

National Conversation on Public Health and Chemical Exposures

**Serving Communities Work Group Report
November 2010**

I. Introduction

The *National Conversation on Public Health and Chemical Exposures* is a collaborative project, supported by the Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR). The *National Conversation* vision is that chemicals are used and managed in ways that are safe and healthy for all people. The project's goal is to develop an action agenda with clear, achievable recommendations that can help government agencies and other organizations strengthen their efforts to protect the public from harmful chemical exposures. The *National Conversation* Leadership Council will author the action agenda, utilizing input from six project work groups, and members of the public who choose to participate in web dialogues and community conversations.

National Conversation work groups were formed to research and make recommendations on the following six, cross-cutting public health and chemical exposures issues: monitoring, scientific understanding, policies and practices, chemical emergencies, serving communities, and education and communication. The Serving Communities work group was formed to ensure that the voices of affected community members and their advocates are an integral part of the *National Conversation* process. This report is the product of the Serving Communities work group's deliberations. While issued to the *National Conversation* Leadership Council, the work group hopes that this report will be of value to others in a position to act on the recommendations contained herein.¹

CDC and ATSDR worked with several groups to manage the *National Conversation*, including RESOLVE, a nonprofit organization dedicated to advancing the effective use of consensus building in public decision making, the American Public Health Association, the Association of State and Territorial Health Officials, and the National Association of County and City Health Officials. These organizations and others helped ensure that a broad range of groups and individuals were engaged throughout this collaborative process, including government agencies, professional organizations, tribal groups, community and non-profit organizations, health professionals, business and industry leaders, and members of the public. For more information on the *National Conversation* project, please visit www.atsdr.cdc.gov/nationalconversation.

Membership

Work groups were formed in 2009 following an open nomination process. Work group members were selected based on a three-stage process designed to ensure that each work group would have the capacity to address and reflect different individual and organizational perspectives.²

¹ This report was developed as part of the *National Conversation on Public Health and Chemical Exposures*, an independent process facilitated by RESOLVE, a neutral non-profit consensus building organization. This report represents the work of one of six *National Conversation* work groups and reflects the consensus of the work group members. Consensus is defined as each member being able to "live with" the report taken as a whole, rather than as agreement with each recommendation. Members were asked to participate as individuals, rather than on behalf of their organizations or constituencies. The Centers for Disease Control and Prevention's National Center for Environmental Health and the Agency for Toxic Substances and Disease Registry provided funding for the facilitation, member travel, meetings, Web dialogues, community conversations, and other costs associated with the *National Conversation*. This report does not necessarily reflect the views of the Centers for Disease Control and Prevention, the Agency for Toxic Substances and Disease Registry, RESOLVE, or other organizations involved in the *National Conversation*.

² For additional information on the work group member selection process, see http://www.atsdr.cdc.gov/nationalconversation/docs/membership_selection_process_report.pdf

In addition to seeking members representing a diverse range of sectors, the following additional skills sets were sought in selecting members of the Serving Communities work group: depth and range of experience, unique disciplines or perspectives, well-respected individuals or organizations, and familiarity with community engagement processes and/or service delivery. Furthermore, to achieve overall balance, the team sought to compose a diverse work group in terms of discipline, perspective, geographic region, gender, race/ethnicity, age, and representation of low-income communities and communities of color.

The Serving Communities work group is chaired by Peggy Shepard, Executive Director of WE ACT for Environmental Justice and is comprised of 20 individuals representing a broad range of public health and environmental expertise. Members are affiliated with 19 organizations and groups including local, state and federal government agencies; professional organizations; tribes; environmental justice, community and nonprofit organizations; industry; and academia. Carolyn Harper serves as the Senior Liaison from CDC's National Center for Environmental Health (NCEH)/ATSDR to the work group. Kathy Grant, from RESOLVE, facilitates the work group and Kim DeFeo from NCEH/ATSDR, staffs the work group. The following individuals were active participants in the Serving Communities work group throughout the *National Conversation* process.

Chair

Peggy Shepard, Chair, WE ACT for Environmental Justice

Members

Lisa Conti, Florida Department of Health
Steve Crawford, Passamaquoddy Tribe at Pleasant Point
Jeannie Economos, Farmworker Association of Florida
Karla Fortunato, Health and Environmental Funders Network
Lori Geckle, U.S. Army Public Health Command
Derek Guest, formerly of Eastman Kodak Company, currently of Environmental and Sustainability Solutions
Rita Harris, Sierra Club Environmental Justice Program
Mercedes Hernández-Pelletier, North Carolina Department of Health and Human Services, Division of Public Health
Michael Kent, Contra Costa Health Services
Scott Levy, The Permanente Medical Group
Egide Louis, U.S. Environmental Protection Agency, Region 4
Mildred McClain, Harambee House Inc. / Citizens for Environmental Justice
Pamela Miller, Alaska Community Action on Toxics
Mark Mitchell, Connecticut Coalition for Environmental Justice
Liam O'Fallon, National Institute of Environmental Health Sciences
Suzi Ruhl, U.S. Environmental Protection Agency
Barbara Sattler, University of Maryland School of Nursing
Hilda Sheppard, Agency for Toxic Substances and Disease Registry
Arturo Uribe, Mesquite Community Action Committee

Support

Carolyn Harper, Senior Liaison from NCEH/ATSDR to the work group
Kathy Grant, RESOLVE facilitator
Kim DeFeo, NCEH/ATSDR staff

Work group charge, scope, and objectives

In order to protect communities from harmful chemical exposures and advance environmental justice, the Serving Communities work group has focused its efforts on four overarching themes:

1. Community Advocacy, Leadership and Research

Assist communities to advocate for themselves by providing access to useful information; building community leadership capability; supporting community-based participatory research; facilitating community members' access to resources, including funding and education; and developing a dialogue and building trust between all stakeholders; etc.

2. Government Operations (Internal and External)

Strengthen governmental responses at the local, state, federal and tribal levels by expanding, enhancing, increasing, and improving 1) data and evaluation, 2) training, 3) coordination and partnerships, 4) regulation and enforcement, 5) communication and education, and 6) operations and practices.

3. Addressing Past and Current, and Preventing Future, Environmental and Chemical Exposures

Assess current regulatory, enforcement and compliance processes and apply best practices and innovative models learned from the field; employ a community-based participatory research approach to the collection and interpretation of data for the purpose of responding to contaminated sites; raise awareness to the public and government agencies about the impact of low, chronic, synergistic and cumulative exposures on health; and engage involved stakeholders in efforts to achieve the production and use of safer chemicals.

4. Restoring Health and Developing Community Resiliency

- Identify and foster approaches which help ensure that emerging government initiatives benefit communities at greatest risk;
- Promote integration between environmental and public health governance, practice and infrastructure with the delivery of health care services; and
- Focus on disease prevention and methods to promote healthier, sustainable communities.

Caveats and/or limitations

With this report, the Serving Communities work group aims to address critical issues that communities face in their struggles to protect their health from harmful chemical exposures. Given the wide scope of the work group charge and time constraints, however, the work group was not able to address every issue of concern.

Work group process

The Serving Communities work group held its first meeting in September, 2009 and has met regularly, holding eight conference calls and three in-person meetings. In order to accomplish its work, the work group divided into four subgroups which each met regularly to advance work in its topic area. The four subgroups are 1) Community Advocacy, Leadership and Research; 2) Government Operations (Internal and External); 3) Addressing Past and Current, and Preventing Future, Environmental and Chemical Exposures; and 4) Restoring Health and Developing Community Resiliency.

The work group compiled this report to review some of the issues and gaps that exist when serving communities affected by chemical exposures. The work group also puts forth twelve recommendations that, if implemented, would increase protections for communities from harmful chemical exposures.

Note on terms and definitions

The following are the working definitions used by the Serving Communities work group.

Aggregate exposure- exposure by all routes and pathways and from all sources of each given agent or stressor (EPA, 2003).³

Community- a group of people affiliated by residence in a defined area, or by virtue of their innate personal characteristics (e.g., gender, race, or ethnicity) (Institute of Medicine, National Academy of Sciences, 1995), health or disability status, or by a uniting common interest (HHS, n.d.), occupation, or belief.

Community-based organizations (CBOs)- locally based organizations that operate from a “bottom up” or “pro-people” doctrine and represent a community or significant segment of a community on several different issues including community services, education, training, advocacy, etc. “The nature of their work requires CBOs to interact with local communities on a daily basis, building relationships of cooperation and trust to understand local needs and tailor projects that respond to those needs” (Adapted from Elementary and Secondary Education Act of 1965 20 USC § 7801(6); Kamat, 2006).

Community-based participatory research (CBPR)- a “collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities” (Center for Advancing Health, 2003-2010).

