



CDC's
National Center on
Birth Defects and Developmental Disabilities



Connection

*Birth Defects & Developmental Disabilities
Hereditary Blood Disorders
Human Development and Disability*

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IN THE SPOTLIGHT

NCBDDD AND STRATEGIC PLANNING

Many of you are no doubt aware that NCBDDD is in the formative stages of efforts to develop a strategic plan that will help to govern the center's development for the next 5 years. However, many of you might not be familiar with what that means, either for the center as a whole or for you as a partner.

What is strategic planning? Well, as the name implies, it's a planning strategy. However, it's much more than that. Strategic planning is defined as a dynamic, integrated, organizational process that defines strategies, goals, and actions and refines them based on changes in the environment. For NCBDDD, that means using the center's mission to develop the vision, direction, and actions required to achieve that mission. It also entails developing specific action plans to "make things happen".

The strategic planning process consists of several components that are currently in different stages of development within the center:

- *Mission:* This broad statement of purpose is what NCBDDD is all about.
- *Vision:* The vision part of the process articulates where NCBDDD is heading over the next 5 years. It tells where NCBDDD would like to be by that time.
- *Strategic Goals:* These goals incorporate the center's current identity and provide performance measures to record progress toward the center's eventual vision.
- *Strategic Action Plans:* These plans provide a blueprint for achieving strategic goals and take into consideration each NCBDDD core activity. They cover cross-cutting issues, the center's communication and research agendas, and organizational and external partner management.

NCBDDD is working with a contractor, Booz Allen Hamilton (BAH), to bring strategic planning to fruition. Within NCBDDD, Kate Galatas and Candice Jalonen are co-leaders of the strategic planning process and are working with BAH representatives to facilitate efforts. Kate is Deputy Associate Director, Behavioral Science and Health Education Team, and Candice is a health scientist with the Policy, Planning, and Evaluation Team. The center leadership is committed to strategic planning and to making the process an open, transparent activity. This means having lines of communication that run both ways, from the top down and from the bottom up. Their goal is to have the total involvement of all center staff and partners so that the plan that is developed will be embraced by all who will be instrumental in making the plan a reality.

THIS ISSUE

Director's Corner

NCBDDD's Second Conference

Strategic Planning

Spanish-language Folic Acid Campaign

Autism Summit Conference

Muscular Dystrophy Surveillance Tracking and Research Network

Hail and Farewell

Quote for the Day

"You must be the change you wish to see in the world."

Mahatma Gandhi

Director's Corner

Welcome to the first edition of Connections for 2004. We at the National Center on Birth Defects and Developmental Disabilities (NCBDDD) anticipate a very busy year, with our Strategic Planning efforts in full swing and planning for the second NCBDDD conference "Navigating Our Future: Aligning Strategies and Science", to be held July 26 through 28, 2004, in Washington, D.C., forging ahead.



CDC is currently engaged in creating its vision for the 21st century through the Futures Initiative. In parallel, NCBDDD is in the midst of creating its own strategic plan. This plan will be key in enabling NCBDDD to reach the mutual goals that the center and its partners will identify. NCBDDD has uniquely been given the opportunity to develop its own strategic plan under the framework being established by the Futures Initiative. This opportunity is critical because of the rapid growth of the center and the number of activities that we at NCBDDD are involved in, covering a wide range of public health and programmatic objectives.

The strategic planning process is an exciting opportunity for all of us, both internally and externally. It will provide the center the means to achieve objectives and be prepared to meet future needs. This edition's "In the Spotlight" article about the strategic planning process explains how center personnel can provide input into the development of the strategic plan. NCBDDD staff participation is critical to the center's ability to realize its vision, and I and those involved in development and implementation of this process know we can count on staff to share their thoughts. There will be additional opportunities for input during the NCBDDD conference. This is an open invitation, not only to NCBDDD staff, but to our partners as well, to attend this important event, so that we can personally share our future plans with you.

