Evidence-based Policies that Promote Access to Health Care and Wellness

NASDDDS – AUCD/CORE

Webinar Conference

November 7, 2012

Webinar Description

The panel discussion will review findings from the national core indicator and BRFSS datasets regarding health care access and wellness for people with disabilities and how ethnicity and gender impacts health care.

The speakers will discuss policy implications to improve services that promote quality health care outcomes for people with disabilities.

Webinar Overview

- Introductions and Overview of EBP Initiative
  - Susan Havercamp and Charles Moseley
- Presentations
  - Willi Horner-Johnson, Research Assistant Professor of Public Health and Preventive Medicine, OHSU Institute on Development and Disability
  - Julie Bershadisky, Research Associate, Human Services Research Institute
- Q&A (submit questions via chat box on right side of screen)
- Evaluation Survey
  - Please complete our short survey to give us feedback

Evidence Based Policy
NASDDDS - AUCD Collaboration

- Recognizes the need to work together to identify and document research evidence in support of progressive policy and practice
- Competition for resources
- Expectations for efficiency/cost effectiveness
- Demand for data-based decisions
- Attention to the sustainability of systems
- EBP Initiative is a “natural” point of collaboration between public agencies and universities
- Desire for accessible information by all stakeholders

NASDDDS: “Evidence-Based Policy”

Evidence-Based Policy is the responsible application of best available evidence to the design and management of programs, services and supports for persons with developmental disabilities in a manner consistent with achieving greater independence, productivity, inclusion and exercise of free will for individuals and cost-effectiveness in public expenditures.

Adopted NASDDDS Research Committee, 2009

The Evidence-Based Policy Commitment

We recognize that:

- Individual policymakers do not control all aspects of policymaking, and that competing interests may impede application of the best evidence.

But we believe that:

- Individual policymakers have a responsibility to acquire, understand and interject best evidence into policy deliberations.

Because we know that:

- Failure to use the best available evidence in policymaking reduces the likelihood of benefit and increases the likelihood of detriment in services provided to people with disabilities

Two Major Parts of Evidence-Based Policy Initiative

1. <u>Identifying and Synthesizing Existing Evidence</u>:
   - Too little research is accessible to policymakers
   - Policymakers need brief authoritative summaries
   - Credible partners with research credentials
   - AUCD/NASDDD synergy

2. <u>Gathering and Analyzing Original Data</u>: *Policymakers need data that responds to current issues and is:*
   - Reliable and accessible
   - Enables comparison of programs, funding, and outcomes
   - Provides answers to complex questions (low incidence disabilities, controlling for related factors)
   - Utilizes nationally recognized datasets - AUCD/NASDDD partnership's focus NCI

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Health Care Access and Wellness for People with Disabilities

Willi Horner-Johnson, PhD

November 7, 2012

Purpose

- Present data on health and health care differences between people with and without disabilities overall
- Present data on the intersection of disability with race and ethnicity in relation to health care access

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Photo courtesy of NCPAD and FODH

Overall Differences between People with and Without Disabilities:

Data from the Behavioral Risk Factor Surveillance System

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Acknowledgements

- Eva Hawes, data analyst, Oregon Office on Disability and Health
- OODH is funded by the Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD)

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Behavioral Risk Factor Surveillance System

- Population-based telephone survey of adults (age 18 and older)
- Conducted by each U.S. state and territory
- Key source of public health data on health behaviors and health risks

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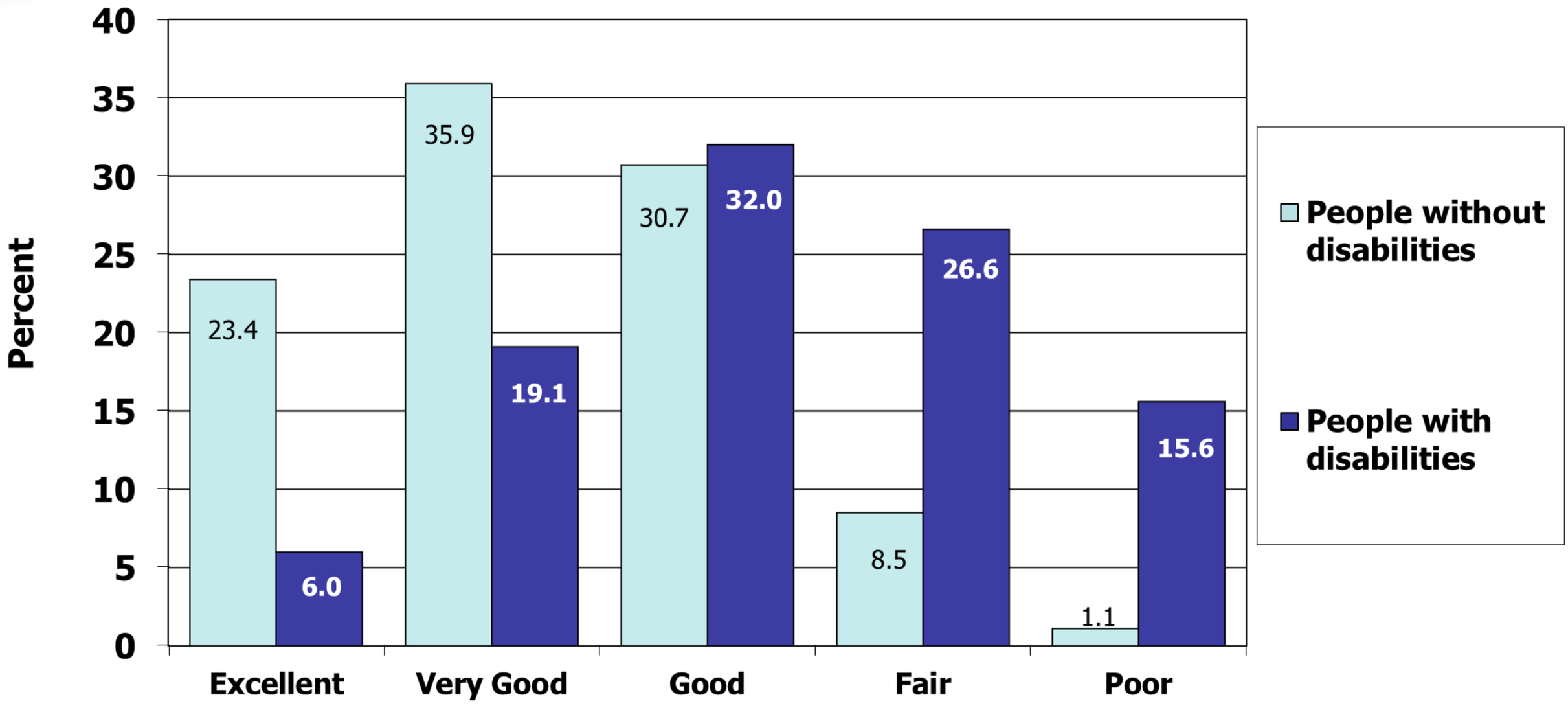
BRFSS Disability Items

- Since 2001:
  - Are you limited in any way in any activities because of physical, mental, or emotional problems?
  - Do you now have any health problem that requires you to use special equipment…?
- Transitioning to new items in 2013

General Health



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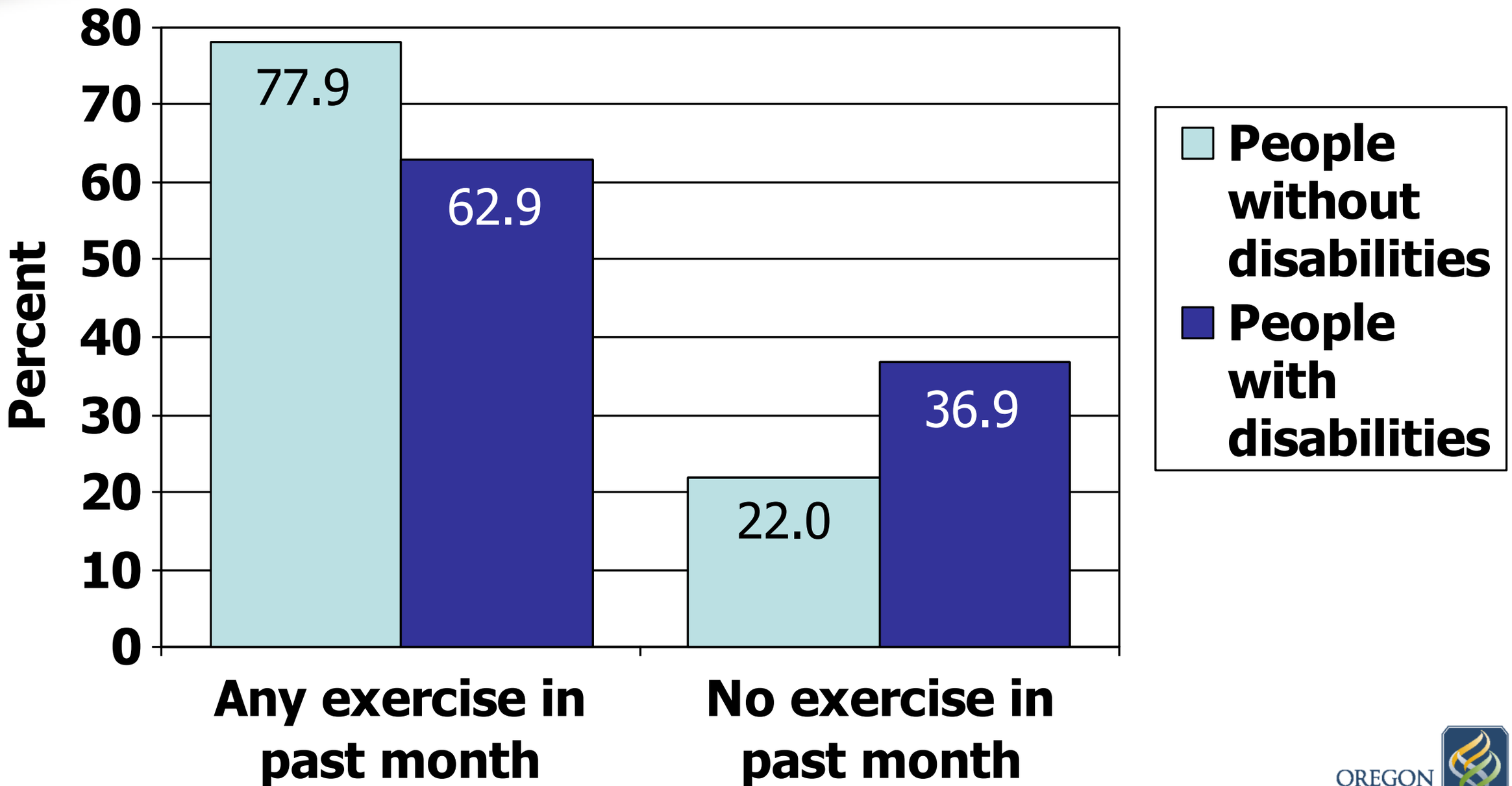
Physical Activity



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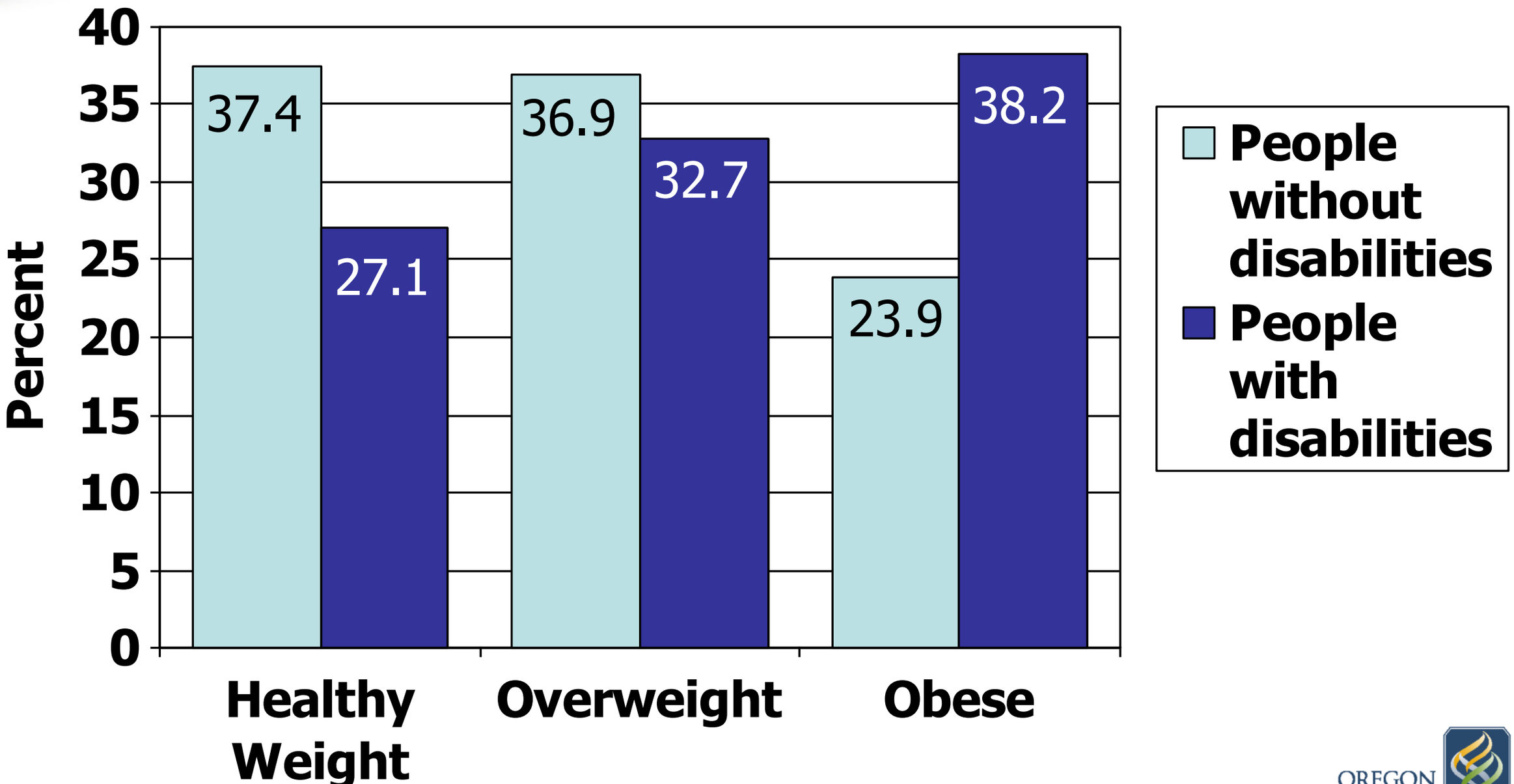
Body Mass Index



