The Brown Paper is a groundbreaking compendium and review of health research and literature on South Asians in the United States. Published in 2002, the Brown Paper evaluates and summarizes existing knowledge about key health indicators for South Asian Americans. For a full, print copy of the Brown Paper, please e-mail info@sapha.org. Electronic versions of individual chapters are available online at http://www.sapha.org/pages.php?id=42.
**Women’s Health**

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**Objectives:** The authors reviewed the health conditions that are particularly relevant to women of South Asian origin including anemia, osteoporosis, and reproductive health, and report on methods to improve their knowledge, access, and utilization of health care services.

**Key Findings:** Physicians in the United States have noticed a greater number of women from Bangladesh and Pakistan presenting with anemia due to thalassemia, a hereditary trait for abnormal hemoglobin, which contributes to early destruction of red blood cells. Although South Asian women in the US receive first trimester prenatal care at about the same rate as White women (80% vs. 82%), women who have immigrated from India are more likely to delivery low birth weight infants than White women and women in other ethnic groups. Women’s health is greatly affected by family structures and expectations, guilt, pressure, isolation, and socioeconomic status.

**Recommendations:** South Asian, Asian American and Pacific Islander, and mainstream health, services, policy, and advocacy organizations must work together to include South Asian women in efforts to collect, analyze, develop and program around information about their needs. South Asian women want to be better informed about disease and illness, how to access health care services, and the benefits of prevention efforts such as healthy behavior and decision making.

**Introduction: The Health Experience of South Asian Women**

Health is a concern for all South Asian women in the United States, yet few perceive themselves at risk for many health problems. Furthermore, society often overlooks women’s health issues. Many factors contribute to the perception that women are immune to health risks.\(^1\)\(^2\) While there are some data shedding light on risk factors and outcomes for Asian American and Pacific Islander (AAPI) women, rarely have studies adequately explored South Asian female populations in the US as a unique group.

Although the health needs of South Asian women do not vary significantly from their general female population in the US, their health-seeking behaviors need to be better understood as they influence accessibility to mainstream health services.\(^3\) South Asian women have traditionally played the role of primary caregiver for both family and community, often limited their ability to make their own health and well-being a priority.

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3. From work with South Asian women. New York, NY: 1999-2001 and published material from other assessments around the country referenced below.
Several factors influencing women’s attitudes and behavior towards health services include: fear of the establishment or authority; embarrassment of self or body; low self-esteem; isolation; lack of knowledge about health issues, services available, and preventive care; and difficulty with adherence, coping, and communication skills. Fear of rejection and discrimination may also prevent women from disclosing information regarding their health and sexuality.\(^1\)\(^,\)\(^4\) Quite often, information on various health topics is not readily accessible, and may result in neglect of one’s own physical and emotional well-being, especially when women do not know how or where to access services or are afraid or ashamed to seek assistance. Limited language capacity in English adds to feelings of discomfort and isolation, further complicating the process of seeking mainstream health care services.\(^3\)

Some South Asian women are challenged by financial and economic restrictions that hinder access to good-quality health care services. Immigrant women do not always control their own finances.\(^5\) This may be because they lack employment opportunities or options outside of the home and have limited financial independence. Financial dependence limits their access to knowledge and awareness of existing services and creates physical barriers to care, such as a reliance on others for trans-care, such as a reliance on others for transportation, thus restricting their mobility to and from health care providers. Inadequate health care coverage and high medical costs also prevent the use of needed services. A 2001 report by Families USA in Washington, DC notes that 21% of South Asians are uninsured in the US.\(^6\)

In many ways, South Asian Americans are still considered a “model minority,” an ethnic group who face few health problems, are wealthy, and can easily afford health care costs as needed.\(^7\) Over time, this myth has further perpetuated the problem. The perception that South Asian women are not at risk for health problems as become accepted, minimizing the need for early intervention and prevention of disease and resulting in treatment at later stages of illness.

