



Working through the IDD Data Conundrum

November 13, 2018



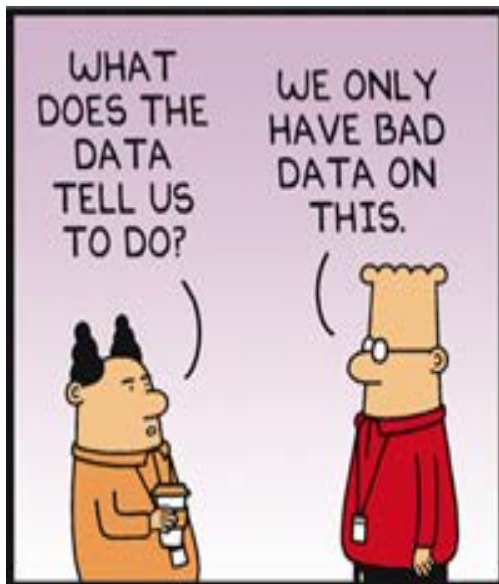
Panelists:

- Jennifer Johnson, PhD, Deputy Director, Administration on Intellectual and Developmental Disabilities, Administration for Community Living, USDHHS
- Gloria Krahn, PhD, MPH, Oregon State University
- Sherri Larson, PhD, University of Minnesota
- Alixe Bonardi, OTR, MHA, Human Services Research Institute
- Tawara Goode, MA, Georgetown University
- Andrew Morris, MPH, Policy Analyst, Administration for Community Living, USDHHS



The Who & What

- The Administration on Intellectual and Developmental Disabilities (AIDD) at the Administration for Community Living (ACL) has been leading an effort within the United States Department of Health and Human Services (USDHHS) to:
 - Update national prevalence data
 - Gain better understanding of health and health status of people with IDD
 - Look at best practices for the collection of state data



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The Why

- To improve standardization and utilization of state data about health status and factors that influence health of individuals with ID/DD.
- Need for better national and state information that influences federal and state agencies:
 - Solid Fiscal policy
 - Solid program policy
 - Performance evaluation
- Inform education, research, and stakeholder engagement in policy discussions.

Brief History

2015:

- Initial exploratory discussions with ASPE, NCHS, CDC/NCBDDD and ACL colleagues

2016:

- Continued discussions with NCHS, ASPE ACL and CDC/NCBDDD

Brief History

2017:

- Expanded the group to include CMS and OMH
- Engaged with external experts/researchers within our network to explore the data issues and current data available and research
- Held meeting of federal partners and external researchers and subject matter experts to discuss and identify next steps (November).

2018:

- Formed two workgroups of federal and non-federal experts to develop recommendations on:
 - Workgroup 1: Identifying Prevalence of the Population of Individuals With Intellectual and Developmental Disabilities
 - Workgroup 2: Maximizing Use of State and Local Data to Inform Surveillance of the Population with Intellectual and Developmental Disabilities.




Health Surveillance for People with Intellectual and Developmental Disabilities

Gloria Krahn, Oregon State University





Overview

- Importance of health data for people with intellectual and developmental disabilities
 - Surveillance as context for understanding other data
 - Previous work leading to Inter-agency meeting in November, 2017
- 



Need for Health Data about People with IDD

- HHS agencies need data for projections and planning
- AIDD need for prevalence data
- High need for services → Cost
- Monitor health status and changes



