Enhancing Genomic Research Through a Native Lens

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Executive Summary

In "Custer Died for Your Sins: An Indian Manifesto," Standing Rock Sioux scholar Vine Deloria Jr. argued that non-Native researchers and academics were mainly interested in their own research goals and advancing their careers, and essentially not concerned about the real challenges that American Indians/Alaska Natives face. Dr. Frank Dukepoo (Hopi/Laguna) also questioned the *bilagáana*[1] (Western) approach to research, especially scientific research in American Indian/Alaska Native communities. Dr. Dukepoo always deferred to his Native culture and upbringing whenever he challenged the status quo. During one of his many talks, he questioned who makes the decision on whom, what and how people are studied in stating the following:

> So, from the Indian point of view, the Whites make the decisions. Who should identify human groups for genetic study? Indians are saying, well, why study it at all? For what reason? For what purpose? We have our own origin myths; we have our own concerns. Is this research valid? Are there promises made that maybe won't be kept? What is your rationale for doing this study anyway? Well, promises: medicinal promises, other kinds of promises: "we're going to tell you who you really are, where you really came from"(Dukepoo 1999).

This type of questioning is what Dr. Kim Tallbear (Sisseton Wahpeton) (2012) refers to as the first step in democratizing scientific research. As Native scientists and researchers, we have made inroads in many disciplines to advance our understanding of how to optimize scientific discoveries for our people. However, in the field of genetic and genomic research, we currently have a limited number of Native geneticists, genomicists, bioinformaticians, and bioethicists. All is not bleak, for there are efforts to increase the number of Native scientists and researchers in the aforementioned fields. There may be challenges, but we will come to a point in time where we will conduct genetic and genomic research utilizing research study designs from a Native perspective that will benefit our people without fear of exploitation. In the meantime, we can continue to tap into our network of non-Native allies to assist us in our training goals and research objectives. Many of these allies have mentored and guided us in becoming scientists, researchers and faculty members.

The Platypus

When the platypus' genome sequence was completed a few years ago, I was prompted to share my work in bioethics with my family, particularly my late uncle who was a medicine man/healer. I admired him dearly since he had traditional and cultural knowledge and healing ways that are comparable to an academic with a PhD or MD. He asked about the platypus since he had heard about it in the news and wondered why it was so important. I explained that the platypus is native to Australia and is one of the few mammals that can lay eggs. "How odd is that?" my uncle mused. I further explained that its peculiarity does not end there, as these odd animals have a duck's bill and thick fur coats adapted for the icy waters where they reside. I also explained that the male platypus could produce venom in its hind leg spurs when it is threatened. My uncle then asked why genome "sequencing" was important information. He preferred to speak Diné, so as best as I could and as often as I could, I explained in Navajo the significance and relevance of this recent accomplishment. However, since there are no Navajo words for genetics, genomics, and bioinformatics, I mixed in a lot of English. These cultural and language barriers are some of the challenges that I have faced in

working with the Navajo Nation to better inform them of the potential benefits of genomic research. The Navajo Nation Institutional Review Board (IRB) includes scientists, elders, leaders and medicine people and they stress the sacredness of life, so genetic studies should not be taken lightly. To that end, Dr. Dukepoo observed years ago that geneticists are especially mistrusted because Native people consider any part of their body sacred and taking genetic samples can be seen as sacrilegious. It is for these primary concerns that the Navajo Nation has placed a moratorium on any type of genetic study until they are informed at all levels of the value and importance of such studies. The Navajo Nation is aware that these studies are inevitable, but they want studies conducted on their terms. Moreover, genetic information is unchanging throughout one's life, and it provides information not just about a person, but also about his/her family, and possible the entire tribe and other Native people. Thus, the Diné people are considering genetic research in a careful manner, which reflects the sovereignty of the Navajo Nation.

