Inclusion of Families of Children with Disabilities in Health Services Research

Health Outcomes Among Children and Families Living in Rural Communities
NIH, December 1-2, 2011

Research and Training Center on Disability in Rural Communities
University of Montana, Rural Institute on Disability

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Recruitment & Retention

- Points to Consider about Recruitment and Retention While Preparing a Clinical Research Study
- Outreach Notebook for the Inclusion, Recruitment and Retention of Women and Minority Subjects in Clinical Research *(suggestion: revise to include disability*)
- NIH Plan to Enhance Diversity
  - NIH/NSF leadership in increasing workforce development and participation of researchers /scientists with disabilities
  - Long term approach to help external researchers (and NIH review panel members) incorporate a function oriented perspective which also includes the role of environmental factors in disabling conditions, etc
  - The essence of meeting today's challenges:
    - Participation is the gold standard for measuring health outcomes
    - A primary functional health outcome for youth is participation in the workforce/economy. Youth with disability graduate and have much lower employment rates than peers with no disabilities.
- **We cannot wait that long – lets get started**

Recruitment

- Children with a disability are one of the easiest populations to find -- they are often in multiple systems
- They are in school, and have IEPs (Individualized Education Plans) and the right to a free and appropriate public education (note: partnering with rural school districts can be challenging)

Recruitment, cont.

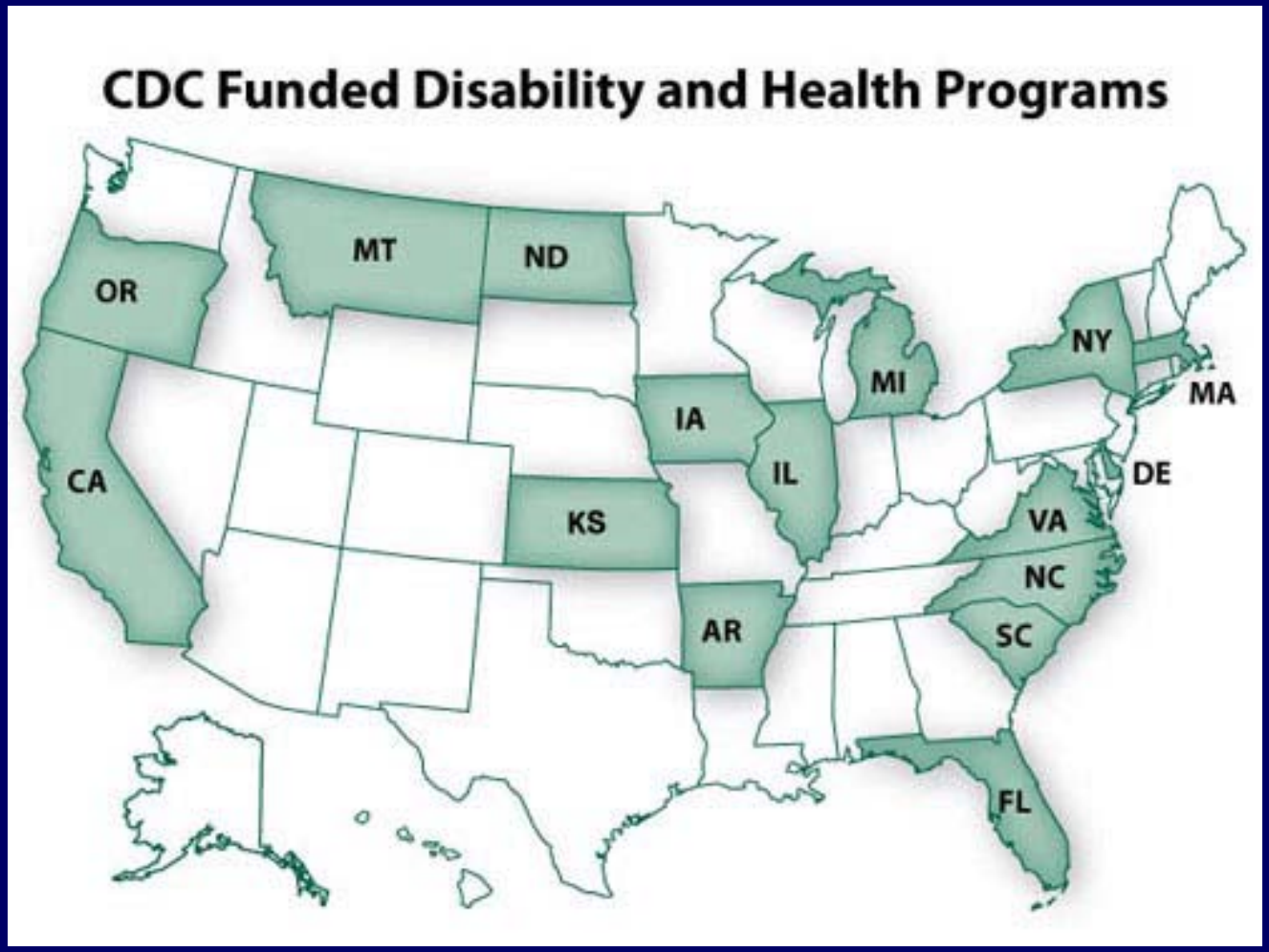
- Use generic rural recruitment strategies
- List of trusted organizations, service systems, administrative record holders may be new to you, but the approach is the same
- Physical and programmatic accessibility; material in accessible formats; interpreters; phone and online access; etc.

