

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

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



**Summary Report  
January 14-15, 2009  
Atlanta, Georgia**

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## Acronyms

AAP	American Academy of Pediatrics
AARP	American Association of Retired Persons
ADDM	Autism and Developmental Disabilities Monitoring Network
AHA	American Heart Association
AMA	American Medical Association
AMCHP	Association of Maternal and Child Health Programs
ASA	Autism Society of America
ASD	Autistic Spectrum Disorders
BSC	Board of Scientific Counselors
BRFSS	Behavioral Risk Factor Surveillance System
CADDREs	Centers for Autism and Developmental Disabilities Research and Epidemiology
CDC	Centers for Disease Control and Prevention
CCHP	Coordinating Center for Health Promotion
CCID	Center for Infectious Disease
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
DNPAO	Division of Nutrition, Physical Activity, and Obesity
DOE	Department of Energy
DOH	Division of Oral Health
DRH	Division of Reproductive Health
EHDI	Early Hearing Detection and Intervention
EIS	Epidemic Intelligence Service
FACA	Federal Advisory Committee Act
FAS	Fetal Alcohol Syndrome
FDA	Food and Drug Administration
GSA	General Services Administration
HHS	Department of Health and Human Services
HIA	Health Impact Assessment
HRSA	Health Resources and Services Administration
IOM	Institute of Medicine
MACDP	Metropolitan Atlanta Congenital Defects Program
MCHB	Maternal and Child Health Bureau MCHB
MASO	Management Analysis and Services Office
<i>MMWR</i>	<i>Morbidity and Mortality Weekly Report</i>
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
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

NINDS	National Institute of Neurological Diseases and Stroke
OAR	Organization for Autism Research
OGC	Office of General Council
OGE	Office of Government Ethics
OMB	Office of Management and Budget
OGH	Office on Global Health
OPHG	Office of Public Health Genomics
OSH	Office on Smoking and Health
OSI	Office of Strategy and Innovations
OWCD	Office of Workforce and Career Development
PAHO	Pan American Health Organization
PART	Program Assessment Rating Tool
PEHEB	Prevention Effectiveness and Health Economics Branch
PEPFAR	President's Emergency Plan for AIDS Relief
PRCs	Prevention Research Centers
RCT	Randomized Controlled Trial
REACH	Racial and Ethnic Approaches to Community Health
SAMHSA	Substance Abuse and Mental Health Services Administration
SCHIP	State Children's Health Insurance Program
SEED	Study to Explore Early Development
SES	Socioeconomic Status
SGEs	Special Government Employees
SMEs	Subject Matter Experts
TEPHINET	Programs in Epidemiology and Public Health Interventions NETWORK
UK	United Kingdom
US	United States
VFC	Vaccines for Children
WHO	World Health Organization
YRBS	Youth Risk Behavior Survey

## Executive Summary

### Introduction:

The Coordinating Center for Health Promotion (CCHP) held its first meeting of the Board of Scientific Counselors (BSC) on January 14–15, 2009. The following presentations were given over the two days of the meeting, each followed by lengthy discussion among the BSC members and with questions to the presenters: 1) a review of the regulations provided for in the Federal Advisory Committee Act (FACA) including issues related to Ethics and Financial Disclosure, 2) an overview of the Coordinating Center including budgetary issues, and 3) an overview of each of the National Centers (the National Center on Birth Defects and Developmental Disabilities [NCBDDD] and the National Center for Chronic Disease Prevention and Health Promotion [NCCDPHP]). Members of the BSC made wide-ranging suggestions for potential BSC roles. Through these deliberations, the BSC agreed 1) to use work groups to focus on specific topics to accomplish its goals, 2) to address external review (specifically PART on behalf of NCCDPHP), 3) that although nine areas of interest for work groups were identified, those nine areas could be more usefully configured into three work groups, with one added and overarching group, i.e. OMB/PART reviews. The two of the nine identified areas, that received the most attention, after PART reviews, were population health/disease burden and social determinants of health. Below is a synthesis of the discussion of areas that the group agreed to address first.

**Work Group #1 CDC Actions to Improve Population Health: Analysis of Burden of Disease, Health Care Reforms and Partnerships** – This Work Group would review and synthesize pertinent materials to create a succinct report and recommendations for CDC regarding population health. It was suggested that the Work Group would review Burden of Morbidity and Mortality, Integrated Health Care and Public Health Reform, and Public-Private Partnerships. The end product for this Work Group was envisioned to be a report that might: (a) articulate causes of the most substantial morbidity and mortality burdens and costs in the United States including mental health; (b) offer specific, feasible actions CDC might take to address the greatest of these burdens and costs; (c) identify specific, feasible health care and public health reforms that will reinforce the recommended actions; (d) identify specific, feasible means by which public-private partnerships might serve among the actions recommended above; and (d) describe how to communicate to various stakeholders the importance of CDC taking these actions.

**Work Group #2 CDC Actions to Improve Population Health: Analysis of a Social Determinants of Health Approach** - This Work Group would review and synthesize pertinent materials to create a succinct report and recommendations for CDC regarding population health. The end product for this Work Group was envisioned to be a report that could briefly: (a) summarize a “social determinants” approach to improving health in the United States; (b) describe how social determinants of health are applied to population health in Europe, including the policy of “Health in All Policies;” (c) enumerate specific, feasible actions CDC might take to apply a social determinants approach to improving health in the United States, and the respective rationales and potential costs of such actions; and (d) describe how to communicate to various stakeholders the importance of CDC taking these actions in the very near future.

**Work Group #3 External Peer Review of the Chronic Disease Prevention and Health Promotion Program** - This Work Group would develop processes and procedures to review a

variety of materials that would result in an external peer review of NCCDPHP's overall activities. The end product for this work group was envisioned to be a response to a recommendation made to NCCDPHP by the Office of Management and Budget (OMB), which was to conduct an external peer review of the Center's overall activities. The OMB applied its Program Assessment Rating Tool (OMB-PART) to NCCDPHP's programs in 2007. One area that the Center had a less than completely successful score was in the area of conducting an external review of the Center as a whole and integrated unit. Since the time of the PART review all of the Divisions have conducted external peer reviews of their activities. The Work Group would include *ex officio* subject matter experts and act as an agent of the BSC to develop processes and procedures to conduct an external review of the overall activities of NCCDPHP. This external review would be similar to those conducted by the individual programs/divisions that have been conducted over the past three years.

## **Follow-up to January 14<sup>th</sup>-15<sup>th</sup> BSC Meeting:**

Drs. Lloyd Kolbe, Karen Steinberg, and Nancy Cheal worked with the CCHP Directors (Dr. Kathleen Toomey [CCHP], Dr. Edwin Trevathan [NCBDDD], and Dr. Janet Collins [NCCDPHP]) to include the National Centers most immediate needs from the areas that the BSC identified as first priorities. Recommendations of that process are enumerated below.

A number of issues had arisen since the January 2009 BSC meeting that have direct bearing on the formation and foci of the Work Groups. These issues include:

- A change in administration and leadership at CDC. The Acting CDC Director has charged an Organizational Issues Committee to examine changes made at CDC over the last six years. Changes requested in the Organizational Issues Committee's charge included expansion of scientific advisory committees and internal decisions and activities attributed to the Futures Initiative.
- A recognition that work to be carried out by both Work Groups 1 (Burden of Disease/Health Care Reform) and 2 (Social Determinants of Health) is cross-cutting and underpins much of what the programs in both National Centers are doing.
- A clearer understanding of the need for external peer review processes for each of the National Centers.
- The NCBDDD asked to work with the BSC and a Working Group dedicated to NCBDDD issues and activities, to develop processes and procedures for 1) strategic planning in 2009, and 2) external peer review of their center (beginning in 2011-2012) that would conform to FACA regulations and would satisfy the CDC requirement of a 3–5 year review of their activities (research and program).
- A need to align specific BSC expertise along programmatic/National Center lines.
- A related need to provide some BSC members with more in-depth knowledge of one specific National Center and its complex programs, priorities, and issues, rather than attempting to provide such detailed information about both Centers to all BSC members.

## **Recommendations:**

Taking these background and contextual factors into consideration, it appears that the most effective use of the BSC's time and talents would be to form two Work Groups that would address external peer review requirements for each center while incorporating the perspectives of social determinants of health and a population health perspective into their work. Each of the Work Groups would have a Chair from the BSC to lead the external peer- review activities, and a senior-level representative of the respective Center. Work Groups would include BSC members with appropriate subject matter expertise, as well as non-work group ex-officio members to round out areas of expertise.

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

**January 14-15, 2009  
Atlanta, Georgia**

### **Summary Report (minutes)**

The Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC) convened the first meeting of the Coordinating Center for Health Promotion's (CCHP's) Board of Scientific Counselors (BSC), hereinafter referred to as the CCHP BSC, at CDC's Century Center Facility in Atlanta, Georgia. In accordance with the provisions of public health law, this meeting was open to the public from 1:00 p.m. to 5:00 p.m. EST on the first day, and from 8:00 a.m. to 3:30 p.m. on the second day.

#### **Call to Order, Welcome, Introductions**

**Kathleen Toomey, MD, Director  
Coordinating Center for Health Promotion  
Centers for Disease Control and Prevention**

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

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

Dr. Toomey called the first CCHP BSC meeting to order, welcoming those present and thanking them for their time and attendance. She expressed her excitement about convening the CCHP BSC, and the commitment and expertise represented in the membership, acknowledging what a humbling and tremendous opportunity the BSC would be for those at CDC to learn and grow from the members' knowledge.

Dr. Kolbe added his welcome and gratitude to the CCHP BSC members for taking time not only for the two days of this particular meeting, but also for an extensive period of time into the future to work with CDC on some of the most complex problems facing the nation with respect to public health. In accordance with the Federal Advisory Committee Act and transparency of the process, he pointed out that detailed summaries of the BSC meetings would be published, stressing the importance of ensuring that all discussion got into the record and that a public comment period be offered.

Dr. Steinberg also welcomed and thanked the CCHP BSC members, expressing the center's gratitude for their attendance and generosity.

Those present then engaged in a round of introductions. The list of members may be found at the end of this document in the roster on page 10.

## Committee Roster

Collins O. Airhihenbuwa, Ph.D., M.P.H., Professor and Head, Department of Biobehavioral Health, College of Health and Human Development, The Pennsylvania State University

Dileep G. Bal, M.D., M.S., M.P.H., District Health Officer, Kauai (Hawaii) District Health Office

Terri Hagan Beaty, Ph.D., M.A., Deputy Chair, Department of Epidemiology, Johns Hopkins University Bloomberg School of Public Health

Christina Bethell, Ph.D., M.P.H., Director, The Child and Adolescent Health Measurement Initiative (CAHMI), General Division of Pediatrics, Oregon Health and Science University

Herbert J. Cohen, M.D., Professor Emeritus of Pediatrics and Rehabilitation Medicine, Emeritus Director of the Children's Evaluation and Rehabilitation Center (CERC), and the Rose F. Kennedy University Center for Excellence in Developmental Disabilities, Education, Research and Service (UCEDD), Albert Einstein College of Medicine (AECOM)

Michele Groark Curtis, M.D., M.P.H., Associate Professor, Department of Obstetrics, Lyndon B. Johnson Hospital Campus, University of Texas-Houston Health Science Center Medical School

Karen Maria Emmons, Ph.D., Professor, Department of Society, Human Development, and Health, Harvard School of Public Health; Associate Director, Initiative to Eliminate Cancer Disparities, Dana-Farber/Harvard Cancer Center

David Calvin Goff, Jr., M.D., Ph.D., Professor and Chair, Department of Epidemiology and Prevention, Wake Forest University School of Medicine

Sharon Lee Reilly Kardia, Ph.D., Associate Professor, Department of Epidemiology, School of Public Health, University of Michigan

Dushanka Vesselinovitch Kleinman, D.D.S., M.Sc.D., Associate Dean for Research and Academic Affairs, School of Public Health, University of Maryland

Lloyd J. Kolbe, Ph.D., Associate Dean for Global and Community Health and Professor of Applied Health Science, Indiana University (Committee Chair)

Caroline A. Macera, Ph.D., Professor of Epidemiology, Department of Epidemiology and Biostatistics, Graduate School of Public Health, San Diego State University

David Grayson Marrero, Ph.D., Professor, Department of Medicine, Indiana University School of Medicine

James H. Rimmer, Ph.D., Professor, Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago

Mark Lee Wolraich, M.D. Professor and CMRI/Shawn Walters Chair in Developmental and Behavioral Pediatrics, University of Oklahoma

## Summaries of Presentations and Discussions

### Overview: Federal Advisory Committee Act, Ethics, and Financial Disclosure

#### Federal Advisory Committee Act (FACA)

**Renée Ross**  
**Management Analysis and Services Office**  
**Centers for Disease Control and Prevention**

Ms. Ross indicated that the Management Analysis and Services Office (MASO) oversees all of CDC's 24 federal advisory committees. During this session, she reported on the Federal Advisory Committee Act (FACA), which provides the legal foundation for establishing and managing federal advisory committees, with respect to the following: congressional intent, oversight and management of advisory committees, establishing advisory committees, the role of advisory committees, advisory committee meetings, membership, subcommittees and workgroups, and advisory committee communication.

Congress found that advisory committees are a "useful and beneficial means of furnishing expert advice, ideas, and diverse opinions to the federal government." Congress intended for FACA to ensure that new advisory committees are established only when they are determined to be essential. Advisory committees are to provide advice that is relevant, objective, and open to the public. Standards and uniform procedures govern the establishment, operation, administration, and duration of advisory committees. Congress and the public have knowledge of the purpose, membership, activities, and cost. Advisory committees terminate when they have fulfilled the purposes for which they were established.

Each standing committee of the Senate and the House of Representatives reviews the activities of each advisory committee under its jurisdiction to determine whether a committee should be abolished or merged with any other committee, whether the responsibilities of the committee should be revised, and whether a committee performs a necessary function not already being performed. Through executive order delegated to the Administrator of the General Services Administration (GSA), all of the functions vested in the President by FACA, except the annual report to the Congress, are to be prepared by the Administrator for the President's consideration and transmittal to the Congress. GSA monitors and reports the executive branch compliance with FACA; provides written guidance and FACA training; and compiles the annual report for the President's consideration. Agency heads establish uniform administrative guidelines and management controls for advisory committees that are consistent with directives of the Administrator of GSA and designate an Advisory Committee Management Officer. The Committee Management Officer, in consultation with the agency's leadership, exercises control and supervision over the establishment, procedures, and accomplishments of the advisory committees established by the agency; and maintains and ensures the public accessibility to reports and records and other papers of the committees.

Federal Advisory Committees may be established by Congressional Order, Presidential Mandate, or at the discretion of an agency. Mandated committees are authorized by statute or by the President through an Executive Order. Discretionary Committees are established when an agency determines a need for advice and recommendations from a committee and receives authorization from GSA to establish the new committee. This committee is a discretionary committee. The purpose of the advisory committee is determined and outlined in a charter. An Executive Secretary or Designated Federal Officer (DFO) is selected. He or she is familiar with the matters under consideration by the committee. Some DFO responsibilities include approving the meeting agenda, ensuring notices of meetings are published in the *Federal Register*, and attending all committee meetings. The members are appointed by the President or agency head and a chair is designated.

The role of the federal advisory committee is to provide federal officials and the nation access to information and advice on a broad range of issues affecting federal policies and programs, and allows the public the opportunity to participate actively in the federal government decision making process. The membership of a federal advisory committee must be fairly balanced in terms of points of view represented and the functions to be performed by the committee to the fullest extent possible. The membership of a Federal Advisory Committee includes Special Government Employees (SGEs). SGEs are private citizens who are appointed based on their expertise, and they are subject to the "Standards of Ethical Conduct for Employees of the Executive Branch." A committee may or may not include ex-officio members. An ex-officio member is a federal official who represents an agency as a subject matter expert (SME). In addition, a committee may or may not include liaison representatives. Liaison representatives represent special interest groups, organizations, or affected populations. This BSC does not have any ex-officio or liaison representation at this time.

FACA outlines the requirements for holding advisory committee meetings. A *Federal Register* announces the meeting at least 15 days in advance and it includes the purpose of the meeting, summary of the agenda, time, location, and contact information. The DFO or Executive Secretary must approve the agenda and be present at the meeting. Any member of the public must be given the opportunity to speak or file a written statement. Detailed minutes must be kept and made available to the public 90 days after the meeting is over. Any official records generated by or for the committee must be retained for the life of the committee. When the committee terminates, the records must be processed in accordance with the Federal Records Act.

From time-to-time committees need to perform special tasks and they form subgroups to do this. The subgroups are known as subcommittees or workgroups. A subcommittee consists of at least one member of the parent committee, reports directly to the parent committee, and is not subject to the provisions of FACA. However, CDC policy requires compliance with FACA. The subcommittee recommendations must be deliberated upon by the parent committee. Subcommittee recommendations are usually established for long-term projects or on-going work. There is a legal, formal process by which to establish a subcommittee. In addition to having at least one member of the parent committee, the remainder of the subcommittee can be made up of ad hoc members. Ad hoc members will be deemed as GEs, meaning they will file the personnel papers and an annual OGE 450. A workgroup consists of at least two members of the parent committee or subcommittee, reports to the subcommittee or parent committee, and is not subject to the procedural requirements of FACA. The workgroup cannot bring forth advice or recommendations. They are usually convened to gather and analyze information as well as conduct research and analyze issues and facts. FACA committees have been used to provide significant recommendations to the President, federal government agencies, and the nation on a

variety of issues. One example would be the Commission on the Intelligence Capabilities of the United States Regarding Weapons of Mass Destruction. This commission was formed in response to the events of September 11, 2001. An example of a CDC committee is the Advisory Board on Radiation and Worker Health. This is CDC's only Presidential advisory committee. This board provides advice on the development of guidelines, scientific validity, and quality of dose reconstruction efforts and possible radiation exposure of employees at Department of Energy (DoE) facilities. It is a very busy committee.

With respect to the flow of federal advisory committee communications, once the full committee has deliberated and voted on the recommendations, these become the product of the committee and can be sent forward through the agency to the Director of CDC and the Secretary of Health and Human Services (HHS). Communication from the committee flows through the agency to the department, to GSA, to the President, and to Congress as follows:



In conclusion, the Act formalizes a process for establishing operating, overseeing, and terminating advisory committees. FACA ensures that advice rendered to the Executive Branch by advisory committees is both objective and accessible to the public.

### **Discussion Points**

- Dr. Bethell inquired as to what the impetus was for the establishment of the CCHP BSC.
- Dr. Toomey responded that Dr. Gerberding, CDC's Director, made the recommendation that all Coordinating Centers have BSCs. These are on-going committees that were not convened due to any special issues. Instead, BSCs will examine how various groups within CDC do their jobs and will offer advice based upon the findings. While agency wide FACA-chartered committees advise Dr. Gerberding, the CCHP BSC represents the two centers which fall within CCHP's purview: National Center on Birth Defects and Developmental Disabilities (NCBDDD) and National Center for Chronic Disease Prevention and Health Promotion (NCCDPHD).

- Dr. Kolbe noted that approximately four to five months earlier, Dr. Gerberding convened a two-day meeting of the chairpersons of all of CDC's FACA-chartered committees in order to help them better understand the BSC process across CDC, particularly with respect to the potential for there to be interaction among committees, and to understand the BSCs as an on-going mechanism by which to ensure excellence in input from outside experts in various fields.
- Having been on an advisory group previously, Dr. Cohen wondered what the format would be for making recommendations.
- Dr. Kolbe responded that his sense was that it was incumbent upon each group to develop the processes by which each wishes to function. He stressed that as a group, they must recognize the sobriety of the task upon which they were embarking. At the same time, they could function relatively informally until the points at which they may need to make formal recommendations using a voting procedure in order to achieve unanimity or to understand where variations might be on any given issue.

