IVC. Centers for Disease Control and Prevention (CDC)
Coordinating Center for Health Promotion (CCHP)
National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP)
National Center for Birth Defects and Developmental Disabilities (NCBDDD)

Minutes of the Teleconference Meeting of the Board of Scientific Counselors
September 15, 2009

The CDC CCHP Board of Scientific Counselors (BSC) held a conference call on September 15, 2009. The call, which previously was announced in the *Federal Register* and was open to the public, was convened to enable the BSC specifically to vote on Recommendations to CDC leadership. Those in attendance were:

In attendance:

Collins O. Airhihenbuwa, Ph.D., M.P.H.
Dileep G. Bal, M.D., M.P.H.
Terri Hagan Beaty, Ph.D., M.A.
Herbert J. Cohen, M.D.
Michele G. Curtis, M.D., M.P.H.
Karen Maria Emmons, Ph.D.
David C. Goff, M.D., Ph.D.
Sharon L. Kardia, Ph.D.
Dushanka V. Kleinman, D.D.S., M.Sc.D.
Lloyd J. Kolbe, Ph.D. (Chair)
Caroline A. Macera, Ph.D.
David G. Marrero, Ph.D.
James H. Rimmer, Ph.D.
Mark Lee Wolraich, M.D.

Absent: Christina Bethell, Ph.D., M.P.H., M.B.A.

CDC staff attending were: Dr. Thomas Chapel, Dr. Ed Trevathan, Dr. Karen Steinberg (Designated Federal Officer [DFO]), Dr. Janet Collins, Dr. Sam Posner, Mr. Scott Campbell, Ms. Rosie Henson, Dr. Jeff McKenna.

Each Board member previously had received three documents relevant to issues for the National Center for Birth Defects and Developmental Disabilities (NCBDDD) and to the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP: 1) a Draft Report sent on September 1, 2009; 2) full Recommendations stemming from that Report; and 3) a spreadsheet with a summary of the Recommendations to expedite the voting process. The BSC Chair advised the committee that any recommendations adopted by vote at this September 15 meeting could not be changed substantively without another official meeting of a quorum of BSC members to vote on any proposed changes, although some technical or conforming edits could be made. The fact that the votes were on the original more detailed Recommendations submitted in writing to the BSC, not on the very brief Recommendation Summaries presented by the Chair to expedite the voting process, was repeated several times.

To enable these Minutes to be briefly written, the Recommendation Summaries are listed below. The full Recommendations can be found both in the Executive Summary of the Final Report, and embedded within the more detailed Final Report.

A. NCCDPHP Recommendations

Recommendation 1. Recommendation for increased CDC involvement and CDC Center Directors' involvement in any Congressional process developing budgetary issues and appropriations.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/Not attending: Bethell, Curtis; Emmons; Goff; Wolraich
Opposed: None
Abstentions: None

Discussion:

- Clarify that the intent of this CDC input is to educate, provide appropriate updated information, and inform, not to advocate to Congress.
- The BSC can work closely with CDC to establish the parameters through which this would be achieved.
- The brevity of this recommendation is fleshed out in its accompanying full recommendation, which provides such specifics as hiring at least one experienced full-time staff person to work on this activity, establishing fellowship programs, adequately funding chronic disease and disease prevention, etc. The focus of the Recommendation was on a strong statement on CDC's proactive work with Congress to educate and develop relevant initiatives.

Recommendation 2. Conduct a review of equity among CDC groups, focusing on leadership and management.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Goff, Wolraich
Opposed: None

Recommendation 3. NCCDPHP and NIH should collaborate to integrate chronic (NCCDPHP) programs and research with relevant NIH-supported research.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Goff, Wolraich
Opposed: None

Recommendation 4. NCCDPHP should establish sufficient means to facilitate communication among NCCDPHP's divisions, health communication groups and informatics.

