

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION**

Joint Meeting of the Ethics Subcommittee of the
Advisory Committee to the Director (ACD), CDC
and the CDC Public Health Ethics Committee



***Executive Summary
June 16-17, 2011***

**Joint Meeting of the Ethics Subcommittee of the Advisory Committee to the Director
Centers for Disease Control and Prevention (CDC)
and
CDC’s Public Health Ethics Committee**

June 16 – 17, 2011

**Thomas R. Harkin Global Communications Center, Distance Learning Auditorium
Atlanta, Georgia**

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Introductory Remarks and Overview of Meeting Goals

Marion C. Wheeler, Advisory Committee to the Director Representative to the Ethics Subcommittee

Mr. Wheeler, Advisory Committee to the Director (ACD) representative to the Ethics Subcommittee, acted for the Ethics Subcommittee Chair, Ruth Gaare Bernheim, JD, MPH, as she was late for the meeting due to a delayed flight. After establishing that there was a quorum of members present at the meeting or on the telephone, Mr. Wheeler called the meeting to order at 1:06 PM on Thursday, June 16, 2011. Mr. Wheeler welcomed the group and called upon the Ethics Subcommittee members to declare any conflicts of interest. No conflicts of interest were reported. After introduction of meeting participants, Mr. Wheeler reviewed the meeting agenda and goals. The meeting agenda is included in Appendix 1; the list of meeting participants is included in Appendix 2.

Drue Barrett, PhD, Designated Federal Official (DFO), Ethics Subcommittee, and Chair, Public Health Ethics Committee (PHEC) noted that Mr. Wheeler, Dr. Ronald Bayer, and Dr. Bernard Lo were rotating off of the Ethics Subcommittee. Certificates of appreciation from the CDC Director, Dr. Thomas Frieden, were presented to Dr. Bayer and Mr. Wheeler. Dr. Lo was unable to attend the meeting.

Public Health Ethics Tools to Support State and Local Health Departments: Development of Case Studies

Norman Daniels, PhD, Ethics Subcommittee Member

Dr. Daniels reminded the Subcommittee that their task was to discuss the six proposed case studies, agree on a format for them, discuss a framework for analyzing them, determine options for their dissemination, and discuss the possibility of creating other tools to support state and local health departments.

Dr. Barrett explained that CDC has been considering how best to support state and local health departments in their efforts to address public health ethics issues. A series of webinars were held with

state, tribal, local, and territorial health officials at various levels. Participants in the webinars identified several public health ethics challenges:

- Issues related to resource allocation
- Issues of policy, legislation, and politics
- Data use management, including privacy and confidentiality issues
- Control of infectious diseases
- Immigration issues
- Community engagement issues
- Questions regarding balancing individual choice while protecting the public good
- Jurisdictional issues

Dr. Daniels pointed out that based on input from the webinars, a workgroup of the Ethics Subcommittee chose case topics that would likely be of interest to state and local health departments and created cases to serve as models. The cases target tuberculosis (TB), vaccines, and injury.

The model for the cases includes a relatively short and concise presentation of the case, followed by a set of questions designed to elicit various ethical issues, and then a “scenario shift” to explore how different contextual factors impact the analysis of the case. Although not developed yet, the intent is to develop additional instructional material to guide state and local officials through the process of ethical analysis. Several Ethics Subcommittee members noted that the cases focused on infectious disease issues. Dr. Barrett said that they intend to develop additional cases on non-communicable disease topics, but wanted to wait until after this meeting to learn how CDC leadership would like them to proceed on the topic (this discussion scheduled for day two of the meeting).

The following comments were offered on the cases distributed for discussion:

Case #1: School-Based TB Screening

- This case involves a local board of health that is considering revising its guidance regarding TB screening and testing of school age students. The case is based on the experience of one of the workgroup members, a local health official in Ohio. School-based testing raises several issues, including concerns about differential treatment of foreign-born students and issues related to stigmatization.
- Currently, TB in the foreign-born has become a problem in the United States. Specific countries have been identified as origins of TB, allowing for targeting of populations with high risk. The case raises ethical issues and practical concerns about how to act on the epidemiologic data.

- There was discussion regarding why this screening was proposed for school settings as opposed to the health department or clinical settings. Historically, schools have important functions in public health monitoring of certain childhood conditions.
- There was discussion regarding the difference between a screening program that is a benefit, and a program that is a burden. The relationship between epidemiological data and public health policy can create unintended burdens even as benefits to individual persons are sought.
- Screening all foreign-born children may reduce the appearance of targeting. There was discussion about the levels of stigma and discrimination in schools.
- There is not enough room for extensive background discussion in the case. Unless the ethical discussion accepts that the health department recommends testing in schools, the discourse will not be useful.

