

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

Stuart K. Shapira, MD, PhD

Chief Medical Officer
Associate Director for Science

Interagency Collaborative to Advance Research in Epilepsy (ICARE) Meeting
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Office of the Director

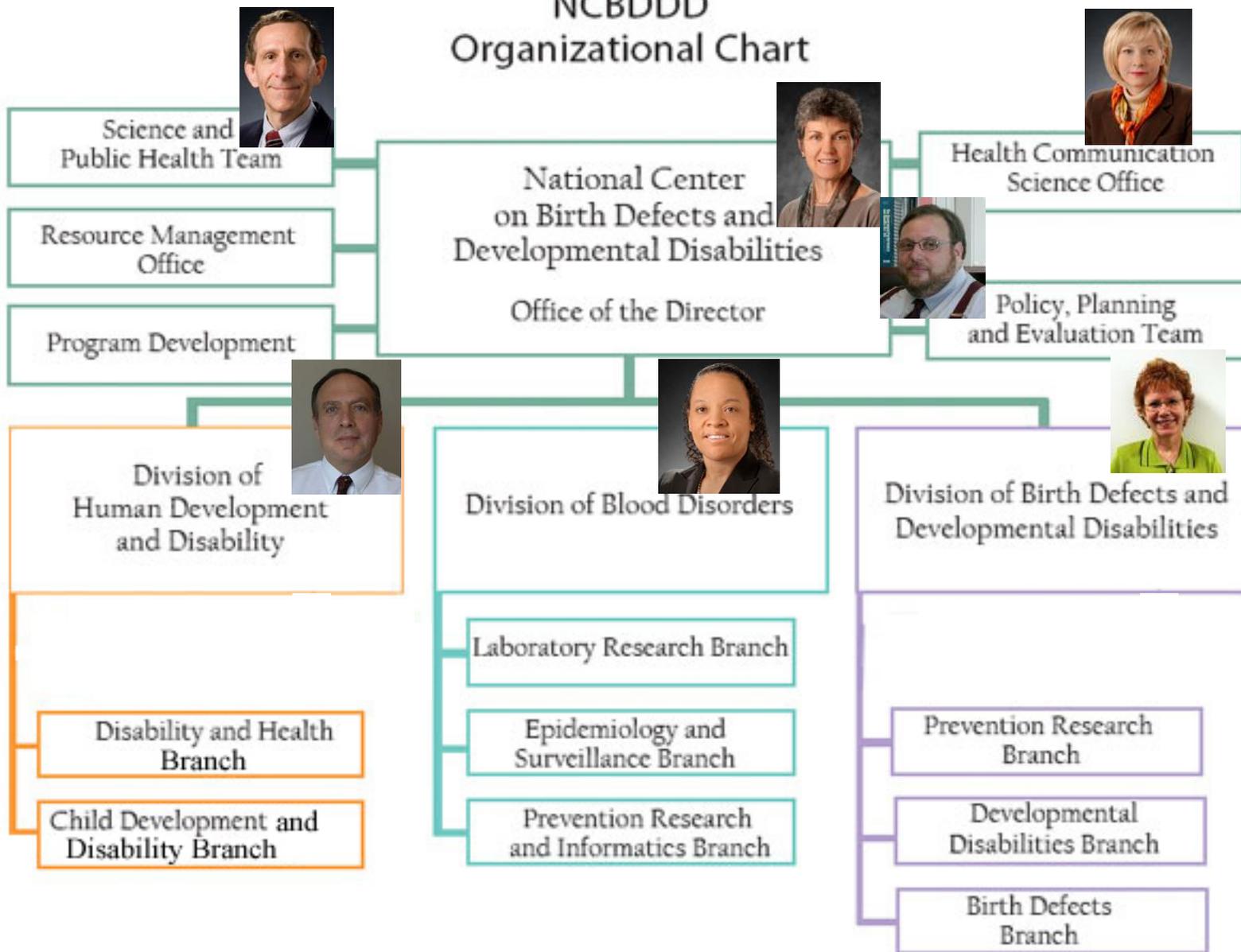
National Center on Birth Defects and Developmental Disabilities



