



# Environmental Health Disparities and Environmental Justice Meeting

July 29-31, 2013 | NIEHS, Bldg. 101, Rodbell Auditorium | Research Triangle Park, NC

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## Keynote

### *It Takes a Village: Integrated Methods for Addressing Environmental Health Disparities*

**Speaker:** Marie Lynn Miranda, *University of Michigan*

**Room:** Rodbell ABC

#### **Keynote Description:**

Although it is widely agreed that health and well-being are determined by multiple forces, surprisingly little is known about the interactions of those forces. Adverse environmental contaminant exposures often occur in communities facing multiple social stressors like deteriorating housing, inadequate access to health care, poor schools, high unemployment, crime, and poverty — all of which may compound the effects of environmental contaminant exposures. Using work focused on air pollution and pregnancy outcomes, this talk highlights the need for collaborative work that crosses disciplines and employs multiple methods, which are necessary if we are to succeed in addressing the many health disparities that persist in our country. Understanding, and then intervening, to prevent adverse environmental and social exposures is of critical importance to the health of our nation.



## Concurrent Sessions #1

### *Research to Action: Translational Research to Address Health Disparities and Environmental Inequities*

**Moderator:** Caroline Dilworth, *NIEHS*

**Presenters:** Laurel Schaider, *Harvard School of Public Health*

Rebecca Jim, *L.E.A.D. Agency*

Linda McCauley, *Emory University*

Patrick Ryan, *Cincinnati Children's Hospital Medical Center*

Jeannie Economos, *Farmworker Association of Florida*

**Room:** Rodbell BC

#### **Session Description:**

Studies funded through the NIEHS Research to Action program have focused on health disparities from environmental and occupational exposures that community members identify as a local concern. This session highlights three Research to Action projects and the close collaborations formed with community partners from health disparate communities who, together with their academic partners, sought to address environmental inequities and health disparities at the local level. These academic-community partnerships led to the development of education, prevention, and intervention programs and to the translation and dissemination of the research findings in culturally appropriate language and formats. The presenters will discuss their interactions with community partners in research and how these active partnerships have implemented public health initiatives and policy changes that are leading to the prevention or reduction of harmful environmental and occupational exposures as well as to improvements in human health. This includes research conducted with Latino farmworkers in Florida exposed to high doses of pesticides, with parents and teachers in Ohio to address a high prevalence of asthma among schoolchildren, and with community members in northeastern Oklahoma to address mercury exposure resulting from subsistence and recreational fishing.

#### **Discussion Questions:**

- Has the coupling of research with an identified public health action plan in a single project led to greater progress in addressing environmental health disparities than if these activities were conducted separately? If so, what are the specific attributes of the project that have led to this synergy?
- How can this type of research help address structural problems responsible for health disparities in the communities?
- How can this research be translated into improved clinical practices in community health centers?
- What are you and your partners doing to ensure these projects are sustainable? What is needed to keep the momentum going?
- How well have expectations going into the study matched actual study findings? How have you reconciled differences between what you expected to find and what you actually found?



## *Innovative Tools and Technologies for Environmental Public Health Research*

**Moderator:** Symma Finn, *NIEHS*

**Presenters:** Sharon Croisant, *University of Texas Medical Branch*  
Jose Antonio Tovar, *Farmworker Association of Florida*  
Sara Wylie, *Northeastern University*

**Room:** F193

### **Session Description:**

Researchers in environmental public health and related fields have been developing new modalities for measuring and assessing environmental risks and adapting existing tools specifically for use in environmental health research. These methods, approaches, and tools are often developed to allow the fuller engagement of community partners in the research process and have the potential to be used by community organizations to sustain environmental assessment activities beyond the period of funding. This session will highlight the work of three researchers who have leveraged existing tools, such as geographic information system (GIS) mapping, for community-based research, and developed new approaches that are being applied in environmental public health research. This includes the use of Social Network Analysis to track family and community connections in a study of post-disaster resilience, and the development of cost effective, open source, Do-It-Yourself tools to stimulate community-based involvement in research and to promote increased environmental health literacy in health disparate communities.