A handwritten signature in black ink that reads "José F. Cordero". The signature is written in a cursive, flowing style.

José F. Cordero, MD, MPH
Assistant Surgeon General
Director, National Center on Birth Defects
and Developmental Disabilities

(strategic planning cont'd)

To this end, a number of activities that solicit input from everyone at NCBDDD will be conducted. During the next couple of months, center staff members will participate in individual interviews, discussion groups, and retreats that will be used to gather and share information and help in the decision-making process. In addition, the center will be engaging the external partners working group to spearhead the collection of input from its partners. Based on all this input, BAH will help NCBDDD craft a draft strategic plan that will be shared with staff and partners alike.

Some of you who are external partners might already have shared information through the Future's Initiative, but you might be called on again to share insights directly with center staff.

We at NCBDDD will seek your input throughout this process, and will rely on our time together at the NCBDDD conference in July to solicit additional input from you on our draft plan. This is an exciting time for NCBDDD and we look forward to the collective thinking and planning around our meaningful public health work. Effective strategic planning will enable the center to achieve its mission and to continue to serve all constituencies in the most efficient and effective manner possible.



Spanish-language Folic Acid Campaign(SFACES)

The Spanish-language Folic Acid Campaign (SFACES) is currently in its third year. For the past 2 years, intervention activities have taken place in San Antonio, Texas, and Miami, Florida. This year, the campaign moves to two new cities—Denver, Colorado, and Philadelphia, Pennsylvania. As part of SFACES, NCBDDD is working in collaboration with national partners such as the National Alliance for Hispanic Health and March of Dimes, along with local community partners such as the Latin American Research and Service Agency in Denver and Congreso de Latinos Unidos in Philadelphia.

SFACES aims to increase folic acid awareness, knowledge, and consumption among Hispanic women of child-bearing age living in the campaign cities. To reach these women, the campaign uses a combination of paid media airtime through Spanish-language television, radio, and print outlets, and interpersonal communication at the community level through the use of promotoras (or lay) health outreach workers. These promotoras attend health fairs, conduct presentations for interested groups, and promote folic acid at events that attract large numbers of young Hispanic women.

Although the data for the current campaign year are not yet available, data from previous years have shown large increases in awareness and knowledge about folic acid in the campaign cities. Folic acid consumption has also steadily increased.



Next year's campaign is now in the planning stages. Project researchers are looking forward to receiving the results for this campaign year, while also planning and preparing to take the folic acid message to two new cities in the near future.

Autism Summit Conference

The Autism Summit Conference was held November 19 and 20, 2003, in Washington, D.C. The conference, which was organized by the U.S. Department of Health and Human Services and the U.S. Department of Education, dealt with a number of issues, including the role of the federal government in autism-related research, screening and diagnosis, and health care services.

Representatives from the government, the autism community, and NCBDDD partners presented on a range of topics. Tommy G. Thompson, Secretary of Health and Human Services, and Dr. José Cordero, Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD), were among a group of government leaders who spoke about the need to address autism on a national level. Members of the NCBDDD staff, including Coleen Boyle, Katherine Lyon Daniel, and Diana Schendel, also contributed to the conference. Boyle took the lead in organizing sessions on early screening and diagnosis, specifically, how to build awareness, how to test, and how to put ideas into practice. Lyon Daniel spoke about the CDC Autism Awareness Campaign, and Schendel presented on NCBDDD surveillance and epidemiologic studies of autism. Members of Congress talked about the importance of expanding research into autism and of finding conclusive answers concerning the causes of autism. Other presenters dealt with the significance of early diagnosis and intervention, education issues, and services for individuals with autism throughout their lifespan.

However, the cornerstone of the conference was announcement by the government of a 10-year plan—the Autism Research Roadmap—to address these and other autism issues in the United States. The roadmap provides an overview of short- (1- to 3-year), medium- (4- to 6-year), and long-term (7- to 10-year) goals and activities designed to move autism research and response forward. In addition to timeframe, these goals and activities are also rated according to level of risk, from low to high. The plan requires increased collaboration between scientists, experts from federal agencies, and the autism community. The plan should be presented to Congress during this fiscal year.

Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet)

The Division of Human Development and Disability (DHDD) at the National Center on Birth Defects and Developmental Disabilities has begun a new initiative to further study muscular dystrophy (MD). MD comprises a group of genetic disorders characterized by progressive muscle weakness. There are many forms of MD, having different genetic causes, affecting different muscles, and affecting people at different ages. Among these various forms are Duchenne muscular dystrophy (DMD) and Becker muscular dystrophy (BMD). These two forms of MD are also classified jointly as Duchenne/Becker muscular dystrophy (DBMD). DBMD is the most common MD in children and most often affects males. About one-third of all cases of DBMD occur in families in which others also have had the disorder. However, one-third of all cases are the result of a brand new mutation in the mother and the remaining one-third are the result of a brand new mutation that occurs in the affected person.

One of the major projects in which DHDD is currently engaged involves the study of DBMD. The Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet) is a multistate project that initially will focus on the childhood onset of these disorders. Currently, four states—Arizona, Colorado, Iowa, and New York (the western part of the state)—are participating in the project. The goal of the project is to identify all children with DBMD in the defined geographic areas using information from such sources as clinic and hospital medical records. Identification of children with DBMD and systematic collection and analysis of data will be ongoing. This surveillance project will provide better estimates of the number of people with DBMD, which in turn will allow communities to identify resource needs and provide better services.

In addition, by identifying males with milder forms of DBMD, researchers might be able to find out precisely why these males have milder forms. Also, public health officials will collect information at regular intervals to keep track of each child's treatments and how each is doing medically.

Families will be invited to participate in interviews with public health representatives to gather information related to DBMD that might not be found in the medical records. All data will be pooled anonymously from the different participating sites and will be used to help answer questions researchers have about DBMD, including:

- How common is DBMD?
- Is DBMD equally common in different racial and ethnic groups?
- What are the early signs and symptoms of DBMD?
- Do factors such as the type of care received or the type of mutation affect the progression of DBMD?
- What services are families currently receiving and what other services would be helpful?
- Do different populations receive different care?

In addition to the division's efforts with MD STARnet, DHDD is also working with several other research partners to collect information on family service needs, look at health concerns of female carriers, and study issues related to potential newborn screening for DBMD.



Interested in working together with other NCBDDD partners on mutual goals? Join the External Partners Group today! For more information, contact Barbara Kilbourne at 404-498-3084, or BKilbourne@cdc.gov

Save the Date

April 28-29, 2004: Biologics Summit for the National Birth Defects Prevention Study (NBDPS); Executive Park, Bldg. 12, Room 1002A/B; Contact information: Mary Jenkins, MMJenkins@cdc.gov.

2ND NCBDDD Conference

Please plan to join your colleagues at the 2nd national conference—*Navigating Our Future: Aligning Strategies and Science*—sponsored by the National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC), to be held at the Omni Shoreham Hotel, Washington, D.C., July 26 through 28, 2004. More than 1,200 health professionals and other interested parties are expected to attend. The conference will be large enough to address a broad range of interests, yet small enough to enable participants to meet speakers and network with other participants. The NCBDDD website (<http://www.cdc.gov/ncbddd/conference.htm>) will be updated soon to include additional information about this exciting event.



Forty Years and Counting

When Joe Smith retired from CDC last August, he had logged more than 40 years of federal service. However, CDC didn't lose this valuable repository of institutional knowledge and know-how. Joe graciously opted to continue his longstanding relationship with CDC by returning to work in another capacity. Currently, Joe is using his hard-earned years of experience to provide CDC with continuing support in the areas of technical assistance to extramural grantees and cooperative agreement recipients. However, it was a long and varied road that led him to this present assignment.