Contributed to these obstacles is providers’ lack of resources, information, and training on the specific health problems and social realities South Asian women encounter.\(^2\) Often, physicians of South Asian descent are ill-equipped to address women’s health issues or may have gender biases. Inhibition between South Asian women and their physicians prevents complete disclosure of personal information and health problems and results in faulty health assessment and treatment.\(^8\)


Yoshioka and DiNoia explain well the obstacles that AAPI women may face in obtaining health services:

Limited research suggests that there is a complex interweaving of cultural, environmental, and interpersonal factors that contribute to placing immigrant families at risk...traditional Asian values of privacy, honor, self-restraint, harmony, and order may encourage the minimization and hiding of serious family problems. Also, recent immigrants lack the natural informal support networks customary in their native countries. They may be unfamiliar with the organization of American social services systems and the way they function. Furthermore, the sense of isolation among women is often compounded by their limited command of English.⁹

The complex interrelationships between these social, cultural, and individual factors described above are not easily altered. They are nonetheless realities of many women’s lives, influencing their decision-making processes, their ability to negotiate personal needs, and their health-seeking behavior. They require exploration and should be considered in future evaluations of South Asian women’s health.

**Epidemiology in the AAPI and South Asian communities**

Although statistical data on South Asian women living in American and on barriers to health care are limited, researchers are making efforts to develop an understanding of the emerging health risks for this population. Several health issues in particular impact the lives of women who are of South Asian descent and living in the US.

In 1992, five leading causes of death were reported for AAPI women: heart disease, malignant tumors (such as breast cancer), cerebrovascular diseases (such as strokes), accidents and adverse effects, and pneumonia and influenza.¹⁰ For the category Asian Indian, the top causes were heart disease, malignant tumors, cerebrovascular diseases, accidents and adverse effects, and diabetes. Compared with AAPI women, Asian Indian women had the same top three causes for death, but where as likely to die from accidents as from strokes. In addition, diabetes was more common and complications of diabetes were listed more frequently as a cause of death compared with other AAPI groups. Compared with the US population as a whole. These women were less likely to have chronic obstructive pulmonary diseases as cause of death and more likely to have accidents or adverse events listed as the cause of death.

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Several lesser-known health conditions are significant, yet under-acknowledge, among South Asian women. Heart disease, cancer, intimate partner violence, and mental health all impact women’s lives and are explored in this report in separate chapters on each health topic. Other conditions and health concerns that are particularly relevant to the South Asian female community include anemia, osteoporosis, polycystic ovarian syndrome (PCOS), and reproductive and sexual health.

**Anemia** is a common medical disorder with many causes: inadequate production of red blood cells, due to iron and vitamin deficiency and malnutrition; early/increased destruction of red blood cells, due to certain illness/infections; and excessive loss of blood, due to menorrhagia, a heavy and un-usual blood flow during menstrual cycles. Violence, poor nutritional intake, lack of or delayed medical attention, socioeconomic status, pregnancy, and uterine fibroids (benign growth/mass in the uterus) aggravate anemic conditions. The most common symptom of anemia is fatigue. Other symptoms include shortness of breath, pale skin, heart palpitations, excessive thirst, weight loss, memory problems, and jaundice (yellowish skin). Pregnant women who are anemic, without proper treatment, face the repercussions of both higher maternal and child mortality, as well as lower infant birth weight.

Anemia affects almost a third of the world’s population according to the World Health Organization, with 90% of those affected in living in developing countries. Based on studies conducted in India, Bangladesh, and Nepal, 60-70% of women in South Asia are estimated to have anemia. Though anemia impacts a large number of women in South Asia, there is limited information on rates of disease once they have migrated to the US. When compared with the general female population in the US, the prevalence (percentage of cases in the population) of anemia for women in Pakistan is four times

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higher. As many as 20% of all women of childbearing age in the US have iron-deficiency anemia, compared with just 3% of men.

A few studies have evaluated the rate of diagnoses of anemia among South Asians in Europe, with iron deficiency identified as causing the majority of cases. For Indian and Pakistani women living in the United Kingdom (UK), menorrhagia (usually secondary to uterine fibroids or endometriosis, abnormal tissues which grow inside the uterus) contributes to high rates of anemia. One study suggests that cultural beliefs and food habits may also contribute to the high prevalence observed. This analysis found that heavy blood flood flow during a menstrual cycle was viewed positively because the flow was thought to remove impure blood. In response to a heavy blood flow, women abstained from certain foods replete with iron such as meat, fish, and eggs. Women with vegetarian diets are at a disadvantage if they do not supplement with iron-rich foods and Vitamin B-12. In another study, South Asian individuals surveyed were twice as likely to have anemia if meat was not part of their diet, similar to patterns observed in both Chinese and European participants.

