

Friends of NCBDDD Annual Meeting - Minutes
December 5th, 2012
Washington, DC

Opening Remarks. Roberta Carlin opened the meeting by welcoming attendees and thanking members of the planning committee, AUCD, NCBDDD leadership, and the Friends Executive Committee for their support in making the meeting possible. Roberta noted that she will be rotating out of the Chair's position at the end of the month and wanted to thank members for their support and involvement. During the last 2 years membership in the Friends of NCBDDD rose to nearly 500 different entities, or 115% increase. We have also seen the creation of the Advocacy Coalition, the development of quarterly webinars, and a monthly newsletter.

Coleen Boyle then thanked attendees for participating in the meeting, noting that this would provide a great opportunity to let members know what has been occurring at the NCBDDD and for the Center to gather ideas regarding future plans and directions. Dr. Boyle presented plaques to Roberta Carlin, who has served as the outgoing Chair, and Joe Canose, who has served as the outgoing Vice Chair. Dr. Boyle thanked them for their service and key roles in helping the Friends grow. Plaques were also presented to members rotating off of the Executive Committee, including Adriane Griffen, who has served as Membership and Communications Chair, Clarke Ross, who has been involved with the Friends for 9 of the last 11 years, and Patricia Wright, who has served as Member at Large for 3 years. Eileen Ouellette, who has served as Member at Large, was unable to attend and her plaque was accepted by an AAP representative. New members of the Executive Committee were also formally announced. These include Adriane Griffen, who will serve as Chair; Craig Mason, who will serve as Vice Chair; Judit Ungar and Jeff Cohen, Membership/Communications Chair; Carolyn Mullen, Mary Andrus, and Cindy Brownstein, Members at Large; Emil Wigode, Advocacy Coalition; and Roberta Carlin, Past Chair.

Overview by Dr. Boyle: Dr. Boyle discussed some of the changes in leadership within the Center. During the past year, she feels they have put together a great team that will provide creativity and stability to NCBDDD projects. Dr. Boyle also noted that the Center has several focus areas for 2013, including a general focus on structural birth defects, as well initiatives addressing autism, sickle cell disease, and initiatives addressing obesity and weight-related health issues in individuals with disabilities. The Center is also considering new areas, including the quality of health care for individuals with select birth defects, developmental disabilities and genetic disorders, as well as strategies for reducing associated adverse health consequences.

Efforts to expand inclusion of individuals with disabilities in projects and products will continue in NCBDDD and CDC as a whole. This is a high profile topic with considerable traction at the most senior levels. The goal is for all activities, whether survey information, programs, communications, etc., to include information on individuals with disabilities.

Dr. Boyle noted that NCBDDD continues to explore new ways and ideas for engaging partners across all areas. For example, during the past year, staff have worked at leveraging social media, including the use of Twitter and Facebook, on Sickle Cell and other topics. In addition, in response to a charge by Dr. Frieden to provide enhanced mentorship opportunities, a pilot program was implemented through a recent FOA that required PIs to have junior investigators. Dr. Boyle also shared a *Quality Performance Report* that captures what a program is doing, what it aims to accomplish, and how activities and success are being measured.

Finally, Dr. Boyle noted several areas in which the Center would particularly like to engage members of the Friends network. This includes a new FOA on the *Birth Defects Study to Evaluate Pregnancy Exposures (BD-STEPS)*, and efforts to bring public health to the public through efforts such as Grand Rounds. The Center is also seeking input regarding emergency preparedness for people with disabilities—trying to bring together activities and programs working with children and adults. Dr. Boyle ended by noting key individuals that partners can approach for making these connections, including Melody Stevens Parkhurst, Gaylon Morris, and Julie Beckett (NCBDD Partner Liaisons).

Dr. Boyle then turned to podium over to Cindy Moore and others for Division overviews.

Division of Birth Defects and Developmental Disabilities. Dr. Moore shared a few key accomplishments of the past year. This included the release of the 2008 Autism prevalence estimates. This reflects long-term effort on the part of the Center and partners nationwide, and the latest prevalence estimate of 1:88 received considerable national attention, including a briefing at the White House. In addition, SEED II (Study to Explore Early Development) was launched.

A variety of projects examining birth defects are underway, including research on the impact of medications for treating epilepsy and migraines. The goal is to inform decisions regarding medication use in combination with other risk factors, such as obesity. Additional work has addressed birth defects surveillance and prevention. This includes new cooperative agreements targeting critical congenital heart defects, as well as general technical assistance to states and partnership with Friends members such as NBDPN. The division continues to promote corn masa flour fortification, and work has begun on alcohol screening and related brief intervention approaches, including a pilot project on FAS.

