

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

**Coordinating Center for Health Promotion (CCHP)  
Board of Scientific Counselors Meeting (BSC)**



**Summary Report  
July 1, 2009  
Atlanta, Georgia**

Table of Contents	Page
Acronyms	3
Call to Order, Welcome, Introductions	5
NCCDPHP Workgroup: Summary of Findings Solicitation of Input from Full BSC	14
NCBDDD Workgroup: Summary of Findings Solicitation of Input from Full BSC	38
Next Steps, Timeline, Products	56
Public Comments	56
Certification	57
Participant Roster	58

## Acronyms

AAP	American Academy of Pediatrics
ACC	American College of Cardiology
ACES	Adverse Childhood Event Studies
AHA	American Heart Association
AMA	American Medical Association
ASA	Autism Society of America
BSC	Board of Scientific Counselors
BRFSS	Behavioral Risk Factor Surveillance System
CADDREs	Centers for Autism and Developmental Disabilities Research and Epidemiology
CBPR	Community-Based Participatory Research
CDC	Centers for Disease Control and Prevention
CCHP	Coordinating Center for Health Promotion
CCID	Center for Infectious Disease
CHD	Congenital Heart Defect
CIOs	Centers, Institutes, and Offices
CMS	Centers for Medicare and Medicaid Services
COGH	Coordinating Office for Global Health
CSTE	Council of State and Territorial Epidemiologists
DACH	Division of Adult and Community Health
DASH	Division of Adolescent and School Health
DBD	Division of Blood Disorders
DCPC	Division of Cancer Prevention and Control
DDT	Division of Diabetes Translation
DFO	Designated Federal Officer
DHDD	Division of Human Development and Disability
DHDSP	Division for Heart Disease and Stroke Prevention
DOE	Department of Energy
DRH	Division of Reproductive Health
DVT	Deep Vein Thrombosis
EIS	Epidemic Intelligence Service
FACA	Federal Advisory Committee Act
FDA	Food and Drug Administration
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
ICC	Interagency Coordinating Committee
IOM	Institute of Medicine
L & M	Leadership and Management
MCHB	Maternal and Child Health Bureau
MASO	Management Analysis and Services Office
MEPS	Medical Expenditure Panel Survey
<i>MMWR</i>	<i>Morbidity and Mortality Weekly Report</i>
NBDPC	National Birth Defects Prevention Center
NCBDDD	National Center on Birth Defects and Developmental Disabilities
NCCDPHP	National Center for Chronic Disease Prevention and Health Promotion
NCHM	National Center for Health Marketing
NCHS	National Center for Health Statistics
NCPHI	National Center for Public Health Informatics
NHLBI	National Heart, Lung, and Blood Institute
NICHD	National Institute of Child Health and Development
NIH	National Institutes of Health
NIMH	National Institute of Mental Health

OCSO	Office of the Chief Science Officer
OGC	Office of General Council
OMB	Office of Management and Budget
OMB-PART	Program Assessment Rating Tool
OGH	Office on Global Health
OPHG	Office of Public Health Genomics
OPHR	Office of Public Health Research
OWCD	Office of Workforce and Career Development
PART	Program Assessment Rating Tool
PE	Pulmonary Embolism
PHEC	Public Health Ethics Committee
PRAMS	Pregnancy Risk Assessment Monitoring System
PRCs	Prevention Research Centers
RCT	Randomized Controlled Trial
RWJ	Robert Wood Johnson
SAMHSA	Substance Abuse and Mental Health Services Administration
SES	Socioeconomic Status
SMEs	Subject Matter Experts
UK	United Kingdom
US	United States
VFC	Vaccines for Children
WHO	World Health Organization
YRBS	Youth Risk Behavior Survey

## **Board of Scientific Counselors (BSC) Coordinating Center for Health Promotion (CCHP)**

**July 1, 2009  
Atlanta, Georgia**

### **Summary Report**

The Department of Health and Human Services (HHS), the Centers for Disease Control and Prevention (CDC), and the Coordinating Center for Health Promotion (CCHP) convened an External Review Panel on June 30 – July 1, 2009. The purpose of this meeting was to examine the relevance, quality, and impact of the National Center for Chronic Disease Prevention and Health Promotion's (NCCDPHP) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD) portfolios and provide recommendations for the future.

On June 30, 2009, work groups representing each of the CCHP's two centers met separately to hear overviews from center staff. Subsequently, each workgroup engaged in deliberations during closed sessions to develop draft recommendations based upon their findings from the peer review process.

On July 1, 2009, the two workgroups reconvened with the larger CCHP Board of Scientific Counselors (CCHP BSC) to present their findings and engage in further discussion with the full board and CDC staff. During this session, in accordance with the provisions of public health law, the meeting was open to the public from 8:15 a.m. to 5:15 p.m. EST.

### **July 1, 2009**

#### **Call to Order, Opening / Welcoming Remarks, Overview & Introductions**

**Karen Steinberg, PhD  
CCHP BSC Executive Secretary  
Senior Science Officer  
Centers for Disease Control and Prevention**

Dr. Karen Steinberg called the meeting to order, welcoming those present and introducing Dr. Tanja Popovic who offered the opening remarks.

#### **Opening Remarks**

**Tanja Popovic, MD, PhD, F(AAM), AM(AAFS)  
Chief Science Officer  
Office of the Chief Science Officer (OCSO)**

Dr. Popovic shared some of the recent experience CDC had had over the previous four weeks of having a new director at CDC. She stressed that the most important things always stay the same, transition or no transition. The quality, relevance, and impact of CDC's science has always been the most important component of the agency and absolutely will be emphasized and they hoped supported more. Nobody has ever said that CDC does not do good science or

are not people of integrity. Although CDC does good science and has a staff with great integrity, the agency does not necessarily provide enough support for everything that must occur before and after science. Before someone can actually do the work on the bench, in the field, or in the office, many things have to be in place. Once the information is produced, there has to be a lot of support for that information to remain intact and not massaged by all sorts of influences. There have been discussions about this already with Dr. Frieden and everyone feels extremely optimistic about it because that is what gives the excellence in science excellence.

In September 2008, a very useful meeting was convened with all chairs of the BSCs and all Federal Advisory Committee Act (FACA) committees. At that time, there were plans to convene a smaller group of people to include BSC chairs and Designated Federal Officials (DFOs) to determine how closer contact could be established among the many BSCs and how each group could benefit from the other. Although the transition has delayed this activity, the agency is again thinking about this need and will follow-up to facilitate the BSCs and DFOs working more closely together.

The task of reviewing the quality, relevance, and impact of science requires a lot from a body like this. To put that into perspective, Dr. Popovic shared some efforts underway at CDC to help them appreciate the range of activities going on within the agency. The pace has been unbelievable the previous four weeks with Dr. Frieden in office. Dr. Frieden is unbelievably focused, energetic, and is likely to move the agency wonderfully well. Everyone is working to provide whatever support Dr. Frieden requires to be brought up to speed with the agency.

One of the major issues everyone is talking about is health system reform. CDC recently held the Shepard Award in which best scientific publications are recognized and an award is given for lifetime scientific achievement. Professor Paul Krugman, Nobel laureate in economics, 2008, gave the guest lecture on health care reform and our economic future. That this was the most well-attended event that Dr. Popovic believes she ever witnessed in the last 20 years at CDC was testimony to the interest in health care reform and its effect on the economy.

Regarding H1N1 activities, hundreds of people continue to be engaged. Even though it may seem that activity has decreased since last winter's increase in cases of influenza and subsequent decrease over the spring and summer months, within CDC there is still a tremendous amount of activity.

A field that is particularly important to CCHP is comparative effectiveness research. CDC believes that comparative effectiveness research should look not only at the clinical world, but also should include public health and prevention activities. CDC has developed a proposal that will be assessed by the stimulus groups and councils. It is hoped that CDC will be funded to conduct some activities in that area. CDC is making comments in that proposal about the importance of addressing activities that work not only in a clinical trial setting, but in real life. Perhaps effectiveness can be compared from different sectors, and it is important to examine the populations that are most vulnerable where the most difference can be made. Comparative effectiveness research at CDC and in the public health arena is not new. It may not have been called "comparative effectiveness research" per se, but there are some activities and infrastructural assets that public health can offer to the comparative effectiveness research enterprise. The Institute of Medicine (IOM) has been charged with advising HHS on what areas of comparative effectiveness HHS should focus on initially, and has recently published their report. While the words *public health* are not specifically included, there are many words such as *wellness, community, social responsibility, home, and community access* that very well-

define the kinds of activities that are ongoing in the programs for which the work groups would be providing guidance.

In closing, Dr. Popovic thanked the BSC members for their work. One issue she spoke with Dr. Frieden about is the need to be very specific in terms of how CDC addresses the recommendations from the BSCs. Although an existing policy discusses program and science reviews, OSCO is developing a two-page document to address how the agency will respond to BSC recommendations with very specific requirements, for example, following the meetings, recommendations need to be posted on the web, and the programs will need to respond to each of the recommendations. The programs will be given more time to define specifically what steps will be taken, what the measures will be, and what outcomes are expected. There will then be annual reporting to Dr. Popovic's office, the CDC director, and the national center directors. There will be an emphasis on ensuring that the agency actually does listen to the recommendations and advice of the BSCs.

## **Welcoming Remarks**

**Karen Steinberg, PhD  
CCHP BSC Executive Secretary  
Senior Science Officer  
Centers for Disease Control and Prevention**

Dr. Steinberg stressed how great it was to see everyone again after six months. She stressed that Dr. Kolbe has shown her what great patience is in a time of tsunami-level change. Change is good, but it is a challenge to engage in a review process in the midst of great change.

She offered greetings from Dr. Toomey, who was unable to attend during the morning session. Dr. Steinberg recognized that after having met for only the second time in six months, the group had been asked to make recommendations to two national centers, with drafts due by the end of the day and final reports due by the end of November, which represented a tremendous amount of work. She also recognized the massive amount of information that was sent to each BSC members over the last few weeks that they had to digest. Despite that, the members moved through this process in a deliberate and thoughtful manner. She was confident that the BSC would get the job done and have a product that they could be proud of and that would be very helpful to CCHP, for which CCHP was very grateful. No matter what changes occur at CDC, the need for the BSC's time and expertise would not change. With that in mind, she thanked them for their time.

She then introduced Dr. Lloyd Kolbe, the CCHP BSC Chair.

## **Overview**

**Lloyd Kolbe, PhD, CCHP BSC Chair  
Associate Dean for Global and Community Health  
Professor of Applied Health Science  
Indiana University**

Dr. Kolbe recognized Dr. Steinberg for having done a job beyond the call of duty, and for having been an enormous comrade in working with the BSC. He added his welcome and gratitude to the CCHP BSC members for taking time for the two days of this particular meeting, as well as for the extensive amount of time and effort they put into the review process. He extended gratitude to the ad hoc consultants who worked with NCBDDD and NCCDPHP, who offered wonderful expertise. He had heard nothing but glowing remarks about the leadership and deliberations during the review sessions the previous day.

He charged the group to begin to draft articulate specific, useful, and feasible priority recommendations from the discussions the previous day, and to put on paper the most compelling rationale for why these recommendations should be implemented. Prior to the September 15, 2009 teleconference, an informal draft would be expected from both groups that would be shared with the full BSC and ad hoc consultants such that they would have time to review it before then. Drafting a final document by September 15, 2009 would allow time to have it reviewed by email, by the full BSC, and meet the requirement of having a completed report by November 1, 2009.

Dr. Kolbe then reviewed the agenda. He stressed that the meeting was taking place under federal regulations and must include a public comment period. In order to include a public comment period, a quorum of the BSC must be maintained of 8 members. With a show of hands, it was determined that 13 members would be able to remain for the full day.

## **NCCDPHP Work Group: Summary of Findings / Solicitation of Input from Full BSC**

### **Overview**

#### **Duskanka Kleinman, Rapporteur NCCDPHP Work Group**

Dr. Kleinman reported that the NCCDPHP Work Group had a wonderful day on the previous day, with an opportunity to learn a lot about the center. The day was clearly too short to have grasped the immense work that has been done over the past two decades. Nevertheless, the overviews helped the group build upon the very rich background information they received. Their hope during this session was that the presentations would allow the remainder of the BSC an opportunity to hear what the work group heard and ask questions.

The NCCDPHP Work Group approached this task by following and overseeing three categories of the programs within the center: administrative, research and surveillance, and programmatic direction. Dr. Kleinman stressed that the presentations represented a condensed, very rough, first draft of recommendations of what the group heard and thought following the first phase of the process. She asked the full BSC to help ensure that recommendations were specific, clear, feasible, and had a very strong rationale.

In terms of background, the NCCDPHP Work Group was charged to assess the quality, impact, relevance, collaborations of the three categories, looking at the center as an organizational unit from the 35,000 foot view. The purpose of this review is to inform funding and management decisions, help the center build on its strengths, and take advantage of the opportunities. Michele Curtis and David Marrero oversaw the administrative and financial operations, Karen Emmons and Carol Macera oversaw the research and surveillance portfolio. Dileep Bal and Frank Bright (ad hoc member, American Cancer Society, Ohio Division) oversaw the public health program portfolio. Sharon Kardia, David Goff, and Dushanka Kleinman were the generalists overseeing the overall center.

The center goals are to reduce the rates of morbidity, disability, and premature mortality due to chronic diseases; synthesize and contribute to the science base; and achieve equity by eliminating disparities and achieving optimum health for all.

The work group was provided with a wonderful logic model that was shared during the January 2009 meeting, which put the context of the center very clearly in the work group members' minds in terms of how the center proceeds from outcomes to acquiring the essential data that are needed. The structure that was put in place in the Venn Diagram that focused on the clustering of risk factors, diseases, and conditions that are being emphasized in the centers, and the multiple settings in the context of the life course, was very beneficial to the group.

During the previous day's meeting, the group heard very rich presentations beginning with an overview from the director of the entire center, Dr. Janet Collins. Dara Murphy, Management Officer, provided an overview of the administrative and financial operations. Dr. Samuel Posner presented the portfolio for research and surveillance. Rosemarie Henson, Deputy Director, presented the public health program portfolio. It was the one-page logic model that really put the strategies in context for the group. The presentations that they heard and the way they were going to speak to the larger BSC about their interpretation really followed the logic model strategy and framework.

The center's strategic priorities include a focus on wellbeing, health equity, research translation, policy formation, and workforce development. In FY 2008, the center's budget was \$931 million, about one seventh of the agency's budget. About \$738 million of this budget are allocated to extramural programs. The center has 1400 employees, 10 divisions, and a very rich Office of the Director, with senior staff overseeing such functions as communication, planning, evaluation, legislation, global affairs, health promotion, medical affairs, public health practice, and science.

### **Team One: Administrative and Financial Operations**

**Dr. Michele Curtis**

**Dr. David Marrero**

Dr. Curtis reported that this work group engaged in some very lively discussions. She and Dr. Marrero were charged with overseeing / evaluating the administrative and financial operations and making recommendations. This was a rather difficult task to do trying to follow the outline of quality, evaluation, relevance, and impact because this topic did not easily lend itself to that sort of categorization. They will be submitting a narrative in that format to the best of their ability, as well as another narrative with a different format but might be easier to read. It would then be up to the entire board to determine which format might be more useful.