Individuals residing in developed countries do not face anemia as a notable health risk overall. However, certain groups show a higher rate of risk for iron-deficiency anemia due to diet and pregnancy and anemia due to thalassemia, a hereditary trait for abnormal hemoglobin, which contributes to early destruction of red blood cells. Physicians have noticed a greater number of women from Bangladesh and Pakistan presenting with the thalassemia trait.

While access to health care and nutritional intake may improve when migrating from a developing country to a developed one, the rate of anemia among women remains a health concern for South Asian women. If diagnosed in time through proper medical attention, most cases of anemia are treatable with iron, folate, Vitamin B-12 rich roods, and supplements, and a high-protein diet.

Osteoporosis is a disease caused by decreased bone density that gradually weakens bones, resulting brittleness and increased risk of fractures (breaking of bones). These

20 From clinic work of Dr. Daksha Shah in Northern California and Dr. Sabitha Rao in New York City, as discussed in March 2002.
Fractures occur most commonly in the hip, spine, and wrist. They can impair a person’s ability to walk and function unassisted, contribute to loss of height, cause severe back pain and deformity, and may cause prolonged or permanent disability, and even death (often due to hip fracture). Women are four times more likely than men to develop osteoporosis. A women’s life-time risk of hip fracture alone is equal to the combined risk of developing breast, uterine, and ovarian cancer, and osteoporotic fracture are four times more common than strokes.\(^{21}\) According to one study, one out of five women over age 65 with osteoporosis ends up with a hip fracture.\(^{22}\)

Due to the low calcium and vitamin D intake of many Asian women and the varying nutritional status of Asian women around the world, the World Health Organization has placed people of Asian origin at higher risk of developing osteoporosis. Osteoporosis is prevalent in over one-fifth of AAPI women. The National Osteoporosis Risk Assessment found that 65% of API women have low bone mineral density, the highest rate of all racial groups. Of these women, 8.2% have developed full osteoporosis compared with only 5.2% of Caucasians.\(^{21,23,24,25}\) Indian women over age 50 have approximately a 40% chance of developing an osteoporotic fracture at some point during their remaining lives.\(^{23}\) It is estimated that up to 25% of Indian women over age 50 may be osteoporotic.\(^{26,27}\)

Risk factors for osteoporosis include a small, thin body frame; family history of osteoporosis; a diet low in dairy products and other sources of bioavailable calcium; lack of physical weight-bearing activity and regular exercise; excessive smoking or alcohol consumption, which decrease calcium absorption; abnormal levels of thyroid hormones and the female sex hormone estrogen; extended use of steroids; ongoing menstrual irregularities; early menopause; removal of the ovaries, a natural source of estrogens; and age.

For South Asian women, a leading contributor toward facing osteoporotic conditions is the number of pregnancies they experience. Repeated pregnancies lead to a lost of calcium due to prolonged lactation and breast feeding, denying bones the opportunity to regenerate and recuperate, thus leading to osteopenia (decreased bone mass) and osteoporosis.

\(^{22}\) Shad D. Personal communication. March 22, 2002.
In addition, many South Asians are vegetarian, and the American diet may or may not provide them with sufficient absorbable calcium in their dietary intake. Most studies in the available current literature focus specifically on the Indian population, both in South Asia and in the Diaspora. Osteoporotic status of other South Asian women, with their varied diets, nutritional lifestyles, and environments, is unknown. Investigations of osteoporosis have increased due to the potential morbidity and mortality associated with it, mostly morbidity and mortality from hip fracture.\(^\text{22}\)

Treatments have focused on lessening progressive bone loss and reducing the risk of fractures. Drug treatments include the use of calcium supplements, estrogen replacement, and estrogen modulators. Calcium-absorption enhancing drugs are used less commonly. Non-drug treatments include exercise; tai chi; acupuncture; herbal therapies; changes in diet; physical therapy; use of magnets, which are thought to enhance bone repair and growth; pain management; and surgery.

