

***National Conversation on Public Health and Chemical Exposures***  
**Draft Serving Communities Work Group Report**

**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.

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](http://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.<sup>1</sup>

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.

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<sup>1</sup> For additional information on the work group member selection process, see [http://www.atsdr.cdc.gov/nationalconversation/docs/membership\\_selection\\_process\\_report.pdf](http://www.atsdr.cdc.gov/nationalconversation/docs/membership_selection_process_report.pdf)

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

55  
56 **Chair**

57 Peggy Shepard, Chair, WE ACT for Environmental Justice

58  
59 **Members<sup>2</sup>**

60 Lisa Conti, Florida Department of Health  
61 Steve Crawford, Passamaquoddy Tribe at Pleasant Point  
62 Jeannie Economos, Farmworker Association of Florida  
63 Karla Fortunato, Health & Environmental Funders Network  
64 Lori Geckle, U.S. Army Center for Health Promotion and Preventive Medicine  
65 Derek Guest, formerly of Eastman Kodak Company, currently of Environmental and Sustainability  
66 Solutions  
67 Rita Harris, Sierra Club Environmental Justice Program  
68 Mercedes Hernández-Pelletier, NC Department of Health and Human Services, Division of Public Health  
69 Michael Kent, Contra Costa Health Services  
70 Scott Levy, The Permanente Medical Group  
71 Egide Louis, U.S. Environmental Protection Agency, Region 4  
72 Mildred McClain, Harambee House Inc. /Citizens For Environmental Justice  
73 Pamela Miller, Alaska Community Action on Toxics  
74 Mark Mitchell, Connecticut Coalition for Environmental Justice  
75 Liam O'Fallon, National Institute of Environmental Health Sciences  
76 Suzi Ruhl, U.S. Environmental Protection Agency  
77 Barbara Sattler, University of Maryland School of Nursing  
78 Hilda Sheppard, Agency for Toxic Substances and Disease Registry  
79 Arturo Uribe, Mesquite Community Action Committee

80  
81 **Support**

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

85  
86  
87 **Work group charge, scope, and objectives**

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

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<sup>2</sup> This report is a draft document. This list of work group members does not yet reflect endorsement by any individual.

91 **1. Community Advocacy, Leadership and Research**

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

96  
97 **2. Government Operations (Internal and External)**

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

101  
102 **3. Addressing Past and Current, and Preventing Future, Environmental and Chemical Exposures**

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

109  
110 **4. Restoring Health and Developing Community Resiliency**

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

116  
117 **Caveats and/or limitations**

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

122  
123 **Work group process**

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

130  
131 The work group has compiled this report to review some of the issues and gaps that exist when serving  
132 communities affected by chemical exposures. The work group also puts forth twelve recommendations  
133 that, if implemented, would increase protections for communities from harmful chemical exposures.

134  
135 **Note on terms and definitions**

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

137  
138 **Community-** a group of people affiliated by residence in a defined area, or by virtue of their innate  
139 personal characteristics (e.g. gender, race, or ethnicity) (Institute of Medicine, National Academy of

140 Sciences, 1995), health or disability status, or by a uniting common interest (HHS, n.d.), occupation, or  
 141 belief.

142  
 143 **Community-based participatory research (CBPR)** - a "collaborative approach to research that  
 144 equitably involves all partners in the research process and recognizes the unique strengths that each  
 145 brings. CBPR begins with a research topic of importance to the community, has the aim of combining  
 146 knowledge with action and achieving social change to improve health outcomes and eliminate health  
 147 disparities" (Center for Advancing Health, 2003-2010).

148  
 149 **Community health workers (CHW)**- "lay members of communities who work either for pay or as  
 150 volunteers in association with the local health care system in both urban and rural environments and  
 151 usually share ethnicity, language, socioeconomic status and life experiences with the community  
 152 members they serve...CHWs offer interpretation and translation services, provide culturally appropriate  
 153 health education and information, assist people in receiving the care they need, give informal counseling  
 154 and guidance on health behaviors, advocate for individual and community health needs, and provide some  
 155 direct services such as first aid and blood pressure screening" (HRSA, 2007).

156  
 157 **Community resiliency**- the ability of a community to respond to crises in ways that strengthen  
 158 community bonds, resources, and the community's capacity to cope. Community resilience is the  
 159 individual and collective capacity to respond to adversity and change. In communities, resilience is  
 160 related to: (1) magnitude of shock a system can absorb and remain competent; (2) degree to which a  
 161 system is capable of self-organization; and (3) degree to which a system can build capacity for learning  
 162 and adaptation (Kelly, n.d.).

163  
 164 **Cultural competence**- a "set of congruent behaviors, attitudes, and policies that come together in a  
 165 system, agency, or among professionals and enable that system, agency, or those professionals to work  
 166 effectively in cross-cultural situations" (HRSA, 2002).

167  
 168 **Enabling services**- "non-clinical services (i.e., not direct patient services) that enable individuals to  
 169 access primary health care services and improve health outcomes. Enabling services include case  
 170 management, referrals, translation/interpretation, transportation, eligibility assistance, health education,  
 171 environmental health risk reduction (e.g., educational materials, nicotine gum/patches), and outreach"  
 172 (HRSA, n.d.).

173  
 174 **Environmental justice communities**- low-income communities, indigenous communities and  
 175 communities of color that are disproportionately burdened with environmental hazards and suffer  
 176 disproportionately from environmentally-related diseases.

177  
 178 **Health**- not only the absence of infirmity and disease but also a state of physical, mental, social and  
 179 spiritual well-being (Preamble to the Constitution of the World Health Organization, 1946).

180  
 181 **Physician**- a doctor of medicine, osteopathy, dental surgery/medicine, podiatry, or optometry, or a  
 182 chiropractor (Social Security Act, §1861(r), 2007).

183  
 184 **Precautionary principle**- "when an activity raises threats of harm to human health or the environment,  
 185 precautionary measures should be taken even if some cause and effect relationships are not fully  
 186 established scientifically" (Wingspread Conference on the Precautionary Principle, 1998).

187

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

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

197  
198

## 199 **II. Developing an Effective System**

200

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

208

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

219

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

227

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

233

234 Communities will be informed of and have ready access to information about the chemicals to which they  
235 are exposed, including the known and/or suspected health impacts of those chemicals. There will be a

236 central hub of environmental health information where people can easily find answers to the questions  
237 they have, including information about disease prevalence collected by new disease registries. A national  
238 health database of patient information will be created to help us better understand exposures and their  
239 relationship to disease. Business and industry will share information on the chemicals they use and will  
240 also share research, progress reports, and updates on remediation activities with the public frequently.

