

# BUILDING TRUST IN COMMUNITIES

## **The Narragansett Indian Tribe and the State of Rhode Island**

### A CASE STUDY FOR PUBLIC HEALTH STUDENTS

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## **Background**

The Narragansett Indians are descendants of the aboriginal people of the State of Rhode Island, where they have existed for more than 30,000 years.<sup>1</sup> According to the 2005 census, the state of Rhode Island was home to 10,725 Native Americans, about 0.9% of the total population. While Native Americans living in Rhode Island report belonging to more than 100 tribes, the Narragansett Indian Tribe, with more than 2,389 members, represents the largest tribe in the state.<sup>2</sup>

The Narragansett people have had long standing disputes with the State of Rhode Island. In 1975, the Tribe filed suite against the State and individual landowners in order to reclaim land the Tribe asserted rightfully belonged to them. An out-of-court settlement in 1978 concluded with the return of 1,800 acres of land, where the Tribe established its reservation. Finally, in 1983, the Tribe was given federal recognition of its sovereignty and has participated in federal programs funded by the Bureau of Indian Affairs and the Department of Indian Health Services.

“Through the Federally funded programs the tribe is able to service many of its Tribal Body members in all aspects of life. The mission of the Tribe is to continue to promote and develop awareness among Tribal members the importance of education, culture, and family life within their own tribal community.”<sup>3</sup>

## **Public Health Issues for Native Americans Living in Rhode Island<sup>4</sup>**

A number of public health issues face the Narragansett people. The median age for the Native American population is 26 years, whereas the overall state median is 38 years. Over 82% of the Native American population is age 50 or less, while 70.2% of the overall state population is age 50 or less.

*Socioeconomic Indicators:* The percentage of Native Americans living below poverty is over three times higher than the overall state population, and almost five times higher than the White population. The median household income for Native Americans is \$22,800— \$21,700 less than the state median and \$22,500 less than the White population. A lower percentage of Native Americans graduate from high school compared to the overall state and the White populations. A greater percentage of Native Americans are unemployed compared to the overall state and the White population.

*Mortality:* For the period between 2000 and 2004, the three leading causes of death for Native Americans were heart disease, cancer, and diabetes. While diabetes is ranked as the third leading cause of death for the Native American population, diabetes is not ranked among the top five causes of death for the White or the overall state populations.

*Behavioral Risk Factors:* Native Americans have a similar percentage of overweight or obese individuals compared to the White and the overall state populations. When only the obese percentages are presented, Native Americans show a higher percentage of obese individuals compared to the White and the overall state populations. The percentage of Native Americans

(47.5%) who smoke cigarettes is over two times higher than the White (21.6%) and the overall state (21.4%) populations.

*Maternal and Child Health:* The overall state and the White populations have more favorable maternal and child health outcome indicators than the Native American population in Rhode Island. Native Americans are about twice as likely to receive delayed prenatal care compared to the White or the overall state populations. The percentage of Native American teens (ages 15-19) that give birth is almost five times greater than the overall state or the White populations. The percentage of Native American children who grow up in poverty is over two times greater than the overall state population and over 3.5 times greater than the White population.

*Access to Health Care:* Most samples are too small to draw reliable conclusions regarding Native Americans and access to healthcare. The percentage of Native American adults who said there was a time when they could not afford to see a doctor is over two times that of the overall state population and over three times that of the White population. The percentage of Native Americans having no health insurance is more than double that of the overall state population and nearly three times that of the White population.

*Environmental Concerns:* A number of environmental issues are being addressed by the Tribe including: surface and ground water pollution; “incremental non-point source pollution from surrounding residential development and Tribal development;” air pollution; hazardous waste; highway run-off; illegal dumping; lead paint; Radon; and “biological and chemical contamination of drinking water.”<sup>5</sup>

### **Rhode Island Plan for Minority Care<sup>6</sup>**

In order to address the public health needs of minorities, The Rhode Island State Department of Health facilitated the development of a community action plan, which was developed based on the results of a community assessment and feedback process initiated in 1998. This was followed by an internal assessment conducted in 1998 and three state breakout sessions of the New England Region Conference for the Elimination of Health Disparities that took place in 1999, 2001 and 2003.

