Developmental Disabilities Across the Lifespan: A CDC Perspective

7th Annual Developmental Disabilities: An Update for Health Professionals
University of California, San Francisco

Overview

- What is disability?
- Definitions of disability
  - ICF
  - CDC (developmental disability)
- Childhood disability
  - CDC studies
    - Prevalence
    - Prevention
  - Prevalence from national surveys
- Transition
- Disability in Young Adults/Older Adults
- Status report on disability from HP 2010

What is Disability?

- Confusing Case Definition
  - Over 50 federal definitions of disability
- Defined by mode of attainment
  - Born with a disability = Developmental Disability
  - Midlife disability = Injury
  - Develop a disability late in life = Chronic condition

“The absence of universally accepted and understood terms and concepts with which to describe and discuss disability continues to be a major barrier to consolidating scientific knowledge about the circumstances that contribute to disability and the interventions that can prevent, mitigate, or reverse it.”

The Future of Disability in America, IOM Report, 2008
Disability…

- Defined to determine rights to services
  - Civil rights claims (ADA)
  - Work disability compensation
  - Early intervention (IDEA)
  - Special education (IDEA)
  - Medicaid (SSI)

CDC definition of Developmental Disability*

A diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person’s lifetime.

* Metropolitan Atlanta Developmental Disabilities Surveillance Program

International Classification of Functioning, Disability, and Health:

- Assesses the health of people with a "disabling" condition regardless of the disease or disorder involved
- Helps to understand why two people with the same condition may have different outcomes
- Focuses on:
  - Health status outside of the disabling condition
  - Relationship between activity limitation and barriers in the environment
  - Inclusion in society

http://www.who.int/classifications/icf/en/

ICF defines disability as:

An umbrella term for impairments, activity limitations, and participation restrictions

ICF starts with the concept of a health condition - this is the starting point for the possible development of a “disability” as defined above

http://www.who.int/classifications/icf/en/
ICF Conceptual Model

Disorder/Disease
  ICD- 9/10
  Impairment of Structure or Function
    Activity Limitation
    Participation Restriction
  Environmental Factors
  Personal Factors

ICF Components

<table>
<thead>
<tr>
<th>Body Functions &amp; Structures</th>
<th>Activities &amp; Participation</th>
<th>Environmental Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functions</td>
<td>Capacity</td>
<td>Barriers Facilitators</td>
</tr>
<tr>
<td>Structures</td>
<td>Performance</td>
<td></td>
</tr>
</tbody>
</table>

CDC and Disability

- CDC uses both the definition of developmental disability (Metropolitan Atlanta Developmental Disabilities Surveillance Program) and the ICF definition of disability to track conditions across the life span.

CDC's Methods for Monitoring Disability

- Population-Based Surveillance
  - MADDSP
  - ADDM
- National Surveys
  - NHIS
  - BRFSS

Disability at various ages, at various points in time

Disability at a specific age, at a specific point in time
Both methods are necessary to give us a “complete” picture of disabilities across the lifespan.

What is Public Health Surveillance?

The ongoing, systematic collection, analysis, and interpretation of outcome-specific data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease or injury.

http://www.cdc.gov/epo/ads/section-x.htm

How to count: Prevalence

Number of people in a defined population with disease during time x

\[ \frac{\text{Number of people in the population during time x}}{\text{X}} \times 1,000 \]

CDC’s Population-Based Surveillance of Developmental Disabilities

- MADDSP
  - Hearing Loss
  - Vision Impairment
  - Intellectual Disability
  - Autism
  - Cerebral Palsy

- ADDM
  - Autism
  - Cerebral Palsy
  - Intellectual Disability
**CDC’s MADDSP Model**
Atlanta, Georgia

- Ongoing population-based, multiple source surveillance system for developmental disabilities (DDs):
  - MR
  - CP
  - Hearing loss
  - Vision impairment
  - Autism (added 1996)
- Since 1991
  - 3-10 year-old children in 5 county metro Atlanta area (8 year olds in 1996)
- Data abstracted from Special Ed and medical provider records;
  - clinician review
- Generate population-based prevalence estimates for the five DDs and identify cases for special studies.