Dr. Moore also identified several opportunities for collaboration with Friends partners this year. Several studies will be coming out on risk factors associated with autism and other related topics. Help disseminating these findings would be valuable. The division is also working with partners to promote 3-5 community engagement events with the goal of helping the underserved access services. Additional help would be appreciated. Dr. Moore noted that this is just a snapshot of the work in which Friends could become involved—other partnerships are looking at promoting early identification, women's pre-pregnancy health, prevention, screening and surveillance.

Division of Human Development and Disability. Dr. Krahn noted that this has been a highly productive year with the Division of Human Development and Disability, with numerous activities relevant to Friends partners. Some projects have been active for years, while others continue to unfold. Highlights include work by the EHDI team on electronic health records and their use in reducing loss to follow-up. Dr. Krahn noted that EHDI is seen as leaders in this area across CDC. Work by the *Legacy for Children* team has been active for over a decade, with new results documenting the effect of positive parenting. Additional Division projects are examining the prevalence of ADHD through active case finding, as well as partnerships with multiple groups exploring the development and refinement of registries for Fragile X and other disorders. This includes examining the use and utility of retrospective administrative data.

Dr. Krahn elaborated on work addressing disability disparities. This includes making promoting disability as a stratification level in public health work in general, including the value of analyzing public health data by disability status. The Division is exploring ideas for a policy on addressing disability in FOAs, and are in discussion with various national and international partners (e.g., WHO, AMCHP) on expanding disability-related data, education, and outreach.

Opportunities for the coming year include helping the division increase the visibility of disabilities and developing unifying messages that partners can share on health disparities for individuals with disabilities. What opportunities may exist through healthcare reform is also a question worth exploring. The division is also interested in developing strategies for providing evidence of the value of public health and prevention investments, both through data and evaluation systems, as well as effectively communicating the message.

Division of Blood Disorders. Chris Parker presented on the accomplishments and opportunities in the Blood Disorders Division. Dr. Parker noted that the division is interested in continually evolving strategies and programs as needs and situations change. For example, during the past year, the division brought together various stakeholders for input on reshaping work on bleeding. Similarly, they have brought together stakeholders interested in sickle cell disease to discuss how the field of public health can help with both data collection and health promotion in the field. Several projects are also underway addressing venous thromboembolism, including partnerships examining the use and utility of electronic health records for surveillance. In addition, a chapter on risk and prevention during travel will be coming out.

Dr. Parker also discussed how the Division is interested in building new partnerships. In particular, the Division would like to see blood disorders more closely integrated with broader public health efforts, and Friends members may be able to help with that effort. In addition, healthcare access for individuals with blood disorders is a concern, as is prevention of venous thromboembolism. Healthcare reform may create opportunities for this, particularly with the focus on quality care. Assistance at inserting venous thromboembolism and other blood disorders into these discussions would be valuable. There is also considerable interest in continuing to expand social media as a tool for dissemination and education.

Questions and Answers. Dr. Boyle then opened the discussion to questions from attendees.

Several questions addressed the expanded focus on inclusion of individuals with disabilities. Dr. Boyle noted that this reflects a national effort and presents an opportunity for the NCBDDD.

Questions also returned to the use of social media. Attendees were interested in working with NCBDDD on developing strategies for leveraging this resource. Dr. Boyle and other NCBDDD personnel noted the possibility for future presentations and discussions on this topic. Other ideas included a white paper for partners that would outline how to engage in social media. Attendees were encouraged to contact Melody (sme1@cdc.gov) for more social media information.

Attendees asked how to best communicate their activities to the Center. They were encouraged to go directly to Melody or Dr. Boyle. Division directors also noted a willingness to hear from partners. It was noted that partners must be aware of the deadlines for offering input prior to the FY14 embargo.

Several questions were asked about the fiscal cliff and sequestration; however, ultimately OMB will be the deciding factor on how these are addressed.

There was a question of whether NCBDDD is feeling more pressure to offer contracts versus cooperative agreements. Dr. Boyle indicated that she was unaware of any pressure, other than that there has always been an emphasis to put money “out the door” and contracts aren’t considered “out the door” to the same degree as cooperative agreements.

There was a question of the extent and nature by which division directors communicate with each other. It was noted that they meet, both formally and informally, multiple times a week. Division staff also work together and look for opportunities for collaborations across divisions.

There was a question regarding the role of PGO. It was noted that PGO is responsible for general oversight of procurement actions, including getting money to recipients. When someone receives a grant, PGO is the one that formally lets them know and how much.

Finally, a question was asked regarding whether the Center website would be redesigned. Betsy Mitchell noted that the Center plans to continue to improve and redesign the site. As part of this, they have been looking at various metrics regarding usage and flow. In addition, NCBDDD is considering reorganizing some content and material by topic rather than Divisions and units. If there are specific concerns or navigation issues, attendees were encouraged to contact Betsy.