241  
242 Affected community members will become actively engaged in decisions that affect them. It is incumbent  
243 upon government agencies to provide opportunities for community members to become involved early,  
244 and have the tools to participate effectively, in decisions that affect them. The input of community  
245 members will not only be listened to but will make a demonstrable impact in the decisions being made.  
246 Agencies will institute practices to ensure that community members are aware of permit requests,  
247 changes, violations and alterations, as well as enforcement actions by advertising and announcing these  
248 activities in several local venues, such as the local daily newspapers that have a broad readership, radio  
249 public service announcements, email to a broad range of known community stakeholders, and any other  
250 means that has the potential of reaching a broad cross-section of the community. It will no longer be  
251 acceptable that a public notice can be used to check off a public involvement requirement.

252  
253 Public forums or listening sessions will be held to share information and serve as an outlet to hear the  
254 concerns of community members in all phases of a project and to address concerns. These forums and  
255 listening sessions will also allow community members an opportunity to share their own independent  
256 findings and research, as well as to refute claims and challenge reports by government agencies and  
257 industry that will influence the decision making. The agencies will plan and allow for adequate review  
258 and comment periods with consideration for and sensitivity to cultural differences, customs, and activities  
259 that might impact the agency's timeline.

260  
261 Agencies and foundations will provide more grants to communities in need so that communities have the  
262 resources they need in order to research their concerns, hire their own experts, and participate in the  
263 decisions that are made and that will affect them. Agencies and foundations will provide training and  
264 technical assistance to communities on topics such as grant writing and conducting research.  
265 Agencies will reach out to collaborate with communities on research, using community-based  
266 participatory research methods. Agencies will also train communities in validated methods for data  
267 collection so that communities can collect their own information and have it be accepted as valid by those  
268 doing analyses on exposures or health outcomes. Aligning data collection methods and standards among  
269 agencies will also streamline the ability to collect and analyze environmental health data.

270  
271 Government agencies at all levels will communicate effectively with affected communities by using  
272 trained, culturally competent staff who have experience communicating with communities in a way that  
273 they can understand. Government agency staff and researchers will acquire enhanced training in areas  
274 such as cultural competency, cross-cultural communication, inclusive decision making, and facilitation in  
275 order to be able to work effectively with affected communities. Such training, along with involving  
276 communities in processes from the beginning, will improve working relationships between government  
277 officials and community members and allow for increased progress towards environmental justice.

278  
279 In addition, community members will have access to affordable and quality health care from providers  
280 who understand environmental health concerns. These providers will recognize that social conditions  
281 including racism, socioeconomic status/class, gender, place of residence, access to quality food, job loss  
282 (Boston, 2010), language barriers, lack of transportation and fear of deportation are conditions that  
283 impact, and can be determinants of, people's health and wellness. The overarching goal of protecting the  
284 health and quality of life of those in all communities will be paramount.

285

286 **III. Current Context**

287

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

292

293 The Serving Communities work group believes that every person has a right to a safe and healthy  
 294 environment. Although these rights should be fundamental, people across this country are being denied  
 295 this right. The Environmental Justice (EJ) Movement grew from the recognition that people of color and  
 296 low-income communities bear the brunt of harmful environmental exposures (Bullard, Mohai, Saha, &  
 297 Wright, 2007) and recognizes the right to a safe environment “where we live, work, and play” (United  
 298 Church of Christ, n.d.).

299

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

311

312 Environmental injustice extends beyond proximity to toxic waste sites. People are exposed at varying  
 313 degrees to harmful chemicals throughout the lifecycle of chemicals: from their extraction and production,  
 314 to their use in manufacturing and industry, to their recycling and disposal and well beyond their useful life  
 315 such as in contaminated soil or leaded chipping and peeling paint. Data from the CDC from 1992-1994  
 316 show that, for all income levels, non-Hispanic black children had a greater risk of elevated blood lead  
 317 levels than white children (Environmental Protection Agency, 2010). The data show this disparity is  
 318 greater for black children whose families live below the poverty line. More than 68 percent of African  
 319 Americans live within 30 miles of a coal-fired power plant—the distance within which the maximum  
 320 effects of the smokestack plume are expected to occur—compared with 56 percent of white Americans  
 321 (Black Leadership Forum, Clear the Air, Georgia Coalition for the People's Agenda, & The Southern  
 322 Organizing Committee for Economic and Social Justice, 2002). In *The State of Childhood Asthma: 1980-*  
 323 *2005*, the CDC reports that children of American Indian or Alaska Native descent have asthma prevalence  
 324 rates 25% higher, and black children 60% higher, than white children (Akinbami, 2006). Not only are  
 325 these prevalence rates higher, but compared with white children, black children have a 260% higher  
 326 emergency department visit rate, a 250% higher hospitalization rate, and a 500% higher death rate from  
 327 asthma. Birth prevalence of major congenital anomalies in Alaska is twice as high as in the United States  
 328 as a whole. Alaska Native infants have twice the risk of major congenital abnormalities as white infants  
 329 born in Alaska (Schoelhorn, 2008). In addition to suffering higher rates of many environmentally-related  
 330 diseases, racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities,  
 331 even when taking into account patients' insurance status and income (Smedley, Stith, & Nelson, 2003).

332

333 Enforcement of environmental and public health laws is another area in which disparities exist,  
 334 particularly in people of color and low-income communities. A 1992 study published in the *National Law*  
 335 *Journal* found that monetary penalties for violations of hazardous waste laws, such as the Superfund law,

336 were about 500 percent higher in white communities than for those in people of color communities  
337 (Lavelle & Coyle). The study also found that people of color communities waited 20 percent longer for  
338 sites in their neighborhoods to be put on the National Priorities List.

339  
340 This trend of unequal enforcement continues. A 2004 study, published in *Society and Natural Resources*,  
341 found that petroleum refineries situated within Hispanic and low-income ZIP codes were fined 95 percent  
342 less than those located in non-Hispanic, more affluent ZIP codes (Lynch, Stretesky, & Burns, 2004). The  
343 study also found that median household income is strongly correlated with assessed fines; each thousand  
344 dollar increase in median household income in ZIP codes was associated with an over 11 percent increase  
345 in the average fine against petroleum refineries. The findings of this study revealed that residents living in  
346 non-Hispanic, more affluent ZIP codes benefited from vigorous enforcement compared to residents living  
347 in Hispanic, low-income ZIP codes.

348  
349 Unequal protection from environmental harm continues for many reasons. In Florida, for example, many  
350 violations of worker protection standards and field sanitation laws go unreported and uninvestigated in the  
351 agricultural sector. Workers often do not report these violations because of fear of job loss, retaliation by  
352 employers, the threat of deportation, and physical harassment, as well as lack of knowledge of their rights  
353 and protections under the law. When violations are identified, warnings are often issued first. Fines are  
354 often imposed only in egregious cases, with the fine being small in proportion to the actual and/or  
355 potential harm that is caused. For example, while pregnant women that worked for AgMart Farms gave  
356 birth to babies with severe birth defects, AgMart was fined a relatively small amount despite being cited  
357 for multiple violations of health and safety regulations in both Florida and North Carolina (Stapleton,  
358 2008). The regulatory system having failed them, one family resorted to filing a civil lawsuit against the  
359 company for their baby boy who was born without arms or legs.