Examples of Potential Partners

- **CSAVR** http://www.rehabnetwork.org/ The Council of State Administrators of Vocational Rehabilitation represents the chief administrators of the 80 Public Vocational Rehabilitation Agencies serving persons with physical and/or mental disabilities in the United States. These agencies constitute the state partners in the State-Federal Program of Rehabilitation Services provided under the Rehabilitation Act of 1973, as amended. The CSAVR's members supervise the rehabilitation of some 1.2 million persons with disabilities annually across the nation.
- **CANAR** http://www.canar.org/ The Consortia of Administrators for Native American Rehabilitation, represents 81 programs that provide vocational rehabilitation services to Native Americans and Alaskan Natives with disabilities living on or near reservations or villages.
- APRIL http://april-rural.org/ Association of Programs for Rural Independent Living is a national grass roots, consumer controlled, nonprofit membership organization consisting of centers for independent living, their satellites and branch offices, statewide independent living councils, other organizations and individuals concerned with the independent living issues of people with disabilities living in rural America.
- **AUCD** http://www.aucd.org Association of University Centers on Disabilities is a network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities. Represents 3 national networks, including the 67 University Centers for Excellence in Developmental Disabilities (UCEDDs), at least one in every state. Centers work with people with disabilities, members of their families, state and local government agencies, and community providers in projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens. Federal partners include: ADD, NICHD, MCHM, CDC-NCBDDD.

16 CDC-NCBDDD Funded State Disability and Health Programs

http://www.cdc.gov/ncbddd/disabilityandhealth/programs.html



Arkansas
California
Delaware
Florida
Illinois
Iowa
Kansas
Massachusetts
Michigan
Montana
New York
North Carolina
North Dakota
Oregon
South Carolina
Virginia

National Center on Physical Activity and Disability

NCPAD: http://www.ncpad.org

- "Adaptations to Community-based Obesity Reducing National Strategies" (ACORNS). The obesity-prevention strategy adaptation portal, www.24acorns.org, was created so that persons with disabilities, teachers, clinicians, researchers, policy makers, and more could have a place to contribute their input on how to best adapt the CDC's obesity-prevention strategies to be inclusive**. The strategies for the prevention or reduction of obesity have been developed from an evidence-base of research that typically excludes participation by people with disabilities.** It is part of a grant funded by the National Institute on Disability and Rehabilitation Research (NIDRR) to **promote more inclusive community-based obesity prevention programs that represent the needs of youth and young adults with disabilities**.

Issue is not how to recruit, its WHY to recruit

- [1] Disability itself is a disparity determinant
- [2] Disability brings a framework for the contextual impact of the rural environment. WHO-ICF interaction of person/environment.
- [3] Multiple opportunities for research: inclusive; disability/chronic condition focused; routinely "longitudinal" ; retrospective analysis
- [4] Don't ask, Don't tell (if we do not ask, we cannot tell)
- [5] Innocent until proven guilty ("include" unless there is a compelling reason to "exclude")
- [6] Threats to external validity (they are going to use the generic rural systems, so they need to be included – does the research generalize appropriately)

Sec 4302 of the Affordable Care Act

- On 10-31-2011 HHS released final standards to more consistently measure race, ethnicity, sex, primary language, and disability status, thereby improving the ability to highlight disparities in health status and target interventions to reduce these disparities.
- The new data collection requirements also will improve researchers' ability to consistently monitor more dimensions of health disparities among people with disabilities.
- The standards apply to health surveys sponsored by HHS where respondents either self-report information or a knowledgeable person responds for all members of a household.
- The standards will be used in all new surveys and at the time of revision to current surveys.

www.minorityhealth.hhs.gov/section4302

Eliminating Health and Health Care Disparities Among the Growing Population of People with Disabilities

Lisa Iezzoni, *Health Affairs*, October 2011, pp 1947-1954

The Healthy People 2010 report “cited common misperceptions about people with disabilities that contribute to disparities in the services they receive, especially an ‘underemphasis on health promotion and disease prevention strategies’ ”

