20. The Centers for Disease Control and Disease Tracking

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MS. JONES: Dr. Daley is up next. Dr. Daley is with the Centers for Disease Control and Prevention. He is currently assigned to the Environmental Health Tracking Branch. Dr. Daley.

DR. DALEY: Thank you. One thing that I'll have to warn you about is that most of my work at CDC has been in disaster epidemiology, and in preparing for this presentation, I borrowed heavily from my slides on disasters, and so you may see and hear some things that you weren't quite expecting.

I think that we all recognize that the World Trade Center terrible tragedy of September 11 has affected us in public health. (Figure 20-1) But in addition to the immediate death and injury, the World Trade Center, or the remnants of it, continued to burn for a number of weeks. There was tremendous concern in the community and among the residents surrounding the World Trade Center as to what this smoldering mass might be doing to them. To what risks were they being subjected? As part of our overall response, CDC participated in a community assessment.

We actually went to the residents. We talked to them. We got information on a variety of factors, including preexisting health conditions and symptoms that had developed subsequent to September 11.

When I was talking to the residents, I got a lot of questions about risk. Was it safe for them or their children still to be living there? A lot of these were questions that I couldn't answer. We had information, but we had no background information. We didn't have a good frame of reference. I was told multiple times by residents that I spoke with that the entire nation was concerned about anthrax except for the residents of lower Manhattan—they were concerned about what was coming out of the World Trade Center. And that shows clearly that sometimes the priorities of one area of the nation may not be the priorities of another, or one community's priorities may not be those of another. We will want to take this into account in developing this nationwide environmental health-tracking network.

Now, what is tracking? Well, those of us in public health are comfortable with the term "surveillance." Unfortunately to so many others, surveillance brings up the image of a health officer sitting in a car late at night outside of somebody's house, trying to determine if they're going to get sick or not. But really, what is surveillance? Surveillance is the ongoing, systematic collection, analysis, and interpretation of health-related data. It's central to the planning, implementation, and evaluation of public health practice and closely integrated with the timely dissemination of data to those responsible for disease prevention and control.

I think the important point here is that surveillance is more than just collecting data. Surveillance data needs to be disseminated in a manner than can affect public health practice. If it's not doing that, then it's not surveillance. Figure 20-2 shows our public health approach, and surveillance is down here as an initial block. Another thing that's important to note is that surveillance is just one step, but a lot of times it can tell us what the problem is. Are there increased rates of disease? Are there exposures that are occurring? But it's just one step, and a lot of times surveillance raises more questions than it answers. There is a strong role for some of these other steps, such as risk factor identification.

This points out the critical need for studies—basic research and epidemiologic studies—to help us answer some of these environmental questions. A tracking network alone is not going to answer all the questions, but it's going to be one critical component.

What makes a good surveillance system? (Figure 20-3) In the interest of time I won't go through all of these. Let me just say that you really do need to have a condition of importance. It must be useful; the information must be useful. You must have sustainable resources to keep the process going.

It has to have attributes that will give you good information. Figure 20-4 illustrates that. If we have an increase of disease that we're picking this up from a surveillance system, what does it mean?

I think the first thing people are going to jump to is that we've got a change in disease incidence, but this can mean a lot of other things, too. It could just be a periodic temporal fluctuation, and this happens frequently. There are certain conditions that you're well aware of that do have a temporal pattern. It may not be anything in the disease itself. It may be that you have an increase in the population or a shift in population within an area that's causing the increase in your numbers. Or you may have changes in population demographics. You may have a younger population that's moving to an older population area or vice versa; this can change the rates of diseases that you may be tracking. Or it could be a change in the surveillance system itself that's created the change in incidence.

Change in health care access, diagnostic changes, different methods or different ways of coding diagnoses, all can have an effect. So these are some of the issues that need to be addressed, and these are some of the difficulties in establishing a surveillance system.

Now if we look at environmental health tracking, it becomes even more complex. (Figure 20-5) Our typical public health surveillance is focused on disease, but as Laura mentioned, we've got issues of exposure and issues of hazards that we want to try to bring into an environmental health tracking system. Let me go over these quickly. (Figure 20-6) We have hazard here first. Currently, there is a difference in understanding and a difference in definition of the terms "hazard and exposure," especially between those of us in public health and in our environmental colleagues. What one person may call exposure others may view as hazard. This is an issue that needs to be worked out. We need to talk the same language.