Engaging in this process generated a great number of questions, some of which are quite provocative and some of which will be easily answered while others will not. They plan to include these questions in their narrative as well. Their fear was that if they actually raised these questions during this meeting, everyone may attempt to answer them and they would never get past this presentation. Therefore, the presentation was limited just to Team One's recommendations. Dr. Curtis then proceeded to review the team's recommendations.

### **Budgetary Recommendations**

- ❑ CDC should more heavily promote their involvement in the Congressional process of budgetary initiatives and appropriations. The reality is that marketing exists in everything, particularly in politics and governance, and the CDC's budgetary allocations as well as its reputation is dependent upon this just as any other organization's is. There were sub-recommendations to this as well.
- ❑ The center, through CDC, should increase its influence in crafting language that defines intent. It was very clear to this team that congressional intent drove the use of the dollars, where they went, and how they were spent. At times there appears not to be any clarity about what the intent was. While there are certain situations in which that allows for creativity, there are also times that might cause confusion and may, in fact, inhibit people

from taking action and being too creative in their interpretations. The center should also develop increased interactions with health policy fellows in terms of increasing awareness of operations and activities. The problem is that there are a number of people who really do not know what the CDC does and how well they do it. That must be changed, so the center could increase the awareness of their activities through the agency / operations activities by inviting staff on the Hill to come to CDC on an on-going basis. It is the Hill's staff who are writing the legislative language and intent, so they must be convinced about where the center believes the priorities lie. They must be shown what the center has done and can do. In the on-going effort to increase awareness, there should be more effort to reach out and engage in more interactions with a variety of Health Policy Fellowships that exist in Washington, DC (e.g., American Political Science Association, Robert Wood Johnson Health Policy Fellowship). Dr. Curtis indicated that she was honored to be chosen as a fellow and they came to tour CDC. Even as a practicing clinician, the depth of what she learned and saw was quite amazing. The center should also have local CDC representatives meet with the center staff as well as with staff members from the Hill regularly when those staff members are in their home state. There are CDC personnel in the field who should be able to talk to the Hill staff to tell them what is being done in their backyard in order to increase awareness and presence.

- The center must have discretionary funds. The hamstringing that occurs by virtue of the inability to have flexibility in where most of the dollars are spent is causing many difficulties. These discretionary funds would be used for innovative program development, but would not be part of program mandates. It would be used for strategic planning, true strategic development, and strategic investment. It would also be used as a rapid response mechanisms for emerging problems because there is no way to predict what will emerge in the future, as well as for pilot testing.
- The center should review equity among its various units, as well as all of the CDC units to examine the equity of leadership and management (L & M) allocations in accordance to group size, mandates, and programmatic needs. The director of CDC has the authority to make some of these allocations. This work group believed that some of the interest in infectious disease may have overshadowed the allocation of funding for the presence of more chronic diseases in the past, and recommended that perhaps a review of this equity among allocations should be conducted. At a minimum, the recommendation was that the centers should have their L & M budgets increased back to the 2005 levels.
- The center should contact other federal grantees to inform them of potential opportunities to collaborate and leverage the potential of those funds. For example, if there is a grantee recipient from an National Institutes of Health (NIH) award working on a project that could have overlap and lends itself to collaboration with an on-going CDC project in their state or area, they should be contacted. The center could offer them the potential to collaborate and leverage the potential use of those funds.
- The center should centralize the communication process among its own divisions, particularly informatics and communications.
- The center should also assess the degree of dependency it has currently from a budgetary standpoint on foundational support, including CDC foundational support, cost sharing with the states, co-funding, and the impact that elimination of the streams of funding would have on the center's mission and strategic plan. The idea is that if this evaluation is done, it could be used as a part of a rationale for requesting increased use of discretionary funds.

- ❑ The center director should have a direct reporting line to the CDC national director.
- ❑ The center should also move toward integrating programs without losing focused areas and funds. There must be a blend of both specific view points and much more interdisciplinary, collaborative, and integrated approach.
- ❑ There should be a systematic review of the system's programs to develop overlaps between on-going activities. The potential for cost sharing will arise through this process and can be identified.

### Workforce Development Recommendations

- ❑ The center should create fellowships and practicums in order to increase the visibility of the center as an agency for true translational research. That is what is being done. It has gone from science to the street; from the bench to the bedside. The work group believed that being able to increase awareness of this would be quite beneficial for the center and ultimate for the agency.
- ❑ There should be an assessment of the impact on the center itself because they have a blended workforce whereby two-thirds are considered FTEs and one-third are considered non-FTEs. It is important to understand the impact of this blended workforce on direct and indirect costs, program functionality, cross-training, et cetera.
- ❑ The center should clearly state how labor is divided among contractors. For example, the center was easily able to tell the team how many of the FTEs were in science, program, and administrative positions, but were unable to do so for contractors.
- ❑ There is a need for indicators for assessing the quality and impact of current workforce development efforts. How well is it working? What impact is it having.
- ❑ There is a need to evaluate the needs for development of a global workforce program.
- ❑ There is a need to determine what is necessary for an externally focused workforce development program. The one that currently exists is internally focused.
- ❑ Additional experts are needed for mission critical functions (e.g., Health Economist, Political Scientists, Social Economists, Medical Geneticists, Bioethicists, Medical Anthropologists).

### Discussion

- With regard to the budgetary recommendations, Dr. Cohen expressed concern about a couple of issues. Having served on numerous advisory groups, there is always a tendency to make recommendations that may not be feasible or consistent with policies of the organization. In particular, the advocacy efforts of CDC staff may be problematic. The NCBDDD group discussed this as well. This appeared to be reaching into issues of policy that it was not clear were within their jurisdiction, though the ideas were good. The issue of good public relations and advocacy efforts of CDC is certainly a relevant issue to bring forth. However, it was not clear to Dr. Cohen that it was within the purview of the work groups to make specific recommendations with regard to that issue. In terms of the internal structure,

which Dr. Cohen understood was undergoing review, it was not clear that they could make recommendations about having the center director report directly.

- Dr. Kolbe responded that these issues cut across not only these two centers, but many centers within CDC. This is an interesting transitional period between administrations. His sense was that for their deliberations, it might be useful for people such as Dr. Cohen to raise concerns these issues were posted and at the same time to listen to those concerns. Once all of the issues were on the table from both groups, they could begin discussions with CDC regarding how they might articulate concerns that both groups had, and to better understand what was within the work groups' and BSC's purview.
- Dr. Kleinman stressed that it was important to keep in mind that there is a spectrum. At one end there is straightforward advocacy and policy recommendations, while at the other end was the act of raising awareness of what has been and is being done. Both ends can serve the center well. How far the center decides to or is capable of moving along the spectrum is the subject of future debate and deliberation. Identifying that the center needs to fall somewhere along that spectrum was the group's primary goal at this point in terms of that specific recommendation.
- In terms of workforce development, Dr. Kleinman was asked to speak further on what was meant by "external workforce development."
- Dr. Kleinman responded that the impression the work group had in reviewing the materials and from the presentations the previous day was that efforts for internal workforce development are currently geared toward personnel already working at CDC, particularly with respect to the Individual Learning Accounts. The feeling was that perhaps there had been more effort to develop an internal versus an external foci. In reality, there should be both. What it would take to develop both, and to bolster or strengthen the external workforce, must be determined. The first step before that is done is that there must be a quality assessment of the impact of the current workforce development program that is in place, in order to determine the gaps and opportunities are for future development internally and externally.
- Dr. Marrero added that this speaks somewhat to the blended workforce represented in the center, with some being FTEs and others being contractors and other associations. A lot of development programming appears to be aimed at the FTEs versus those associated but not of FTE status.
- It was interesting to Dr. Kleinman that they were told that while there is a workforce development program, including leadership programs to try to help bring new or mid-career level workforce up and prepare them for taking over positions of seniority, when the senior positions are vacated, they are often not refilled. That is a disparity between the effort and what is being done with the results of the effort.

### **Team Two: Surveillance, Research, and Translation Efforts**

**Karen Emmons**  
**Carol Macera**

This team was asked to review research, surveillance, and translation efforts. In the surveillance portfolio, there are activities related to disease surveillance, behavior surveillance,

and policy surveillance. Priority areas focus on systems quality to ensure that systems are of the highest quality possible, assessing the needs of high risk populations and documenting disparities, providing local level data for local level action, and developing and using evolving technology. In the applied research and translation area, there is an emphasis on methods and design, content areas, and collaboration. The priority areas for applied research and translation include health equity and social determinants, assessing the leading causes of morbidity and mortality, supporting community engagement in the use of these data, and in translation efforts to develop an evidence base to support health reform and develop and evaluate interventions. Opportunities that are coming down the pike, particularly in research and translation are to build the evidence base for public health action (comparative effectiveness fits squarely here), accelerate the translation for program dissemination, and evaluate cost and health impact. There is also an emphasis and opportunity for policy and systems research. Overall, the team found this to be an excellent area and would like to see it continue at a robust level. Dr. Emmons then presented the team's recommendations.

### Surveillance, Research, and Translation Efforts Recommendations

- Provide discretionary funds to the center for flexibility in new areas and emerging opportunities related to surveillance. This should not suggest that the teams were not paying attention to each other. This will arise in most of this work group's recommendations, is purposeful, and reflects the group's feeling of importance for this issue. Any innovation the center may have will be very limited if it does not have discretionary funds to engage in developing opportunities.
- Better utilize/increase utilization of key surveillance system, such as the Pregnancy Risk Assessment Monitoring System (PRAMS). With additional resources, the center could determine why such systems are underutilized and better understand how to increase use. This would ultimately benefit research and translation efforts.
- Provide more support for current surveillance systems to maintain a high level of participation by the states. Over time, as the budget has been reduced, there has been a need in some of these surveillance systems for the states to put in increasingly more resources. While that is seen as a good partnership between CDC and the states, as states are being hit harder and harder, there is a risk that states may have to contribute less. Thus, some of these surveillance systems may be in serious jeopardy. Thus, there must be resources to provide a stable level of support on the CDC side to help maintain participation by the states.
- Maximize use of multiple data systems to provide comprehensive surveillance for specific diseases as is currently being done for diabetes. There is a wonderful example about the work in diabetes in which multiple surveillance systems are utilized to present a full picture of diabetes at the national, state, and local levels. This is an outstanding model that should be utilized across different disease areas.
- Maximize the use of surveillance systems to support evaluation of policy effectiveness at the state and local levels. Policies are of no use if they are not implemented. Someone must pay attention to how well policies that are put into place are implemented and what their impact is. Existing systems are well-poised to do this in a robust manner.
- Resources must be allocated to maintain the work that the center has been doing in methods development related to surveillance. The level of methodology work that is done

related to these systems is highly impressive and very important. There is a considerable amount of collaboration involved in this effort, and that should continue.

- ❑ Consideration must be given to where new technologies coming on line need to go in surveillance. There should be a plan to incorporate e-health records as part of surveillance systems. While this is a very good idea, a considerable amount of methodological work must be done. Thus, the work group would support ensuring that the methodology in place to assure that this is done in a robust manner, particularly across settings. Some settings may have tremendous capabilities already, while others such as community health centers may have less. With the roll out of the HITECH funding for community health centers, this is going to be occurring very rapidly. This is a great example of an important and emerging area.
- ❑ Leadership should be provided to the community related to survey methods and how to access and utilize CDC surveillance data systems. This is very important for translation efforts. There are two ways for translation. One is that information can sit at CDC and be pushed out, and the other is that information can reside in the community and come back in the other directions. The work group felt strongly that this must occur bi-directionally. There is a considerable amount of expertise in this within CDC. If some of that could be transferred to the community, there would be much greater use of this data for the community good.
- ❑ Increase outreach to academics to use surveillance data. Academics could be very important advocates for maintaining funding for surveillance data. The more that there is an effort to engage academics to help them understand that this is a valuable resource, the more they will be vocal about their need for such efforts to continue.
- ❑ Utilize the center's data to conduct modeling studies to estimate potential costs and social impacts of many of the proposed interventions, medical procedure, and policies that are currently recommended and / or that are anticipated with health reform. Specific attention should be focused on primary prevention.

### **Discussion**

- Dr. Kolbe wondered whether there was discussion regarding social determinants of health and "health in all policies" as an approach, especially for this center.
- Dr. Curtis responded that there was a significant amount of discussion about these factors. This certainly comes into play with respect to surveillance systems. There is some attention to these topics, but this could be further maximized.
- It was noted that a cross-cutting recommendation that addresses social determinants of health is the general increase in focus on mental health, quality of life, incidence data, et cetera. The team felt that this should be sprinkled across all areas (e.g., training, implementation, program development, et cetera).

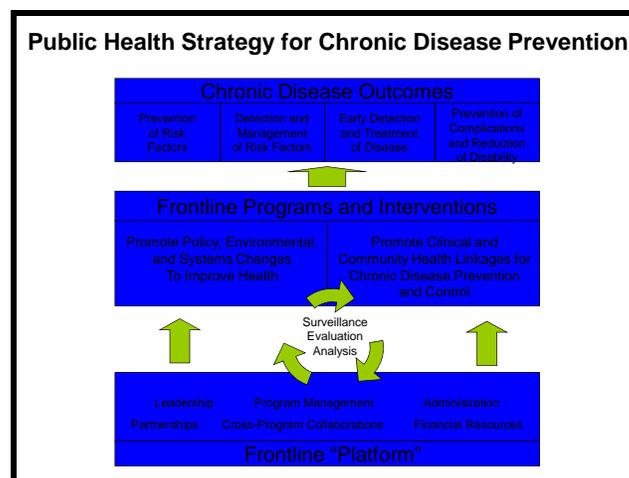
### **Team Three: Public Health Program Portfolio**

**Dr. Dileep Bal**  
**Dr. Frank Bright**

Dr. Dileep Bal reported that the following recommendations were made by the Public Health Program Portfolio team:

- ❑ More horizontal (e.g., geographical coverage) and vertical (e.g., breadth of interventions) integration are needed. Horizontal coverage refers to the fact that all 50 states are not covered by all of the divisions. Vertical, breadth of interventions, refers to the whole spectrum of diseases (e.g., primary, secondary, tertiary prevention). This is not being covered by all of the divisions.
- ❑ Adjust the funding mix to ensure the focus on program, primarily with research support. The work group was provided with materials that indicated that 40% of the budget is allocated toward research and 40% is allocated to program. Some work group members thought that this was an inappropriate mix, and they were rightly informed that the numbers in the materials provided were wrong. Must more goes to program, so the work group wanted to ensure that this point was made.
- ❑ Ensure that CDC funding across centers reflects the burden of disease. Considerable concern was expressed that the morbidity and mortality burden of chronic diseases are not appropriately reflected in the budget of CDC at large. This is a key issue. There is a new director incoming who needs to examine funding versus where the potential for intervention in morbidity and mortality lies. Given the wealth of talent at CDC, someone should be able to provide him with those numbers.
- ❑ Focus on the socio-ecological model rather than medical model. Even now this country is focused on the medical model.
- ❑ Arguably the most important recommendation is that policy as a discrete intervention needs to change. CDC, in general, has been somewhat diffident in using policy as a discrete intervener. This is linked to the issue of aggressive education versus lobbying.