Mitakuye Oyasin: All My Relations

So, I continued explaining to my uncle that, in addition to the platypus, scientists are now working on completing the genome sequences of an enormous number of living organisms. Furthermore, DNA sequencing technology has become more readily available, accessible, and affordable. This type of research could potentially lead to personalized medicine and treatment of illnesses and diseases. He listened intently, as I told him about an article I had read in *Nature* (Warren, et al. 2008) describing how an international team (from the United States, Australia, England, Germany, Israel, Japan, Spain and New Zealand) had found that the platypus genome contained approximately the same number (about 18,500) of protein-coding genes as other mammals. Furthermore, I told them that the international team also discovered that 80% of the platypus genes are also found in humans, mice, dogs, possums and chickens. He found this to be fascinating and amazing. He listened intently with his eyes closed and nodded in acquiescence.

This indicated that he was very interested so I continue to describe how scientists have completed the sequencing of genomes of many animals and plants, as well as marine life, flies, and even yeast, and these sequencing exercises are occurring on a daily basis. He then asked what I thought about these discoveries. I explained that the scientific community's increasing understanding of these connections and commonalities among humans and different animals might help society to respect nature even more. I then made a cultural connection by informing him that *bilagáana* scientists now see that we share common genes with everything in nature, so we are all connected. As the Lakota say in ceremony, "*Mitakuye Oyasin*," to acknowledge and honor the connections that we have as people with plants, animals, marine life, and even microscopic organisms. I felt a sense of accomplishment and pride in being able to help my uncle understand the work I was involved in so I asked him what he thought. He was silent for a few seconds with his eyes still closed and he finally answered my question. He opened his eyes and said, "It's good to know that those *bilagáana* scientists finally caught up to us, because we already knew that." I had to smile and remember that he was also teaching me. I will always remember those words for they keep me culturally grounded as I pursue my research interests in bioethics.

Though I am not a genome scientist, I have directed various training programs in genomics and bioinformatics for under-represented populations. It should be noted that you do not have to be a biologist to pursue genomics. As I prepared for my career, I studied human science and education so when I was appointed as director of minority training in bioinformatics and genomics at Harvard University, I became aware of bioethics and how this discipline influences and shapes biological research. Through bioethics, I learned about career opportunities in the ethical, legal and social aspects of genomic research. This particular branch of study is commonly called "ELSI," which is an acronym for ethical, legal, and social implications of genomic research. The National Human Genome Research Institute (NHGRI) of the National Institutes of Health (NIH) established the ELSI

program in 1990 “to foster basic and applied research on the ethical, legal and social implications of genetic and genomic research for individuals, families and communities” (NHGRI 2012). Through ELSIthere are opportunities for lawyers, sociologists, anthropologists, and even business entrepreneurs to address multiple ethical, legal and social issues that are best explored using multidisciplinary approaches. I have had the fortune of pursuing my ELSI interest focusing on bridging the gap between Native people and *bilagaana* science at Harvard University, Georgetown University and now, Johns Hopkins University. As greater and more significant scientific discoveries are being made, we now need even more American Indian/Alaska Natives to represent our communities when it comes to genetic testing and teaching science.

Furthermore, there should be culturally appropriate methods and processes that can be developed by Native scientists to overcome the history of mistrust with the scientific community. If we, as Native people, are trained in these fields, we can play key roles in the development of scientific discovery that will benefit our nations. With an increased number of Native scientists focused on genome sciences and bioethics, we could return to our communities to assist with research studies and protocols at the tribal governance level. In addition, we could serve as faculty members, mentors, advisors and role models at tribal colleges and universities, as well as mainstream institutions. Research indicates that when minority students are mentored and advised by caring faculty in a welcoming environment, they are even more successful in their academic and research endeavors. The Association of Public and Land-grant Universities (APLU) recently released their landmark study, “The Quest for Excellence: Supporting the Academic Success of Minority Males in Science, Technology, Engineering, and Mathematics (STEM) Disciplines,” which supports this assertion (APLU 2012). While this study focused on minority males, it also included information that would be useful for minority females. Thus, with more Native scientists, male and female, we could have an impact at all levels—grassroots, community, tribal governance, higher education, and policy.

Degree Attainment

As American Indian/Alaska Native peoples, we have made inroads in increasing our number of science, technology, engineering, and mathematics (STEM) graduates at all levels, but there is still a lot of work to be done. You will note in the following tables that we are still far behind all other minority graduates, especially at the doctoral level.

