



How Do Services for People with Intellectual and Developmental Disabilities Compare by Race and Ethnicity?

Sarah Taub NCI Webinar Series
October 29th, 2013

Agenda

- Mary Lee Fay, NASDDDS: **Intro to NCI**
- Dorothy Hiersteiner and Julie Bershadsky, HSRI: **Race/Ethnicity and the Use of Preventive Care Among Adults with Intellectual and Developmental Disabilities**
- Alberto Migliore, Institute for Community Inclusion, University of Massachusetts: **Employment Trends of People with Intellectual and Developmental Disabilities, by Race and Ethnicity: 2002–2012**
- Brent Watkins, Oregon Developmental Disabilities Services: **Comparing Access to Services by Race and Ethnicity**



WHAT IS NATIONAL CORE INDICATORS (NCI)?

- 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 13 participating states
- Supported by participating states
- NASDDDS – HSRI Collaboration



39 states, District of Columbia, Columbia, sub-state n

■ State contract awarded in 2013-14 through AIDD funding

OH*- Also includes the Mid-East Ohio Regional Council



WHAT IS NCI?

- 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: Mortality, Staff Stability





Race/Ethnicity and the Use of Preventive Care Among Adults with Intellectual and Developmental Disabilities

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Agenda

- Data source
- Methods, Measures and Sample
- Findings
- Conclusions
- Limitations

Do NCI data demonstrate differences by race/ethnicity in use of preventive healthcare?



Data Source:

Adult Consumer Survey

- Standardized, face-to-face interview with a sample of individuals receiving services
 - Background 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)



Methods, Measures and Sample:

- **2011-2012** data collection cycle
- **Background Information section:** demographics, residence, health, and employment information. Generally collected from records by case managers.
- 19 states, one regional council
(AL, AR, AZ, CT, GA, HI, IL, KY, LA, MA, ME, MI, MO, NC, NJ, NY, OH, PA, SC and the Mid-East Ohio Regional Council)
- Total N: 12,236 individuals



Methods, Measures and Sample:

Race/Ethnicity

- Source: two items from Background Section
 - Ethnicity (Hispanic, or non-Hispanic)
 - Race (American Indian or Alaska Native, Asian, Black or African American, Pacific Islander, White, or Other race not listed)
- Items combined to create: Race/Ethnicity
 - White, Non-Hispanic
 - African American, Non-Hispanic
 - Hispanic
- Other race/ethnic categories too small for analysis



Methods, Measures and Sample: Preventive Care

- Person has a primary care doctor:
 - No
 - Yes
- Last complete annual physical exam (routine):
 - In the past year
 - One year ago or more
- Last dentist visit:
 - In the past year
 - One year ago or more
- Last eye exam/vision screening
 - In the past year
 - One year ago or more



Methods, Measures and Sample:

Preventive Care

- Last hearing test:
 - Within the past 5 years
 - 5 years ago or more (or never)
- Flu vaccination in the past 12 months:
 - Yes
 - No
- Ever had a vaccination for pneumonia:
 - Yes
 - No
- “Don’t know” responses were excluded from these analysis – i.e. excluded from both denominator and numerator

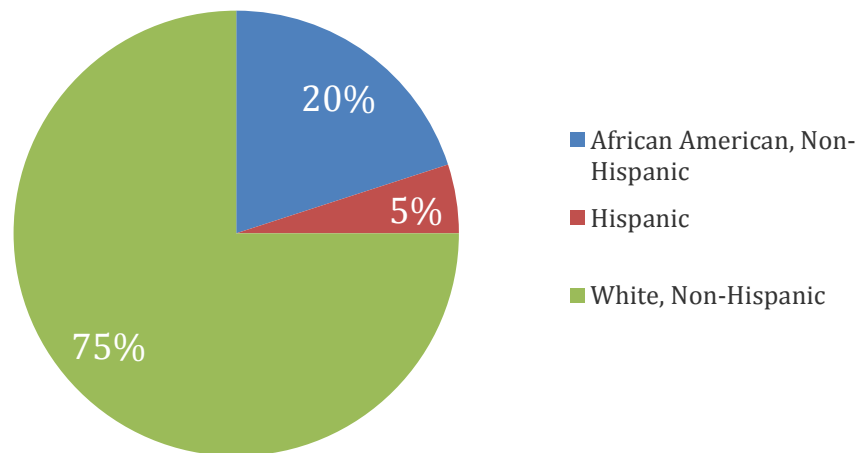


FINDINGS

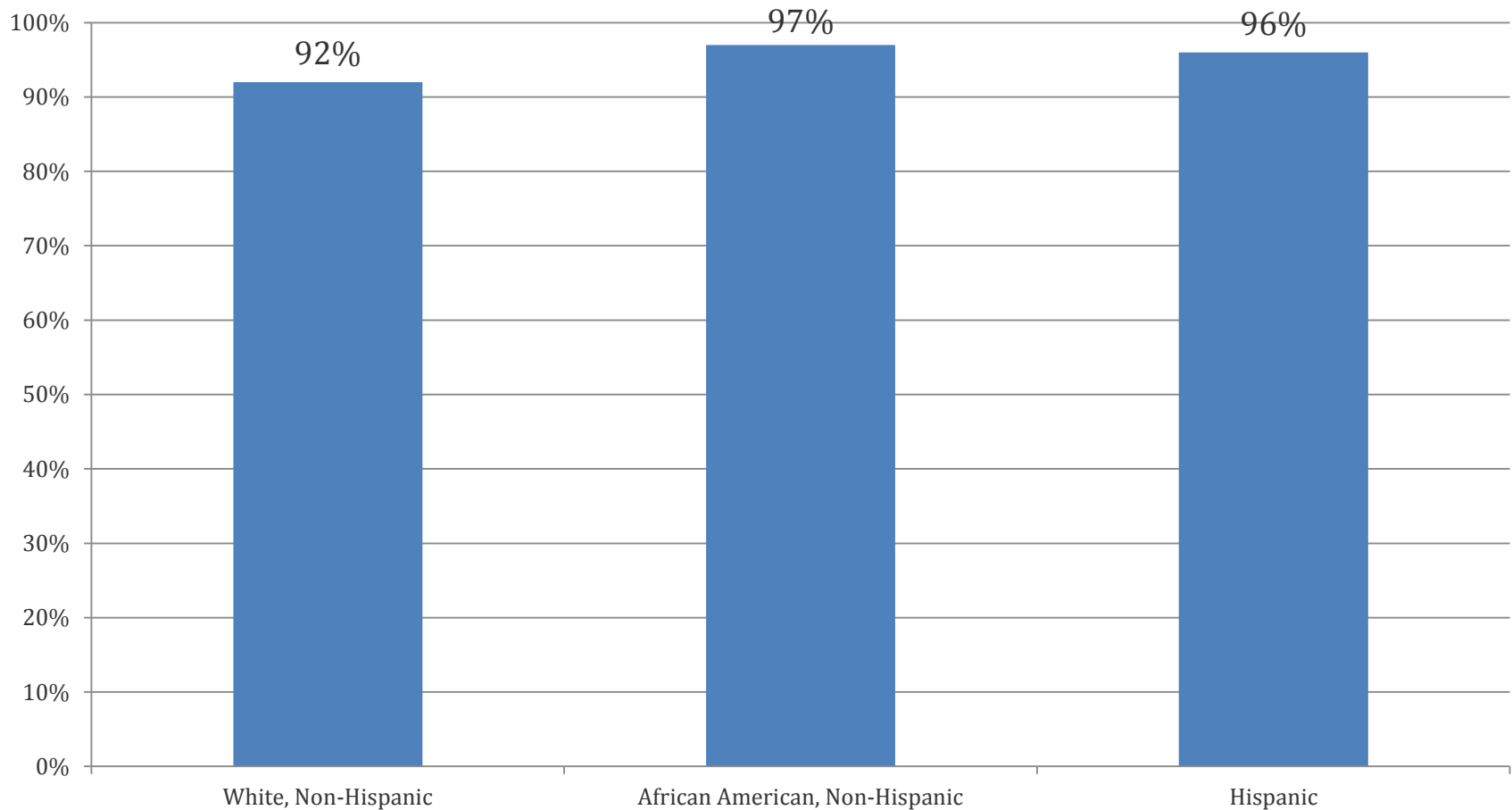


Race/Ethnicity of Sample

Race/Ethnicity	Percent of total
African American, Non-Hispanic	20 %
Hispanic	5%
White, Non-Hispanic	75%
<i>Total (N=11,199)</i>	<i>100.0%</i>

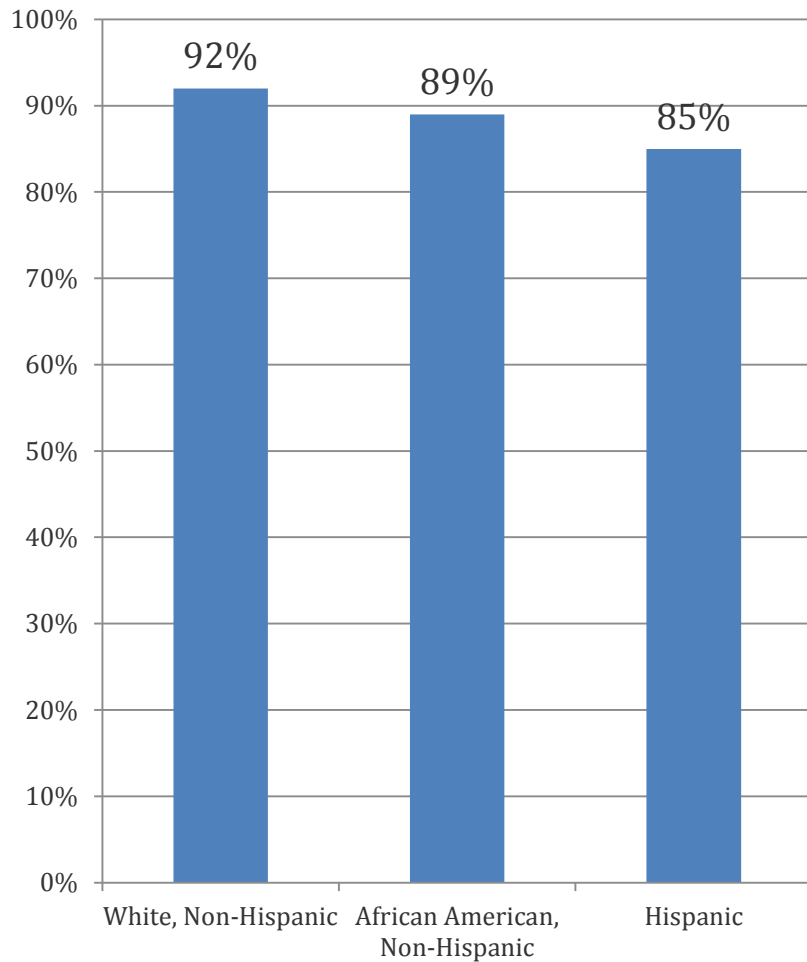


Preventive Care: Primary Care Doctor ($p < .001$)

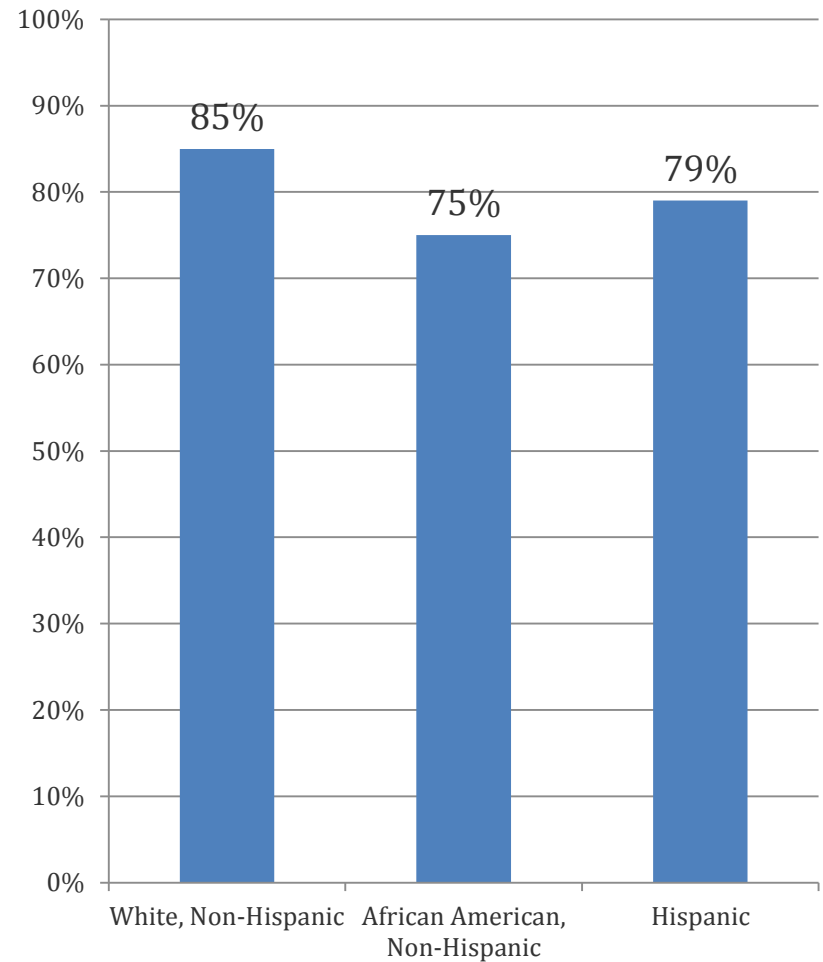


Preventive Care:

Physical Exam in Past Year ($p < .001$)

