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Problems in the Past, Potential for the Future?

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On Oversight

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Chairman Miller, Member Broun and Members of the Sub-Committee. My name is David Ozonoff. I am a physician and Professor of Environmental Health in the Department of Environmental Health at the Boston University School of Public Health. I was the founding Chair of the Department that teaches and researches the effects of chemicals on health, a Department which I led for 26 years. I continue at Boston University as a full Professor where I direct a multimillion dollar research program on the health and environmental effects of chemicals, funded by NIH.

By way of background, I received my undergraduate degree in mathematics from the University of Wisconsin in 1962, my MD degree from Cornell in 1967 and my Master of Public Health degree from Johns Hopkins School of Hygiene and Public Health (now the Bloomberg School) in 1968. I spent the first ten years of my career at MIT, where I taught and did research, before moving to Boston University in 1977. The Department I founded there had as its focus understanding the health effects of chemicals on communities. We were then, and remain today, 30 years later, one of the few academic units specializing in this subject. Most investigations of community health effects are carried out in the public sector by state and federal agencies, one of which is ATSDR. In most of our research and technical assistance we have worked closely with communities and while this helped me to see the problem from their perspective, I am also intimately familiar with the underlying science and its formidable technical difficulty. I know quite well that judgments that appear straightforward on the surface are anything but.

Difficult as such work may be, there have been persistent problems with how ATSDR carries it out. In 1991 Congress asked the GAO to examine how well ATSDR was performing the public health evaluations around superfund sites required by the 1986 SARA legislation. Public health assessments are meant to determine if hazardous waste sites were causing harmful exposures to surrounding communities and, if so, whether these exposures should be stopped or reduced. I was a member of the GAO expert panel whose judgments formed the basis for the report's main findings. The GAO concluded that ATSDR health assessments required more time and care on the technical aspects and better consideration of community health concerns; that there should be independent peer review of the assessments; that the contents of the assessments were redundant

of EPA efforts and not useful to EPA or the community; and that the assessments were incomplete and not reliable for indicating when follow-up studies were needed. A number of recommendations were made, including that Congress should check back later on progress. I see this Hearing as fulfilling that recommendation.

Because of our relationship and reputation working with communities, in the 1990s we were engaged by ATSDR via a Cooperative Agreement to assist them in community involvement activities around several federal facilities. In the course of that work we met frequently with community members at community sites. Dr. Cole, the next panelist, helped us with some of that work. Our assistance was requested because there continued to be persistent complaints from communities that ATSDR's public health assessments were flawed, unhelpful or misleading. A common view was that someone had already shot the arrow and ATSDR was dutifully painting the target around it.

As a result of this background I have seen the problem from several different perspectives, an experience which surely tempers my judgments. I think I have a good feeling for what it is like to be in ATSDR's shoes, always useful for fairness. I also have the advantage of distance from the immediate fray. As my Department grew, my research group expanded greatly and other problems began to claim my attention. As a result I have spent considerably less time in recent years with either the communities served by ATSDR or the agency itself. I remain close to many community activists and their leaders for whom ATSDR represents, at the least, a serious problem. I have the greatest respect for these residents and activists and for their dedication to making their communities safer for themselves, their families and their neighbors. The toll this takes on them is very large and their stories are heart wrenching. I am not just a scientist but I am a spouse, a father and a grandfather, and it takes little imagination for me to identify with their concerns. I also know many of the principal players from both the early days of ATSDR and the current leadership. To prepare for my appearance today and to get as objective a view as I could, I made a number of calls to people, both in the environmental health profession and those connected to communities with toxics problems, to see what has changed in recent years.

The bottom line is this: not very much. The health assessments are better on average than in the early years but their quality remains uneven and some are unsatisfactory. Some of the recent ones I have seen are incomplete and do not give sufficient weight to the most up-to-date human information, tending to de-emphasize epidemiology while spending disproportionate time on toxicology and animal evidence. Often much of the detail involves exposure analysis, a function of at least three things: the experience and training of many of the health assessors is more in the area of earth science and engineering; site-specific detail is available from parallel EPA efforts; and the lack of experience and training that makes assessors more dependent on summary statements like ATSDR toxicology profiles and fact sheets, a number of which are dated or even obsolete. And although the focus of the public health assessments is rightfully on current potential exposures, the reports often do a less than satisfactory job characterizing (or addressing as well as they can) past potential exposures. Finally, the reports are difficult to read for community members and have a one-size-fits-all feel which does not convey the feeling that the special concerns of the community have been heard and understood.

While ATSDR provides a short public comment period on its reports, the health assessment documents need independent peer review from experts. At the very least the reports have a tendency to miss the most current information or adopt lowest common denominator judgments when evidence conflicts. In addition, there is insufficient breadth and depth of technical expertise among the health assessors who are required to know sciences as disparate as hydrogeology, meteorology, architecture, industrial hygiene, toxicology, epidemiology, social psychology and sociology, to name a few. As good as some of them are (or as inadequate as are others), this is almost an impossible task for the one or a few people responsible for drafting the average health assessment. There also needs to be a full review of ATSDR Fact Sheets used for public education for relevance to the concerns of communities and their overall usefulness and appropriateness in specific situations.