Case #2: Multi-Drug Resistant Tuberculosis (MDR-TB)

- This case addresses ethical issues involved in treating non-U.S. citizens with MDR-TB. The case explores issues relating to allocation of scarce resources and the government's role in providing treatment for TB infection, especially in cases involving non-U.S. citizens.
- There was discussion regarding whether the case concerns public health ethics or clinical ethics. The public health system provides treatment for most people in the United States who are infected with TB, but public health may or may not provide clinical oversight for the case. In MDR-TB, public health officials err on the side of caution and have options for mandating treatment compliance.
- This case raises questions regarding the role of American public health authorities in addressing public health in other countries. There are public health questions about transmission of an infectious disease in a country that does not have the ability to treat it. Allocation issues apply as well, as do questions about state and national borders. Public health has a moral obligation to see that others are not infected. There was discussion regarding whether the concern was the moral obligation to keep the individual from returning to his home country and potentially infecting others, or to treat the individual case.

Case #3: Mandatory Vaccination of Healthcare Workers

- This case deals with the topic of mandatory influenza vaccination for healthcare workers. There is a long history of debating this issue, and efforts to educate and encourage healthcare workers to take the influenza vaccine have been largely unsuccessful. There is a drive for more vaccinations because healthcare workers represent risk to people in healthcare facilities. Protecting these workers will guard against work shortages due to illness as well. These arguments need to be made more effectively.
- There was extensive discussion regarding objections among healthcare workers to mandatory vaccinations. Some healthcare workers have concerns about chemical sensitivity, some do not trust

the pharmaceutical companies, and some believe that the vaccine can cause influenza. These concerns are not ethical, but personal. There was discussion regarding whether mandatory vaccinations were justifiable for these workers in this context. Recent literature frames this dilemma in moral terms, rather than in terms of the evidence of benefits of protecting patients.

- In the nursing home setting of this case, one of the questions to consider is the importance of protecting the vulnerable population from a condition that could be transmitted by vaccine-denying workers.
- It was suggested that the case incorporate a scenario shift to address a different condition, such as smallpox, or a different set of workers, such as first responders.
- It might be useful to address issues relating to health literacy barriers among many healthcare workers. In addition, the ethical implications of positive incentives for vaccination might be considered.

Cases #4 and #5: Parental Refusal: Varicella Vaccine and Pertussis Vaccine

- Two cases were developed dealing with parents who refuse to vaccinate their children – one dealing with varicella, the other with pertussis. There was discussion about the need for both cases, but it was pointed out that there are relative differences between the two cases because people think of chickenpox as “no big deal.”
- There was discussion regarding the number of exemptors a community can tolerate and the level of risk that justifies requiring everyone to be vaccinated, versus requiring most to be vaccinated. A modest risk might not be a problem if there is significant herd immunity, but if everyone refuses a vaccine, then there could be a real public health problem that requires mandatory vaccinations. One variable is the prevalence of the attitude, and another is the seriousness of the condition.
- There was discussion about the social epidemiology of refusers. Many of the communities with high levels of refusals are “naturalists” who feel that vaccinations are dangerous and unnecessary. These objections are philosophical. The issue centers on perceived coercion of mandates. Mandating could provoke some people to resist the vaccinations just because the government requires them.
- An exploration of autonomy versus justice might be helpful in this case. People question not only the efficacy, but the safety of the immunizations. Other issues concern the pharmaceutical companies that make a profit from these vaccinations.

Case #6: Table Saw Safety

- This case deals with the role of government in mandating product safety measures in order to prevent injuries. There was discussion regarding precedents in other safety mechanisms in other power tools and appliances.

- ❑ This case could be juxtaposed with seatbelts, as it concerns a measure that is required of manufacturers, which some people might find less objectionable than, for instance, motorcycle helmets, which focus on the individual.
- ❑ There was extensive discussion regarding whether the main problem with this case was financial. This case raises questions of the infringement of personal rights and unreasonable mandates, but these issues are surrogates for the cost issue. However, the fact that the argument of personal rights is raised shows the context of the public health issues. When should public health restrict the risks that people are allowed to take for themselves? This case does not have a “downside” for not including the safety feature, other than cost. The magnitude of the cost skews the discussion. The amount of money raises the question of whether the government has the right to force an individual to purchase an item that includes a safety element that he or she might not want. Costs are relevant not only because of possible lawsuits, but also because health insurance and healthcare costs are affected when consumers injure themselves.

General Discussion of Case Reports

- ❑ The group liked the general format of the cases, which included a brief description of the issue and a focus on real-life situations. Questions after the case description highlight ethical issues. These cases will be very useful for training state and local health departments about public health ethics. In addition to training, these health departments would benefit from a public health ethics consultation service and a mechanism to network quickly about public health ethics challenges.
- ❑ The workgroup debated how much science to include in the cases. As the cases are being developed primarily for use by public health professionals, a greater emphasis on science might be useful. All of the cases require some assumptions regarding public health so that the discussion will focus on the ethical issues in the case. If a case studies “workbook” is created, an introductory chapter could describe the background information and assumptions.
- ❑ The cases should be designed to invite discussion on issues of public health obligations. Case studies on non-communicable disease issues will lead to discussions of the history of public health and its responsibilities. Non-communicable interventions may stretch the boundaries of public health and will require balancing state authority with public input and opinion.
- ❑ A broad range of non-communicable disease cases could be explored. Additional cases could address questions about the relationships among science, ethics, policy, and decision-making in public health. Suggestions for potential cases included:
 - Mandatory use of motorcycle helmets, which can examine the state’s role in preventing injuries.
 - Ethical issues raised by public health interventions for reducing salt in American’s diet.
 - Interventions that ban smoking in public spaces, such as parks, beaches, and malls.
 - Use of interventions that motivate or incentivize people to change their behavior.