The vision from the action plan was to allow for all racial and ethnic minorities in Rhode Island to have an equal opportunity to live safe and healthy lives in safe and healthy communities. The minority community set as its mission to reduce health risks and improve health outcomes by disseminating health education materials and engaging the community in healthier behaviors.

To support this mission, minority communities in Rhode Island were asked to participate in the development of policies, plans and tracking systems to ensure that the needs of their communities are integrated and addressed within all State health department programs. Specific outcomes of the plan: (1) racial and ethnic health disparities are eliminated by 2010 and (2) racial and ethnic minority populations have equal access to high quality health services.

In order to achieve these outcomes, 6 goals/priorities were identified and planned to be implemented within a three year period:

1. All health programs meet the needs of racial and ethnic minority populations.
2. Establish uniform guidelines and procedures regarding the collection, use, analysis and dissemination of data on racial and ethnic populations.
3. Establish policies and procedures ensuring meaningful and productive minority community involvement and participation in all planning, monitoring and evaluation of health activities.
4. Improve work force diversity within the Rhode Island Department of Health (HEALTH) and promote the need for diversity in all health care institutions.
- 4a. Ensure that all Limited English Proficiency individuals receive the same quality health services (Title VI of the Civil Rights Act)
5. Build community capacity to provide health education, health promotion and disease prevention activities that are aligned with HEALTH overall priorities targeting racial and ethnic minority populations
6. Facilitate and develop public/private partnerships at the state, regional and national level to eliminate racial and ethnic health disparities.”

While not specifically developed for the Narragansett people, the Tribe has used the plan as a blueprint for evaluating and addressing its own process for improving health outcomes for its people.

### **Current Issue**

In July of 2003, the Narragansett Indian Tribe, a federally recognized tribe that maintains a government-to-government relationship with the United States of America, began selling cigarettes from a shop on tribal lands to promote economic development. The state and tribe have disagreed on certain rights on the reservation. The sale of cigarettes without the state-required tax took place over the objections of Rhode Island Governor Donald L. Carcieri, who did not believe the tribe could legally sell cigarettes without charging state taxes. On July 14, 2003, the Governor ordered a raid on the tribe's tax-free smoke shop, which devolved into a physical confrontation between Rhode Island state troopers and Narragansett tribal members, including several members of the Tribal Leadership. Following the conflict, seven tribal members were charged with misdemeanors, including simple assault, disorderly conduct, and resisting arrest. The Tribal Leadership contended that their sovereignty was under attack and demanded that state troopers be held responsible for the force used during the conflict. However, no state troopers were charged as a result of their behavior in the raid. After the raid, Chief Sachem Matthew Thomas of the Narragansett Indian Tribe and Governor Carcieri issued the following statements:

“The Narragansett Tribe did what it has always done- protect its land. It’s unfortunate [we had to do this] because it’s 2003.”<sup>7</sup>

Chief Sachem Matthew Thomas

“Today’s actions were precipitated by the Narragansett Indians and their flagrant violation of state law.”<sup>8</sup>

Governor Donald L. Carcieri

In 2005, a three judge panel of the U.S. First Circuit Court of Appeals declared the raid a violation of the tribe's sovereignty, but reversed the decision during a hearing by the full court. The decision held that the raid was not a violation of the tribe’s sovereignty because of an agreement signed by the Narragansett Tribe that agreed the tribe would adhere to state laws, even on its own land<sup>9</sup>.