What are some hazards? (Figure 20-7) As a public health practitioner, I think in terms of an agent or a condition that could potentially cause an adverse health effect. So the F5 tornado that ripped through metropolitan Oklahoma City in 1999 is an example of an environmental hazard. The volcano, El Popo, in Mexico is another example—you could have hazards from kinetic effects, from chemicals, from heat flows. A home electric generator, used when commercial power is down, let's say after a storm, can produce carbon monoxide and be a hazard.

Then we get to exposure. (Figure 20-8) If a strong tornado or a strong earthquake occurs in an unpopulated desert, we're not going to have a problem.

Likewise, if a chemical exists but is not getting into a child, then we don't have exposure and we shouldn't have a health effect. Well, exposure can be looked at in a variety of ways. Computer modeling can be helpful. Another method is on-site monitoring, such as of breathing air levels. There are portable sensors to quantify volatile organic exposure that we used in these Malaysian children to measure their exposure to toxicants produced by severe vegetation fires.

Our standard, and one of the areas that we are really excited about, is biomonitoring—the measuring of constituents in blood, urine, or other biologic samples to determine the exposure level. This brings up an important point in the area of exposure. We in public health are going to have to develop strong collaborations with our laboratory partners, because it's through this sort of laboratory work that we get much of our data. We've got to work together with our laboratory partners to make this a reality. I think that we're probably the furthest behind in exposure than in any of the other areas. We do have a childhood lead-poisoning prevention program that you're all probably aware of, and this is perhaps one of the best examples of exposure surveillance. Laura mentioned NHANES, so I won't go into that, but that is an exciting new field, and it's something that we think will be more and more important.

And finally, health effect. (Figure 20-9) I think that as practitioners or as public health professionals, we can feel most comfortable here. Mortality is one of the easier health effects to quantify and monitor, whether it be death from a severe tornado or death from an earthquake. Morbidity is a more difficult nut to crack, although we definitely do have ways to approach this. What we want to do is to be able to get some good data about morbidity.

For example, there are data on carbon monoxide mortality over about a 20-year period, but we don't have good information on carbon monoxide morbidity on individuals who have survived carbon monoxide exposure.

We have a lot of data sources. Vital statistics is one of the easiest to get, and one of the best sources. There's a lot of information coming from hospital discharge, but it's a very small part of the puzzle, although it's one of the better-developed systems. We have cancer registries and birth defects registries as well as national surveys. Outpatient surveillance is one area that is going to become more and more important. It presents a burden to practitioners. It's an area where we in public health will really need assistance from the practice community, and we hope that we will be able to give a product to justify that. We need to be able to have interventions, whether as community education, as regulatory actions, or as improvement in practice and treatment methodologies, there needs to be a tie-in, a pay-out.

What's our vision? (Figure 20-10) We envision developing this environmental public health tracking network that looks at hazards, exposures, and health effects, integrates the data and disseminates the knowledge.

There are a lot of difficulties. We're just starting out. Figure 20-11 is an example is one of them. This is a picture of the federal environmental maze. We have a number of agencies that either have authority or responsibility in the area of environmental health. This complex also exists in many of our states, and one of our major priorities is to try to foster those relationships.

So what are our objectives? As I mentioned, we need partnerships not only across health and environmental agencies, but up and down—federal, state, local partnerships. For us at CDC, that's really been a mandate. This is nothing new for us. The states and state public health partners are our major constituents. We want to develop an integrated standards base network. It may not end up as one surveillance system. It may be a system of systems, but we need to be able to talk to each other. The systems need to be able to talk to each other.

Fortunately, we already have some initiatives looking at this. You may be familiar with CDC's initiative on the National Electronic Disease Surveillance System, trying to unify our infectious disease surveillance. We want to expand this into the areas of environmental and chronic disease. Also, EPA is working a similar initiative to try to bring environmental information together. We need to tie in to the tremendous work that's being done in the areas of emergency preparedness and bioterrorism. There's a lot that both systems can learn from each other, and many ways they can be useful to each other.

We have our focus areas, and these are determined primarily by the healthy people 2010 project and the Pew Environmental Health Commission report. Our goal is to supplement, not supplant, existing resources. There's a lot of action out there now. We want to see what we can do to improve it and to bring it all together.

