



# Race and Health Disparities in Adults with Intellectual and Developmental Disabilities\*

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Nisonger Center

# Background

- Health disparities are systematic, socially produced, and important differences in health between groups that are unnecessary and unjust. (Whitehead, 1992)
- Health disparities exist for racial and ethnic minorities, the poor, and other at-risk populations including people with disabilities.

# Background

- People with intellectual and developmental disabilities (IDD) may be the most underserved (Public Health Services, 2002).
  - Similar risk of chronic health conditions (Shireman et al., 2010)
  - Low rates of primary health care visits despite insurance (Hall, Wood, Hou, & Zhang, 2007)
  - Low rates of specialty care (Tyler, et al., 2011)
  - Untreated medical conditions (Lennox & Kerr, 1997)
  - Lack of preventive care (Haveman et al, 2010)

# Racial & Ethnic Disparities

- Disparities remain regardless of income, health insurance, and access to care
- Infant mortality, life expectancy, prevalence of chronic disease, and insurance coverage (Weinick, Zuvekas & Cohen, 2000)
- Disparities constant over time between Black and White and growing between White and Hispanic groups (Cook, McGuire & Zuvekas, 2009)

# Study Essence

- We explore factors predicting six different routine health care services and hypothesize that racial and ethnic minorities with IDD have a compounded risk of underutilization of health care services beyond the risk associated with IDD.

# Research Questions

1. Among adults with IDD, are there differences in health care utilization by race or ethnicity?
2. When analyses control for age, level of ID, and residence type, do differences persist?

# Measure

- National Core Indicators (NCI) is a Quality Management protocol for DD service delivery system
- Coordinated nationally by Human Services Research Institute (HSRI)
- Standard instrument, interviewer training, and methodology
- Three sources of information: self-report, proxy (informant), and records (case file)

# Participants

- Combined NCI data from 2009-2010 and 2010-2011 cycles
- 20,395 adults randomly selected from state DD service registries
- 25 states were represented in this sample
  - A minimum of 400 adults from each state
- Participants self-identified as White, Black, or Hispanic



# Access to 6 health services

- Prostate-Specific Antigen test (PSA)
- Pap test (Pap)
- Mammogram
- Routine physical exam
- Dentist visit
- Flu shot

# Factors Predicting Lack of Health Care

- **Older** adults were generally more likely to use health care services
- Adults with **more severe ID** were more likely to get flu shots and physical exams
- Women with **more severe ID** were 2 times less likely to get mammogram (OR 2.0)
- Living with **family** predicted lowest utilization of health care

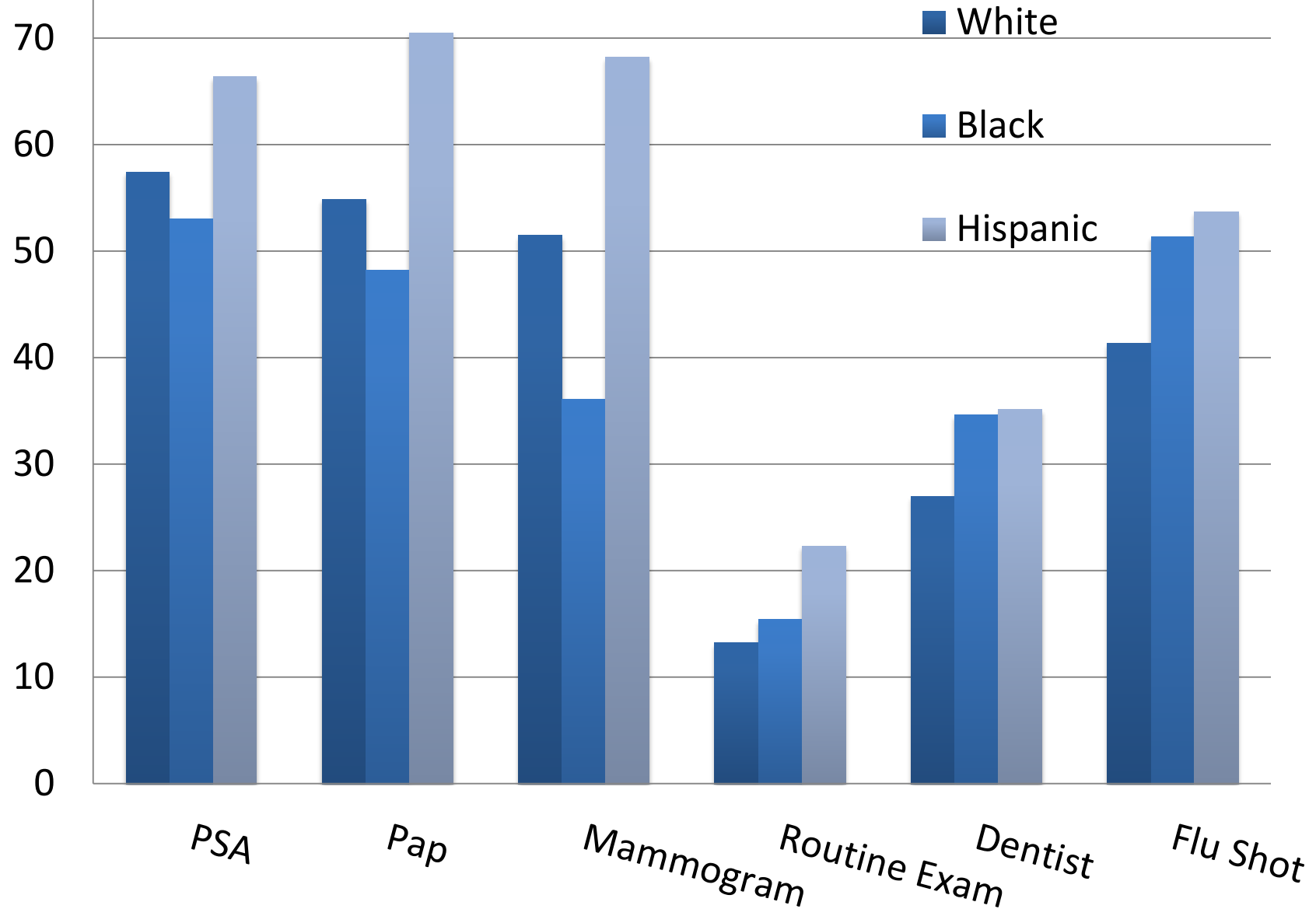
# What about race/ethnicity?

