

"Natural Laboratories"
Medical Experimentation in
Native Communities

In 1929, we were removed from under the Catholic Church into the Indian Bureau. When we got into the Indian Bureau we were also used as guinea pigs. They gave us vaccinations. Needles broke in some of the people's arms. They were not removed.

Then they came into the reservation for dental work. They drilled from under our jaws into our mouths, and caused infections. They put black stuff into our teeth as experiments. This was very painful. We were used by the government to test a new material as fillings for teeth. Today, the dentists look at our mouths and tell us there was never anything wrong with our teeth in the first place.

Our eyes were scraped. They told us we had acoma [sic] which the eye specialist now says we never had. Now our eyes are gone, our teeth are gone.

They used us to make drugs for other people. They gave us many vaccinations and after the vaccinations many people became sick with tuberculosis. Most of our people died of tuberculosis and small pox that were given to us by the government.

This was forced on us. We had no choice. They put vaccinations in our arms. Then some of our people died. Some

lived. They would not allow us to go to school because they said we had acoma.

I will answer to anyone that this is what happened to us in Big Valley in California, 1931–1933.

—Theresa Brown, letter dated March 24, 1993

In her letter, Theresa Brown of Clear Lake, California, testifies to her history of medical experimentation to Mary Ann Mills and Bernadine Atcheson, Alaska Native health activists. One of the common demands of many mainstream feminist organizations is increased funding for medical research on women's health, such as breast cancer. What is generally not considered in the making of these demands, however, is who will this research be done on and under what circumstances? As the previous chapter indicates, much contraceptive research has been conducted on women in the Global South or on indigenous women and other women of color in the U.S. with little regard to their safety. However, unethical medical experimentation programs have not been limited to contraceptives.

One example is the controversial 1982 hepatitis B trial vaccine program conducted among Alaska Native children.¹ Mary Ann Mills and Bernadine Atcheson (Traditional Dena'ina) began to investigate this program when a mother came to them inquiring about the vaccine that had been given to her child without her permission. They soon discovered that this vaccine was Heptavax B, a trial vaccine for hepatitis B, that was being administered without parental consent. The rationale for the experiment was that Alaska Natives were at particularly high risk for hepatitis B. However, in checking the statistics, Mills and Atcheson found that hepatitis B was on a sharp decline among Alaska Natives before the immunizations, with a 0–0.5 percent prevalence rate.² Interestingly, they argue that Native people are in fact not at high risk for hepatitis B.

Mills and Atcheson began to question the benefits of vaccines in general. First, they concluded that vaccines are often given credit for eradicating disease when the illness is often already on the decline because of other environmental factors. Vaccines also expose the body to germs which may negatively impact one's immune system. In addition, people can contract the disease for

which they are being vaccinated. For instance, in 1985, the Center for Disease Control reported that 87 percent of the cases of polio in the U.S. between 1973 and 1983 were caused by the vaccine and later declared that all but a few imported cases since were caused by the vaccine—and most of the imported cases occurred in fully immunized individuals. Jonas Salk, inventor of the polio vaccine, testified before a Senate subcommittee that nearly all polio outbreaks since 1961 were caused by the oral polio vaccine.³ And according to Mills and Atcheson, in 1988, William Jordan, former Director of the Infectious Diseases Division at the National Institutes of Health (NIH) stated at an infectious disease conference in New Zealand that virtually all field trials of new vaccines in the U.S. are done amongst indigenous tribes in Alaska, and most do nothing to prevent disease.⁴

Mills and Atcheson argue that a proliferation of "mystery illnesses" seemed to occur soon after vaccination programs were introduced in the Yukon Delta. Merck, Sharp & Dohme, the producers of Heptavax B, as well as other medical professionals involved in the study, sharply contest these claims, arguing that Mills and Atcheson are using "scare tactics" to discourage people from taking the vaccines. However, when members of WARN talked to some of these professionals, they did not deny that the program was done without true informed consent. In Manitoba, concerns also arose over Merck's hepatitis B vaccine. Dr. Byron Hyde, who is generally pro-vaccine, reported an unusually high number of cases with severe side effects, including chronic fatigue syndrome and fibromyalgia. "We have sent 65 cases to the government (Health Canada), two died, some went blind, one could no longer use an arm. I've never seen anything like this in any immunization." Several months later, the government issued a report stating that it had investigated the cases, and discovered no problems. Yet when Dr. Hyde contacted 45 of these patients, he found that none had been medically examined, and only two had been contacted by phone.⁵