In favor: Airhihenbuwa; Bal; Beaty; Cohen; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Goff, Wolraich
Opposed: None

Recommendation 5. NCCDPHP should move towards integrating its various disease-risk population- and setting-specific programs without endangering its focus constituents and funding for the more specific programs.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Goff, Wolraich
Opposed: None

B. Workforce Assessment Recommendations

Background: The BSC wished to emphasize and increase the public's and policy makers' understanding of chronic diseases' magnitude and threat to the productivity and economy of the U.S., and NCCDPHP's potential to reduce those threats. An additional recommendation was added to address actual activity to improve the workforce. Five recommendations were submitted for vote, again elaborated in the summary document. Dr. Goff joined the meeting at this point.

Recommendation 1. NCCDPHP, CDC and others should work together to increase public and policy maker understanding of the magnitude of the threat of chronic disease to health, productivity, and economy in the United States and of NCCDPHP's potential to reduce those threats.

Note: This was linked to the first recommendation, which addressed the overall importance of CDC's activities, but it was separated to reinforce the workforce related fellowship and practicum programs' importance.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Wolraich
Opposed: None

Recommendation 2. NCCDPHP should work to assure that the Public Health workforce at national, state and local levels effectively are trained and enabled to control chronic disease.

Notes:

- Four bullet points (A, B, C, and D) in the summary elaborated on this recommendation.

- Recommendation 3, item D, elaborates on the development of local workforce programs. Dr. Bal proposed revision of the wording to say "workforce at the local, state, national and international level." The vote was taken with that wording.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Goff, Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Wolraich
Opposed: None

Dr. Goff had joined the teleconference at this point and began voting at recommendation B1.

Recommendation 3. NCCDPHP should assess the effectiveness and efficiency of the current model it has in place to assure the public health workforce is trained and able to control chronic disease, and articulate feasible means to improve it.

Note: This recommendation's focus was internal to CDC versus the previous recommendation's attention to the broader public health workforce. These subcomponents are internal to NCCDPHP. Dr. Kleinman suggested replacing, after "assure public health" with "assure the internal NCCDPHP workforce is trained …" There was no objection and the vote was taken on that amended language, with no change to the Recommendation's subsequent bullets.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Wolraich
Opposed: None

Recommendation 4. NCCDPHP should identify critical chronic disease control competencies that will be required for the extramural public health workforce, establish means to measure attainment of those competencies and develop training strategies.

Note: The issue focused on whether there's an opportunity to develop extramural training programs, which do not currently exist at NCCDPHP. The intent was to encourage a mechanism to broaden the involvement of people within the workforce. The question of whether grants for training or Schools of Public Health for competencies and fellowships was raised.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Wolraich

Opposed: None
Recommendation 5. NCCDPHP should develop specific recommendations for various disciplines to develop expertise that could be used by that discipline and as part of multi-disciplinary and trans-disciplinary efforts to control chronic diseases, e.g. economics, political science, law, medicine, other.

Note: A few examples were provided, to which it was suggested to add "social sciences" (between "medicine … and others"), as the social sciences are key to reaching high-risk populations. However, the summary recommendations text included "… other disciplines that NCCDPHP believes would be critical or could be critical," and the social sciences are listed in the full recommendation. The recommendation was voted on as it was written.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Wolraich
Opposed: None

C. Research Infrastructure and Surveillance Recommendations

Recommendation 1. NCCDPHP should build collaborative programs on its current model and expand partnerships to generate co-funding and co-infrastructure support to extend the capacity at NCCDPHP and support existing surveillance systems and build new ones.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Wolraich

Recommendation 2. NCCDPHP should adjust funding to support the following: a) provide discretionary funds to allow flexibility to move into new areas and increase use of key surveillance systems, such as PRAMS; b) provide additional support for current surveillance systems to maintain a high level of participation by the states; c) provide stable resources and maintain NCCDPHP's work in improving surveillance system methods; and d) provide support to develop the use of E-health records as part of surveillance, particularly through community health settings.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer
No response/not attending: Bethell; Curtis; Emmons; Wolraich
Opposed: None

Drs. Wolraich and Curtis joined the teleconference at this point.