TYPES OF DATA



Surveillance Data

Panel
Data

Clinical
Data

Administrative Data

Services

Conditions

Incident Reporting

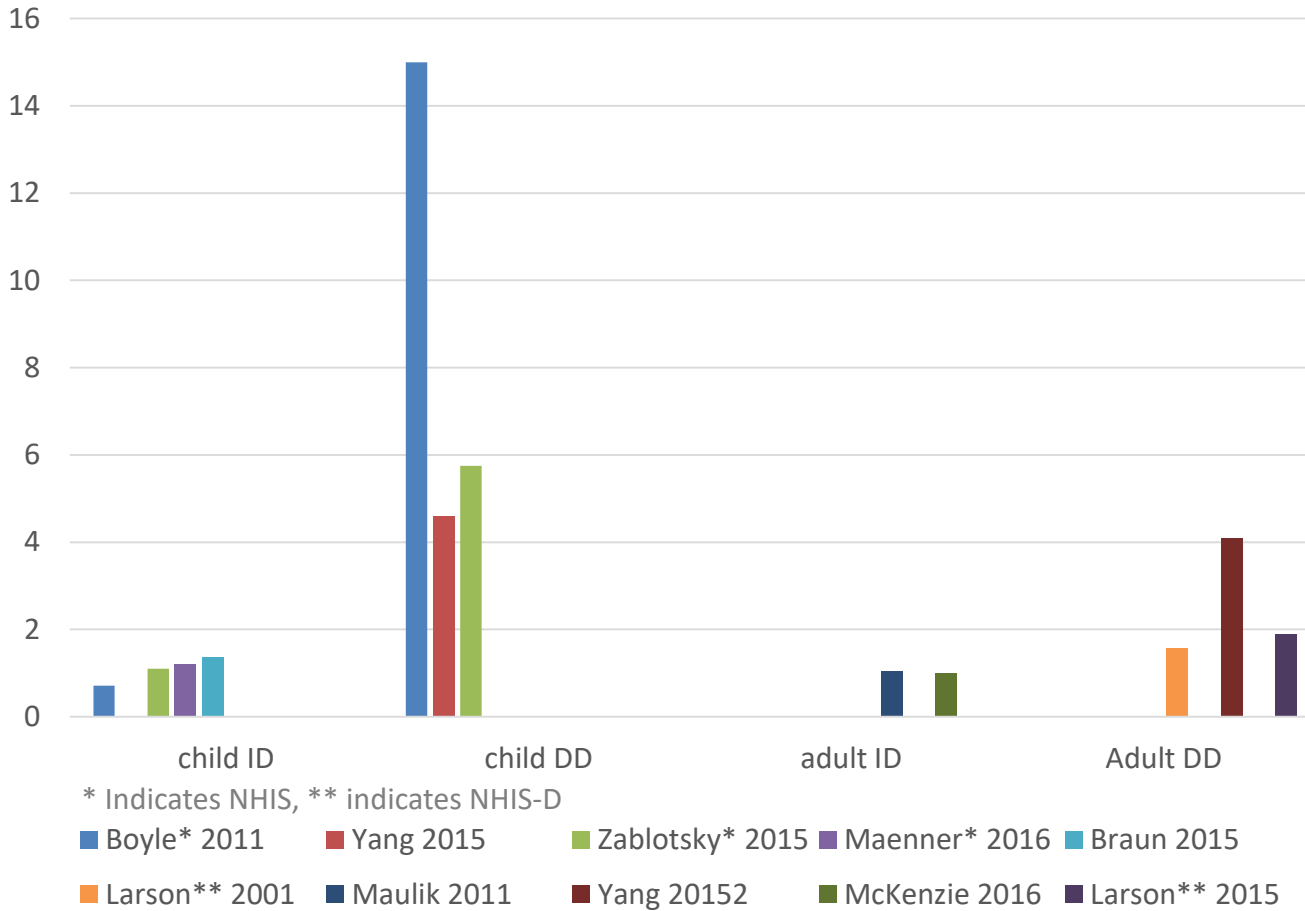
- Deaths
- Serious Injury

Who is
Missing?



PREVALENCE OF INTELLECTUAL DISABILITY AND DEVELOPMENTAL DISABILITIES


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



* Indicates NHIS, ** indicates NHIS-D

Boyle* 2011 Yang 2015 Zablotsky* 2015 Maenner* 2016 Braun 2015
 Larson** 2001 Maulik 2011 Yang 20152 McKenzie 2016 Larson** 2015

* Indicates NHIS; ** indicates NHIS-D, 1994/95



**PREVIOUS WORK ON HEALTH
SURVEILLANCE OF ADULTS WITH
INTELLECTUAL & DEVELOPMENTAL
DISABILITIES**



Recognizing the Need for Health Surveillance

- Surgeon General's Listening Session and Report, 2001
- Special Olympics Healthy Athletes; National Core Indicators data sets
- Numerous papers, including IASSID reports
- CDC/AUCD/ADD meetings—(2009, 2010, 2012)
 - Five-stage plan (2010)

Plan to Advance Health Surveillance and IDD*



Define ID conceptually and operationally
(Bonardi, Lauer, Mitra, Bershadsky, Taub, Noblett, 2011)



Compile and synthesize a knowledge base
(Bonardi, Lauer, Noblett, Taub, Bershadsky, 2011)



Extend past analyses of existing data
Manitoba Data Repository; SC Data Cube; NCI; Healthy Athletes



Pilot state or regional demonstrations
(McDermott, Royer, Cope, Lindgren, et al, 2018)



Expand surveillance nationally
Where we are NOW

*Krahn, Fox, Campbell, Ramon & Jesien, 2010; Fox, Bonardi & Krahn, 2016

Impetus for Inter-agency Meeting, Nov 2017

- Prevalence data from NHIS-D (94/95) are ~ 25 years old; much has changed
- NHIS changes for 2019 will no longer allow identification of people with IDD
- Increased interest across HHS agencies for improved data

Meeting Participants

Federal Agencies:

- Administration on Community Living (ACL)
- Assistant Secretary for Planning and Evaluation (ASPE)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare and Medicaid (CMS)
- National Center for Health Statistics (NCHS)
- Office on Minority Health (OMH)

University Researchers:

- 8 university researchers

National Disability Organizations:

- Association of University Centers on Disabilities (AUCD)
- Center for Epidemiological Research for Individuals with Intellectual and Developmental Disabilities (CERIIDD)
- Human Services Research Institute (HSRI)
- National Association of Councils on Developmental Disabilities (NACDD)
- National Association of State Directors of Developmental Disabilities Services (NASDDDS)



Meeting Summary

- **Agency Uses and Needs for Data**
 - Agencies “cobble together” data
 - Need for more current and differentiated data, including diversity
- **Data Strategies: What we Know about Health of People with ID/DD**
 - Need for national surveillance data
 - Strong support for looking at state data, even though states vary
- **Role of the National Health Interview Survey**
 - NHIS and NHIS-D have been highly useful for health of IDD
 - With reduction of NHIS-2019, identification of IDD is jeopardized
- **Current and Future Strategies for Better Data**
 - Survey question methodologies, including technology
 - Promise in Linking, Mining and Harmonizing data sets
- **Two Work Groups**