Community health workers (CHWs)- “lay members of communities who work either for pay or as volunteers in association with the local health care system in both urban and rural environments and usually share ethnicity, language, socioeconomic status and life experiences with the community members they serve...CHWs offer interpretation and translation services, provide culturally appropriate health education and information, assist people in receiving the care they need, give informal counseling and guidance on health behaviors, advocate for individual and community health needs, and provide some direct services such as first aid and blood pressure screening” (HRSA, 2007).

Community resiliency- the ability of a community to respond to crises in ways that strengthen community bonds, resources, and the community’s capacity to cope. Community resilience is the individual and collective capacity to respond to adversity and change. In communities, resilience is related to 1) magnitude of shock a system can absorb and remain competent, 2) degree to which a system is capable of self-organization, and 3) degree to which a system can build capacity for learning and adaptation (Kelly, n.d.).

Cultural competence- a “set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations” (HRSA, 2002).

Cumulative impacts- exposures, public health or environmental effects from the combined emissions and discharges in a geographic area, including environmental pollution from all sources, whether single or multi-media, routinely, accidentally, or otherwise released. Impacts will take into account sensitive

³ The Serving Communities work group clarifies this definition to mean exposure from all sources of one chemical.

populations and socio-economic factors, where applicable and to the extent data are available (CalEPA, 2006).⁴

Enabling services- “non-clinical services (i.e., not direct patient services) that enable individuals to access primary health care services and improve health outcomes. Enabling services include case management, referrals, translation/interpretation, transportation, eligibility assistance, health education, environmental health risk reduction (e.g., educational materials, nicotine gum/patches), and outreach” (HRSA, n.d.).

Environmental justice communities- low-income communities, Indigenous communities, and communities of color that are disproportionately burdened with environmental hazards and suffer disproportionately from environmentally-related diseases.

Health- not only the absence of infirmity and disease but also a state of physical, mental, social and spiritual well-being (Preamble to the Constitution of the World Health Organization, 1946).

Physician- a doctor of medicine, osteopathy, dental surgery/medicine, podiatry, or optometry, or a chiropractor, consistent with the functions which he or she is legally authorized to perform as such by the State in which he or she performs them (Social Security Act, §1861(r), 2007).

Practice-based research networks (PBRNs)- PBRNs are groups of primary care clinicians and practices working together to answer community-based health care questions and translate research findings into practice (AHRQ, 2010).

Precautionary principle- “when an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically” (Wingspread Conference on the Precautionary Principle, 1998).

Synergistic effect- the interaction of two or more chemicals where the combined effect is greater than the sum of their individual effects. The effect of one chemical enhances the effect of the second the chemical.

Wellness- an active process of becoming aware of and making choices toward a more successful existence. Wellness consists of several types, considered interrelated: emotional wellness, intellectual wellness, occupational wellness, physical wellness, social wellness, spiritual wellness (National Wellness Institute, 2010), environmental wellness, and cultural wellness (University of Nebraska-Lincoln, 2010). Heredity, race/ethnicity, gender, income, education, geography, exposure to violent crime, exposure to environmental agents, exposure to infectious disease, and access to quality health care are factors that can affect health and wellness.

II. Developing an Effective System

The Serving Communities work group envisions a system that promotes health and wellness among all people. This system is one where decision makers work to build the trust of communities and facilitate their access to information about chemical exposures. It is one where the public is actively engaged in environmental health decisions that affect them, where monetary resources are available to community members to ensure they can become effective self-advocates, where communities are educated to collect

⁴ The Serving Communities work group would like emphasize that this definition includes not only all sources of pollution, but all agents.

their own data, and where there are open communication channels between decision makers and affected communities.

In this system, federal, tribal, state and local agencies will work to build trust with affected communities. Rebuilding this trust is essential to ensuring partnerships that can improve environmental health for communities. They will do this by enacting policies and practices that will improve the ability of all communities regardless of race, class, or culture to become more resilient, safe and healthy. To accomplish this, these agencies will look at all known pathways of chemical exposures and institute policies and practices, such as shifting the burden of proof from affected communities to the chemical manufacturers and industrial users of toxic chemicals, and implementing the precautionary principle, that will lead to the eventual elimination of harmful chemicals in the environment. It is not acceptable to have thousands of substances and compounds in commercial use without their having been thoroughly pre-tested for health and environmental hazards.

Agencies will work together to develop and adopt, where needed, stronger standards to ensure our air, water, food, land, and consumer products are protected and meet safety standards for human and animal health, with special attention given to food producing areas and facilities. Although polluters will be expected to pay for the environmental damage they cause, debating liability will no longer delay the quick action needed to protect human health. Federal, tribal, state and local agencies will become accountable to communities and will collaborate with appropriate bodies to ensure the expeditious clean-up of contaminated sites, taking appropriate measures to protect nearby populations.

The agencies will work with industry, community organizations, academics and others to promote speedy and robust research and development efforts that will lead to the implementation of alternatives to toxic chemicals. Agencies will respond to requests in a timely manner and abide by/enforce environmental and occupational laws. Businesses will seek to form good neighbor agreements with fence line communities and will abide by them.

Communities will be informed of and have ready access to information about the chemicals to which they are exposed, including the known and/or suspected health impacts of those chemicals. There will be a central hub of environmental health information where people can easily find answers to the questions they have, including information about disease prevalence collected by new disease registries. A national health database of patient information will be created to help us better understand exposures and their relationship to disease. Business and industry will share information on the chemicals they use and will also share research, progress reports, and updates on remediation activities with the public frequently.

Affected community members will become actively engaged in decisions that affect them. It is incumbent upon government agencies to provide opportunities for community members to become involved early, and have the tools to participate effectively, in decisions that affect them. The input of community members will not only be listened to but will make a demonstrable impact in the decisions being made. Agencies will institute practices to ensure that community members are aware of permit requests, changes, violations and alterations, as well as enforcement actions by advertising and announcing these activities in several local venues, such as the local daily newspapers that have a broad readership, radio public service announcements, email to a broad range of known community stakeholders, and any other means that has the potential of reaching a broad cross-section of the community. It will no longer be acceptable that a public notice can be used to check off a public involvement requirement.

Public forums or listening sessions will be held to share information and serve as an outlet to hear the concerns of community members in all phases of a project and to address concerns. These forums and listening sessions also will allow community members an opportunity to share their own independent

findings and research, as well as to refute claims and challenge reports by government agencies and industry that will influence the decision making. The agencies will plan and allow for adequate review and comment periods with consideration for and sensitivity to cultural differences, customs, and activities that might impact the agency's timeline.

Agencies and foundations will provide more grants to communities in need so that communities have the resources they need in order to research their concerns, hire their own experts, and participate in the decisions that are made and that will affect them. Agencies and foundations will provide training and technical assistance to communities on topics such as grant writing and conducting research. Specifically, agencies should hold language-appropriate, regional, in-person trainings to train community groups in filing web-based grants. Agencies should develop a special initiative to outreach to hard to serve, rural communities and others that have limited access to Internet and computer technologies. Increased broadband access for rural and urban communities will be prioritized in order to facilitate a communities' ability to seek grants. Agencies will reach out to collaborate with communities on research, using community-based participatory research methods. Agencies will also train communities in validated methods for data collection so that communities can collect their own information and have it be accepted as valid by those doing analyses on exposures or health outcomes. Aligning data collection methods and standards among agencies will also streamline the ability to collect and analyze environmental health data.

Government agencies at all levels will communicate effectively with affected communities by using trained, culturally competent staff who have experience communicating with communities in a way that they can understand. Government agency staff and researchers will acquire enhanced training in areas such as cultural competency, cross-cultural communication, risk communication, inclusive decision making, and facilitation in order to be able to work effectively with affected communities. Such training, along with involving communities in processes from the beginning, will improve working relationships between government officials and community members and allow for increased progress towards environmental justice.

In addition, community members will have access to affordable and quality health care from providers who understand environmental health concerns. These providers will recognize that social conditions including racism, socioeconomic status/class, gender, place of residence, access to quality food, job loss (Boston, 2010), language barriers, lack of transportation and fear of deportation are conditions that impact, and can be determinants of, people's health and wellness. In addition, providers must understand that vulnerabilities are greater during certain stages of life such as during childhood or old age. The overarching goal of protecting the health and quality of life of those in all communities will be paramount.

III. Current Context

In this section, the status of the protection of communities from environmental harm will be discussed, including obstacles that are hindering this protection. It will be shown that environmental health protections are insufficient and unequal and will identify and examine several areas in which improvements must be made.

The Serving Communities work group believes that every person has a right to a safe and healthy environment. Although these rights should be fundamental, people across this country are being denied this right. The Environmental Justice (EJ) Movement grew from the recognition that people of color and low-income communities bear the brunt of harmful environmental exposures (Bullard, Mohai, Saha, &

Wright, 2007) and recognizes the right to a safe environment “where we live, work, and play” (United Church of Christ, n.d., p.1).