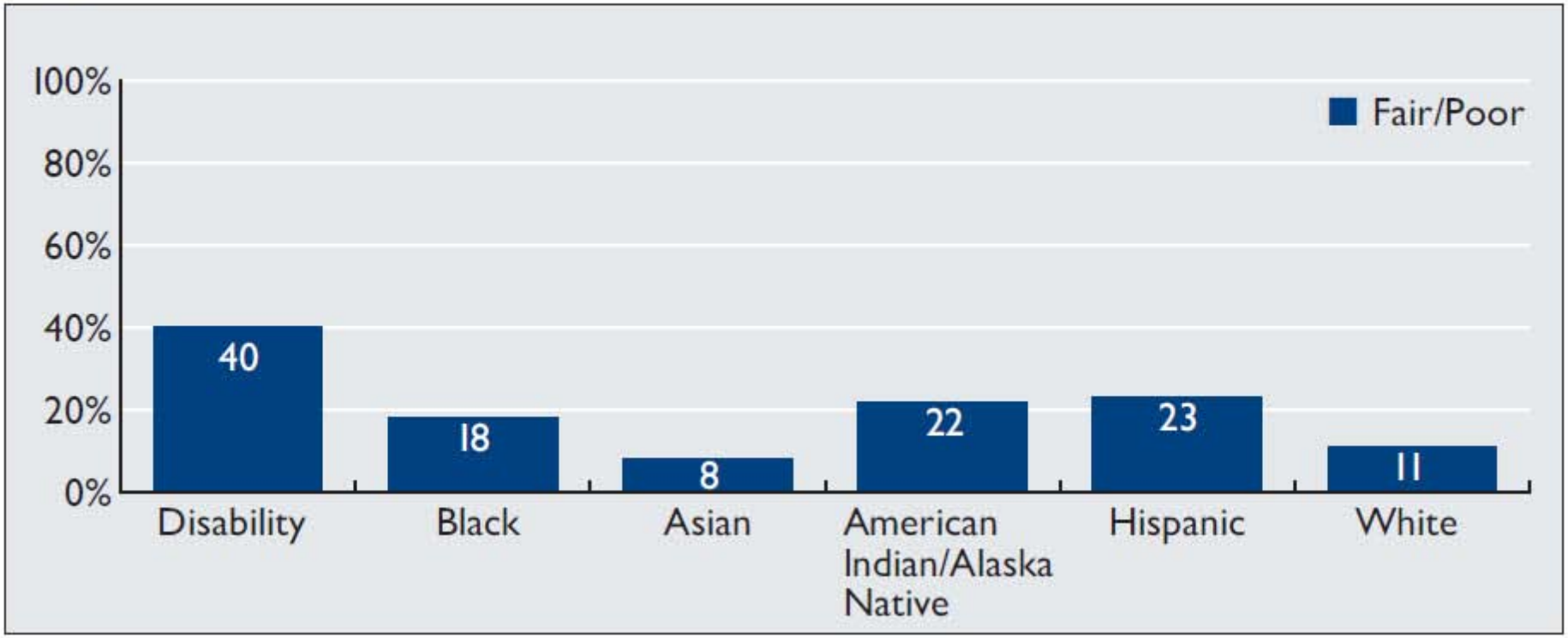
Health Disparities
Chart Book On Disability
and Racial and Ethnic Status in the United States

Charles Drum, MPA, JD, PhD, Monica R. McClain, PhD, Willi Horner-Johnson, PhD, Genia Taitano, MPH.

Institute on Disability, University of New Hampshire, 2011

http://www.iod.unh.edu/pdf/Health%20Disparities%20Chart%20Book_080411.pdf

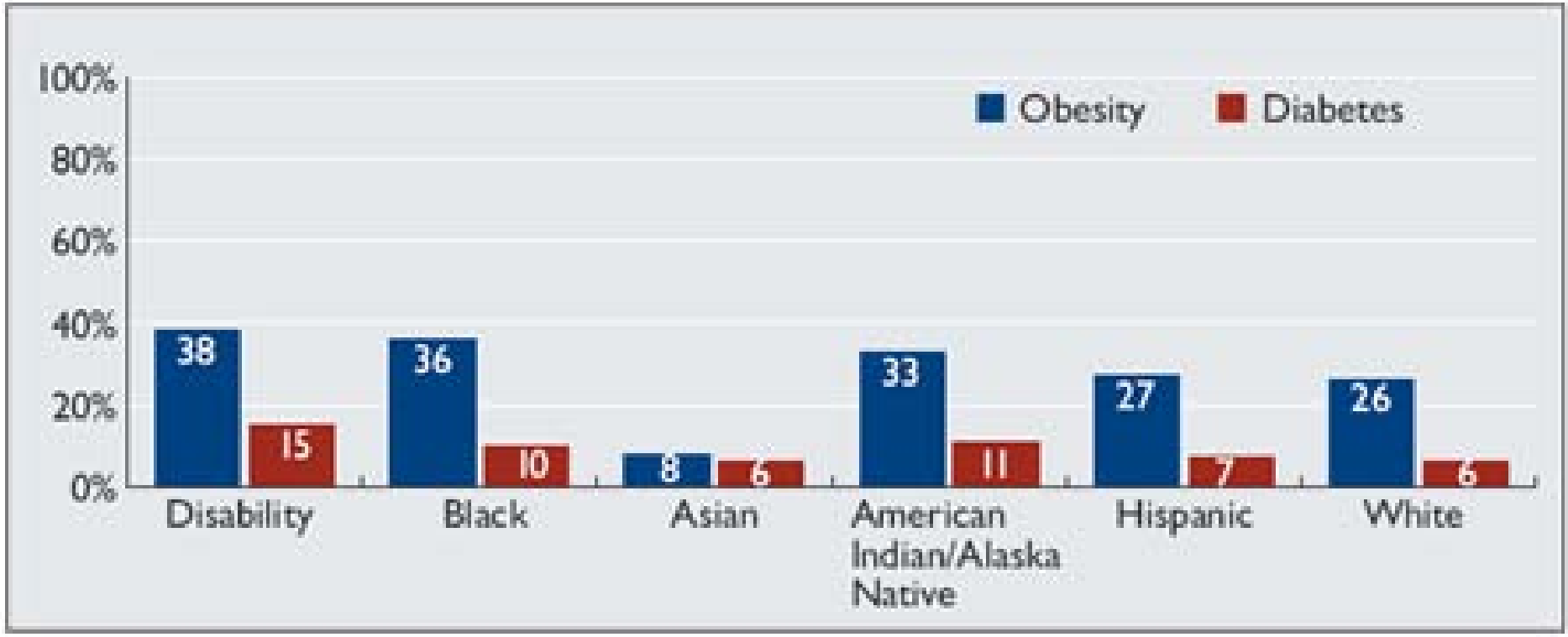
Figure 4. Prevalence of self-reported fair or poor health status among racial/ethnic groups and people with disabilities