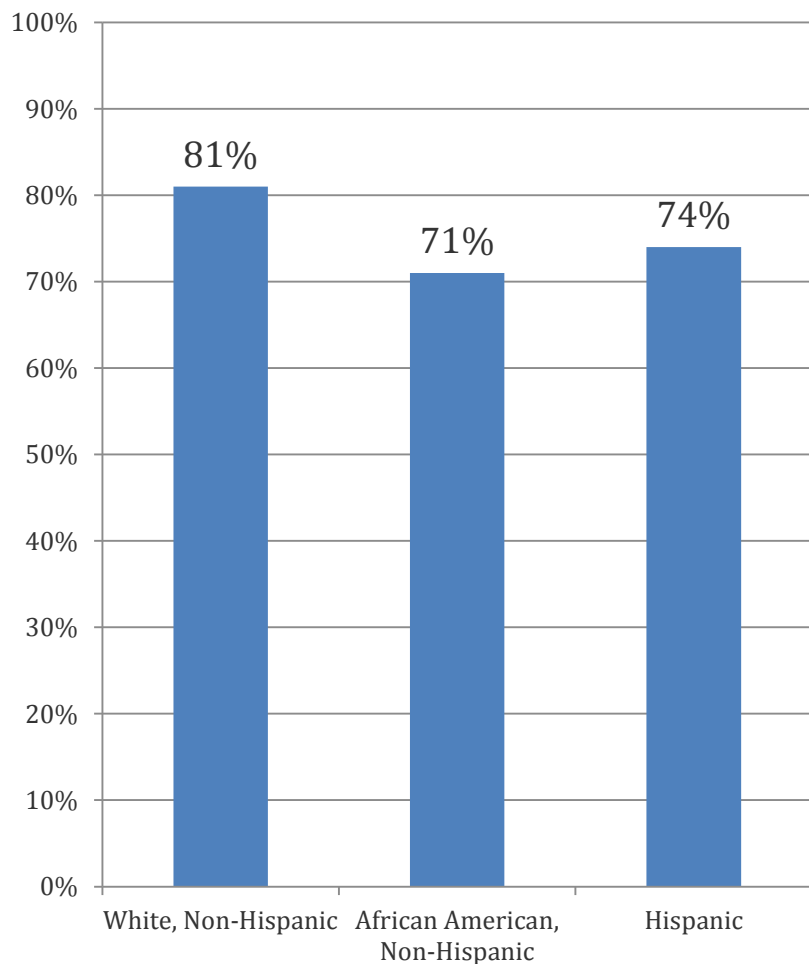


Dentist Visit in Past Year ($p < .001$)

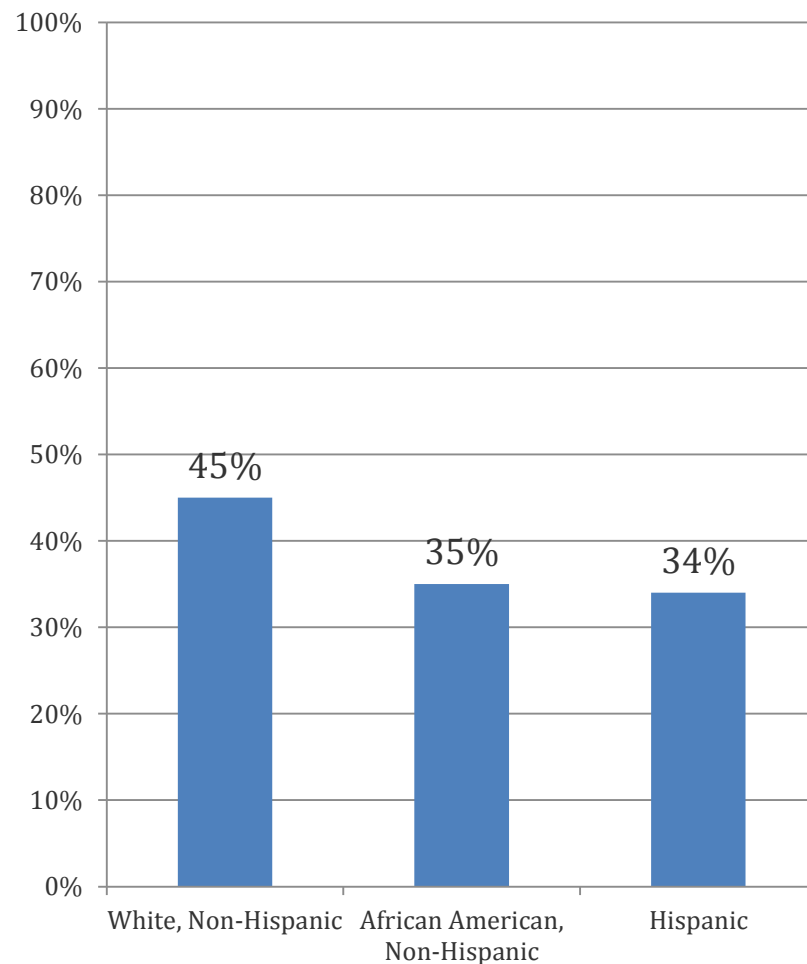


Preventive Care:

Flu vaccine in past year ($p < .001$)

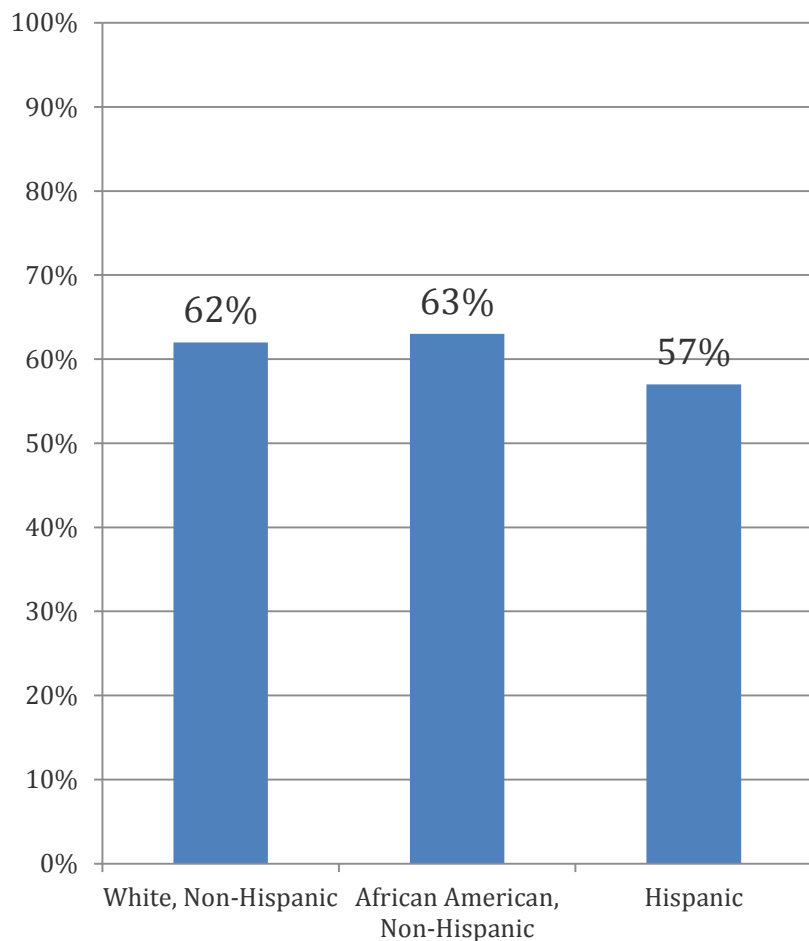


Ever had pneumonia vaccine ($p < .001$)

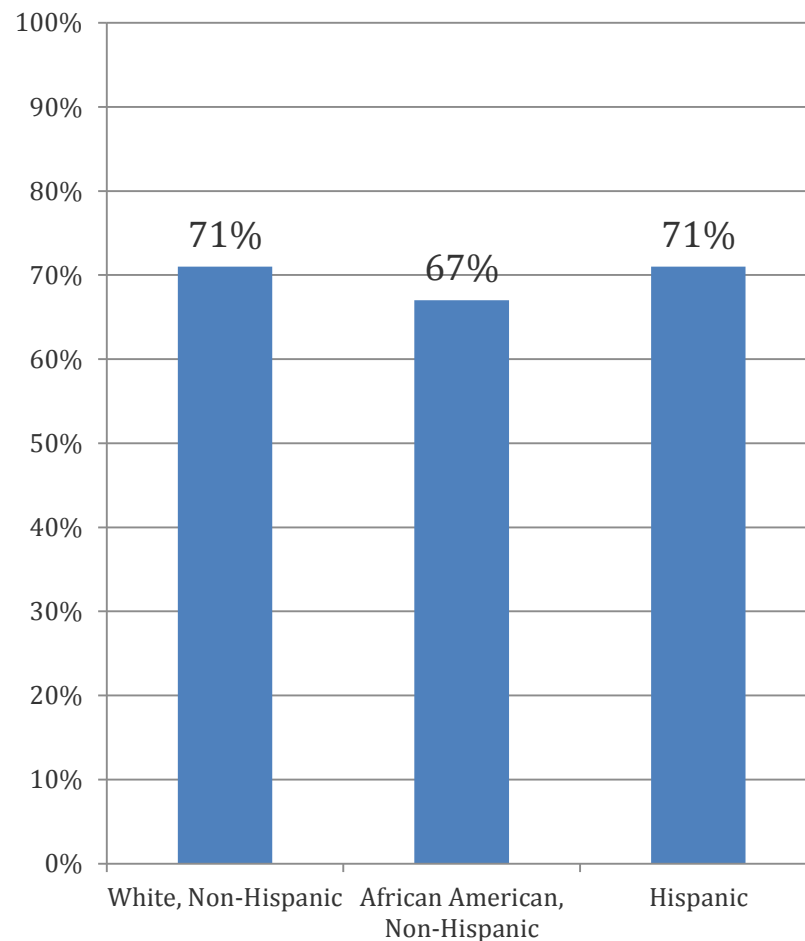


Preventive Care:

Eye Exam/Vision Screening in Past Year ($p = .09$)



Hearing Test in Past Five Years ($p < .05$)



Small Area Variation

- Rates of health care use vary over well-defined geographic areas.
- Significant variation has been shown to exist in the rates of hospitalization for diagnoses such as:
 - chronic obstructive lung disease,
 - pneumonia,
 - hypertension,
 - surgical procedures.
- Potential sources of variation include differences in underlying morbidity, access to care, physician judgment, quality of care delivered, patient demand for services, and random variation, etc.
- Need to control for State of residence.

Parchman, M. (1995) Small area variation analysis: A tool for primary care research. *Family Medicine Journal*. 27(4): 272-6



Preventive Care:

Simple binary logistic regression (odds ratios)

Controlling for state only (coefficients for state not shown)

	Primary care doc	Phys exam	Dental exam	Vision screen	Hear test	Flu vacc	Pneum vacc
White, Non-Hispanic	ref	ref	ref	ref	ref	ref	ref
African American, Non-Hispanic	1.28	0.70*	0.57*	1.12	1.01	0.61*	0.72*
Hispanic	1.33	0.62*	0.72	0.87	0.96	0.65*	0.67*

* p<.01



Controlling for State of Residence...

- African American, Non-Hispanic respondents are significantly less likely than White, Non-Hispanic respondents to have:
 - Had a physical exam in the past year
 - Had a dental exam in the past year
 - Had a flu vaccine in the past year
 - Ever had a pneumonia vaccine
- Hispanic respondents are significantly less likely than White, Non-Hispanic respondents to have:
 - Had a physical exam in the past year
 - Had a flu vaccine in the past year
 - Ever had a pneumonia vaccine



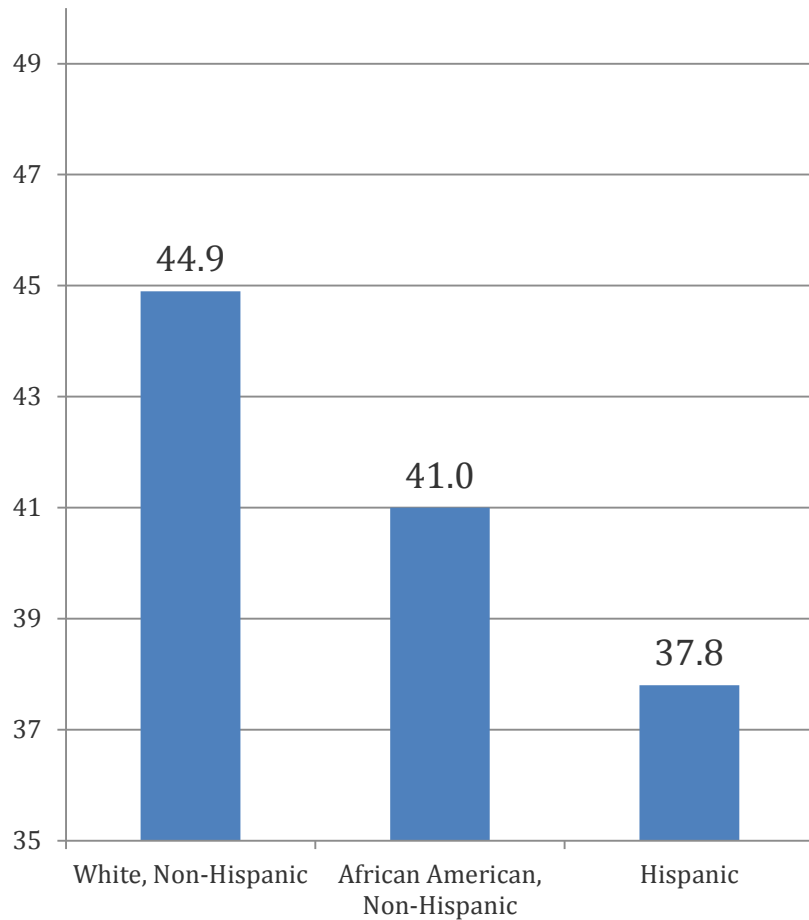
BUT...

