



# U.S. Surveillance of Health of People with Intellectual Disabilities

A Working Meeting  
February 24, 2009

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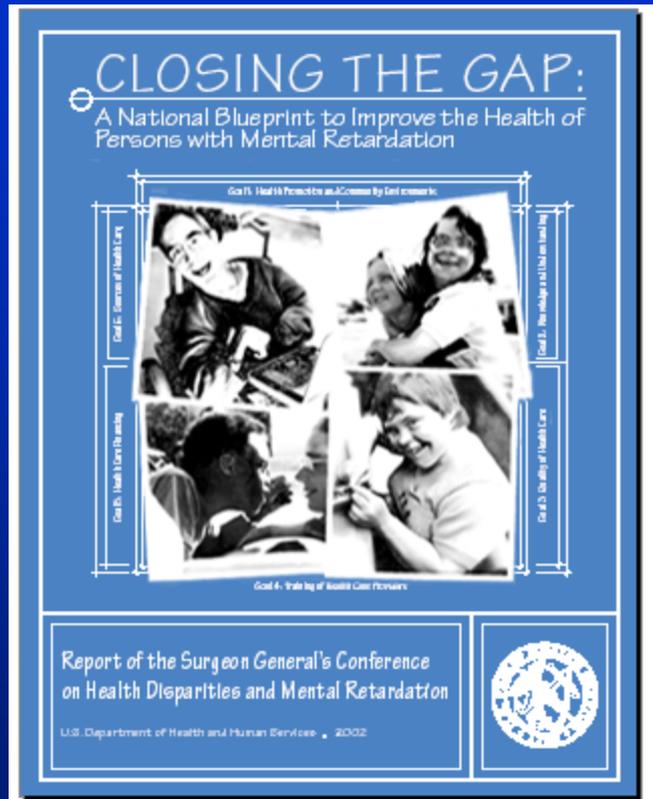
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# The Question:

What is the health status of the population of U.S. adults with intellectual disabilities?



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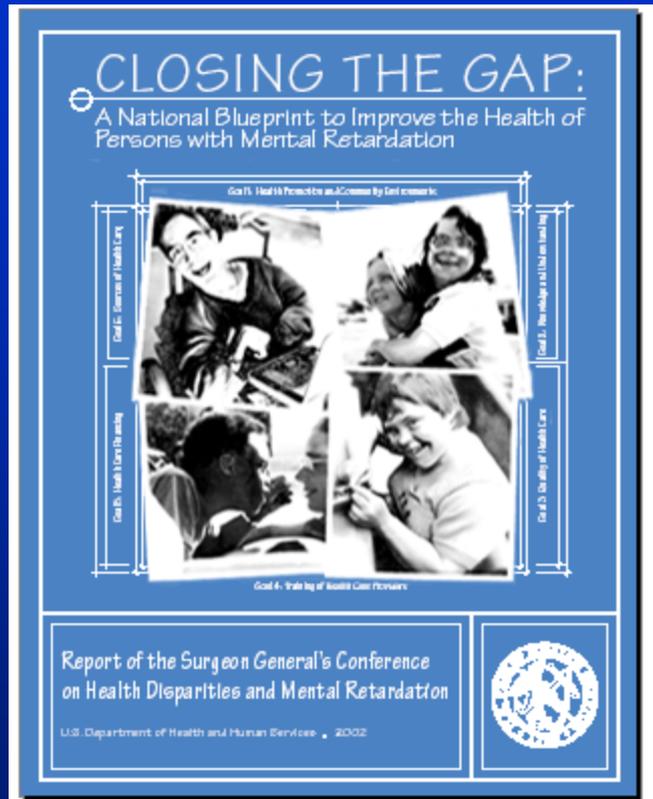


“Collect data on the health status of persons with MR in relation to the utilization, organization, and financing of their health services.”

*USHHS Closing the Gap Report, 2002*



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“Reports don’t have arms and legs. Like many others, this report will just sit on shelves unless we turn it into action.”

*David Satcher, M.D., Ph.D.  
Surgeon General  
January 2002*



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# Need for Data on Health of People with ID

- Need for information on people with ID re:
  - health
  - health care access
  - health risk behaviors
  - health environments
- People with significant ID are typically excluded in national surveys
- People with milder ID are not identifiable in national surveys



# Collecting data

- Meeting 1: Methodology meeting — feasibility of gaining data on health status of population of adults with ID in the US.
- Meeting 2: Stakeholder meeting — availability and perceived need for population health data on adults with ID



# Methodology Meeting

- Matrix of expertise
- International participants for input
- Key questions:
  - Whom to include?
  - What information to collect?
  - How to identify and collect information?
- Brief Report