data source: 2008 BRFSS,
working age, noninstitutionalized adults, 18-64

Source: **Health Disparities Chart Book On Disability and Racial and Ethnic Status in the United States**
Institute on Disability, University of New Hampshire, 2011
http://www.iod.unh.edu/pdf/Health%20Disparities%20Chart%20Book_080411.pdf

Figure 6. Prevalence of obesity and diabetes among racial/ethnic groups and people with disabilities



data source: 2008 BRFSS
working age, noninstitutionalized adults, 18-64

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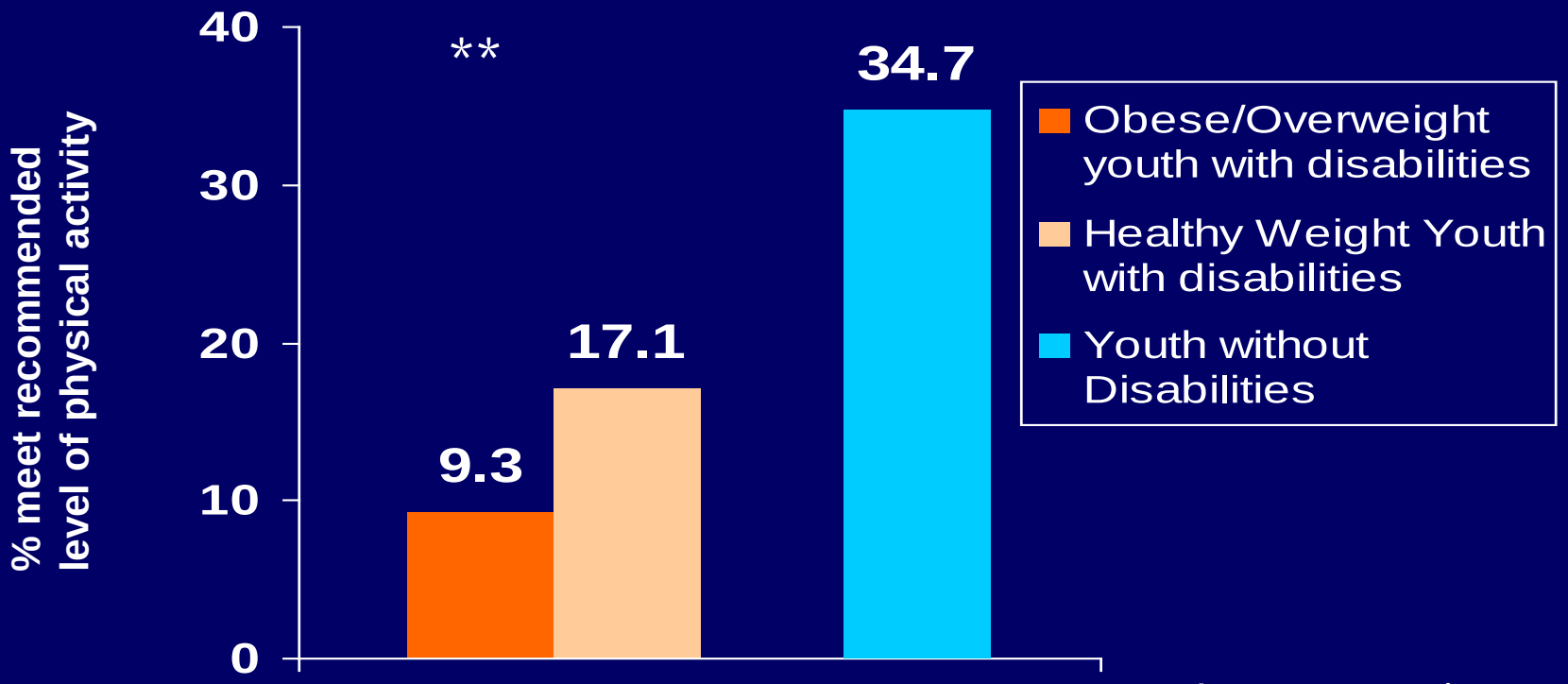
Meeting Physical Activity Guidelines