- 6 regression models on routine health services
- Odds of **not receiving service** for each racial/ethnic group compared to White
- Covariates included age, level of ID, and place of residence

# What about race/ethnicity?

- Minority race/ethnicity predicted **lower odds of routine health care** (dentist, physical exam, flu shot)
- Black participants were **most likely** to receive cancer screening
- Hispanic participants were **least likely** to receive cancer screening

# NOT Using Health Care by Race and Ethnicity



# Conclusion

- Racial and ethnic minorities with IDD have a compounded risk of underutilization of general care services
- Adults living with family were least likely to get health care
  - ❖ Minorities were most likely to live with family

# But why?

- ❖ NCI captures a served population
- Discrimination or prejudice – doubly stigmatized

# Policy implications

- Training health care providers
  - 90% practitioners found it difficult to provide quality care to patients with ID (Lennox, et al., 2000)
  - Implicit bias – cultural competence training
- Insurance reimbursement limits time available to patients with complex needs
- Additional support for families to promote health and access to health care



# Medically Underserved Population Designation

- Medical school loan forgiveness
- Physician and allied health training
- Screening and prevention guidelines
- Health care access through community health centers, FQHCs, rural health clinics
- Medical research

Awareness

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# Exploring Health Disparities Among People with Intellectual and Developmental Disabilities

What Are the Issues and Do Race  
and Ethnicity Play a Role?



Alixé Bonardi  
Erica Hendricks  
Human Services Research Institute



# Agenda



- Research questions
- National Core Indicators
- What are health disparities?
- Health/healthcare disparities and people with ID/DD
- What do NCI data show?



# Research Questions

- Do people with intellectual and developmental disabilities experience health disparities overall?
- Do NCI data demonstrate differences in utilization and access to preventive healthcare by race/ethnicity?



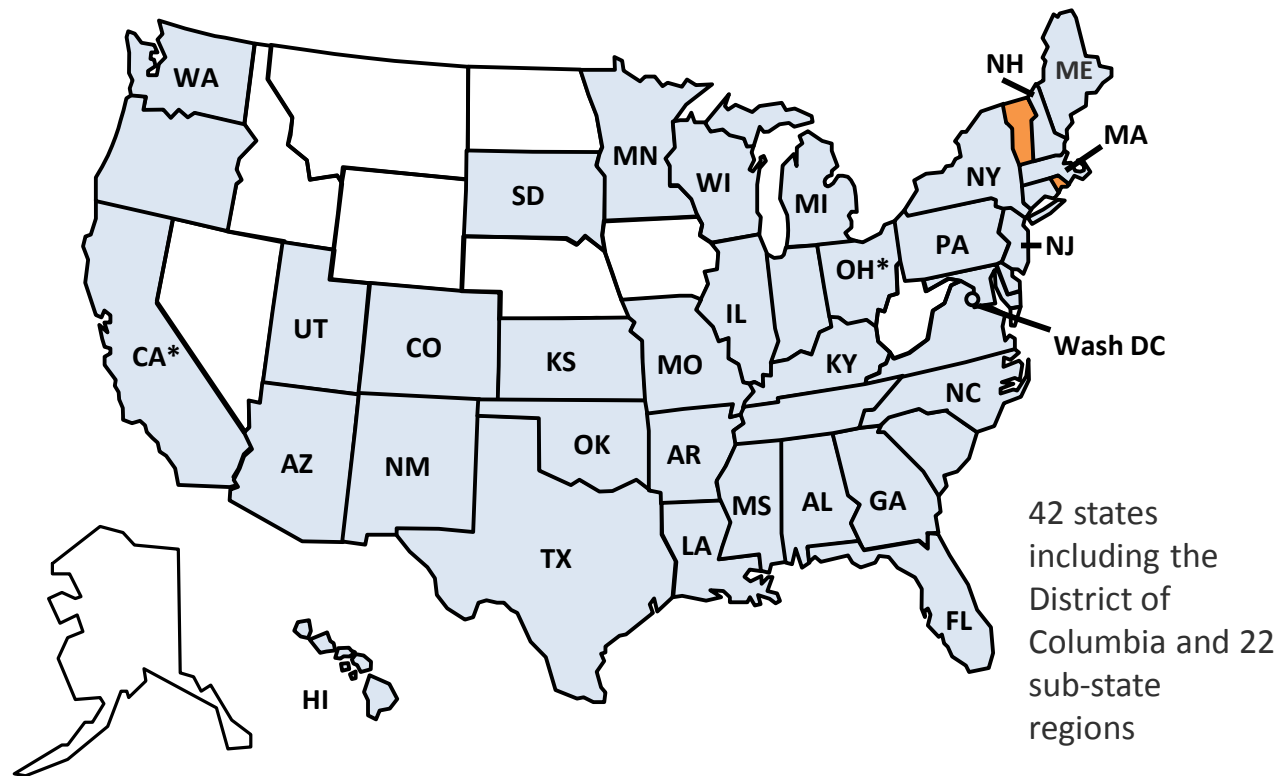
# National Core Indicators (NCI)?



- NASDDDS – HSRI Collaboration
- Multi-state collaboration of state DD agencies
- Measures performance of public systems for people with intellectual and developmental disabilities
- Assesses performance in several areas, including: employment, community inclusion, choice, rights, and health and safety
- Launched in 1997 in 6 participating states – now in 42 states (including DC) and 22 sub-state areas
- Now expanded to elderly and people with disabilities through the NCI-AD



# NCI State Participation 2014-15



■ State contract awarded in 2014-15 through AIDD funding  
CA\*- Includes 21 Regional Centers  
OH\*- Also includes the Mid-East Ohio Regional Council



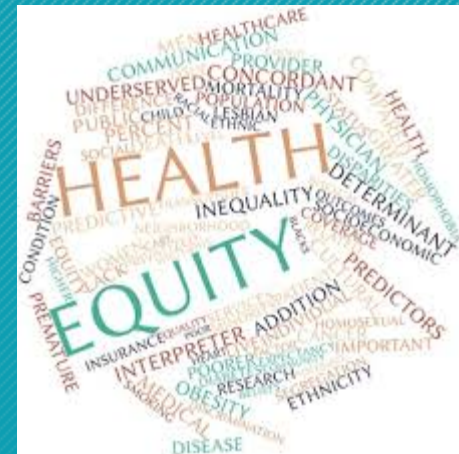


# How Does NCI Collect Data?

- Adult Consumer Survey
  - ✓ In-person conversation with a sample of adults receiving services to gather information about their experiences
  - ✓ Keyed to important person-centered outcomes that measure system-level indicators related to: employment, choice, relationships, case management, inclusion, health, etc.
- Adult Family, Child Family, and Family/Guardian Surveys: mail surveys – separate sample from Adult Consumer Survey
- Other NCI state level data: Staff Stability



# What Are Health Disparities?



# Health Disparity Populations

The National Institute on Minority Health and Health Disparities (NIMHD) defines the population as those with:

A significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population.



