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Quarterly Self-Management Webinar
September 23, 2013

Creating Welcoming Programs

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Agenda

- Disability Data
- Who’s included?
- Why do I need to know about these things?
- Recruitment and registration
- Facilities and physical access
- Logistics, Communication, Environment
- Service animals
- Disability etiquette
- Making inclusivity part of how you do your job
- Handouts and Resources
- Questions and Answers

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Disabilities & Health Disparities

People with disabilities are more likely to experience:

- Poor health
- Secondary conditions
- Early death

But this doesn't mean that PWD:

- Are sick or ill
- Cannot be healthy

It is not necessarily the disability itself that causes the health disparities but environmental and social factors.

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Behavioral Risk Factor Surveillance System

- Population-based telephone survey of adults (18 & up) conducted at state level
- Demographics, health status, chronic conditions, health behaviors, health risks
- In alternate years, 4 years of data are combined & weighted for county-level analysis
  - Example: disability status in Oregon

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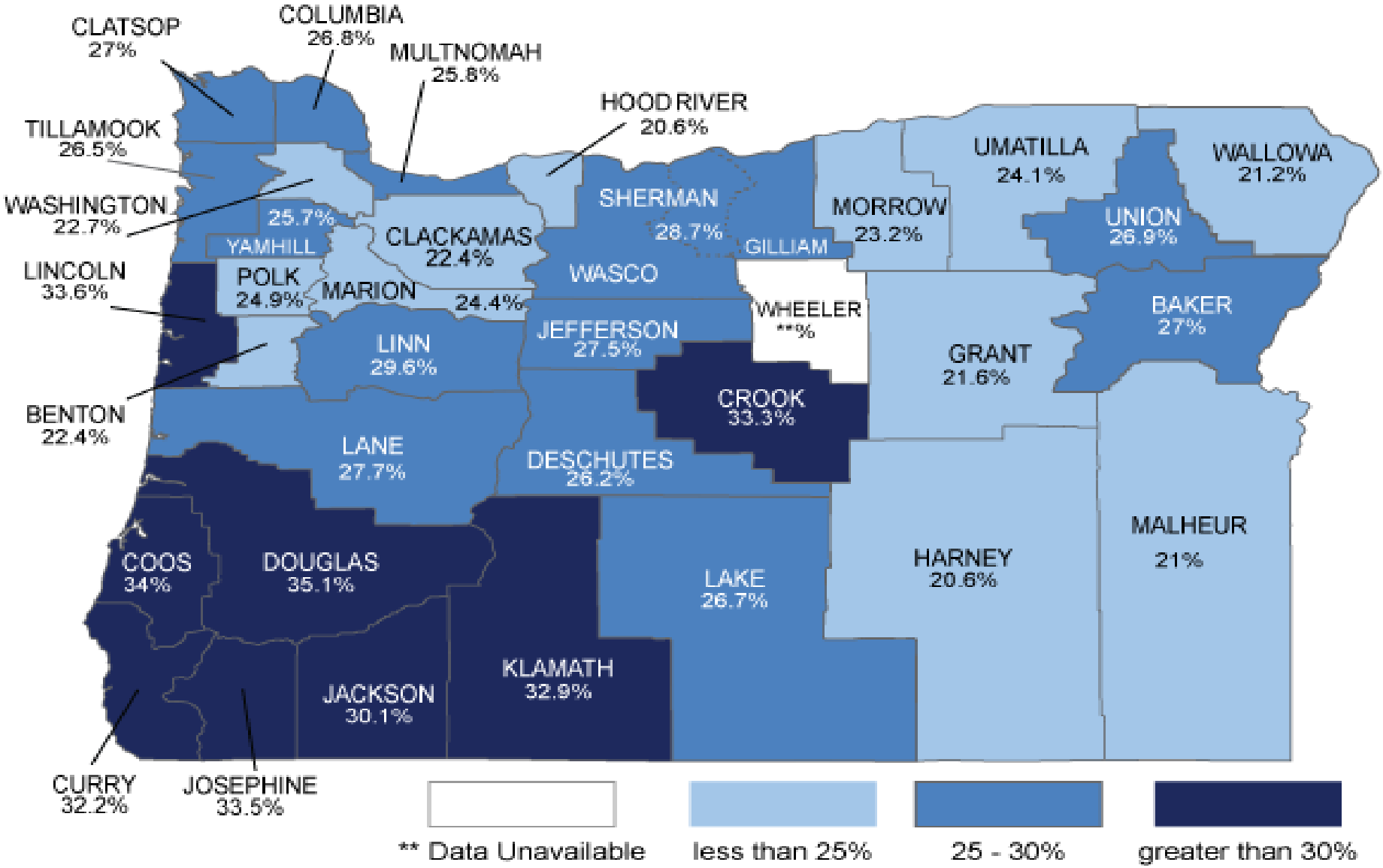
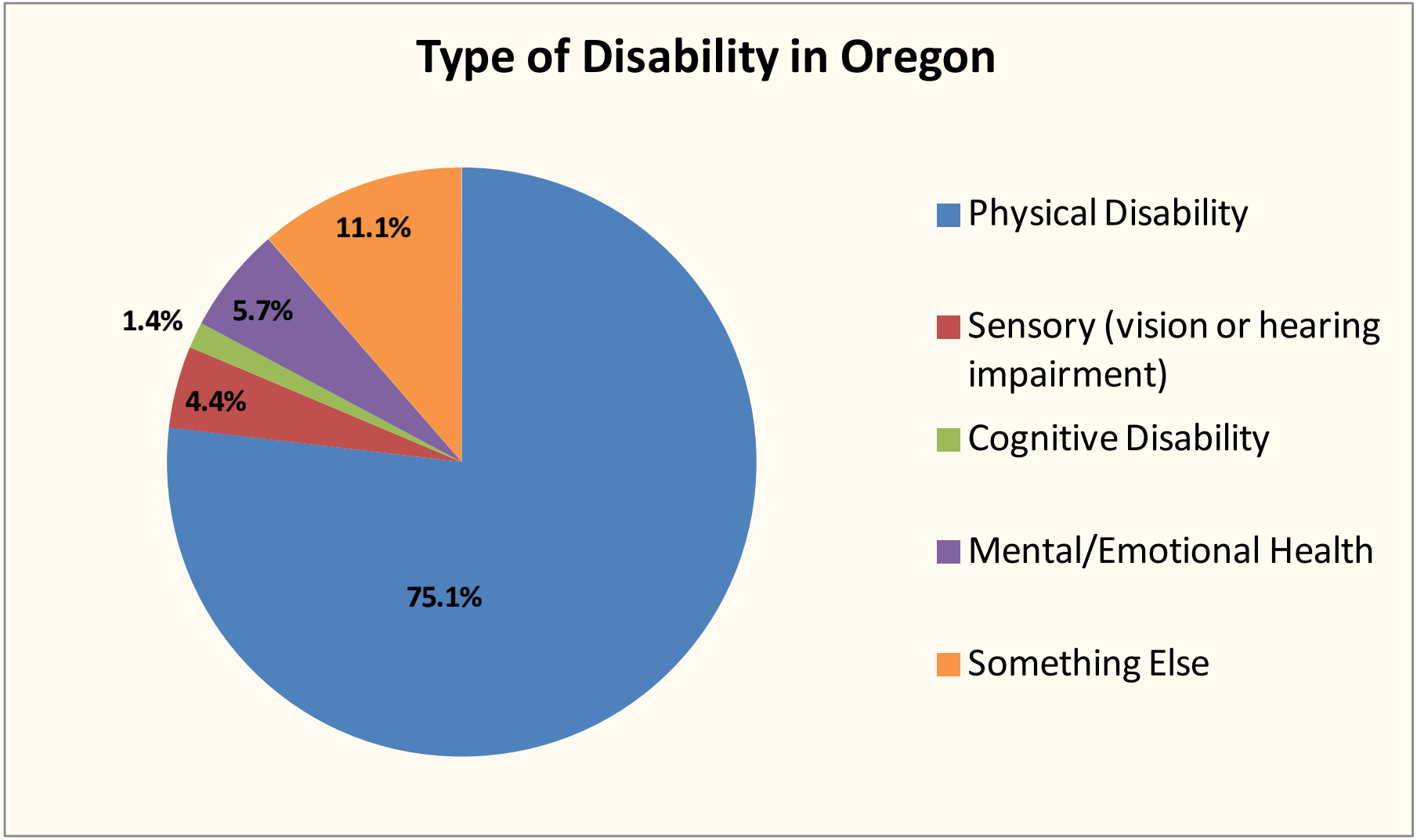
Disability in Oregon – 2008-2011 BRFSS