### **Ethics and Financial Disclosure**

#### **Cathy Ramadei**

#### **Management Analysis and Services Office Centers for Disease Control and Prevention**

Ms. Ramadei noted that the last year had been rather unusual in the history of CDC because five new BSCs were established, which was quite an achievement as establishing advisory committees is done on an extremely limited basis in the federal government. During this session, she reported on the reasons for financial disclosure and the conflict of interest laws that apply to BSC members as SGEs.

With respect to why financial disclosure is required, Ms. Ramadei explained that the Ethics Reform Act (1989) and regulations implemented by the OGE require that each SGE file a financial disclosure report upon appointment and annually thereafter. A financial disclosure report is a mechanism that enables CDC to ensure that the advice and recommendations of advisory committees are free of conflicts of interest. When members file their financial disclosure report (OGE 450), it is reviewed first by the Federal Advisory Committee Management Team, second by the DFO of the committee, and by the Designated Agency Ethics Official, who approves the report. When necessary, attorneys are consulted in the HHS General Counsel's Ethics Division. The financial disclosure protects the member and the agency, and ensures that the BSC's work will be performed without conflicts of interest or the appearance of conflicts, and enables the agency to determine appropriate action to take if a conflict does arise.

To some extent, it is expected that conflicts of interest will arise, because members of advisory committees are active experts in subject areas that are considered by the committees. When conflicts do arise, the law provides several mechanisms as remedies. The most common actions taken are to require that BSC member to publicly disclose any conflicts, and recuse themselves from participation in matters that affect his / her interests. A Conflict of Interest Waiver may be drafted that specifies the requirements for a member's recusal from participation on conflicting matters. For example, a BSC member with grants through the CCHP would probably have a conflict of interest waiver already in place by the time of the initial BSC

meeting. That does not mean that the member would not be able to participate, it would simply mean the member must exercise caution about how his / her participation.

18 U.S.C. 208 is the primary conflict of interest statute that affects advisory committee members. A conflict of interest exists when the recommendations or guidance of an advisory committee would specifically affect a particular interest. Most CDC advisory committees deliberate and recommend on “general matters” of broad applicability, which reduces the likelihood of conflicts of interest. If one of a member’s interests does become a matter under discussion by the BSC, the DFO should be consulted to determine what action should be taken. Generally, financial disclosure reports should cover all interests over the 12-month reporting period, and if it is determined that a conflict exists, the member will be informed and instructed as to what action to take. With respect to the example of a member applying for a new grant or extension / renewal of a grant from the CCHP, if the CCHP BSC engaged in a secondary review of grant applications, this member could not participate in the secondary review because the BSC’s recommendations would directly affect that member.

A few other statutes apply to participation as an SGE include the “Bribery Statute,” which prohibits SGEs from seeking or accepting anything of value in return for being influenced in relation to performance of official duty. Sections 203 and 205 prohibit SGEs from receiving compensation for representing someone or something before the agency in any particular matter involving specific parties where the SGE has acted in an official capacity, or where the United States is a party or has a direct interest. Section 207 imposes a lifetime ban on former SGEs representing another person or entity to the government in any matter involving a specific party if the former SGE participated personally and substantially while serving in the government. With respect to foreign activities, the Emoluments Clause of the U.S. Constitution prohibits any federal employee from receiving any “present, emolument, office, or title from a foreign state without the consent of Congress.” An SGE also may not act as an agent or lobbyist on behalf of a foreign entity under the Foreign Agents Registration Act. This goes back to Benjamin Franklin, who served as an Ambassador when the nation was very young. It was alarming to others in the US Government because they perceived this as a possible opportunity for a foreign government to take over the US by influencing US Government officials. This remains in the Constitution currently.

To exemplify ethics and financial disclosure issues, Ms. Ramadei showed a video from the Office of Government Ethics (OGE) titled, “The Ethical Choice.”

### **Discussion Points**

- Regarding questions pertaining to recusing oneself from the discussion during secondary reviews, Ms. Ramadei responded that issues are addressed on a case-by-case basis. Anytime that it is not clear whether someone should be recused, they should first contact Dr. Steinberg to further discuss the issue (e.g., a member’s university has a grant with CCHP, but the individual board member is in no way involved in the grant and receives no financial benefit from it). When there are unclear areas, discussions can go forth to the Office of General Council (OGC) as necessary. CDC makes every effort to allow SGEs to participate to the fullest extent possible. Limiting participation is not the goal. Efforts simply must be taken to protect the members, BSC as a whole, and the agency.
- Dr. Kolbe requested that members take time during the evening to consider any potential ethical or financial conflicts of interest they may have so that these could be disclosed during the proper time the next day. He suggested erring on the side of liberally defining a

conflict of interest and then working with Dr. Steinberg to ensure that potential issues are handled appropriately.

- Dr. Bal requested that the minutes reflect that in his 38 years in government, he had survived by not accepting money from anyone, least of all the federal government. Any honorarium he receives, he gives to a charity of his choice.

## Population Health and Prevention Opportunities: 2009 and Beyond

### **Dr. Kathleen Toomey, MD, Director Coordinating Center for Health Promotion Centers for Disease Control and Prevention**

Dr. Toomey said she thought that, as the only former State Health Officer on CDC's staff of 15,000 contractors and employees, she had an opportunity to take a 30,000 foot view. Referring to those present to CDC's organizational chart, she noted that CCHP is one of six coordinating centers that were created in the reorganization of CDC through the Futures Initiative that was implemented during that past several years. The coordinating centers were designed in part to reduce the number of direct reports to CDC's director, and to better coordinate functions and activities across the entire agency, internally and externally with partners. Recently, Dr. Gerberding requested that the structure and function within the agency for addressing the mental health of U.S. population be reviewed as there was not a home for addressing population mental health within CDC. However, it is very clear that the mental and physical health cannot be separated. Many articulate spokespeople in public health, such as David Satcher, have made the argument that mental health and public health issues are clearly and inextricably linked.

Charged with reviewing mental and physical health, CDC convened an ad hoc committee, which made recommendations about what the agency's structure and function should be. One of the recommendations was that there should be a single point of contact for mental health within the agency. Because of the work done in CCHP within its two centers, Dr. Gerberding decided that this position should be housed within CCHP and should work across the entire agency. To date, this work has been very productive. CCHP has begun a new and interactive relationship with the Substance Abuse and Mental Health Services Administration (SAMHSA), with a SAMHSA staff person on detail to CCHP. Without a single exchange of additional dollars, CDC has enhanced the agency's ability to work in the mental health arena. Dr. Toomey said she saw that as an example of her unique role as the CCHP director and as distinct from the roles of the two center directors.

CCHP has two centers: The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) and The National Center on Birth Defects and Developmental Disabilities (NCBDDD). Dr. Toomey views her job as working not only within those two centers, but also across the agency with partners to further the work that CDC does. This is a time of tremendous transition at the agency. At the time this BSC meeting was being scheduled, no one could have predicted the results of the election or the results of an organizational change at CDC. This is a significant issue, given that it means there will be some changes in direction. There is danger and opportunity at the same time. There is an opportunity to put the "P" back in CDC. This agency is named the Centers for Disease Control and Prevention, yet its acronym is CDC. The "P" is silent, and minimal within the work of CDC in proportion to its potential to

reduce morbidity, mortality and economic costs. The change of administration is an opportunity for a new look at prevention in order to further that work. During his hearing, Secretary Designate Daschle said, "We want to make prevention hot and wellness cool." Dr. Toomey never thought she would live to see the day that this country had a Secretary Designee talking in those terms. In 1991, she worked for Senator John Chaffee at a time when he was trying to craft healthcare reform legislation. It was an uphill battle that preceded all of the work that Hillary Clinton did. Dr. Toomey was concerned at the time that none of those discussions in 1991 included prevention. It was all about disease care financing and public health was nowhere to be found. It has been energizing for Dr. Toomey to hear the word "prevention" articulated by the highest levels of government lately. She stressed that there was a unique role that public health and the CCHP BSC could play in this time of transition. This is a new world order as they begin to consider the opportunities.

One of the greatest challenges is that much of the agency's funding is categorical and disease-specific. One opportunity is to move beyond the categorical and individual level programs into population, community level interventions to address the broad social, economic, cultural, and environmental conditions and policies that may affect health. That is a different mindset. CDC must bring its partners along to show them that there is some collective good for all, even as they work together on individual efforts (e.g., cancer, heart disease, disability, et cetera). That represents a change in direction from the way CDC has operated for many years. One inspiration for Dr. Toomey has been "Social Determinants of Health" edited by Michael Marmot and Richard G. Wilkinson [Oxford University Press, USA; 2 was the second edition (November 24, 2006); English; ISBN-10: 0198565895; ISBN-13: 978-0198565895]. This publication represents three years of work of the Commission on Social Determinants of Health chaired by Michael Marmot, principal investigator of the Whitehall studies of British civil servants.

Dr. Toomey and Dr. David McQueen attended the rollout of the social determinants recommendations in the United Kingdom (UK). Striking to Dr. Toomey about that meeting was the recognition that progress cannot be made in health until root causes are addressed. That requires the willingness to broadly examine economics, health, and policies on early childhood education within the context of health. Primary care and access to care were also raised as important issues; however, it is difficult to interest medical students and residents in the primary care field in the US. This must be taken into consideration with respect to change in the health care system. Also striking to Dr. Toomey about this roll out meeting was that those at the highest level of government in the UK were present, including Prime Minister Gordon Brown. This gave her hope that in the new administration in the US, social determinants might gain more prominence as part of a comprehensive examination of population-based public health. Also exciting to her during that meeting was how much interest and energy she observed about the results of the US election. She said she shared this information with the CCHP BSC because she thought it was an interesting framework within which to consider their potential work during the shift from an individual level to population-based approach to health. Clearly, outside of government, many groups are considering broader, population-based approaches to health and prevention. The Trust for America's Health has examined social determinants and promoting prevention in a proactive manner. The Robert Wood Johnson Commission to Build a Healthier America is examining the influences beyond the medical care system that can affect health. Clearly, the US has begun the dialogue and CDC is a little late to the table.

One of Dr. Toomey's challenges, which she placed on the table for the CCHP BSC as well, regarded how CDC could or should position themselves during this time of great change within the nation and within the health care system. Should the agency position itself to address population health and prevention more broadly (e.g., upstream prevention)? The challenge is

more than programmatic. It also pertains to research with respect to the limited strength of some of the clinical preventive intervention research base upon which they can draw to make recommendations, as well as the translation of existing research into practice. Often it is known that something works, but what is not known is how to translate the research and take it to scale in order to have an impact beyond the small population in which it was originally tested. These efforts will take some leadership, and thought must be given to the best way to position CDC to take a leadership role.

There is a certain paradox at work as well. With the economic stimulus package being negotiated, there has been word that CDC may receive as much as \$4 to \$6 billion, a good proportion of which would be for prevention efforts. Should that come to pass, along with the funding allocation will be increased accountability and expectations for CDC to demonstrate that its programs are effective and have outcomes that are measurable. That is not always easy, given that sometimes outcomes are not clearly linked to the problems. There will be increased scrutiny of existing programs, so the agency will be even under even greater pressure to demonstrate that current programs and activities are effective—all the more reason for CCHP to welcome the BSC's review and input.

This needs to be framed in a way that resonates with the public and policymakers. There is not significant advocacy for prevention. The average American does not think about prevention as something they want. It is not something that can be visualized. Dr. Toomey was concerned when she read that with respect to the stimulus package one Congressman said, "We don't need more bicycle paths. We just need wider roads." She thought that unfortunately reflected the thinking of many policymakers at the state and federal levels. This is the time for CDC to provide education to demonstrate what some of that impact will be, but CDC needs to do a better job of framing the agency's work with partners. This is a time for CDC to reach out much more proactively and engagingly with new partners as well as partners with whom the agency has had relationships over time, particularly partners in clinical medicine. Too often the debate has been framed as a dichotomy between clinical medicine and public health, which results in a competition for resources and the hearts and minds of the public. In fact, the idea is to create a health system in which there is a continuum with clinical medicine and public health clearly partners aligned together. That will require a change of mindset at many levels within and outside of government and within CDC's partner community. In the absence of clear data, Dr. Toomey requested that the CCHP BSC offer their candid input about what CDC's role should be, how this should be approached, and how they should move forward within this new opportunity. She urged the members to engage in bold discussions, acknowledging that in the past, the agency has been somewhat adverse to risk-taking. If ever there was an opportunity for risk-taking, she thought it was now because the stars had aligned in a way that she had never witnessed in her 30 years in public health to make prevention the priority it should be for this nation. In closing, Dr. Toomey offered appreciation to the members for their time and dedication.

### **Discussion Points**

- Dr. Bethell reminded everyone of the 1991 health care reform and Community Care Network, which tried to blend public health and medical care through capitated financing and requiring health assessments of not-for-profit health systems, noting that would be interesting to determine whether there was anything to resurrect. She thought it would help her to have a better understanding of CDC's role in setting policy.

- Dr. Toomey said she thought that CDC's role would potentially change, and one of the benefits of a new administration is that they were not bound to limitations of the past. The Trust for America's Health Report championed health in all policies. That is getting some traction in every agency. CDC, NIH, transportation, agriculture, et cetera all have roles to play in health. Getting a movement going without exchange of dollars would be extremely beneficial. CDC should be better leveraging its brand, which carries tremendous clout. For example, she should be at the Department of Agriculture talking about WIC as a health program. CDC cannot necessarily come to the table saying, "We are in charge because we are here." CDC also may have agenda-setting and support roles to play.
- Dr. Curtis noted that in the US, the term "health care system" often is perceived as simply having to do with the medical care system. There is no general concept and acceptance that medical care is a component but not the primary determinants of health and health care systems. Based on that philosophy, the Centers for Disease Control is thought of as "disease control" and has categorical disease funding. While the CDC brand has a lot of clout, it seems to be for the very specific approach of managing specific diseases. There is a need for a cultural and paradigm shift with regard to how America as a whole perceives health, the definition of health, what constitutes and creates health, and how health care systems are put together that goes beyond who pays for the delivery of services such as open heart surgery. She has always felt disappointment that CDC has not been able to get past that, though recognized that it is difficult. A decade ago, her institution attempted to integrate medical schools and public health schools, which met with monumental resistance that could not be overcome. Someone has to take the lead role to ensure that America redefines what is meant by health, health care, and health care systems. CDC should become a well-respected and trusted mediator in leading a cultural perception shift in America. Money is a very powerful tool, so perhaps more grants should include language that requires equal partnerships between medical care and public health.
- Dr. Cohen noted that in 1989 he was Vice Chairman of the President's Committee on Mental Retardation, they developed a report and presented at the White House to President and Mrs. Carter on prevention of mental retardation and developmental disabilities. That report was buried after the change in administration in the 1980s. A problem in prevention is that people became very fearful of primary prevention and were not focusing enough on secondary prevention because of the abortion debate. Prevention began to look a like an issue that certain parties would not touch. CDC convened a conference on prevention around that time, although the focus was largely on secondary rather than primary prevention. CDC also launched a major folic acid initiative during that time, which has considerable positive outcomes. The world has changed politically and in medical advances, particularly in biomedicine. It was not clear to him how much CDC could take on, but their natural ally seemed to be NIH. Increases in biomedical and epidemiological research seemed to be critical in order to support productive prevention activities. There seems to be a wonderful opportunity for prevention to be a key element for CDC. It seems that now the abortion issue might be set aside in order to focus on other types of interventions. Even some of the anti-abortion opponents will now accept stem cell research.
- Dr. Steinberg responded that over the years, NIH has been engaged in more clinical and basic research and CDC has been conducting more applied / translational research in public health. The lines are becoming more blurred. NIH is conducting more research in the area of public health, which reflects a paradigm shift there as well. As the lines blur, it will create

issues to be resolved in terms of limited funding. NIH is currently far better funded than CDC.

- Dr. Kleinman called attention to *The Lancet* series of articles published on the 30<sup>th</sup> anniversary of the Alma-Ata Declaration [September 12, 2008], which examines what Alma-Ata stood for in 1978, where the nation is with respect to putting “health” into “public health,” and what future priorities are for accessible and equitable health care worldwide. CDC’s branding does allow for a visibility and a voice for prevention and health promotion, particularly within the CCHP due to its charge and focus. She wondered whether other centers were thinking similarly about the new opportunities. Perhaps a major conference should be convened to bring together leaders from various agencies, non-profit organizations, and industry to explore the area of social determinants to better understand barriers, identify opportunities, and challenge everyone to work together in areas relevant to health, including mental health. There should be a health link to CDC in every one of the cabinet heads and in the offices in the White House. This is the time to bring those points of contact together.
- Dr. Toomey liked the suggestion of convening such a conference. She thought that everyone should be thinking positively about the Economic Stimulus Package. It has particularly resonated with CCHP and its two centers because of the work they do in the community and because “prevention” is included in their names in a way that it is not in other centers. There is a unique opportunity in CCHP that infectious disease does not have. Another clear linkage that CCHP recognizes is that they must partner with environmental health. Social determinants cannot be addressed without examining the environment in which people live. Increasingly, CCHP is developing programs and thinking through how to move that agenda forward, and CCHP’s environmental health colleagues must be at the table with them. Physical activity and the built environment are both highly important, and may represent both structural and philosophical changes in approaches.
- Dr. Rimmer pointed out that a tremendous amount of good research has been funded by CDC and NIH over the years, but translation into the community (the unit of analysis) is often lacking. He is amazed when he travels the country and mentions a program that was funded years ago that most people are not aware of it. “Living Well with a Disability” is considered to be an evidence-based health promotion program, yet primary care providers do not have a clue that it exists. Kate Lorig’s program, “Living Well with Your Arthritis,” has been highly successful in developing and certifying a cadre of people who take the program into communities. Chronic conditions continue to increase, yet the country keeps pouring money into each issue (e.g., obesity, diabetes, arthritis, et cetera). This is a good time to determine a more economical way of doing business. Technology is an excellent focus with the interconnection of internet, television, telephone, et cetera. There are many good technology-based health promotion prevention programs that could be broadcast on television, and health systems could be better connected with smart technologies so that doctors do not have to think too hard or spend a lot of time dealing with health promotion. Perhaps CDC’s National Center for Health Marketing (NCHM) could play a role in such an effort. Even the coordinating centers within CDC need to work together.
- Dr. Toomey noted that if the rumored funds are allocated, there could be a sea change in the way CDC does business. American Association of Retired Persons (AARP) CEO Bill Novelli has said the two things which will have the greatest impact on health in this country are social marketing and policy change. Dr. Toomey has thought about that many times as they frame the work of the CCHP and at CDC in general.