# Health Disparity Populations

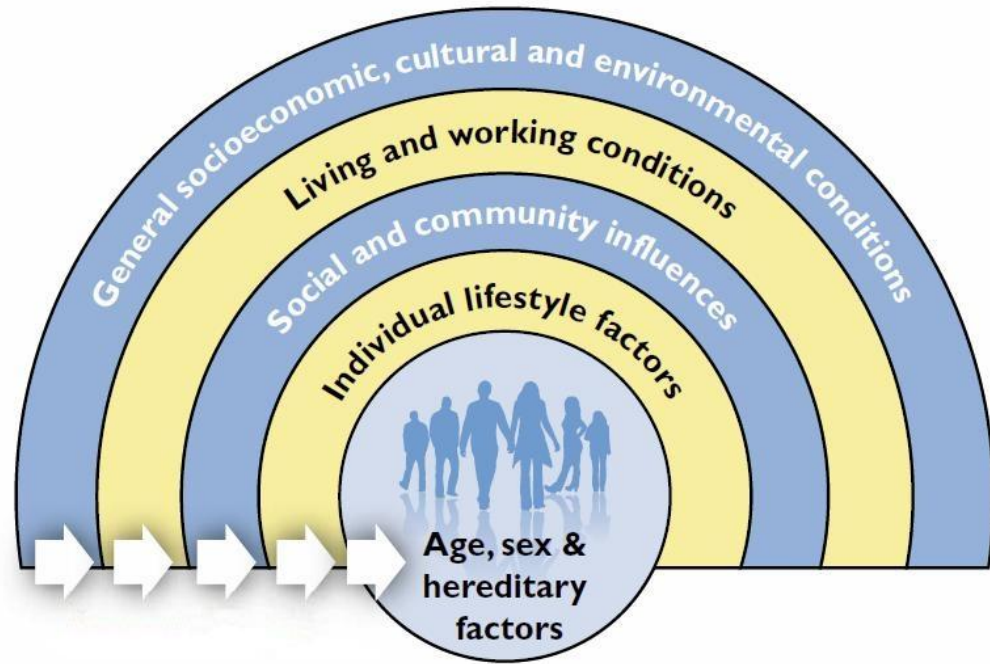
Current NIMHD health disparity target groups include:

- Blacks/African Americans
- Hispanics/Latinos
- American Indians/Alaska Natives
- Asian Americans
- Native Hawaiians and other Pacific Islanders
- Socioeconomically disadvantaged populations and rural populations
- **Disability advocates pressing for inclusion in the definition**



# Health Determinants

- Why are some people healthy/unhealthy?
- Differences in health/healthcare utilization exist because of **unequal distributions of social, environmental, economic conditions within society**
- NCI captures demographics, employment, communication, choice., etc.



*Health Determinants Model*

[http://www.health-inequalities.eu/HEALTH EQUITY/EN/about\\_hi/health\\_inequalities/](http://www.health-inequalities.eu/HEALTH EQUITY/EN/about_hi/health_inequalities/)



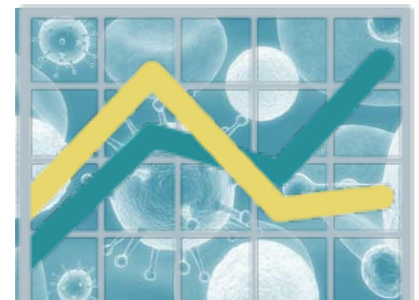




**Do Individuals with ID/DD  
Experience  
Health/Healthcare  
Disparities?**

# ID/DD Population as Potential Health Disparity Population?






- American Academy of Developmental Medicine and Dentistry (AADMD), AMA, and ADA:  
Advocating to have ID/DD population designated as “medically underserved” by Health Resources and Services Administration—would lead to increase in resources to address disparities
- People with ID/DD shown to be “socioeconomically disadvantaged\*”
- People with ID/DD experience:
  - Higher rates of certain diseases/conditions
  - More deaths and morbidity from those diseases when compared with the general population



\*Rehabilitation Research and Training Center on Disability Statistics and Demographics (StatsRRTC), 2004 Disability Status Reports 2004; Ithaca (NY): Cornell University



# What Are the Top 5 Causes of Death in the General Population?

Rank		Cause
1		Heart Disease 24.5%
2		Cancer 23.3%
3		Emphysema, Asthma, Bronchitis 5.68%
4		Stroke 5.3%
5		Unintentional Injury 5.02%

<http://www.cdc.gov/nchs/fastats/leading-causes-of-death.htm>





# What Do People with ID/DD Die of?

## Comparison of the Top 5 Leading Causes of Death as Reported by Four State ID/DD Agencies

Rank	MA DDS CY2010 (Adults)	MA DDS CY2011 (Adults)	CT DDS45 FY2011 (all ages)	OH DDD47 2010 (Adults)	LA OCDD FY2011 (all ages)
Method	Underlying		Primary	Unknown	Unknown
1	Heart Disease 18.0%	Heart Disease 17.5%	Heart Disease 27.4%	Heart Disease 18.9%	Heart Disease 18.4%
2	Cancer 13.8%	Cancer 12.7%	Cancer 13.5%	Cancer 11.3%	Septicemia 17.3%
3	Alzheimer's Disease 12.8%	Alzheimer's Disease 10.9%	Aspiration Pneumonia 12%	Influenza & Pneumonia 9.0%	Congenital Condition 16.3%
4	Aspiration Pneumonia 12.3%	Aspiration Pneumonia 8.0%	Respiratory Disease4 11.1%	Congenital Diseases 8.3%	Pneumonia 10.2%
5	Septicemia 8.6%	Septicemia 7.7%	Pneumonia 8.2%	Aspiration Pneumonia 7.1%	Malignant Neoplasm (Cancer) 7.1%



# At What Ages Do People with ID/DD Die?

Average Age at Death by Gender, 2011

Gender	Average Age at Death MA DDS	Average Age of Death US General Population
Female	<b>62.5</b>	<b>81.1</b>
Male	<b>59.9</b>	<b>76.3</b>



# What Does the CDC Say About the Health Status of People with ID/DD?

Adults with intellectual disabilities experience poorer health outcomes than people without ID. These disparities mean that people with ID are more likely to:

- Live with complex health conditions.
- Have limited access to quality healthcare and health promotion programs.
- Miss cancer screenings.
- Have poorly managed chronic conditions, such as epilepsy.
- Be obese.
- Have undetected poor vision.
- Have mental health problems and use psychotropic medications.

<http://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>



# ID/DD Healthcare Disparities in Preventive Care Use

Women with ID/DD are less likely than women without ID/DD to:

- Have had cervical and breast cancer screenings
- Have ever visited a gynecologist

Individuals with ID/DD are less likely than individuals without ID/DD to:

- Visit dentist regularly
- Get eye and hearing tests
- Receive timely vaccines





**Do Ethnic and Racial  
Disparities Exist Regarding  
Utilization of Preventive  
Care?**

# What Is Preventive Care?



- Prevents people from getting sick by detecting diseases/conditions before they become serious
- Beneficial for both financial purposes and to achieve a high quality of life
- Enhanced attention to preventive care:
  - **Patient Protection and Affordable Care Act (ACA)**
    - Requires that many health insurance companies cover the full cost to the consumer of many types of regular preventive care services (Healthcare.gov).