- Differences may be due to other demographic characteristics.
- The following demographic variables were tested and found to be significantly different among the three racial/ethnic categories:
 - Age
 - Gender
 - Individual's primary language
 - Individual's primary means of expression
 - Level of intellectual disability
 - Mobility
 - Other diagnoses (in addition to ID/DD)
 - Residence type

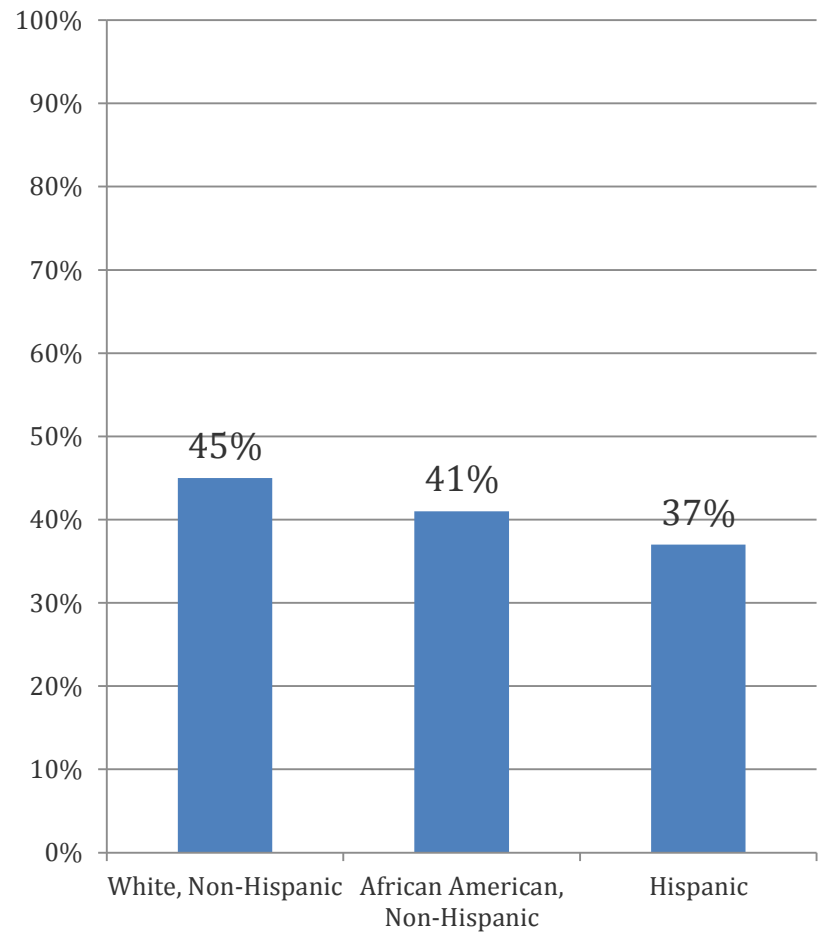


Demographic Differences:

Average Age ($p < .01$)

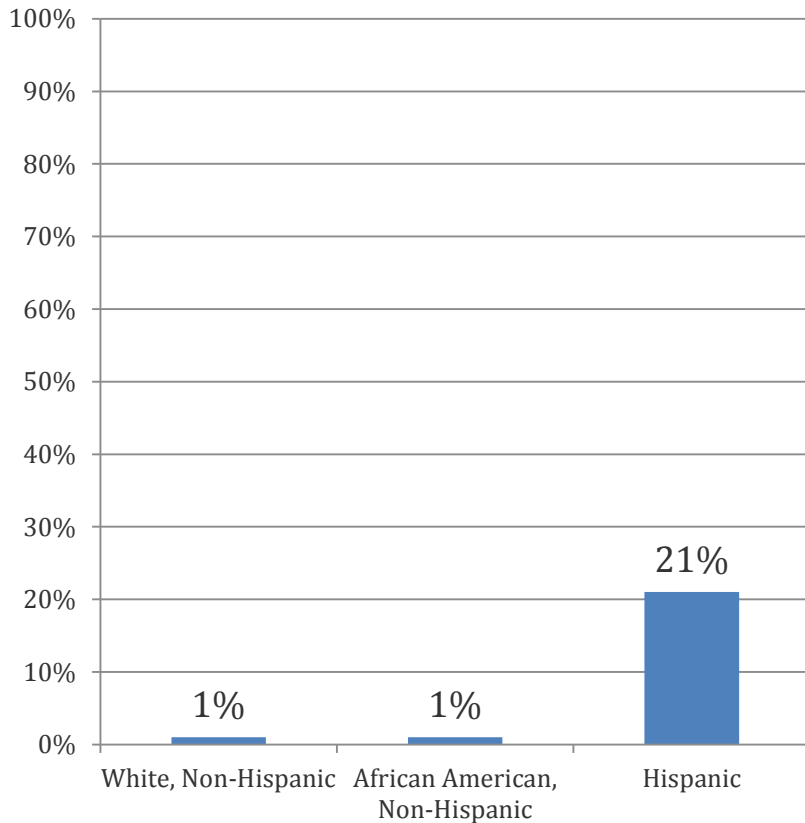


Gender, FEMALE ($p < .01$)

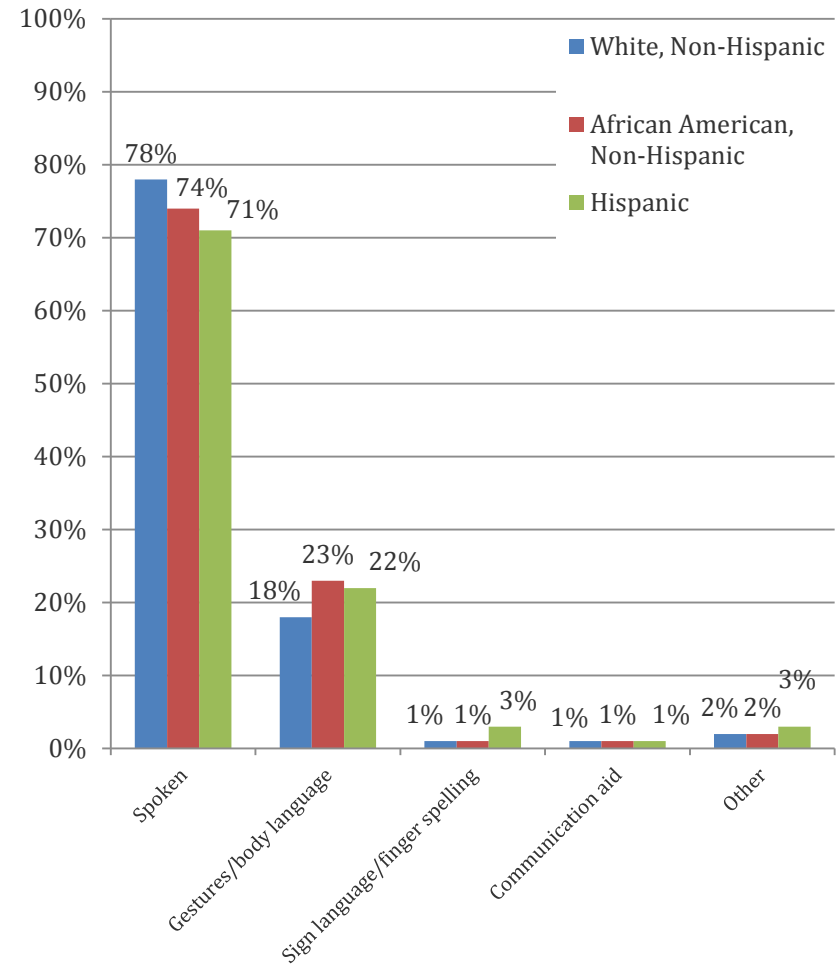


Demographic Differences:

Primary language – NON-ENGLISH ($p < .01$)

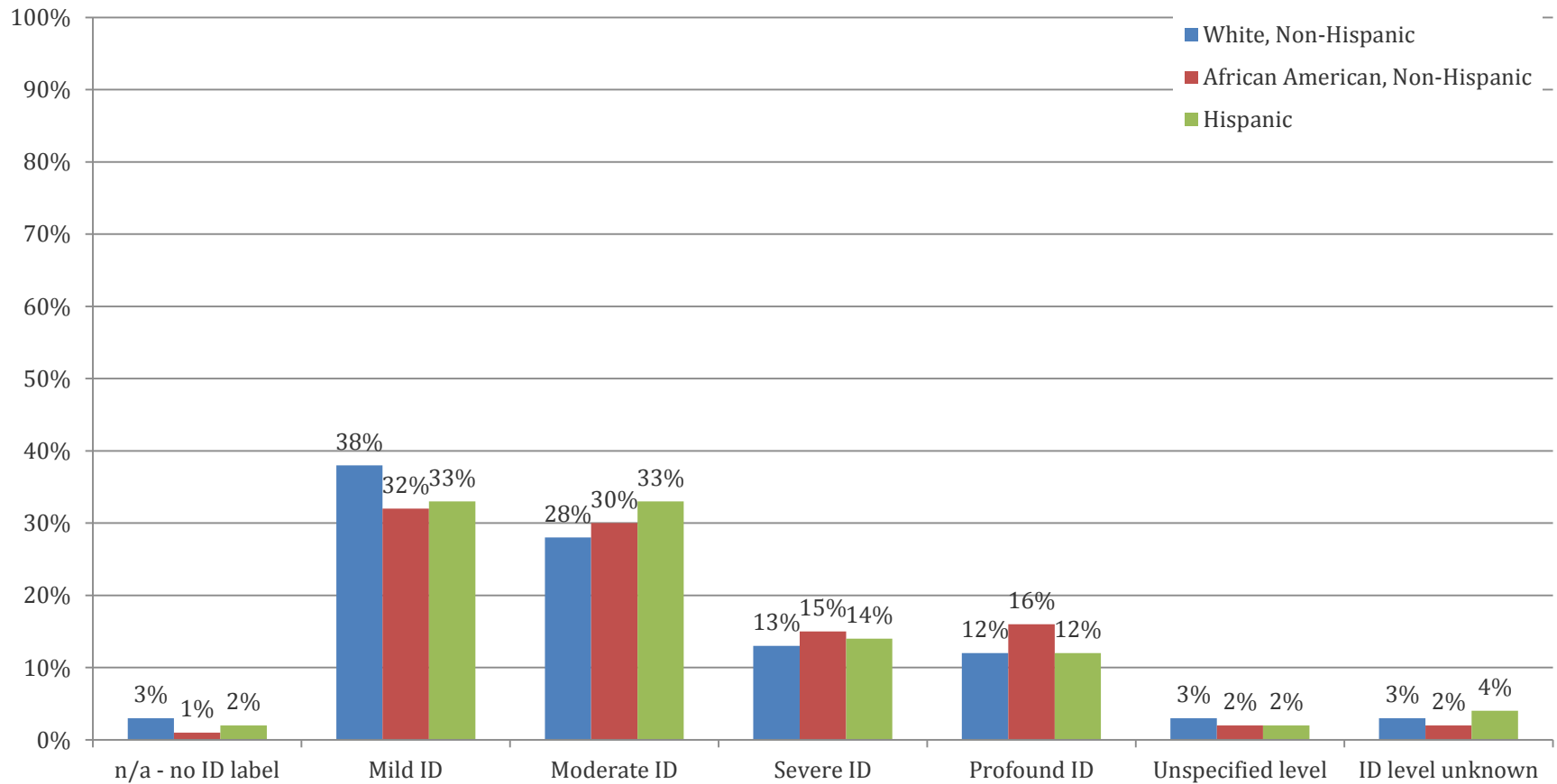


Primary means of expression ($p < .01$)