Recommendation 3. NCCDPHP should align its priorities to address the following issues: a) maximize use of multiple data systems, to provide comprehensive surveillance for specific diseases as is currently being done for diabetes; b) maximize use of surveillance systems to evaluate effectiveness of policy and clinicians at the local level; c) provide leadership and workshops for development of implementation of community based survey methods; d) facilitate access to and utilization of current CDC surveillance system data; e) increase outreach to academic researchers to more efficiently use surveillance data, f) utilize the Center's data to conduct modeling studies to estimate potential costs and social impacts of proposed intervention of medical procedures policies, especially with regard to primary prevention; g) maximize the reach of existing data by encouraging collaboration across divisions within NCCDPHP and across other centers; h) maximize reach and surveillance data by maximizing use of existing data from other agencies; i) coordinate approaches to identifying and addressing surveillance needs to support the implementation and evaluation of programs to prevent and control the major chronic diseases; and j) coordinate approaches to eliminating outdated and redundant data collection efforts.

Notes

- Dr. Cohen suggested that "costs of social impacts," be added to "… cost effectiveness and social impacts of the proposed intervention." In item "f".
- It was suggested to delete the phrase "especially with regard to primary prevention," and stopping after "medical procedures and policies."

The vote thus approved the following text: "Utilize NCCDPHP's data to conduct modeling studies to estimate potential costs, cost effectiveness, and social impacts of proposed intervention of medical procedures and policies; coordinate approaches to identifying and addressing surveillance needs to support the implementation and evaluation of programs to prevent and control major chronic diseases; and eliminate outdated and redundant data collection efforts."

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

D. Public Health Strategies for Chronic Disease Prevention.

Recommendation 1. NCCDPHP should enhance geographical coverage and corrective interventions: a) provide funding for all states, provide core chronic disease prevention programs; b) use and coordinate counsel for cardiovascular health as modeled to enhance integration of programmatic activities across divisions and all centers; c) require and enable states to report on their success in integrating programs across CDC funded programs; d) establish a systematic partnership, development and coordination effort to enhance the capacity of non-government partners to coordinate and integrate their

relevant activities in support of policies and program development, to prevent and control chronic diseases.
Note: (d) was edited for clarity, to: "enhance the capacity of non-government partners to coordinate and integrate their involvement or support into chronic disease prevention control activities."

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Recommendation 2. NCCDPHP should adjust the current funding mix to ensure that the focus on programs is primary, with research as support, and should support rigorous evaluation and program performance.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Recommendation 3. NCCDPHP should work to assure that translation of science to public health actions is equally based on scientific evidence, common sense and good public health practices.

Note: The text was made more specific to distinguish between basic science and public health science: "the translation of science to actions for the public health." The recommendation now reads: "NCCDPHP should work to ensure that translation of science to actions for the public health is equally based on scientific evidence, common sense, and good public health practice."

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Recommendation 4. NCCDPHP should work with CDC to achieve an appropriate balance in CDC funding across NCCDPHP that is reflective of the burden of disease and the potential for enhancing health of the population.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Recommendation 5. NCCDPHP should ensure that program activities are grounded in the socioecological model rather than solely on the medical or behavioral models, and are focused on social determinants of health.
Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Dr. Marrero left the meeting for a few minutes at this point.

Recommendation 6. NCDDPHP should enhance programs that focus on screening to incorporate a greater emphasis on lifestyle counseling and other aspects of prevention.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Recommendation 7. NCCDPHP should establish programs that codify the competencies and roles of community health workers to prevent and control chronic disease.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Rimmer; Wolraich
No response/not attending: Bethell; Emmons, Marrero

E. General Summary Recommendations

Recommendation 1: The NCCDPHP Director must have a direct line to the CDC director.

Notes: The CDC is being reorganized to provide a deputy director who likely more efficiently will support interaction between the CDC director and NCCDPHP directors. The recommendation was amended to read "The NCCDPHP director should have "more direct communication" with the CDC director." Keeping the second sentence under the full Recommendation was also requested in the final editing.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Recommendation 2. The BSC views the Center as a model center for the agency. It can serve to pilot programs for translation to communities and lead the agency's initiatives in primary prevention and in addressing social determinants of health.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Recommendation 3. The NCCDPHP must stay focused on CDC's translation niche effectively moving the science base into practice to grow and improve health.

