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

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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/](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

<table>
<thead>
<tr>
<th>State and Territorial EHDI Program Data</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Births</td>
<td>3,953,986</td>
<td></td>
</tr>
<tr>
<td>Screened (excluding deaths and refusals)</td>
<td>3,820,624 (97.1)</td>
<td></td>
</tr>
<tr>
<td>Failed Screening</td>
<td>52,961</td>
<td></td>
</tr>
<tr>
<td>Documented Diagnosed (based on failed screening)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing Loss</td>
<td>5,475</td>
<td></td>
</tr>
<tr>
<td>No Hearing Loss</td>
<td>23,603</td>
<td></td>
</tr>
<tr>
<td>Diagnosed</td>
<td>29,078 (54.9)</td>
<td></td>
</tr>
<tr>
<td>No documented diagnosis*</td>
<td>23,883 (45.1)</td>
<td></td>
</tr>
</tbody>
</table>

*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**
  - Descriptive paper, Sawin, et al, 2014
  - Future work
    - Pressure Ulcer data analysis paper
    - Demographics paper
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

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**
    - Provides information on the prevalence of diagnosed ADHD, medication treatment, and diagnosed TS
    - 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
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