# Racial/Ethnic Healthcare Disparities in Use of Preventive Care

General Public:

African American and Hispanic individuals

- Visit their personal physician and have dentist visits less frequently than whites
- Are less likely than whites to receive services such as
  - Flu and/or pneumonia vaccines
  - Colorectal cancer screenings
  - Pap tests
  - Mammograms







# What Do NCI Adult Consumer Data Tell Us About Racial and Ethnic Disparities in Utilization of Preventive Care?



# Data Source: Adult Consumer Survey

- Standardized, face-to-face interview with a sample of individuals receiving services
  - Background Information - includes health information
  - Section I (no proxies allowed)
  - Section II (proxies allowed)
- No pre-screening procedures
- Conducted with adults only (18 and over) receiving at least one service in addition to case management
- Section I and Section II together take 50 minutes (on average)



# General Findings



- Individuals living in structured settings (i.e., specialized institutions, group homes) are more likely to have access to preventive screenings and vaccinations—regardless of their race or ethnicity.
- Individuals living with their families and those living independently are less likely to receive preventive care.

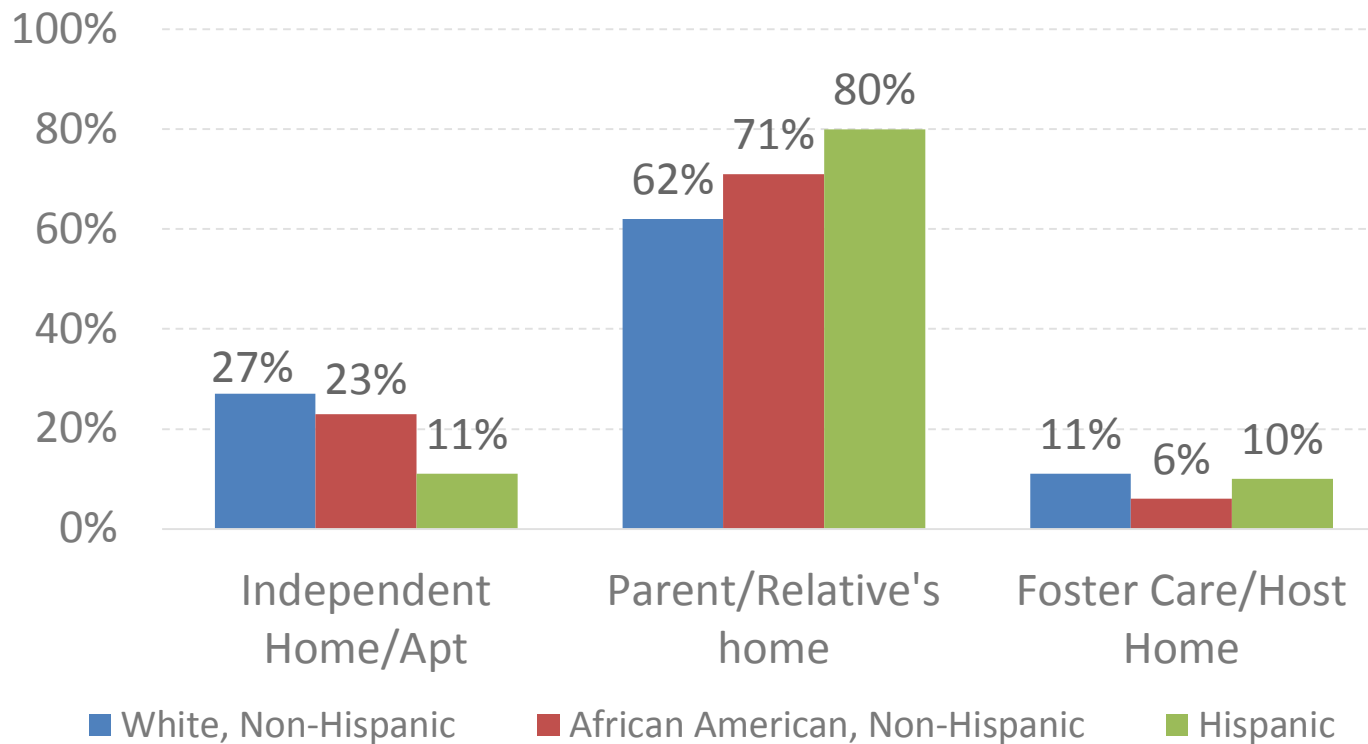
# Residence Type

- To determine whether race or ethnicity played a role in access to preventive care, we only included individuals living in:
  - Independent home/apartment
  - Parent/relative's home
  - Foster care/host home
- N=7,632 from 25 states
- Race/ethnicity collapsed into 3 groups African American (non Hispanic), Hispanic (including black Hispanic), White (non-Hispanic)

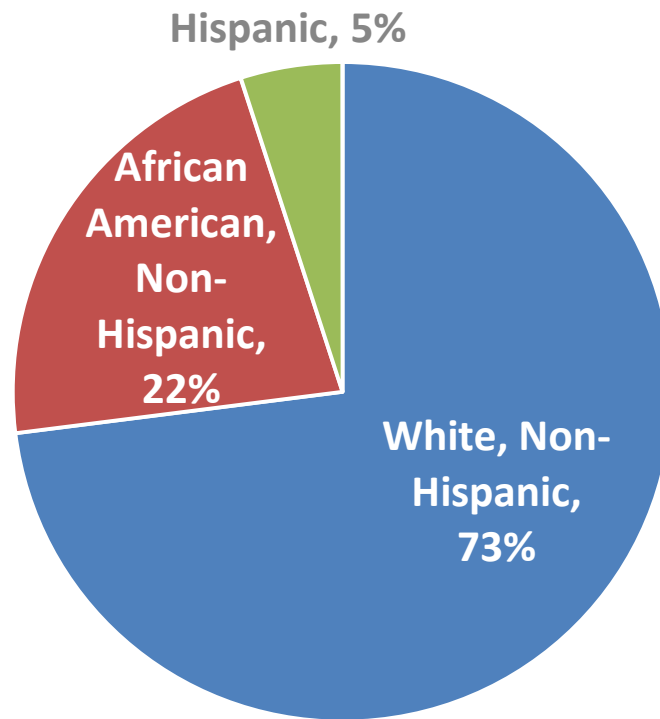


# Demographic Differences

**Final Sample Residence Type ( $p \leq .001$ )**



# Race/Ethnicity of Individuals Living at Home, Independently or in a Foster Home/Host Home



# Preventive Care Utilization Disparities

White respondents, African American respondents, and Hispanic respondents have significantly different rates of:



