

## Holistic Risk-Based Environmental Decision Making: A Native Perspective

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Native American Nations have become increasingly concerned about the impacts of toxic substances. Although risk assessment and risk management processes have been used by government agencies to help estimate and manage risks associated with exposure to toxicants, these tools have many inadequacies and as a result have not served Native people well. In addition, resources have not always been adequate to address the concerns of Native Nations, and involvement of Native decision makers on a government-to-government basis in discussions regarding risk has only recently become common. Finally, because the definitions of health used by Native people are strikingly different from that of risk assessors, there is also a need to expand current definitions and incorporate traditional knowledge into decision making. Examples are discussed from the First Environment Restoration Initiative, a project that is working to address toxicant issues facing the Mohawk territory of Akwesasne. This project is developing a community-defined model in which health is protected at the same time that traditional cultural practices, which have long been the key to individual and community health, are maintained and restored. *Key words:* aboriginal, Akwesasne, American Indian, Mohawk, Native, restoration, risk, Superfund. *Environ Health Perspect* 110(suppl 2):259–264 (2002).

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Native American Nations have become increasingly concerned about the adverse effects that toxic substances have on human health and the health of the environments on which these communities depend (1–3). Many are now working to identify environmental contamination problems and their sources; establish and enforce environmental regulations and standards; and develop long-term environmental protection objectives and restoration plans that will promote balance and health in their communities and in their relationships with the natural environment. As the magnitude and complexity of environmental problems have increased, the scientific and technical competency of Native Americans has grown to the point where they now demand a meaningful role in risk assessment, remediations and restoration decisions.

In the case of the Mohawk territory of Akwesasne (Figure 1), local residents, environmental organizations, and leaders have mounted a strong response to the environmental degradation of their lands and waters. For over 25 years, the people of Akwesasne have waged a long and difficult battle to ensure that polychlorinated biphenyls (PCBs) and other toxic substances released from neighboring industries are adequately remediated and ecosystems are restored to their former health. Traditional Mohawk people have been motivated by their strong desire to provide a healthy, clean environment for future generations and have long argued that cleanup and restoration of the adjacent St. Lawrence River ecosystem is critical for long-term survival (4–6). Despite years of research at

Akwesasne, risk assessment methods used by outside investigators remain inadequate. Such methods fail to account for or include a holistic approach for assessing the social, cultural, and spiritual values, beliefs, and practices that link the Mohawks to their environment.

### Background

Beginning in the 1950s, cheap hydroelectric power provided by the St. Lawrence–FDR Power Project attracted several industries to the area that have since polluted Mohawk waters, land, sediment, and air. As a result, Akwesasne has experienced some of the worst pollution in the Great Lakes and is one of 43 Areas of Concern (AOC) identified by the International Joint Commission (IJC). The community is located immediately adjacent to the General Motors Powertrain Division and is downwind, downstream, and down-gradient from Reynolds Metals and the Aluminum Company of America (ALCOA), all large federal or state Superfund sites. Toxicants such as PCBs, dibenzofurans, dioxins, polyaromatic hydrocarbons, fluorides, cyanide, aluminum, arsenic, chromium, and styrene have been released into the air and water and have contaminated the St. Lawrence River, its tributaries, Mohawk lands, air, and water, thus endangering traditional land usage, subsistence lifestyles, and cultural practices. Careful examination of those who have received the benefits and those who have paid the price for the industrialization of the St. Lawrence River highlights a great disparity between upstream communities and Akwesasne (4,7).

### The Need For Change

Risk assessment has traditionally focused on the analysis of biologic, chemical, and physical data regarding the effects of hazards, primarily to human physical health (8,9). In 1998, the U.S. Environmental Protection Agency (U.S. EPA) released its Final Guidelines for Ecological Risk Assessment, which focus on the evaluation of impacts to ecosystems (10). Risk assessments are performed on a routine basis by government agencies or their contractors and are used as a foundation for decision making and management of risk. The basic process entailed in conducting risk assessments of toxic substances involves estimating toxicity (and lack of toxicity), estimating real-world exposure, and comparing potency of toxicity with expected exposure (Figure 2).