*Data on youth without disabilities from 2007 YRBS

**All group differences are significant at the p<.05 level

NCPAD

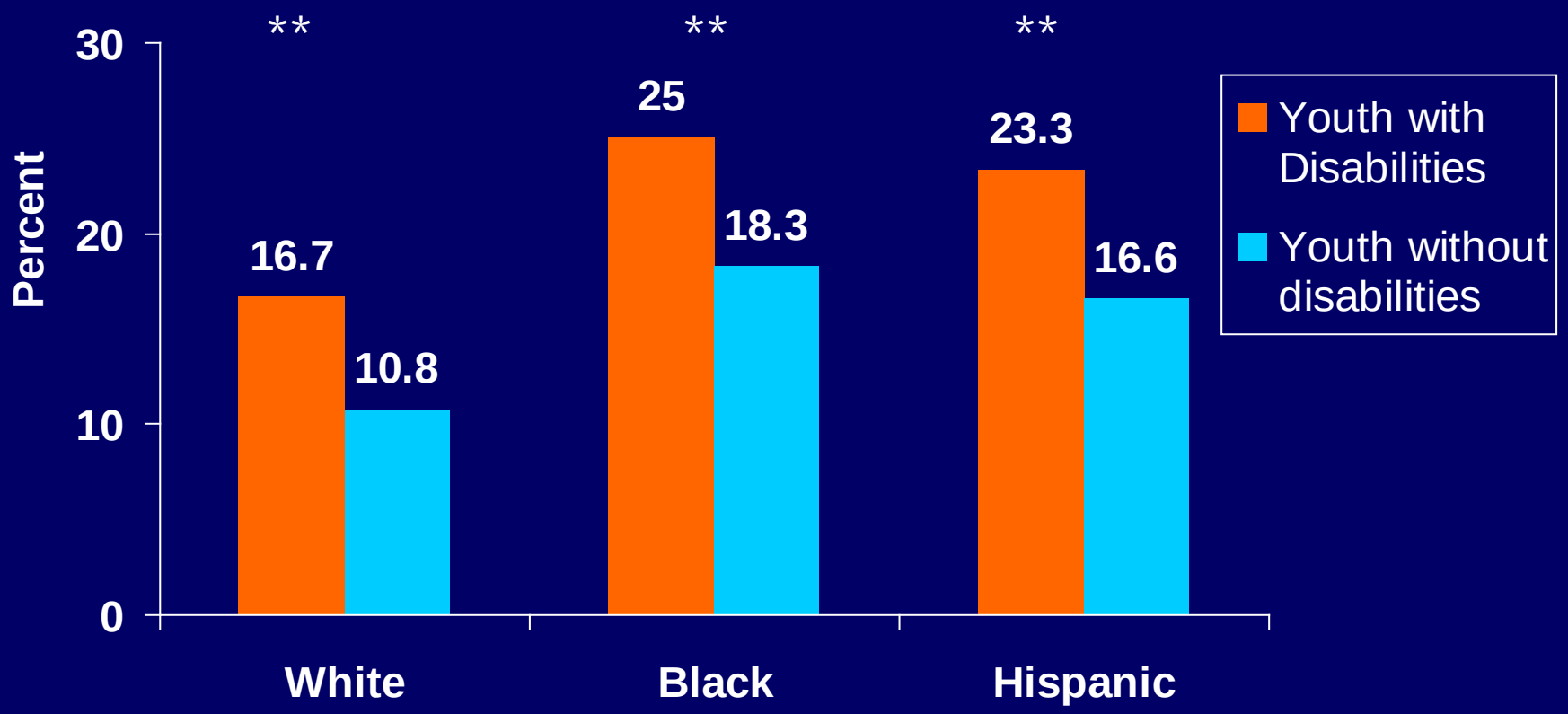
http://www.ncpad.org/

National Center on Physical Activity and Disability

Obesity Prevalence by Race

NCPAD

http://www.ncpad.org/



** **All group differences are significant at p<.05 level**

Data on youth without disabilities from 2007 YRBS

International Classification of Functioning, Disability, and Health (ICF)

- ICD classifies disease, ICF classifies health
- ICF and ICF-CY (children & youth)
  - accounts for environmental factors (physical, social, attitudinal) in causing or eliminating disability among people with functional impairments
  - shifts focus from prevention/cure to function and well-being
  - frames disability as a continuum, relevant “to the lives of all people to different degrees at different times in their lives”
  - an environmental supplement for PROMIS?

Disability Definitions

- Evolving: a medical term; a legal term (60+ federal definitions); redrawing the lines
  - emergency management (FAST), transportation, housing, etc
- A social movement
- New paradigm -- results from interaction of person and environment
- An umbrella term – ”serves the same purpose as race/ethnicity demographic variables” (UNH disparity report -2011) – e.g. “hispanic” includes people who originated from many different places, some experiences are shared, some are not; sometimes the entire group can be considered together, other times it should not be

Multiple Opportunities for Research

- Inclusive – children and youth with disabilities are specifically included in all children's research protocols
  - *Innocent until proven guilty*, i.e. include unless there is a compelling reason to exclude
  - *Avoiding threats to external validity - Rural families and children with disabilities are going to use the generic rural systems. Does the research generalize appropriately?*
- Baseline and Longitudinal – including disability/chronic condition questions in all protocols to see how/when disability/chronic condition increase with age (the HRSA study points to the increases in adolescence)
  - *Don't ask, Don't tell* (if we do not ask, we cannot tell)
- Disability/chronic condition focused; "unpack" into the appropriate disability sub-category(s)

Opportunities for Research, cont.

- Rural research leadership - children with disabilities are not well included even in urban areas; rural can be a good place to explore innovation – and no one pays much attention to rural work (at least initially) so it's a place to try out more inclusive methods

- A science of environment: rural is an "environment" so it's hard to ignore the environment component. Move beyond risk/hazard to examine resilience and protective factors

- Health services systems research; e.g.
  - do doctors adhere to evidence based protocols when the child has a disability?
  - deviation in treatment "judgments" when the child has a disability?
  - relationship between medical care provided and functional outcome/participation

- Retrospective analysis – adults who were rural children with disabilities (did they have to move to urban areas to get services and supports for access and function? What did they need to stay in rural area?)