- It also struck Dr. Rimmer that health must be at the front of every system's change. As he watched Secretary Designate Arne Duncan's testimony on C-SPAN, he thought about what an opportunity this is given his extensive work with under-served communities. One of Duncan's agenda items is to start at a very early age with a basic foundation of health in order to think, read, write, and do well. There are programs, but they are scattered, minimal, and are basically "under-dosing." Scarce resources were certainly an issue. He remembered Dr. Gerberding once saying that she thought they were able to accomplish as much as they did with the SARs vaccine because they went "full steam ahead" dealing with that issue, putting tremendous amounts of resources into the effort. The same result could be achieved in obesity, diabetes, et cetera with that type of effort.
- Dr. Wolraich added that there is a body of research related to health services, which examines how to effectively change provider and / or patient behavior. One problem is that health services issues are scattered throughout numerous agencies and are not always considered as carefully as they should be. The same issues arise when trying to implement something on a broader public health basis.
- Dr. Airhihenbuwa said that social determinates of health interest him greatly. He has recently been reading the book titled, "The Bottom Billion: Why the Poorest Countries are Failing and What Can Be Done About It" by Paul Collier. [Oxford University Press; 1<sup>st</sup> edition (April 27, 2007); ISBN-10: 0195311450; ISBN-13: 978-0195311457]. Measures and social determinants must be addressed at the same time. If someone considers themselves to be a leader, but looks behind to see no one following them, what "leadership" means must be redefined. It will be interesting in 10 years to see whether CDC took the leadership role in social determinates. What would it mean if the plight of the bottom one-sixth of the US population became an obsession, a vision, for CDC? How would that be defined? Is it one-sixth in terms of health? Is it one-sixth in terms of the condition of living? To Dr. Airhihenbuwa all of the conversation regarding disparity, inequity, and social determinates fall into the area of how to bridge the gaps that are evident. He thought that CDC must move beyond a disease-specific focus and to a bigger picture focus to drive the agency over the next decade. A number of researchers in this country are already addressing social determinants, but CDC must consider how to position itself globally to take action.
- Dr. Goff shared the enthusiasm of the others who had spoken of the opportunities that face CDC and the CCHP BSC. He was particularly struck with Dr. Airhihenbuwa's comments, and referred to the report titled, "Eight Americas: Investigating Mortality Disparities across Races, Counties, and Race-Counties in the United States" [Murray CJL, Kulkarni SC, Michaud C, Tomijima N, Bulzacchelli MT, et al. (2006) Eight Americas: Investigating Mortality Disparities across Races, Counties, and Race-Counties in the United States. PLoS Med 3(9): e260 doi:10.1371/journal.pmed.0030260]. Policies must be evaluated from the point-of-view of their health impact. There has been a call for that for a long time; however, this country does not seem to do a very good job of addressing this. Environmental impact analyses are often conducted with respect to policies, but these do not tend to take into account health impacts on human or other populations. This represents a major gap. Within CDC, he has been impressed over the past several years with a number of efforts. For example, he was involved in a recent effort to develop a "Public Health Action Plan to Prevent Heart Disease and Stroke." That document and the process of developing it live on to this day through partnerships and groups that are focusing on implementing action steps from that plan. This is an instructive example of how chronic diseases in general can be approached. With respect to the issue of the failure of primary care in the US, he heard a

recent discussion regarding the technology evolution as a means by which to take health care to a different level and with increased specialization and attention to the high end, complex user. It is difficult to make a land-line telephone call these days, but one can do a lot of other things with a cell phone. The same is occurring in medicine, but it is difficult to encourage physicians to engage in primary care when everything they see around them is highly technical science and medicine. There may be a disruptive technological event that occurs in health care just as has occurred in other industries. Perhaps the mid-level provider will provide primary care in the decades to come rather than the physician. Consideration must be given to the potential for technological evolution that may be disruptive. A different workforce may be necessary.

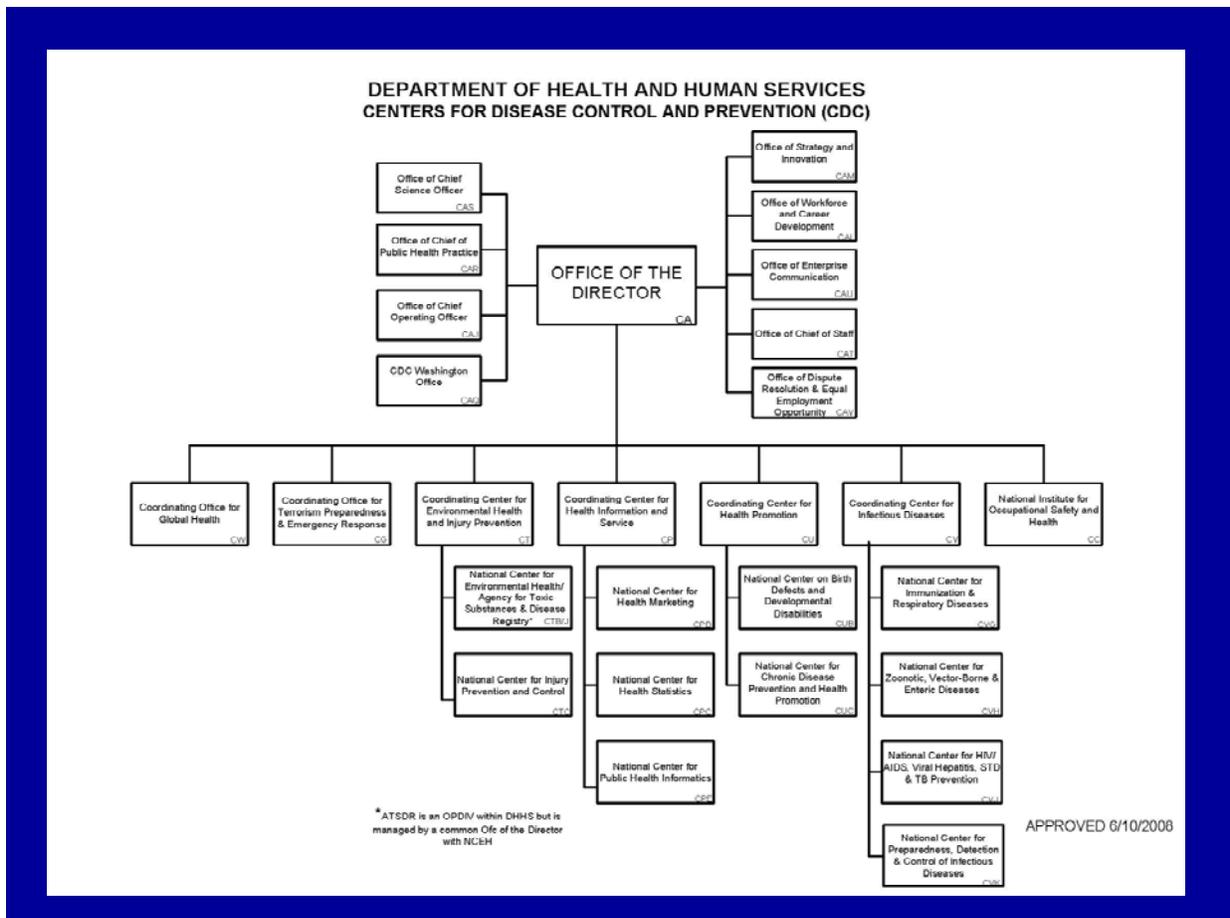
- Dr. Cohen added that primary care also involves a very serious economic issue in terms of who is going into the primary care field and how much emphasis it is being given. In addition, with all of the ideas generated just at this table, he thought it would be prudent of CDC to take the initiative to convene a prevention conference in the next year or two to help set future directions for the agency based on some of the input that they may receive.
- Dr. Toomey responded that a chronic disease conference is already planned, and stressed that this agenda must be moved forward much more aggressively.
- Dr. Kolbe noted that for the past two years Dr. Gerberding has convened a conference of 100 health leaders in the nation in order to address various topics. This CCHP BSC discussion had begun at the 37,000 foot level to take a broad look at these issues, which he thought was a good starting place. There is a dilemma in a democracy when the population misperceives and does not understand even what primary, secondary, and tertiary prevention mean. Historically, the system is funded to be disease-specific. In 1986 at a World Health Organization (WHO) conference in Ottawa, it was suggested by Ilona Kickbursh that redistribution of wealth would be one of the best things to do to improve health. Those at CDC did not know how to engage in this or even talk about it, given that redistribution of wealth is not within the agency's purview. If the UK can address health in a systematic way in all of their policies, the US should be able to do this as well. CDC is the agency to at least lend a shoulder to that effort, which the CCHP BSC should keep in mind as they begin to move into the committee's more specific charges.
- Dr. Bal agreed that poverty / distribution of wealth is a major confounding factor that indeed represents a dilemma and a tragedy in a democracy. To focus on income and social justice as part of chronic disease control is a serious recommendation. He agreed with Dr. Toomey that CDC should be bold. While he loves CDC and has been working with them for 38 years, there has been some shift in direction. The issue of science and the insecurities in science, especially in chronic disease, has sometimes made people insecure. It is not as clean as with communicable disease. To him, CDC is number two to NIH and as a result has used a lot of energy to try harder, but does not have to because CDC has a greater calling with respect to the translation of science to public policy. CDC should not focus on what NIH is doing in a different context. The translation of science into public policy is a messy business. If the randomized clinical trial (RTC) is used as a litmus test to make decisions on chronic disease, everyone engaged in such efforts will have white hair and be six feet under. It is time to walk-the-walk. Many individuals within the agency come from infectious disease backgrounds, including Dr. Gerberding. People put money into what they understand. The tragedy for Drs. Toomey and Collins is that they preside over centers that address the diseases that are the five leading killers and three of the next five; however, there is an incremental budgeting system that results in being under-funded in relationship

to what must be done to make changes in these areas. Funding is incongruous with the magnitude of various problems, and the leadership must be pushed to align these better. For the last eight years, CDC has not been bold and this must change. Social justice is not going to come easy. While there is a ray of hope in the new President, he has a bimodal distribution of advisors. He must appease the Washington suits as well as those who got him elected whose core value is social justice. A sea change is coming and there is a moral imperative for CDC take this opportunity to position the issue within and outside the agency. They should be ashamed if they do not do so.

**Overview: CCHP's Budget**

**Ruth Martin, MS**  
**Chief Management Officer**  
**Coordinating Office for Health Promotion**

Ms. Martin reported on CCHP's budget and programmatic role, pointing out that change usually means resources of some type and resources usually means money. She referred participants to the CCHP organizational chart:



Ms. Martin said she typically refers to the top section as the corporate functions (e.g., Office of the Director, Office of the Chief Science Officer, Office of the Chief of Public Health Practice, CDC Washington Office, Office of Strategy and Innovation, Office of Workforce and Career Development, Office of Enterprise Communications, Chief of Staff, and Office of Dispute Resolution & Equal Employment Opportunity). The coordinating center level was created as a result of Dr. Gerberding's Futures Initiative reorganization process of several years ago. The Coordinating Office for Global Health and the Coordinating Office for Terrorism Preparedness and Emergency Response are hybrids in that they do not have a lot of institutional, workforce, and programmatic capacity themselves. They serve as coordinating / funding offices for CDC's work in global public health issues and preparedness. The others include: Coordinating Center for Environmental Health and Injury Prevention; Coordinating Center for Health Information and Service; Coordinating Center for Health Promotion; and Coordinating Center for Infectious Diseases and then the centers within each of those. She stressed the importance of the organizational chart with respect to understanding the budget. In addition to specific programs, disease-specific or public health issue-specific programmatic funding lines, CDC has several other funding allocations that fund other parts of the agency. For example, there is a budget line called "Leadership and Management" that funds most of the corporate or enterprise-wide sections of the organizational chart. Generally speaking, all of the programmatic activities are funded through the national centers, primarily at the division level.

In terms of the history of the agency's entire appropriations, CDC's non-Vaccines For Children (VFC) funding has remained stagnant since FY 2004 at approximately \$6 billion. That \$6 billion is largely tied to disease-specific or program-specific funding for various programs in health promotion, chronic disease, environmental health, and infectious diseases. CDC's budget, including the President's Emergency Plan for AIDS Relief (PEPFAR) and other reimbursables, totaled approximately \$11.2 billion in FY 2008. Reimbursables such as PEPFAR, and mandatory spending such as VFC, account for approximately 41% of CDC's total budget. VFC funds are basically non-discretionary pass throughs to the states. PEPFAR funding comes through the State Department, so it does not show up as an HHS appropriation. The ratio of non-discretionary to discretionary funding, or those funds more directly under CDC's control, is quite high. Ms. Martin emphasized that CDC's budget is complex and constrained. The agency has surprisingly and troublingly little flexibility to realign investments between categorical disease areas, for emerging public health issues, for new strategic initiatives, for balancing between priorities or filling gaps, or to address preparedness and response. Moreover, very little funding is specifically directed to global health issues and emergency preparedness. Overlaid upon that has been the significant erosion of buying power.

The total budget for CCHP is \$1,081 billion of which \$20 million (2%) is allocated to leadership and management; \$127 million (12%) is allocated to NCBDDD programs, and \$934 million (87%) is allocated to NCCDPHP programs. The program funding is the summation of all of the categorical and disease-specific lines and is managed primarily at the division or below levels.

NCCDPHP's funds are allocated as follows: salaries / benefits (12%), contracts (13%), grants and cooperative agreements (74%), and other (1%). NCBDDD's funds are allocated to: salaries / benefits (15%), contracts (12%), grants and cooperative agreements (63%), and other (10%). The largest portion of funding leaves the agency to go to various types of grantees and partners (e.g., state and local health departments, non-governmental organizations, et cetera). Roughly speaking for both centers, about 20% of the program funding is allocated to the CDC infrastructure and capabilities in Atlanta.

The complexity of CDC's budget is daunting. The detailed budget table contains over 200 lines, which include several cross-cutting activities such as Leadership & Management, Business Services, Centralized Mandatory Services, and Buildings and Facilities; 6 coordinating centers, 12 national centers, approximately 60 functional areas, and over 100 programs. The Leadership and Management line is a fixed number that is allocated across the agency. The Business Services costs are also taken off the top and are a fixed number, which is problematic because as programs grow or change in character, there is no authority or depth of pocket to fund significant changes in business services to accommodate needs. NCBDDD is a prime example of the complexity and the constraints, given that it has 26 budget lines. Funding has not grown significantly in the total except for hemophilia. The most flexible areas are the birth defects, infant health, and disability and health lines. For the rest of lines there is very little flexibility in how those funds are used other than for each specific disease (e.g., Autism, Folic Acid, Special Olympics, Diamond Blackfan Anemia, ADHD, Muscular Dystrophy, Limb Loss, Hemachromatosis, Fetal Alcohol Syndrome, Spina Bifida, Tourette Syndrome, Fragile X, Reeve Paralysis Resource Center, Thalassemia, et cetera). This makes it extremely difficult for leadership in the center to make priority decisions, new investment decisions, or respond to emerging needs.

The NCCDPHP's situation is no more straightforward than the NCBDDD. NCCDPHP has 51 budget lines in 2009. In some cases, NCCDPHP does have fairly good flexibility. For example, the Heart Disease and Stroke line is approximately \$47 million and the division has fairly good latitude in how to invest those funds in terms of surveillance, epidemiology, outreach awareness campaigns, community programs, et cetera. However, there are also a number of very specific budget lines that are much more tightly constrained. Block Grants to states have declined every year. Cancer is approximately \$300 million, of which the largest component is Breast and Cervical at roughly \$180 million. Obesity funds have also been declining. Diabetes is at approximately \$60 million, while Tobacco is at about \$100 million. Ms. Martin referred members to the three-page Detailed Budget Table she distributed, which drives home the points of how complex and varied these programs are. Reviewing the list, there is clearly wide variation in the amounts of money received and the specificity of the types of programs implemented. It is extremely complex to manage this budget from various perspectives (e.g., project management, partner management, coordination, and integration). Many of these are Congressional earmarks. For example, the Chronic Center has an item called "The Mind / Body Institute," which apparently goes to a very senior professor at a very important university with very influential friends in Congress. It is extremely difficult to modify or alter that particular line. Every year the center tries to modify these, but sometimes the difficulty is not worth the effort.

Another initiative that Dr. Gerberding launched several years ago was to challenge the agency to think about four types of health protection goal areas, which are fully described at <http://www.cdc.gov/osi/goals/goals.html>, within which NCBDDD and NCCDPHP investments align as follows:

<b>HEALTH PROTECTION GOAL AREAS</b>	<b>NCBDDD</b>	<b>NCCDPHP</b>
Life Stages	76%	89%
Emerging Health Threats	9%	1%
Healthy Places	13%	9%
Healthy World	2%	1%

Regarding the erosion of buying power, there have been very few general programmatic increases. Programmatic increases have typically been only in narrowly targeted areas. Program funding is not adjusted to compensate for inflation. Federal salaries increase an average of 3% per year as mandated by the federal process, although this is not addressed in appropriations. Annual Congressional rescissions have totaled approximately 4% over the last 5 years. These typically occur mid-year to account for various emergencies. If there had been a scale up from 2001 until now, NCCDPHP should be receiving a quarter of a billion dollars more per year just to produce the same programs and presumably the same outcomes. There is a \$266.5 million difference in NCCDPHP's actual buying power versus the inflation adjusted buying power, and a \$27.1 million difference in NCBDDD's actual buying power versus the inflation adjusted buying power. This represents about a 25% loss of buying power for the two centers combined. The impact of this reduced buying power is serious. This results in the inability to develop timely health statistics and create robust surveillance systems and public health informatics; the inability to implement proven interventions and effective outreach tools in communities; the reduction of grants to state and local health departments; and the inability to provide technical assistance to state and local health departments.

With respect to the research components of NCCDPHP's and NCBDDD's programs, in 2008 there was a \$106.8 million investment in research activities. This is divided into continuation awards (NCBDDD \$ 29.8 million and NCCDPHP \$ 67.0 million) and new awards (NCBDDD \$3.3 million and NCCDPHP \$ 6.6 million). A \$108.0 million investment is projected for 2009, which is again divided into continuation awards (NCBDDD \$ 30.2 million and NCCDPHP \$27.4 million) and new awards (NCBDDD \$12.1 million and NCCDPHP \$38.3 million). In addition, FY 2010 will have an impact in that NCCDPHP will have 12 projects ending totaling \$19 million and NCBDDD will have 8 projects ending totaling \$4 million, or roughly \$23 million that will be up for reprioritization. The CCHP BSC's input could be highly valuable in guiding the two centers with respect to how to invest those funds. In conclusion, Ms. Martin recapped the budget challenges faced by CCHP.

### **Discussion Points**

- Dr. Bethell inquired as to whether the difficulty was because there are legislatively mandated uses of funds.
- Ms. Martin responded affirmatively, noting that the language varies considerably between lines. Sometimes the language is extremely specific and sometimes it is not. There are additional complicating factors that arise from partners or advocates on the outside, such as the Special Olympics—a foundation run by the Kennedy family basically. They have very specific ideas about what should and ought to be done with the funding, and CDC must work with the foundation to ensure quality public health programs.
- Ms. Johnson, NCBDDD's Deputy Director, added that there are good and bad things about the budget. There are people who are very effective at working the Hill, which is the way the system is supposed to work. It does create some constraints for the Center, but it has also brought them together with new partners they probably would have not been engaged with otherwise. Percentage-wise, the greatest growth has been in early hearing in that the Early Hearing Newborn Screening Program has been effective in garnering new funding. Overall, however, there have been only small increases for autism and other categories. The budget has been relatively flat.