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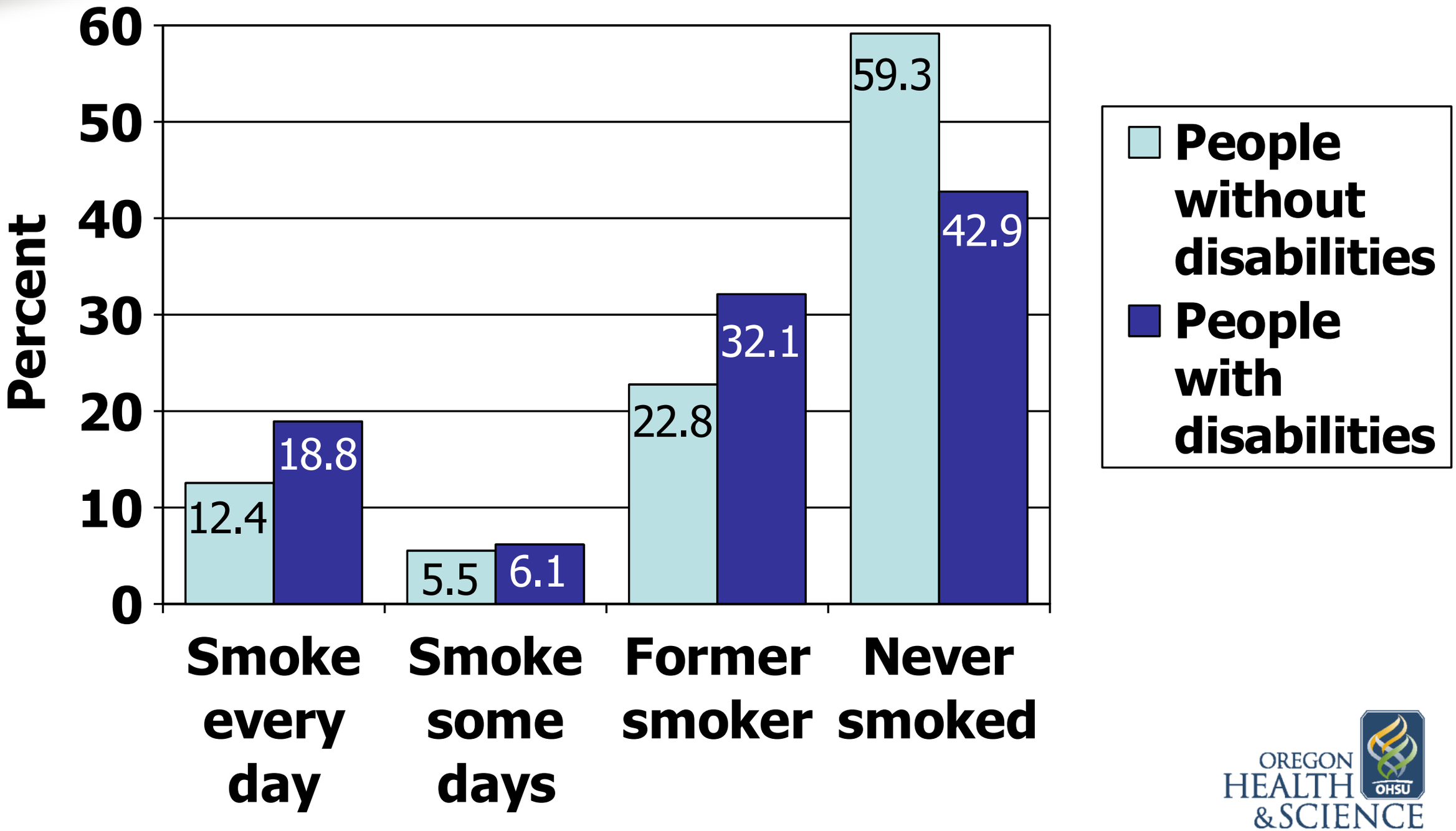
Cigarette Smoking



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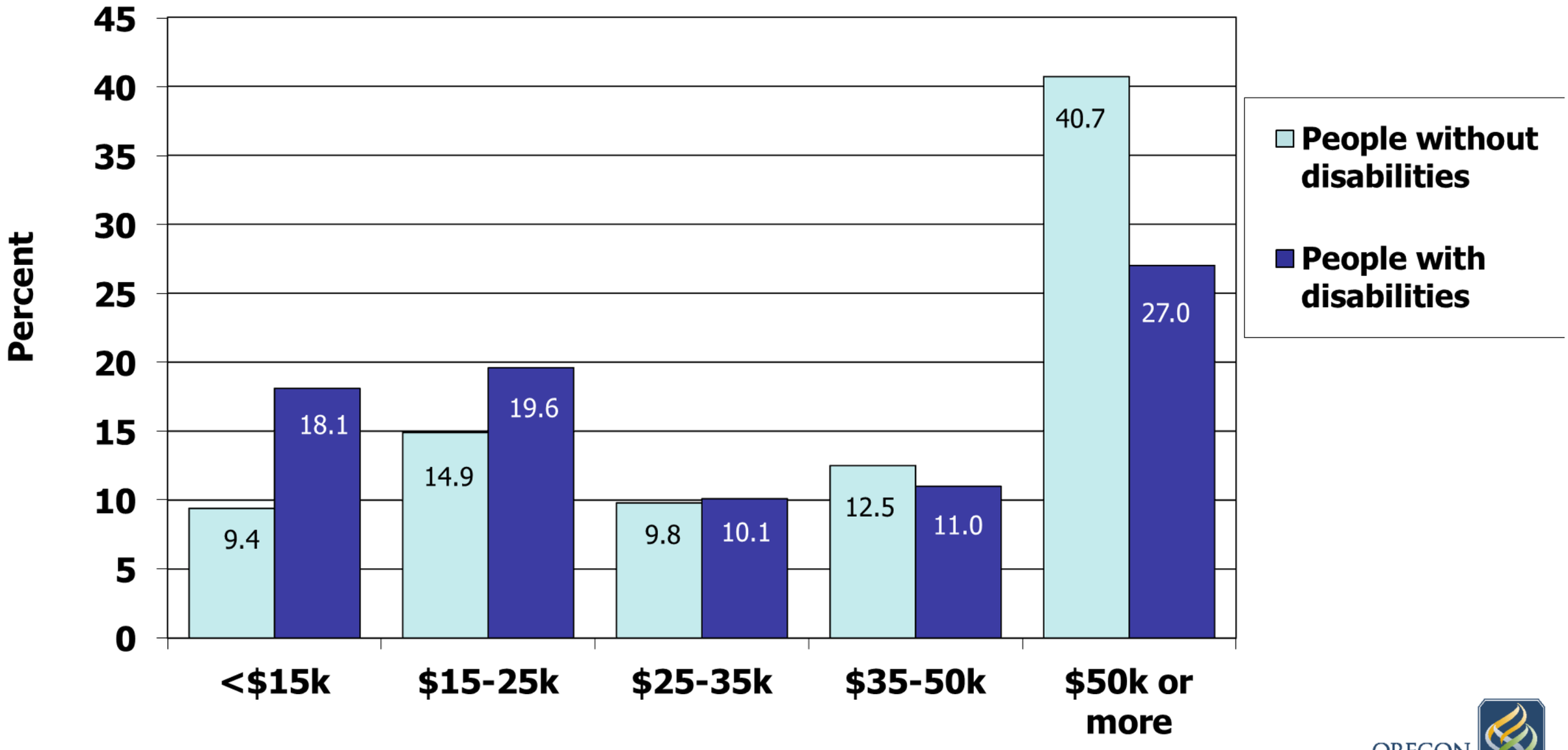
Annual Income



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Insurance and Access to Care

- People with disabilities are slightly more likely to have some type of health care insurance
  - 84.9% of people with disabilities are insured
  - 80.6% of people without disabilities are insured

Insurance and Access to Care

- However, 24.1% of people with disabilities said there was a time in the past 12 months when they needed health care but did not get it because of cost, compared to 14.3% of people without disabilities

Photo by Anna Richerby

Race, Ethnicity, and Disability: Data from the Medical Expenditure Panel Survey

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Acknowledgements

- This research is funded by the Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities (NCBDDD) under Cooperative Agreement U01DD000231 to the Association of University Centers on Disabilities (AUCD). The content of this material does not necessarily reflect the views and policies of CDC, NCBDDD nor AUCD.
- Konrad Dobbertin & Jae Chul Lee

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Medical Expenditure Panel Survey

- Nationally representative survey of health care coverage, utilization, and expenditures
- Analyzed annual data files from Household Component
- Pooled data from 2002-2008

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Sample

- Analyses focused on adults 18-64
- People with and without disabilities
- Disabilities included:
  - Physical functional limitations
  - Limitations in vision or hearing
  - Cognitive limitations
  - Use of assistive technology

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Race and ethnicity

- Coded into 6 groups:
  - Non-Hispanic White
  - Non-Hispanic Asian, Native Hawaiian, or other Pacific Islander
  - Non-Hispanic Black or African American
  - Non-Hispanic American Indian or Alaska Native (AI/AN)
  - Non-Hispanic multiple races
  - Hispanic (of any race)

Group comparisons

Three types of comparisons were made:

1) Racial and ethnic comparisons among people with disabilities: groups significantly different from whites are marked with *
2) Racial and ethnic comparisons among people without disabilities: groups significantly different from whites are marked with †

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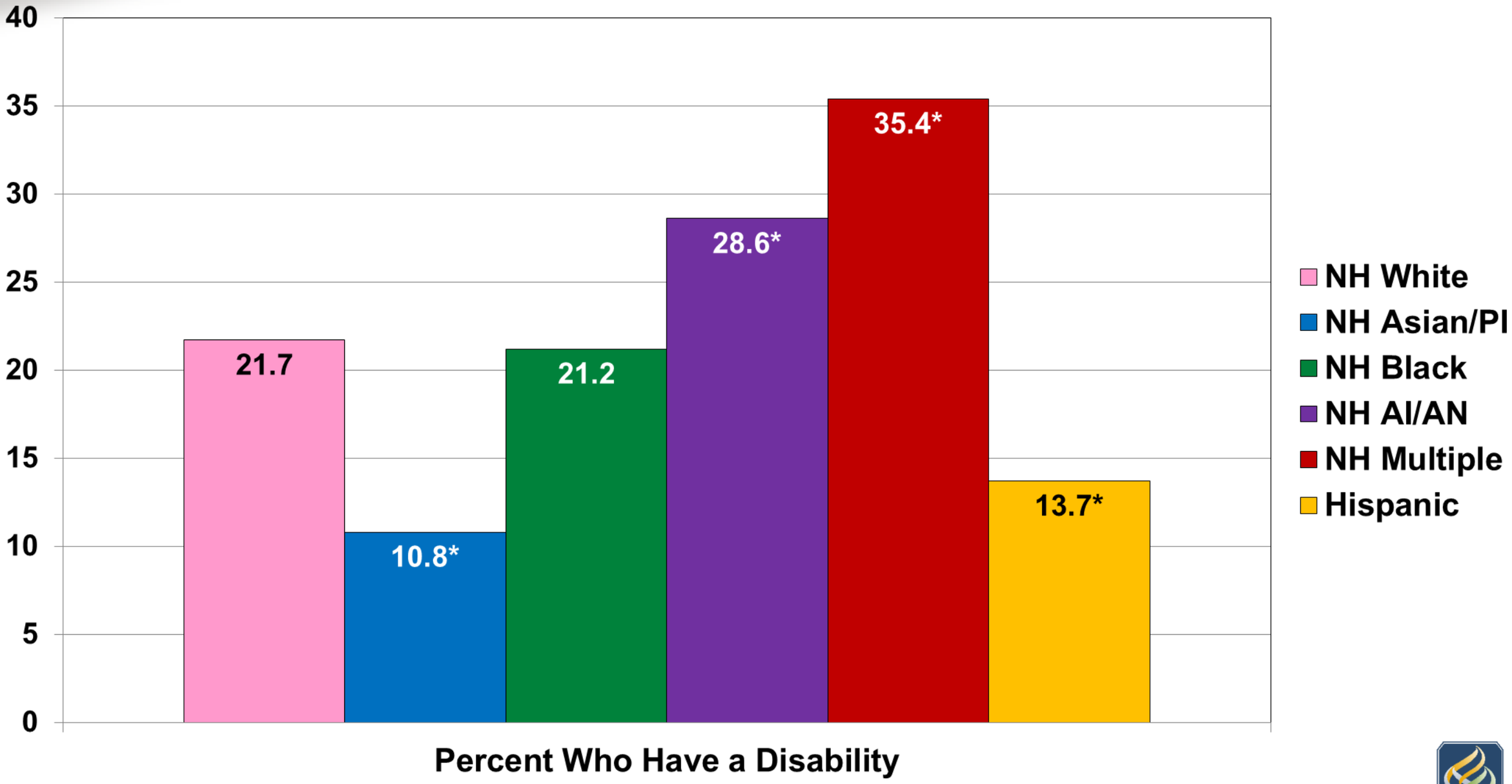
Group comparisons (continued)

