

## Health Disparities and Intellectual and Developmental Disabilities

DDHA & AADMD

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This presentation represents the opinions of the author.

The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention (CDC) and should not be construed to represent any agency determination or policy.

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### Overview

1. Who, What, Why of Health and People with Intellectual and Developmental Disabilities
2. Disparities of People with IDD
3. Emerging Opportunities

### I. IDD and Health

#### Who are “people with IDD?”

Diverse population that shares the characteristic of limited intellectual and adaptive functioning...

## Who are “people with IDD?”

...but varies widely in

- Levels of ability and visibility
- Age, gender, race/ethnicity
- Health care needs
- Living circumstances and family supports
- Interests, talents and ambitions

## IDD and Health

**“Health is the last frontier for intellectual disabilities”**

Charlie Lakin, February, 2010

## IDD and Health

**“Health as the last frontier”**

Why has it taken this long to recognize the unmet health needs of people with IDD?

- De-medicalization of disabilities
- De-institutionalization of people with IDD

## Health is...

... a state of complete physical, mental and social wellbeing, and not merely the absence of disease

World Health Organization, 1946

## Surgeon General’s Report—2002



Where are we in 2010 in improving health of people with intellectual and developmental disabilities?

## Surgeon General’s Report—2002

### Recommendations:

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



## II. Health Disparities of People with IDD--What does the research tell us?

...Poor health of people with IDD results from compounding of factors—"a cascade of disparities."

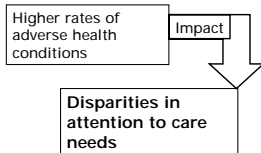
## The "Cascade of Disparities" for People with IDD

Krahn, Hammond and Turner, 2006

Higher rates of adverse health conditions

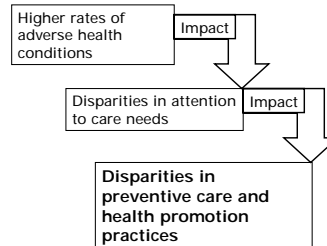
Epilepsy and neurological disorders	17-70%
Dermatology	33-63%
Fractures/lacerations	11-43%
Gastrointestinal	8-10%
Cardiovascular	9-45%
Behavioral/psychiatric	21-49%
Sensory (vision/hearing)	10-99%

### "The Cascade of Disparities"



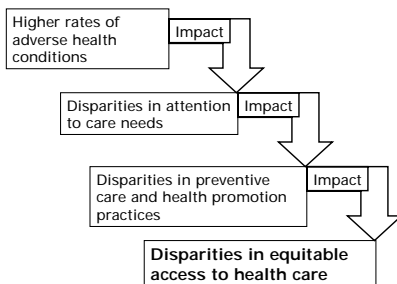
- Undetected vision or hearing loss
- Medication management
- Differences by type of residence
- Training of direct care staff
- Turn-over of direct care staff
- Communication capabilities of the person

### "The Cascade of Disparities"



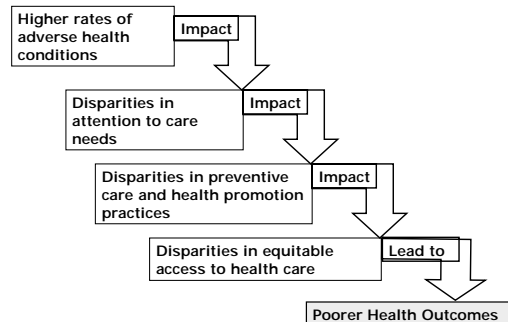
- Physical activity and nutrition--obesity
- Basic hygiene like brushing and cleaning teeth
- Social relationships and anger management

### "The Cascade of Disparities"



- Fewer mammograms and pap tests
- Over/under-medication; especially psychotropics
- Chronic condition management (epilepsy, hypertension)

### "The Cascade of Disparities"



## Health Care Training and Guidelines

- “...surprisingly little literature on programs to improve US training of health care providers for persons with IDD”
- US guidelines for care are few and condition-specific
- Little indication of increased attention to IDD in medical and dental school curricula

(Krahn & Drum, 2007)

## Understanding Health Disparities for IDD

Disability is not equivalent to poor health  
 “You’ve got a disability—of course you’re not (as) healthy”  
 “We often see that in people with...Down syndrome, epilepsy, this condition...”

But, people with IDD do experience more adverse health conditions related to their IDD...

## Defining health disparity in the context of disability

- **Disparity**– population-level difference in health status not directly attributable to the condition leading to or associated with the disability

*Krahn, working definition, 2010*

- If you have a disability, your health could be poorer for any of a number of reasons; our task is to identify and address those reasons that are preventable:

## Distinguishing among Health Conditions

1. **Associated health conditions** led to or are part of a syndrome that led to the impairment in functioning
2. **Comorbid conditions** are unrelated disease processes that have an adverse effect on health
3. **Secondary conditions** are preventable conditions that a person with a disability experiences at a higher rate than the general population
4. **Iatrogenic conditions** are adverse health outcomes related to treatment for a condition

*Krahn, Hammond & Turner, 2006  
 Turk, 2006*

## When is a health difference a disparity?

Condition	Disparity?
Associated condition (e.g. epilepsy)	No
Comorbid condition rates (e.g. later diagnosis of cancer)	Yes, even by conservative standards
Secondary condition (e.g., depression, obesity, pressure sores)	Likely, if not related to treatments
Iatrogenic condition (obesity related to medications)	Perhaps, are there other treatment options?