- With respect to the rumored windfall Dr. Toomey mentioned earlier, Dr. Bethell wondered if the agenda of issues would be expanded to other areas not currently on the list for the NCBDDD or NCCDPHP.
- Ms. Martin responded that given the level of constraints, it is difficult to determine how to move outside of leadership and management.
- Dr. Toomey added that it is possible that unfunded issues had the potential to be funded.
- Dr. Kleinman wondered why for some categories, AIDS / Non-AIDS was differentiated.
- Ms. Martin responded that the AIDS funding actually comes through the Coordinating Center for Infectious Disease (CCID) in somewhat of a circuitous route. It either goes to them or comes from them. It is two separate sources of funding. It is internally distributed after it stops elsewhere.
- Dr. Goff indicated that he had been involved to some extent with the Division for Heart Disease and Stroke Prevention (DHDSPP), and his understanding was that a lot of the money passes through the DHDSPP to the state health departments to fund state-based programs that have been legislated by Congress.
- Dr. Airhihenbuwa responded that those are typically strategic decisions made within the division that are quite historic in nature in terms of ensuring that state health departments are major actors in the infrastructure capacity to respond to these chronic diseases. That is, generally speaking, that has been a strategic decision made within the division rather than as a directive by Congress.
- Dr. Toomey added that by contrast, funding will come through for a specific type of cancer such as ovarian and it is illegal to use those funds for any other activity than ovarian cancer. That is the constraint of the earmarks.
- Dr. Bal wondered why the budget was not cross-shown along with organizational structure, although he applauded the illustration of loss of buying power as being masterfully crafted. Not only has buying power diminished, but also funding is not aligned satisfactorily with disease burden. That is, the centers are under-funded with respect to the actual burden. Perhaps one role for the CCHP BSC would be to recommend that funding be made congruous with disease burden. They must make a case based upon disease burden and the ability to do something about it, which is well-supported by the peer-reviewed literature.
- Dr. Curtis indicated that she wrote a paper about a decade ago arguing about the disproportion of funds that were spent on breast cancer versus coronary heart disease in women's health. Interestingly, the peer-reviewed journal to which she submitted it to sent it to three people to review. None of them reviewed it, but the committee made a unilateral decision not to publish it. This taught her that the euphemism of peer review is not always what it is supposed to be. The concept of the "disease du jour" perpetuates and maintains a very specific disease focus. In that sense, there is a double-edge to making recommendations. If they want to shift the paradigm, an analysis must be done and must be written in such a way that it moves towards that shift because everyone has tired of the "disease du jour" concept. They do not want to lose the idea there is a population burden based distribution.

- Dr. Toomey pointed out that, as noted by Dr. Rimmer earlier, the results reflect that the dose (e.g., of funding to implement effective programs) may not be sufficient enough to have an impact. That has not been addressed with respect to budget lines.
- One Board member suggested reviewing an analysis conducted by Dr. Stephen Thacker a couple of years ago that addressed key areas such as HIV and breast and cervical cancer. While it is not fully comprehensive, it may be a good starting point [Curry, De, Ikeda, Thacker; Am J Prev Med 2006;30(3)].
- Dr. Kolbe pointed out that school programs were constructed with HIV funding to build an infrastructure that could address a wide range of diseases and injuries during youth (e.g., through the Youth Risk Behavior Survey (YRBS), and this be equally if not more effective in preventing HIV and its comorbidities.
- Dr. Cohen noted that the new administration is highly committed to early childhood education as one of its priorities. Perhaps there is a way to approach the poverty issue by linking early health education with maternal and child health education in some constructive way.
- Dr. Kolbe indicated that the Committee on Developmental and Health Outcomes for the 2020 Objectives is taking that exact approach. In the past, there has been a focus on examining cohorts rather than studying data longitudinally to understanding the variety and aggregation of insults to individuals and how combinations of problems influence health.
- Dr. Airhihenbuwa said he anticipated a debate about what constitutes “prevention.” It was not clear to him that the budget reflected how much of the funding is allocated to programs that support primary, secondary, and tertiary prevention. In addition, there is traditional programming and community-based programming.
- Ms. Martin responded that while the budget was not described in graphical form with respect to investment percentage in each primary, secondary, and tertiary areas for this meeting, they could work on developing such a breakdown.
- Dr. Kleinman expressed interest in knowing how many of the specific programmatic initiatives were mandated through legislation and how many were initiated from a programmatic point-of-view. She liked the way the center was described in the narrative of categorizing the overlapping components of the divisions for risk factors, life stages, data, and diseases. She thought that from a discussion point-of-view, it would be useful to consider the budget according to those areas because it begins melting down the walls. She suggested that this be addressed more specifically during a future meeting in order to better understand the genesis of the cross-sectional picture of mandated versus home-grown allocations. It would be beneficial to know what specifically is done with the mandated allocations programmatically within the boundaries.
- Dr. Kolbe indicated that he would include this as a future agenda item. He pointed out that many programs are developed in collaboration with various members of Congress, but sometimes Congressional members will have their own ideas and make changes. Sometimes there are mandates that not only specify the specific disease to be addressed, but also dictate specifically what the agency will do with those funds.

- Dr. Goff wondered whether it would be possible to think about this as a question of how much money is being devoted in a way that supports the strategic plan. Given that the CCHP BSC would be asked to advise on strategy, he thought it would be beneficial to know how much of the resources are currently devoted in a strategic manner versus those that are not.
- Dr. Kleinman requested that the CCHP BSC be provided with a breakdown of intramural research, education, and operations funds as well during a future meeting.
- Dr. Curtis inquired as to whether there was any flexibility for CDC to engage an outside group of people to help the agency develop a better social marketing plan to present to the Hill.
- Dr. Toomey responded that CDC cannot lobby on the Hill and is not permitted to hire an outside resource to market for them. There is, however, great optimism that the new administration may have broader views of prevention and upstream prevention, addressing root causes in a way that the last administration did not.
- Dr. Cohen wondered what CDC's role would be with respect to the State Children's Health Insurance Program (SCHIP) and other extensions in health care.
- Dr. Toomey responded that to her knowledge, CDC does not actively engage in the analysis of SCHIP, although that was not to say that they should not be very concerned about what is covered. She acknowledged that there is woefully little interaction between CDC and the Centers for Medicare and Medicaid Services (CMS) and there is a great opportunity to have an influence, even to the extent of how prevention is covered. The current concept being promoted is the "Wellness Trust" that would be funded in part by CMS through prevention activities. This represents a major opportunity for CDC to become more engaged with CMS.
- Dr. Bal suggested including the slides pertaining to the erosion of buying power and its impact into any reports produced by the CCHP BSC. They must also determine as best they can the disease burden in various areas. In terms of supporting CDC on the Hill, he reminded everyone that the BSC members did not give up their rights as private citizens to speak on either end of Pennsylvania Avenue.
- Dr. Bethell said she believed that the article she mentioned earlier was rejected because when it was written in the late 1990s, it was not the direction women's groups wanted funding to be allocated. Issues are killed for political reasons, which was the unspoken "elephant in the room" when dealing with these issues. She stressed that the reality of politics and policy was that they are intertwined and they will never be able to separate them. To her, the \$23 million coming back on line in 2010 from programs that are ending represents a great opportunity. The Center must determine with whom to partner outside of the agency in order to leverage existing activities. If they focus on the priorities raised during this discussion, it would focus their direction on dealing with cross-cutting issues across populations and cross-cutting influences on health. They must always be prepared with an elevator speech in order to influence the opportunities that become available. There is a good strategic opportunity to scan what is occurring in the world and if it does not represent the goals of CCHP, it would be fairly easy to make sure that CCHP's goals are made known. In addition, childcare and early childhood education represent good opportunities. Moreover, there are very few people who do not have a chronic disease and /

or who are not at risk for developing one. Most people who do have a chronic condition have more than one. Those statistics will help the center lay the groundwork to move toward cross-cutting issues, not that the disease-specific elements should be ignored, but that the budget should begin to better-align with the realities over the next five years.

- Dr. Goff pointed out that those around the table were all probably members of other organizations through which they could spread the word. There are numerous activities through which messages can be coordinated. For example, the American Heart Association coordinates its messages with CDC, NIH, and other agencies like the Diabetes Association and the Cancer Society. No one wants to fight over whose disease is most important. The Wise Woman program represents another tremendous opportunity to leverage existing infrastructure, and other opportunities abound.

### Overview: The BSC's Role

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

Dr. Kolbe reviewed segments of the charter, requesting that members give thoughtful consideration to what the most influential actions would be that they could take as a committee to think through the current economic issues, general public health issues, and issues specific to CCHP and its two centers. He explained that the committee has the capacity to meet and work in a variety of ways that are consistent with FACA regulations, including bringing in experts who are not members of the committee when deemed necessary. Meeting only twice per year will not be sufficiently substantive or productive; therefore, he thought that additional meetings must be convened either face to face or by teleconference. Recognizing that BSC members likely have jobs that require 150% of their time already, he requested that they all make an additional considerable commitment over the next four years to increase the impact of these two programs that are so vital to the wellbeing of the people in this nation. He proposed that they work as a team with their CDC colleagues in a way that is expedient and informal. While he preferred to be as neutral a Chair as possible, he said he would certainly offer his opinions. However, as the members delved into issues that may require resolution, he would make every effort to retain neutrality unless there was a compelling reason for him to render an opinion. He also requested that if he moved meetings along too rapidly, that the members speak up to let him know that a topic required further deliberation. He then reviewed the CCHP BSC Charter with respect to the function, structure, and meetings. He also referred participants to the document titled, "Research and Scientific Program Reviews: Guidance for CDC Programs and Boards of Scientific Counselors," which further explains information that is not as detailed in the charter, and he briefly reviewed some components of the document. He stressed that each member should carefully read these two documents in order to fully understand their charge and the purpose of research and scientific program reviews.

*With no further business posed or discussion raised, Dr. Steinberg officially adjourned the first day of the meeting.*

### Call to Order

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

Dr. Steinberg welcomed everyone to the second day of the CCHP BSC meeting. Having worked toward this meeting for the last two years, she stressed how truly gratifying it was the first day to observe everyone's enthusiasm and engagement. She indicated that the additional pieces of information requested the previous day were being distributed (e.g., Stephen Thacker's article, CDC's health protection goals).

### Conflicts of Interest

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

Dr. Kolbe led the BSC members through the process of stating any conflicts of interest they might have. The following declarations were made:

Member	Declaration
Dr. Airhihenbuwa	No conflicts
Dr. Bal	No conflicts
Dr. Beaty	She is an unpaid consultant on a study funded by CDC out of Mount Sinai Medical School.
Dr. Bethell	No conflicts
Dr. Cohen	No conflicts
Dr. Curtis	She has a consulting relationship with Novartis Pharmaceuticals. There are no grants.
Dr. Emmons	No conflicts
Dr. Goff	He has a training grant that is administered through the Chronic Disease Directors, with funding that originates in NCCDPHP; has a research grant from Merck; has a paid consulting role as Deputy Editor of Archives of Internal Medicine with the American Medical Association (AMA); and has consulted for Scientific Evidence Incorporated.
Dr. Kardia	Not present
Dr. Kleinman	Her faculty submitted a grant application for the Category 2 Prevention Research Center.
Dr. Kolbe	He has been an External Examiner for the past 3 to 4 years for the Medical School at the Chinese University of Hong Kong, although he stepped down from that position in late 2008.
Dr. Macera	She has a grant through the Arthritis Group, which she has reported and for which she has received a waiver.
Dr. Marrero	Not present
Dr. Rimmer	He has two grants with the Division of Human Development and Disability (DHDD), NCBDDD.
Dr. Wolraich	Not present

## Meeting Objectives

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

Referring members to Page 16 of the document titled, "Research and Scientific Program Reviews: Guidance for CDC Programs and Boards of Scientific Counselors," Dr. Kolbe stressed that the BSC would certainly work with the CCHP and center directors to ensure that everyone clearly understands the mandates and the recommendations of the guidelines. Within 30 days after a secondary review, the reviewers will submit a summary report to the BSC, CCHP, and the center directors for their review and response. Within 60 days after the review, CCHP and the center directors would provide to BSC and CDC leadership a response to those recommendations. Included in the process will be individual review comments in advance of the next meeting. On the anniversary of each completed research and scientific program review, a one year follow-up report will be submitted to BSC on the accomplishments being made on specific recommendations of this committee. Dr. Kolbe stressed that recommendations made by the BSC should be worthy of investment of time by this agency, so they must think them through very carefully. He referred members to a sample report on page 24.

Dr. Kolbe inquired as to whether the members thought it would be useful to form two subcommittees of the BSC, one made up of those with experience in chronic disease and one made of those with experience in birth defects and developmental disorders. Each subcommittee could include others as well, and could have a chair who would take responsibility for ensuring the accomplishment of the work for that subcommittee. Perhaps a co-chair could also be appointed for each subcommittee so that those two people could be thinking together and take co-responsibility for putting issues on paper. Anticipating that there are 52 weeks in a year for the annual report, and recognizing that within those 52 weeks they might meet at a halfway point around 26 weeks, Dr. Kolbe suggested that those subcommittees could meet every two weeks (13 meetings) or every three weeks (9 meetings). If they did choose to meet in 26 weeks, perhaps it would be useful at the halfway point between this meeting and June for Dr. Kolbe, the co-chairs of the subcommittees, the CCHP designees, and the center directors or their designees to meet by video conference or in person for a briefing to determine whether the two groups are on track and making good progress. He also thought it would be beneficial for CCHP designees to be on all of the subcommittee conference calls so that there can be good give-and-take.

### **Discussion Points**

- Given that the charge in the charter is generic, Dr. Kleinman wondered to what degree they would conduct a 100% review immediately versus a more tailored review sequenced throughout the next few years. She perceived these two days as more of an introductory overview rather than a detailed description of each center.
- Dr. Kolbe responded that, indeed, they first wanted to hear a broad overview from the center directors about the programs, as well as some of their thoughts about what would be the most useful endeavor for the BSC to undertake.

- Dr. Bethell expressed concern that if they structured themselves into the two subgroups as described, there might be a tendency to prevent innovation in their thinking by basically saying they are sticking with “what is” and how to make that work better versus the potential to make a recommendation to restructure how things are done on a higher order based on cross-cutting issues for both centers (e.g., behavioral issues or socioeconomic status).
- Dr. Kolbe assured everyone that if the group decided to move in the direction of having two subcommittees, he would sit in on discussions with both in order to understand the issues as best he could as they evolved. Moreover, he would ask each subcommittee to consider the issue Dr. Bethell raised as part of their mandate.
- Dr. Curtis pointed out that if they divided into the two subcommittees as suggested, they should establish some type of liaison mechanism to ensure that they do not perpetuate the silo effect. There should be cross-talk between the two subcommittees so that the result is not simply a specialty report for each.
- Dr. Kolbe concurred, suggesting that in addition to being involved in both committees himself, there could be a meeting point midway through the report drafting process with all designees that would include himself, CCHP and center designees, and members of both subcommittees. He welcomed suggestions for other potential ways by which to structure subcommittees. They certainly want to take the best approach possible on this.
- Dr. Toomey agreed that they did not want to lose expertise and cross-fertilization across the two subcommittees.
- Dr. Rimmer stressed the importance of having time to ponder everything they were hearing during this meeting in order to synthesize the information and give careful consideration to how to move forward. He recognized that there were reports and timelines, but perhaps deciding the structure would best be left until the next meeting after they had each had time to think about what they had heard and learned.
- Dr. Airhihenbuwa recognized that they were dealing with two issues as they 1) wrestled with the attempt to capture the activities taking place in the two centers in order to ensure that they receive solid information to guide each center in terms of making decisions, and as they 2) took into consideration the bigger picture. He did not believe this precluded them from having the two suggested subcommittees. Perhaps they could begin with a review of each center and then six months later address the findings that led them to think about the bigger picture. One question might be, “Five to ten years from now, who would you like to be like?”
- Dr. Beaty agreed that there was a certain logic in having two separate groups, but supported extensive interchange between the two with respect to the cross-cutting issues, such as genetics.
- Dr. Cohen noted that in addition to structure, purpose must be taken into consideration. He thought they needed clarification about who the reports really go to and what happens to them after that, as well as how specific information should be. As pointed out during dinner the previous evening, some recommendations may evolve for which there should be enhanced public information efforts.

- Dr. Kolbe clarified that reports would go to CCHP and center directors who would provide their formal responses. The report and formal responses would then go to CDC leadership. Once a report is accepted, it is incumbent upon CDC to implement the recommendations. Within one year of filing a report, CDC is required to articulate how they have responded to the recommendations that were offered.

## **Overview: National Center on Birth Defects and Developmental Disabilities**

**Edwin Trevathan, MD, MPH, Director  
National Center on Birth Defects and Developmental Disabilities  
Coordinating Center for Health Promotion  
Centers for Disease Control and Prevention**

Recognizing the major commitment they were making, Dr. Trevathan expressed his gratitude to the BSC members for agreeing to spend their valuable time on this important committee. He also appreciated their discussions up to this point, agreeing that the issues were interesting but complicated. One important challenge that the BSC members highlighted was how the centers must address broad areas in a scientifically rigorous manner, while at the same time not losing site of cross-cutting and collaborative approaches.

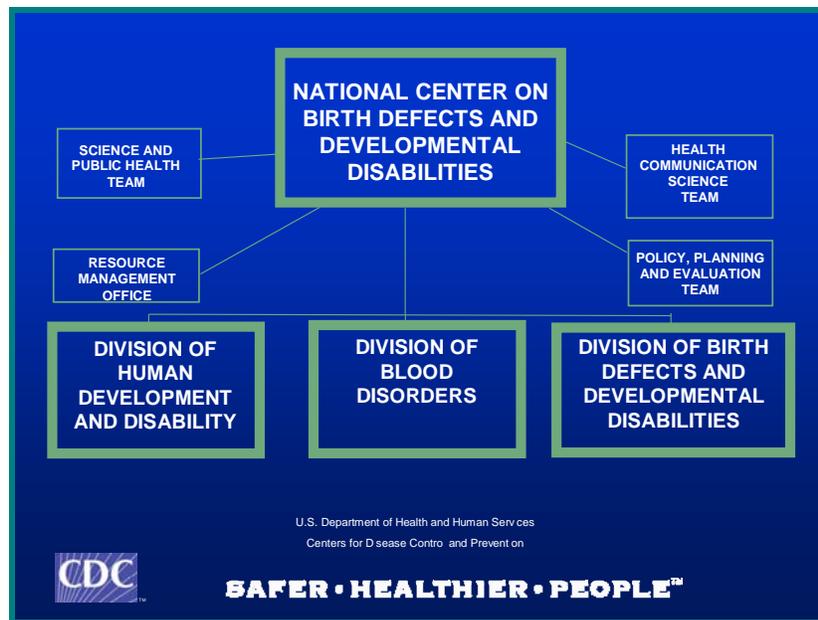
Dr. Trevathan indicated that the stated mission of the NCBDDD is to “promote the health of babies, children, and adults, and enhance the potential for full, productive living.” The goals are to 1) prevent or reduce birth defects and developmental disabilities; and 2) improve the health and development of all people with disabilities or potentially disabling conditions, including blood disorders. The mission is very broad and capturing everything the center does would take an extensive amount of time. The name, NCBDDD, does not necessarily reflect exactly what this center does. There are some aspects of NCBDDD’s activities that no one would guess based upon the center’s name. Probably the most obvious is that the Division of Blood Disorders is housed within NCBDDD. The disabilities addressed in this center are not just developmental disabilities or disabilities in childhood. The center also deals with adult disability and disabilities and disorders across a life-span. The term “birth defects” is actually considerably broader than what most people would think who have not worked within the CDC or within the government.

