Quality data is needed to inform efforts to reduce disparities

Have come a long way in the past 10 years in identifying and exploring MCH issues experienced by the AI population

Identified key challenges and barriers to better data, and have begun to address them

Native Tribes in Michigan

Challenges

- In 1997, no published rates or data
  - Initial numbers and rates based on vital records, WIC, and Fam Planning program data were out of sync with experience in the tribal communities – missing a lot of cases
  - Most survey data sets do not include enough AI respondents to look at results for that population
  - Prompted us to explore the way data is collected and how cases are defined
How do you define who is a Native American Infant?

- Identification as “American Indian” or “Native American” may mean different things to different people
  - Race/biological ancestry
  - Political/legal affiliation
  - Spiritual/cultural
  - Community affiliation

Ultimately we should focus on self identification

Illustration of challenges in Vital Record Data: 2011 Infant Deaths

<table>
<thead>
<tr>
<th>Mom Race (birth cert)</th>
<th>Dad Race (birth cert)</th>
<th>Infant Race (death cert)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>White</td>
<td>American Indian</td>
</tr>
<tr>
<td>American Indian</td>
<td>White</td>
<td>White</td>
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<tr>
<td>American Indian</td>
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</tr>
<tr>
<td>American Indian</td>
<td>missing</td>
<td>White</td>
</tr>
</tbody>
</table>

Critical importance of how race data is collected and analyzed at all levels

- At the program enrollment/delivery level – facilitate self identification;
- Understand, expect and be competent with multi-race responses
- At the analysis level, explore using race variables in a variety of ways – race of father as well as race of mother; exploring any available ancestry or ethnicity variables
- Understand that what is adequate and works for population analysis for the White population may not yield accurate or adequate results for smaller populations
Significance of Multiple Races in Primary Racial Identity

- French, British, Finnish and Norwegian settlers have had a significant presence in Michigan since the 1600’s
- Intermarriage and partnering between people with a variety of racial backgrounds is a reality of modern society
- Statistically, the significance of multi-race identity is greater for small populations than for the majority White population

Multi-race

% of total White Births which include multi-racial background: 1.5% (3,812/256,240)
% of total African American Births which include multi-racial background: 2.7% (1,815/66,288)
% of total American Indian Births which include multi-racial background: 30% (692/1,598)

Perinatal Periods of Risk Analysis

<table>
<thead>
<tr>
<th>American Indian</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Health/Prematurity: 2.3</td>
<td>Maternal Health/Prematurity: 2.1</td>
</tr>
<tr>
<td>Newborn Care: 3.3</td>
<td>Newborn Care: 3.5</td>
</tr>
<tr>
<td>Infant Health: 3.4</td>
<td>Infant Health: 4.9</td>
</tr>
</tbody>
</table>

Overall IMR = 12.2 Overall IMR = 5.3

Overall Excess: 5.3

*Reference group = Non-Hispanic white; age 20+, 13+ years of education

Source: MI Vital Records, 2006-08. Prepared by MDCH MCH Epidemiology Unit
Native American PRAMS Survey
Data Collection Methods

Overview of Michigan PRAMS
- Public health surveillance system of risk factors for infant mortality
- Cooperative effort between CDC and MDCH
- Survey mailed to randomly sampled moms with a live birth each year (phone follow up if needed)
- Self-reported maternal behaviors and experiences around the time of pregnancy
- Conducted in Michigan since 1988
- Only 5-6 Native mothers each year

Native American PRAMS Partners
- Michigan Department of Community Health – PRIME and PRAMS Staff
- Michigan State University - Office for Survey Research
- Inter-Tribal Council of Michigan – MCH Director
- Great Lakes Inter-Tribal Epidemiology Center – MCH Epidemiologist
- Michigan’s 12 Federally Recognized Tribes – Tribal Health Leaders
NA PRAMS Outreach

• General outreach strategies
  ▪ Tribal clinic nurses briefed on project
  ▪ Nurses also given FAQ sheets to help answer questions
  ▪ Ads and articles in tribal newspapers and newsletters
  ▪ Flyers distributed to tribal communities
  ▪ Email blast by MDCH to build awareness of project

• Specific to sampled mothers
  ▪ Endorsement from Inter-Tribal Council with survey
  ▪ Cultural sensitivity training for telephone interviewers
  ▪ FAQ for project on back cover of survey

NA PRAMS Methodology

Cristin Larder, MS
MDCH Epidemiologist

NA PRAMS Sampling

• Broad definition of Native American used
  ▪ American Indian listed in any race fields on birth certificate
  ▪ Mother OR father

• Sampling occurs before NCHS creates bridged race categories

• Michigan PRAMS records are sampled first
  ▪ NA PRAMS cases pulled from remaining records

• Final weighting will incorporate
  ▪ Nonresponse
  ▪ Omissions from frame (e.g. sampled by MI PRAMS)
  ▪ Noncoverage
NA PRAMS Survey

- CDC PRAMS protocol followed, except
  - Mailing schedule delayed for each monthly batch
  - Nine month infant age limit relaxed
- Additions to survey content
  - Place of usual health care (e.g. tribal clinic)
  - Barriers to care (e.g. transportation), referrals for help
  - Differentiated tribal home visiting programs from others
  - Helpfulness of home visiting services
  - Reactions to racism questions, modified for frequency
  - Tribal affiliation of both mother and father

NA PRAMS Response - 2012

- 1,344 completed surveys
- 2,587 records sampled
- 52% response rate

NA PRAMS Online Option

- Starting with April 2013 births, NA PRAMS began offering moms the option to complete survey online
- Goal of online option is twofold
  - Increase response through more convenient way to participate
  - Lower operational costs of mail and telephone survey modes
- Online option is introduced with Mail 2
  - URL for survey website included with introduction letter
  - QR code for cell phones and tablets
  - Unique PIN for each mom to access survey
NA PRAMS Online Survey

NA PRAMS Survey Question

NA PRAMS Progress to Date

- Design and implementation of first statewide surveillance survey among Native American population
- Coordination with Inter-Tribal Council
  - Tribal health leaders included in the planning process
  - Project marketing and education of nurses in tribal health clinics
  - Culturally relevant survey and mailing materials
- Large sample size may allow for tribe-specific estimates
- State funding for second year of data collection
NA PRAMS Innovations

- Revised definition of “Native infant”
  - Response appears similar regardless of Native status
  - Plan to compare state race variables to NOHS bridged race
  - Respondents can be grouped by several definitions of Native

- Online survey option added in 2013
  - Experiments planned to optimize timing of online option
  - Exploring text messaging and online reward redemption
  - Moms’ email addresses allow for future contact (if approved)
  - If successful, online methods can be applied to other surveys

NA PRAMS Challenges

- Possible misclassification of American Indian race in birth records
- Encouraging participation of women who don’t identify as Native
- Protecting privacy and confidentiality of potentially incarcerated sampled women
- Balancing the importance of local community needs and generalizability of survey
- Assessing risk factors among women experiencing fetal loss remains a barrier

NA PRAMS Lessons Learned

- Parallel surveys may help overcome limitations of state PRAMS surveys for specific populations
- Collaboration with tribal organizations is critical to both developing and implementing a culturally relevant survey
- Listening and responding to feedback from tribal elders is an important piece of achieving community buy-in
- Providing tribes with the opportunity to access both tribe-specific results and raw data is an essential part of State/Tribal relations
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- Survey Participants – Michigan Moms