Additional points

- Rural disability demographics challenges
  - 0-5 population: only sensory questions are asked; look for alternatives, eg administrative data (note – the ACS questions are] used in the HHS survey questions standards)
  - ACS disability questions were changed in 2008, which reset the cycle on data availability. First 3 year estimates available this month. First 5 year estimates not available until late 2013. (i.e. no disability available on geographic areas with less than 20,000 population)

- Census November 2011 report: School-Aged Children With Disabilities in U.S. Metropolitan Statistical Areas: 2010 includes some non-metro data: http://www.census.gov/prod/2011pubs/acsbr10-12.pdf

- Community Base Participatory Research methods as a means of setting research agenda and priorities

- Children grow up – parents and grandparents with disabilities

V. Disability Status

Data Standard for Disability Status

1. *Are you deaf or do you have serious difficulty hearing?*
   a. ____Yes
   b. ____No

2. *Are you blind or do you have serious difficulty seeing, even when wearing glasses?*
   a. ____Yes
   b. ____No

3. *Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)*
   a. ____Yes
   b. ____No

4. *Do you have serious difficulty walking or climbing stairs? (5 years old or older)*
   a. ____Yes
   b. ____No

5. *Do you have difficulty dressing or bathing? (5 years old or older)*
   a. ____Yes
   b. ____No

6. *Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)*
   a. ____Yes
   b. ____No

American Community Survey Disability Data by date of release and Areas' Population Size	Year of Data Release										
	2000	2001-2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Decennial census: entire population		Census 2000							Census 2010		
disability data		X							NO		
ACS annual estimates: population 65,000+				2005 data	2006 data	2007 data	2008 data	2009 data	2010 data	2011 data	2012 data
disability data, old ACS question				X	X	X					
disability data, new ACS question							X	X	X	X	X
ACS 3 year averages: population 20,000-65,000						2005-2007 data	2006-2008 data	2007-2009 data	2008-2010 data	2009-2011 data	2010-2012 data
disability data, old ACS question						X					
disability data, new ACS question									X	X	X
ACS 5 year averages: population under 20,000, census tracts and block groups								2005-2009 data	2006-2010 data	2007-2011 data	2008-2012 data
disability data, old ACS question											
disability data, new ACS question											X

Alexandra Enders, RTC:Rural, University of Montana, January 2009
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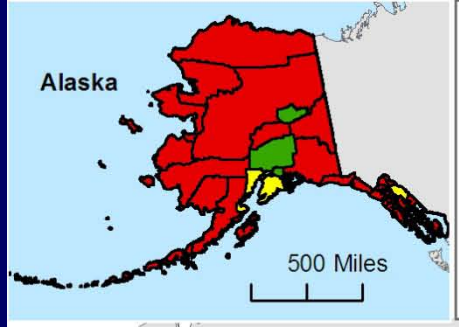
US Census American Community Survey Data Characteristics

Starting in 2010, ACS population data will be available for all counties..

Depending on county population size, data will be drawn from the previous 1, 3, or 5 year period:

- **populations 65,000 and over: 1 year estimates**
- **populations 20,000 to 65,000: 3 year estimates**
- **populations under 20,000: 5 year estimates**



0 125 250 500 Miles

US Counties

2009 Population

under 20,000	(1326)
20,000 - 65,000	(1024)
over 65,000	(792)