3) Within each race or ethnicity, comparisons between people with and without disabilities: significant differences are marked with ☆

Disability in racial & ethnic groups



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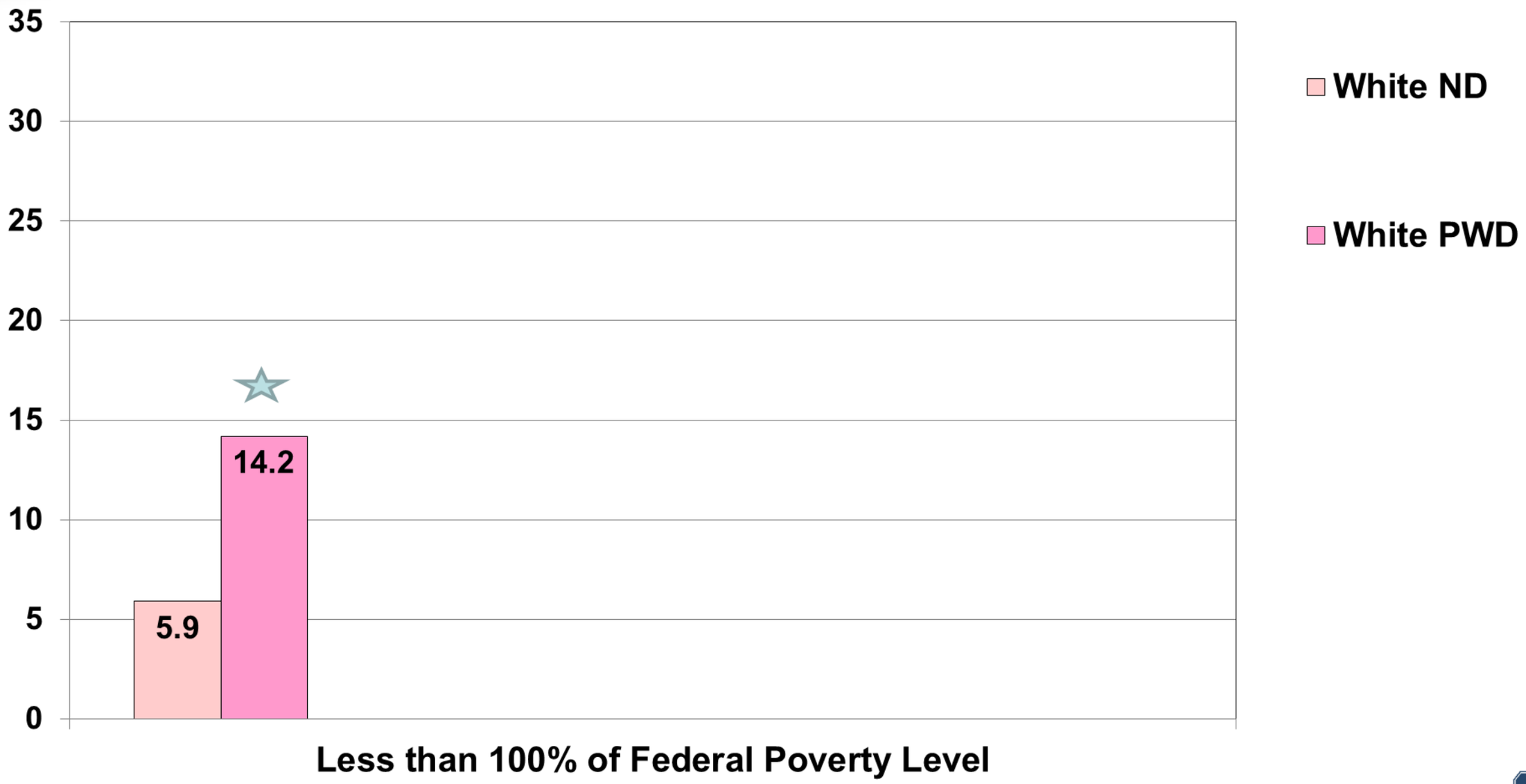
Poverty



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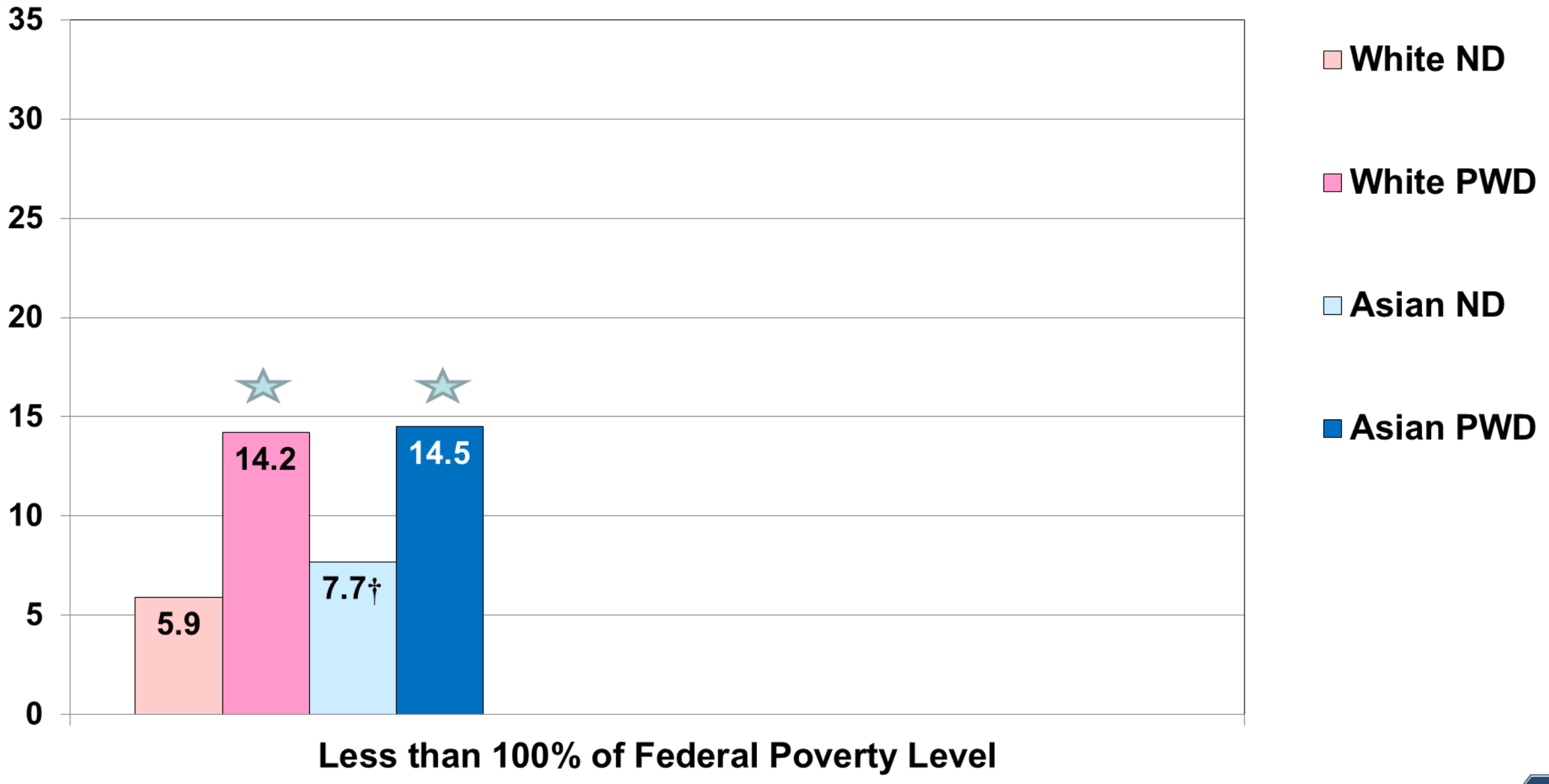
Poverty



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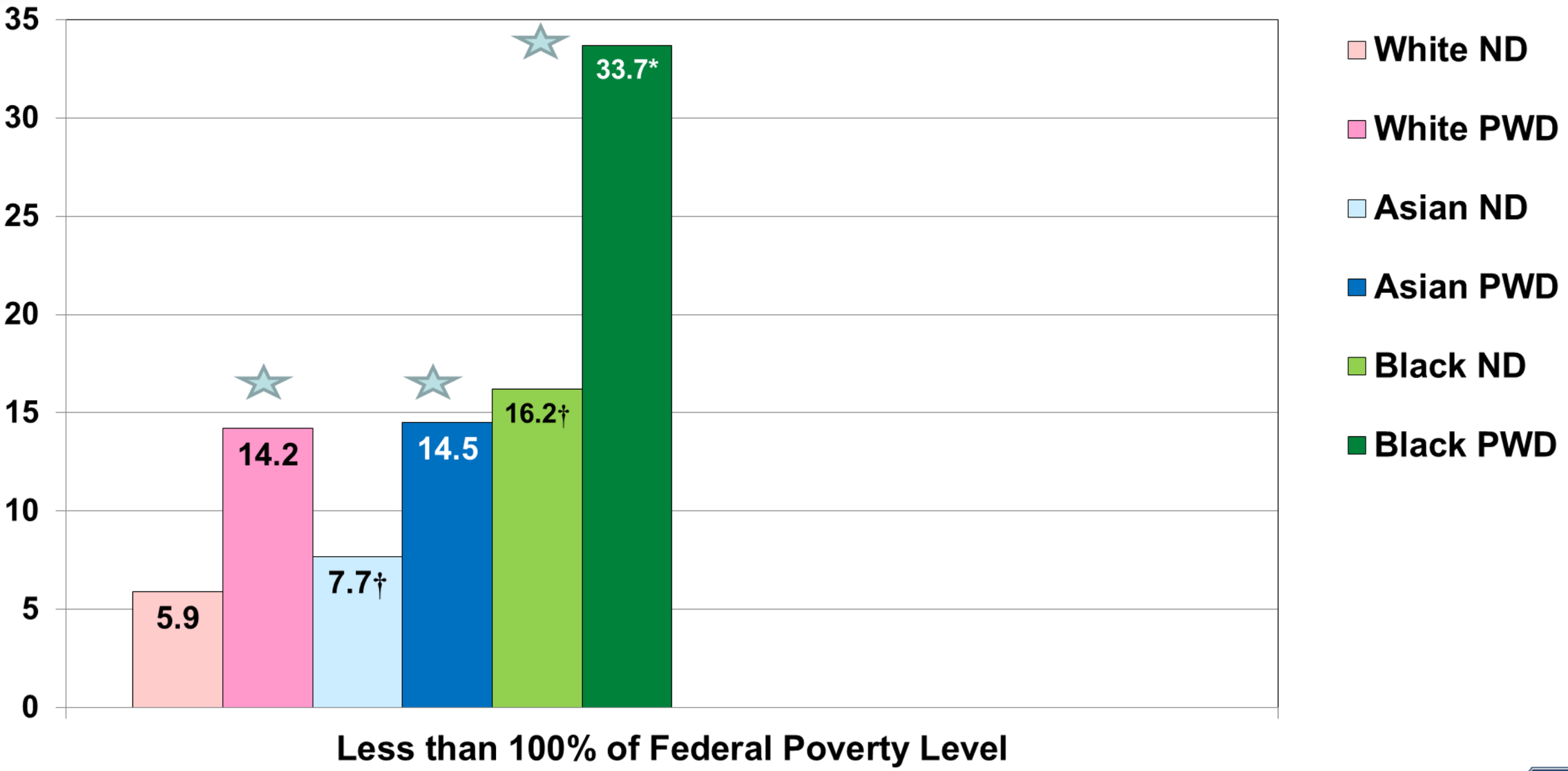
Poverty



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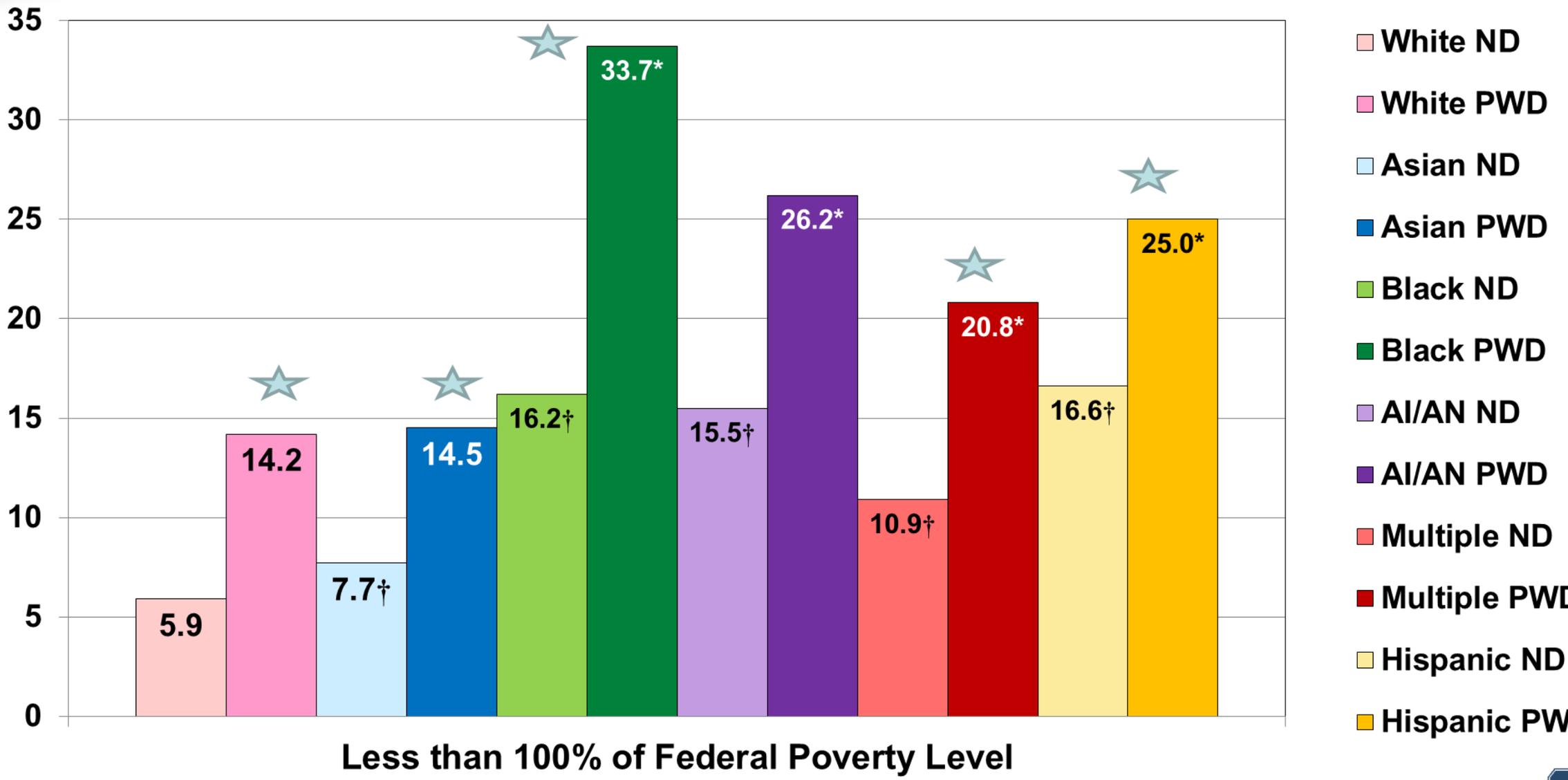
Poverty



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Access to health care

- Presence of health insurance
- For those who have insurance, what type (public or private)?
- Does person have a usual source of health care (besides ER)?