**Polycystic Ovarian Syndrome (PCOS)** is an endocrine distribution in women, related to hyperandrogenemia, an excess of “male-like” hormones. This disorder frequently results in central obesity (an accumulation of fat around the waist area), an increase in body hair, oil-gomenorrhea (in which the interval between periods is greater, i.e., the number of menstrual cycles per year decreases), and infertility related to anovulation (failure to ovulate). More recently, beta cell dysfunction (cells in the pancreas that produce insulin) and profound insulin resistance have been discovered among women diagnosed with PCOS.\(^\text{28}\) The prevalence of this disorder varies among populations and clusters in families; thus, it is thought to be genetically determined.\(^\text{28}\) Actual prevalence rates of PCOS vary depending on the definition. Prevalence rates have generally been estimated for White populations in Europe and have ranged from 2% to 20%. Rates among Black and White women in a prospective prevalence study in the US were 3.4% for blacks/African Americans and 4.7% for Whites/Caucasians, suggesting that PCOS may be one of the most common reproductive endocrinological disorders of women.\(^\text{29}\)

It is suspected that South Asian women have higher rates of PCOS, and this increased prevalence has been noted in one study of South Asian women living in the UK.\(^\text{30}\) While a few other countries have looked at relative rates across ethnic groups and Indian women emerged with higher risks (New Zealand, Singapore), no other specific studies of South Asians have been published in the US. Not all women affected by PCOS have all the traits mentioned, and even among normal weight women with PCOS, insulin resistance is


a key feature. Similarly, variation in insulin and glucose responses to glucose challenge in a study of Caucasian and Indian women with PCOS has been noted.

South Asians have been found to have higher rates of insulin resistance and metabolic syndrome, a condition that generally includes insulin resistance, lipid abnormalities, and central obesity. These disorders, which represent a spectrum of disease related to impaired use of glucose, and can lead to diabetes, are discussed further in the diabetes and cardiovascular sections. However, it important to note that recent studies of women with PCOS have focused on the use of metformin as drug treatment for the underlying insulin resistance to help prevent some of the consequences of PCOS, including infertility, overt diabetes, and heart disease. This medication has also been used among both adult women and teenage girls in order to restore normal menstrual cycles. South Asian women with infertility should be screened for PCOS, and they need to be aware of associated problems of insulin resistance that may predispose them to long-term consequences, such as metabolic syndrome, diabetes, and heart disease.

Reproductive and Sexual Health involves the control women have over their sexuality, the knowledge they possess about their own bodies, and the roles these factors play in influencing their overall health. Minority women experience significant cultural and social barriers that may prevent them from receiving adequate reproductive and sexual health care throughout their life span. Health, women’s bodies, and sexuality are neglected areas of discussion in the South Asian context, because they are topics biased by traditional notions of secrecy and taboo. Stereotyping and control over women’s freedom to make decisions and express sexuality can lead to negative consequences, such as unhealthy emotions about sexuality and reproductive systems; improper gynecological care; decreased protection against unwanted pregnancy and sexually transmitted infections (STIs); as well as other conditions involving the reproductive system and sexual health.

Although South Asian women in the US receive first trimester prenatal care about the same rate as White women (80% vs. 82%), women who have immigrated from India

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37 Office of Research on Women’s Health. National Institutes of Health. “Women of Color Health Data Book: Adolescents to Seniors” examines role of culture, ethnicity, race, socioeconomic background,
are more likely to deliver low birth weight infants than White women and women in other ethnic groups.\textsuperscript{38} One study found Asian Indian women breastfed for shorter periods than White women did and were more likely to depend upon extended family members for information on breastfeeding than to seek guidance from a health professional.\textsuperscript{39} Also, although a yearly pelvic exam and a cervical cancer test (Pap smear) are most effective in helping to detect STIs and cancers early, data from 1998 show that 33\% of AAPI women (age 18 and older) did not have such an exam within the past three years.\textsuperscript{40}

In a recent study on sexual violence among South Asian youth conducted during the spring of 2002, Kamat reports that 78\% of 153 young women ages 18-25 surveyed on the Internet were sexually active, defined as having engaged in any penetrative sexual activity and 29\% of women reported having engaged in sexual contact (without penetration) despite verbal or physical protest or being under the influence of drugs or alcohol (what the author defines as sexual assault).\textsuperscript{41}