Sample Disability Statistics—2011 BRFSS



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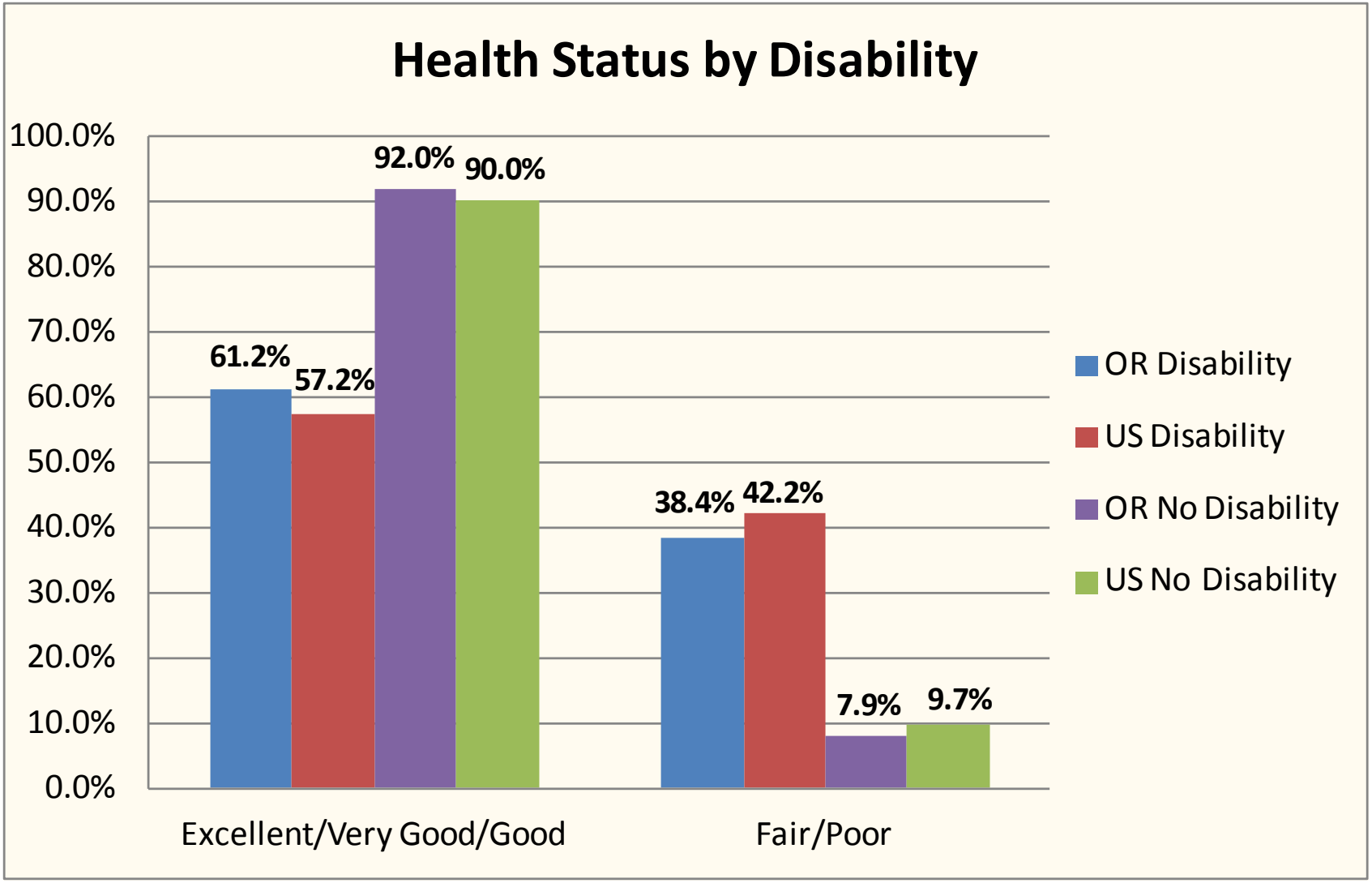