*Metropolitan Atlanta Developmental Disabilities Surveillance Program

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**MADDSP**

- **1991-1994 surveillance years (children 3-10 years old)**
  - Intellectual Disability (ID)
  - Cerebral Palsy (CP)
  - Hearing Loss (HL)
  - Vision Impairment (VI)
- **1996 surveillance year**
  - Children ages 3-10 for Autism
  - Children 8 years of age for ID, CP, HL, VI
  - Children 8 years of age for ID, CP, HL, VI, and Autism

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**2000 Metropolitan Atlanta Developmental Disabilities Surveillance Program**

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>One of 5 Developmental disabilities (%)</th>
<th>ASD*</th>
<th>ID*</th>
<th>CP*</th>
<th>HL*</th>
<th>VI*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black, non-Hispanic</td>
<td>2.1</td>
<td>0.5</td>
<td>1.6</td>
<td>0.4</td>
<td>0.1</td>
<td>0.2</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>1.5</td>
<td>0.8</td>
<td>0.7</td>
<td>0.3</td>
<td>0.09</td>
<td>0.1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.1</td>
<td>0.03</td>
<td>0.08</td>
<td>---</td>
<td>0.01</td>
<td>---</td>
</tr>
<tr>
<td>OVERALL</td>
<td>1.9</td>
<td>0.7</td>
<td>1.2</td>
<td>0.3</td>
<td>0.1</td>
<td>0.1</td>
</tr>
</tbody>
</table>

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**Prevalence of MR, CP, HL, VI and ASDs among Children in MADDSP**

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*Prevalence per 1000 8-year-old children*
- CDC formed the Autism and Developmental Disabilities Monitoring (ADDM) Network in an effort to better understand ASDs in the US.
- Purpose is to establish an ongoing system for better understanding the magnitude and characteristics of the population of children with an ASD in the United States.
- First and largest multi-site report on ASD prevalence to use common methods in the US to date.

**ADDM 2002 ASD Findings**

- The overall ASD prevalence per 1,000 8-year-olds ranged from 3.3 (AL) to 10.6 (NJ).
- ASD prevalence range across 12 of 14 sites was between 5.2 and 7.6 per 1,000 children.
- Weighted average prevalence was 6.6 per 1,000 across all sites (approximately 1:150 children)

2002 MADDSP Prevalence: 7.6 per 1,000

- 3 sites (AL, GA, WI) conducted CP surveillance in 2002.
- Site-specific rates were similar (3.3-3.8 per 1,000) with average of 3.6 per 1,000 8-year-old children.
- Male: female ratio was 1.1 (GA) to 1.6 (AL, WI).
- Spastic CP was the most common subtype (77% of all cases), primarily represented by bilateral spastic CP.
Using Surveillance to Inform Primary Prevention

“Measures that are provided to individuals to prevent the onset of a targeted condition.”

Early Hearing Detection Intervention (EHDI)

- Early 1990s: MADDSP data shows that less than 10% of children had their hearing loss detected by age 1
- Today: 90% of all newborns are screened
- EHDI programs exist in every state to promote screening, follow-up evaluations, and interventions

Percentage of Children with Presumed Congenital Sensorineural Hearing Loss, by Earliest Known Age at Diagnosis + Hearing Level

Mental Retardation and Metabolic Disorders
Metropolitan Atlanta, 1991-1994

<table>
<thead>
<tr>
<th>Metabolic Disorder</th>
<th>Annual Rate per 100,000 live births</th>
<th># Expected Children with MR</th>
<th># Observed Children with MR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phenylketonuria</td>
<td>6.2</td>
<td>23</td>
<td>0</td>
</tr>
<tr>
<td>Homocystinuria</td>
<td>0.3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Maple syrup urine disease</td>
<td>0.5</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Tyrosinemia</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Hypothyroidism</td>
<td>20.3</td>
<td>74</td>
<td>0</td>
</tr>
<tr>
<td>Classic galactosemia</td>
<td>12.8</td>
<td>47</td>
<td>1</td>
</tr>
</tbody>
</table>
New Born Screening

- Almost all infants screened for
  - Phenylketonuria (PKU)
  - Congenital hypothyroidism (CH)
  - Sickle cell disease (SCD)
  - Galactosemia
- Expanded NBS panels rapidly being adopted—
  - Congenital adrenal hyperplasia (CAH)
  - Amino acid disorders (e.g., MSUD)
  - Fatty acid oxidation disorders (e.g., MCAD)
  - Urea cycle disorders—Cystic fibrosis (CF)
  