# Potential Approaches

1. Determine interest and need for data from stakeholders
2. Get input to define ID in clinically, functionally, and operationally valid ways.
3. Synthesize knowledge base, including data sources and surveillance methods.
4. Extend analyses of current data sources
5. Pilot state or regional demonstrations
6. Develop sustainable approaches



# Reporting on Kingston

- Defining the Population—Glenn Fujiura, UIC
- Determining Key Health Variables—Vince Campbell, CDC
- Data Collection Methods and Strategies—Charlie Lakin, U Minn and Mike Fox, CDC
- Self Advocate Input—Ari Ne’eman, ASAN





# Defining the Population

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# ***Who Are We Talking About***

Key Points (per the wisdom of Yogi Berra):

1. *"I wish I had an answer to that because I'm tired of answering that question"*
2. *"It's 90% mental; the other half is physical"*
3. *"When you come to a fork in the road, take it"*



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***“I wish I had an answer because I'm tired of answering that question“***

- Data unavailable or based on different definitional conventions
- Use of existing data
- Decisions about definitional conventions



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# ***“It’s 90% mental, the other half is physical”***

- Definitions available
- Modern conception of ID complex & multidimensional
- Logistics demand decisions about what features of ID take precedence



***“When you come to a fork in the road, take it”***

- Definition is driven by purpose
- Single purpose vs flexible protocols



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# Next Steps

*You've got to be very careful if you don't know  
where you are going because you might not  
get there*

*Yogi Berra*



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***You've got to be very careful if you don't know where you are going because you might not get there***

- We need to carefully reflect on what we want to do with the numbers.



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# What Data Should We Collect?

What is collected is related to:

- the reason data are being collected
- whom are we gathering the data about
- whom are we gathering the data for
- how we are gathering the data
- regularity/infrequency of data collection
- available resources



# Public Health Surveillance

Ongoing, systematic collection, analysis, and interpretation of health-related data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control.

- Koo, 2002



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# Health Indicator Definition

## World Health Organization

A health indicator is a characteristic of an individual, population, or environment which is subject to measurement (directly or indirectly) and can be used to describe one or more aspects of the health of an individual or population (quality, quantity and time).



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# Recommended Health Indicators/Elements

- Yale Report (Horowitz, Kerker, Owens & Zigler, 2001)
- US Surgeon General's Closing the Gap conference and report
- Pomona Project (2008)
- National Core Indicators (HSRI, 2009/2010)
- State of the USA Health Indicators (IOM, 2009)
- Example of survey indicators - Behavioral Risk Factor Surveillance System (BRFSS)



# Yale Report

Horowitz, Kerker, Owens & Zigler, 2001

- Purpose of the report:
  - “to identify the current health status and needs of individuals with (ID),
  - to identify service gaps in supporting these needs and
  - to propose specific recommendations to address the unmet health care needs of individuals with (ID).”
- Noted that health of people with ID had received little attention.



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# Yale Report

**Horowitz, Kerker, Owens & Zigler, 2001**

- Noted
  - lack of large population-based studies on chronic disease and related risk factors, injuries, health behaviors, mental health disorders, vision, and oral health
  - lack of data on immunization status of people with ID
  - Need for data on mortality and morbidity
- Indicated that most data on health of people with ID comes from small convenience, mostly service samples, or from large residential facilities
- Recommended consideration of a registry of people with ID to track health and health care issues.



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# Surgeon General's Report, ■ 2002



■ **Assessment:** Assess the effects of health promotion and wellness activities for individuals with MR on their morbidity, secondary disability, mortality, life satisfaction, independent living, achievement of life goals, and cultural and ethnic identity.

- **Identify and evaluate** existing data on health and MR. Add MR to population-based data collection on health status, health risks, health services utilization, and health care costs.

# HSRI National Core Indicators

- A voluntary collaboration between ID/DD state agencies that are members of the National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI)
- The purpose is to provide a systematic approach to performance and outcome measurement

– <http://www.hsri.org/nci/>



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# NCI Health and Health-Related Indicators

- Health indicators
- Safety
- Community Inclusion
- Medications
- Wellness
- Restraints
- Relationships



# Pomona Project

POMONA II aimed to develop and test a set of health indicators specific to people with intellectual disabilities . It was hoped that these indicators would contribute to health surveillance such as the health information surveys conducted across Member States of the European Union.



