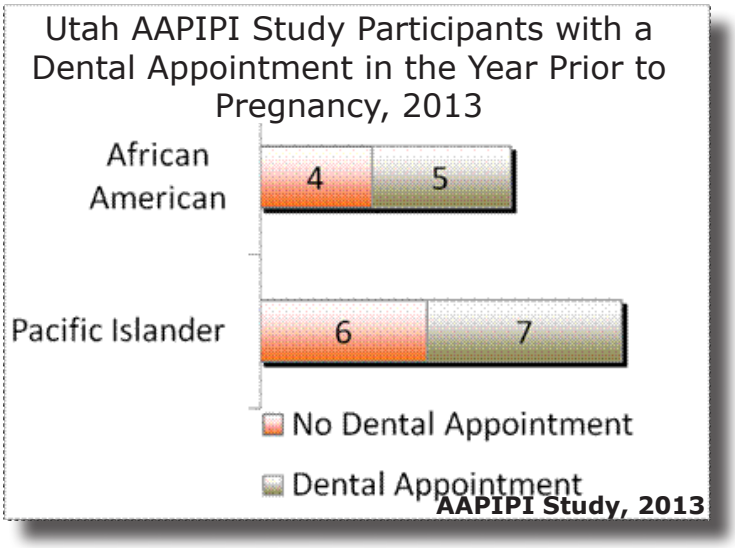
We asked participants about whether they had dental appointments during the year prior to pregnancy. About half of the women of both races had received dental care.

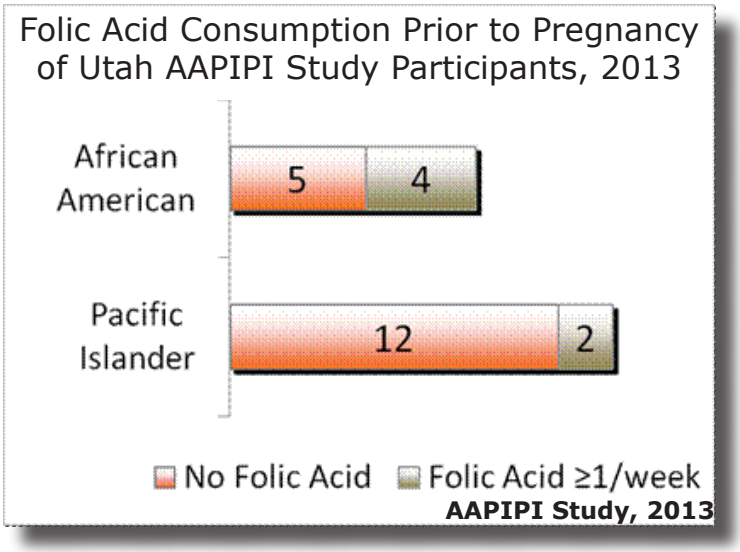
Taking folic acid before and during pregnancy reduces risk for birth defects. To be effective, folic acid must be taken even before a woman knows she is pregnant. Therefore, it is recommended that all women who are able to get pregnant take folic acid daily.[7] Only two of the 14 Pacific Islanders who participated in the study were taking folic acid or a multivitamin at the time they became pregnant. Four of the nine African Americans were taking folic acid or a multivitamin. We asked women who were not taking folic acid why they were not taking folic acid. The most common reason given was that they did not think they needed to take vitamins. Women may not think they need folic acid either because they do not understand the importance of folic acid to prevent birth effects or because they do not believe they will become pregnant. Like their responses to questions about why they weren't using contraception, responses about folic acid reflected ambivalence.

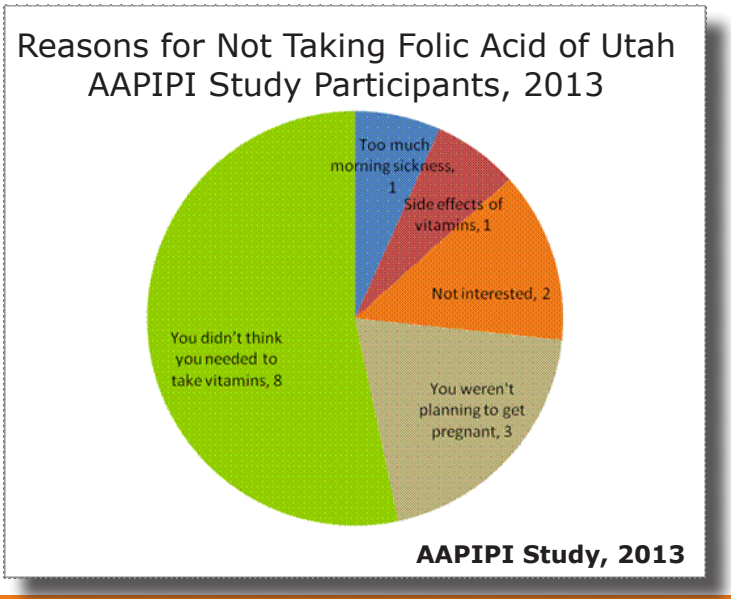
"I just don't like taking medicine, so I just didn't." –African American mother