  *Other screening tests on the horizon*

Prevalence of Cerebral Palsy by Birth Cohort

<table>
<thead>
<tr>
<th>Birth weight (grams)</th>
<th>1975-77</th>
<th>1985-88</th>
<th>1989-91</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td># Births</td>
<td># Cases</td>
<td>Rate 1000</td>
</tr>
<tr>
<td>&lt;1500</td>
<td>916</td>
<td>27</td>
<td>29.5</td>
</tr>
<tr>
<td>1500-2499</td>
<td>4,752</td>
<td>30</td>
<td>6.3</td>
</tr>
<tr>
<td>&gt;2500</td>
<td>60,437</td>
<td>53</td>
<td>0.9</td>
</tr>
<tr>
<td>Total</td>
<td>66,105</td>
<td>110</td>
<td>1.7</td>
</tr>
</tbody>
</table>

Prevention of CP: Magnesium Sulfate

- Previous research suggested magnesium sulfate could reduce rates of cerebral palsy in pre-term infants.
  - The common drug—also known as *Epsom salts*—is used to stop seizures in pregnant women who develop them.
  - But...data about any relationship to cerebral palsy were unclear.
- Study recruited >2000 women who were at risk for giving birth prematurely.
- Randomized controlled trial—followed children for two years
- Result: Women who received magnesium sulfate as they were giving birth had children who were 50 percent less likely to develop cerebral palsy.

Using National Surveys

- Examples of CDC’s use of surveys in disability monitoring
  - National Health Interview Survey (NHIS)
  - Behavioral Risk Factor Surveillance System (BRFSS)
**1999-2000 National Health Interview Survey**

(1% of children 0-17 years of age)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Mental Retardation/ Other developmental disabilities</th>
<th>Learning disabilities</th>
<th>Attention deficit hyperactivity disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black, non-Hispanic</td>
<td>4.2</td>
<td>9.7</td>
<td>5.3</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>4.4</td>
<td>9.3</td>
<td>4.8</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2.4</td>
<td>7.0</td>
<td>3.9</td>
</tr>
<tr>
<td>OVERALL</td>
<td>4.0</td>
<td>9.0</td>
<td>7.0</td>
</tr>
</tbody>
</table>

**Trends in prevalence (per 100 children) of specific developmental disabilities in children, ages 3-17 years, NHIS, 1997-2004**

<table>
<thead>
<tr>
<th>Disability*</th>
<th>No. unweighted</th>
<th>All Years</th>
<th>1997</th>
<th>1999</th>
<th>2001</th>
<th>2003</th>
<th>2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any DD</td>
<td>12257</td>
<td>13.22</td>
<td>12.93</td>
<td>12.17</td>
<td>12.94</td>
<td>12.74</td>
<td>13.50</td>
</tr>
<tr>
<td>Autism</td>
<td>357</td>
<td>0.38</td>
<td>0.08*</td>
<td>0.24</td>
<td>0.34</td>
<td>0.43</td>
<td>0.65</td>
</tr>
<tr>
<td>Cerebral Palsy*</td>
<td>128</td>
<td>0.13</td>
<td>0.09</td>
<td>0.09</td>
<td>0.15</td>
<td>0.13</td>
<td>0.15</td>
</tr>
<tr>
<td>Deafness, a lot of trouble hearing</td>
<td>433</td>
<td>0.47</td>
<td>0.63*</td>
<td>0.54</td>
<td>0.42</td>
<td>0.49</td>
<td>0.27</td>
</tr>
<tr>
<td>ID</td>
<td>700</td>
<td>0.72</td>
<td>0.59</td>
<td>0.70</td>
<td>0.77</td>
<td>0.65</td>
<td>0.61</td>
</tr>
</tbody>
</table>

**Behavioral Risk Factor Surveillance System (BRFSS)**

- CDC added two disability questions to the core section of the annual BRFSS
- Questions will enable all 50 states, territories and the District of Columbia to
  - Identify people with disabilities who participate in the survey
  - Describe the health status of people with disabilities living within their state
  - Examine health risk behaviors

**BRFSS Disability Questions**

1. Are you limited in any way in any activities because of physical, mental, emotional problems
2. Do you now have any health problem that requires the use of special equipment, such as a cane, wheelchair, a special bed, or a special telephone?
Transition by Age

- Age 3: Early Intervention
- Age 3-4: Preschool
- Age 5-6: School (Special Education)
- Age 18-22: Education System to Vocation
- Late Life: Home care to Institutional Care

Transition by Type of Care

- Medical Home Model (pediatric care)
- Adult Care Model
- Institutional Care
- Community Care
- Community Care to Institutional Care
Predictors of Employment in Young Adults with Developmental Disabilities

- Period of transition from adolescence to adulthood—challenging for individuals with DDs:
  - Spectrum of new experiences and need to acquire new knowledge and skills to succeed.
  - Vulnerability with changing support systems:
    - Rehabilitation, special educational, and specialized pediatric care often cease at 18-22 years of age.