Studies have documented that people of color, Indigenous communities, and low-income communities are disproportionately impacted by environmental harm. In the seminal report *Toxic Wastes and Race* authored by the United Church of Christ in 1987, it was shown that race was the most important factor in predicting where commercial hazardous waste facilities were located in the U.S. (Bullard, Mohai, Saha, & Wright, 2007). The follow-up report issued twenty years later, *Toxic Wastes and Race at Twenty: 1987-2007*, concludes that “people of color are found to be more concentrated around hazardous waste facilities than previously shown” (p. 155). In fact, the updated report shows that host neighborhoods of commercial hazardous waste facilities are 56% people of color whereas non-host areas are 30% people of color. Percentages of African Americans, Hispanics/Latinos and Asians/Pacific Islanders in host neighborhoods are 1.7, 2.3, and 1.8 times greater, respectively. Poverty rates in the host neighborhoods are 1.5 times greater than those in non-host communities.

Environmental injustice extends beyond proximity to toxic waste sites. People are exposed at varying degrees to harmful chemicals throughout the lifecycle of chemicals: from their extraction and production, to their use in manufacturing and industry, to their recycling and disposal, and well beyond their useful life such as in contaminated soil or leaded chipping and peeling paint. Data from the CDC from 1992-1994 show that, for all income levels, non-Hispanic black children had a greater risk of elevated blood lead levels than white children (Environmental Protection Agency, 2010). The data show this disparity is greater for black children whose families live below the poverty line. More than 68 percent of African Americans live within 30 miles of a coal-fired power plant—the distance within which the maximum effects of the smokestack plume are expected to occur—compared with 56 percent of white Americans (Black Leadership Forum, Clear the Air, Georgia Coalition for the People's Agenda, & The Southern Organizing Committee for Economic and Social Justice, 2002). In *The State of Childhood Asthma: 1980-2005*, the CDC reports that children of American Indian or Alaska Native descent have asthma prevalence rates 25% higher, and black children 60% higher, than white children (Akinbami, 2006). Not only are these prevalence rates higher, but compared with white children, black children have a 260% higher emergency department visit rate, a 250% higher hospitalization rate, and a 500% higher death rate from asthma. Birth prevalence of major congenital anomalies in Alaska is twice as high as in the United States as a whole. Alaska Native infants have twice the risk of major congenital abnormalities as white infants born in Alaska (Schoelhorn, 2008). In addition to suffering higher rates of many environmentally-related diseases, racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when taking into account patients’ insurance status and income (Smedley, Stith, & Nelson, 2003).

Enforcement of environmental and public health laws is another area in which disparities exist, particularly in people of color and low-income communities. A 1992 study published in the *National Law Journal* found that monetary penalties for violations of hazardous waste laws, such as the Superfund law, were about 500 percent higher in white communities than for those in people of color communities (Lavelle & Coyle, 1992). The study also found that people of color communities waited 20 percent longer for sites in their neighborhoods to be put on the National Priorities List.

This trend of unequal enforcement continues. A 2004 study, published in *Society and Natural Resources*, found that petroleum refineries situated within Hispanic and low-income ZIP codes were fined 95 percent less than those located in non-Hispanic, more affluent ZIP codes (Lynch, Stretesky, & Burns, 2004). The study also found that median household income is strongly correlated with assessed fines; each thousand dollar increase in median household income in ZIP codes was associated with an over 11 percent increase in the average fine against petroleum refineries. The findings of this study revealed that residents living in

non-Hispanic, more affluent ZIP codes benefited from vigorous enforcement compared to residents living in Hispanic, low-income ZIP codes.

Unequal protection from environmental harm continues for many reasons. For example, many violations of worker protection standards and field sanitation laws go unreported and uninvestigated in the agricultural sector (Farmworker Justice & Oxfam America, 2010). Workers often do not report these violations because of fear of job loss, retaliation by employers, the threat of deportation, and physical harassment, as well as lack of knowledge of their rights and protections under the law (Farmworker Justice & Oxfam America, 2010; Health Outreach Partners, 2010). When violations are identified, warnings are often issued first. Fines are often imposed only in egregious cases, with the fine being small in proportion to the actual and/or potential harm that is caused. For example, while pregnant women that worked for AgMart Farms gave birth to babies with severe birth defects, AgMart was fined a relatively small amount despite being cited for multiple violations of health and safety regulations in both Florida and North Carolina (Stapleton, 2008). The regulatory system having failed them, one family resorted to filing a civil lawsuit against the company for their baby boy who was born without arms or legs.

As another example, Indigenous communities reliant on traditional diets of fish and marine mammals are among the most exposed of any population on earth to certain contaminants including bio-accumulated persistent chemicals that are transported via atmospheric and oceanic currents (Arctic Monitoring and Assessment Programme, 1998).

It is clear that improvements must be made in order to ensure people are sufficiently, and equally, protected from chemical exposures. Below, key areas in which progress must be made are examined.

Trust

Many communities do not trust industry to protect them from harmful chemical exposures and do not have faith that the government will enforce environmental and health regulations. This mistrust stems from a long history of unequal treatment, a lack of responsiveness to communities' concerns, and the lack of community involvement in decisions, among other reasons. For example, the pervasive fear, not only of job loss and retaliation, but of possible deportation and family separation due to a person's and/or worker's immigration status contributes to a community's and/or worker's fear, intimidation, and reluctance to both either seek help for exposure issues that are of concern and that are impacting them and/or to become engaged in any civic and/or political process to remedy their situation (Farmworker Justice and Oxfam America, 2010; Health Outreach Partners, 2010).

Access to Information

Access to information is another area that needs attention. Local communities need enhanced access to information about the environmental exposures and adverse health outcomes they are experiencing in their communities. Currently, community members are often frustrated by the number of places they need to search to try to get this information and by the amount of information that is unavailable.

Another information gap exists due to the lack of disease registries in every state for important health outcomes such as autism, Parkinson's disease, birth defects, endocrine disorders (including reproductive health problems and thyroid disease), and asthma, as well as for exposures of concern like exposure to mold, pesticides, and lead. Registries that do exist lack important information. While most registries collect information on place of residence or birthplace, date of occurrence, and personal characteristics (such as sex, ethnicity and social status), the treatment protocol and/or intervention as well as mortality is often missing. Many times there is a lag between the time a person develops a medical condition and when the incidence is noted in the registry.

Public Engagement

The engagement of affected communities in environmental health, siting, and permitting decision making processes is critical to ensuring that communities' questions are answered, their concerns are addressed, and their views are an integral part of decisions that are made. Unfortunately, many barriers to such participation exist. Few government agencies are mandated to involve communities directly in the decision making process and there is no guidance on the roles, responsibilities, effort, extent of power, or goals of that community involvement (National Research Council, 2008). Concern has been expressed by community-based organizations that when outreach is attempted by agencies it is often begun well after a process is underway and is poorly conducted (Hartford Park Tenants Association et al. v. Rhode Island Department of Environmental Management et al., 2005). When community members do participate in decision making processes, too often they feel that agency scientists are "explaining away" their concerns with science while not acknowledging the realities that they are experiencing. In addition, language barriers and lack of cultural sensitivity can reduce the effectiveness of community engagement or prevent it entirely. When community members do find out about public involvement opportunities, often they do not have the tools to effectively engage in these processes.

Monetary Resources

The most environmentally-affected and contaminated communities often do not have the resources they need to be effective self-advocates. While some agencies offer grants like EPA's Technical Assistance Grants (TAGs) and Community Action for a Renewed Environment (CARE) grants to assist affected communities, these are not sufficient. Many people do not have access to computers, know how to find out about funding sources, possess the tools and/or language skills to develop a grant proposal, and/or are afraid to request or accept assistance from government agencies (e.g., some immigrant communities).

Data Collection

Difficulty collecting data is another hurdle that communities face. While communities often have to collect their own environmental and health data, the validity of community-collected data is often considered to be sub-standard, invalid, or anecdotal. Another obstacle in collecting data is that different agencies maintain different standards and use different techniques to perform testing. For example, the Occupational Safety and Health Administration (OSHA) focuses on chemical exposure assessment in indoor environments while the EPA deals with ambient air conditions. Both of these federal agencies have established their own "acceptable" sampling and analysis plans.

Communication

While the agency officials and researchers that go into communities are usually well-trained and well-meaning, they often have little experience working with affected community members or have limited training in cross-cultural communication and risk communication. This lack of ability to successfully communicate with community members can lead to misunderstandings, unclear goals, and disagreement over research methods or approaches to remediation, among other issues.

