Improving the Health of People with Intellectual and Developmental Disabilities

A Public Health Approach

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CDC's National Center on Birth Defects and Developmental Disabilities

Promoting the health of babies, children, and adults, and enhancing the potential for full, productive living
Division of Human Development and Disability

Serving as a national and international resource to promote optimal development, health and well-being of children and people with disabilities.

Before & During Pregnancy
- Fetal Alcohol
- Infections
- Medication
- Preconception Care
- Preventing Birth Defects

Infants
- Birth Defects
- Health and Safety
- Hearing Screening
- Developmental Delays

Child Development & Parenting
- ADHD
- Autism Spectrum Disorders
- Child Development
- Tourette Syndrome
- Milestones
- Parenting Tips

People with Disabilities
- Disability and Health
- Intellectual Disabilities
- Spina Bifida
- Duchenne Muscular Dystrophy
- Fragile X

http://www.cdc.gov/ncbddd/disabilityandhealth/aboutus.html
Overview of DHDD by Lifespan

Infancy/Early Childhood

Childhood

Adolescence

Adulthood/Elder

Early Hearing Detection and Intervention

Legacy for Children

Parenting

Childcare

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Overview of DHDD by Lifespan

Infancy/Early Childhood

Childhood

Adolescence

Adulthood/Elder

AD/HD

Tourette syndrome

Spina Bifida

Duchenne Becker Muscular Dystrophy

Fragile X

CDC

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Overview of DHDD by Lifespan

Infancy/Early Childhood

Childhood

Adolescence

Adulthood/Elder

Self Management of Health

Special Olympics
Healthy Athletes

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Overview of DHDD by Lifespan

Infancy/Early Childhood

Childhood

Adolescence

Adulthood/Elder

Disability & Health Surveillance

Disability and Health State Network

Information Centers
Improving the Health of the Public

The Health Impact Pyramid

- Counseling and Education
- Clinical Interventions
- Long-Lasting Protective Interventions
- Changing the Context to Make Individuals’ Default Decisions Healthy
- Socioeconomic Factors

Increasing Population Impact

Increasing Individual Effort Needed
Improving the Health of People with Intellectual and Developmental Disabilities

- Health status of people with intellectual and developmental disabilities (IDD)
- Limited data that we have, and importance of population-level data
- Initiative on Health Surveillance of people with IDD
- What it means for you
IDD is an Important Population to Address

People with IDD represent 4.9% of the Medicaid population and account for 15.7% of total Medicaid expenditures.

(U.S DHHS, Office of the Surgeon General, 2002)

A 2003 cost analysis estimated the following costs:

- Mental retardation: $51.2 billion (Intellectual Disabilities)
- Cerebral palsy: $11.5 billion
- Hearing: $2.1 billion
- Vision impairment: $2.5 billion

(Honeycutt et al., 2004)
Current Health Status of People with Intellectual Developmental Disabilities

People with IDD are more likely to experience:

- Complex health conditions
- Poorly managed chronic diseases
- Limited access to quality health care and health promotion programs
- Mental health problems and potential overuse of psychotropic medications
- Overweight and obesity

(CDC ID Surveillance Factsheet, 2010)
Health Conditions in People with IDD

Epilepsy and neurological disorders 17-70%
Dermatology 33-63%
Fractures/lacerations 11-43%
Gastrointestinal 8-10%
Cardiovascular 9-45%
Behavioral/psychiatric 21-49%
Sensory (vision/hearing) 10-99%

(Krahn, Hammond and Turner, 2006)
Surgeon General’s Report—2002

Recommendations:

- Health promotion in communities
- Research on health
- Health care quality
- Train HC providers
- Financing
- Increased sources of care
Progress: 2002-2010

- Health promotion effectiveness for people with IDD
- Research – Surveillance
- Renewed interest in training of health care providers
- Defining “medically underserved”
- Financing and access—Health reform
Omission of People with IDD in Population Surveys

1. People with significant ID are typically excluded in national surveys —“non-institutional populations”

2. People with ID are often not identifiable in national surveys or sample sizes are small
Percentage of People with MR (ID)/DD by Age in US Non-Institutional Population, NHIS-D 1994-95 Survey

Percentage (%)

2.5
2
1.5
1
0.5
0

0-5 6-16 17-24 25-34 35-44 45-54 55-64 65+ Total

Age Group (Years)

(RESEARCH & TRAINING CENTER, UNIVERSITY OF MINNESOTA, 2010)
Transitioning Out
Prevalence of Mental Retardation in Administrative Data
State of Alabama, 1992-93

