



Friends of NCBDDD Annual Meeting

Making the Connection

December 5, 2012



National Center on Birth Defects and Developmental Disabilities

Division of Birth Defects and Developmental Disabilities

NCBDDD Focus Areas 2012

- **Autism: Smarter service provision, research, policy, and prevention because of accurate and timely reporting of prevalence estimates**
- **Maternal Factors and Birth Defects: Prevention of congenital heart defects and other major birth defects associated with maternal risk factors (medications, chronic diseases, alcohol, and folic acid)**
- **Sickle Cell Disease: Better health for people with SCD through increased uptake of disease-modifying therapies like hydroxyurea**



NCBDDD Focus Areas 2012

- **VTE: Reduced incidence of healthcare-associated VTE through the use of evidence-based prevention and management guidelines**
- **Disability Inclusion: Inclusion of disability in all appropriate CDC surveys, programs, and communications**
- **Disability and Healthy Weight: Healthier weight in people with disabilities through awareness of increased risk, inclusion in obesity prevention and intervention initiatives, and identification of research and intervention needs**



NCBDDD 2013 Priorities (draft)

- **New Focus Area:**

- Improve quality of health care and reduce adverse health consequences from select birth defects, developmental disabilities and genetic disorders

- **Revised Focus Area:**

- Improve disability inclusion in CDC's surveys, programs and communications and in the Center's disability funded programs
- Fold disparities activities under the disability inclusion umbrella



Snap Shot 2012: Inside NCBDDD

- Forging strategic partnerships
 - Executed proactive partner engagement plan to advance key focus areas

- Leveraging social media
 - 5 Twitter handles with over 3,400 followers
 - 4 Facebook chats and 18 Twitter chats

- Strengthening our workforce
 - Piloting CDC's first Disability Internship Program



QPR Reporting: Hemophilia

We've Done

Gathered expert input into design of an inhibitor surveillance system

Finalized a pilot-ready draft surveillance form with inhibitor elements

Developed laboratory testing protocols for inhibitor testing as part of national surveillance

Developed, with partners, a protocol to investigate inhibitor clusters

Validated the modified Nijmegen-Bethesda assay to demonstrate its applicability as a standard for national surveillance

We'll Do

Pilot new surveillance form for inhibitors in hemophilia treatment centers and develop a 6-month interim report of surveillance indicators measured with the new form

Implement national inhibitor testing and year one result reporting using developed laboratory testing protocols

Pilot test inhibitor incident case ascertainment form in North Carolina cluster and report results

Develop a database for tracking global patterns of hemophilia gene mutations and associated inhibitor development

Publish a white paper on the proceedings of an expert work group meeting on national inhibitor surveillance

Establish a publically accessible on-line database that assesses hemophilia and inhibitor development

Develop partnerships to promote uptake of the Universal Data Collection system

Increase by 10% over baseline the percentage of persons with hemophilia enrolled in the UDC who are screened for inhibitors

We'll Measure

Percent of people with hemophilia enrolled in Universal Data Collection who are screened for inhibitors

2011 Actual:
37.4%

2012 Target:
41.14%

2013 Target:
44.88%

The Vision

Improved outcomes for people with hemophilia because of reduced inhibitor complications

Key Updates

- **New FOA: Birth Defects Study to Evaluate Pregnancy exposureS (BD-STEPS)**
 - FOA released on December 3, 2012
 - 6-9 grantees will be funded for 5 years (funding starts August 2013)
 - Objective is to identify modifiable maternal exposure in early pregnancy that may increase the risk of birth defects
- **Disability and Health Grand Rounds**
 - December 18, 2012, 1:00 p.m.
 - <http://www.cdc.gov/about/grand-rounds/>
- **Venous Thromboembolism (VTE) Grand Rounds**
 - January 15, 2013, 1:00 p.m.
 - <http://www.cdc.gov/about/grand-rounds>
- **Emergency Preparedness for Children and Adults with Disabilities**
 - NCBDDD Emergency Preparedness Partners Integration (EPPI) Workgroup



Connecting with NCBDDD

- **NCBDDD Partner Liaisons**
 - Melody Stevens Parkhurst
 - Gaylon Morris
 - Julie Beckett
- **Opportunities for Cross Communication**
 - Melody Stevens Parkhurst
 - Ursula Phoenix Weir
 - AUCD
- **Engaging NCBDDD in Social Media**
 - Betsy Mitchell
 - Conne Ward Cameron