IV. Action recommendations

In order to realize our vision that everyone lives, works, and plays in a safe and healthy environment, we must take concrete steps to protect people from harmful chemical exposures. Towards that end, the Serving Communities work group presents the following twelve recommendations that, if implemented, would help protect communities from environmental harm.

- 1. Establish a new federal law, executive order, rules or policies that require federal government agencies to 1) formalize mechanisms for substantive community engagement in government**

471 **decision making and 2) require government agencies and their funding recipients to engage**
472 **environmental justice communities in environmental decision making processes that affect their**
473 **communities. Government agencies shall develop mechanisms to engage and dialogue with**
474 **communities at the earliest possible stages and throughout environmental decision making**
475 **processes.**

476
477 **Rationale:** For many communities, there is a general lack of trust and understanding between
478 stakeholders because communities are not involved in the decisions that affect their daily lives.
479 Communities need a forum in which they can participate with representatives from government agencies
480 and local businesses together to address issues in a climate of mutual respect and trust, and a mechanism
481 by which they can receive clear and complete answers to all their questions and concerns. Through this
482 process, communities can build self respect and independence and, for Tribal Nations, sovereignty.
483

484 An effective community engagement process needs to be established that would incorporate 1) access to
485 mutually acceptable technical resources, including scientific experts, non-profit organizations,
486 ombudsmen and alternative dispute resolution representatives; 2) sensitivity to issues such as language,
487 culture, gender, and socio-economic group; 3) clearly identified opportunities early in the decision
488 making process for the community to help define the problem and influence the solution; 4) public access
489 to all relevant information in clearly understandable format; 5) mutually agreed upon meeting locations,
490 agendas and logistics; and 6) an effective mechanism for ensuring that impacted communities are notified
491 of scheduled meetings.
492

493 **Implementation:** We recommend passage of a new federal law or executive order, rules or policy that
494 requires federal government agencies and government-funded organizations to involve environmental
495 justice communities in environmental decision making processes that affect their communities. The
496 processes and oversight might be accomplished through the Interagency Working Group on
497 Environmental Justice. This new policy would be applied to the following types of decisions: economic
498 development funding, siting, permitting, site remediation, health assessments, community notification,
499 facility closures, emergency response, and enforcement. The same standards and practices will apply to
500 state government agencies.
501

502 While many federal agencies promote community engagement at a local level, we recommend that
503 agencies model inclusive practices by formalizing and publicizing mechanisms for substantive
504 community engagement at the agency level. For example, federal agencies should implement community
505 advisory committees similar to the National Institutes of Health Director's Council of Public
506 Representatives or the Environmental Protection Agency's National Environmental Justice Advisory
507 Committee. All Federal Advisory Committee Act committees, advisory boards, and commissions should
508 include significant representation from community-based organizations early in the process. Agencies
509 could also use less structured models such as hosting community forums across the country as a way of
510 engaging community groups and residents from across the country. We recommend that government
511 agencies develop and document a community engagement plan at the start of each year and evaluate their
512 success at the end of the year. We recommend that government agencies develop accessible tools (for
513 example, online surveys) to solicit feedback from their community partners. The results can be used for
514 evaluation purposes and for consideration in establishing the next year's goals.
515

516 **Timeframe:** We recommend that the Interagency Working Group on Environmental Justice develop a
517 policy in the next two years and implement an approved process through official regulatory mechanisms
518 within an additional two years that would create an effective and responsive public participation process.
519

Evaluation: Key milestones for evaluation would include passage of the new law or executive order, establishing an interagency coordinating group, developing regulations or policies, and submitting annual reports to Congress that demonstrate adequate funding and implementation of the process.

2. Congress should amend the Agency for Toxic Substances and Disease Registry's (ATSDR) mandate and mission to ensure the agency serves public health more effectively.

Rationale: In recent years there has been increasing public concern about the role ATSDR plays in protecting public health and conducting environmental health assessments in identified communities. The *National Conversation* process presents an opportunity for ATSDR to revise its mission and mandate to address expressed community concerns.

Implementation: We recommend that ATSDR develop and implement a process to engage community groups and stakeholders across the U.S. to help re-envision its mission and mandate. The goal is to identify the best methods for the government to respond to community concerns related to environmental exposures including:

- a. Requirements to collect primary data and analyze it at environmental justice-designated sites when data received is incomplete, insufficient, or not available from other agencies/entities (e.g., Environmental Protection Agency, federal, state, local environmental agencies, industry, etc.). Collection of data and scientific analysis will not delay immediate and intermediary changes necessary to protect the health of impacted communities. These changes can include erecting or constructing temporary barriers or buffers, or other such remedies, to protect communities from migration of toxins into residential and/or public spaces in the interim while waiting for studies and analysis to be completed.
- b. Establishment of a formal peer-review process for all products developed or funded by ATSDR.
- c. Requirement to identify and coordinate a community dialogue with other agencies/organizations as part of its community engagement mandate to address health issues and health care gaps beyond ATSDR's environmental health mission.
- d. Establishment of policies and procedures to ensure community advisory groups (or similar structures) are used in disproportionately affected communities (including communities of color, Indigenous communities, and low-income communities).
- e. Requirement to systematically review, update, distribute, and make available in plain language ToxFAQs and site-specific fact sheets as science changes, new information is acquired, and new hazardous chemicals/substances are identified.

Timeframe: Submit immediately to the newly reconstituted Interagency Working Group on Environmental Justice (EJ IWG) immediately upon *National Conversation* Leadership acceptance/approval of this recommendation. By October 2011, the EJ IWG will submit the report to Congress.

Evaluation: This recommendation will be evaluated by considering whether the amendment has been enacted, funded, initiated, and implemented.

3. Government agencies shall develop coordinating structures/mechanisms across agencies to improve communication with and accountability to communities.

Rationale: Communities affected by the release of toxic chemicals encounter many challenges accessing information from government agencies. Coordinating and communicating information within government

structures as well as externally with communities is an important precursor to effective and sustainable community engagement. The burden of this coordination should lie on government structures and not on affected communities. It is unreasonable to expect the public to contact every single public agency to make sense of government activities or methods for collecting or interpreting data. Communities should be able to track information about federal, state, local and tribal governments' activities in their communities from a central location. Communication should be bi-directional, from government to communities and vice versa, and mechanisms for this communication should be coordinated and streamlined. The type of information available to communities should include mechanisms to track issues in their communities, government activities, resources and tools available, "best practices" pertinent to their communities, agency standards or guidelines, mechanisms to ask questions and receive answers, and mechanisms available for community involvement, among others. This one source of information should be deemed accurate, complete, meaningful, timely and easy to understand.

Implementation:

Coordination among federal agencies: For coordination across the federal partners, we recommend that the Department of Health and Human Services (HHS) re-establish and support an interagency working group on environmental public health comprised of the federal agencies with a shared commitment to environmental public health (Agency for Toxic Substances and Disease Registry/Centers for Disease Control, the Environmental Protection Agency [EPA], National Institutes of Health, the Health Resources Services Administration and the Departments of Health and Human Services, Defense, Energy, and Justice, etc.). Similar mechanisms to coordinate government activities exist such as the federal Interagency Working Group on Environmental Justice and the EPA-Department of Housing and Urban Development-Department of Transportation Partnership for Sustainable Communities working group. However, these working groups do not adequately address human health issues. This Federal Interagency Working Group on Environmental Public Health would have a mandate to coordinate research, communication, and training efforts as well as funding announcements across the federal agencies and establish a centralized resource for community groups with a focus on human health. The working group could also review and implement Open Government Plans that address government transparency and engage existing community advocacy groups in a manner similar to the National Institutes of Health Director's Council of Public Representatives (COPR). These efforts could be expanded to increase government accountability, streamline government operations and ensure communities' involvement in the process. The Federal Interagency Working Group on Environmental Public Health and the „Partnership“ should also address more fully human health concerns of community groups exposed to environmental contaminants.

Coordination within individual agencies: To promote coordination within each of the federal agencies we recommend that the Federal Interagency Working Group on Environmental Public Health establish a mechanism to direct "navigation" services within the participating federal agencies. The purpose is to ensure that federal agencies better assist community residents when they seek information from the agencies.

Coordination between government and communities: To promote coordination across and among the various levels of government and communities, we recommend that the Federal Interagency Working Group on Environmental Public Health establish a Public Ombudsman coordination mechanism to ensure that communities have access to complete and comprehensive information and to assist communities in communicating with government agencies at all levels. In the United States, public ombudsman offices have been created—through legislative, executive, or judicial authorization—as independent agencies that monitor the delivery of services for certain populations (e.g., children, the elderly, incarcerated adults, university students, government workers) (Jones & Cohn, 2005). Such a strategy could address the

challenges currently faced by local communities in interacting with the different levels of government offices and agencies.