To illustrate these five recommendations, Dr. Bal offered additional information. He explained that the public health strategies cross the vertical integration—the issue of primary, secondary, tertiary prevention, the frontline programs, et cetera. The entire spectrum of what they have (e.g., surveillance, evaluation, analysis) is not uniform across the entire center. The breadth of coverage, or the issue of not covering all states, is a major problem.

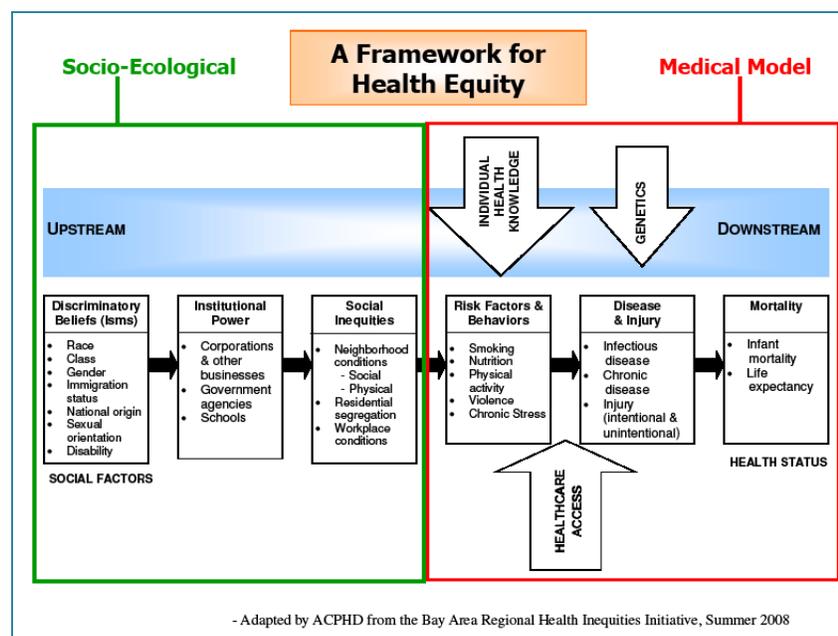


In terms of chronic disease and health promotion grants, many of the programs fund all of the states (e.g., Diabetes, Cancer, Registries, Tobacco, BRFSS, Block Grant). However, many are not covered in all states. Dr. Bal stressed that there was no pejorative intent in raising this issue. It was merely to illustrate that the center must be adequately funded to ensure that all states are covered. The funding process is sometimes competitive, which means the states that cannot compete are selectively penalized, although they are the ones that need it the most.

Dr. Bal used a sample of the Surgeon General's Report to illustrate policy efforts. The Surgeon General's 2006 Report, *The Health Consequences of Involuntary Exposure to Tobacco Smoke*, was the first report since 1986 to focus on secondhand smoke exposure and only the second of 29 Surgeon General reports to focus on secondhand smoke. Release of this report drove the policy action that has been witnessed across the nation over the past three years. This type of effort begins with an examination of the science. The translation of science into public policy is then written into reports and hopefully enshrined in statutes. Tobacco is a good example. This is a great mechanism for the evolution from science to public policy. These documents reflect the science and then tell people "on the street" what to do about it.

In terms of challenges and opportunities, health reform needs a strong prevention emphasis that must be pushed strongly at both ends of Pennsylvania Avenue. It is not just the roads and bridges that are broken in this country, the public health infrastructure is broken as well. There also must be program integration within the center, across CDC, and in state health departments.

Dr. Bal shared a socio-ecological model from Dr. Anthony Iton's known as a "Framework for Health Equity." The classic medical model is downstream addressing such issues as risk factors and behaviors, disease and injury, and mortality. The socio-ecological model is upstream and addresses discriminatory beliefs, institutional power, and social inequities:



Dr. Bal shared his model, *The Dileep Conundrum*, pointing out that people “do not see the forest for the trees.” Public health leaders face conflicting pressures (e.g., political, science, unions, employers, et cetera). People are afraid. The top issues are the du jour boss and the de facto boss. The de facto boss is the population served, which must never be forgotten. However, this is a very central issue in public health that tends to be forgotten.



CDC must not forget in everything they do that, “Government is a contrivance of human wisdom to provide for human wants. Men have a right that these wants should be provided for by this wisdom” (Edmund Burke 1729 – 1797; From “Reflections on the Revolution in France—1790). That is another macro objective that CDC has tried to translate into practice. They do it well sometimes, and they do it poorly sometimes.

## Discussion

- Dr. Goff wondered whether the third recommendation meant a strict focus on burden of disease, or whether the group had in mind the potential for making a positive impact on human health.
- Dr. Bal responded that he had to start by giving the entire group credit for ginning up his recommendations. There is a thread between the recommendations presented by Dr. Curtis and his. His five recommendations were developed by committee. These are broad recommendations that can be taken in many ways. There can be 100 metrics: morbidity, mortality, disease burden, potential for intervention, cost-benefit, et cetera. The model can be made as complex as desired. The point is that this center, in a zero sum game, has less funds than the facts warrant currently. This center has 7 of the top 10 leading causes of death and all of the leading causes of morbidity. The potential for intervention is massive.
- Dr. Goff clarified that the reason he raised this issue was somewhat philosophical. He primarily conducts heart disease research and does not want to get into an argument or discussion even with his dear friends about whose disease deserves the most money. There is a tendency for this to occur at times. If instead the focus is on the potential for improving human health or population health and funding those aspects (e.g., organizational units or whomever) best poised to make an impact on improving population health in substantive ways, that can shift the current thinking about what constitutes good health.

Good health is more than just the absence of disease. It is important to gain colleagues in this effort versus squabbling amongst themselves. Perhaps some slightly different language for the third bullet would help to frame this in a way that nurtures everyone working together and invites others to join them.

- Dr. Bal replied that he was very comfortable with such editorial changes. The day before, several people in this group gave considerable thought to this very point—that there can be a broader focus or a disease-specific focus. A disease-specific focus results in a fight in terms of intervention—the older locker room debate: my science is bigger than your science. He agreed that no useful purpose was served. Conversely, Dr. Bright made the very thoughtful point that there is an advantage in focusing funds on priorities. There are two problems with block grants. The states are pirates. They will steal it if it is not categorical money. Dr. Bright said when approaching legislators and saying, “I have block grant disease,” they do not understand. There are plausible arguments on both sides of the issue.
- Dr. Kleinman added that what Dr. Bal described “fit the bill.” The issue is that there are insufficient funds for the task at hand, which is both disease prevention and health promotion. They are dealing with a huge bolus of burden of chronic diseases and a demographic that is increasing. They wanted to put this into context, which she thought they could do on the health side, still maintaining the focus that is necessary on the individual conditions. She also welcomed rewording. This will ultimately become a BSC document. The work group was really the engine that examined the situation and made their best judgment in terms of recommendations. She stressed that this was the opportunity to debate whether it was clear and how / if it should be reworded.
- Dr. Kolbe thought that Dr. Goff’s point did need further clarification. Dr. Frieden and Congress will face increasingly difficult dilemmas with respect to choosing where to direct resources. Measuring only mortality is one thing. Measuring years of life lost offers a completely different picture, especially for the Chronic Disease Center. Especially in these very serious economic times, economic measures will create yet a different picture for this center.

Dr. Popovic said she thought the recommendations were fantastic and were exactly what was being sought. She thought about them in three categories: 1) Funding: Everyone appreciates that funding cannot be ignored. General support for funding is always helpful, but those recommendations are the least helpful for what CDC does. The agency is aware that increased funding would be helpful. CDC has tried for years to achieve more discretion in funding; 2) Surveillance: A recommendation that was extremely helpful regarded facilitating access to CDC surveillance data. Not only is that very important, but also it is very specific. It places CDC in the position of determining how to accomplish better access to surveillance data. Those are the kinds of questions that Dr. Frieden has already asked. This is a very specific recommendation. What would it take to be able to do that? 3) Actionable recommendations: Another helpful recommendation pertained to focusing on how CDC can better use policies as an important tool for implementing important issues. Dr. Popovic thought that about 70% of the recommendations that she had heard were so specific, she would be looking forward to the center’s replies with regard to what can be done. The most creative thing that the BSC could do would be to help the NCCDPHP director best direct available resources. The first time Dr. Frieden met with the leaders in an All Hands meeting, he said, “We will have to do better with what we have, or better with less.” This is where the creative

thinking needs to come into play. She was delighted that out of about 20 recommendations, thus far, most were extremely important and could be implemented, preferably with existing funds. She thought more thinking was needed about more integration within the Center and within CDC. The agency often hears from constituents that they need to hear what CDC recommends versus what individual Divisions recommend. As they thought about efforts in individual programs, Dr. Popovic encouraged the group to think about how the Division efforts could be made more relevant to agency goals.

- Dr. Kleinman noted that one issue which had not yet come to the surface was the fact that this work group feels that this center is a model for CDC in that it touches every state, and has the capacity for building, rebuilding, and creating the infrastructure that does not exist. It has extensive partnerships in place that are integrated across the federal government (e.g., professional organizations, communities, et cetera) that can be built. Partnerships with the communities that are part of the community-based participatory research (CBPR) partnerships, beginning with their ability to learn to utilize/apply the data themselves, are very important opportunities. While speaking for the center, the work group views the center as a leader in the agency. The budget reallocations being revisited are very critical for the entire agency to be seen as an agency that is moving the field into and accelerating translation. The staff have engaged in incredible excellence in creativity in an environment that continues to decrease their capacity in people and funds. This is undermining at a time when the state economic budget pictures are in dire straits. While there are difficult decisions to be made, and better has to be done with less, the center is at a very vulnerable floor. The work group does not believe the story of the center/CDC is being disseminated effectively. Although CDC is everywhere in the entire world, people do not know what is done on a daily basis. The work group is asking for more outreach in workforce development to mobilize the public health workforce. Based on the numbers projected for 2020, it will not be possible to maintain the existing workforce, nor is the existing workforce being trained. Thus, the technical assistance this center provides to states is essential. The data this center is providing is amazing. Having local and state data available, and the partnering that is possible with the National Center for Health Statistics (NCHS), are major assets. The work group examined this from the perspective of "health for all" and the fact that this agency needs to have its budget not doubled but tripled or quadrupled. This is something that really has to change with health reform. Dr. Kleinman highlighted the fact that the work group lauded that the center is moving forward in exploring the health reform debate. The work group wants the center to be a place that brings all of these communities together to speak about "health reform" not "healthcare reform" and what is necessary in that area.
- Dr. Cohen indicated that he had been in the developmental disability field for 45 years in an academic center, and has been involved with various advisory, policy, and other groups. However, until he joined the CCHP BSC, he had no idea what CDC actually did other than the infectious disease component. Clearly, the entire spectrum of CDC's activities are not well-known to the general community. Unless there are better public information efforts in that regard to indicate successes and triumphs that CDC has achieved, there is not going to be more public or legislative support. The two are closely intertwined; that is, better public relations/public information efforts will result in more successful budgetary advocacy efforts.

- Dr. Popovic said that she could not agree more. For the past 60 years, CDC has always been viewed as an infectious disease agency. Approximately 6 to 7 years ago, a major survey was conducted to determine what the population knew about CDC. The fact is, when CDC is mentioned, people list outbreaks, influenza, et cetera and very few people will say anything else. This is unfortunate because 60% of CDC is not engaged in infectious disease work. This has been a major issue, although an understanding of CDC's role in non-infectious disease has lately improved. As CDC becomes visible in the health reform effort, there is increased engagement in the process. The first agency Secretary Sebelius visited when she became the Secretary of HHS was CDC, and her first two sentences regarded engaging CDC in the health reform activities. As an agency, CDC is realizing that this is where the change in health and quality of health is going to occur. Dr. Frieden has been focused on issues such as tobacco, nutrition, general wellness, and health. Thus, Dr. Popovic thought the "stars were aligned" for CDC to productively contribute to this process. The BSC's support in that thinking is very important. She stressed that any kind of thinking that does not touch on money per se is usually more helpful to the agency, because they are acutely aware that CDC does not have enough funding for what needs to be done. Major efforts were made on Dr. Gerberding's behalf to work with Congress to allow CDC more discretion in terms of internal funding and distribution, and that has not been successful. It is a challenge for CDC that almost every cent of every dollar is very specifically assigned. The agency no longer even has what was known as the Director's Discretionary Fund. Funds must be pulled from on-going efforts to address emergencies. The BSC would find no one who would disagree with the statements and positions made by the BSC. It will be valuable to have them in writing. While the work group has the framework of three areas, she suggested that they select something as an overarching idea, which is more focused on chronic diseases, prevention, and wellness. The agency must support the Center in the effort to make it more visible. The center itself cannot do everything.
- Dr. Goff said he recently heard someone say that most people limit themselves through their own small thinking. Now is not the time for small thinking. With that in mind, he wondered whether Dr. Popovic was challenging them to think big about what the center should be doing in these areas that the work groups were asked to evaluate. This work group evaluated what exists and made some recommendations that are important, but might not be big recommendations about what the world would look like 10 years from now if the center were engaged in efforts even bigger than they are currently.
- Dr. Popovic replied that the short answer was "yes. The first requests coming from the director regard what the big thinking is about any given priority. It is hard to do both and everything at the same time, but your recommendations provided thus far cover both. The overarching recommendation with a focus on wellness/prevention is the big picture that may have some specifics within it: advocating more as an agency, building partnerships, being able to divert funds where needed.
- Dr. Bal pointed out that Dr. Curtis's first few bullets specifically addressed these issues. With regard to the money, 41 years ago when he was doing his residency, Dr. Bal's guru Herb Abrams told him to always remember that "It's not the money; it's THE MONEY." At this point, CDC's priorities are still focused. It is not about whether one disease is more important than the other. It should be based on the morbidity/ mortality picture of the turn of

the last century when it was primarily infectious disease with the leading killers in the US. That retooling has not come to the level that many would like to have seen over the last 40 years. There are going to be very strong recommendations from this work group that will include overall CDC overall priorities—not just the center. In a zero sum game, somebody has make decisions regarding what will/will not be funded.

