THE Native American Women's Health Education Resource Center (NAWHERC) demonstrates a whole life approach to reproductive rights; for NAWHERC, reproductive rights are integral to all other Native health and political struggles. A comprehensive understanding of health guides the organization as it conducts direct service, research, public policy, and advocacy to improve Native women's health. Being rooted in the Yankton Sioux reservation gives the center an authentic voice with which to effectively advocate for Native peoples at the local, national, and international level. For the past 16 years, the center has been dedicated to ensuring the reproductive rights, health, and well-being of Native American women and children in the broader context of the Native struggle for cultural and community survival.

NAWHERC begins with the story of the dedicated leadership of Charon Asetoyer, a tireless voice for Native women's health concerns in the national and international women's health and reproductive rights movements. Prior to founding NAWHERC, Asetoyer, a Comanche from Oklahoma, worked for the American Indian Health Clinic and sat on the board of the American Indian Center in San Francisco. She also served as the director of the Health Program for Women of All Red Nations (WARN) for the Yankton Sioux, Cheyenne River, and Standing Rock Reservations. Asetoyer's perspective and activism were deeply influenced by the philosophy of the American Indian Movement (AIM); she believed that indigenous rights, sovereignty, and nationhood were closely tied to community health issues and that a community needed to be healthy to ensure its political rights.
While studying criminal justice at the University of South Dakota, Asetoyer met her future husband, Clarence Rockboy. After she completed her degree in 1985, the couple decided to live on Rockboy's Yankton Sioux Reservation (Ihanktonwan). Once on the reservation, Asetoyer began to work locally on women’s health by identifying several unmet health needs. Together, Asetoyer and Rockboy founded the Native American Community Board (NACB). In 1988, three years after NACB started working in the community, it purchased a building and incorporated the Native American Women's Health Education Resource Center.

The center was established to raise awareness of Native women's rights over their bodies and their lives. While representatives from the center speak nationally and internationally about reproductive rights issues in the Native American community and work in coalition with other Native American groups and organizations of women of color, the center is firmly rooted regionally. It is specifically committed to improving the health of Native American women living in the Aberdeen area, which, as defined by the Bureau of Indian Affairs (BIA), consists of North Dakota, South Dakota, Iowa, and Nebraska, where 54.5 percent of the Native American population live below the poverty line, almost four times the US all-race rate of 13.1 percent.¹

The Historical Context of NAWHERC

NAWHERC places its struggle to attain reproductive rights in a historical perspective. According to NAWHERC, before colonization, Native women enjoyed freedom, participated in decision making, and exercised control over their reproductive functions. Generally, across tribes and nations, women's power over their own bodies was culturally implicit, in the sense that their bodily autonomy was "institutionalized." Native American lawyer and health activist Sarah Littlecrow-Russell explains that the concept of institutionalized liberation is hard for many white feminists to comprehend, because they have never had this authority or control over their own bodies. Instead, white feminists understand their reproductive capacities within the context of institutionalized oppression.² The resource center describes life before the Europeans in the North Central Plains in the following way:

The aboriginal people of the North Central Plains lived in not only a democracy, but also a matrilineal society when Pierre Radisson, the first white person, visited the village in 1654. The Native women enjoyed a life unknown to white women in Europe, being free to own their own
homes, participate in decisions about their government, and have control of their bodies.

In the ensuing years, the people were herded into reservations and today live in hostage status, suffering every deprivation and loss of freedom. Our children were forcibly taken from their families...the insidious erosion of identity, culture, spirituality, language, scientific and technical knowledge and power created the chaos and violence in which we, as women, struggle to survive and live a decent life.

With knowledge and appreciation of our history, we fully realize our status in today's society, as we state our rights and aspirations as Native women.³

Retrieving, nurturing, and affirming Native culture and spirituality is central to NAWHERC's philosophical and political orientation. This orientation grounds the center's work, which includes providing direct services, conducting research, organizing advocacy programs, and forging coalitions with other Native American women in the framework of cultural renewal and Native sovereignty. The center has worked closely with other groups of women of color, promoting an understanding of the reproductive rights concerns of Native women and lobbying for reproductive rights in indigenous communities worldwide.