360  
361 As another example, indigenous communities reliant on traditional diets of fish and marine mammals are  
362 among the most exposed of any population on earth to certain contaminants including bio-accumulated  
363 persistent chemicals that are transported via atmospheric and oceanic currents (Arctic Monitoring and  
364 Assessment Programme, 1998).

365  
366 It is clear that improvements must be made in order to ensure people are sufficiently, and equally,  
367 protected from chemical exposures. Below, key areas in which progress must be made are examined.

### 368 369 **Trust**

370 Many communities do not trust industry to protect them from harmful chemical exposures and do not  
371 have faith that the government will enforce environmental and health regulations. This mistrust stems  
372 from a long history of unequal treatment, a lack of responsiveness to communities' concerns, and the lack  
373 of community involvement in decisions, among other reasons.

### 374 375 **Access to Information**

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

380  
381 Another information gap exists due to the lack of disease registries in every state for important health  
382 outcomes such as autism, Parkinson's disease, birth defects, endocrine disorders (including reproductive  
383 health problems and thyroid disease), and asthma, as well as for exposures of concern like exposure to  
384 mold, pesticides, and lead. Registries that do exist lack important information. While most registries  
385 collect information on place of residence or birthplace, date of occurrence, and personal characteristics

386 (such as sex, ethnicity and social status), the treatment protocol and/or intervention as well as mortality is  
 387 often missing. Many times there is a lag between the time a person develops a medical condition and  
 388 when the incidence is noted in the registry.

389

### 390 **Public Engagement**

391 The engagement of affected communities in environmental health, siting, and permitting decision making  
 392 processes is critical to ensuring that communities' questions are answered, their concerns are addressed,  
 393 and their views are an integral part of decisions that are made. Unfortunately, many barriers to such  
 394 participation exist. Few government agencies are mandated to involve communities in these activities and  
 395 when outreach is attempted it is often begun well after a process is underway and is poorly conducted.  
 396 When community members do participate in decision making processes, too often they feel that agency  
 397 scientists are "explaining away" their concerns with science while not acknowledging the realities that  
 398 they are experiencing. In addition, language barriers and lack of cultural sensitivity can reduce the  
 399 effectiveness of community engagement or prevent it entirely. When community members do find out  
 400 about public involvement opportunities, often they do not have the tools to effectively engage in these  
 401 processes.

402

### 403 **Monetary Resources**

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

410

### 411 **Data Collection**

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

419

### 420 **Communication**

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

426

427

## 428 **IV. Action recommendations**

429

- 430 **1. Establish a new federal law, Executive Order, rules or policies that require federal government**
- 431 **agencies to (1) formalize mechanisms for substantive community engagement in government**
- 432 **decision making and (2) require government agencies and their funding recipients to engage**
- 433 **environmental justice communities in environmental decision making processes that affect their**
- 434 **communities. Government agencies shall develop mechanisms to engage and dialogue with**

435 **communities at the earliest possible stages and throughout environmental decision making**  
436 **processes.**

437

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

444

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

453

454 **Implementation:** We recommend passage of a new federal law or Executive Order, rules or policy that  
455 requires federal government agencies and government-funded organizations to involve environmental  
456 justice communities in environmental decision making processes that affect their communities. The  
457 processes and oversight might be accomplished through the Interagency Working Group on  
458 Environmental Justice. This new policy would be applied to the following types of decisions: economic  
459 development funding, siting, permitting, site remediation, health assessments, community notification,  
460 facility closures, emergency response, and enforcement. The same standards and practices will apply to  
461 state government agencies.

462

463 While many federal agencies promote community engagement at a local level, we recommend that  
464 agencies model inclusive practices by formalizing and publicizing mechanisms for substantive  
465 community engagement at the agency level. For example, federal agencies should implement community  
466 advisory committees similar to the National Institutes of Health Director's Council of Public  
467 Representatives or the Environmental Protection Agency National Environmental Justice Advisory  
468 Committee. Agencies could also use less structured models such as hosting community forums across the  
469 country as a way of engaging community groups and residents from across the country. We recommend  
470 that government agencies develop and document a community engagement plan at the start of each year  
471 and evaluate their success at the end of the year. We recommend that government agencies develop  
472 accessible tools (for example, online surveys) to solicit feedback from their community partners. The  
473 results can be used for evaluation purposes and for consideration in establishing the next year's goals.

474

475 **Timeframe:** We recommend that the Interagency Working Group on Environmental Justice develop a  
476 policy in the next two years and an approved process implemented through official regulatory  
477 mechanisms within an additional two years that would create an effective and responsive public  
478 participation process.

479

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

483

484 **2. Congress should amend the Agency for Toxic Substances and Disease Registry's (ATSDR)**  
 485 **mandate and mission to ensure it serves public health more effectively.**  
 486

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

491  
 492 **Implementation:** We recommend that ATSDR develop and implement a process to engage community  
 493 groups and stakeholders across the US to help re-envision its mission and mandate. The goal is to identify  
 494 the best methods for the government to respond to community concerns related to environmental  
 495 exposures including:

- 496 a. Requirements to collect primary data and analyze it at environmental justice-designated sites  
 497 when data received is incomplete, insufficient, or not available from other agencies/entities  
 498 (e.g., Environmental Protection Agency, federal, state, local environmental agencies,  
 499 industry, etc.)
- 500 b. Establishment of a formal peer-review process for all products developed or funded by  
 501 ATSDR.
- 502 c. Requirement to indentify and coordinate a community dialogue with other  
 503 agencies/organizations as part of its community engagement mandate to address health issues  
 504 and health care gaps beyond ATSDR environmental health mission.
- 505 d. Establishment of policies and procedures to ensure community advisory groups (or similar  
 506 structures) are used in disproportionately affected communities (including communities of  
 507 color, indigenous communities, and low income communities).
- 508 e. Systematically review, update, distribute, and make available in plain language ToxFAQs and  
 509 site-specific fact sheets as science changes, new information is acquired, and new hazardous  
 510 chemicals/substances are identified.

511  
 512 **Timeframe:** Submit immediately to the newly reconstituted Inter-Agency Workgroup immediately upon  
 513 National Conversation Leadership acceptance/approval of recommendation. By October 2011 IAW will  
 514 submit the report to congress.