Health care insurance

- People in underserved racial and ethnic groups more likely to be uninsured all year
- People in underserved racial and ethnic groups less likely to have private insurance

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Health care insurance

- In most racial and ethnic groups, people with disabilities are no more likely to be uninsured than people without disabilities
- However, in most racial and ethnic groups, people with disabilities are significantly less likely to have private insurance

Usual source of care

- People in underserved racial and ethnic groups are less likely to have a usual source of medical care
- Within each racial and ethnic group, people with disabilities are more likely than those without disabilities to have a usual source of care

Receipt of health care

- Cancer screening
  - Mammography
  - Pap testing
  - Colorectal cancer screening
- Time in past 12 months when delayed or did not get needed health care
  - Medical, dental, or prescription

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Mammogram

- Recommended every 1-2 years for women age 40 and older (2002-2008)
- Analyzed percent who were out of compliance with this recommendation (> 2 years with no mammogram)

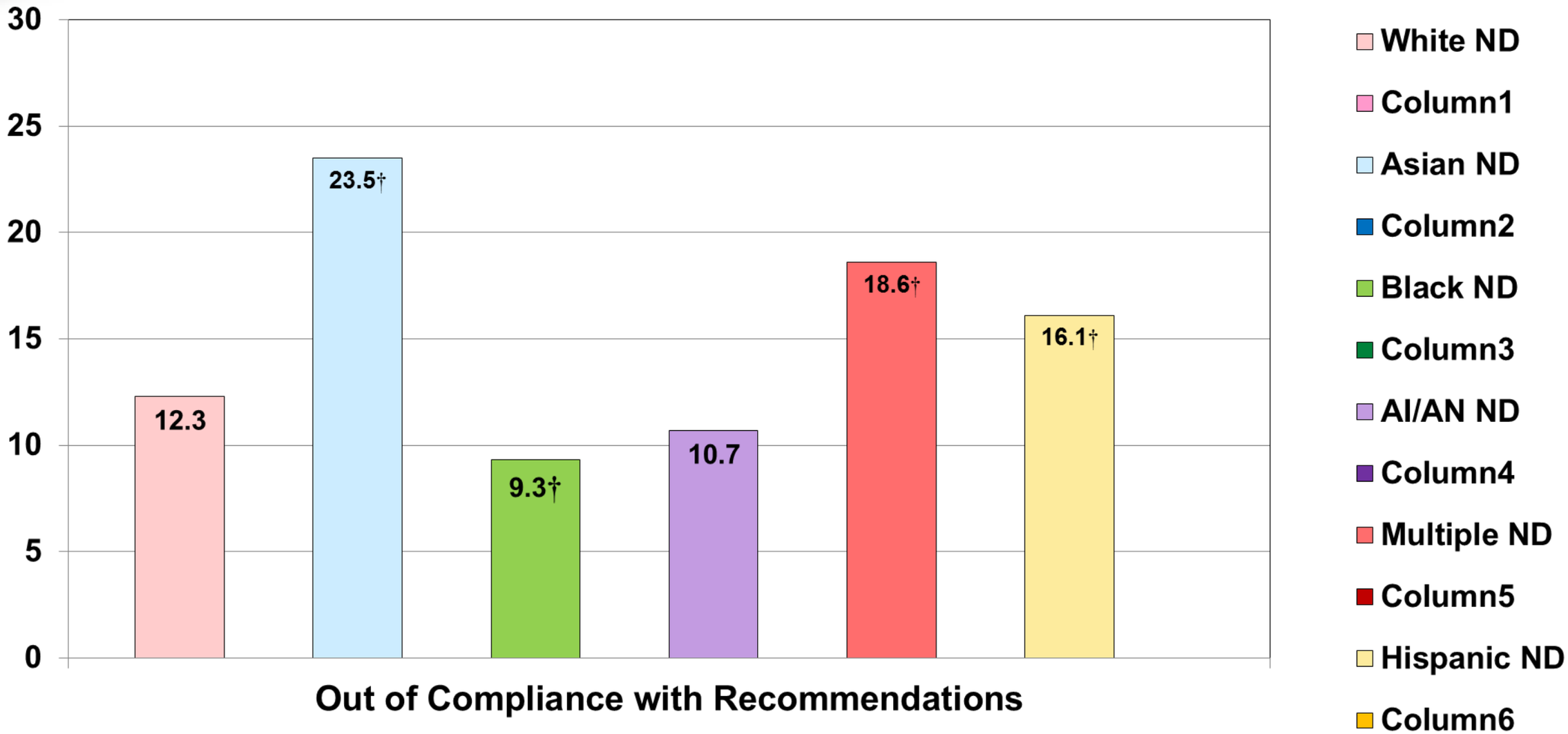
Mammogram

- Across racial and ethnic groups, women with disabilities were more likely to be out of compliance than women without disabilities
- Overall, all underserved racial and ethnic groups except Blacks were more likely to be out of compliance than Whites

Pap testing

- Recommended every 3 years for women age 18 and older
- Analyzed percent out of compliance with recommendation (> 3 years with no Pap test)

Pap testing



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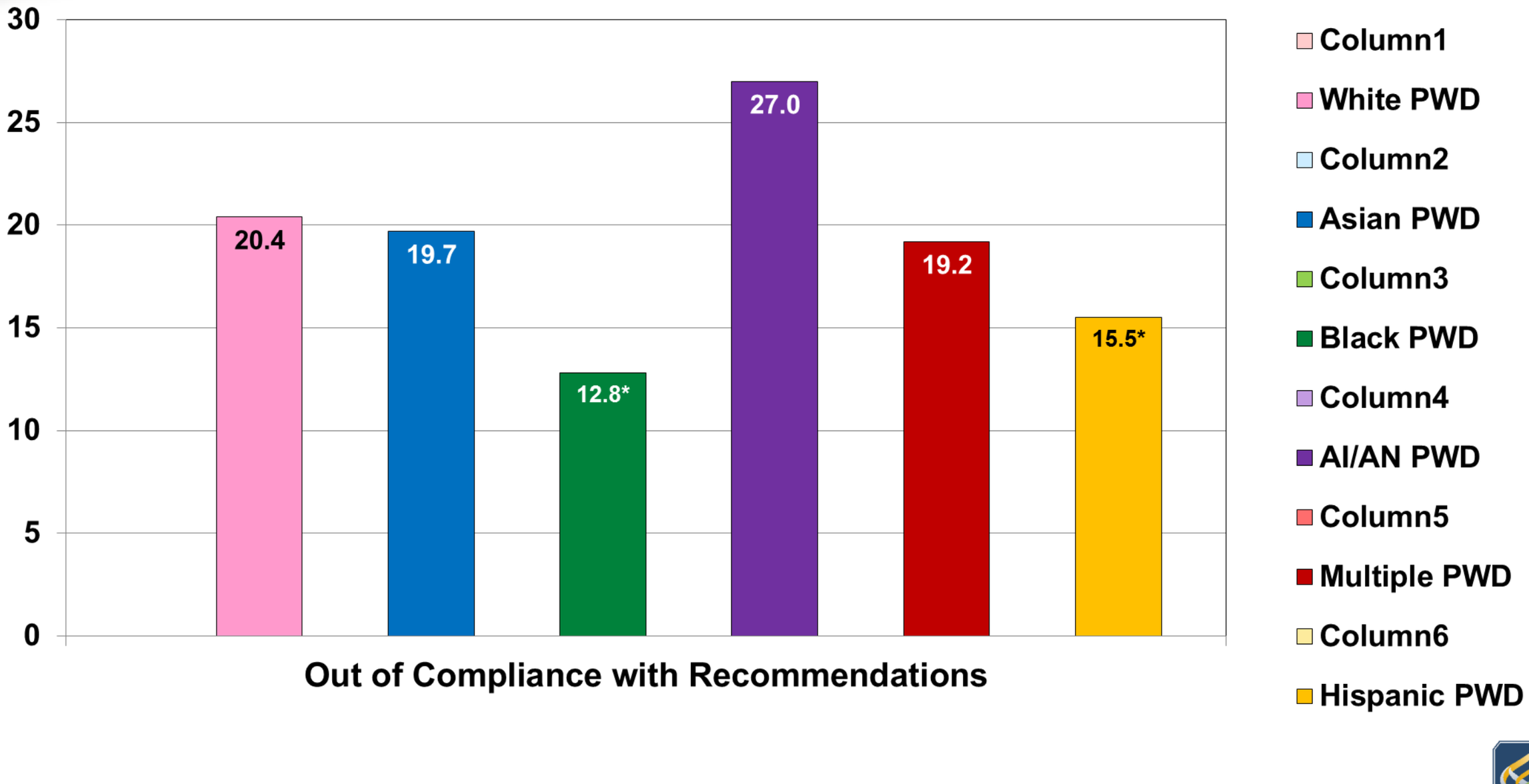
Pap testing



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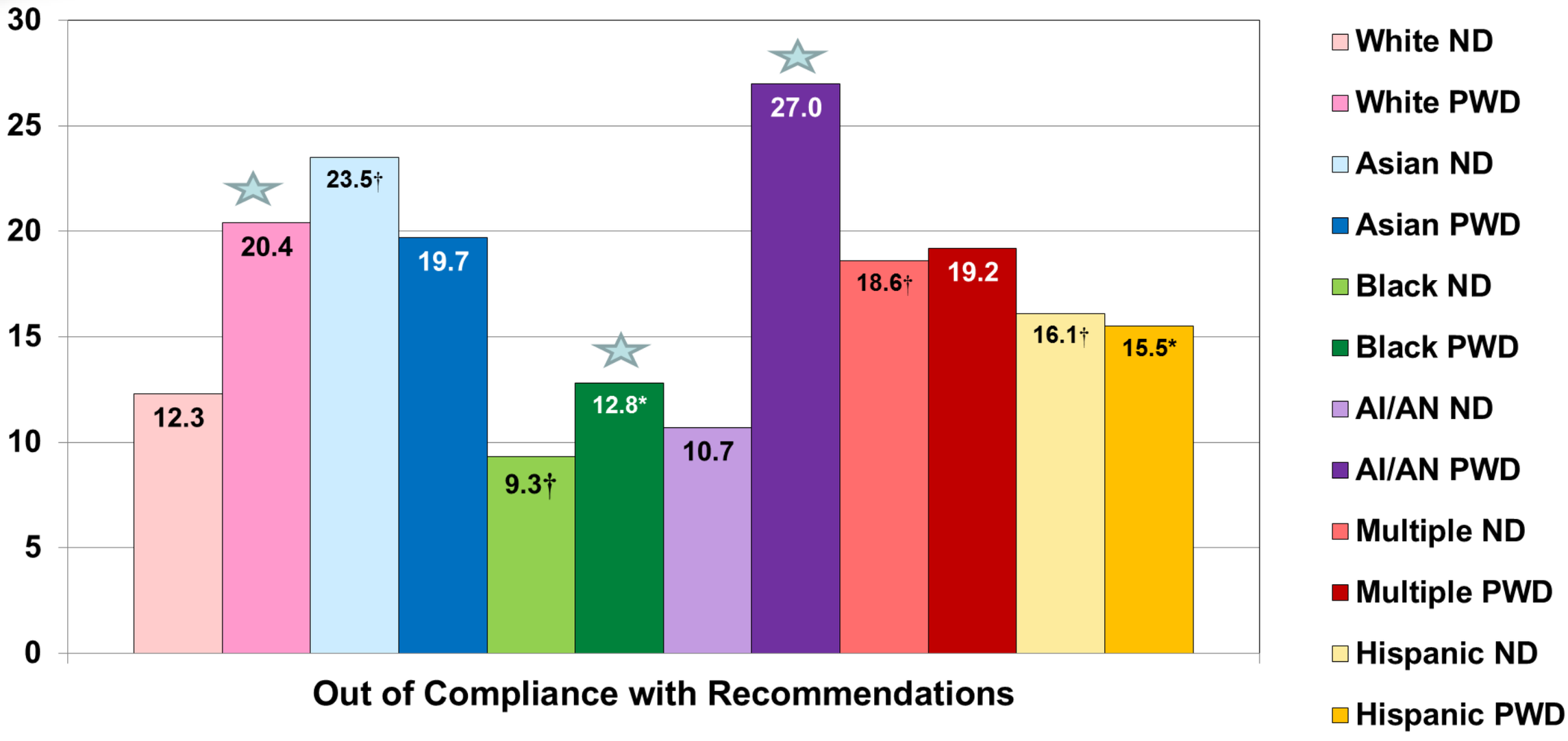
Pap testing