In a separate federal civil rights lawsuit, the tribe charged the police with the use of excessive force during the 2003 raid on the smoke shop. One Narragansett man suffered a broken leg in the confrontation. The case was being retried in the summer of 2008. Competing police experts testified on each side of the case.<sup>10</sup>

On April 4, 2008, a Superior Court jury found Chief Sachem Matthew Thomas and two other elected tribal members guilty of misdemeanor charges while clearing four others. Upon his conviction, Chief Sachem Matthew Thomas stated, “I didn’t expect anything really different. I was waiting to get it over.”<sup>11</sup>

While acquitted of all the charges against her, Ms. Bella Noka, a former tribal councilor and wife of Randy Noka, First Councilor, was quoted as saying, “We are reminders of their awful past and we are constant reminders of everything they’ve done and they won’t stop until we no longer exist.”<sup>12</sup>

Meanwhile, Governor Carcieri issued the following statement through his spokesperson, “With the conclusion of this trial, Governor Carcieri hopes that the Narragansett Indian tribe and the State of Rhode Island can put the smoke-shop incident behind us and move forward into a more cooperative future.”<sup>13</sup>

## **Discussion**

Moving forward may be difficult for member of the Narragansett Tribe. Abuse at the hands of government agents, government entities, and even those working to improve the lives and health of Native Americans is still a real fear for many tribal members. These abuses are not just about sovereignty, land rights, and cultural identity, but also about research conducted on Native Americans under the guise of health research.

For many Native Americans, experiences with public health researchers, governmental or institutional, have been negative, and as a result, have severely impacted trust. Mistrust is not limited to solely those institution(s) conducting the research – it affects the individuals conducting the research as well. “Too often, research has been conducted ‘on’ rather than ‘with’ American Indian communities, resulting in their being stigmatized or stereotyped.”<sup>14</sup>

Research activities such as those on “Navajo Flu,” the “Barrow Alcohol Study,” and the collection of blood samples, consented for one study but then used for other studies without

consent, are but a few of the unethical behavior by researchers that caused deep mistrust in the Native American community.<sup>15</sup> Other minorities have similar issues of mistrust based on past public health initiatives - African-Americans experienced similar health research deception in the Tuskegee syphilis study<sup>16</sup> and stories have been passed down from times of slavery regarding experiments being conducted on their ancestors and the sale of their bodies for medical experiments following their death.<sup>17</sup> Today, one-third of African-Americans believe that HIV/AIDS was introduced into their community by the federal government. Other scandals have generally undermined the general public's trust in community organizations, businesses, and public figures, including the Clinton-Lewinsky scandal, the Enron bankruptcy scandal, and the legal troubles for American icon Martha Stewart.<sup>18</sup>

Signs of distrust can be found in each of these situations. Broken promises, leaders acting in their own best interest, individual rights sacrificed for expediency or lack of compassion, and the desire to advance research at any cost illustrate the need for more accountability.<sup>19</sup> But accountability alone cannot build public trust. There must be transparency of action and decision-making; a consensus-building process that includes community members; dissemination of materials and information that provide for informed consent; a reason for the community to participate; and finally, incentives to facilitate participation.<sup>20</sup>

### **Building Trust in a Community to Further Public Health**

Following graduation from GW, you move to the state of Rhode Island and begin working as a public health analyst at the Rhode Island Department of Health (a State affiliated agency). You have been asked to head a team that will design a comprehensive health program that will address the need for medical, behavioral, and preventive care for the Narragansett people, including prevention of heart disease, diabetes, and cancer. In addition, you will need to address tobacco and alcohol use among the Narragansett people. Your program will include researching public health issues in the minority communities of Rhode Island, designing prevention and primary care programs that target these communities, developing a health promotion campaign in collaboration with the communities, and reviewing currently available evaluation tools to assess the effectiveness of current initiatives

You and your team have been asked to collaborate with Native American communities in the State of Rhode Island, including the Narragansett Indian Tribe, on the implementation of such health programs.

### **Learning Objectives**

Using the information provided in the case study, the case presentation, and the posted readings:

1. Describe who should participate on the public health team and why their contribution is important.
2. Describe the underlying causes of health disparities affecting Native American communities in Rhode Island.

3. Describe the potential issues of trust that may arise between research, the government, and the study population regarding the delivery of public health services in conflict ridden areas.
4. Describe the implications of the international/global nature of the study, i.e. a federally recognized tribe vs. an American state.
5. Describe manifestations of mistrust in different communities and contexts, i.e., health care access, rural communities, sexual minorities, clinical trial participation, racial/ethnic minority care .
6. Describe potential barriers to building trust between state agencies in Rhode Island and Native American communities in the State, and strategies for overcoming those barriers.