515  
 516 **Evaluation:** Has amendment been enacted, funded, initiated and implemented?  
 517

518 **3. Government agencies shall develop coordinating structures/mechanisms across agencies to**  
 519 **improve communication with and accountability to communities.**  
 520

521 **Rationale:** Communities affected by the release of toxic chemicals encounter many challenges accessing  
 522 information from government agencies. Coordinating and communicating information within government  
 523 structures as well as externally with communities is an important precursor to effective and sustainable  
 524 community engagement. The burden of this coordination should lie on government structures and not on  
 525 affected communities. It is unreasonable to expect the public to contact every single public agency to  
 526 make sense of government activities, or methods for collecting or interpreting data. Communities should  
 527 be able to track information about federal, state, local and tribal governments' activities in their  
 528 communities from a central location. Communication should be bi-directional, from government to  
 529 communities and vice versa, and mechanisms for this communication should be coordinated and  
 530 streamlined. The type of information available to communities should include mechanisms to track issues  
 531 in their communities, government activities, resources and tools available, "best practices" pertinent to  
 532 their communities, agency standards or guidelines, mechanisms to ask questions and receive answers, and

533 mechanisms available for community involvement, among others. This one source of information should  
 534 be deemed accurate, complete, meaningful, timely and easy to understand.

535

536 **Implementation:**

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

555

556 Coordination within individual agencies: To promote coordination within each of the federal agencies we  
 557 recommend that the Federal Interagency Working Group on Environmental Public Health establish a  
 558 mechanism to direct “navigation” services within the participating federal agencies. The purpose is to  
 559 ensure that federal agencies better assist community residents when they are seeking information at that  
 560 agency.

561

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

572

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

576

577 **Evaluation:** By January 2012, it should be determined if these structures have been established. If so, it  
 578 should be identified where they have been established and by whom. It should be documented how these  
 579 structures have been used, including key highlights or outcomes. A baseline customer satisfaction survey  
 580 should be conducted of a representative sample of these structures from across the country. A follow-up  
 581 survey should be conducted after a year of implementation and thereafter periodically.

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

**Rationale:**

Self Advocacy: Communities don't 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, 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, the Environmental Protection Agency, and the Departments of Health and Human Services, Agriculture, Defense, Energy, Interior, Transportation and Justice), various foundations, and academic institutions 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;
- b. a shared clearinghouse for communities to access information on best practices and resources offered by state and federal agencies, and 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

631 baseline analysis should be conducted to determine the current level of funding for independent research  
 632 by community groups within the next 6 months and funding levels should be reported annually thereafter.

633 The evaluation of this program would include the:

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

641  
 642 **5. Federal agencies shall establish, facilitate and promote training programs for government**  
 643 **employees, community groups/residents, academia, industry, and community health volunteers**  
 644 **to develop and advance their capacity to ensure the success of community-engaged projects.**

645  
 646 **Rationale:** To work effectively in partnership with communities, building the skills and capacity of all  
 647 partners is vital (Ahmed & Palermo, 2010). Too often, skill building is focused solely on community  
 648 organizations and residents and not on other partners, especially government employees who oversee and  
 649 administer federal programs that promote and foster community partnerships. All partners need to  
 650 develop and advance their skills to ensure the success of community engaged projects. The need for  
 651 capacity building for community groups is addressed in a previous recommendation. Therefore this  
 652 section focuses on the needs of the other partners: government employees, academia, industry, and  
 653 community health volunteers.

654  
 655 Following are specific recommendations to meet the needs for each of the partners. All efforts would be  
 656 implemented and evaluated by the Federal Interagency Working Group on Environmental Public Health.

657  
 658 **Timeframe:** Within 12 months have a baseline assessment of existing materials and training programs.  
 659 Identify gaps and opportunities. Within 12 months of assessment have at least 5 training programs that  
 660 meet the identified needs.

661  
 662 **Evaluation:** Availability: Complete a baseline assessment of materials/programs currently available in  
 663 these areas. Identify successful models and programs and make them available. After one year, conduct a  
 664 follow-up analysis to see what new programs have been created. Variety: From the baseline, examine the  
 665 different types of training programs available. Utility: How many groups/individuals have taken the  
 666 training? Determine the baseline and conduct an annual review. If activities are part of a grant, review  
 667 annual reports to look at the attendance and participant lists. For volunteer programs, look at the number  
 668 of volunteers recruited from where and to work on what issues. Outcomes: Monitor government programs  
 669 that serve communities. Consider implementing “customer satisfaction” surveys to evaluate the  
 670 effectiveness of the services provided to communities. Are there a greater number of programs that reflect  
 671 the needs of community residents? Are systems in place to respond appropriately? Monitor the number of  
 672 community-university grant projects and the number of investigators gaining tenure who have a greater  
 673 focus on community-engagement work. Monitor the number of community-based organizations that have  
 674 community health corps volunteers and that build a stronger infrastructure to work in partnership with  
 675 academic partners as Principal Investigators. Grant money is leveraged. For industry and businesses,  
 676 monitor how they have changed their practices to work in partnership with communities to address  
 677 community concerns.

678

679 **a. Government Employees**

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

687  
 688 The U.S. Department of Health and Human Services, Office of Minority Health offers an example of  
 689 cultural competencies for clinicians and others. This type of curriculum should be used for government  
 690 employees who are a part of programs that serve communities. All resources would be made available in  
 691 a central location to make it easy for government employees to take advantage of the training.

692  
 693 **b. Academia**

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

702  
 703 There are existing federal programs that support this type of training. The National Institute of Minority  
 704 Health and Health Disparities (NIH) maintains a loan repayment and training program for young  
 705 investigators. The NIEHS (NIH) encourages applications to its fellowship program from investigators  
 706 wishing to do work in environmental public health. However, there has been little coordination among the  
 707 agencies to make this information easily accessible to academics.

708  
 709 **c. Volunteers**

710 **Implementation:** We recommend the creation of a new Community Environmental Public Health Corps  
 711 Program to bring in young graduates committed to working with community groups. For the most part,  
 712 AmeriCorps participants are placed with larger, not community-based, non profits often due to the  
 713 requirement for matching funds from communities. This program would break down the financial barrier  
 714 and focus on environmental public health and environmental justice concerns. This program would  
 715 provide critical training to the program members and also ensure grant dollars, and volunteers, for  
 716 community-based organizations, especially in communities of color and low-income. The objective of  
 717 this recommendation is to develop the skills and tap into the enthusiasm of young graduates and  
 718 individuals with a commitment to volunteerism, to work in partnership with community groups to build  
 719 community capacity to address the environmental health concerns of community residents. To this end,  
 720 there should be an increase in the number of volunteers with a focus on environmental health-related  
 721 projects.