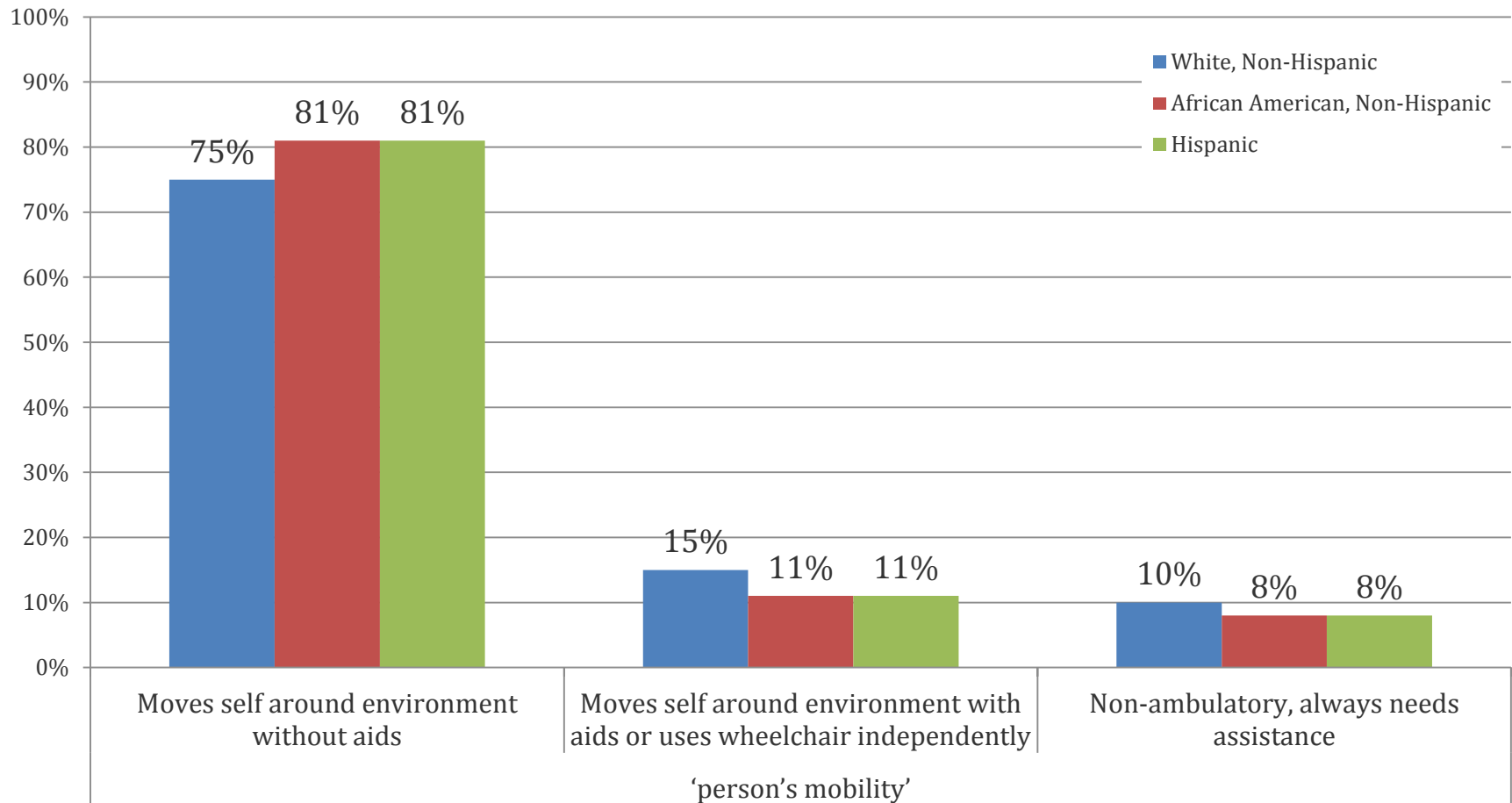
Demographic Differences:

Level of Intellectual Disability ($p < .01$)



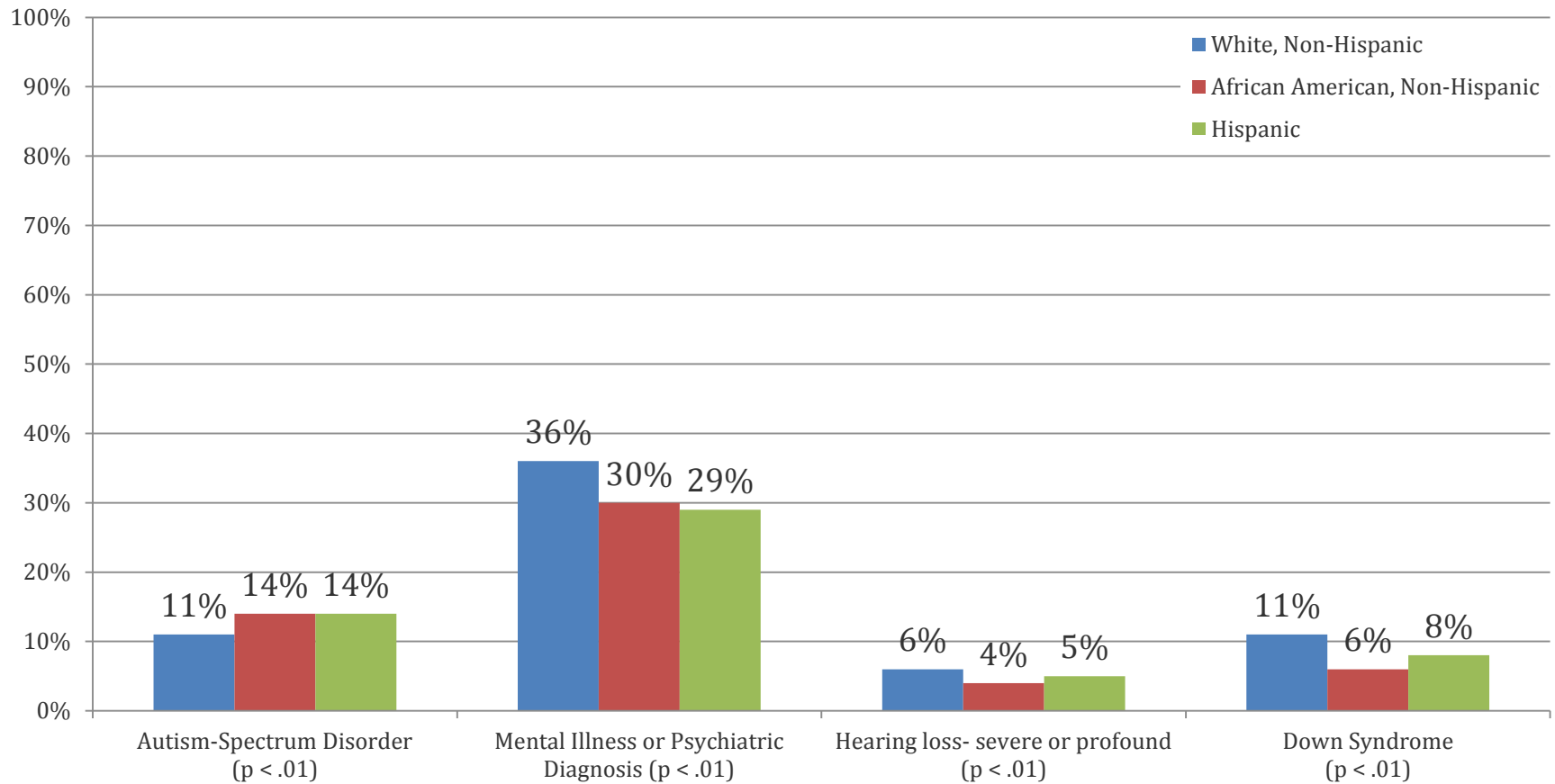
Demographic Differences:

Mobility level ($p < .01$)



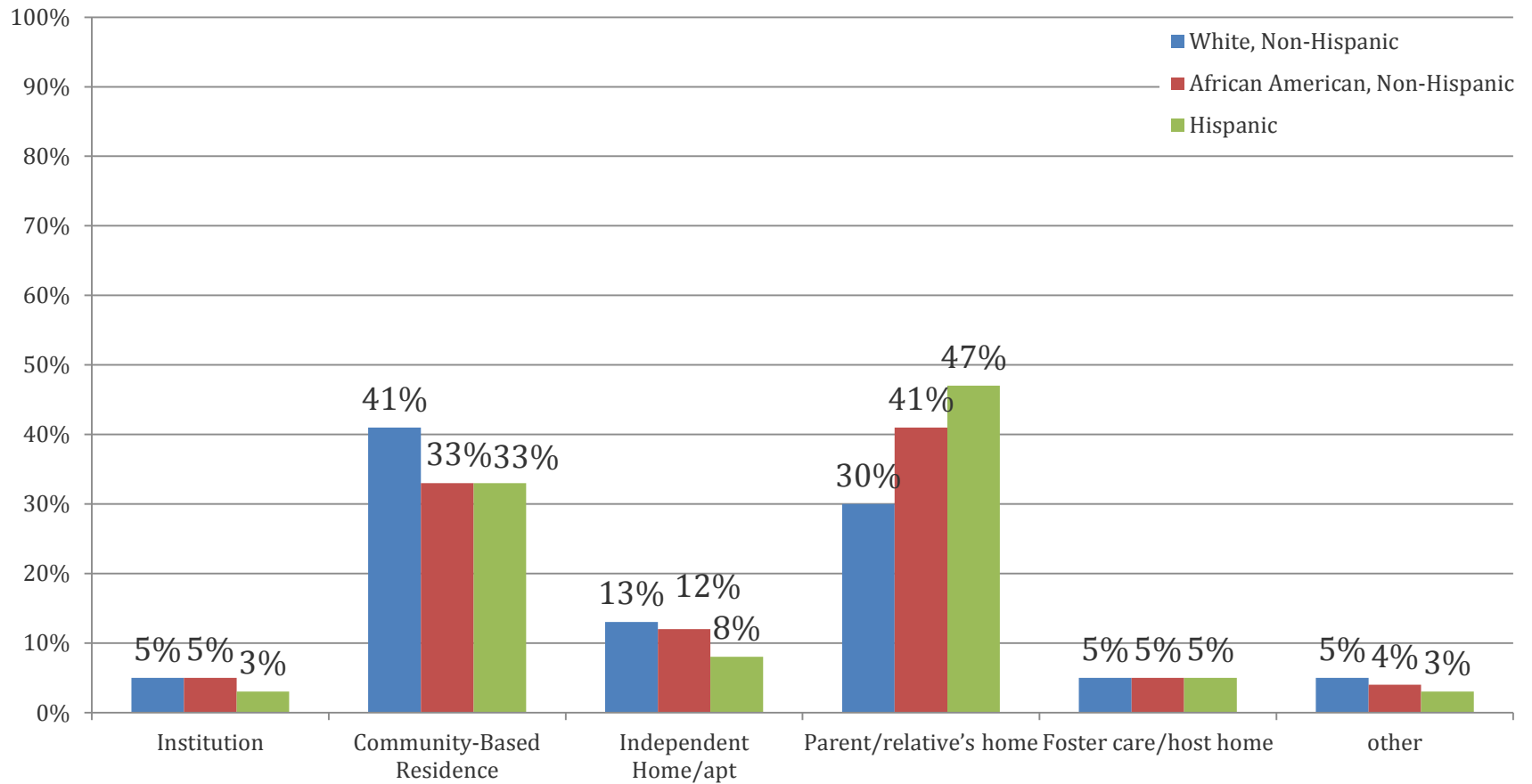
Demographic Differences:

Other diagnoses



Demographic Differences:

Residence Type ($p < .01$)



We see.....

- There are significant differences in demographic characteristics amongst individuals of differing races/ethnicities.
 - Could those differences be influencing the racial and ethnic disparities we see in preventive healthcare use?
- Logistic regression to control for these demographic differences.



Logistic Regression Results

- Controlling for:

- State;
- Age;
- Gender;
- Primary language;
- Level of ID;
- Diagnosis of mental illness;
- Diagnosis of hearing loss;
- Diagnosis of Down Syndrome;
- Poor health status;
- Residence type;
- Mobility;
- Primary mode of expression;



Coefficients not shown

	Primary care doc	Phys exam	Dental exam	Vision screen	Hear test	Flu vacc	Pneum vacc
White, Non-Hispanic	ref	ref	ref	ref	ref	ref	ref
African American, Non-Hispanic	1.6	0.82	0.60*	1.25*	1.14	0.68*	0.83
Hispanic	0.9	0.95	0.86	1.22	1.55	0.8	0.9

* $p < .01$



Controlling for State & Demographics...

- Race/ethnicity is still a significant predictor for :
 - Has had dentist visit in past year
 - African American, Non-Hispanic respondents are significantly less likely to have had a dentist visit in the past year
 - Has had eye exam in past year
 - African American, Non-Hispanic respondents are significantly more likely than White, Non-Hispanic respondents to have had an eye exam in the past year
 - Has had flu vaccine in past year
 - African American, Non-Hispanic respondents are significantly less likely than White, Non-Hispanic respondents to have had a flu vaccine in the past year
- Controlling for other demographic factors, race/ethnicity is no longer a significant predictor for:
 - Has primary care doctor
 - Has had physical exam in past year
 - Has had hearing test in the past five years
 - Has ever had pneumonia vaccine



Conclusions:

- There are apparent differences in likelihood of receiving preventive care by race/ethnicity
 - White, Non-Hispanic respondents less likely to have a primary care doc
 - White, Non-Hispanic respondents more likely to have had a physical exam, a dental exam, a flu vaccination and/or a pneumonia vaccination
- Adults with IDD of different racial/ethnic backgrounds also differ in other demographic factors
 - Where they live (both type of residence and state of residence)
 - Their age
 - Their means of expression
 - Their language
 - Their level of ID
 - Other diagnoses
 - Their level of mobility
- It is crucial to control for these demographic factors.



Conclusions:

- After controlling for demographics and state:
 - Many differences observed in descriptive analyses are no longer significant.
- However, some differences remain:
- Race/ethnicity is still a significant predictor for :
 - Has had dentist visit in past year
 - African American, Non-Hispanic respondents are significantly less likely to have had a dentist visit in the past year
 - Has had eye exam in past year
 - African American, Non-Hispanic respondents are significantly more likely than White, Non-Hispanic respondents to have had an eye exam in the past year
 - Has had flu vaccine in past year
 - African American, Non-Hispanic respondents are significantly less likely than White, Non-Hispanic respondents to have had a flu vaccine in the past year



Conclusions:

- State in which individual resides is a highly significant predictor of receipt of all preventive care variables.
- Residence type is strongly related to use of preventive care.
- Speaking a language other than English has a negative effect on receipt of a physical exam in the past year and receipt of a dental exam in the past year
- Individuals with less mobility are significantly more likely than those who are self-mobile (without using aids) to have been vaccinated against the flu and pneumonia. However, individuals who move themselves without aids are significantly more likely to have had a vision screening in the past year.
- Age is significantly related to receipt of physical exam, dentist visit and flu and pneumonia vaccines.