### **Case Study Break-Out Discussion Questions**

Based on the information in the case study, the readings previously assigned, and the presentation of the case, students should address the following questions, with the facilitator guiding the discussion based on the learning objectives:

1. Who are the stakeholders in this dispute?
2. Which stakeholder do you identify with in this dispute? Does your individual race, gender, ethnicity, etc. matter in this context?
3. What are the underlying causes of the dispute?
4. How are the underlying causes in the current dispute and the impact of mistrust relevant to the delivery of public health services in the Narragansett community? In other communities (i.e., rural communities, sexual minorities, clinical trials, other racial/ethnic minorities)?
5. Are these issues unique to Native American communities? To the United States? Why or why not?
6. Given the current political issues facing the State of Rhode Island and the Narragansett Tribe, how would you approach addressing the most pressing health issues of the Narragansett people (heart disease, cancer, and diabetes)?
7. What barriers/opportunities exist within the current political environment?
8. How could you gain trust in communities that have historically been marginalized?
9. What two or three issues do you feel must be resolved in order for the State of Rhode Island and the Narragansett Tribe to work together to address the health disparities of the Narragansett people?

## **Readings on Building Trust in Communities**

### Biostatistics and Epidemiology

Pinto, R.M., McKay, M.M. & Escobar, C. (2008). “You’ve gotta know the community”: minority women make recommendations about community-focused health research. *Women Health*, 47(1), 83-104.

### Environmental and Occupational Health

Adler, P. & Birkoff, J. (2002). When knowledge from “here” meets knowledge from “away.” Report: National Policy Consensus Center, Portland, OR.

### Exercise Science

Krishnan, A. & Kapoor, S.K. (2006). National health promotion initiative: an idea whose time has come. *Indian Journal of Community Medicine*, 31(2), 51-52.

### Global Health

Gilson, L. & Erasmus, E. (2006). Trust and accountability in health service delivery in South Africa. Technical Report: Centre for Health Policy, Johannesburg.

### Health Services Management Leadership

Berwick, D.M. (2003). Improvement, trust, and the healthcare workforce. *Quality and Safety in Care*, 12(2).

### Health Policy

The Institute of Medicine (2002). *Unequal treatment: what healthcare providers need to know about racial and ethnic disparities in healthcare*. US DHHS Office of Minority Health.

### Prevention and Community Health

Christopher, et al. (August 2008). Building and maintaining trust in a community-based participatory research partnership. *American Journal of Public Health*, (98)8, 1398-1406.

## **Additional Background Readings**

Behringer B., Friedell G. H., Dorgan K., Hutson S., Naney C., Phillips A., Koyamangalath K., Cantrell E. (2007). Understanding the challenges of reducing cancer in Appalachia: addressing a place-based health disparity population, *Californian Journal of Health Promotion* (5) Special Issue (Health Disparities & Social Justice), 40-49.

Moreno-John G., Gachie A., Fleming CM., Napoles-Springer A., Mutran E., Manson SM., & Perez-Stable EJ. (November 2004). Ethnic minority older adults participating in clinical research: developing trust, *Journal of Aging & Health*, 16(5 Suppl),93S-123S.

## Endnotes

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<sup>1</sup> <http://www.narragansett-tribe.org/history.html> accessed August 18, 2009.

<sup>2</sup> Rhode Island Office of Minority Health. (2007). Minority Health Facts: Native Americans in Rhode Island. The Rhode Island Department of Health. <http://www.health.state.ri.us/chic/minority/MHFS2007NAFinal.pdf> accessed August 18, 2009.

<sup>3</sup> <http://www.narragansett-tribe.org/history.html> accessed August 18, 2009.

<sup>4</sup> Excerpts from Rhode Island Office of Minority Health. (2007). Minority Health Facts: Native Americans in Rhode Island. The Rhode Island Department of Health. <http://www.health.state.ri.us/chic/minority/MHFS2007NAFinal.pdf> accessed August 18, 2009.

