

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

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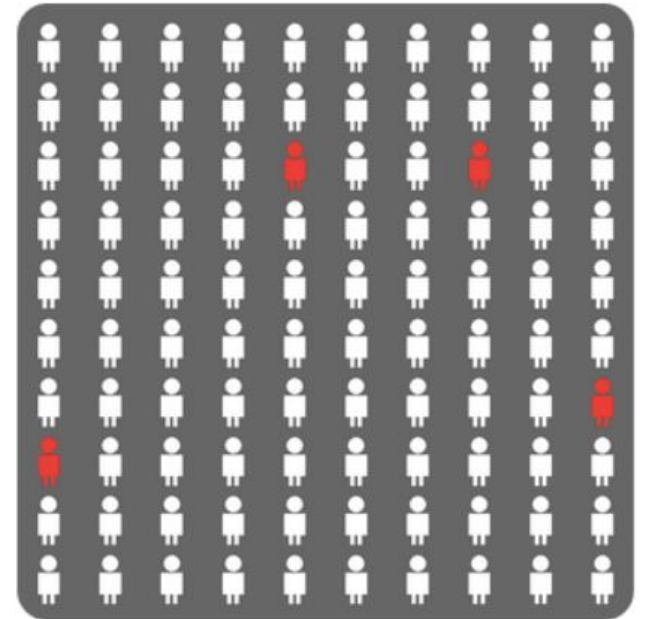
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The number of people with IDD (prevalence) in the U.S. population is hard to define.

- **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)