Limitations

- “Don’t know” responses are excluded from analyses. For some health care variables, the rate of “don’t know” responses are fairly high.
- Data less likely to be available in independent/family home settings – i.e. higher rates of “don’t know” responses.
- Choice is not taken into account - what if person does not want to get a specific test?
- There may be other pertinent factors affecting likelihood of receipt of care that were not controlled for.
- Standards regarding recommended frequency of care used are for general population.
- No data on income or SES. Previous research has shown that racial/ethnic disparities are often confounded by disparities based on SES.
- **It’s important to continue research on this topic in order to inform the development of more targeted education and outreach.**



Contacts

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 - Dorothy Hiersteiner: dhiersteiner@hsri.org
- NASDDDS
 - Mary Lee Fay: MLFay@nasddds.org
- NCI website: www.nationalcoreindicators.org



NASDDDS



Employment Trends of People with Intellectual and Developmental Disabilities, by Race and Ethnicity: 2002–2012

Alberto Migliore
Institute for Community Inclusion
University of Massachusetts Boston

National Association of State Directors of Developmental Disabilities Services
Webinar on October 29, 2013 - 3:00 to 4:00 EST

Part I

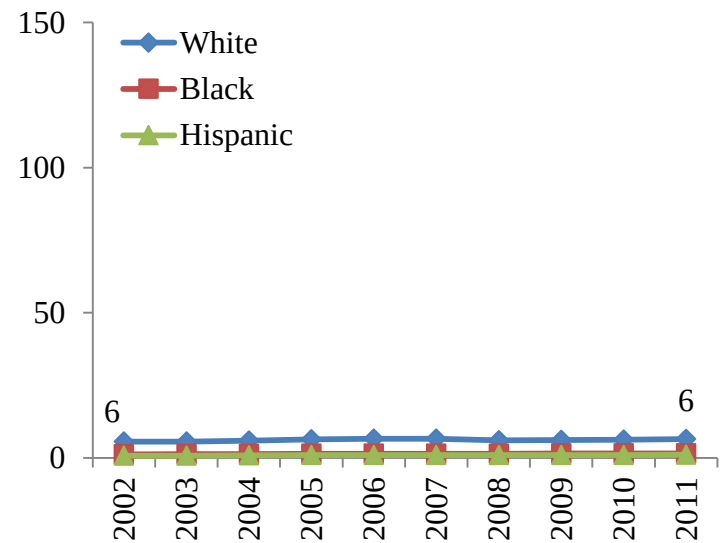
American Community Survey

- Annual survey from a sample of about three million people randomly selected from the 50 states and DC.
- Parallels the decennial census.

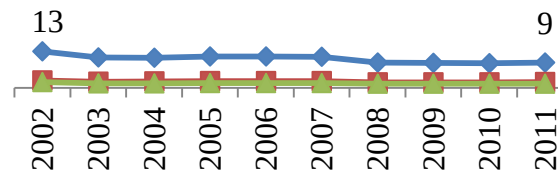


Total population ages 16–64 (in millions)

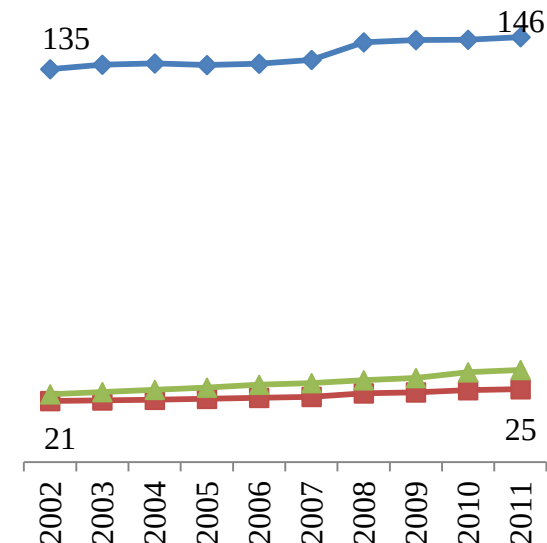
Cognitive disability



Other disabilities

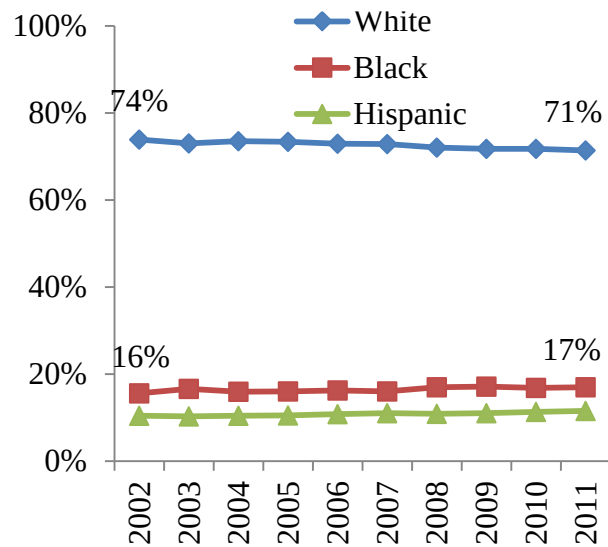


No disability

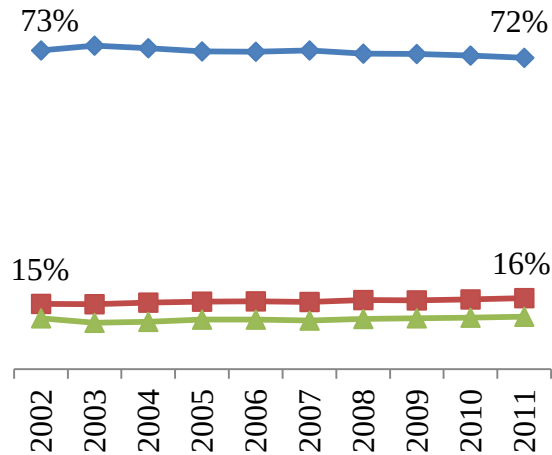


Race distribution within each group

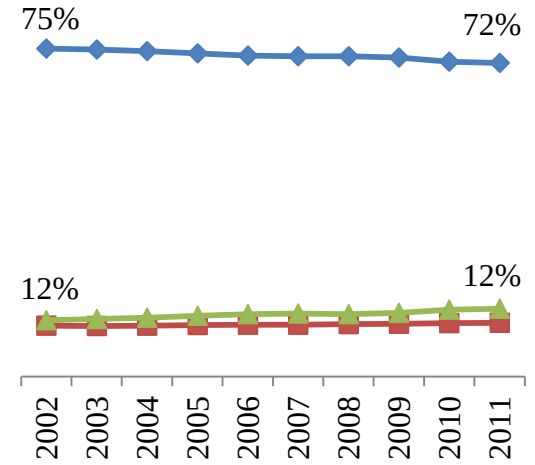
Cognitive disability



Other disabilities

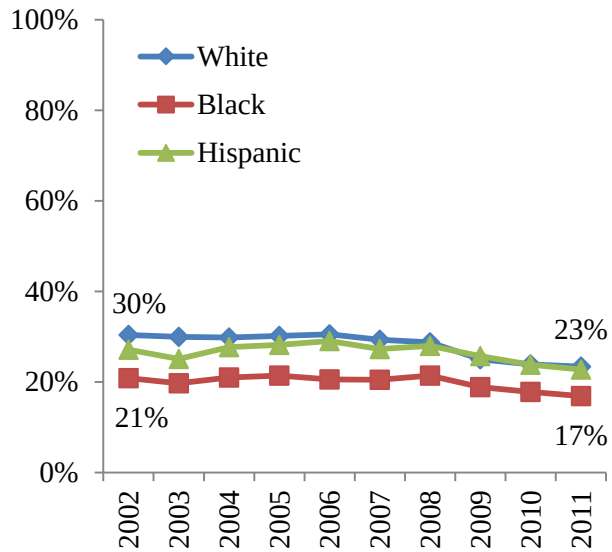


No disability

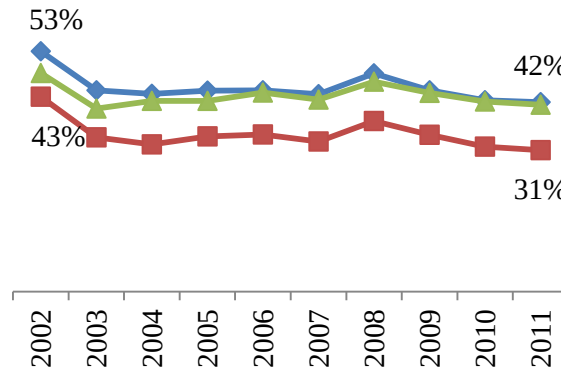


Employed

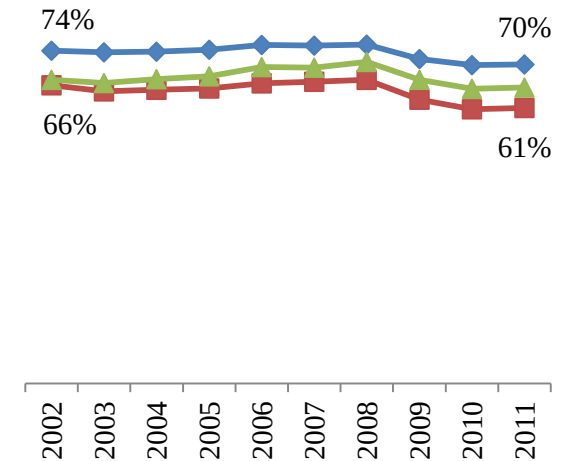
Cognitive disability



Other disabilities

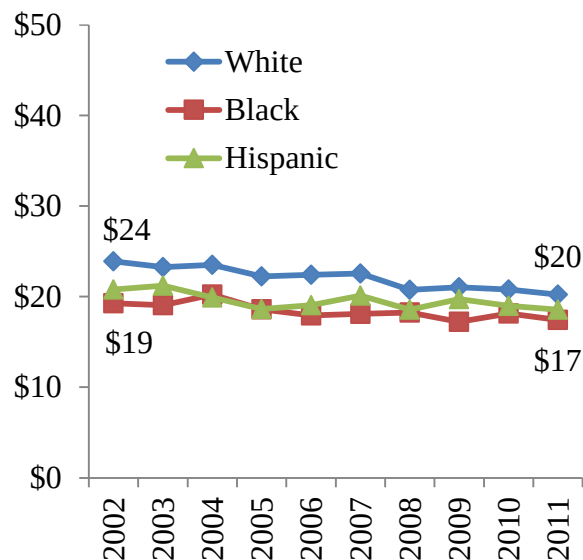


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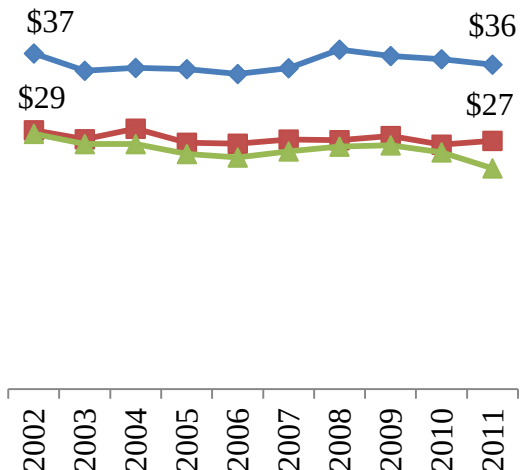


Mean annual earnings in 2011 dollars (in thousands)

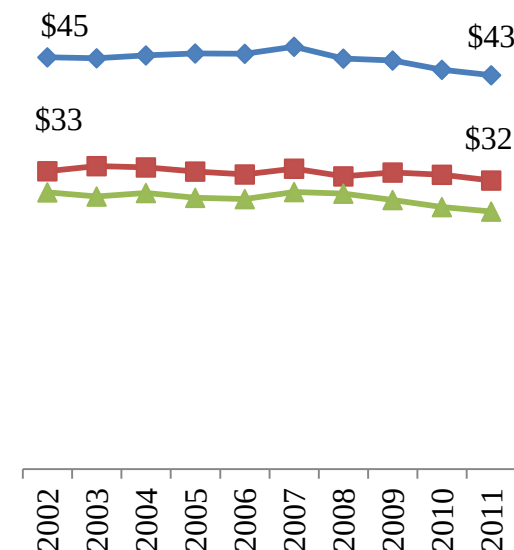
Cognitive disability



Other disabilities

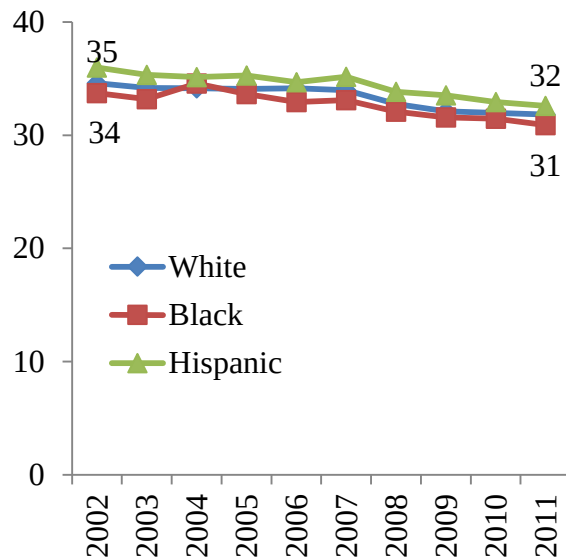


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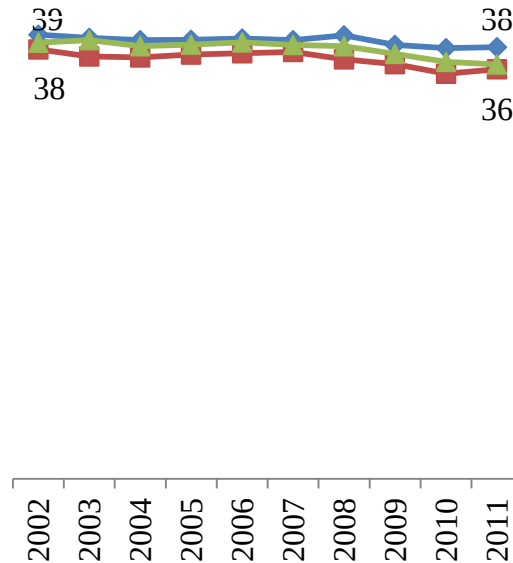


