

**NATIONAL CONVERSATION ON PUBLIC HEALTH AND CHEMICAL EXPOSURES
LEADERSHIP COUNCIL**

**Meeting No. 7 Summary
Washington Plaza Hotel
10 Thomas Circle, Washington DC
December 15, 2010**

Meeting Objectives:

- Review and revise draft Action Agenda for public comment
- Plan remaining steps for completing the Action Agenda
- Share ideas for the implementation plan

Upcoming Calls and Meetings	When & Where	Suggested Agenda Items
<i>National Conversation on Public Health and Chemical Exposures Action Agenda review calls</i>	<i>February 7 and 11, time TBD; conference calls</i>	<ul style="list-style-type: none"> ○ Consider how to integrate response to public comments received into Action Agenda ○ Agree on next steps to finalize Action Agenda chapters for publishing
<i>National Conversation Leadership Council Meeting</i>	<i>March 11; Washington, DC, venue TBD</i>	<ul style="list-style-type: none"> ○ Seek consensus on the Action Agenda ○ Discuss implementation plans for Action Agenda

I. Action Items

	Who	Completed by
1. Revise the Action Agenda for public comment	Staff	Complete
2. Participate in the Web Dialogue on January 5 and 6	Leadership Council Members	Complete
3. Complete small group assignments to revise segments of Action Agenda chapters	Leadership Council Members	December 20-mid January
4. Collate public comments on the draft Action Agenda	NCEH staff / RESOLVE	December 20-mid January

	Who	Completed by
5. Revise the Action Agenda considering Leadership Council contributions and public comments received through the public comment website and Web Dialogue.	NCEH staff / RESOLVE	December 20-mid January
6. Schedule Chapter review calls for February	Staff	Mid-January

II. Agreements Reached

- Leadership Council members agreed to label the draft Action Agenda to be posted for public comment on December 20 as a “staff draft.”
- Leadership Council members agreed to publish this draft of the Action Agenda for the public comment period. Small groups of Leadership Council members accepted assignments to draft or revise segments of Action Agenda chapters during the public comment period.

III. Meeting Summary¹

Welcome, Introductions, Meeting Objectives and Agenda

Nsedu Witherspoon, Leadership Council co-chair, opened the meeting, thanking the meeting organizers and those who travelled to attend. Henry Anderson, Leadership Council co-chair, shared the objective of the meeting – to revise and prepare the draft Action Agenda for public comment. Dr. Christopher Portier, NCEH/ATSDR director, thanked the meeting attendees for their hard work and wished them a successful meeting.

Gail Bingham, the meeting facilitator, reviewed the agenda, underscoring that the meeting will focus on obtaining revisions and comments from the Leadership Council about the draft Action Agenda.

Draft Action Agenda²

Gail Bingham, gave a brief presentation (Appendix C) on the process that staff used to implement Leadership Council members’ guidance on which work group recommendations to include in the draft Action Agenda. Valuable input from other sources has yet to be integrated into the draft (e.g., summaries from the community conversations, the Web dialogues, and reports from two National Conversation partners [the National Association of City and County Health Officials and the Association of State and Territorial Health Officials]. Staff highlighted several issues for Leadership Council consideration at this meeting, including some of the key points from the other input as well as work group recommendations that were not included in the current draft.

¹ Note: Unless explicitly noted, comments are those of individuals and not necessarily the views of the Leadership Council as a whole.

² This meeting summary does not include specific editorial comments. These revisions have been captured by staff and will be reflected in the final Action Agenda.

Ms. Bingham guided the Leadership Council through a review and discussion of each section of the draft Action Agenda. She reminded the group that the chapters are organized by overarching theme, with two to three featured recommendations followed by additional recommendations. During the review, Ms. Bingham suggested Leadership Council members consider the following questions:

- Are the appropriate recommendations featured?
- How can they be strengthened?
- Do some recommendations raise concerns, and how can those concerns be addressed?
- What should be included from other inputs?
- Does the Action Agenda have the desired impact?