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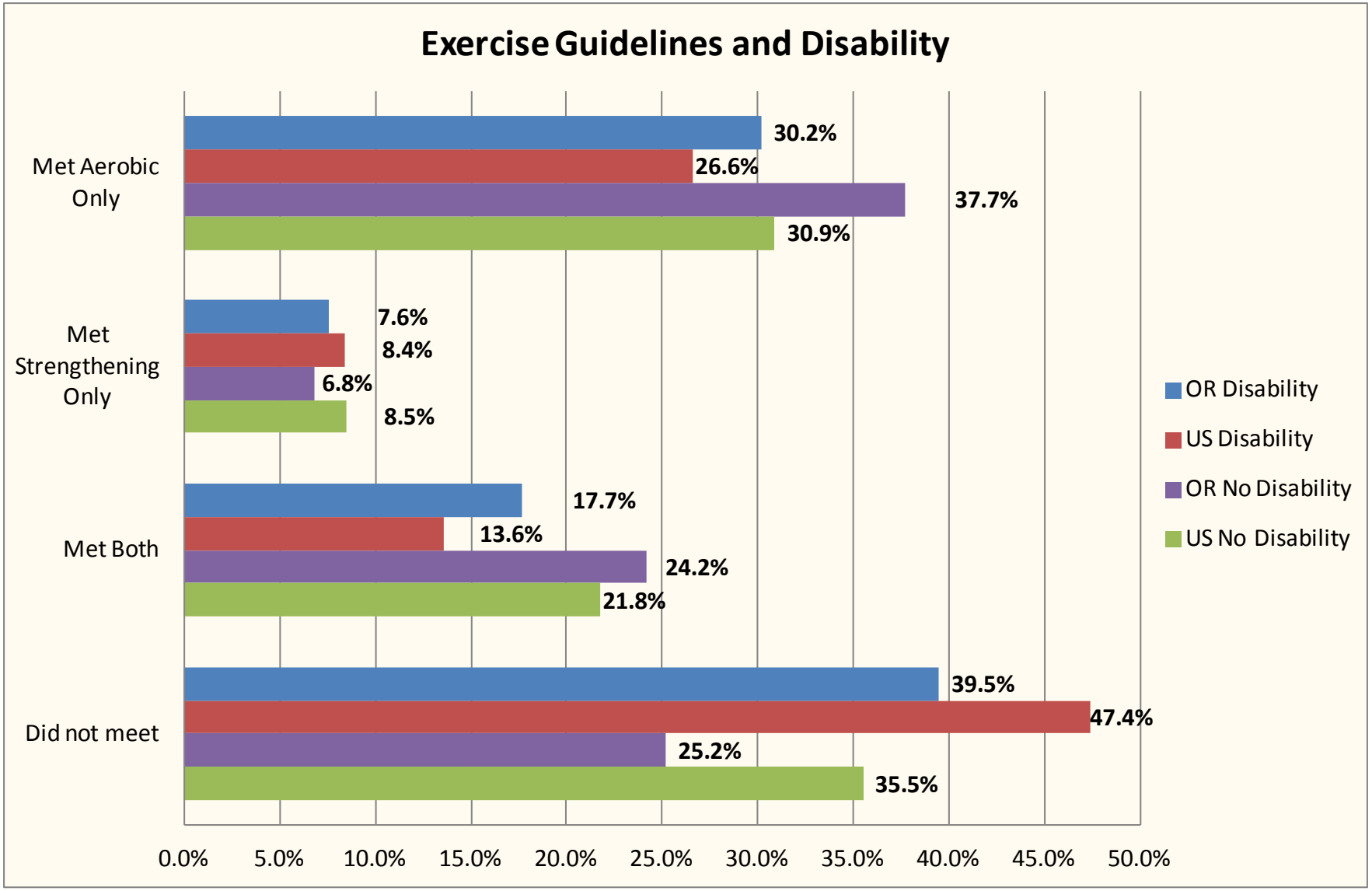