- How to develop a policy when there is substantial disagreement among stakeholders about how to proceed. This case could focus on how to best engage stakeholders.
- A progressive presentation of cases with increasing complexity of the ethical issues was suggested. The cases could progress so that by the end of the series, the audience is empowered to understand how to have an ethical deliberation on these topics.
- Because their work is to support state and local health officials, as well as individual Centers at CDC in their ethics training, different cases might address different audiences, in different contexts. It might be helpful to specify the audience for each case and to describe the case format. Cases can also be modified to suit the needs of the audience.
- The Ethics Subcommittee is most useful when it responds directly to needs from the agency and the field. State and local health departments and CDC programs should be engaged as the Subcommittee chooses topics to address. State and local officials will have to address chronic disease issues, and they will likely need help as they advocate for policies and as they engage stakeholders with differing opinions in ethical discussions.
- There is a great deal of diversity at the local level, where community engagement is a significant part of what they do and where ethics guidance is needed. It would be helpful to discuss issues that state and local health departments face on an ongoing basis, such as allocation of resources and building trust. Creating a way to examine the justifications for different policies would be helpful.
- It was suggested that the cases take the form of continuing public health education for practitioners. The product could take different forms in different settings, given the different needs, including regional, in-person training sessions as well as webinars.
- It was recommended that at least one case be pilot tested with state or local health officials prior to the October Ethics Subcommittee meeting. It was also recommended that a workshop on use of cases to train public health professionals about public health ethics be developed, perhaps for an upcoming NACCHO meeting.

Their next steps for the workgroup are to:

- Develop more cases
- Pilot-test at least one case with an audience of state and/or local officials
- Explore options for presenting to NACCHO
- Formulate approaches for conducting the ethical analysis and bring it to the Subcommittee in October

Public Health Ethics Tools to Support State and Local Health Departments: Possible International Collaboration

Sarah Viehbeck, PhD, Senior Evaluation Associate, Canadian Institutes of Health Research (CIHR), Institute of Population and Public Health

Dr. Viehbeck described her Institute's priority of population and public health ethics and how Canadian officials have grappled with several of the issues that CDC and the Ethics Subcommittee have been discussed. Their work began with webinars focusing on discussion of key readings in population and public health ethics. Participants in the sessions included a cross-section of individuals from different Canadian provinces involved in research, policy and practice. Based on feedback from the webinars, they transitioned to the discussion of applied case studies. These cases addressed a mix of public health topics, including infectious diseases, chronic diseases, and environmental health issues. Much of their discussion focused on the complex environments in which public health interventions unfold, as well as the role of public health in these interventions and the possibility of unintended consequences. Their discussion also considered situations in which sectors other than public health are involved in the interventions, such as industry, and issues related to the base of evidence and whether it is available to guide interventions.

CIHR is now developing a public health ethics case book by calling for cases in population and public health. Dr. Viehbeck expressed hope that there would be an opportunity to collaborate with the Ethics Subcommittee and PHEC on a common approach for analysis of cases and on an examination of the differences between how the United States and Canadian public health systems approach the cases based on their differing social values and other cultural factors.

The Case Studies Workgroup will explore potential avenues for international collaboration on development and analysis of cases and the Ethics Subcommittee will revisit this issue at the October meeting.

Public Comment Period

At 4:50 pm, Ms. Bernheim, who joined the meeting at the 3 pm break, opened the floor for public comment. Hearing none, she provided a short summary of the day's discussions and adjourned the meeting at 5:00 pm.

Friday, June 17, 2011

At 8:30 am on Friday, June 17, 2011, Ms. Bernheim called the meeting to order. She established that there was a quorum of Ethics Subcommittee members present.

Comments of CDC Principal Deputy Director

Ileana Arias, PhD, Principal Deputy Director, CDC/ATSDR

Dr. Arias thanked the group for their hard work, and said she looked forward to hearing their guidance.

Dr. Arias pointed out that CDC works to be as effective as possible in accomplishing its goals and in realizing its mandate to ensure that people in the United States and around the world live longer, healthier, and more productive lives. The agency has identified strategic directions and topical focus areas where the available science offers the possibility to make significant differences. The agency is committed to science guiding everything it does but also realizes that ethics is crucial. Because “it is the right thing to do,” and because their effectiveness depends on it, CDC must understand the ethical implications of its activities.

The work of the Ethics Subcommittee will be critical for CDC's ability to implement effectively the solutions that they and their partners identify. Because of this high level of importance, Dr. Arias is making sure that the work of the Subcommittee is shared not only with the ACD and the CDC Director, but with all of CDC.

She thanked Dr. Bauer and Dr. Degutis for addressing the meeting, and she again thanked the Subcommittee for their work and Dr. Bernheim for her presentation to the ACD in April 2011.