Source: US Census
2009 Population Estimates

Alexandra Enders, 2010
Alexandra.Enders@gmail.com

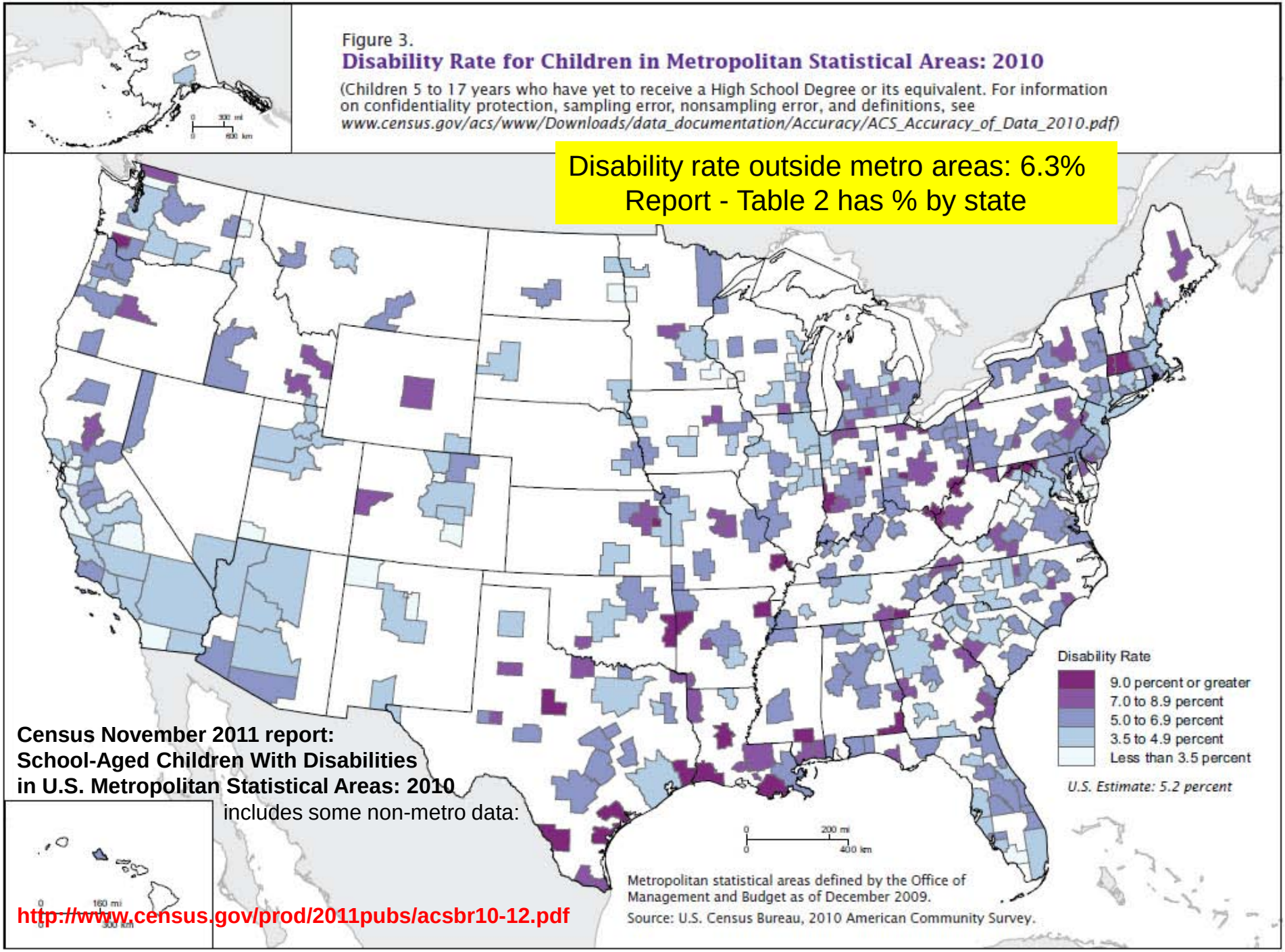
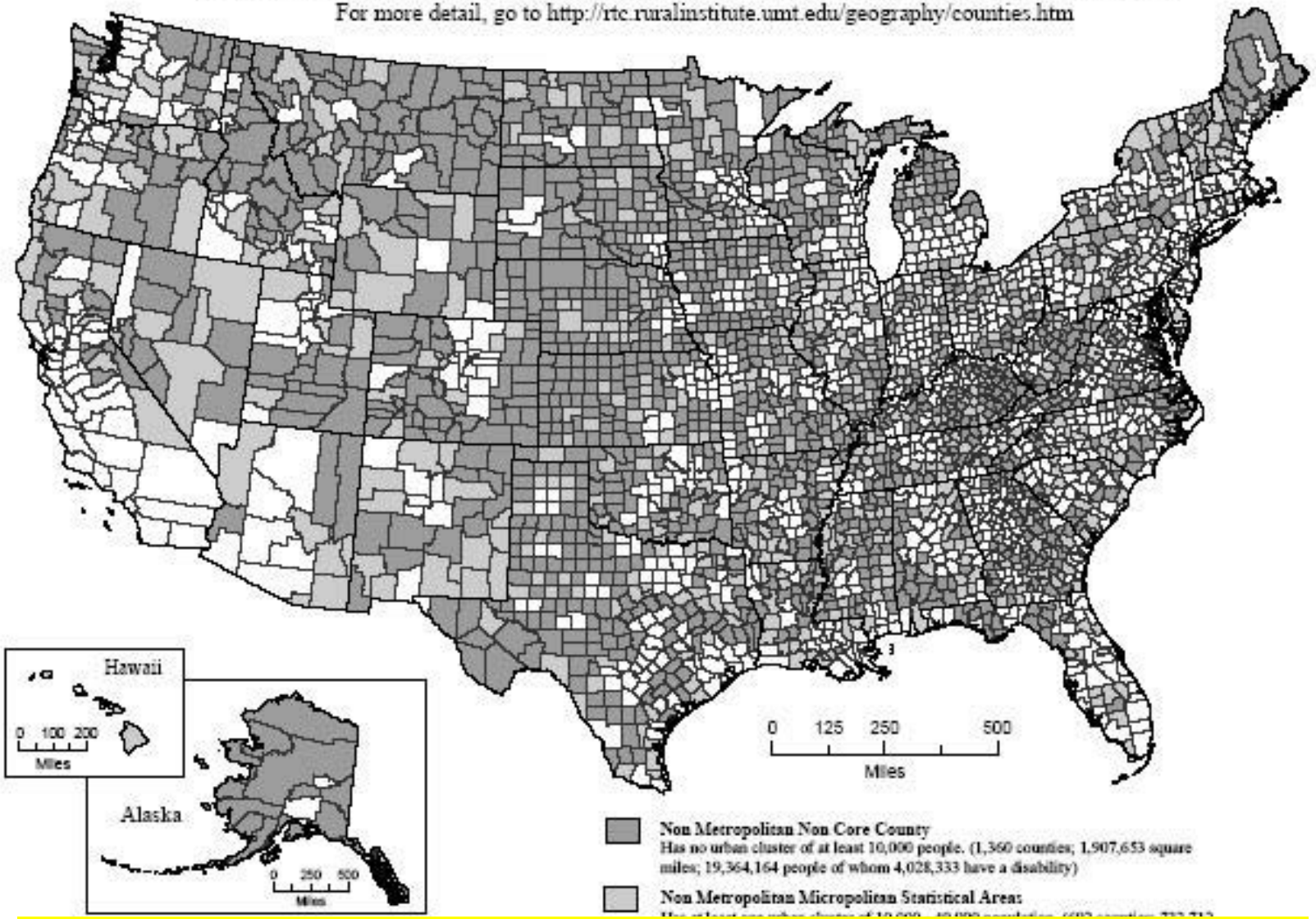