- Dr. Popovic said they would absolutely welcome those recommendations, but just saying “we need more money” is not helpful. She stressed that all of the thinking about the big picture and refocusing should be included as well. CDC needs to be able to use the BSC recommendations to say, “This is not what CDC says. This is what the group of advisors told us.” Those are powerful and useful statements to the agency.
- To give a concrete example, Dr. Goff noted that when the country was focused on the childhood polio epidemic, nurses were placed in schools and there were mass vaccination campaigns. If focused on chronic disease prevention and health promotion, there might be health coaches in communities, especially communities that have poor access to health care. There could be community health workers trained through local health departments and placed in low income housing residential units and rural areas. This type of initiative can be put in place, and there are proven models for training/use of community health workers. If that is to be a component of a specific recommendation in the area of program, a sustainable model of training, funding, et cetera are needed. If vetted through the committee and determined to be one of the specific examples, this could fit in these recommendations as a way to integrate across chronic and other disease conditions. Community health workers would not necessarily have to focus on chronic diseases, and could revolutionize the way prevention is delivered in communities with poor access.
- For the record, Dr. Bethel informed Dr. Popovic that the NCBDDD Work Group would be reporting later in the day and that its recommendations had a great deal of synergy with the recommendations set forth so far, as well as some distinct pieces. She expressed hope that Dr. Popovic would hear those as well.
- **Dr. Wolraich (not sure this was his comment)** noted that some of discussion the previous day in the other work group related to the pros and cons of the mechanisms with earmarks and the impact that this has. He wondered if they needed to have further discussion about this as an overarching issue in order to develop recommendations about that mechanism.
- Dr. Kleinman thought that would be a wonderful and rich discussion, but requested that they finish their center discussions first. In terms of using the center as a model, one of the things that really intrigued the NCCDPHP Work Group regarded the collaborative funding opportunity announcement experiment. The process of testing something out, having select states implement it, and carefully and extensively evaluating the impact is very important with precious dollars. This also fits with policy development and evaluation, and builds the grassroots effort and capacity of showing the cases and being able to grow what could be a national model and implementation plan.
- Dr. Cohen reminded everyone that an early slide had raised the issue of health education in schools, which had been lost somewhat in the chronic disease discussion. The administration is very interested in early intervention and education in terms of whether introducing health education at an even earlier age will be productive in some of the long-term goals of avoiding effects of chronic illness. He wanted to ensure that this was included as an overarching recommendation for both work groups.

- Dr. Popovic agreed to return in the afternoon to hear the report from the second work group.
- Dr. Rimmer noted that Dr. Frieden's emphasis in some of his work in New York City as Commissioner was on regulations (e.g., controlling smoking and tobacco consumptions, nutrition/trans-saturated fats, et cetera). He asked Dr. Popovic if, in the brief time Dr. Frieden has been at CDC, whether she had gotten any sense of whether this is a topic or agenda of his that he would like to carry forward for the nation. The NCBDDD Work Group felt that there had to be an alignment at the top. Using a coaching analogy, if a team gets a new coach, the dependency of that team's success is not only on the players, but also on the coaches leadership. Obviously, Dr. Frieden has a track record and has been successful in New York, so the BSC wanted to get a sense of what the lay of the land might be with a new coach. This is a critical time for the BSC in terms of moving its recommendations forward, given that they meet only twice per year.

Dr. Popovic responded that although she had not worked closely with Dr. Frieden before he came to CDC, and it is early in his tenure, she could report that he has identified some of his top priorities which include strengthening epidemiology and public health surveillance, focusing on support for local and state health departments, focusing on community-based activities, focusing on global health, and focusing on health system reform. She stressed that the BSC could rest assured that their recommendations would be considered at several levels within the agency. To demonstrate his emphasis on implementation of advice from external review, Dr. Frieden responded to a recent review with the following,

- "Thank you, but please include in your report to me who will be responsible for implementation, how the recommendations are going to be implemented, who will be accountable, and what the timelines are,." The point is that Dr. Frieden will see these recommendations and the BSC will receive feedback as soon as possible. Dr. Frieden is absolutely paying attention to the external reviews.
- Dr. Kolbe expressed appreciation for the opportunity to have Dr. Popovic's advice and response to the BSC's recommendations, particularly given her crowded schedule.

*At this point, the group shifted their focus to a general discussion pertaining to further defining NCCDPHP's recommendations, next steps, and timelines.*

- Dr. Kleinman highlighted a few other aspects of the themes from the NCCDPHP Work Group. They felt the recommendation of CDC and the center staying focused on its niche of translation efforts is very important. This is a unique role and is highly necessary. Routine review/refresh of key initiatives, such as WISEWOMAN, to ensure that all relevant programs are included such that these initiatives evolve to the next level is an important on-going integration of programs. Maintaining and increasing economic analysis and impact of the programs is another area of importance. The group also engaged in an informal discussion on the stimulus funds during the previous day's session. This might be a good discussion across both centers, given that this opportunity and challenge is quickly coming down the pike. During the break it was noted that while the work group mentioned the importance of moving further into the social determinants of health, this recommendations was not specific enough. This group plans to work in their respective sections to add narrative that will succinctly address the very rich presentations made the previous day, acknowledge the role of these functions within the center, and add more specific actionable components.

- Dr. Cohen was struck by the common themes that came out of both groups. He wondered when they might discuss some of the overarching themes to include priorities/issues raised by both groups.
- Dr. Kolbe deferred to Drs. Kleinman and Goff, given that this was the NCCDPHP work group's allotted time period.
- Dr. Kleinman indicated that she wanted Dr. Goff to first speak to some of his thoughts that would allow them to develop the "big picture" recommendations first. In addition, she wanted to ensure that they allowed time for discussion regarding earmarks as well as health education in schools.
- It was noted that given the way the agenda was set up, it did not permit time to deliberate the overarching issues for both groups. Given that the second group's recommendations had yet to be heard, it would be difficult at this point to engage in a meaningful discussion about the overarching issues.
- Dr. Goff reminded everyone that they had been asked to "think big" and to think specific and actionable such that someone could be assigned responsibility and held accountable for following through on the recommendations. Several recommendations need to be fleshed out to include more specifics so that a document results that serves the purpose of giving recommendations that are specific, actionable, and accountable. In the process of drafting the recommendations from the draft status into a more final status, it occurred to Dr. Goff that if they were going focus on the social determinants of health, they must move beyond the public health apparatus as it is currently envisioned and often thought of. Relationships are required with other sectors that are not always at the table when discussing public health (e.g., transportation, housing, agriculture, et cetera) where many factors that influence health occur outside the traditional public health arena, especially for chronic diseases. Given that such groups are unlikely to approach to the center, the center must go to them. Thus, there should be some recommendations pertaining to the establishment of those sorts of relationships so that policy can be evaluated and improved in those areas that are not usually thought of as being health policy. In order to do that, the center also needs to have substantial expertise in the process of conducting health impact assessments of non-health related policies. There has been a great deal of focus on environmental impact assessments, but there must be a similar focus on the health impact of policies that do not appear to be directly focused on health, but which may have major impact on health. One place where that expertise needs to exist is in the NCCDPHP. That means the mission critical list of expertise should also include legal expertise in order to evaluate policy and law, and expertise relative to health impact assessment.
- Dr. Marrero inquired as to whether legal expertise already existed within CDC.
- Dr. Collins responded that there is a Public Health and Law Office (PHLO) at the Office of the Director level, with whom the center interacts. However, people with specific expertise in food and law, tobacco and law, et cetera do not exist within that office. The center could have a better marriage with more legal expertise within the center.
- Dr. Goff thought expertise would also be needed in transportation law/policy, housing regulations/policy, environmental law, et cetera.

- Dr. Cohen noted that much of what Dr. Goff listed in some way or other overlapped with the other work group. The issues of translational research, health education, better public information efforts, apportionment of funds, social determinants of health, environmental factors, and policy issues all arose within the NCCBDDD Work Group. He thought there was a lot of room to add some broader, overarching recommendations. How exactly they would be implemented would be the tricky part. The NCCBDDD Work Group did not get into the administrative aspects as much as the NCCDPPH Work Group did. He stressed that some side should be set aside to determine the overarching themes. The NCCBDDD Work Group raised the issue of genetics, which did not appear to be raised by the NCCDPPH group.
- Dr. Kleinman replied that genetics was raised in the NCCDPPH work group in terms of incorporating and integrating that expertise. Aligned with the workforce development recommendation to move more externally is the notion of community health workers and how the center is positioned to incorporate this new formal workforce, which is now being legislated, into the state roster in order to take full advantage of it. This would give more substance to the recommendations that are sprinkled with workforce development, surveillance, research, and program.
- Dr. Goff said he was not aware that there was a movement going forward to codify community health workers as an occupational line within health department structures. He suggested that it may be useful to further discuss this issue to inform the board so that the most appropriate recommendations could be made about promoting training and use of community health workers.
- Dr. Curtis reported that Texas was the first state to pass a set of certification requirements that must be met, which is interesting because it was also the first state to use Promotorés. Promotorés were lay people who took on this role in Hispanic communities. In a move toward recognizing a career, profession, or specialty, the first things a state can do is create credentialing requirements. As a result, other states are considering similar legislation. The organization of community health workers, such as it is, is working hard to lobby for recognition as a vital part of the health care system. Houston uses them quite a bit for the network of over 200 not-for-profit safety net organizations known as Gateway to Care, and they play a vital role in interfacing patients with the health care system, and provide a critical point of understanding for patients in terms of how to navigate and get through the system. In Houston, community health workers are referred to as “navigators.” They help people find public health insurance that they would not otherwise have in terms of public plans or qualifications for district care. They do much more than simply telling people to live healthy.
- Dr. Marrero indicated that in the Robert Wood Johnson (RWJ) Community Initiative Program, which is focused predominantly on diabetes prevention and obesity management, there is extensive work done in the development of Promotorés across 14 centers throughout the US. They have some very rich material and collaboration between CDC and RWJ struck him as a natural.
- Dr. Kleinman thought a recommendation that could evolve or be built from this discussion pertained to the bridge between public health practice and medical care. Given that community health workers are evolving as a workforce, perhaps it would be useful for the center to convene a conference on this particular issue to examine the implications for each of the major functions of the center, and to take it to the next level of how the future may look in health reform within the context of community health.

- Dr. Curtis indicated that she part of an effort at the university to figure out a way to get the medical school to interact more with the public health school, nursing school, dental school, et cetera—the idea of cross interdisciplinary training among the students. That was a top-down approach that failed miserably. She saw a glimmer of hope in that community health workers would be the success story approaching this from the bottom up. Community health workers are the perfect place to have medical care meet public health in the creation of a health system. There is a lot of promise in this and it is time to abandon the idea that this is going to be done from the top down. There are too many legacies, egos, and politics involved. Dr. Curtis agreed to draft this recommendation.
- It was noted that a similar approach had been used in Oklahoma that is focused on children with special needs. County coalitions have been developed in 9 counties, given that these children have issues that cut across health, human services, mental health, and education. These coalitions bring agencies together to help families navigate the various systems as part of the process. This is the same concept of looking beyond just the health issues. This has been a focus in terms of systems integration, with initial funding received from Maternal and Child Health. The state took up where that funding ended as part of the process. Oklahoma has also addressed this as a complex, adaptive system. Information feedback is provided for the process, but it is left up to the coalitions to determine how they will expand capacity in their respective communities. If the coordinators are presented with a problem by the family or provider which they cannot solve, they can take it forth to the coalition. This has been a strong motivating force to get them to expand capacity in the community. This is a bottom up approach with no assumptions that one type of approach will fit all programs. Each group has had very different solutions. This is currently funded with a combination of Title V funds, Maternal and Child Health, and some state funds that are matched with Medicaid. A patchwork is used to fund this as part of the process.
- Dr. Cohen thought mental health should be added as an overarching issue as well.
- To put some of the lexicon of academic public health into this, mindful of Dr. Bal's differentiation between research and development, Dr. Kolbe said he thought that how to implement/integrate community-based participatory development and research was a cross-cutting issue for both centers. This should be bottom up and there should be assurance that state agencies are involved so that an agency such as CDC does not come in to undercut them without them knowing what is being done. Conceivable, the state agencies could be involved in dissemination efforts.
- Dr. Kleinman indicated that the NCCDPHP Work Group did speak to this issue somewhat when they discussed the stimulus funds and the concern about what impact that initiative might have on CBPR. A recommendation should be carefully crafted so that it does not “get stuck down the throats” of the communities with which they have been working hard to partner because of the finite timeframe and funding. Thus, in addition to the broader discussion about community-based participation development and research, consideration must be given to funding models that support both of the those in the short- and long-term. The group did make a recommendation that one concept is to possibly marry the haves with the have-nots during the short-term. For example, the Prevention Research Centers (PRCs) might be a natural recipient of some of the stimulus funds, but the charge might be for them to work with new communities and build new partners that would be able to establish the foothold for future research.

- Dr. Goff inquired as to whether there were other areas of discussion that people wanted to pursue in greater depth, such as facilitating greater use of the center's data for research and programmatic evaluation purposes; the role of genetics and genomics in the national center from the research and programmatic points of view; et cetera.
- Dr. Kardia said she thought that in general, there were ways in which the genomics field was creeping into just about every chronic disease, the mindsets of departments of health, et cetera. There are ways in which CDC's Office of Public Health Genomics (OPHG) is uniquely positioned to be a leader in key translational and community awareness aspects. NIH has been the main engine pushing out the results, but does a very poor job of integration and evaluation of whether that genetic information has utility. Much needs to be done so that there is a better translational highway. Michigan decided to turn its last 25 years of bloodspots into a biobank. They have worked with the department of health over the last two to three years to develop a community awareness and engagement campaign; however, there has been no funding to do that. This is extraordinarily frustrating because this is a great potential resource that could be linked with surveillance, yet it is also a "ticking time bomb." Without the ability and infrastructure to engage the Michigan public, this is going to explode. Multiple states want to do this, but if there is nothing within the public health infrastructure to support the deep and deliberative process that a state must go through in order to decide the constraints on research, the oversight required by the department of health and the public, and the amenable ways in which to obtain informed consent, then a whole new way of conducting public health research will evaporate.
- Dr. Cohen indicated that the use of bloodspots arose in their discussions the previous day, but was dropped because of all of the issues/concerns involved. Thus, they did not pursue this at all despite the obvious connections to the birth defects and developmental disability field. Noting that among the NCCDPHP Work Group's listed recommendations were the capacity and training that are necessary to move forward in terms of translation and effectiveness of prevention activities, he wondered what CDC's role was in this regard.
- Dr. Goff responded that the group discussed the idea of an increased emphasis on training grants from CDC. NIH funds a fair number of training grants that go to individuals or institutions that predominantly train scientists. CDC has a number of training grants, some of which train public health workers. For example, the Cardiovascular Practitioners Institute funds training of state and regional health department staff on cardiovascular disease prevention activities. They also fund other research training grants. There could be an emphasis on training grant development that would be in particular areas of interest. For example, if there is a call for more public health genomics expertise, an RFA could be published for training grants that schools of public health, medical schools, et cetera could compete for to train that workforce. Perhaps an RFA could be published to fund training in CBPR. That would be a mechanism and is the sort of discussion that should take place in order to decide whether the BSC wants to make a recommendation that the center should issue RFAs or RFPs for training grants in areas of critical need for mission impact.
- Dr. Cohen thought CDC had some fellowships, although he recalled that they were limited. He wondered how these activities could be expanded.
- Dr. Trevathan responded that CDC has a variety of training programs. The oldest is the Epidemic Intelligence Service (EIS) Training Program. This is a program that has not grown with the rest of the agency over the last few years, and many people believe this needs to be enhanced. Dr. Frieden and Dr. Thacker, who directs Workforce and Career

Development, believe this program needs to be enhanced. There are numerous fellowship programs in addition to EIS within the agency. He did not believe his center had capitalized enough on attracting the candidates in some of the related fields (e.g., genetics, genomics, neurodevelopmental disabilities in children, cancer, et cetera) into EIS or other fellowships. This is a major opportunity, especially if workforce and career development becomes a priority in this administration and some of these programs are expanded. However, it is not entirely clear to what degree these programs may be expanded.