"Um, it's not that they were too expensive or I didn't think that I needed them. I just didn't care to take them I guess." –African American mother

7 http://womenshealth.gov/publications/our-publications/fact-sheet/folic-acid.html







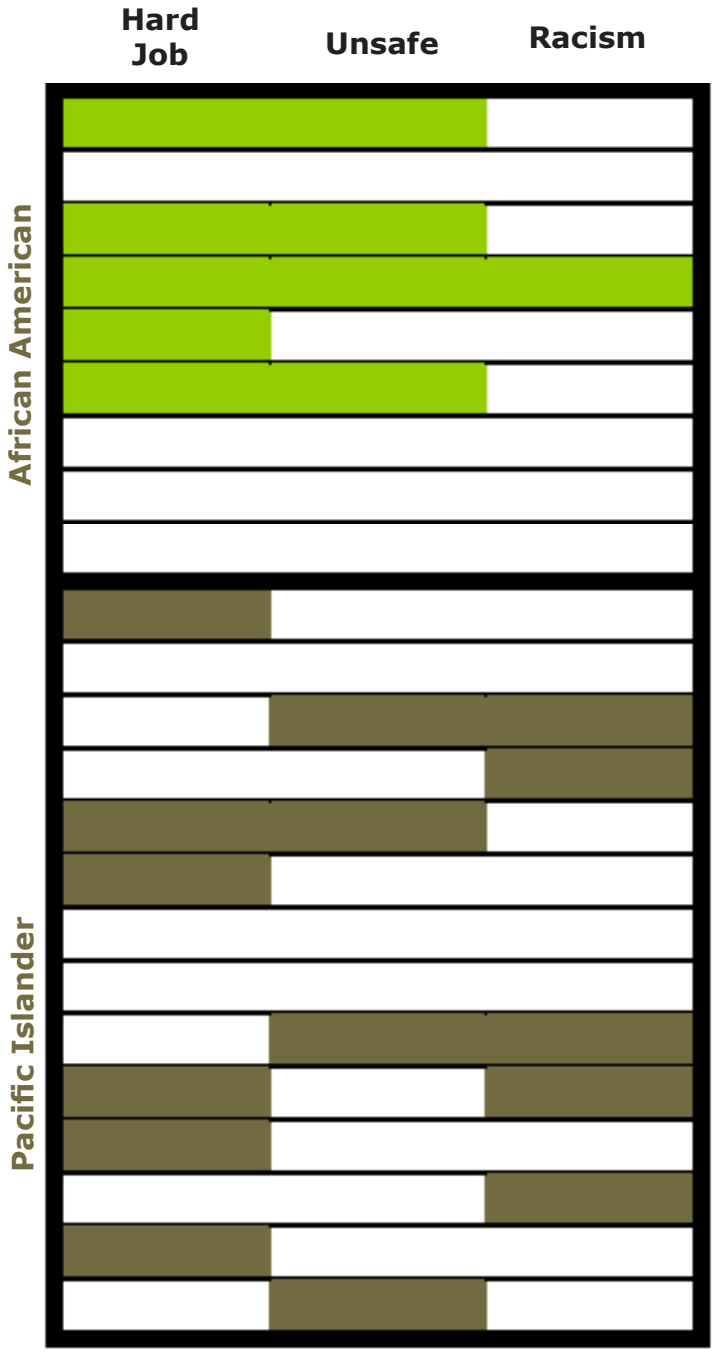
Living Conditions and Economic Issues

Utah birth certificates do not contain information about income, but they do contain information about participation in public assistance programs. According to 2012 birth certificates, African Americans and Pacific Islanders participated in WIC and Medicaid at higher rates than Non-Hispanic White mothers. This suggests that these racial groups may have lower incomes. Birth certificates also tell us that higher percentages of Pacific Islander and African American mothers lacked high school diplomas. In the case of African American mothers, this may be related to the higher rates of teen pregnancy in this population.