NCBDDD

- ❑ The National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to advance the health and well-being of our nation's most vulnerable populations
- ❑ Our focus on women, children, and people with a range of disabilities and complex disabling conditions, positions us as a resource within public health that is unique and vital

NCBDDD Organizational Chart



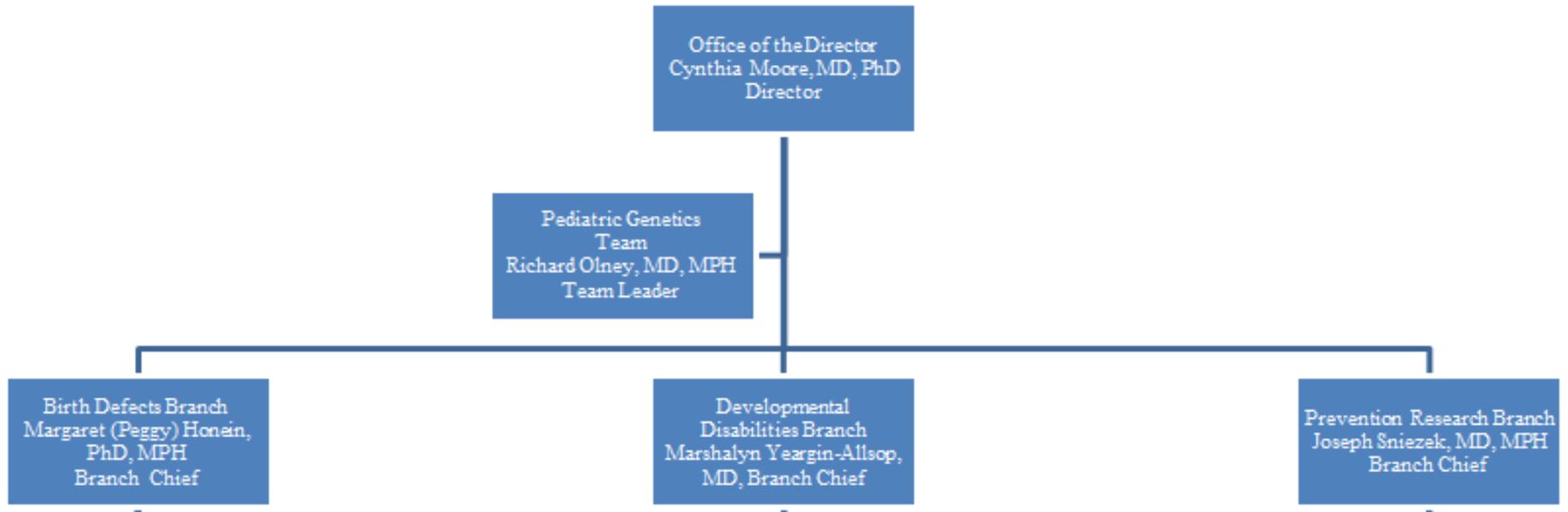
Center Focus Areas

- ❑ **Saving babies through birth defects prevention and research**
- ❑ **Understanding autism to help children live to the fullest**
- ❑ **Protecting people and preventing complications of blood disorders**
- ❑ **Improving the health of people with disabilities**

Topics of Interest in Epilepsy Research

- ❑ Characterize individuals wherein epilepsy co-occurs with other neurologic, developmental, and genetic disorders (e.g. ADHD, autism spectrum disorder, fragile X syndrome, spina bifida, Tourette syndrome)
- ❑ Research conducted through existing national surveys or surveillance or research systems
 - Prevalence and treatment of epilepsy
 - Health among persons with epilepsy (e.g. functional status and co-occurring mental and behavioral conditions)
 - Health insurance coverage; medical care costs
 - Health services use; use of developmental services
 - Quality of health care; disparities in access to health care and ease of care
 - School enrollment
 - Family financial and employment impact

Division of Birth Defects and Developmental Disabilities



Role of Division of Birth Defects and Developmental Disabilities

- ❑ Develop and support state-of-the-art *surveillance* programs
- ❑ Conduct *research* into causes and risk factors
- ❑ Develop, implement, and evaluate *prevention* programs

