



Report of the Expert Panel Workshop on the Psychological Responses to Hazardous Substances

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CONTENTS

Executive Summary	1
Introduction	7
Workshop Panelists	9
Background	11
Keynote Speeches	13
Dean Baker, MD	15
Delores S. Herrera	19
Panel Results	23
Panel One: Biomedical and Psychophysiological Effects	23
Panel Two: Community and Social Science Perspectives	35
Panel Three: Protecting and Promoting Psychosocial Health	45
Overarching Issues Discussed by All Three Panels	55
Next Steps	59
References	61
Appendix A: Background Documents From the Expert Panel Workshop on the Psychological Responses to Hazardous Substances	63
Appendix B: Bibliography for the Psychological Effects Program	67
Appendix C: There Is No Away!	75
Glossary	85

Executive Summary

Introduction

Although much has been written about the physical health effects of toxic substances and much research is underway today, there has not been a compilation of the social and psychological effects that exposure to toxic substances can engender. In September 1995, ATSDR co-sponsored with Emory University and the Connecticut Department of Health, an expert panel workshop on the Psychological Responses to Hazardous Substances. The purpose of this workshop was to thoroughly explore and examine all that is known about how communities and individuals respond socially and psychologically to hazardous substances and the possible effects of those responses on their health.

To present a broad view of this complex and intertwined subject, many different perspectives and viewpoints are presented. Both community members and scientists from different disciplines, including social, psychological, and neurological, were invited to interact and present their opinions. What emerged from the panels is an initial attempt to define and discuss a newly emerging public health issue—how to respond to the psychosocial distress in communities affected by exposures to hazardous substances.

The approach taken during this workshop reflects the complexity of the topic to be examined. The workshop used the holistic biopsychosocial model as its underpinning philosophy. This model, as opposed to the Cartesian dualistic model, which defines the body as separate from the mind, assumes that health is an intertwined, inseparable entity made up of biological, psychological, and social factors. Therefore, not only were physical factors (e.g., hazardous substances and their potential impact on the nervous system) and the physical effects of psychological stress under discussion, but also how psychological coping skills and social

influences operating at Superfund sites can affect the health of both individuals and communities.

The workshop consisted of three panels focusing on three sets of issues. Panel One (Biomedical and Psychophysiological Effects) examined the possible biological effects on the public's health related to the chronic stress documented to occur in communities near hazardous waste sites, as well as how to perform neurobehavioral testing to differentiate between neurotoxic effects of chemicals and psychological stress effects on the nervous system. Panel Two (Community and Social Science Perspectives) discussed how people respond psychologically to exposures to hazardous waste and the effect social and cultural factors have on community reaction to hazardous waste sites. Panel Three (Protecting and Promoting Psychosocial Health) began developing public health strategies to prevent and mitigate psychosocial distress related to exposures to hazardous substances.

Workshop Findings

The first panel had the task of examining the biological portion of the biopsychosocial responses to exposure to hazardous substances. This area involves many topics such as:

- How does the chronic stress, described in studies of communities near hazardous waste sites, affect public health, if at all? To what disease states would it render people susceptible?
- In cases where sufficient levels of community exposures to neurotoxins have occurred (e.g., spills), can organic effects from exposure be differentiated from psychological effects of the trauma of being exposed to a spill or high-dose exposure?

The neurobiology panel noted the significant lack of information available on the subjects they were given to consider. They stated that more studies are needed on how often communities near hazardous waste sites suffer chronic stress reactions. There is however much that is known about psychological stress and how it affects health. Psychological stress causes both psychological changes that can be measured by self-reports and objective tests as well as physical changes such as increased blood pressure, heart rate, and biochemical parameters (e.g., changes in stress hormones). Stress reactions have been studied in both individuals and communities near hazardous waste sites but the study of the full effect on the public's health, in terms of specific disease outcomes, is still in the very early stages.

The panel discussed ways to clinically examine an exposed individual and differentiate whether or not the results seen are from neurotoxic chemicals or stress. The importance of careful history-taking (especially to determine exposure parameters) was emphasized as well as the importance of correctly interpreting the results of neuropsychological test batteries.

The second panel, Panel Two, was composed of psychologists, social scientists, and community members, (along with all the other panels) who outlined the unique aspects of the psychological and social responses to toxic exposures and the reasons behind these responses. One of the first and most important points they emphasized was that the viewpoint of the exposed person is crucial to understanding the diverse reactions that can occur in affected communities; that community members must be accepted as experts on their own community. A second significant point made was that the majority of the responses people have to exposure to toxic substances are normal (i.e., normal people behaving normally in an abnormal situation).

There are many reasons why psychosocial responses to hazardous substances are unique.

Unlike the damage and injuries caused by a natural disaster, many toxic substances are invisible to the senses. This invisibility results in feelings of uncertainty. People cannot be sure without instrumentation if they have been exposed to a toxin and to how much they have been exposed. Also, due to the lag time between exposure and the appearance of a chronic disease related to the exposure (e.g., mesothelioma as a result of asbestos exposure), it is very difficult to relate past exposure to subsequent disease. Health outcomes therefore are uncertain and leave individuals with a loss of control. Two areas where people have the most difficulty coping are with uncertainty and loss of control.

In the face of no external cues and uncertain circumstances, each person affected by a hazardous exposure develops their own beliefs about the nature of the resultant harm. These beliefs are based on the facts available to them, pre-existing opinions, cultural factors, sensory cues, and the beliefs of leaders and others in the community. On the other hand, scientists tend to rely on objective data produced by specialized testing that is subject to statistical analysis. The results of surveys and studies are highly technical and may be difficult to explain to a lay audience that may not share the same underlying beliefs and values as the scientist. Also, technical experts may and frequently do differ in their interpretation of the data.

This lack of external validity makes a shared community consensus (i.e., a common point of view) difficult to achieve. Many sociologists have noted that communities affected by hazardous exposures tend to split into factions centered around shared viewpoints.

The generally long life cycle of a hazardous waste site and slow response for clean up can also strain a community's patience and lead to much frustration. At the beginning or incubation period, the threat exists but it is not recognized. During the discovery phase, the hazard is discovered and the community learns of its existence. At this point, unlike a natural

disaster, which hits and has a low point after which recovery can begin, the response to a hazardous waste site can take 12 to 20 years. The length of this response tends to embed communities in a cycle of discovery, warning, threat, and impact with eventual recovery taking place over a very long period of time.

One theme repeatedly mentioned by community members and social scientists was the importance of understanding how each community is affected individually by its nearby hazardous waste site. Culture can have a strong effect both on how government agencies involved in the Superfund process are perceived and on how the community responds to the contamination. For example, contamination may disrupt traditional lifestyles and ties to the land and result in much more than physical or economic damage to a community or tribe. Cultural considerations also must be taken into account in communicating and working with communities.

The third panel, Panel Three, was composed of psychologists, disaster relief specialists, and community members and looked at solutions to the problems facing communities and tribes affected by toxic substances. One cause of the demoralization found in Superfund communities is a feeling of isolation because many people have not shared the experience of what possible exposure to toxic substances is like. Another cause is the difficulty of working with and trusting a complicated, multi-agency cleanup process. Panel Three made many suggestions for solutions based on past experience with disaster relief work:

- A community needs assessment based on listening to the desires of a community is the critical first step in shaping the design of intervention and adapting an intervention to fit a community. The community's permission and input should be obtained before implementing any interventions to reduce stress in the communities.
- The 14 key concepts of disaster mental

health are crucial to guiding interventions in communities near hazardous waste sites. The key concept of disaster relief is that disaster stress is a normal response to an abnormal situation and that most people involved in a disaster require practical assistance dealing with problems engendered by the disaster. There needs to be recognition of the special problems of Superfund communities.

- There are specific strategies that have been used in relief work for natural disasters for many years that could be modified to use with communities affected by hazardous substances. These include early intervention, validation of the reality of disaster-related stress, educating people about the normality of disaster-related stress, allowing people to tell their story, and involving the community in the design of disaster relief activities.
- A primary way to prevent or lessen demoralization in these situations is to help citizens gain a true sense of control over their situation. As much as possible, residents need to be involved in the decision-making and problem-solving processes involved in the public health response to and the cleanup of their community.
- Education regarding the normality of stress related to hazardous substance exposures needs to be given to both community members and responders from the various agencies involved.

Data Gaps and Future Steps

Disagreement existed among the experts regarding the amount of data available on the range of psychosocial reactions at hazardous waste sites. Some felt the evidence was overwhelming, others felt there was a need for more precise

epidemiological studies measuring the levels of stress in communities near hazardous waste sites. Panel One outlined many data gaps, which, if filled, would clarify the public health significance of psychosocial distress following exposure to hazardous waste sites. To fill these gaps, instruments are needed to

- measure stress in communities affected by hazardous exposures;
- determine how special populations such as the elderly, children, and ethnic groups respond psychologically to hazardous exposures;
- estimate the time course of the chronic stress reaction at these sites;
- determine how health outcomes related to the stress of the exposures can be quantified;
- establish long-term studies of the physical effects of neurotoxic substances on the developing nervous system; and
- understand how aging affects the nervous system's response to neurotoxins.

Panel Two emphasized the strong need to understand how culture affects an individual's and community's psychosocial responses to hazardous substances and to the chance of exposure to toxins due to different lifestyles. This panel also stated the need to respect each community's values. The third panel identified program evaluation as an important area to develop when implementing public health intervention strategies designed to reduce stress.

At the conclusion of the workshop, ATSDR identified five future steps to address the issue of psychosocial effects in communities near hazardous waste sites:

1. Produce a proceedings of this expert panel workshop,
2. Publish articles in the scientific literature regarding the psychosocial effects found in communities exposed to hazardous substances,
3. Write a training handbook for local and state public health officials on ways to minimize stress

in Superfund communities,

4. Develop direct interventions in communities faced with exposures to hazardous substances, and
5. Develop and implement an overall public health strategy to help prevent and mitigate psychosocial distress found in Superfund communities.

This workshop was the first step in the implementation of ATSDR's Division of Health Education and Promotion's Psychological Effects Program. The Program comprises a 4-phased approach: *Phase 1*-Define current science and practice, *Phase 2*-Develop an action plan, *Phase 3*-Implement a public health action plan, *Phase 4*-Build capacity and evaluation efforts.

The Psychological Effects Program will provide communities with the basic information necessary to help them cope with the stress of environmental contamination and potential relocation because of environmental hazards. The Program will also provide training for health care providers, social workers, and others to ensure they have the information needed to help reduce adverse health effects associated with the stress from exposure or possible exposure to hazardous substances.

INTRODUCTION

On September 12 and 13, 1995, the Agency for Toxic Substances and Disease Registry (ATSDR) convened an expert panel workshop on the psychological responses to hazardous substances. Participants were asked to discuss an integrated approach to addressing the neurobiological, psychological, and social health effects found in communities near hazardous waste sites or following a chemical spill. An integrated approach to this issue was achieved by inviting experts from many different disciplines, as well as public health personnel and concerned community members, to share their viewpoints and experiences.

The workshop was organized into three panels:

Panel One— *Biomedical and Psychophysiological Effects*—discussed the potential public health consequences (both physical and psychological) of a chronic stress response, which has been documented to occur in some residents of communities located near hazardous waste sites or following a chemical spill. The panel outlined ways to approach how to define the health effects caused by chronic stress.

Panel Two— *Community and Social Science Perspectives*—discussed psychosocial effects in communities near hazardous waste sites and made suggestions regarding ways of reducing possible stress caused by these factors.

Panel Three— *Protecting and Promoting Psychosocial Health*—began developing public health strategies to prevent and mitigate distress related to

exposures to hazardous materials in communities near waste sites.

Panel candidates were identified through nomination by their peers or through a literature search for authors of publications on the neurobehavioral and psychophysiological effects of residence near hazardous waste sites. Panelists were selected to ensure representation with respect to relevant scientific disciplines and affiliations, including community members.

During the workshop, the panel members did not attempt to reach a consensus of opinion but to express a broad spectrum of viewpoints. This report summarizes the highlights of those discussions along with salient information from the background literature. This report includes the advice and recommendations of each panel as well as advice and recommendations on overarching issues presented to all three panels. The panels also identified critical data gaps and knowledge needs that must be addressed to develop effective science-based public health strategies.

The opinions and recommendations in this report should be continually reexamined and action plans updated as new data become available.

WORKSHOP PANELISTS

KEYNOTE SPEAKERS

Dean Baker, MD, MPH

Mrs. Delores S. Herrera

PANEL MEMBERS

Panel One

Biomedical and Psychophysiological Effects

Richard Letz, PhD
Chair

**Mildred
Williams-Johnson, PhD, DABT**
Rapporteur

Robert W. Amler, MD

W. Kent Anger, PhD

Rosemarie Bowler, PhD, MPH

Joan M. Cranmer, PhD

Laura Davidson, PhD

Eugene Emory, PhD

Jean Harry, PhD

Lawrence M. Schell, PhD

Panel Two

Community and Social Science Perspectives

Stephen Couch, PhD
Chair

Pamela G. Tucker, MD
Rapporteur

Gershon Bergeisen, MD, MPH

Dianne Dugas, MSW, MPH

Michael Edelstein, PhD

Mrs. Sue Komick

Mildred McClain, PhD

Mrs. Mary Minor, SFO

John S. Petterson, PhD

Heather Tosteson, PhD

Panel Three

Protecting and Promoting Psychosocial Health

Jarrett Clinton, MD, MPH
Chair

Robert F. Spengler, ScD
Rapporteur

Mrs. Cynthia Babich

John Eyles, PhD

Charles R. Figley, PhD

Brian W. Flynn, EdD

Jeffrey D. Kindler, PhD

Stephen King, MD

Vincent La Fronza, MS

Teresa Richardson, BS, RN, MSN

Randall M. White, MD

Overall Conference Rapporteur

ACKNOWLEDGMENT

Participation by community members and others in this program was and is vital to its success. We would like to extend a special thank you to Mrs. Mary and Mr. Joe Minor, SFO, Mrs. Sue Komick, Mrs. Cynthia Babich, Dr. Mildred McClain, Gail Godfrey, and Cate McKinney.

BACKGROUND

The workshop was one activity of a larger ATSDR program, the Psychological Effects Program. The purpose of this program is to examine the possible effects that psychological stress associated with exposures to hazardous substances can produce on psychological and physical health. Three situations in which the public could possibly be affected by hazardous substances are proximity to a chemical accident, residence near a hazardous waste facility, or permanent relocation from a community because of its contaminated environment. A search of the scientific literature was performed regarding the neurobiological, psychological, and social effects of possible exposures in these three settings.

Much of the earlier work on psychosocial responses to exposures to hazardous substances was field research. To do this research, social scientists recorded their observations of communities being affected by possible exposures to hazardous substances. Psychologists and sociologists who observed communities exposed to toxic contaminants, such as the toxic leachate at Love Canal, New York, and contaminated groundwater in Legler, New Jersey, reported a splintering of the community into opposing factions and possible increases in psychologic distress because of the difficulty of the experience (1–3).

Since the early field studies, research has branched in several directions. First, psychologists and psychiatrists have studied the coping mechanisms involved in how people deal with the threat of an “invisible” toxic exposure (4–6).

Second, several clinical descriptive studies on the effects of possible exposures to hazardous substances on communities’ psychology have been

performed. This line of inquiry grew out of research into the psychological effects of natural disasters. Disaster effects research, which began in the 1950s, indicates that a small portion of residents after various disasters, such as fires, hurricanes, and floods, can develop psychological complications from the stress involved in these experiences. Stress can lead to disorders such as major depression, chronic anxiety, and post-traumatic stress disorder (PTSD). The stress following a natural disaster also can lead to temporary increases in stress-related physical illnesses.

A third area of research emerged when psychologists focused on the epidemiology of psychological responses in communities affected by hazardous substances. The results of these psychiatric epidemiologic studies have been mixed. The work of Baum and Fleming (7) points to the presence of physiologic changes indicative of long-term chronic stress in a community near a hazardous waste site. Horowitz and Stefanko (8) reported high levels of demoralization but no clinical disorders in a community located near a hazardous waste site. A study in Alsen, Louisiana, (9) revealed high levels of near-clinical anxiety and depression in an African-American community located near a hazardous waste facility. One recent study (10) conducted in a California community following an evacuation because of a toxic railroad spill reported significantly higher levels of depression and anxiety syndromes in the evacuated population versus the control population. Another recent study by a group of epidemiologists in Texas (11) documented a linear relationship between the level of exposure to a spilled chemical and the amount of psychological stress present 2 years after the accident.

If higher than normal levels of psychological stress and psychological sequelae are being found in communities affected by possible exposures to hazardous substances, then this presents a public health problem. The effects of long-term stress on physical health at these sites is unknown and

requires further study.

The psychological effects workshop was convened to outline the extent of this new public health issue and to develop a strategy to address this potential public health problem.

**KEYNOTE
SPEECHES**

DEAN BAKER, MD

Dr. Baker is Director for the Center of Occupational and Environmental Health and a clinical professor at the University of California at Irvine. His major areas of research are the cardiovascular effects of occupational stress and the social and organizational factors that play a role in indoor air quality problems. He is the author of numerous articles and chapters on occupational stress. Currently, he is the head of an ATSDR-sponsored program to provide medical education, community and professional help, and education and consultation to communities living near two hazardous waste sites in Torrance, California.

Dr. Baker's speech is reprinted verbatim.

We are currently doing projects with a community out in California where these issues are very relevant. I have participated before in working with other communities around hazardous waste sites, but a major focus of my research in the past has been occupational stress. One of the approaches that I thought I would take today is to present some of the ideas that we have derived from occupational stress research that I think are focused a little bit more on the environmental characteristics that are constantly responsible for occupational stress.

It is interesting hearing Dr. Johnson's¹ comments about the emphasis on psychological factors in environmental health, and it reminds me of the struggles that we have had in the field of occupational stress: from people working on the assembly lines and the physical hazards facing toll takers in New York City, to people working in office buildings, there has been a concern among individuals and unions that discussions of psychological effects might somehow detract from the need and the emphasis on dealing with toxins and the physical hazards directly. I think that one sees over time that these are really inseparable; that you have to deal with both. So, the theme that I want to present to you is the need to present an integrated, more holistic approach where you don't separate out the toxic physical hazards and the toxic psychosocial hazards.

Today, I am going to be talking about stress as a phenomenon that includes both physical and psychological outcomes. Another theme from the literature is the chronic perception of threat (in communities

around hazardous waste sites). There is uncertainty because of invisible exposures with possible health effects. In many instances, the degree and extent of exposure is unknowable and therefore invisible. The health effects are oftentimes unmeasurable because of latency, etc. and are therefore invisible.

The literature on this topic focused on several major human disaster episodes, such as Three Mile Island (TMI), Love Canal, or more recently, the Exxon Valdez incident. Actually there have been dozens and dozens of human disasters and hazardous waste sites that have been studied.

First of all, stress is a psychobiological process that is heavily influenced by individual appraisals. The most classic definition of stress is that of McGrath: *stress* is a perceived substantial imbalance between demands and response capabilities under circumstances where failure to meet the demands has important perceived consequences. To give an example of the importance of perception: if you are hot out on the beach, there might be an imbalance between your thermal comfort and the sun, but this may be something you desire; however, if you are trying to get work done in an office building, and you have the same imbalance, and you can't control the thermostat, and you can't get your work done, the perceived consequences may be different.

The other thing about stress is that it is really a two-way street. Psychosocial factors, such as stress and threat, can cause both psychological and physiological outcomes. The focus of my research has been on hypertension and cardiovascular disease, where there

¹ Barry L. Johnson, PhD, former Assistant Administrator for the Agency for Toxic Substances and Disease Registry. Dr. Johnson presented the workshop's opening remarks.

have been documented associations between occupational stress and cardiovascular disease. There is some evidence for effects on immune and endocrine function. These are physiological effects from psychosocial factors. On the other hand, psychological effects may derive from both psychosocial factors as well as toxic chemical exposures. For example, where you have hazardous waste sites where there may be neurotoxic compounds, there may be both psychosocial contributions to psychological effects as well as a toxic contribution from various neurotoxins.