722  
 723 **d. Industry/Business Partners**

724 **Implementation:** We recommend the creation of training programs to develop the skills of business  
 725 partners to work more effectively with community organizations/residents as they address environmental  
 726 health and justice issues of concern to the affected community. The training programs should include  
 727 topics such as cultural competencies, communication, trust building, collaborative problem solving, etc.  
 728

729 **6. The Centers for Disease Control and Prevention (CDC) and/or the Agency for Toxic Substances**  
 730 **and Disease Registry (ATSDR) should establish a National Health Outcomes Database to be**  
 731 **used to create a standard process for governmental agencies to assess community health and**  
 732 **potential synergistic, cumulative, and aggregate environmental factors.**  
 733

734 **Rationale:** Although national disease registries do exist, they are far from complete. With any registry  
 735 there is always the potential for numerous sources of error (Wolfe & Fairchild, 2010) including  
 736 underreporting. The data typically tracked in a registry includes the place (residence or birthplace), time  
 737 of occurrence and personal characteristics (such as sex, ethnicity and social status). Missing from the  
 738 typical registry is treatment protocol and/or intervention as well as mortality. There is typically a lag  
 739 between the time a person develops a medical condition and when the incidence is noted in the registry.  
 740

741 There has been significant discussion in the recent past by both the Pew Environmental Health  
 742 Commission (2000) as well as CDC (n.d.) and ATSDR on the value of having the ability to perform  
 743 nationwide public health tracking (Pew Environmental Health Commission, 2000). The potential value to  
 744 be able to identify illness in real-time significantly increases the odds of identifying and remediating a  
 745 toxic situation as opposed to reviewing old registry data in an attempt to piece together a puzzle.  
 746

747 Communities can be an invaluable source for identifying emerging local environmental health concerns  
 748 and often recognize issues before agencies do. There is currently no standardized national dataset of  
 749 health indicators. Creating such a resource would help localities and federal agencies identify those  
 750 communities with disproportionately lower environmental health status in order to implement targeted  
 751 interventions. In addition, federal agencies do not currently use a standard methodology for assessing  
 752 community health or consistently explain to communities how they chose a methodology to conduct the  
 753 local health assessment. This lack of transparency results in confusion and distrust between communities  
 754 and academics. Without incorporation of community environmental health priorities, the value of the  
 755 assessment from the local perspective will be greatly diminished.  
 756

757 **Implementation:** We recommend that the Centers for Disease Control and Prevention, in coordination  
 758 with the Environmental Protection Agency and state and tribal public health agencies, establish a National  
 759 Health database similar to the Food and Drug Administration's (FDA) Sentinel System<sup>3</sup> from which real-  
 760 time data would be accessible in the original format and would have the potential of de-identifying  
 761 information. To modify or adapt the "Sentinel System" to one where the population can be surveyed by  
 762 the CDC for toxic exposures in real-time, effectively monitoring those at risk for long term-health effects,  
 763 as well as maintaining targeted surveillance to their offspring and successive generations would be  
 764 invaluable. This National Health database would be a centralized database where either all medical  
 765 providers would be able to upload their medical information into one source, or have their existing  
 766 electronic health records (EHR) accessible by a third party, such as the CDC. The database must integrate  
 767 information from vital records, geographically-based environmental exposure monitoring (e.g. National  
 768 Health and Nutrition Examination Survey biomonitoring data) as well as environmental hazard data (e.g.  
 769 Toxics Release Inventory, hazardous and solid waste facilities, groundwater/surface water contamination,  
 770 air pollution sources).  
 771

772 We recommend that the CDC:

773 1) Develop a national baseline health assessment which will augment the power and functionality of a  
 774 National Health Outcome Database. This assessment should consider local environmental health data and  
 775 community priorities. This baseline assessment should collect data which will help to develop a

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<sup>3</sup> See <http://www.fda.gov/Safety/FDAsSentinelInitiative/default.htm>

776 standardized minimum set of environmental health indicators (asthma rates, lead levels, birth weight, etc.)  
 777 to allow for comparisons over time. The CDC should update the data used in the health assessment  
 778 periodically based on current knowledge and evaluate whether there are additional environmental health  
 779 indicators such as the Disability-Adjusted Life Year (DALY) (Arnesen & Nord, 1999; Flores, Davis, &  
 780 Culross, 2007; McKenna, Michaud, Murray, & Marks 2005; Murray, Kulkarni, Michaud, Tomijima,  
 781 Bulzacchelli, Iandiorio, & Ezzati, 2006; Sutherland, & Fielding), which may be of value.

782  
 783 2) Develop standardized guidelines for how to conduct local health assessments, taking into account local,  
 784 state, and national indicators, as appropriate. The guidelines should evaluate both environmental  
 785 indicators and health outcomes and retain the flexibility to incorporate additional community-specific  
 786 information as well as community-based knowledge, where appropriate (the guidelines should also  
 787 address the need for agencies to explain to communities how they intend to conduct the local health  
 788 assessment).

789  
 790 3) Develop and provide technical support to enable communities to ensure that the local health  
 791 assessment is fully representative without bias.

792  
 793 **Timeframe:** In 2012 the FDA is anticipating that they will have 100 million EHR's linked to their  
 794 network. To adapt/mimic this Sentinel System would in all likelihood take 2-5 years from inception if  
 795 fully supported with adequate resources. The more we can share the FDA's platform instead of  
 796 developing it from scratch, the shorter the anticipated development time. We expect that a baseline health  
 797 assessment can be easily accomplished in the 2-5 year range as well.

798  
 799 **Evaluation:** Evaluation of this program would include (1) issuing an annual report to Congress on  
 800 progress towards meeting the milestones described above, (2) monitoring and reporting the number of  
 801 communities that have accessed and published reports based upon the national baseline health data, and  
 802 (3) monitoring the number of communities that have used the national guidelines to assess the  
 803 environmental health in their communities.

## 804 805 **7. Increase access to health and health care for populations experiencing environmental justice** 806 **challenges.**

807  
 808 **Rationale:** Populations with environmental justice challenges who bear the burden of pollution also bear  
 809 a burden of disease, regardless of any association between exposure to pollution and adverse health  
 810 effects. These populations also lack access to essential comprehensive, culturally competent and quality  
 811 primary health care services, and holistic, integrated health care. For example, Alaska Native  
 812 communities are often distant from full service health care facilities, accessible only by boat or plane. As  
 813 such, they are served by community health aids rather than physicians (as defined by Social Security Act  
 814 section 1861(r)) or nurses and are not yet benefiting from new access points of delivery or telemedicine.  
 815 In addition, populations with environmental justice challenges have not fully benefitted from emerging  
 816 prevention approaches related to sustainability, physical activity, and nutrition, which has exacerbated  
 817 obesity and chronic diseases.