During the discussion, Leadership Council members volunteered to assist in the revision process. Given the timing of the release of the draft for public comment, the draft Action Agenda to be posted will include those changes made at this meeting. Leadership Council members will work during the public comment process to draft additional language, as needed. Leadership Council members agreed to label the draft Action Agenda as a “staff draft” for the purposes of the public comment period.

General Feedback

During the discussion about the Action Agenda introduction, members proposed adding a statement of purpose, executive summary, or preface. This section would provide an overview of the Action Agenda, a brief summary of the process, and a description of and links to the work group reports. Leadership Council members discussed the following overarching themes that could be included in an executive summary or introduction to the Action Agenda:

- Community right-to-know.
- Need for improved toxicology data.
- Limitations of existing tools used to assess risk.

The Action Agenda could also include an appendix with more detail about the process conducted throughout the *National Conversation*.

Several Leadership Council members felt that short sentences with active verbs would help readers of the Action Agenda. Each chapter also should have an introduction in a standard format, identifying the issue or problem, the challenges in overcoming that issue, and proposed actions or new directions.

Introduction

Leadership Council members shared that the introduction should acknowledge the *National Conversation* as one of many activities that aim to understand and remedy problems regarding public health and chemical exposures. Tone is important: striking a balance between being bold, calling for important change, and supporting improvements already underway.

One member suggested that the footnote discussing funding from NCEH/ATSDR should expand on the purpose of NCEH/ATSDR involvement; specifically, that the *National Conversation* is part of an effort to revisit and explore potential changes in the U.S. chemicals management system to be undertaken by NCEH/ATSDR as well as others federal and nonfederal organizations.

Chapter 1 - Improving Public Health through Prevention

The draft Action Agenda references several definitions for the precautionary principle in footnote 2. Leadership Council members agreed to reference only the Wingspread definition.³ Members also agreed that while the recommendations have value on the international level, the Action Agenda should highlight U.S. chemicals policy.

Leadership Council members discussed views about the roles of different actors in implementing regulations, developing new regulations, and participating in the legislative process. Some were concerned that a recommendation calling for collaboration between federal agencies and the private sector needs to clearly distinguish between settings and respect federal agencies' enforcement role, where appropriate. Members also discussed the appropriate balance for communication and collaboration in the legislative process, concluding that the Action Agenda should emphasize recommended actions and results, rather than prescribing means of achieving them.

Recommendation 1.2⁴ calls for reform of the Toxic Substances Control Act (TSCA) to facilitate prompt action to eliminate or reduce harmful exposures to toxic chemicals. The Leadership Council decided to add that when undertaking TSCA reform, Congress should consider a model that affords states the opportunity continue innovating solutions to chemical issues while recognizing the benefits of consistent national regulatory requirements. The Council further determined that Recommendation 1.2 should be the primary recommendation in Chapter 1, because it provides a foundation for subsequent recommendations on safer chemicals and technology. Members agreed to add a highlighted text box to this chapter that lists the twelve principles of green chemistry. A member suggested that the recommendations include a call to strengthen the scientific criteria for identifying safer alternatives. To reduce the complexity of Recommendation 1.2, members agreed to break the recommendation into three parts.

Chapter 2 - Enhanced Knowledge about Chemical Exposures and Health Outcomes

Members felt the title for this chapter should reflect more accurately the broad charge to the Monitoring Work Group. The group discussed the need for increased access to medical information aggregated at the local, regional, and national levels in order to develop the health-tracking capacity needed to understand the actual health experience of communities. Recognizing that clinicians may lack the training or capacity to analyze and apply environmental health data once it is available, Leadership Council members agreed that health care provider education should include a component that trains providers to utilize environmental health tracking data. The Leadership Council agreed to add language such as "appropriate consideration of privacy" to ensure that important idea is retained.