Figure 20-12 shows some examples of some of the focus areas—a number of chronic health defects, poisoning, health effects due to environmental factors, chemical agents, physical, biomechanical stressors or biological toxins. Our focus is not in the area of infectious disease; there are a number of other people at CDC currently working with infectious disease. We want to hook into those efforts, but we feel that our focus needs to be in a different area.

What are we doing to develop this network? We are in the first stage. We're just starting. Initially, we convened in coordination and association with ATSDR environmental health tracking work groups, experts from public health, multidisciplinary experts, engineers, information technologists, surveillance experts, and practitioners to give us some ideas about where we should be going. We have had meetings with a number of our partners—state public health and environmental agencies, professional organizations and interest groups, other federal agencies such as EPA and even NASA. You might ask, "What would NASA have to offer?" Actually, they do have a public health initiative.

We have already started some projects. We have proposed an environmental health module for the behavior risk factor surveillance system, which is a continuous survey conducted by states around the nation. We've also developed a technical team at CDC and EPA to look at the data specifications that our two networks are developing.

I would like to push a button and get the information and then analyze it, but there's an awful lot of work needs to be done before that can happen. We've convened a technical team to look at that, but probably what most people are interested in are the cooperative agreements. We have entered into cooperative agreements with 20 state and local health departments and three academic centers of excellence to begin development of this network.

Figure 20-13 is a map that shows two levels of agreements. We have what we call our Part A states, which are working on planning and developing capacity, but we realized that some states would be further along than others. So we also have some states (Part B states) that are enhancing what they have already done. These states will actually have a demonstration project by the end of the three-year period, showing some type of linkage and integration of components of a tracking network looking at hazard exposure and health effect. Then we also have our three centers of excellence, located at Berkeley, Tulane, and Johns Hopkins.

What have we asked our health departments to do? We're looking at them to evaluate existing capacity, form partnerships not only with our environmental sister agencies but also with community groups, establish a planning consortium, and identify and prioritize the tracking needs within their state. We want them to look at legislation and regulations. What legislation needs to be in place to further this? We expect them to develop and enhance those surveillance systems that are identified as priorities, plan a staged development of the tracking network, make arrangements and think about what types of training their staff will need to best utilize all the money that we will be putting onto this.

If we don't have a trained public health and environmental health staff, we're not going to be able to make this a reality. We need to develop and evaluate communication strategies. We can produce an awful lot of information, but it's critical to be able to communicate it to those who need it and to be able to communicate it in different ways to different audiences, so that it's effective.

I would also ask them to investigate the feasibility of our environmental public health indicators. There are a number of joint network development activities in which they will be participating, from workshops to data standardization, case definitions, and information technology specifications.

With our Part B states, we've asked for demonstration projects. Figure 20-14 shows a few examples, just to give you a flavor for some of the demonstration projects that have initially been proposed as candidates from some of the different states. You may be able to find your favorite health effect or favorite exposure in there. I hope so.

Finally, our centers of excellence. (Figure 20-15) Once again, we're evaluating our current surveillance methodology. We want them to look at what we're doing in surveillance and tell us where it can be improved. We want them to look at methods of linking data and information and at statistical algorithms so that we can detect and determine trends, problems and outbreaks.

States and local health departments need training. We want our centers to be developing and providing that training. Our centers will be working very closely with our states. In fact, we want our centers to work very closely together so that they can share their expertise and we can all build this together. We need joint network activities, and as I said earlier, surveillance is one component.

We know that there are going to be questions raised by our network that the network can't answer. There will be some that it can. We're here today on an Air Force base, so I'll use a military analogy. If you have a camp, you have sentries to detect problems as they come in. We feel our surveillance systems work pretty well as sentries to detect problems. But you also need scouts to go out there to try to determine what's going on outside the camp. That's where our epidemiologic studies come in, and so we've also asked our centers to perform epidemiology studies to address these issues.

In conclusion, let me say that we do have significant challenges. It's not going to be easy and it's not going to be quick, but I hope that by the time I retire, we'll at least have something going on. We're building it from the bottom up as well as the top down. (Figure 20-16) Not just a national system. We want a network that allows integration at the state and even at the local level, so that public health feedback and action can be occurring at the local level as well as the national level. It's a staged approach.