We asked study participants about their living conditions and economic issues during the year prior to the birth, death or stillbirth. The column "Hard Job" is marked for each woman who reported that her job required hard physical labor or was emotionally stressful. "Unsafe" was marked when women reported dangerous working conditions, such as working with dangerous chemicals, or that their home was unsafe. While no women reported domestic violence, some reported that the conflict in their homes made them feel unsafe. Some women reported racism. Interestingly, some women who answered that they did not experience racism on the written, quantitative survey, later went on to describe racism during the qualitative interview as one of the stressors they experienced during or just prior to their pregnancies.

We asked participants about their incomes and family sizes and found that several of them were in poverty. Even more of them reported problems with bills, such as being unable to pay bills or having utilities turned off.

Problems Reported By Utah African American and Pacific Islander Mothers During the Year Prior to a Preterm Birth, Stillbirth or Infant Mortality



AAPIPI Study, 2013

Some women described financial problems:

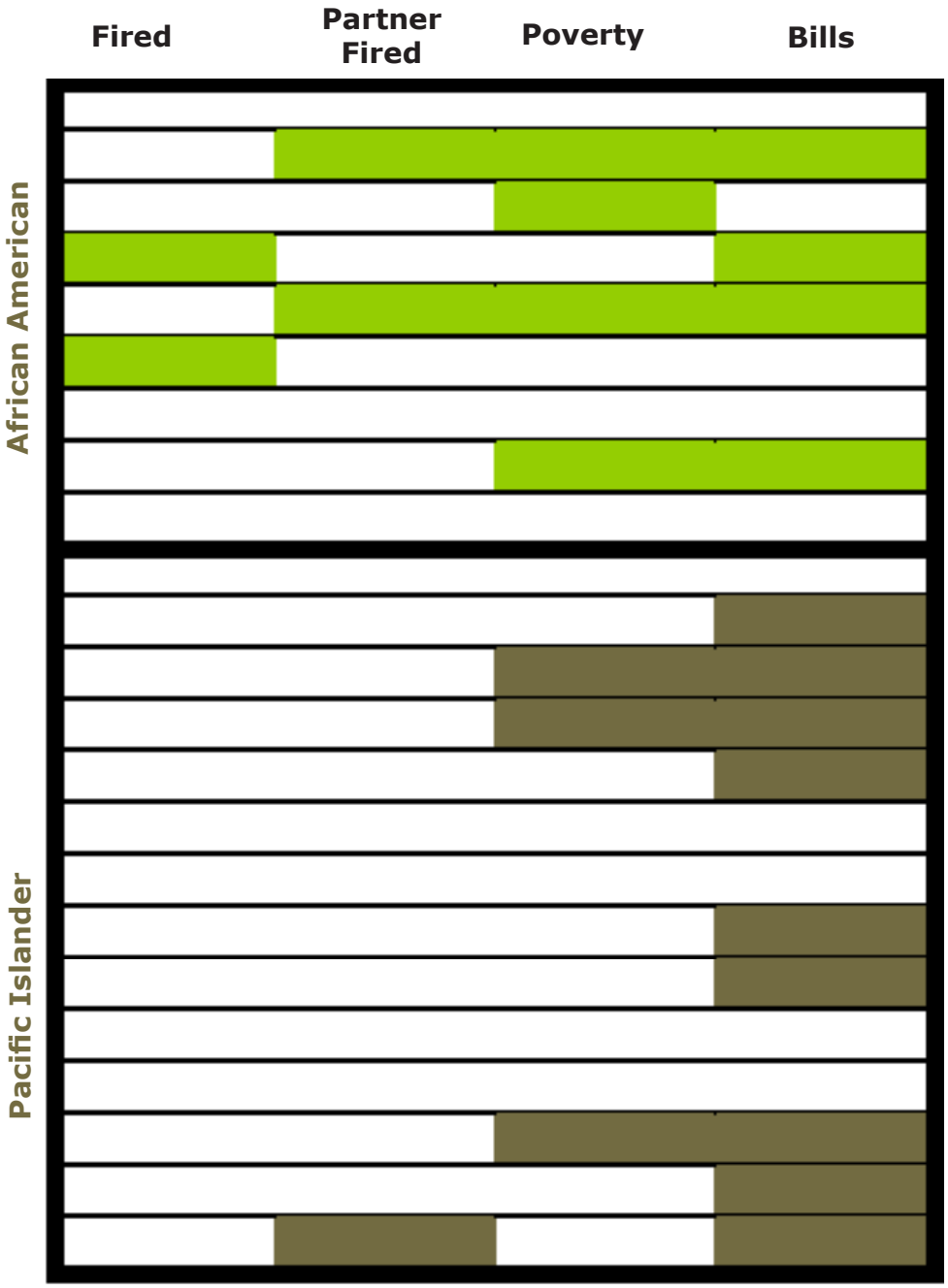
"I'm there to help them but they overlooked it as far as just give me the money, money, money. And you know. And then you guys go your own way but we are there at home living with them kind of thing. And it's like they just want the money, money, money coming in, coming in paying the bills, paying whatever. ...We wanted to move there to help them but not to the extent that we were the main income." –Pacific Islander mother