Notes: The medical community tends to think of bench science in terms of translation. While not ignoring that, text to emphasize the public health focus was suggested. The addition of "community practices and policy" (after "effectively moving the science base into…" and before "to promote and improve health") was suggested and was the final recommendation text voted upon.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell; Emmons

Dr. Emmons joined the meeting at this point.

Recommendation 4. The NCCDPHP must have robust funding for the core programs even in this budgetary environment. We strongly believe the NCCDPHP Director must have flexibility in budget execution to address opportunities and priorities. In addition, the NCCDPHP director must have discretionary funds. Without these funds innovation will be stifled.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell

Recommendation 5. The NCCDPHP should document and assess the effects of funds resulting from partnering with the CDC Foundation, cost sharing and co-funding. These additional funds should not substitute for base funding.

Note: The bottom line provided to the BSC included co-mingled contributions from the Foundation. The recommendation's intent was to ensure that NCCDPHP need not increasingly rely on additional funds from other sources.

Vote:

In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell

Recommendation 6. The NCCDPHP should use partners more strategically to educate policy makers inviting foundation association policy fellows and Congressional staff to visit and learn about programs and physically create an external coalition of champions for chronic disease prevention.

Vote:
In favor: Airhihenbuwa; Bal; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bethell

At this point, Dr. Bal thanked Dr. Kolbe and Dr. Steinberg for their excellent work in directing the BSC. He expressed his pleasure in working with all the members and the CDC staff. Dr. Kolbe thanked him in turn, and requested his and all the members continuing input as the final steps are completed. Due to a previous commitment, Dr. Bal then exited the teleconference as he previously had notified the BSC Chair and DFO.

Recommendation 7. The NCCDPHP routinely should review key initiatives, such as the Wise Woman program, to ensure that all relevant science based programs are integrated and included and so these initiatives evolve to the next level.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell

Recommendation 8. The NCCDPHP should shift its focus further to primary prevention and to socioecological models. The Center can build on a strong partnership base within DHHS and professional and non-profit groups and is in an ideal position to convene and work with all Cabinet Level agencies to raise their awareness of the health effects of their respective Cabinet Level agency policies and programs and to facilitate collaborations across such programs.

Note: The increasing need to shift from secondary prevention to a focus on primary prevention was noted. It stemmed from an emerging discussion in public health not only to more aggressively act to prevent sequelae but also to move back to true primary prevention through the social and environmental determinants. There is some overlap here with recommendation 5, which will be addressed as the co-chairs and liaisons write the final report.

Vote:
In favor: Airhihenbuwa;Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich

No response/not attending: Bal, Bethell

Recommendation 9. State level chronic disease prevention programs must be extended to all states that are prepared, able and interested in these programs.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell

Recommendation 10. NCCDPHP should expand its efforts to improve mental health, quality of life, health literacy, incidence data, social determinants of health and health impact and policies outside the traditional health fields.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell

Recommendation 10. State level chronic disease prevention programs must be extended to all states that are prepared, able and interested in these programs.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell

Recommendation 11. NCCDPHP should explore e-health and personal health records to further extend its surveillance capacity, coordinate surveillance approaches that can support the implementation and evaluation of programs to prevent and control major chronic diseases, and eliminate outdated and redundant data collection efforts.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell

Recommendation 12. NCCDPHP should monitor the effects of the economic downturn on key state programs to prevent chronic disease and promote health.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich

No response/not attending: Bal, Bethell

Recommendation 13. NCCDPHP should continue its analysis of the economic impact of its programs.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell

Recommendation 14. NCCDPHP should engage in health reform, making sure primary prevention of chronic diseases and conditions is an essential part of any health reform plan. The Guide to Community Preventive Services can provide strong and specific data about the effectiveness of many chronic disease programs.

Note: The text of "engage" was changed to "participate in health reform…"

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell

Recommendation 15. Both NCCDPHP and CDC should consider the NIH experience with stimulus funds as it might move to use and distribute these funds and recommend that NCCDPHP use potential stimulus funds to support transitions between program funding and to extend successful programs.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Emmons; Goff; Kardia; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell

The BSC members took a short break, during which Dr. Kardia was called away on an emergency. Drs. Emmons and Marrero also were not on the call.