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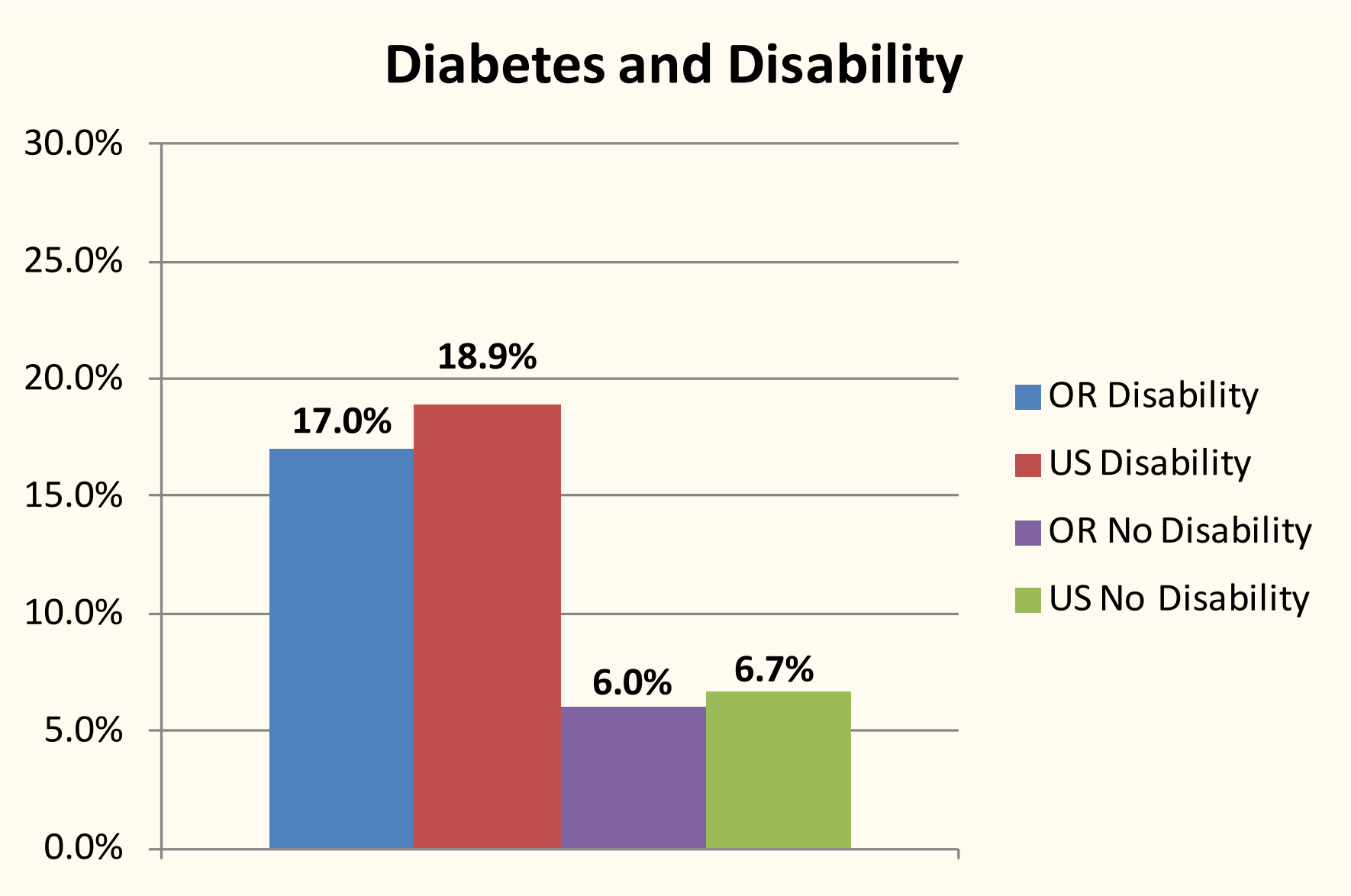

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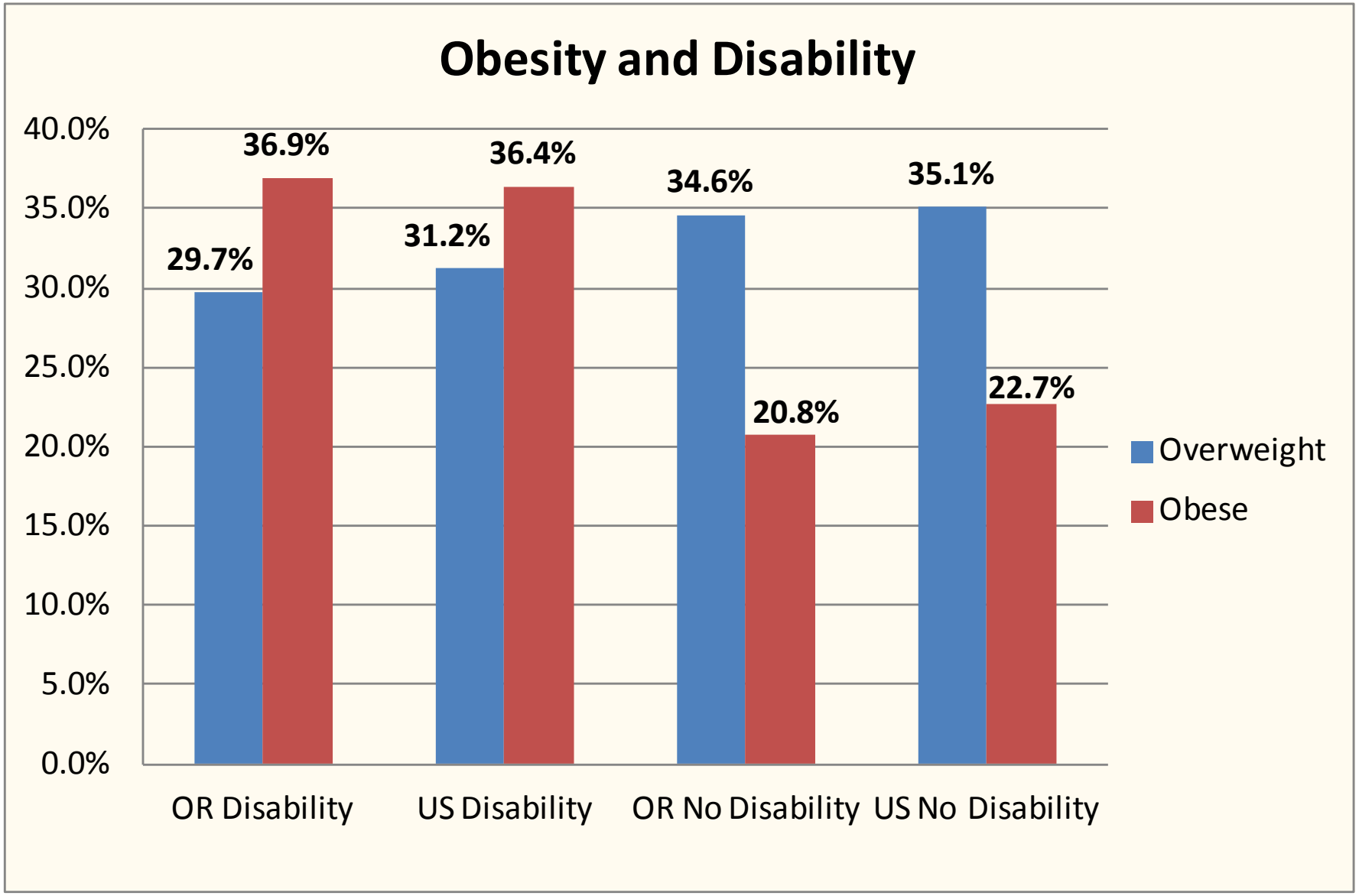