- Dr. Goff noted that a recommendation for funding of training could be internal or external.
- Dr. Posner indicated that there is a limited amount of funding for K01 R36 type grants for career development out of the Office of Public Health Research (OPHR) at the agency OD level. While there is an opportunity, there is limited funding for that. Many of those applications do come to the center. This opportunity is not as well-developed or well-funded as it could be.
- Dr. Kardia added that with respect to the translation pipeline the very beginning and very end are not shored up. Community awareness and education pertaining to genetics has been so bad, people do not even know that their children's bloodspots are being taken for genetics. The very first step is getting past this and informing people about newborn screening. While separate from the translational pipeline, it is a necessary first step. In Michigan's engagement of communities, this is what they spend the majority of their time doing. The other component of the translation pipeline that is sorely deficient is the integration of public health with medicine, with researchers, with communities, and people sitting around the table creating standards for when it will be said that something genetic is ready for prime time. That type of convening is something that CDC does very well, and from that comes the development of research agendas. These are at key leverage points in which CDC could be a major power.
- Dr. Curtis agreed, stressing that before they have an RFA for a training grant, they must know what they are training. This is not known. In the world of OBGYN this is a major issue. She is also trying to write a thesis on biobanks. Interesting to her was that in France, a political officer who was sexually assaulted estimated her perpetrator's age, adding a few years on either side, and was able to genetically match this using bloodspots to find the perpetrator. People do not think about the potential uses of this biological material. Patents will result with or without their consent or their knowledge for use or drugs or treatments in which they may or may not want to be involved. She strongly echoed the idea that there should be a convening of bioethicists, lawyers, patient advocacy groups, et cetera to kick off a dialogue in America about genetics and genomics similar to what was kicked off about eight years ago regarding stem cells. The public knew very little about it, and now they know a lot more. When people understand that genetics/ genomics will be one of the revolutionary forces changing the face of medicine, it will initiate a national dialogue that should last for years, be very heated, be very controversial, but will come out the other end with the best options available. This includes training.
- Dr. Goff thought this discussion could be summarized and put into some recommendations regarding a focus on public health genomics. The work group will do this in a way that it is specific, actionable, and helpful.
- Dr. Kolbe noted that CDC has a wonderful resource in the Office of Genomics. As they recently heard Dr. Popovic say, the recommendations that the BSC makes that are more

cross-cutting would be the most likely to have the greatest currency with the director. Having said that, they had yet to hear the recommendations from the NCBDDD Work Group on the same types of issues. At least these two centers and other centers could convene for a conference to develop a plan to bring together the best in the country, which might generate a means to move forward on some of these political, ideological, ethical issues and also to articulate what the most promising next steps might be once the moral complexities are resolved.

- Dr. Steinberg mentioned that there was a meeting convened in the early 1990s of lawyers and geneticists to discuss ethical use of stored specimens for genetic research. She wondered if deciding when testing is “ready for prime time” (e.g. screening purposes) isn’t the same for genomics as for any test that might be used for screening, that is, clinical utility must be established.
- Dr. Collins thought there was a great deal of depth raised in many of the issues raised by the committee. The notion of horizontal coverage has so many implications about not just funding states, but also what the reach is in the nation of putting effective practice into place. Assessing reach at present and maximizing that reach over time may take some transformational thinking about how to reach more numbers than are currently being reach. The issues of visibility, training and the external workforce, et cetera all have enormous implications for the center. She was just beginning to think of them operationally. The area of discretionary funding is extraordinarily important, not only with respect to what someone else might be able to do for the center in terms of getting it into Dr. Frieden’s mind and the work he may be able to do with Congress to acquire that latitude, but also in thinking about how, within the current constraints, to garner more flexibility. Even though it is difficult, they must push themselves to think about what can be done to have that kind of latitude within current constraints. She thought the work group had given them an enormous array of critical issues with which to grapple.
- Dr. Rimmer noted that the NCBDDD Work Group took a very different approach to addressing the issues and got down into more of the specifics on key areas they and Dr. Trevathan felt was a viable approach to get at key specific issues. He thought these were outstanding recommendations, but they were so broad in nature it was not clear where to begin once the report was received or how it matched with the visions of the new CDC director, Dr. Popovic, the center directors, and the division directors. It made him nervous when he heard wonderful, broad-based presentations with a lot of specifics that must go underneath. The NCBDDD took a different approach in terms of addressing key issues that could be resolved in the near future.
- Dr. Goff responded that over the coming weeks, they NCCDPHP Work Group would add specificity to their recommendations so that people could be assigned responsibility and accountability could be established. This will occur in an iterative process over the coming weeks. The final document will have a lot more granularity, but not so much granularity that it handcuffs the flexibility of the center.
- With regard to the training issue, Dr. Cohen noted that they had thus far heard three possible avenues: 1) funding internal fellowships targeted to particular areas of concern or interest to the various centers; 2) external funding to academic or other institutions to provide training in specific areas where expertise is needed; and 3) sponsoring of conferences to educate the academic and professional communities, and publishing

proceedings of those to help further disseminate the information to a broader community. He wondered if there were other mechanisms.

- Dr. Goff indicated that the workshop with which he was familiar was similar to a conference. CDC also does a lot of training through technical assistance. When a state or local health department has an issue that is vexing, they can contact CDC for technical assistance on a case-by-case basis. That sort of training is extraordinarily, but is also labor-intensive and is not efficient from the point of view of one trainer to many learners. However, it is very efficient of just in time, need to know development of competencies and skills that are put into place immediately and, therefore, probably get mastered. How efficiency is viewed and quantified can make a difference in terms of the priority of different training mechanisms. Technical assistance is extraordinarily important, and is probably an area that could be enhanced.
- Dr. Cohen added that there is the public education component. There is an office for this, for which the capabilities for public education could be enhanced.
- Dr. Marrero said that in listening to this discussion, he wanted to ensure that the recommendations reflected the critical role of the center in preventive care. In terms of surveillance, there is an amazing amount of data that should be applied to emerging issues. While there had been some discussion of primary prevention, they had not really hone in on it specifically as an emerging and preeminent area for emerging public health initiatives.
- Dr. Kleinman indicated that within the context of the charge they had been given, she wanted to revisit next steps for the work group. This is an on-going process, but they need to get to some piece of paper in front of them. This discussion added to and helped to flesh out the requirements of the review. She asked the leaders of the work group teams to subsume the information gleaned from the discussion into their respective sections, adding specific recommendations and examples soon in order to finalize a draft to be circulated. A report must be completed by the September 15, 2009 conference call.
- With that in mind, Dr. Kolbe suggested that each of the two work groups complete and submit draft reports within 8 days of the September 15<sup>th</sup> meeting.
- Dr. Goff said that they would like to have the sub-groups within the working group get their thoughts back to him and Dr. Kleinman within two weeks so that there will be time to combine them, add some overarching issues within this report, and acquire some feedback from the center.
- Dr. Kolbe suggested convening a conference call between the four co-chairs, Dr. Posner, Scott Campbell, and the center directors in order to deliberate some of the cross-cutting issues and to provide some meaningful analysis of both report simultaneously. This would permit the group to make whatever comments they would like to be sent forward along with the reports themselves.
- Dr. Kleinman inquired as to what the agenda would be for the September 15<sup>th</sup> conference call.
- Dr. Kolbe responded that the agenda for the 15<sup>th</sup> would be to review what ideally would be the draft final report, so that people would have an opportunity to review the cleanest version of a report from both work groups that would have as much integration as possible,

recognizing that it may not be the final integration, and that already would include comments from CDC so that CDC was not commenting for the first time.

- Dr. Marrero inquired as to what the mechanism for review would be prior to the 15<sup>th</sup>.
- Dr. Kleinman responded that they were looking to Dr. Posner to be their anchor in the process. The thinking is that they will patch everybody's pieces together, give everyone an opportunity to review it as a whole, and will then assign themselves to review the patched process to determine whether this work group has questions and whether the level of comments and recommendations are equivalent across areas. This can be done via emails. Then she and Dr. Goff can review these to determine whether a call is needed versus an email that enumerates any pending issues.
- Dr. Trevathan pointed out that the centers needs are so different, if the board tried to merge the findings of the two groups into one report, it would dilute both. There are some common areas, but it would help his center most to have a separate report.
- Dr. Kolbe responded that he anticipated two reports, within which there would be some commonalities and perhaps some overarching issues. They would not be merged. They would be combined in the required November report that is due from this joint BSC. No one knows when or whether there will be a decoupling of the CCHP mechanism. Under the current BSC language, the BSC is required to provide one report. They board certainly can make the decision to ensure that it includes two reports. His hope was that they have the best report possible by the 15<sup>th</sup>. Dr. Steinberg has engaged in conversations with the FACA representative through which she learned that the BSC will be required to vote on September 15<sup>th</sup>. They may be voting on a final document or a document with changes that are agreed to.
- Dr. Steinberg indicated that there are FACA regulations that must be attended to in order for the BSC to make recommendations, that is, that a quorum of the entire BSC must vote on recommendations. Although most members and Center leadership might agree that it would be more efficient to have two separate reports at this time, they must conform to the requirement for one document eventually.
- Dr. Kolbe clarified that there would be two reports included in the one document to be completed by November 1<sup>st</sup>. There may be complementary elements in each that might strengthen each. They may or may not have overarching elements as they had begun to discuss.
- Dr. Steinberg responded that she would have to confirm whether the separate reports could each be considered as FACA advice.
- Dr. Goff said what he was hearing was two chapters in a report. That is, there will be one FACA report from one BSC that includes two chapters or sections—whatever language is necessary to make it one report.
- Dr. Kolbe recognized that there are two types of expertise in the room. They hoped to maintain their ad hoc consultants and perhaps add to that in the final analysis. The entire BSC, according to FACA regulations, will vote on the entire report with each member recognizing where they have and do not have expertise.

- Dr. Bal thought Dr. Trevathan's point was a very good one. They should not attempt to make a contrived connection where there is not one. He agreed with Dr. Goff that it could be one report with two chapters or sections. From his perspective, he had seen documents where there was a contrived connection, which satisfy no one.
- Dr. Kolbe indicated that this was their expectation after engaging in long deliberations following the first meeting, which led to these two work groups.
- Dr. Rimmer thought the two reports could be coupled by including an opening executive summary that makes the statement that these are two distinctive centers that were initially chartered under the Coordinating Center for Health Promotion, but there are as difference as France is from Africa and these two reports reflect that. He stressed that a lot of this discussion was based on the group not having yet heard from the other work group. He thought after hearing that, they would all understand how critical it is to keep the two documents separate.
- Dr. Kolbe stressed that this will be done in close consultations with both centers and FACA to ensure that they do not run afoul of FACA regulations.
- It was suggested that consideration be given to three chapters, one with overarching issues common to both centers and a chapter for each center.
- Dr. Cohen supported that approach. It may be useful to reinforce overarching issues in an executive summary.
- Dr. Kolbe thanked Drs. Kleinman, Goff, and Posner for setting the BSC up for great presentations and discussions, and concrete and focused recommendations to be massaged and evolved.
- Dr. Collins thanked the panel, pointed out that she and her staff learned a lot by preparing the information for the work group members and from the thoughtful discussion that evolved from that. It truly exceeded their hopes of input. The input was at the right level, and encouraged the center to be bold in some of these areas at a time at CDC during which there is tremendous opportunity. The center will take the input very seriously and will think through the issues with all of the center and division staff. Her senior leaders within each division were present for all of the discussions and will analyze and think through the implications, which will impact the direction of the divisions and center alike. There is a tremendous amount to work with, which is exactly the point of this sort of input—when so immersed in the daily operations, to step back and have outsiders with different positions, perspectives, and orientations assess this, it is extremely beneficial in terms of strengths, weaknesses, and possible direction. She thanked everyone for their thoughtful interchange, and expressed her confidence that the center would be strengthened by the input received.

## **NCBDDD Work Group: Summary of Findings / Solicitation of Input from Full BSC**

### **Overview**

**Edwin Trevathan, MD, MPH**  
**Director, NCBDDD**

Dr. Trevathan explained the process and why NCBDDD took a slightly different approach in its request for their work group. NCBDDD is at the initial phase for strategic planning for this center, realizing that they do not have much time from the work group, yet there are major scientific questions that need to be addressed. The NCBDDD Work Group was asked to focus on three questions that the center believes can actually help the center with decision points in direction in terms of the scientific research components of the strategic plan for the center. Thus, the results of the NCBDDD review sounded somewhat more specific and focused than the approach of the NCCDPHP Work Group's approach. Out of necessity, a larger percentage of the NCBDDD Work Group members are not members of the overall BSC. While some of the key members were unable to attend this meeting, they are aware of the questions, have the materials, and will be submitting their input. Drs. Rimmer and Bethel will incorporate this input as well.

### **Recommendations**

#### **Dr. Christina Bethell, Rapporteur NCBDDD Work Group Report**

During this session, Dr. Bethell reviewed the NCBDDD Work Group charge and agenda, reviewed input on key questions posed to the workgroup, and summarized overarching and question-specific recommendations for further consideration.

With respect to the charge and agenda, key questions for each division were framed by the NCBDDD director. It was wonderful to know that the center had been through a strategic planning process, had identified some priorities, and then sequestered those upon which they felt they could use more input. The work group was specifically asked not to address budgetary or operational topics as these would/could be addressed later. It was difficult not to creep into budgetary issues, but the work group tried diligently to stay away from budgetary issues. Background presentations were offered by each division director. The work group then engaged in discussion of key questions, followed by which they began to identify starting point recommendations (e.g., directly related to the key questions; and overarching). This group did not settle clearly on specific recommendations in a number of areas because they felt certain areas required further discussion among the committee members. However, they got very close in many areas.

Key questions proposed to the work group for each of the three divisions, which included the following:

Division of Blood Disorders (DBD) Focus:

- ❑ What methods of surveillance and tracking should be used to monitor the outcome of future programs to prevent deep vein thrombosis (DVT) and pulmonary embolism (PE) related deaths? This is an issue that rose to the top for this division in terms of strategic planning.

Division of Birth Defects / Developmental Disabilities (DBDDD) Focus:

- ❑ Should steps be taken to incorporate digital imaging and genomic data of the brain and heart in the classification of outcomes for epidemiologic research?
- ❑ Should more be done to incorporate genomics, genetics, and epigenetics into epidemiologic research, with an immediate focus on congenital heart disease and cerebral palsy?

Division of Human Development and Disability (DHDD) Focus:

- ❑ What methods should be considered to: (a) reduce smoking rates; (b) reduce rates of obesity; and (c) prevent avoidable infections among children and people with disabilities?
- ❑ What techniques for surveillance should be considered to monitor progress in these areas?