Here are some examples of racism experienced by mothers who participated in the study:

"Sometimes you hear comments. You know what I mean. Tongans are all big. [Someone] introduced everybody when they came to us, 'You know how Polynesians are. They are big.' That's just unnecessary. That makes me mad. Even his sisters were like why would he say that. That is such a racist comment." –Pacific Islander mother

"Me and my boss didn't get along a lot and I feel like a lot of it was because of the pregnancy...I feel like she was more lenient with a lot of other employees and I felt that the reason that she wasn't so much with me is partly because of my race." –African American mother

Problems Reported By Utah African American and Pacific Islander Mothers During the Year Prior to a Preterm Birth, Stillbirth or Infant Mortality



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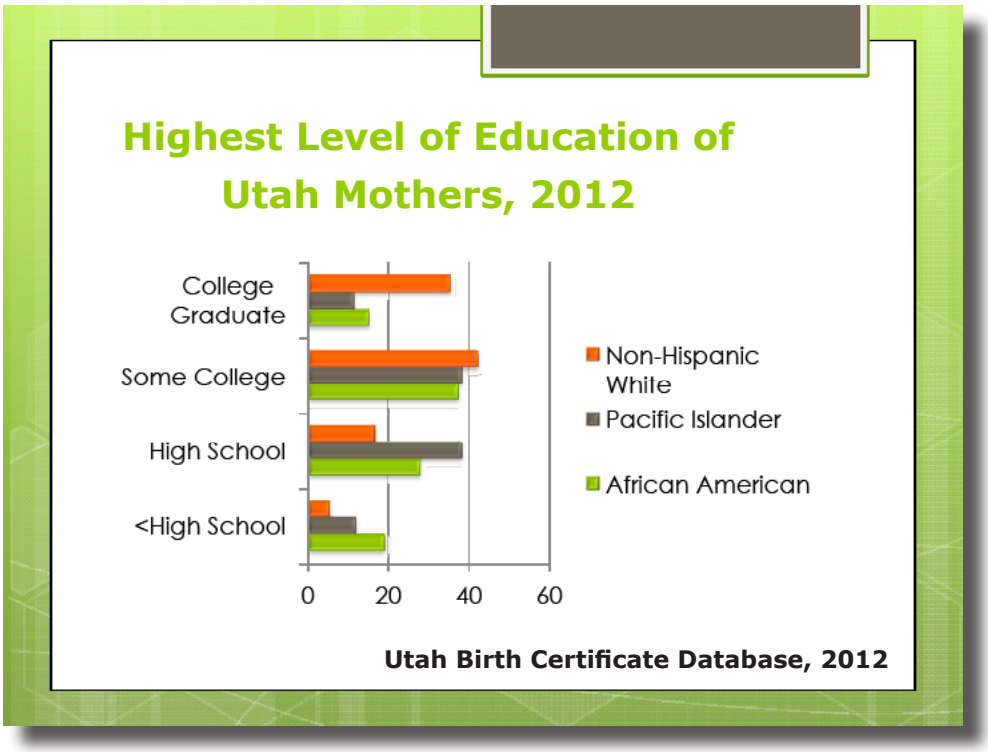
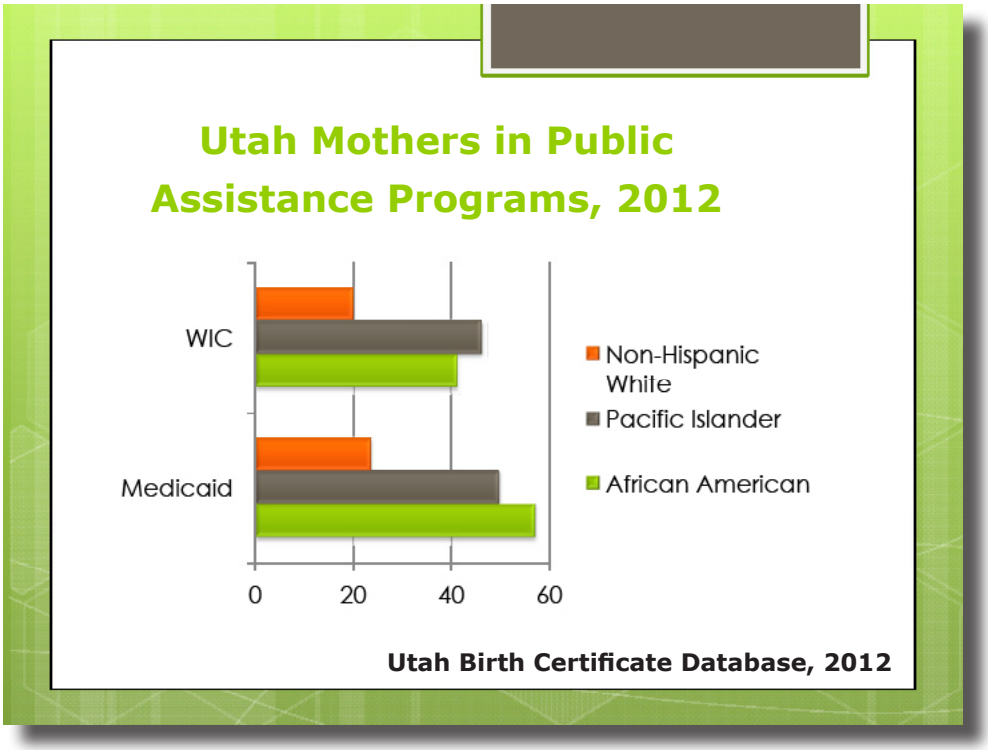


