Overview of Disability Data Disseminated by CDCs Division of Human Development and Disability

2014 Annual Disability Statistics Compendium: CDC Disability Statistics: Recent and Future Developments

Brian S. Armour, PhD

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DHDD Teams

- Disability Research and Epidemiology Team
  - Disability and Health Data System – Dianna Carroll, Michelle Sloan
- Early Hearing Detection and Intervention (EHDI)
  - EHDI-Infant Screening – Marcus Gaffney
- Rare Disorders and Health Outcomes Team
  - Spina Bifida Patient Registry – Judy Thibadeau, Julie Bolen
  - Fragile X Syndrome Registry – Catharine Riley
  - Muscular Dystrophy Surveillance Tracking and Research Network – Natalie Street
- Child Development Studies Team
  - Diagnosis and Treatment of ADHD – Joseph Holbrook

Disability and Health Data System (DHDS)

- Source for state-based data on the health of PWDs
- Developed using CDCs Behavioral Risk Factor Surveillance System
- DHDS
  - State level disability surveillance tool
  - Open and accessible online (http://dhds.cdc.gov/)
  - Provides reliable, standard, and timely information
  - Approximately 80 health and demographic indicators
    - Stratified by Disability (2004 to 2012)
  - Disability Associated Health Care Expenditures
    - Public Payer (Medicare and Medicaid), Private Payer, Total

DHDS Recent Data Updates

- 2012 BRFSS estimates recently added
- Disability data by demographic groups now available for all indicators
- P-values are now available for all disparity estimates
- Dual Area Profiles
  - Ability to compare two geographic areas side-by-side on number of health indicators

DHDS New Features

- Interactive Map for Mobile Devices
  - Standard and High Contrast
  - Can be viewed on any smartphone, tablet, and all web browsers except Internet Explorer 8 or earlier
- DHDS Tutorial Videos
  - Four videos available on DHDS Homepage or YouTube
    - Introduction to DHDS
    - Interactive Map
    - Customizable Data Table
    - State Profiles

Early Hearing Detection and Intervention (EHDI)

- CDC EHDI supports the development of state-based EHDI Information Systems (EHDI-IS) to ensure deaf and hard of hearing infants receive recommended diagnostic and intervention services

- Early identification of hearing loss and intervention can help ensure children are able to reach their full potential

- Data obtained from an annual survey of programs in 50 states, 6 territories and the District Of Columbia
  - CDC EHDI Hearing Screening and Follow-up Survey
    - www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

EHDI DATA 2012

State and Territorial EHDI Program Data	N	(%)
Total Births	3,953,986	
Screened (*excluding deaths and refusals*)	3,820,624	(97.1)
Failed Screening	52,961	
Documented Diagnosed (*based on failed screening*)		
Hearing Loss	5,475	
No Hearing Loss	23,603	
Diagnosed	29,078	(54.9)
No documented diagnosis*	23,883	(45.1)
*In process, died, moved, loss to follow-up.		

EHDI Current Work and Future Directions

- Making progress identifying deaf and hard of hearing infants and providing early intervention services
  - However despite continued progress, some U.S. infants are still not documented as receiving recommended testing and intervention
- CDC MMWR Supplement (September 12, 2014 / Vol. 63)
- Future Work
  - Supporting states in the continued development and enhancement of their EHDI-IS
  - Lead efforts to improve interoperability between child health data systems and advance the exchange of data between providers and public health programs
  - Develop improved ways to collect and analyze data to better assess progress and highlight areas for improvement

Spina Bifida (SB) Program

- Spina bifida is the most common permanently disabling congenital condition in the U.S.
  - More than 70,000 Americans are living with SB
  - SB occurs in 3.4 per 10,000 live births in the US
- Limitations to current SB research include few:
  - Multisite studies; randomized control trials; studies on long-term treatment outcomes
- Variation across SB clinical programs in terms of structure; services; staffing; and, care delivered

Spina Bifida Association (SBA) Patient Registry

- SBA and CDC established Spina Bifida Patient Registry to:
  - Identify best practices for SB care
  - Implement use of a shared electronic reporting system to set standards for completeness, timeliness, and quality of data among SB clinics
  - Collect longitudinal data to evaluate current medical interventions
  - Help support clinical research and a systematic approach to improving quality of care
  - Compare SB patient care among clinics, population groups, and geographic areas
  - Guide and help prioritize future SB research areas

Funded Sites, Publications and Future Work

- Data collection
  - began 2009, 10 clinics
  - 14 clinics funded 2014-2019
  - longitudinal data on over 4000 patients

- Papers
  - Methods Paper, Thibadeau, et al, 2012
  - Descriptive paper, Sawin, et al, 2014
  - Future work
    - Pressure Ulcer data analysis paper
    - Demographics paper

Fragile X **O**nline **R**egistry **W**ith **A**ccessible **R**esearch **D**atabase