Dr. Bethel reported first on DBD, pointing out that DBD's vision is to be the global leader in the practice of public health to improve the lives of people at risk of or affected by blood disorders. Its mission is to promote a comprehensive public health approach to reduce morbidity and mortality from blood disorders. The group learned a great deal about blood disorders, their prevalence and importance, and how addressing these helps the broader issue of ensuring the health of the blood supply, et cetera to help the public at large.

The group discussion focused on the questions that were posed on the prevention of DVT and PE. The first task was to clarify the rationale for the focus on DVT / PE, to confirm it as a priority area, and to identify and refine any starting point recommendations.

The rationale to focus on preventing DVT and PE was that DVT and PE deaths per year amount to more than breast cancer, HIV, and motor vehicle accidents combined. There is a very wide range of prevalence estimates, which supports the need for improved surveillance when there is a margin of error that is between 100,000 to 1 million or more. There is also a high level of disparities that. Many of these deaths are preventable. Guidelines exist and there is an understanding about treatment, but guidelines are often not implemented. Sudden death is often the first presentation, so there is a particular need to move upstream to focus on what mechanisms are in place for early recognition and prevention in a variety of settings—not only in medical and surgical contexts, but also in community contexts. There must also be a focus on reducing environmental triggers that engage any predisposing genetic factors. The goals of a national DVT/PE initiative would include prevention, early diagnosis, and effective treatment.

The emerging recommendations were to:

- Focus on surveillance and prevention versus treatment.
- Define the population and measure the burden of disease.

- Produce cross-sectional snapshots using a variety of data sources (e.g., population-based; hospital discharge data; claims/encounter data), given that there is not one good way to acquire this information from surveillance.
- Engage experts to determine specific methods.
- Focus on patient-driven interventions and public education. This is increasingly important and there is a lot to learn about how to make the patient drive prevention by asking questions like, “What are you going to do to prevent a clot when I have this surgery?” This is similar to reducing safety errors in infections by asking doctors to wash their hands. The power of the patient is an important strategy and was specifically discussed for this area.

Further input on surveillance included discussion about the purpose of surveillance, which is that the data (incidence and prevalence) are needed to be able to frame what the issue is, and in order to measure impact in order to determine whether what is being done is actually making a difference. Surveillance requires resources. Intra and extramural approaches are likely to be needed, especially in the frame of cooperative agreements that allow the relationship to be close between the center and the extramural effort. Infrastructure is in place for a number of surveillance efforts within CDC. Consideration must be given to what can be done to build upon that, and at what intervals.

Specific levers to consider in terms of community-based and practice levels include working across the array of health and medical provider associations for which this issue is important; examining hospital regulations, accreditation, payment, CMS, pay for performance, et cetera; collaborating across agencies (e.g., AHRQ, HRSA, NHLBI / NIH, comparative effectiveness leaders); and framing in the context of the quality measurement and improvement and patient safety movement.

Dr. Bethell next reported on DBDDD, the visions of which is healthy birth and optimal development for all children. DBDDD’s mission is to be the public health leader in preventing the occurrence or adverse consequences of birth defects, developmental disabilities, and pediatric genetic conditions through surveillance, research, and intervention programs.

The key questions posed were: Should NCBDDD enhance surveillance and epidemiologic research to identify more modifiable risks for CP and congenital heart defects? How might NCBDDD modify the research and surveillance portfolio to do so? Should more genomics, genetics, and epigenetics be incorporated into epidemiologic research? Should digital imaging data (e.g., MRI, echocardiograms) and / or genetic markers be used in surveillance?

The opening discussion on genomics pertained to the current scope of this type of data collection. Genetics research occurs throughout the center, but is small operationally. Genetics is instrumental in the National Birth Defects Prevention Center (NBDPC). Thus, data are currently collected and there are samples that can be drawn upon to learn more about these issues. There is focus and interest, but it is not deep—it is broader and is not a major focus. The key issue regards environmental influences versus genetics and how much these issues pervade, and whether they can be separated. Are there opportunities to conduct large scale research studies? Are there opportunities to leverage or enhance existing datasets or surveillance systems (e.g., CP via autism work). While these issues were never really resolved, the goal was primarily to determine the status.

With regard to the rationale for focusing on congenital heart defects and CP, congenital heart defects represent 30% of all birth defects and 1% of all births. That is important and compelling. In addition, there is a lot that needs to be explored and understood about this in terms of its lifelong impact and prevention. What are the identifiable, preventable causes of congenital heart defects? As long as that is an open question, this issue should remain a focus. CP is also prevalent. There are advocacy interests, staff expertise, potential prevention opportunities to be explored, the intractable problem of public concern, and the ability to impact outcomes of affected individuals. This focus can help lead the DBDDD and NCBDDD into a new era of surveillance and research applying new science and new diagnostic tools. This will have implications for thinking about and investigating conditions below level of syndrome (e.g., neonatal stroke). Life or death issues are a CDC focus/priority. It is difficult to focus on birth defects other than as single conditions. There was discussion about other conditions for potential focus, such as ADHD. There are many questions about prevention, diagnosis, treatment, prevalence, and prematurity as a cross-cutting risk factor.

The emerging recommendations in this area were that the work group emphasized that mortality and morbidity, including quality of life, are important. Health and related services costs are driven by morbidity. There is also an impact on quality of life. It is unclear at this point, given the state of the science, whether collecting imaging data as part of surveillance system has value. There were also concerns about sensitivity and specificity of this type of data. After all of the discussion, it was agreed that congenital heart defects does warrant enhanced focus. This was as far as the work group got in terms of pinning down concrete recommendations, although these will evolve further in the coming weeks. There was discussion about the potential use of newborn bloodspots. Dr. Bethel did not believe they had reached a conclusion about this, but there was certainly a discussion regarding whether bloodspot use had potential value. The group emphasized that collecting surveillance data connecting physical, function, and services / intervention data would provide a powerful profile for understanding health issues, and that there should be continual global thinking about collecting those together wherever possible.

Dr. Bethell then reported on the findings from DHDD, which has a mission to improve the health of people with disabilities to foster participation in society and reduce disparities. The focus for this division was on reducing smoking rates, obesity rates, and preventing infections. The early focus of the discussion picked up where the group left off in January. In the review of NCCDPHP and NCBDDD, something that rose to the top was a possible gap focusing on early childhood development. Thus, CDC's should enhance its focus on early childhood development, building on the January meeting discussion, in early prevention and reduction of disparities in obesity and smoking. The child, family, and community should all be engaged in early intervention. It is important to fill the in public health in the country, especially given the evidence that has continued to emerge: 1) Adverse Childhood Event Studies (ACES) linking adult chronic disease with early childhood experiences; 2) the Neurons to Neighborhoods report which summarizes many of these findings; and 3) the economic studies coming out of the University of Chicago and otherwise that document the importance of focusing on the first five years of life in order to sustain the economic viability of countries.

Recommendations regarding an enhanced focus on early childhood development include the following:

- ❑ Expand beyond the current administration's emphasis on early care and education, early intervention, and home visiting that are more well-established in the dialogue to well child care, developmental screening, and building on efforts that are underway in the states.
- ❑ Promote CDC-NCBDDD in documenting outcomes and trajectory of conditions, prevention research, and health education. Taking a leadership role could be very powerful.
- ❑ Connect to the national movement focused on early childhood development, developmental screening, improvement of well-child care, and school readiness. There is a potential to support states by providing national leadership.

Partnerships are a central theme. The role of DHDD and synergies with other units of CDC also addressing smoking and obesity should be clarified. Interagency collaboration is also essential (e.g., DOE, AHRQ, SAMHSA, HRSA). Connections/partnerships with health providers and care delivery systems are critical.

Functioning, quality of life, lifespan, family centeredness, and social determinants are central themes. This has special implications in terms of how programs are developed and how surveillance and research are conducted. Social determinants are an imbedded aspect of dealing with any issues related to disabilities in children or adults and certainly when dealing with smoking and obesity. There is need for a special foci on children with special health care needs and people with disabilities pertaining to smoking and obesity. There are many efforts underway, but often they leave out some of the special issues that occur for children with special health care needs or peoples with disabilities, one of which is the higher prevalence of both smoking and obesity. Thus, there is a need to maintain a special disability focus for prevention and management of health risks and risk behaviors. Another issue for certain sub-groups is the built environment. There is a need to advance awareness of problems with the design of environment and ways to overcome them through inclusion, adaptation, and universal design (e.g., weight measurement, exam tables, health information materials, playgrounds, parks, swimming pools).

The last cross-cutting theme for all of this group's discussion was mental health. Mental health has important public health links to obesity, child development, CSHCN, and has a strong association with disability. What is the role of CDC/NCBDDD/DHDD? The work group was informed that there has been a clear statement to encourage the center to continue its efforts to integrate a focus on mental and physical health working on its own as well as through collaborative efforts with other agencies (e.g., SAMHSA, NIMH, AHRQ). This does not pertain to only diagnostic mental health issues, but also has to do with the natural mental health issues that are a part of daily life for anybody with a special need or families with special needs children and people with disabilities. A bold statement was to establish the integration of assessment and consideration of mental health in all aspects of health care as a standard of care/expectation for children with special health care needs and people with disabilities. This has training and referral implications. Ideas were also offered about how to build upon the work of the American Academy of Pediatrics (AAP) and pediatricians, and working with the mental health community.

The final recommendation from this group was just a note to continue to pay attention to the development of measurement methodologies in both defining and identifying people with disabilities, and to use consistent and clear definitions across data and surveillance systems. There is a role for a range of approaches, including broad, non-diagnostic approaches and those that go beyond functioning as a key criterion, especially for children with special health

care needs. If children are receiving good care, they will not have a functional impact that shows up. When combined with the positive way people often report about their health even if they have very strong health problems, there is a potential for losing ground by only defining it functional terms versus broadly. There are contexts in which that would not be appropriate, so it is important to continue to get linguistics and methodologies down, and examine how conclusions are drawn by different denominators that essentially evolve from different surveillance and data systems. Understanding this will be very empowering by ensuring that one is not thinking about all apples when really there are apples and oranges.

Overarching recommendations for NCBDDD included the following:

1. *Enhance leadership to advance coordinated and effective engagement of partners and stakeholders:*

- The key rationale is that the NCBDDD has the opportunity to fill key gaps in public health surveillance, research, and prevention, including birth defects, smoking, obesity, early childhood development, DVT/ PE, and mental health.
  - Starting point recommendation: The NCBDDD should enhance efforts to communicate priorities and the importance of cross-agency and multi-stakeholder collaboration to ensure adequate resources and effective efforts are put in place to support public health improvements in these and other areas. This is an important effort because without it, it is difficult to organize the efforts needed to share values and goals across advocacy groups who represent diseases, for example.

2. *Leverage and enhance existing surveillance and data systems:*

- The key rationale is that the NCBDDD has established successful and innovative community-based models for surveillance and the CDC leads critical data collection efforts that can be enhanced or leveraged to advance the goals of the NCBDDD.
  - Starting Point Recommendation: The NCBDDD can advance its mission and goals by leveraging and enhancing existing surveillance and other data collection systems such as Youth Risk Behavior Survey (YRBS) and Behavioral Risk Factor Surveillance System (BRFSS) as well as those not led by the CDC such as Medical Expenditure Panel Survey (MEPS), hospital discharge data, and the MCHB/HRSA led National Survey of Children's Health and National Survey of Children With Special Health Care Needs.

3. *Focus on cross-cutting risk factors and health impacts such as mental health:*

- The key rationale is that many cross-cutting factors exist that are associated with the prevalence and impact of the health conditions, disability and death.
  - Starting Point Recommendation: The NCBDDD should continue to identify and address key non-condition specific, cross-cutting risk factors and health impacts and facilitate collaboration within the CDC and across agencies and private sector organizations in doing so. This should include a focus on mental and emotional health as both a risk factor and health impact for people and families with disabilities.

4. *Proactively define and implement a public education and translational role in advancing health care quality measurement and improvement efforts:*

- Key issues set forth for discussion to the NCBDDD workgroup are also issues of priority focus for other federal agencies, including obesity, patient safety/DVT/PE, and quality of primary care prevention and care for people with disabilities and special health care needs.
  - Starting Point Recommendation: The NCBDDD should proactively interface with existing efforts of other agencies and define and advance its public education and translational role to improve the health of the public through effective quality measurement and improvement, obesity prevention research and in other priority areas.

5. *Advance the focus on primary prevention, morbidity, and quality of life in addition to secondary prevention and mortality:*

- Starting Point Recommendation: Primary prevention and morbidity and quality of life are essential priorities that must complement a focus on secondary prevention and mortality.

6. *Anchor research portfolio reviews to center and division goals and needs (ensure value / clarify):*

- Starting Point Recommendation: Ensure that research portfolio reviews emanate from and advance goals of the NCBDDD and its divisions.

(The workgroup also requested more information on who is requiring these reviews, goals, and desired outcomes)

The NCBDDD should continue to identify and pursue cross-agency linkages and collaboration (e.g., DOE, CMS, AHRQ, HRSA, SAHMSA, NIH). A special note was made that this might be a good way to advance goals related to potential use of imaging data in surveillance efforts. This work group did not really talk explicitly about coordination between the two centers, except in situations where it was obvious and to assume that the NCCDPHP is focusing on children with chronic conditions that are not otherwise captured in the NCBDDD's activities, given that not all children with chronic conditions are actually a focus of NCBDDD.

Dr. Rimmer thanked the ad hoc committee members who helped considerably with expertise and knowledge in the three areas the work group was asked to assess: Charlotte Dreschel, New York; Nigel Key, University of North Carolina; Gary Raskob, University of Oklahoma; and Paul Romitti, University of Iowa College of Public Health. In comparison to what the other work group did, this work group spent a lot of time at the micro level addressing three very important areas, which are in some respects life and death issues. The group heard compellingly that DVT is a preventable condition leading to 100,000 to 300,000 deaths per year. What resonated with him and several of the committee members was that primary care providers are not utilizing the evidence-based treatment guidelines that are available. The key expert in this areas said that if he had to begin in one of the three areas (prevention, research, or surveillance) he would

choose prevention as a lead in to the area of surveillance in terms of identifying what is working and what is not working. This is a highly critical issues, and is one that has been largely ignored by CDC. Thus, the agency must begin to address this issue in terms of future resources. The other part of the discussion dealt with what the connections are with the other centers. The work group learned from several members that surveys like the YRBS and some of the surveillance data that is being collected from the other center could, if there was a disability identifier added, provide a rich body of data on youth, adults, and seniors with disabilities. The work group felt that this would be extremely important. The work group also learned that there are earmarks and Congressional lines that are associated with much of the funding in each of the centers. The NCBDDD felt that it was not their responsibility to oversee the level earmarks or how to make changes in terms of its structure, but that what they could do would be to develop a set of priorities for the center, which could then be distributed to those earmarked centers or programs so that they could develop their proposals around the key areas for each of the centers.