This woman was not able to go on bed rest because she was a business owner:

"Just the normal stresses of running the business and balancing the life. ...If I would have actually stayed on bed rest (laughter), if I would have that might have helped. ...I would be interested to know if the majority of these women, these Polynesian women that have a premature baby maybe here in Utah, if they worked all the way through their pregnancies. You know what I mean. ...Because that would be stressful but for us we have mouths to feed so it is automatic." –Pacific Islander mother



This woman had a physically demanding job during her pregnancy:

"I was pushing big machines. I was shampooing carpets because I was the only one who knew how to do it...and I would do it within like a fast speed. We were wiping down stuff and I was lifting up tables, helping the boys lift up tables because I didn't know I was pregnant. ...I think it was a pretty hard task because you had to carry the vacuum on your back and the vacuum was probably like the same size as me so it was like hard." –African American mother

Social Support

Women who had a strong social support network often reported that their social support was what helped them most during their pregnancy.

Answers to the question, "What was most helpful or supportive for you?"

"My husband." –Pacific Islander mother

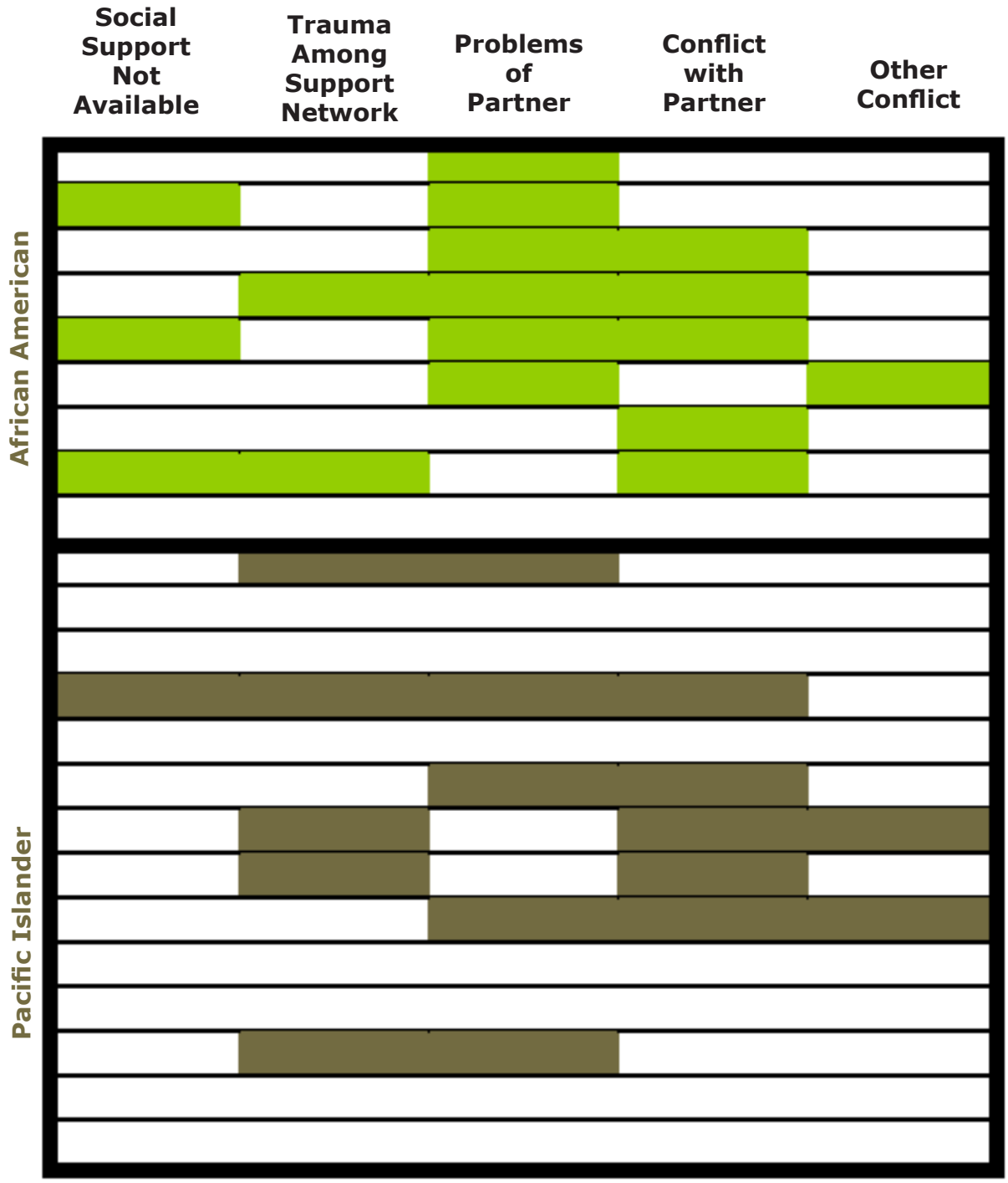
"My family and my best friend because she went with me to my doctor's appointments and stuff and yeah, just family and friends." –African American mother

"My family and my husband." –Pacific Islander mother

"I did have support, family support, I guess, and financial support." –African American mother