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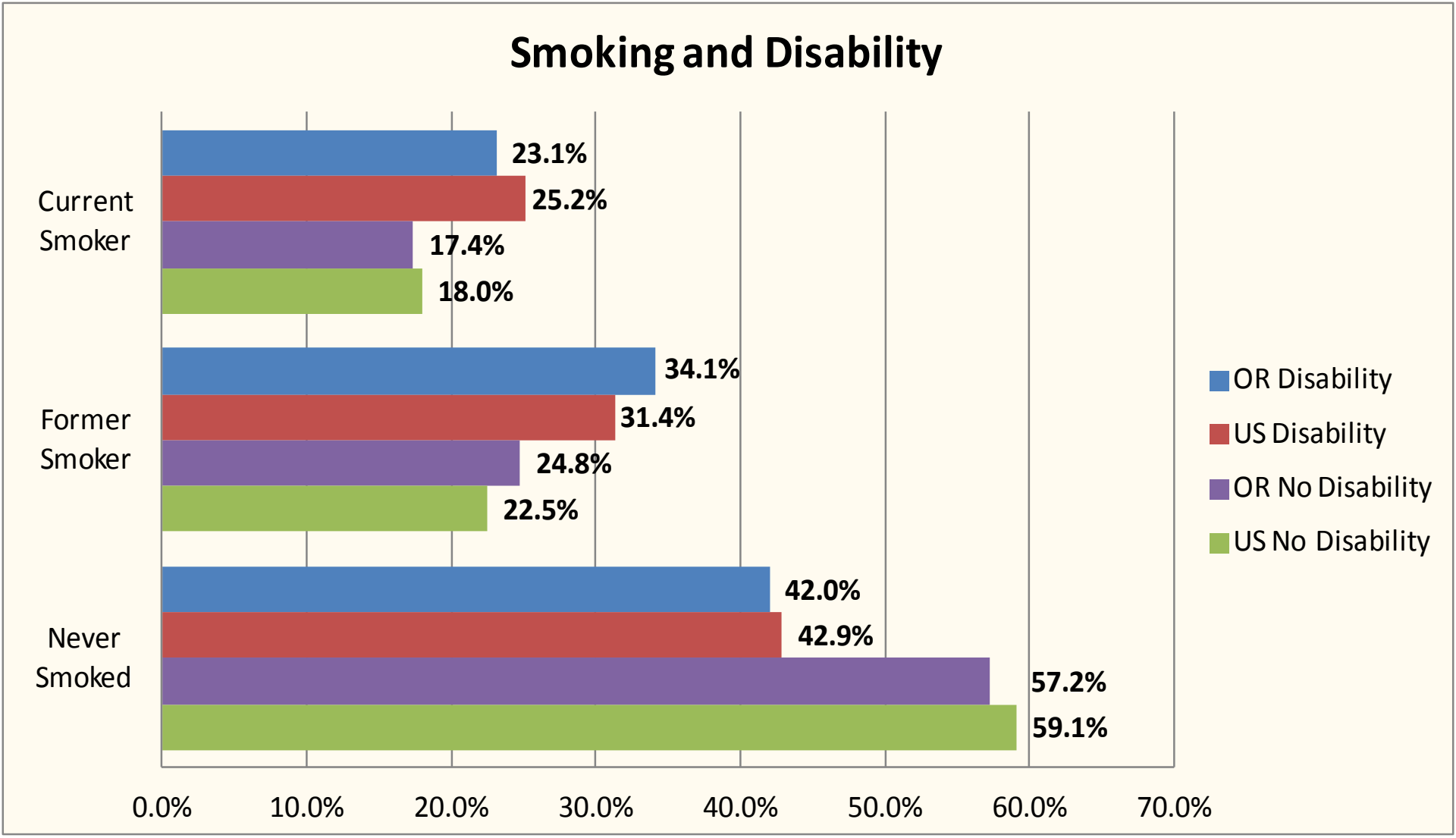