Because the scientific community can never know all the ways that a substance can affect individuals, it is impossible to state with certainty that exposure will cause no harm or minimal harm. Scientists and activists alike have questioned the purpose of risk assessment, suggesting that it appears to justify harm inflicted on certain people by using the vocabulary of science to draw attention away from the need for action (11–13). At the same time attention is focused on justifying acceptable levels of exposure, those concerned with exposure endlessly procrastinate or completely ignore the difficult task of finding ways to prevent impacts, stop emissions and discharges, remediate existing problems, and find solutions to restore the damage that has been done. Through its community-based research, the Akwesasne Task Force on the Environment has found that traditional risk

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assessment and management models have not been effective in defining environmental risk, promoting effective remediation, decreasing exposure, or restoring community health at Akwesasne (4,7). Further experiences reflect the use of scientific studies and debates as tools by responsible parties to manipulate situations and impede remediation and restoration, all to the benefit of the polluter (4,14,15).

It also is equally important to remember that exposure is only one part of susceptibility to disease. Variations in susceptibility exist within Native communities and are based on a wide variety of factors including age, sex,

genetic susceptibility, state of health, and many other variables (3,16,17). Many toxicologic studies upon which risk assessments are based have been conducted using healthy groups of adult animals. However, in a Native community, there are subpopulations of exposed individuals that include elders, pregnant women, young children, persons who are ill, and individuals who have compromised immune systems or limited liver and kidney function. Cultural value systems followed by Native people often mandate special protections and considerations be given for groups of individuals, including elders, unborn generations of children, and

sensitive species of wildlife, who are most vulnerable and in need of protection (3,5,18,19). This concern for all people, especially the most vulnerable, may run counter to the processes followed by scientists conducting epidemiologic studies and risk assessments, who tend to focus on identifying average exposures in a given population and providing protection based on the average exposed individual. However, it is those persons in the 95th percentile in exposure scenarios who are the very people that First Nations' decision makers are mandated to protect.

Compromising this mandate is a difficult decision, yet this type of situation represents one of many reasons why the risk assessment process is inadequate for First Nations (11–13,18,20–25). Despite treaties, agreements, compacts, covenants, and statutory obligations that affirm sovereignty and self-determination, Native Nations often are not respected or considered sufficiently competent to have meaningful participation in decisions that affect their Nations, lands, and resources. The traditional, cultural, ecologic, and scientific knowledge of Native people is a tremendous asset to all decision makers. When they are not respectfully included at the decision-making table, sovereignty and treaty rights are often violated. In addition, many Native governments continue to lag behind in being able to access financial resources, infrastructure, institutions, and other resources needed to address their environmental concerns (13). Participation in discussions about risk, remediation, and restoration are limited when the U.S. EPA and other federal agencies fail to fund tribes on an equitable basis with states.

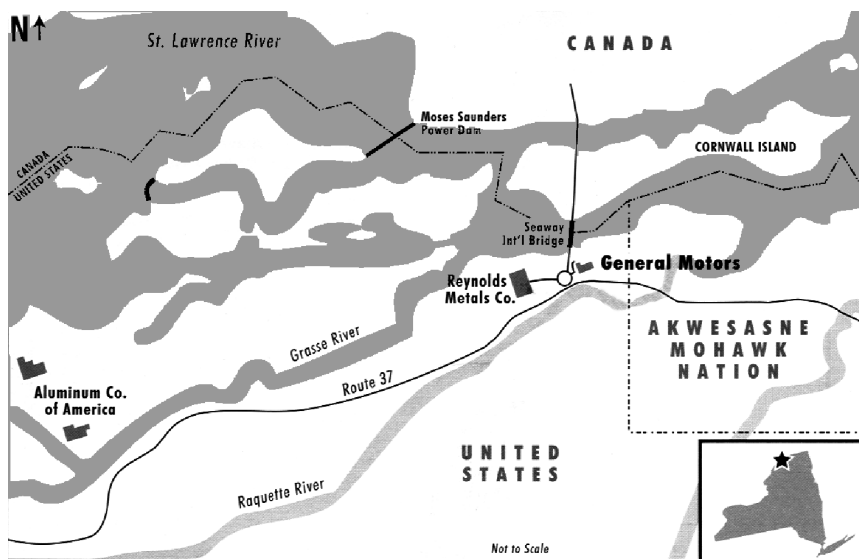


Figure 1. Mohawk Nation Territory of Akwesasne.