- Having had a physical exam in the past year ( $p < .001$ )
- Having gone to the dentist in the past year ( $p < .001$ )
- Having had a routine vision screening/eye exam in the past year ( $p < .001$ )
- Having had a flu vaccine in the past year ( $p < .001$ )
- Having ever had a pneumonia vaccine ( $p < .001$ )

# HOWEVER...It's Important to Control for Other Factors

- Individuals of different races and ethnicities also differ in other demographic characteristics such as:

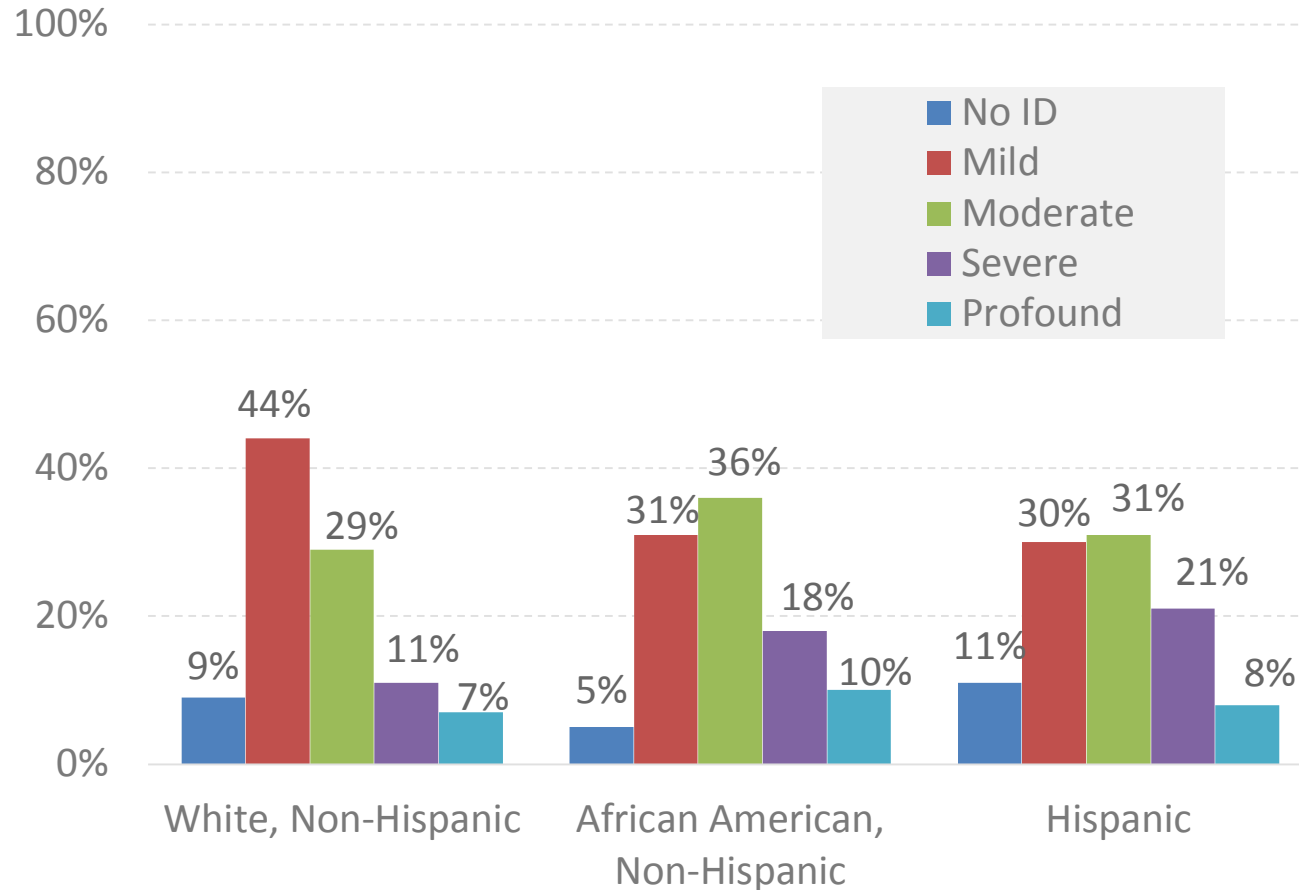
- State of residence
- Age
- Individual's primary language
- Individual's primary means of expression
- Level of intellectual disability
- Mobility
- Other diagnoses (in addition to ID/DD)
- Residence type

- These differences may affect their rates of preventive care use.
- Some examples of demographic differences are seen in the next few slides...



# Level of ID by Race/Ethnicity

Level of Intellectual Disability (p<.001)