Who is included?

- People with and without disabilities
- People with functional impairments, particularly seniors do not always identify as “having a disability”
- A person’s chronic condition may or may not be related to their disability

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Why do we need to know about these things?

- People with disabilities are disproportionately affected by chronic conditions
- People with disabilities are living longer, and everyone who lives long enough will acquire a disability
- Equal access is the law
- Make sure that everyone who needs these programs can access them helps expand your reach AND it’s the right thing to do!

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Recruitment

- Make sure registration and informational sessions are accessible, and potential participants have multiple ways to get more information (phone, TTY, Relay, e-mail, web, radio, etc.)
  - Post flyers at disability service agencies, medical clinics, pharmacies, durable medical equipment stores, churches, food banks, grocery stores and community bulletin boards.
  - Advertise on CraigsList, in local disability community newsletters, on local university websites, in your local newspaper, and on social media sites such as FaceBook.

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Recruitment

- Referrals from
  - Centers for Independent Living partners
  - local mental health network
  - disability advocacy or support groups
  - disability services agencies (have their own consumer base for recruiting)
- Make flyers and promotional materials available in accessible formats, are relevant to PWD and include an accessibility statement:

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Recruitment

"If you are deaf or hard of hearing, or are a person with a disability who requires accommodation, please contact [**Name of organization or individual responsible for making arrangements**] at [**Telephone Number], [Fax Number], [Email Address] or [TTY Number] by [Date].“

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Registration - Accommodations

Accommodation checklist

Scheduling:

- ❑ Location: _____
- ❑ Size of room: _____
  - ❑ Preferred days:
    - ❑ Monday
    - ❑ Tuesday
    - ❑ Wednesday
    - ❑ Thursday
    - ❑ Friday
    - ❑ Saturday
    - ❑ Sunday
  - ❑ Days **not** available:
    - ❑ Monday
    - ❑ Tuesday
    - ❑ Wednesday
    - ❑ Thursday
    - ❑ Friday
    - ❑ Saturday
    - ❑ Sunday
  - ❑ Preferred times:

    _____

    _____
  - ❑ Times **not** available:

    _____

    _____
  - ❑ Inclement weather plan:

    _____

    _____

    _____
  - ❑ Are any customers arriving/departing via paratransit or ride-share?
    - ❑ Yes
    - ❑ No

    (Note that customers arriving/departing via paratransit may arrive quite early/stay quite late in relation to your event.)

Transportation

- ❑ Accessible parking
  - o Van-accessible
  - o Standard-size accessible
- ❑ Bus access at location?
- ❑ Paratransit / Ride-share
  - o Type of vehicle: _____
  - o Mobility device: _____

Childcare

- ❑ Is Resource List available?
- ❑ Is financial assistance available?
- ❑ Breastfeeding: private room available?
- ❑ Restroom with child changing table available?