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# Pomona Project Final Report

## ■ Demographics

- Living arrangements
- Daily Occupation
- Income/Socio-Economic Status

## ■ Determinants

- Physical Activity
- Challenging Behavior
- Medication Use

## ■ Health status

- Epilepsy
- Oral health
- Body Mass Index
- Mental Health
- Sensory
- Mobility

## ■ Health Systems

- Health Promotion
- Hospitalization
- Contact with Health Professional in Last Year



# State of the USA Health Indicators (IOM, 2009)

In 2008, State of the USA, Inc. requested the IOM to provide guidance on the development of 20 key indicators that would be valuable in assessing health to be used on the organization's website. Each indicator was required to demonstrate:

- a clear importance to health or health care,•
- the availability of reliable, high quality data to measure change in the indicators over time,
- the potential to be measured with federally collected data, and•
- the capability to be broken down by geography, populations subgroups including race and ethnicity, and socioeconomic status.



# Example of Survey Health Indicators – Behavioral Risk Factor Surveillance System

- Purpose – to gather and report comparable state-based data on prevalence of health conditions, preventive health practices, and risk behaviors. Data are collected using random digit dial telephone (land-line) interviews conducted among each state’s non-institutionalized, household-based civilian population over 17 years of age.
- State-specific data used by health departments in all states, DC, 3 territories
- Assess key health indicators and health behaviors
- Annual core – 22 sections in 2009
- Optional modules - 29 in 2009



# Summary

- A variety of factors bear on what data are collected
- Health indicators can consist of information on health status, health care service utilization, adequacy of health care and, for people with disabilities, in particular, accessibility
- A number of existing health indicator systems have been developed and are in use





# How Do We Get (Useful) Health Information About People with Intellectual Disabilities?

Charlie Lakin

Director, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota

Michael Fox

Associate Director for Science, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disabilities, Centers for Disease Control and Prevention

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# Five Challenges in Getting Better Information about Persons with Intellectual Disabilities

1. **Identifying units of measure and “sample frame”**
  - Person-level; Community-level; State/National/etc.
2. **Identifying the data source and implications**
  - Administrative; Survey; Clinical; Other
3. **Understanding “case” definitions and limitations**
  - Operational definition of “intellectual disability”
4. **Clarifying intent of information gathering and use**
  - Intended purpose and use of data; Stakeholder involvement
5. **Assuring relevance and quality**
  - Evaluation of data; Applications of findings to policy



# Challenge #1: Identifying the Unit of Measure and “Sample Frame”

Goal: Data to *guide individual and collective action*

- Person level:
  - The implications of intellectual disabilities for health at the *person level*
  - **Interaction** of intellectual disabilities, environment and health events, services and behavior
- Collective level:
  - How systems perform in health outcomes (Nation, states, federal programs (ICF-MR vs HCBS), families vs agencies)
  - ID as of unique interest or part of mosaic of larger groups



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# Challenge #2: Identifying Data Sources and Implications

Goal: *Systematic use of routinely collected data to guide public health action*

Reality: *Useful, but limited sources of information*

- National data from federal surveillance programs
  - e.g., National Health Interview Survey (NHIS)
- National administrative programs
  - e.g., Medicaid, Medicare, Social Security
- State level administrative or surveillance data
  - e.g., Medicaid eligibility, Behavior Risk Factor Surveillance System (BFRSS)
- State level and merged multi-state data of program participants
  - e.g., National Core Indicators, Personal Experience Survey
- Other applicable studies of health events, services and behavior
  - e.g., Healthy Lifestyles for People with Intellectual Disabilities (Oregon/NICHHD), Special Olympics (CDC)



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# Challenge #3: Understanding the Nature of “Case” Definition and Limitations

Goal: *Reliability, duplicability, consensus, operability*

- Representation of a population of interest
- Ability to identify important subgroups
- Congruence between level of analysis and source of public health action
- Ability to integrate data on health events, services and behaviors with key individual descriptors
- Understanding variability and inconsistencies deriving from different sources of data



# Challenge #4: Clarifying the Intent of Information Gathering and Use

Goal: *Understanding and improving health data and use*

- Developing an agenda for useful data collection
- Learning from past experience
- Building a collaborative of data gatherers and users
- Assuring involvement from the ID community
- Demonstrating value and success
- Achieving the “health surveillance ideal” – systematic collection



# Challenge #5: Assuring Relevance and Quality

Goal: *Improve ongoing data collection for improved health outcomes*

- Assuring that the data will be used
- Being able to identify important subgroups
- Achieving congruence between level of analysis and source of public health action
- Increasing access to data integrating health events, services and behavior with individual & environmental descriptors
- Understanding variability and inconsistencies deriving from different sources of data
- Evaluating the quality and coverage of health data collection



# Building a Community Commitment for Surveillance and a Focus Health

Building and sustaining surveillance and public health outcomes research

- Supporting data use and sharing
- Advocating for identification of ID in health-related programs
- Promoting cross-agency initiatives in health data

Supporting a focus on interventions for health events, services and behavior

- Making health of persons with ID a national commitment
- Improving the knowledge base of effects of health policy and programs for persons with ID



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