Discussion Points

- ❑ CDC has worked in the area of chronic disease for more than 20 years. The most significant threats to human health today are from chronic diseases. The agency has approached chronic diseases with the model it used for infectious diseases in the past, and the model works at some levels, but it may need to be changed in order to be more successful.
- ❑ There was discussion regarding “pushback” on certain laws, such as motorcycle helmet laws and smoke-free air laws. CDC increasingly has to defend policies after they are implemented in order to sustain them. It would be useful to look at policies that encountered similar initial resistance, but have since been supported by the public, such as car seatbelt use.
- ❑ These issues illustrate the need for CDC to understand the social implications of health policies. America has a strong tradition of individualism and libertarian sentiments, which must be understood and addressed effectively.
- ❑ Strengthening policy is one of CDC's strategic directions. Ethical dilemmas in each policy area must be discussed. Otherwise, the policies may not be implemented as intended, or may be associated with adverse unintended consequences.
- ❑ It is important to align public health interest with the public's interest to affect policies or interventions. For example, Mothers Against Drunk Driving (MADD) changed the rhetoric around impaired driving from a question of individual rights to a question of taking care of the people you love.
- ❑ A priority-setting process resulted in the “winnable battles.” Ethics did not explicitly figure into the process. CDC looked at issues that had a high public health burden and about which science was available. They also looked at the extent of political and social will available. Ethical issues arise implicitly, but should be addressed in a more explicit way.

- ❑ The new models for chronic disease could include new roles for CDC in working with states and locals. Given that many regulations and policies are set at the state and local levels, there was discussion about a role for CDC.
- ❑ One of the greatest issues is financial, as state and local entities have less and less money and have to consider ending programs or initiatives. How are decisions to end programs made? The ethical issues in closing programs or services are significant. CDC hopes to do more with less, rather than to end programs.
- ❑ It was suggested that CDC focus on explaining what people are losing if government programs that have an impact on the people's well-being are lost. Public health has not done a good job of taking a comparative approach to make the case for its importance. There is an absence of moral language regarding the mission of public health. When public health is threatened, it is important to incorporate the ethical and moral impulses behind public health. The Ethics Subcommittee could be helpful to CDC in this area.
- ❑ There was discussion regarding the public's perception and understanding of CDC. In general, the feedback is positive. The negative feedback stems from a lack of understanding about what public health does and about the totality of CDC's work for the public. CDC has the highest credibility and trustworthiness rating in government, and they are careful to keep that credibility. The public thinks of CDC as the infectious disease prevention entity and has little understanding of CDC's work in non-communicable diseases. The public expects CDC to provide information, not to provide guidance or tools for behavior change. CDC needs to communicate better about these functions.
- ❑ Public health, by definition, focuses on population health, not individual health. In order to be more effective in communicating, CDC must make its work more personal. Personal, individual stories could be effective, but should focus on evidence for impact of interventions and tell a clear story in numbers of lives saved by public health measures. Combining the stories with statements about an ethical mission may be useful in times of budget cuts. Past accomplishments, such as work in measles, could be compelling. It is possible to quantify the number of lives saved by seatbelts and make it clear that this effort is connected to CDC's work in non-communicable disease areas. Another effective example might be reductions in tobacco use over time.
- ❑ Public health generates policies and recommendations based on the best available scientific data. However, the impact of the policies and recommendations is sometimes unknown in advance because of many other variables. CDC needs help in articulating the moral argument for "doing the best you can with the best data you have, right now."
- ❑ While people do not want the government to tell them what to do, they often fail to recognize that their behavior is being manipulated by advertising, marketing, and the built environment. CDC can serve as a counterforce to these other influences in the public. It would be helpful to make these other influences more explicit and to recognize their motivations.
- ❑ The Ethics Subcommittee could build guidance from a topic-specific point of view. Nutrition and physical fitness issues are challenging. Motorcycle helmets present another important issue. Another

approach would be to consider interventions rather than topics, such as taxation. Either approach would be helpful.

Examples of CDC Interventions for Non-Communicable Diseases

Ursula Bauer, PhD, Director, National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), CDC

Dr. Bauer presented information on the three “winnable battles” that fall under NCCDPHP which include tobacco use prevention, improving nutrition and physical activity, and preventing teen and unintended pregnancy. These behaviors have enormous personal and societal costs. The first two issues exist in the context of aggressive marketing of tobacco products and of low-nutrition products. While no corporations support teen pregnancy, and teen pregnancy is not glamorized, structural and environmental forces are at play.

In tobacco prevention, CDC set four core goals, which include preventing people from starting tobacco use, eliminating exposure to secondhand smoke, promoting quitting among young people and adults, and eliminating tobacco-related disparities.

The strategies for which there is a solid evidence base include promoting implementation of 100 percent smoke-free policies; using aggressive media and marketing campaigns so that the graphic effects of tobacco use are well-known to the public; restricting tobacco marketing in retail stores; and increasing the price of tobacco products.

Goals for obesity prevention include increasing consumption of fruits and vegetables; increasing physical activity; increasing breastfeeding initiation, duration, and exclusivity; and decreasing consumption of sugar drinks and high energy-dense foods. Other nutrition goals that are not primary drivers of obesity include reducing sodium in the food supply, and eliminating industrially-produced trans fats from the food supply.

