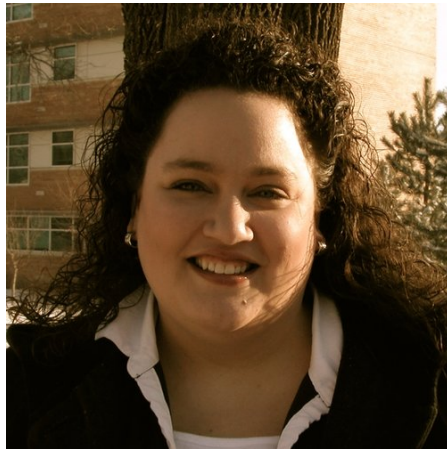


Health Disparities Experienced by People with ID and Those with Other Disabilities



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Presentation Overview

- Background
- Health disparities for people with disabilities
- Social determinants of health
- National Survey on Health and Disability (NSHD) overview
- NSHD findings & limitations
- Data availability
- Further reading

Background

- **Disability measurement and surveillance**
 - Census, American Community Survey
 - CDC, Behavioral Risk Factor Surveillance System (BRFSS) and the Disability and Health Data System (DHDS)
- **Lack of an accurate measure of Intellectual Disability (ID)**
 - Administration on Intellectual and Developmental Disabilities data workgroups convened in 2017, with reports released in late 2019
- **KU-IHDPS method of disability measurement**
 - Open-ended question (categorized) used for more than 20 years

Health Disparities

- In the past decade disparities for people of certain groups has emerged as a unifying framework for many researchers, funders and policymakers (e.g., Healthy People 2010, 2020, 2030).
- Disparities between people with disabilities and people without disabilities have been widely studied and published.
- CDC funds 19 state Disability and Health Programs.
(<https://www.cdc.gov/ncbddd/disabilityandhealth/programs.html>)
- The CDC updates national and state data comparisons and infographics on disparities annually.
(<https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>)

Adults with Disabilities are more likely to

be inactive



have high blood pressure



smoke






be obese



Source: 2018, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

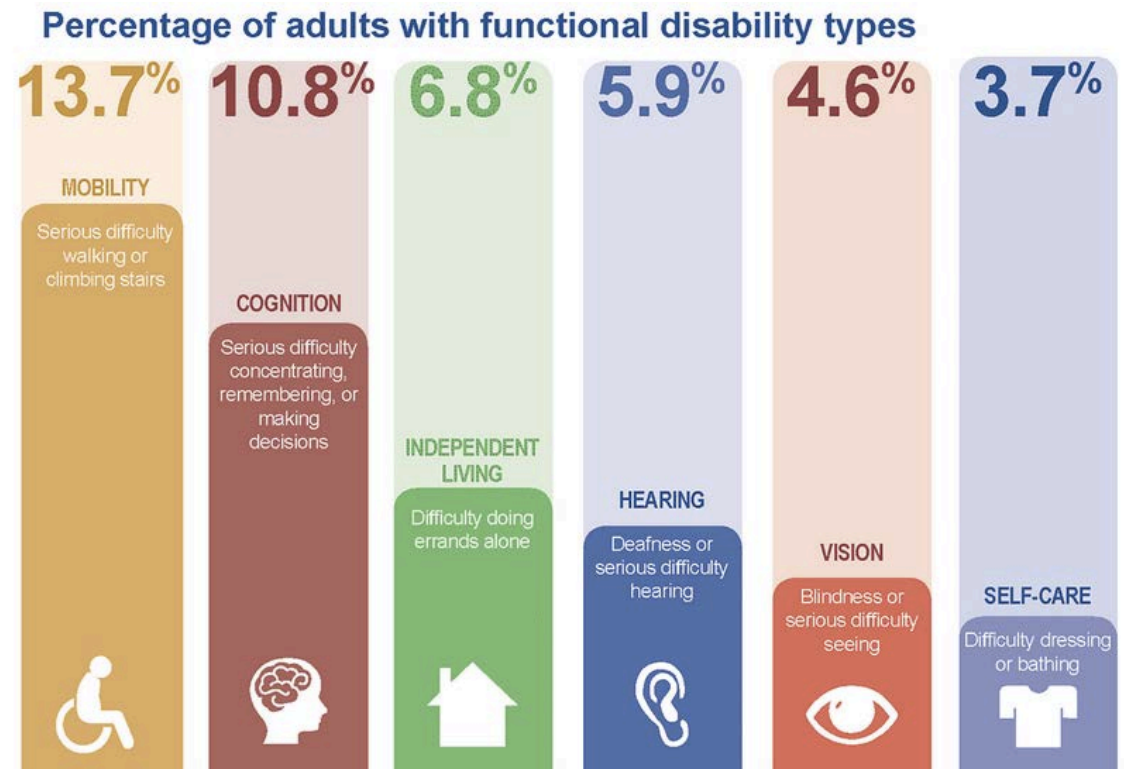
Adults living with disabilities are more likely to