In recognition of the need for a public health response to these compelling issues, Congress authorized the creation of the program under the Children’s Health Act of 2000. This elevated existing CDC programs addressing public health concerns around birth defects, developmental disabilities, child development and disability. CDC established NCBDDD in April 2001, and in 2003, Congress reauthorized the center by the Birth Defects and Developmental Disabilities Prevention Act of 2003. This reauthorization further clarified the mission of the program to include the promotion of health among people of all ages living with a disability. Jose Cordero served as the first Center Director from 2001 to 2006. Alison Johnson, NCBDDD’s Deputy Director, served as the Acting Director during the search for a new Director. Dr. Trevathan became the Director about 18 months ago.

Some aspects of NCBDDD’s work are still relatively new, while some aspects of the work of the center have existed for a long time from a research and scientific point-of-view. For example, the birth defects surveillance program, the Metropolitan Atlanta Congenital Defects Program (MACDP), has been operational for over 40 years. There is a mixture of programs in the center, so one challenge regards how to fully maximize the public health impact of these programs,

update the science, and ensure that all science and public health programs within the center are relevant and are cutting edge.

The organizational structure is as follows:

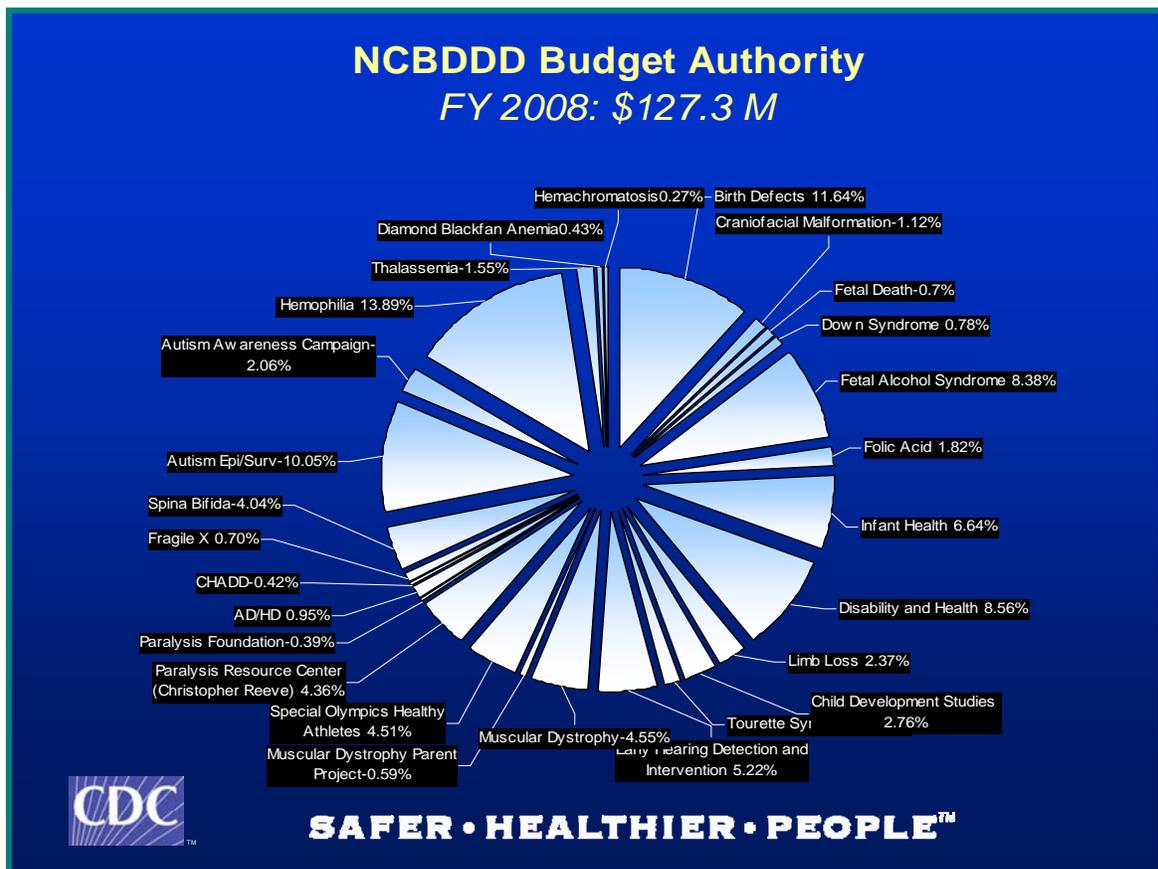


How the center is organized is not always intuitively or programmatically obvious, but it relates to historical development of work before and after creation of the center. NCBDDD has three divisions: the Division of Human Development and Disability (DHDD), the Division of Blood Disorders (DBD), and the Division of Birth Defects and Developmental Disabilities (DBDDD). In line with the President's Management Agenda, many of the center's support functions have been centralized at the Office of the Director level including policy, communications, scientific administration and support, and resource management. There is a great deal of current interaction in terms of science between DHDD and DBDDD. Moving forward, he thought there could be more interaction. Within DBDDD, there is a Pediatric Genetics Team, which works very actively in areas of new born screening and genetic disorders. This team of pediatric and medical geneticists serves as an important resource, not only for the division and center, but also agency-wide. Also housed within DBDDD is a Prevention Research Branch that conducts research connecting directly with programs in important areas such as folic acid fortification, early identification of children with autism and developmental disabilities, and Fetal Alcohol Syndrome (FAS) prevention research and activities.

The Developmental Disabilities Branch (DDB) conducts autism and developmental disabilities surveillance and epidemiology activities. The Birth Defects Branch (BDB) conducts birth defects epidemiology surveillance and research. That group of birth defects includes diverse areas such as neural tube defects and related abnormalities of the developing brain and nervous system, congenital heart disease and others. It is a considerably more diverse division than one might think from the name. DDB addresses cerebral palsy, intellectual disabilities, and vision and hearing impairment. The DBD historically has been very successful and focused primarily on hemophilia programs. Despite the fact that these hemophilia programs represent a majority of the funding at this point, they are not necessarily representative of the majority of problems in blood disorders health. They are currently considering the launch of new programs in deep vein

thrombosis, sickle cell anemia, and other major public health problems. Sometimes funding is representative of the magnitude of the public health problems, and sometimes it is not. Although quality data are limited at this point, it appears that there could be roughly 100,000 potentially preventable deaths in the US every year from deep vein thrombosis. While this is obviously a major public health problem, there are not clear funding streams for deep vein thrombosis at this juncture. However, the division is making efforts to develop programs with the hope that funding will follow and they will be able to sustain these programs with key partnerships. DHDD is extremely diverse and heterogeneous. Its activities include muscular dystrophy surveillance and epidemiology, early hearing detection and intervention programs for hearing impairment, infant hearing impairment, et cetera. The Early Hearing Detection and Intervention (EHDI) programs have been quite successful in 46 states throughout the country. Also housed in this division are state-based disability and health programs that consist primarily of health promotion activities among people with disabilities.

With respect to how funds are distributed across the center's three divisions, DBDDD receives \$53.79 million; DBD receives \$19.43 million, and DHDD receives \$54.13 million. The funding within DBD is relatively small compared to the two other divisions. Conversely, the emergence of some new programs may change the relative distribution over the next few years because of the interest in developing and implementing programs for sickle cell and deep vein thrombosis. Overall, the center's funding lines are relatively small compared to the magnitude of some of the programs. NCBDD's budget authority for FY 2008 was \$127.3 million, which breaks down as follows:



One of the greatest challenges is that there is extraordinarily little flexibility within the NCBDDD budget. Some funding lines are quite broad in terms of what the funds can be used for (e.g., Birth Defects, Infant Health, and Disability and Health), but the funds are small and have been decreasing over the last few years. There are some extremely targeted lines (e.g., Tourette's Syndrome and Muscular Dystrophy). There are also some remarkably small lines (e.g., Folic Acid Fortification Research), which have resulted in considerable impact. That is, several high impact lines have very small budgets. It is easy in the big picture for people to think that if a line is very small, it must not be very important. However, that is not necessarily the case. Breaking the budget up by goals, 43% of funds fall into Goal 1 to prevent or reduce birth defects and developmental disabilities, while 57% fall into Goal 2 to improve the health and development of all people with disabilities and potentially disabling conditions. Some budget lines actually impact multiple goals.

Although NCBDDD is one of the smaller centers at CDC, many achievements have been made possible because of the dedication and hard work of the center staff, partners, and leadership. Success stories include a 26% reduction in neural tube defects in the US due to folic acid fortification (N = ~1000 babies a year); 143 hemophilia treatment centers, which have resulted in more people with hemophilia leading longer, healthier lives and the reduction of HIV transmission; expansion of early hearing detection programs to 46 states and territories; documented effectiveness of health promotion programs for persons with disabilities; and state centers to study autism surveillance and research causes / risk factors. Dr. Trevathan pointed out that many of this center's programs represent an interface between medical care and bio-medical and public health research. The center engages actively with the medical care community, but is simultaneously careful not to lose sight of its public health mission and connection to high quality science.

Sharing data from the Behavioral Risk Factor Surveillance System (BRFSS) to emphasize the issues involved in working with people with disabilities, Dr. Trevathan reported that nearly 20% of Americans (N = 50 million) are living with a disability. The annual economic cost associated with disabilities is estimated at \$300 billion. The health of people with disabilities has emerged as a public health priority. People with disabilities are more likely to report fair or poor health and are less likely to report very good or excellent health than people without disabilities. Also, people with disabilities have higher rates of obesity and report more smoking and less physical activity than people with out disabilities. These needs cannot be dealt with in a silo. NCBDDD's interactions with its colleagues in NCCDPHP, elsewhere within CDC, and outside the agency are critically important in addressing the major health disparities among people with disabilities. There is significant work to do in the health promotion field, which is a major area for collaboration across centers, the agency, and with outside partners. With regard to the economic impact of disabilities across the lifespan, the estimated lifetime cost for infants born in 2000 with a developmental disability are estimated to total \$51 billion for people with intellectual disability, \$12 billion for people with cerebral palsy, \$3 billion for people with vision impairment, and \$2 billion for people with hearing loss. Birth defects are responsible for 12% of all pediatric hospital visits and contribute substantially to health care costs, with life-long costs associated with the 17 most common defects exceeding \$6 billion annually.

Developmental disabilities represent another set of common conditions targeted by NCBDDD. Developmental disabilities initially manifest in childhood, and impair a child's physical and mental health, cognitive ability, speech, language, and / or self-care. Examples of common developmental disabilities include mental retardation, cerebral palsy, vision impairment, and hearing loss. As a whole, these conditions affect 17% of American children, with approximately

2% of US school children having a serious developmental disability that requires lifelong supportive services. These conditions have a major impact on the children and adults living with them, as well as their families, communities, and society as a whole. Like birth defects, the causes for the majority of developmental disabilities also remain unknown. The economic impact of developmental disabilities is significant. The estimated lifetime economic costs of selected developmental disabilities are as follows:

<b>Developmental Disabilities</b>	<b>Total Costs (billions)</b>	<b>Average Costs Per Person</b>
Intellectual Disability	\$51.237	\$1,014,000
Cerebral Palsy	\$11.470	\$921,000
Vision Impairment	\$2.484	\$566,000
Hearing Loss	\$2.102	\$417,000

A year ago, NCBDDD met with center leaders to review all programs and develop priorities, which include: 1) Birth Defects & Autism / Developmental Disabilities Surveillance, Epidemiology, and Research; 2) Longitudinal Population-Based Disability Data; 3) Deep Vein Thrombosis; and 4) Health Disparities Among People with Birth Defects, Disabilities, and Blood Disorders. Three of these are very specific, while one cuts across the entire center. These are not necessarily long-term priorities, although they are not short-term problems. They intended to establish these priorities at the end of this administration to try to provide some focus. Long-term priorities will be addressed over the next year or so as they engage in these discussions further. The birth defects, autism, developmental disabilities surveillance and epidemiology, and research programs are key to the center's work, yet they have been under considerable financial strain lately. It has been necessary to reduce the number of funded programs due to flat budgets and the erosion of buying power over the years. There have also been opportunities and challenges with major advances in the science in these areas, so the center must ensure that its epidemiology and surveillance are consistent with what is known about the biological nature of these disorders. The center has a major commitment to disability across the life span and health promotion among people with disabilities, yet there is a lack of adequate longitudinal data from communities and people with disabilities in order to measure outcomes precisely.

While the causes of many birth defects are not known, the causes are known for some. An ongoing success story is in the area of neural tube defects. Anencephaly (e.g., lack of a cerebrum) is a fatal condition. Spina bifida is associated with increased mortality and morbidity, and is not associated only with the visible malformation. Children with spina bifida also suffer severe motor problems, bladder function problems, brain malformations, hydrocephalus, et cetera. Hydrocephalus is a major co-morbidity in these children. They also have associated developmental disorders and brain malformations that are not necessarily associated with spina bifida that potentially fall into the biological spectrum of hydrocephalus. Those issues could potentially be addressed with some of the center's interventions, which concentrate on co-morbid conditions associated with spina bifida. The center is not only committed to reducing the

incidence of Spina bifida, but also to enhancing the quality of life of people who have spina bifida and related conditions.

State-based programs have faced a number of problems in their attempts to measure the long-term successes of programs addressing secondary conditions. A significant amount of research was conducted in the late 1980s and early 1990s, even before showing that there is an inverse relationship between red blood cell foliate levels and the prevalence of neural tube defects, which led to a fortification of the grain supply through work between CDC and the Food and Drug Administration (FDA). CDC's scientists are working with collaborators around the world, and there has been a spread of folic acid fortification throughout the Americas and various other areas of the world, including some areas that would not be thought of in terms of direct collaboration (e.g., Sudan and Yemen). There are active global programs that have been spin-offs of some of the work done in the US, which NCBDDD is very proud of. Moving forward, some of these global activities, research opportunities, and measurement of these activities in developing countries could be an important area of interest for NCBDDD.

With respect to the science behind this, there is a clear reduction in neural tube defects before and after fortification in the countries for which there are data before and after fortification, which is one of the more straightforward outcome measures. In the US, the neural tube defect rate decreased per 10,000 live births from 10.6 to 7.6; in Canada from 15.8 to 8.6; in Costa Rica from 9.7 to 6.3; and in Chile from 17.1 to 10.1. Because there are now outcome data, it is possible to perform a post economic evaluation. NCBDDD began with updated estimates of the per child cost of live-born infants with spina bifida and anencephaly. Using these estimates, along with a projected 612 live births with neural tube defects prevented each year due to folic acid, the total annual benefit is conservatively estimated at \$425 million per year. The cost of fortification is approximately \$10 million per year. Costs associated with adverse effects are not projected. The only study to date found no evidence of increased cases of neurological damage associated with vitamin B12 deficiency following fortification [Grosse, Waitzman, Romano, Mulinare; *Am J Public Health*, 2005]. The cost of fortification is actually quite small compared to the savings. NCBDDD believes that this should justify more investment in these areas and to look for the next folic acid.

NCBDDD has a variety of birth defect programs in place throughout the country. State monitoring programs conduct population-based surveillance of birth defects. From 2003-2008 this includes Arizona, Florida, Illinois, New Jersey, New York, Ohio, Puerto Rico, and Vermont. From 2005 to 2010 this includes Colorado, Michigan, Minnesota, New Hampshire, Oklahoma, Rhode Island, and Virginia. A great deal of work has been conducted by the Centers for Birth Defects Research and Prevention located in Arkansas, California, CDC / Georgia, Massachusetts, North Carolina, and Utah; and in Iowa, New York, and Texas through November 2008. In order to expand sample sizes, take greater advantage of more narrowly defined homogeneous groups, and to examine gene / environmental interactions, more expertise and funding are needed in these important centers. However, level funding has placed the centers under some of the most severe budgetary strains. This is a major challenge and a tremendous opportunity.

The Autism and Developmental Disabilities Monitoring Network (ADDM) sites are located in 10 states plus CDC (Alabama, Arizona, Colorado, Florida, Michigan, Missouri, North Carolina, Pennsylvania, South Carolina, and Wisconsin). It is estimated that the average prevalence of autistic spectrum disorders (ASD) as a group across these different sites is about 1 in 150 children. These data have become an important standard as ASD is monitored in the US. Four of these states are also conducting cerebral palsy surveillance and epidemiology, from which

important data are beginning to come forth (Alabama, Missouri, Michigan, and Wisconsin). The center would like to expand this effort in the future. This is another area that has been under particular funding pressure. NCBDDD's Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDREs) are located at the Colorado Department of Public Health and Environment, Kaiser Permanente Division of Research, Johns Hopkins University, the University of North Carolina at Chapel Hill, University of Pennsylvania, and CDC-Georgia CADDRE. The coordinating center at Michigan State also plays an important role. These centers are now conducting a study known as the Study to Explore Early Development (SEED). This is currently the largest case-control study examining ASD that has been conducted, with approximately 2,700 children to be enrolled ultimately. Approximately 1,000 children have been enrolled to date, which is on target. The purpose of the SEED project is to better understand the range of characteristics among children with and without autism and other developmental disabilities and to identify what might put children at risk for ASDs and other developmental disabilities. ASD is a very complicated disorder that likely has a large number of gene-environmental interactions, so this must be a long-term commitment for NCBDDD. The center is hopeful that if funding permits, the infrastructure that has been developed over a period of many years could be used as a platform for examining other developmental disabilities and conducting cohort control studies.

The "Learn the Signs Act Early" campaign is not research but there is the potential for research. This campaign builds on familiar experiences of parents, such as monitoring their child's growth; aims to educate parents, health care professionals, and childcare providers about child development; encourages early screening and intervention—strategies that hold the most promise for affected children and their families; and was launched by CDC and its partners in 2004. This program is moving into its "Act Early" phase. This program began with the a series of guidelines developed in partnership with the American Academy of Pediatrics (AAP), Autism Speaks, First Signs, the Autism Society of America (ASA), and the Organization for Autism Research (OAR). These guidelines state that all children should be screened twice during their first two years of life. Regional meetings are occurring in every region of the US, with programs being implemented in each state. This involves interaction and collaboration between special educators, physicians, the Health Resources and Services Administration (HRSA) funded clinics, and a large number of organizations coming together, often for the first time in their state, to consider how children with developmental problems can be identified early and linked with services.

With regard to what this has to do with research, the methods for implementing interventions have not been studied as much they should have been. There appears to be a major opportunity to conduct translational research in this area, which connects directly to NCBDDD's potential role in children's health care reform. Clearly, the infrastructure for acting early does not exist in many states and communities. There must be a solid interface between health care, public health, and surveillance moving forward. It is difficult to identify and act early when the structures are not in place to do so. With ASD, children are being identified predominantly between the ages of 4 and 6. Progress must be made in that area. Surveillance data will help to identify exposures, which will result in better surveillance and epidemiology to link this information to potential modifiable risk factors. There is an important connection between surveillance, epidemiology, early diagnosis, and referral.

Longitudinal population-based disability data is an important issue that has been raised in large part by the states that have been funded through the Disability and Health Program. These programs conduct a lot of work in secondary disability prevention state-based programs for people with a variety of disabling conditions. Developing longitudinal outcome data in these populations is a challenge. According to the US Census, approximately 50 million people in the US have a disability, many of whom are children and young adults whose quality of life and participation is threatened by preventable health conditions. Not enough is known about the health and quality of life of people with disabilities across the lifespan. The recent Institute of Medicine (IOM) report, "The Future of Disability in America," recommended improved surveillance of the national incidence, prevalence, severity, and duration of disability. Toward this end, CDC could initiate a national longitudinal study of the characteristics and health of people with disabilities. Information on the health and quality of life for people with disabilities will lead to the development and adoption of proven interventions that promote health and reduce disparities at the state, territory, and tribal levels.