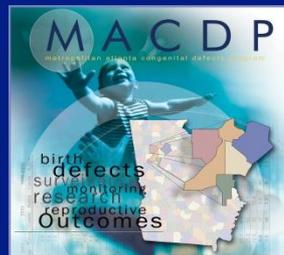
Division of Birth Defects and Developmental Disabilities: Surveillance

□ Birth Defects:

- The Metropolitan Atlanta Congenital Defects Program (MACDP) **INTRAMURAL**
- State-based birth defect surveillance/The National Birth Defects Prevention Network (NBDPN) **EXTRAMURAL**

□ Developmental Disabilities:

- Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) **INTRAMURAL**
- Autism and other Developmental Disabilities Monitoring (ADDM) Network **EXTRAMURAL**



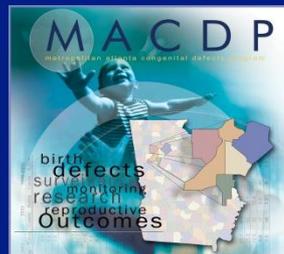
Division of Birth Defects and Developmental Disabilities: Surveillance

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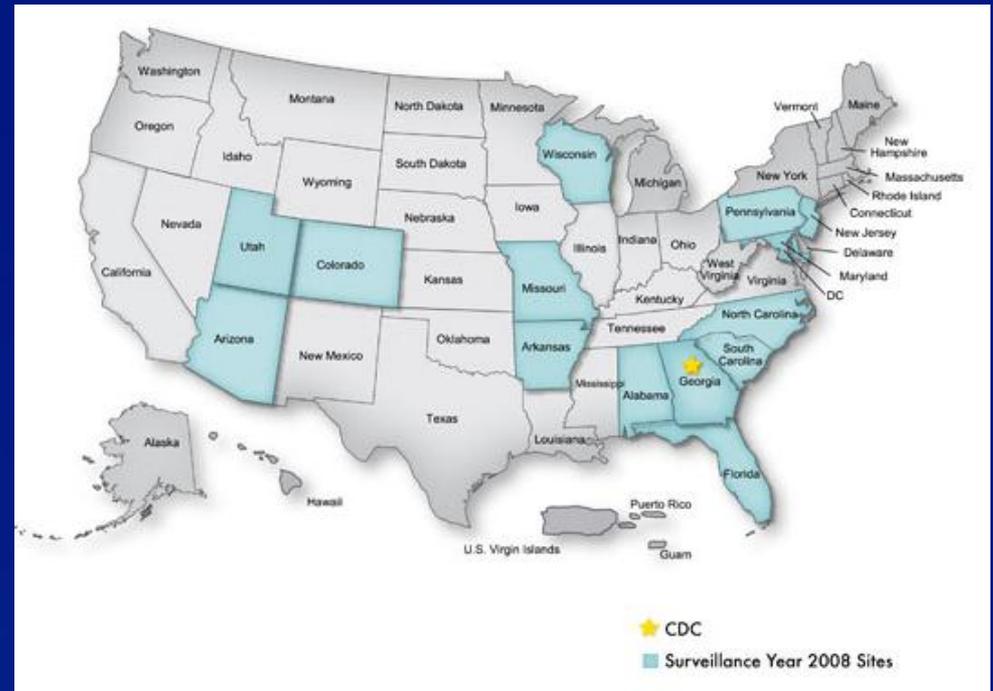
□ Developmental Disabilities:

- Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) **INTRAMURAL**
- Autism and other Developmental Disabilities Monitoring (ADDM) Network



Autism and Other Developmental Disabilities Monitoring (ADDM) Network

- Collaborative network of funded sites in 14 diverse U.S. communities
 - Surveillance regions cover ~8% of U.S. population
 - Rigorous, consistent, population-based methods of surveillance
 - Determine the number and characteristics of children with autism spectrum disorder (ASD) and other developmental disabilities