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Colorectal cancer screening

- Recommended for men and women age 50 and older
- Analyzed percent who had never received any type of screening (sigmoidoscopy, colonoscopy, or blood stool test)

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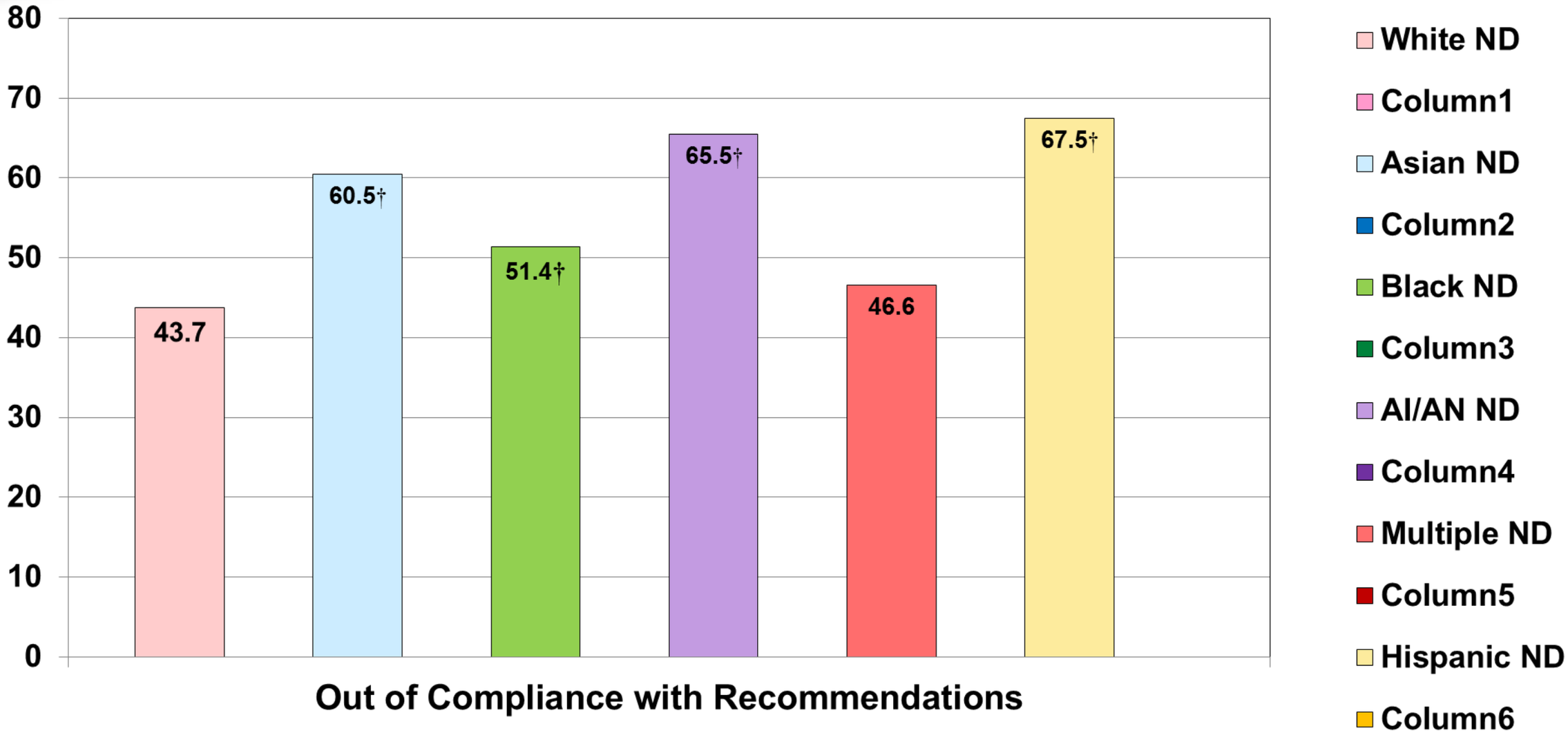
Colorectal cancer screening



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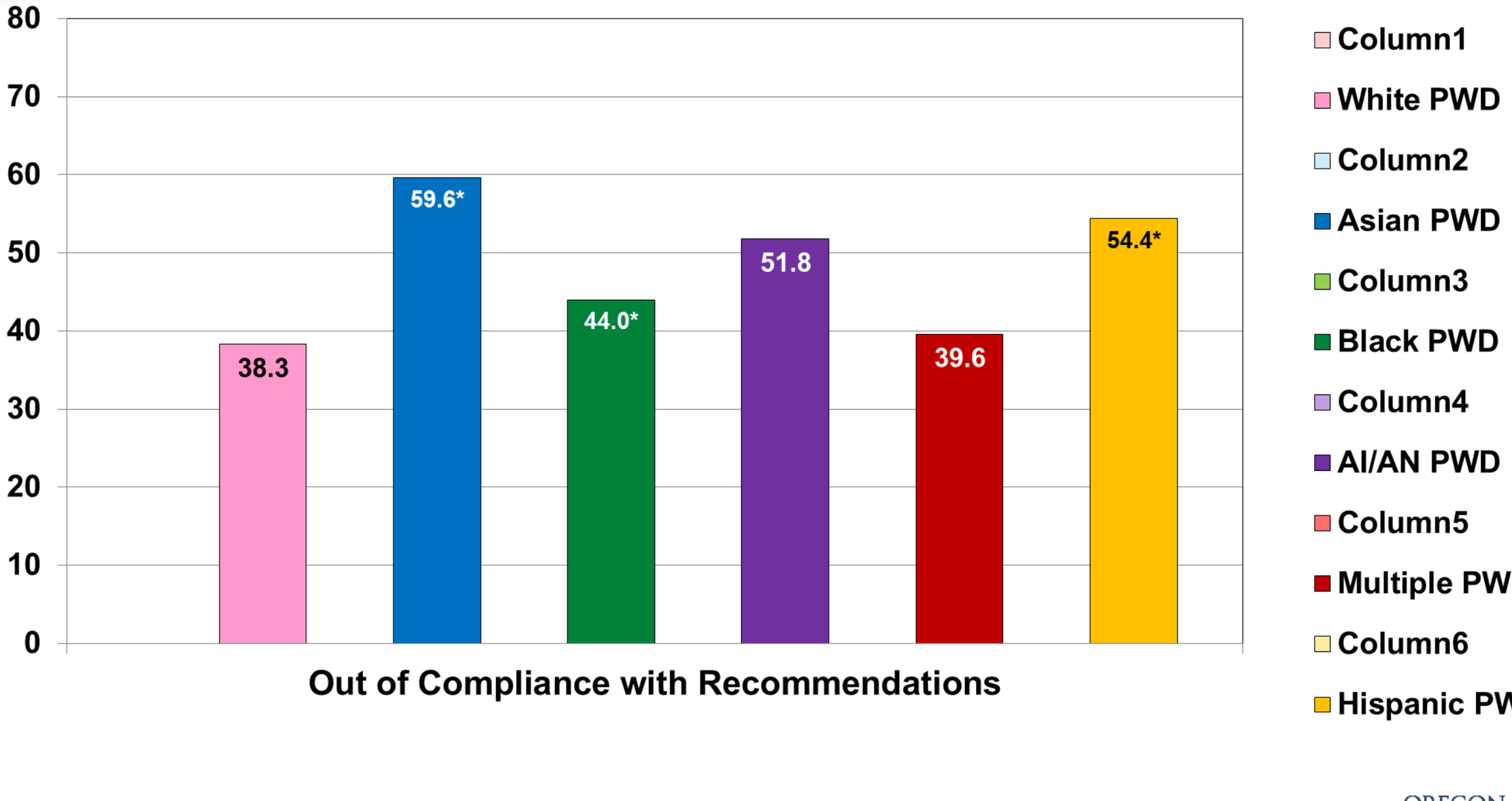
Colorectal cancer screening



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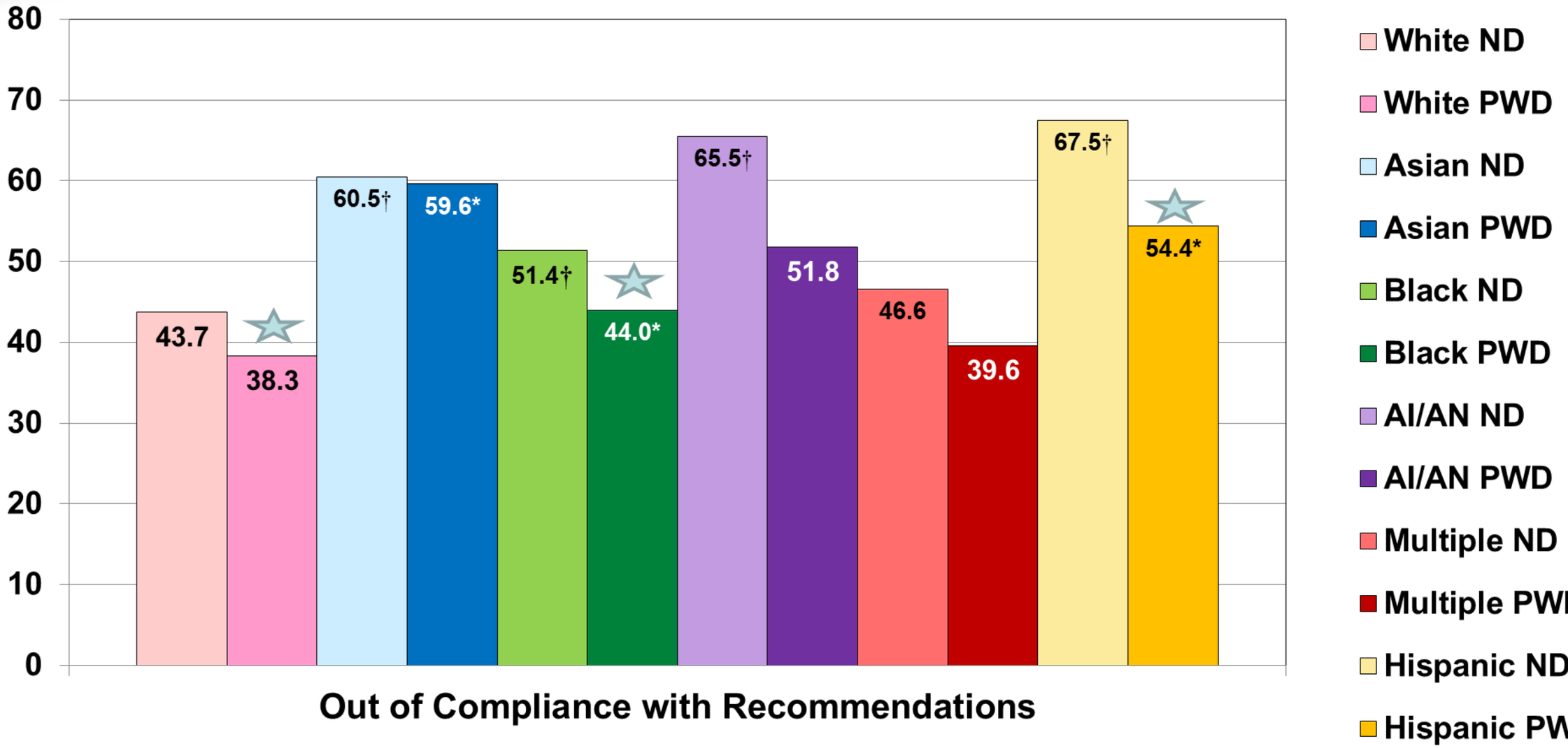
Colorectal cancer screening



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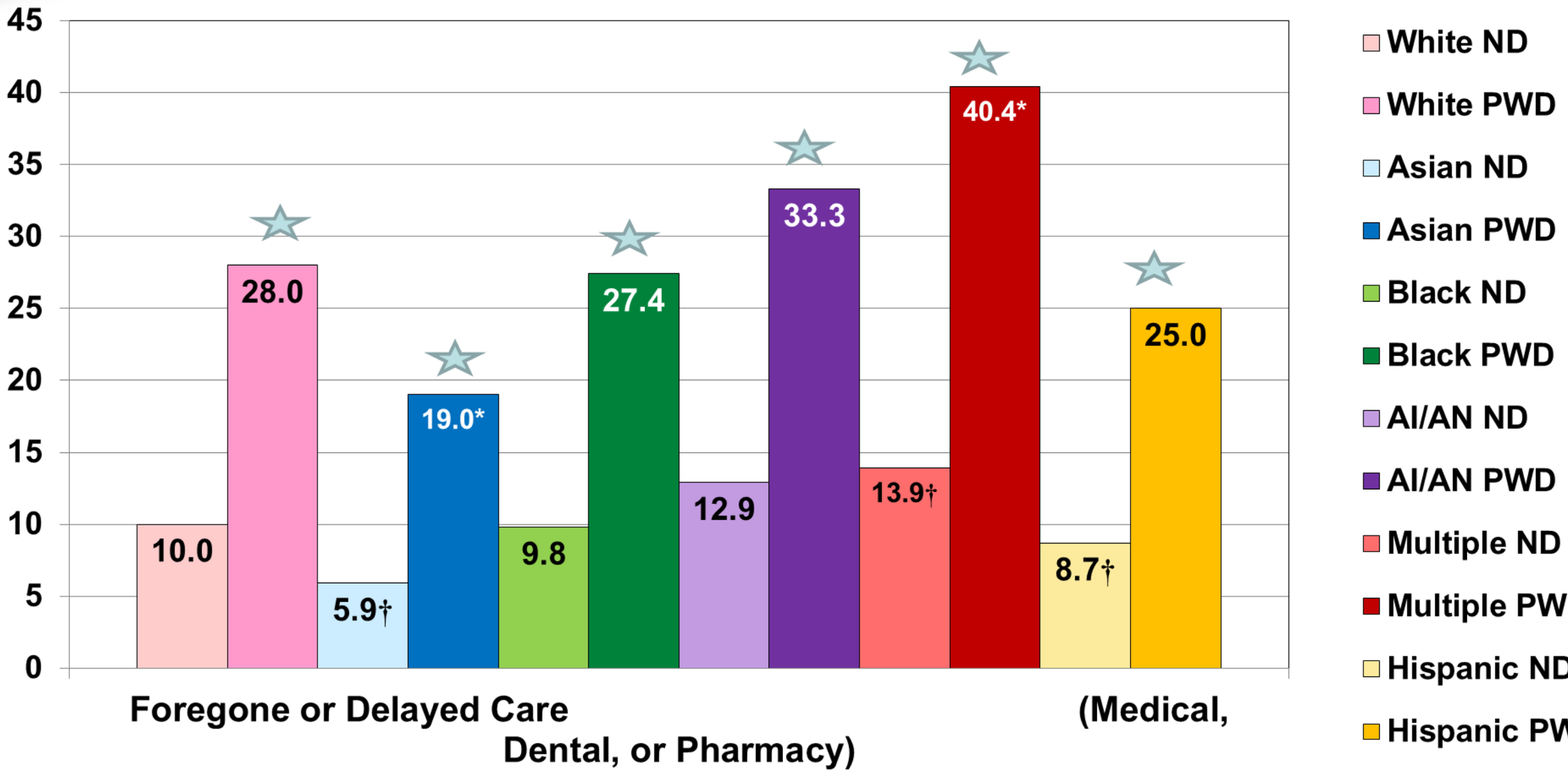
Unmet health care needs



