

Health Disparities Data Issues: *Listening to the Voices*

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and Health Statistics**

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Introduce self

Worked & researched in Bangladesh, Thailand, Swaziland, Bhutan, FSM - Chuuk, Pohnpei, Ngatik

Executive Director c-b organizations for leprosy and HIV/AIDS

Currently health policy coordinator for SSRI

Testimony Overview

- **Research Project - Brief Description**
- **Preliminary Results**
- **Future Directions**
- **Perspectives for Health Disparities Research**



Briefly discuss current research methodology and preliminary results as example of some of the is

Brief Project Overview

- **Quantitative research**
 - Refining numbers
 - Economic modeling
- **Qualitative research**
 - Interviews of uninsured and providers
- **Policy options developed by workgroups**
- **Leadership group forwards recommendations**



HRSA SPG to combine research and policy development for issues of covering the uninsured in H

Research includes both quantitative research to refine estimates of the uninsured and model costs o

And qualitative research involving interviews of uninsured persons and providers

The table is full - state agencies - DLIR, DHS, DOH, labor, chamber, small business council, 2 ins
except - we have somewhat the same situation as you do in that there are not uninsu

Qualitative Research Team

Carol Murry, Health Policy
Heather Young Leslie, Anthropology
D. William Wood, Sociology

with
J. D. Baker
Jin Young Choi
Jill McGrath Jones



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esented - 3 on qualitative side,

Methodology

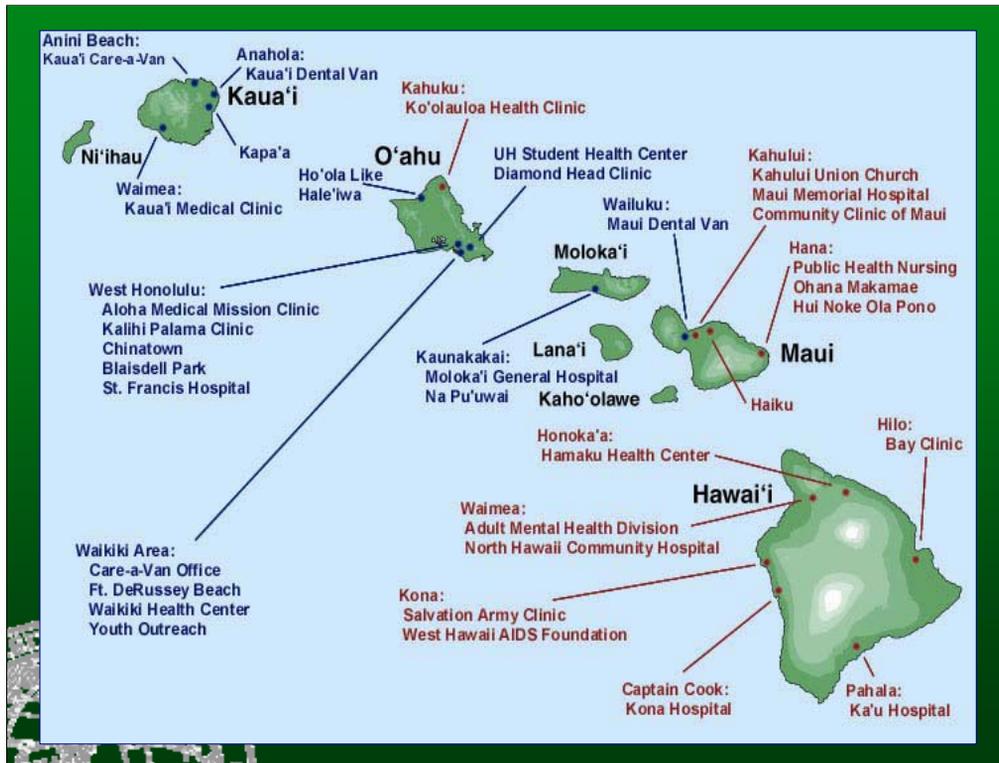
- Long semi-structured field interviews
- Interviews recorded in digital audio format
- Detailed field notes with post-interview summaries
- Transcription, coding with ATLAS/ti, key issues & themes



Interdisciplinary team

In brief interviewed >200 uninsured and 50 providers

Ave. 45” recorded digital, notes, audio translated to digital, transcribed 1/2, summarized, coded and



Kauai, Oahu, Molokai, Maui, Hawaii with telephone interviews of providers on Lanai

Varied sites, including CHC, hospital, dental and care-a-vans, pharmacy, MH, HIV, student, NH, Y

Grouped results to match policy work groups

Who Are the Voices?