818  
 819 Communities burdened with pollution and disease have articulated a model to increase their access to  
 820 health and health care, including the full range of essential primary health care services necessary to  
 821 assure optimum health and quality of life. This model (hereinafter referred to as "community health  
 822 access model"), includes the following core elements:

- 823 a. Holistic, integrated, comprehensive and sustainably-designed community health centers  
 824 offering the full range of essential primary health care services (incorporating the definition  
 825 of physician as defined by Social Security Act section 1861(r)) together with well-funded

- 826 enabling services, such as mobile care, telemedicine, outreach, health education,  
 827 transportation, interpretation, and translation
- 828 b. Community health, wellness and resilience (ombudsmen) resources/programs
  - 829 c. Special environmental health care to deal with multiple exposure and diseases, as appropriate
  - 830 d. Multi-disciplinary team approach, including minority institutions (e.g. Historically Black  
 831 Colleges and Universities), physicians (as defined by Social Security Act section 1861(r)),  
 832 allied health professionals, and community beneficiaries
  - 833 e. Data gathering (i.e. expand and standardize metrics, use better community-level profiles and  
 834 personal histories to improve diagnosis and treatment and address environmental sources,  
 835 apply all these results to national level policy)
  - 836 f. Single clearing house that includes best practices, contact information for communities,  
 837 success stories and reality check of communities
  - 838 g. Holistic, sustainable framework that responds to the relationship between community health,  
 839 and the natural, built and social environments and incorporates sustainability principles in the  
 840 design and implementation of health and health care access
  - 841 h. Strategy to better connect the public health community to community health delivery workers  
 842 and health aids, particularly for primary health care services

843  
 844 **Implementation:** Increase access to health and health care for disadvantaged, environmentally-burdened  
 845 communities by facilitating the establishment of the community health access model through the  
 846 following measures:

- 847  
 848 1) Health Resources and Services Administration’s (HRSA) requirements for federally qualified health  
 849 center funding, as authorized under section 330 of the Public Health Services Act, as amended, and  
 850 related Indian Health Service requirements, will be revised to recognize:
- 851 a. Permissible designation for medically underserved populations for those recognized by  
 852 Executive Order 12898, which are minority, low-income and tribal populations (hereinafter  
 853 referred to as “EJ populations”) experiencing disproportionately high and adverse  
 854 environmental effects
  - 855 b. Additional health services related to environmental health, as appropriate, for use of funds  
 856 that include special environmental health care to deal with multiple exposures to pollutants  
 857 and diseases that are caused or exacerbated by such exposures
  - 858 c. Additional health services related to environmental health, as appropriate, for use of funds  
 859 that include special environmental health care to deal with special, vulnerable populations,  
 860 such as children and elderly
  - 861 d. Requirement that the availability and accessibility of the primary health care services of the  
 862 center address sustainable design and placement (e.g. walkability, public transportation,  
 863 mobile care) so that holistic, integrated, comprehensive centers are developed that respond to  
 864 the relationship between community health, the built and social environments
  - 865 e. Requirement for multi-disciplinary team approach that supports the full range of primary care  
 866 services and leverages agency resources/programs to support community health, wellness and  
 867 resilience (ombudsmen)
  - 868 f. Requirement for data gathering and management, including modifications to Universal Data  
 869 Set (UDS) and clearing house functions addressing best practices

870  
 871 **Timeframe:** By June 2011

872 **Evaluation:** Revised guidelines are published and implemented

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

876

877 **Timeframe:** By December 2013

878

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

888

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

893

894 **Timeframe:** By June 2011

895

896 **Evaluation:** Report on the funding that has been provided to pilot projects (e.g. EPA Region 4 EJ  
897 Showcase Community initiative) seeking to implement community model health care access.

898

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

903

904 **Timeframe:** By December 2010

905

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

910

## 911 **8. Incorporate reimbursable environmental health services into primary health care services.**

912

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

918

919 Health care providers (nurses, physicians, and others) do not receive training in environmental health in  
920 their basic education and therefore do not learn the knowledge and skills to integrate environmental  
921 assessments/interventions into their clinical practices. Recommendations regarding the deficit in health

922 care providers' educational preparation are being addressed by the Communication and Education work  
 923 group.  
 924

925 Individualized assessment of environmental exposures and associated risk communication, health  
 926 education, and anticipatory guidance are virtually absent from primary care settings. Adding such a  
 927 repertoire of environmental health services can contribute to disease prevention, early disease detection,  
 928 and potentially avoid the use of more expensive health services from diseases that would otherwise  
 929 progress.  
 930

931 Our most at-risk communities are often communities that are served by community and public health  
 932 centers, including health-department sponsored clinics, federally qualified health centers, Indian and  
 933 Alaska Native health centers, migrant health centers, and rural health centers. The communities they serve  
 934 represent those who have more compromised health status, are more likely to live in substandard housing  
 935 and near hazardous industries/waste sites, and work in hazardous industries and workplaces. Community  
 936 health centers provide primary care, health education, and some community outreach. These centers also  
 937 have the potential to offer a wider array of preventative and environmental health services.  
 938

939 **Implementation:**

- 940 a. Create and integrate standardized environmental health assessment tools and recommended  
 941 interventions into the scope of work for public health clinics and federally-funded community  
 942 health centers (federally qualified health centers, Head Start-related health services, Indian  
 943 Health Services, and other health programs). Ensure that both assessment and intervention  
 944 involve providers who are properly trained and qualified to interpret and manage the findings  
 945 on these assessment tools.  
 946 b. Work with other divisions within HHS to develop a mechanism for reimbursement via health  
 947 insurance schemes (public and private) in a way that does not discriminate against the  
 948 communities being served. Create a "billing code" for environmental health services that are  
 949 provided in primary care settings.  
 950 c. Establish and incorporate environmental health assessments/interventions into the model/best  
 951 practices for clinical care, i.e. National Guideline Clearinghouse. Keep this current through a  
 952 process of peer-review.  
 953 d. Work with manufacturers of electronic medical records to include environmental health  
 954 assessment components.  
 955 e. Reintroduce community health workers who are trained to assist with assessment and  
 956 intervention strategies for environmental exposures.  
 957

958 **Timeframe:** By 2011, create a mandatory environmental health assessment tool and require it as part of  
 959 electronic health records. By 2011, establish billing codes and reimbursement schemes for environmental  
 960 health assessments, risk communication, health education, and other associated interventions.  
 961

962 **Evaluation:** Integration of and reimbursement for environmental health services in primary care  
 963

964 **9. Ensure effective compliance and enforcement of industrial and federal facilities and  
 965 agricultural operations with environmental health regulations, laws and policies.**  
 966

967 **Rationale:** The regulatory agencies have been less than effective in protecting communities, especially  
 968 low-income communities of color, and even though the agencies currently have enforcement powers,  
 969 communities are still suffering health and environmental impact due to lack of enforcement and

970 compliance. Federal regulatory agencies (including the Environmental Protection Agency [EPA] and  
 971 Occupational Safety and Health Administration [OSHA], in partnership with the Agency for Toxic  
 972 Substances and Disease Registry [ATSDR] and Federal Occupational Health [FOH] at the Department of  
 973 Health and Human Services [HHS]), must ensure effective compliance of industrial, federal facilities, in  
 974 particular the Departments of Energy and Defense facilities, and agricultural operations by implementing  
 975 strong enforcement and prevention measures through actions including: 1) bans on production of harmful  
 976 industrial or pesticidal formulations; 2) revocation of discharge/emission permits; 3) prevention of new or  
 977 revocation of existing pesticide registrations; 4) assessing significant fines for non-compliance; 5)  
 978 requesting/conducting independent monitoring; 6) providing increased oversight over state enforcement  
 979 agencies (e.g., state environmental and agricultural departments); 7) improving pesticide use and toxic  
 980 emissions reporting requirements; and 8) imposing civil and criminal penalties.