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Summary of disparities

- Underserved racial and ethnic groups experience significant disparities in social determinants of health, access to health care, and health status
- People with disabilities experience disparities in social determinants of health, access to care, health behaviors, and health status

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Combined disparity

- Many disparities are substantially greater for people with disabilities in underserved racial or ethnic groups

Implications for Policy and Practice

- Include attention to disability in efforts to reduce racial and ethnic disparities
  - Addressing ADA accessibility issues
  - Training for health care providers
- Recognize diversity of disability population
- Overcoming cost as a barrier to health care and wellness

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NATIONAL CORE INDICATORS
NASDDDS & HSRI

Health Care and Medications in National Core Indicators Data

Julie Bershadsky, HSRI

AUCD: Evidence Based Policies that Promote Access to Health Care and Wellness

11/7/2012

WHAT IS NCI?

NASDDDS

HSRI Human Services Research Institute

Participating State DD Agencies

WHAT IS NCI?

- Multi-state collaboration of state DD agencies
- Interested in measuring how well public systems for people with developmental disabilities perform along several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 15 participating states
- Supported by participating states

WHAT IS NCI?

- Vision:
  - Establish indicators that measure the performance of ID/DD services and supports within and across states
  - Strengthen practice at the state level
  - Improve the well-being and participation of people with intellectual and developmental disabilities in community life.
  - Influence national and state policy
  - Inform strategic planning and priority setting at state and national levels

WHAT IS NCI?

- Indicators:
  - Reflective of the mission, vision and values of the field/ meaningful
  - Measurable
  - Practical to implement/ actionable
  - Reliable and valid
  - Sensitive to changes in the system
  - Representative of issues the states had some ability to influence
  - Reflective of outcomes that were important to all individuals regardless of level of disability or residential setting

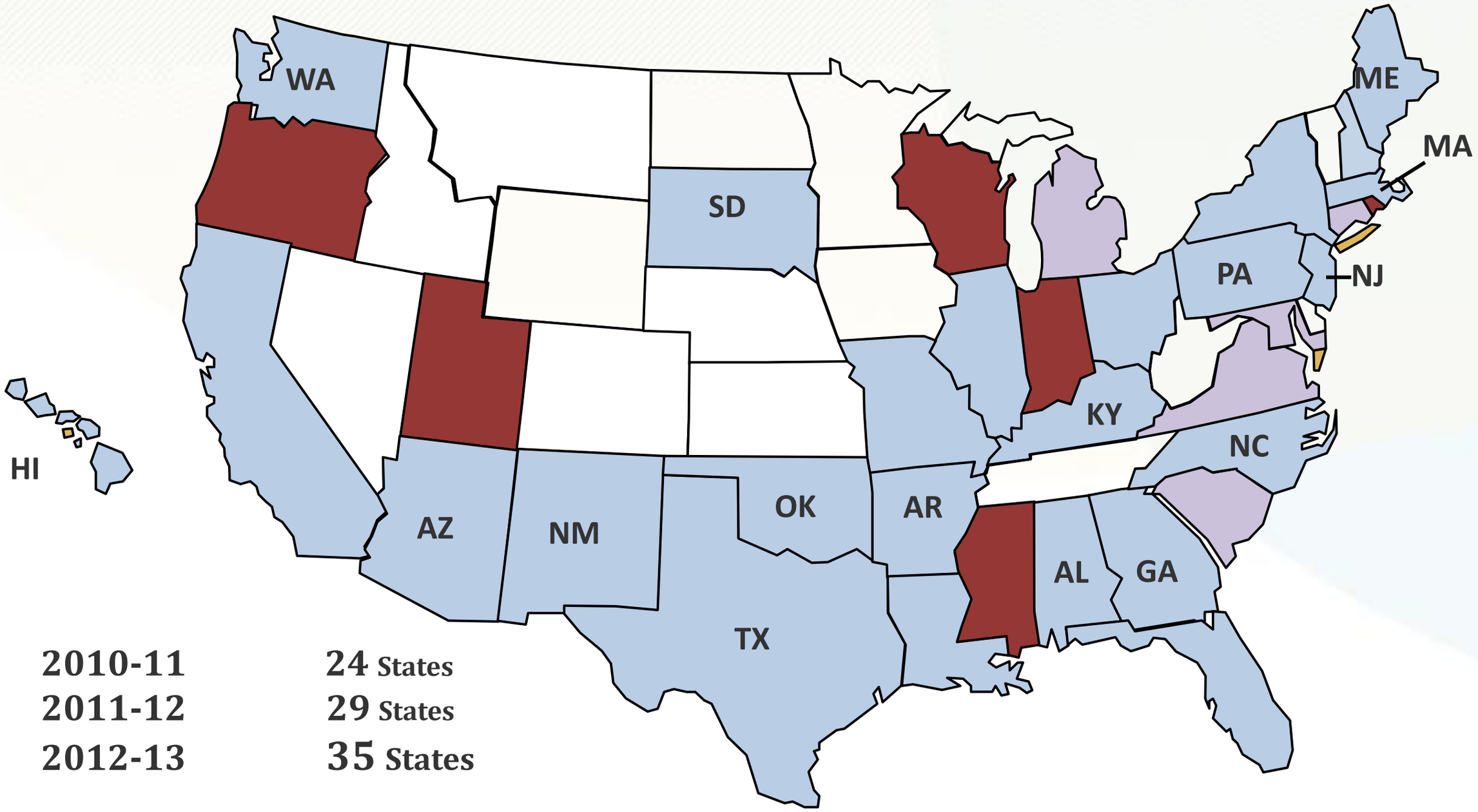
WHAT IS NCI?

Domain	Sub-Domain
Individual Outcomes	Work
	Community Inclusion
	Choice and Decision-Making
	Self-Determination
	Relationships
	Satisfaction
Family Outcomes	Information and Planning
	Choice and Control
	Access and Support Delivery
	Community Connections
	Family Involvement
	Satisfaction
	Family Outcomes

WHAT IS NCI?

Domain	Sub-Domain
Health, Welfare, and Rights	Safety
	Health
	Medications
	Wellness
	Restraints
	Respect/Rights
Staff Stability and Competence	Staff Stability
	Staff Competence
System Performance	Service Coordination
	Access

NCI, 2010-2013



WHAT IS NCI?

- Future:
  - Goal: 51 - all states participating
  - ADD Contract to expand to 51 states
  - Funding for up to 5 states / year for the next five years.
  - Stimulus grants to encourage participation

WHAT IS NCI?

- Adult Consumer Survey

- Family Survey
  - Adult Family Survey (person lives at home; 18 and older)
  - Family Guardian Survey (person lives out-of-home; 18 and older)
  - Children Family Survey (child lives at home; under 18 years old)

- Provider Survey
  - Staff Stability

- System Data
  - Mortality
  - Incidents

WHAT IS NCI?

Adult Consumer Survey

- Standardized, face-to-face interview with a sample of individuals receiving services
- No pre-screening procedures
- Conducted with adults only (18 and over) receiving at least one service besides case management
- Takes 50 minutes on average
- Background section filled out by case managers and workers

Adult Consumer Survey

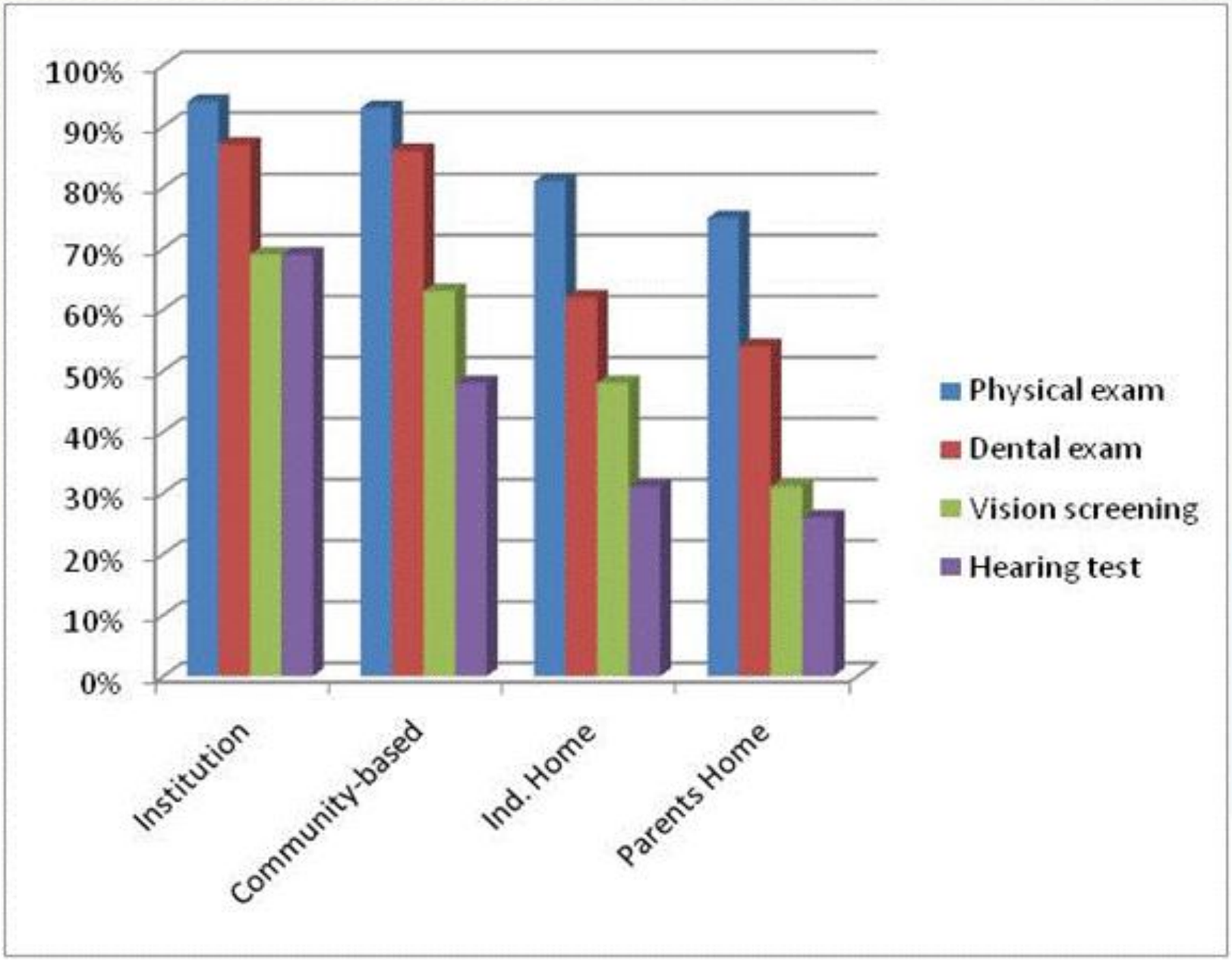
- Tested for
  - Validity
    - Face
    - Content
    - Discriminant
  - Reliability
    - Inter-rater
    - Test-retest
- Training materials/ training interviewers

Adult Consumer Survey

- Background Section
  - Demographic information
  - Preventive health care, medications
  - Filled out by cases managers, etc
- Section 1
  - Subjective
  - No proxies allowed
- Section 2
  - Less subjective
  - Proxies allowed