After college graduation, Joe first served his country during a 2-year stint with the Army (where he continued as reservist for several years), and then labored as a sales representative for General Foods Corporation.

However, in 1965, he decided that the world of sales was not for him and cast about for a more fulfilling life's work. In that quest, he arrived at CDC in April of that year, working initially in venereal disease case finding and later in state health department communicable disease assignments in sexually transmitted diseases (STDs) and tuberculosis control programs.

In the early 1970s, he switched assignments and became involved in what he would later describe as his most interesting job at CDC—functioning as national recruiting and training coordinator for entry-level VD program representatives and supervising field recruiters. Many of the people he recommended for hiring during this period eventually moved into senior management berths at CDC. Because of his involvement in this phase of CDC's tremendous growth, he has always felt a deep personal pride and sense of accomplishment in helping to shape the future of the agency.

From 1976 until 1983, Joe served as Regional Consultant for Disease Control in the Division of Preventive Health Services in the Atlanta Regional Office. Subsequently, he was a project officer with the Agent Orange Studies, developing the contractual specifications and providing management support for the scientific and epidemiological components of one of three major subcomponents. It was during this time that he made the acquaintance of some people whose names and faces are familiar to many of us at NCBDDD—Pierre Decouflé, Dave Erickson, Ed Brann, Tony Fowler, Coleen Boyle, and Owen Devine. Later, Joe served on a detail with the Agency



for Toxic Substances and Disease Registry, where he developed the initial contract specifications for the development of toxicological profiles for hazardous substances.

With the establishment of the Disability and Health Program at CDC in 1988, Joe accepted a position as senior project officer, a position he held under both the National Center for Environmental Health and the National Center on Birth Defects and Developmental Disabilities. In this position, he had primary responsibility for the development of multiple and diverse program announcements; continuation guidance; and technical assistance and onsite monitoring for state capacity projects, research grants, and national information and resource centers.

As an experienced and valued member of CDC's corps of senior project officers, Joe believes that his CDC career afforded him many opportunities to serve in a variety of challenging and interesting assignments. His expertise and diligence in the stewardship of public funds and his contributions to the personnel infrastructure of CDC are a lasting legacy. Fortunately, when Joe retired, he didn't go away. Instead, he chose to remain with CDC in another capacity, continuing to serve in the best traditions of public service in the federal government. We can only hope he chooses to remain with us for a long, long time.

Hail and Farewell

The Division of Birth Defects and Developmental Disabilities Welcomes —

Matt Cahill, contract program analyst, Developmental Disabilities Surveillance and Epidemiology (DDSE) Team.

Afiya Celestine, abstractor for the Metropolitan Atlanta Developmental Disabilities Surveillance Program, DDSE Team.

Sabrina Cheng, ATPM fellow, Pediatric Genetics Team.

Keisha Davenport, contract administrative assistance, Birth Defects Epidemiology (BDE) and Birth Defects Surveillance (BDS) Teams.

Bonita Foley, management analyst, Office of the Director (OD).

Charlene Fontaine, contract lead financial analyst, OD.

Steve Sepe, DD Planning and Partners Liaison, DDSE Team.

Nicole Shumpert, ASPH fellow, DDSE Team.

Meow Thong, Fulbright Scholarship Program researcher, Birth Defects Surveillance Team.

Electra Veson, medical student, Fetal Alcohol Syndrome Prevention (FAS) Team.

The Division of Human Development and Disability welcomes —

John Eichwald, team leader, Early Hearing Detection and Intervention (EHDI) Team.

Mary M. Jenkins, biologics coordinator for the National Birth Defects Prevention Study, Pediatric Genetics Team.

Christine Kennedy, ASPH fellow, CDS Team.

Mariel López, ASPH fellow, CDS Team.

Dianne Ochoa, public health analyst, CDS Team.

The Office of the Director welcomes —

Adam Brush, presidential management intern, Policy, Planning, and Evaluation (PPE) Team.