**Fetal Alcohol Syndrome**

Due to the high rate of fetal alcohol syndrome (FAS) among babies on the Yankton Sioux reservation and among children born to Native American women in general, the first issue that NAWHERC tackled was FAS. The rate of alcoholism in Native men and women is higher than in any other ethnic group in the US. At the time NAWHERC began grappling with FAS in the community, statistics showed that among Native Americans and Alaska Natives, mortality rates due to alcoholism for women aged 25 to 34 were nearly 21 per 100,000, compared with 2 per 100,000 for women of all races. Native women between the ages of 35 and 44 had a mortality rate of 47 per 100,000, nearly 10 times the rate of women of all races.⁴ Native Americans often yield to alcohol and drugs to cope with prior victimization from incest, rape, and other forms of sexual assault. Annette Jaimes describes the collective and individual hopelessness engulfing Native America as a "colonially induced despair" that has given rise to a host of socially disruptive behaviors, with alcoholism—and concomitantly FAS—chief among them.⁵
NAWHERC crafted its approach to slowing FAS in the community within a reproductive rights framework. The center explicitly opposed the "right-wing approaches" to reducing the incidence of FAS that entailed preventing Native women from having children. The center challenged the widely held notion that the sterilization of Native women was an appropriate response to FAS. New reproductive technologies such as Depo-Provera and Norplant were also gaining popular support as a solution to FAS by those who did not want to deal with the root causes of high rates of addiction among Native women. Instead of addressing why Native women were delivering babies with FAS, the government's approach was to control their reproduction.

The national attitudes toward drug and alcohol addiction have tended to ignore the structural issues fueling it. Furthermore, rather than dealing with addiction as a public health issue, it has been criminalized and characterized as an individual failure. These attitudes, coupled with institutional racism, isolation, and a lack of resources have had an adverse impact on Native American communities. Minimal efforts have been made to address the real issues that could effect prevention. Asetoyer and her colleagues have pointed to the lack of treatment—and the lack of culturally appropriate care when treatment was offered—for those women who are already pregnant and are alcohol- and drug-dependent. Native American women who are substance abusers are rarely hospitalized and rarely receive detoxification or counseling for their addictions. Instead, they are often jailed or deprived of their parental rights. The center's work on FAS led to research on a wide range of other health issues, including the underlying causes of alcoholism and drug addiction. NAWHERC's understanding of the real causes of FAS, and their critique of the responses to it, motivated them to strive to make health policies and services appropriate and responsive to the cultural needs of Native women.

Redefining Reproductive Rights

In 1990, NAWHERC organized "Empowerment Through Dialogue." This historic three-day gathering brought more than 30 Native women, representing over 10 nations from the Northern Plains to Pierre, South Dakota. Many wanted to address the social, cultural, economic, and community concerns that affected their daily lives and go beyond a narrow focus on abortion and contraception. They created "The Agenda for Native Women's Reproductive Rights," informed by Native American history and ancestral teachings in which "all matters pertaining to us as indigenous women, including reproductive rights
issues, were, are, and always will be the business of women.” At
the Pierre meeting, women redefined reproductive rights to include: age-,
culture-, and gender-appropriate information and education for all family
members about sexuality and reproduction; affordable health care,
including safe childbirth within Native communities; and access to
safe, free, and/or affordable abortions, regardless of a woman’s age,
with confidentiality and free pre- and post-abortion counseling. They
called for active involvement in the development and implementation
of policies concerning reproductive rights issues, including, but not
limited to, pharmaceuticals and technology. They saw domestic
violence, sexual assault, and HIV/AIDS as reproductive rights issues.

They also determined that reproductive rights work should in-
clude programs to reduce infant mortality and high-risk pregnancy
and to meet the nutritional needs of women and families. Culturally
specific, comprehensive chemical dependence-oriented prenatal
programs—including, but not limited to, prevention of fetal alcohol
syndrome and its effects—were an integral part of their reproductive
rights agenda, as well as putting an end to coerced sterilization. They
underlined the importance of cultural and spiritual development,
culturally-oriented health care, the right to live as Native women, and
Native determination of tribal members. Support for women with dis-
abilities, as well as the right to parent in a non-sexist and non-racist
environment, were also part of their far reaching reproductive rights
agenda. The programs and outreach activities of the center are built
around this set of principles proclaimed at Pierre.

This agenda still guides Native women’s thinking and activism. In
January 2000, 10 years after the first meeting, 37 women represent-
ing over 10 tribes met again to set guidelines for implementation of
the reproductive health and rights agenda for Native American orga-nizations and other concerned groups. These women stressed that re-
productive health and rights continue to be major concerns for Native
peoples.