Let's compare the effects of natural disasters to exposures to hazardous substances. For example, consider the effects of a hurricane. You can see that even though hurricanes can have significant consequences, the effects are relatively transient. It is coming, it is there, it lasts, it goes away, and recovery can begin. There is a clear low point. You are hit very hard, but then you can see that it is over and now you can move on to the point of recovery. At times like these, people feel like they don't have any control over the situation, but they feel that it is a natural situation, so nobody has any control over it. In contrast, with exposure to hazardous substances, you don't know whether or not you've been exposed. You don't know whether health effects could occur. You don't know how much you've been exposed to. Oftentimes, the exposures are invisible to the senses, even in a spill. You can see a hurricane or a volcano erupting. You can see the dust. You can see the damages.

In some ways, hazardous substances exposures are much more like occupational stress exposures. The toxic hazards are the principal stressors. Oftentimes, in occupational settings, you will have multiple stressors. You will have multiple stressors in a community, but oftentimes the focus is on the toxic hazard. In both settings there are persistent stressors, and in both there is no clear low point. I think in both settings there is a loss of control. Long-term uncertainty is existent for both, and in both the exposures can be visible and invisible. Oftentimes, the consequences of occupational or environmental exposures are not clear.

So, in many ways, occupational stress and

exposure to hazardous substances are similar. Let me present a model of occupational stress and try to integrate some of those notions into environmental stress. First of all, there are the stressors that exist out in the environment, and these are the factors that cause stress. Cognitive appraisal of those factors occurs, meaning that a person looks and interprets the nature of the threat—which would be both the exposure and its possible consequences—as well as how to respond or cope with the threat. Coping or adaptation involves many modifying factors such as social support and an individual's resources. All these modifying factors lead to various responses, which can be psychological, somatic, emotional, cognitive, or behavioral (smoking or drug abuse), or social effects such as conflict.

You can see that the stressors go through cognitive appraisal to a short-term response. If the response does not solve the problem, and it goes unresolved, over time this stress can lead to long-term health outcomes. In terms of modifying factors, there are social or community factors that can help coping or pull individuals down. On an individual level, people with different coping styles may actually be able to look at the situation differently and be able to minimize exposure to the stress of the situation.

One thing the model of occupational stress doesn't answer is what makes an environment stressful? To answer this, we looked at the role of cognitive appraisal. One of the concerns about that view—although it has been richly rewarding in understanding the stress process—is that it gives the view that stress is purely a subjective phenomenon. It is all in the eyes of the beholder. It tends to ignore somewhat what goes on in the objective environment.

The other contributing line of research has been physiological stress theories. These focus on what is happening in the brain during stress. Basically, they have discovered two mechanisms of how the body responds to stress. One is the adrenal medullary response, which involves the secretion of epinephrine, norepinephrine, and the other is the adrenal cortical response, involving cortisol. The first response is the fight or flight response of an organism challenged by a threat. The second, the cortisol response, is really more of a response of defeat and withdrawal, and in

this state, you have higher levels of cortisol and behaviors such as helplessness.

Another way to look at stress is to view human behavior and the environment as a transactional process—where you say what goes on between the human and the environment is what results in stress and you look at what goes on in the environment. One offshoot of this model is demands and decision latitude, or demand-control in the workplace. There is now a whole body of literature that has studied workplace conditions. Instead of looking just inside the brain and inside the person, the environment has been examined. The essence of this model is that rather than looking at the limitations of being the individual, being able to respond, it says, “what’s a stressful environment?” A stressful environment is one that presents demands on the individual and at the same time constrains the individual’s ability to respond and therefore creates an imbalance between demand and response that leads to stress.

In looking at the literature, one area where I tried to make the transition from the occupational model to the environmental exposure setting was in interpreting the threat of long-term fear. The persistent threat from environmental exposures represents a psychological demand on the individual, and the lack of control—either because the community and the individual have relatively low control in the situation or because of uncertainty about the nature of the hazard or what to do about it—represents a constraint on responding. Therefore, in these communities, you can have a situation of persistent threat and at the same time low control over response. This could plausibly be associated with stress and high strain.

Let’s now focus on the issues of fear and threat as stressors and on lack of control interacting with fear as a combination stressor. First of all, fear is a rational response to an imagined or actual threat. This is a rational response. Fear is not a pathological response. Persistent fear may cause chronic stress situations, and this has been documented in the literature that you were given. Also, persistent repeated exposures may become increasingly frightening if the experiences are deemed unavoidable, so there is a lack of control. Both psychological and physical risks from these exposures could contribute to disease and diminished

mental health, so there is this interaction between the physical and the psychological. I think that one of the characteristics of living in a community near a hazardous waste site is that it is a very, very long-duration situation. There is loss of control. Again, there is this interaction between threat and loss of control.

Perceived control may be defined as the belief that one can influence an event, but the important thing to keep in mind is that, ultimately, perceived control depends on actual control. I think that the issues that will come later in terms of strategies and approaches are how much can we try to build up the concept of perceived control among community members and how much do we have to deal with the issue of actual control, particularly in a situation where the duration is long? How long can you get people to fool themselves? Learning that events are uncontrollable results in a whole range of motivational, cognitive, and emotional deficits that can eventually result in learned helplessness. So, individual and community control is a key factor that affects stress response.

I think that in these situations uncertainty is associated with the perception of loss of control. Uncertainty not only represents a stressor, it makes appraisal and adaptation difficult. How can you adapt if you cannot fully grasp the threat? The invisibility of these exposures leads to the uncertainty. This concept occurs in an article by Henri Vyner (12). Environmental invisibility is when the contaminant cannot be detected by human senses. There is also medical invisibility associated with environmental exposures. Latent invisibility means that many of the chronic effects of toxic exposures have a long latency period. Sometimes, this period is just a few years for reproductive problems; for neurological disease, sometimes as long as 20; and it can be up to 40 years for cancer. During that latent period of time, even if you have been exposed, and even if you will develop that disease, there is usually no way of detecting that. There are yet no signs or symptoms of that future illness, so it is medically invisible during that latent period.

It is just amazing how many aspects of the problem of environmental exposures are uncertain:

whether or not you were exposed, how much of a toxic substance you might have been exposed to, latency of any health effects. You may get undiagnosable symptoms like headaches and fatigue. Prognostically, if you do develop a disease from an exposure, what is the future?

So what are some possible solutions? One thing is the importance of community cohesion. Sometimes it is not totally possible to get rid of the hazard, but I think it's important that the community can pull together and not just deal with people as individuals. There has to be an effective dialogue between community residents and the scientific experts. There has to be a sharing of knowledge. We have to empower the community. Support of the community's development, cooperative community problem solving, coalition building, and advocacy

approaches are all things that you can do to try to empower the individuals in the community.

So ultimately, you see that one of my themes here is that while I think emotion-focused approaches are essential and important, there is still going to be persistent threat and uncertainty in these situations. People at some level have to learn to live with the environment. But at the same time, like in occupational stress, we don't want people to just continue working in the same environment and just learn to live with it, we want people to the extent possible to be able to change the environment. The problem-solving approach is just as important where you work with the communities to minimize threat, to minimize uncertainty, and to enhance individual and community control.

DELORES S. HERRERA

Delores S. Herrera is the Executive Director of the Albuquerque San Jose Community Awareness Council, Inc. (ASJAC). She was born and raised in Albuquerque, New Mexico, and has lived in her neighborhood for 24 years. She received the 1995 Governor's Award for Outstanding New Mexico Women, the 1995 Human Rights Award from the City of Albuquerque, and the Latino Peace Officer's Association 1995 Community Service Award. Ms. Herrera was featured in the project, "Women and Social Change—Education at the Grassroots: Women and the Struggle for a Safe Environment," the Kathleen Ridder Conference, Smith College, Massachusetts. She was appointed as the first Hispanic/Latino to the National Environmental Justice Advisory Council (NEJAC) by the U.S. Environmental Protection Agency (EPA) Administrator Carol Browner and is presently completing her second term. She sits on a number of boards and organizations to improve the quality of life for people, especially children, in her community and other similar neighborhoods locally, nationally, and internationally.

Ms. Herrera's speech is reprinted verbatim.

Hello, I am Delores Herrera from the community of San Jose in Albuquerque, New Mexico. It is not San Jose, California; it is New Mexico. I am very, very proud to come from New Mexico because every time I go somewhere people ask about New Mexico. They always have lots of questions. People still have not figured out what I am or who I am. I am a servant of the people, not a slave; there's a difference. My community is going to feel really proud when I tell them I was validated by Dr. Baker as being crazy. People ask everyday, I do not know how many times, "Why do you do this work? You must be crazy." So, I think I am crazy.

Many people have become so accustomed to the smell, the pollution, the lack of attention, accepting the deterioration, the lower quality of life as everyday in the "hood," the low student test scores, the crime, all of the negativism. That is the way that it has always been. Just accept it. Nobody cares about normal. How can things change? San Jose is the oldest community in the South Broadway area of the Albuquerque South Valley. It is the place I am privileged to call home.

A "Mayordomo" system began when settlers moved in around the river, organized the inhabitants, and completed a water irrigation system. The community's boundaries were re-channeled by relatives such as the grandpas giving parcels of their land to their kids because that is all they had to pass on to the future generations. All we have is our land.

We are tied to it and have always been. It is our hope that we will thrive again some day. Our homes, our land are not an investment in that we are going to buy, sell, and trade it like stock on the stock exchange or to buy a bigger house in a better neighborhood. San Jose is our neighborhood; it is our heritage, "La Tierra." Most of the people stay because they are historically and spiritually tied to the land, because their grandfathers and others before them are a part of it, and they continue the tradition. Sadly, it became a polluted mess. It is sickening. What has happened? Many people feel trapped. The land today is not worth much in dollars, but it is our home. Industry came in, raped it, and left it for dead until the government mandated cleanup, restoration. Wow, what a deal, 20 to 30 years of remediation—no guarantee?

People in our community and others around the country—of color, poor communities, lower socioeconomically depressed neighborhoods—do not vote because they do not believe in a system that does not work for them. And why should they? We could attack the scientific statistics to validate the problems because that is a part of the process, but there is a human side, the people side—El corazon de la gente: the heart of the people.

Going back to the "gente," what we are left with is the political structure of the Mayordomos, who were actually perceived as "mini-mayors." They decided who was to receive water. They relinquished

power to the individuals in communities. They had the voice and established the social and economic climate that retains a pseudo presence today. San Jose was an agricultural community, a farming community. Then the railroad came in and people became attached to wage labor. The railroad shut down major operations and left, leaving an unemployed population and a creosote deposit which is now our Superfund site II. The historical and human perspective should not be relinquished in favor of "true science." We must look at the biological and psychological effects coupled with the socioeconomic and environmental impacts. The whole enchilada, total, including the multifaceted stresses that attack our people and make them feel helpless and trapped. I always visualize those big traps in which a bear or wolf or some other animal's leg is clamped within the metal teeth. You watch the animal's terror-stricken eyes, squirming. It is a horrible, ugly scene! Those poor creatures, trapped without mercy. The people in contaminated communities are victims with no retreat...sick and dying a slow death....Think about it. How would you feel? The neighborhood didn't have to change in the negative. What a price we pay for progress.

I am an activist for people who have been left out, left behind, and without a voice. Many of the reasons people stop being part of the system may possibly be categorized as sometimes my people do not feel comfortable enough; they lack the self-confidence and self-assurance to stand up and be counted; or they are suffering from apathy. The list is probably endless. For whatever reason, it is a tragedy because their destiny is not under their control but rather someone else's. That is a real drag! We do not have grocery stores or shopping centers in our community. The infrastructure is decomposing. We have lots of crime, contamination, and sick people living in an industrial corridor. The totality of injustice sometimes is that the self-confidence needed is nonexistent to assume the challenging leadership position. This is stress unto itself. I am not a scientist; I am a community organizer. I will not dictate the stats. I do know and understand people and I work with them everyday. As I drive out of my driveway, I am in my community. I work in my community, and when I come back home, I am in my community. It is very difficult for me to be here

today, as I am always torn between here and there and San Jose.

Now poor, what's poor? Let's talk poor.... I do not know how many people have ever been poor. I am not talking about poor in spirit. I am speaking financially—moolah, dollars, sin dinero.

Empowering? No, in fact it's the complete opposite. Our youth and others in our communities are not being educated. They take all kinds of stuff—drugs—to become numb and escape from reality.

In communities that are so environmentally contaminated, we are all crazy, and everybody in this room is crazy. We have to be. Right? I am not going to leave here saying anybody in here is real rational. I think the whole world is crazy in some fashion. Don't you? Think about it: everyone in here cares about what happens to people. Yet, when we look around and see the people that are suffering, what can we do to help in the struggle? What happens to the less fortunate? What will we do? We will stay and fight, work with the system as far as it works for us, and then formulate another plan. Mother Earth and her people are in trouble. What is our recourse? Taking drugs? Young women getting pregnant? Last year, we had 25, 27 students in 3 classrooms of an alternative education program in Albuquerque, and out of 75 of the young ladies, there were 30 that were 12 and 13 years old. What happens? The moral fiber in our society is decaying and we are all to blame. The situation is frightening! Look at the social and financial burdens on all of us, the lives lost and wasted. It isn't just environmental contamination; it is degradation of the human spirit. What are we doing about it?

In my community, people are worried about how they are going to pay their gas bill or light bill, about becoming homeless, and many, many other problems. The most important issue is not about what is going on at Chevron or what the AT&SF railroad has done to poison the people, the environment, or what cancer risks are out there. They are worried about today, survival! They are worried about domestic violence, alcohol, insurmountable social concerns, their sons, their daughters, grandchildren, hearing gunshots, living in the midst of violence every night and day. There are many forms of contamination.

Yesterday, I was visiting with one of my neighbors. On Saturday night, she heard a loud noise and thought it was a gun. Sure enough, somebody had shot at her son's car. She lives in the middle of the Superfund area. It is stressful enough when she looks out her kitchen window to see the GE (i.e., General Electric) water tanks around her, and compounded with the violence, she is feeling under siege.

When we talk about negative effects we are talking about socioeconomics correlated with environmental racism—poor, no money. Turn on the television and everything is about money. I got a kick out of a show this morning. Somebody was talking about retiring, where they would go. Wow! Retiring, we are going to see that rainbow in the sky and reach the pot of gold. Retirement for some is not a reality. The trapped animal syndrome, where the heart is beating and we wait to die a slow death. We stay, we struggle, we fight.

Another story is about a woman named Esther, with whom I started teaching religious education about 18 years ago. She began experiencing a little cough. She lives right in Superfund, right by the drainage dump. Over the years, she said, "it's okay, it's okay, my little cough." I know that it is not okay. Her cough is upper respiratory and it has progressively worsened. She still says, "it's nothing." The cough is not normal, but her demeanor is another form of acceptance. We as Chicanos, Mexicanos, Latinos, as Hispanics suffer silently. It is an assumable part of our culture—the culture of people of color and what we stand for. Linking that with the fact of poverty, helplessness, and lack of self-esteem has bolstered our spirit, and we are still going strong as a people.

Whenever I go visit anybody, I am very respectful of their home and their valuable time. As a community, we ask for respect from other people; that is important. We are all products of society. We are responsible for each other. We share a common dignity; remember that. Our problems are environmental, economic, and social. When you go to a bank and you cannot get a loan because the area that you live in has environmental problems or it's located in a socioeconomically depressed area, that is unfair lending banking practices and against the

federal law. Hello? How many times do corporations/potential responsible parties break the law? Our community has suffered redlining. We pay back the loans, don't owe as much, but we are many times refused those very things that others take for granted. Does that make sense?

I visit many places and I have to laugh because sometimes people are so freaked and so stressed because they cannot visualize the next half-hour, much less tomorrow. They have lost hope. I never laugh at their misery. I laugh to keep from sobbing. Life is so precious. This work is hard, and you watch people who are suffering that do not even know that they are suffering. Many have learned to accept it. I do not. I will never accept injustice for anyone anywhere. We will mobilize and continue to share all we have to teach others, to stand up for civil and human rights. Not being in control of your own destiny, whether it is because of economics or power or whatever, is injustice. America was built on justice for all the people, not just for some, for everyone—rich, poor, male or female, young or old, or color or not.

A hand-up stabilizes; a handout controls. We want to be in control of our future, and therefore we understand that partnerships stabilize. A good example may be when the ASJAC was approached by an engineer to work with the Sandia National Labs. Condescending in his attitude, he bugged me, telling me what they could do for the "poor" people in the neighborhood. I said, "We don't need anyone coming in to our community wearing a white hat and riding a white horse to tell us what's best for us. We are the 'experts.' We will solve our own problems. If you want to help and partner, that's a different story. The problems do not belong to us alone. People drive cars, have gas and electric utilities, flush toilets, and running water. We have conveniences, right? San Jose suffers the impact of having industry in our community because they are located here, but it is not just San Jose's problem." He looked at me and said, "Well, Delores, we need to have some serious discussion." I replied, "No, first what we really need to do is come to an understanding." The understanding is that human life is not expendable. Every living creature and every living thing matters. It took a while, but he

got it. We have formed a wonderful relationship, and we help each other. I respect him to this day because the partnership is based on trust and mutual accountability.

In conclusion, I wish to state that the impacts from social, economic, and environmental racism are strongly felt in San Jose. The helplessness, the guilt, the unhealthy communities, the stuff that people feel every day and every night from every negative force flourishes. It isn't a bed of roses yet, but we are

planting seeds and have hope that we will nurture accordingly, and we will grow a strong, healthy, beautiful future for all. We all want a better quality of life for our future generations, especially for our children. We all love babies. What are we going to do about the babies? They grow up into adults. We want to raise healthy, productive members of society that sustain their families and stimulate the economy. That creates a better San Jose, better neighborhoods everywhere, a better world.

PANEL RESULTS

PANEL ONE: BIOMEDICAL AND PSYCHOPHYSIOLOGICAL EFFECTS

Composition: Neurobiological scientists (such as psychologists with expertise on the psychophysiology of chronic stress and resulting health effects), neurobehavioral toxicologists, neuropsychologists, and psychiatric or psychological epidemiologists.

Charge: To examine what is known about the potential effects of possible chronic stress on public health. Some studies provided information on possible chronic stress occurring in communities near hazardous waste sites. Focus areas for the panel included the pattern of stress—acute, chronic, or both— that may occur among community members living near hazardous waste sites; the effects of psychological stress on physiological responses to exposure; and whether neurobehavioral disorders caused by chronic low-dose exposure to neurotoxicants, which may manifest as psychological distress, are a public health phenomenon near hazardous waste sites.

Topic One

What is known about the long-term health effects of chronically increased stress among individuals living near hazardous waste sites?

Background

Research into the psychological effects of disasters began with the study of natural disasters in the 1950s. Scientists and clinicians recognized that a small number of people exposed to the stress of various natural disasters, such as fires, hurricanes, and floods, could develop psychological sequelae such as major depression, chronic anxiety, and post-traumatic stress disorder (PTSD). Current thought among disaster relief workers holds that most people will suffer no or only transient effects from the stress of a natural disaster (i.e., acute stress disorder) or, in other words, “people reacting normally to an abnormal situation” (B. Flynn, 1995, personal communication). For excellent summaries on the psychological sequelae to natural disasters, see Rubonis and Bickman (13), Dew and Bromet (14), and Green and Solomon (15).

There are important differences between technologic and natural disasters that are believed to affect the psychological and social responses to technological disasters. In addition to direct health effects, exposure to technologic disasters—acute exposure, as in chemical spills; or chronic exposure, as in residence near a leaking hazardous waste site—can cause people to experience psychological uncertainty, worry, and chronic stress. Some postulate that the chronic stress documented to occur in some communities near hazardous waste sites could possibly lead to an array of biopsychosocial effects, including physical health effects from chronic stress (possible health outcomes affected by stress include cardiovascular, gastrointestinal disorders, and skin), increases in the prevalence of certain psychological disorders, and social disruption.

Sociologists studying communities near leaking hazardous waste sites have defined this kind of situation as a “chronic technological disaster” (Kroll-Smith and Couch [16]). Unlike a natural disaster—which has a discernible low point and a recovery phase during which life begins to return to “normal”—many chronic technological disasters have no discernible starting points, no distinct low points,

may last for many years, and may leave behind people at risk for latent health effects (2). These events are not clear-cut, easily defined disasters, and the slow onset and recovery may make the adjustment more difficult (17).