In another recent dialogue, Apna Ghar, a Chicago agency serving South Asian American women and children who are victims of domestic violence, found the following among women who participated in four focus groups (women of faith, women living in Apna Ghar’s shelter, and two groups of young professional women) on reproductive and sexual rights.\textsuperscript{42}

\begin{itemize}
  \item Cultural or societal influences bear a strong influence on their right to choose to have children. They are concerned that a preference for boys dominant in the Indian culture was resulting in an increased number of abortions for gender selection.
  \item Some identified the culture of silence around issues of sexuality and reproductive choice as contributing to the limited understanding girls and women have about their bodies and their rights.
  \item They experience tremendous barriers in accessing contraception – from discomfort in asking South Asian providers for reproductive health guidance, for fear they carry cultural biases to their practice or may violate confidentiality and
\end{itemize}


\textsuperscript{42} Chicago Foundation for Women (CFW). Our Voices, Our Choices: Broadening the Conversation on Reproductive Rights, Stage One Report. Chicago, IL: CFW; June 2002. Apna Ghar is a grantee of CFW’s Reproductive Rights Initiative to involve women of color, women of faith, and younger women in the reproductive rights movement.
share information with community members, to single women who felt social and religious beliefs that sex is reserved only for purposes of procreation prevent them from accessing family planning services. Affordable and complete birth control education and information was mentioned as a serious necessity.

Education, knowledge, healthy sexual behavior (e.g., using condoms and contraception), and screenings are the best ways to protect women from various reproductive health problems. However, reproductive health care behavior, knowledge, and prevention among South Asian women are difficult to assess due to scarce supporting data and a lack of organizations and services catering to such needs.

Assessing Health Needs: The Work of National and Community-Based Organizations

South Asian women need to be better informed about disease and illness, how to access health care services, and the benefits of prevention efforts. As with immigrant and minority health in general, this population’s health care needs can be addressed through accessible, effective, sensitive, and appropriate delivery of health services. Within the past decade, community and national efforts have targeted the South Asian population, highlighting social, mental, community, and public health implications of the lack of education and health services.

During 1994 and 1995, the California-based group Asians and Pacific Islanders for Reproductive Health (APIRH) carried out an extensive project, *The Health and Well-being of Asian and Pacific Islander American Women*. Through focus groups, forums, and conferences, they compiled perspectives on the health and well-being of over 300 AAPI women in California and performed an extensive review of medical and academic research. The studies revealed that the women did not know where or how to access help, faced linguistic barriers in seeking health care, and had difficulty integrating two cultures. The study also identified the need for providers to be more culturally sensitive. South Asian American participants specifically mentioned that they want more information on “birth control” and named these issues as impacting their health: “stress, female sexuality, females’ role in the family, immigration and adaptation, domestic violence [and] depression.” They reported that when they do not feel well physically, they use “home remedies” or “call mom/parents”. And when they do not feel well mentally, they “drink, sleep, eat, seclude self, get aggressive/passive.”

The National Asian Women’s Health Organization (NAWHO) in San Francisco completed a needs assessment with approximately 300 South Asian women in Northern California in 1996. Their *South Asian Women’s Health Project* is the first study to document the broad health needs of South Asian women in America. Key findings of the research included the following:

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• Mental Health: Women’s mental health is largely affected by guilt, pressure, isolation, and stress due to socioeconomic status and family structures.

• Nutrition: Availability of foods and variations in eating habits make nutrition particularly important. Older women expressed adjusting to new ways of preparing foods in the US as challenging, while younger women mentioned uncertainty about what constitutes a well-balanced meal and differences in at-home versus out-of-home meals.

• Reproductive and Sexual Health: Many participants reported difficulty in communicating with their families and providers about sexuality, body image, sex, relationships, and marriage.

• Health care education and services: Knowledge, access, and utilization were impacted by the isolation and fear women felt.

The study highlighted the diversity found within the South Asian community, as well as the need for increased and improved advocacy, policies, and programs on South Asian women’s health. It also touched upon the pervasive inaccessibility to specific health and social services required for the South Asian community.