One member shared that IT systems exist to support the electronic record tracking initiatives currently underway. These systems can be very expensive, however, and the inability to access information designated as confidential business information remains an obstacle to comprehensive environmental health tracking.

³ "When an activity raises threats of harm to human health or the environment, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically" (Wingspread Conference on the Precautionary Principle, 1998).

⁴Recommendation 1.2: Establish new and complementary roles for both government and industry to integrate a prevention focus into chemical regulation and private sector practices to ensure the phase-out of hazardous chemicals and processes where viable, safer alternative technologies and approaches exist or could be developed.

Chapter 3 - Achieve a More Complete Scientific Understanding of Chemicals and Their Health Effects

Leadership Council members expressed concern that this chapter's recommendations could take a long time to implement. Clear, short term actions are important to reach long term goals. Members agreed to add language clarifying that this is a long-term effort that requires focused energy in the short term. The recommendations included in this chapter lend themselves to Leadership Council support for international coordination to accelerate the development of necessary technologies.

In the discussion of this chapter, members made the following points:

- The challenges identified in the NAS report, *Science and Decisions*, are important. However, language prescribing specific technologies in Recommendation 3.1⁵ is too limiting. Accordingly, staff will revise this recommendation to include "other novel approaches."
- The recommendations to fill data gaps and to improve exposure assessment are priorities.
- Recommendation 3.4 (data bases) should be linked to Recommendation 5.3 (portals).
- The Action Agenda should take into account the reality of chemical exposures that are mixtures.
- Improved understanding of chemical sensitivities is within the realm of science and current understanding.

Following suggested revisions to other recommendations in this section, the Leadership Council agreed that Recommendation 3.7⁶ is no longer necessary.

Chapter 4 - Promote Health and Wellness in Communities Affected by Environmental Exposures

Recommendation 4.1

Although the original intent of the Policies and Practices work group for Recommendation 4.1⁷ was to focus on environmental justice, the current text, which focuses on chemicals policy reform obscures that goal. Leadership Council members agreed to redraft this recommendation to clarify the focus on environmental justice and provide supporting policy elements. Members also agreed the revised recommendation should still include language concerning exposure to legacy chemicals.

Recommendation 4.2

Recommendation 4.2⁸ comes from the Serving Communities work group. Leadership Council members proposed that staff separate this recommendation into two parts, one advocating

⁵ Recommendation 3.1: Federal agencies should identify and evaluate hazards of chemicals and their potential alternatives more quickly through encouraging further development and use of modern molecular biology techniques and computational systems biology. When possible, groups of chemicals, instead of individual chemicals, should be considered in the evaluation.

⁶ Recommendation 3.7: Federal agencies should lead an effort to evaluate the translational relevance of in vitro screening technologies utilized in toxicity testing to the impact on human health.

⁷ Recommendation 4.1: EPA and ATSDR, in cooperation with other relevant federal, tribal, state, and local agencies, should develop and implement strong chemical policy reform within the context of current laws that will protect communities disproportionately affected by chemical exposures.

⁸ Recommendation 4.2: HHS should establish an independent body consisting of scientists, doctors and community and environmental health leaders to 1) review the limitations and effectiveness of ATSDR's scientific methods of

improvements to public health assessment methods and other scientific issues, and another recommending an independent review body for ATSDR's mission and mandate. The second part should also include recommendations for funding and mechanisms to support the independent body. Wording should have a more positive tone. One Leadership Council member proposed adding Policies and Practice work group Recommendation #10⁹ to Recommendation 4.2.

Chapter 5 - Strengthen the Public's Ability to Participate Effectively in Environmental Health Decision-making

The Leadership Council decided that Recommendation 5.6¹⁰, which advocates for a multi-directional communication model, should be listed as a featured recommendation in this chapter. They also decided to add a component related to education and training of professionals at the college and graduate school levels to Recommendation 5.2¹¹, which currently focuses on K-16 education. In addition, the Council discussed the appropriate placement of some of the recommendations, reorganizing the chapter and moving some recommendations to other chapters.