The first scientific studies of the health effects of stress associated with environmental contamination occurred after the Three Mile Island (TMI) accident. Baum and colleagues (18) found indicators of psychophysiological effects from stress, including elevated levels of psychological distress, perceived threat, subclinical anxiety disorders, and depression in many of the community members they surveyed at TMI as compared with controls. The comparison revealed biological signs of chronic stress consisting of increased blood pressure (elevations were subclinical) and higher than normal levels of urinary cortisol and norepinephrine metabolites. They also found that the psychophysiological pattern of anxiety, poor concentration, and biological indicators of stress in community members affected remained subclinically elevated for 6 years and only returned to normal levels 10 years after the accident. Baum and colleagues then looked for this same chronic stress response in a community located near a leaking hazardous waste site and found similar results. Baum and Fleming (7) concluded that “distress and mental health outcomes also represent major outcomes of environmental disasters.”

The findings of Baum and colleagues are supported by observations made by a group of researchers in California who studied the towns affected by the Cantara loop railway spill (10). They studied the physical, psychological, and psychophysiological reactions of those who had been exposed to a spill of metam sodium. Psychological assessments of the residents showed increased worry, perceived decreases in social support, and biological changes indicative of chronic stress. Testing also showed greater levels of depression, anxiety, and somatic symptoms—which the researchers felt were possibly connected to chronic arousal states—in the exposed versus a control population. They postulated that “physiological and

psychosocial effects of the chemical spill trauma precede long-term physiological manifestations.”

Other recent findings also suggest that the experience of exposure to hazardous substances and the resulting psychosocial changes can result in adverse physical and psychological health effects. In 1994, epidemiologists at the University of Texas investigated the physical and psychological effects found in a community that had been exposed to a toxic cloud of hydrogen fluoride (11). These researchers first performed a study that documented both short- and long-term physical health effects in those exposed to the vapors. Then, they evaluated the psychological effects of this exposure situation and found that a linear relationship exists between the degree of gas exposure and increased psychological distress. Specific findings included increased anxiety and somatic concerns among the affected persons.

Panel Discussion

The panel members generally agreed that the background literature on long-term health effects from chronic stress associated with living near a hazardous waste site is sparse; however, the panel also referred to knowledge on effects of chronic stress gained from related studies on chemical or natural disasters and in the occupational setting.

Stress is a whole-body process with effects that can be measured using self-reports from groups or individuals as well as from other more objective measurement techniques. There are inherent difficulties in self-reporting measures because the reports may reflect concerns or actual changes related to the incident. Other methods used to evaluate the consequences of dealing with a stressor for a prolonged period include direct behavioral observations by a trained observer; psychophysiological measures of stress, such as increased blood pressure, heart rate, and changes in skin conductance; and biochemical parameters, such as measurable changes in stress hormones (cortisol) and in the catecholamine levels, such as norepinephrine and epinephrine. Though these indicators may provide some clues to the altered whole-body response to stress, interpretation of the results may be problematic (e.g., the timing of cortisol measures is crucial because the secretion of

cortisol shows a daily, biphasic variation). It is important to control for other factors such as smoking, exercise, and diet, which may elevate measurements.

The panel discussed studies conducted using the methods mentioned above. A study by Davidson and colleagues (19) found that, compared with a control group, residents near TMI showed significant stress effects over the first 5 years of follow-up. The effects noted included increased symptom reporting; difficulties with attention and concentration; and alteration in heart rate, blood pressure, levels of urinary catecholamines (epinephrine and norepinephrine), and blood cortisol levels. In other research on effects of chronic stress in communities exposed to toxic substances, residents living near a hazardous waste site showed alterations in psychological and psychophysiological stress indicators similar to those seen at TMI (20).

An important general discussion point was that the critical factors and underlying causes for sensitivity to the effects from stress are not clearly understood. Studies done at TMI and the toxic waste site, as well as other studies, conclude that effects may be largely related to event characteristics and the responses of each person to the event. These responses can range from little concern to extreme agitation. The differing reactions most likely reflect many factors, such as the characteristics of the event (e.g., did actual chemical exposures occur?); imagery associated with the episode; media coverage; and the individual's coping mechanisms, perceptions of the situation, appraisal of threat, and perceived sense of control over the circumstances.

Data Gaps and Recommendations

1. How well do commonly measured indices of stress used in the past to study natural disasters or combat-related trauma in Vietnam veterans apply to residents living near hazardous waste sites?
2. What are the age-specific effects of living near a hazardous waste site? How do children respond? How do the elderly respond? More information is

needed on how these special populations respond to this type of experience.

3. What is the time course of the physical and psychological responses to chronic stress? During periods of recorded stress at TMI, physical measures showed increased stress compared to controls; however, self-reports of stress showed no differences. Are psychophysiological baselines being shifted to future stress?
4. There is a need to quantify the effects of chronic stress on the health of these communities, especially when conditions express themselves in nonspecific outcomes (e.g., increased frequency of headaches). It is recommended that ATSDR evaluate existing instruments for their adequacy in assessing the prevalence of these nonspecific health outcomes.
5. There remains uncertainty in the interpretation of measures of stress. ATSDR should attempt to define criteria for when a change in these stress measures is considered a problem. In toxicologic terms, when are changes in stress indicators considered “adverse” or capable of causing unwanted health effects in a person and in a community?
6. Although there is some background information on what the disease outcomes are and how they are related to chronic stress, these outcomes are not fully characterized. What do the physiological and biochemical changes in these populations mean (i.e., what is their relationship with diagnosable illnesses?).

Topic Two

Are there certain neurobehavioral effects found in individuals exposed to chronic low-doses of toxins who live near hazardous waste sites that, if detected, could constitute sentinel health events at these sites? If they exist, can their early detection be used as an intervention screening tool?

Background

Before the beginning of industrial hygiene, employees in some industries were chronically exposed to very high levels of chemicals that led to toxic effects on their nervous systems, specifically in the neurobehavioral diseases of sensory, motor, and cognitive functions, as well as memory and attention. Examples of chemicals that are known neurotoxins at occupational levels of exposures are carbon disulfide, hexacarbons, mercury, lead, organophosphates, and organic solvents.

Historically, there have been far fewer episodes of neurotoxic effects found in the general community as compared with the occupational population, and most of those episodes resulted from contaminated food. During Prohibition in the United States, there was an outbreak of “Ginger Jake” paralysis, which was associated with drinking extracts of Jamaican ginger that were contaminated with tri-ortho cresyl phosphate (21). In 1968, an outbreak of Yusho (the name of the disease caused by polychlorinated biphenyls [PCBs]) occurred in

Japan after adults and children drank rice oil contaminated with high levels of PCBs. Chloracne and numbness and weakness of the extremities occurred in the adults. Children born to mothers exposed to the oil during pregnancy had abnormal pigmentation, decreased reflexes, and intelligence quotients of 70 (22).

The most well-known case of environmental contamination leading to neurotoxic effects in a community occurred in Minamata, Japan. Metallic mercury used as a catalyst by a local factory was discharged into the bay. The bacteria and microscopic aquatic life in the bay bottom converted the metallic mercury to organic mercury compounds, especially methyl mercury. The fish and shellfish in the bay picked up the high levels of methyl mercury. After a period of time, an epidemic of neurologic effects (e.g., paresthesias, ataxia, and deafness) was noticed in the fisher people who lived by the bay. These effects were traced back to the mercury in the bay. Median doses of 11 milligrams per kilogram of methyl mercury in fish resulted in these effects (22).

Neurobehavioral disorders, such as lead poisoning, have occurred in communities exposed to high doses of lead.

There is still a great deal of controversy about the potential occurrence of neurobehavioral effects with chronic, low-dose exposure to hazardous substances. The panel discussed this specific concern.

Panel Discussion

Much is known and substantial evidence has been found about the neurobehavioral effects in humans resulting from exposures to neurotoxic substances; however, much of this information comes from observations from high exposures in occupational settings. Occupational exposures to neurotoxins differ significantly from chronic low-dose exposures experienced by most community members near a hazardous waste site. Occupational exposures tend to be high-level, sometimes short-term exposures that happen to a more homogeneous population (i.e., healthy adult employees).

How does our knowledge about occupational neurobehavioral effects compare with the possible effects of chronic low-dose exposures? Existing literature (Baum and Bowler [5, 7, 10, 18, 20, 23]) points to measurable changes in memory and attention as neurobehavioral effects observed in groups living near hazardous waste sites. What is the cause of these neurobehavioral effects—chronic low level toxic exposure or effects of concern over a possible exposure?

Neuropsychological methods are used to test for neurobehavioral effects. Field batteries, such as ATSDR's Adult Environmental Neurobehavioral Test Battery (AENTB), are sufficiently sensitive to detect psychophysiological effects associated with chronic stress, such as decrements in memory and concentration. The data gathered could then be interpreted epidemiologically in light of several

potential confounders, such as clear indicators of exposure to a neurotoxin, test administration bias, subject bias, ethnic or cultural factors, education, sex, and age. The need to document exposure to neurotoxins points to the lack of selectivity in the neurobehavioral testing methods (i.e., the inability to differentiate whether changes in memory and attention are toxicant-induced effects versus stress-related effects).

Data Gaps and Recommendations

1. The components of existing field neurobehavioral testing batteries would likely capture anxiety-related responses on a group basis. Therefore, they would be useful as tools for screening groups of people, but would not be useful as clinical instruments or individual screening instruments. They also would not be useful for separating physiological from psychological effects. To gain maximum usefulness for community evaluations, there is a need for community-based norms for many tests. These screening measures would be helpful in determining the magnitude of a problem in a community, but not for determining specific intervention strategies.
2. Existing field neurobehavioral testing batteries are not capable of detecting adverse health effects resulting from chronic, low-dose exposures, which would constitute sentinel health effects. It is unlikely that differences between groups can be detected by existing field neurobehavioral testing batteries, such as AENTB. Results on specific subtests would be helpful in identifying issues for further evaluation. However, results from existing batteries would not allow attribution of observed group differences to physiological versus psychological mechanisms.

Topic Three

What is known about how to clinically differentiate between organic behavioral disorders caused by exposure to certain neurotoxicants and purely psychological responses to possible exposures? This discussion will consider methodological questions such as testing for stress and neurobehavioral effects as well as other issues.

Background

The previous discussions were based on instruments designed to screen large groups of people for neurological and behavioral problems possibly related to chronic low-dose exposure to neurotoxins. This discussion relates to the individual, clinical workup of a person concerned about possible health problems from a previous neurotoxic exposure, with consideration of methodological questions such as testing for stress and neurobehavioral effects.

Panel Discussion

Dr. Rosemarie Bowler and Dr. Eugene Emory were co-leads on this topic. Dr. Rosemarie Bowler discussed work she has done studying communities that have been exposed to acute chemical spills. A study of approximately 1,500 people who were evacuated following a spill of Catacarb was presented (23). Catacarb contains boron, potassium, metavanadate, and diethanolamine. Environmental data suggested that exposures to the spill were low; however, despite the low exposures, there were a substantial number of self-reported health effects at statistically significant levels compared with the effects reported by the control group. These effects included problems with memory, anxiety, depression, sleep disorders, headaches, chemical sensitivity, dermatological problems and rashes, visual problems, respiratory and gastrointestinal problems, and eye discharge. Dr. Bowler's clinical evaluations of the residents affected by the Catacarb showed that 60% had post-traumatic stress syndrome and 30% showed cognitive deficits involving verbal learning and memory. In another study performed with a community that had experienced a spill of metam sodium following a railroad accident, Dr. Bowler found a significant increase in salivary cortisol, a physiological indicator of elevated stress, compared with the level found in controls (10). In both of these studies, it was noted that all of the effects (self-reported versus objective) were observed within

a relatively short period following exposures. It was not possible to differentiate whether these changes resulted from chronic psychological stress or the effects of exposures to neurotoxins.

There are many considerations in diagnosing organicity (i.e., effects of neurotoxic exposures on the brain versus the psychological stress from the exposure). The issues and questions to be considered when attempting to differentiate organic effects from psychological effects are as follows:

- Is the agent a known neurotoxicant (i.e., dangerous to the human nervous system)?
- What are the exposure variables (e.g., the duration of exposure, level of exposure, and patients' prior knowledge of the effects of neurotoxicants)?
- Are the symptoms consistent with neurotoxic effects (such as micromercurialism, which results from chemical mercury poisoning, or cognitive and attentional deficits associated with moderate lead exposure)?
- Are mediating factors taken into consideration (e.g., age, prior exposures, prior illnesses, premorbid mental health, premorbid personality, social support, other central nervous system [CNS] trauma, and prior sensitization to other toxins)?
- What are the general effects observed on neuropsychological function (e.g., are there perceptual disturbances, changes in states of consciousness or awareness, or memory impairment)?
- What are the specific effects on neuropsychological functions such as verbal learning and short-term memory?
- Are the deficits observed consistent across neuropsychological domains?

- Have developmental (i.e., age-specific) issues been considered? In children, the maturation of the nervous system influences their susceptibility. Children are frequently the most sensitive population to neurotoxins, and assessing the effects of an exposure on the youngest (preverbal) children may be difficult.
- Other diagnostic considerations in differentiating neurotoxicity versus psychological effects include looking for inconsistent test performance, varied medical history, secondary gain (e.g., dependency, avoidance of activity, and financial gain), consistent history of exposure, and whether test results indicate an organic versus a psychological disorder.

When performing individual clinical tests, the following pattern of results indicate a probable organic cause rather than a psychological cause. Neuropsychological findings consistent with organic impairment are 1) impairments in cognitive flexibility, memory (especially sustained concentration and visual memory), verbal fluency, motor speed, grip strength, reaction time, and visual-spatial and visual-motor deficits; and 2) intact functions or normal scores in the area of word knowledge, simple attention, malingering scores (i.e., frequency of pretending illness or disability), and comprehension.

Data Gaps and Recommendations

1. There is a need for long-term, longitudinal studies of neurotoxic substances. These studies would examine exposure, specific effects of exposure on neuropsychological functions, developmental issues such as maturation of the

nervous system, and how factors such as premorbid personality and other CNS trauma affect responses. Also examined would be aging and susceptibility to neurotoxins.

2. There is a need for further study on the issues related to psychological effects of exposures to hazardous substances. Among the factors to be considered in these studies are actual or perceived control over the exposure situation or ability to develop a personal solution, community factors affecting responses, cultural impacts, and what actual measures of stress should be taken.
3. Multiple indicators of psychological stress should be included when evaluating communities that have experienced exposure to hazardous substances. This stress battery would involve multiple psychological indicators and physiological measures of stress, as well as biochemical indicators such as cortisol responses/catecholamine levels and immune system functions. In terms of the physiological measures that could be used to differentiate psychological from neurotoxic reactions, cortisol levels may be good indicators of cognitive coping strategies and catecholamine levels may be indicative of physical coping.
4. When interpreting results of stress batteries, it is very important to consider how factors such as perceived control over the situation and having or not having community and social support networks may affect stress responses in the communities at hazardous waste sites.

Topic 4

Given what is known regarding the psychobiology of stress, are there interactions between chronic stress and exposure to neurotoxicants that could shift the dose-response curve for neurotoxins?

Background

This section discusses how to investigate the hypothesis that biological changes caused by chronic stress could shift the dose-response curve of the body to various types of neurotoxins, thereby changing the possibility of human health effects from possible exposures. According to *Casarett and*

Doull's Toxicology (22), a dose-response relationship describes the correlation between the characteristics of exposure to a toxin and the spectrum of effects that it causes. Other factors can also influence the body's response to toxins (e.g., age, gender, general health).

Three assumptions must be met if a dose-response curve is to accurately show the relationship between exposure and effect: 1) the observed response is caused by the chemical administered; 2) the response is related to the dose; and 3) there is a way to measure, quantify, and express the toxicity.

Panel Discussion

Neurotoxicants can have a multitude of effects, including systemic effects. Neurotoxicity can include an early noticeable effect on a specific part of the nervous system and/or a delayed health effect that may manifest with aging or illness.

Three assumptions must be met if a dose-response curve is to accurately show the relationship between exposure and effect: 1) the observed response is caused by the chemical administered; 2) the response is related to the dose; and 3) there is a way to measure, quantify, and express the toxicity.

One of the panelists, Dr. Jean Harry presented on how to investigate this possible interaction experimentally. Currently, there are no human studies available to support this hypothesis.

A methodology does not exist that would allow for discrimination between stress or neurotoxicant-mediated effects in community-based studies. Any efforts would also require knowledge of the toxic chemical present and its expected biological effects. Experimental animal data exist to suggest that stress levels can modulate a toxic response; however, the question of specificity remains. Given that stress can induce or unmask a latent effect of a toxicant, there is the possibility that chronic stress could alter basal levels of neurofunctioning and shift the threshold for neurotoxicity. Indeed, one may find a shift in the dose response to a neurotoxicant; however, a specific effect of the neurotoxicant needs to be examined in greater detail than the generalized non-specific end points. Detecting such a shift would require the knowledge of toxicant-specific biological mechanisms of actions, which most often are not known.

A possible question to be investigated is what end points should be measured to determine if a shift in dose-response has occurred?

Data Gaps and Recommendations

The following data gaps will affect the ability to investigate the proposed question:

1. Neurotoxic end points may be specific to the chemical, but most often they are not.
2. We often do not know the optimal range of dose to measure the effects.
3. We may know the mechanism of action but not the health consequences of the measured biochemical response (e.g., catecholamines).

The panel had the following recommendations for investigating the effects of stress on susceptibility to neurotoxicants:

1. There needs to be an examination of shifts in general toxicity or other target organs with end points not confounded by stress. Experimental descriptive animal models need to be used to test the hypothesis about the synergistic interaction between stress and specific neurotoxic effects of chemicals. Animal models of stress, such as auto-analgesia, reactivity (startle response), learned helplessness, and yoked-control could be used.
2. Target organs other than the nervous system, such as the cardiovascular and gastrointestinal systems, must be included in the examination.
3. Common cellular pathways (i.e., mechanisms of action) need to be investigated.
4. The expected toxicant-induced responses need to be identified and a shift in that specific endpoint rather than an unrelated endpoint should be found.

Topic 5

What is known about the proportion of individuals who are most sensitive to the uncertainty of possible exposures? This question includes consideration of populations who are medically, psychologically, and physiologically sensitive.

Background

In public health practice, consideration of medically, psychologically, and physiologically sensitive populations who are unusually sensitive or susceptible is especially important. Identification of those unusually susceptible to a pathogenic influence—be it bacterial, viral, or toxic—enables specifically targeted interventions to be designed to prevent exposure or to mitigate exposure that has already occurred. People may be unusually susceptible to a chemical because of a medical condition that interferes with the body's detoxification process or excretion of a toxin. They may be culturally at risk because of traditional practices that expose them to a greater than average dose of a toxin (e.g., native tribes who live extensively on "country" food, such as fish and wild game, that may have bioaccumulated [i.e., toxins have built up in the organism]). Other people can be physiologically at risk because of a genetic variant in an enzyme needed for the detoxification of a chemical.

Panel Discussion

Dr. Lawrence Schell was the discussant for this topic. Dr. Schell stated that there is substantial scientific evidence to demonstrate that there are categories within populations that are defined in biological terms, such as the very young and the very old, that are unquestionably more susceptible to toxic effects than others. In addition, other subpopulations might show more psychological effects and other indirect effects because of their cultures.

Biological/Developmental Factors

Sensitivity to a given toxicant exposure varies with stage of human development. The fetus is the clearest example of heightened sensitivity, but aspects of sensitivity may be present in later stages of development such as the neonatal period, childhood, and adolescence. Specific "windows of injury" may exist when exposure occurs during

critical periods of growth and development. According to the theory of critical periods, there exist specific developmental periods when environmental factors can be especially disruptive, with immediate or late-developing effects. These critical periods may be related to times of rapid cell proliferation, cell migration, or other processes that are specific to the development of each organ system, as well as the interaction of these processes. Another developmental theory—set point theory—states that physiological parameters are "tuned" (i.e., operating limits and modal functioning parameters set) within the individual at specific times of development and that these "set point" times may be influenced by the environment.