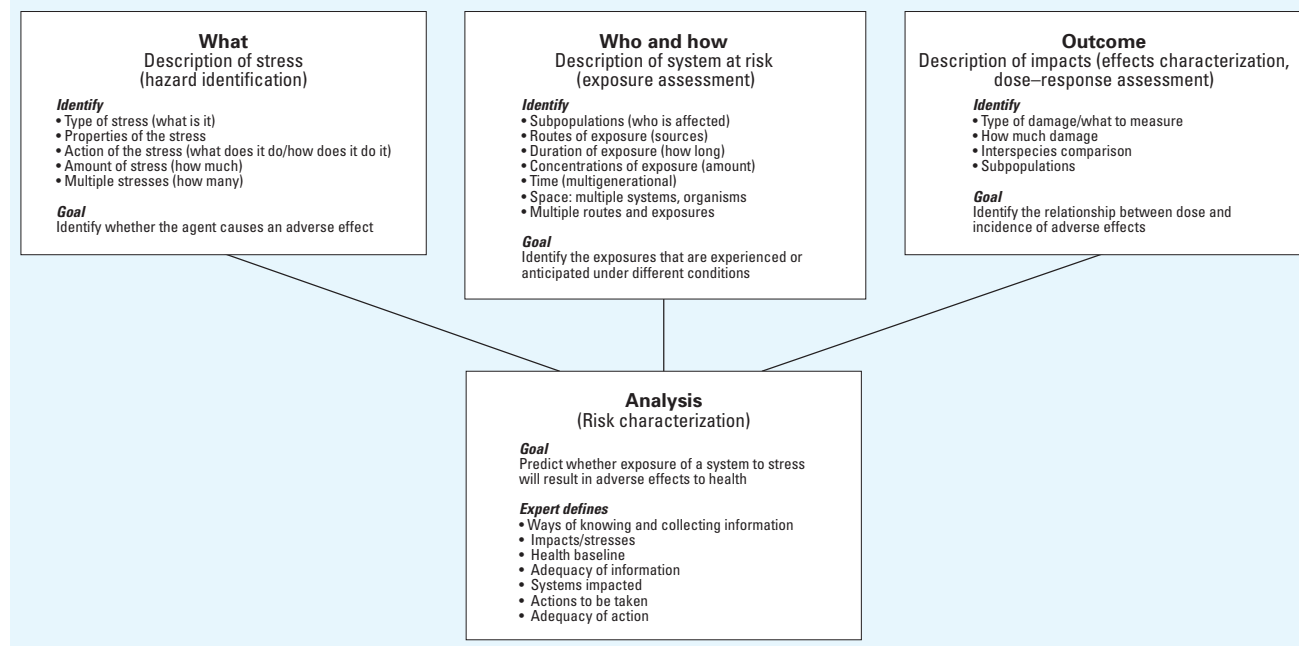


Figure 2. Environmental risk assessment model.

The lack of resources has been recognized as an important environmental justice issue by indigenous leaders, who have gone so far as to state that reliance on risk assessment promotes environmental injustice (12,13).

In addition to the special status of Native Nations as sovereign governments with distinctive legal relationships with the United States, each Native Nation also has its own unique history and exposure to toxic substances that result from a mixture of traditional activities including cultural and spiritual practices. Not only are individuals affected, as they avoid important cultural activities such as gardening, hunting, fishing, trapping, and gathering of plants in order to protect their health, but effects are also felt at the extended family, clan, community, and Nation level (4–7,26–31).

The need for better site- and Nation-specific data emphasizes an important area of research for Native Nations. In addition to providing Native decision makers with very practical information about contaminant levels in various media and biota, collecting information about traditional cultural practices and natural resource use can have far-reaching effects. The collected information can be used to support the protection of important natural resources both on Native lands and in aboriginal territories protected by treaty rights. More important, the research itself can support the transfer of traditional knowledge and cultural practices to future generations (18,30).

Finally, it is important to acknowledge that risk assessment is only one of many ways to identify and make decisions regarding the effect of contaminants on health. Native processes of decision making, including the use of traditional value and political systems, are equally important in making well-informed decisions about exposure to chemical compounds, cleanup of contaminated sites, and restoration of impacted ecosystems (29–31). Presently, there is a need to identify and explore alternatives to the classic technical risk assessment methodology in order to find ways to support existing decision-making paradigms that are relevant to Native communities.

