Health Surveillance in the population with intellectual disability: Case definition in state level data

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Learning objectives:

1. Use of operational definition of ID for health surveillance.

2. What state level data is available to describe health status of the population with ID?

3. How representative is available data?
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Health Surveillance of Americans with Intellectual Disability

We know:

Adults with ID experience poorer access to quality health care and poorer health outcomes than people without ID.¹

Surveillance gaps:

- Underrepresentation in national surveys.
- Variable population definitions and case-finding methods.
- Individuals diagnosed in school-based setting but not identifiable once reaching adulthood unless receiving ID-specific supports.
We’re invisible in the data. We can’t make people believe we need more services if we don’t have data to back us up.”

Participant – Surgeon General’s Conference on Health Disparities and Mental Retardation 2001
A coordinated effort

CDC/ NCBDDD sponsored international meetings

White Paper ‘Road Map’ (2009):

1. Define Intellectual Disability operationally (RTOI)
2. Compile and synthesize knowledge base
3. Extend past analyses (RTOI, Coop. Agreement)
4. Pilot state or regional demonstrations (RTI)
5. Develop sustainable approaches to expand surveillance.
Affordable Care Act (PL 111-148)  
Section 4302

• Requires development of federal standards for measurement of disability status
• Minimum standard (e.g. American Community Survey) 6 ‘disability questions’
• Population with ID is not well identified with 6 disability questions

>>>> limited information about health status of the national population with ID
Operational Definition

- Multi-stakeholder process, current clinical/admin. definitions
- ID definition summit April 2011
- Definition proposed November 2011.

A 2010 Research Topic of Interest (RTOI), awarded by the Association of University Centers on Disabilities (AUCD) and funded through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDDD)
ID Definition (Conceptual) for Public Health Surveillance

Adults with ID includes people who:

1. Have intellectual limitations* that significantly limit the person’s ability to successfully participate in normal day-to-day activities…, and

2. Limitations developed during the ‘developmental period’ (before approximately age 22), and

3. Have anticipated long-term adaptive or functional support needs, and/or

4. Are eligible for State or Federal public support programs because they have been diagnosed as having an intellectual disability.
Using State-Level Data for Health Surveillance

**Case Definition:** Can we identify the population with ID in existing datasets?

**Sample Frame:** To what extent are available data representative of the entire population with ID?
State Data Pilot

Purpose: Explore **feasibility** of using **state-level data** for **population-level** health surveillance.

- State level investigation of available data, population definition, health measures, data dictionaries.
- Administrative data and survey data considered
- 8 participating states – recruitment of volunteer states through NASDDDS
Pilot States
AZ, TX, TN, KY, SC, PA, MA, HI
State-level Data Abstraction Profiles

Data Abstraction Profiles
System details (data climate, structure)
Datasets reviewed: inclusion and exclusion
presence of health indicators
existing or potential linkages
permission needed for access
data access costs

Proposed steps to abstract data
State-level reflections
## Population Identification ‘Pathway’

<table>
<thead>
<tr>
<th>Population Identification Step</th>
<th>Data Example</th>
<th>Include?</th>
</tr>
</thead>
</table>
| 1. Determined eligible for I/DD services? | • State I/DD systems admin data.  
• **National Core Indicators** (health questions) | Yes                            |
| 2. IQ approximately 70 or below    | • Diagnosis code in administrative data  
• Clinical diagnosis recorded in electronic data systems (e.g. Dept of Corrections) | Yes                            |
| 3. Diagnosis of ‘related condition’ | • Administrative data  
• BRFSS                                                                     | Only with support need, developmental, long term. |
| 4. Hx of receiving Special Education | • Special education eligibility category data. (‘Intellectual disability/MR’) adequate for inclusion, other categories need additional screening |                                |
‘Pathways to Population Identification’

State or Federal assistance or supports because of ID?

Clinician’s determination of ID (MR)?

Received Special Education services?

N

Support needs for ADL / IADL?

Onset during devel. period?

Temporary Condition?

Y

ID (MR) or ‘Multiple Disability including ID’? (IDEA definition)

Autism, severe learning disability, or other related condition?

Reason?

Population with ID for the purpose of National Health Surveillance
<table>
<thead>
<tr>
<th>State</th>
<th>1. I/DD Services</th>
<th>2. Clinical Diagnosis</th>
<th>3. Related Condition**</th>
<th>4. Hx of SpED</th>
</tr>
</thead>
<tbody>
<tr>
<td>AZ</td>
<td>FFS (not including managed care)</td>
<td>Focus (LTC)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HI</td>
<td>State I/DD services</td>
<td>(Medicaid)</td>
<td>DOC</td>
<td></td>
</tr>
<tr>
<td>KY</td>
<td>DDID records</td>
<td>(Medicaid)</td>
<td></td>
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<tr>
<td>MA</td>
<td>DDS HCSIS</td>
<td>APCD (incl Medicaid)</td>
<td>APCD (incl Medicaid)</td>
<td></td>
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<tr>
<td>PA</td>
<td>HCSIS</td>
<td>(Medicaid)</td>
<td>DOC</td>
<td></td>
</tr>
<tr>
<td>SC*</td>
<td>DDSN Hospital d/c record, DMH</td>
<td>Medicaid</td>
<td>Medicaid</td>
<td></td>
</tr>
<tr>
<td>TN</td>
<td>DIDD</td>
<td>(Medicaid)</td>
<td>DOC</td>
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</tr>
<tr>
<td>TX</td>
<td>DADS</td>
<td>(Medicaid)</td>
<td>DOC</td>
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</tbody>
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State Level DATA using the ‘Pathways’ approach.
Sample frame and estimates of available data

MA
- EHR: 10,000
- DD agency: ~32,000
- Est. adult population*: 80,500
- Est. ID population*: 103,600

HI
- EHR: ~4,000
- DD agency: ~4,000
- Est. ID population*: 21,500

SC
- Datacube: ~23,000
- DDSN: ~30,000
- Medicaid
- Est. adult ID population*: 55,300
- Est. ID population*: 73,700

* Braddock et al (2013) State of the States in Developmental Disabilities (1.58% total population)
Who does available state data represent?
The population identified as eligible *in a given state*
*EXAMPLE: Hawaii’s limited eligibility for services*

The population *receiving supports*
*EXAMPLE: Tennessee’s waiting list*

Data from the population *in a specific program*
*EXAMPLE: AZ FFS program but not managed care.*
Opportunities in using state level data for surveillance

- Administrative data linkages (e.g. SC data cube, All Payer Claims Databases) hold promise.

- Using ‘Pathways approach’ may efficiently identify a population that approaches representativeness within resource limits. Limited ability to capture data beyond the adult population served.

- State data infrastructure is variable, requires a ‘champion’ at state level.
References


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