Division Overviews



Division of Birth Defects and Developmental Disabilities



Division of Birth Defects and Developmental Disabilities Accomplishments - 2012

- **Autism surveillance and research**
 - Reported prevalence data for 2008
 - Launched Study to Explore Early Development (SEED) II
- **Birth defects surveillance and research**
 - Identified risk factors related to diet, medication use
 - Launched surveillance of adolescents/adults with congenital heart defects
 - Provided assistance to states and other federal agencies involved with screening newborns for critical congenital heart defects
- **Birth defects prevention**
 - Advanced alcohol screening and brief intervention methods and opportunities
 - Provided TA on corn masa flour petition to FDA



Division of Birth Defects and Developmental Disabilities Opportunities - 2013

- **Autism surveillance and research**
 - Research on risk factors for autism
 - Community engagement
- **Early identification**
 - Partnering with Federal agencies and others
- **Birth defects surveillance and research**
 - Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS)
- **Birth defects prevention**
 - Preconception care communication campaign
 - Alcohol screening and brief intervention



Division of Human Development and Disability



Division of Human Development and Disability Accomplishments - 2012

Disability Disparities:

- **Including Disability in Public Health**
 - CDC surveys, reports, interventions
- **Collaborations**
 - increase visibility of people with disabilities
- **State Disability & Health Programs**
 - Health care access, health promotion, emergency preparedness
- **Public Health Practice & Resource Centers**
- **Disability Data**



Division of Human Development and Disability Accomplishments - 2012

Hearing Loss Screening & Intervention:

- **Improved data and outcomes**
 - Maintain screening at 97%; Reduce loss to follow up
- **Electronic Health Record (EHR):**
 - CMS adoption of EHDI EHR measure for hospitals

Child Development Outcomes:

- **Legacy for Children™ (positive parenting)**
 - Feasibility in Early Head Start programs; published evidence base
- **Attention Deficit and Hyperactivity Disorder**
 - Community-based prevalence; analyses of medication use
- **Complex Disabling Conditions (Fragile X, MD, SB)**
 - Registries refinement; cross-condition study of SC administrative data
 - PH agenda for complex conditions (MD); Renal health and SB

Division of Human Development and Disability Opportunities - 2013

- **Disability Inclusion**
 - Inclusion where possible, cross-disability where necessary, condition-specific where essential
- **Disability Visibility**
 - Unifying messaging and strategy
- **Demonstrate Value of investments**
 - Evaluation systems--reporting
 - Messaging—what would “excellence” look like?
- **Health Disparities**
 - Partner on interventions
- **Health Care Reform**
 - Partner Roles/CDC niche

Division of Blood Disorders



Division of Blood Disorders Accomplishments - 2012

- **The 2nd National Conference on Blood Disorders in Public Health**
- **Bleeding**
 - New UDC- redesigned based on stakeholder input to include new and emerging issues (i.e. inhibitors)
- **Sickle Cell Disease (SCD)**
 - SCD Stakeholder Meeting with SCDA and ASH
 - RuSH Strategies from the Field: Data Collection
 - RuSH Strategies from the Field: Health Promotion
- **Venous Thromboembolism (VTE)**
 - Chapter on VTE Risk and Prevention during travel for 2014 Yellow Book
 - Launched population-based VTE surveillance pilot
 - Hospital Acquired-VTE surveillance stakeholder meeting



Division of Blood Disorders Opportunities - 2013

- **Build new partnerships to integrate blood disorders into broader public health initiatives**
 - SCD in the context of public health disparities
- **Work with partners to increase access to quality of care for people of blood disorders**
 - Organizations focused on healthcare quality to champion prevention of hospital-acquired –VTE
 - Dissemination of SCD clinical management guidelines
 - Develop consensus guidelines for hemophilia care addressing issues like inhibitor screening, prophylaxis, and other treatment issues that could be implemented both inside and outside of HTC
- **Work with partners to engage and educating public through social media**



Thank you!