Chai Chat: A Health and Safety Education Program for Violence Prevention in South Asian Immigrant Women in Chicago was designed and implemented in 1999 by public health graduate students at Loyola University in Chicago, IL. It confirmed the existing needs of its population and identified emerging needs through a series of eight health-promoting educational sessions. The program educated 12-15 South Asian women, identified through community-based organizations (CBOs) and leaders, on such topics as body wellness, mental health, accessing community resources, and family communication skills in a cultural context. Chai Chat aimed to empower women through education and skills development.

The South Asian Outreach Project (SAOP) at the American Cancer Society in Queens, New York provides targeted care to members of a specific community in the hopes of educating them to make basic health care decisions and access preventive services. Founded in 1997, SAOP has worked to increase cancer awareness and access to cancer information, services, and programs for the South Asian community in the New York area. The effort has found many successes, including screening hundreds of women for breast cancer, sponsoring approximately 10-15 educational programs each year, providing patient services, and developing language-specific and culturally-appropriate cancer information. The community has received the program with great appreciation, interest, and support.

SAKHI for South Asian Women, a community-based organization in New York City which aims to empower women, particularly survivors of domestic violence, has also

launched a special project to address the health care issues of South Asian women – The Women’s Health Initiative (WHI). Founded in 1999, WHI works to provide access to women-specific health care information, education, and services. WHI volunteers, comprised of public health practitioners, social service providers, physicians, nurses, and students, educate women who approach Sakhi through support group meetings and health education sessions; assist with access to health care services through development of a local health resources reference guide and establishment of an on-call system; raise awareness in the South Asian community around issues of women’s health through brochures and a speakers bureau; develop and maintain a provider network of health care professionals who can provided culturally competent and sensitive care; and train health care professionals on providing culturally sensitive care for South Asian women.

Conclusion: Improving Health Outcomes for South Asian Women in America

Despite the fact that South Asians are the third largest Asian community in the US and that AAPIs make up 4% of all women in the US,45 few studies exist on health issues facing this population as a whole and fewer studies have focused on women’s health and well-being from the South Asian perspective.

A more systematic approach to addressing the issues of South Asian women’s health is needed. Empowering women with the ability to control their bodies and minds, to enhance their health and well-being, and to maintain a degree of self-sufficiency, confidence, and self-respect is critical to ensure progress and healthy outcomes. As women understand their bodies and feel empowered to make decisions about their health, they can better seek out basic health care services and information. Simply providing information, however, is insufficient. Social norms, the surrounding environment, community resources, and support structures also need to be challenged in order to enable and promote continued healthy living.

Recommendations

The follow are general recommendations for service providers, advocates, researchers and policy-makers to work toward an agenda of improved advocacy, programs, and policies on South Asian women’s health:

- Increase and improve data collection, analysis, and sharing of data to further study and assess. South Asian, AAPI and mainstream health, service, advocacy, and policy organizations and institutions must work together to include South Asian women in efforts to collect, analyze, develop, and program around information on the needs of South Asian women. Traditionally, there has been a lack of use of women in clinical trials and other research. Most research to identify health behavior and screening practices has been directed toward White women. More

recently, attention has been drawn to the need for specific minority-based research and this trend needs to continue in order to improve health outcomes for South Asian women.

- Advocate individualized attention to the various Asian women populations. The grouping together of all “Asian” women when findings are reported makes it difficult to sift out a specific subgroup.
- Build effective outreach and health education programs and campaigns (culturally appropriate and linguistically sensitive services) to inform all women about healthy behaviors, regardless of race, ethnicity, class, and economics.
- Use existing health and service programs serving South Asian and Asian groups to develop targeted and appropriate programming for women. Primary health care services should ensure that preventive measures are part of daily lifestyles.
- Enhance the capacity of organizations and government agencies to serve South Asian women’s groups through knowledge of attitudes and the cultural context of service.
- Design comprehensive training on culturally competent and sensitive care for providers working with Asian women.
- Encourage the South Asian community, of health professionals in particular, to take a pro-active role in raising awareness on women’s health and assisting women in need.
- Increase the number of South Asian and South Asian-language specific programs and materials available at health and social welfare centers.
- Focus long-term efforts on creating sharing model programs with others in the field, expanding resources, and ultimately developing plans of action in conjunction with other organizations, government agencies, and communities.

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