### **Discussion Questions:**

- Is there any advantage to developing new tools and approaches rather than adapting existing ones for use in environmental health sciences research?
- What have been the major challenges to adapting tools and approaches?
- What is the value of developing new approaches or tools that measure risk in novel ways, if regulations are based on traditional, established measurements of risk? Within a project term, is it reasonable that a research outcome be recommendations to adjust common standards for evaluating risk?
- Does the use of existing tools allow for greater data sharing or generalizability across studies, based on common measurements or assessment tools?
- Should funding agencies and funded researchers be promoting greater sustainability beyond the term of funded projects? Should research projects and programs promote cost-effective and easy-to-use tools and approaches as the optimal means to promote sustainability or are there other ways to achieve sustainability?
- Should the goal to increase scientific literacy, numeracy, and capacity to understand and participate in research be central in or the focus of community-engaged projects? Should funds be designated for such activities in all community-engaged research?



## *Effectively Reaching Underserved Populations: Lessons Learned on Culturally Appropriate Communication Strategies and Tools*

**Moderator:** Marti Lindsey, *University of Arizona*

**Presenters:** Neasha Graves, *University of North Carolina, Chapel Hill*  
Sara Quandt, *Wake Forest School of Medicine*  
Monica Ramirez-Andreotta, *Northeastern University*

**Room:** Rodbell A

### **Session Description:**

The purpose of this session is to examine the ways in which projects are communicating environmental health disparities (EHD) research findings in culturally appropriate ways. Communication and dialogue among all research partners is central to effective community-engaged research. Such communication requires that community residents, health care professionals, and decision-makers understand the connection between environmental factors and health and have the ability and capacity to act on this knowledge to prevent, mitigate or regulate exposures. In this session, panelists will begin the conversation by sharing how they investigated the educational needs of young African American women, Latino farmworker families, and rural gardening communities to understand environmental health science on breast cancer risk and exposure to arsenic and pesticide. They will highlight the culturally appropriate materials and tools developed in response to those needs. The panelists will describe how they are translating their findings about the systemic issues affecting black women's breast health, farmworkers' pesticide exposure, and a rural Arizona community's exposure to arsenic near a Superfund site into information that can be used by policy makers, community members, and health care professionals in addressing environmental health disparities. Meeting participants will then discuss other approaches and identify priority actions to further advance translational work.

### **Discussion Questions:**

- Which projects presented by the panelists resonated with you as you consider communication strategies and tools for your own constituents (communities)?
- What specific EHD and environmental justice (EJ) issues/communities is your organization working to address/impact?
- Based on what you learned from the panel presentations about culturally appropriate communication strategies and tools, what are some potential opportunities (or gaps) in addressing EHD/EJ issues? What are some challenges?
- What resources are needed (knowledge, partners, funding, etc.) to address EHD/EJ through effective communication strategies and tools?
- In terms of effective communication to address EHD/EJ, what are the priority next steps? How can we evaluate the success of these next steps?
- What steps can we take to help community partners frame their environmental health research questions? How do we help them locate and partner with researchers who conduct studies that could answer those questions?



## ***Addressing 'Research Disparities': Building Connections to Build Capacity***

**Moderator:** Liam O'Fallon, *NIEHS*  
**Presenters:** Senaida Fernandez, *University of California*  
Sacoby Wilson, *University of Maryland*  
Doug Stevens, *Salish Kootenai College*  
Alice Park, *Community-Campus Partnerships for Health*

**Room:** D350

### **Session Description:**

Through a variety of federal, state, and foundation-supported programs, many community-engaged (community-university) projects have been supported, developed, and implemented to address environmental health concerns of community residents. However, as noted in several recent reports, there are communities that are not able to tap into and benefit from federal and foundation support. Such 'research disparities' present a challenge and an opportunity. In this session, panelists will describe training programs they have developed or benefited from, reflect on the importance of filling the gaps of these research disparities, and consider ways in which existing models can be built upon. Panelists will discuss multiple excellent examples of training activities and curricula, all designed to build the capacity of community residents, health care professionals, and researchers to work collaboratively in the full research process. Special attention will be given to issues surrounding project sustainability and transitions from capacity to research to implementation. Participants will consider how various programs and partnerships (for example, federal, state, and foundation programs as well as public-private partnerships) can advance the training needs to address EHD and EJ.

At the end of the 90-minute session, the group will identify two to three priority next steps that can be implemented by participants of all levels of involvement (community, researcher, and federal).