NCBDDD Recommendations

A. Division of Blood Disorders

Recommendation 1. The Division of Blood Disorders should focus more on surveillance and prevention of DVT and PE than on treatment: a) generate data about both incidence and prevalence with intramural and extramural approaches; b) produce cross-sectional snapshots using a variety of approaches and data sources, such as population –based epidemiological studies; hospital discharge data; claims/encounter

data.; c) create surveillance program infrastructure and/or build on existing infrastructure; d) convene a panel with expertise in DVT, PE, and surveillance methods to advise about strategies; e) surveillance should be conducted at appropriate intervals since DVT and PE would not change quickly; f) consider one surveillance structure to coordinate other relevant surveillance systems among states; g) work with a variety of provider associations to capture prevalence data (for example, hospital regs, accreditation payments, MS, P4P, et cetera); h) frame efforts to monitor DVT, PE within context of quality measurement and improvement movement, and patient safety movement; i) develop and implement DVT and PE, patient driven interventions and public education; j) use cooperative agreements to fund specific initiatives; and k) collaborate with other CDC units to conduct priority research on etiology of risk factors for and incidents of DVT and PE.

Notes: (k) involves work across both NCCDPH and the National Center for Health Statistics (NCHS).

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

B. Division of Birth Defects and Developmental Disabilities.

Recommendation 1. As it appears premature to recommend digital imaging in routine surveillance, convene a panel of experts to review the state of the art and imaging research, applicability to brain imaging studies and feasibility of this technology for surveillance, especially for CP studies.

Notes: A more positive way of phrasing this recommendation was suggested (e.g., delay recommendation of digital imaging until after a panel of expert is convened to review the state of the art"). The original text was chosen to clearly note the uncertain sensitivity and specificity of the digital imaging data, but to endorse inviting an expert panel's review of the data's accuracy.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 2. Incorporate more genomics, genetics, and epigenetics into epidemiologic research.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Rimmer; Wolraich
No response/not attending: Bethell; Emmons; Kardia; Merrero

Recommendation 3. Both cerebral palsy and congenital heart disease are influenced by interactions between environmental influences and genetic susceptibility. Leverage existing data sets or surveillance systems to such studies; collaborate with existing and well established infrastructures for large scale, high throughput laboratory analysis about biologic specimens to set a genetic environment interaction for CP and CHD; consider residual newborn screening blood spots to include in genetic studies; help identify procedures to make access to this resource more feasible.

Note: Change the text to "surveillance systems to conduct such studies."

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marerro, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 4. Focus research on cerebral palsy and congenital heart disease; convene groups with shared interest for support; establishing a focus on CHD should help NCCDPHP launch a new era in surveillance and research.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 5. Along with CP and CHD as appropriate research topics for NCDDP, include other prevalent conditions and risk factors, such as ADHD (including prevalence, prevention, diagnosis, and treatment; and prematurity.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marerro, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 6. Establish programs and research priorities not only to reduce mortality but to reduce morbidity and improve quality of life. Undertake collaboration with NIH and other organizations, to conduct priority comparative effectiveness research (or CER) to improve prognosis of young children with cerebral palsy.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

C. Division of Human Development and Disability.

Recommendation 1. Work with the National Center for Chronic Disease Prevention and Health Promotion and other CDC units to reduce smoking, obesity and infections among people with developmental disabilities: a) explore inter-agency collaborations with DOE, AHRQ, SMPSA, HRSA to develop more robust research plan to address obesity, smoking and infections among those with developmental disabilities of a broader framework; b) build a stronger partnerships with healthcare providers, the healthcare delivery system to better understand higher rates of obesity, smoking, and infections among those with developmental disabilities; c) promote a broad definition of health and well-being to address needs of children, adults, seniors with developmental disabilities across the lifespan; d) with NCCDPHP, assure functional assessments and quality of life indicators are used in assessments of needs and outcomes among those with disabilities; e), with NCCDPHP, address the role of families and caregivers in promoting health among children and adults with developmental disabilities; f) with the NCCDPHP, address those with what's stated as developmental disabilities as an important population that should be disparately affected by the social determinants of health on incidence of obesity, smoking, and health complications; g) with NCCDPHP, maintain a central focus on people with disabilities in their programs and research to prevent and manage key health risk behaviors, especially in physical activity; and h) with NCCDPHP, address the built environment as an important variable in NCCBDD programs, and research to increase physical activity among developmentally disabled populations.