Workgroup Findings: Identifying Persons with Intellectual and Developmental Disabilities in National Population Surveys

Sherri Larson, University of Minnesota



Workgroup members

Andrew Morris- ACL	Jennifer Johnson - ACL
Susan Havercamp, OSU (Ohio) (chair)	Gloria Krahn, OSU (Oregon) (co-chair)
Glenn Fujiura, UIC	Ellen Blackwell, CMS
Alyssa Stevens, CDC	Bill Martin, ASPE
Julie Weeks, CDC	Sherri Larson, UMN
Amanda Reichard, NIDILRR, ACL	Barbara Kornblau, Coalition for Disability Health Equity
John Drabeck, HHS (Now Retired)	Helen Lamont, ASPE



The Workgroup Charge

To collaborate with NCHS to develop criteria/guiding principles and identify existing or draft additional (1-3) question(s) for use with the revised NHIS and other national surveys to identify persons with intellectual and developmental disabilities in order to determine prevalence of IDD (denominator)



Process and Product

1. Meetings from February - July 2018
2. White paper provides historical context, alternative conceptualizations that underlie measurement approaches
3. Defines ID and DD
4. Describes current IDD prevalence estimates (child and adult)
5. Identifies gaps in current surveillance efforts
6. Identifies key constructs that must be measured
 1. Minimal questions needed to identify for health research
 2. Additional domains needed for incidence and prevalence
7. Proposed strategies for national survey programs
8. Methodological considerations
9. Anticipated next steps



Life Activity	ID
Learning	✓
Conceptual Skills	✓
Self-Care	✓
Social skills	✓
Communication	
Mobility	
Self-direction	
Independent living	✓
Economic self-sufficiency	
Other Criteria	
Age of onset	✓(18)
Severity	✓
Duration	

Intellectual Disability* (Schalock et al, 2010)

Significant limitations in both intellectual functioning and in adaptive behavior, which originates before the age of 18

Related conditions

- Cerebral palsy
- Spina Bifida
- Epilepsy
- Hydrocephalus

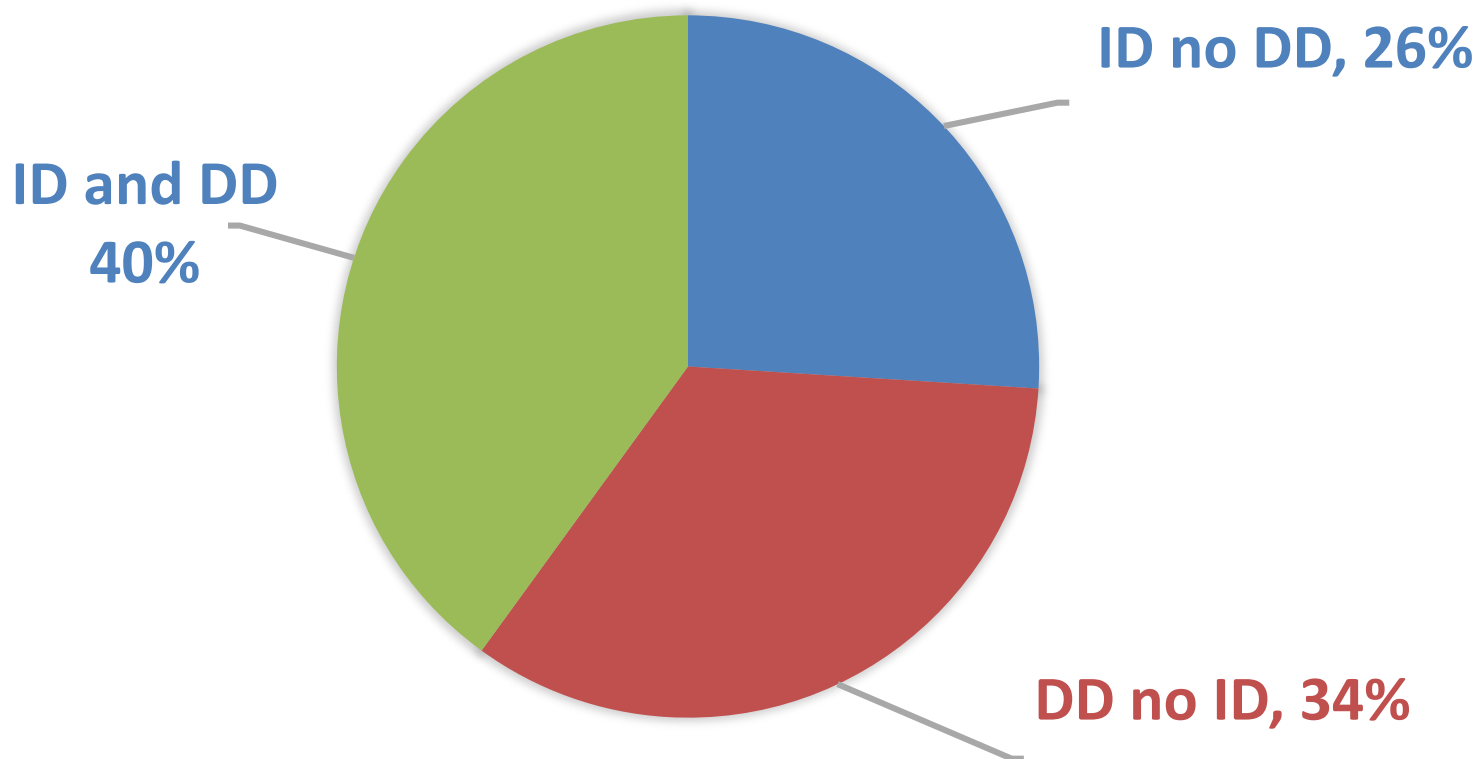
Life Activity	DD
Learning	✓
Conceptual Skills	
Self-Care	✓
Social skills	
Communication	✓
Mobility	✓
Self-direction	✓
Independent living	✓
Economic self-sufficiency	✓
Other Criteria	
Age of onset (22 years)	✓
Severity	✓
Duration	✓
Individual services and supports	✓