Chapter 6 - Strengthen the Capacity of the Public Health and Health Provider Work Force to Address the Needs of People Exposed to Harmful Chemicals

Leadership Council members agreed to revise Recommendation 6.1¹² to include both emergencies and releases and move the recommendation to chapter 7. Members also discussed revisions to the introduction to Chapter 6, including moving some additional content to Chapter 7 for consistency with the relocation of Recommendation 6.1.

Chapter 7 - Reduce Harm from Chemical Emergencies through Prevention, Planning and Coordination

When discussing Recommendation 7.4¹³, Leadership Council members agreed that the proposed Office of the Chemical Emergencies Coordinator needs funding and support;

investigating the public health impacts of community-wide exposures to toxic substances and 2) recommend revisions in their procedures for conducting Public Health Assessments, disease cluster investigations, epidemiological studies and exposure investigations with the goal of instilling in the agency a broader public health focus that will allow it to more effectively investigate and address community toxic hazard exposures. Once the review is completed, Congress should amend the agency's mandate accordingly and ATSDR should implement the independent body's recommendations.

⁹ PP #10: Direct resources available at ATSDR/CDC to help identify best practices, provide training and/or increased consultation for local public health improvement, broaden the scope of monitoring environmental contamination and establish a threshold that triggers appropriate public health protective actions

¹⁰ Recommendation 5.6: EPA, CDC/ATSDR/NCEH, NIEHS, and OSHA should convene a multi-stakeholder group to identify and elaborate the essential elements of an effective multidirectional communication model for government agencies involved in chemicals and public health and develop guidelines and processes to effectively integrate this model into agencies' standard operating procedures

¹¹ Recommendation 5.2: The Department of Education, CDC/ATSDR, NIEHS, EPA, academic institutions, and localities should convene a multi-state collaboration to develop 21st century environmental and occupational health education for K-16+.

¹² Recommendation 6.1: ATSDR, in collaboration with the Health Resources and Services Administration (HRSA), the HHS Office of the Assistant Secretary for Preparedness and Response, and other federal government agencies, should develop an ongoing national program to assess and improve the health care response to hazardous chemical releases, and to develop an evidence base for chemical emergency planning

¹³ Recommendation 7.4: The federal government should establish an office or program whose goal would be to serve as a coordinating unit, unifying and integrating the efforts of federal, state, local, and tribal government agencies with responsibilities related to preventing, preparing for, responding to, recovering from, and mitigating

furthermore, the recommendation should not be prescriptive about where the office might be housed.

Public Comment

Mary Lamielle

Mary Lamielle, executive director of the National Center for Environmental Health Strategies, read a prepared statement, which is attached to this summary as Appendix B.

After reading her statement, Ms. Lamielle emphasized that the Leadership Council should include people with chemical sensitivities in its definition of vulnerable populations. She also suggested that the Action Agenda refer to marginalized and burdened “populations” instead of “communities” to account for varying frames of reference. Ms. Lamielle stated that the Action Agenda should promote the use of the Quick Environmental Exposure and Sensitivity Inventory (QEESI) tool and Environmental Medical Units.

Angel White

Angel White expressed the view that the *National Conversation's* Action Agenda should address the need for research on the impact of chemical exposures on aging populations. She mentioned the importance of developing guidelines for chemical emergency response that take the needs of children, seniors, and low-income groups into account. She also shared her concern that agencies be accountable for implementation. Ms. White stated that companies should include potentially harmful chemical mixture information in their product labeling protocol.