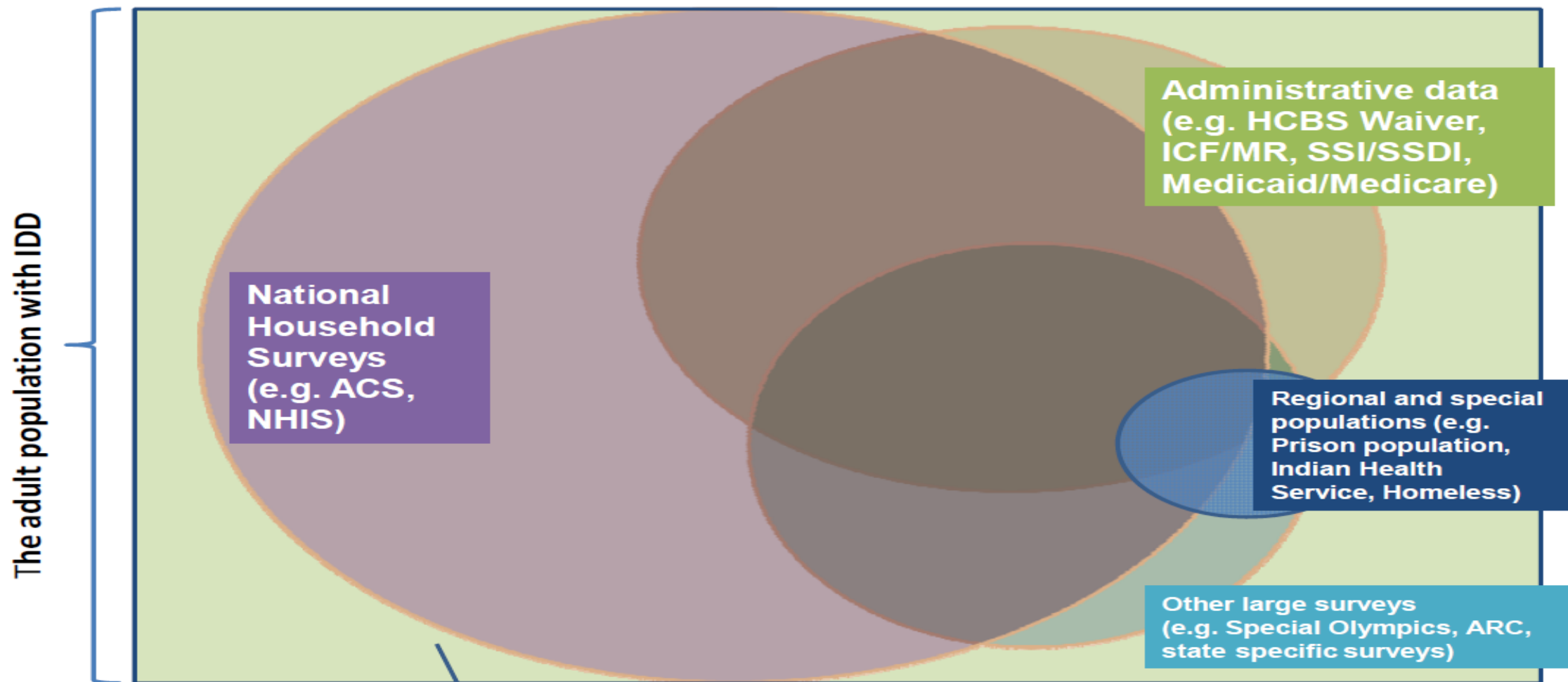
Administrative data—

- 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



Bonardi, A., Lauer, E, (2011) Developing an Operational Definition of Intellectual Disability for Health Surveillance. Center for Developmental Disabilities Evaluation and Research (CDDER), E.K. Shriver Center, University of Massachusetts Medical School.

*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

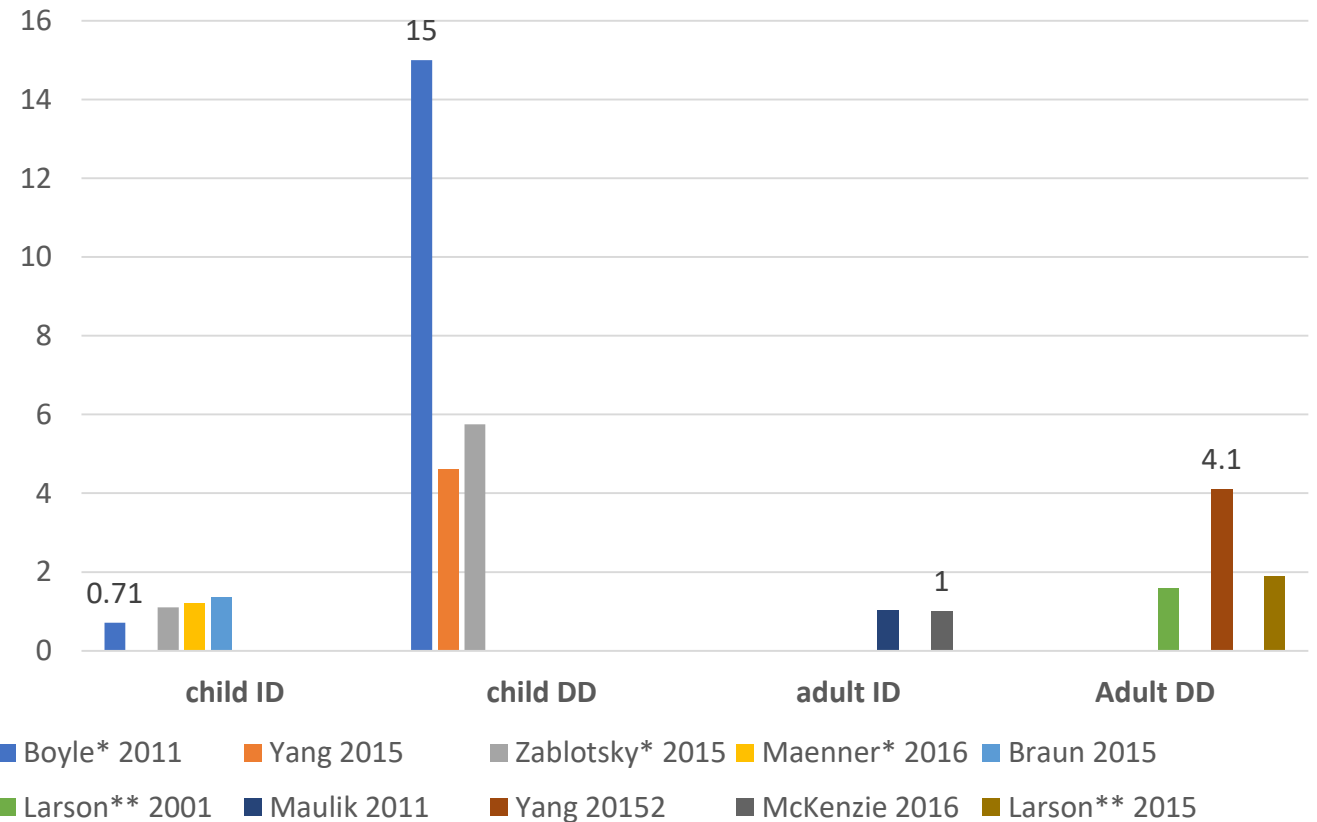
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- We don't have good prevalence estimate
 - Population health data are from 1994-95
 - Through other ACL-sponsored Centers, we have information on
 - Residential services and supports
 - Employment
 - Expenditures for long term services and support
 - 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).