DD Act of 2000

Developmental disabilities are a severe, chronic disability that is

- attributable to a mental or physical impairment, is
- manifested before age 22,
- is likely to continue indefinitely,
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive or expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency;
- and reflects the individual's need for a combination and sequence of services and supports

Overlap between Intellectual and Developmental Disabilities in Adults



Based on NHIS-D analyses (Larson, et al., 2001)

Life Activity	ID	DD
Learning	✓	✓
Conceptual Skills	✓	
Self-Care	✓	✓
Social skills	✓	
Communication		✓
Mobility		✓
Self-direction		✓
Independent living	✓	✓
Economic self-sufficiency		✓
Other Criteria		
Age of onset	✓(18)	✓(22)
Severity	✓	✓
Duration		✓

Life Activity	ID	DD	Construct captured in current survey (NHIS)
Learning	✓	✓	
Conceptual Skills	✓		
Self-Care	✓	✓	✓
Social skills	✓		
Communication		✓	✓
Mobility		✓	✓
Self-direction		✓	
Independent living	✓	✓	
Economic self-sufficiency		✓	✓
Other Criteria			
Age of onset	✓(18)	✓(22)	
Severity	✓	✓	✓
Duration		✓	

Life Activity	ID	DD	Construct captured in current survey (NHIS)
Learning	✓	✓	
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Self-Care	✓	✓	✓
Social skills	✓		
Communication		✓	✓
Mobility		✓	✓
Self-direction		✓	
Independent living	✓	✓	
Economic self-sufficiency		✓	✓
Other Criteria			
Age of onset	✓(18)	✓(22)	
Severity	✓	✓	✓
Duration		✓	



Learning

Survey	Question
NHIS-child	Ever told by a doctor or other health professional that you have an intellectual disability?
	Ever told by a doctor or other health professional that you have autism spectrum disorder?
	Ever told by a doctor or other health professional that you have another developmental disability?
2008-2013 SIPP	Does _____ have (a) learning disability such as dyslexia? (b) a developmental disability such as autism or cerebral palsy?
NHIS-D	Does _____ have serious difficulty learning how to do things most people their age can learn?
Ohio Medicaid Assessment Survey	Do you have a developmental disability?
Diagnostic Adaptive Behavior Scale	If you attended school, did you receive special education?
	Did you have significant difficulties learning in school or to read or write?

Learning

Survey	Question
NHIS-child	Ever told by a doctor or other health professional that you have an intellectual disability?
	Ever told by a doctor or other health professional that you have autism spectrum disorder?
	Ever told by a doctor or other health professional that you have another developmental disability?
2008-2013 SIPP	Does _____ have (a) learning disability such as dyslexia?
NHIS-D	Does _____ have serious difficulty learning how to do things most people their age can learn?
Diagnostic Adaptive Behavior Scale	If you attended school, did you receive special education?
	Did you have significant difficulties learning in school or to read or write?
WHODAS 2.0	In last 30 days, how much difficulty did you have analyzing and finding solutions to problems in everyday life
	In last 30 days, how much difficulty did you have learning a new task such as how to get to a new place

Self-Determination

Survey	Question
NHIS-D	Because of a physical, mental or emotional problem, the person needs to be reminded or have someone close by for <ul style="list-style-type: none">• Eating• Bathing• Dressing• Using a toilet• Transferring in and out of bed
	Do you have a court appointed representative currently authorized to make decisions on your behalf such as a guardian, conservator, power of attorney, or medical proxy?
	If you do not live with a family member, did you choose the place you are living?
	Do you decide what to wear, how to spend your money, when to eat, and when to go to bed?
	Lives with a family member as an adult
NHIS	Had proxy response because of disability

Age of Onset and Expected Duration

- Only if a person indicates they have a substantial limitation (a lot of difficulty or unable to do) in any of the qualifying domains, ask
 1. Did limitation first occur before age 22?
 2. Are limitations expected to continue at least 12 months?