Timeframe: The new interagency working group should be established by October 1, 2011. Within 6 months, a plan to improve customer service should be created and the plan should be implemented within a year. The plan should be evaluated every year thereafter.

Evaluation: By January 2012, determine if these structures have been established. If so, identify where they have been established and by whom. Also, document how these structures have been used, including key highlights or outcomes. Conduct a baseline customer satisfaction survey of a representative sample of these structures from across the country. Conduct a follow-up survey after a year of implementation and thereafter periodically.

4. Government agencies shall provide communities with funding, technical assistance and resources to build capacity to address environmental health problems.

Rationale:

Self Advocacy: Communities do not always know how the community/public participation process works, how decisions are made by policy leaders, how they can influence the decision making process, how to apply for funding and technical resource support, or how to develop partnerships with government, academia, and public health officials to address their environmental health concerns. In addition, communities do not always get the necessary guidance from government officials, which can lead to frustration.

Community Based Participatory Research: Communities have diverse public health concerns and priorities and often identify problems and trends before government agencies have prioritized those concerns. However, communities lack the funding and technical resources to conduct the independent research necessary to document local problems. Communities are well positioned to document emerging issues, and providing communities with support can help increase ownership and trust and enrich the research. Communities play a major role in defining and prioritizing the issues and setting the priorities for research about their health and safety concerns especially when they receive resources, access to environmental and health information, advice on appropriate technical resources, and support in the development and implementation of community-based participatory research.

Implementation: To address this issue, appropriate federal agencies with environmental responsibilities (e.g., the Centers for Disease Control and Prevention, the Environmental Protection Agency [EPA], the Agency for Healthcare Research and Quality, and the Departments of Health and Human Services, Agriculture, Defense, Energy, Interior, Transportation and Justice), various foundations, practice-based research networks (PBRNs), and academic institutions (e.g., schools of medicine, osteopathy, optometry, dentistry, nursing, pharmacy, chiropractic, public health, mental health professionals, social workers, pharmacists, physical and occupational therapists, and physician assistants) should develop and expand programs to provide support and funding, for:

- a. intermediary environmental justice and other non-profit organizations to provide technical assistance and funding support to smaller environmental justice groups and communities (e.g., technical assistance grants and EPA's Community Action for a Renewed Environment grants);
- b. a shared clearinghouse for communities to access information on best practices and resources offered by state and federal agencies, and to connect communities to additional resources including training;

- c. training on how to negotiate government systems, engage with political and regulatory decision makers, work with government agencies to get health information, and develop partnerships with government, academia, and public health officials;
- d. training and other resources to become effective advocates (e.g., legal, scientific, health, organizing, engineering);
- e. information and resource support in applying for funding to address public health concerns; and
- f. expanded programs to support and fund community-based participatory research at different levels of complexity and focus appropriate for individual communities.

Timeframe: We recommend that the relevant agencies develop a funding program within the next two years that describes the level of funding available and the process to be followed by communities in applying for support. We further recommend that funding for community-based research be increased by 100% within the next three years.

Evaluation: The effectiveness of the community self advocacy program would be evaluated by requiring that agencies report annually on the level of funding and resource support for community-based organizations. In order to measure progress of the community-based participatory research program, a baseline analysis should be conducted to determine the current level of funding for independent research by community groups within the next 6 months and funding levels should be reported annually thereafter. The evaluation of this program would include:

- a. the number of independent community-based research projects and the level of funding,
- b. the number of university/community partnership projects that fund community groups as lead partners,
- c. the number of grants to universities for environmental justice projects that allocate at least 10% to community groups for research, and
- d. a qualitative analysis by the agencies of the partnership between universities and community groups.

5. Federal agencies shall establish, facilitate and promote training programs for government employees, community groups/residents, academia, industry, and community health volunteers to develop and advance their capacity to ensure the success of community-engaged projects.

Rationale: To work effectively in partnership with communities, building the skills and capacity of all partners is vital (Ahmed & Palermo, 2010). Too often, skill building is focused solely on community organizations and residents and not on other partners, especially government employees who oversee and administer federal programs that promote and foster community partnerships. All partners need to develop and advance their skills to ensure the success of community engaged projects. The need for capacity building for community groups is addressed in a previous recommendation. Therefore this section focuses on the needs of the other partners: government employees, academia, industry, and community health volunteers.

Following are specific recommendations to meet the needs for each of the partners. All efforts would be implemented and evaluated by the Federal Interagency Working Group on Environmental Public Health.

Timeframe: Within 12 months, conduct a baseline assessment of existing materials and training programs to identify gaps and opportunities. Within 12 months of the assessment, develop at least 5 training programs that meet the identified needs.

Evaluation: Availability: Complete a baseline assessment of materials/programs currently available in these areas. Identify successful models and programs and make them available. After one year, conduct a follow-up analysis to see what new programs have been created. Variety: From the baseline, examine the different types of training programs available. Utility: How many groups/individuals have taken the training? Determine the baseline and conduct an annual review. If activities are part of a grant, review annual reports to look at the attendance and participant lists. For volunteer programs, look at the number of volunteers recruited from where and to work on what issues. Outcomes: Monitor government programs that serve communities. Consider implementing “customer satisfaction” surveys to evaluate the effectiveness of the services provided to communities. Are there a greater number of programs that reflect the needs of community residents? Are systems in place to respond appropriately? Monitor the number of community-university grant projects and the number of investigators gaining tenure who have a greater focus on community-engagement work. Monitor the number of community-based organizations that have community health corps volunteers and that build a stronger infrastructure to work in partnership with academic partners as Principal Investigators. For industry and businesses, monitor how they have changed their practices to work in partnership with communities to address community concerns.

a. Government Employees

Implementation: We recommend that federal agencies create and promote programs that build the capacity of government employees to work in partnership more effectively with community groups and residents. The objective of this recommendation is to develop a trained cadre of government employees who better understand the community perspective and can communicate more effectively with the citizens they serve. As such, there should be an increase in the number of government programs that better meet the needs of community groups and residents. Training programs should include topics such as environmental justice competencies and principles of community engagement.

The U.S. Department of Health and Human Services’ Office of Minority Health offers an example of cultural competencies for clinicians and others. This type of curriculum should be used for government employees who are a part of programs that serve communities. All resources would be made available in a central location to make it easy for government employees to take advantage of the training.

b. Academia

Implementation: We recommend that grant making institutions promote, and that academic institutions offer, programs to build the skills of current and future researchers with a commitment to community-engaged research. Such activities could include fellowships, training, and loan repayment programs. The objective of this recommendation is to develop the skills and commitment of young investigators to work in partnership with community groups, government, and public health officials to address the environmental health concerns of the residents. To this end, there should be an increase in the number of researchers who are submitting projects that involve community participation (full partnership and sharing of resources throughout the planning, grant-seeking, and implementation process).

There are existing federal programs that support this type of training. The National Institute of Minority Health and Health Disparities (National Institutes of Health) maintains a loan repayment and training program for young investigators. The National Institute of Environmental Health Sciences (National Institutes of Health) encourages applications to its fellowship program from investigators wishing to do work in environmental public health. However, there has been little coordination among the agencies to make this information easily accessible to academics.

c. Volunteers

Implementation: We recommend the creation of a new Community Environmental Public Health Corps Program to bring in young graduates committed to working with community groups. For the most part,

AmeriCorps participants are placed with larger, not community-based, non-profits often due to the requirement for matching funds from communities. This program would break down the financial barrier and focus on environmental public health and environmental justice concerns. This program would provide critical training to the program members and also ensure grant dollars, and volunteers, for community-based organizations, especially in communities of color and low-income communities. The objective of this recommendation is to develop the skills and tap into the enthusiasm of young graduates and individuals with a commitment to volunteerism, to work in partnership with community groups to build community capacity to address the environmental health concerns of community residents. To this end, there should be an increase in the number of volunteers with a focus on environmental health-related projects.

d. Industry/Business Partners

Implementation: We recommend the creation of training programs to develop the skills of business partners to work more effectively with community organizations/residents as they address environmental health and justice issues of concern to the affected community. The training programs should include topics such as cultural competencies, communication, trust building, and collaborative problem solving.

6. The Centers for Disease Control and Prevention (CDC) and/or the Agency for Toxic Substances and Disease Registry (ATSDR) should establish a National Health Outcomes Database to create a standard process for governmental agencies to assess community health and potential synergistic, cumulative, and aggregate environmental factors.

Rationale: Although national disease registries do exist, they are far from complete. With any registry there is always the potential for numerous sources of error (Wolfe & Fairchild, 2010) including underreporting. The data typically tracked in a registry includes the place (residence or birthplace), time of occurrence and personal characteristics (such as sex, ethnicity and social status). Missing from the typical registry is a list of the person's previous relevant locations and occupations, treatment protocol and/or intervention as well as mortality. There is typically a lag between the time a person develops a medical condition and when the incidence is noted in the registry.