- Fragile X Syndrome (FXS) is the most common known inherited cause of intellectual disability
  - Estimated prevalence: 1 in 4,000 - 5,000 males and 1 in 6,000 – 8,000 females
  - People who have FXS show a range of intellectual disability and may also experience emotional, behavioral, sensory, and/or social difficulties
- Information is needed to
  - Enhance the understanding of FXS, its co-occurring conditions and its risk factors
  - Identify service barriers and needs
  - Determine the effect of current services on health
  - Document medical and behavioral treatment use and efficacy

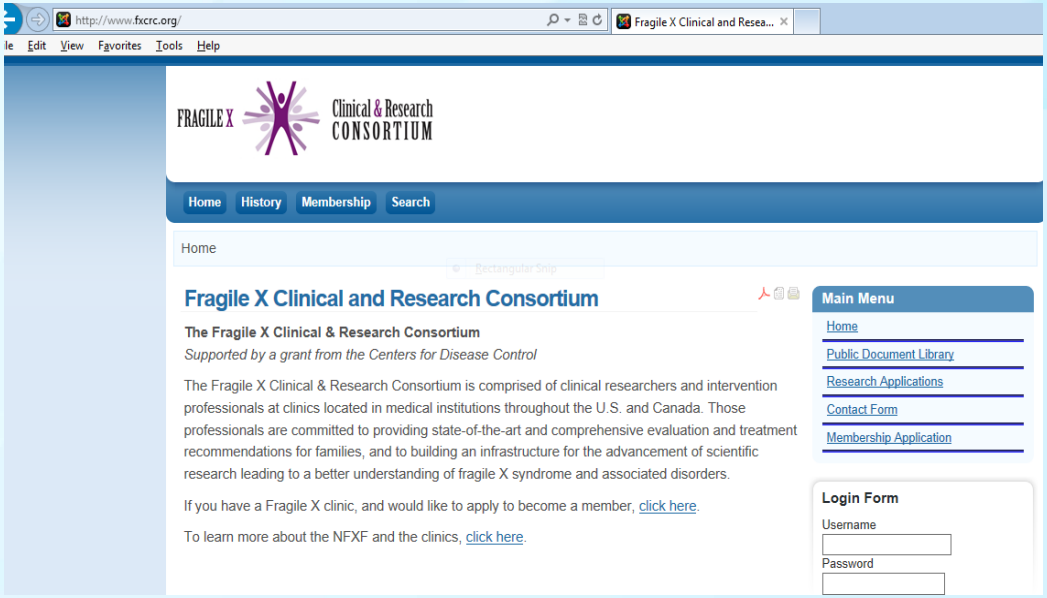
FORWARD Registry and Longitudinal Database

- CDC supports the Fragile X Clinical and Research Consortium (FXCRC) to implement FORWARD
- Data Sources:
  - REGISTRY: a one-time Registration Form - individuals with pre and full mutation FXS and their family members (both affected and unaffected).
  - LONGITUDINAL DATABASE: Clinician Report Form, Parent Report Form, and standardized parent-report instruments on behavior and communication (i.e. SRS, SCQ, ABC) - focused on full mutation FXS patients aged 0-24 years.
- Data Collection
  - Pilot study (2008-2011): data on 276 individuals with full mutation FXS collected from 9 clinics
  - FORWARD Registry and Database (2011 – current):
    - Registry includes data on over 2,000 individuals
    - Longitudinal database includes data over 500 individuals with full mutation FXS
    - 25 clinics participating (24 clinics as of June 2014)

Fragile X Consortium

- FXCRC has established a process for clinicians/researchers to request analyses of de-identified data or access to registrants through the clinics…. see **www.fxcrc.org**

- All requests are reviewed by the Application Review Committee



The Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet)

- Background
  - Muscular Dystrophies (MD) are a group of rare inherited disorders characterized by progressive muscle weakness and wasting
  - Vary by age of onset, muscle groups affected, genes involved, severity, and progression of disease
  - Population-based studies needed to more accurately estimate prevalence and mortality, and describe access to care and treatments

- MD STARnet Objectives
  - Characterize prevalence, natural history, healthcare service use and costs, and disparities in access to care
  - Assess whether specific treatments, interventions, or changes in healthcare use are associated with disease progression and survival

MD STARnet Data Sources

- Medical records
  - Clinics, hospitals, etc.
  - Search using criteria (ICD code, birth year, resident)
  - Trained abstractors input data
  - Require reporting law or IRB review (approval or exemption)
- Administrative data
  - Birth and death records (state and NDI)
  - Hospital discharge
  - Medicaid (Colorado)
- Interview and surveys

MD STARnet Data

- Data Collection
  - Began for Duchenne/Becker in 2002. For all MDs in 2011.
  - Currently 6 funded sites: Colorado, Iowa, 12 counties in Western New York, South Carolina, Utah/Nevada, North Carolina (piedmont area)
  - Longitudinal data collection