Implementation

The Leadership Council discussed implementation of the Action Agenda, including potential audience(s) and continued outreach and promotion. The Leadership Council could deliver the Action Agenda to federal advisory groups, agency heads, professional associations, and elected officials. Another approach is to share the Action Agenda with participating agencies and have each agency select a recommendation to pursue. Leadership Council members identified a need for a mechanism to track the outreach strategy and implementation. Members discussed developing a professional marketing and information plan that would include an initial press conference, blogging and media coordination, a Web site, professionally-reviewed articles, and speaking engagements. One Leadership Council member suggested hiring a technical journalist to review the Action Agenda so that it is consistent and compelling to the public. Staff will check to see if the Action Agenda can be hosted on the CDC.gov Web site. Staff will to share the Leadership Council's ideas for implementing the Action Agenda and with Dr. Christopher Portier, director of NCEH/ATSDR, and seek his advice and suggestions. The Leadership Council agreed that staff should prepare two potential marketing and outreach approaches with corresponding budgets - an ideal one and a more basic one - for potential funders to consider. Staff will also poll Leadership Council members to identify their outreach interests and develop a matrix of connections and opportunities.

Leadership Council members requested the creation of a standard, polished presentation that can be distributed and used by individual Leadership Council members to share information on the Action Agenda. This presentation could highlight a few recommendations or focus on the larger transformative ideas of the Action Agenda. Leadership Council members agreed to continue to think about how the Leadership Council markets, discusses, and implements the Action Agenda.

chemical emergencies, and serving as a central coordinating program charged with creating consistency and avoiding redundancy of information on chemical emergencies on the national, state, local, and tribal levels

Process for Revising the Action Agenda & Next Steps

Gail Bingham, the meeting facilitator, discussed the next steps that Leadership Council members and staff will take to move forward with revising the Action Agenda. Based on feedback from this meeting, staff will revise the Action Agenda and release the next draft for public comment on the RESOLVE Web site. Small groups of Leadership Council members will continue to revise or draft language for sections of the Action Agenda as *National Conversation* staff intakes and collates comments from the public comment and the January 5-6 Web Dialogue. Following the public comment period, staff will revise the Action Agenda and track the changes for discussion on chapter review calls in early February.

Appendix A: Participation

* Denotes participation via conference call

Members Present:

- George Alexeeff, California Environmental Protection Agency*
- Henry "Andy" Anderson, Wisconsin Division of Public Health
- John Balbus, National Institute of Environmental Health Sciences
- Ken Cook, Environmental Working Group
- Lisa Conti, Florida Department of Health*
- Henry Falk, National Center for Environmental Health/Agency for Toxic Substances and Disease Registry, U.S. Centers for Disease Control and Prevention
- Lois Gibbs, Center for Health, Environment, and Justice
- Daniel Goldstein, Monsanto
- Robert Peoples, American Chemical Society, Green Chemistry Institute
- Kathleen Rest, Union of Concerned Scientists
- Robert Rickard, DuPont
- Jennifer Sass, Natural Resources Defense Council
- Gail Shibley, Oregon Department of Human Services
- Martha Stanbury, Michigan Department of Community Health*
- Andrea Kidd Taylor, School of Community Health and Policy, Morgan State University*
- Nsedu Witherspoon, Children's Environmental Health Network (Co-chair)

Regrets:

- Tina Bahadori, American Chemistry Council
- Scott Becker, Association of Public Health Laboratories
- Stacy Bohlen, National Indian Health Board
- John Bresland, U.S. Chemical Safety and Hazard Investigation Board
- MaryAnn Danello, Consumer Product Safety Commission
- Jesse Goodman, Food and Drug Administration
- Rick Hackman, Procter & Gamble
- Richard Jackson, School of Public Health, University of California Los Angeles
- Paul Jarris, Association of State and Territorial Health Officials
- Jim Jones, U.S. Environmental Protection Agency
- Elise Miller, Collaborative on Health and the Environment
- Franklin Mirer, Hunter College, City University of New York
- Robert Pestronk, National Association of County and City Health Officials
- John Peterson Myers, Environmental Health Sciences
- Susan Polan, American Public Health Association
- Roger Rivera, National Hispanic Environmental Council
- Alan Roberson, American Water Works Association
- Peggy Shepard, WE ACT for Environmental Justice
- Rosemary Sokas, U.S. Occupational Safety and Health Administration
- Kevin Teichman, U.S. Environmental Protection Agency
- David Wegman, University of Massachusetts Lowell

