Developing the Road Map to Improve Data on the Health of People with IDD

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Alexandra Bonardi, Human Services Research Institute
Susan Havercamp, Ohio State University
Jennifer Johnson, ACL/HHS
Gloria Krahn, Oregon State University
Amanda Reichard, NIDILRR/ACL/HHS
The number of people with IDD (prevalence) in the U.S. population is hard to define.

- **Prevalence** is usually described as a percentage.
- Adult U.S. population includes *somewhere between 1% and 4%* with an intellectual or developmental disability. This is higher for children.
- How you define intellectual and developmental disability matters in how many people get included.
Ways of collecting “population” data

Population Data—
• Whole country sampled so that everyone has the same chance of being included
• Examples are national census and national surveys like National Health Interview Survey (NHIS)
• Often exclude people in large group facilities (e.g., prison, large group homes)

Administrative data—
• People who are eligible for services
• Examples are Medicaid and Medicare, Social Security data

Large Group Data—
• People enrolled in specific services or programs
• Examples are National Core Indicators, Special Olympics Healthy Athletes
People with IDD are not always included

Being counted is a civil rights issue

- If people with IDD are not counted in the census and surveys, your needs are not recognized and not addressed.

- You can be counted and still not be visible—if surveys don’t have a way of recognizing your intellectual and developmental disabilities.
Prevalence and health are biggest data gaps for IDD

- We don’t have good prevalence estimate
- Population health data are from 1994-95
- Through other ACL-sponsored Centers, we have information on
  - Residential services and supports
  - Employment
  - Expenditures for long term services and support
- We have very little current information on health
What we DO know about prevalence of IDD

• Multiple studies show big variance in the prevalence of DD.

• We have better data for children than adults.

• Some people are or are not counted (because of survey differences).

What we DO know about health of people with IDD

• Health and health care access are likely poorer than the general population in important ways

• Health depends on where and with whom you live

• Health depends on your age, gender, race/ethnicity among other factors

(from National Core Indicators, Special Olympics, national studies of “cognitive limitations”)

Federal efforts to improve availability of data

Ensuring Individuals with ID/DD are being counted
National surveillance workgroups reports—2019

- National surveys—agency collaborations and identification questions

- State level—administrative data and promising practices
  https://aclprdep01.azureedge.net/cdn/ff/OATVJImFLs5gbVqdM6iUN0xHELxw4o-ogEah3HIsULA/1569854246/public/Aging%20and%20Disability%20in%20America/Final_State_Data_Paper_09.25.2019%20word%20master%20508%20compliant.pdf

- Easy Read Summary
Next steps in national surveillance—Gathering data through national surveys

- **Developing ?’s**
  - The National Center on Health Statistics, CDC is testing questions to identify intellectual and developmental disabilities on the NHIS.

- **Collect Data**
  - Using the NHIS, collect population-based data on the ID/DD population

- **Analyze for baseline**
  - Analyze the data to update prevalence estimates, identify health status

- **Benchmark**
  - Continue to collect data to benchmark prevalence estimates and health status

- **Consider**
  - Consider how to collect similar data from the U.S. territories
Next steps in health surveillance—Utilizing state administrative data

Collaborate
Continue federal and non-federal collaboration to continue to use of administrative data in understanding the health status of the ID/DD

Improve
Improve state administrative data by developing consistent operational definitions in data collection; facilitating data linkage; including race, ethnicity and primary language

Promote
Promote research to fill knowledge gaps by scanning for best practices; training data super-users; supporting community of practice for administrators and learning collaborative to develop and test system changes; increase data linkages; longitudinal study; replicate demonstration projects; study experience of people at intersection of race/ethnicity and IDD; data collection for ID, DD and mental health conditions
Developing new identification questions for national surveys

**Goal:** To update prevalence estimates of IDD in the U.S. population

**Steps:**

- Areas from workgroup 1: age of onset, learning, independent living
- With NCHS, develop and test additional Identification questions
- Challenge: pick up ALL but ONLY people with IDD
- Cost for NHIS is $150,000/question/year
- 3 years for benchmark data
- Age of onset question being fielded in 2020
Special Issue

October 2019
Special issue: Intellectual and Developmental Disabilities, 2019, 57(5)