Notes: The BSC favored dropping the term "developmental" as it focuses only on the life cycle to age 21. The BSC agreed "developmental" should be deleted in every place in all Recommendation (unless otherwise indicated) where it appeared to modify "disability."

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 2. Conduct research to: a) examine effectiveness of physical activity and nutrition interventions for obesity and weight management among people with disabilities; b) identify evidence-based smoking cessation programs and adapt them for disability groups with high smoking rates; c) enhance surveillance efforts to reduce the rate and prevalence of infections among various disability groups.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 3. Use a range of approaches to operationally define disability and make definitions clear and consistent across surveillance systems.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 4. With other CDC units, enhance focused programs and research on early childhood development: a) emphasize early prevention and reduction of disparities, and obesity and smoking; b) examine efforts and early detection and intervention, especially in primary care settings in collaboration with organizations, such as American Academy of Pediatrics; c) provide leadership in current national movement to expand developmental screening, promote early childhood development, improve well child care and encourage school readiness.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal; Bethell; Emmons; Kardia

Recommendation 5. Consider collaborating with others in an examination of best practices and comparative effectiveness research for early identification and intervention of children with developmental delays and disabilities.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 6. Articulate the role NCBDDD most appropriately and effectively could play in improving mental health, especially among those with developmental disabilities: a) NCBDDD should consider means to help assess mental health as part of standard health care, especially for children with special healthcare needs and people with disabilities; b) the NCBDDD should collaborate with the mental health and child health communities, including the AAP and pediatric training organizations.

Notes: This addresses great concerns about mental health and developmental disabilities being ignored. In this case, the word "developmental" should remain in the first part of the Recommendation. The second part discusses children with special healthcare needs, which span beyond the developmental disability framework into children with other chronic illnesses; there it is appropriate to say only "disabilities."

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero; Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

D. Overarching Workgroup Recommendations

Recommendation 1. Enhance efforts to advance coordinated and effective engagement of partners and stakeholders: NCCDDD should enhance efforts to communicate priorities and the importance of cross agency and multi-stakeholder collaboration to ensure adequate resources are put in place to support effective efforts to address birth defects and developmental disabilities.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 2. Leveraging and enhancing existing surveillance and other data collection systems, such as the YRBS, BRFSS, as well as those not led by CDC, such as NPS, hospital discharge data, and the HRSA-led National Survey of Children's Health and National Survey Of Children With Special Healthcare Needs, to fill existing gaps and surveillance on key issues related to DVT, CHD, obesity, smoking, and infections among people with disabilities.

Note: Change the end of the Recommendation to "surveillance of the entire population for DVT and congenital heart disease and then among those, the key issues related to obesity, smoking, and infections among people with disabilities." It should be clear that people with disabilities are not excluded from the recommendation to increase surveillance on DVT and congenital heart disease.

The text for the vote was now, starting with "… survey of children's health and national survey of children with special healthcare needs: "… to fill existing gaps in surveillance on key issues related to population surveillance on DVT and congenital heart disease. NCBDDD should work to fill existing gaps in surveillance by investigating obesity, smoking, and infections among people with disabilities."

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 3. Focus on cross cutting risk factors and health impacts, such as mental health. Continue to identify and address key non-condition-specific cross cutting risk factors and health impacts. Facilitate collaboration with CDC units and across agencies and private sector organizations in doing so. Focus on mental and emotional health as both the risk factor and health impact for people with disabilities and their families.

Vote:

In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 4. Define and implement a public education and translational role in advancing healthcare, quality measurement and improvement efforts for those with birth defects and disabilities.