### Sociocultural Implications of Exposure to Contaminants

In spite of years of research on environmental health issues, methodologies for identifying and incorporating sociocultural issues into risk assessment models are still in the developmental stage. Impacts and risks to the social, cultural, and spiritual practices of Native peoples must be included in identifying and addressing risks to health (3,4,16,18,26–28,32–34). In the case of Akwesasne, it has been found that the traditional cultural practices

that express and reaffirm identity and culture increase exposure of community members to toxic substances. At the same time, however, healthcare providers, community members, researchers, and environmental staff have been quick to note that adverse health effects have resulted when Mohawk people were forced to abandon traditional cultural practices in order to protect their health and the health of future generations (4–7,15,35,36). Contrary to the conclusions of current risk assessment models, community-based researchers have found that adverse health effects can and do occur even when there is no physical exposure to toxicants. As a striking example, a distinguished toxicologist was invited to speak at Akwesasne about adverse health effects associated with exposure to PCBs. She began her talk by noting that many Akwesasne residents, especially women of childbearing age, had virtually eliminated consumption of local fish and wildlife and congratulated Mohawk people for taking such an active role in decreasing the adverse health effects associated with PCB exposure. Much to the surprise of this toxicologist, Mohawk residents did not agree that the solution to contaminant issues was to change traditional cultural practices and behaviors to eliminate toxicant exposure. After a long discussion, this speaker was quick to point out that current risk assessment models state that if there is no exposure, then there are no adverse health effects. In Akwesasne, as in many other communities, potentially serious adverse health effects can result when people stop traditional cultural practices in order to protect their health from the effects of toxic substances. When traditional foods such as fish are no longer eaten, alternative diets are consumed that are often high in fat and calories and low in vitamins and nutrients. This type of dietary change has been linked to many health problems such as type II diabetes, heart disease, stroke, high blood pressure, cancer, and obesity (35–37). Consequently, serious health problems can result when, in the case of Akwesasne, traditional foods are no longer consumed, even if there is little or no exposure to toxic substances.

Another example of how risk assessment fails to measure adverse health effects is the case in which traditional plant medicines are no longer used because the community fears that air pollution and volatile toxicants have contaminated local plants and trees (4–7). Even when there is no exposure to toxic substances, health problems certainly can result when community members no longer have access to an effective means to heal themselves. This situation is further compounded when it occurs in a medically underserved community facing serious health consequences due to toxic substances.

Vastly different languages, cultures, and world views present real barriers to effective communication (2–7,38). At Akwesasne, for example, elders, mothers, children, and other community members have presented eloquent testimony about social, cultural and health effects they have experienced as a result of contamination of area ecosystems. The presentation of effects such as these have been met with resistance, a few yawns, and overt eye-rolling, and deemed “nice stories” with little relevance to scientific discussions of risk-based scientific decision making. Other Native Nations have experienced even more hostile responses when discussing their unique sociocultural impacts. This is especially the case when spiritual matters are a central focus. Native people have been told they have a “religion of convenience,” that “no one wants to live like their grandparents,” or that “there are no ‘Indians’ left that live a ‘real’ traditional lifestyle” (39–41).

Although most affected communities would agree that sociocultural impacts should be included in any discussion of risk assessment, we find that current models have no way to incorporate or deal with these effects except to call them value judgments (42). Even recent attempts to develop frameworks that incorporate broader real world contexts and stakeholder participation into risk assessment continue to be flawed because alternative types of information (social, cultural, economic, environmental justice) are viewed as merely providing a context for the risk assessment. No methodologies exist to allow valuable information about all effects to be integrated into the risk assessment itself.

If we look across disciplines, however, we find that social scientists in the fields of anthropology, history, education, ethnography, and sociology have been developing and using sociocultural assessment methodologies for many years (43–51). By crossing and bridging disciplines and using tools that are specific and relevant to the community of study, social science research strategies can be modified to address environmental health issues as well. A metadisciplinary approach to risk assessment and risk management would allow decision makers to supplement existing (and often incomplete) scientific data on human health and ecologic impacts with a more holistic and comprehensive evaluation of all impacts on health. This approach not only allows researchers to identify the sociocultural context of environmental hazards, but also allows them to incorporate the knowledge and experience of the at-risk population into any assessment or risk management scenario. For this approach to succeed, however, it is essential that

affected communities be involved directly in the research. In the case of Akwesasne, for example, it has been imperative for community members to have the opportunity to identify the ways in which traditional cultural practices have been affected by contaminants (4,52,53). As part of any risk management strategy, the affected community needs to play a key role in identifying ways to remediate, restore, or replace resources that have been affected.