We know it's not going to happen overnight. Collaboration is essential. This will come. I think that our physicians, our practitioners, will definitely need assistance. In the early stages of data recording, we'll be getting information back to them. We need advice.

There'll be a lot of areas where we'll need your collaboration. And all this is just one component of a much bigger picture. I've just touched the tip of the iceberg, but we hope to be able to provide a good product for your use.

Thank you.

DR DANIELS: Thank you, Dr. Daley. While we're getting set for questions, I'd like to give you a website that has information on tracking. It's www.cdc.gov/nceh/gov.

DR. DALEY: That's actually our NCEH home page.
DR DANIELS: Yes, it is.

DR. DALEY: And the first item up there, at least presently, is tracking. We hope to improve our website with time, so please visit it.

DR DANIELS: The first question. Despite all the concerns about privacy, is anyone seriously looking at that?

DR. DALEY: Privacy is clearly an issue, and we at the federal level need to work with it, but it's probably more critical at the state level. The effect of HIPAA—I know that's a tremendous concern with our state public health partners, not just with environmental health tracking but with a lot of the activities that our state public health agencies perform. The privacy issue definitely needs to be addressed.

MS. KING: I know that privacy is a subject that is not taken lightly. My organization had focus groups with physicians, a couple right here in Texas. We did one in Houston and one in San Antonio, and that that was a major concern that physicians had about this kind of network. I was also involved in the work groups that Dr. Daley mentioned, and I know that in one of the work groups that was a huge topic of conversation.

MS. DANIELS: Laura, the next question is addressed to you. It's, How would you answer the political issues that must be addressed in developing tracking systems? For example—privacy, Big Brother looking at us, concerns about citizens losing insurance and even jobs, the time and cost of reporting by providers.

MS. KING: Well, one of the things, I think about a lot is the time and costs of reporting by providers, but I don't know that that's necessarily what I consider a political issue. I know that providers—from my perspective in talking to a lot of providers—think of surveillance as only physician reporting or nurses reporting in physicians' offices. That is one type of reporting, and I know that that's something that infectious disease people use for surveillance, but that is not the only type of surveillance or tracking that exists. There are also computerized systems. There are survey-type systems. There are many, many types of surveillance. Physician reporting is only one type.

As far as the political issues such as the Big Brother fear, we deal with that. We deal with that with HIV/AIDS in terms of losing insurance coverage. We're working on privacy issues. I think those things do need to be dealt with by groups at a national level.

MS. DANIELS: I flipped the card over and there was a follow-up comment by the questioner that says: All of these are arguments put forth by persons opposing the immunization register tracking in Texas, as well as other health status reporting for public health purposes.

DR. DALEY: Yes. I think that actually the follow-up comment leads in very well to what I was going to say. This certainly is not only an environmental health tracking issue; it's an issue with surveillance and public health surveillance overall.

I think that there has been a lot of work done in this area already. I know that at CDC, we get an awful lot of surveillance information, but we never have personal identifiers. And so at a federal level, it's not as big of an issue. At a state level and a local level, it's probably a greater issue where there are those personal identifiers.

There are laws in place, but these laws vary from state to state, and so that's why I said a lot of these issues will have to be dealt with on a state-by-state basis. You may recall, one of the activities that we're asking of our states is to look at legislation and regulations that will be needed, not just regulations to allow this, but regulations to protect individuals. I think that that's critical.

As far as the burden of reporting, it is a burden, and I think we at CDC recognize it, as our state colleagues also do. I would say two things. One is I think that the burden is easier to bear if the people who are providing that data get some usable product in return, and I think that maybe that's where sometimes we have been remiss. I hope that a lot of our infectious disease surveillance at CDC has been, to some degree or another, valuable. I hope that it has helped in practice, but that's something that we need to be very cognizant of in developing our surveillance system.

The second thing is that for surveillance as a whole, and not just environmental health tracking, we're really beginning to look at new methodologies as we come into the computer age and as more and more operations become computerized. There are technologies and methodologies that can be put in place to decrease this burden. One that we hear a lot about is stovepipe surveillance systems—surveillance systems set up for one particular disease. If we can unify diseases into one reporting system, that might decrease the burden. Also, I have seen demonstrations of some unbelievable systems that take information directly from computer feeds, going back and forth between different departments of a hospital, and develop reporting and surveillance data from those feeds so that involvement of an individual is not even necessary at that step. Certainly, involvement of an individual would be necessary in the development and the monitoring, but it decreases the burden tremendously.