Exposure itself varies with developmental stage, whether the intake is passive or active. Absorption can vary with developmental stage whether the absorption is passive dermal, respiratory, or gastrointestinal (GI). The heightened GI absorption of lead during infancy is a prime example. Another would be the heightened affinity of fetal neurons for methyl mercury in comparison with that of their mothers. Intake of toxicants also varies developmentally. Infants and children breathe more rapidly per unit body weight than adults and their higher dietary intakes related to their growth mean a greater intake of foodborne and waterborne toxicants per unit of body weight compared with adults' intakes. Furthermore, there are developmental stage-specific behaviors, such as mouthing, that increase intake of dust and contaminants. Metabolism, detoxification, and excretion vary with developmental stage as well.

Interaction of Culture and Environment

In addition to extra sensitivity because of biological factors, heightened susceptibility to exposure can occur because of cultural factors. An example of this is Native American groups that are at heightened risk because of their religious beliefs and subsistence diets that generally involve greater

contact with indigenous wildlife as well as water and soil. A specific example comes from the experience of the Mohawk Indians of Akwesasne (St. Regis Mohawk Reservation, New York) with contaminants from a Superfund hazardous waste site on the St. Lawrence River. Traditional Mohawk subsistence lifestyle includes consuming locally grown plants and local game, including fish from the St. Lawrence River, waterfowl, and wild mammals. Because of the PCB levels in locally caught fish, the St. Regis Mohawk Environmental Health Services and the New York State Department of Health suggested in the mid-to-late 1980s that people limit consumption of locally caught fish or, if of child-bearing age, to avoid consumption entirely. Locally grown foods and waterfowl are suspect as well.

Avoiding locally caught fish and other types of subsistence food constitutes a significant departure from the traditional diet and a loss of one aspect of traditional culture (24). The social importance of diet should not be underestimated. Today, diet is a common marker of ethnicity, and it is also integrated into a culture in several ways. For example, in Native American cultures, the traditional subsistence methods were carefully taught to each generation. This teaching itself was an important component of culture building in each generation; however, if eating locally obtained foods is no longer healthy, children are not taught how to obtain, prepare, serve, or consume them and a core component of the culture is affected. In addition, Native Americans are caught between two diet-related health risks. They are already at high risk because of obesity, with its attendant health risks of diabetes and cardiovascular disease. To reduce the risk of these conditions, they are advised to eat fish and vegetables—the very foods that are lost from the local diet because of contamination. One may ask, “Which poses the greater risk, consumption of contaminated food or consumption of processed foods?” Thus, the loss of the traditional diet constitutes not only a loss of the culture but can be perceived as a direct blow to one’s health.

Culturally imbedded values can strongly impact reactions to the discovery of a hazardous waste site in one’s community (25). For example, among many

Native American groups, land has a different meaning than it does in mainstream American culture. In some groups, land has religious meaning and/or is a symbol of sovereignty and cannot be sold. In contrast, in mainstream American culture, land rarely has this significance. Thus, most U.S. residents would move away from a hazardous waste site without feeling that their religion has been affected. Some lands are regarded as sacred by mainstream culture. Arlington National Cemetery is a good example, because many Americans would be dismayed if a hazardous site were discovered there. There probably are sacred lands in every culture, but, in some cultures, all of one’s homeland is sacred in some sense. Restricting access to, or use of, such lands because of contamination could be disturbing and stressful.

Culture has other, wider effects on susceptibility to toxic exposures; culture can affect symptom expression. Certain “diseases,” called culture bound syndromes, are found only among specific cultures. These syndromes include *susto* (a folk illness that is attributed to a frightening event). This illness is found among some Latinos in the United States and among people in Mexico, Central America, and South America. *Nervios* (a general state of vulnerability to stressful life experiences and to a syndrome brought on by difficult life circumstances) is common among Latinos in the U.S. and Latin America. There is a similar concept of “nerves” among Greeks in North America (*nerva*), and *pibloctoq* (an episode of extreme excitement, which lasts up to 30 minutes and is often followed by convulsive seizures and coma lasting up to 12 hours) is found among Alaskan Eskimos (26). Culture can also affect how symptoms are reported. People in some societies may be more comfortable reporting a certain type of symptom (bodily versus emotional); alternatively, certain symptoms may be emphasized. Thus, the biological effects of a hazardous waste site may be experienced and reported differently depending on the culture of the people affected by it.

Culture affects the individual’s role in day-to-day activities, thereby directly influencing behavior that could lead to exposure. People with cultures that involve more subsistence activities will have a

greater chance of contact with hazardous waste in the land or native plants and animals affected by contamination.

The psychological stress found among some people reacting to exposures to hazardous waste may be mediated by social support. Culture—as a shared system of values, rights, obligations, and expectations—defines the conditions under which support is given, the members of the social network, and the types of support available (27). Measuring social support in a multicultural situation will probably not accurately define social support in each cultural group.

A disaster is the result of an unexpected loss of apparent or perceived control of natural or manmade forces. Baum and Fleming have shown that in the United States a key psychological dimension in predicting health-related reactions to disasters is individual control (7). Furthermore, they have shown that disasters caused by human failure, including the creation of a hazardous waste site, produce greater stress and health effects than natural disasters.

In the United States, hazardous waste sites are more likely found near communities populated by minority groups, especially African-American and Hispanic groups. Minority communities may have a tradition of distrust of government authorities. A culture of distrust may prepare residents for the discovery that the government's control of hazardous waste has broken down and human exposure to toxicants is likely. Models of reaction to hazardous waste sites that are based on the assumption that the loss of control is a significant feature may require modifications when applied to communities that have a history of disempowerment and genuinely expect ill treatment by governments.

Members of subordinated cultures and minority groups that have been dominated by a mainstream culture may perceive less control of events and circumstances because of their history of powerlessness against mainstream culture. The premise that accidents caused by breakdowns in technology are different from nature-caused misfortunes is culturally limited (25). While members of mainstream American culture may perceive human failure as more

surprising, less forgivable, and less understandable than nature-based “failure,” non-mainstream members may see human systems as more prone to disaster, less trustworthy, and their failure not as surprising as compared with circumstances created by nature.

Two types of control may be considered in a multicultural context (28). Primary control refers to control exerted by changing existing circumstances. It is proactive and the form of control emphasized on most scales that measure control. Secondary control refers to control exerted by changing one's self to suit the existing circumstances. Primary control is the type most Western observers prefer, and secondary control may be viewed as noncontrol, an absence of responsibility for circumstances. Secondary control may be more typical of non-Western cultures. Among these heterogeneous groups, accommodation to the natural environment may be more common, and fewer technological means are used to make large-scale changes to the environment.

Data Gaps and Recommendations

1. Little work has been done on how various subcultures within the United States respond to exposure to hazardous substances.
2. Measurement of control mechanisms in toxicant-impacted populations will need to take into account different cultures' varying styles of coping.
3. Cultural factors affect the actual risk of exposure, the perception of risk from exposure, the perception of consequences of exposure, and the perception and expression of personal symptoms. Reactions to the breakdown of control over hazardous waste exposure depend on culturally defined expectations of control over human-made and natural forces.
4. Non-Western cultures and minority groups that have been dominated by mainstream culture and society may experience hazardous waste sites differently and more severely than people integrated into mainstream American culture. Health consequences of hazardous waste sites

may exacerbate already existing social and health problems.

5. Recommendations for working with sensitive populations:

- Create a true and equal partnership with the affected community.
- Base the project in the community. This will mean learning the community values and empowering the community to solve its problems.
- Use a holistic approach. The indirect effects of hazardous waste exposure (e.g., cultural damage, socioeconomic impacts, and psychological distress) may have more severe health effects than the chemicals.
- Use good science.

PANEL TWO: COMMUNITY AND SOCIAL SCIENCE PERSPECTIVES

Composition: Composed of community and social psychologists, sociologists, anthropologists, political scientists, and community members affected by hazardous waste sites.

Charge: To review what is known about the psychosocial responses in communities located near hazardous waste sites and to make recommendations regarding ways of interacting with communities, outline problems in need of further investigation, and suggest possible psychosocial interventions to reduce stress.

Panel members were not asked to evaluate community and psychosocial issues associated with specific sites. Instead they were asked to use their complementary backgrounds and areas of expertise to provide an overview of the following three areas: 1) the factors that might render some community members susceptible to the stress of living near a hazardous waste site, 2) the known psychosocial responses of community members living near hazardous waste sites, and 3) the psychological impact of experienced uncertainty of the consequences of toxic exposures.

Topic One

Are there factors (both internal and external) that might render some communities more or less susceptible to the stress of living near a hazardous waste site?

Background

With the discovery of toxic contamination, many affected communities will suffer social conflicts. The sources for social conflict are many. The invisibility of most toxic contaminants may make it difficult for community members to reach agreement on their effects. The uncertainty can heighten individual and family distress and may lead to disputes between neighbors, particularly when the contamination is spread unevenly throughout a community. Residents who live close to hazardous waste sites frequently have different views of their possible exposure and its health effects than residents of the same community who live farther away and do not believe themselves to be affected. For that reason, factions can develop in communities between those living inside and those living outside the affected area.

The chair of the panel, Dr. Stephen Couch, introduced this topic by comparing how communities respond to natural disasters with how they respond to technological (human-related) disasters.

Dr. Couch: (Dr. Couch's introduction is reported as transcribed from tapes of the meeting.)

I began my work on this topic in a town called Centralia, Pennsylvania, in 1981. This was a community affected by an underground mine fire. Rather than the pulling together of a community as described following a natural disaster, I observed a community breaking apart, neighbor fighting neighbor over what to do. Since then, I and my colleague Steve Kroll-Smith have studied social responses to human-made disasters. We define location near a hazardous waste site as a chronic technological disaster—chronic because it's a long-lasting experience with potentially long-lasting or future health effects and technological because it is caused by the use of human technology. As Erikson so eloquently said, here is a "new species of trouble."

I see chronic technological disasters as the consequences of how we have set up our technological society. Charles Perrow's paper on normal accidents explains the inevita-

bility of accidents occurring in complex, interdependent technical systems (29). The work of Ulrich Beck on the "risk society" is about how modern society organizes the distribution of risks (30).

With chronic technological disasters, the impact varies in different communities. At the worst, the impact can be severe, causing social conflict both within and between communities and other social entities. These conflicts are seen not only in our society but in other cultures. I traveled to Minamata, Japan, where methyl mercury contamination and resulting health sequelae occurred. There I found social conflict occurring more than 30 years after the contamination. The fact that all the community factions could sit face-to-face at a table and talk was viewed as great progress.

In chronic technological disasters, the social process exacerbates rather than ameliorates the primary stress of the exposure. There are two types of stressors: the stress of living near contamination and the stress that results from the social process that arises from contamination.

The members of the panel who are residents of communities living near hazardous waste sites asked that community members be fully accepted as experts on the problems in their community.

Panel Discussion

There are ethical issues associated with how a community effectively works through the stress from a technological rather than a natural disaster. For example, industry has suggested affecting public perceptions at a hazardous waste site by giving tours of the site and making therapy available at the site. This would be an unethical use of therapy to change people's minds in a pre-determined way.

This raises the question, should efforts be focused on helping people to cope with an unjust situation or helping them to change the situation. According to represented community members, this is the heart of the matter.

However, the community also feels that if the

consequences for the public's health could be stopped as soon as detected, the high price of having to treat continuing stress, resulting from a continuing identified hazard entering the environment, could be avoided. If the causes of stress are curtailed or stopped completely, it won't have to be treated.

This discussion includes:

- Individual and community dynamics,
- Cultural factors affecting responses,
- Community (e.g., marginalized), and
- Factors involved in a community's response (i.e., duration of exposures, socioeconomic and demographic factors, and factors unique to a community).

Consideration of Both Individual and Community Dynamics

The panel began by discussing the chronology of the Superfund process as presented by Dr. Michael Edelstein. It is important to realize that the environment of a Superfund site changes over time. At the beginning, there is the incubation phase. A hazard exists but is not recognized as such by the community. Then, there is the discovery stage. The public learns of the existence of a problem with a hazardous substance, usually by some type of announcement. After the discovery of a hazard, a long stage of environmental turbulence begins. First, there is short-term adjustment or initial coping on individual, family, social network, and institutional levels. If the initial coping fails, then a disabling and frustration of the community occurs with social turbulence. At this stage, efforts at collective coping are initiated. These efforts include mobilizing social support, seeking sources of trusted information, and utilizing community or individual power. If proactive coping works, then the community can successfully form a response to contamination. If efforts at collective coping fail, social turbulence occurs, dissension or community destruction ensues, and an environmental stigma is cast on that community.

All communities are susceptible to the stress of environmental contamination but in different ways.

The following are some prevariables that affect susceptibility: age, length of residence, location or proximity to the site, socioeconomic status, specific cultural factors, and coping vulnerabilities (e.g., state of psychological health). Intrinsic factors are preexisting health status and the physiological impacts of hazardous substances. Extrinsic factors are the social context in which the contamination occurs and the social response to that contamination. To evaluate the community, the ecohistorical context in which the contamination occurs must be understood.

Environmental contamination or chronic technologic disasters take place over time. This changes the disaster cycle known from studies of natural disasters. In a natural disaster, such as a hurricane, there are distinct stages—warning, threat, impact, and so on—to recovery and rehabilitation. In environmental contamination, communities get stuck in certain stages; there is no linear progression through them. Environmental contamination leads to cycles of the warning, threat, and impact stages.

Another difficulty of these situations is the dependence of communities on external government agencies. Few communities have the resources to cope with or respond to environmental contamination. Another important factor is the trust relations between the parties involved. The decentralized structure of dealing with a hazardous waste site means that many government agencies participate but without a clear line of command. This results in differing information from various agencies, which leads to a loss of trust and a reason for dissension in the communities.

Also, what can these communities expect in the way of final outcome and resolution of chronic technologic disasters? The solutions range from a technical fix (which many people may have difficulty believing has solved the problem) to relocation (which destroys the community because it disperses the individuals within it).

Cultural Factors Affecting Response

Dr. John Pettersen led the panel discussion on this topic. Culture plays a direct role in perception of threat and response to threat. People of certain

cultural backgrounds are more sensitive to threat and have lower thresholds for suspicions. Some of these perceptions are based on historical events (e.g., Native Americans' history with U.S. government treaties), lack of political control, and impoverishment.

Additionally, traditional communities are often more tightly knit, have kinship groups, have religious ties to the land, and find it harder to leave an area impacted by environmental contamination. Different groups of people have different vested interests in the land (i.e., development versus subsistence) and even different belief systems in relation to the land.

After an environmental disaster, such as the Exxon Valdez accident or the discovery of a leaking hazardous waste site, the response may alter existing customs within a culture. For example, in Alaska after the Exxon Valdez accident, the high-wage clean-up jobs displaced employees from traditional subsistence hunting. When you alter existing customs within a culture, structures within a community, or even regulations within a large social structure like an industry, the rebound amplifications create social tensions and disruptions. These are secondary responses to contamination. The primary stress comes from exposure to the contamination; other parts of the psychosocial stress come from the secondary social response to the contamination.

Other secondary responses are related to mitigating suspected, potential, or actual exposure to contaminants within a community. For example, if a fish consumption health advisory is issued because of environmental contaminants present in fish, the stress for some community members worried about the contamination will decrease but may increase in other groups within the community, such as commercial or subsistence fishermen. Such an intervention could reduce or eliminate the income of the commercial fishers or the low-fat dietary source of protein for subsistence fishers. Either of these outcomes could ultimately have a negative effect on the health status of the members within these groups. The health benefits of any intervention within a community should be assessed in relation to the health risks they could potentially generate.

All stakeholders should be identified and their concerns addressed before interventions are implemented to reduce the psychosocial effects and stress associated with the interventions.

It is important to remember that often health is stated as the central concern of communities affected by contamination; however, a health concern is also often the only issue that some community members feel they can cite to legitimize their concerns. Quality of life, social "toxic" stigma, and reduction in community resources (e.g., loss of equity and tax base resulting from property devaluation) are valid areas of concern. Frequently, however, those issues go unstated because residents believe they will not generate much response and support.

Finally, communities and scientists have different cultural assumptions. The scientists look for material proof of physical health problems. Community members rely on feelings (i.e., symptoms) as cues for problems. These differing assumptions make communications between the groups difficult.

Marginalized Communities

Dr. Mildred McClain led this discussion. (*Dr. McClain's comments are reported verbatim from the tapes of the workshop.*)

In marginalized communities, disenfranchised communities, uncertainty is an everyday way of life. People are not recognized as full citizens. There is a loss of control over community life. There are multiple layers of stress: violence, poverty, poor health, lack of knowledge about environmental problems, and lack of understanding of the science.

There is a lack of understanding of the problems of a marginalized community in the mainstream culture. African-American communities are a non-homogeneous population. There is a diversity of political persuasions. We suffer from poor health services. There are economic deprivations. We are dependent on jobs with the polluting industry. Racism. Acceptance of what is. Fear of speaking out. Programmed belief in Cain vs. Abel. The curse of Cain rooted in Biblical validation. Lack of any services or systems to help deal with any stress. Internal violence within these communities coupled with substance abuse and lack of respect. There is a high level of mistrust in government agencies—history of not addressing the problems. Add

to that a lack of resources to empower people to participate and a perceived lack of power. Add to this stress the extra stress of living near a hazardous waste site as well as the recurrence of pollution and accidents in an industrialized zone.

What is the impact of the stress and impact of environmental toxins? What was the effect of industrial intrusions in our communities? "Walking poison time bombs." How does poor nutrition affect our response to environmental contamination? We believe the environment is everything. Environment encompasses everything. If the land is injured, then the people are too. The general society believes "we are in control." In marginalized communities there is no separation. The Superfund assumption is that you can isolate one source of contamination. This assumption ignores the multiple sources of contamination.

What Factors to Consider When Assessing a Community's Response

As stated before, communities are not homogeneous. When you consider the various coping mechanisms of different groups within a community, group culture plays a large part in shaping responses to situations. Groups provide alternatives, different strengths, as well as resilience and capacities to respond.

The following is a list of factors to consider when assessing a community's response to an exposure to a hazardous substance:

- Other stressors affecting the community,
- Community values,
- Sex roles,
- Demographics,
- Percentage of renters versus homeowners,
- Primary language (may not be English),
- Odors from the hazardous waste site,
- Visibility of toxins such as fires and smoke, and
- Physical factors (e.g., cancer incidence and outcome, low-term birth weights, stillbirths, birth defects).

Data Gaps and Recommendations

1. There is a need for more work on explicating the following gaps in the data:
 - Sources of stress in conversations about environmental hazards,
 - Amount of stress inherent in learning of contamination,
 - Nature of known or believed exposures,
 - Fear of the unknown regarding hazardous exposures, and
 - Stages of where a community is in the Superfund process.
2. There is a need to explore and compare responses of mainstream culture to hazardous substances with that of traditional and marginalized communities.
3. There is a need for greater understanding of how culture shapes response to the threat of environmental contamination.

To meet these needs, the following recommendations must be considered:

1. Treat communities with dignity and respect.
2. Don't try to solve the communities' problems for them; rather, assist them in solving their own problems.
3. Be thoughtful of race/ethnicity.
4. Realize that scientists may not have all the answers for a community near a Superfund site.
5. Give communities practical actions to take.
6. Identify the different sectors of a community. Take into account that communities are diverse, and identify centers of respect between diverse groups.
7. Don't use technical language or jargon when communicating with communities.
8. Two-way communication between government agencies and communities is critical.

Topic Two

What are some of the psychosocial responses that communities have given to the stress of living near a hazardous waste site, and what have the results of those responses been?