We asked mothers about their access to social support during, before and after their pregnancies. We asked a series of questions about the kinds of support social networking usually provides. If the mother told us she did not have anyone to offer that kind of support to her during her pregnancy, we marked the column "Social Support Not Available." The column "Trauma Among Support Network" was marked if the mother reported that an issue made her support network unavailable to her, such as distance, death, or a traumatic event.

Problems Reported By Utah African American and Pacific Islander Mothers During the Year Prior to a Preterm Birth, Stillbirth or Infant Mortality



AAPIPI Study, 2013

Similarly, the column, "Problems of Partner" was marked if the partner had issues going on in his life that made it difficult for him to support the pregnant woman, such as losing a job, alcoholism, or separation. "Conflict with Partner" was marked if the mother reported conflicts with her partner and "Other Conflict" was marked if the mother reported conflict with other individuals.

In 2012, more than half (55.3%) of African American mothers who gave birth in Utah were not married. This may indicate that they lack an important source of social support, but not necessarily. This single African American mother described the support she received from her parents:

"My parents. …help out a lot but I just wish things would have went a lot different. Like I wish I would have had my own place but at the same time I can't fight it because they do help a lot. I have a lot of support." –African American mother

For those women who were experiencing conflict with their partners, this was a primary source of stress during the pregnancy:

"Okay, so [my husband] gets stressed at work. ...So it can get to the point where it is very high, high. High stress. Intense. There is that and then coming home and I try to get the kids out of his way or whatnot. And if anything does bother him he does blow up a little bit." –Pacific Islander mother

"[My partner] cheated on me." –African American mother

Some women described conflict coming from sources other than their partner:

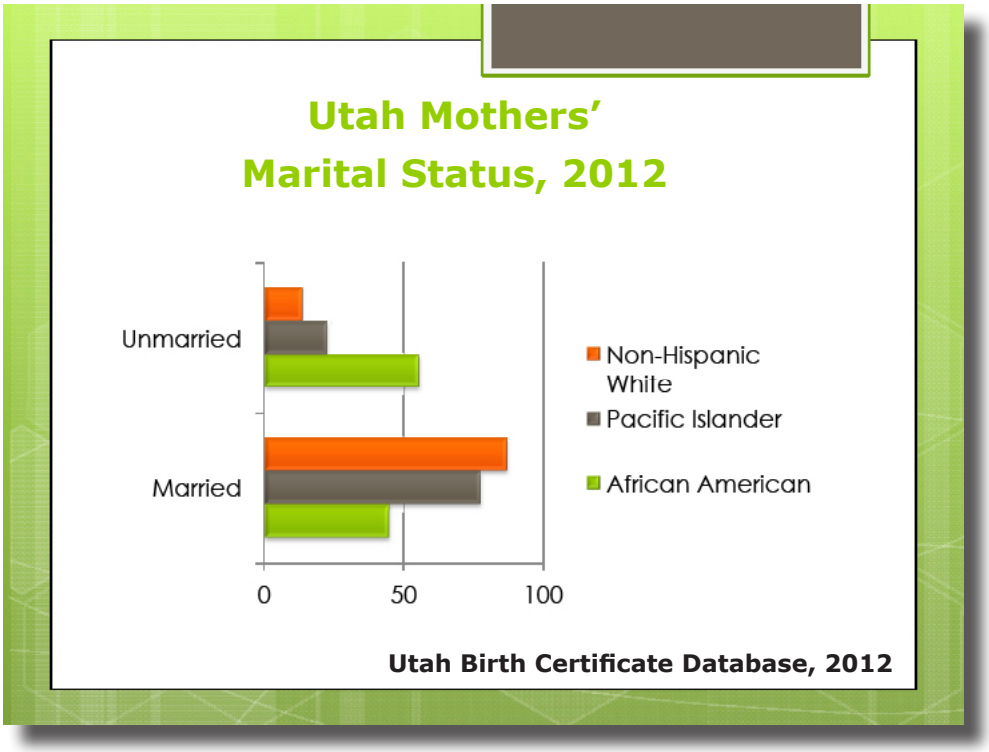
"We had kind of a crazy neighbor. ...It was pretty bad." –African American mother

"Individual fights with my mom. Then she'd be gone and then I'm here at home. Staying at home with my dad and then me and my dad arguing. Really, oh my gosh. But then with the separation and stuff our relationship is like you know, holy cow, that is all that had to happen, really. You know?" –Pacific Islander mother

Some women had social support networks that were unavailable to them during their pregnancy, due to distance, illness, death, or other traumatic events of urgency:

"I wanted my mom there. ...Not that I'm not close to my mom but…she was in Samoa you know a bazillion miles away." –Pacific Islander mother

"My whole family dynamic was kind of changed and turned upside down and I lost contact with most of my siblings. ...I was stressed and feeling bad that we were so far away and we weren't able to help [my extended] family as well." –African American mother



Postnatal Support

Grief Support

We asked participants whose babies had died about the grief support they received. Support was uneven across participants.

Photo by Now I Lay Me Down To Sleep

"I think that one of the best things that I received while I was in the hospital was these foundations [like] *Now I Lay Me Down to Sleep*, who sends a professional photographer over. ...And I think that all the hospitals should tell people about it because it is something that you will cherish forever. ...Those are beautiful. They are a moment and I think that nowadays it is accepted that we can take pictures of that because before they used to just take the baby away and like, no pictures. ...A lot of people don't know about these foundations because you never think about them until it happens to you. Another foundation that was available to us was *izzyjane foundation* and for stillborns here in Utah they will donate up to $500 for funeral costs and I think everyone should know that." –Pacific Islander mother

"That specialist lady came in but like she had appointments like crazy she was going so it was kind of like an in and out thing. I was appreciative of it but I would have liked something more." –Pacific Islander mother

Postpartum Depression

Some women did not realize they needed support when it was first offered.

"It's hard. Like, you lose a lot of sleep and I don't think I was postpartum depressed when they were in the NICU, I was just more stressed and worried hoping they were making it and then right when they came home I was depressed. I didn't want to do anything because I was sleep deprived. And at times I felt like I didn't want them but that is not how I feel now. …I had a good social worker at the hospital and they kept asking me if I needed help but at the time I didn't. I was like, I'm fine. I'm good, I'm just happy they're healthy. But now I see what they mean." –African American mother

Breastfeeding

This is a good example of a woman who had not breastfed her first two children long-term but was successful with her third child thanks to lactation counseling. However, although the counseling was helpful, she did not receive important information about the availability of electronic pumps that she needed to return to work.