### **Discussion Questions:**

- What are best practices and/or successful models?
- What are the opportunities/strategies to advance those efforts?
- How can the challenges to addressing 'research disparities' be met?
- What are the different pipelines? What are the unique needs of those pipelines? What are the similarities?
- Are there examples of scaling up activities? How can existing initiatives be scaled up? Should they? Why or why not?
- What strategies have been used to sustain capacity-building efforts? What made them work?
- How can we ensure smooth transitions from capacity to research to application? How do we show impact along the continuum?
- What are the priority next steps (for each level) in addressing 'research disparities'?
  - What can people do at an individual level?
  - What can community organizations and academia do?
  - What can funding agencies do?



## Concurrent Sessions #2

### *Examining Environmental Determinants of Health and Engaging Communities around EPH Issues Using Geographic and Spatial Analysis*

**Session Leads:** Richard Callan, *U.S. EPA*

Nishadi Rajapakse, *NIMHD*

**Moderator:** Ken Olden, *U.S. EPA National Center for Environmental Assessment*

**Panelists:** Paul Juarez, *University of Tennessee Health Science Center*

Sacoby Wilson, *University of Maryland*

Beverly-Xaviera Watkins, *Weill Cornell Medical College*

**Room:** Rodbell BC

#### **Session Description:**

There is a substantial body of evidence linking social and physical environmental factors (i.e., increased exposures to toxins and pollution) and limited access to healthy foods and recreational activities, to adverse health outcomes. Adverse health outcomes include acute conditions such as respiratory illnesses (including asthma) to more chronic conditions such as cardiovascular disease, obesity, cancer and poor mental health. Efforts to both engage communities around environmental public health issues and examine environmental determinants of health disparities can be enhanced by the use of spatial analysis system and geographic information system (GIS) community level mapping of data on:

- *Socioeconomic and demographic indicators:* Income levels, housing, vital statistics, census, and employment data
- *Natural and built environment characteristics:* Indoor and outdoor air quality, surface and ground water quality, food safety, contamination of soils, and placement of noxious land uses
- *Local environmental health risk factors:* Emissions from vehicles, waste removal and disposal, use of pesticides, local industry (i.e. dry cleaners, restaurants)
- *Health care services:* Outreach services, clinics, hospitals, and first responder organizations
- *Ecological data:* Land use changes including flooding risk related to climate change
- *Health data:* available from local, state, and federal agencies

These provide a visual tool for identifying disease outcomes that may be environmentally linked and developing interventions to diminish physical hazards, increase positive attributes in the community, and reduce vulnerability to environmental harms and negative health effects. In addition, these maps enable local community-based organizations to increase public awareness of environmental public health issues and advocate for policy change.

This panel will provide an overview of their research with community level mapping of GIS data.



### Discussion Questions:

- How can GIS be integrated into exposure science?
- What is the role of community in GIS related research?
- What environmental exposures increase the risk of development and/or progression of cancer?
- Does exposure to toxins at different life stages increase risk for neurodevelopmental disorders?
- GIS mapping has the potential to enhance the capacity of community-based organizations to change public policy, yet it is not mentioned in most community engagement RFAs. Is it time, as was the case for project evaluation, for the funding institutes to consider GIS mapping in its assessment of community engagement research proposals?
- Although linking health outcomes to environmental factors at the neighborhood level is important for the development of targeted interventions and public policy, aggregation of local health data has made it difficult, if not impossible, to conduct these analyses. How can community-based organizations and researchers overcome this barrier?



## *Inequities Persist: Environmental Justice from a Native American Perspective*

**Moderator:** Symma Finn, *NIEHS*

**Presenters:** Katsi Cook, *Running Strong for American Indian Youth*  
Clarita Lefthand-Begay, *University of Washington*  
Johnnye Lewis, *University of New Mexico*

**Room:** D350

### **Session Description:**

Environmental justice (EJ) has emerged as an important component of environmental public health that moves beyond the identification of environmental health disparities to research and policy changes that attempt to address ongoing grievances and injustices related to environmental exposures. Since the development and implementation of the first DHHS EJ strategy in 1995, progress has been made in identifying and addressing disproportionately high and adverse environmental exposures among low-income populations and Indian tribes, but inequities persist.