Estimated Prevalence of Child and Adult ID and DD (%)



Krahn, GL. (2017). Briefing Report: data needs to inform program planning and policies on health of people with intellectual and developmental disabilities. Administration on Intellectual and Developmental Disabilities, USHHS.



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**

https://aclprdep01.azureedge.net/cdn/ff/1iflcHhToo9FRTlfo47Yw-wct5dWX-Sf_RHQqY0XJhI/1569854188/public/Aging%20and%20Disability%20in%20America/National_Data_Paper_AIDD-ACL_09.25.2019%20508%20compliant.pdf

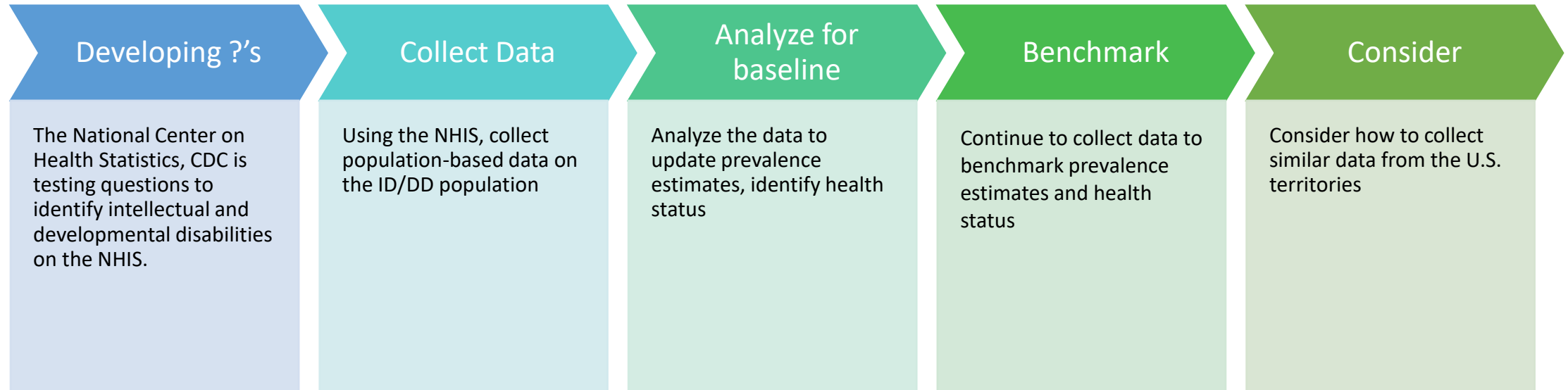
- **State level—administrative data and promising practices**

https://aclprdep01.azureedge.net/cdn/ff/OATVJImFLs5gbVqdM6iUN0xHELxw4o-ogEah3HlsULA/1569854246/public/Aging%20and%20Disability%20in%20America/Final_State_Data_Paper_09.25.2019%20word%20master%20508%20compliant.pdf

- **Easy Read Summary**

https://aclprdep01.azureedge.net/cdn/ff/iD18_yTvSrqXwljihVXNfKNANn5WjPXP9ySdpJZNQUM/1569854262/public/Aging%20and%20Disability%20in%20America/Easy_Read_Final_Version--How_to_improve_health_surveillance_of_people_with_IDD%209.25.2019%20508%20compliant.pdf

Next steps in national surveillance—Gathering data through national surveys



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

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Intellectual and Developmental Disabilities



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Perspective

347 What Matters in Population Health and How We Count It Among People With Intellectual and Developmental Disabilities

By Susan M. Havercamp and Gloria L. Krahn

"This special issue of Intellectual and Developmental Disabilities emerged from almost two decades of work to improve data that can inform policy and practice at the federal and state levels. This work has involved collaborations across agencies within the Department of Health and Human Services, most notably the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC, the Administration on Intellectual and Developmental Disabilities (AIDD) at the Administration for Community Living, and the National Center for Health Statistics (NCHS) at CDC."