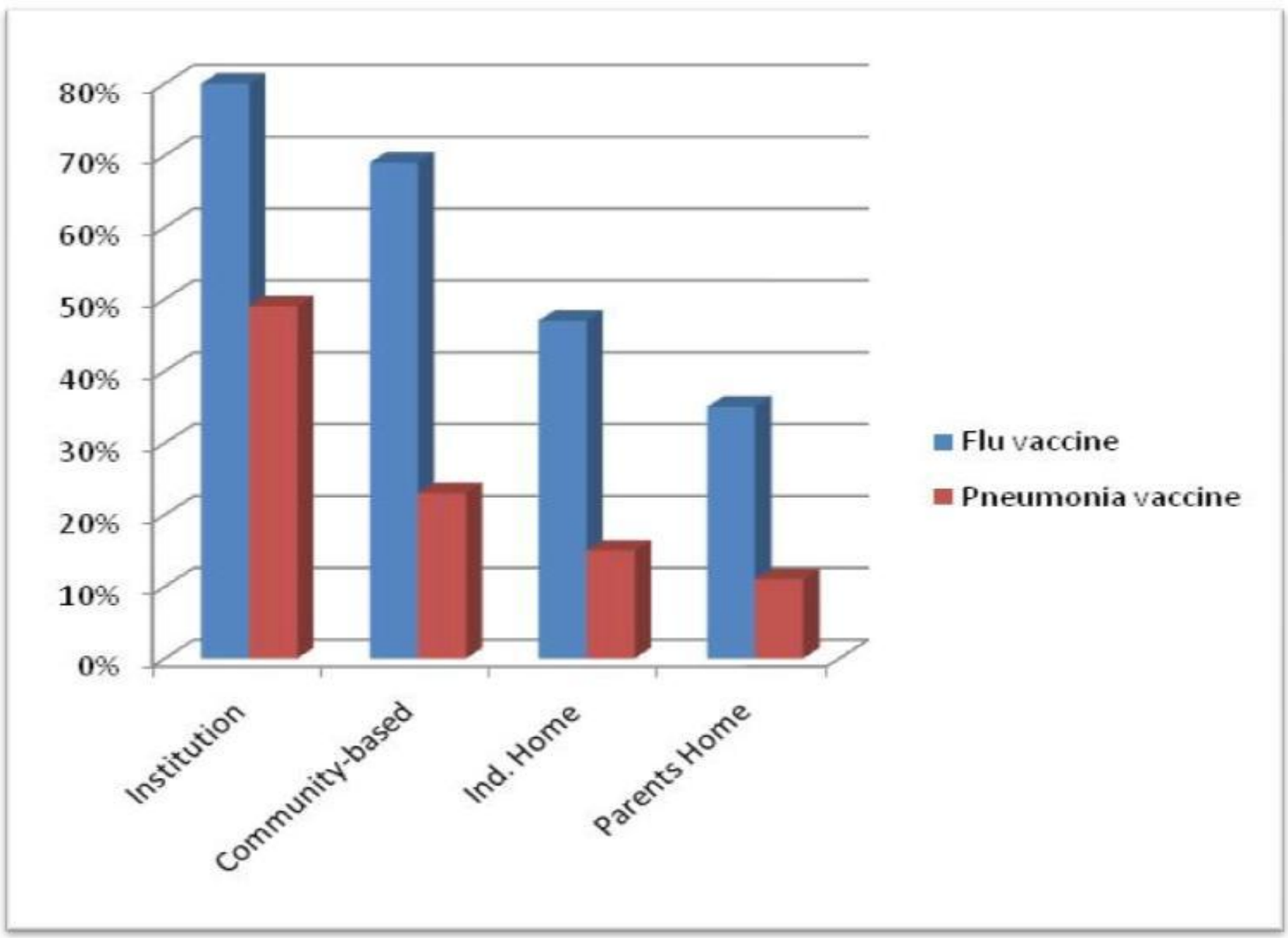
Health Care in NCI
Basic Exams and Screenings

- Higher percentages in provider-based settings
- Lowest for people living in parent/relative home
- Similar trend across indicators

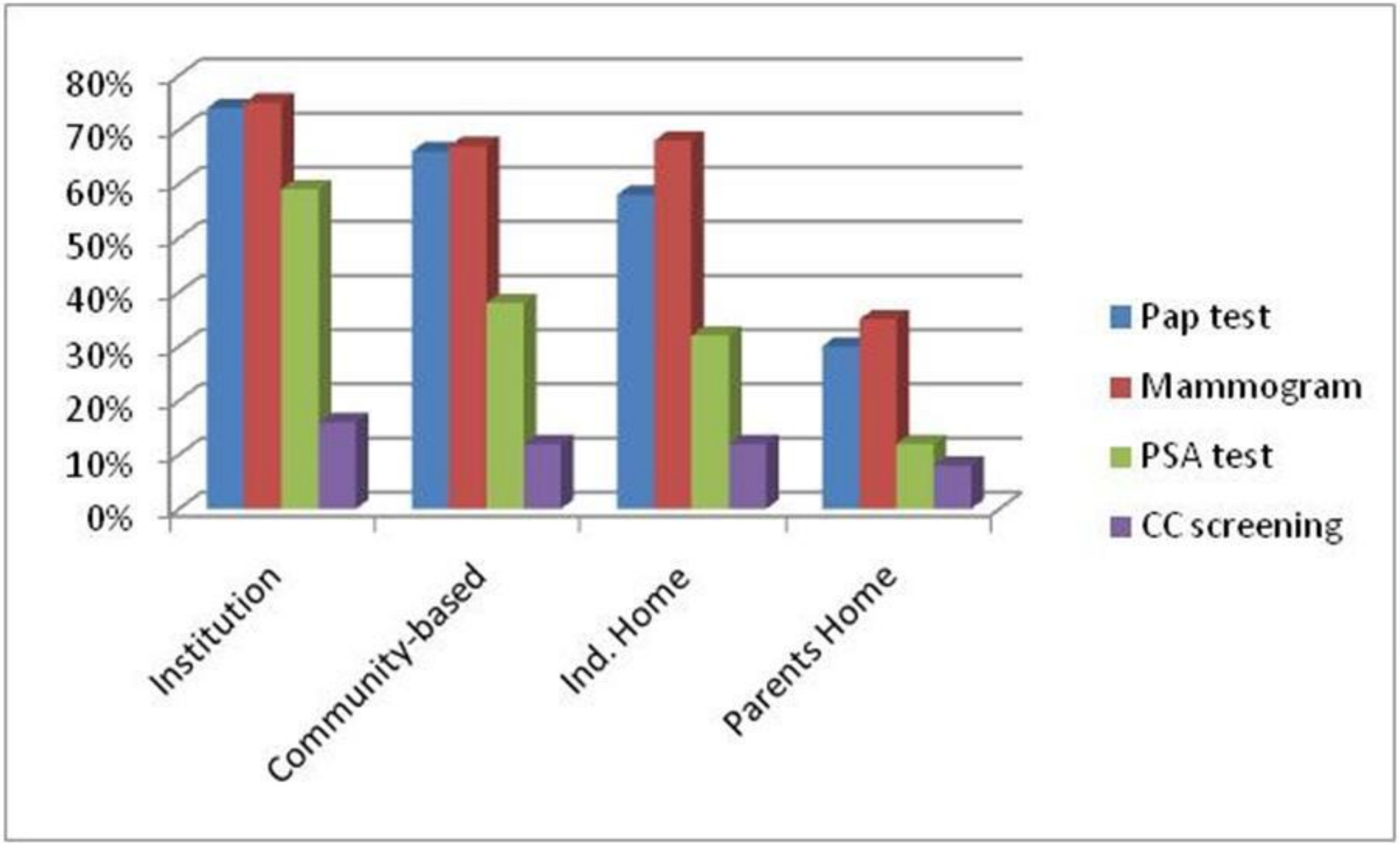


Health Care in NCI

Vaccinations



Health Care in NCI
Cancer Screenings



Health Care in NCI

Controlling for demographics and disability

	Phys exam	Dental exam	Vision screen	Hear test	Flu vacc	Pneum vacc	Pap test	Mamm	PSA test	CC screen
Institution	3.0*	7.8*	5.1*	8.8*	8.3*	2.9*	8.3*	9.2*	9.1*	2.4*
Community-based	3.7*	6.0*	3.7*	3.5*	3.6*	1.4*	4.7*	4.1*	4.6*	1.8
Independent home/apt	1.3	1.4*	1.5*	1.3*	1.3*	0.9	2.7*	2.3*	1.9	1.6
Parents/ relatives	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Mobility – self	0.5*	0.7	1.1	0.7*	0.5*	0.4*	1.4	1.0	1.1	0.9
Mobility – w/ aids	0.8	0.8	1.2	0.8	0.6*	0.6*	0.9	1.0	1.3	1.3
Not mobile	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Mental illness	1.2	1.1	1.1	1.2*	1.1	1.0	1.3*	1.1	1.1	1.1
Support for behavior	1.1	1.2*	1.0	1.1	1.1	1.0	1.0	1.2	1.4	1.0
Health – excellent	0.9	1.7*	0.9	1.2	1.2	0.7*	1.8*	2.1*	1.1	0.8
Health – fair	0.8	1.3	0.8	1.1	1.2	0.7	1.6	1.8*	1.1	1.0
Health – poor	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Express – spoken	0.9	1.0	1.2	1.0	0.9	0.9	1.2	1.0	0.9	1.3
MR – none	0.4*	0.7	0.9	0.7	0.6	1.1	1.1	1.2	1.0	0.5
MR – mild	0.7	0.9	1.2	0.8	0.8	0.6*	1.4	1.9*	1.0	0.9
MR – moderate	0.9	1.0	1.1	1.0	0.9	0.7*	0.9	1.5	1.0	0.8
MR – severe	0.8	1.0	1.0	0.9	1.0	0.8	0.8	1.0	1.3	0.9
MR – profound	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref	Ref
Age	1.01	1.00	1.01*	1.00	1.02*	1.03*	1.01	1.0	1.0	1.00

Health Care in NCI

- People living in parent/relative homes and independent homes/apartments have consistently lower odds of receiving procedures
- Disability does affect the odds of getting procedures, but not necessarily in direction expected – those with fewer/lower disabilities often have lower odds of getting them (e.g., mobility). Exception – screenings for cancer.
- Even after disability is taken into account, differences by residence type hold – lowest odds for those living with parents or on their own, followed by those living in community-based settings and institutions

Health Care in NCI

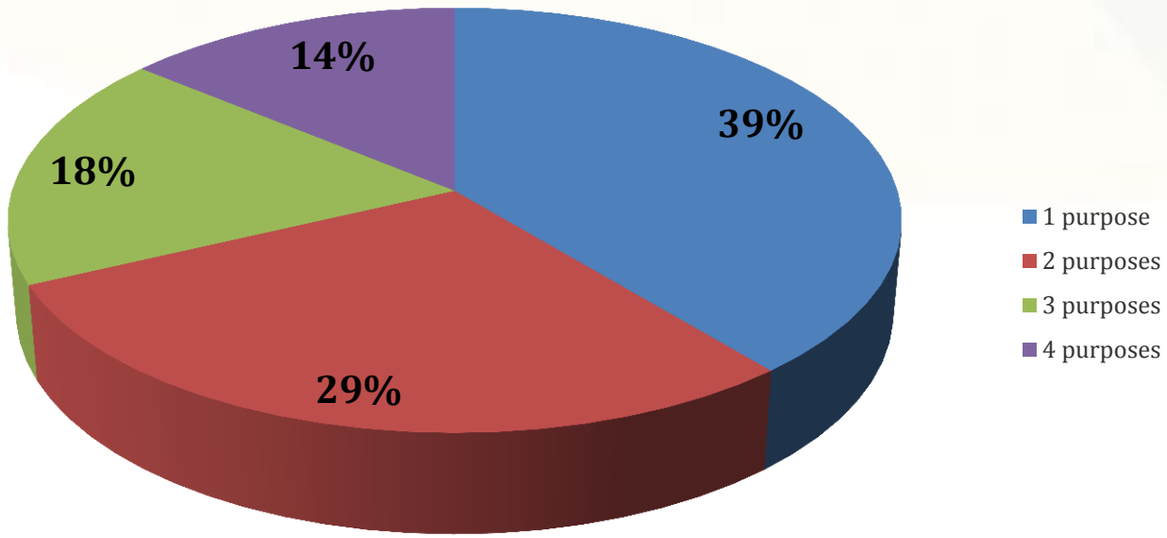
- **Limitations…**
  - Choice is not taken into account - what if person does not want to get a specific test?
  - Data less available in independent/family home settings
  - Standards used are for general population, recommendations are different for ID/DD population
- Data suggest policy-makers should strengthen efforts to improve preventive health care access for people living at home with family and those living independently
- Increase awareness/education efforts
- Ensure that people transitioning from institution to community-based settings maintain access to care

Medications in NCI

- Takes medications for ***mood disorders***: **38%**
- Takes medications for ***anxiety***: **29%**
- Takes medications for ***behavior problems***: **25%**
- Takes medications for ***psychotic disorders***: **18%**
- Takes medications for ***at least one of the above***: **53%**

Medications in NCI

- Of those who take medications for ***at least one*** condition/purpose, how many take meds for 1, 2, 3 and all 4 of them?



Note: this is not the same as the number of medications taken. A person may take one medication for more than one purpose/condition.