These inequities disproportionately affect the 566 federally recognized tribes and 5.2 million Native Americans and Alaskan Natives in the United States who experience high levels of environmental exposures, and the effects of multiple exposures, over the life course. This session will explore several ongoing EJ issues that these tribal groups have mobilized around for many years and highlight the ongoing health and environmental health disparities that disproportionately affect these groups. The case studies presented exemplify culturally sensitive approaches that have successfully addressed EJ issues and that do not represent “forced acculturation” of investigator-driven, evidence-based interventions. The session will also touch upon issues that remain unresolved despite existing efforts to mitigate or prevent environmental exposures that are known to be harmful. This includes the harmful effects of mining on tribal lands, the contamination of traditional foods by persistent organic pollutants, and the disruption of Native Americans’ sustainable and reciprocal relation with the environment from policies, environmental threats, and global climate change.

### **Discussion Questions:**

- What priority issues cut across tribal nations?
- Can we leverage past successes and apply these methods in different Native American settings, or should tribal groups work at a more regional and local level to address inequities unique to their region?
- Should we be increasing researchers’ and government officials’ understanding of the differences between tribal groups, or is there greater power in being considered a single, unified ethnic community with common issues?
- How are we addressing the historical issues? What are the challenges? What strategies should we recommend for keeping these historical inequities a priority in the context of the current national movement to address environmental justice?
- Should funding agencies and funded researchers be mandating greater sustainability beyond the term of funded projects? Should research projects and programs require cost-effective and easy-to-



use tools and approaches as the optimal means to promote sustainability, or are there other ways to achieve sustainability?

- Should the goal to increase scientific literacy, numeracy, and capacity to understand and participate in research be required as a component of community-engaged projects? Should funds be designated for such activities in all community-engaged research?



## *Community Experience of Contaminated Communities: Contributions from the Social Sciences*

**Moderator:** Beth Anderson, *NIEHS*

**Presenters:** Phil Brown, *Northeastern University*  
Michael Edelstein, *Ramapo College of New Jersey*  
Elizabeth Hoover, *Brown University*

**Room:** Rodbell A

### **Session Description:**

Social scientists have been central to improving our understanding of the impacts of Superfund and other hazardous waste sites, chemical explosions, oil spills, and human-exacerbated natural disasters. This session focuses on ethnographic case studies that explored environmental inequities. Some of these are "stand-alone" studies by social scientists, and some of them are parts of interdisciplinary collaborations with environmental health scientists. In both cases, social science research offers much for environmental health science and to environmental policy. We will additionally address the past and potential future role of NIEHS in advancing such research. NIEHS has played an important role in supporting environmental justice and community-based participatory research, which has contributed to the study of communities impacted by environmental hazards. Community-level understanding of contaminated communities has also benefited from the community engagement cores that are part of center grants: Superfund Research Program, Children's Environmental Health Center, Environmental Health Core Centers, and Breast Cancer and the Environment Research Centers. A 2012 Superfund Research Program workshop at Brown University further contributed to this research area.

This panel includes scholars from sociology, anthropology, and psychology, who will review the state of knowledge about community experience of contaminated communities.

### **Discussion Questions:**

- Should contaminated communities undergo a "social and cultural impacts assessment" by social scientists in addition to an environmental impacts assessment and a health impacts assessment?
- How could we develop a few long-term research sites to provide longitudinal research on contaminated communities?
- The stress of dealing with the post-contamination process is roughly equal to the stress of becoming "contaminated" to begin with. How do we minimize that "post-discovery" stress to the people in the contaminated community?
- What is the role of community activist organizations in pushing government and business to adequately clean up hazardous sites?
- How can we best partner with affected residents in order to incorporate community input into study design and implementation to thoroughly research social impacts? How do we best present our research to the communities that we study?



## Day 1 General Session

### *Institutional Review Boards and Community-Engaged Research: How can Universities and Community Organizations Work Together to Strengthen the Ethics Review of Community-Based Research?*

**Session Leads:** Sharon Beard, *NIEHS*  
Joan Pakenham, *NIEHS*

**Moderator & Presenter:**

Alice Park, *Community-Campus Partnerships for Health*

**Presenters:** Katie Barnes, *University of North Carolina, Chapel Hill*  
Emily Anderson, *Loyola University Chicago*  
Eric Wat, *Special Service for Groups*

**Room:** Rodbell ABC

**Session Description:**

Community engaged research raises ethical questions that go beyond individual level of protections to include those at the community level. This session will address the successful integration of community based organizations into the human ethics review process by sharing best practices and lessons learned on engaging community members on University Institutional Review Boards, Community-based Research Review Boards or Community Investigations Review Boards. These concerns can range from training all individuals involved in community engaged research on IRB processes and the protection of human subjects, proper informed consent processes, understanding cultural and community influences towards human research, return of data and data sharing with the community and determining effective training to meet community and academic researcher needs.