Additional Domains: Communication

Survey	Question
NHIS-D	Because of a physical mental or emotional problem, the person has a lot of difficulty or is unable to use the telephone
	Person has serious difficulty communicating with people outside of the family
	Person has serious difficulty understanding others when they talk or ask questions
WHODAS 2.0	In last 30 days how much difficulty understanding what people are saying
	In last 30 days, how much difficulty starting and maintaining a conversation

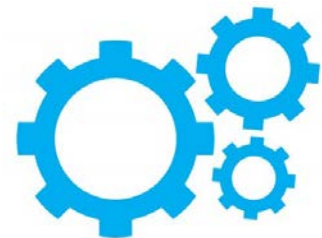
Additional Domains: Capacity for Independent Living

Survey	Question
NHIS-D	Because of a physical mental or emotional problem, the person has a lot of difficulty or is unable to use the telephone
	Person has serious difficulty communicating with people outside of the family
	Person has serious difficulty understanding others when they talk or ask questions
WHODAS 2.0	In the last 30 days how much difficulty did you have staying by yourself for a few days?
	In the last 30 days, how much difficulty did you have doing the most important household tasks well?
	In the last 30 days, how much difficulty did you have getting your household work done as quickly as needed?

Methodological Considerations

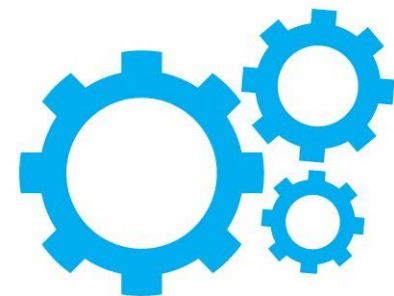
- **Benchmarking**

- Benchmark estimates of the number of people with IDD in the US vary by source
 - Public health surveillance
 - Administrative data
 - Nationally representative surveys
- Which segments of the population are included and excluded from the survey (e.g., age, type of disability)
- Three years of survey data will be needed to benchmark an updated prevalence rate.



Methodological Considerations

- **Item development and testing:** NHCS lab conducts extensive testing on all items included in the NHIS
 - learning and self-direction have been difficult to measure in cognitive testing
- **Ensure inclusion of diverse populations**
 - culturally sensitive survey design includes a sampling frame that contains diverse populations and oversamples for underrepresented groups
 - attend to cultural and linguistic differences in questions



Anticipated Next Steps

1. AIDD has entered into an interagency agreement with NCHS to construct and cognitively test survey questions to identify adults with IDD
2. Continue to build collaboration and awareness of the need for national prevalence and health surveillance practices to allow regular and timely updating
3. Explore questions in future iterations of the NHIS to meet benchmarking requirements





**State and Local Data to Inform
Surveillance of the Population with
Intellectual and Developmental
Disabilities**

Workgroup Charge

- Describe **approaches for better standardization and utilization of state administrative data sets** that can provide richer data on health status and factors that influence health (e.g., health care access and utilization, place of residence, service use) of persons with intellectual and developmental disabilities;
- **Identify the potential data sources:** (e.g., SSA, commercial claims, Medicaid, other administrative claims);
- Describe **processes for some degree of standardization across states and data sets**; and
- Identify **datasets that could be used at the state and territory level**, including datasets that describe the population of children (birth-18 years old) with developmental disabilities.

Work Group Members....

Andrew Morris- ACL	Jennifer Johnson - ACL
Alixé Bonardi, Human Services Institute (Chair)	Gloria Krahn, OSU
Kristen Robinson, ACL	Maggie Nygren, AAIDD
Katie Okoro, CDC	Bill Martin, ASPE
Mary Lee Fay, NASDDDs	Jareen Meinzen-Derr, CCMHC
Ilka Riddle, CCMHC	Jean Hall, KU
Andrew Houtenville, UNH	Elsa Haile, CMS
Shea Tanis, UC	Amy Lulinski, UC
Melissa Harris, CMS	Amanda Reichard, ACL



Previous efforts have described potential data at the state level. ¹

- Administrative data from state service systems
- Health insurance (payor) claims
- State level (population-level) surveys.

Unlocking the potential of state level data

1. Intra-state. Establish effective approaches for population identification, along with priority measures **within a state.**
2. Across states. Ability to interpret state level data at a national level requires data collection and population identification with a view to combining **across multiple states.**





Potential for use of data within states

Data sources considered for using administrative data to examine health and other outcomes for people with IDD.

- State DD service agencies
- Education / Transition programs
- Medicaid and other Health Care claims data
- Social Security Administration
- State level surveys (National Core Indicators, HCBS-CAHPS, BRFSS)
- Registries

Data collection in the US

Territories



- Keep in mind – data is not as robust as in states and District of Columbia
- All territories participate in census but not ACS
- USVI has HeadStart data, including numbers of children with developmental delay, disability
- No territories participate in Medicaid ICF/ID or HCBS (administrative data not available)
- Takeaway – additional challenges in population level data collection in territories.