### **Discussion**

- Dr. Cohen indicated that the way his work group dealt with the issue of the earmarks was to try to encourage more flexibility in discretion in funding. The statement about listing priorities might preclude bringing forth items that are not currently identified, but that may arise as important issues that do not have earmarks. In terms of the issue of DVT, this group did discuss public education efforts as part of prevention, which is a very important component in prevention of DVT. There was a recommendation to do more in the area of ADHD in the previous review of the center. The point was made that it is a high prevalence of 7% to 10% of the child population. More epidemiological studies and studies related to how to identify, classify, and prevent ADHD are certainly relevant, which is why this became a more highlighted issue along the way. They did discuss bloodspots, but did not come to any conclusions because all of the ethical and moral concerns were brought forth and because many states do not store bloodspots. Thus, it would be difficult to conduct a nationwide program, although perhaps there could be some state by state work. Nevertheless, all of the concerns in that area prohibit further work currently. He reiterated that in addition to school health, there should be a greater focus on early health education (e.g., child care, pre-school programs, et cetera) which is in sync with some of the priorities of the administration and in which CDC could play a role in expanding the health education component that goes along with early intervention and education as well.
- Dr. Wolraich thought Dr. Cohen's comments reflected their work group's discussions from the previous day. There were a number of issues that cut across the different programs within centers and across centers, such as the Legacy Program and SafeCare Program that are similar parenting programs. There needs to be enhanced communication within the centers on similar programs in order to coordinate some of that. There was a sense that bloodspots are an important resource for the future, particularly from a genomics standpoint and in being able to obtain large samples in the long-run. However, this work group had the same issues as discussed earlier in the morning, that this is a mess with respect to obtaining permission and what parents understand about availability. It is important to try to clarify that and get a process going forward so that this important resource can be utilized in the future to assess gene-environment. In terms of communication among stakeholders, this is an approach to inform key stakeholders who then are involved much more in an advocacy role for the organization. What occurs frequently is that these become diagnosis-specific groups. Therefore, attempting to develop a more coordinated stakeholder group would provide them an opportunity to work together so that there are fewer competing forces. A

strength in the surveillance programs that have been set up, and the fact that much of the medical/health community is moving into the idea of registries and quality improvement initiatives, suggests a strong role that CDC could play in terms of the models that have already been developed.

- Dr. Curtis urged the NCBDDD Work Group and the board as a whole not to assess birth defects singularly any longer. When birth defects are considered singularly, it is looking for a bullet for a disease. The reality is that it is not a single bullet, and it is not a single etiological agent. In very few instances, despite all of the research endeavors, has a single smoking gun been found. It is a coalition of forces (e.g., genetics, environment, behavioral conditions, et cetera). She thought that when birth defects were no longer examined from the reductionist model of seeking the single causative agent for X birth defect, and they begin to imagine birth defects as more of a global manifestation of those three entities, progress would be made. Cancer research is coming to grips with this. There is a cross-cutting issue in both centers related to chronic diseases and birth defects and developmental disabilities, which is the concept of the fetal origins of disease. The fetal origins of disease harkens back to the concept that was promoted heavily under the rubric of preconception care. Leaving that out of the equation leaves a very important component out of understanding the epidemiology and treatment approaches to these diseases. It is not just a congenital heart defect, but there is clearly emerging evidence in the literature that, for example, intrauterine growth restricted babies have a higher incidence of heart disease or cardiovascular disease later in life. Thus, what contributed to the defect before birth is very important. To her, this linked the two centers the most strongly—the advocacy for a global view of health in the fetal and embryonic origins and those of the parental lineage that brought that particular individual about and how the health of all of those people involved can be optimized and not just the child after it's born with whatever defects it is unfortunate enough to have.
- Dr. Trevathan stressed that topics not included in the list the work group was asked to assess did not signify that the center did not believe they were important and was not addressing them. For example, the center agrees that preconception care is very important and it is subsumed under one of the center's priorities in terms of assuring child health. There is an active preconception care group across centers. Dr. Posner is the lead on preconception care and chronic disease prevention and health promotion. There is a large preconception care mini summit upcoming. While preconception care is a very important issue to the center, it was not a specific question posed to this work group.
- Dr. Cohen indicated that it did arise in the discussion the previous day. For example, he mentioned specifically that diabetic mothers have higher incidence of a variety of congenital defects, including spinal abnormalities, which is one of the things being surveyed. Perhaps the message did not come through strong enough, but there was considerable discussion the previous day about the issue of genetic and environmental interactions, their end results, and how more has to be explored in that regard. The group did discuss the issue of prematurity and its relationship to a host of disabilities in children. Those are critical issues, although it was not clear how much it was within their purview to make recommendations about it, other than they are in favor of reducing prematurity, improving prenatal care, and reducing the impact on future disabilities in that regard. Another reason for joining the two groups in common recommendations is that children with birth defects and developmental problems often grow up to be chronically ill adults. The American Heart Association (AHA) deals very little with congenital heart defects and how common they are, yet many of them survive into adulthood and have chronic heart conditions. There is an interrelationship

between early childhood disabilities and adult chronic illness. This must be dealt with in interventions to help children.

- Dr. Goff stressed that there was significant potential in a partnership with the AHA, although this did not come through as clearly as it might have in their report. Perhaps that had to do with a lack of awareness about what the AHA is actually doing. There is a Council on Cardiovascular Disease in the Young within the AHA, which is very active in the area of congenital heart disease. That activity has been elevated substantially in the AHA in the past several years. He was privileged to be head of their Statistics Committee a few years ago, which got representation from the Council on Cardiovascular Disease in the Young. There are five full pages of statistical attention to congenital heart disease in the *2009 Heart Disease and Stroke Statistics Update*, although there is only one page on the topics of pulmonary embolism and venous thromboembolism statistics. Kathy Jenkins is currently a representative on the ACCAHA Performance Measures Task Force, which is a group that is responsible for developing performance measures that are used in clinical practice to determine whether good health care quality is being delivered. She is representing the field of congenital heart disease in that task force, which has begun to recognize that enough is currently known to develop performance measures on how health care should be delivered to children and adults with congenital heart disease. Although the area has come a long way, there is still a long way to go. A partnership between NCBDDD and AHA, the American College of Cardiology (ACC), et cetera would be very beneficial. Some of the surveillance expertise that is represented in the annual update from the AHA is provided by the Division for Heart Disease and Stroke Prevention (DHDSP) within the NCCDPHP. This is a tremendous opportunity for cross-center collaboration internally at CDC and for external collaboration with the AHA and the ACC.
- Dr. Trevathan responded that NCBDDD has a very strong relationship with AHA and has spent a great deal of time with them. There is a new group of experts who are now meeting to examine advice and input on congenital heart disease. The AHA and AAP are jointly heading that group. Dr. Trevathan and other leaders, including Peggy Honein, Chief of the Birth Defects Branch recently briefed the AHA leadership in Washington on NCBDDD's congenital heart disease.
- Dr. Emmons noted that the measures recommendations were very much focused on a population perspective, which is fantastic, but some of the intervention aspects were more individual patient education oriented. Another cross-section with the other center would be to think about social determinants. She imagined if there are racial, ethnic, and income disparities in DVT, there would be some very important social determinants as well that increase risk.
- Dr. Kardia inquired as to whether the group deliberated on the relationship with the National Children's Study. It seems like a multi-fold intersection would be important, because as CDC is implementing programs in 50 states affecting the health of children, and the National Children's Study is on-going, this is creating, experimentally, an intervention at the population level that they should be aware of, as well as an on-the-ground intersection to be able to collect data on particular issues (e.g., frequency of birth defects, social determinants, et cetera) that feed into that. With that in mind, she wondered what the relationship is between CDC and National Institute of Child Health and Development (NICHD) in that study, which is just getting underway.

- Dr. Yeargin-Allsopp responded that CDC is one of the lead agencies for the National Children's Study and has been involved in the planning since the beginning. There are members of the Interagency Coordinating Committee (ICC). Dr. Trevathan is the representative to the advisory committee from CDC. This is a nationally representative sample of 100,000 children who are identified before birth up to age 21. With respect to some of the outcomes of interest, although the study is not designed to assess very common outcomes, it is designed to examine outcomes with a prevalence of 2 to 3 per thousand. Originally the prevalence estimates were for autism, birth defects, and other conditions. The sample size may not be huge for some of the outcomes of interest, particularly when thinking about the ages of the children and the sub-groups. There may not be the large number of cases in which people may be interested in order to assess possible associations. However, the strength of the study is that it is prospective. Environmental data and a range of outcomes will be collected on these children so that possible associations and multiple associations can be examined in the context of this study. There is a CDC Interest Group, so CDC scientists have been involved in the planning of the study through working groups, and will have the opportunity to design adjunct studies, and to drill down and examine particularly hypotheses/questions. Thus, it is a great resource that CDC will leverage. However, it is not the answer to everything. When people begin to raise questions, the first thing they say is, "Well, we have the National Children's Study." She stressed that this cannot be the end all be all to all of the questions.
- Dr. Kardia indicated that she was on the IOM committee that reviewed the National Children's Study. Her understanding was that they were enrolling half a million families or mothers, expecting only to identify that 100,000 to carry through. However, the half a million seems like a significant number because they are following pregnancies—the prenatal trajectory. This is why she thought birth defects would be a natural intersection.
- Dr. Yeargin-Allsopp responded that there would not be information on the half a million. There may be some information, but complete longitudinal information will not be available on more than 100,000 children.
- Dr. Trevathan added that a lot of the National Children's Study and a lot of NCBDDD's project complement one another. For example, the autism case-control study conducted by the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) sites has roughly 2700 children to examine risk factors for autism. NCBDDD is estimating that in the National Children's Study there are approximately 600 to 700 cases with autistic spectrum disorders. The irony is that although the National Children's Study is huge in terms of total number of children, the sample size for some of the outcomes is not very large. Another area in which the National Children's Study complements some of the center's work, that was not related specifically to the questions posed to the work group, is in studying normal early child development in terms of what enhances child development in the population. The National Children's Study does have a really nice sample size for normal child development and various gradations of that.
- Dr. Rimmer indicated that the work group met with the NICHD director a few months ago and learned that they are collecting data on families with disabilities and plan to track children with certain developmental disabilities. The structure for that is somewhat vague because with intellectual disabilities or autism, there is a process of assent-consent. There may need to be variations in that process, which they have not considered. Their comment was, "Well, that's way down the road. Right now we're just trying to get the infrastructure set up."

- Dr. Yeargin-Allsopp replied that the detail on the study is during pregnancy and up to age two. It is obviously going to move forward, so the details of identifying children at school age or adolescence have not yet been worked out.
- Dr. Cohen thought there was also a question about appropriate use of instruments in terms of evaluating those children.
- Dr. Yeargin-Allsopp responded that there is a protocol that addressing the identification of children in terms of cognitive abilities up to age two with the use of specific language instruments, which are appropriate. However, she did not know about discussions regarding instruments beyond that.
- Dr. Kleinman inquired as to whether there was a linkage across all of the NIH institutes that deal with issues related to birth defects and disabilities. Some of these research areas lend themselves to co-funding or co-RFA approach.
- Dr. Trevathan responded that there is not one answer to that question. NCBDDD has very close communications and collaborations with NICHD in a variety of areas. There are ICCs for some of these disorders, through which NCBDDD works very closely with its colleagues at various NIH institutes. For the most part, the public health research that NCBDDD conducts relates more to risk factor and epidemiology research conducted in population representative samples, which is a different approach from NIH.
- With regard to the recommendation for patient education, Dr. Klein man thought the area of health literacy represented an important opportunity for both centers to approach aggressively, taking advantage of beginning research in measurement and moving from a provider and patient point of view to the community aspects of health literacy enhancement. Regarding the issue of imaging and the opportunity to incorporate imaging with clinical and other epidemiologic findings, this might be another bridge to NIH since they have been doing this more from a technological point of view focused on diseases and conditions. If the technology issue is the question about what it would bring versus a bioethical issue, that might be a useful exploration.
- Dr. Wolraich indicated that there is an example in ADHD in which a project is funded by CDC, in which there is a collaborative arrangement with National Institute of Mental Health (NIMH) in terms of brain imaging of some of the subjects. The issue was raised more with respect to resources and what is realistic to do. The group saw the strength of CDC in having the large number of subjects in terms of surveillance, which really will be needed moving forward to examine epi-genetic and environmental genetic interactions, but there will not be resources to do imaging studies under the type of control needed. Doing the imaging simply did not seem feasible for CDC to do, not that it should not be done or is not an important factor.
- Dr. Rimmer inquired as to whether Drs. Klein man and Goff would agree that the work groups took two different perspectives on this in terms of how each approached the review process.
- Dr. Goff replied that he heard a few things that were certainly cross-cutting that arose in both presentations: translation, enhancing surveillance, prevention of adult chronic diseases in people with congenital defects and developmental disabilities, community health

workers, and primary prevention. Mental health came out more strongly in the afternoon as a focus than it did during the morning session. It is obviously a very important component of what occurs in the NCCDPHP, especially in the Division for Adult and Community Health (DACH). There is a lot of opportunity for addressing some of the same themes, either in a preamble to the two chapters or in an overarching set of recommendations that would apply to both centers.

- Dr. Cohen added that a mental health focus is a very clear need for children, but the resources are not available. CDC's role in that regard needs to be clarified. These are children who have mental health needs that are not being met, and adults with chronic illness likely experience similar problems accessing mental health services. There is not very good data, so some broader data collection and surveillance in that regard could lead to more specific recommendations about what to do.
- Dr. Ruth Perou, CDC Mental Health Coordinator, indicated that there had been an increasing focus from a center-wide perspective to view mental health as an important public health issue that is being defined in multiple areas; that is, the importance of viewing mental health as part of overall health and wellbeing. They are getting consensus within and outside of CDC on this issue from sister agencies, which really want to see CDC playing a leadership role with respect to mental health, and very much pushing forward the public health perspective to integrate physical health and mental health. The other issue regards viewing mental illness as a specific disorder and bring a public health perspective to that. This is evident in both centers in that there is already some research underway in that area. The public health framework is being brought to these issues (e.g., depression and ADHD). The other piece is seeing mental health as a risk factor. There are broad and very targeted mental health activities underway across all centers at CDC. The key is that CDC is receiving a lot of support from its federal and private partners to be the leader with respect to mental health from a public health perspective. Dr. Wong, from Substance Abuse and Mental Health Services Administration (SAMHSA) recently visited CDC, who did an extraordinary job of getting to know the work going on in CDC in this area, and some immediate projects were identified that CDC could be working on, which are taking off.
- Dr. Wolraich thought that a very important role CDC could play is primary prevention. There really is not a strong agency function of primary prevention issues in mental health, yet that is a very important area that needs to be addressed. This is not just about disorders, but also has to do with determining what will support good mental health beginning with young children.
- Dr. Perou added that the SAMHSA administrator had set the impact of trauma as a priority on mental health outcomes. There is now a growing literature on the biological possibility of what is occurring with respect to the impact of stress, not just on mental health outcomes, but on chronic disease outcomes and overall. Starting early is critical, as is assessing social determinants, the impact of families and parents, the gene-environment interactions, et cetera. All of these components are critical, so all that was discussed during this meeting is very relevant, and brings together a broader discussion that gets closer to the WHO definition of "health" and where CDC should be moving in this area. The stars seem to be aligned in terms of more respect, acknowledgement, and awareness of these issues and integrating them better in the work that the agency does. She has been amazed with the support and receptiveness within and outside of CDC. In terms of what can be done without additional funding, this is being done immediately. Some synergies have already been identified in terms of the work that is going on in both centers. There was a meeting the

previous day between someone from NCCDPHP doing work on geo-mapping and someone from NCBDDD doing work on ADHD, who are going to write a paper together in an effort to better explain prevalence rates and access to care issues.