To make the connection:

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Questions for Discussion

- **How can we improve our communication/outreach on focus areas?**
- **What updates are most useful from the Center?**
 - How do you want to receive them?
- **How can we better facilitate cross communication/collaboration?**



Back up slides – if asked



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The Vision

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QPR Reporting: Sickle Cell Disease

We've Done

Convened the SCD in Public Health stakeholder meeting to inform CDC's SCD agenda

Funded three state health departments to establish a surveillance system to identify SCD complications and those receiving disease-modifying therapies

Analyzed data on SCD prevalence, hospitalizations, and prescriptions for hydroxyurea

Updated the SCD National Resource Directory, a compilation of organizations serve people with SCD

Published "Strategies from the Field" documents on data collection and health promotion

Funded two states to develop audience-tested messages about the importance of disease-modifying therapies

We'll Do

Develop and issue a report that establishes baseline estimate of persons with SCD receiving disease-modifying therapies in five of seven RuSH states

Develop and post on website a 5-year agenda for SCD program activities, include validating population-based estimates for SCD

Disseminate state profiles for all RuSH states on burden and health utilization trends using RuSH data; publish report estimating prescription of hydroxyurea

Convene an expert meeting to evaluate current SCD testing methods and areas for improvement to better assess the number of patients eligible for hydroxyurea

Develop an implementation plan for support of model programs to up hydroxyurea use

Implement first year of new surveillance project, PHRESH; design data collection plan and validation protocol for RuSH with attention to vaccination, hydroxyurea, and transcranial doppler screening

Help the National Blood Disorders Program Working Group develop strategies and materials to assist health care professionals in using clinical guidelines for hydroxyurea

We'll Measure

Percent of people with SCD who receive hydroxyurea

2013 Target:
Establish a
Baseline

The Vision

Better health for people with SCD through increased uptake of disease-modifying therapies like hydroxyurea

QPR Reporting: Venous Thromboembolism

We've Done

Documented increasing trend (↑ 102% from 1994 to 2009) in pediatric VTE - related hospitalizations

Helped develop framework for conducting surveillance of hospital-associated VTE and hospitals' prevention practices

Convened VTE stakeholder meeting and an expert working group to inform a new hospital-associated VTE surveillance system

Published findings that about 28,726 hospitalized adults with a VTE diagnosis die each year

Authored chapter on VTE risk and prevention while traveling for the 2014 CDC Yellow Book

We'll Do

Publish an analysis of the occurrence of post-operative VTE among surgical inpatients in Veterans Administration hospitals in relation to the use of hospital prophylaxis

Develop and obtain approval of materials to launch the next module of the "This is Serious" campaign for women, which will focus VTE risk in surgery and trauma

Complete design and development of an FOA or contract for a hospital-associated VTE surveillance system for pilot testing

Report comparison of existing professional guidelines for preventing of hospital-associated VTE, identifying common and conflicting recommendations that will inform practice monitoring

We'll Measure

Annual incidence of hospital-associated VTE

2013 Target:
Establish a Baseline

The Vision

Reduced incidence of hospital-associated VTE through the use of evidence-based prevention and management guidelines

QPR Reporting: Disability & Obesity

We've Done

Submitted report for publication showing the higher risk for obesity among children with mobility and intellectual disabilities

Educated leading health services and policy research professionals on developing a national strategy for healthy weight among people with disabilities

Collaborated with partners to develop a research agenda on obesity in persons with disabilities

Awarded grants for national public health practice and resource centers and state disability and health programs for health promotion in people with disabilities, including resources for healthy weight management

We'll Do

Review and issue report on the current recommendations to health care providers on weight measurement in persons with paralysis and limb loss

Submit into clearance a report on the effectiveness of current generic and disability-specific obesity prevention/intervention programs.

Create and disseminate at least one report, three fact sheets and two journal articles that describe obesity in children and adults with disabilities and public health strategies to address it

Develop at least one project to address research gaps for healthy weight in people with disabilities and create and post online a source guide for research effectiveness of obesity programs for people with disabilities

Generate a CDC report documenting the number of people reached by Public Health Practice and Resource Centers on healthy weight topics to establish baseline data for improvement

Convene an expert panel to develop recommendations on weight measurement and monitoring for people with targeted mobility limitations and issue a synthesis of the resulting expert recommendations

We'll Measure

Percent of targeted people contacting our resource centers on weight-related issues who report increased knowledge afterward

2012 Target:

20%

2012 Target:

22.5%

Percent of funded State D&H programs that implement evidence-based health promotion programs inclusive of nutrition and physical activity for people with disabilities

2013 Target:

50%

The Vision

Healthier weight in people with disabilities through awareness of increased risk, inclusion in obesity prevention and intervention initiatives, and identification of research and intervention needs

QPR Reporting: Disability Inclusion

We've Done

Identified HHS-standard disability indicators to include in CDC surveys and secured their adoption by BRFSS for 2013

Submitted for clearance policy to include disability language in CDC FOAs

Analyzed availability and use of disability identifiers in Vital Signs published topics