**HIGHLIGHTS
FROM
STATES
USING
AVAILABLE
DATA**

WASHINGTON

OHIO

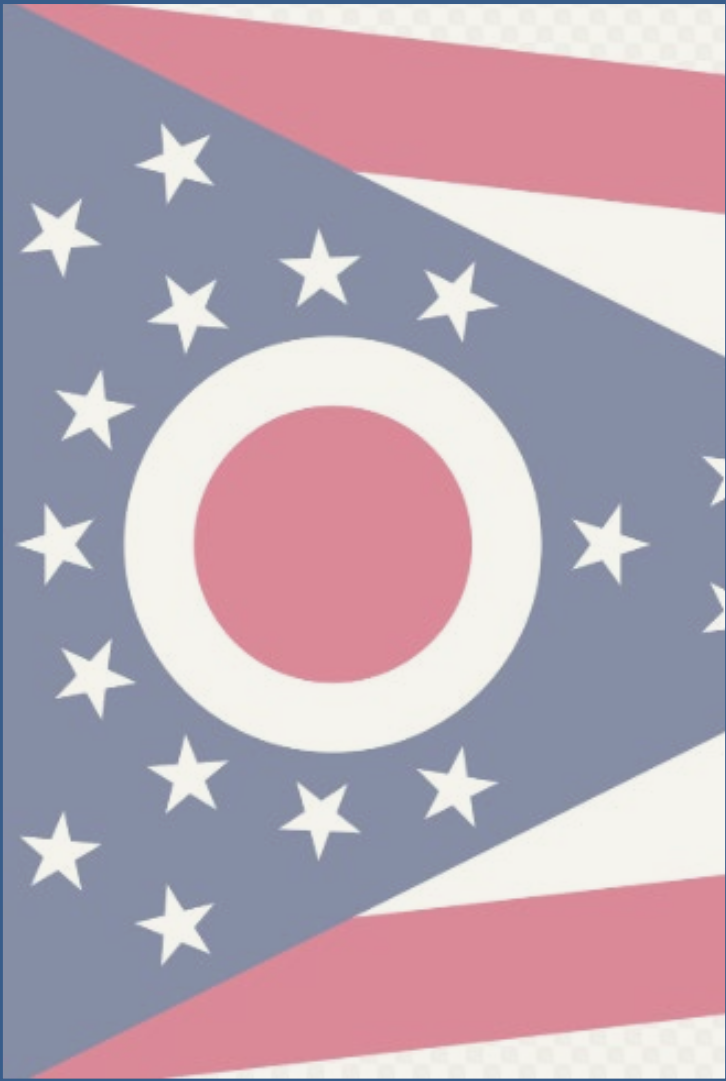
SOUTH CAROLINA

CALIFORNIA



Washington

- State tracks people receiving closely, can produce detailed reports about services received.
- Outreach to people beyond those deemed 'eligible for IDD services'. Families-informing families directed outreach (tools, info, culture-specific info.)
<http://informingfamilies.org>
- Presently, transition to behavioral health services through managed care, possibly raising issue of availability of data going forward.



Ohio

- Department of Developmental Disabilities (DODD) used a matching methodology to link Medicaid records to active recipients from DD state agency.
- Allows for robust analysis of targeted health services utilization.
- Made possible by ensuring adequate analysis capacity within DODD, with knowledge of state Medicaid data.
- Other states have demonstrated data linkages with state IDD agency, but a minority do this routinely



South Carolina

- Partnership between University of South Carolina and state repository of numerous datasets allowed for creation of “Disability Cube”.
- Ongoing linkage allows for multiple analyses.

Recent publication:

McDermott, S., Royer, J., Mann, J.R., Armour, B.S. (2018).

Factors associated with ambulatory care sensitive emergency department visits for South Carolina Medicaid members with intellectual disability.

Journal of Intellectual Disability Research, 62(3), 165-178.



California

- Launched initiative to monitor, publicly report service data by race, ethnicity, language spoken, among other personal characteristics.
- Examination of access and outcomes and potential disparities.
- Race/ethnicity in general population in regional center's catchment area compared to demographics of population receiving services.
- Legislative action encouraged monitoring and public reporting of data – included an appropriation of \$11M annually in targeted funding to work with communities to ensure equitable access.



CDC/NCBDDD

Seven state Cooperative Agreement

- AK, IA, MA, NH, MY, OR, SC funded to implement Medicaid analyses across states

Multiple publications have resulted, most recently:

McDermott, S., Royer, J., Cope, T., Lindgren, S., Momany, E., Chul-Lee, J., et al. (2018). Using Medicaid data to characterize persons with intellectual and developmental disabilities in 5 US states. *American Journal on Intellectual and Developmental Disabilities*, 123(4), 371-381.

- Large, multi-state dataset and standardized case-identification algorithm in Medicaid data
- Includes only Medicaid members – identified with IDD
- Variation in Medicaid eligibility rules, data coding procedures across states



Strategies and opportunities to enhance available data

- Expanding electronic data systems (e.g. T-MSIS)
- Linkages (e.g. SC, OH)
- Data harmonization (e.g. 7 state Medicaid project)
- ‘Indirect estimation’ (e.g. CMS Office of Minority Health project with RAND Corporation to enhance quality of race, ethnicity, language data).
- Proposed: Capture/Recapture methodology ²



Considerations and suggestions that emerged re. State level data collection

Capacity Building:

- Learning collaboratives.
- Further disseminate successful strategies states are using to collect data, merge files, share findings.
- Encourage federal and state partners to include measures of race, ethnicity, primary language.

Expanded data collection:

- Promote data collection efforts that include categories of ID, DD, mental health/behavioral health diagnoses
- Longitudinal studies and efforts to understand intersections of race, ethnicity, primary language, and disability.