Data include special education, MR (ID) institutional and community (clients and waiting list), and vocational rehabilitation

Mild | Mod/Sev/Pro | Total

Number of people in formal service system decline dramatically after school age mostly due to mildly affected departing school (age out or drop out); more severely affected remain in formal service system

(Campbell, Causey, Collier, Ramey, Shearer & Stokes BR, 1995)
Age Adjusted Prevalence Rates for Chronic Health Conditions, MEPS 2006

Chronic Health Conditions

(Reichard, Stolze and Fox, 2010)
Prevalence of Preventive Care Comparing Cognitive Limitations to No Disability, MEPS, 2006

Preventive Care

(Reichard, Stolze and Fox, 2010)
Developing a Health Surveillance System for People With Intellectual Disabilities in the United States

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Abstract Adults with intellectual disabilities (ID) experience poorer access to quality healthcare and poorer health outcomes than people without ID. They are more likely to live with complex and poorly managed health conditions, have limited access to quality healthcare, receive cancer screenings at lower rates, be obese, have undetected vision and hearing problems, and be at risk for overuse of psychotropic medications. While health disparities appear endemic, there remains a dearth of population-based information, leading to lack of recognition of this problem by policy makers, public health, and even healthcare professionals. Efforts to address these disparities are insufficient, owing in part to the challenge of documenting the problem’s scope and nature. In the U.S., nearly 4 million adults are currently estimated to have ID. In contrast to European countries and despite attention from the U.S. Surgeon General in 2002 on the poor health of people with ID, little progress has been made on obtaining related population-based data in the U.S. Substantial challenges exist relative to gathering representative data on the population with ID. In response, two international meetings of experts were convened to discuss possible approaches to gathering population-based health information on people with ID. The discussions included about whom to gather information, what data to collect, and options for how to gather the data. Authors note that efforts to improve health surveillance of people with ID in the U.S. can be enhanced through a multistage strategy. Recent healthcare reform in the U.S. sets a new context for major changes in access to and the way that our healthcare system operates. These changes highlight the need to develop accurate and reliable surveillance systems that can monitor the impact of these changes on this often neglected population.

Keywords: case definition, ICF, intellectual disabilities, public health, surveillance
5-Step Plan for Health Surveillance of People with IDD

1. Define ID in clinically, functionally, and operationally valid ways.
2. Synthesize knowledge base, including data sources and surveillance methods.
3. Extend analyses of current data sources.
4. Pilot state or regional demonstrations.
5. Develop sustainable approaches.
What Does this Mean for You in Your State?

- Health is critically important, and is a big cost driver in your state
- National data are needed to document disparities
- Health care access is a national and local issue—training, reimbursement, retention of qualified professionals
- Obesity is a very local issue
Obesity and IDD

- Obesity is a national problem
- Obesity puts people at risk for a range of immediate and long-term health problems, including earlier death
- People with intellectual and mobility limitations have significantly higher rates of obesity
Obesity by Select Condition/Limitation, NHIS 2001-2008

<table>
<thead>
<tr>
<th>Condition/Limitation</th>
<th>Percent $</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability*</td>
<td>35.4</td>
</tr>
<tr>
<td>Mobility/movement limitation</td>
<td>39.4</td>
</tr>
<tr>
<td>No limitation</td>
<td>20.4</td>
</tr>
</tbody>
</table>

$ Age adjusted and based on self-reported height and weight
*Reported intellectual disability was a cause of reported limitation
Improving the Health of Persons with IDD

Being Part of the National Campaign to Reduce Obesity

- CDC initiative to:
  - Include people with disabilities in obesity campaigns
  - Determine what is effective to prevent and intervene with obesity
  - [http://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html](http://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html)
The importance of overweight and obesity related to people with disabilities is a particular problem of public health importance. Obesity is more prevalent among people with disabilities than for people without disabilities and is an important risk factor for other health conditions.
People with disabilities can find it more difficult to always eat healthy, control their weight, and be physically active. This might be due to:

* A lack of healthy food choices
* Difficulty with chewing or swallowing food, or with the taste or texture of foods
* Medications that can contribute to weight gain, weight loss, and changes in appetite
* Physical limitations that can reduce a person’s ability to exercise
* Pain
* A lack of energy
* Lack of accessible environments
* Lack of resources

Challenges Facing People with Disabilities
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* Physical limitations that can reduce a person’s ability to exercise.
* Pain.
* A lack of energy.