Facilitation & Staff Team Members Present:

- Gail Bingham, RESOLVE
- Adam Brush, NCEH/ATSDR

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- Julie Fishman, NCEH/ATSDR
- Ben Gerhardstein, NCEH/ATSDR*
- Jason Gershowitz, RESOLVE
- Dana Goodson, RESOLVE
- Brian Mattes, RESOLVE

Others Present:

- Alan Bookman, New Jersey Department of Environmental Protection*
- Tony Flood*
- Mary Lamielle, National Center for Environmental Health Strategies
- Megan Latshaw, Association of Public Health Laboratories
- Jennifer Li, Association of County and City Health Officials
- Leslie Patton*
- Christopher Portier, NCEH/ATSDR
- Amanda Raziano, American Public Health Association
- Mary Rubino*
- Angel White
- Kerry Williams, Association of State and Territorial Health Officials

Appendix B: Public Comment

National Center for Environmental Health Strategies, Inc.
1100 Rural Avenue
Voorhees, New Jersey 08043
(856)429-5358; (856)816-8820
marylamielle@ncehs.org

December 15, 2010

Public Comment

National Conversation on Public Health and Chemical Exposures

Good Afternoon Dr. Anderson, Ms. Witherspoon, and Members of the Leadership Council:

My name is Mary Lamielle. I'm executive director of the National Center for Environmental Health Strategies. NCEHS is dedicated to protecting the public health and improving the lives of people sick or disabled by chemical and environmental exposures.

I'm pleased to be able to attend today's meeting. I had hoped to attend the October 5 meeting of the Leadership Council. Unfortunately I discovered several days before the meeting that the Omni Shoreham was not accessible for me due to the routine use of pesticides in the guest rooms and throughout the hotel.

I'm a member of the Education and Communication Work Group. I've been involved more peripherally with a task group of the Scientific Understanding Work Group.

I posted comments on the Scientific Understanding and Policies and Practices Work Group Reports during the most recent web comment period though I have not yet been able to determine if the recommendations were incorporated into the respective reports. I sponsored a Community Conversation whose participants included professionals disabled by chemical sensitivities/intolerances. I would add that participants were disappointed to see that their comments were not reflected in the summary that was provided to the Leadership Council.

I've been fortunate to be part of the National Conversation but its been a very difficult assignment. This is primarily due to the failure of the federal government, particularly research agencies, to address chemical sensitivities over the last several decades. The lack of awareness and understanding about these disabilities among the general population, professionals, and federal agency personnel, and the limited number of participants in the National Conversation who were knowledgeable about these issues made it difficult to discuss this serious public health problem to ensure that specific recommendations addressing chemical sensitivities would be incorporated into the work group reports.

Furthermore, for individual participants or those who would like to attend meetings of the Leadership Council, access to public meeting spaces can be very difficult or impossible. CDC and other federal agencies need to make an effort to make public meetings accessible for people with chemical and electrical sensitivities. I thank CDC personnel for efforts to ensure that today's meeting would be more accessible. I strongly encourage CDC and other federal agencies to adopt policies which would ensure that all meetings are accessible for those disabled by indoor pollutants. I would refer you to our organization's accessible meeting

guidance and to the U. S. Access Board's "Indoor Environmental Quality Report" (www.access-board.gov/research/ieq) which focuses on making public and commercial buildings healthier for all and more accessible for people with chemical and electrical sensitivities.

When my colleagues and I first heard about the National Conversation, many of us thought that we were the "poster child" for a "conversation" on public health and chemical exposures. Many of those same individuals were soon disillusioned when we observed the nature and direction of the "conversation."

Up to 6% of the American population is disabled by chemical sensitivities/intolerances with nearly one-third of Americans reporting reactions to everyday exposures.