	With Disabilities	Without Disabilities
 HAVE OBESITY	38.2%	26.2%
 SMOKE	28.2%	13.4%
 HAVE HEART DISEASE	11.5%	3.8%
 HAVE DIABETES	16.3%	7.2%

Source: 2018, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

Disparities and those with ID

- The ACS-6 questions are required in all federally-funded surveys
- Do not consistently capture individuals with ID
- Inability to accurately measure disparities for different disability groups



In a statewide survey we conducted, **76% of people with I/DD** in Kansas reported being overweight or obese, compared to 63% of the general population.

Source: 2018, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

Social Determinants of Health

- **Social determinants of health (SDOH)** are economic, social and other conditions that influence differences in health status. SDOH can include, but are not limited to:
 - Economic stability
 - Community/Environment
 - Geography
 - Employment
 - Social supports
 - Housing
 - Education

- "The unequal distribution of experiences is not in any sense a 'natural' phenomenon but is the result of a toxic combination of poor social policies, unfair economic arrangements and bad politics." – World Health Organization

National Survey on Health and Disability (NSHD)

- University of Kansas portion of the NIDILRR-funded Collaborative on Health Reform and Independent Living (CHRIL)
- Longitudinal: fielded in **Spring 2018** (n=1,246) and Winter 2019/2020 (n=2,175)
- Multiple measures of disability (ACS-6, WGSS, HRMS) with our open-ended disability item allows for categorization in a variety of ways and most importantly we know which individuals have intellectual disability.
- More information on NSHD methodology:
<http://ihdps.ku.edu/collaborative-health-reform-and-independent-living-chril>

NSHD 2018 Findings

Hall & Kurth (2019). A Comparison of Health Disparities Among Americans With Intellectual Disability and/or Autism Spectrum Disorder and Americans With Other Disabilities. *Inclusion*, Vol. 7, No. 3, pp. 160-168. <https://www.aaidjournals.org/toc/inc/7/7/3>

A Comparison of Health Disparities Among Americans With Intellectual Disability and/or Autism Spectrum Disorder and Americans With Other Disabilities

Jean P. Hall and Noelle K. Kurth

Abstract

This article uses recent survey data to compare and contrast American adults with intellectual disability (ID) and/or autism spectrum disorder (ASD) and those with other disabilities with regard to overall health, access to health care, and other aspects of community participation. Although people with ID and/or ASD and others with disabilities share many issues related to poorer health and access to care compared to the general population, adults with ID and/or ASD reported different experiences and outcomes than other people with disabilities. An examination of these differences provides insights into policy changes and targeted interventions that might improve overall health and community inclusion specifically for people with ID and/or ASD.