Not all health assessments are done by ATSDR staff. The agency outsources the health assessment task to a number of states under Cooperative Agreements. This practice is beneficial for building capacity in cash strapped state health departments but carries with it the risk that local pressures from the Governor's office or the legislature will affect the result. ATSDR is not immune to these state-based pressures but they are more distant and ATSDR has a greater chance of independence. I have written about this problem in the past and ask that our paper on the subject be appended to this testimony.

In summary, I would repeat and add to some of the recommendations we made in 1991, including:

- an effective arrangement for independent and timely expert peer review of ATSDR health assessments, consultations and studies.
- an across the board review of the fact sheets and recommendations ATSDR is giving to communities for relevancy to their concerns. It is not uncommon for a community to be told by ATSDR there is no hazard and then to be given advice they should wash their hands and take off their shoes after being in a contaminated outdoor environment.
- an increase in the breadth of scientific talent recruited by the agency.
- a re-evaluation of the practice of outsourcing work to state health departments. Perhaps regional style consultation units, based at universities, would be useful.

Finally, you have specifically asked me to give my opinion about whether ATSDR is meeting its mission. Let me try to answer the question by giving you my own view and the view of most community members I consulted. It is this. The routine work of ATSDR *remains* deeply disappointing. ATSDR has acquired, partly on its own, partly for reasons beyond its control, a reputation with communities it will have a difficult time remedying. It is not alone in the government in being a deep disappointment. But it is the disappointment we are here to talk about today.

Disappointment is relative to what one expects. One way to think about this is on the doctor – patient model. A patient with health concerns or complaints expects a doctor to listen, to hear and interpret beyond what's being said, and to be competent -- or at least competent enough so the patient will not be able to see obvious errors. A patient also expects the doctor to be able to

do things that make them feel more comfortable if not to make them better. The most damaging thing that can happen to the doctor – patient relationship is loss of trust and faith by the patient. And that is what is at the core of the problem with ATSDR. If a doctor doesn't meet basic expectations the patient will look for another doctor. But there is no other recourse when the patient is a neighborhood and the doctor is ATSDR. This has produced a self re-inforcing feedback loop where ATSDR frankly admits their reluctance to hold public meetings because of the abuse they receive in these settings, opting instead for one-on-one encounters. This is seen as a further withdrawal from the organized community, which responds in kind, increasing the alienation.

This is a difficult situation. But I am strongly of the view that it remains vitally important that there continue to be an agency whose job it is to look at community chemical exposures from the public health point of view. EPA is primarily an environmental regulatory agency, not a public health agency. Public health has the word "public" in it, which implies looking at the situation from the community's standpoint. ATSDR was supposed to step into the gap.

There is no simple technical or legislative fix for what ails ATSDR. The problems are problems of leadership at virtually every level. Presidents from Nixon to Obama have declared we must make an effort to cure cancer in our lifetime. For those whose friends, family and indeed themselves are in the cancer years, this appears to us an important goal. But for my children and grandchildren's sake, I would have also liked to hear that we will *prevent* cancer in our lifetime. ATSDR depends upon advances in basic science to do its job and the recent stimulus package recognized the importance of basic health science to our economy and the terrible cost of dread disease in our communities by injecting badly needed resources into the NIH. Investment in science pays off in many multiples. But left out entirely was money for the science of preventing cancer and other diseases acquired in the environment and workplace. NIOSH got nothing, which means it will get less again this year than last year. The NIH's program for basic science underlying superfund, the Superfund Basic Research Program, got nothing, which means it, too will shrink. CDC and its Center for Environmental Health got nothing. CDC's only stimulus money is for bricks and mortar projects. Bricks and mortar don't prevent cancer. It is a wry adage in the public health community that no Senator champions an agency because his wife didn't get breast cancer or any Congressperson because her child was born healthy. Much of essential public health and its importance remains invisible to the public. Until this changes other things that need to change, like ATSDR, won't.

I'm not talking about money here. The amount involved are almost lost in the accounting noise among the sums we are talking of these days. This is a question of leadership. The unglamorous parts of health science, the parts that are true public health infrastructure and upon which much else depends, like surveillance and vital records, things ATSDR depends upon, have not had the necessary champions. I include those in the private sector, like myself and in Congress but also the Executive Branch. Indeed the agency needs to signal to you in Congress what must be done. ATSDR is a sister agency of CDC, but the CDC administrator did not visibly, vocally or strenuously fight for it or even her own agency, publicly. Whether she fought these battles internally I don't know, but we needed visible and strong *public* champions for *public* health and we didn't have them. We had a skilled communicator but not a champion. Morale at CDC has

dropped precipitously. That's a leadership question. Similarly, ATSDR needs not only the trust and confidence of the communities it is supposed to serve, but its own leadership needs the trust and confidence of the many dedicated professionals in the agency itself. That's not a question for legislation.

In the context of the enormous problems we face in the economy and foreign policy, ATSDR's problems seem trivial, and in terms of cost they are. But for the affected communities, they are far from trivial. In some cases they are matters of life, death and happiness. If pressed hard to name the single effect of living in a contaminated community I see most consistently, it would be divorce. In a world where the stresses on marriage are already large, the additional burden of worrying about one's family and what might happen to them or coping with what did happen to a child, is too much for too many. Chemical contamination doesn't just *take* lives, as terrible as that is. It can also wreck lives.

I thank you for your attention to this urgent matter, of which the problems at ATSDR are real but only a part.