Supported the development and implementation of data standards to include disability identifiers in HHS supported surveys

Assessed interventions in the Community Guide for adaptability and secured agreement from the Guide to include links with information on adapting interventions

We'll Do

Ensure that one additional CDC survey includes disability identifiers

Through cooperation with Community Guide, add disability considerations to their recommended interventions in at least 7 of 15 topic areas

Prepare and submit for publication at least one manuscript summarizing results of project on the Guide to Community Preventive Services

Ensure two targeted CDC papers (through Vital Signs or MMWR) use disability identifiers as a demographic stratification variable

Submit and help implement one CDC policy or set of guidance for FOAs on disability inclusion

We'll Measure

Number of additional population-based self-report CDC surveys that include HHS-recommended standard disability questions

2013 Target:

1

Percent of CDC FOAs including appropriate language on people with disabilities

2013 Target:

5%

The Vision

Inclusion of disability in all appropriate CDC surveys, programs, and communications

QPR Reporting: Disability & Obesity

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The Vision

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QPR Reporting: Early Hearing

We've Done

Secured CMS adoption of EHDl electronic health record measure as a qualifying measure for incentive program

Enhanced data collection by providing assistance to 52 jurisdictions to collect and report screening, diagnostic and intervention data

Enhanced care coordination and data-sharing by developing health information technology standards for EHDl-Info Systems

Successfully demonstrated at a health IT showcase that it is possible to electronically exchange hearing screening results and patient information between clinical and public health entities

Improved outcomes for children with hearing loss through increased rates of audiological follow-up and referral to services

We'll Do

Publish a manuscript on data for calendar year 2011 on infant hearing screening, audiology examinations, and referral to early intervention through the CDC EHDl Hearing Screening and Follow-up Survey

Issue a report that prioritizes specific areas for enhanced technical assistance, as informed by Interim Progress Reports, TA communications, and the CDC EHDl national survey as a step toward the development of an EHDl TA strategy toolkit

Begin a working group of EHDl stakeholders that delivers strategies for developing and modifying guidelines, policies, and procedures to close gaps in EHDl services

Issue a white paper describing the trial implementation of an electronic quality measure (eMeasure) for the performance of newborn hearing screening

We'll Measure

Percent of infants with a documented diagnosis who receive their audiological evaluation no later than age 3 months

2010
Actual:
71.8%

2011
Target:
72%

2012
Target:
72.5%

2013
Target:
73.5%

Percent of infants with confirmed hearing loss with known referral for intervention services no later than age 6 months

2012 Target:
75%

2012 Target:
76%

The Vision

More informed services, policies, and programs for children with hearing loss due to improved data

QPR Reporting: State Disability & Health

We've Done

Posted on Grants.gov an FOA with required activities in health care access, obesity, emergency preparedness

Funded two extra state disability and health programs and convened grantee meeting of all

Developed a consistent evaluation and reporting system and standardized work plan format

We'll Do

Publish best practices for alliances between D&H programs and other state public health entities and among programs to further state capacity to improve the health of people with disabilities

Issue a common evaluation framework for DHDD's Public Health Practice Resource Centers; finalize and report out the evaluation protocol for the network of disability and health programs

Issue a report assessing the 18 state disability and health programs' activities and accomplishments and analyzing key stakeholders to advance the mission of disability and health state based programs

Develop and disseminate disability scorecards on the 18 state disability and health programs' activities, health, and health care access, including indicators of facility access and use of preventive services

Develop tools (templates and forms) for people with disabilities on how to include people with disabilities in local emergency exercises

Make available to all funded states current (updated annually) state-level surveillance data on disability status and health care access for use in policy and practice

We'll Measure

Percent of funded state D&H programs providing people with disabilities tailored access to emergency resources

2013 Target:

50%

Number of states with Disability Scorecard data produced every 2 years to identify gaps and help prioritize resources

2012 Target:

18

Number of states/territories with access to current state-level disability and health surveillance data

2011

Actual:

18

2012

Actual:

50

2013

Target:

50

The Vision

Improved health for people with disabilities due to enhanced state capacity to implement needed program and policy interventions

QPR Reporting: Autism

We've Done

Implemented a new web-based data collection system for Autism and Developmental Disabilities Monitoring (ADDM) Network

Completed the first phase of data collection and initiated the second phase of data collection for the Study to Explore Early Development (SEED)

Released online the Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum

Expanded the reach of "Learn the Signs. Act Early." (LTSAE) messages and enhanced capacity within states through the Act Early Ambassadors Program