Native peoples have every right to be concerned about trial vaccine programs because of the evidence that vaccination programs can cause illness. For instance, hepatitis B outbreaks started in 1945, when soldiers were given yellow fever vaccines that had

been tainted with the virus.⁶ Vaccination programs are not always about promoting health; vaccines are big business, and some doctors even receive benefits for the number of children they vaccinate. In addition, side effects ranging from fever to even death, are common. For instance, the United Kingdom is considering withdrawing the MMR (Mumps, Measles, and Rubella) vaccine because over 2,000 claims have been filed against the government on behalf of children injured or killed as a result of the vaccine.⁷ There is also a lawsuit filed in 2001 in the U.S. against pharmaceutical companies which distributed vaccines that contained poisonous mercury. According to the law firm litigating the case,

on July 7, 1999, the American Academy of Pediatrics (AAP) issued with the US Public Health Service (USPHS) a joint statement alerting clinicians and the public of concern about thimerosal, a mercury-containing preservative used in some vaccines. The reason for the warning is that thimerosal contains a related mercury compound called methyl mercury. Mercury is a toxic metal that can cause immune, sensory, neurological, motor, and behavioral dysfunctions. The Food and Drug Administration suggested that some infants, depending on which vaccines they receive and the timing of those vaccines, may be exposed to levels of methyl mercury that could build up to exceed one of the federal guidelines established for the intake of methyl mercury. Symptoms of mercury toxicity in young children are extremely similar to those of autism. This can explain the recent increase in the numbers of children diagnosed with autism since the early 1990s. The numerous amount of children diagnosed with autism seems to directly correlate with the recommendation of both the hepatitis B and HIB vaccine to infants in the early 1990s.⁸

Vaccination programs should not be assumed to be safe; rather, Native communities (and all communities) deserve to have full information on vaccination programs before participating in them.

Caution about vaccine programs is also warranted because indigenous peoples have been regarded as expendable by the dominant society. For instance, the Interagency Arctic Research Policy Committee (which includes agencies such as the National Science Foundation, the Department of Defense, and numerous U.S. government agencies) states that because Alaska Native villages are covered under IHS, they constitute a comprehensive

"extensive data base" which "provides a resource for studying health problems which will benefit *other* populations [emphasis mine]."⁹ Furthermore, according to this policy committee, Alaska is "a natural laboratory and as such a region where health research may have broad implications and applications."¹⁰

Another hepatitis trial vaccine program was established in South Dakota in 1991, with participating children given an experimental hepatitis A vaccine. In this case, the control group was not given a placebo, but a hepatitis B vaccine.¹¹ But shortly after the trials began, the producers of this hepatitis A vaccine, Smith Kline, resigned from the Australian Pharmaceutical Manufacturer's Association after complaints about unethical school promotions and misleading advertising were lodged against the company.¹² Smith Kline also claimed to be procuring informed consent, but children were offered candy and parents were promised free diapers if they participated in the South Dakota program.¹³

Disturbingly, Mills and Atcheson point out that the consent forms for the vaccine trial in Alaska were startlingly similar to the forms used in the Tuskegee syphilis study that started in the 1930s and ran into the 1970s. In this infamous case, African Americans with syphilis were told by the U.S. Public Health Service that they were being treated for the disease, but they were actually not treated so researchers could chart the trajectory of the disease. In a letter sent to Tuskegee patients, they were told,

...some time ago you were given a thorough examination and since that time you have gotten a great deal of treatment for bad blood. You will now be given your last chance to get a second examination...Remember, this is your last chance for special free treatment.¹⁴

From the letter to Alaska Native patients,

Hepatitis B vaccinations are available to you at the Dena'ina Health Clinic. Because you qualify for ANS benefits you can be screened and immunized at no cost to you. This service is scheduled for this year only. Without this program, the cost of the vaccination will cost \$100. We urge you to take advantage of this program now!¹⁵

Besides the sociomedical questions they have about trial programs, Mills and Atcheson also note that less invasive remedies are not widely funded or studied. For instance, hepatitis A could be eradicated through improved plumbing and sanitation; seventy-three percent of hepatitis A cases among Alaska Natives are in villages with no flush toilets.¹⁶ However, financial support goes to areas that are most likely to be profitable for pharmaceutical companies. This limited research agenda not only benefits pharmaceutical firms, but those corporations linked to pollution and environmental degradation that result in disease.

These vaccine trials represent the tip of the iceberg with regards to the medical experimentation that has been conducted in Native communities. For instance, a GAO report on sterilization abuses in IHS also found that there were 36 medical experimentation programs conducted by IHS during 1974 and 1975.¹⁷ The GAO denied that any of the programs resulted in negative medical consequences for Native peoples, but the report indicates serious lapses in informed consent procedures. The Children's Defense Fund reported that Indian children in boarding schools were subjected to a trachoma experiment during the years 1967-68 and 1972-73 without parental consent. The Proctor Foundation, which conducted the research, maintained that informed consent was not necessary because "Indian Health Services acts as legal guardian for the children while they attend boarding schools."¹⁸ Several other programs were assessed in this report, including one study of pulmonary disease among White Mountain Apache children which consisted of painful tests that were conducted without consent.¹⁹ Furthermore, the GAO also found that the IHS did not have standardized procedures to ensure that researchers were actually following the protocol approved by IHS research committees.²⁰