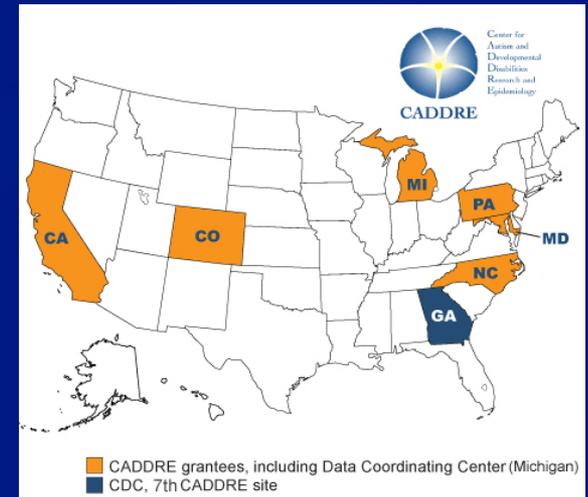


Autism and Other Developmental Disabilities Monitoring (ADDM) Network

- ❑ Missouri ADDM project to determine the prevalence of co-occurring epilepsy among 8 year old children with ASD or cerebral palsy (CP)
- ❑ Information collected: demographics, EEG/MRI information, seizure type (including epilepsy syndromes), age at onset, etiology, medication history, and additional medical information
- ❑ Clinical review by a pediatric neurologist determined case status
- ❑ Results
 - Surveillance year 2002: 9.3% of 8 year old children with ASD were confirmed to have epilepsy
 - Surveillance year 2006: 8.7% of 8 year old children with ASD were confirmed to have epilepsy; 32.9% of children with CP were confirmed to have epilepsy
- ❑ ADDM Network methodology can identify children with epilepsy in a population and provide important medical and healthcare information

Division of Birth Defects and Developmental Disabilities: Research

- Study to Explore Early Development (SEED)—Autism
 - Case-control study design: 6 Sites (including CDC)
 - Main research areas
 - ASD phenotypic variation
 - Infection and immune function, including autoimmunity
 - Reproductive and hormonal features
 - Gastrointestinal features
 - Genetic features
 - Sociodemographic features
 - 3899 children evaluated
 - 722 definite autism case
 - 584 possible autism case
 - 1304 developmental disability, non-autism
 - 1289 population controls



Study to Explore Early Development (SEED)

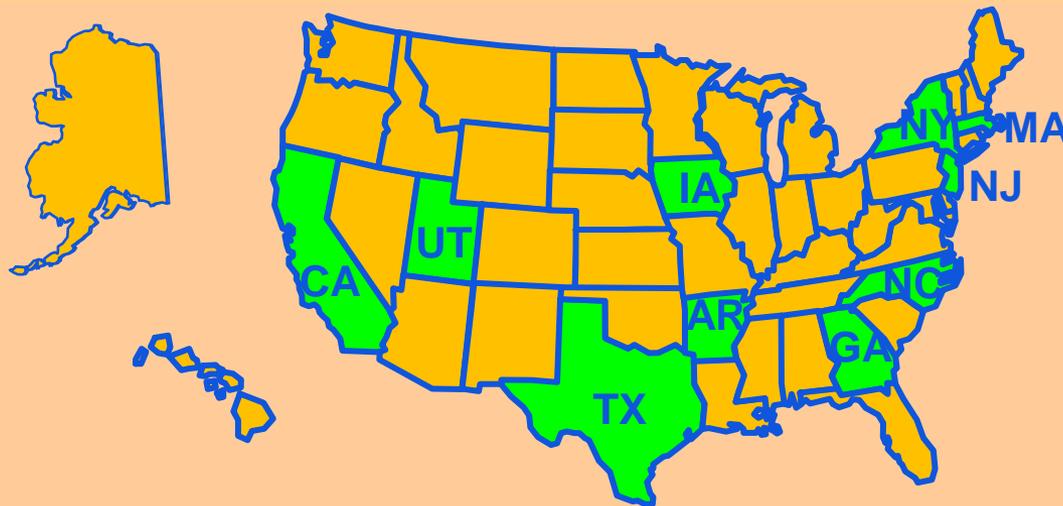
- ❑ Population-based ascertainment of cases and controls from diverse communities
- ❑ Participants aged 3-6 years
- ❑ Computer-assisted maternal interview to evaluate prenatal risk factors for ASD and other developmental disorders
- ❑ Medical records review (prenatal and pediatric)
- ❑ Survey forms for other research areas: e.g. autoimmune diseases, diet and stool diaries, health services and treatments
- ❑ Neurocognitive examination of participants for final case classification: ADOS, ADI-R, Mullen, Vineland
- ❑ Clinical genetics/dysmorphology evaluation
- ❑ Biologics: blood (DNA, RNA, serum, plasma, WBC), hair