There has been significant discussion in the recent past by both the Pew Environmental Health Commission (2000) as well as CDC (n.d.) and ATSDR on the value of having the ability to perform nationwide public health tracking (Pew Environmental Health Commission, 2000). The potential value to be able to identify illness in real-time significantly increases the odds of identifying and remediating a toxic situation as opposed to reviewing old registry data in an attempt to piece together a puzzle.

Communities can be an invaluable source for identifying emerging local environmental health concerns and often recognize issues before agencies do. There is currently no standardized national dataset of health indicators. Creating such a resource would help localities and federal agencies identify those communities with disproportionately lower environmental health status in order to implement targeted interventions. In addition, federal agencies do not currently use a standard methodology for assessing community health or consistently explain to communities how they choose a methodology to conduct the local health assessment. This lack of transparency results in confusion and distrust between communities and academics. Without incorporation of community environmental health priorities, the value of the assessment from the local perspective will be greatly diminished.

Implementation: We recommend that the Centers for Disease Control and Prevention, in coordination with the Environmental Protection Agency and state and tribal public health agencies, establish a national

health database similar to the Food and Drug Administration's (FDA) Sentinel System⁵ from which real-time data would be accessible in the original format and would have the potential of de-identifying information. To modify or adapt the "Sentinel System" to one where the population can be surveyed by the CDC for toxic exposures in real-time, effectively monitoring those at risk for long term-health effects, as well as maintaining targeted surveillance to their offspring and successive generations would be invaluable. This national health database would be a centralized database where either all medical providers would be able to upload their medical information into one source, or have their existing electronic health records (EHR) accessible by a third party, such as the CDC. The database must integrate information from vital records, geographically-based environmental exposure monitoring (e.g., National Health and Nutrition Examination Survey biomonitoring data) as well as environmental hazard data (e.g., Toxics Release Inventory, hazardous and solid waste facilities, groundwater/surface water contamination, air pollution sources).

We recommend that the CDC:

1) Develop a national baseline health assessment which will augment the power and functionality of a National Health Outcome Database. This assessment should consider local environmental health data and community priorities. This baseline assessment should collect data which will help to develop a standardized minimum set of environmental health indicators (asthma rates, lead levels, birth weight, etc.) to allow for comparisons over time. The CDC should update the data used in the health assessment periodically based on current knowledge and evaluate whether there are additional environmental health indicators such as the Disability-Adjusted Life Year (DALY) (Arnesen & Nord, 1999; Flores, Davis, & Culross, 2007; McKenna, Michaud, Murray, & Marks, 2005; Murray, Kulkarni, Michaud, Tomijima, Bulzacchelli, Iandiorio, & Ezzati, 2006; Fielding & Sutherland, 1998), which may be of value.

2) Develop standardized guidelines for how to conduct local health assessments, taking into account local, state, and national indicators, as appropriate. The guidelines should evaluate both environmental indicators and health outcomes and retain the flexibility to incorporate additional community-specific information as well as community-based knowledge, where appropriate (the guidelines should also address the need for agencies to explain to communities how they intend to conduct the local health assessment).

3) Develop and provide technical support to enable communities to ensure that the local health assessment is fully representative and without bias.

Timeframe: In 2012 the FDA is anticipating that they will have 100 million EHRs linked to their network. To adapt/mimic this Sentinel System would in all likelihood take 2-5 years from inception if fully supported with adequate resources. The more we can share the FDA's platform instead of developing it from scratch, the shorter the anticipated development time. We expect that a baseline health assessment can be easily accomplished in the 2-5 year range as well.

Evaluation: Evaluation of this program would include 1) issuing an annual report to Congress on progress towards meeting the milestones described above, 2) monitoring and reporting the number of communities that have accessed and published reports based upon the national baseline health data, and 3) monitoring the number of communities that have used the national guidelines to assess the environmental health in their communities.

7. Increase access to health and health care for populations experiencing environmental justice challenges.

⁵ See <http://www.fda.gov/Safety/FDASentinelInitiative/default.htm>

Rationale: Populations with environmental justice challenges who bear the burden of pollution also bear a burden of disease, regardless of any association between exposure to pollution and adverse health effects. These populations also lack access to essential comprehensive, culturally competent and quality primary health care services, and holistic, integrated health care. For example, Alaska Native communities are often distant from full service health care facilities, accessible only by boat or plane. As such, they are served by community health aids rather than physicians (as defined by Social Security Act section 1861(r)) or nurses and are not yet benefiting from new access points of delivery or telemedicine. In addition, populations with environmental justice challenges have not fully benefitted from emerging prevention approaches related to sustainability, physical activity, and nutrition, which has exacerbated obesity and chronic diseases.

Communities burdened with pollution and disease have articulated a model to increase their access to health and health care, including the full range of essential primary health care services necessary to assure optimum health and quality of life. This model (hereinafter referred to as the “community health access model”), includes the following core elements:

- a. Holistic, integrated, comprehensive and sustainably-designed community health centers offering the full range of essential primary health care services (incorporating the definition of physician as defined by Social Security Act section 1861(r)) together with well-funded enabling services, such as mobile care, telemedicine, outreach, health education, transportation, interpretation, and translation
- b. Community health, wellness and resilience (ombudsmen) resources/programs
- c. Special environmental health care to deal with multiple exposure and diseases, as appropriate
- d. Multi-disciplinary team approach, including minority institutions (e.g., Historically Black Colleges and Universities), physicians (as defined by Social Security Act section 1861(r)), allied health professionals, and community beneficiaries
- e. Data gathering (i.e., expand and standardize metrics, use better community-level profiles and personal histories to improve diagnosis and treatment and address environmental sources, applying all these results to national level policy)
- f. Single clearing house that includes best practices, contact information for communities, success stories and reality check of communities
- g. Holistic, sustainable framework that responds to the relationship between community health, and the natural, built, and social environments and incorporates sustainability principles in the design and implementation of health and health care access
- h. Strategy to better connect the public health community to community health delivery workers and health aids, particularly for primary health care services

Implementation: Increase access to health and health care for disadvantaged, environmentally-burdened communities by facilitating the establishment of the community health access model through the following measures:

1) Health Resources and Services Administration’s (HRSA) requirements for federally qualified health center funding, as authorized under section 330 of the Public Health Services Act, as amended, and related Indian Health Service requirements, will be revised to recognize:

- a. Permissible designation for medically underserved populations for those recognized by Executive Order 12898, which are minority, low-income and tribal populations (hereinafter referred to as “EJ populations”) experiencing disproportionately high and adverse environmental effects

- b. Additional health services related to environmental health, as appropriate, for use of funds that include special environmental health care to deal with multiple exposures to pollutants and diseases that are caused or exacerbated by such exposures
- c. Additional health services related to environmental health, as appropriate, for use of funds that include special environmental health care to deal with special, vulnerable populations, such as children and elderly
- d. Requirement that the availability and accessibility of the primary health care services of the centers address sustainable design and placement (e.g., walkability, public transportation, mobile care) so that holistic, integrated, comprehensive centers are developed that respond to the relationship between community health, the built and social environments
- e. Requirement for a multi-disciplinary team approach that supports the full range of primary care services and leverages agency resources/programs to support community health, wellness and resilience (ombudsmen)
- f. Requirement for data gathering and management, including modifications to Universal Data Set (UDS) and clearing house functions addressing best practices

Timeframe: By June 2011

Evaluation: Evaluation of this recommendation will be conducted by determining if revised guidelines are published and implemented.

2) Twenty percent of new federally qualified health centers established under section 330 of the Public Health Service Act, as amended, will be established in disadvantaged, environmentally-burdened communities.

Timeframe: By December 2013

Evaluation: The Department of Health and Human Services (HHS), in collaboration with the Environmental Protection Agency (EPA), will assess the geo-spatial relationship between the location of federally qualified health centers and environmentally-burdened communities to identify the environmentally-burdened areas which lack access to health care. HRSA will report on the underserved, vulnerable and environmentally-burdened communities that have received section 330 funding to ensure community health care access, including implementation of the community health access model. HRSA will also report on the percentage of total funding that is allocated to disadvantaged, environmentally-burdened communities for federally qualified health centers and the provision of and access to the full range of primary care services for these communities.

3) Federal Agencies (e.g., HHS, EPA, Department of Transportation, Department of Housing and Urban Development [HUD], Department of the Interior [DOI], Department of Labor [DOL]) should support local and regional demonstration projects (i.e., funding, technical assistance, and training), including EPA's placed-based pilot projects, to develop and implement the community health access model.