- **>200 uninsured and >50 providers**
- **60 Native Hawaiian/part-Native Hawaiian uninsured**
- **24 Asian and Pacific Island immigrants**
- **10 Native Hawaiian healers**



Qualitative research undertaken to answer who, why, what do they do for care, how do they pay and

Why - almost always cost

Where care - ER, CHC/safety net, pay cash, or get no care - “just suffer”

How pay - pay cash, incur debt, or don't pay

Impact - will discuss

Policy Issues

- Uncovered workers
- Children and families
- Low income adults
- Compacts of Free Association
- Safety Net



*"I worked half my life...I'm not asking for a hand out, I'm asking for help. For me as a worker, it breaks my pride."
...I told him I would be trying to get health insurance for him and he said, you mean when I have aches and pains, I would go to the doctor?
"Why haven't you gone back to see the doctor?" "Because I don't have insurance now. I can't afford it."*

Native Hawaiian

- Poor health indicators
- Ni'ihau patients may lack documentation for QUEST enrollment & may not speak English
- Native Hawaiian health system
- Access to land and water impacts health
- Spirituality important to indigenous healing
- Loss cultural identity is risk factor



*“If I made only \$800, I’d get free medical coverage?
(Yes) How to survive? How to keep my leg?”*

Aging, pride, self treatment

Perceive unequal treatment - not ethnicity but for lack of coverage

(we interviewed one CHW who was using stereotypes)

Can't get through system- NH homeland as asset

Believe that NH should get care from trust funds

Didn't get the care they needed despite SN - suffer, debt

Life change - would get screening treatment

Pacific Island Immigrants

- Information gap
- Language and cultural issues
- Uneven coverage
- Poverty, fear, expectations

“Right now, we have a problem because we don’t have insurance..we don’t have money.” “ I don’t know why - our island is very different. You go to the hospital, you get everything free.”



CFA experience more difficulties - understanding sx, language, culture, false expectations, fear of

Another Paradigm Shift

- Start from perspective of reducing health disparities
- Disparity won't be addressed unless it is identified - small & "mixed" populations must be included
- Need to understand underlying reasons for disparity - social factors must be included



In Pohnpei, I screened Kapingamarangi people for 5 years - epidemiologists dream 1100 people of factors different - genetically polynesian in micronesian culture, experienced discrimination, had d

Mixed - most of our NH sample was "part-NH" - over-represented because blood quantum is entiti

Adaptation of surveys must include method as well as language and cultural relevance - CADI not

Include open-ended questions to understand issues

In my own family I have 2 kids - ethnically Thai and Vietnamese who grew up in Africa, Californi

For my kids - their background was important - exposure to issues of violence (war) and poverty

Hawaii is considered paradise - if suggested, people usually laugh

Both Hawaii and PI are considered "too far"

In our interviews we could discern violence/abuse being passed down as if it were DNA

Data Collection

- Multiple translations necessary
- Ethnic classification techniques dependent on purpose
- Necessity for inclusion of “outer” island populations
- Recommend
 - Funding for translators
 - Classification matched to purpose
 - Distinguishing geographic location is critical for disparity related to access, include “mixed” geographic location



We interviewed in about 15 languages

In Ponpei - I interviewed in 5 languages

Selected RA's who could understand/be understood in pidgen, brought in one community-based R

In Hawaii, NI are over-represented in uninsured and even those who are covered lack access to ser

Ethnicity Classification

- “Pacific Islander” or “Asian Pacific Islander” lacks meaning for addressing disparity
- Issues of Native Hawaiian or part-Hawaiian reporting
- Recommend
 - Retain fine detail for ethnicity
 - Address issues of “mixed” populations



Mixed populations are probably the fastest growing group - can probably tell us about factors unde

Barriers

- \$\$\$\$\$
- Time
- Infrastructure
- Recommend
 - Adequate funding for qualitative data collection
 - Ongoing support for capacity building and data collection



Qualitative data collection is costly - takes time

Data gains meaning and cost goes down when repeated

Must include ANHOPI persons in framing research questions, designing instruments, data collection

Isolation is factor - in Hawaii travel to another county is by plane or to neighboring state

In PI may be by field trip ship 1/month

Build inclusion - phone, PEACESAT, recognize time difference

Privacy and Confidentiality

- “Small town” effect
- Qualitative data - used pseudonyms
but -
identification of island, pseudonym, or other
details jeopardize confidentiality



Capacity Building Strategies

- Guidelines for community partnership research
- Inclusion in health professional education
- Carve-out funding for infrastructure ongoing



CPR - headed group of WKK funded CP who worked on CP research issues

required benefit to C, involvement of C in all steps, communication and availability

need to train researchers - culturally sensitive, but more important - indigenous

Build infrastructure e.g. Momi

Avoid competition for same funds - biggest/most powerful minority wins

Partnership Building Strategies

- **Avoid reinventing wheel - models**
 - Ke Ola O Hawai'i
 - HRSA SPG
- **Build on existing partnerships**
- **Loooong term funding**
- **Require, facilitate and fund community participation**



Start with Committee - inclusion, PEACE-SAT

Model of ASG-SSRI - limited data, infrastructure

Accountability Mechanisms

- **Require community participation in design**
- **Require community-based evaluation**
- **Require results be presented to community in intelligible form**



Partnerships for Safety & Quality

- Introduce community to partner-user relationship
- Involve community in development of requirements



What Difference Will it Make?

- Many health disparities have improved little over time
- Problems related to data issues remain very similar over time
- Ideally, the Committee could work itself out of a role



Ultimate Costs

- Individuals suffer. Children's lives are impacted.
- Lack of preventive & primary care leads to avoidable complications
- Health disparities are passed down as legacy to children and to community
- Who pays?

We all do – the minority populations, providers, and all of us.



You need to keep in mind the costs of ongoing disparity - social and financial
People are suffering (3rd world country), impact ability to work, pts. Died, unnecessary cost incurred
Children entire lives impacted - broken wrist leads to permanent damage

Who pays? Clearly we all do

Points to take away