Study to Explore Early Development (SEED)

- ❑ It is noted in the data collection forms whether or not the participant has epilepsy, but that is all
- ❑ With additional resources, neuroimaging results, EEG findings, and neurology evaluation results could be added to data collection
- ❑ Collection of diagnostic testing results could expand dimensions of risk factor analysis for epilepsy co-occurring with ASD and other developmental disabilities

Division of Birth Defects and Developmental Disabilities: Research

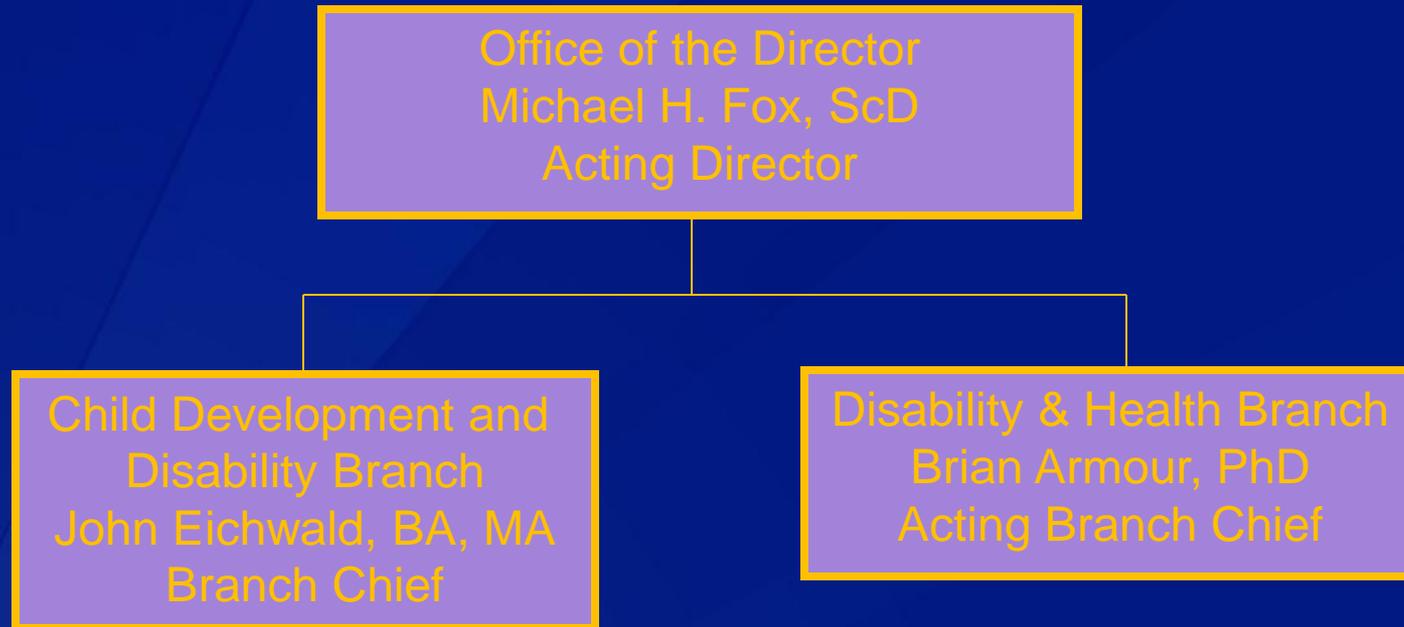
- National Birth Defects Prevention Study (NBDPS):
 - Ongoing (since 1997) population-based case-control study
 - 10 Centers (including CDC)
 - Includes about 30 major types of birth defects
 - 32,182 cases and 11,798 controls for a total of 43,980 women interviewed as of 3/31/2013 (end of study)