The strategies used to achieve these goals include the following:

- Developing and promoting nutrition standards for childcare and school settings so that more nutritious foods are available, and fewer low-nutrition foods are available
- Increasing the number of healthy food retail outlets in under-served areas and improving access to those outlets
- Increasing access to a variety of means for obtaining fruits and vegetables, including retail stores and supporting farm-to-institution policies
- Leveraging work of food policy councils at the state level
- Increasing access to safe, cool, and good-tasting water
- Reducing accessibility to sugared drinks, particularly in childcare and school settings

The evidence base for the obesity strategies is tenuous, but CDC is developing the evidence base. Often in public health, evidence follows practice as they learn from innovative strategies. CDC works with FDA and restaurants. Procurement policies are a tool for both sodium and trans-fat reduction efforts. Labeling initiatives are also important.

CDC goals for teen pregnancy are to reduce the rate of teen pregnancy and childbirth in priority populations; increase the number of youth who have access to evidence-based or evidence-informed programs; increase the links between teen pregnancy prevention programs and community-based clinical services; and educate stakeholders and decision-makers about the evidence-based and evidence-informed strategies.

Specific strategies include the following:

- Supporting prevention programs and policies that address the needs of teens who are abstinent or who are sexually active
- Increasing access to youth-friendly family planning services, including confidential services, for youth (this strategy raises ethical concerns and concerns of parents who want to know what services their children accessing)
- Increasing access to, and use of, the most effective contraceptives for teens who are sexually active (long-acting, reversible contraceptives are at the top of this list)

Dr. Bauer urged them to think about whether corporate interests in influencing individual behaviors trump society's interests in influencing those behaviors, and also to think about how to have ethical deliberations on that question.

Discussion Points

- There was discussion regarding the enormous exporting of tobacco targets and products. CDC works globally to advance policies in other countries. American corporations that export tobacco are given tax "breaks" for profits made overseas.
- CDC is concerned about the export of American diseases through American behaviors, including the food environment as well as tobacco.

Linda Degutis, DrPH, MSN, Director, National Center for Injury Prevention and Control (NCIPC), CDC

Dr. Degutis explained that injury is defined as tissue damage that results from an energy transfer, whether it is kinetic energy, as in a motor vehicle crash, or chemical injury, such as poisoning and overdoses, or thermal injury, such as burns. Injuries are classified as intentional and unintentional. Unintentional injuries include accidents, which are preventable. Intentional injuries include violence.

NCIPC tries to convey that, similar to diseases, injuries are predictable and preventable, and the consequences can be minimized. Many people do not know that CDC has an Injury Center. There is a long history of injury prevention efforts. Several of these successes are regulatory, while others are successes in health promotion.

NCIPC's priorities include motor vehicle injury prevention, one of CDC's winnable battles; prescription drug overdose prevention, a significant emerging issue; violence prevention; and traumatic brain injury (TBI).

Regarding motor vehicle injury prevention, NCIPC has worked with states to improve their policies on ignition interlock devices as a tool to reduce alcohol-impaired driving. NCIPC's strategies for this effort include a policy statement on alcohol-impaired driving; *The Community Guide on Alcohol-Impaired Driving*, which identifies these devices as a successful strategy; and providing states with data to help them understand the burden in their state and how the policies can make a difference in their state. Other initiatives include passing primary seatbelt laws and graduated driver licensing (GDL) programs.

Prescription drug overdose is an emerging issue. One strategy for addressing this problem is prescription drug monitoring programs. A number of states have these programs, but not all states have operationalized them. NCIPC is funding projects to study the impact of these programs. Most states have Medicaid patient review and restriction programs, and some private insurance companies have adopted similar programs. NCIPC is working on clinical guidelines for opioid prescriptions. One of their challenges will be to balance the desire to decrease inappropriate opioids prescriptions with the need to ensure that people who truly have pain receive the help they need. Multiple federal agencies are working on this problem, and a frequently encountered challenge is how to work with the pharmaceutical companies.

In the area of violence prevention, NCIPC is in a global partnership that is considering how to end sexual violence against girls, which is a particular problem in developing countries. They are in the survey stage, generating data to guide actions and looking at how to mobilize communities to make this type of violence unacceptable. Cultural issues and the response of certain sectors to the government have been challenging. Initiatives in the United States are built on evidence from NCIPC regarding what works in violence prevention. NCIPC also works in intimate partner violence on several other levels, including funding "Dating Matters," a teen dating violence prevention initiative implemented at the local level; funding the Triple P Positive Parenting Program, a population program for the prevention of child maltreatment that focuses on strengthening parenting skills; and work with the National Institutes of Justice (NIJ) and Department of Defense (DoD) on the National Intimate Partner Violence and Sexual Violence Survey.

In the area of traumatic brain injury, NCIPC has a Memorandum of Understanding (MOU) with the National Highway Traffic Safety Administration (NHTSA), and they are developing policy impact statements regarding motorcycle helmets.