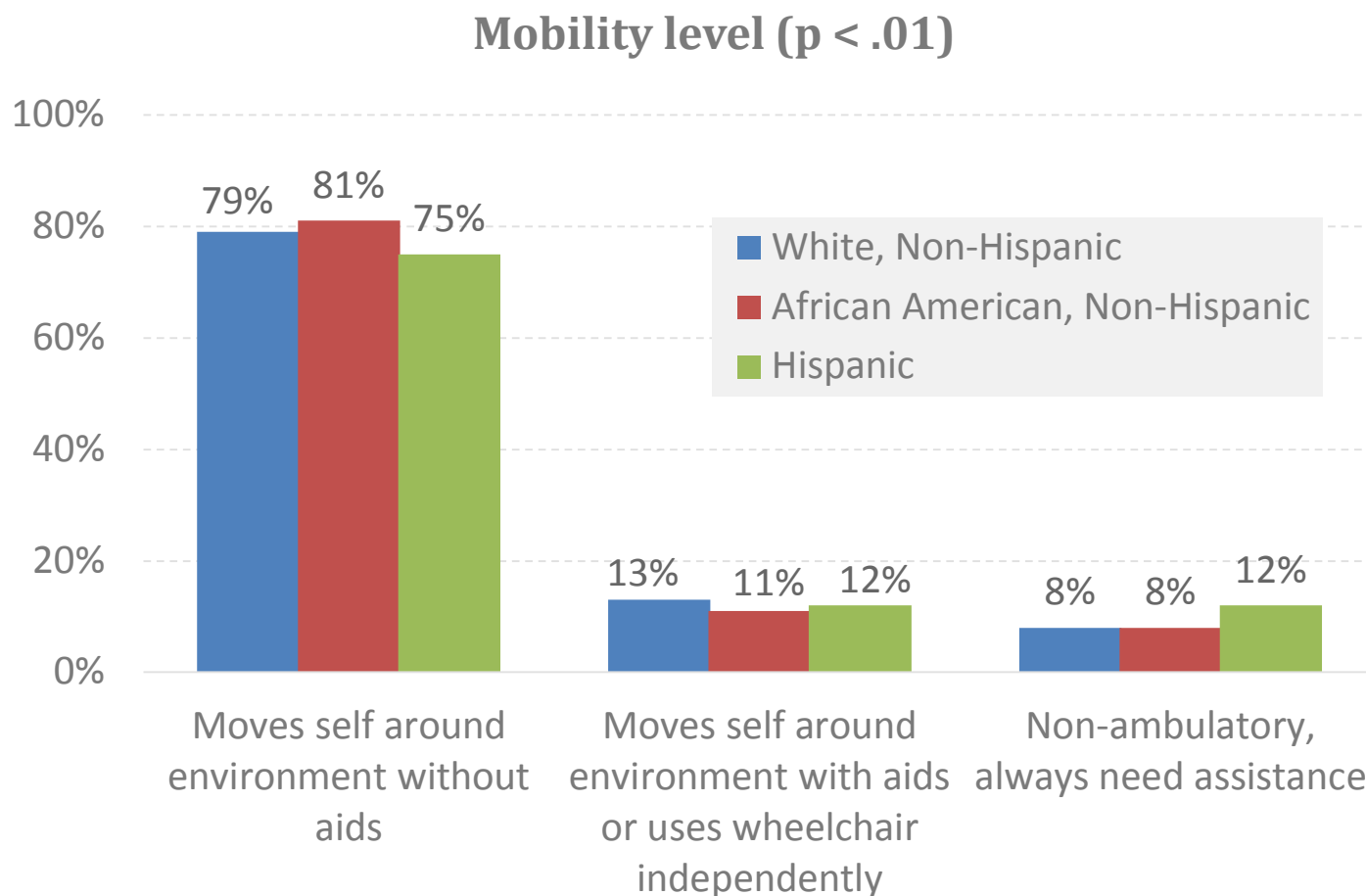


- White respondents more likely to be diagnosed with mild ID
- African American and Hispanic respondents more likely than White respondents to be diagnosed with moderate, severe, or profound ID



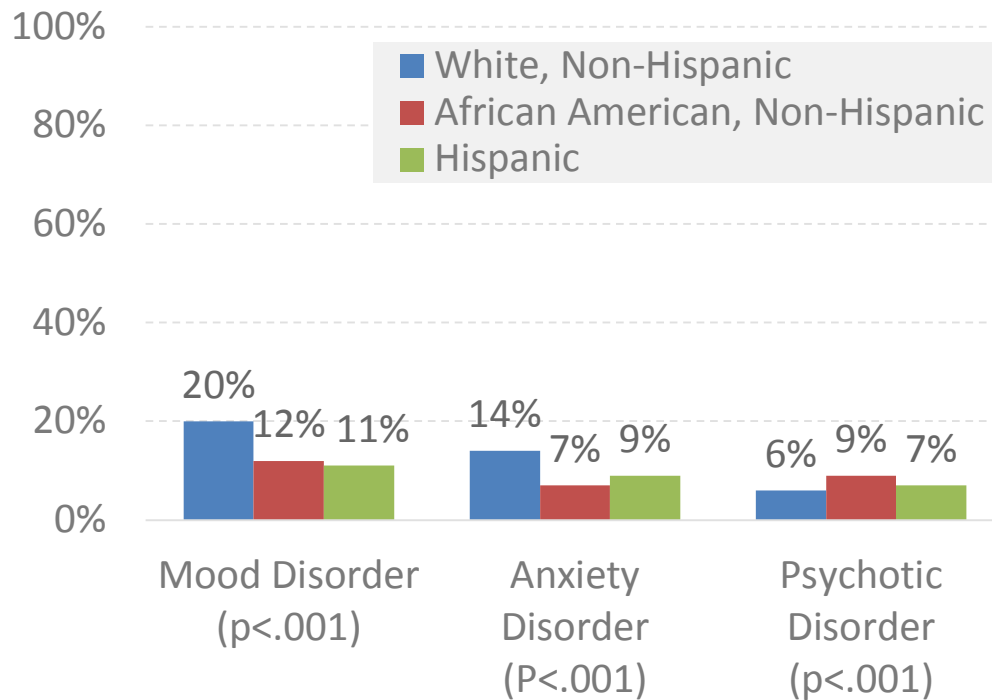


# Mobility Level by Race and Ethnicity



# Other Diagnoses by Race/Ethnicity

## Mental Illness/Psychiatric Diagnosis



- White respondents are more likely to be diagnosed with mood disorder and/or anxiety disorder
- African American and Hispanic respondents more likely to be diagnosed with psychotic disorder



# After controlling for demographic factors...

For individuals not living in institutional or community-based settings, the following preventive care exams showed differences by race/ethnicity that were still statistically significant:



African American respondents and Hispanic respondents were less likely than White, Non-Hispanic respondents to have had a physical exam in the past year.



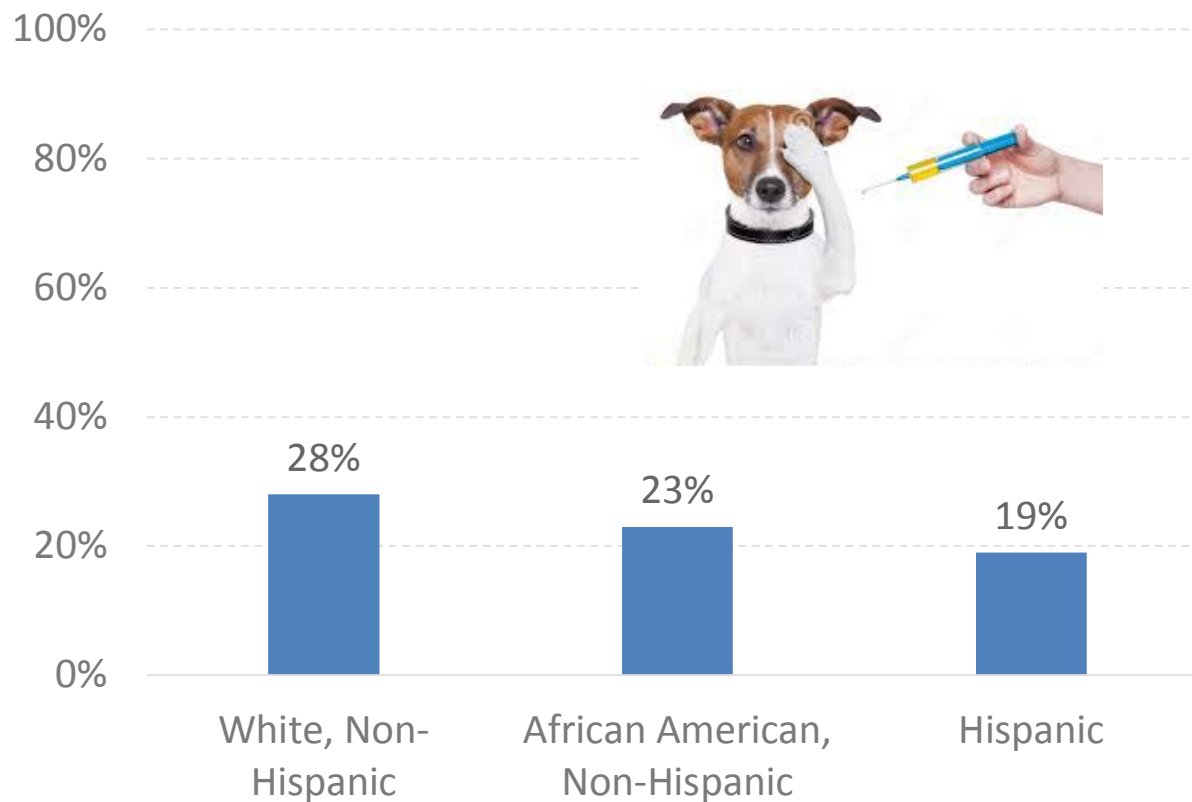
African Americans were less likely than Whites to have had a dentist visit in the past year.