The Mission of the Resource Center

The center’s goal is to meet the reproductive rights and health needs
of women in the Aberdeen community by offering a range of services
and educational programs. It conducts primary research on the health
status of women in its own community to advocate on their behalf and
to address the health concerns of other Native women. To carry out this
mission, it has established partnerships with both local and regional
(South Dakota, North Dakota, Minnesota, Nebraska, and Iowa) agencies
and organizations. The center also works with local Native women’s
societies and with progressive Native women in the area."
The resource center collaborates with national and international women's organizations and groups, like the Indigenous Women's Network, that share their efforts to advance the rights of indigenous women. It brings Native women's concerns to mainstream reproductive rights and health groups through published reports and advocacy in the broader reproductive rights community, participation in conferences and meetings, and in coalitions with other women of color. Through its work with women of color groups (such as the National Black Women's Health Project, the National Latina Health Project, and the Women of Color Coalition for Reproductive Health Rights) and their mostly white counterparts (such as the National Women's Health Network and the Boston Women's Health Book Collective), NAWHERC established a national and international presence. The center is truly distinctive in its ability to work at all of these levels while remaining firmly grounded in the Yankton Sioux Reservation community.

Community-Based Research and Reporting

To anchor its research in the community, NAWHERC uses the roundtable process, a traditional Native American approach to information sharing and processing. In many ways, it incorporates some of the concepts of Self-Help as utilized by the Latina and African American women's organizations in this book. The philosophical basis of the roundtable is a belief that participants can demystify problems and find appropriate solutions to challenges facing the community. The roundtable provides a safe space for individual participants to discuss issues such as domestic violence, rape, and drug, alcohol, and sexual abuse. Participants are encouraged to verbalize their personal, social, and historical realities and to identify crucial issues relating to the specific topic being addressed. This space enables participants to deal with internalized oppression and reinforces the traditional systems of women's societies where women come together to address their problems. Furthermore, the format acknowledges that all community members are experts through their life experiences and have the necessary information and solutions to address their concerns.

Through speaking and sharing, partnerships are forged, creative abilities sparked, and women work to solve problems for themselves, their families, and their communities. They share knowledge of traditional teachings so that they may be integrated into their analysis and solutions. A facilitator who is charged with providing direction, support, and encouragement often leads these discussions. The facilitator is encouraged to work creatively with the group and is not expected
to conform to a particular preset format. Typically, the participants generate a set of recommendations collectively. The roundtable process is an example of consensus decision making based on traditional principles that fosters women's leadership in the Native American community.

In the 1990s, the center conducted three Dakota Roundtables on reproductive rights. These meetings brought together Native women from the Aberdeen area to look at specific issues utilizing the roundtable process. The first Dakota Roundtable discussion, in 1993, focused on problems faced by children in the community and paid a great deal of attention to the high rates of mortality for infants and young children. The Second Dakota Roundtable, in 1994, elicited their perspectives on key concerns facing women. They identified their reproductive health as a key concern. The Third Roundtable, in 1996, brought mature and young women together to address issues faced by Native teenage mothers and their experiences of pregnancy.

NAWHERC scrupulously documents and publishes the words of the speakers anonymously so that they "will inspire local, regional and national Native American communities towards the activism necessary to bring about policy changes in all of the spheres that affect Native American women's lives." Consistent with NAWHERC's roundtable-consensus approach, participants are mailed a copy of the compiled report for input prior to general dissemination to the public. Thereafter, the reports are sent out to participating tribes, tribal councils, tribal health boards, community-based organizations, members of the US Congress, national women's organizations, and other groups. The concerns raised by participants in the roundtables determine the center's research priorities and activities, inform the development of their educational materials, and direct the training of community activists.

In 1999, NAWHERC convened a focus group, using the roundtable process, to investigate the status of reproductive health care services provided by the Indian Health Service (IHS). The focus group consisted of eight women—representing six different Lakota and Dakota nations—who used IHS as their primary and reproductive health care provider. The focus group served as a study tool to craft effective and accurate ways to improve IHS delivery of reproductive health services to Native women and community members. The focus group report made many recommendations, including that direct training for practitioners be made more culturally sensitive. It notes:

It is important to understand that within Native American culture, Elders and people of high accomplishment, such as health care practitioners, are in a position to be treated
with respect. Thus, the recipient of care respects the position of the health care provider and trusts the person to keep them informed about their condition. Because of this Native women are often necessarily viewed as passive participants in their health management.\textsuperscript{15}

Among its recommendations was the need for IHS to demonstrate commitment to

following policies and procedures and disciplining aberrant behavior among service providers. This includes everything from informed consent forms to confidentiality policies. Patients need to know that going into the IHS clinic won’t violate their civil rights. This, too, will serve to reduce the gap between provider and patient and encourage trust in the IHS system.\textsuperscript{16}

The report also recommended that the IHS provide more information about reproductive tract infections, sexually transmitted diseases, and contraception and make condoms more easily available.