Mean weekly work hours

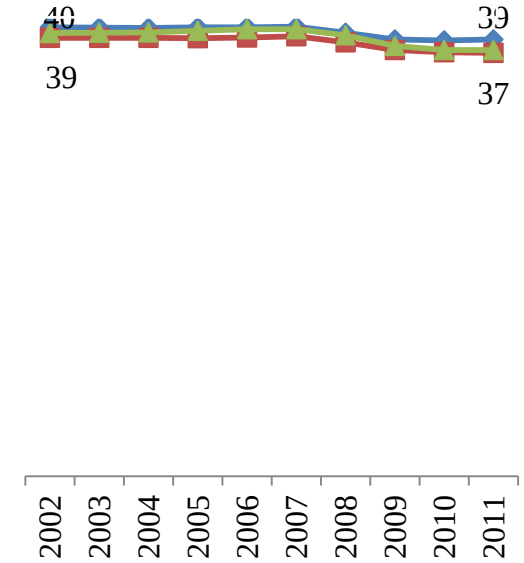
Cognitive disability



Other disabilities

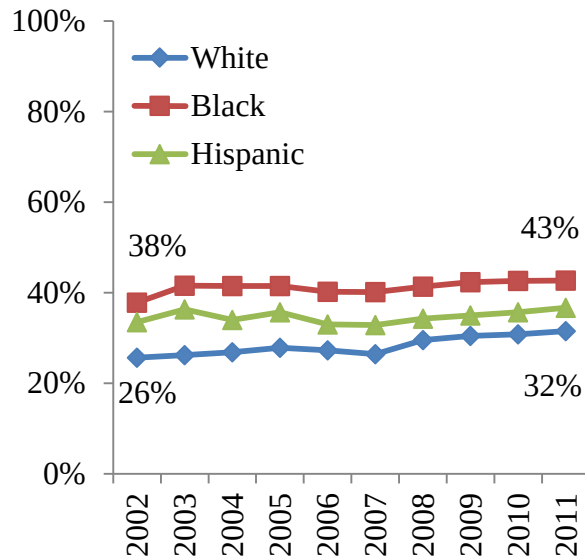


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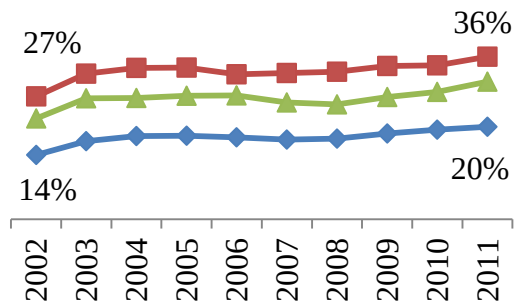


Below the poverty line

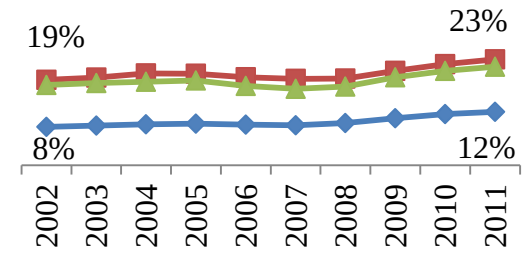
Cognitive disability



Other disabilities



No disability



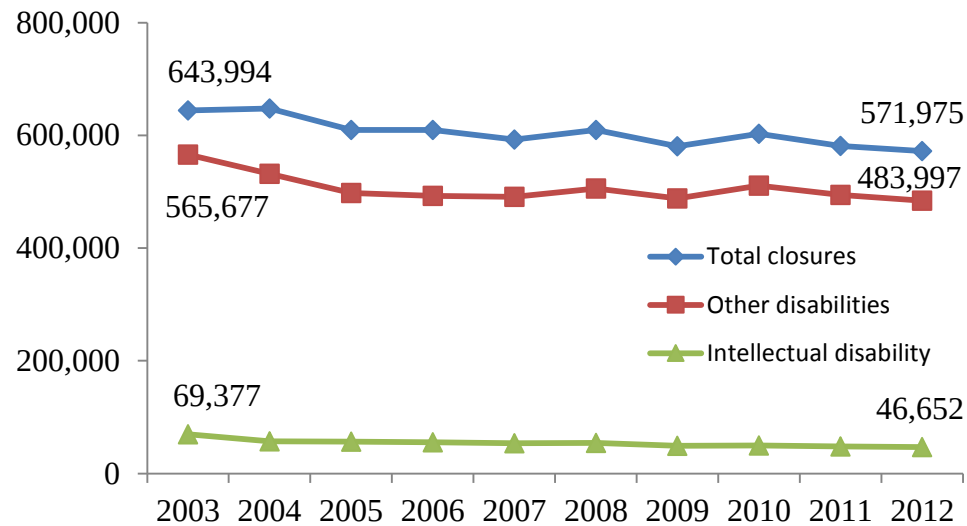
Part II

Vocational Rehabilitation Program (RSA-911)

- Administrative case-reporting about people who exited the VR program during the prior fiscal year
- Released annually