It is clear that a new paradigm is needed that not only recognizes the requirement for unique and shared decision making with Native governments but that also recognizes the important role that community-based research, specialized communication strategies, and community participation play in decision making. This is particularly true in the area of risk-based decision making, where Native people often find themselves in a reactive mode, committing valuable resources to constantly comment on and attempt to improve poorly conducted risk assessments. Experience at Akwesasne has shown that collecting, recording, and utilizing environmental health data, which characterizes the expert approach, is too far removed from the social and cultural phenomenon of many communities. By using a top-down model, the capacity for science to create change is very limited. The First Environment Program at Akwesasne has worked to follow a community environmental health research paradigm that is based on principles of environmental justice. This paradigm states that knowledge must be generated and disseminated in a shared process within the community in a way that allows people to reclaim their power to protect their families and the natural world (54). To do this, communities must believe in the power of their own knowledge and trust in their experiences, observations, and data-collection abilities. Native people, with countless generations of traditional knowledge about the interaction between humans and the natural and spiritual worlds, possess a unique ability to contribute to solving many of the current human health and ecologic crises faced in the twenty-first century (18,55–57).

### Holistic Risk-Based Decision Making: A New Paradigm

Community health, risk assessment and environmental restoration have typically been thought of as separate concepts, when in fact they are intrinsically linked. They simply provide different viewpoints for examining many of the same issues. The challenges now faced by risk-based decision makers are multiple. Necessary is the development and use of an integrated framework that gives adequate consideration to the

effects of contaminants on the physical health of human beings, and that holistically examines impacts on the natural world, and on cultural, social, subsistence, economic, and spiritual practices.

Holistic risk assessment has been discussed as a way to integrate human health and ecologic risk and make better decisions that are more protective of people and the earth as an whole (58–61). It is clear that to develop more holistic environmental health models, there is a need to identify and measure sociocultural impacts and integrate them with human health and ecologic effects. To incorporate these many different effects, a holistic model would need to examine and include aspects from many fields of study, integrating qualitative research findings with the sciences of toxicology, epidemiology, and ecology. Such an integrated model would need to be based on a very broad and flexible understanding of health, risk, and restoration, while acknowledging that these definitions are culturally based and community specific. This expanded definition of health would be more inclusive than just the absence of disease or injury. It would encompass alternative definitions of health such as that developed by the World Health Organization in the 1940s to include concepts of wellness that integrate physical, mental, social, and ecologic well-being (62). Many community members at Akwesasne, for example, believe that concepts of health should include and reflect traditional Native American values, attitudes, beliefs, and practices. As with many Native communities, however, traditional views of health are integrated such that it becomes impossible to consider physical, mental, spiritual, and social well-being in isolation (5,36).

The complex interactions of these many factors profoundly affect health. Research has clearly shown, for example, that the degree of control that people have in their life and their capacity to take action, especially during times of stress, are key influences to health (63). Meaningful work, security, freedom to make and influence decisions, social support, and the ability to take control of stress, especially the pace of work, all contribute to healthy living and work environments (64). In addition, equity is an important issue for communities. Research has shown that sharing and equity in wealth distribution within Nations is critically important to health, more so than merely the amount of wealth that individuals possess (65). Some researchers have suggested that the social environment, including social support networks, knowledge, the ability to be self-reliant, the ways in which individuals are treated and accepted in society, and the strength of coping skills can

have as much impact on health as the physical environment (63). The contrary is also true—the stressors that negatively impact these same social support networks have tremendous power to cause impacts to all aspects of human health (45,52,66–69).

In addition to the physical, social, and cultural determinants of human health, the health of the natural world is central. This is especially true for Native peoples, where relationships among and between human beings and the natural and spiritual worlds are built on concepts of respect, caring, appreciation, duty, purpose, and responsibility, rather than on power and status (3,4,18,57,70–72). In addition, time is an important component to health, because protecting future generations is key to ensuring good community and cultural health (4,5,57). Language is also critical for good health, as it maintains our connection to community and to the natural world. Language is a living part of one's being, and as such is inseparable from culture (71). Within the Mohawk language, for example, we clearly find a cultural philosophy that is relational, integrated, holistic, and female focused. Health, then, has many definitions for the Mohawk people of Akwesasne. Health is spiritual. Health is rooted in the heart of the culture. Health is based on peaceful, sustainable relationships with other peoples including family, community, Nation, the natural world, and spiritual beings. Health is supported by the solid foundation of a healthy natural world (54,57,72).