Thus, the roundtable process and ensuing report placed pressure on the IHS to provide better-quality health care services and be alert to the culture and perceptions of its clients. The report itemized the services clients wanted. Improvements in the attitudes and behavior of health care providers were underlined. This report is a good example of how NAWHERC used community-based research to improve IHS health care and services to make them more culturally appropriate.

NAWHERC’s research and roundtable reports have been circulated widely to draw attention to Native needs. Asetoyer reports that they have affected IHS policies:

And we have taken our realities, documented them, moved them forward with or without the permission of Indian Health Service all the way to IHS Headquarters, to senators, to foundations, and all the way to the UN so that we can share our realities and the way some policies have affected our lives.

We’ve gotten some incredible feedback... We have a program committee member who recently retired from IHS and who still has access to information. She said: “Do you know that you’ve changed policy? You’ve got them all scurrying around changing things because they’re getting inquiries from senators’ offices, from the press; they’ve been calling.” ... Whenever I get ready to go to an international
meeting, I get a call from IHS asking for an advance copy of whatever we’re going to release there. They’ve learned to respect the work we do.17

NAWHERC’s research has also been effective in changing the way that the Centers for Disease Control (CDC) collects statistics about Native women. Through its research and documentation efforts, the center has proved to be a voice to be reckoned with and has impacted the development of health policy and practice in Indian communities.

In its first decade, the center carried out many community research projects to better address the reproductive health concerns and needs of Native women in Aberdeen and throughout the United States. It conducted studies on fetal alcohol syndrome (1986 to the present), the impact of Norplant in the Native American community (1992), the abuse of Depo-Provera and Norplant by the IHS (1993), and the revictimization of battered women (1994). Using a community-based research approach and the roundtable process, NAWHERC has been able to gather data and document various inequities and their effects on Native American women. Through its advocacy and reporting, NAWHERC has advanced a critique of the Indian Health Service that stimulated Native activists to demand better health care. It forced the IHS to revise its approach to health care to be more attentive and culturally sensitive to the needs of Native peoples, to improve its data collection, and to adopt culturally appropriate health care practices as well as changes in some of its protocols.

Direct Services to the Community

NAWHERC has about ten full-time staff, four three-quarter-time positions, and four to six volunteers. The staff and volunteers provide a wide range of women’s health and education services in the Yankton Sioux–Aberdeen community that reflect the center’s broad vision of health and the relationship between health rights and cultural integrity. These services address community needs identified through research and engagement in the community. The center’s projects cover a wide swath of activities, including leadership and youth development. It operates a hotline and runs a domestic violence shelter and food pantry. The center conducts AIDS awareness programs and runs a variety of other health programs, such as diabetic nutrition, child health, and cancer prevention. It also conducts an environmental issues program. This impressive range of activities shows how the center is involved in most facets of women’s lives on the reservation.
Coalition Work

Over the last decade, the center has made strategic alliances with other Native women’s groups (such as the Women’s Circle on the Sisseton Reservation and the White Buffalo Calf Society) and several tribal colleges on reservations in South and North Dakota, as well as with organizations outside the Dakotas.18 One example of the center’s power in coalition was its joining with other groups of women of color to monitor the federal government’s guidelines regarding Depo-Provera and Norplant. Charon Asetonot found that the IHS has not followed protocol regarding Depo-Provera and Norplant distribution, and that women using these devices have not been systematically tracked or monitored. The center also keeps a close watch on IHS promotion of Norplant in many Native communities. The center has brought attention to the fact that the IHS lacks uniform policies and procedures regarding the use of these contraceptives. Since Depo-Provera must be administered quarterly to be effective, and Norplant users have to remove the implants after five years to avoid ectopic pregnancies, it is imperative that the women who use this type of contraception be monitored. The center continues to fight for a uniform federal protocol that is followed consistently in all IHS clinics.

Participation in the SisterSong Collective has enabled NAWHERC to work with a select group of Native women’s organizations and other women of color to share learning and develop education, outreach, and advocacy strategies that aim to increase awareness among indigenous women and women of color on reproductive health issues, inform health care practitioners about culturally appropriate treatment, and advocate for better legislation to improve women’s health. In 2002, the four Native American groups of the SisterSong Collective spent time reassessing the 1990 health agenda put forward at Pierre and plan to move forward with that set of principles.

NAWHERC has also engaged in international collaborations. During the Cairo and Beijing conferences, it worked with women from the Indigenous Women’s Working Group—Mothers of Nations—to place the issues of Native communities on the international agenda. These included issues of health and reproductive rights, violence against women, land and environmental rights, and self-determination.