Key Words: *intellectual disability; health care; Medicaid*

Americans with disabilities are considered a health disparity population, which means as a whole they experience poorer health and less access to care than other Americans (Krahn & Fox, 2014; Iezzoni, 2011; Peacock, Iezzoni, & Harkin, 2015). For example, the Centers for Disease Control and Prevention (CDC; 2016) noted this population experiences much higher rates of chronic diseases associated with lack of physical activity and poor nutrition. Indeed, in 2016, Americans with disabilities were much more likely to have diabetes (16.3% vs. 7.2%) or heart disease (11.9% vs. 3.8%) and to be obese (38.2% vs. 26.2%; Centers for Disease Control and Prevention [CDC], 2019a). Overall, people with disabilities were almost five times more likely to report being in fair or poor health (41.7% vs. 8.7%) and four times more likely to report ever having depression (40.3% vs. 10.1%). At the same time, Americans with disabilities were much more likely to report not seeing a doctor due to cost (25.7% vs. 10%) and not having seen a dentist in the past year (46.0% vs. 30.4%).

Based in part on these data, the CDC awarded funds to 19 states to develop and implement Disability and Health Programs (DHPs) that address health disparities among people with intellectual disability (ID) and/or mobility impairments. Reasons for these disparities are many, including discrimination, social determinants (e.g., income, education), and barriers to medical care (Iezzoni, 2011; Krahn & Fox, 2014; Krahn, Walker & Correa-DeAraujo, 2015). The DHPs across the 19 states have taken many varied approaches to addressing these underlying causes, however, all of the programs recognize that poorer health for these populations can limit opportunities for full inclusion in community participation (CDC, 2019b).

Although people with disabilities share many issues related to poorer health and access to care compared to the general population, people with ID and/or autism spectrum disorder (ASD) may have different experiences and outcomes than other people with disabilities. The purpose of this article is to examine the similarities and differences between Americans with ID and/or ASD and

Disability Type

Frequencies of Self-Reported Primary Disability Types of Survey Respondents and All Self-Reported Disability Types

Responses	n	% of Total
Primary Disability Type ^{a,b}		
Neurological	324	26.0
Physical	268	21.5
Chronic illness or disease	238	19.1
Psychiatric	193	15.5
ID or ASD	87	7.0
Sensory	74	5.9
Prefer not to answer	62	5.0
Reports more than one disability type	609	48.9
Disability Prevalence by Type (not mutually exclusive)		
Chronic disease or illness	493	39.6
Physical	417	33.5
Psychiatric	398	31.9
Neurological	382	30.7
ID or ASD	109	8.7
Sensory	107	8.6

- “What is your disability and/or chronic health condition? If you have more than one, please list your main one first.”
- Primary – listed first
- Prevalence – all conditions listed by respondent
- Categorization
- 2019/2020 data larger sample

Demographic Differences

- Those with ID were significantly more likely to:
 - be younger and male
 - have high school education only
 - have more than one disability or health condition
 - have income <138% of FPL
 - Receive SSI
- Less likely to be:
 - married
 - employed for pay full time
 - receive SSDI
- Social Determinants of Health

Group Comparisons of People With Self-Reported Intellectual Disability and/or ASD and People With Other Self-Reported Disability

Characteristic	% of ID and/or ASD Group (n = 109)	% of Other Disability Group (n = 1,075)	p-value
Demographics			
Sex, female	41.3	71.3	< .00001 ^a ***
Race, non-White	22.9	24.0	.725 ^a
Marital status, married	6.5	35.4	< .00001 ^a ***
Highest education level high school or less	46.9	11.4	< .00001 ^a ***
Mean age	32.8 years [CI: 30.6, 35.1]	45.3 years [CI: 44.6, 46.0]	< .0001 ^b ***
Employed or self-employed	50.5	59.4	.198 ^a
Full time	36.4	48.0	.026 ^a *
More than one disability type	65.1	44.3	< .00001 ^a ***
Household income level below 138% federal poverty level	51.4	31.3	< .00001 ^a ***
Received Supplemental Security Income (SSI)	43.0	14.1	< .0001 ^a ***
Received Social Security Disability Insurance (SSDI)	18.9	33.7	.002 ^a **
Received other public benefits (e.g., food stamps, childcare, TANF)	35.5	23.2	.004 ^a **
Has a usual source of medical care	90.8	87.1	.013 ^a *
Had less than \$1,000 in medical out-of-pocket costs in the last year	72.8	54.3	.012 ^a *