MS. DANIELS: Thank you. The next question: At the current rate, is there sufficient funding to develop the infrastructure necessary to implement a nationwide health tracking network this decade? What additional support will you need?

DR. DALEY: Well, the short answer to that is no. Right now, as you know, the federal government is functioning under a continuing resolution. The $17.1 million from Congress, we feel was extremely generous, considering that funding for CDC, if you take out the bioterrorism and terrorism preparedness portions, did not go up very much. This is one of the few programs that actually got an increase, and our increase was $17.1 million because we didn't exist beforehand.

We don't know what type of funding we're going to get this next year. Obviously, a lot may depend on whether we go to war or not. We feel pretty comfortable that we will at least have the 17.1 million to continue what we are doing presently. That will go a long way in the early stages, but to actually put this into effect, we'll probably need a lot more resources. And it's not just money. There are a lot of other resources in terms of personnel and expertise. Maybe the most critical resource is to be able to develop those partnerships. We can accomplish a lot with partnerships that we can't with just dollars.

MS. KING: The Pew Environmental Health Commission in its report—and again, you can download it and read all of the background at www.healthyamericans.org—estimated it would cost $275 million annually. So absolutely, this is a drop in the bucket, but it's a place to start. And what happened, we are operating on a continuing resolution. We haven't passed appropriations bills yet. The Senate requested $30 million for fiscal year 2003. The House basically took the President's budget request as their request, so that's at $17.5 million. So we expect it to be somewhere between the two, with a worst case scenario of $17.5 million. Now it probably does have a lot to do with whether or not we go to war and what our priorities end up being.

But there are organizations on a national level who are working very, very hard on this and already working on fiscal year 2004, working with OMB and working with the budget committees, and working on making sure that that request gets in there. So we're being as helpful as we can on that level.

MS. SHANKLIN: My name is Sherry Shanklin. I'm with the Texas Department of Health. I have a comment in regards to the burden that you were talking about with physicians and the possibility of using computerized technology to report their information. Particularly in the state of Texas, and I'm sure in other states around this country, when you get into the rural areas, there is not that technology.

Even at the local health departments, they do not have the capabilities to forward that information electronically to the state level. And so it's very well and good to think that they don't have that burden, but unless we're able to go in and fund it, at the rural local level they're not going to be able to pass the information up the chain or up the pipe, so to speak.

DR. DALEY: That comment is definitely true, especially in rural areas. I think that we are seeing a tremendous shift in our hospital systems in a lot of urban areas, where that type of reporting can be a reality.

We hope that a number of bioterrorism grants and proposals aimed at increasing capacity at the local level to report electronically will help with tracking. Now obviously, that's not going to answer the question for the private physician, and so we will have to look at a system that's flexible enough to be able to account for both types of reporting.

MS. SHANKLIN: I have a question as well with regards to NHANES. I agree that's it's exciting about the biological sampling with regards to potential chemical exposures. Has there been any effort made at this point to try to link the biological samples that are being taken with NHANES data and some of the environmental health exposures that are out there? It would be exciting to be able to take some of that data from NHANES and correlate it with the knowledge that this person lives in this general exposure area. This is what was going on, and this is what we measured at the environmental level. Has there been any progress made in trying to combine that?

MS. KING: It is very exciting, and they're definitely working on improving their capability to do that. I think that that's the hope some day. One of the limitations of NHANES is that they are only able to get national data. This is only 5,000 people annually, and they just started taking samples, I think, two years ago, and they're on a two-year cycle for reporting. It would be wonderful to have state-based HANES, but it would be so expensive. We're talking about thousands of dollars a participant.

DR. DALEY: I would like to echo that. Yes, NHANES is wonderful for national estimates. The sample size doesn't give us the ability to do exactly what you were suggesting. In my dreams I certainly envision that. It would be wonderful. It would give us a lot of those answers. Unfortunately, it's extremely expensive. However, I will mention that our center, the National Center for Environmental Health, does have a program to try to increase the public health laboratory capacity at the state level. So the federal government may not be able to do it, certainly our lab at NCEH, even if we had the money, could not process those samples. But as we increase capacity in the states, it may become closer to being reality.