**Discussion Questions:**

- How can we strengthen community involvement in the research ethics review process?
- What can we do to support community members involvement in research ethics review processes?
- How can we strengthen the relationship between community review processes and academic IRBs?
- How can we address challenges faced by community review processes?
- What factors contribute to effectiveness of community review processes? What impact do community review processes have?
- What changes could be made to strengthen community review processes?
- What recommendations can we offer to community organizations that are interested in developing their own processes for research ethics review?
- What training opportunities and resources are available for training community and researchers on the IRB process?



## Day 2 General Session

### *Challenges and Opportunities for Supporting Community-Based Research to Address Environmental Health Disparities and Environmental Justice*

#### **Moderators & Presenters:**

Pamela Miller, *Alaska Community Action on Toxics*  
Molly Puente, *NIEHS*

**Presenters:** Thomas Arcury, *Wake Forest School of Medicine*  
Karla Fortunato, *Health and Environmental Funders Network*

**Room:** Rodbell ABC

#### **Session Description:**

Community-based research requires building partnerships with many different people and organizations. While the partnerships themselves can provide invaluable resources to conduct environmental health research, often groups need to seek additional resources and funds from other sources. Some groups may face the challenge of identifying potential collaborators and funding sources to initiate new partnerships, while others are looking for opportunities to sustain a successful partnership to continue existing research projects. This session will include a panel of speakers representing the perspectives of community-based organizations, academic institutions, non-profit foundations, and federal agencies. The speakers will discuss what their organization can bring to the table in terms of providing resources and some ideas they have on where their organization has been successful in providing or securing resources in the past. Additionally, there will be a larger discussion of the challenges and best practices for engaging communities that tend to fall outside the reach of most federally funded research programs.

#### **Discussion Questions:**

##### General:

- What are the major factors that limit community/non-profit organizations participation in grant-funded projects?
- What makes a particular funding source a good match for an organization or project? How can an organization adapt if its traditional funding source no longer meets its needs?

##### For Non-Profit/Community Organizations:

- Beyond training in environmental health and research methods, what are the topics for which you (your organization) need additional training in order to participate in grant-funded projects? Are there any helpful resources your organization has developed or used to address some of these training needs?
- Beyond funding support, what types of support would help your participation in research grant-funded projects? How does this change as a project/collaboration matures? Are there ways to leverage resources to get this support (e.g., access to a general IRB)?



- Federal government grants work on a cost-reimbursement basis, but many non-profits do not have the cash flow or cash on hand to undertake expensive programs and wait for reimbursement. How has your community organization handled cash flow issues? Does your role on a grant — as a consultant, consortium partner, or the prime grantee — impact your organization’s ability to manage cash flow?
- The time from application to award can often be up to a year. Does this cause any unique problems for organizations working on environmental health disparity/environmental justice issues? How has your organization dealt with start-up delays?
- The model that federal research grants use for tracking effort levels is based on an academic appointment system. For organizations that do not primarily conduct research, staff are hired to do other activities and may not be able to devote a set amount of time to a research project. Do the way research grants handle personnel commitments prohibit community partners from participating on projects? Does other support make sense? How has your community organization worked with this?

For Academic Partners:

- How have you collaborated with community-based organizations to secure and manage federal grants, and to ensure that the community-based organization has the capacity to support their participation in the project?
- As a university partner, it is likely that you have a grants management infrastructure to manage your grants. Do you offer training opportunities or assist community-based organizations to participate in federally funded projects?

For Funding Partners:

- What types of community-based research projects have been supported through your organization? How does the level of support for community-based research compare with support for work in other areas such as advocacy and policy work?
- What are the major differences in private foundation support and federal support for environmental justice & environmental health disparities research? How are their processes and scope of research considered different?
- What opportunities do private foundations offer for support of community-based research? Are there particular foundations that emphasize this area of support?