Figure 3.
Disability Rate for Children in Metropolitan Statistical Areas: 2010
(Children 5 to 17 years who have yet to receive a High School Degree or its equivalent. For information on confidentiality protection, sampling error, nonsampling error, and definitions, see www.census.gov/acs/www/Downloads/data_documentation/Accuracy/ACS_Accuracy_of_Data_2010.pdf)
Disability rate outside metro areas: 6.3%
Report - Table 2 has % by state
Disability Rate
9.0 percent or greater
7.0 to 8.9 percent
5.0 to 6.9 percent
3.5 to 4.9 percent
Less than 3.5 percent
U.S. Estimate: 5.2 percent
0 200 mi
0 400 km
Metropolitan statistical areas defined by the Office of Management and Budget as of December 2009.
Source: U.S. Census Bureau, 2010 American Community Survey.
Census November 2011 report:
School-Aged Children With Disabilities
in U.S. Metropolitan Statistical Areas: 2010
includes some non-metro data:
http://www.census.gov/prod/2011pubs/acsbr10-12.pdf


Where Do Rural Americans Live?
For more detail, go to http://rtc.ruralinstitute.umt.edu/geography/counties.htm
Hawaii
0 100 200
Miles
Alaska
0 125 250 500
Miles
Rural America.
3,444,930 square miles; more than 97% of the total U.S. land mass; 21% of the total U.S.
When you are analyzing non-metro data, you may think you are describing the people who live in the grey area of this map
Data Source:
Summary Files 1
OMB 11/2004 M
http://www.
Prepared by Bra
Montana
National Institute on Disability and Rehabilitation Research,
U.S. Department of Education. For more information, please contact us at:
RTC: Rural 406.243.5467 Email: anders@ruralinstitute.umt.edu
Both this map and the one on the other side show a picture of Rural America. The Rural-Urban map is based on Census 2000 population density criteria, the Metropolitan-Micropolitan-NonCore map is based on OMB county designations, applied to Census 2000 data.

Rural America: Where Rural = Non Metropolitan Counties

For more detail, go to http://rtc.ruralinstitute.umt.edu/geography/counties.htm



But you are actually describing the people in the grey areas of this map

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RTC: Rural 406.243.5467 Email: rtcinfo@ruralinstitute.umt.edu

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Do the differences matter?

Using Census 2000 data:

- 9,654,261 non-metropolitan people with disabilities.
- 10,852,330 rural people with disabilities.
- This difference doesn't seem very large, until you realize they are not the same 10-11 million people.
- Focusing rural attention only on non-metropolitan counties overlooks the almost half of rural Americans with disabilities who live in metropolitan counties.
- However the "rural" category does not include the 5 million people with disabilities in urban clusters - towns with 2,500 - 49,999 people.

Rural
is not the same as
Non-Metropolitan

- Most national surveys and data sets equate rural with non-metropolitan, if rural is included at all
- The Grand Canyon, most of California's Sierra Nevada mountain range, and a million farmers are in metropolitan America
- Over 50% of rural people live in metropolitan counties

  (47% of rural people with disabilities live in metro counties)
- Only 35 of the 3141 counties have no rural people with disabilities

Rurality has many different population cut off points:

- **2,500** upper limit for the US Census definition of rural
- **5,000** exceptionally rural, upper limit, Rural Utilities Service
- **10,000** lower limit for an urban cluster to trigger a county to be nonmetropolitan-micropolitan
- **25,000** Federal Communication Commission, upper limit, e-rate discounts
- **50,000** lower limit for an urbanized area to trigger a county to be metropolitan; also used as an upper limit for rural (non-urbanized) transportation, Federal Transit Administration
- **200,000** Housing and Urban Development, Community Development Block Grants (CDBG): lower limit for cities to apply for grants directly from the federal government, those under 200,000 must go through the State administrative program

Why do rural definitions matter?

- Disability numbers need to be tied to sub-state geographic units (counties, towns, rural areas, non-urbanized areas, school districts, etc) for local, place based decisionmaking & resource distribution
- Definitions are critical when tied to
  - Resource allocation/distribution patterns
  - Programmatic and formula funding
- Several distinct, inconsistent rural definitions are applied by federal and state programs to establish rural funding eligibility.
- Health care, housing, transportation, and telecommunications agencies all use different population thresholds and geographic boundaries to demonstrate rural status and determine program eligibility.