- Dr. Toomey indicated that initiating the discussion about the mental health and public health nexus was one of her goals on which she worked very hard. She believes that CDC needs to take a leadership role in raising this broadly with the public health community. The BSC could raise and elevate this to the attention of the new director, who very much support mental health aspects in the context of public health, as well as to the attention of CDC's public health partners. She has raised this with other state health officials who really did not perceive mental health as part of their core mission, but instead saw it as competitive. CDC has a major job to do in educating people about the tremendous impact there can be by building a bridge between these two disciplines. There is a nexus for health and wellbeing that is equally CDC's, and that leadership roles is a critical one for the agency to play.
- Dr. Kolbe indicate that after 2001, there was a National Commission on Disaster and Children that prepared a report for Secretary Thompson, making all of the recommendations that one would assume would be made for children in addressing mass casualties. This also included a major section on mental health. Although this seems to have rested in the Secretary's office without being dusted for a couple of years, it contains good recommendations related to mental health.
- Dr. Goff noted that in the Division of Adolescent and School Health (DASH) there is a substantial focus on things that affect the health of children, including ADHD. In the report from NCBDDD that there is also a substantial focus on ADHD and there is some collaboration going on between those groups. They heard earlier in the day the imperative of doing better with what there is, or even doing better with less. The work of these two groups represents a tremendous leverage point. There are probably other leverage points in other centers as well.
- Dr. Collins noted that SAMHSA provided CDC with funding to add a mental health and an alcohol module to the BRFSS. This is indicative of SAMHSA seeing the role of public health in mental health, and that their missions are complementary in these efforts rather than competitive. Although a cohesive understanding of where CDC is headed in this domain remains to be thought through, efforts are underway. The school health work tends to be very general population oriented in a variety of areas (e.g., tobacco, nutrition, physical activity, injury, sexual health, disparities, et cetera) rather than focused on special populations such as ADHD. They are not necessarily using the platform that exists to tackle some of the pieces. One way to think about this is in terms of making maximal use of existing platforms, with NCBDDD address the issues they understand while NCCDPHP addresses the broader population issues.
- Dr. Bethell expressed concern that every time she heard "Birth Defects Center" she worried that there would be a loss of the real scope in which NCBDDD is engaged. In the report it will be really important to be careful about how it is termed so that it does not appear to be focused only on birth defects. The issues of primary prevention, healthy development, smoking, obesity, et cetera are very cross-cutting for all people with disabilities.
- Dr. Rimmer indicated that this had been a discussion since the inception of the center in 2000 through the Children's Health Act. When discussing prevention, people with disabilities are often left out because primary prevention usually is tagged onto disability.

There is the concept of “Nothing about us without us.” There will be people with disabilities, and there will be new disabilities, emerging disabilities, people in transition with disabilities with diabetes/heart disease/COPD/arthritis. The work of the two centers has to be connected.

- Dr. Trevathan inquired as to whether there were any aspects of the areas the NCBDDD Work Group addressed for which they would recommend having a sub-group or another work group examine some of the questions further.
- Dr. Bethell responded that there was a specific recommendation for a sub-work group for DVT and PE. She personally was not clear about the issue of imaging and genomics.
- Dr. Cohen noted that questions were raised about the value of the imaging issue as a surveillance technique. As an individual diagnostic technique, clearly it is of value, but even then from a clinical point of view there are children with Grade 4 hemorrhages who look pretty good and there are children with Grade 1 hemorrhages who look terrible in terms of their cerebral palsy, degree of disability, degree of mental deficiency, et cetera. They were not clear, based on the potential for variability (e.g., among centers, equipment, reading of the studies, ability to follow subjects, et cetera) that a good study could be conducted on a national basis or a multi-center basis, when there are individual reports from top-notch places that report on follow-ups of children with imaging studies due to IVH. At the same time there is an interesting issue about all of the different causes of stroke, what they mean, and how some of them can be prevented. The question regards how feasible a study would be on such a major effort and how clinically useful it would be.
- Dr. Trevathan thanked everyone for all of the work that they had done and would continue to do on these issues. He found this to be very helpful. Some of the overarching recommendations will be very helpful. These issues are not simple. The question is, “Which child do you like the best? Your oldest or your youngest? Which do we need more? Digital imaging or genetic data and epidemiological research.” For him, the emphasis would be epidemiologic research. Some members of the work group were unable to attend, including someone with special expertise in imaging. There are limited resources, but the center wants to do everything possible to be on the cutting edge of epidemiologic research. Coming from a Teratology Society meeting the previous day, he recognized that they were going to have to soon get more into genomics and epi-genetics to avoid losing opportunities to identify modifiable risk factors in populations and potentially do things from a public health point of view that can change gene expression and improve health in populations. That must stay on the “radar screen.” The discussions during this meeting were profoundly helpful even if some of the issues were not on the agenda. The issue of bloodspots was raised. The issue of newborn screening and the utilization of data will be important issues. Perhaps in the next version of the BSC, these issues can be further addressed. In addition to using biological specimens prudently, ethically, and communicating results to the public, there is the ethical need to track those children who are screened positive to ensure that they receive the interventions they need. This is an area that connects public health to health care. Connecting public health to health care is going to be a major issue for this center in the future. The center sees this review as a beginning and knows that this will help their strategic planning process and daily work. He expressed his gratitude for all of their hard work and time.
- Dr. Cohen stressed that genomics issue is of key importance, particularly combined with the environmental effects. In order to fully address newborn testing / bloodspots, perhaps CDC

should convene an expert group, including ethical consultants. There must be a way of developing a compromise on assent-consent that would please everyone.

- Dr. Trevathan responded that this is a critically important issue. Dr. Colleen Boyle is the agency's representative on a Newborn Screening Coordinating Committee at the Secretary's level. That committee and others have and will continue in the future to assess this issue. While this issue has not received adequate attention, it will. The area in which NCBDDD feels they need to spend more time is developing the tracking systems and populations to identify children who screen positive to determine how they connect with services or do not. Then there needs to be feedback on the system to improve health, and to assess outcomes to determine whether a difference is being made in communities of children in terms of their health by doing newborn screening.
- Dr. Wolraich thought that connecting to the EMR record would be needed for going forward in the future.
- Dr. Trevathan added that one reason the center decided to push out the issue of imaging data pertained to the transformation over the next few years to electronic health records. Dr. Lenert, who directs the National Center for Public Health Informatics (NCPHI), is a physician and public health informatics expert. He feels that imaging data will be of such a nature in the next few years that it can be captured in populations and do things that have not been thought possible in the past. Even if the technology is not available currently, it is important to think about developing platforms.
- Having now heard the presentations and discussions from both groups, Dr. Popovic said she wanted to draw some parallels and offer some unsolicited advice. She stressed that the agency did not want to be prescriptive in terms of what specific questions the boards are asked by various centers. She has been charged with oversight of all of the BSCs in terms of who is responsible, how long it is going to take, when it will be finished, who will monitor and track, et cetera. She said that it was perfectly fine that the NCCDPHP Work Group used a different framework than the NCBDDD Work Group. Whether they realized it or not, both groups discussed specific issues and big picture items. In the end, they addressed the questions that were ultimately important. Within the next week or so, she planned to share the two-page recommendations with Dr. Frieden. The OCSO recommendations would provide a timeline, for example, BSC would provide reports to the programs within 30 days; after receiving the report from the BSC, the program should develop a response within 30 days that states what steps they will take with regard to each recommendation. All of this will be posted on web for the sake of transparency, et cetera. There are many specific issues. As they began to develop their report, she suggested that they keep in mind that their recommendations must have these characteristics: 1) the recommendations should be specific enough to be actionable.; 2) they should reflect consideration of the big picture because that sort of thinking stimulates CDC's strategy; and 3) they should think in an integrated manner. In working with colleagues on the stimulus package, Dr. Popovic has learned that it is not always wise to separate public health and the medical world. People like to say that 95% of money in this country goes to the medical world, while only 5% goes to public health. At the same time, people forget that public health recommendations are used in the clinical world. These areas should be integrated rather than being pitted against one another. A good example was recent work with Dr. Carolyn Clancy, Director of the Agency for Healthcare Research and Quality, in comparative effectiveness research during which she asked, "What are the things that public health surveillance and registry information can provide for the clinical world?" In terms of what Dr. Lenert is doing for

informatics, it would be beneficial for a general practitioner to sit in his or her office, turn on the computer, and be able to see what is occurring in their county if suddenly patients present with something unusual. She heard a number of overlapping themes from the two work groups, and she felt very good about the general themes. CDC has an advisory committee on public health ethics, the Public Health Ethics Committee (PHEC) that has been in place for five years. The head of the Office of Public Health Genomics (OPHG), Dr. Muin Khoury is working very closely with PHEC. There have been a number of public health ethics issues, one of which regards how to ethically use genetic information and information that can be obtained from screening. Throughout the day, the importance of internal and external partnerships was raised. CDC has health protection goals, goal teams, and cross-agency activities. While it is unknown whether Dr. Frieden will continue in the direction of using the goal teams and activities in their current form, most people at CDC agree that the experience the agency has in identifying cross-cutting areas, in grooming 14 or 15 people to think across programs and centers has been beneficial to the agency. CDC has been working in a cross-cutting manner. For example, approximately 20 divisions at CDC focus on adolescent health.

- Dr. Toomey expressed her amazement that in the two times this group had met, they had come together for a short and intense two days and covered a tremendous amount of breadth and depth. She led the first meeting saying that it was a time of great transition and they did not know what was going to happen, so she said she would close this meeting saying it is a time of great transition and great excitement. Having spent the last five months working on the stimulus package and seeing the potential for that package to help transform prevention within the context of community health, has been a tremendous opportunity for her and the agency. She stressed the importance of the BSC's role, perhaps now even more so, because their input was coming at a time of forward momentum. It really will help them fine tune their thinking as they move forward. With that, she expressed her profound thanks to the BSC for their work.
- Dr. Bethell indicated that in the next few days, they would develop an outline with a proposal for some delegation for refining and adding depth to what was presented in the form of a written report. The group already discussed who among the group would be responsible for each component, given their expertise. They will collect additional input, specifically from the members who were unable to attend. They will follow-up with Dr. Trevathan to acquire further background about any other framing information that might be needed to put the questions that were specifically addressed in the context of the center's broader goals so that there would not be the risk of anyone thinking that these are the center's only priorities. A call would be convened the first week of August to review whatever had been developed, with a plan for a full draft by the end of August, and another round of input, and a submitted draft by September 5<sup>th</sup>.
- Dr. Popovic noted that this was beyond the 30-day deadline, which is not yet official. Dr. Frieden has not made a decision about this yet, but the deadlines will be set for the simplest of versions of the recommendations within 30 days of the meeting. While this was not yet in place, she wanted to share this.
- Dr. Bethell responded that if work group members and the committee were comfortable with what had been presented, there is no reason why they could not put that forth as a preliminary outline. She agreed to put that into some type of document form over the next couple of days.

- It was noted that the BSC was told the final report was due November 1, 2009.
- Dr. Popovic clarified that they should continue on the current timeline, but that the timelines were in the process of being revised. No one would be interrupted in the midst of what they were doing. She is currently trying to understand how each of the committees work.
- An inquiry was posed regarding the BSC's role and requirement for the review, and why these reviews are required.
- Dr. Popovic replied that CDC's link between the program, surveillance, and research is really unique. To look at the components outside of what is done internally would be impossible in terms of assessing the effectiveness of a national center or a program within it. Even though these are called BSCs, the task is broader than looking at the research per se. In terms of why these reviews are required, people ask how CDC makes decisions. Although CDC used to deal primarily with state and local health departments, there is now a lot more openness and work with many partners. In addition, they were attempting to implement a peer-review process that resembles that of NIH, but not entirely because these are different organizations. CDC decided that a traditional, full-blown peer-review for all extramural research and a mechanism to review everything that the agency does was needed. It seemed that the BSCs would be the most appropriate bodies to actually have a sense of both research, and how that research is implemented in practice. This process has been almost 10 years in the making, and was not a single decision made in a single time, even though the BSCs were officially only about two to three years old.
- Dr. Bal thought the BSC's mandate was to advise the Secretary of HHS/CDC on strategies and goals programs, peer review scientific programs, and monitor overall strategic direction and focus of the national CDC. Arguable, the other two are as important, if not more important, than the research. The end objective was not to make CDC NIH-like. It was to have an intervention agency that actually changed occurrence of disease covered by a particular center.
- Dr. Popovic responded that if they were truly only focused on research, the discussion throughout the day would be completely different in that they would be talking about very specific topics, the quality, et cetera. The work groups addressed all three areas. It will take some settling for everybody to feel comfortable. The big picture is really the strategy of where CDC wants to go and whether the agency is making a health impact. Part of the peer review process is to assess whether the work the agency does has quality and relevance, and whether it really matters in the grand scheme of things.
- Dr. Kolbe thanked Dr. Popovic for taking time to attend this meeting, acknowledging that her participation had been very beneficial. He also thanked Dr. Toomey for her wonderful support throughout the process in helping to keep the work groups moving along on a daily basis.

### Next Steps, Timeline, Products

- The four co-chairs will work closely with their respective center directors to develop very specific recommendations, doing so within the constraints of existing resources, offering the most compelling rationale/justification for each recommendation, and keeping in mind that CDC is in a state of transition, such that it is like “sailing a boat and building it at the same time.”
- As soon as possible, the four co-chairs will be provided with a schedule for the draft recommendations. Rough recommendations may be submitted to Dr. Popovic. What was presented during this meeting may be put forth as a preliminary outline.
- The four co-chairs should convene within a short period of time to harmonize the format of the two preliminary sets of recommendations, finalize the timeline, and determine the format of final product
- Eight days before September 15<sup>th</sup>, each group should have fleshed out their recommendations, keeping in mind that the timeline may change based on CDC director's decisions.
- Potential document format: 1) pursuant to FACA charter, only one final document should be prepared; 2) the document could include a preamble that addresses background, overarching/cross-cutting issues; 3) two section should be included, one for each workgroup, that follow a similar formatting scheme.

### Public Comment Period

No public comments were offered.

**Certification**

I hereby certify that to the best of my knowledge, the foregoing Minutes of the July 1, 2009 CCHP BSC Meeting are accurate and complete:

\_\_\_\_\_  
Date

\_\_\_\_\_/s/\_\_\_\_\_  
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