There are state implementation projects for preventing secondary conditions and promoting the health of people with disabilities in Arkansas, California, Delaware, Florida, Illinois, Iowa, Kansas, Massachusetts, Michigan, Montana, New York, North Carolina, North Dakota, Oregon, South Carolina, and Virginia. Activities targeting people with disabilities include breast and cervical cancer screening. For example, women with motor disabilities have had problems with access to appropriate mammograms and breast cancer screening programs because of the technical ways that the equipment is made, which is typically crafted such that women have to stand in order to have their mammogram performed. The obesity problem among people with disabilities has been significant, and targeting obesity in this vulnerable population has been highly important. There are also programs in smoking cessation and urological health.

Measuring the outcomes of these programs is a major research opportunity and a priority for NCBDDD moving forward. Having longitudinal data is absolutely critical, and there has been an effort that has been successful in examining snapshots of what is occurring with disability in various states. CDC publishes a "Disability and Health State Chartbook" periodically that has been very helpful. This publication includes state-level reporting of comparative health status of people with disabilities. Plans are underway for the development of a web-site for up-to-date state-specific reporting on the comparative status of people with and without disabilities on key health variables. With approximately 50,000,000 people in the US with some form of a disability, it is clear that this is a critically important population to address as NCBDDD moves forward.

Another current NCBDDD priority is the public health response to deep vein thrombosis. This is a good example of the interface between science, public health, and medicine. Deep vein thrombosis is an under-diagnosed and preventable medical condition that occurs when a blood clot forms in a large vein. Every year 30,000 to 60,000 people in the US die when part of the clot breaks off and travels through the bloodstream to the lungs, causing a pulmonary embolism. Using existing monitoring capabilities and expertise in blood disorders and health promotion, NCBDDD will conduct research to determine the prevalence of and risk factors for DVT and how best to inform providers and the public about prevention. This type of research will allow for a better understanding of those individuals at risk for deep vein thrombosis, while encouraging public health education regarding the risk factors and early warning signs of this condition.

Now known from the science is that there are certain susceptibility genes that are common, which make some people more susceptible to having a deep vein thrombosis and subsequent pulmonary embolism that has a high risk of death. Collaboration across centers is critical in this area. Within the susceptible groups, simply riding in airplanes can be more risky, especially if they do not move their legs, exercise, and consume fluids. Among the elderly, this is a major problem that is often related to other chronic diseases. In pregnancy, there is no doubt that deep vein thrombosis is a major contributor to maternal mortality. Whether this plays a role in some of the racial and ethnic disparities in maternal mortality is not clear, but there is no doubt that it is critically important. It is also known that people who are immobilized with hospitalization are at increased risk. There is good reason to believe that motor disability is associated with increased of deep vein thrombosis, although the population base for this is not as clear. However, these are all clear target groups for interventions. A number of meetings pertaining to deep vein thrombosis have been convened between multiple groups of experts contemplating how a more appropriate public health response can be developed to this major problem. NCBDDD has recently begun a small series of Thrombosis and Hemostasis Research Centers that are located at Duke University, the Mayo Clinic, the Robert Wood Johnson Medical School, University of Colorado, and University of North Carolina—Chapel Hill. It is hoped that this group will become an important scientific base from which NCBDDD can launch some of its public health science and research in the area of deep vein thrombosis. The “Surgeon General’s Call to Action to Prevent Deep Vein Thrombosis and Pulmonary Embolism” was published in 2008, which he urged BSC members to read, given that it clearly outlines the need and potential roles that NCBDDD can play in this comprehensive response to the problem of deep vein thrombosis.

Racial and ethnic disparities among people with birth defects, disabilities, and blood disorders are another important NCBDDD priority. Examples of disparities of interest to NCBDDD include the rates of neural tube defects among Hispanics, which are significantly higher than among other racial and ethnic groups in the US; sickle cell disease, which is a major cause of preventable morbidity and mortality among African Americans; life expectancy among children with down syndrome, which has almost doubled in the past 20 years, but African American children with down syndrome have lagged far behind whites in survival; and racial and ethnic minorities with disabilities report significantly worse health status than other groups with disabilities. The causes of these racial and ethnic disparities among people with birth defects, disabilities, and blood disorders are not well understood. NCBDDD will conduct research to better understand why these disparities exist for certain racial and ethnic minority groups. One of the two major goals of Healthy People 2010 calls for eliminating health disparities. It is likely that some of the health disparity represents inequities in access to prevention opportunities and the quality of medical interventions for long term care. These are factors that can be targeted and that can have positive impact in terms of health outcomes.

NCBDDD does not currently have any funding for sickle cell disease, although that has not stopped them from engaging in work in this area. This is another area in which relationships are critically important. The Division of Blood Disorders worked with the National Heart, Lung, and Blood Institute (NHLBI) regarding what the public health response to sickle cell disease should be. Recently, a group of experts was convened at CDC to examine how surveillance and epidemiology could be defined and conducted for sickle cell anemia. Consideration was given to what connection could be made with state-based programs, and what the role would be for CDC, NHLBI, and HRSA. NCBDDD is highly optimistic that this endeavor will result in some nice work. NCBDDD has engaged in a similar relationship with the National Institute of Neurological Diseases and Stroke (NINDS) that they hope will be productive going forward. They are also engaged in collaborative efforts with the National Institute of Child Health and

Development (NICHD), the National Institute of Mental Health (NIMH), and various NIH institutes.

Examining the success of folic acid in greater detail, as noted earlier, fortification of wheat flour with folic acid and nationwide folic acid education programs, have led to a 26% decline in the neural tube defects spina bifida and anencephaly. While neural tube defects have not been eliminated entirely, solid progress has been made. Hispanics have the highest rates, but many Hispanic families do not use wheat flour. An alternative solution is to fortify corn flour in order to help reduce this persistent health disparity among Hispanics. Recently GRUMA, a major corn flour and tortilla manufacturer, announced its intention to fortify its corn products with folic acid in the US by the end of the year. Many of NCBDDD's partners have worked side-by-side with them on this effort. Policy and science have worked together in this effort. The science going forward on this will be extremely important with respect to defining the next steps.

There remain many challenges. Not only do surveillance and epidemiology systems need to be maintained, but also consideration must be given to incorporating cutting-edge science so that the best public health research possible is being conducted. For example, birth defects surveillance has been conducted throughout the country for over 20 years and for 40 years in Atlanta. The quality of the data from neural tube defects, in terms of defining a homogenous population for conducting research, is vastly different from conducting a population-based study and collecting those data for hydrocephalus or disorders that require detailed imaging data for appropriate classification. Consideration must be given to what improvements are needed for existing systems (e.g., the technology to conduct better research); the cost-benefit ratio; how one priority compares to other priorities; what the relative investment should be in programs versus research; how broadly to incorporate mental health into the disability work of the center; taking programs to scale; how to deal with measurement issues in disability; working across the center and other areas of the agency; et cetera. These are areas in which a subcommittee or working group of the BSC could be extremely helpful.

### **Discussion Points**

- Dr. Cohen thought the 26% reduction figure seemed on the low side compared to FAS, especially from a clinical point of view. He wondered what factors there may be other than the racial disparity issue, and whether public information efforts were helpful and could be advanced.
- Dr. Trevathan responded that he thought there had been successes in both folic acid and FAS, although major work remains to be done in both areas. More communication and health education work needs to be done with respect to folic acid in terms of getting the message out to various sub-populations, particularly Hispanic groups. The 26% reduction is from population-based data, so it is accurate. With respect to why it is not higher, even with fortification some people are being missed. It is especially challenging because the level must be quite high at the beginning of pregnancy and realistically before conception. One major problem with preconception in general is that so many pregnancies are unplanned. Thus, a more comprehensive preconception program could be beneficial. Another reality is that not all neural tube defects are preventable with folic acid. There is every reason to believe that there are probably multiple other mechanisms as well. Thus, an area of particular interest is more research to find the next folic acid. At the same time, they do not want to forget that this intervention is available and it should be optimized. One problem with FAS is that there has not been a uniform message from providers that there is no safe level of alcohol in pregnancy. In addition, the broad-based, large campaigns have not been

as successful as would be preferable. More research is needed in that respect as well. There are also some potential policy research opportunities. For example, in the US, insurance often does not pay for preconception care/counseling. Many women are not seen until the 12<sup>th</sup> week of pregnancy, which is outside the window of the opportunity for prevention for some of these disorders.

- Dr. Cohen requested further clarification about the indication that the average age for identification begins at 4 years old. It seemed to him that with all of the intervention activities underway, identification was occurring at a younger average age. Given that in the last couple of years, Autism Speaks and others have implemented more aggressive public information campaigns, it seemed that from a clinician point-of-view, that would have resulted in younger children being identified.
- Dr. Yeargin-Allsopp responded that they initially found that the average mean age was 4.5 to 5.5 years of age. The most recent data (2006) show that there has been no change in mean even with all of the awareness campaigns, AAP, Learn the Signs Act Early., and Autism Speaks.
- Dr. Trevathan added that they have been able to document enormous interest in educational materials from providers and parents. The number of hits on NCBDDD's website for some of these materials measures in the millions, and millions of copies of these materials are being reproduced. It is possible that they are simply measuring too early to see a lower mean. There could be a research component to this later. Special educators, therapists, physicians, and state health department representatives who attend the "Learn the Signs. Act Early." Regional Summits indicate that their systems for interventions are absolutely swamped and overwhelmed. That has been a relatively recent development. Thus, there is some anecdotal evidence that some progress is occurring. There remain challenges with respect to what the system is going to do about it.
- With respect to how NCBDDD could leverage resources within other centers at CDC to help address the needs of NCBDDD, Dr. Kleinman wondered whether the NCBDDD agenda interacted with the agendas of other centers already, and if not whether they could build on the agendas of those centers in order to extend their work.
- Dr. Trevathan quipped that the answer to this was probably a day-long conversation. That notwithstanding, it is the right question, but there is a government culture at CDC and a reality of needing to do the right thing for the people they serve. Everyone thinks about what is in their budget lines and is accountable for that. They also know they are responsible for doing what they can that is not in their budget and working across centers to try to help each other do that. In some areas, rather than a lot more money perhaps they simply need to be in a position to provide technical expertise and collaboration with other groups. For example, NCBDDD has been very interested in having disability-related outcomes included in other areas of the agency, and seems to be making some important progress in that area. He did not think anyone believed that they had to own something in order to make it an important priority for their work. At the same time, they want to receive expert input on areas for which they have budgetary responsibility. His personal belief is that there is not a structure or a policy that encourages cross-relationships. These are simply relationships they all have to have with each other, and they should be held accountable for that.

- Dr. Rimmer wondered whether a need was perceived to create some type of structure that would allow for the priorities of the center to filter into the 66 goals and objectives set forth by the Office of Strategy and Innovations (OSI), particularly with the possibility of additional funds coming in.
- Dr. Trevathan responded that one scientific, programmatic, relational challenge with partners is that they have common platforms that can potentially benefit multiple areas. In the current environment, infrastructure cannot be produced over-and-over to address different problems if there is one platform that can address all. He personally did not believe that even if they had the funding it would be the right approach. A more proactive approach is represented by an upcoming meeting to be convened with NIH jointly funded by NCBDDD and the National Institute of Neurological Diseases and Stroke (NINDS) to discuss how to examine neuromuscular disease, collaboration possibilities, existing platforms, et cetera. Another example is that there are programs in the disability and health arena pertaining to urological health needs and outcomes among children and adults with spina bifida which mirror the needs of those with spinal cord injuries. However, these have separate funding lines, so consideration must be given to how these can be brought together to develop and / or identify and implement common interventions that are beneficial in both areas. All of the programs within the center align with one or more of the 66 goals. It would be beneficial for the CCHP BSC to help NCBDDD identify gaps. He thought the goal action plans had been remarkably beneficial in helping the center determine where to focus.
- Dr. Airhihenbuwa stressed the importance of showcasing the needs of the center and the necessary interface with other units within CDC. In order to do so, it is important to understand disability burdens and how that is spread across the board in terms of the amount of funding that is allocated into the different areas. He also requested further information about the meaning of the term “intellectual disability.” In addition, he remained concerned about the name of the center in that perhaps it limits the center’s potential.
- Dr. Trevathan agreed that the incongruence of the name of the center with all of the center’s activities has been an on-going issue. The center was named by Congress and does have a rich history, so while the name is limiting in many respects, this is a delicate issue with respect to partners. He supported the current name of the Center, but welcomed suggestions from the CCHP BSC. With respect to the terms “disability” and “intellectual disability,” one of the greatest challenges within the center in terms of research, surveillance, and epidemiology is that the activities come to the center in rather clearly defined funding lines to address certain issues such as Autistic Spectrum Disorders. Definitions or terms change with time, yet the underlying biological substratum is not different. The center must be able to conduct its work using the correct terminology in terms of the defined diagnostic criteria, while not forgetting that there is a biological reality that should guide research. When NCBDDD says they are conducting surveillance and epidemiology on “intellectual disabilities” they are talking in large part about the group of children who have IQs below 70 that are defined as having mental retardation in previous publications. There are also challenges in terminology that relate to political correctness or using terms that are appropriate. There is an important need to move beyond intellectual disabilities to address learning disabilities, and the center is already doing that to some degree with ADHD programs and the EDHI program. The center does not have programs that address dyslexia, for example. While the center’s definition of “intellectual disability” for some of its programs may not be exactly what is found in the literature, that does not signify that center is not potentially interested in some of those areas.

- Dr. Cohen noted that England uses the term “learning disability” rather than the terms “mental retardation” and “intellectual disability.” However, in the US, the term “learning disability” is very specific to academic learning difficulties at a particular level as defined in the education arena and includes dyslexia. The intellectual disability terminology used currently evolved because of political correctness, but the issue was that “mental retardation” was viewed as being a pejorative term. The terminology has changed to “intellectual disability,” which is more acceptable to advocacy groups and others.
- Dr. Trevathan agreed, noting that other terminology strikes an emotional chord as well, such as “birth defects.” He has had a number of parents tell me they do not like NCBDDD’s use of the term because their child’s birth was not defective, although they have a birth defect.
- With regard to the disability burden, Dr. Airhihenbuwa wondered if there was a way to connect the burden in each state with whether any funds / activities are allocated to each specific burden.
- Dr. Trevathan responded that the “Disability and Health State Chartbook” would be helpful. State snapshots are available which can be provided to the BSC members. NCBDDD has important programs in Pennsylvania that are critically important. For example, one of the center’s primary ADDM sites is located in Philadelphia.

## Overview: National Center for Chronic Disease Prevention and Health Promotion

**Janet Collins, PhD, Director**  
**National Center for Chronic Disease Prevention and Health Promotion**  
**Coordinating Center for Health Promotion**  
**Centers for Disease Control and Prevention**

Dr. Collins extended her thanks to the CCHP BSC for their commitment to this work, with a special thanks offered to Dr. Kolbe for the added burden of the leadership of this group. Everyone at CCHP recognizes that this is not a one-time committee. It is an investment in learning about CCHP and providing time and leadership to assist the center in doing the best job it can. She stressed that luckily, the center title did not restrict them much at all. They are broad and have quite a span of responsibility. She then reported on the activities of the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP).

Chronic diseases are responsible for 7 of every 10 US deaths, cause major limitations in daily living for 1 in 10 Americans, account for about 75% of the \$2 trillion annual US medical care costs, and cause significant racial/ethnic disparities in health. A priority of NCCDPHP is to ensure that the issue of racial/ethnic disparities in health is built into absolutely everything that is done throughout the entire center. While the center’s perspective comes from an orientation of population-health, within that they focus on those populations that are most disparately affected. Some of NCCDPHP’s recent work in Racial and Ethnic Approaches to Community Health (REACH) has taught them that declaring a specific goal to eliminate disparities can produce that effect. She stressed that it had to be an explicit goal within all of their work because raising the bar on population health sometimes leaves population groups behind.

Maternal and child health, reproductive health, oral health, and HIV prevention are intricately related to chronic disease; that is, the interface between these areas of work and chronic disease is very tight. For example, the Reproductive Health Group is working on gestational diabetes, tobacco, pregnancy, et cetera. They also carry some health responsibilities that extend beyond chronic disease. Maternal and child health work falls within the Division of Adult and Community Health (DACH) and the Division of Reproductive Health (DRH). These groups deal with issues far broader but related to chronic disease that include maternal morbidity, infertility, family planning issues, and child health risks that extend beyond chronic diseases to include issues such as injury. Oral health is a chronic disease and is associated with acute disease issues. NCCDPHP is extremely pleased to have the Division of Oral Health (DOH) in its group. Oral health is an extraordinarily important contribution to quality of life in this country that often goes unnoticed. Dr. Collins expressed her hope that oral health would not go unnoticed in the health care reform discussions, although a great deal must be done to get oral health issues included in these discussions. They are a very small and very under-financed group for the extent of scientific expertise that they have to deliver on the outcomes in a population-based manner (e.g., water fluoride and sealant work). The resources have been very limited and oral health has, in large part, been overlooked. NCCDPHP has a rich history in HIV work, which continues in very interesting ways. Some recent work examined issues of fertility among discordant couples as one example.

NCCDPHP's goals are to develop, synthesize, and apply the research base; reduce rates of morbidity, disability and premature mortality; and achieve equality in health by eliminating health disparities due to socio-economic, racial, ethnicity, or regional differences. Often, NCCDPHP will synthesize the research base and disseminate it to the field through guidelines and other means in order to translate the research base into practice. Dr. Collins divided the organizational chart into three categories: 1) Disease-focused divisions: Division of Cancer Prevention and Control (DCPC), Division of Diabetes Translation (DDT), Division for Heart Disease and Stroke Prevention (DHSP), and Division of Oral Health (DOH); 2) Risk factor divisions: Division of Nutrition, Physical Activity, and Obesity (DNPAO); Office on Smoking and Health (OSH); and Office of Public Health Genomics (OPHG); and 3) Division of Adolescent and School Health (DASH), Division of Adult and Community Health (DACH), and Division of Reproductive Health (DRH). While these divisions do not do all of the work inherent in their areas, they provide the leadership for the public health planning and strategies necessary to make a difference in these leading causes of death. There are unique differences among these divisions. For example, OPHG is really a service organization to the entire CDC because by no means are genomics issues limited to chronic disease.

The structure as it exists has served NCCDPHP extraordinarily well. For example, every program, whether they are risk factor or disease programs, are interested in working with schools to ensure that the right policies, environments, and education are being delivered in the school setting. That can be done in a comprehensive and uniform way through the DASH, such that it does not have to be replicated in each of the group areas. Dr. Collins highlighted the community health aspect of DACH's work. In the last five years, NCCDPHP has re-established a very strong community health program that had waned in prior decades. This was made possible because of some investments in programs such as REACH and Steps to a HealthierUS (Steps) programs, which have given the center the resources to work at the community level. There is a very integrated model of work at the community level. She was very taken by the BSC's earlier discussions pertaining to social determinants of health. She distributed a copy of one of their first pieces of work titled, "Promoting Health Equity: A Resource to Help Communities Address Social Determinants of Health." An extramural panel was convened to examine what is possible to do with respect to social determinants of health in

communities, and they are learning how to do this work “on the ground” through the Steps and REACH programs. Dr. Collins said she was thrilled that they were positioned as they were, because as a result of this activity, they went back into the field to seek applications from communities throughout the country to engage in this type of work. Although they knew they could only fund a few, hundreds of communities came in to work with NCCDPHP. The center now has a list of approved, though unfunded, communities across the country standing ready for the Obama team.