- With this data we plan to
  - Identify geographical distribution of individuals with each type of MD and their access to care and resources
  - Highlight similarities and differences in treatment, morbidity, and mortality and the factors that lead to differences
  - Provide information to service providers, advocates, and policy makers to improve decision making

Key MD Articles

- Centers for Disease Control and Prevention (CDC). Prevalence of Duchenne/Becker muscular dystrophy among males aged 5-24 years - four states, 2007. MMWR Morb Mortal Wkly Rep. 2009 Oct 16;58(40):1119-22.
- Ciafaloni E, Fox DJ, Pandya S et al. Delayed diagnosis in Duchenne muscular dystrophy: data from the Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet). J Pediatr. 2009 Sep;155(3):380-5.
- C. Holtzer, F.J. Meaney, J. Andrews, et al. Disparities in the Diagnosis of Duchenne and Becker Muscular Dystrophy. Genet Med. 2011 Nov;13(11):942-7.
- R. Arias, J. Andres, S. Pandya et al. Palliative care services in families of males with Duchenne muscular dystrophy. Muscle Nerve. 2011 Jul;44(1):93-101.
- NA West, Yang ML, Weitzenkamp DA et al. Pattern of Growth in Ambulatory Males with Duchenne Muscular Dystrophy. J Pediatr. 2013 Dec;163(6):1759-1763.e1. doi: 10.1016/j.jpeds.2013.08.004. Epub 2013 Oct 6.
- D Fox, Kumar A, West NA et al. Trends with Corticosteroid Use in Males Born 1982-2001 with Duchenne Muscular Dystrophy. In press with J Child Neurol.
- BJ Barber, JG Andrews, Z Lu et al. Oral Corticosteroids and Onset of Cardiomyopathy in Duchenne Muscular Dystrophy. J Pediatr. 2013 Oct;163(4):1080-4.e1. doi: 10.1016/j.jpeds.2013.05.060. Epub 2013 Jul 15.

Attention-Deficit/Hyperactivity Disorder and Tourette Syndrome

- Attention-deficit/hyperactivity disorder (ADHD)
  - Difficulty staying focused and paying attention, difficulty controlling behavior, and over-activity
  - Childhood onset, but often lasts into adolescence and adulthood
  - 6.4 million children aged 4-17 years (11%) have an ADHD diagnosis

- Tourette syndrome (TS)
  - Motor and phonic tics that persist for >1 year
  - Tic severity typically peaks between ages 10-12 years
  - 95,000 children aged 6-17 years (0.19%) have TS

ADHD and TS Data Sources

- National Surveys
  - National Survey of Children's Health (2003, 2007, 2011-12)
    - Provides information on the prevalence of diagnosed ADHD, medication treatment, and diagnosed TS
  - National Survey of Children with Special Health Care Needs (2001, 2005, 2009)
    - Provides information on ADHD treatment including medication, behavioral therapy, and dietary supplements

- Community-based/clinical data projects
  - Tourette Syndrome Impact (2009-11)
    - Focus on tic severity, treatment costs, access to care, relationships
  - Project to Learn about ADHD in Youth (2002-2012)
    - Provides information on ADHD community prevalence, co-occurring conditions, health risk behaviors
  - Project to Learn about Youth Mental Health (2013-current)
    - Builds upon PLAY to include more focus on internalizing disorders, externalizing disorders, and TS

Highlight: National Survey – Diagnosis and Treatment of ADHD (NS-DATA)

- Contacted all parents who reported a diagnosis of ADHD or TS in National Survey of Children's Health in 2011-12 to investigate:
  - Diagnostic context for ADHD and/or Tourette Syndrome
  - Presence of co-occurring conditions
  - Treatment types, adherence, barriers, satisfaction
  - Academic Health and Discipline
  - Family impact of ADHD and/or Tourette Syndrome

- Papers
  - Visser SN, Danielson ML, Bitsko RH, Holbrook JR, Kogan MD, Ghandour RM, et al. Trends in the Parent-Report of Health Care Provider-Diagnosed and Medicated Attention-Deficit/Hyperactivity Disorder: United States, 2003–2011. *J Am Acad Child Adolesc Psychiatry*. 2014;53(1):34-46.e32.
  - Bitsko RH, Holbrook JR, Visser SN, Mink JW, Zinner SH, Ghandour RM, et al. A National Profile of Tourette Syndrome, 2011-2012. *J Dev Behav Pediatr.* 2014;35:317-322.

Contact Information

Brian Armour
Centers for Disease Control and Prevention
1600 Clifton Road NE,
Mail Stop E-88
Atlanta, GA 30333
Tel. 404 – 498-3014
Email. barmour@cdc.gov

For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333
Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov Web: http://www.cdc.gov

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