Policy

390 Unlocking the Potential of State Level Data: Opportunities to Monitor Health and Related Outcomes in People With Intellectual and Developmental Disabilities

By Alexandra Bonardi, Emily Lauer, Amie Lulinski, Mary Lee Fay, Andrew Morris, Margaret A. Nygren, and Gloria Krahn

"The challenge of unlocking the potential of state level data for health surveillance is at least three-fold ... it is necessary to establish intra-state approaches that consistently identify this population ... State level data must be collected in ways that allow the data to be combined across multiple states ... there must be processes to assure that data at the state and local level are reliably cleaned, linked and routinely examined ..."

Practice

439 Data Linkage: Canadian and Australian Perspectives on a Valuable Methodology for Intellectual and Developmental Disability Research

By Robert Balogh, Helen Leonard, Jenny Bourke, Kate Brameld, Jenny Downs, Michele Hansen, Emma Glasson, Elizabeth Lin, Meghann Lloyd, Yona Lunsky, Melissa O'Donnell, Shahin Shooshtari, Kingsley Wong, and Gloria Krahn

"As policymakers and researchers recognize the major contribution that social factors make to physical and mental health, there is an obvious desire to connect social variables with physical health data to investigate, understand and improve health outcomes."

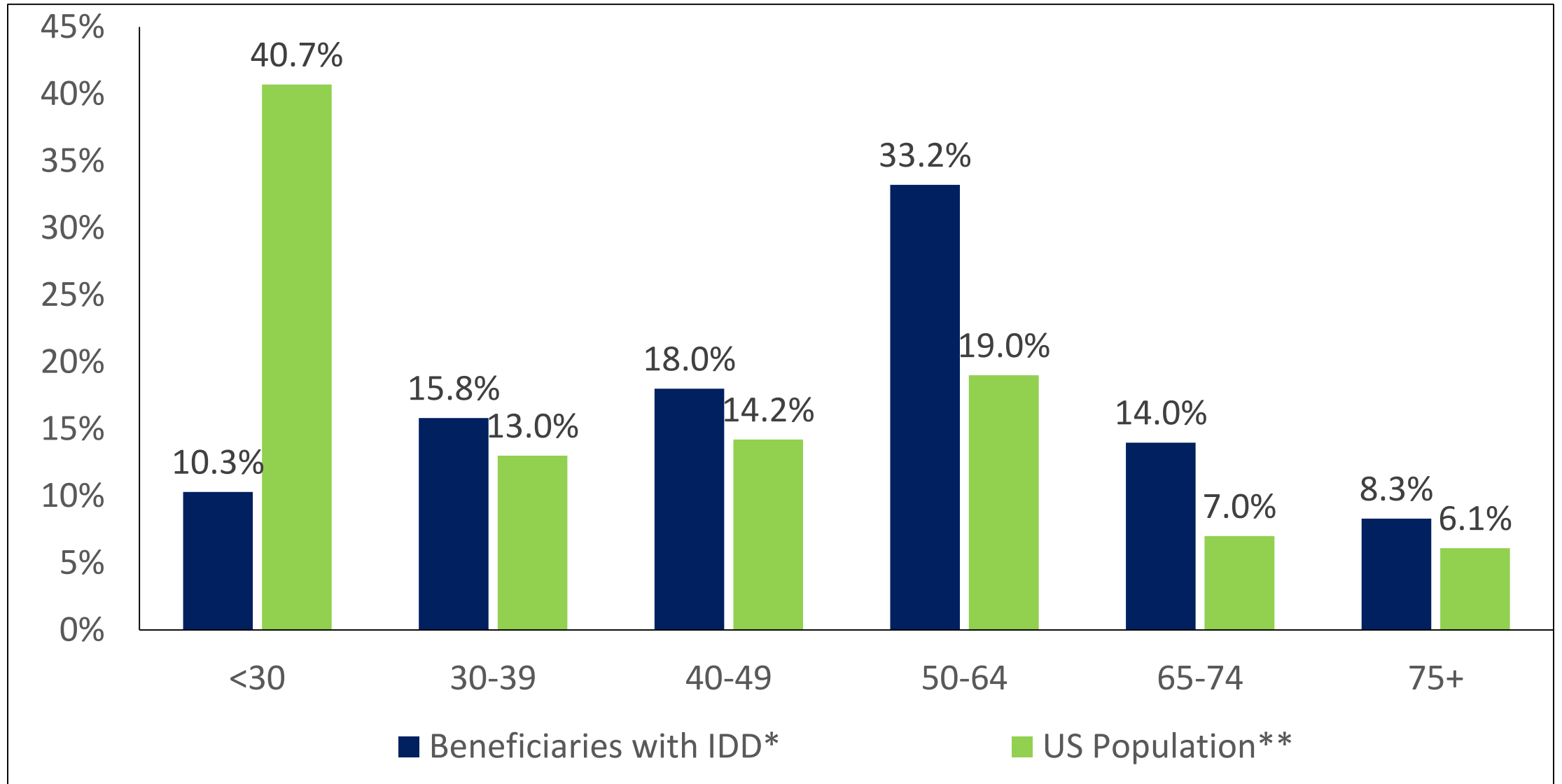
Available online at www.aaidd.org

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

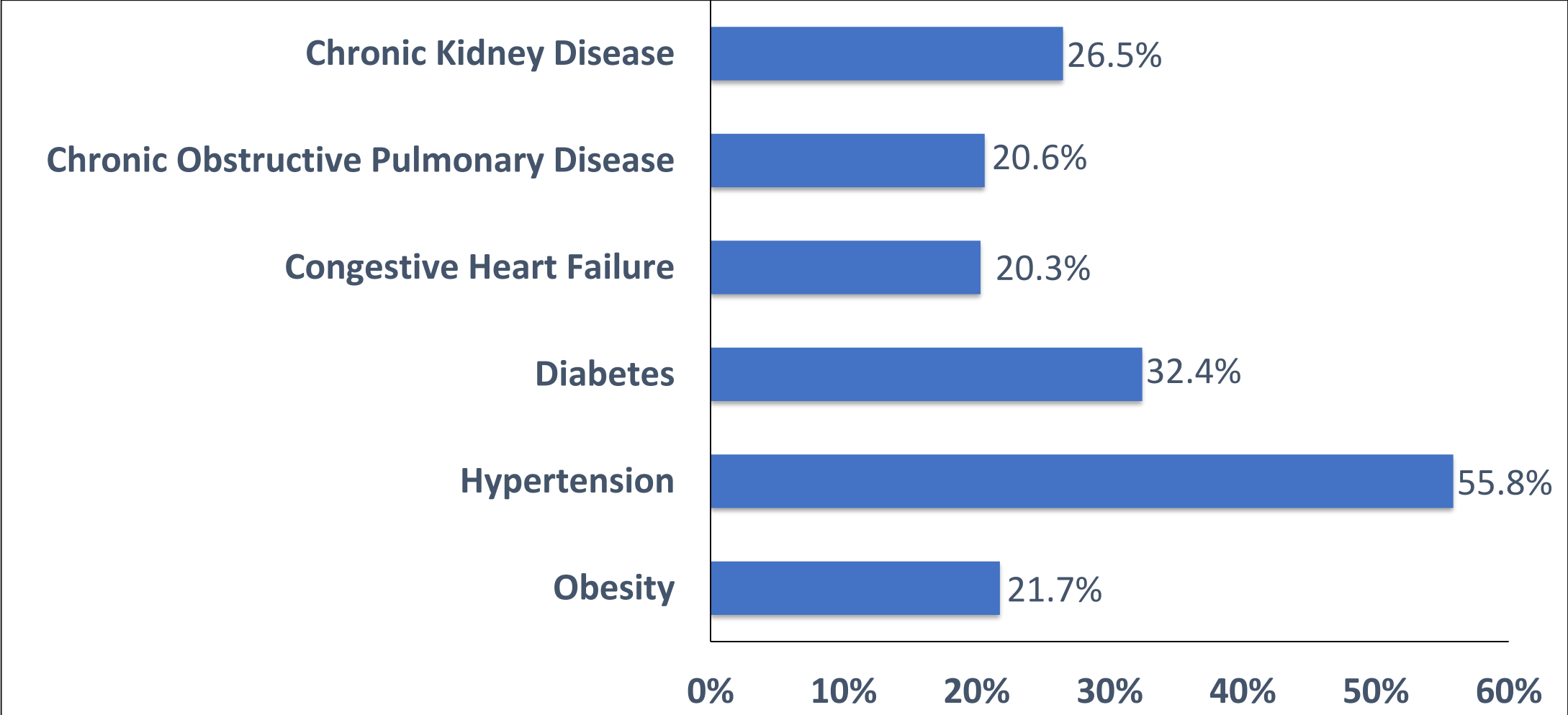
- **What Matters in Population Health and How We Count It Among People With Intellectual and Developmental Disabilities.** Susan M. Havercamp and Gloria L. Krahn
- **A Call for Better Data on Prevalence and Health Surveillance of People With Intellectual and Developmental Disabilities.** Gloria L. Krahn
- **Identifying People With Intellectual and Developmental Disabilities in National Population Surveys.** Susan M. Havercamp, Gloria L. Krahn, Sheryl A. Larson, Glenn Fujiura, Tawara D. Goode and Barbara L. Kornblau
- **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
- **A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000.** Lynda Lahti Anderson, Sheryl A. Larson, Sarah MapelLentz and Jennifer Hall-Lande
- **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
- **Technology Tools: Increasing Our Reach in National Surveillance of Intellectual and Developmental Disabilities.** Jordan B. Wagner, Minje Kim and Marc J. Tassé
- **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