Table 1

Bachelor’s degrees conferred in biological sciences, 2007-2008

Race/Ethnicity	Total	Male	Female
All Students	77,854	31,637	46,217
White	50,875	21,853	29,522
Total Minority	24,776	9,413	15,363
Black	6,113	1,639	4,474
Latino	5,180	2,031	3,149
Asian/Pacific Islander	12,961	5,520	7,441

American Indian/ AlaskaNative	**522 0.0067%**	**223**	**299**
Non Resident Alien	2,203	871	1,332

SOURCE: U.S. Department of Education, National Center for Education Statistics, 2007-08 Integrated Postsecondary Education Data System (IPEDS), Fall 2008. (This table was prepared June 2009.)

Table 2

Doctoral degrees conferred in biological sciences, 2007-2008

Race/Ethnicity	Total	Male	Female
All Students	6,918	3,403	3,515
White	3,690	1,873	1,817
Total Minority	1,106 (16%)	485 (14%)	621 (18%)
Black	241	91	150
Latino	253	118	135
Asian/ Pacific Islander	595	271	324
American Indian/ AlaskaNative	**17 0.0024%**	**5**	**12**
Non Resident Alien	2,122 (31%)	1,045	1,077

SOURCE: U.S. Department of Education, National Center for Education Statistics, 2007-08 Integrated Postsecondary Education Data System (IPEDS), Fall 2008. (This table was prepared June 2009.)

Table 3

Doctoral degrees Conferred in 2006-2007 (for careers in genome sciences)

	American Indian/ AlaskaNative	White	Black	Hispanic	Asian & Pacific Islander	Non-Resident Alien	Totals
Health Sciences/ Clinical Sciences	26	6,530	363	255	483	698	8,355
Biological & Biomedical Sciences	23	3,463	182	203	566	1,917	6,354

Physical Sciences & Science Technologies	10	2,233	100	107	249	2,147	4,846
Computer & Information Sciences	3	496	34	19	127	916	1,596
Total	62 0.0029%	12,722	679	584	1,425	5,678	21,151

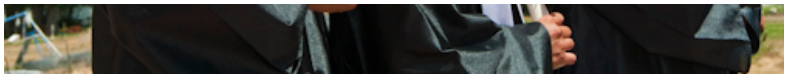
Source: NCES, U.S. Department of Education, National Center for Education Statistics, 2006–07 Integrated Postsecondary Education Data System (IPEDS), Fall 2007. (This table was prepared July 2008.)

According to the U.S. Census Bureau, the 2011 estimate of our country's population is 311,591,917 and based on 2010 estimates, Whites comprise 63.7%, Blacks are 12.6%, American Indian/Alaska Natives are .0.9%, Asians are 4.8%, Native Hawaiian/Pacific Islanders are 0.2%, Hispanic/Latinos are 16.3%, and multiracial individuals make up 1.7%. So, as Native people, we comprise approximately 1% of the U.S. populations but as the tables clearly indicate, we are far below 1% in degree attainment.

Training Opportunities

To address the disparities illustrated in the tables above, various federal programs such as the Minority Action Plan (MAP) Program of the National Human Genome Research Institute (NHGRI) of the NIH, the Indian Health Service (IHS) Scholarship Program of the Department of Health and Human Services, the Native American Research Centers for Health (NARCH) program, and the Tribal Colleges and Universities Program (TCUP) of the National Science Foundation (NSF), have focused their efforts on increasing the number of Native researchers, scientists, and health care professionals. Not only have I personally been influenced by NHGRI MAP programs by becoming an ELSI researcher, I have also witnessed the growth and development of other Native scientists because of the MAP program training activities. For example, through the MAP program, I was able to assist aspiring Native scientists to complete post baccalaureate, PhD, and post doctoral programs and they are thriving in their careers.