<sup>5</sup> [http://www.micmac-epa.us/html/body\\_tribal\\_fact\\_sheets.html](http://www.micmac-epa.us/html/body_tribal_fact_sheets.html) accessed August 18, 2009.

<sup>6</sup> Excerpts from “The Rhode Island Department of Health Minority Plan for Action, (2004) Introduction, <http://www.health.ri.gov/chic/minority/MH2004ActionPlan.pdf>, accessed August 18, 2009.)

<sup>7</sup> Staff and Wire Reports (July 14, 2003). State police raid of Narragansett smoke shop turns violent, Providence Journal, <http://www.projo.com/digitalbulletin/content/projo-20030714-charlestown.8ae1b340.html>, accessed August 18, 2009.

<sup>8</sup> Mulvaney K. & Davis, P. (July 14, 2003). Violent raid shuts tribe's tobacco shop, Providence Journal, <http://www.projo.com/digitalbulletin/content/projo-20030714-charlestown.8ae1b340.html>, accessed August 18, 2009.

<sup>9</sup> <http://www.ca1.uscourts.gov/pdf.opinions/04-1155-01A.pdf> accessed August 18, 2009.

<sup>10</sup> [http://en.wikipedia.org/wiki/Narragansett\\_\(tribe\)#cite\\_note-9#cite\\_note-9](http://en.wikipedia.org/wiki/Narragansett_(tribe)#cite_note-9#cite_note-9) accessed August 18, 2009.

<sup>11</sup> Bakst, C. M. (April 5, 2008). Reflections on the verdicts in the Narragansett Indian smoke-shop trial, [http://www.projo.com/news/mcharlesbakst/BAKST\\_COLUMN\\_05\\_04-05-08\\_IE9LFBJ\\_v13.35849d4.html](http://www.projo.com/news/mcharlesbakst/BAKST_COLUMN_05_04-05-08_IE9LFBJ_v13.35849d4.html) accessed August 18, 2009.

<sup>12</sup> Ibid

<sup>13</sup> McKinney M. P. (April 5, 2008). Verdict mixed in Narragansett Indian smoke-shop raid-case, Providence Journal,

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[http://www.projo.com/extra/2003/smokeshop/content/projo\\_20080404\\_smokeshop\\_verdict.302f9f22.html](http://www.projo.com/extra/2003/smokeshop/content/projo_20080404_smokeshop_verdict.302f9f22.html), accessed August 18, 2009.

<sup>14</sup> Christopher et al. (August 2008). Building and maintaining trust in a community-based participatory research partnership. *American Journal of Public Health*, 98(8), 1398-1406.

<sup>15</sup> Ibid.

<sup>16</sup> Freimuth, V., Quinn, S., Thomas, S., Cole, G., Zook, E., & Duncan, T. (2001). African Americans' views on research and the Tuskegee syphilis study. *Social Science & Medicine*, 52(5), 797-808.

<sup>17</sup> Whetten et al. (2006). Exploring lack of trust in care providers and the government as a barrier to health service use. *American Journal of Public Health*, (96(4), 716-721.

<sup>18</sup> Dwyer, R. & Beauvais, C. (2006). Building and maintaining trust: the essential ingredient for organizational success. *Revue-e-Journal* (1)1, [http://www.ustpaul.ca/Philosophy/revue/articles/2006\\_dwyer.html](http://www.ustpaul.ca/Philosophy/revue/articles/2006_dwyer.html) accessed August 18, 2009.

<sup>19</sup> Gilson, L. & Erasmus, E. (2006) Trust and accountability in health service delivery in South Africa. Technical Report: Centre for Health Policy, Johannesburg.

<sup>20</sup> Quah, SR, ed., (2007). On trust and health consensus-building in the governance of epidemics. *Crisis Preparedness: Asia and the Global Governance of Epidemics*: Stanford University APARC, 113-133.

## **Acknowledgements**

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### **Patrik Johansson, MD, MPH**

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