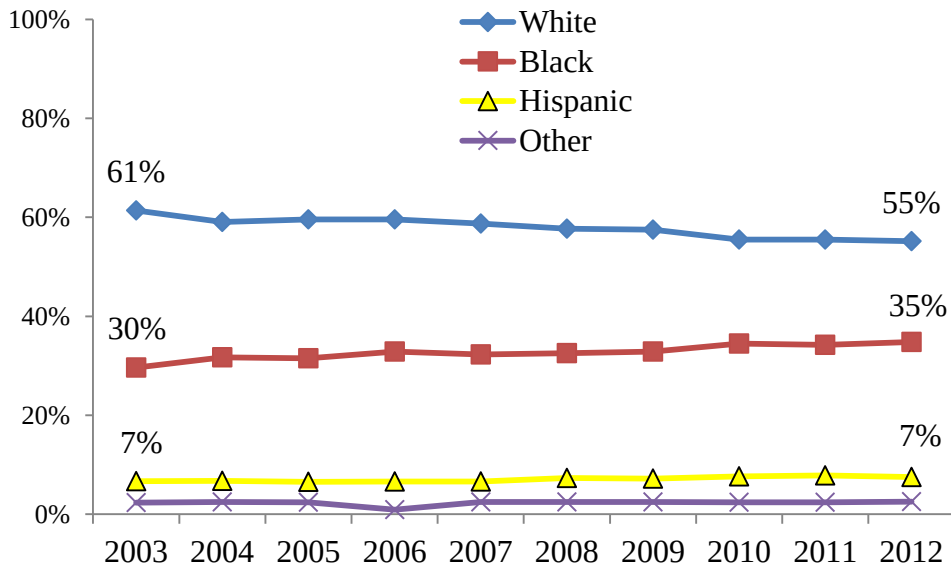


Number of people who exited VR, by disability

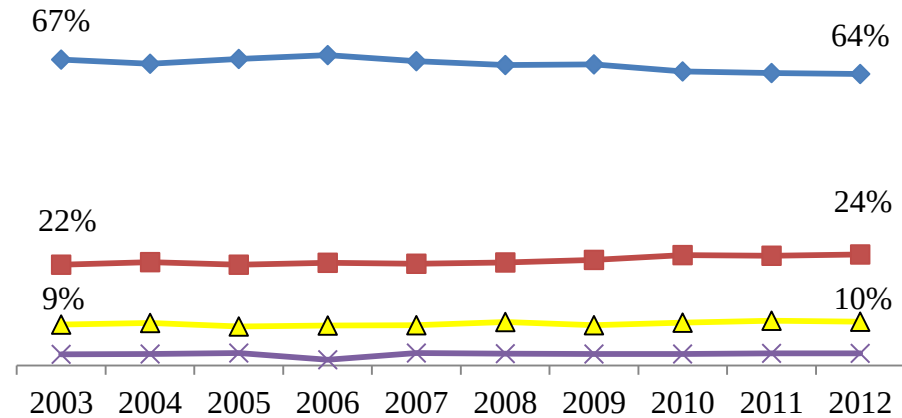


Disability and race/ethnicity distribution

Intellectual disability

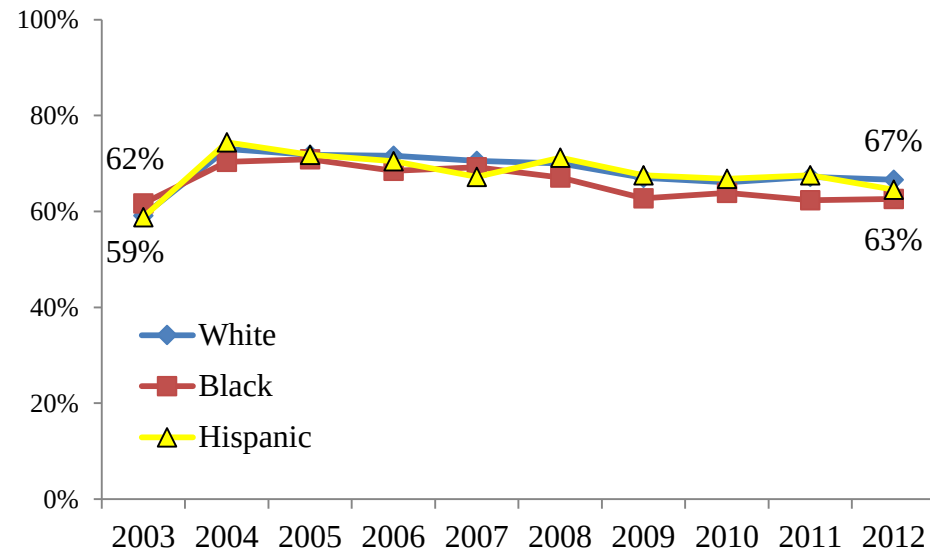


Other disabilities

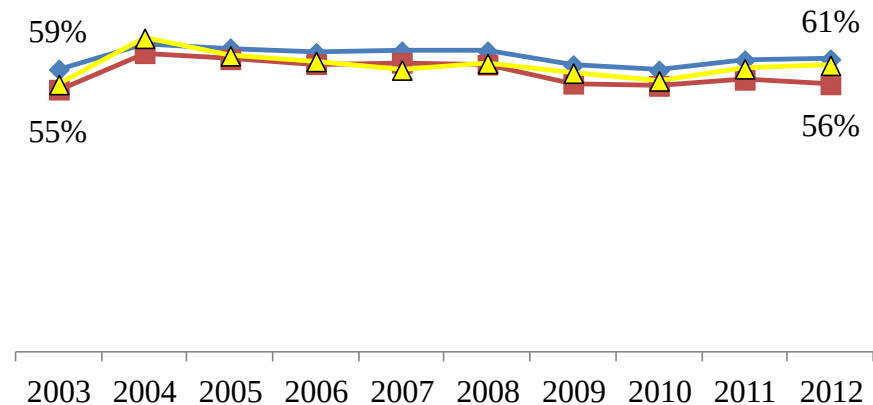


Received services

Intellectual disability

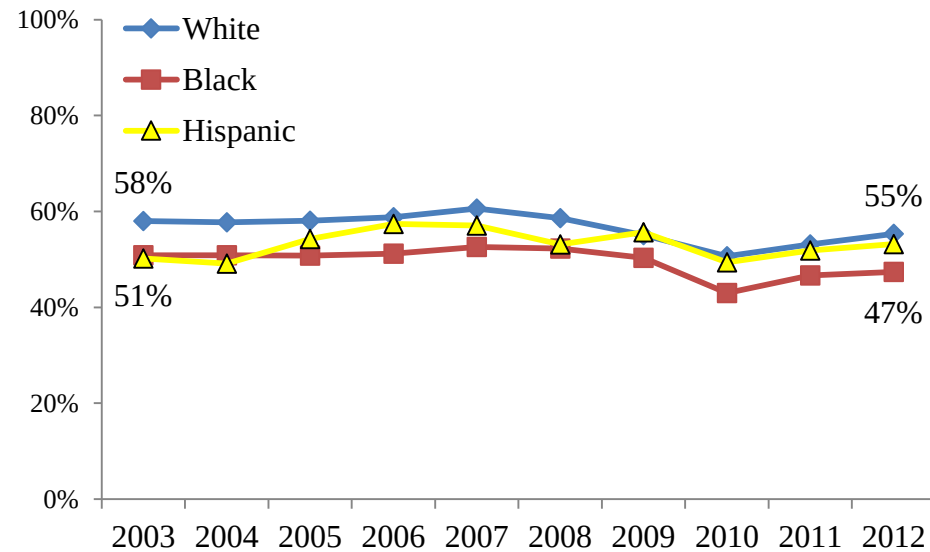


Other disabilities

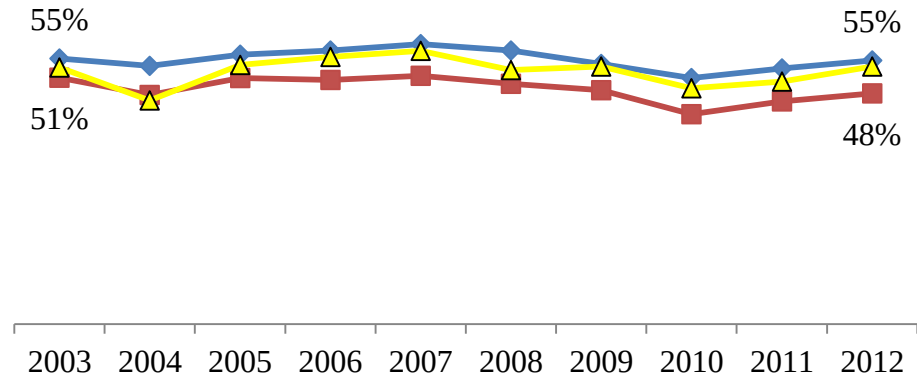


Employed after receiving services

Intellectual disability

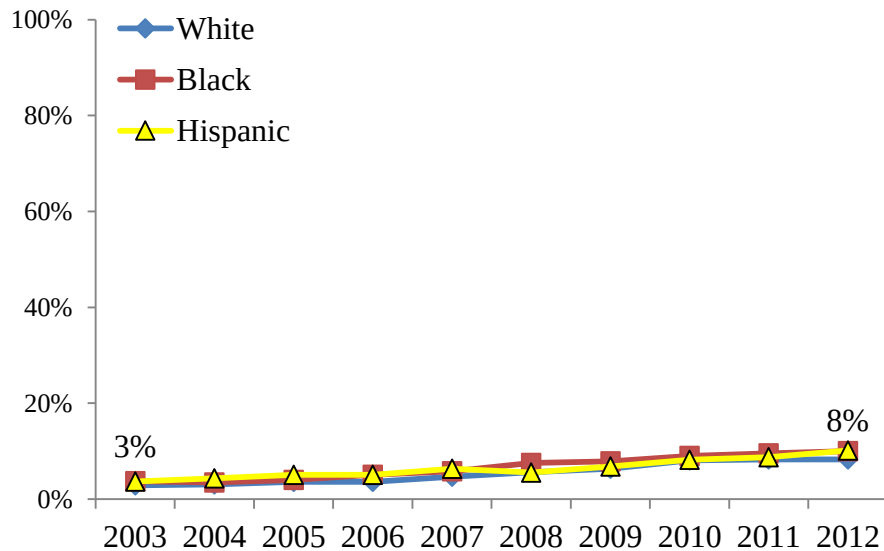


Other disabilities

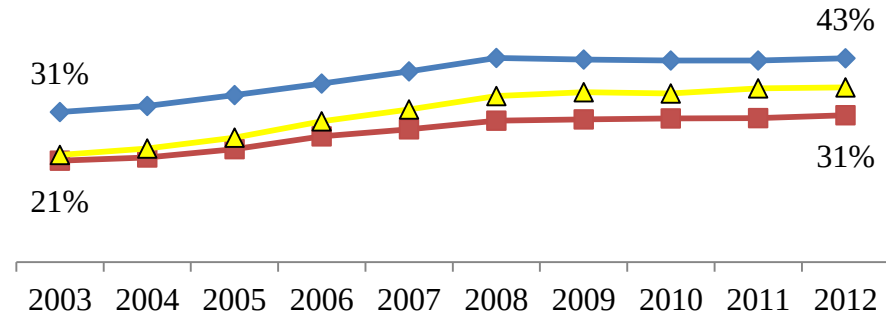


Earned \$10 per hour or more

Intellectual disability

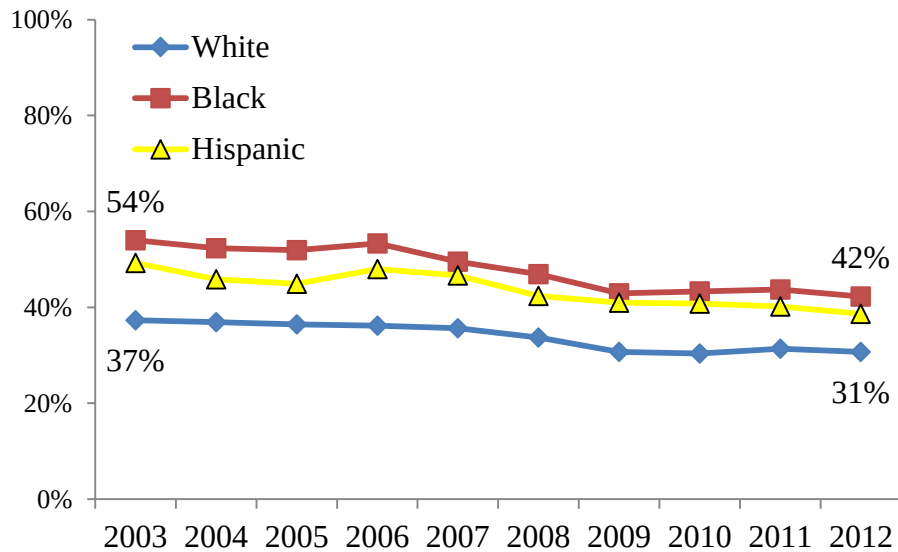


Other disabilities

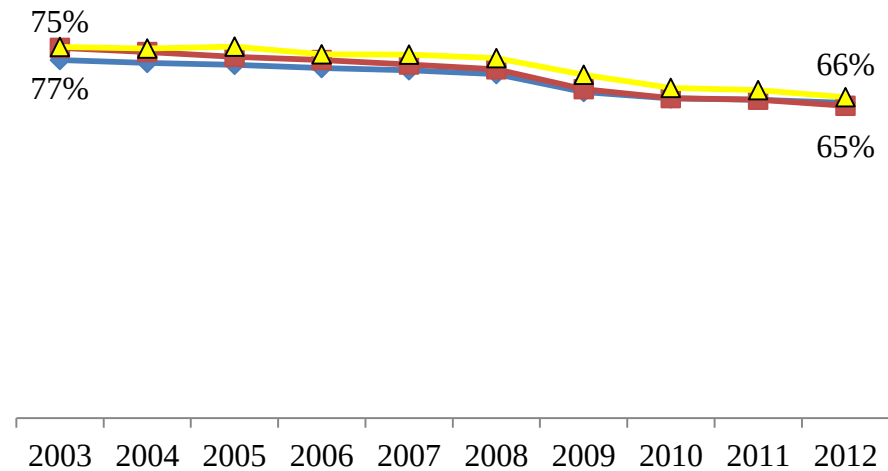


Worked 30 hours a week or more

Intellectual disability

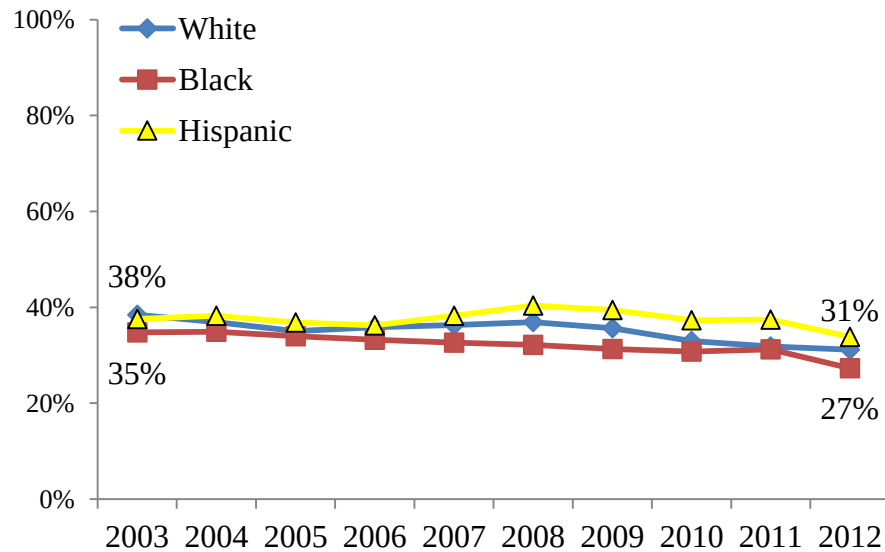


Other disabilities

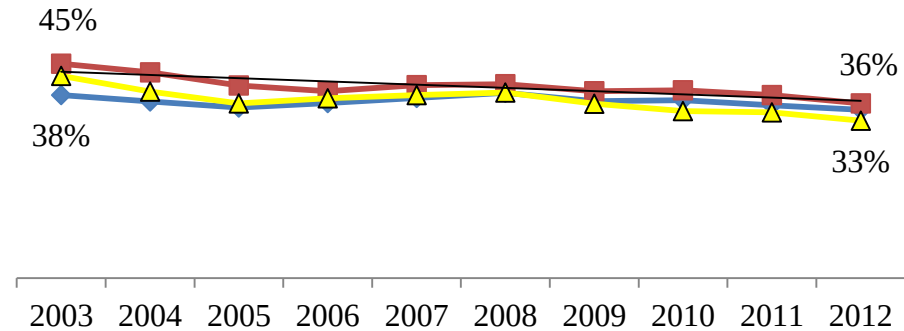


Got a job in less than one year

Intellectual disability

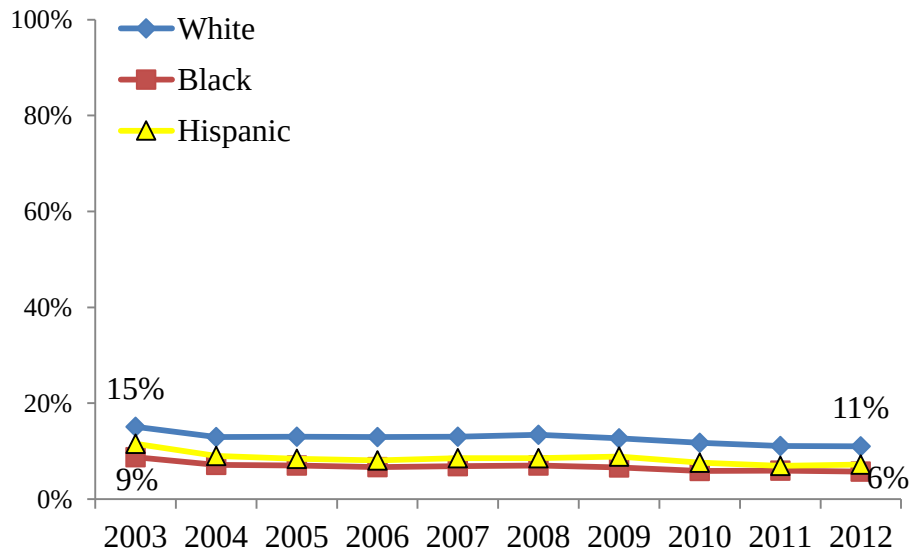


Other disabilities

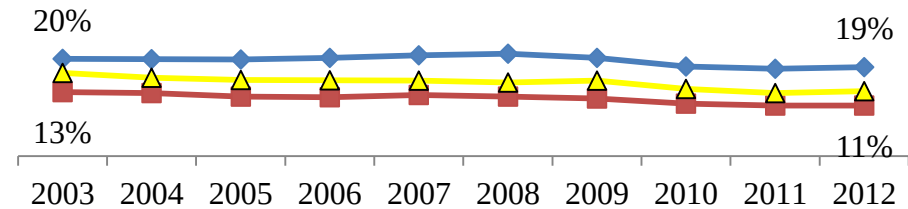


Already had a job at application

Intellectual disability



Other disabilities



Questions?

Contacts:

alberto.migliore@umb.edu

617-287-4306

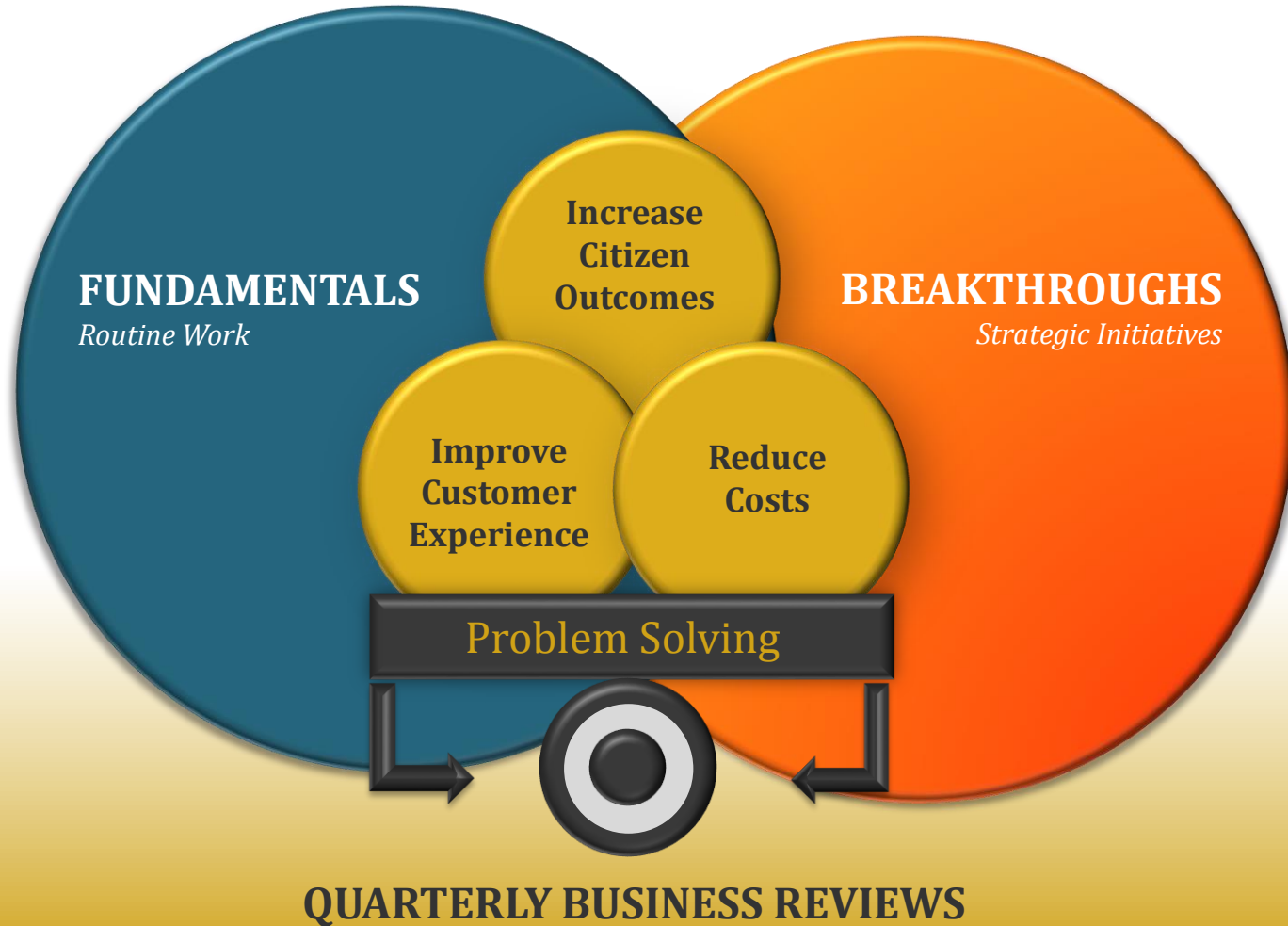
More employment charts at:

<http://www.statedata.info>

With support from Frank Smith for data analysis of the American Community Survey dataset and Anya Weber for copyediting.
Supported in part by a cooperative agreement from the Administration on Developmental Disabilities, U.S. Department of Health and Human Services, grant #90DN0295.