NCCDPHP recently completed an entire round of external panels that were convened to examine each of these divisions, the reports from which she offered to make available for the CCHP BSC members to review. In fact, some of the CCHP BSC members served on these panels. Dr. Bal was involved in the OSH external review, which was a very exciting review in which NCCDPHP scored very well. Where they were short on points was that NCCDPHP did not have an independent, external review in place to address impact and effectiveness (e.g., an extramural review of the center’s work).

While some of the work does not rise to the level of a division, it is very important to NCCDPHP and tends to be reflected in branches or teams of work within the center. Dr. Collins divided the activities into an architecture to include: 1) Disease-Focused Activity: Arthritis (DACH), Chronic Kidney Disease (DDT), COPD (DACH), Epilepsy (DACH), Mental Health (DACH), and Vision Health (DACH); 2) Risk Factor Activity: Alcohol Use (DACH), and Sleep (DACH); and 3) Population / Setting Activity: Healthy Communities (DACH), Healthy Aging (DACH), Healthy Worksites (OD), Infant Health (DRH), and Healthy Motherhood (DRH). She agreed that there should be a mental health component to all aspects of public health; however, this area is vastly under-funded and needs a tremendous amount of attention. SAMSHA provided CDC with additional resources to include a mental health module in the BRFSS, which allow CDC to obtain some initial information about mental health and its connectivity to all of the items that BRFSS measures. This is a natural way for CDC to step forward from an epidemiologic perspective to show important connections and to build out programmatic approaches from there. DACH has historically been an incubator, so when NCCDPHP received fairly small funds and does not know how committed they are to an issue or how far they will be able to grow it, DACH often houses, grows, and births divisions out of this work. The community work would be an example of this. Dr. Collins also highlighted the aging work in the population / setting arena, stressing that she thought older adult health would prove to be very important work for them. NCCDPHP characterizes its work in four major settings: Schools, Communities, Healthcare, and Worksites. She believes that they are underinvested in worksites as a location in which the adult population spends a great deal of time. With that in mind, they are beginning to build models, tools, and ways to approach business. In the last few years, businesses have strongly communicated their understanding of how health issues are affecting their bottom lines in terms of retention, productivity, and hard health costs. Using heart disease as an example of how this all works together, Dr. Collins shared an example of DHSP taking a leadership role on the overall picture of heart disease, and discussed how they went about a national action plan on heart disease and stroke prevention. Heart disease prevention and control cannot be accomplished without addressing tobacco, nutrition, obesity, school health, community health, et cetera.

NCCDPHP very much works across the entire life stage, beginning with pre-conception. The basis of their work is in health promotion, early detection, and preventing complications. While they are lagging somewhat behind in early education issues, the infrastructure and capabilities are in place with school groups to step up more fully in the early education arena. The base of the model is health promotion across the life stages. They have found that health promotion even in those who are 85 years of age and older is a significant issue in terms of cost containment, health, and independence. The other parts of the model, early detection and preventive services, take many forms such as early detection in high blood pressure and preventive services in the immunization arena. Preventing complications from chronic diseases once diagnosed is also an important part of the center's activities, and incredible cost saving and health enhancing actions can be taken. While this is often thought of as the control work in "prevention and control," it can also be thought of as prevention at another stage in the disease course.

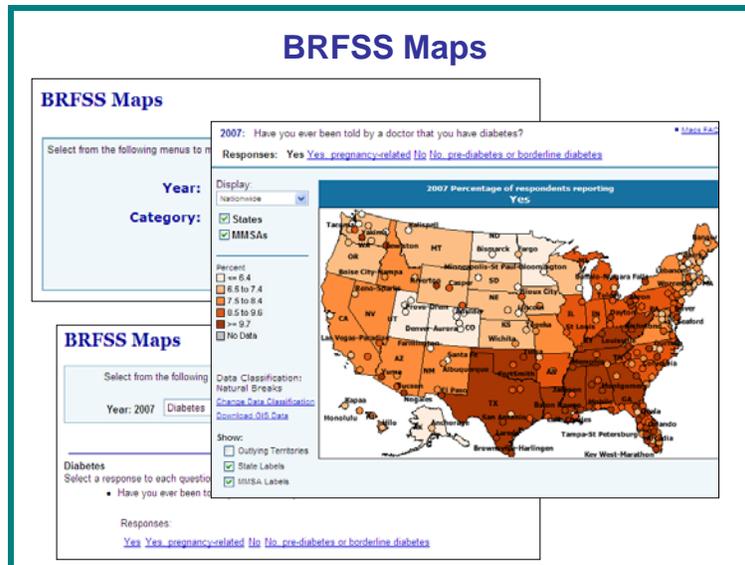
Dr. Collins offered several examples to illustrate this work, focusing first on tobacco control success from a focused, multi-component approach that included surveillance and evaluation, applied research (including the NCEH lab), state programs, policy interventions, national quitline, media, and schools. The tobacco arena has the research and experience to put in place recommendations to states and localities information not only about the most effective strategies that can be used, but also the size of financial and resource investments that it takes to get the work done. This is a fine piece of work and is a model for other areas. With respect to what that investment and comprehensive model has produced, Dr. Collins shared data on cigarette smoking prevalence among youth in the US from 1991-2007 from the National Youth Risk Behavior Surveys (YRBS) reflecting the percentage of high school students who smoked cigarettes on at least 1 day during the 30 days before the survey, which was 27.5% in 1991 and 20% in 1997. After a period of growth in the late 1990s, there was a tremendous decline between the late 1990s and the 2003-2004 timeframe. Those declines are extraordinarily significant on a national basis and will play out in reduced adult prevalence in the years to come. However, NCCDPHP is very concerned about the flattening observed in the youth picture that is probably significantly related to state investment issues. It is necessary to renew strategies in this arena, because if they could have maintained the kind of forward motion observed in the early 2000s, the level would be approximately 13%. A major struggle in the area of chronic disease is that there may be a sense of complacency that there is really nothing that can be done about these issues. There are illustrations of the type of impact that can be achieved with focused and strategic programs; however, strategies must be kept fresh in order to continue to produce dramatic effects. She then shared a video of a newscast to illustrate the kind of work that drives the policy agenda in very important ways.

Turning to early detection work, Dr. Collins shared an example from DCPC's work in encouraging and providing access to mammography screening in the US. Referring to data reflecting the percentage of US women ages 40 and above having had a mammogram within the past two years by state from 1991-2006, she pointed out that one of the service delivery areas NCCDPHP provides is mammography and cervical cancer screening for women who are uninsured or under-insured and who are very hard to reach. Part of the responsibility of this program is not only serving these women with good quality, but also is about promoting the importance of mammography for all women across the country. NCCDPHP tracks receipt of services and has observed dramatic increases in the percentage of women obtaining mammography. The combination of improvements in early detection, screening rates, and treatment translates fairly directly into significant improvements in the breast cancer death rate. Dr. Collins then shared a clip titled "The Screening" with actor Jimmy Smits to highlight the

media work that has been done within NCCDPHP. There is a clearly evidenced effective and available screening tool that can make a difference in terms of cancer outcomes in the US, but it is vastly under-utilized. Perhaps with the health care reform movement ahead, people will be able to access the service under-coverage issues. There remains a monumental amount of work to do in terms of outreach and connection of individuals to service.

To illustrate NCCDPHP's work with respect to prevention of complications, Dr. Collins highlighted work in diabetes. It is known from the research evidence that there are simple, easy, and clear ways to improve the outcomes of persons with diabetes (e.g., annual eye exams, routine foot exams, careful glucose and lipid control, flu vaccine, et cetera). This is approached from a health systems orientation to produce improvement in care issues for persons with diabetes. Based on data from national samples of individuals [Saaddine, Ann Intern Med, 2006; Hoerger et al., Diab Care, 2006], between 1990 and 2002 dramatic progress was made in controlling blood sugar and cholesterol, and in regular eye exams and flu vaccinations among people with diabetes. This is not based on a pilot study in one sample or one state, but rather included every representative sample of everyone with diabetes in the country. With respect to progress in control, observed between 1995 to 2005 were 25% reductions in vision loss, 35% in amputations, 23% in end stage renal disease, 16% in CVD hospitalizations, and 33% in total hospitalizations.

The interesting issue in diabetes is that they dare not let go of this important work at the same time that there is an immediate opportunity to prevent diabetes in this country. There is a dilemma because the resources used in large part to date have focused on the control of diabetes, and there have been important and significant results that the center is deeply committed to continuing. At the same time the results of the Diabetes Prevention Program Trials out of NIH, to which NCCDPHP contributed in a number of ways, showed that lifestyle interventions with persons with pre-diabetes would have significant results in prevention of diabetes. Efforts are now underway in pilot settings to translate that from a clinical trial into effectiveness research, working in concert with the YMCA of America to establish community services programs to which clinicians can refer their patients. While this is an important piece of pilot work, NCCDPHP must move on to rapidly scaling up in a significant manner. The BRFSS is a very nice way to make data more accessible to users on the web. In the NCCDPHP website, BRFSS maps can be pulled up for any year and any category of health, risk factor, and outcome in order to see mapping information about the percents of adults in the country who have ever been told by a doctor that they have diabetes. The circles in the maps within the state information illustrate BRFSS's innovations to combine their data over years and expand samples where possible in order to get increasing localized data for these important BRFSS measures. The more localized the data, the more effective and impactful it is in terms of driving responsiveness at the local level to these concerns. Also reflected in this illustration is that with the obesity epidemic, diabetes numbers are rising considerably and action must be taken on the prevention mission within the diabetes challenge:



There are 50 state programs within NCCDPHP that fall under block grants, tobacco control, diabetes, breast and cervical cancer, and comprehensive cancer. It is unfortunate for the nation that there are not 50 state health programs in issues such as nutrition, physical activity, obesity, heart disease, stroke prevention, et cetera. Instead, it is a patchwork quilt of resources into the states in terms of chronic disease prevention. One example of a way around the inflexibility of funding is a program developed by DCPC titled "Comprehensive Cancer." This program is driving some very exciting work throughout the nation in that states are analyzing their cancer epidemiologic data and setting forth state-based cancer plans pertaining to what they want to address. This is very cross-sectional with respect to examining risk factors, populations at risk, and important issues to address at state and local levels. The beauty of this model is that funds may be used from ovarian cancer, blood cancer, prostate cancer, et cetera in order to make the funding lines into a cohesive whole at the local and state levels. This is an interesting model that can be used to deal conceptually with the multitudes of funding lines.

NCCDPHP is engaged in some very exciting work with states. Approximately 20 states have all of NCCDPHP's core funding, having competed in such a way that they ended up with the full package. NCCDPHP is moving forward in four of those states to conduct an innovative pilot to work with the states' chronic disease dollars to turn those dollars into a single grant mechanisms, fully coordinating the categorical funding streams, and giving the states a single point of contact (POC) at CDC with completely unfettered access to CDC's technical expertise (e.g., they do not have to go through their single POC to get to tobacco control to get a quick answer about what to do about something). This is a three-year pilot project with a planned evaluation to examine the outcomes of this effort, planned and unplanned. NCCDPHP has some very strong programs and wants to be very careful as they move forward to work in a way that will take the center into the future with very strong and more cohesive chronic disease programs. These pilots do not take away the connection between the dollar and its categorical function; that is, tobacco dollars work on tobacco, cancer dollars work on cancer, et cetera. They are simply asking states to examine their entire set of dollars in each domain to craft a comprehensive plan regarding how those dollars are to be used. NCCDPHP can report back to Congress what is being done with tobacco dollars while at the same time the state can plan for their tobacco activities within the breadth of the chronic disease program. This likely represents the future in terms of doing business with the states.

With regard to intramural science at NCCDPHP, scientific work is planned for within the divisions as part of their strategic planning. When NCCDPHP's scientific work is at its best, it really is very much planned to answer questions that are on the minds of practitioners in the field. One example of that was research to determine whether sealants could be provided to children in schools without having to use a dentist in order to make it affordable and efficient. By showing what the outcomes could be, they can now move forward with a program of that nature. Some other examples include the following in each area of NCCDPHP's research categories:

❑ **Surveillance and Epidemiology**

Ford ES, et al. Explaining the decrease in US deaths from coronary disease, *NEJM*

❑ **Economics and Modeling**

Jones AP, et al. Understanding diabetes population dynamics through simulation modeling, *AJPH*

❑ **Program Evaluation**

Farris RP, et al. Evaluating the public health impact of the WISEWOMAN program  
*AJPH*

❑ **Applied Research**

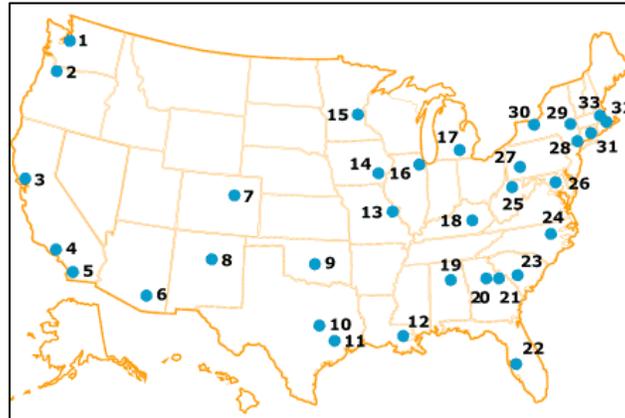
Sabatino SA, et al. Health insurance coverage and cost barriers to needed medical care among US adult cancer survivors less than 65 years of age. *Cancer*

Tucker MJ, et al. The black-white disparity in pregnancy-related mortality, *AJPH*

❑ **Research Synthesis**

Malhotra A, et al. Metaanalysis of genome-wide linkage studies of quantitative lipid traits in families with type 2 diabetes, *Diabetes*

Approximately 400 peer-reviewed publications come out of the center each year. In terms of the allocation of research dollars between intramural and extramural projects, almost without fail the intramural costs are primarily personnel. NCCDPHP does not tend to engage in a great deal of new data collection, which is typically extramurally funded. The center's researchers tend to work closely with the academic researchers outside of CDC on their publication and work. Much of that extramural funding is driven by the center's work with the 33 Prevention Research Centers (PRC) program, which is a major flagship for the center and offers an excellent way to conduct applied research in communities. The following map illustrates the location of the centers, which include: 1) University of Washington, 2) Oregon Health & Science University, 3) University of California at Berkeley, 4) University of California at Los Angeles, 5) San Diego State University & University of California at San Diego, 6) University of Arizona, 7) University of Colorado, 8) University of New Mexico, 9) University of Oklahoma, 10) Texas A&M Health Science Center, 11) University of Texas Health Science Center at Houston, 12) Tulane University, 13) Saint Louis University, 14) University of Iowa, 15) University of Illinois at Chicago, 16) University of Minnesota, 17) University of Michigan, 18) University of Kentucky, 19) University of Alabama at Birmingham, 20) Morehouse School of Medicine, 21) Emory University, 22) University of South Florida, 23) University of South Carolina, 24) University of North Carolina at Chapel Hill, 25) West Virginia University, 26) Johns Hopkins University, 27) University of Pittsburgh, 28) Columbia University, 29) University at Albany, SUNY, 30) University of Rochester, 31) Yale University, 32) Boston University, and 33) Harvard University:



These centers respond to the need for an interface between schools of medicine, schools of public health, and schools of education. These are interdisciplinary centers within their academic setting. They are required to work with a community panel that drives their research decisions about what they are going to pursue, and their work is actually research in the community.

Five years ago, NCCDPHP put into place a peer-reviewed journal titled “Preventing Chronic Disease,” which is a fully on-line journal that is completely free and accessible throughout the world. In reviewing the journals in chronic disease, NCCDPHP noticed that there was a gap in the interface between science and practice, and that there is oftentimes an inability for people to describe more fully what they have done from a practice perspective, publish issues pertaining to program evaluation, and discuss more in-depth about how programs were established and what outcomes they have achieved. This journal is now translated into Spanish, with abstracts in French and Chinese. NCCDPHP is very proud of this journal and the response has been tremendous.

With regard to responding to the global burden of chronic disease, although this is a very important issue, NCCDPHP is vastly under-funded in this arena. In terms of chronic disease, there is very little worldwide public health infrastructure and capacity, although some unique opportunities are on the horizon. One of these opportunities is with the PEPFAR program, which has been the platform of work in HIV prevention around the world. There is likely to be an opportunity with the new administration for that to have a much broader focus of opportunity for NCCDPHP with respect to using some of the infrastructure that has been built in the platforms to serve HIV prevention needs, and to build out from that in the chronic disease arena. NCCDPHP is engaged in a considerable amount of applied surveillance and research throughout the world. All of these efforts greatly enhance the exchange of information and lessons learned. Brazil is engaged in some efforts that the US is not yet working on in terms of the built environment, and NCCDPHP is able to conduct the wrap-around evaluation as they work on their built environment issues. NCCDPHP has many strategic partnerships, such as a Pan American Health Organization (PAHO) collaborating center; some important work and a person stationed to work at the US / Mexico border; and a developing collaboration between China CDC and CDC on chronic disease issues, with the two directors of these agencies meeting annually to discuss strategic issues upon which they would like to work together. Other global activity partners include the Bloomberg Family Foundation (donated over \$20 million to the CDC Foundation), CARE Inc, CDC Foundation, Carter Center, Department of State, Gates

Foundation, and the World Health Organization (WHO), academic institutions, Training Programs in Epidemiology and Public Health Interventions NETWORK (TEPHINET), UNICEF, United States Agency for International Development (USAID), International Union for Health Promotion and Education (IUHPE), Ministries of Health, and World Bank.

Regarding challenges and opportunities, NCCDPHP needs to focus on having resources, capacity, and infrastructure match the scope of the problem that needs to be addressed. The scopes of the problems are enormous, and the populations that need to be addressed are vast. State and local public health capacity for chronic disease prevention must be established in order to address these issues. NCCDPHP is providing leadership, but needs to do even more in the upcoming environment to provide leadership on the clinical / public health interface to addresses issues such as electronic medical records and their interface to public health, surveillance and clinical-community linkages, and helping to provide public health input to the reform movement. NCCDPHP hopes to provide leadership on social determinants of health across multiple sectors, and to learn from those who are ahead of the US in Europe, Canada, and elsewhere with respect to these issues. One idea with which the CCHP might like to grapple is addressing social determinants of health through a health in all policies approach and through the Health Impact Assessment (HIA) as a methodology to get that done. For example, it would be interesting to see what the impact of No Child Left Behind would have been if there had been an HIA before the campaign hit the nation. This was a very important piece of legislation, but it did some significant harm to physical education and health curricula in this country. Perhaps unintentional consequences could have been avoided if a health assessment had been conducted prior to that legislation moving forward. While it was not yet clear what CDC's role should be in that; however, it seems that some type of independent group is called for in order to address this. Dr. Collins thought it would be extremely powerful if the CCHP BSC could speak to the health in all policies approach. In addition, it is imperative to establish mental health and alcohol / substance dependence as public health issues and to establish a robust global health response to the burden of chronic disease.

Most of the centers at CDC were participants in the Office of Management and Budget's (OMB's) Program Assessment Rating Tool (PART) Review, which is a systematic method of assessing the performance of program activities across the federal government. NCCDPHP scored well on the review, but the center's primary shortcoming was in demonstrating effectiveness and efficiency through external review. It seemed that it would fall under the purview of the CCHP BSC to consider assisting the center to fulfill this charge. Regardless of whether the OMB PART morphs or changes entirely as a function of the new administration, the essence of the idea is right—to have an external examination of NCCDPHP's strategies and approaches and to receive feedback.