Physical Activity for People with Disabilities
Evidence shows that regular physical activity provides important health benefits for people with disabilities. Benefits include improved cardiovascular and muscle fitness, improved mental health, and a better ability to do tasks of daily life.

Sufficient evidence now exists to recommend that adults with disabilities should get regular physical activity. Learn more about Physical Activity Guidelines for Americans at [http://www.health.gov/PAGuidelines and www.ncpad.org](http://www.health.gov/PAGuidelines and www.ncpad.org)

Physical activity can help people of all abilities improve their overall health and fitness, and reduces the risk for many chronic diseases.
Among all people with disabilities, children and adults with mobility limitations and intellectual or learning disabilities are at greatest risk for obesity.

Overweight and obesity increases the risk of other conditions, such as:
- Coronary heart disease
- Type 2 diabetes
- Certain cancers
- Hypertension
- Lipid disorders
- Stroke
- Sleep apnea
- Osteoarthritis
- Gynecological problems

The Obesity Epidemic

Obesity affects different people in different ways and may increase the risk for other health conditions among people with and without disabilities.

For people with disabilities:
- Children and adults with mobility limitations and intellectual or learning disabilities are at greatest risk for obesity. 1,2,3
- 20% of children 10 through 17 years of age who have special health care needs are obese compared with 15% of children of the same ages without special health care needs. 6
- Annual health care costs of obesity that are related to disability are estimated at approximately $44 billion. 4

In the United States:
- More than one-third of adults—more than 72 million people—in the United States are obese. 5
- Obesity rates are significantly higher among racial and ethnic groups. Non-Hispanic Blacks or African Americans have a 51% higher obesity prevalence and Hispanics have a 21% higher obesity prevalence than non-Hispanic Whites. 7
- Annual health care costs of obesity for all adults in the United States were estimated to be as high as $147 billion dollars for 2008. 8

Health Consequences of Overweight and Obesity

Overweight and obesity increases the risk of a number of other conditions, including:
- Coronary heart disease
- Type 2 diabetes
- Cancers (endometrial, breast, and colon)
- High blood pressure
- Lipid disorders (for example, high total cholesterol or high levels of triglycerides)
- Stroke
- Liver and gallbladder disease
- Sleep apnea and respiratory problems
- Osteoarthritis (a degeneration of cartilage and its underlying bone within a joint)
- Gynecological problems (abnormal periods, infertility)
Improving the Health of People with IDD

Increasing Exercise and Good Eating

The National Center on Physical Activity and Disability
http://www.ncpad.org/

NCPAD is an information center concerned with physical activity, health promotion and disability. Being physically active is good for every body. Being active is an important part of getting and staying healthy.
Improving the Health of People with IDD

Increasing Exercise and Good Eating

The “new” Special Olympics:
Building communities of sports, joy & social change...

• Sport for those frequently excluded
• Community participation through athlete leadership, unified sports, family empowerment, health programming, research, advocacy and volunteerism
• Communicate the gifts and value of every person to audiences around the world

http://www.specialolympics.org/

BE A FAN OF ACCEPTANCE, DIGNITY, AND THE HUMAN RACE.
This site has information for family caregivers such as yourself to help you and those you care for stay safe and healthy. These general caregiving tips provide families with information on how to stay healthy and positive. Information, support, advocacy, empowerment, care, and balance can be the foundation for a healthy family and are appropriate no matter what the challenge.
For some people with disabilities and their parents, change can be difficult. Planning ahead of time may make transitions easier for everyone.

There are many important decisions to make, such as deciding whether to go to college, a vocational school, or enter the workforce. It is important to begin thinking about this transition in childhood, so that educational transition plans are put in place.

Ideally, transition plans from teen years to adulthood are in place by age 14, but no later than age 16.
Improving the Health of People with IDD

*Integrating Health into Life*

CDC’s Disability and Health Program, Healthy Living


The Disability and Health program at CDC funds states and universities to study how people with disabilities can live healthy lives and to help people do so.
1. Effective *Surveillance*
   a) What do you now do?
   b) What can be done better?

2. Using surveillance to affect *policy* at national, state and local levels
   a. What is the most pressing policy issue facing people with IDD now?
   b. What can the CDC do to help address it better?

3. *Assuring* that the policies are effective and lead to improvements in health for people with intellectual and developmental disabilities
   a. How will we know when we are successful?
   b. What measurement tools will help us determine success?
Questions or Additional Resources

CDC Disability and Health Website:
www.cdc.gov/disabilities

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