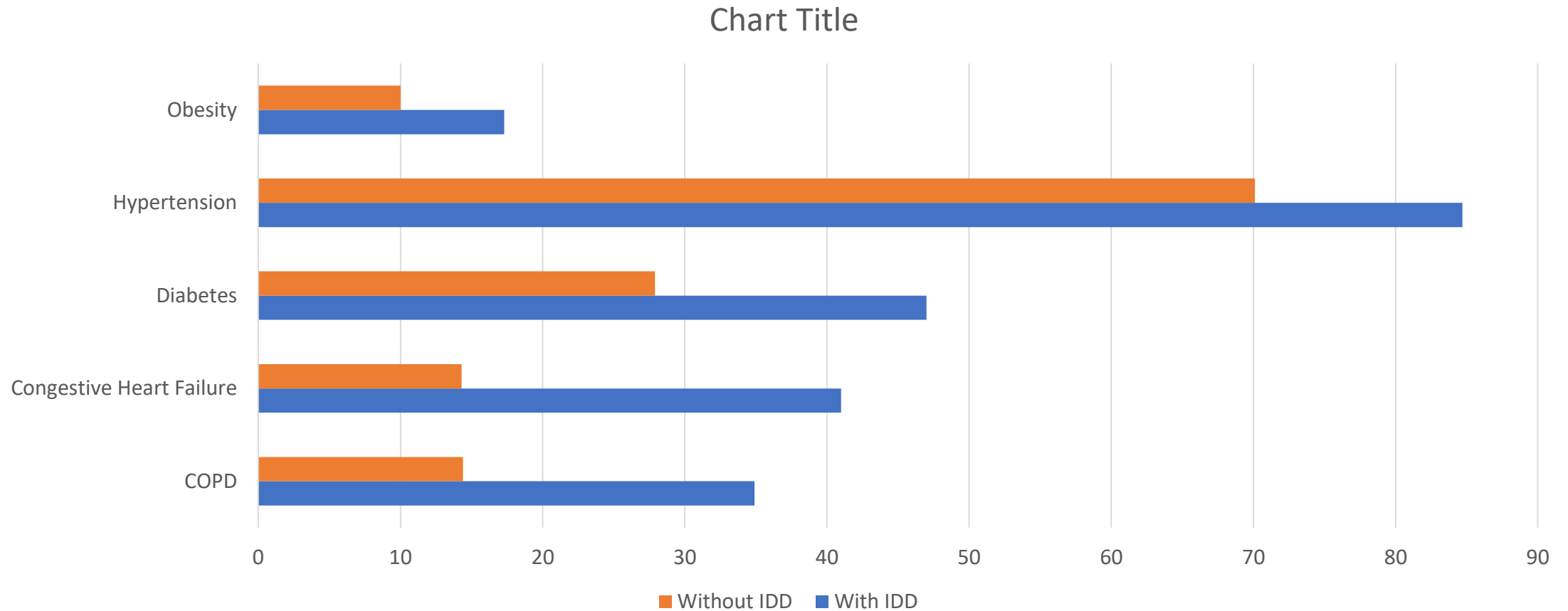


Prevalence of Chronic Conditions for All Medicare FFS Beneficiaries with IDD, CY2016