### When could lack of difference still mean a disparity?

Measure	Disparity?
Number of Health care visits per year	Likely
Rates of eye checks, influenza vaccinations	Perhaps
Unmet Health care needs	Yes

- When looking at measures of health care access:
1. Consider the likely level of need –measures of receiving health care are not as good indicators of health disparity as are measures of unmet health care
  2. Consider the need for increased attention to health condition—e.g., medication levels, hearing/vision loss
  3. Unmet care needs are a clear measure of disparity

### Equity and Equality

- “Inequities” and “Inequalities”
- Used more in UK and Europe
- Regarded as more positive
- Require the same careful attention to pre-existing conditions

### “Ableism/Disabilism” as a contributor to health disparities

- **Ableism** is discrimination against people based on the [physical] ability of their body, especially discrimination against people with disabilities in favor of people who are not disabled.

*Wikipedia, 2010*

### “Ableism/Disabilism”

- Research on attitudes towards persons with IDD, including health care providers
- Provider attitude as major barrier to health care as perceived by PWD

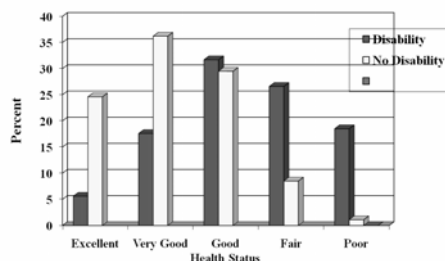
### III. Emerging Opportunities— Health Surveillance of People with ID

#### What gets counted, counts.

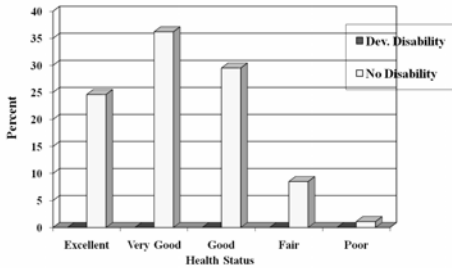
Information on health of people with IDD is largely from clinical or convenience samples.

There is a lack of population data on health status and health behaviors of people with IDD.

### Health Status of People with and without Disabilities



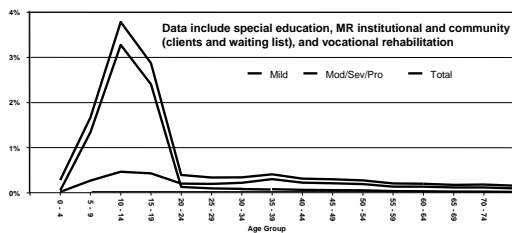
### Health Status of People with and without Developmental Disabilities



### Omission of People with IDD in Population Surveys

- People with significant ID are typically excluded in national surveys “non-institutional populations”
- People with milder ID are not identifiable in national surveys

### Prevalence of Mental Retardation in Administrative Data, State of Alabama, 1992-93



Number of people in formal mental retardation 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)

### Need for Population Data on Health of People with IDD

Need for information on people with IDD re:

- health status
- health care access
- health risk/promotion behaviors
- health environments

### “HSPID” Organized Working Meetings

CDC and AUCD organized:

- Meeting 1: Methodology meeting (9/09)—feasibility of gaining data on health status of population of adults with ID/D in the US—who? what? and how?
- Meeting 2: Stakeholder meeting (2/10)—availability and perceived need for population health data on adults with ID/D

### 5-Step Plan for Health Surveillance of People with ID/D

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.

### Future of Health Surveillance and ID/D

- CDC is initiating the process, with other federal agencies coming together to examine extant data
- Will require a funding line for sustained surveillance into the future

### 3. Emerging opportunities— Patient Protection & Affordable Care Act

- Defining “medically underserved”
- Disability identifiers and health care provision--Understanding Health Disparities
- Accessible Medical Diagnostic Equipment
- Cultural Competency and Disabilities Training

### In Summary...

- People with intellectual disabilities are a richly diverse group of people
- Surgeon General’s report of 2002 still holds
- Poor health results from a cascade of disparities
- Be mindful of what is and is not a disparity
- There is a need for population data to document disparities
- There are opportunities in health reform to address health needs of persons with disabilities.

- *“The landmarks of political, economic and social history are the moments when some condition passed from the category of the given into the category of the intolerable.”*

- Vickers G. What sets the goals of public health? Lancet. 1958;1:599–604.

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Thank you