Research question: Does impairment at age 10 predict difficulty with attaining adult social roles?

Methods: MADDS and Follow-up


Disabilities: Mental retardation, Cerebral palsy, Hearing loss, Vision impairment, Epilepsy

Children without impairment selected from regular education classes

Where: 5 counties of metro-Atlanta

How: Multiple source record review

Follow-up as young adults using ICF framework

Predictors of Being Unemployed

- Strongest predictor of being unemployed is having multiple impairments.
- Young adults with Isolated MMR, Isolated CP, and isolated HL are more likely than young adults without impairment to be unemployed.
- Demographic and socio-economic characteristics do not significantly influence likelihood of unemployment.
- Level of educational attainment is a significant predictor of being unemployed.

Public Health Implications

- Being unemployed is not solely attributable to an individual's impairment.
- Efforts to improve attendance of post-secondary education may improve the chances of securing employment.
- Intervention to prevent or lessen the severity of limitations in ADLs may reduce the likelihood of being unemployed for young adults with certain impairments.
**Barriers to Successful Transition**
- Multiple service delivery systems with no organized system of care
- Lack of clearly defined roles for each member of a care team
- Not enough communication between care teams and health care professionals
- Not enough information about community resources
- Insufficient reimbursement of time/work required to coordinate care/transition

**IOM Recommendations for Improvement**
- Strengthen public/private health care programs
- Expand use of Electronic Medical Records
- Extend Medicaid and SCHIP through 21
- Fund MCHB to expand medical home for those over 21 who need support
- Revise Ticket to Work - lower age to 16
- Advise CDC to examine transition through state/national surveys or longitudinal data collection efforts

**Secondary Conditions Across the Lifespan**

“I was about 35 years old when I started to feel the signs of aging that I later learned were being brought on prematurely by my disability (cerebral palsy)...I became aware that I wasn’t alone with these symptoms, that they weren’t all in my head...But I was frightened because aging with a disability was an uncharted course.”

Kathleen Lankasky, IOM Report, 2008

**Secondary Health Condition**
- Any additional physical or mental health condition that occurs as a result of having a primary disabling condition.
- Biology, lifestyle, and behavior determine whether these conditions affect activity or contribute to the development of other impairments
- Examples include depression, arthritis, and cardiovascular disease
- These can also be primary health conditions
Factors Affecting Aging and Disability

- The number of years spent with a particular disability
- Years of exposure to a particular medication (e.g., corticosteroids) or other therapy or environmental factor
- Individuals era of disability onset and initial medical treatment
- Age at onset of disability in relation to the individual’s developmental maturity

Recent Updates: Healthy People 2010

- Sadness or depression among children with disabilities, 4-17 years of age, decreased from 31% in 1997 to 27% in 2005.
- The number of states with health surveillance for people with disabilities increased from 14 states in 1999 to all 50 states, the District of Columbia, Guam, Puerto Rico and the Virgin Islands in 2003 and beyond.
Summary

- Disability is defined in various ways based on purpose
  - CDC and ICF measures are important public health tools to determine rates of disability and to inform intervention strategies
  - National Surveys complement population based surveillance to provide a more complete picture of disability

Summary Continued

- Transition points in life are challenging for those affected by a disability
  - Employment status and education may be affected by a disability or impairment
  - IOM has recommended improvements for successful transition including advising CDC to examine transition through state/national surveys or longitudinal data collection efforts

Summary Continued

- Secondary conditions are a problem for those aging with a disability
  - Many factors exert their influence on a person including the how long the person has had the disability, how severe the disability is, and what limitations the disability presents
  - But...Sadness and depression have been reported as declining in this population and more and more states are adding surveillance systems to monitor the health status of people with a disability

CDC: Committed to Care Across The Lifespan
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