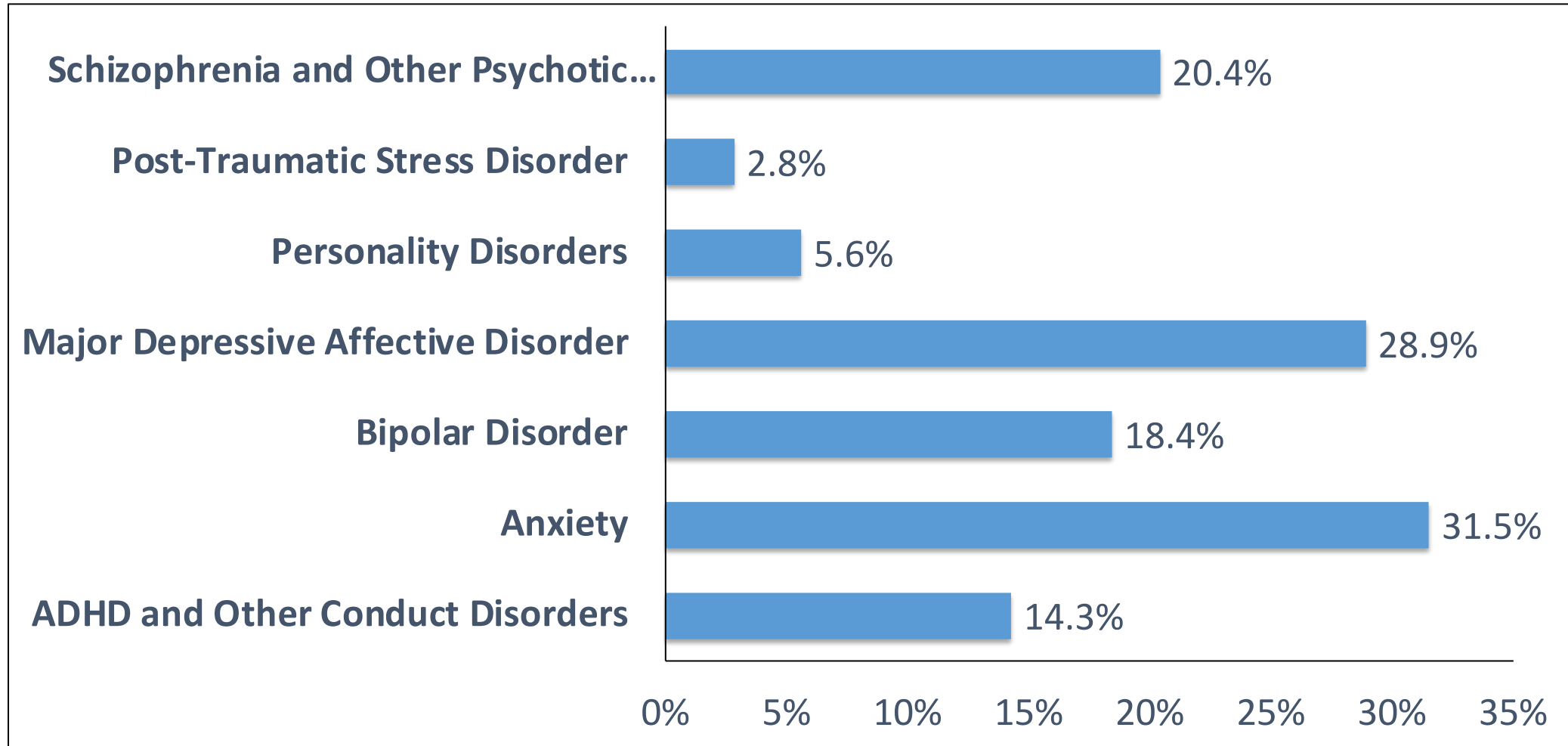
A Medicare FFS beneficiary with IDD related conditions has been diagnosed with ASD, CP, intellectual development, learning disability, or other development delay.

Comparison of Older (65+ Years) Medicare FFS beneficiaries with and without IDD.



Reichard, Haile & Morris, 2019. Characteristics of Medicare beneficiaries with intellectual or developmental disabilities. IDD, 57 (5), 405-420.

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



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:

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