981  
 982 **Implementation:** We recommend that compliance be monitored through frequent and unannounced  
 983 inspections to ensure worker and community health and safety. ATSDR should participate in inspections  
 984 of industrial, federal facilities, in particular the Departments of Energy (DOE) and Defense (DOD)  
 985 facilities and agricultural operations by entering into a memorandum of understanding (MOU) with EPA  
 986 and OSHA and exposed communities in order to identify/assess potential health hazards and exposure  
 987 pathways; prevent chemical exposures to workers and surrounding communities; and protect public  
 988 health. If ATSDR identifies health hazards, they should immediately notify the affected community and  
 989 individuals and work with EPA or OSHA to take immediate enforcement action to prevent further  
 990 exposures/hazards. Inspections must take into consideration a community's perception, and  
 991 documentation, of health hazards in their communities and should employ independent testing (e.g.  
 992 bucket brigade, drift catcher).

993  
 994 **Timeframe:** Within one year, EPA and OSHA, in collaboration with ATSDR and FOH, will develop and  
 995 implement an effective inspection program that requires frequent, unannounced inspections at industrial,  
 996 DOE and DOD facilities and agricultural operations. Within one year, EPA and OSHA will develop  
 997 MOUs with ATSDR and with exposed communities for effective participation in inspections to assess  
 998 health hazards.

999  
 1000 **Evaluation:** 1) Track through measureable decreases in releases reported through EPA's Toxics Release  
 1001 Inventory; 2) track through Workers Compensation and worker complaints; 3) track environmental  
 1002 enforcement actions relative to improvements in compliance; 4) track through measureable improvements  
 1003 based on independent testing and community-based research; and 5) track through measureable  
 1004 improvements in community health and health outcomes.

1005  
 1006 **10. Congress and States shall develop strong, consistent citizen suit provisions to empower**  
 1007 **communities.**

1008  
 1009 **Rationale:** Communities must have a satisfactory, effective, simplified, and anonymous complaint  
 1010 process and the opportunity to initiate and participate in the enforcement process. Citizen suit provisions  
 1011 specify a role for citizens and community groups as "private attorneys-general" to ensure implementation  
 1012 and enforcement of environmental laws that agencies may be unwilling or unable to accomplish.  
 1013 Although Congress added citizen suit language to twenty federal environmental regulatory statutes, these  
 1014 provisions are conceived and applied unevenly in state law and with differences among the federal  
 1015 environmental laws (Meltz, 1999). Communities and individuals must be accorded the assurance of  
 1016 strong citizen suit provisions as well as a citizen appeal process within the system of federal  
 1017 environmental and worker health law, including injunctive relief, recovery of legal costs, Supplemental  
 1018 Environmental Projects, and empowerment to sue polluters for civil and criminal fines. Federal

1019 Insecticide, Fungicide, and Rodenticide Act (FIFRA) is one of the major environmental laws that does not  
 1020 include citizen suit provisions.

1021  
 1022 **Implementation and Timeframe:** Within one year, EPA and OSHA will convene an independent panel  
 1023 of independent academic and public interest law experts to evaluate and make recommendations to  
 1024 strengthen and unify citizen suit provisions among the federal environmental and worker health protection  
 1025 laws. Within 6 months of completing the final report of this independent panel, EPA and OSHA will  
 1026 present it before relevant agency congressional offices. Within three years, EPA and OSHA will  
 1027 implement rules to strengthen citizen suit provisions within the regulatory system for protection of the  
 1028 environment, community and worker health. We recommend that within one year, EPA and OSHA will  
 1029 develop a procedure to receive and respond to anonymous citizen complaints as described above and a  
 1030 system that enables community members to initiate and participate in enforcement processes (for  
 1031 example, Supplemental Environmental Projects).

1032  
 1033 **Evaluation:** An annual survey of impacted communities should be conducted by ATSDR to document  
 1034 the successes of citizen suits and the level of improvement in compliance and enforcement of toxic  
 1035 emissions and to document any incidents of retaliatory actions toward the communities resulting from  
 1036 such suits. Survey results will be made public, such that interested communities can learn lessons from  
 1037 the experiences of other communities.

1038  
 1039 **11. Federal permitting agencies shall revise permitting and permit renewal processes to include a**  
 1040 **standardized method for consideration of existing exposures and/or underlying health status of**  
 1041 **the community when responding to a request for an environment permit and develop a**  
 1042 **meaningful mechanism by which communities can influence permitting processes on the basis**  
 1043 **of public health concerns.**  
 1044

1045 **Rationale:** The current permitting process is flawed. There is no standardized mechanism by which all  
 1046 state and federal environmental agencies take into account existing pollution sources and/or special health  
 1047 vulnerabilities of the community when the permitting process is initiated. Given the government's  
 1048 responsibility to protect human health, the existing health status of a community combined with the  
 1049 knowledge of existing environmental exposures, should inform the permitting process in its initial stages.  
 1050 Such considerations should have the potential to halt the permitting process its earliest stages. If the  
 1051 permitting process moves forward, the community should have the right to protect their health by  
 1052 influencing permitting decisions.

- 1053  
 1054 **Implementation:**
- 1055 a. The Environmental Protection Agency (EPA) Office of Environmental Justice (OEJ) in  
 1056 partnership with National Center for Environmental Health/Centers for Disease Control and  
 1057 Prevention (NCEH/CDC) will create a standard set of public health profiles of communities  
 1058 that state and federal permitting agencies must review and take into account before initiating  
 1059 a public permitting process.
  - 1060 b. EPA OEJ, in partnership with NCEH/CDC, will create a meaningful process by which  
 1061 community comments regarding public health concerns can impact the permitting process.

1062  
 1063 In addition, regulatory agencies will take the following actions through placement of conditions on  
 1064 permits that ensure accountability to the community:

- 1065 a. Require third party certification for standards of social and ethical responsibilities to workers  
 1066 and communities in order to give industry economic incentives.
- 1067 b. Require legally-binding good neighbor agreements among industry, government agencies and  
 1068 the community.