Note: The surrounding language should note the BSC's general agreement that both Centers should enhance the CDC's public education efforts in these areas.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

Recommendation 5. Focus on primary prevention, morbidity and quality of life in addition to secondary prevention and mortality.

Vote:
In favor: Airhihenbuwa; Beaty; Cohen; Curtis; Goff; Kleinman; Kolbe; Macera; Marrero, Rimmer; Wolraich
No response/not attending: Bal, Bethell; Emmons; Kardia

General Comments
The generators of the recommendations and supporting documents were thanked for their excellent work. It was noted that the two parallel efforts produced a clear theme, endorsed by the BSC: to revisit, prioritize, and embellish strong surveillance systems and surveillance methods development that is strong across the two.

Next Steps
The deliverable timetable had been distributed to the BSC members. Dr. Kolbe reviewed it; it also will be emailed to the members.

- September 15: Third BSC meeting
- September 22: Delivery to the BSC Members of the synthesized and certified July 1 BSC meeting minutes. These will also be posted on the CDC Website.
- September 22: The BSC's Designated Federal Officer sends the draft BSC report to BSC members and relevant CDC staff for their review. Each Center's leadership will identify those recommendations they feel will best help the Center achieve its mission.
- Final report development: Those perspectives will be considered as the final report is written, working closely with each of the NCBDDD and NCCDPHP's co-chairs and liaisons. Dr. Kolbe will officially ask NCCDPHP and NCBDDD to provide the BSC with some editorial support to compile the final report, which will include as its major focus the recommendations voted upon at this meeting, with explanatory language. There will be an introduction, an executive summary

that will comprise only the full Recommendations, and a full report in which these Recommendations will be embedded. During the process of completing the Final Report due on November 1, further comments by BSC Members and CDC leadership will be welcomed.

- September 30: Comments on these Recommendations are due from the co-chair office, NCBDDD and NCCDPHP; they will be sent to the BSC members for their review and comment.
- October 6: BSC member comments are due; the co-chairs and the centers' leadership will be asked their suggestions for final recommendation. No substantive changes will be made without reconvening the entire BSC.
- October 12: the final draft will be sent to the BSC for the members' final review
- October 19: BSC comments are due.
- October 22: the final report will be completed, sent to the entire BSC, and posted on the internet site.
- November 1: the final report of BSC activities will be completed and submitted

Dr. Steinberg added her own thanks to the members and co-chairs for their long hours of work to synthesize a coherent document from a massive amount of information. She particularly thanked Dr. Kolbe for being "a joy to work with," and Dorthina Grant for her steadfast administrative support. Dr. Kolbe thanked Dr. Collins, Dr. Trevathan, their respective staff, and particularly the BSC members and workgroup co-chairs.

Dr. Trevathan was impressed with the BSC's very well considered, clear and actionable recommendations. He remarked that some are ambitious, but not so ambitious as to be impossible, and their orientation to public health and the Centers' mission remind the CDC staff of why they do their work. He was completely gratified with the BSC's product, which far exceeded his expectations. Dr. Trevathan asked if he might use some of the BSC Recommendations to brief the CDC director on September 21st. Dr. Kolbe expected, to no demurral, that this would be amenable to the BSC members, as long as Dr. Trevathan noted that the Recommendations would not be final until the Final Report was filed on November 1. Dr. Trevathan noted Dr. Frieden's interest in cost effectiveness and comparative effectiveness.

Dr. Collins added her thanks for the BSC's synthesis of abundant information and provision of some very challenging directions. She announced her upcoming appointment as CDC's Associate Director for Program. The new NCCDPHP will be greatly helped by the BSC's input and the Center leadership's response.

Public comment was solicited by Dr. Kolbe, to no response. He and Dr. Steinberg remained on the conference line until 5:00 PM to ensure that anyone wishing to comment would be heard.

I hereby certify that, to the best of my knowledge and ability, the foregoing Minutes of the September 15, 2009 CCHP BSC teleconference meeting is an accurate and complete representation of the proceedings.

_____	_____
Date	Lloyd Kolbe, PhD, CCHP BSC Chair