African Americans were less likely than Whites to have had a flu vaccine in the past year.

## Example:

Though Whites Are More Likely to Have Ever Gotten Pneumonia Vaccine ( $p < .001$ ) – Bigger Predictor was Risk Factors Including Age (older), Down Syndrome, Poor Health, and Reduced Mobility





# What Do NCI Adult Family Survey Data Tell Us About Racial and Ethnic Disparities in Access to Preventive Care?

# Adult Family Survey 2012-13

- Mail-in surveys
- Adult Family Survey: respondent is a family member of an individual with ID/DD over age 18 who lives in the family home
- 2012-13: N=5,010
- 13 states



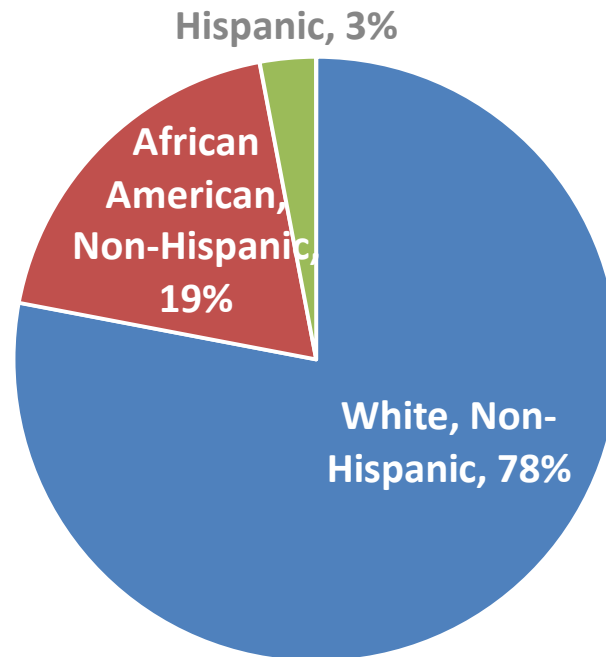
# Administration of Adult Family Survey

- Mail-in
  - Selection bias!
- Sent to families with an adult family member living at home
- The Adult Family Survey (AFS) asks about *access* to health services as opposed to *utilization*. For example:
  - “Do you have access to health services for your family member?”
- Also asks about dental services, medications, and mental health services.



# Demographic Breakdown

Adult Family Survey 2012-13 (N=4,760\*)



\*Only those cases for which a racial/ethnic identity was provided were included in this analysis.





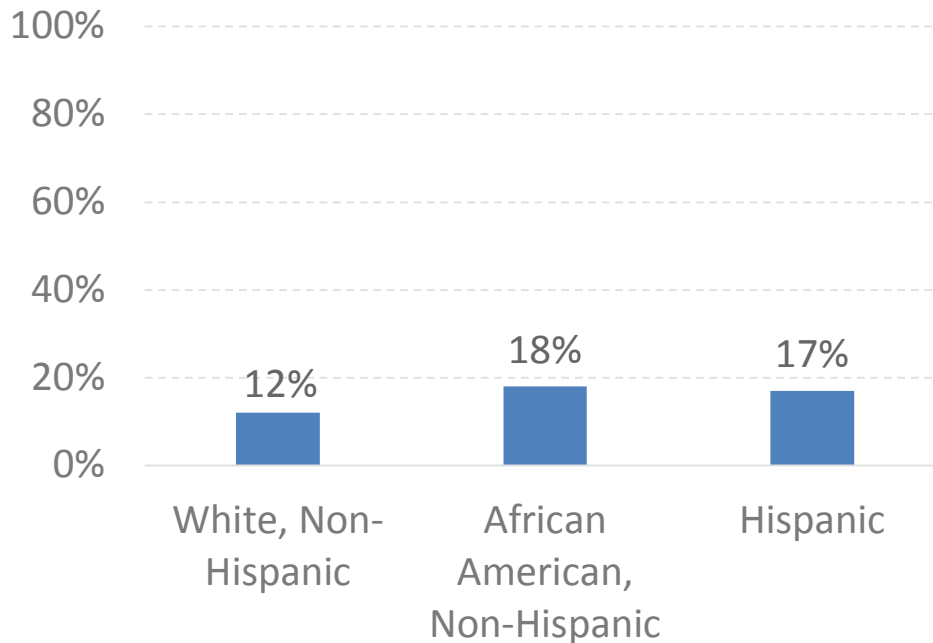
# Though Data Showed Some Differences in Access (e.g., dental, doctors visits) Needed to Control For:

- State of residence
- Family member's age
- Whether there is more than one person with a disability in the household
- Family member's primary language
- Family member's primary means of expression
- Family member's other diagnoses (in addition to ID/DD)
- Family member's highest level of education
- Frequency at which family member requires medical care
- Whether family member needs behavior support
- Level of support family member needs for activities of daily living
- Respondent's highest education level
- Household income