## Concurrent Sessions #3

### *Cumulative Exposures: The Role of Epidemiology in Elucidating Environmental Contributions to Health Disparities*

**Moderator:** Christine Ekenga, *NIEHS*

**Presenters:** Paul Juarez, *University of Tennessee Health Science Center*  
Gary Miller, *Emory University*  
Amy Schulz, *University of Michigan*

**Room:** Rodbell BC

#### **Session Description:**

Epidemiology aims to evaluate the relative contributions of different types of exposures on health outcomes. It has long been recognized that the single-exposure approach to exposure assessment does not capture the multifactorial nature of many chronic diseases. The session will include presentations on the exposome and the study of environmental exposures from multiple sources, including the internal biological environment, the physical environment, and the social environment. Panelists will provide an overview of their research and discuss current approaches to evaluating the relationship between multiple environmental exposures and health outcomes. The session will conclude with a discussion on how these methods can be used to improve our understanding of health disparities.

#### **Discussion Questions:**

- What are the best practices and emerging trends for studying multiple environmental exposures?
- What are the major challenges to cumulative exposure assessment?
- How should we engage communities in this research?
- How can we incorporate emerging technologies for data collection and analysis (e.g. GIS, GPS, online data collection, and high throughput “omics” methods) into this research?
- How do we ensure that technological advances do not have the unintended consequences of excluding populations of interest (e.g. minority, low SES, people unwilling to donate specimens, people who lack internet access, etc...)?



## ***Using Health Impact Assessments (HIAs) to Address Environmental Health Disparities and Create Equity in Communities***

**Moderator:** LaToria Whitehead, *CDC*

**Presenters:** Ogonnaya Dotson-Newman, *WE ACT for Environmental Justice*  
Kenneth Smith, *National Association of County and City Health Officials*  
Alexandra Nolen, *Center to Eliminate Health Disparities, University of Texas Medical Branch*

**Room:** Rodbell A

### **Session Description:**

The purpose of this session is to explore the use of health impact assessments (HIAs) in (or by) environmental justice communities to build capacity and improve environmental conditions potentially linked to disease outcomes or health disparities, as well as move toward a health-in-all-policies framework.

*Objectives:* Participants will understand the use of HIA to create equity in communities, as well as become familiar with actions taken that impact policy at the local level by environmental justice organizations.

### **Discussion Questions:**

- What are some of the local political challenges communities face in implementing Health Impact Assessments (HIAs)?
- What are some of the "tools" used by communities to understand environmental exposures and outcomes?
- What other ethical issues/challenges have you seen of researchers and community representatives working together in creating change in environmental justice communities?
- What are some practical ways environmental justice advocates can use an Health Impact Assessment (HIA) to bring about systems changes leading to health in all policies?



## *Conflicts over Research that Identifies Community Impacts of Environmental Exposures*

**Session Leads:** Steven Wing, *University of North Carolina, Chapel Hill*  
John Sullivan, *University of Texas Medical Branch*

**Presenters:** Wilma Subra, *Subra Company*  
Gary Grant, *North Carolina Environmental Justice Network*  
David Lewis, *Neural Dynamics Research Group, University of British Columbia*  
Sharon Croisant, *University of Texas Medical Branch*

**Room:** D350

### **Session Description:**

When evidence of exposure or health impacts is released, environmental health and environmental justice researchers sometimes experience negative responses from polluters or groups that represent them. Threats to the confidentiality of research participants, personal attacks, or challenges to funding agencies that provide research support, may occur. This session offers perspectives from research groups and community organizations that have experienced such responses, describes the kinds of problems that can be expected, and will help to prepare others to best navigate conflicts that could occur because of their research.

### **Discussion Questions:**

- Do environmental health researchers avoid topics viewed as controversial by polluters and regulatory agencies? How does choice of research questions affect the ability of researchers to serve the interests of people exposed to pollutants?
- How can researchers and community members prepare for possible retaliation by polluters, government agencies, industry trade associations, and institutions that receive financial support from these entities?
- How can scientists from institutions with resources (e.g., universities, government agencies) help community research partners avoid harms that could come from retaliation?
- How can independent scientists collaborate with communities that experience environmental injustice to address research needs that are not met by universities and government?