"As far as breastfeeding, I used a counselor for breastfeeding. She sort of guided me through because with my other two I was doing breastfeeding but only three weeks and I ended it. But with this one I am still breastfeeding. I am surprising myself really. ...But that is sort of keeping me down that I want to go back to work." –Pacific Islander mother

"Can you pump?" –Interviewer

"I hate pumping. I hate pumping." –Pacific Islander mother

"WIC will give you the free electric pump." –Interviewer

"It's electric? Because I'm doing this. …I do have the WIC. Oh." –Pacific Islander mother

"Just say, hey, I need an electric pump. Okay, we've got one." –Interviewer

"They didn't even tell me about the nutritionist. …Oh my gosh. Because I think that will work for me. That's getting my mind going. …I'm surprised because they handed me the manual one." –Pacific Islander mother

Recommendations

We asked participants for their recommendations. Participants did not appear to be thinking about public health solutions. They focused on what they, personally, might do—a "pull yourself up by your bootstraps" approach.

"Um, probably just stay healthy. Exercising." –Pacific Islander mother

"I don't know. I could have probably just watched pretty much what I ate during the beginning. Especially at the beginning I could have avoided being gestational so early in the pregnancy. I think that probably played a part." –African American mother

"I would just suggest taking care of yourself. You got to maintain yourself to help your child because once there is something inside you it's not just thinking about you it's thinking you and your child and what you can do to better that life for your child and I mean if you don't want to get pregnant do things to stop yourself from getting pregnant." –African American mother

"I think people that have like high risk pregnancies I guess like me should, I don't know, should just be more cautious and just take it more easy or more seriously." –African American mother

"Just not choosing sides and making it just to the point and simple. And just be one with your husband. Just being one. That's it. That's just my answer." –Pacific Islander mother

"Maybe just more, being more aware or being educated." –Pacific Islander mother

Some participants were simply baffled.

"Um, if there were two of me. (Laughs.)" –Pacific Islander mother

Recommendation 1

Remember that these women are independent-minded.

- Follow-up on multiple occasions to offer help. They may not realize they need it the first time it is offered.
- It may not occur to them that outside support is even an option. Be explicit in explaining the kinds of support that are available.
- Empower, don't take over. Respect their independence.

"Don't be afraid to ask for help. Make sure you get the help that you need before it is too late. ...So get the help that you need even though if you feel like you don't need it I still advise you to get it." –African American mother

Recommendation 2

Intervene before pregnancy and between pregnancies.

- Encourage women to attain a healthy weight before they become pregnant. Emphasize the correlation between weight and birth outcomes.
- Educate mothers who have had poor birth outcomes about reducing risk for their next pregnancy.

- Especially among Pacific Islander women, promote adequate pregnancy intervals and folic acid consumption before pregnancy begins.
- Develop policies among health care plans to identify Pacific Islander and African American pregnant women as a higher risk for poor birth outcomes.
- Motivate, don't just educate, especially about family planning, prenatal care and folic acid.

"I felt like if I was like in better health before the pregnancy that maybe that could have helped during." –Pacific Islander mother

"I have recently lost [weight]. So that is what I'm trying, that's my goal. I actually started the day after we buried my daughter. ...Because I know my health or weight may not have affected it at all but it can only help so that is why." –Pacific Islander mother

"It is not really cute for every young girl to get pregnant and think babies are just the cutest thing. They are cute but they are more work than that. ...So there should be classes on how not to get pregnant and how to deal with all the stress after you're done getting pregnant, after you're done having your baby because it's hard." –African American mother

Recommendation 3

Help the whole woman.

- Some women need support for the traumatic life events they experience during and before pregnancy more than they need health advice. Inquire and offer resources.
- Consider incorporating incentives that address financial concerns and alleviate other stressors alongside health information.
- Social support is key. Look for opportunities to create social support networks.

"A better diet. ...Probably before and especially during and someone to make me food would be nice." –African American mother

"I know on Facebook there are a lot of groups of women who have had premature babies and stuff like that. And they are really great support groups." –African American mother

"Just supportive groups. I think that would be awesome. ...Nobody in my family has gone through anything like this. ...I would love that, I would seriously love it. I don't know anybody." –Pacific Islander mother

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