Health Disparities at the Intersection of Race, Ethnicity, Culture, and Language

Tawara D. Goode

Georgetown University National Center for Cultural Competence
Georgetown University Center for Excellence in Developmental Disabilities
Center for Child and Human Development
Georgetown University Medical Center

November 12, 2018



WHAT WE WILL EXPLORE TOGETHER TODAY

- Current demographic trends in the U.S. territories, and tribal communities
- What we know and don't know about health disparities among people with developmental disabilities
- What are challenges in question development and data collection for the NHIS survey



Who lives in the U.S.,
territories, and tribal
communities?



ACS 2017 United States Demographic Estimates



One Race or Latino or Hispanic and Race

Total Population = 325,719,178

RACE	NUMBER	Percent of POPULATION
One Race	315,003,713	96.7%
White	235,507,457	72.3%
Black or African American	41,393,491	12.7%
American Indian or Alaska Native	2,726,278	0.8%
Asian	18,215,328	5.6%
Native Hawaiian & Other Pacific Islander	608,219	0.2%
Some Other Race	16,552,940	5.1%
Two or More Races	10,715,465	3.3%
HISPANIC OR LATINO AND RACE		
Hispanic or Latino of any Race	58,846,134	18.1%

Data Source: Source: U.S. Census Bureau, 2017 American Community Survey (ACS), Demographic & Housing Estimates, Table DP05, 1-Year Estimates.

Slide Source: © 2018 - Georgetown University National Center for Cultural Competence



Population Self-Identified by Race & Ethnicity Categorical Listings

White and Black or African American

White and American Indian and Alaska Native

White and Asian

White and Native Hawaiian and Other Pacific Islander

White and Some Other Race

Black or African American and American Indian and Alaska Native

Black or African American and Asian

Black or African American and Native Hawaiian and Other Pacific Islander

Black or African American and Some Other Race

American Indian and Alaska Native; Asian

American Indian and Alaska Native and Native Hawaiian and Other Pacific Islander

American Indian and Alaska Native and Some Other Race

Asian and Native Hawaiian and Other Pacific Islander

Asian and Some Other Race

Native Hawaiian and Other Pacific Islander and Some Other Race

Three or more races

Languages Spoken at Home in the U.S. in 2017



Estimated Total Population 5 years and over **305,924,019**

Speak only English **78.2%**

Speak a language other than English **21.8%**

Speak Spanish **41,017,620 (13.4%)**

Speak Indo European languages **11,321,488 (3.7%)**

[French (Patois, Cajun), French Creole, Italian, Portuguese, Portuguese Creole, German, Yiddish, Other West Germanic languages, Scandinavian languages, Greek, Russian, Polish, Serbo-Croatian, Other Slavic languages, Armenian, Persian, Gujarathi, Hindi, Urdu, Other Indic languages]

Speak Asian and Pacific Island languages **10,839,407 (3.5%)**

[Chinese, Japanese, Korean, Mon-Khmer, Cambodian, Miao, Hmong, Thai, Laotian, Vietnamese, Tagalog, other Pacific Island language]

Other Languages **3,413,791 (1.1%)**

[Navajo, Other Native American languages, Hungarian, Arabic, Hebrew, African languages, other unspecified languages]

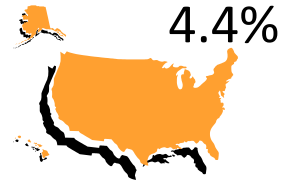


Limited English Speaking Households

Limited English Speaking Households formerly (linguistic isolation) refers to households in which no member 14 years old and over: (1) speaks only English or (2) speaks a non-English language and speaks English “very well.”

Limited English Speaking Households in the United States in 2017

All households




Households speaking--

- Spanish 21.7%
- Other Indo-European languages 14.9%
- Asian and Pacific Island languages 24.6%
- Other languages 17.0%



Top 10 Countries of Birth of Lawful Permanent Residents in the United States in 2017

Total **1,127,167**

Mexico		170,581
China, People's Republic		71,565
Cuba		65,028
India		60,394
Dominican Republic		58,520
Philippines		49,147
Vietnam		38,231
El Salvador		25,109
Jamaica		21,905
Haiti		21,824

Data Source: U.S. Department of Homeland Security, Yearbook of Immigration Statistics: 2017 Legal Permanent Residents, Supplemental Table 1 – Persons Obtaining Legal Permanent Resident Status by State or Territory of Residence and Region or Country of Birth: Fiscal Year 2017



What we know and don't know about health disparities among people with intellectual and developmental disabilities.



WHAT WE KNOW AND DON'T KNOW

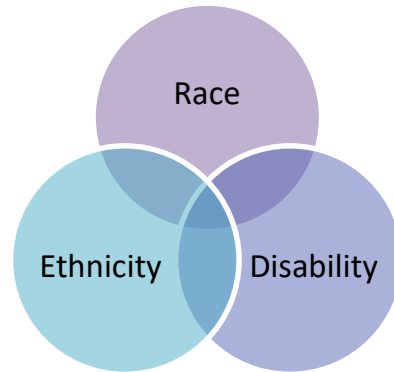


- ✓ There are numerous published reports and studies about health disparities among people with disabilities in general.
- ✓ We know far less about health disparities among people at the *intersection* of race, ethnicity, and disability.