Timeframe: By June 2011

Evaluation: This recommendation will be evaluated through the production of a report on the funding that has been provided to pilot projects (e.g., EPA Region 4 Environmental Justice Showcase Community initiative) seeking to implement community model health care access.

4) Federal agencies (e.g., HHS, EPA, DOT, HUD, DOI, and DOL) should ensure that federal initiatives on sustainability, health, environmental justice and workforce development align their planning, programmatic, and funding efforts to address access to health and health care for disadvantaged, environmentally burdened communities.

Timeframe: By December 2010

Evaluation: Identify measures taken by federal initiatives to incorporate access to health and health care, including the full range of primary care services, as goals and performance measures. Initiatives include HUD-DOT-EPA Partnership for Sustainable Communities, EPA's Urban Waters, DOI's Great Outdoors and Let's Move initiatives, and HHS' National Partnership for Action to End Health Disparities.

8. Incorporate reimbursable environmental health services into primary health care services.

Rationale: In communities throughout the U.S. environmental exposures are being associated with a range of diseases including cancer, asthma, cardiovascular diseases, fertility, adverse birth outcomes, depression, learning disabilities, and many more. As important as environmental exposures are to the development of many diseases, these exposures are often not considered when primary care health services are being delivered.

Health care providers (nurses, physicians, and others) do not receive training in environmental health in their basic education and therefore do not learn the knowledge and skills to integrate environmental assessments/interventions into their clinical practices. Recommendations regarding the deficit in health care providers' educational preparation are being addressed by the Education and Communication work group.

Individualized assessment of environmental exposures and associated risk communication, health education, and anticipatory guidance are virtually absent from primary care settings. Adding such a repertoire of environmental health services can contribute to disease prevention and early disease detection and help eliminate the need for more expensive health services that would result from diseases that would otherwise progress.

Our most at-risk communities are often communities that are served by community and public health centers, including health department-sponsored clinics, federally qualified health centers, Indian and Alaska Native health centers, migrant health centers, and rural health centers. The communities they serve represent those who have more compromised health status, are more likely to live in substandard housing and near hazardous industries/waste sites, and work in hazardous industries and workplaces. Community health centers provide primary care, health education, and some community outreach. These centers also have the potential to offer a wider array of preventative and environmental health services.

Implementation:

- a. Create and integrate standardized environmental health assessment tools and recommended interventions into the scope of work for public health clinics and federally-funded community health centers (federally qualified health centers, Head Start-related health services, Indian Health Services, and other health programs). Ensure that both assessment tools and interventions involve providers who are properly trained and qualified to interpret and manage the findings of these assessment tools.
- b. Work with other divisions within the Department of Health and Human Services (HHS) to develop a mechanism for reimbursement via health insurance schemes (public and private) in

- a way that does not discriminate against the communities being served. Create a “billing code” for environmental health services⁶ that are provided in primary care settings.
- c. Establish and incorporate environmental health assessments/interventions into the model/best practices for clinical care, i.e., National Guideline Clearinghouse. Keep this current through a process of peer-review.
 - d. Work with manufacturers of electronic medical records to include environmental health assessment components.
 - e. Reintroduce community health workers who are trained to assist with assessment and intervention strategies for environmental exposures.

Timeframe: By 2011, create a mandatory environmental health assessment tool and require it as part of electronic health records. By 2011, establish billing codes and reimbursement schemes for environmental health assessments, risk communication, health education, and other associated interventions.

Evaluation: This recommendation will be evaluated through the integration of and reimbursement for environmental health services in primary care.

9. Ensure effective compliance and enforcement of industrial and federal facilities and agricultural operations with environmental health regulations, laws and policies.

Rationale: The regulatory agencies have been less than effective in protecting communities, especially vulnerable groups such as children, low-income communities of color, and Indigenous communities, and even though the agencies currently have enforcement powers, communities are still suffering health and environmental impacts due to lack of enforcement and compliance. Federal regulatory agencies (including the Environmental Protection Agency [EPA] and Occupational Safety and Health Administration [OSHA], in partnership with the Agency for Toxic Substances and Disease Registry [ATSDR] and Federal Occupational Health [FOH] at the Department of Health and Human Services [HHS]), must ensure effective compliance of industrial, federal facilities, in particular the Departments of Energy and Defense facilities, and agricultural operations by implementing strong enforcement and prevention measures through actions including 1) bans on production of harmful industrial or pesticidal formulations, 2) revocation of discharge/emission permits, 3) prevention of new or revocation of existing pesticide registrations, 4) assessing significant fines for non-compliance, 5) requesting/conducting independent monitoring, 6) providing increased oversight over state enforcement agencies (e.g., state environmental and agricultural departments), 7) improving pesticide use and toxic emissions reporting requirements, and 8) imposing civil and criminal penalties.

Implementation: We recommend that compliance be monitored through frequent and unannounced inspections to ensure worker and community health and safety. ATSDR should participate in inspections of industrial, federal facilities, in particular the Departments of Energy (DOE) and Defense (DOD) facilities and agricultural operations by entering into a memorandum of understanding (MOU) with EPA and OSHA and exposed communities in order to identify/assess potential health hazards and exposure pathways; prevent chemical exposures to workers and surrounding communities; and protect public health. If ATSDR identifies health hazards, they should immediately notify the affected community and individuals and work with EPA or OSHA to take immediate enforcement action to prevent further exposures/hazards. Inspections must take into consideration a community’s perception, and

⁶ The Serving Communities work group defines “environmental health services” as environmental screening, assessment (including testing as needed), and environmental management.

documentation, of health hazards in their communities and should employ independent testing (e.g., bucket brigade, drift catcher).

ATSDR should work with the other regulatory agencies (EPA, OSHA, DOD, etc.) for an increase in the number and frequency of workplace inspections in order to identify and prioritize the worst violators and to increase the penalties and fines on violators to serve as a deterrent to continued violations and exposures of workers and communities. Significant fines are needed to serve as a deterrent. Additionally, public officials who fail to properly execute their jobs enforcing regulations should be subject to a set of consequences, ranging from a first time warning to ultimate expulsion after three or more failures to act in the public interest and to protect the communities they serve.

Timeframe: Within one year, EPA and OSHA, in collaboration with ATSDR and FOH, will develop and implement an effective inspection program that requires frequent, unannounced inspections at industrial, DOE and DOD facilities and agricultural operations. Within one year, EPA and OSHA will develop MOUs with ATSDR and with exposed communities for effective participation in inspections to assess health hazards.

Evaluation: 1) Track through measureable decreases in releases reported through EPA's Toxics Release Inventory, 2) track through workers compensation and worker complaints, 3) track environmental enforcement actions relative to improvements in compliance, 4) track through measureable improvements based on independent testing and community-based research, and 5) track through measureable improvements in community health and health outcomes.

10. Congress and states shall develop strong, consistent citizen suit provisions to empower communities.

Rationale: Communities must have a satisfactory, effective, simplified, and anonymous complaint process and the opportunity to initiate and participate in the enforcement process. Citizen suit provisions specify a role for citizens and community groups as "private attorneys-general" to ensure implementation and enforcement of environmental laws that agencies may be unwilling or unable to accomplish. Although Congress added citizen suit language to twenty federal environmental regulatory statutes, these provisions are conceived and applied unevenly in state law and with differences among the federal environmental laws (Meltz, 1999). Communities and individuals must be accorded the assurance of strong citizen suit provisions as well as a citizen appeal process within the system of federal environmental and worker health law, including injunctive relief, recovery of legal costs, supplemental environmental projects, and empowerment to sue polluters for civil and criminal fines. Federal Insecticide, Fungicide, and Rodenticide Act (FIFRA) is one of the major environmental laws that does not include citizen suit provisions.

Implementation and Timeframe: Within one year, EPA and OSHA will convene an independent panel of independent academic and public interest law experts to evaluate and make recommendations to strengthen and unify citizen suit provisions among the federal environmental and worker health protection laws. Within 6 months of completing the final report of this independent panel, EPA and OSHA will present it before relevant agency congressional offices. Within three years, EPA and OSHA will implement rules to strengthen citizen suit provisions within the regulatory system for protection of the environment, community and worker health. We recommend that within one year, EPA and OSHA will develop a procedure to receive and respond to anonymous citizen complaints as described above and a system that enables community members to initiate and participate in enforcement processes (for example, Supplemental Environmental Projects).

Evaluation: An annual survey of impacted communities should be conducted by ATSDR to document the successes of citizen suits and the level of improvement in compliance and enforcement of toxic emissions and to document any incidents of retaliatory actions toward the communities resulting from such suits. Survey results will be made public, such that interested communities can learn lessons from the experiences of other communities.

11. Federal permitting agencies shall revise permitting and permit renewal processes to include a standardized method for consideration of existing exposures and/or underlying health status of the community when responding to a request for an environment permit and develop a meaningful mechanism by which communities can influence permitting processes on the basis of public health concerns.