Health Disparities

Group Comparisons of People With Self-Reported Intellectual Disability and/or ASD and People With Other Self-Reported Disability

Characteristic	% of ID and/or ASD Group (n = 109)	% of Other Disability Group (n = 1,075)	p-value
Health Status			
Overall health status, fair or poor	28.4	40.8	.046 ^{a*}
Mean physical health days not good in last 30	6.4 days [CI: 4.6, 8.2]	9.5 days [CI: 9.8, 11.1]	< .0001 ^{b***}
Mean mental health days not good in last 30	12.3 days [CI: 10.2, 14.3]	9.5 days [CI: 8.9, 10.1]	.006 ^{b*}
Smokes/uses tobacco	11.9	14.1	.113 ^a
Insurance Coverage Type			
Has Medicaid coverage	60.4	29.8	< .0001 ^{a***}
Has Medicare coverage	23.4	33.0	.111 ^a
Has employer-sponsored health insurance	42.5	49.3	.177 ^a
Through own employment	31.8	66.0	< .00001 ^{a***}
Through a family member	65.9	29.6	< .00001 ^{a***}

Barriers to Care and Unmet Need

Characteristic	% of ID and/or ASD Group (n = 109)	% of Other Disability Group (n = 1,075)	p-value
Barriers to Care & Unmet Need			
Inadequate provider network	30.2	30.2	.993 ^a
Did not get prescription due to cost	27.2	35.1	.106 ^a
Did not see doctor due to cost	19.6	18.6	.802 ^a
Did not see specialist due to cost	31.3	34.5	.518 ^a
Did not get medical test or treatments due to cost	27.1	35.7	.089 ^a
Did not get dental care due to cost	40.6	50.2	.066 ^a
Did not get mental health treatment due to cost	36.9	39.1	.694 ^a
Did not get substance use treatment due to cost	3.2	6.3	.497 ^a
Did not get Durable Medical Equipment (DME) due to cost	29.4	45.4	.026 ^{a*}
Has paid Personal Assistance Services (PAS; among those needing PAS)	45.9	34.2	.046 ^{a*}
Refused services by a medical provider	9.2	3.0	.001 ^{a**}

Community Participation and Isolation

Group Comparisons of People With Self-Reported Intellectual Disability and/or ASD and People With Other Self-Reported Disability

Characteristic	% of ID and/or ASD Group (n = 109)	% of Other Disability Group (n = 1,075)	p-value
Community Participation			
Not satisfied with time spent on leisure activities	18.7	26.0	.027 ^{a*}
Not satisfied with current level of social activities	24.8	30.0	.499 ^a
Not satisfied with activities in the community	22.2	30.6	.383 ^a
Feel socially isolated from others and community	86.1	73.9	.040 ^{a*}

Study Limitations

- Survey conducted primarily online with telephone option
- Combining ID with ASD
- Proxy survey response: 44% for this group with 60% of proxies answering questions for the respondent

In Summary...

- Analyses of 2018 NSHD data found significant differences between people with ID and those with other disabilities in the areas of:
 - Educational level, income/employment, social supports and feelings of isolation from the community
 - Employer-sponsored health insurance themselves versus through a family member
- People with ID have a higher likelihood of not getting certain types of health care services (seeing doctors and durable medical equipment) and have significantly poorer mental health status
- While these disparities can be explained in various ways, we need to work to improve how our health care system serves people with intellectual disability and address disparities and social determinants of health.

NSHD Data Available

A limited data set (LDS) from the National Survey on Health and Disability (NSHD) is available to other researchers at no cost. The richness of the NSHD data supports many varied analyses related to health disparities, social determinants of health, insurance coverage, quality of life, and community participation of people with disabilities. We welcome data requests from other disability researchers, post-docs, graduate and doctoral students, etc. For more information about obtaining the LDS for 2018 or 2019/20 or questions about the development and fielding of the NSHD, contact Noelle Kurth, pixie@ku.edu, 785-864-7085.

Further Reading...

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Questions and Discussion

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