While the GAO concludes that for many of the programs, consent was documented, the GAO relied solely on records provided by IHS and did not interview patients themselves. As with the report on sterilization abuses, GAO states:

We did not interview patients to determine if they were adequately informed of the risks, discomforts, and benefits of the project. We believe that such an effort would not be productive

because (1) no serious hazard existed for the patients and (2) recently published research noted a high level of inaccuracy in the recollection of patients 4 to 6 months after giving informed consent.²¹

Again, how informed can the consent be if one cannot remember giving it? In addition, the report claims that "no serious hazards existed" while stating in other sections that some of the experimentation programs, particularly those involving trial vaccines, had to be terminated because "the reaction rate was too high to risk any more immunizations."²²

As anti-prison activist Luana Ross writes, Native women in prison are particularly subjected to medical experimentation programs in order to "cure" them of the ailment that supposedly led to their incarceration.²³ Former prisoner Stormy Ogden described her ordeal with the medical industry while in prison:

I was given a combination of 300 milligrams of Elavil, Mellaril, Thorazine and Chlorhydrate, to keep me calm. What it did was make you stop talking. I still stutter and still have problems getting my words out because too much medication has gone through my body. I had to take this. There was no way I could get around taking it; they make sure. And a lot of Indian women are being given Thorazine, to keep us calm, because we are the savages.²⁴

Meanwhile, despite these programs intended to improve community health, Native peoples still have little in the way of actual and effective health care. In 1976, Congress passed the Indian Health Care Improvement Act, which affirmed its "special responsibilities and legal obligations to the American Indian people, to meet the national goal of providing the best possible health status to Indians and to provide existing Indian health services with all resources necessary to effect that policy." In *White v. Califano* (1978), the U.S. Court of Appeals for the Eighth Circuit affirmed that the U.S. was obliged to provide health care in Native communities: "We do not refer to a relationship that exists only in the abstract but rather a congressionally recognized duty to provide services for a particular category of human needs." Yet since 1997, 16 of the 49 IHS hospitals did not meet the minimum standards in one or more areas set by the Joint Commission on Accreditation of Healthcare Organizations, which monitors national

quality standards for hospitals. By contrast, less than 1 percent of hospitals nationwide ranked as poorly. And between January 1997 and September 2000, patients or relatives filed 342 formal malpractice complaints against IHS. (This equals more than one complaint for every three doctors.) Although most of these claims were denied, in the last four years IHS has paid at least \$23.6 million in malpractice settlements and judgments.²⁵

Because Native peoples are among the poorest in the country, they generally cannot afford alternative health care services. In addition, Native peoples are often entangled by various bureaucratic requirements that prevents them from accessing health care. For instance, it is not uncommon for IHS to require Native peoples to access services through Medicaid. Then, Medicaid will require that Native peoples first access care through IHS. The result is that American Indians suffer from the most serious health problems in the U.S. On reservations, American Indians have a life expectancy of 47 years. The tuberculosis rate for Natives is 533 percent higher than the national average; the accident mortality rate 425 percent higher; the infant mortality rate 81 percent higher; the sudden infant death syndrome rate 310 percent higher; the alcoholism rate 579 percent higher; the diabetes rate 249 percent higher; and the suicide rate 190 percent higher than the national average.²⁶

Conclusion

The biocolonial ideology that casts Native people as guinea pigs, instead of as people who deserve quality health care, was summed up by an IHS administrator who, during a 1992 meeting with WARN activists, said she encouraged Native people to participate in medical experiments because they provided the only access to health care for Native people. She added that once drugs are proven "safe," they are generally no longer available to Indian Health Services.²⁷

These attitudes have a long history in the U.S. During the colonial massacres of Indian peoples, colonizers attempted to defeat

Indian people *and* to eradicate their identity and humanity. They attempted to transform Indian people into tobacco pouches, bridle reins or souvenirs – objects for the consumption of white people. This history reflects a disrespect not only for Native people's bodies, but a disrespect for the integrity of all creation, the two being integrally related.

Unlike Native people, who see animals as beings deserving of bodily integrity and, furthermore, view their identities as inseparable from the rest of creation, colonizers see animals as rapable and expendable. By extension, because colonizers viewed Indian identity as inextricably linked to animal and plant life, Native people have been seen as rapable, and deserving of destruction and mutilation. This equation between animals and Native people continues. In the 1992 edition of the Physicians' Desk Research Manual, it is noted that Merck, Sharp & Dohme experimented on "chimpanzees and . . . Alaska Native children."²⁸

Mills and Atcheson question the precepts of Western medicine, which senselessly dissects, vivisects and experiments on both animals and human beings, when there are much more effective preventative and holistic forms of medicine. States Mills, "Today we rely on our elders and our traditional healers. We have asked them if they were ever as sick as their grandchildren or great-grandchildren are today. Their reply was no; they were much healthier than their children are today."²⁹