Background

A survey of the literature shows that living near a hazardous waste site can cause great stress within a community and within the individuals living in that community. Some of the psychosocial responses of community members living near a hazardous waste site are:

- Fear and uncertainty over the possible health effects of exposure,
- Feeling a loss of control over the present situation and the future,
- Anger over loss of security and safety within the community,
- Confusion brought on by trying to understand various government documents,
- Community conflict over who is to blame and what actions to take,
- Frustration over the lengthy clean-up process,
- Increased family conflict,
- Concerns over economic losses (e.g., property devaluation, doctor bills, and business losses),
- Feelings of being stigmatized and isolated because of living near a hazardous waste site,
- Frustration of dealing with bureaucratic agencies, and
- Frustration of being accused of “overreacting.”

Panel Discussion

Mrs. Mary Minor led a participatory discussion between the audience and the panel on this topic. A list of responses to the experience of living near a

hazardous waste site was compiled from letters from her community. The letters indicate that the community members are experiencing the following: outrage, anger, depression, stigmatization of affected community members, distrust, fear, guilt, redlining of properties, violence inside the community, threats of violence because of social discord, intimidation, disenfranchisement, activism, and loss of community members through illness, burnout (i.e., exhaustion), or death.

Audience Response

There is a gap between the government agencies that deal with environmental contamination and the communities that experience it. The agencies have the power and authority to deal with the problem. The scientists know the problem better than community members, so agency representatives have a tendency to talk rather than listen to community members. Often, agency control over a situation produces little communication about the process. On the other hand, the community members are often fearful, lack true knowledge of the consequences of environmental contamination, can't or don't express their feelings about the situation, have no control over the situation, and need more communication with agency representatives. The situation must change so that agencies and communities work together to find solutions for environmental contamination.

Joint Audience and Panel Recommendation

1. There is a need for a training handbook for state and local public health officials on how to work with communities in these situations.

Topic Three

Discuss how the human response to uncertainty may lead to different understandings of a possible exposure to a hazardous substance and its relationship to psychological responses such as learned helplessness.

Panel Presentation

Dr. Heather Tosteson presented her work on this question. (*Dr. Tosteson's presentation is transcribed from tapes of the workshop. It is not printed verbatim.*)

To get us started, I'm going to present some ideas about uncertainty and environmental health. First, I'll run through some of the effects uncertainty can have at the individual, social, and political levels, then discuss the distinctive content of our uncertainty in situations of environmental exposure. I'll conclude with some suggestions about how this content might affect our choice of a social response as a government agency to the distress we are seeing.

Distinctions

Disaster: I'd like to begin by making three distinctions to help us better define the specific situations we are looking at. Although we are discussing a disaster paradigm here, the situation at most of the sites we see is very different from the disasters—even technologic disasters—that have been studied because of the pervasiveness of the uncertainty involved. The Three Mile Island, Bhopal (India), and Exxon Valdez incidents were all socially defined as threats or disasters. The situation at National Priorities List (NPL) sites is often not that clear. Although listing on the NPL means the site is an environmental threat, whether it is a human disaster is often not as clearly defined. The disaster here is the undefinedness of the situation.

Siting/Exposure: The uncertainty posed by a siting decision and that posed by possible current or past exposure are quite different because the types of threat are different. It is not uncertainty alone that is stressful. For example, we can be uncertain if the sun will shine next weekend but not lose any sleep about it. What bothers us is uncertainty associated with possible danger to ourselves or those close to us combined—as is the case with technologic disasters—with some sense of responsibility for determining and avoiding the danger. When people

fear they have suffered toxic exposures, they feel personally implicated in a more immediate and inescapable way than if they are contemplating the acceptability of a future risk. In other words, the situation we have here is one that is deeply undefined, but also one where the personal stakes are perceived as very high.

Normal/Abnormal: All the responses here are normal responses to chronic and pervasive uncertainty in general and to the range of uncertainty common to these specific situations of environmental exposure.

Coping

Uncertainty in these situations accentuates an already threatening and divisive situation. Its effect is to polarize views and to freeze the natural sequence of our responses so that we find it difficult to reach psychological or social closure and to integrate the experiences either individually or as a society. We cannot fight or flee. We can't resolve and move on. At a personal level, uncertainty interferes with the first step of coping, which is our ability to appraise the level of threat a situation poses for us. If we can't decide how dangerous a situation is, we can't decide how to cope with it. Further, if other people can't decide how dangerous a situation is or come to radically different interpretations from us, it is difficult for us to act in concert. And environmental threats are communal threats, so the role of community consensus is central.

A number of panelists—in particular Drs. Couch and Edelstein—have studied the damaging social effects of differing appraisals of threat, differences that cannot be resolved because the science is not there to “prove” who has been exposed and what will happen to them. Dr. Edelstein wrote in his book on Legler that there may be no psychologically healthy way to respond to the uncertainty of toxic exposures—there was only obsession and denial. At a social level, fragmentation and stigmati-

zation are ways of trying to limit uncertainty—obsession and denial on a larger scale. Different groups may be frozen at different stages in the disaster process—some still at the appraisal stage, while others are convinced that impacts have already occurred and that concerted communal action is required. Uncertainty also pervades public policy and politics because science cannot be used in its conventional role as an “objective” basis for decisions. Litigation and protest are evidence of the broad social and philosophical conflict these uncertain but highly resonant situations provoke.

Content

Because science as we now know it is insufficient to resolve the questions people have about the safety of their environment, what uncertainty does in these situations is put up a blank screen on which some of our greatest fears flash continuously. This is a situation that as human beings we try to protect ourselves from constantly. It is the resonance and the unboundedness of the content of our fears about environmental hazards that we need to talk about because we can't get away from them. It's not just that we are uncertain, but that we are uncertain about things that are deeply—I would suggest primarily—frightening. This is what gives these situations their particular emotional force. And it is the broad symbolic power, the philosophical and emotional validity of these issues, that ensures that we cannot wish them away. Environmental exposures can come to challenge our faith in ourselves, our physical and social worlds, and in our future.

Here are some of the issues that come up when considering environmental exposures:

Disease and mortality: Usually people begin to get actively involved in issues of toxic exposure because they have seen some evidence of harm, usually diseases in their family or community. Often these diseases are poorly explained by existing paradigms. Disease itself is frightening, particularly certain kinds of diseases, for example cancers and especially childhood cancers. Cancers frighten us because they are evidence that the body can turn on itself, that normal processes can suddenly twist back on themselves and become deadly.

Contamination: Environmental exposures also provoke our fear of contamination, which is a fear about the boundaries between ourselves and our environment dissolving. How can we protect ourselves from something we can't see or touch, something we can't measure, something whose effects we can't predict? Horror movies often play on this basic fear of a threat we can't see, control, or escape—one that can invade our homes and threaten everyone we hold dear.

Stigma: An extension of the fear of contamination is the fear of the consequences of social contamination, or stigma. Even if scientists think there is no threat, the world may see the situation differently. People can find their property values falling and their future economic security jeopardized by social processes over which they have no control.

Justice: Environmental exposure can challenge our trust in the justice of our social system because we realize that environmental exposures are not evenly distributed in society, that the people who suffer most from the fallout of our highly technologic society are not usually those who benefit most from the fruits of our way of life.

Social Structure: Our trust in our whole social structure can be challenged. We can begin to distrust industry, and more devastating, our scientists, who are meant to know what dangers they are creating with their technologies. We can begin to distrust our medical and health systems, which we have counted on to be able to identify and treat our illnesses, and we can begin to distrust our government, which is charged with protecting us.

Community: Environmental exposures can pose even more immediate, thus more devastating, threats to our sense of community. We can find that our sense of the reality of threat and our neighbor's sense of the reality of threat are so different that it is as if we live in completely different worlds. We can begin to wonder if anything holds us together.

Physical World: Our relationship with our physical world can be changed dramatically. What seemed beautiful and benign can now seem filled with invisible and thus unlimited threat.

Future: Most devastating, environmental exposures, particularly our uncertainty about them, lead us to questions of ultimate concern. One of the most frightening of these is the issue of irreparable harm—that the way we are living now may end up destroying us and our children without our willing it. When we find out the true level of danger, it may be too late to change it. This fear is especially triggered by past exposures—things that have happened to us without our knowing it but which may pose threats to us and our families for generations to come.

Because of the resonances of these ideas and because of the sheer number of shocks to our belief system that can be associated with these environmental issues, people can come to see both their physical and their social worlds as profoundly unsafe. There is no place they can escape to and there is no one they can trust to help them. This, finally, is an unbearable way to live. The social distrust may well be the most damaging consequence, particularly when we are talking about past exposures. In siting decisions, people require fair choice—an equal voice in deciding on the acceptability of exposure to risks. Illness speaks more specifically to our dependency on each other. Here the relationship people need with their society is one of care. Part of that care is acknowledging the psychological and social stress caused by these situations of ineradicable uncertainty and potentially disastrous personal threat.

People who have been profoundly affected by these situations are different people when the situation is over. They see the world differently and may well need to have this shift in their world view expressed in social terms. Psychologically, it is the impact of this crisis of faith that needs to be addressed because it won't go away. Even if you label people as anxious or demoralized, any intervention will require that you return in the end to the content of that demoralization—the issues and ideas involved. Only by respecting both the rational source of the distress, its specific symbolic/philosophical/emotional power, and the need for us as a society to provide a social fabric that can contain these questions—that can discuss and debate them consciously rather than be driven by them—will we be able to find social, if not scientific, resolution. And I think social resolution is crucial in these situations.

Uncertainty is a fact of life. It is also a dreadful mystery and one that we all find difficult to look at too long and too directly. It is a function of culture and of social structure to help us find ways to make the uncertainty of life bearable, and it is this role that I think we are not successfully fulfilling at this time. I think one of the questions we are being asked to answer here is who will care for us when we have looked too long and too directly into the abyss. How, when our faith in our way of life has been so severely challenged in so many ways, can we find a way to make life meaningful and trustworthy again?

Here it might be important to point out that the uncertainty of these situations has strong emotional impact on scientists as well. The level of scientific uncertainty can bring scientists to question the adequacy of the scientific method, to question the biomedical paradigm, to question the rightness of the professional control of the discipline, to challenge their belief that science is a value-free activity and that science plays a benign role in social conflicts. These challenges to their way of life are as pervasive and threatening as the challenges toxic exposures have been to communities. Thus, they resist any suggestion that they enlarge their definition of the problem to include the psychological and social effects of exposure, for to include them, to acknowledge the emotional force and philosophical resonance of the experiences of the communities, will expose them to a crisis of faith.

Data Gaps and Recommendations

1. There needs to be open, honest discussion of the victims' concerns. They need to be treated with respect and compassion as real people, not just as scientific or clinical cases.
2. Part of a community assessment for a Superfund site should include an overview of a community's options for action and the constraints to action.
3. The process needs to openly confront the issue of values involved in environmental contamination. No amount of data will resolve fundamental differences in world views or belief systems.

Special Topic

What are the psychosocial effects of relocating a community when environmental contamination cannot be safely remediated?

Special Presentation

At the request of Dr. Gershon Bergeisen, from the EPA, a special presentation of a relocated community member's perspective was given by Mrs. Cindy Babich, a community member from the Del Amo site in Torrance, California. The following is a summary of Mrs. Babich's presentation.

Mrs. Babich: To address the question of relocation, you must consider the effects of no relocation on a community affected by hazardous substances, the effects of relocation, as well as the psychosocial reasons to relocate a community.

Effects of no relocation: To the Superfund community, no relocation represents a lack of caring from the wider community. "Condemned" and "trapped" are terms frequently used to describe community perceptions. Real or perceived continuing exposure to the contamination occurs as well, and this may lead to continued stress.

Effects of permanent relocation: Government agencies could take steps to keep costs of relocation down by preplanning. There is a need for a set of permanent environmental relocation criteria. There also needs to be policies to address differing needs of homeowners versus renters. Home owners will wish to be bought out at fair market price. Renters will need help in finding similar housing. Agencies will need to consider whether or not the whole community wishes to move together. There will be a need for special outreach to inform community members and help them deal with relocation. There are the needs of special populations. Elderly can't deal with relocation. On the basis of our experience, there is a need for those undergoing relocation to

have help and guidance in solving problems of daily life—mail forwarding, change of address, address expenses of increased travel to and from work, and possible change in schools for children.

Effects of temporary relocation: These effects are different from permanent relocation.

There is separation from the rest of the community by "being privileged" to be relocated. Coordination is needed with schools regarding the effects of environmental contamination and temporary relocation on children's performance at school. In our experience, children in our neighborhood who have been relocated have shown improved opportunities for learning, decreased rage, and less problems with concentration and attention.

Data Gaps and Recommendations

1. There is a need to look at the effect of environmental contamination and relocation on children in these communities.
2. There may exist a need to consider such actions as retraining for new jobs (if relocation involves loss of old jobs) and how relocation affects job performance.
3. Early interventions to prevent physical and psychological stress need to be implemented in these communities. Maybe they could be based on the Federal Emergency Management Agency (FEMA) emergency response model.
4. We recommend providing a list of government agencies involved in the Superfund process to the communities so they can sort out the players.

PANEL THREE: PROTECTING AND PROMOTING PSYCHOSOCIAL HEALTH

Composition: Composed of clinical psychologists, psychiatrists, occupational medicine physicians, disaster relief specialists, and community members affected by hazardous waste sites.

Charge: To develop public health strategies to prevent and control long-term stress-related health problems in communities near hazardous waste sites. Panel members were not asked to evaluate prevention and intervention strategies associated with specific sites. They were asked to use their complementary backgrounds and areas of expertise to provide an overview of 1) what is known and not known about the effectiveness of previous prevention and therapeutic strategies in these communities, 2) the most effective methods for preventing and mitigating stress-related health problems in communities near hazardous waste sites, and 3) methods for increasing public and professional capacity to respond to psychological issues related to hazardous waste sites.

Topic One.

How has the extent of the psychosocial effects and possible public health impacts in these communities been assessed to date?

Background

Most of the recent psychological research on the effects of technologic disasters has been designed according to the principles of psychiatric epidemiology with the use of case-control populations and known standardized instruments. According to these studies, psychological disorders found in populations possibly exposed to hazardous substances are similar to those found in communities that have experienced natural disasters: heightened incidence of anxiety, clinical depression, and post-traumatic stress disorder (PTSD).

Panel Presentation

Dr. John Eyles began the discussion on this question. The following is a summary of the discussion and is divided into three parts:

How we currently assess impacts and effects: Currently, there are three to four scientific ways of assessing psychosocial impacts and effects. These include a small number of epidemiologic studies, clinical studies, case studies of communities, and the use of key informants' studies. Epidemiologic studies are usually based on cross-sectional or case-control designs. The evidence from these few epidemiologic studies does not seem to be particularly strong. Clinical studies are symptom-based and rely to a great extent on case studies by physicians or self reports of symptoms. Studies based on physician judgments are few in number and have very small sample sizes. Therefore, they lack the power to provide the usual quality of evidence that scientists want. Many more of the studies of psychological effects rely on self reports, and there are differences of opinion on what is scientific evidence. Some in the scientific community regard self-reports as quite meaningless and open to reporting and observer biases. Others regard self-reports as key information sources. Self reports are the first means to identify the psychosocial impacts of any event. Key informants can be used to help chart out the effects on communities. This might be useful in the early stages as a rapid assessment technique.

How we might assess impacts and effects: A determinants of health approach could be used to assess impacts and effects. This approach looks at how certain demographics and socioeconomics contribute to health, well-being, or illness. This important information can add to the assessment process. Another approach that could be used involves the values and interests of stakeholders or other involved parties. This means understanding their values and what they feel threatens their interests. This may involve property values, children, and/or the future in general. Essentially, that is what has come from the in-depth studies of Edelstein and others. For this type of study, a partnership with the community is critical. Strategies that could be used include those mentioned above, as well as data pooling to look for common themes, reviewing and learning from occupational health studies of stress, and creating and instituting rapid assessment tools to assess the problem swiftly.

The context of assessment: Responses to contaminating events are socially and culturally mediated in complex ways. To some degree, they are unique to the particular study setting and cannot be divorced from context. Each community's circumstances are unique.

Data Gaps and Recommendations

1. The extent to which psychosocial public health impacts have been assessed to date is relatively limited. There are opportunities for more studies to define the problem. There are various techniques and processes that warrant further use.
2. A comprehensive community needs assessment is a critical first step in shaping the design of interventions and adapting implementation plans to unique community characteristics.

Topic Two.

What previous prevention and therapeutic strategies have been used in these communities? What were the results of these interventions and what issues did they raise?

Background

Prior research on stress prevention and therapeutic strategies following trauma has focused primarily on natural disasters. Scientists and clinicians recognized that some people who have been exposed to various natural disasters, such as earthquakes, hurricanes, and floods, could develop psychological sequelae such as major depression, chronic anxiety, and PTSD. As the number of studies devoted to the psychological effects of disasters increased, findings indicated that disasters did not always result in widespread, severe psychological disturbance. These studies found that only a relatively small number of disaster victims suffer serious, long-term psychological damage. A somewhat larger portion of the affected community may be expected to manifest at least transient symptoms of various forms of emotional disturbance (31). Current thought among disaster relief workers is that these symptoms of emotional disturbance are normal reactions to an extraordinary and abnormal situation and should be expected.

The treatment model used for victims of natural disasters involves aggressive outreach and crisis counseling that combines psychological support, education, and practical disaster relief (e.g., helping meet needs for food and shelter). People who appear more severely affected by the disaster are referred to the local mental health system for continued care. The use of crisis intervention techniques in the aftermath of a disaster is recommended for several reasons. 1) As previous studies suggest, disaster victims typically do not sustain serious, long-term mental health impairment. Much of the initial mental health response involves normalizing feelings. Victims need to be assured that the emotions they are experiencing are normal. 2) Disaster victims are often reluctant to seek out mental health services or facilities on their own. Because of this, outreach to the community is essential. 3) Outreach and crisis intervention emphasizes the use of paraprofessionals and volunteers. Individuals who are perceived by the affected community as “being one of us” can play a vital role

in intervention activities.

In addition, 14 key concepts of disaster mental health have come out of the outreach/crisis intervention model (32). These key concepts could serve as a valuable framework and guide for planning and implementing successful mental health services at hazardous waste sites. These concepts are as follows:

- No one who sees a disaster goes untouched by it.
- There are two types of disaster trauma: individual trauma and collective trauma.
- Most people pull together and function during and after a disaster, but their effectiveness is diminished.
- Disaster stress and grief reactions are normal and appropriate responses to an abnormal situation.
- Many emotional reactions of disaster survivors stem from problems of everyday living brought about by the disaster.
- Disaster relief procedures have been called “The Second Disaster.”
- Most people do not see themselves as needing mental health services following a disaster and will not seek out such services.
- Survivors may reject disaster assistance of all types.
- Disaster mental health assistance is often more practical than psychological in nature.
- Disaster mental health services must be uniquely tailored to the communities they serve.
- Mental health staff need to set aside traditional methods, avoid the use of mental health labels, and use an active outreach approach to intervene successfully.
- Survivors respond to active interest and concern.
- Interventions must be appropriate to the phase of disaster.

- Stable support systems are crucial to recovery.

Panel Presentation

Mrs. Cynthia Babich reported her observations of the things that have been conducted at the Superfund site in her community. There are now some counselors in the community who are talking to some of the people, but there is a stigma associated with doing so. Some residents, particularly the men, see asking for help as a weakness. Mrs. Babich believes what is needed is someone who is going to listen to the community members and document what they are saying.

Dr. Brian Flynn followed up by talking about nine strategies that have been consistently used in disaster mental health programs. These experience-based, not research-based, strategies are as follows:

Early intervention: Intervention should begin as soon as possible. It is a myth that psychological problems occur only later in a situation. We know a great deal about what can be done early in situations to help mitigate stress. Providers who assist early are much more accepted than those who are late-comers. This can be a problem because the majority of Superfund sites have been around for many years, but the sooner psychological aid is provided, the less total stress individuals will experience. Additionally, residents at hazardous waste sites may believe that their circumstance is something that cannot be understood by someone who has not shared the experience. Early intervention allows providers to see, hear, and feel experiences very similar to those of the residents. It can also help establish the community members' trust in the provider.

Validation: The effects of stress are real, and any prevention or intervention strategy should include validation of the stress-related problems.

Normalization of reactions: Many people find themselves demonstrating signs or symptoms of stress. Counseling interventions, such as those based on psychoeducational or psychosocial models, are more appropriate as opposed to the more traditional mental health interventions. This counseling should help individuals understand that their responses are normal, typical, and expected in an abnormal situation.