Health Disparities at the Intersection

“Our understanding of the intersection of disability with race and ethnicity in health care is very limited.”



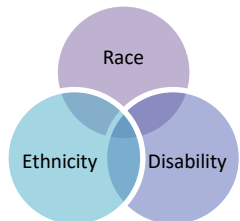
“Both quantitative and qualitative studies are needed to understand the experiences of people “at the intersection” and determine whether the barriers they face are multiplied because of their unique status.”



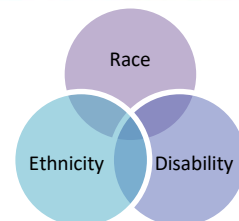
Horner-Johnson, W., Fujiura, G., & Goode, T. Promoting a new research agenda. Health disparities research at the intersection of disability, race, and ethnicity. *Medical Care*, October 2014, Volume 52. Issue 10, S1-S2.

Goode, T., Carter-Pokras, O., Horner-Johnson, W., & Yee, Silvia. Parallel tracks: reflections on the need for collaborative health disparities research on race/ethnicity and disability. *Medical Care* October 2014, Volume 52, Issue 10, S3-S8.





Health Disparities at the Intersection



- Hispanics or Latinos and non-Hispanic blacks with IDD were less likely to have received recent preventive care than non-Hispanic whites with IDD.
- African-American/black women with intellectual disabilities were significantly and substantially less likely to have received a mammogram compared to white women with intellectual disabilities
- In particular, African American/black youths with muscular dystrophy had lower overall health care use and less use of primary care, therapy, and specialist care, but higher use of hospital and emergency treatment.
- African Americans/black and Hispanic or Latino parents of children with developmental disabilities have also reported poorer quality of interactions with health care providers compared to white parents.



What We Know: Health Disparities Among People with IDD

A Focus on Oral Health



- Children with ID/DD were more than 30% more likely to have their first dental visit delayed.
- In addition, studies have shown that children without ID/DD were more likely to receive preventive care.



Data source: Michael Milano, DMD. *Oral Healthcare for Persons With Intellectual or Developmental Disabilities: Why Is There a Disparity?* Retrieved on 6/4/18 from <https://www.aegisdentalnetwork.com/cced/2017/11/oral-healthcare-for-persons-with-intellectual-or-developmental-disabilities-why-is-there-a-disparity>



What We Know: Health Disparities Among People with IDD

A Focus on Oral Health



- Individuals with ID/DD have significant dental needs and that these needs are often untreated.



- Unmet dental needs often result in individuals with ID/DD having poor oral health – with dental needs that are more severe than for individuals without ID/DD.



- Unmet dental needs negatively affect daily activities and quality of life for individuals with ID/DD.



Implications of these factors for the NHIS Survey



- ✓ IDD is a statistically small population and those from racial and ethnic groups other than non-Hispanic White are even a smaller subset and difficult to measure.
- ✓ There is no data on American Indian/Native American population with IDD with the exception of those collected documenting fetal alcohol syndrome.
- ✓ People with developmental disabilities from racial and ethnic groups other than non-Hispanic white are often over diagnosed or under diagnosed.
- ✓ Data collected by states and territories for IDEA are disaggregate data by race, ethnicity, and language spoken
- ✓ Testing of NHIS questions have to be conducted in English



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Next Steps Workgroup One:

1. AIDD has entered into an interagency agreement with NCHS to construct and cognitively test survey questions to identify adults with IDD
2. Continue to build collaboration and awareness of the need to implement national prevalence and health surveillance practices that allow regular and timely updating of the population with IDD
3. Explore how to have questions included in future iterations of the NHIS to meet benchmarking requirements

Next Steps Workgroup Two:

- Work collaboratively with internal federal partners and stakeholders to review work group recommendations.
- Consider federal/state; public/private; federal/federal partnerships to fund recommendations

How Long????

- 1 to 5 year goal:
 - Jan 2020: Complete survey questions
 - Begin learning collaborative, community of practice, and/or demonstrations to improve data collection at the state level
 - 2022/2023: NHIS Year 1 survey
 - 2023/2024: NHIS Year 2 survey
- 5 to 10 year goal:
 - 2025/26: NHIS Year 3 survey
 - 2027: Benchmark New IDD Prevalence
 - Data from state data projects becomes available
- 10 + year goal:
 - Regular updates of IDD prevalence
 - 50% of states have improved state level data for individuals with IDD



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Discussion

- How would you or your organization use updated prevalence of IDD?
- What do you see as greatest gaps?
- Which populations are not being adequately in health data?
- How do these efforts tie to the federal MUP legislation that has been proposed related to the population with I/DD?

Discussion

- In addition, or as a compliment to the state level efforts described in the presentation, what effective state level data linkages do you know of that can extend available knowledge about people with IDD who are eligible for services, who are eligible and receiving services, and those who have not been identified as eligible and are residing in the community?
- We are looking for self advocates who would be willing to participate in question testing.
- Would your organization like to have an opportunity to discuss the data project more in-depth with ACL?
 - Please email andrew.morris@acl.hhs.gov



THANK
YOU