- What Matters in Population Health and How We Count It Among People With Intellectual and Developmental Disabilities. Susan M. Havercamp and Gloria L. Krahn
- A Call for Better Data on Prevalence and Health Surveillance of People With Intellectual and Developmental Disabilities. Gloria L. Krahn
- Unlocking the Potential of State Level Data: Opportunities to Monitor Health and Related Outcomes in People With Intellectual and Developmental Disabilities. Alexandra Bonardi, Emily Lauer, Amie Lulinski, Mary Lee Fay, Andrew Morris, Margaret A. Nygren and Gloria Krahn
- Characteristics of Medicare Beneficiaries With Intellectual or Developmental Disabilities. Amanda Reichard, Elsa Haile and Andrew Morris
- Data Linkage: Canadian and Australian Perspectives on a Valuable Methodology for Intellectual and Developmental Disability Research. Robert Balogh, Helen Leonard, Jenny Bourke, Kate Brameld, Jenny Downs, Michele Hansen, Emma Glasson, Elizabeth Lin, Meghann Lloyd, Yona Lunskey, Melissa O’Donnell, Shahin Shooshtari, Kingsley Wong and Gloria Krahn
- From Invisible to Visible to Valued: Improving Population Health of People With Intellectual and Developmental Disabilities. Gloria L. Krahn and Susan M. Havercamp
Highlights of new findings using administrative data
Distribution of Medicare FFS Beneficiaries With IDD (CY2016) Compared to the Total U.S. Population (CY2010), by Age Group

- 10.3% of Beneficiaries with IDD are under 30 years old.
- 15.8% of Beneficiaries with IDD are 30-39 years old.
- 18.0% of Beneficiaries with IDD are 40-49 years old.
- 19.0% of Beneficiaries with IDD are 50-64 years old.
- 14.0% of Beneficiaries with IDD are 65-74 years old.
- 6.1% of Beneficiaries with IDD are 75+ years old.

- 40.7% of the U.S. Population are under 30 years old.
- 13.0% of the U.S. Population are 30-39 years old.
- 14.2% of the U.S. Population are 40-49 years old.
- 19.0% of the U.S. Population are 50-64 years old.
- 7.0% of the U.S. Population are 65-74 years old.
- 6.1% of the U.S. Population are 75+ years old.
Prevalence of Chronic Conditions for All Medicare FFS Beneficiaries with IDD, CY2016

- **Chronic Kidney Disease**: 26.5%
- **Chronic Obstructive Pulmonary Disease**: 20.6%
- **Congestive Heart Failure**: 20.3%
- **Diabetes**: 32.4%
- **Hypertension**: 55.8%
- **Obesity**: 21.7%

A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.
Comparison of Older (65+ Years) Medicare FFS beneficiaries with and without IDD.

Figure 3. Prevalence of Mental Health Disorders for All Medicare FFS Beneficiaries with IDD, CY2016

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia and Other Psychotic Disorders</td>
<td>20.4%</td>
</tr>
<tr>
<td>Post-Traumatic Stress Disorder</td>
<td>2.8%</td>
</tr>
<tr>
<td>Personality Disorders</td>
<td>5.6%</td>
</tr>
<tr>
<td>Major Depressive Affective Disorder</td>
<td>28.9%</td>
</tr>
<tr>
<td>Bipolar Disorder</td>
<td>18.4%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>31.5%</td>
</tr>
<tr>
<td>ADHD and Other Conduct Disorders</td>
<td>14.3%</td>
</tr>
</tbody>
</table>

A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.
Next Steps: Developing a road map for 2020-2030
Summit—Health Equity Data for People with IDD.

November 15, 2019

• ~30 participants from federal agencies, advocacy organizations, researchers

• Panels:
  • Available data – now and on the horizon
  • Perspectives from the territories, federal government, and states
  • Utilizing, disseminating and translating data
  • Data analytics in achieving health equity
Reach out and partner!

- Persons with IDD, families, and care-providers
- Researchers
- Federal agencies
- Health care providers
- Health care industry
Steps on the roadmap

• Prevalence
  • Need for a consistent measurement definition of intellectual and developmental disabilities
  • Implement and test new identification questions

• Health Indicators
  • identify key indicators of health and wellbeing -- outreach
  • identify social context indicators

• Communicating
  • Practices for utilizing and disseminating cognitively accessible data briefs for different audiences (persons with IDD, legislators, advocacy groups)
Steps on the roadmap (cont’d)

• Learning more from what we have:
  • Map current/emerging data sources, populations covered (e.g., Medicaid, NCI for served) and their findings
  • Disaggregate analyses by key variables to better target problems and interventions
  • Data analytics to maximize information from existing data (data linking, interoperability, and harmonization of findings)

• Research
  • need for new data such as long-term studies
  • standardized strategies for proxy- vs self-reporting
What are the health questions that are important to you?

What should we find out?
How should information be presented to you?

How can you use it?
What can you do to help keep this work moving forward?
Contact Information:

This work has been organized and led by the Administration on Community Living, HHS. Questions about the Roadmap should be addressed to:

Jennifer.Johnson@acl.hhs.gov

Contact information for other presenters:

Abonardi@hsri.org
Susan.Havercamp@osumc.edu
Gloria.Krahn@oregonstate.edu
Amanda.Reichard@acl.hhs.gov