### **Discussion Points**

- Dr. Goff noted that some common themes existed in the presentations made by Drs. Trevathan and Collins, which included: 1) the potential for the CCHP BSC to communicate with other FACA-chartered boards and/or advisory councils for other federal agencies, which might pose an opportunity for the BSC to help enhance the centers' missions; 2) the importance of collaborations and partnerships with other federal agencies, which he encouraged both centers to continue to develop and requested continual updates to the board about on-going efforts in this area to better understand leveraged opportunities; 3) the importance of HIAs and ensuring that such efforts are funded and attention is paid to training people and building the capacity to conduct them; 4) the importance of collaboration across the two centers, particularly in terms of the notion of chronic disease prevention in

people with disabilities; and 5) advancing public policy with the use of research (e.g., smoking bans in public places); good data are crucial with regard to the ability to move policy forward.

- Dr. Curtis pointed out that while each center has its own mission and its own set of goals, there did not seem to be specific common goals for the two centers to work together. It seems that some type of culture needs to be set forth in order to improve relational opportunities.
- Dr. Collins responded that this was the foundation of the CDC Goals Project and the CDC Goals Leaders in the agency as a whole. All centers are under the rubric of the CDC life-stages in setting goals and each center sees itself within those goals. She agreed that in a number of regards, they tended to use different language across divisions, and probably use different conceptual models at various times. Sometimes the titles do not carry the essence of the work. She felt that she had inherited some nice titles and ways of thinking about the problems so that her division names aligned more closely with each division's work.
- Dr. Trevathan added that while NCBDDD does work across the lifespan, the center's name is an on-going issue. He, too, inherited the structure. It is true that there is a difference in the way the language is used, and a difference in the relative weight of how the budgets are done. NCBDDD has a higher percentage of research relative to health promotion activities. Nevertheless, the two centers do complement each other very well and they are constantly looking for opportunities to work across centers. He welcomed any specific observations about how they could do this better.
- Dr. Emmons noted that one struggle in the field as a whole regards how to develop the next generation of young researchers, who are much more imbedded in practice. It struck her that there were some wonderful opportunities for partnerships with respect to training.
- Dr. Collins replied that training and training partnerships to develop the next generation of researchers is not particularly formalized or comprehensive, although CDC has established an Office of Workforce and Career Development (OWCD) to address these issues. There are a number of innovative fellowships and other opportunities available, although there is a scale problem in that there are funding limitations with respect to the number of students who can be placed.
- Dr. Bowman, Division of Cancer Prevention and Control (DCPC), added that most investments in training have been at the post-graduate level, both through the Epidemic Intelligence Service (EIS) Program where the center has seen an increasing number of EIS Officers over the last several years, and through the Prevention Effectiveness and Health Economics Branch (PEHEB). There is a CDC Experience Program where a number of fellows have recently trained in reproductive health and in cancer. These are medical students who engage in a fellowship before their graduation from medical school, which has been an extremely influential experience for them in terms of their long-term career goals. There has not been the impetus to invest as much as they could, however, other than through the PRC program. CDC has work study programs and extensive summer research fellowship programs.
- Dr. Goff asked whether there was any experience with programs at CDC such as NIH's T32 or K12 programs, and if not whether there were any plans to develop such programs.

- Dr. Bowman responded that there are such programs at the CDC level. One of Dr. Gerberding's important priorities was to increase research funding. Over the last several years, there have been a fair number of investments in fellowships for mid-career, change of career, and dissertation fellowships. While the funding has been relatively limited, there has been a major emphasis and interest from the CDC level.
- Dr. Colley-Gilbert added that most of the effort has been focused on dissertation awards. A number of those have come through CDC's Office of the Director (OD) funding that has been made available across all of the centers. There also has been some limited funding for mentored research awards and change of career post PhD awards. The two CCHP centers here have benefited from a few of those awards. Another program that has been underway for about five years, through that same source of funding, are the P30 awards in institutional centers of excellence in order to train new professionals in the public health arena.
- Dr. Wolraich inquired as to whether any relationships had been developed with Maternal and Child Health Bureau (MCHB) training.
- Mr. Lehnherr, DRH, responded that they had conducted some distance-based work with Emory University in collaboration with MCHB, as well as through fellowships with the Council of State and Territorial Epidemiologists (CSTE). DRH has worked closely in on-going training with the Association of Maternal and Child Health Programs (AMCHP) and CitiMatCH at each of the national annual conferences, as well as its own Maternal and Child Health Annual Conference. DRH also provides scholarships for students to attend each of those three meetings to participate and network, which has become a very useful recruiting tool for states and CDC.
- Dr. Kolbe wondered to what extent the 33 PRCs had written within their mandates some type of responsibility for assuring the training of people who are working on graduate degrees with them.
- Hearing the presentations about the centers seemed to Dr. Bal to be like a "Tale of Two Cities." One center justifiably, given the fact that their portfolio broadened, has increased its funding over the last few years; that is, based on Dr. Trevathan's presentation, the fairly big additional increases seem justifiable. However, NCCDPHP's budget has decreased. Dr. Collins drew cause/effect relationships between mammography rates and the dose-response effect, for example. It is necessary to consider the money with respect to the docimetry versus the effect. Exposure, effect, and money are easy to quantify. It would benefit the centers to show the dose-effect responses that have been achieved. He found the word "securitization" used in conjunction with tobacco settlement dollars to be an atrocity, and that that the BSC should address this. Another huge sound bite that they should be using regards the fact that all programs are not in place in all states, but should be. Global burden of disease and social determinants are also very important concepts to address. He also thought they could make the case using any general metrics for morbidity, mortality, and disability to justify the doubling of these two centers' budgets very easily, and that this should be a major focus of the BSC.
- Dr. Kleinman wondered how often the program reviews were conducted, whether a particular protocol was used, and how those reviews were utilized in terms of the setting and implementation of priorities for the two centers and the CCHP as a whole. With respect to the concept of health assessments and impact, she wondered whether there was an

assessment across the center to examine new initiatives within the divisions. For instance, the diabetes example did not include an oral health component, yet it is one of six major signs of diabetes and contributors to glycemic control. Using opportunities, regardless of the topic or risk factor, to examine the possible roles of other risk factors, diseases, interventions, or settings seems to present a wonderful opportunity for enhancing the work of each of the component parts. This could begin with a protocol of health assessment impact within programmatic areas that might then become a generic protocol for assessing legislation and other aspects as well.

- Dr. Collins responded that on an annual basis, the centers go through a planning process with each of the divisional budgets, during which consideration can be given to potential new opportunities for better integration. The external reviews are required to be conducted every five years in the divisions. The center responds to the divisional reviews programmatically.
- Dr. Airhihenbuwa noted that in the area of global activity, the centrality of social determinates was very important. Discussions should focus on globalization versus internationalization, given that international activity in the past suggested a focus on activities that take place beyond the border. With globalization, there is a recognition that issues are not just occurring outside the US. They must determine how to have conversations that transcend borders to address the issues that are common concerns to everyone and the timing is right for this. CDC has a Coordinating Office for Global Health (COGH) and within the NCCDPHP there is an Office on Global Health (OGH), although he was not sure if there was such an office in NCBDDD or any other centers. They must capitalize on the excellent work that is being done in this country, such as the smoking work. Banning smoking in France in public places took a cultural change. The REACH project is another good program on which they should capitalize. The conversation around global social determinates is not an invitation to go to Europe to discuss it, but an invitation for a unit such as this to have a meeting and a committed program that is actually bringing all this to bear in terms of how to move forward in global health and globalization.
- Dr. Bethell requested that the BSC members be provided with the division and PART reviews, given that a lot of thinking had already been done as a result of those. In order to justify the need for more funds, she thought it would also be important though to review each center's priorities and how they are also being addressed by other CDC centers and other agencies. Children with special health care needs and promoting healthy early childhood development seem to be increasingly important areas. While this is part of the NCCDPHP's agenda, it is not really on the preventive or developing side. It is more on dealing with screening, secondary conditions, and onward. She wondered if perhaps that was because other groups or agencies were dealing with it as well. She worried about the imbalance between how much children are attended to versus adults, and whether those issues were discussed within the center. These issues do play out at CMS and elsewhere, so it would be important to consider the relative investment in children versus adults with respect to chronic disease.
- Dr. Trevathan responded that it is true that NCBDDD has relatively more childhood-focused activities, but is not exclusively childhood focused. He estimated that two of the three divisions probably spend as much of their time and effort on programs with adults as they do with children. The DBD and the DHDD deal with adult disability and adult blood disorders. Deep vein thrombosis is remarkably adult-oriented. NCBDDD works very closely with MCHB and while they have different roles, they do work together. There are still gaps that neither is addressing, so this is a productive area to investigate.

- Dr. Toomey ask that DRH provide data support to HRSA Title V activities. So, there is cross-fertilization. Other child health efforts are scattered across the agency, such as immunizations and injury.
- Dr. Rimmer reminded everyone that the two centers were developed in very different eras, one in 2000 (NCBDDD) and the other 20 years ago (NCCDPHP). Disability is a relatively new field in terms of surveillance and epidemiology, so resources in that area need to be increased to the level where chronic disease has been for a number of years.
- Dr. Beaty thought part of the challenge was going to be in documenting what she has always thought was a rather confusing role between CDC and the states in terms of who stimulates whom, who benefits from interactions, et cetera. Beneficial interactions should be easy to document and could become fodder for arguing why this is worthy of support and growth.
- Having learned many things during these two presentations that he did not know, which it seemed he should know working in the field as long as he had, Dr. Cohen stressed how this illustrated the importance of communicating what is going on at CDC to the professional community and the general public.

### Discussion of the CCHP BSC's Potential Roles

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

During this session, Dr. Kolbe led those present in a discussion of the CCHP BSC's role in: 1) assessing quality, relevance, and impact; 2) the OMB / PART review process; and 3) in the secondary review process. He summarized the list of issues which had predominated the CCHP BSC's deliberations during the past two days, within which additional comments made also have been subsumed:

- 1) Characterize the disease burden that is being addressed by each and both centers and the comparable funding that is being provided to address that disease burden:
  - Address this as part of the concern about dose response and the impact of the efforts of these centers with the resources that they have been provided
  - Update the numbers in order to make a very strong case
  - Perhaps have an article in-hand that can be shared at anytime to make the case for comparable funding based upon disease burden
  - This information can be used to make the case that all good programs should be funded in all 50 states

- Consider the “low hanging fruit”, such as a focus on the connection between tobacco and chronic diseases which could help to garner funding; sentiment was expressed that this should be done fairly quickly in order to capitalize on the tobacco tax funding coming down the pike—6 months down the road will be too late
  - Longer term goals must be pursued simultaneously with shorter term efforts such as tobacco funding
  - Examine the issue of where obesity is today versus 15-20 years ago, perhaps sponsoring or co-sponsoring with MCHB an assessment to determine whether this is a new primary direction for increasing funding
  - Make a business / economic case for productivity, especially in terms of programs that address children
- 2) Each and both centers need to optimize the ability to communicate important messages to stakeholders (e.g., state health departments, the public, Congress, and many others) to make the case for the critical work that is being done and the work that needs to be done:
- Getting sound bites into the media, such as Senator Daschel’s remark that he wanted to “make prevention hot and wellness cool,” is imperative
  - Amplify messaging through the Health Marketing Center and other means is also essential; many great things are occurring that no one knows about
  - There should be integrated, coordinated communications both intra- and inter-agency; the CCHP’s role in this effort should be strengthened and it should be someone’s specific duty to promote the focus on all areas under the center’s purview (e.g., physical activity, nutrition, obesity, et cetera)
- 3) Examine existing and potential collaborations with other FACAs, agencies, academia, et cetera:
- It is important to understand the work of both centers in the context of what is being done more broadly across other agencies, which can help the centers’ find their niches and make the greatest impact
  - Collaborative efforts are massive in number and type and could result in an enormous amount of information, so the BSC should give the CCHP some direction in which to focus (e.g., social determinants efforts or health assessment impact work)
  - Perhaps this should be selective and strategically focused depending upon the direction of the work rather than across the board
  - The BSC likely needs to understand the most important collaborations for moving forward and leveraging funding
  - Programs “in the back pocket” or “shovel ready” might be addressed with partnerships in order to move them into implementation more rapidly

- Not only could the BSC suggest new connections that CCHP is not currently making, but also they could assist in making those connections
  - While it is clear that the two centers within CCHP collaborate on a number of efforts, it is not clear that this is done in a coordinated manner (e.g., having a formal process and a dedicated person(s) responsible for orchestrating and tracking such efforts)
  - More extensive collaborative efforts are required between academic medical centers and schools of public health, particularly given that the current generation of students takes a much more comprehensive view of health
  - Make the business case to promote partnerships; encourage the development of a business case to promote prevention more broadly
- 4) Address social determinants, including:
- Income disparities
  - Population- /-health impact assessments
  - Health in all policies, using illustrations such as policies to ban tobacco
  - Learning from our colleagues in other nations and understanding whether that would reap benefits for the centers
  - The strong evidence that suggests that an early childhood focus is strongly connected to productivity and is also a way to get at socioeconomic issues, given that a lot of the risk factors and highest risk groups are from socioeconomically disadvantaged groups in America
- 5) Prepare for the change in the administration, as well as in CDC leadership:
- Prepare/--position CCHP and its centers and divisions for that change
  - Perhaps there will be a renewal of interest in early childhood development and some opportunities in that arena
  - Within days of the new administration, there is a potential for re-uptake of FCTC, FDA regulation, and considerable tobacco excise tax increases to fund SCHIP
  - Have all programs that are “in the back pocket” or “shovel ready” (e.g., unfunded social determinants, nutrition, school health, oral health, et cetera programs) or that should be “in the back pocket” or “shovel ready” (e.g., birth defects surveillance) ready to go
- 6) Address the charge from OMB to engage in an independent evaluation of CCHP and its centers and divisions:
- This might include an examination of the structure of the centers in general, which may result in learning where change is needed or that having the structures of each dictated by funding streams and history is appropriate

- Effectiveness of projects and programs should be tackled within this evaluation
  - Perhaps Phase 1 of the BSC's work should be an examination of the reviews that have been conducted to date in order to avoid making assumptions that those reviews have already taken care of certain issues and/or to avoid duplicative efforts; Phase 2 could then be a co-imagination with center staff to consider scenarios / goals for moving forward (e.g., implementation of "back pocket" programs, 100% of programs in all states, developing / testing interventions, et cetera)
- 7) Training and preparing the next generation of leaders, researchers, and practitioners is a critically important issue:
- Perhaps health education can be included, particularly with respect to the relationship of chronic illness and disability to productivity / infrastructure issues
  - Work with the Office of Workforce and Career Development (OWCD)
- 8) Maximizing the use of technology (e.g., in surveillance systems, health records, family histories, personal records, incorporating multiple databases, imaging, et cetera)
- 9) Address issues pertaining to research and program:
- Should research and program be addressed separately or in combination?
  - Not enough applied/translation research is being conducted
  - NCBDDD has a higher investment in research, given that they do not have interventions in some areas
  - An examination should be made of where there is enough research so that resources can be shifted to policy emphasis
- 10) Potentially address the issue of the NCBDDD name:
- This is a politically sensitive issue
  - There was sentiment that this is not the right time to tackle this issue, given that they are likely to get a lot of push back from advocacy groups that will oppose a change
  - Restructuring can be a daunting task; CDC is still recovering from the Futures Initiative that began in 2003 to restructure the agency
  - It was suggested that the BSC focus on the scientific and collaborative questions so that function can drive structure rather than the other way around
  - There appeared to be consensus pertaining to not attempting to change NCBDDD's name at this juncture

Prior to making some determinations regarding which issues the CCHP BSC might tackle and what type of subcommittee(s) might be formed to address these issues that might be undertaken, Dr. Kolbe requested the Cathy Ramadei review the charter with respect to proper protocol and ethical issues.

At this point, the following determinations, suggestions, and comments were made with respect to moving forward:

- The format to be utilized will be workgroups, which should include representative(s) from each of the centers to be part of the team thinking things through
- The consensus seemed to be that the workgroups should be focused topically/priority-wise rather than by centers
- Each BSC member will receive copies of the five-year center reviews, and the responses to those reviews from both centers, which would be reviewed by the full BSC rather than by each workgroup; also suggested was that the reviews and responses should be evaluated through the lens of the 9 topical areas suggested
- It would be timely to address the PART review on behalf of NCCDPHP
- The 9 topical areas could be coupled in some manner so that the workgroups could tackle them in pairs, with the following beginning suggestions offered (those with members' names attached represent the first cut ultimately decided upon):

TOPICS		CHAIRS / MEMBERS
<b>Overarching:</b> OMB / PART reviews		Beaty, Emmons, Goff (Chair), Macera,
<b>Set 1:</b>	1 disease burden / "shovel ready" 5 changing the environment	Bal (Chair), Curtis, Wolraich
<b>Set 2:</b>	2 communication with stakeholders 8 use of technology	
<b>Set 3:</b>	3 collaboration with others 6 external evaluation	
<b>Set 4:</b>	4 social determinants 7 training / capacity-building)	Dr. Airhihenbuwa (Chair), Bethell, Cohen, Kleinman, Rimmer
<b>Crosscutting Issues:</b> Research, Programs, Children, Women		

- Some panel members did not feel they could commit to specific topics until they had a more in-depth understanding of what was occurring in the CCHP and its centers and divisions. After the reviews are read and with more historical background, it may be that these topic areas will change. It is also important to speak not only with the directors, but other levels of staff in each area as well. A teleconference could be convened after everyone has had an opportunity to review all of these data.

- There will be an opportunity for a mid-course review in order to revise what the workgroups are doing if necessary.
- The workgroups should not be trying to micromanage what is going on in the centers and divisions.
- Two of the nine areas were identified as being more time-urgent than the others (e.g., the OMB evaluation and the “shovel ready” projects). The other areas could then be evaluated upon receipt of the reports the members will receive, and the work could perhaps be divided by report rather than by area.
- The outline on Page 24 of the Charge offers some direction with respect to higher level assessment.
- It was not clear to everyone how workforce development and social determinants fit together.
- It was suggested that something broader was needed with respect to health policy issues.
- Perhaps the chair of a workgroup who is an expert in chronic disease could be matched with a co-chair whose expertise is in disabilities or vice versa.
- The OMB/Part effort is going to be daunting and really should not be coupled with any other tasks. It would be helpful to NCCDPHP to have a workgroup standing by with which they can work to complete an external review as required by the PART review.
- It was suggested that consideration be given to first addressing the following: 1) OMB/-PART; 2) disease burden / “shovel ready” issues; and 3) social determinants, with a commitment to review where these efforts stand within the next three months. A system, including a feedback loop, can be built in.
- Consideration should be given to having a webpage or listserv.

### Public Comment

No public comments were offered during this CCHP BSC meeting.

### Closing Remarks

Drs. Toomey, Steinberg, and Kolbe offered their gratitude to the CCHP BSC members for their commitment, enthusiasm, lively discussion, and the enormous amount of work in which they agreed to engage. With no further business posed, the first meeting of the CCHP was officially adjourned.



**Certification**

I hereby certify that to the best of my knowledge, the foregoing Minutes of the January 14-15, 2009 CCHP BSC Meeting are accurate and complete:

\_\_\_\_ May 22, 2009 \_\_\_\_\_  
Date

\_\_\_\_\_/s/\_\_\_\_\_  
Lloyd Kolbe, PhD, CCHP Chair