To support healthy communities, empowerment is an essential component of any assessment, action, or intervention (4,53,73). Native people need to have opportunities to meet their own physical, mental, emotional, spiritual, social, and ecologic needs using their own culturally defined paradigms. The integration of Mohawk attitudes, beliefs, and practices into environmental health definitions, research, and planning is seen as central to achieving healthy individuals, communities, and ecosystems at Akwesasne (4,5,54). This finding, supported by our preliminary research, is consistent with the goals of environmental justice. The Symposium on Health Research Needs to Ensure Environmental Justice stated that

Environmental justice encompasses more than equal protection under environmental laws (environmental equity). It upholds those cultural norms, values, rules, regulations and policies or decisions to support sustainable communities. . . . Environmental justice is supported by democratic decision making and personal empowerment . . . where both cultural and biological diversity are respected.” (74)

To be successful in developing a holistic, integrated approach to addressing environ-



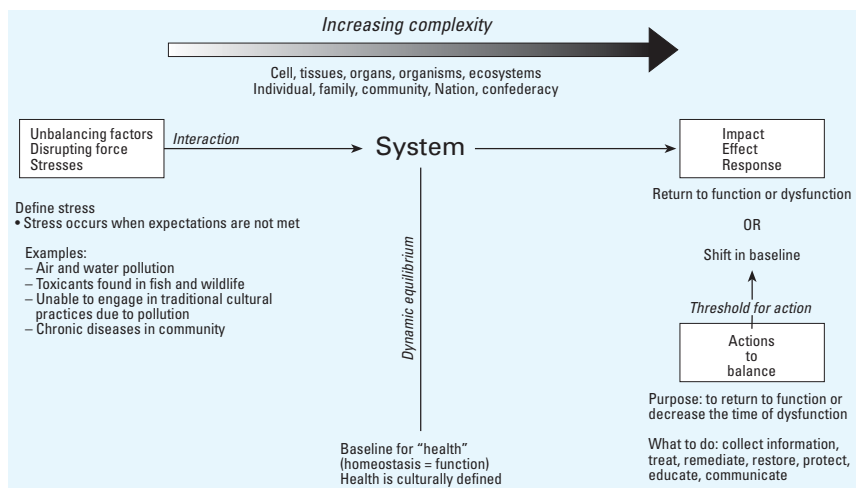


Figure 3. Holistic environmental assessment model.

mental contamination problems, it is essential that affected communities be involved directly in both meaningful decision making and in researching impacts and alternatives. Support for community capacity building, training, community-level action, communication, and leadership building are integral to any successful research. It is clear that if a holistic approach is to be used to solve human health and environmental problems, it must integrate the best information that can be found from many different sources, especially those that are most knowledgeable and intimately connected to the problems at hand. Many cultures have long used multiple alternative ways to make decisions, and when broken down (Figure 3), we realize that risk assessment is not that different from other processes of making decisions. When viewed as a means to gather information about stresses to multiple systems and measure baseline and impacts, holistic risk-based decision making has the potential to be inclusive of many different types of effects.

## Conclusion

As we work toward developing and using a more integrated, holistic model for risk-based decision making, we must ensure that there is a sound foundation for such an approach. It is clear that affected communities must play a central role in the broader risk assessment process. In order to promote health, justice, and equity, long-term investments must be made in community-based research, including efforts that develop specialized strategies for communication and community participation. This requires movement away from the hierarchic nature of the current expert-based risk assessment approach to one that includes collaboration, partnership, and respect for flexible, multidisciplinary approaches. The diversity

among Native Nations alone requires an understanding that no single approach will suit all peoples and all problems. Decision makers need to consider the very specific needs and legal requirements associated with certain populations. For example, by virtue of their treaty status, Native Nations have an even greater legal and moral right to be involved on a government-to-government, Nation-to-Nation basis in any decision making that affects their people, lands, and aboriginal and treaty rights. When considering true risk, social and cultural impacts must be included with toxicologic and ecologic factors. Finally, because it is essential to minimize the time in which individuals, communities, and ecosystems are negatively impacted, an effective means for evaluating decision-making processes needs to be developed to ensure that actions have focused on the right issues, have served to prevent problems, and have produced sound results in a timely fashion. In developing an integrated framework for risk-based environmental decision making, there is much to be learned from Native people, who have experience in developing equitable partnerships and using holistic, integrated thinking to solve problems.

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