We'll Do

Issue report on implementation of the LTSAE campaign based on findings from implementation grants

Refine LTSAE "call to action" based on parent interviews and conduct environmental scan of health campaigns targeting pediatricians

Evaluate CDC's children's book on developmental milestones to determine use by parents and effectiveness

Complete data collection, data cleaning, and assembly of an analysis file for the first "Early ADDM" surveillance year

Submit to CDC clearance at least three analyses of behavioral phenotype, sociodemographic factors, and gene-environment interaction from SEED

Issue a strategic plan to improve the reach and utility of ADDM data based on data compiled from stakeholder focus groups

Prepare for publication an analysis of the average population-attributable fractions of three perinatal risk factors

Conduct at least three community planning events with stakeholders in ADDM Network states to understand and address disparities

Develop and implement one continuing education, web-based curriculum for early childhood educators

We'll Measure

Proportion of children with ASD having a first evaluation by 36 months

2010 Actual:

39%

2012 Actual:

41.8%

2014 Target:

??%

The Vision

Smarter service provision, research, policy, and prevention because of accurate and timely reporting of prevalence estimates

QPR Reporting: Fetal Alcohol

We've Done

Identified strategies to increase the demand for alcohol screening and brief intervention (SBI) through feedback from stakeholders

Estimated alcohol use among women of reproductive age who are pregnant or not (7.6%/51.5% report any use; 1.4%/15% binge drink)

Expanded the focus of three Regional Training Centers to move beyond training to implement alcohol SBI

Identified strategies on messaging about alcohol use and pregnancy through a risk communication meeting of professional medical groups

Tested messages about alcohol and pregnancy in focus groups

Initiated development of a Training of Trainers CHOICES curriculum

Finalized an optional module for the 2014 BRFSS survey that assesses the delivery of SBI-related services

We'll Do

Issue revised messages and materials for women and health care providers regarding alcohol and pregnancy

Implement one demonstration project to increase uptake of and demand for SBI

Pilot the CHOICES Train the Trainers curriculum with up to 12 trainers

Submit for publication one report monitoring trends and further defining characteristics of women at risk for an AEP

Issue a final report on the feasibility, impact, and cost of CHOICES in two STD clinics serving women at risk for an AEP

Implement and begin data collection at up to eight primary care sites through three FASD Regional Training Centers to assess the feasibility of alcohol SBI in primary care

Submit for publication national estimates for risk of AEP among women of reproductive age using the National Survey on Family Growth

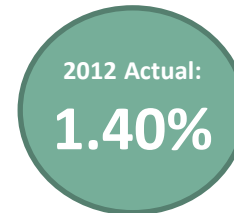
Issue joint statement with professional organizations regarding alcohol use during pregnancy

We'll Measure

Percentage of pregnant women reporting any alcohol use



Percentage of pregnant women reporting binge drinking



The Vision

Prevention of fetal alcohol syndrome through increased uptake of alcohol SBI, improved awareness and education, enhanced and data sources

QPR Reporting: Meds in Pregnancy

We've Done

Established an interagency coalition of partners to collaborate on medications and pregnancy research and programmatic activities

Convened interagency meeting in September 2012 between CDC, FDA, AHRQ, NIH, and HRSA to review each agency's activities and discuss short-term goals

Drafted a prototype for a formal review process to evaluate the evidence for fetal risk associated with commonly-used medications in pregnancy

We'll Do

Develop and approve a formal review process to evaluate the quality and strength of existing evidence for risks associated with the most commonly used medications during pregnancy

Submit least studies for publication that more fully characterize the known fetal risk of medications commonly used during pregnancy or on those with suspected risk

Convene meeting of experts to present draft prototype for a formal review process to evaluate the maternal and fetal risk associated with commonly used medications in pregnancy

Conduct at least three focus groups to assess knowledge, attitudes, beliefs, and actions related to medications in pregnancy among women of reproductive age, pharmacists, or health care providers

Submit a report for a peer-reviewed publication that identifies the medications that are most commonly used during pregnancy

We'll Measure

Decrease in percentage of women of child bearing age in U.S. adult population unaware that prescription and over-the-counter medications and herbals can be risk factors for major birth defects

2013 Target:

5%

Additional medications from the top twenty highest use medications with a rating of undetermined risk during pregnancy at baseline which have a risk determined

2013 Target:

1

The Vision

Prevention of congenital heart defects and other major birth defects associated with the use of medications in pregnancy