# For example...

## More than One Person With ID/DD Lives in Household ( $p \leq .001$ )



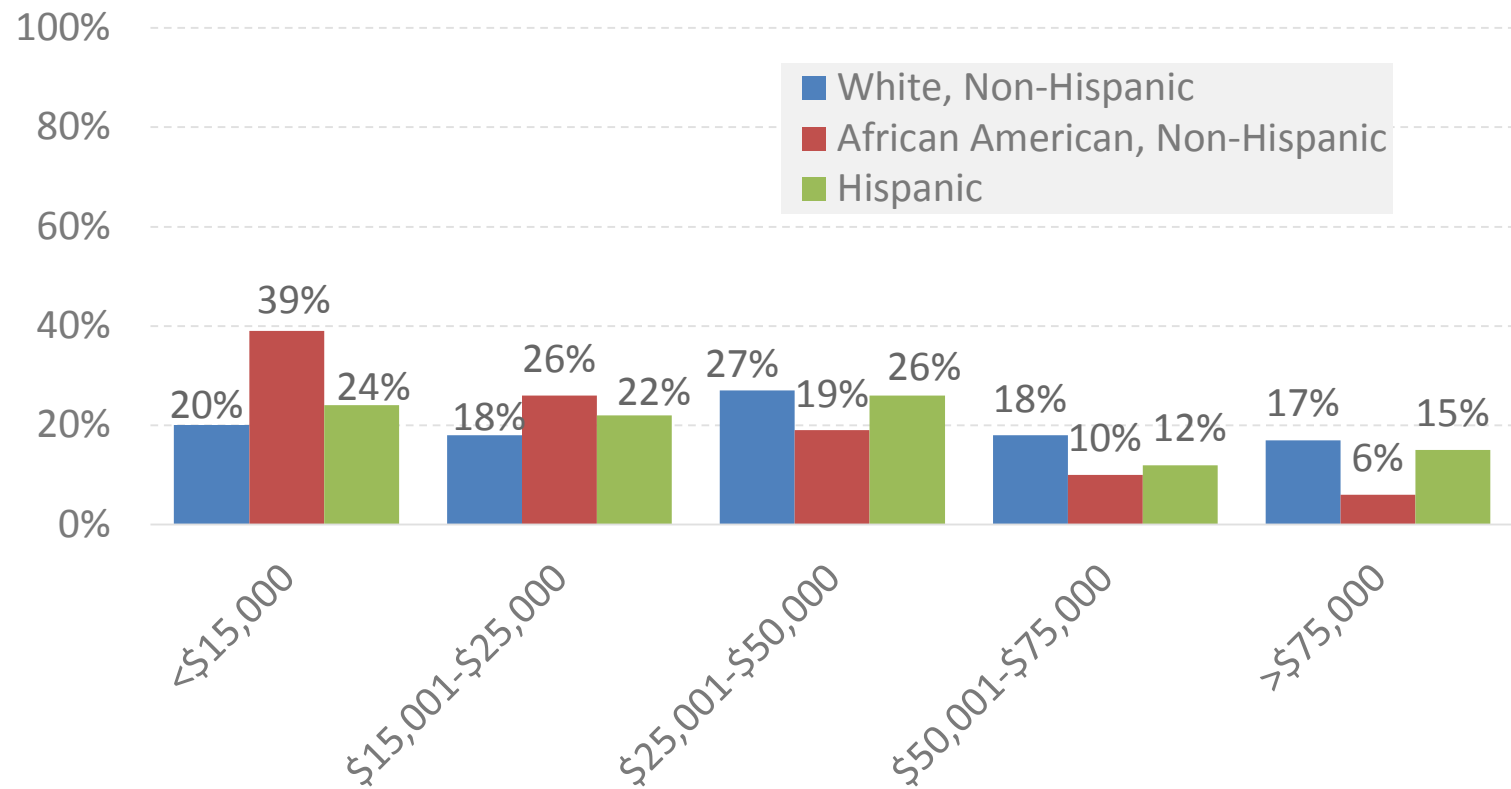
Hispanic respondents significantly more likely to need moderate or complete help with daily activities (such as bathing, dressing, eating) than White, Non-Hispanic and African American, Non-Hispanic respondents.



# For example.....



## Household Income in Past Year ( $p \leq .001$ )



# Findings

Interestingly...

- Household income is a significant predictor of access to dental care.

When we control for these demographic differences

- Race/Ethnicity is no longer a significant predictor of access to any of the preventive care specified in the AFS.



# Summary

- While people with ID/DD do experience health disparities and are disproportionately affected by disease, and untimely death, they are not a federally designated group.
- People with ID/DD are more likely to die of preventable causes and to die at an earlier age.



# Summary (cont.)

While a variety of factors may explain disparate access to preventive health services,



African American respondents and Hispanic respondents were less likely than White respondents to have had a physical exam in the past year



African Americans were less likely than Whites to have had a dentist visit in the past year



African Americans were less likely than Whites to have had a flu vaccine in the past year

# Summary (cont.)

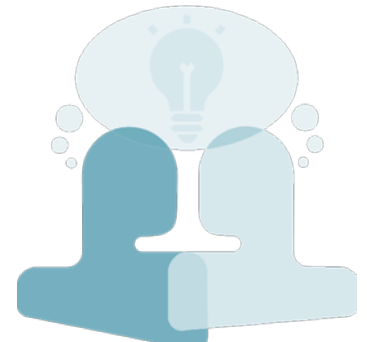
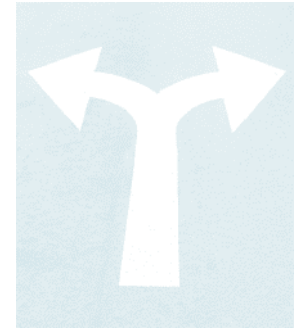


- Family income is a bigger predictor than race and ethnicity of access to preventive health services.
- NCI data show that African Americans and Hispanic respondents to the Adult Consumer Survey are less likely to achieve outcomes such as employment and choice and to have their rights respected.



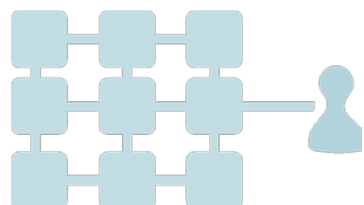
# What To Do Now?

- Advocate that HRSA include individuals with ID/DD as a medically underserved population.
  - Allocate more resources to research into disparities
- As more people with ID/DD live in their own homes, with their families and in foster/host homes, public managers and MCOs will need to find other means to ensure that individuals with ID/DD utilize preventive services – especially in light of their health challenges
  - Track data
  - Targeted outreach campaigns to different populations

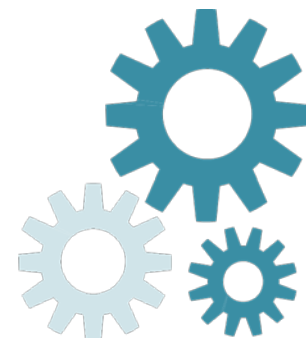




# What To Do Now? (cont.)



- Conduct continued research into racial and ethnic disparities in preventive and general healthcare
  - Help tease out root causes/social determinants of disparities and what can be done to mitigate them
- Support more systematic examination of mortality data for individuals with ID/DD
- Track the implementation of the ACA including broader coverage, better training, more accessible facilities
- Explore reasons for differential results regarding employment, choice, rights



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[www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)



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