Discussion Points

- ❑ There was discussion regarding why mental health issues and other chronic conditions are addressed by the Injury Center. Intimate partner violence and domestic violence have traditionally fallen into the injury field. Most of the agencies that work in suicide focus on mental health issues and do not look at prevention and public health impact in the way that CDC does. Further, violence and maltreatment in childhood has a definite impact on chronic disease later in life, and safety in the community impacts these issues as well. Substance abuse and poisoning are chemical injuries.
- ❑ There was discussion regarding ethical tensions in passing motorcycle helmet laws. These ethical tensions are often an impediment to getting from data to implementation. NCIPC has state-by-state analyses of motor vehicle crashes, including costs, are available on their website. It was suggested that data bearing on ethical issues, such as family disruption, could be gathered.
- ❑ In most states with ignition interlock device laws, the laws do not apply to first-time convicted offenders. Some of the past federal transportation bills attached highway funding to implementation of a .08 blood alcohol content (BAC) law, zero tolerance laws, or open container laws.
- ❑ There was discussion regarding overlap of issues of violence and sexual health and human trafficking, as well as sexual exploitation.
- ❑ Issues of stigma and profiling arise frequently in violence. They need to look at issues of stigma more, especially in youth violence, when it is assumed that the violence is gang- or drug-related. Stigma is also a problem in prescription drug overdose work, and there is stigma among practitioners as well as among the public.

Next Steps for Addressing Potential Public Health Ethics Issues Associated with Implementation of Non-Communicable Disease Interventions

- ❑ Dr. Bauer requested assistance in the nutrition realm. They have strong evidence in tobacco and support in teen pregnancy, but nutrition is an emerging issue. These issues are intensely personal and sensitive, and there are huge profits in this area. NCCDPHP strives to understand the psychological and social dimensions of food and nutrition and how to communicate the compelling case for nutrition. They can be candid in the messages they share, but it can be a struggle, because people do not want to hear that they are being manipulated by advertisers.
- ❑ The conversation should include issues such as food insecurity. Consumers are accustomed to inexpensive food, and the food production system is created to ensure that food is cheap. Because people want cheap, convenient food, and many people cannot afford healthy food, so they turn to cheap, filling food. "Food deserts" are being addressed by several policies and initiatives.

- ❑ The focus on individual behaviors implies that the battle is between an unchallenged industry giant and CDC as a counterforce. Without large campaigns, CDC may not be effective in making individual behavior change. For instance, zoning laws were enacted for alcohol outlets. Zoning regulations may have initial unintended consequences and the Ethics Subcommittee could create a case study to illuminate this issue. It was pointed out that CDC focuses on environmental and policy change as opposed to individual behavior change. For example, individuals have no control over sodium in the food supply. CDC is working with the food industry on this issue and many manufacturers are supportive of government regulation of sodium content in food.
- ❑ There was discussion regarding financial incentives and disincentives. Good food could be made cheaper, either through subsidizing purchases or making it cheaper to locate grocery stores in certain areas. There is emerging evidence regarding differential pricing strategies. There are ethical implications for taxation and its disproportionate effects on different groups.
- ❑ It was noted that behavior can be influenced through powerful social norms. CDC's work in tobacco does not attack the smoker, and in the same vein, they do not focus on the overweight or obese individual, but rather push for interventions that allow for better nutrition and more physical activity. The goal is to prevent overweight and obesity while avoiding stigmatizing the individual.
- ❑ Dr. Degutis indicated that the prescription drug overdose issue is significant for NCIPC. Stigma is one piece of the issue, and there are concerns regarding working with industry. Another challenge is considering whether their efforts might result in negative consequences as people seek other substances and abuse them. Further, they must balance what is needed for pain management versus abuse. Consumers assume that because physicians prescribe drugs, then they must be safe.
- ❑ Nutrition, food marketing for children, and prescription drug abuse and were raised as topics for further examination through case studies. Dr. Barrett indicated that the Case Development Workgroup will work with the appropriate CDC subject matter experts to develop cases on these topics.

Outcome of the April Advisory Committee to the Director Meeting

Ruth Gaare Bernheim, JD, MPH, Chair, Ethics Subcommittee

Dr. Bernheim shared the presentation that she gave at the ACD meeting in April 2011. The central question regarding the ethics of non-communicable disease (NCD) interventions:

“How can we address ethical tensions that arise when public health intends to implement restrictive or regressive policies and approaches that focus on chronic diseases and injuries rather than infectious diseases?”

The ethics of NCD interventions raise specific questions:

- ❑ When it is appropriate or acceptable for public health to limit individual choice, either directly, such as by requiring use of helmets or prohibiting use of food vouchers for soft drinks, or indirectly, such as increasing taxes on cigarettes?

- What are the ethical considerations that need to be thought through in these situations?
- How do we best facilitate the adoption of public health interventions for NCDs?

The gap between knowledge and implementation is an important area for policy makers and public health officials. In this gap, it is critical to have information about social values and norms as well as the competing claims of various stakeholders. Implementation of publicly acceptable programs and policies requires understanding the competing moral claims, and developing counter claims and policy rationales that resonate ethically with the public at any given time.