Telling of the story: The intervention strategy should promote the "telling of the story." This seems to be a common thread across various kinds of trauma. There are three benefits to telling one's story: 1) it is a way to gain control of an experience that is outside of the individual's past experience; 2) it can have a cathartic effect; 3) it provides an opportunity for bearing witness to what happened and for documenting and putting on the record what the experience has been. Whether you're dealing with disasters, refugee situations, torture situations, or other situations, it seems to be important for people to tell their story.

Outreach orientation: People do not usually seek assistance for a variety of reasons, including stigma and not identifying themselves as appropriate recipients of psychological services. Providers of intervention strategies need to be aggressive in their outreach to people in the community. Services will have to be provided in nontraditional, community-based settings where people live, work, and socialize.

Blending response teams: Licensed mental health professionals and trained community leaders should work together. Some services could be provided by trained nonprofessionals who are part of the community. This community involvement helps to build trust and may be more appropriate where ethnic and cultural differences exist between citizens and outside intervention teams.

Designing and encouraging actions: Actions that involve the community and increase community control have a high probability of some success.

Training: A need for training in crisis intervention and traumatology exists; therefore, training should be provided to survivors on how to prevent, identify, and reduce their stress. Training should also be provided to the members of helping professions (e.g., clergy, school counselors) and mental health professionals or any others in the community that people may turn to for assistance.

Consulting with community leaders: It is important to establish ongoing communication with community leaders and to keep them involved throughout the process.

The rest of the panel discussion focused on which of the nine techniques outlined by Dr. Flynn

would be most amenable or transferable to a Superfund setting and which might be problematic. Panel participants stated that in contrast to disaster situations, in which communities affected usually pull together, community division often exists at Superfund sites. Communities tend to coalesce around problems, so having a community take an action that is noncontroversial is tougher in this context. Consultation with community leaders may not be as easy at a hazardous waste site as it is in a natural disaster. The types and number of support systems may be lacking.

Validation may be difficult as well. Natural disasters are more salient. People can see the problems and aftereffects. This is not always true of Superfund sites where the contamination is often invisible. Some may deny there is a problem. Others may state that they know or feel there is a problem but not be taken seriously. At times, environmental

agencies are a part of the problem because they state there is an environmental problem but do not show compassion for the affected community or provide a rapid response to the problem. Government agency staff do care, but often are experiencing their own set of frustrations and worries.

Data Gaps and Recommendations

1. If early interventions are provided, many of the remaining eight actions would not be needed.
2. Some type of measurement and program evaluation should be built into any intervention strategy to determine its success.
3. Another action to take is to “help the helpers.” Sometimes those most impacted are the helpers—researchers, government field workers, therapists, or the first responders. As a result of overwork, they may experience burnout. Helpers should be trained to recognize early signs of burnout, and support should be provided.

Topic Three.

What methods are most effective in preventing the acute stress of learning of the existence of a hazardous waste site from becoming chronic in adults? In children?

Background

The basic principle in working with children or adults who have experienced any type of disaster is to remember that they are essentially normal people who have experienced great stress (33). Many people can effectively use their existing coping skills to deal with the consequences of a traumatic event if they are made aware of the normal and predictable responses to expect as recovery progresses. Thus, education about stress reactions and ways to handle them should be provided. This normalizing or validating of feelings and help in recognizing some very common signs of a stress reaction can help to mitigate the effects of acute and chronic stress in both adults and children.

For adults living near a hazardous waste site, the uncertainty about health consequences inherent in exposures to hazardous substances will most likely be their greatest source of stress. For example, in some cases people (e.g., community residents, epidemiologists, and health assessors) aren't sure who has been

exposed to a hazardous substance or how much they have been exposed to. In most cases, the exact degree of individual exposure, in terms of duration and level, cannot be determined. This creates uncertainty and heightened feelings of powerlessness and lack of control, both of which are associated with higher levels of stress (34). Access to information and educational activities about the consequences of toxic exposure is necessary to prevent or mitigate chronic stress in these adults; therefore, primary care physicians and mental health and other health care providers should be informed about the contamination, its potential health consequences, and field assessment difficulties that may contribute to their patients' feelings of uncertainty (e.g., fluctuating contamination levels). Provider support and understanding of the contamination and psychological stressors associated with living near a hazardous waste site are vital to helping individuals living near the site cope with the situation.

Panel Presentation

Dr. Charles Figley discussed the possibility of using PTSD research; traumatology research such as that done with prisoners-of-war (POW) and missing-in-action (MIA) families, agent-orange families, hostage families, and terminally ill patients; and crisis intervention strategies as models for preventing acute or chronic stress in individuals living near a hazardous waste facility.

Dr. Figley also made the following recommendations for preventing stress in adults and children living near a hazardous waste site:

Establish trust: The situation invites a general loss of trust in others and in government specifically. Efforts will have to be made to establish trust and credibility. If you don't have trust, no one is going to listen to you, not to mention hear you or follow your interventions.

Bear witness: Individuals should be encouraged to bear witness. They should be given the opportunity to articulate what took place and what happened to them, why it happened, and their beliefs and fears about the situation. One very effective strategy that has been used in traumatology research is to videotape these conversations so that when a person is talking into the videotape, they are talking to everybody. This method can provide an oral history, not only for the person giving the account, but in many cases, for those people who don't want to bear witness. For those community members who don't want to share their pain and emotion, they can watch the videotapes and their heads will nod quite a bit, and they will feel understood. They will say "that person on that video is like me."

Identify standards of measurement: Substantial research exists with respect to understanding the immediate and long-term psychosocial consequences of highly stressful events. What we now need is a model to understand the trauma induction and trauma reduction processes. On the basis of an established model, ways to prevent suffering and other consequences can be identified—ways to stop and prevent peoples' suffering from reactions to a traumatic event as thoroughly and quickly as possible.

Identify needs: Do not assume knowledge of what

a community wants. Ask the community members to identify their needs and goals. Listen during the process of bearing witness and identify what the individuals think their needs are.

Implement interventions: Implement the most appropriate types of interventions (e.g., stress reduction and management, psychosocial education, post-traumatic stress symptom elimination) one at a time or together.

Utilize existing infrastructure: Utilize the media, business groups, religious organizations, school systems, and other social institutions as a means to providing psychosocial education to both adults and children.

These principles are the same for children and adults. What is critically important, however, is that children even more than adults live in an external world, defined by the outside environment. Any time intervention is necessary, even in terms of assessment, the work must involve the significant people in the children's lives.

Data Gaps and Recommendations

1. A number of public health agencies in the United States are finding their resources increasingly cut back. Their efforts to try to get out into the community and to deal with the behavioral and social issues around a site are often limited by a lack of adequate resources. However, a number of individuals in the faith groups or church communities share our values about health. By enlisting these individuals, we may find very natural allies and trusted sources in a community. These groups may be able to reach the people we cannot.
2. In preventing stress, anger must also be considered. Anger often exists at these waste sites and needs to be validated. It's part of the method of coping for some. When people are angry, they need to know that they have every reason to be angry. In both natural and technologic disasters, there are so many system frustrations and problems that are real that, as they build up, people naturally react with anger. That's when intervention is needed to help them find and solve problems that are within their control to change and cope with those that are not.

Topic Four.

What are the best methods to prevent demoralization from occurring in these communities?

Background

Demoralization, according to the *Comprehensive Textbook of Psychiatry*, is a “state of mind of hopelessness and helplessness” (35). Demoralization is a common distress response when people find themselves in a serious predicament and can see no way out. Demoralization stems from a perceived lack of control. Control is defined as the belief that one can influence an event; whereas, lack of control is defined as the belief that nothing one does or can do will change what will occur (19). Some studies of technologic disasters have reported increased rates of demoralization in affected communities (8, 19). For example, Dohrenwend and colleagues (36) found evidence of heightened demoralization during the months following the Three Mile Island incident.

Panel Presentation

Dr. Jeff Kindler and Dr. Charles Figley led the discussion on the issue of demoralization.

Dr. Kindler suggested that environmental agencies concentrate on enhancing two-way communication between agency representatives and community residents. In other words, communication plans should be designed to increase the mutual understanding of issues, data, and possible solutions to the problems that are contributing to community demoralization. These agencies should continually strive to improve their partnerships with communities and the sharing of decision-making power with residents.

Models for improving partnerships can be found in the adult education, group dynamics, and interaction analysis research literature.

When communicating scientific information in communities, residents need to be assisted in processing this information through an encouraging, indirect style. This will help residents talk about and discuss their concerns about the meaning of the information provided. Talking with the community and inviting residents into the process helps reduce their anxiety, anger, and suspicion and is a good

beginning to building trust. In return, communities give back ideas that agency representatives can use to develop better scientific models to help us all.

Dr. Figley stated that there is significant overlap between demoralization and learned helplessness. There are a number of ways to prevent learned helplessness. Part of demoralization and learned helplessness is the extensive isolation and not knowing that other people are having the same experience. Communities should be given as much accurate information as possible so they can devise solutions or options to improve their situation. A helpful intervention may be to help them connect with other communities that have experienced similar circumstances.

Data Gaps and Recommendations

1. A primary way to prevent or lessen demoralization is to help citizens gain a sense of control over their situation. Government, state, and local agencies should seek meaningful input and participation of community members. Of particular importance is residents' involvement in the decision-making and problem-solving processes concerning the cleanup of their community. In most instances, the cleaning or remediation of the waste site is lengthy, and causes residents chronic stress and feelings of helplessness. Cleanup of the site should be quickened, when possible, and the community should be involved throughout the process.
2. Demoralization often occurs when people feel isolated and alone. Often conflicts occur between those neighbors living within the impacted area and those living outside the impacted area. Many of those living within the impacted area may disagree on exposure and health effects. Better communication between neighbors could prevent this.

Topic Five.

How can seriously affected individuals be identified and appropriately referred in these communities?

Background

An effective method for identifying seriously affected individuals is an active outreach approach like that used in crisis management programs after natural disasters. The first step is to perform a thorough needs assessment with the community to determine which individuals and groups are most severely impacted and which persons are experiencing the most difficulty. The second step is to contact those who can be assumed to be in the most need of psychological help. Such persons include those who have lost one or more family members, those whose homes have been destroyed, those being relocated from their homes, those who are seriously ill, and those who have been or are currently under psychiatric care (37).

In toxic contamination, there may be an absence of concrete (i.e., identifiable) death and destruction. High-risk groups should include those who are likely to have been exposed to chemical hazards or who have experienced property devaluation. Underserved segments of the population, such as the poor and racial and ethnic minorities, should be given priority as well. The third step should be to attempt to reach those who are geographically isolated or without transportation.

Educational efforts should be designed to reach as many people as possible and should express simple themes relating to Superfund sites and communities, such as stress reactions and management. Educational materials should also include information about available sources of mental health services and provide specific directions on how to locate help. Because people often identify “mental health” with “mental illness,” measures should be taken to avoid these labels. Emphasis should be placed on the common practice of people experiencing stress to use such services.

Not all community members will experience the same types of needs at the same time; therefore, the needs assessment should be ongoing and should include periodic reassessment of both mental health

needs and services.

Panel Presentation

Dr. Brian Flynn led the discussion on this issue.

Dr Flynn:

In some cases, these individuals will “self identify,” i.e., they will seek treatment on their own. Others may be identified by their support systems (e.g., family, friends), while others may be identified by their family doctors, counselors, or other health providers.

Once these individuals are identified, how they are referred for further treatment varies. Referral depends on their eligibility for treatment and whether they have the financial resources (e.g., private monies or health insurance) to cover treatment costs. They may be limited in their choice of providers for treatment, and their geographical location may hinder access to treatment.

To whom they get referred may vary as well. Before referral, trained professionals with expertise in crisis counseling or traumatology should be identified. Often the local mental health system is the least prepared to handle these problems. Its services and resources are generally restricted to those with serious mental illness and/or drug addictions. In addition, they often lack staff with expertise or training in crisis counseling or disaster relief work.

The expertise of volunteer providers should also be qualified. Sometimes those who go out of their way to volunteer their help are the least prepared and qualified. Additionally, mental health providers should coordinate their efforts and establish a close link with the primary care physicians in the area. There may be a need to provide training to the mental health and primary care providers. This training should be designed to help providers develop a sensitivity to the issues of contaminant invisibility and health uncertainty.

Data Gaps and Recommendations

1. Because individuals stress response can vary, those living near hazardous waste sites will differ in the degree of stress they exhibit. Some may experience little or no stress, others a moderate amount of stress, and some will exhibit high levels of stress. Individuals who exhibit high levels of stress might include those who are unable to deal with the situation because of inadequate coping skills, an inadequate support system, a lack of trained providers to accurately diagnose and treat their problems, or a preexisting mental or physical illness. Those experiencing high stress levels may require more long-term, structured treatment, so identification of these individuals is important.
2. Public health agencies should be in a position to deal with stress or mental health problems emerging at waste sites. Unfortunately, they are not in that position at present. This is one of the problems facing public health officers right now: the whole business of redefining the role of public health.

Topic 6.

What is the best method for increasing public and professional capacity to respond effectively to psychological issues related to hazardous waste sites?

Background

One of the most effective ways to build capacity within a community is through education. Neither public nor professional community members can effectively respond to psychological issues unless they understand what those issues are. An awareness and understanding of disaster-related psychosocial effects, in particular those associated with living near a hazardous waste site, are vital to increasing a community's ability to respond. An effective way to provide this education is by establishing a community-level outreach program.

Panel Presentation

The discussion centered around five key factors for increasing public and professional capacity:

Community-based education: Community-based education programs would help to heighten awareness of community members, public health professionals, and providers and to teach them how to identify psychological sequelae.

Evaluation: An evaluation of any existing programs in the community should be conducted to determine their appropriateness and usefulness in addressing psychological issues.

Empowerment: Ask community members what their needs and concerns are. Give them the infor-

mation and training they need to help them understand and cope with the problem. Agencies should form partnerships that enable discussions and decisions about their community.

Collaboration: Trained mental health and health care providers should collaborate and communicate with each other on the issues.

Data Gaps and Recommendations

1. Increase public and professional capacity for responding, including making the issue of psychological responses at hazardous waste sites less marginalized. Rather than "preaching to the choir," attempts should be made to bring this social issue to the attention of the American public.
2. More must be done to enable communities to respond to the problem. Ask communities what assistance, resources, and education efforts they want, and then make sure you can come through for them. Give them technical assistance and education. Teach them how to access environmental resources from the Internet, libraries, and other information sources.

OVERARCHING ISSUES DISCUSSED BY ALL THREE PANELS

Topic One.

Evaluate information about susceptible populations. This information may include preexisting conditions (i.e., medical and/or psychological), as well as individual variability in reactions to stress, cultural patterns of reaction to stress, and targeting interventions to vulnerable populations.

Panel Discussion

Most people cope very well with stress; however, people with preexisting mental or physical health problems, limited coping strengths, or meager family and community support systems may be more vulnerable to psychological stressors than others. For example, the following question was raised: “Can an individual already experiencing depression from other circumstances experience exacerbated depression from the stress associated with living near a hazardous waste site?” An individual’s response to stress is multifactorial. Episodes of mood disorders, such as depression, may be triggered by psychosocial stress associated with different situations.

In addition, some age groups appear to be more vulnerable than others, particularly young children and older adults. Children’s perceptions of stress and their coping skills differ by developmental level and are not the same as that of adults’. A change in

environment, such as that which occurs with relocation, may leave children frightened and insecure. They may display a variety of emotional responses. How a parent reacts to the situation makes a great difference in the child’s understanding and recovery. People with children may be a susceptible group themselves because of their concerns over the potential adverse health effect on their children. Older adults may suffer because their familiar routines are disrupted, particularly when there is residential loss and relocation.

In marginalized communities, there is a sense of internalized oppression. This results in incapacitation and loss of self-esteem and efficacy. Drawing site boundaries (e.g., putting a fence around the contaminated area) can create a specific susceptible community by attaching an environmental stigma and changing a community’s perception of safety. The trigger for psychosocial effects is perception.

Environmental cues, such as odors associated

with waste sites, may make a community more susceptible to the stress associated with exposure. Communities who have suffered changes in threat levels (i.e., being told at first that there is no harm, then that the exposure is a threat, or vice versa) may be more at risk to have increased stress. Communities exposed to multiple contaminants might also be more susceptible to the stress associated with multiple exposures.

Helpers and responders themselves have the potential to become “secondary victims.” They may

Topic Two.

Examine the reports of increased incidence of psychologic disorders in these communities and make recommendations regarding the directions for future strategies.

Panel Discussion

The members of all three panels had very mixed opinions on the adequacy of the literature on psychological disorders from the stress related to hazardous waste sites. Some felt the evidence was adequate to overwhelming; others thought that the literature was sparse and that more studies, including epidemiologic and qualitative methods were needed before drawing any firm, final conclusions.

The first question to be answered by these studies would be to assign statistical causality to the site (i.e., to determine how much of the reaction is caused by the site and how much to a preexisting condition). How do we differentiate effects from different stressors? The suggestion was made that a convergent strategy be used to do this. This convergent strategy would involve using a mix of qualitative (e.g., clinical screenings by neuropsychologists and sociological studies of the factors that influence community responses) and quantitative methods (e.g., psychophysiological research, application of standardized research instruments to measure the psychological disorders in the communities near these sites, and pre- and post-data on how stress levels change in a community affected by hazardous substances). Two important points to remember are that 1) the psychosocial effects of a hazardous waste site change over time and 2) not every community is affected in the same way.

Panel Three suggested rewording the issue to

experience “burnout” syndrome—a state of exhaustion, irritability, and fatigue.

Data Gaps and Recommendations

1. Acknowledge the unique problems of Superfund communities.
2. Seek to understand the problem from a community point of view.
3. Train staff of various agencies in recognizing different patterns and types of psychosocial responses to environmental contamination.

read “psychological distress” rather than “psychological disorders.”

Data Gaps and Recommendations

For a specific site, one must first ask whether the site is old or new. For a new site, the relevant issues are prevention and intervention before stress has a chance to build within a community. A recommendation was made to incorporate mental health services into the process of helping victims of an acute technologic disaster (e.g., a spill). Another recommendation was to standardize the psychological assessment tools and to work toward a wider recognition for the need to address psychological responses to hazardous substances, including encouragement of state health departments to incorporate means of addressing these effects.

All panels recommended a need for further study on the topic of psychosocial stress in communities exposed to hazardous substances. Panel Two gave the following set of recommendations for how to conduct further research in these communities:

1. Listen to the concerns of the community.
2. During a community needs assessment, look at census data and demographics for factors such as the male-to-female ratio, number of children and elderly, number of homeowners versus renters, and the minority makeup.
3. Map the community using geographical information systems to assist in tracking health

impacts and community psychological and social needs.

4. Have joint fact-finding activities with communities to build trust in the data.

Topic Three.

What ethical concerns need to be addressed in dealing with the psychological responses to hazardous substances? This question addresses the appropriateness of various intervention strategies.

Panel Discussion

The panel concluded that the following are practical questions that will help preserve an ethically balanced and appropriate intervention:

- Do we know enough about the pathophysiology and natural history of the psychological conditions that are present?
- Can we provide effective remedies?
- Who is responsible for the intervention?
- Which organization (e.g., federal, state, or local) is most appropriate to deliver services?
- What is the appropriate way to deal with the question of invasion of privacy?
- How would the situation change if the event were natural?

- What are the appropriate parameters for policy governing the behavior of the media? The principal responsible party? The government agencies?
- Should the principal responsible party be a part of the planning, implementation, and evaluation of the intervention?

Data Gaps and Recommendations

1. Do no harm.
2. Obtain the community's permission and input before designing or implementing any interventions intended to reduce stress in that community.
3. Have experts on the subject, such as bioethicists, explore the issue further.

Topic Four.

Identify future directions for investigation of the biopsychosocial effects from possible exposures to hazardous waste substances.