National Birth Defects Prevention Study (NBDPS)

- ❑ Computer-assisted maternal interview to evaluate prenatal risk factors for birth defects
- ❑ Maternal information from the interview about diagnosis and medication treatment for epilepsy
- ❑ Epidemiologic studies can evaluate the risk for specific birth defects in relation to the treatment (or not) during pregnancy for epilepsy

Division of Human Development and Disability



Division of Human Development and Disability

- Mission: To lead public health in preventing disease and promoting equity in health and development of infants, children, youth and adults with or at risk for disabilities to live to the fullest potential

Division of Human Development and Disability

Improved health
and development
Increased participation

OUTCOMES

Obesity & other health indicators
Developmental outcomes for children
Early hearing screening & referral
Health care access
Disability inclusion

STRATEGIC PRIORITIES

MUSCULAR DYSTROPHY Early Hearing Detection and Intervention
Disability and Health (CDS) Spina Bifida FRAGILE X *PARALYSIS*
Tourette Syndrome *Infant Health* **ADHD** *Limb Loss*

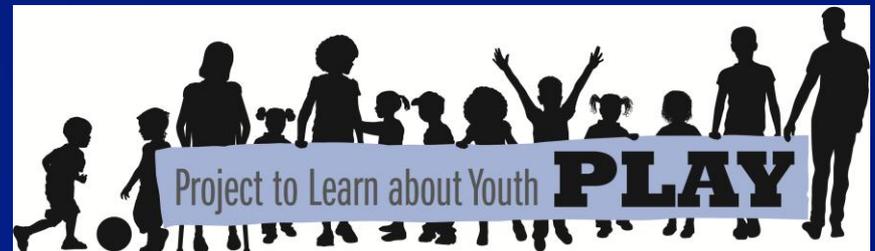
Division of Human Development and Disability

- Surveillance and Research
 - Attention-Deficit/Hyperactivity Disorder (ADHD)
 - Tourette Syndrome
 - Muscular Dystrophy
 - Impact of Poverty on Development

- Research/Translation – Clinical Registries
 - Spina Bifida
 - Fragile X Syndrome

Division of Human Development and Disability: Research

- **Project to Learn about Youth – Mental Health (PLAY-MH)**
 - 2 funded research sites (Univ. of SC, Univ. of CO-Denver)
 - School districts with diverse populations from varied geographical settings
 - Cross sectional epidemiologic study of childhood mental, emotional, and behavioral disorders
 - Characterize community-based prevalence, diagnosed prevalence, and treated prevalence
 - Examine relationships between demographics, diagnoses, and services needed and received
 - In 2014-2015, the study is including epilepsy in diagnosis and treatment questionnaires to describe community-based diagnosis and treatment patterns



Division of Human Development and Disability: Research

□ Health Services Research

- Collaboration with the Univ. of SC and the state
- Evaluate health, well-being, and social participation of adolescents and young adults (aged 15-24 years) through linked datasets (health care, social, economic, housing, education, and employment)
- Example: study involving individuals with fragile X syndrome
 - Care in outpatient/primary care setting is insufficient to prevent the higher cost and greater intensity of care associated with hospitalizations and ER visits due to epilepsy/seizures
- This robust data system could answer important questions for persons with epilepsy
 - Co-occurring conditions
 - Ambulatory care
 - Hospitalizations and ER use

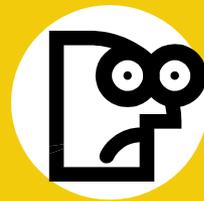
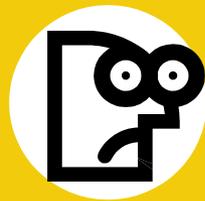
National Center on Birth Defects and Developmental Disabilities

*Promoting the health of babies, children, and adults
and enhancing the potential for full, productive living.*



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Developmental Disabilities**





It's QUESTION TIME!!