People with chemical sensitivities suffer daily from the lack of information, education, policies, programs, and research. We suffer from the lack of access to healthcare and medical services and the lack of knowledgeable physicians and public health professionals; we suffer from lack of access to employment, educational opportunities, public accommodations, and public services.

It is critical that the action agenda address chemical sensitivities by recommending an educational component for patients, the public, physicians, and public health professionals.

It is critical that the action agenda include recommendations for regulatory policies and programs that would improve indoor environmental quality. One easy though significant way to begin to address problems with indoor contaminants would be to recommend promulgation of the CDC Fragrance Free policy across federal agencies. A federal workplace fragrance free policy would serve as a model for the business and educational communities where so many people are unable to be employed or attend school due to severe reactions to fragrances and fragranced products.

I also recommend the creation of an Interagency Committee on Chemical Sensitivities to catalyze research and coordinate a federal response to these disabilities. The Education and Communication Work Group Report, p. 62 details the failed effort on the part of ATSDR to create an interagency committee on chemical sensitivities with the issuance of the *predecisional draft* "A Work on Multiple Chemical Sensitivity (MCS)." The report was factually and historically inaccurate and received over 400 public comments, the majority of which challenged the validity, bias, and usefulness of the report. The publication was never finalized; however, it is posted on several government websites, notably NIEHS and OSHA, thereby giving it a legitimacy it does not have. We again call for its removal from all agency websites.

The Leadership Council should recommend the creation of an Interagency Committee on Chemical Sensitivities comprised of agency representatives from research, policy, and disability agencies, together with physicians, indoor air experts, patient advocates, and others to review what has been done to address this issue, identify the policy and research gaps, and develop a plan of action to address these public health problems in a timely and professional manner that involves impacted populations and responds to their needs.

While there have been a number of significant federal policies that address chemical sensitivities, the response has been piecemeal; the research agencies have failed to step up to the plate to support the work necessary to address these disabilities. People with chemical sensitivities have been forced to live devastating lives at enormous expense, with significant loss of health and productivity.

In addition to the need for substantial informational and educational efforts and the creation of an Interagency Committee, I give my enthusiastic support for Scientific Understanding Work Group Recommendations 7, 6, and 4 and strongly recommend that the details of these recommendations be included in the action agenda put forth by the Leadership Council.

I support **Recommendation 7 *Improve understanding of individual susceptibility to chemical exposures***. These comprehensive research recommendations to improve understanding of individual susceptibility and chemical intolerance through improved data collection and research are essential to advance the science necessary to address the health and disability needs of these individuals and prevent future illness and disability. The Quick Environmental Exposure and Sensitivity Inventory (QEESI) and the Environmental Medical Unit (EMU) are important research and diagnostic tools. They will also play a role in identifying chronic medical conditions in children such as autism, ADHD, and asthma.

Last week I attended an NIEHS Public Interest Partners meeting. An NIEHS epidemiologist researching the impact of the Gulf Oil Spill on health-affected individuals noted that she was seeing numbers of people sick with multiple symptoms some of which looked like chronic fatigue syndrome or fibromyalgia. I would offer that researchers and others unfamiliar with chemical sensitivities who don't understand how chemical sensitivities presents itself will not find it.

Once ill people with chemical sensitivities react to more and more substances and products at lower and lower exposure levels. When chronically exposed, it is difficult to tease out the exposure-response patterns. The Environmental Medical Unit (EMU) as proposed in Recommendation 7 will allow researchers to examine patients in a deadadapted state to see the exposure-response phenomenon and to conduct research on affected individuals to look for the causes of this debilitating condition, how to prevent illness and disability, and the ways in which physicians can address the health needs of those already sick or disabled.

I also support **Recommendation 6 on gene-environment interactions** and **Recommendation 4 on the adverse health effects from indoor air pollution**. Indoor environmental quality is one area that has been examined in the context of chemical sensitivities/intolerances. The U. S. Access Board contracted with the National Institute of Building Sciences in a multidirectional project and issued the "Indoor Environmental Quality Project Report" (www.access-board.gov/research/ieg). Recommendations in this report are important considerations for work on indoor environmental quality.