The Significance of NAWHERC

The center has provided much-needed reproductive health care advocacy and education to Native women. Due to the center’s public education and outreach programs, and because of the influence it has had on IHS policies, Native women are better informed about their health and their rights. More indigenous women have become
knowledgeable advocates for their health care. The center has brought national attention to the health needs of Native American women and enriched thinking and practice on cross-culturally competent health care.

The center has been prolific in producing research and policy recommendations and educational materials of remarkably high quality. Its research plays an integral role in illuminating community needs from within—to fellow Native Americans and non-Native people—and in devising appropriate health care interventions. The center's numerous reports cover a range of topics, giving much needed information on mental, physical, and environmental health concerns. NAWHERC has influenced the development of activist agendas and policy initiatives in Indian nations across the country and engaged Native women in establishing research priorities. Its recommendations have been used in the development of IHS protocols and in the training of health practitioners. The research serves as an important source of information about the health of Native Americans and has implications far beyond the reservation.

NAWHERC’s educational materials contain up-to-date, practical information about how people can improve their health. Pamphlets are written in accessible language and are widely available in the community. Its culturally appropriate sexual and reproductive health programs serve as a model for other communities. It looks to the elders as a source of knowledge on traditional health practices and culturally relevant teachings on coming of age, childbirth, breastfeeding and child rearing, sexuality, and sexually transmitted diseases. Many of the center’s reports and roundtables pay particular attention to the teachings of elders, and NAWHERC always looks for ways to incorporate traditional practices into its work.

NAWHERC is impressive in its ability to consistently and simultaneously work at many different levels. The particular concerns of indigenous women are quite distinct from those of other women of color, and the center has brought that awareness to other women of color groups. It has also brought this sensitivity to mainstream groups, and often serves as a representative of Native American women's issues in these forums.

With Asetoyer as its primary spokesperson, the center has been an inexhaustible advocate for Native American women's health in the United States. NAWHERC's work on women's health and rights, economic development, land and water rights, and cultural preservation provides a solid foundation for further Native activism on this set of issues and shows us how broad based an organization must and can be to adequately address the complex and multidimensional needs of underserved communities.
NOTES


2 Native American activist, Sarah Littlecrow-Russell, pointed this out in her thoughtful reading of an early draft of this chapter.


7 In fact, as Elizabeth M. Armstrong shows in her article “Diagnosing Moral Disorder: The Discovery and Evolution of Fetal Alcohol Syndrome,” *Social Science Medicine* 47, no. 12 (1998): 2025–2042, the very construction of FAS as a medically recognized syndrome is problematic, since the original studies involved a very small number of cases and tended to ignore other conditions (such as poverty, malnutrition, etc.) that can also contribute to poor health in newborns, preferring instead to focus on the moral deficiencies of “alcoholic” mothers.

8 This is the way in which the Pierre meeting is discussed in several NAWHERC publications.

9 This agenda was set in Pierre on May 18, 1990. It can viewed in its entirety, including amendments, at http://www.nativeshop.org/pro-choice.html.

10 From a statement issued on July 7, 1992 by the the women of color meeting co-sponsored by the Religious Coalition of Abortion Rights, the Ms. Foundation, and the NAWHERC held in Washington, DC.

11 Some of these native societies include the Treaty Council, Tribal Councils, the South Dakota Coalition Against Domestic Violence, and the Minnesota Women’s Task Force. Included among the progressive women they work with are Cecilia FireThunder and Karen and Sharon Day, who work on women’s health issues.

12 This process is similar to the Latina Roundtable process. Many aspects of the Latina Roundtable process were influenced by Chicana history, and the indigenous histories shared between many Chicana and Native women create some overlap in their approaches.

13 In the appendices for *Moving Forward* there is a note on women’s societies, from which the roundtable has consciously drawn. Traditionally, matters pertaining to women, including all decisions concerning reproductive health care, were the business of women. Each individual woman’s decision on these matters was final and respected. However,
women would often turn to other women within the society for advice, mentoring, and assistance.


15 NAWHERC, *The Current Status of Indian Health Services Reproductive Health Care: Report 1: A Focus Group Examining the Indian Health Service's Reproductive Health Care for Native American Women in the Aberdeen Area* (Lake Andes, SD: NAWHERC, 1999), 20.

16 Ibid.


18 These organizations include the American Indian Community House and the American Indian Law Alliance in New York City, the Minnesota American Indian AIDS Task Force, the Indigenous Women's Network and the American Indian Center in San Francisco, and the Gibson Foundation of Hawaii.