Medications in NCI

Medications and mental illness

		Meds for behavior problems		
		No meds	Meds	
Support needed for behavior problems	No	92%	8%	100%
	Yes	51%	49%	100%

8% of people who **did not need** support for behavior problems **were taking meds** for behavior problems

30% of people **w/o** a Mental Illness or a Psychiatric diagnosis **were taking meds** for mood/anxiety/ psychotic disorders

		Meds for mood/ anxiety/ psychotic		
		No meds	Meds	
Mental Illness/ Psychiatric Diagnosis	No	70%	30%	100%
	Yes	12%	88%	100%

Meds for mood or anxiety disorder are more common w/o an MI dx than meds for psychotic disorder

Medications in NCI

Medications and mental illness

		Meds for behavior problems	
		No meds	Meds
Support needed for behavior problems	No	71%	18%
	Yes	29%	82%
		100%	100%

18% of people who **were** taking meds for behavior problems **did not need support** for behavior problems

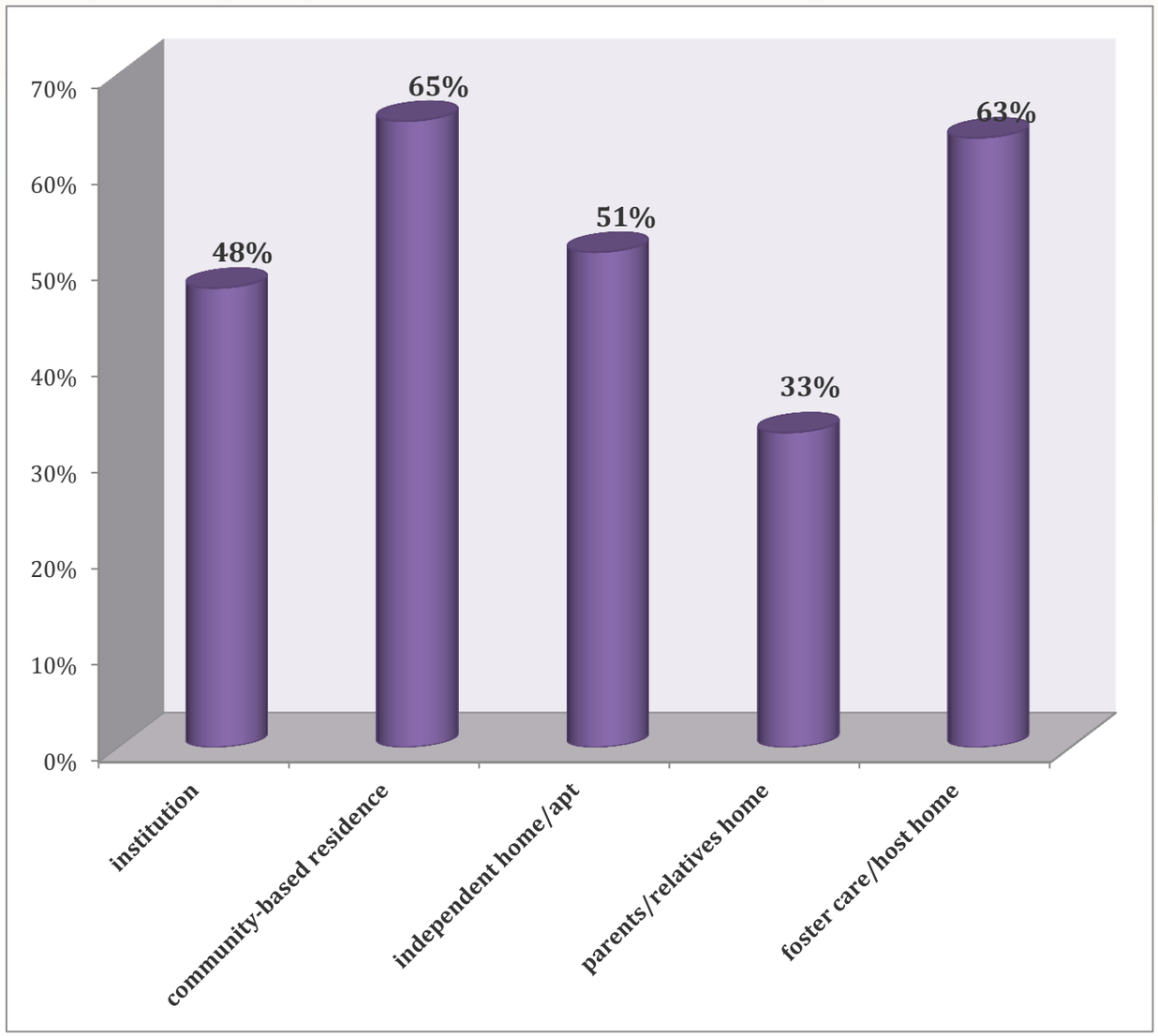
41% of people who **were** taking meds for mood/ anxiety/psychotic disorders **did not have** a Mental Illness or Psychiatric diagnosis

		Meds for mood/ anxiety/ psychotic	
		No meds	Meds
Mental Illness/ Psychiatric Diagnosis	No	92%	41%
	Yes	8%	59%
		100%	100%

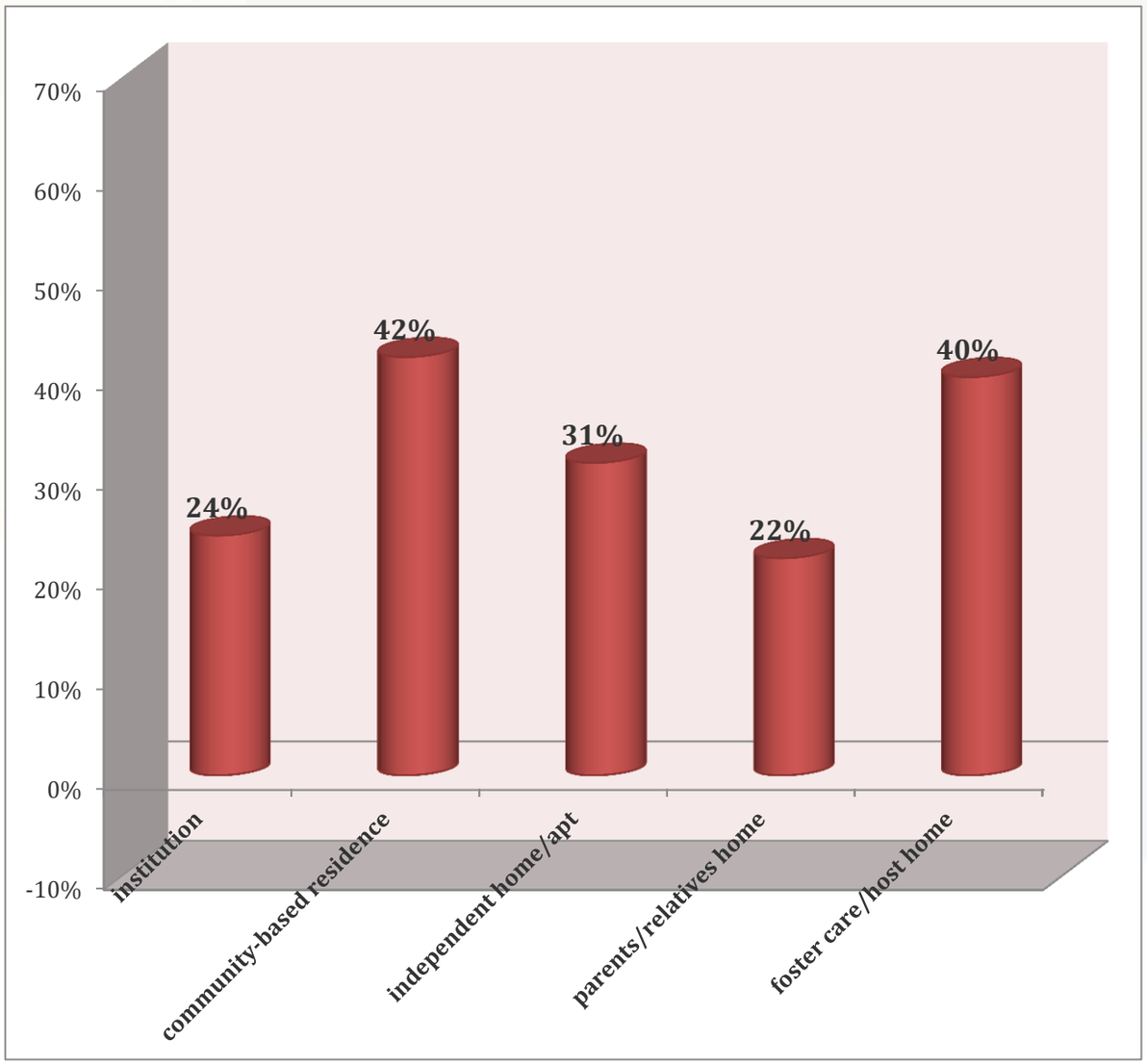
Medications in NCI

Medications and mental illness

Takes at least one psych med

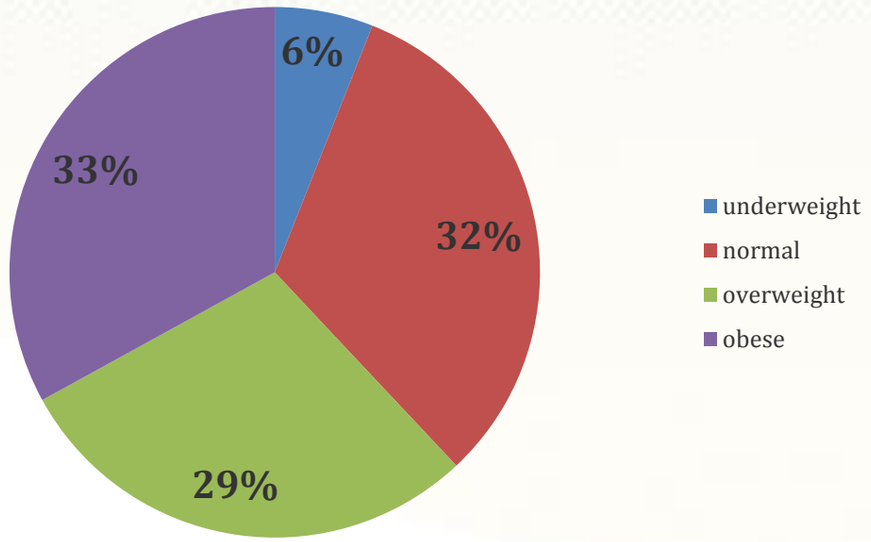


Takes at least one psych med w/o dx of MI



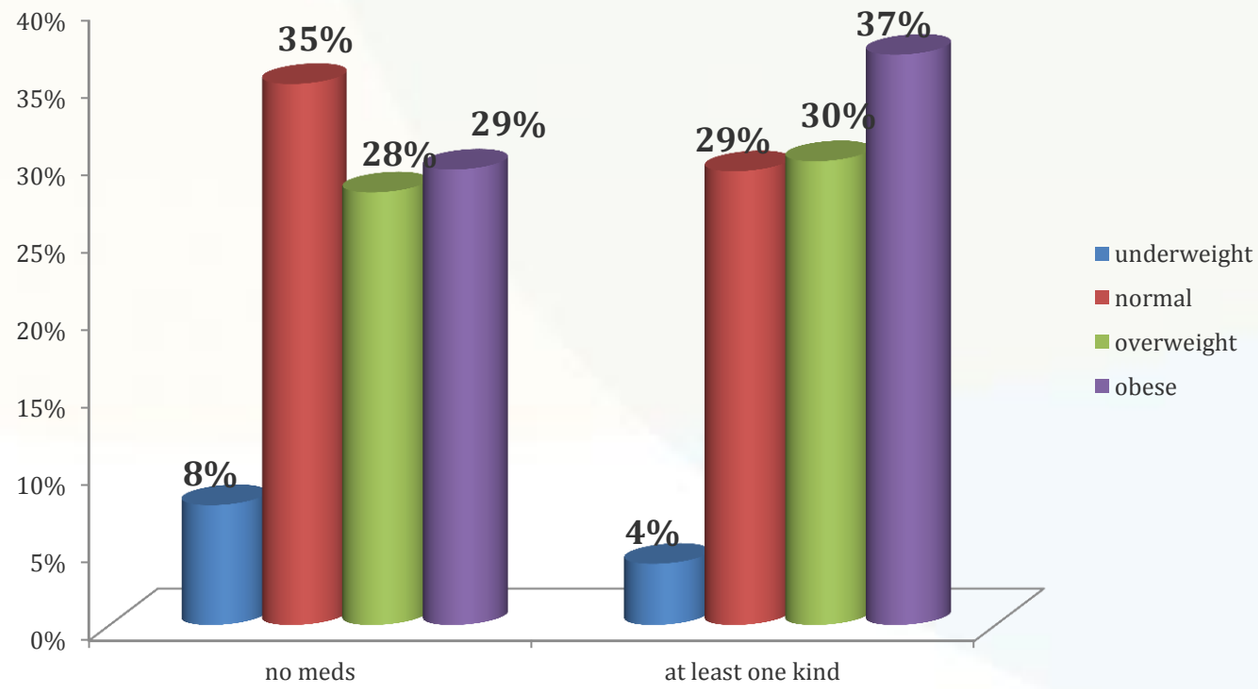
Medications in NCI
Obesity and medications

Weight



62% overweight or obese

Weight and meds



No meds: 57% overweight or obese

At least one med: 67% overweight or obese

Odds ratio: 1.49 ($p<0.001$)

Medications in NCI
Obesity and medications

- Personal characteristics (diagnoses, age, mobility) and place of residence may also affect weight,
- AND, may be related to whether a person is taking medications,
- Risk-adjustment

Medications in NCI

Obesity and medications

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	totmeds	.362	.056	41.120	1	.000	1.437
	Mob_self	.953	.099	92.789	1	.000	2.593
	Mob_self_waids	.602	.111	29.659	1	.000	1.826
	res_type			47.007	5	.000	
	res_type(1)	-.486	.153	10.051	1	.002	.615
	res_type(2)	.077	.124	.386	1	.534	1.080
	res_type(3)	.334	.132	6.365	1	.012	1.397
	res_type(4)	.161	.128	1.577	1	.209	1.174
	res_type(5)	.052	.154	.114	1	.736	1.053
	DXAUTISM08(1)	.315	.087	13.165	1	.000	1.371
	DXCP(1)	.478	.080	35.512	1	.000	1.613
	DXDOWN(1)	-.774	.109	50.017	1	.000	.461
	Age	.009	.002	19.360	1	.000	1.009
	Constant	-.951	.221	18.517	1	.000	.386

All control variables are significant at 0.01 level

After risk-adjustment: Odds ratio = 1.44 (p-value < 0.001)

Medications in NCI

- Those who take meds are more likely to live in group homes and less likely to live with parents or relatives
- Those who take meds are more likely to be diagnosed with ASD and less likely to be diagnosed with CP or Down Syndrome
- 53% take at least one medication for mood/anxiety/behavior/psychotic disorders
- High percentage of people without an MI diagnosis still take these meds

Medications and obesity in NCI

- 62% of people in the study are overweight or obese
- People who take at least one med are more likely to be overweight or obese
- This persists even after controlling for personal characteristics and place of residence (odds ratio of 1.44)

CONTACT

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