I previously noted that I thought that the concepts in the Policies and Practices Work Group Report were impressive, but I was disappointed to find too few specifics. I have a similar concern with the Education and Communication Work Group Report.

With regard to Policies and Practices **RECOMMENDATION #5** and the discussion of product labeling, pesticides and fragrances are two exposure categories that need research to identify chemicals in the mixtures and product labeling to protect the public health.

I recommend that the Leadership Council include an action agenda item that promulgates the CDC Fragrance-Free Policy, pages 9-10 in the agency's Indoor Environmental Quality Policy, June 2009, across federal agencies.

Final Document

I recommend that the list of vulnerable or at risk populations referenced in the various reports include “children, the elderly, pregnant women, those with chronic illness, and people already sick or injured by chemical exposures including those with chemical sensitivities.”

I was pleased to see that the Policies and Practices Work Group didn’t use the word “green” but words such as “safe”, “safer alternatives”, etc. I think that the word “green” should be removed from other work group reports in favor of descriptors that capture the specific meaning-- most notably in the Serving Communities Work Group Report.

Many months ago members of the Education Work Group were asked to describe themselves in 6 words. My response: “the voice of long neglected populations.” I hope that the Leadership Council’s Action Agenda will ensure that we are no longer “neglected” by including specific research recommendations, notably 7, 6 and 4, by recommending specific policy initiatives including the CDC Fragrance-Free Policy, by recommending the creation of an Interagency Committee on Chemical Sensitivities, and by including educational initiatives for the public, patients, and the medical and public health communities.

I’d be pleased to answer any questions you may have. You can also contact me by phone at (856)816-8820 or by e-mail at marylamielle@ncehs.org.

Thank you,

Mary Lamielle, Executive Director
National Center for Environmental Health Strategies, Inc.

Appendix C:
Gail Bingham's Presentation



Questions

- **What perspectives should be considered other inputs into the National Conversation?**
- **Which recommendations could be integrated?**
- **Overall, does this have the impact you want this effort to have?**



***National Conversation on
Public Health and Chemical Exposures***

Action Agenda Overview

Leadership Council Meeting

December 15, 2010

Gail Bingham
RESOLVE

www.atsdr.cdc.gov/nationalconversation



Sources Used

- **Annotated Table of Contents** discussed at last meeting
- **October 5 Leadership Council meeting notes**
- **Leadership Council survey monkey input**
- **Work group reports**
- **November 30 chapter review calls**
- ***Today: integrate other inputs***



Concepts

- **Each proposed chapter is intended to focus on a desired outcome or result**
 - *Discussion:* are any important outcomes missing?
What improvements would you suggest in wording?
- **Proposed chapter structure**
 - Desired outcome
 - 1-3 priority recommendations
 - Additional important recommendations



Chapters/Themes

- 1. Improving public health through prevention**
- 2. Enhanced knowledge of chemical exposures and health outcomes**
- 3. Achieve more complete scientific understanding of chemicals & health effects**
- 4. Promote health and wellness in communities affected by environmental exposures**



Chapters/Themes

5. **Strengthen the public’s ability to participate effectively in environmental health decision making**
6. **Strengthen the capacity of the public health and health provider work force to address the needs of people exposed to harmful chemicals**
7. **Reduce harm from chemical emergencies through prevention, planning & coordination**



Proposed Criteria

- **Specific and actionable**
- **Can be completed in three years or less OR
Is a significant measurable step toward
long-term change**
- **Maximizes public health impact**
- **Reduces disparities in public health
outcomes by promoting equity, justice, and
the protection of vulnerable populations**



Questions

- **Are the featured recommendations the most effective choices for achieving the desired outcome of each chapter, or are there other recommendations that should be featured instead? In what ways can each be strengthened?**
- **What recommendations raise concerns or need more discussion? (*see comment fields in each chapter*)**