Panel Discussion and Recommendations

The panel identified four areas in need of greater attention:

Data collection: There is a need to collect more data on psychosocial effects of living near a hazardous waste site. This data collection should include a systematic, community-based study that collects a wide range of psychosocial data, such as the community's level of knowledge and understanding of stress reactions; variations and characteristics of positive coping skills; evaluation of policy responses; and an evaluation of the efficacy of various treatment methods, including early intervention.

Training: Further training on psychosocial effects should be provided to community members and their health care providers to elevate their

knowledge and understanding of stress reactions. This should include validation of the community's stress response as a normal reaction to the situation.

Earlier intervention: Early intervention with more community involvement is needed. Noninvolvement and mistrust can be avoided by establishing partnerships early with key stakeholders and treating them as equals. These partnerships should include local officials and respected community members.

Evaluation: The impact of the government response should be evaluated. Do certain policy responses, such as relocation of the community, cause more stress or additional harm? Additional consideration should be given to how information is delivered and understood by the community. Attempts should be made to know what and how the community thinks and feels before delivering the message.

NEXT STEPS

At the end of the workshop, Dr. Maureen Lichtveld presented a five-point action plan for the agency to address the issue of psychosocial effects in communities near hazardous waste sites. The actions to be taken include the following:

1. Produce a proceedings of this expert panel workshop;
2. Publish articles in the scientific literature regarding the psychosocial effects in communities near hazardous waste sites;
3. Write a training handbook for local and state public health officials on ways to minimize stress in communities exposed to hazardous substances;
4. Develop direct interventions in communities faced with exposures to hazardous substances based on disaster relief strategies; and
5. Develop and implement public health strategies designed to mitigate the psychosocial stresses that can be found in communities exposed to hazardous substances.

Since the expert panel workshop, ATSDR has moved forward with the development of a psychological effects program. Since September 1995, the agency has designed a public health strategy that combines enhancement of the public health system's capacity to respond by developing and implementing a training program for public health partners. Additionally, the agency has delivered several direct interventions in communities.

ATSDR developed a training module for health assessors and public health officers; this module is designed to enhance their awareness of the psychological responses that accompany exposures to

hazardous substances. The first training course using that module was presented on February 3–7, 1997. Several training sessions for county health officials have been conducted through the agency's partnership with the National Association of County and City Health Officials. Also, training has been held for staff in state health departments.

There have been several different projects with communities. This has involved sponsoring a 1996 educational workshop regarding ways of reducing stress caused by acute exposures to a hazardous substance and a subsequent sudden evacuation for a relocated community. A series of workshops for residents of a community permanently relocated because of environmental contamination was given on February 26–28, 1997. The series of workshops gave the residents basic information on how to cope with the stress of a relocation related to environmental contamination. Additionally, training on how to help temporarily relocated residents was given to social workers involved with the hundreds of displaced people during the methyl parathion response on the Gulf Coast. Also, expert opinion was provided to an EPA task force that is looking at the issue of how to handle environmental relocations.

ATSDR continued to advance the public health science on this topic through a September 10 and 11, 1997, expert panel workshop entitled "The Feasibility of Measuring Stress Related to Hazardous Waste." The workshop convened in Atlanta, Georgia. The proceedings from that workshop are forthcoming.

In 1998, ATSDR worked with the Missouri Department of Health and ATSDR's Office of Regional Operations to develop a needs assessment

for public health personnel to use to determine the desires and needs of a community when coping with the psychological effects of exposure to hazardous substances.

Most recently, ATSDR and EPA have joined in an initiative, *ATSDR-EPA Initiative Regarding Community Stress Related to Hazardous Substances*, to train EPA personnel in the area of community stress. The initiative will increase awareness and improve staff ability to respond to communities facing exposure to a hazardous substance. Public health responses

will be piloted at three sites over the next 3 years. During 1999, a community support network involving social workers will assist a community facing both permanent and temporary relocations due to environmental contamination.

A handbook, *Training Handbook on Psychological Responses to Hazardous Substances*, is expected to be completed by September 1999 and published in FY 2000.

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APPENDICES

APPENDIX A

BACKGROUND DOCUMENTS FROM THE *EXPERT PANEL WORKSHOP ON THE PSYCHOLOGICAL RESPONSES TO HAZARDOUS SUBSTANCES*

Panel One.

Biomedical and Psychophysiological Effects

Defining the Problem: Biomedical and Psychophysiological Effects. Composed of neurobiological scientists such as psychologists with expertise on the psychophysiology of chronic stress and resulting health effects, neurobehavioral toxicologists, neuropsychologists, and psychiatric/psychological epidemiologists.

Charge: To examine what is known about the potential effects on public health of the chronic stress response that some studies have documented in communities near hazardous waste sites. Focus areas include the pattern of stress that may occur at hazardous waste sites (i.e., acute or chronic, or both); the effects of psychological stress on physiological responses to exposure; and whether neurobehavioral disorders caused by neurotoxicants, which may manifest as psychological disorders, are ever a public health phenomenon near hazardous waste sites.

Topics to be addressed by Panel One include the following:

1. What is known about the long-term health effects of chronically increased stress among individuals living near hazardous waste sites?
2. Are there certain neurobehavioral effects found in individuals living near hazardous waste sites that, if detected, could constitute sentinel health events at these sites? If they exist, can their early detection be used as an intervention screening tool?
3. What is known clinically about how to differentiate between organic behavioral disorders caused by exposure to certain neurotoxicants and purely psychologic responses to possible exposures? This discussion will consider methodological questions such as testing for stress and neurobehavioral effects as well as other issues.
4. Given what is known regarding the psychobiology of stress, are there interactions between chronic stress and exposure to neurotoxicants that could change the dose-response curve for

neurotoxins?

5. What is known about those individuals who are most sensitive to this stressor (i.e., the uncertainty of possible exposures)? This includes consideration of medically, psychologically, and physiologically sensitive populations.

Overarching Issues For Discussion By All Three Panels:

Overarching Issue 1: Evaluate information about susceptible populations. This may include: a) preexisting conditions (i.e., medical, psychological), b) individual variability in reactions to stress, c) cultural patterns of reaction to stress, and

d) interventions targeted to vulnerable populations.

Overarching Issue 2: Examine the reports of increased incidence of psychological disorders in these communities and make recommendations regarding the direction for future strategies.

Overarching Issue 3: Address ethical concerns pertinent to dealing with the psychological responses to hazardous substances. This addresses the appropriateness of various intervention strategies.

Overarching Issue 4: Identify future directions for investigation of the biopsychosocial effects from possible exposures to hazardous waste sites.

Panel Two.

Community and Social Science Perspectives

Defining the Problem: Community and Social Science Perspectives. Composed of community and social psychologists, sociologists, anthropologists, political scientists, and community members.

Charge: To review what is known about the psychosocial responses in communities living near hazardous waste sites and make recommendations regarding ways to interact with communities, outline problems in need of further investigation, and suggest possible psychosocial interventions to reduce stress.

Topics to be addressed by the second panel include:

1. Factors (both internal and external to a community) that might make some communities susceptible to the stress of living near a hazardous waste site. This discussion will include:

Individual and community dynamics,

 - Cultural factors affecting responses,
 - Type of community (e.g., marginalized),
 - Community's response (i.e., duration of exposures, socioeconomic and demographic factors, and unique community factors).
2. The human response to uncertainty may lead to different understandings of a possible exposure to hazardous substances and its relation to

psychological responses, such as learned helplessness.

3. Some of the psychosocial responses that communities have given to the stress of living near a hazardous waste site and the results from these responses.

Overarching Issues for Discussion by All Three Panels

Overarching Issue 1: Evaluate information about susceptible populations. This may include a) preexisting conditions (medical, psychological), b) individual variability in reactions to stress, c) cultural patterns of reaction to stress, and d) interventions targeted to vulnerable populations.

Overarching Issue 2: Examine the reports of increased incidence of psychological disorders in these communities and make recommendations regarding the direction for future strategies.

Overarching Issue 3: Address ethical concerns pertinent to dealing with the psychological responses to hazardous substances. This addresses the appropriateness of various intervention strategies.

Overarching issue 4: Identify future directions for investigation of the biopsychosocial effects from possible exposures to hazardous waste sites.

Panel Three.

Protecting and Promoting Psychosocial Health

Responding to the Problem: Protecting and promoting psychosocial health. Composed of clinical psychologists, psychiatrists, occupational medicine physicians, disaster relief specialists, and community members.

Charge: To develop public health strategies to prevent and control long-term, stress-related health problems in communities near hazardous waste sites.

Topics to be addressed by the third panel include:

1. Assessing the extent of the psychosocial effects and possible public health impacts in these communities to date.
2. Previous prevention and therapeutic strategies that have been used in these communities. What were the results of these interventions and what issues did they raise?
3. The most effective methods for preventing the acute stress of learning of the existence of a hazardous waste site from becoming chronic in adults and children.
4. The best methods to prevent demoralization from occurring in these communities.
5. Identification and appropriate referral of susceptible persons in these communities.
6. The best methods for increasing public and professional capacity to respond effectively to psychological issues related to hazardous waste sites.

Overarching Issues for Discussion by All Three Panels

Overarching Issue 1: Evaluate information about susceptible populations. This may include a) preexisting conditions (i.e., medical, psychological), b) individual variability in reactions to stress, c) cultural patterns of reaction to stress, and d) interventions targeted to vulnerable populations.

Overarching Issue 2: Examine the reports of increased incidence of psychological disorders in these communities and make recommendations regarding the directions for future strategies.

Overarching Issue 3: Address ethical concerns pertinent to dealing with the psychological responses to hazardous substances. This addresses the appropriateness of various intervention strategies.

Overarching issue 4: Identify future directions for investigation of the biopsychosocial effects from possible exposures to hazardous waste sites.

APPENDIX B

BIBLIOGRAPHY FOR THE PSYCHOLOGICAL EFFECTS PROGRAM

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APPENDIX C

THERE IS NO AWAY!

(Following is the manuscript of a talk given by Mary Minor in 1995
at the International Congress on Hazardous Waste.)

Mary and Joseph have vivid childhood memories of life in America during the great depression and later on of World War II struggles. It was after his discharge from military service that he took Mary for his bride in 1949. Together with millions of other young couples they began their quest for the post-war American dream.

Their story is shared with the hope that it will help others to help themselves and those around them.

“THERE IS NO AWAY!!”

by

Mary Minor, SFO¹

This presentation combines an autobiographical narrative and published results of clinical research to compare the symptoms of post-traumatic stress disorder to those symptoms evidenced by the survivors of Technological Disasters (TDs).

The chronic psychophysiological trauma often experienced by people living near toxic and hazardous waste disposal sites is presented in a personalized account. Deficiencies in government and institutional and community victim-assistance programs are discussed. Alternative approaches for providing this assistance and to promote emotional healing are described.

THE TRUTH IS

Technological Disasters & Resulting Psychophysiological Victimization Happen.

Let's Run Away!!

¹SFO = Secular Franciscan Order. Mrs. Minor is a professed member of the SFO, which is an organization that works for social justice and the resolution of other issues according to the dictates of their faith.

The day had finally come. After nearly 16 years of saving and dreaming, we set eyes and feet on the land where we would learn the true meaning of “stewardship.”

We found our dream home in 1966. It was an old farm house with 16 acres in the foothills of the mountains. We wanted our three girls to be able to hear only the wind in the trees. We wanted clean air, peace, and good water. The girls were all grown up and away before a Technological Disaster (TD) struck in 1983.

Please call me Mary. Dorothea is my middle name. It means “gift of God.” It is my belief that since I’ve been given the gift of life, I must offer something in return. So, what I do with my life is my gift to God and to society.

I am finding a measure of peace in doing “my part” and hoping to inspire others to do likewise. The bad news is that I did experience exposure to toxics released into our environment by technological failures or TDs. The good news for me is that I am healing. Victims of TDs, like myself, suffer in a variety of ways as a result of exposure to hazardous substances in our communities. Chronic exposure to toxic substances at never to be known levels is part of the trauma. Stress related health effects are a major concern along with other toxic exposure effects. Worst of all is the unknown; the invisible . . . and that never ends! And, if adverse physical effects to toxic exposure don’t “get you,” dealing with our regulatory, legal, and government systems will.

Some individuals never admit the problem—they simply have another viewpoint. Others become (due to loss of control of certain aspects of their lives) totally frustrated, filled with guilt, (how could a person let this happen to him or herself?), with a loss of confidence in government, a loss of value and meaning in life. They deal with present and future health concerns; physical illnesses; depression; anxiety; impotency; a sense of helplessness and violation; damage to property; self-blame; victimization; feelings of being trapped; alterations in family, social, and work relations; daily physical hassles (such as hauling drinking water); difficult economic situations; alterations in attitudes and feelings; serious generalized psychopathology; and impaired functioning levels.

These are not irrational hysterical reactions, but are rational—given the unnatural and threatening circumstances. The invisibility of hazardous substances is a large part of the dilemma. When you can’t see an invisible enemy, how can life be protected? When and where will it strike? This is stressful! You cannot know, unless you experience trying to protect your children and yourself in such a situation.

Stress is a global disease. Stress and the mind and body’s response to it can shatter individuals, communities, entire societies. We see now the growing breakdown of our society—things are getting out of control. Frustrations, anger, and violence are everywhere!

No one in the world can escape stress. Even in the best and less stressed segments of society, stress-related health effects are known to occur. You and your loved ones may be coping with whatever life situation you are in and taking it all “in stride.”

What would happen to you and your children if you suddenly were faced with poisonous chemicals in your local drinking water supply? Imagine the levels of lead (considered safe by the U.S. Environmental Protection Agency [EPA] 50 µg/Liter [µg/L]) found at 49 µg/L in the water coming from Helen’s faucet. Helen knew that 50.1 µg/L is considered by the EPA to be “unsafe” for her children. Helen and Al learned that their water is not yet contaminated enough at 49 µg/L. They were expected by government environmental regulators to just stay there and wait with their family for the toxic level to rise. In another year or two the water may again be tested to see if the family was yet poisoned enough for action to be taken. What would your reaction be? Think about it! Bottled water, filtering the system, testing the water yourself (it can cost thousands of dollars). Many pay the price to protect their families. Researching public records, acting to ensure regulations are being upheld, traveling to the state capitol and to Washington, D.C. to interact with elected officials to ensure that little “Sue’s” and “Willie’s” present and future constitutional rights are upheld are all part of citizens’ responsible response to community TD’s.

Try to imagine yourself in Al and Helen’s shoes. What could you do? Fathers have to go to work. For

that matter, so do wives. Now what about that little baby in its mother's womb? Enough? Get the picture? This is the world of the victims of TDs. Some of your neighbors, your own facility members, your state and federal departments of environmental protection may insist this should not worry you. Maybe you wouldn't —some people don't. Countless informed and realistic responsible parents think better of believing you can hand your child a glass of water with 49 µg/L of a toxin and not worry because 50 µg/L is the level considered "safe" for consumption by the EPA.

There are people who choose to remain in TD communities and work to better the situation. For some families experiencing TDs, the trauma has no end. Parents and children stay on and on in the contaminated community. Maybe they would like to leave. But, who would buy their home? They should reveal the presence of the TD in any real estate contract offer. This is only fair to prospective buyers. Informing buyers is the only ethical way to offer such properties for sale. Information made available allows for informed decisions about purchase and appropriate decisions for any protective measures needed. Will sellers get fair market value? Not likely.

Not all individuals admit the environmental and human threats in communities that experience TDs and hazardous substances releases. In ascribing to other perceptions of the threat to human health and welfare to their community, they also may deny themselves the opportunity to become better educated; thus they may not consider the risks or make informed decisions as to whether or not to take steps to protect their person and/or children and loved ones. There are those who may remain close minded and ignorant of continuing available information, which could be beneficial to their health and well-being. It must be remembered that these TDs are most often chronic and ongoing in nature. This may make it impossible for individuals to heal from the adverse effects of a TD

Dealing with agencies and institutions who have power over people and who are most often non-responsive or inefficient only exacerbates the stress.

As one who has become "expert" at living with

chronic exposure to trauma in an EPA Superfund site community and through extensive review of scientific studies and personal contact with other victims, **I believe:**

- People living with chronic stress in TD communities may acquire a syndrome which is similar to (but is not in fact) **POST Traumatic Stress Disorder (PTSD)**
- Most symptoms exhibited by some residents in these communities are the same as those seen in PTSD.
- How does the syndrome seen in TD areas (for chronically exposed persons) differ from PTSD? A significant portion of our entire local area has been affected by the TD in our local township— Pennsylvania Landfill Superfund Site. The following material is an excerpt from the *International Handbook of Traumatic Stress Syndrome: 1993:*

Posttraumatic Stress Disorder

The person has experienced an event that is outside the range of usual human experience and that would be markedly distressing to almost anyone (e.g., serious threat to one's life or physical integrity; serious threat of harm to one's children, spouse, or other close relatives and friends...).

The traumatic event is persistently reexperienced in at least one of the following ways:

- Recurrent and intrusive distressing recollections of the event (in young children, repetitive play in which themes or aspects of the trauma are expressed).
- Recurrent distressing dreams of the event.
- Sudden acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative [flashback] episodes, even those that occur upon awakening or when intoxicated).
- Intense psychological distress at exposure to events that symbolize or resemble an aspect of the traumatic event, including anniversaries or the trauma.

Our trauma is not POST?

- It is a never-ending process! - It is NOT a POST Traumatic Stress Disorder experience for affected persons in TD communities. The toxins do not go away and dealings with government officials and others are continual.
- TDs such as leaking landfills may not always be cleaned up; containment of toxics may be the only solution. Continued monitoring and vigilance is required.
- What is the syndrome? Acquired Toxic Exposure Syndrome (ATES).
- The disorder is something which one acquires as a reaction to the knowledge of toxins (usually man-caused) released into one's environment and the potential exposure for self and family and neighbors.
- ATES victims may suffer physically, psychologically, socially, economically (e.g., through local businesses, in the tax base) when people become aware of potential for toxic exposure from a TD in a community.

In an interview with Stephen R. Couch, PhD, Department of Sociology, Penn State University, I was told that I am remarkably consistent in my TD and related trauma experience with all others he has studied. He added that the difference in my response to this life altering TD experience made my story unique. How different? The question is a new one for me. There are likely to be multiple answers.

The first that comes to mind is that my natural concerns for myself and my own family immediately focused on the children's environmental education limitations. For me, the needs of the little ones in my own family and other communities soon became multiplied by the millions of exposed, victimized, and helpless children. They needed to be educated about technological failures and human victimization so they could make better and more informed decisions than we did.

The technological disaster impacting our community in south central Pennsylvania is a landfill that is leaking toxic substances into local ground water, drinking water, and streams. The children in

my family and community soon came to me personally to ask their questions and voice their concerns when the area's four recognized TDs (Superfund sites) in our county were making the headlines. That's natural. I'm a caring grandmother. Laura, a local high school student, was the first to ask me to come and talk to her biology class. We began to talk about the environment because I asked her to wrap my order in foil instead of Styrofoam at the carry out restaurant where she was employed part time.

I spoke to her class in a sensitive, factual, and informative way. Our children already know there is a lot wrong with their world. They are curious about environmental dangers, especially when it happens in their own or a friend's backyard. They want to learn: what, how, why, and who did it (sometimes). Mostly what's important to them is not who's responsible but how do we change things and stop doing whatever caused the disaster in the first place. And they are working to make those changes as we show our willingness to admit the problems and seek solutions together with them.

My personal healing process began thanks to the children. How could I, a mother, a grandmother, an example setter, remain frozen for an extended time in a state of apprehension and impotency? I couldn't and did not. Immediately, I sought the best information and moved forward to assess the communities' environmental concerns about the TD. We were all looking for a return to our normal family life and social conditions in our beautiful rural neighborhood.

Did it happen? No! Often, I dream of the time when we trusted that the two small landfills in our county would be run safely to protect the health, safety, and welfare of local citizens. But it was only a dream. Do I wish to go back? Not really. But the reality was that things had to change. We needed the public officials to listen to us. We now knew the landfill was damaging our community, mind, body, and soul, and we knew it could have been prevented if only the public officials on any level, city, county, state, or federal, had intervened or gotten involved at the first hint of an environmental health threat. We wanted and needed our concerns and interests to be met; our health to be protected. But that's not the

way it was. Not many of us would want to turn back the clock in our township. Prior to 1983, as a local businessman described our situation: We were to be “sacrificial lambs” in this issue. This was written in a February 1988 letter to our Governor of Pennsylvania. The local businessman had been “naive enough to trust . . . elected representatives . . . will not sell us out....” He soon lost this trust.