In NCD issues, the goal is to use a combination of interventions that are least restrictive and most empowering of individuals. They may begin with interventions that focus on information and non-coercive nudges so that over time, social norms are changed without the need for sanctions and enforcement. Ethical analysis in public health provides information about stakeholder social values, norms, and ethical tensions.

The context of the public's view of the use of governmental public health authority to override individual liberty changes along the spectrum from government protection to prevention and promotion. In chronic disease prevention, some public resistance focuses on the appropriateness of government's role in health. Some perceive these types of interventions as unnecessary because there is no imminent risk of grave harm. These interventions are also sometimes perceived as unjustified intrusions into individual liberty and a slippery slope to the "nanny paternalistic state." Approaches to chronic disease are especially challenging because they often involve behavior change in the population, which can also lead to claims about a "nanny" government. Unlike in infectious disease control, where there is more support for government authority, judicious use of government authority is key in NCD issues.

In chronic disease, it is important to counter claims of paternalism and "nanny government" by demonstrating support for individual responsibility and enhanced consumer choice. It is also important to remember that changing social norms and behavior is a gradual process. There are advantages to working with coalitions and in collaboration with stakeholder groups, including affected industries. Legal intervention or policy may be helpful, and should be within already-accepted government mandates whenever possible. Ethical frameworks and precedent cases can be helpful in developing interventions in a gradual sequence, taking into account evolving social values, unintended consequences, and the policy rationales in the public arena. Health equity is also an important ethical concern.

To achieve implementation and best outcomes, CDC must not only gather data and provide scientific evidence about health impact and effectiveness of interventions. It should also gather information about this gap between knowledge and implementation. To do that, public health officials at all levels need information about ways to address ethical tensions in the gap. Science and data are the foundation of public health and are critically necessary, but may not be sufficient to win the battles involving competing moral claims in the gap.

Discussion Points

- The ACD responded positively to the NCD presentation and encouraged the Ethics Subcommittee to work with CDC leadership to determine next steps.

- ❑ It was pointed out that the government's role is complex in these public health problems. For instance, the government used to subsidize tobacco farming and now subsidizes corn, which allows for cheap fast food. Government is not of one mind on this issue.
- ❑ Different groups influence the political process, even if the groups do not represent the majority of constituencies. While these political questions are beyond the scope of the Ethics Subcommittee, it is important to understand these conflicting ideas and mechanisms.

Public Comment

At 12:03 pm, Dr. Bernheim opened the floor for public comment. Hearing none, Dr. Barrett proceeded with the agenda.

Meeting Wrap-Up

The ACD reviewed the ventilator document at their April 2011 meeting and offered no comments or requests for changes. The document was sent to the Director of CDC and was sent to HHS on May 20, 2011. If there are no requests for changes, the document will be released on the CDC website.

Two new members have been selected to serve on the Ethics Subcommittee: Eric Meslin (Indiana University) and Jeff Kahn (University of Minnesota). Their terms begin on July 1, 2011.

The next Ethics Subcommittee meeting will take place on October 5 and 6, 2011.

This meeting's action items included the following:

- ❑ The Case Development Workgroup will make adjustments to the case studies and will develop additional cases addressing the topics of nutrition, food marketing, and prescription drug abuse.
- ❑ A webinar will be held to pilot test one of the cases. Matt Stefanak from Mahoning County, Ohio, volunteered to participate as the pilot (case on TB screening in schools).

Dr. Barrett thanked everyone for their participation. The meeting adjourned at 12:08 PM.

Certification

I hereby certify that to the best of my knowledge, the foregoing minutes of the June 16-17, 2011 Ethics Subcommittee meeting are accurate and complete.

8-29-11

Date

Ruth Gaare Bernheim, JD, MPH
Ethics Subcommittee Chair

Appendix 1

Meeting Agenda

Joint Meeting of the Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention (CDC) and CDC's Public Health Ethics Committee

June 16-17, 2011

Thomas R. Harkin Global Communications Center, Distance Learning Auditorium

Atlanta, Georgia

Call-in Information: 1-877-928-1204, Pass Code 4305992#

Day 1 – Thursday, June 16, 2011

1:00 – 1:30 **Introductory Remarks and Overview of Meeting Goals** – Ruth Gaare Bernheim, JD, MPH, Chair, Ethics Subcommittee

- Welcome and introductions
- Ethics Subcommittee members declaration of conflicts of interest
- Acknowledgement of retiring Ethics Subcommittee members
- Overview of meeting goals
 - Share information about the April 28 Advisory Committee to the Director (ACD) meeting
 - Review workgroup progress on developing practical tools to assist state, tribal, local, and territorial health departments in their efforts to address public health ethics challenges
 - Discuss next steps on addressing potential public health ethical issues associated with implementation of effective preventive interventions for noncommunicable disease

1:30 – 3:00 **Discuss and Approve: Public Health Ethics Tools to Support State and Local Health Departments**

- Review draft cases

- Reach agreement on case format
- Discuss criteria for the development of additional cases

3:00 – 3:15 **BREAK**

3:15 – 4:45 **Discuss and Approve: Public Health Ethics Tools to Support State and Local Health Departments (Continued)**