Carole Craft, contract writer-editor, Behavioral Science and Health Education Team.

Peter Rzeszutowski, Deputy, PPE Team.

Esther Sumartojo, Deputy Associate Director for Science.

Farewell NCBDDD says goodbye to —

Karen Hymbaugh, FAS Team, who is moving to the Global Immunization Division of the National Immunization Program.

Lee Ann Ramsey, EHDI Team, who has accepted a position with the National Center for Chronic Disease Prevention and Health Promotion, Division of Adult and Community Health, Health Care and Aging Branch.

Change of Duties —

Vince Campbell, Assistant Director for Science, DHHD.

Chris Kochtitzky, acting lead, Disability and Health Team, DHHD.

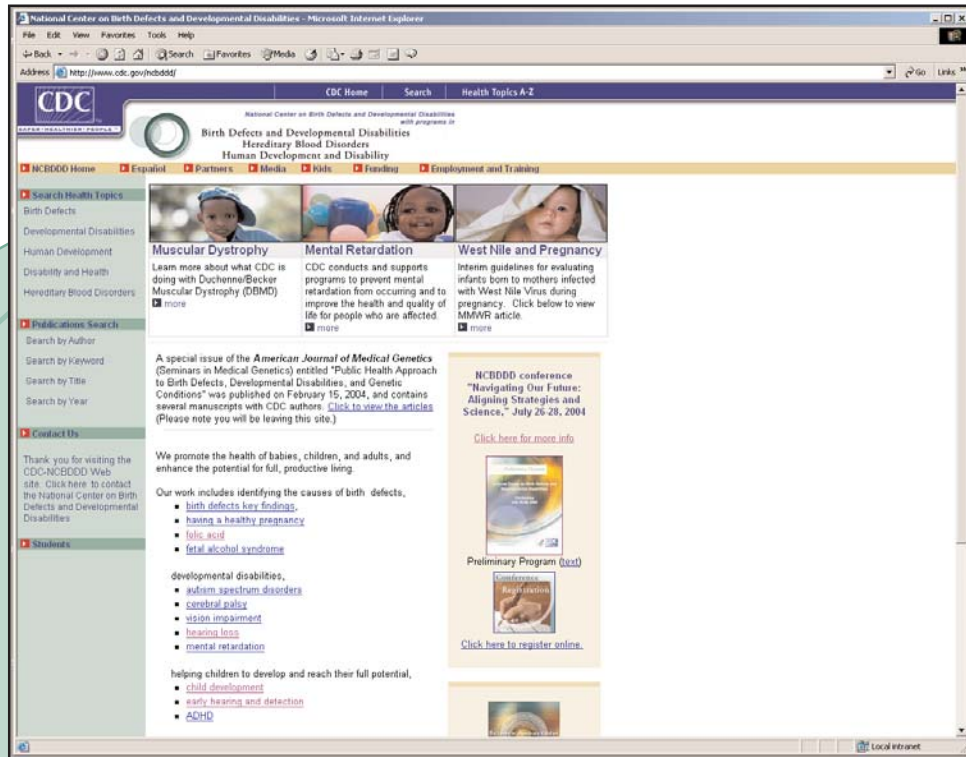
Ruth Perou, team leader, Child Development Studies, DHHD.

Congrats/Kudos to —

Tanya Karapurkar Bhasin, recipient of the 2003 CDC Pierre Decouflé Fellowship for Excellence in Developmental Disabilities Epidemiology. Tanya was honored in September for her valued scientific work, pursuit of knowledge, and mentoring activities. She has been an asset to NCBDDD's research on the prevalence and characteristics of autism spectrum disorders (ASDs), as well as the association between ASDs and measles, mumps, and rubella (MMR) vaccine. Currently, Tanya leads a team developing methods and instruments aimed at revealing risk factors for ASDs.

Kim Van Naarden Braun, DD Team, for successfully completing all requirements toward her PhD in epidemiology from Columbia University.

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