Rationale: The current permitting process is flawed. There is no standardized mechanism by which all state and federal environmental agencies take into account existing pollution sources and/or special health vulnerabilities of the community when the permitting process is initiated. Given the government's responsibility to protect human health, the existing health status of a community combined with the knowledge of existing environmental exposures, should inform the permitting process in its initial stages. Such considerations should have the potential to halt the permitting process its earliest stages. If the permitting process moves forward, the community should have the right to protect their health by influencing permitting decisions.

Implementation:

- a. The Environmental Protection Agency (EPA) Office of Environmental Justice (OEJ) in partnership with National Center for Environmental Health/Centers for Disease Control and Prevention (NCEH/CDC) will create a standard set of public health profiles of communities that state and federal permitting agencies must review and take into account before initiating a public permitting process.
- b. EPA OEJ, in partnership with NCEH/CDC, will create a meaningful process by which community comments regarding public health concerns can impact the permitting process.

In addition, regulatory agencies will take the following actions through placement of conditions on permits that ensure accountability to the community:

- a. Require third party certification for standards of social and ethical responsibilities to workers and communities in order to give industry economic incentives.
- b. Require legally-binding good neighbor agreements among industry, government agencies and the community.
- c. Require industry to implement extended product stewardship programs to prevent hazards associated with waste and disposal.

Timeline: In year one, the EPA OEJ, in partnership with NCEH/CDC, will create a set of recommended public health considerations that must be addressed at the onset of an environmental permitting process in order to determine whether the permitting process should proceed.

Evaluation: A key milestone for evaluation of this recommendation would be whether a set of public health impact guidelines are adopted by state permitting agencies for their consideration during the earliest stages of the permitting process.

12. Government agencies and the private sector/industry shall adopt green practices in partnership with communities.

Part 1—Actions within Government Agencies

Rationale: Government agencies are often at the forefront in championing new approaches and methodologies to promote better health and environmental practices. These same agencies may not be quick to adopt the same practices they endorse. Consequently, the federal government sends a confusing mixed message, which decreases the government’s credibility in the eyes of community groups and others. For government agencies to lead more effectively, they will need to go beyond service, regulation and enforcement by modeling green and inclusive practices that they encourage others to pursue. Government agencies will need to become the model for change.

Implementation: We recommend that government agencies begin with a focus on green practices with community engagement. Government agencies should adopt green practices, including procurement (for example, recycled paper, green cleaning products, recycled plastics) and other business operations (for example, integrated pest management, green janitorial practices, using hotels that are green for conferences, and purchasing hybrid vehicles for motor pool). We recommend that agencies document their greening goals at the start of the year and evaluate their success at the end of the year. To provide agencies with incentives to develop and implement such practices, the Office of Management and Budget should require such programs within agencies including the Agency for Toxic Substances and Disease Registry/Centers for Disease Control, the Environmental Protection Agency, National Institutes of Health, and the Departments of Health and Human Services, Defense, Energy, and Justice.

Part 2—Actions to Create Incentives for Research and Development of Safe Alternatives

Rationale: Long-standing public policies that govern chemical design, production, and use have failed to protect public health and the environment, especially in light of new science concerning health and environmental effects at low-dose exposures, often related to the endocrine-disrupting effects of anthropogenic chemicals. In addition to regulatory reform of the Toxic Substances Control Act; Federal Insecticide, Fungicide, and Rodenticide Act; and the Occupational Health and Safety Administration that are necessary to protect the integrity of ecosystems and human health, public policy should also enhance research, development, and innovation to support a rapid transition to systems of agriculture and industry based on safe methods of production and use.

Implementation: Agencies including Environmental Protection Agency, Department of Defense, Department of Energy, Occupational Safety and Health Administration, National Institute for Occupational Safety and Health, and U.S. Department of Agriculture (USDA), both independently and collaboratively, incorporating public comment and recommendations, must allocate time and financial resources to undertake immediate steps to develop and vet market-based incentive programs to engage industry such as:

- a. Congress should promote and fund green chemistry initiatives that foster education, research, development, technical assistance, entrepreneurial activities, and innovation in the creation and production of safe, non-toxic alternative substances (Schwarzman & Wilson, 2009; Wilson, 2006).
- b. EPA should permit expedited (fast-track) approval of new chemicals which are proven to be significantly safer than their older counterparts.
- c. USDA should support and allocate sufficient resources (in the next Farm Bill and through allocation of money to land grant schools for promotion of Integrated Pest Management, biological controls, and safer alternatives to promote to growers) for the transformation (including research and implementation) of agriculture to organic methods that replace the need for chemical fertilizers and pesticides.

Timeframe: These recommendations should be acted upon immediately following the release of the *National Conversation* report.

Evaluation: Part 1—This recommendation will be evaluated through tracking the implementation and effectiveness of green practices programs within federal agencies and subsequent increases in recycling and reductions in use of hazardous products/materials, energy use, etc. Agencies will create annual goals for waste reduction, integrated pest management, recycling, and procurement of safe alternatives for cleaning and other products. Agencies will evaluate their programs by comparing goals with achievements. Agencies will make their green practices programs' plans and evaluations open for public review, scrutiny, and comment.

Part 2—This recommendation will be evaluated by tracking increases in funding for research and development of innovations in green chemistry and product development. The development and approval of safe alternatives to replace hazardous chemicals/products on the market should also be tracked. These innovations should also result in improvements in environmental public health through reductions in release and exposure of toxic substances.

V. Conclusion

The Serving Communities work group recognizes everyone's right to a safe and healthy environment and envisions a system that promotes health and wellness among all people. However, because communities still suffer from harmful environmental exposures and because these exposures are borne disproportionately by low-income communities, Indigenous communities, and communities of color, the Serving Communities work group has developed twelve recommendations that, if implemented, would help protect communities from environmental harm.

The recommendations presented in this report address several areas in which progress must be made. Historically, affected communities have mistrusted both government and industry due to lack of responsiveness to their concerns and the misinformation and unequal treatment many have received. Government and industry must work to build this trust. Communities must also be provided with easy access to information about the chemicals to which they are exposed, including the health effects of these chemicals. In addition, community members should be trained in how to collect community data so that it will be considered valid and can be used in research.

It is critical that those making decisions ensure that affected community members are engaged in the process and that the final decisions made reflect community input. In order to ensure that community members can participate in these decisions and become effective self-advocates, government agencies, private foundations and others should provide more monetary support and technical assistance to affected communities. Those who work with community members should receive training in order to facilitate these working relationships. Such training might include classes in cross-cultural communication, risk communication, environmental justice, and conflict resolution. Finally, communities affected by harmful chemical exposures should be provided access to quality health care by medical professionals who understand environmental health.

Protection from harmful chemical exposures must include protection for those who are most vulnerable, including children, low-income communities, Indigenous communities, and communities of color. The Serving Communities work group views the implementation of the recommendations in this report as an important step towards achieving this goal.

Appendix A
Acronyms

1246	
1247	
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1249	AHRQ: Agency for Healthcare Research and Quality
1250	ATSDR: Agency for Toxic Substances and Disease Registry
1251	CARE: Community Action for a Renewed Environment
1252	CBPR: Community-based participatory research
1253	CDC: Centers for Disease Control and Prevention
1254	CHW: Community health worker
1255	DOD: United States Department of Defense
1256	DOE: United States Department of Energy
1257	DOI: United States Department of the Interior
1258	DOL: United States Department of Labor
1259	DOT: United States Department of Transportation
1260	EHR: Electronic health record
1261	EJ: Environmental justice
1262	EJ IWG: Interagency Working Group on Environmental Justice
1263	EPA: United States Environmental Protection Agency
1264	FOH: Federal Occupational Health
1265	FDA: United States Food and Drug Administration
1266	HHS: United States Department of Health and Human Services
1267	HRSA: Health Resources and Services Administration
1268	HUD: United States Department of Housing and Urban Development
1269	FIFRA: Federal Insecticide, Fungicide, and Rodenticide Act
1270	MOU: Memorandum of Understanding
1271	NCEH: CDC's National Center for Environmental Health
1272	NEJAC: National Environmental Justice Advisory Committee
1273	NIEHS: National Institute of Environmental Health Sciences
1274	NIH: National Institutes of Health
1275	NIOSH: National Institute for Occupational Safety and Health
1276	OEJ: Office of Environmental Justice
1277	OMB: United States Office of Management and Budget
1278	OSHA: Occupational Safety and Health Administration
1279	PBRN: Practice-based research network
1280	SEP: Supplemental environmental project
1281	TAG: Technical assistance grant
1282	TRI: Toxics Release Inventory
1283	UDS: Universal data set
1284	

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