- Discuss ethics framework(s) for analysis of cases
- Review options for dissemination of cases
- Next steps for development of other public health ethics tools
- Possibilities for international collaboration

4:45 – 4:55 **Public Comment**

4:55 – 5:00 **Concluding Comments** – Ruth Gaare Bernheim, JD, MPH

5:00 **Adjourn**

Joint Meeting of the Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention (CDC) and CDC's Public Health Ethics Committee

June 16-17, 2011

Day 2 – Friday, June 17, 2011

8:30 – 9:00 **Information Sharing: Outcome of the April Advisory Committee to the Director Meeting** - Ruth Gaare Bernheim, JD, MPH and Cass Wheeler, ACD Representative to the Ethics Subcommittee

- Presentation on ethical considerations for noncommunicable disease interventions
- Status of the ventilator allocation document

9:00 – 10:00 **Information Sharing: Examples of CDC Interventions for Noncommunicable Diseases**

- Chronic Disease – Ursula Bauer, PhD, Director, National Center for Chronic Disease Prevention and Health Promotion, CDC
- Injury – Linda Degutis, DrPH, MSN, Director, National Center for Injury Prevention and Control, CDC

10:00 – 10:15 **BREAK**

10:15 – 12:00 **Discuss and Approve: Next Steps for Addressing Potential Public Health Ethics Issues Associated with Implementation of Noncommunicable Disease Interventions**

12:00 – 12:15 **Public Comment**

12:15 – 12:30 **Procedural Issues and Meeting Wrap up** – Ruth Gaare Bernheim, JD, MPH

- Review action items
- Recommendations for new Ethics Subcommittee members
- Complete evaluation forms

12:30 **Adjourn**

Appendix 2

Meeting Participants

June 16, 2011

1:00 – 5:00 pm Eastern Daylight Savings Time

Ethics Subcommittee, Advisory Committee to the Director

Ronald Bayer, Columbia University

Ruth Gaare Bernheim, University of Virginia

LaVera Marguerite Crawley, Stanford University

Norman Daniels, Harvard University

Kenneth Goodman, University of Miami

Jennifer Prah Ruger, Yale University

Pamela Sankar, University of Pennsylvania (phone)

Marion C. Wheeler, ACD Member, Strategic Consultant

Leslie Wolf, Georgia State University

Centers for Disease Control and Prevention

Drue Barrett (Designated Federal Officer, Ethics Subcommittee)

Mary Ari

Ursula Bauer

Elise Beltrami

Clive Brown

Scott Campbell

Cynthia Cassell

Gwendolyn Cattledge

Joanne Cono (phone)

Laurie Dieterich

Lindsay Feldman

Neelam Ghiya

Scott Goates

Gail Horlick

John Iskander

Harold Jaffe

Mark Johnson

James F. Jones

Vikas Kapil

Rachel Kaufmann

Mim Kelly

Lisa M. Lee

Megan Lindley

Bryan Lindsey

Aun Lor

Josephine Malilay

Daniel McDonald

Kathy Meyer

Micah Milton

Paul Moore (phone)

Amy Neuwelt

Leonard Ortmann

Deesha Patel

Tim Pizatella (phone)

Sam Posner

John Powers (phone)

Joan Redmond Leonard

Lee Sanderson

Scott Santibanez

Tom Simon

Dixie Snider

Cristen Suhr

Esther Sumartojo

Jerry Thomas

Mark White

Members of the Public

Subha Chandar, NACCHO (phone)

Brenda Robertson, Emory University

Matt Stefanak, Mahoning County, OH (phone)

Sarah Viehbeck, Canadian Institutes for Health Research (phone)

June 17, 2011

8:30 am – 12:30 pm Eastern Daylight Savings Time

Ethics Subcommittee, Advisory Committee to the Director

Ronald Bayer, Columbia University (phone)

Ruth Gaare Bernheim, University of Virginia

LaVera Marguerite Crawley, Stanford University

Norman Daniels, Harvard University

Kenneth Goodman, University of Miami

Jennifer Prah Ruger, Yale University

Pamela Sankar, University of Pennsylvania (phone)

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Ileana Arias

Mick Ballesteros

Ursula Bauer

Elise Beltrami

Erin Black

Scott Campbell

Cynthia Cassell

Gwendolyn Cattledge

Linda Degutis

Sandra DeShields

Barbara Ellis (phone)

Lindsay Feldman

Neelam D. Ghiya (phone)

Gail Horlick

Sonja Hutchins (phone)

Robin Ikeda

John Iskander

Harold Jaffe

James F. Jones

Vikas Kapil (phone)

Rachel Kaufmann

Lisa M. Lee

Leandris Liburd

Bryan Lindsey

Aun Lor (phone)

Josephine Malilay

Daniel McDonald (phone)

Micah Milton

Amy Neuwelt

Leonard Ortmann

Ron Otten

Deesha Patel

Tanja Popovic

Joan Redmond Leonard

Lee Sanderson

Scott Santibanez

Dixie Snider

Esther Sumartojo

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Members of the Public

Brenda Robertson, Emory University