MAP Programs were established to increase the number of underrepresented minority scientists in genome sciences, as well researchers in ELSI research. The National Science Foundation (NSF) instituted the Tribal Colleges and Universities Program (TCUP) in 2001 to provide funding to strengthen the quality of STEM instructional and outreach programs at TCUs. The Indian Health Service (IHS) Scholarship Program was established in 1977 to provide scholarships



at three levels: preparatory, pre-graduate, and health professions. The IHS program has single-handedly produced the consistent number of American Indian physicians and health care graduates since its inception. We need our allies to increase our numbers in STEM fields, and we have found them through national advocacy groups. The three most prominent advocacy and mentoring groups for Native Americans include: the Association of American Indian Physicians (AAIP); American Indian Science and Engineering Society (AISES); and Society for Advancement of Chicanos/Latinos and Native Americans in Science (SACNAS). In addition to advocacy and mentoring, these groups assist with training and employment opportunities in academe, research, industry, and health care while assisting with capacity building in Native communities.

When I discuss science careers with aspiring Native scientists, such as my nieces and nephews, I remind them that we have always had science, technology, engineering and math (STEM) in our cultures for centuries. We use different words and concepts that are not always acknowledged by *bilagaana* science. For example, science can be found in our understanding of ethnobotany through the use of plants for medicinal, dietary or artistic use. Biology has always present in the agronomy and agricultural techniques of Native people, most notably in the practice of planting corn, beans and squash next to each other. These ways of knowing were not written down so they were not considered to be science. However, these ways of knowing are part of life and continue to be passed on through oral traditions by our people. By illustrating that we already know science, my nieces and nephews have become that more excited about learning science in another form and language. I also remind them that there are plenty of training opportunities through various mechanisms at the colleges and universities they attend or plan to attend.

Training the Scientific Community on How to Work with American Indians and Alaska Natives

With the increased use of community based participatory research (CBPR) methods in all disciplines, Native people and communities are taking more active roles in scientific research. Some tribal communities and nations have begun to develop thorough vetting processes through Indigenous institutional review boards (IRBs) or other review structures to engage in culturally appropriate consultation and community consent with scientists and researchers who desire to conduct research among Native peoples. The most seminal educational program that both Native and non-Native researchers can reference while designing genetic/genomic research studies is the Genetic Education for Native Americans (GENA) program based in Colorado. GENA seeks better to inform Native college students and community members about genomics, while informing non-Native researchers on how to conduct research in culturally appropriate and respectful ways. This program has been very effective in creating productive dialogue and enriching interaction among scientists and Native communities. In addition, we could explore other emerging scientific methodologies such as Connected Healthcare to assist us in understanding the benefits of genetic testing. The Center for Connected Healthcare in Boston, MA, describes the benefits of using objective data to monitor chronic illnesses by creating phenotype (physical characteristic) maps to reveal how acquired behaviors affect health (Center for Connected Healthcare2012). Thus, health interventions could be personalized using new technologies. The Center also emphasizes that "the occurrence of complex diseases, such as diabetes, depression and heart disease, can only be explained by a combination of genetic make-up, developmental factors and environmental modifiers" (p. 689, Jethwani, K, Kvedar, J. & Kvedar, J. 2012). Thus, to address our health disparities and challenges, we need a multidimensional, multidisciplinary and multicultural approach to scientific research.

Conclusion

Dr. Frank Dukepoo once opined that after many decades, thousands of papers written mainly by white researchers have not produced the results that Native communities need to address their health disparities and challenges. Therefore, as we train more Native researchers and scientists, we can begin to democratize scientific research on our own terms without fear of exploitation to address the real life concerns that our communities face. By continuing to observe "*Mitakuye Oyasin*," we will be guided in our approach to research in respectful ways, and contribute to the body of knowledge that will enable the non-Native community to better understand how we acknowledge the sacredness of our connections with nature. In our continual respect of our connections, we should encourage our younger aspiring Native scientists to pursue fields of study that will complement genomic research, such associology, law, anthropology and business. Scholars in these fields can help to address the multiple ethical, legal and social issues raised by genomics research through using multidisciplinary approaches. Furthermore, we can affect change by capitalizing on training programs that are offered at national and institutional levels to produce a cadre of Native academics and scientists. Finally, as scientists and researchers, we will be able to enter the faculty ranks and scientific community to steer research studies and protocols, and eventually have an impact on policy to better assist our people.

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[1]Bilagáana means white in Navajo.