Oregon Office of Developmental Disability Services

Comparing Access to Services by Race and Ethnicity



MANAGING FUNDAMENTALS

OBJECTIVES

- To get the routine work done effectively with efficient use of available resources
- To connect every individual to what matters to the organization
- To create transparency about Fundamentals performance by using measures
- To transfer accountability for results to those who do the work

Race & Ethnicity Measures

Race and Ethnicity Measure: Compares distribution of services between people in I/DD services and people that self-report a disability

Outcome:	O5: Service Equity - O5a, Access
Program Indicator:	DD: Percent of minority and special populations of all DHS users divided by those same populations' % of the total disability population in the state or a geographic area.

Calculation specifications:				
Program population	Distinct count of DD services recipients in quarter. Non-Hispanics of unknown race or of two or more races should be <u>excluded</u> from all calculations, including total number served by the program. Also exclude those of races/ethnicities not listed below. Source: Administrative Data			
State Population for Comparison	Oregonians with a self-reported disability. To be consistent with the way the administrative data are pulled, the total Oregon population <u>excludes</u> non-Hispanics of 'Some Other Race' and of 'More than One Race'. Source: 2011 American Community Survey PUMS file, DHS Office of Business Intelligence calculations			
Calculation	% of distinct DD services recipients of each raceðnicity / % of Oregon disability population of each raceðnicity = Disproportionality Ratio The race/ethnicity with the greatest disproportionality ratio is entered into the QBR.			
Outcome Range	Red <0.5 OR >1.5	Yellow 0.5-0.74 OR 1.26-1.5	Green 0.75-1.25	

Period	Administrative Data			Population Data			Disproportionality Ratio
	Total Recipients of DD services (of races/ethnicities below)	Number receiving DD services of each race/ethnicity	% DD services recipients of each race/ethnicity	Oregonians with disabilities (of races/ethnicities below)	Number with disability of each race/ethnicity	% Oregonians with disabilities of each race/ethnicity	Ratio (indicator for QBR)
QBR 2013_Q2							
Non-Hispanic African American	19,778	824	4.2%	524,081	9,920	1.9%	2.2
Non-Hispanic Asian		520	2.6%		9,217	1.8%	1.5
Non-Hispanic White		16,420	83.0%		462,155	88.2%	0.9
Hispanic (all races)		1,671	8.4%		32,053	6.1%	1.4
Non-Hispanic Native American/Alaskan Native		314	1.6%		9,645	1.8%	0.9
Non-Hispanic Pacific Islander		47	0.2%		1,091	0.2%	1.1

Data indicates some groups access services at a percentage disproportionate to the larger disability community of the same race or ethnicity

Race and Ethnicity Measure: Compares distribution of services within I/DD service setting to total I/DD service population

Outcome:	O5: Service Equity - O5b, Outcomes
Program Indicator:	DD: % of distinct DD comprehensive services recipients of each race & ethnicity / % of Oregon DD population of each race & ethnicity

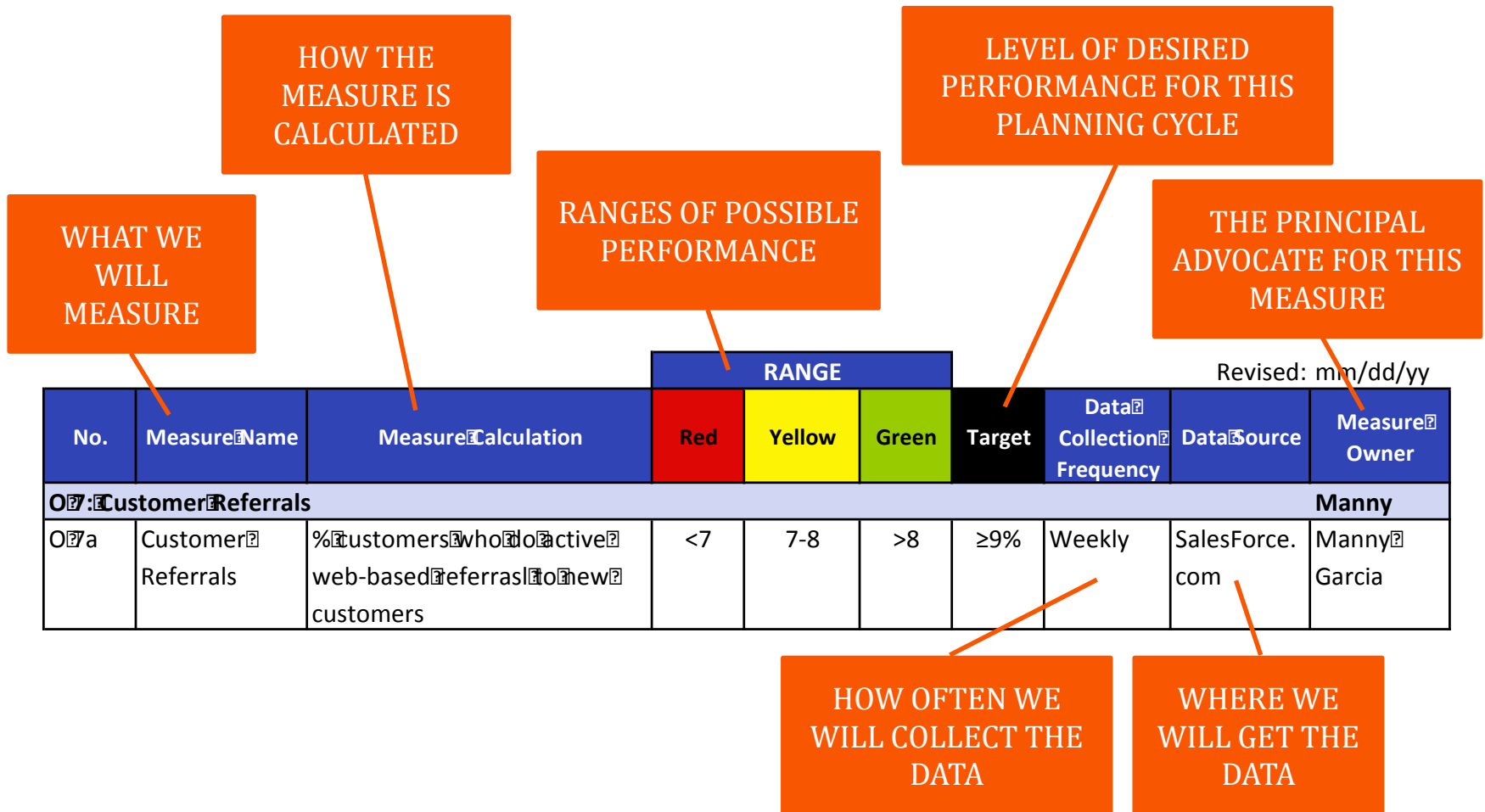
Calculation specifications:				
Program population	Distinct count of DD comprehensive services recipients in quarter. Non-Hispanics of unknown race or of two or more races should be <u>excluded</u> from all calculations, including total number served by the program. Also exclude those of races/ethnicities not listed below. Source: Administrative Data			
Comparison population: Total DD Population	Total Developmental Disabilities Population receiving at least one funded service. Source: Administrative Data			
Calculation	% of distinct DD comprehensive services recipients of each raceðnicity / % of Oregon DD population of each raceðnicity = Disproportionality Ratio The race/ethnicity with the greatest disproportionality ratio is entered into the QBR.			
Outcome Range	Red <0.5 OR >1.5	Yellow 0.5-0.74 OR 1.26-1.5	Green 0.75-1.25	

Period	Administrative Data			Total DD Population			Disproportionality Ratio
	Total Recipients of DD Comprehensive services (of races/ethnicities below)	Number receiving DD Comprehensive services of each race/ethnicity	% DD Comprehensive services recipients of each race/ethnicity	Total Oregon DD population (of races/ethnicities below)	Number of each race/ethnicity	% Oregonians in DD services of each race/ethnicity	Ratio (indicator for QBR)
QBR 2013_Q2							
Non-Hispanic African American	6,954	265	3.8%	19,778	824	4.2%	0.9
Non-Hispanic Asian		99	1.4%		502	2.5%	0.6
Non-Hispanic White		6,213	89.3%		16,420	83.0%	1.1
Hispanic (all races)		223	3.2%		1,671	8.4%	0.4
Non-Hispanic Native American/Alaskan Native		143	2.1%		314	1.6%	1.3
Non-Hispanic Pacific Islander		11	0.2%		47	0.2%	0.7

Data indicates some groups access services at a percentage disproportionate to others within I/DD services--some over-utilizing and others under-utilizing

Race & Ethnicity Scorecard

Scorecard Anatomy



Scorecard: Service Equity--Access to Services

DHS	No.	Measure Name	Measure Calculation	Red	Yellow	Green	Target	Data Collection	Data Source	Measure Owner	2013 Q2	2013 Q1	TREND	2012 Q4	Comments
DHS	OUTCOMES														
DHS	O1: Service Equity														
DHS	a	Access	Ratio: Number of members of a specific group that access/receive a specific service divided by the number of members of that specific group eligible for that specific service.	R <0.5:1 or R >1.5:1	0.5 <R >0.75 or 1.25 <R >1.5	0.75 <R >1.25	R=1	Quarterly	Forecasting Group	Carol Lamon					
DD		DD	% of individuals enrolled in ODDS services by race/ ethnicity in comparison to the disability population as a whole.							Brent Watkins		2.30%	↓	0.8 (17.7%)	
DHS	b	Outcomes	% of Programs meeting established equity goals as defined within the program.	R <0.5:1 or R >1.5:1	0.5 <R >0.75 or 1.25 <R >1.5	0.75 <R >1.25	R=1	Quarterly	TBD	Carol Lamon					
DD		DD	% of individuals receiving comprehensive services by race/ ethnicity in comparison to the total enrolled in DD services.							Brent Watkins	0.4%	Comp 12.3%, 0.4	-	Comp 12.3%,	
		DD	% of individuals receiving support services by race/ ethnicity in comparison to the total enrolled in DD services.							Brent Watkins	0.8%	1.3%	↑	0.8%	
		DD	% of individuals receiving case management only services by race/ ethnicity in comparison to the total enrolled in DD services.							Brent Watkins	2.1%	2.1%	↑	1.7%	

Each quarter, data is reviewed with department leadership by measure owners. Trends are discussed and possible explanations for the trends

How is Race & Ethnicity Data Used?

- To evaluate disproportionality of service equity
- To engage department personnel and stakeholders in a collaborative problem solving process

PROBLEM SOLVING

OBJECTIVES

- Ultimately, to improve performance
- To use data to define the problem
- To analyze the most significant root causes
- To develop and implement solutions
- Hold the gain and reflect based on learning
- Engage all levels of the organization

What have we learned?

- Some races or ethnicities are “over or under utilizing” some service settings
- The greatest disproportionality exists in our out-of-home services vs. in-home services, in which there is nearly no disproportionality
- We have more questions than answers at this point—like...

Questions driven by the data?

- What is the utilization threshold for out-of-home services? At what point do we consider utilization as “over-utilization” and conversely “under-utilization” ?
- Is over-utilization a concern?
- Are there cultural and economic considerations that affect whether out-of-home or in-home services are utilized?

Questions driven by the data?

- What is the demographic breakdown of the Office of Developmental Disability Services' out-of-home provider community? Does greater emphasis need to be given to the diversification of the provider base? If so, would more self-identified Asians and Hispanics utilize out-of-home services?
- Is there a shortage of culturally and linguistically competent services and outreach in Hispanic and Asian communities?
- Is there a demand for out-of-home services that is going unmet?

Current Activities

- The Office of Developmental Disability Services (ODDS) is making more bi-lingual forms available for public use via paper and electronic format (Application for DD services, Family Support forms, etc.). However, ODDS needs to look at other materials utilized by race and ethnicity groups for translation into native languages
- A Communications Committee was created to look at access issues related to race and ethnicity with the intent of developing statewide policies and practices to improve service equity

Next Steps

- Multi-year data analysis to evaluate trends within the race and ethnicity categories
- Gather demographic information about out-of-home provider base
- Survey service participants to glean why a particular service was chosen instead of another
- Evaluate what forms of media would improve access to information for service participants
- Use race and ethnicity data in the development of employment first policies that ensure equal access to vocational services.

Thank You!