- 1069 c. Require industry to implement extended product stewardship programs to prevent hazards  
1070 associated with waste and disposal.  
1071

1072 **Timeline:** In year one, the EPA OEJ, in partnership with NCEH/CDC, will create a set of recommended  
1073 public health considerations that must be addressed at the onset of an environmental permitting process in  
1074 order to determine whether the permitting process should proceed.  
1075

1076 **Evaluation:** A set of public health impact guidelines will be adopted by state permitting agencies for  
1077 their consideration during the earliest stages of the permitting process.  
1078

1079 **12. Government agencies and the private sector/industry shall adopt green practices in partnership**  
1080 **with communities.**  
1081

1082 Part 1—Actions within Government Agencies

1083 **Rationale:** Government agencies are often at the forefront in championing new approaches and  
1084 methodologies to promote better health and environmental practices. However, these same agencies are  
1085 usually the last to actually adopt the same practices they endorse. Consequently, the federal government  
1086 sends a confusing mixed message, which decreases the government's credibility in the eyes of community  
1087 groups and others. For government agencies to lead more effectively, they will need to go beyond service,  
1088 regulation and enforcement by modeling green and inclusive practices that they encourage others to  
1089 pursue. Government agencies will need to become the model for change.  
1090

1091 **Implementation:** We recommend that government agencies begin with a focus on green practices with  
1092 community engagement. Government agencies should adopt green practices, including procurement (for  
1093 example, recycled paper, green cleaning products, recycled plastics) and other business operations (for  
1094 example, integrated pest management, green janitorial practices, using hotels that are green for  
1095 conferences, and purchasing hybrid vehicles for motor pool). We recommend that agencies document  
1096 their greening goals at the start of the year and evaluate their success at the end of the year. To provide  
1097 agencies with incentives to develop and implement such practices, the Office of Management and Budget  
1098 should require such programs within agencies including the Agency for Toxic Substances and Disease  
1099 Registry/Centers for Disease Control, the Environmental Protection Agency, National Institutes of  
1100 Health, and the Departments of Health and Human Services, Defense, Energy, and Justice.  
1101

1102 Part 2—Actions to Create Incentives for Research and Development of Safe Alternatives

1103 **Rationale:** Long-standing public policies that govern chemical design, production, and use have failed to  
1104 protect public health and the environment, especially in light of new science concerning health and  
1105 environmental effects at low-dose exposures, often related to the endocrine-disrupting effects of  
1106 anthropogenic chemicals. In addition to regulatory reform of the Toxic Substances Control Act; Federal  
1107 Insecticide, Fungicide, and Rodenticide Act; and the Occupational Health and Safety Administration that  
1108 are necessary to protect the integrity of ecosystems and human health, public policy should also enhance  
1109 research, development and innovation to support a rapid transition to systems of agriculture and industry  
1110 based on safe methods of production and use.  
1111

1112 **Implementation:** Agencies including Environmental Protection Agency, Department of Defense,  
1113 Department of Energy, Occupational Safety and Health Administration, National Institute for  
1114 Occupational Safety and Health, and U.S. Department of Agriculture, both independently and  
1115 collaboratively, incorporating public comment and recommendations, must allocate time and financial  
1116 resources to undertake immediate steps to develop and vet market-based incentive programs to engage  
1117 industry such as:

- 1118 a. Congress should promote and fund green chemistry initiatives that foster education, research,  
 1119 development, technical assistance, entrepreneurial activities, and innovation in the creation  
 1120 and production of safe, non-toxic alternative substances (Schwarzman & Wilson, 2009)  
 1121 (Wilson, 2006).  
 1122 b. EPA should permit expedited (fast-track) approval of new chemicals which are proven to be  
 1123 significantly safer than their older counterparts.  
 1124 c. USDA should support and allocate sufficient resources (in the next Farm Bill and through  
 1125 allocation of money to land grant schools for promotion of Integrated Pest Management,  
 1126 biological controls, and safer alternatives to promote to growers) for the transformation  
 1127 (including research and implementation) of agriculture to organic methods that replace the  
 1128 need for chemical fertilizers and pesticides.  
 1129

1130 **Timeframe:** These recommendations should be acted upon immediately following the release of the  
 1131 *National Conversation* report.  
 1132

1133 **Evaluation:** Part 1—Track the implementation and effectiveness of green practices programs within  
 1134 federal agencies and subsequent increases in recycling and reductions in use of hazardous  
 1135 products/materials, energy use, etc. Agencies will create annual goals for waste reduction, integrated pest  
 1136 management, recycling, and procurement of safe alternatives for cleaning and other products. Agencies  
 1137 will evaluate their programs by comparing goals with achievements. Agencies will make their green  
 1138 practices programs plans and evaluations open for public review, scrutiny, and comment.

1139 Part 2—Track increases in funding for research and development of innovations in green chemistry and  
 1140 product development. Track development and approval of safe alternatives to replace hazardous  
 1141 chemicals/products on the market. These innovations should also result in improvements in  
 1142 environmental public health through reductions in release and exposure of toxic substances.  
 1143  
 1144

## 1145 V. Conclusion

1146  
 1147 The Serving Communities work group recognizes everyone's right to a safe and healthy environment and  
 1148 envisions a system that promotes health and wellness among all people. However, because communities  
 1149 still suffer from harmful environmental exposures and because these exposures are borne  
 1150 disproportionately by low-income communities, indigenous communities, and communities of color, the  
 1151 Serving Communities work group has developed twelve recommendations that, if implemented, would  
 1152 help protect communities from environmental harm.  
 1153

1154 The recommendations presented in this report address several areas in which progress must be made.  
 1155 Historically, affected communities have mistrusted both government and industry due to lack of  
 1156 responsiveness to their concerns and the misinformation and unequal treatment many have received.  
 1157 Government and industry must work to build this trust. Communities must also be provided with easy  
 1158 access to information about the chemicals to which they are exposed, including the health effects of these  
 1159 chemicals. In addition, community members should be trained in how to collect community data so that it  
 1160 will be considered valid and can be used in research.  
 1161

1162 It is critical that those making decisions ensure that affected community members are engaged in the  
 1163 process and that the final decisions made reflect community input. In order to ensure that community  
 1164 members can participate in these decisions and become effective self-advocates, government agencies,  
 1165 private foundations and others should provide more monetary support and technical assistance to affected  
 1166 communities. Those who work with community members should receive training in order to facilitate  
 1167 these working relationships. Such training might include classes in cross-cultural communication,

1168 environmental justice, and conflict resolution. Finally, communities affected by harmful chemical  
1169 exposures should be provided access to quality health care by medical professionals who understand  
1170 environmental health.

1171

1172 Protection from harmful chemical exposures must include protection for those who are most vulnerable,  
1173 including low-income communities, indigenous communities, and communities of color. The Serving  
1174 Communities work group views the implementation of the recommendations in this report as an  
1175 important step towards achieving this goal.

1176

DRAFT

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