We’re all part of the problems that brought forth these growing number of TDs. All of us should take on the burden of **HEALING** for other communities and individuals, before being personally affected. We need common assessments, common goals, and the best solutions for us all; **HEALING** for millions of TD victims depends on our collective efforts on behalf of society and the safety of our environment. In 1995, there were at least 41 million people living within a 4-mile radius of Superfund sites in the United States according to the EPA (today, this number is 71 million). Remember, TDs can happen anywhere. Your community could be next.

“Pollution causes violent crimes,” according to a Dartmouth College scientist, Roger D. Masters. His study used “Federal Bureau of Investigation and EPA databases.” Such crimes and violence can be prevented if we intervene in our public health practices. Let’s begin to intervene.

How can you help? **Care** enough to become informed. **Learn** about the communities and people who are burdened with TDs. If you don’t come to know us and the nature of our disastrous experiences, you will not be able to understand and take action. Much is now known about the seriousness of stress-related and toxic exposure effects on human life and well-being of persons living in TD communities. When technology fails, environments may be contaminated and everyone can suffer (e.g., human health, nature, personal and business economy, growth potential).

A tremendous amount of information is available. I have included below a beginning list of references. To find information on how to deal with community issues regarding TDs and their long-term effects the following text is essential:

International Handbook of Traumatic Stress Syndrome,
 Edited by John P. Wilson (Cleveland State

University, Cleveland, Ohio) and Beverley Raphael (University of Queensland, Herston, Australia), publisher: Plenum Press - New York and London: 1993.

Contents of Interest

- Biological Response to Psychic Trauma
- Posttraumatic Stress and Adjustment Disorders
- Posttraumatic Stress...Common Themes
- Technological Hazards: Social Responses as Traumatic Stressors
- Intervention Considerations in Working with Victims of Disasters
- Posttraumatic Stress Disorder in Natural Disasters and Technological Accidents
- Chernobyl
- Responses to Children and Adolescents to Disasters
- Children...Stresses of Unrest and Oppression
- Coping with Disaster

References for Psychosocial Effects of Hazardous Waste Sites

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Environmental Issues: Today's Challenges for the Future: Fourth National Environmental Health Conference; 1989 June 20-23; San Antonio, Texas; p 257-64.

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Kroll-Smith S. As if exposure to toxins were not enough: the social and cultural system as a secondary stressor. *Environ Health Perspect* 1991;95:61-6.

Sherman JD. *Chemical Exposure and Disease: Diagnostic and Investigative Techniques*. Princeton, NJ: Princeton Scientific Publishing Co., Inc.

Vyner HM. *Invisible Trauma: Psychosocial Effects of Invisible Environmental Contaminants*. Lexington, MA: D.C. Health & Co.; 1988.

Citizens Urge Rescue of the Environment (CURE) Library

Being informed and alert allows us to make the best choices and changes needed to protect our future and that of our children.

You may not be aware of how close you and your own loved ones are to becoming names on the lists of victims (growing by the minute) in the government registries of persons exposed to toxic substances resulting from TDs.

This is serious business. Some of these hazardous substances enter the human body and take up permanent residence in tissues and organs. For those individuals in toxic pathways, "there is no away"; nowhere to run. Exposed persons may carry bioaccumulating toxins in their bodies indefinitely. Victimization is more of a concern today than yesterday. How can we protect ourselves and our children?

Education. Educate ourselves, our children, the bureaucracy, and appointed and elected public servants. We will never be aware of all toxins present or released in our environment. Pure is gone forever. We can admit we have a serious problem; a flawed system of priorities. **Choosing what we need** and trying to do the best to our ability to **make** and use

the things we **consume safely** will help. How can we participate in fostering the end to unnecessary use of technologies which are known to fail and bring disaster to human life? What we **want** and what we **need** can be very different. Better choices are in order for society, because millions are suffering unnecessarily. We want too many things which we **do not** need and now that we have them do not know what to do with them. Conserving energy could prevent the need for more nuclear power plants like Three Mile Island or Chernobyl. As we tender care to the present victims of TDs could we not practice conservatism and lessen tomorrow's growing registry of exposed persons? Finding a better way than throw away is a must for a safer environment. "Away" is a place we will have to try and clean up someday; like the leaking landfill in my community.

If you have been a TD victim, I know your pain. I weep with you for your adversely affected quality of life. Your sleepless nights are understood by me. You understand me. I know your frustrations. On the other hand, I am experiencing a measure of **HEALING** with my family and community. What encouragement! There were times when I saw very little "light at the end of the tunnel." Will I ever completely **HEAL**? Maybe. Maybe not. I am joyful for my degree of wellness today. I look for a better tomorrow. Scientific studies have shown that TD victims may show serious psychopathological dysfunction. The public has the right to know that groups studied were adversely affected and that "for about half the subjects (studied), functioning levels were seriously impaired (Gibbs, Margaret, 1989)." With the aid of such studies, we can predict the affects of TDs. If we can predict such disastrous affects, we can and should move to prevent them. We cannot afford **NOT** to adopt preventative measures for the common good.

Such groups of victimized persons are not health segments of society. Unhealthy people means human suffering and economic loss, which affects us all.

If your life has not been shattered by a TD and related exposure, I am happy for you. I hope it never happens to you.

For the victims and those yet untouched, I say we need to continue to look for solutions to environmen-

tal contamination and preventive measures and act to implement them. TDs do not have to happen.

Because of you who know and share my losses and those of you who care enough to come to our aid in communities which need help in **HEALING**, I write this paper.

In the **HEALING** experience the helped and the helpers will benefit. We can lessen future victimization by acting to change our system. We should further study and acknowledge general psychopathology as an effect of TDs. The EPA, the United States Department of Health and Human Services, and other government institutions have historically been largely in the "dark" on this subject. Shall we "turn on the light" and show the need for health intervention for these "wounded millions."

Only if society admits the present lie about the victimization resulting from TDs and the vast number of suffering individuals can the process of **HEALING** expand to include all. If this does not happen soon, will the breakdown of our country be beyond repair? I was taught from childhood that a peaceful and healthy mind is a must for a healthy body.

I share this story because of you who can help and those who need help. You have read it. Do you believe? Do you care enough to help? I have learned and am doing my part. May readers learn theirs.

Peace be with you.

Mary

"Remember - for evil to triumph, it is necessary only for good men to do nothing."

- Edmund Burke

Note: Except for the author and her family, names of individuals have been changed.

UPDATE

Since December 1993, a multidisciplinary research team has been investigating stress within our community. Sociologist, Stephen R. Couch, PhD, and psychologist, Jeffrey D. Kindler, PhD, are exploring community interventions to pilot in our community.

In April 1995, at the invitation of the Agency for

Toxic Substances and Disease Registry (ATSDR) and the Keystone Landfill Task Force (Steering Committee), the ATSDR began to investigate a new agency involvement approach with our community. The 2-day procedure included 2 covered dish dinners and informal dialogue. ATSDR came and listened to our concerns in detail. These concerns led to the development of new objectives and a resurgence of cautious hope among community participants.

The author, with her husband, three daughters and elderly mother, lived in rural Pennsylvania in the area of a landfill leaking toxic substances (an EPA Superfund site). She served as president of Citizens Urge Rescue of the Environment (CURE), the Victim's Academic Network (VAN) and CITIZEN; a member of the Union Township Planning Commission, the Keystone Landfill Task Force (TF), People Against Contamination of the Environment (PACE), and Union Township RESOURCE Committee, and other community service. She is also a certified Pennsylvania Municipal Landfill Inspector.

May 23, 1995

Quote on blood disorders near superfund sites

Following is a portion of the testimony of Barry L. Johnson, PhD, Assistant Surgeon General, Assistant Administrator for ATSDR, Public Health Service, U.S. Department of Health and Human Services, given before the Subcommittee on Commerce, Trade, and Hazardous Material Committee on Commerce, U.S. House of Representatives:

Cancer and Immune System Function

"Blood samples from approximately 6,000 persons who live near 10 hazardous waste sites showed an increased rate of an unusual production of abnormal blood cells that has been associated with chronic lymphocytic leukemia. Thus far these observations have been predominantly among people who were potentially exposed to volatile organic compounds."

May 17, 1995

Polycythemia vera (a rare blood disorder)

Mary's husband, Joseph, had been diagnosed with polycythemia vera (PV). He has begun chemotherapy (drugs to kill extra blood cells in the body) and

presently the disease is in “control.” Doctors say there will be no remission. More research needs to be done.

Joseph and Mary had thought to live out their days in their dream house. In May 1996, 30 years later, they left their dream home to another family: Roy, Elizabeth, and son Noah. They finally had had to downsize to a small stone house not far away because of age, ill health, and economic circumstances. Stewardship of their beloved “Minor’s Folly” (named by their three daughters in 1966) was given over by old friends to new friends who share in common devotions to responsible stewardship of creation and commitment to county service.

We need to remember the Keystone Sanitation Landfill disaster to better define our system’s weaknesses and strengths. The children will always need to such stories. Their informed choices depend on keeping the memory of struggles for justice alive. Joseph and Mary experienced technological disasters and resulting economic devastation. They are grateful to serve and are devoted to helping others avoid such experiences.

CURE Adopts Education Committee (Victim’s Academic Network [VAN])

VAN Mission Statement

The Victim’s Academic Network was formed in response to the need for the education of citizens, governments, and other institutions to bring about awareness of the dangers of environmental contamination. This group is networking with others to implement educational programs and presentations.

IN MEMORIAM:

Marianna Cates

New Paltz, New York, died on June 21, 1995. She was co-chair of CURE and VAN Education Committee, and Foundress and Executive Director of the Cancer Awareness Coalition.

Herbert Lee Green

Fairfield, Pennsylvania, died suddenly on March 16, 1995. He was mentor and friend of CURE and countless other citizens who sought environmental justice. He was a former employee of the Pennsylv-

nia Department of Environmental Resources.

*We mourn our loss and continue to work,
inspired by their example.*

**“Justice will not come . . .
until those who are not injured
are as indignant as those who are.”**

- Thucydides

Following is a list of some things we can do:

- *Take action* and encourage others to aid victims of TDs.
 - *Support* timely, multidisciplinary mitigation actions for TD communities.
 - *Intervene* by caring, sharing, planning, implementing, teaching, guiding, learning about experiences for victims.
 - *Promote* a better way than throw away.
 - *Reduce* use of toxic substances.
 - *Admit* the facts about TD victimization
 - *Insist* on honest health, chemical, and environmental reporting.
 - *Love* those affected by TDs enough to act socially, politically, economically.
 - *Support* scientific reviews of existing studies and support further health studies.
 - *Help* victims who have lost control of their environment regain power.
 - *Recognize* that victims of TDs may need self-implemented solutions to help with the healing process.
 - *Acknowledge* the normalcy and predictability of people’s actions in light of their stressed lives.
 - *Work* for social change to educate ourselves and our children about TDs and environmental degradation and victimization.
 - *Stop* acceleration of TDs and resulting victimization, societal breakdown, and environmental degradation.
- Let the shared task of HEALING begin!*
- *Commit* to personal action.
 - *Hope* that others see the change and take action to facilitate it.

Most recently, the Agency for Toxic Substances and Disease Registry (ATSDR), the U.S. Environmental Protection Agency (EPA), the Citizens Urge Rescue of the Environment (CURE), and representatives from Penn State University met in Arlington, Virginia, November 16, 1998, to discuss the Keystone community's ongoing concerns about stress related to the Keystone Sanitation Landfill Superfund Site. Presentations were made by Mary Minor, CURE, and Reverend Julian Hall, Trinity United Church of Christ, on the community perspective of living near a Superfund site; by Stephen Couch, PhD, Penn State University, Center for Environment and Community, on the predictability of adverse effects to human health and quality of life in chronic technological disasters, human and economic costs, ideas on how to mitigate trauma to communities, and community empowerment; by Maureen Lichtveld, MD, MPH, ATSDR, on ATSDR's Psychological Effects Initiative; and Pam Tucker, MD, ATSDR, on the psychobiological effects of stress, the current state of science and data gaps, case studies and lessons learned, and a training module developed for public health officials.

The one-day meeting included Mary Minor retelling the story of the Keystone Landfill disaster. Following this introduction, an open multiperspective discussion ensued on outreach, education, and proactive intervention on the stress-related health effects, as well as the social dimensions, for communities located near Superfund sites. The science of stress-related effects was shared and a dialogue was begun on stress and the development of partnerships to help implement stress-intervention programs. New goals were set for relieving the chronic problems of the Keystone Landfill and reducing the chronic stress of the Keystone community.

By the end of the meeting, the group had agreed upon a number of "next steps" focused on the continued healing of the Keystone Landfill Superfund Site community. Following is a list of some of the next steps and a progress report:

- Recognize stress as a major health concern,
- Determine if Keystone is candidate for an ATSDR community-based demonstration project,
- Open communication with Mary Minor

concerning her presentation and the community's participation in the meeting,

- Develop a means to incorporate psychological stress into risk assessments and public health evaluations,
- Identify instruments to measure the success of programs,
- Establish a working museum or archive of the Keystone Incident, and
- Complete a community needs assessment.

In addition, the Community Stress Task Force (CSTF) subcommittee was formed, with representatives from CURE, Penn State University, EPA, and ATSDR, to support the sharing of the story of the Keystone Landfill Disaster to inspire others to take responsibility to ensure the well-being of our environment, to provide education, and to raise public awareness. The CSTF is focusing on the goal to build and maintain a library/archives, to write documentation and history, to begin outreach efforts and the production of educational materials and activities.

During the summer months of 1999, several meetings have been held in the community. The program, sponsored by CURE and the CSTF, initiated the organization and preservation of materials contained in the CURE archives to make them more readily accessible to community members. The program also developed a plan on how to use archived materials to develop research and educational activities, and continue the implementation of initial educational activities. A video is planned to document the Keystone Incident and give an historical account. Also, through Penn State University, an internship program began in July 1999.

GLOSSARY

Adrenal cortical response

a response of defeat or withdrawal (i.e., helplessness) that is biologically based on cortisol secretion by the adrenal cortex.

Adrenal medullary response

a first response to fight or flee when challenged by a threat (e.g., exposure to a hazardous substance) that is biologically based on the sympathetic.

Bioaccumulation

process by which organisms retain chemical pollution in their tissues at levels that are higher than those found in the surrounding environment.

Cognitive appraisal

looking at and interpreting the nature of a situation (e.g., a threat).

Demoralization

feelings of hopelessness and helplessness.

Depression

a disorder of mood characterized by feelings of low self-esteem, hopelessness about the future, little activity and appetite, and sleep disturbance.

Detoxification

the process of removing a poison or toxin or the effect of either from an area or individual.

Disempowerment

to lose legal capabilities or control, to lose authority.

Ecohistorical

the environmental record or account of an area.

Epidemiologist

a person who studies how often, in whom, and why a disease occurs in a population. An epidemiologist looks at the sum of the factors controlling the presence or absence of a disease and the possible causes (e.g., coming into contact with a hazardous substance).

Epinephrine

adrenaline; a hormone that is released in response to stress or other stimuli (e.g., a reaction to a stressful situation, can raise blood pressure).

Field research

a type of research during which social scientists record their observations of communities (e.g., communities being affected by possible exposures to hazardous substances).

Heterogeneous population

a group of people (e.g., in a community) who are different (e.g., in culture, socioeconomic level, age).

Holistic view

a way of looking at something that includes all of its parts at one time, looking at the whole or complete picture (e.g., how humans and the environment work together) or how medicine can treat both the mind and body at the same time.

Homogeneous population

a group of people (e.g., in a community) who are similar (e.g., culture, socioeconomic level, or age).

Interaction analysis research

a way of studying groups of people by looking at the members' reactions in categorized emotional and problem-solving responses.

Longitudinal study

a study that looks at changes (e.g., in a person or group of people) over a long period of time.

Marginalized community

a community that feels disenfranchised, or without legal right or other privileges; a susceptible or vulnerable community (e.g., created by establishing boundaries to indicate environmental contamination).

Mercurialism

mercury poisoning. Preclinical signs of mercury poisoning resulting in tremor and emotional changes occur at urine mercury levels greater than 500 micrograms/Liter.

Nervios

a general state of vulnerability to stressful life experiences and to a syndrome brought on by difficult life circumstances. This type of distress is common among Latinos in the United States and Latin America, with similar concepts of "nerves" among Greeks in North America, *nerva*.

Neurobehavioral disorder

a response to an occurrence (e.g., exposure to a hazardous substance) that results symptoms of a neurological (e.g., a tremor) or behavioral (e.g., mental distress) nature.

Neurotoxins

poisonous substances that can have a negative effect on the nervous system.

Nonspecific health outcomes

negative physical responses to a situation or an exposure that do not seem to fit a defined pattern.

Norepinephrine

a hormone that is produced before epinephrine (adrenalin) and results in a similar reaction in the body. (See Epinephrine.)

Occupational stress

strain or tension associated with one's job. In the context of this report, the word refers specifically to strain or tension associated with working near or in a hazardous environment or with a hazard substance.

Physiological health effects

adverse effects to health resulting from psychological and social factors.

Pibloctog

an episode of extreme excitement, which lasts up to 30 minutes and is often followed by convulsive seizures and coma lasting up to 12 hours among Alaskan Eskimos (26).

Post-traumatic stress syndrome (PTSD)

a pattern of symptoms (e.g., anxiety, tension, depression, nightmares) that follows a disaster (e.g., exposure to a hazardous substance).

Psychiatric epidemiologist

a person who studies how often, in whom, and why a mental disorder or disturbance occurs. A psychiatric epidemiologist looks at the sum of the factors controlling the presence or absence of a mental disorder or stress and the possible cause (e.g., coming into contact with a hazardous substance).

Psychobiology

a field of psychology that looks at how an organism (e.g., a human) adapts to its environment through its physical makeup (e.g., the nervous system).

Psychosocial

the way a group of people interacts mentally (e.g., social interaction).

Qualitative method

a means of studying factors that influence a response on the basis of attributes that are or aren't present

Quantitative method

a means of studying factors that influence a response that is measured on a numerical scale of equal intervals.

Secondary control

an attempt to change one's self to suit the existing circumstances.

Secondary gain

a positive outcome or advantage that occurs as a result of an incident (e.g., illness results in attention, time off from work).

Secondary victims

workers or participants who enter a situation to offer help and who subsequently react with exhaustion or irritability.

Sensitivity

a state of being responsive to an occurrence or substance.

Sensitization

the process of becoming easily hurt or affected by exposure to or the possibility of being exposed to a hazardous substance.

Sequela(e)

an effect that occurs after an illness or injury (e.g., depression, a constant state of nervousness).

Siting decision

to make the choice to locate a building, facility, or project in an area that can affect the environment in a number of ways.

Somatic

having to do with the body.

Statistical significance

a difference found among groups after a comparative randomized investigation that is not likely to be caused by chance alone. The probability of it occurring by chance alone is often reported as $P < 0.05$.

Stress

a state of physical or psychological strain or tension.

Subcultures

an ethnic, regional, economic, or social group having patterns of behavior that are specific to their group.

Subjective phenomenon

an occurrence that is seen through the eyes of the beholder.

Subpopulations

an identifiable part of a larger population (e.g., health care workers, factory workers).

Susto

a folk illness that is attributed to a frightening event. This illness is found among some Latinos in the United States and among people in Mexico, Central America, and South America.

Syndrome

a group of symptoms that occur together and indicate a specific health problem.

Target Organs

A part of the internal body, for example, the nervous system, cardiovascular and gastrointestinal systems, that could be adversely affected by exposure to a hazardous substance and resulting stress.

Threat

an individual's awareness of an imminent, widespread change in their environment that poses a possible danger (e.g., a large chemical spill).

Trauma induction

the process by which a person begins to experience suffering from a highly stressful event.

Trauma reduction

the process by which an individual's suffering from a highly stressful event begins to lessen.