Interpreter:

- ❑ Sign language interpreter
- ❑ Other language (specify): _____

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Registration - Accommodations

Alternative Formats

- ❑ Large Print
  - How large does the customer need? _____ OR
  - What is the font size of your preprinted document? _____
- ❑ Braille
- ❑ Electronic format (specify file type): _____
- ❑ Assistance with reading
- ❑ Assistance with writing
- ❑ Other (specify): _____

Alternative Seating

- ❑ Specialized chair (to reduce pain)
- ❑ Table lifters (height of table needed: _____)
- ❑ Close to presenter
- ❑ Close to door
- ❑ Space to move around during meeting
- ❑ Has mobility needs (see next section)

Mobility needs / uses:

- ❑ Uses (mobility) cane
- ❑ Uses (white) cane
- ❑ Uses crutches
- ❑ Uses walker
- ❑ Uses manual wheelchair
- ❑ Uses power wheelchair
- ❑ Uses bariatric wheelchair
- ❑ Uses service animal
- ❑ Other (specify):

_____

_____

Dietary Needs

- ❑ Medications
- ❑ Food Restrictions (specify):

_____

_____

- ❑ Diabetic
- ❑ Vegetarian
- ❑ Other (specify):

_____

Environmental allergies

- ❑ Need fragrance-free room/participants
- ❑ Need smoke-free room/participants
- ❑ Allergy to dogs
- ❑ Other (specify)

_____

Preferred Method of Contact

- ❑ Phone
- ❑ Email
- ❑ Text
- ❑ Facebook
- ❑ Other (specify): _____

Other comments:

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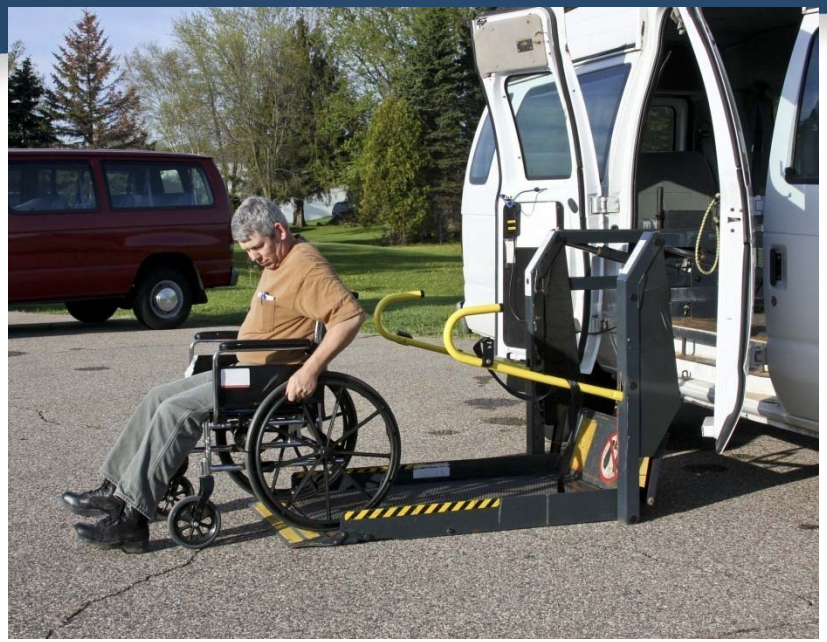
Facilities and Physical Access



- Hold the event where the people are located
- Conduct a site visit ahead of time
- Use an accessibility checklist
- Can non-drivers, including people with mobility aides, get to the site?
- Make sure the curbside drop off site has an accessible route to the workshop site
- Assess: parking, approach and entry

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Facilities and Physical Access

- Look at signage and ease of navigation
- Water fountains, other features
- Make sure that emergency evacuation plans take everyone into account
- Restrooms

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Facilities and Physical Access

Workshop/training space

- Do the tables need to be raised for people using scooters and/or power chairs?
- Are the chairs provided comfortable and do they meet the physical needs of participants?

Tip: Imagine if you used a wheelchair, could you get into the room and move around safely?

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Logistics

- Plan for a Session 0/pre-session, during which you can meet with your participants as a group sometime before the workshop begins
- Be aware of constraints around paratransit – participants with disabilities may not have a say in when they arrive or leave
- Offer assistance before the workshop begins to help people complete forms, but do not start class late as a result

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Logistics

- Avoid early morning events
- Take scheduled breaks
- Give clear directions to rest rooms and water fountains, avoiding pointing or saying “over there”

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Communication

- Living a Healthy Life with Chronic Conditions is available on audio CD from Bull Publishing –have several copies
- Know where to get interpreters, CART reporters and assistive listening devices
- Prepare staff for TTY and relay calls (call 711)
- Verbalize all agendas, posters + brainstorming
- Leader Manuals and Master Trainer Manuals can be obtained from Stanford in accessible electronic formats for producing large print and/or Braille

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Environment

- If you are providing refreshments, know what the ingredients are
- Avoid wearing perfume, cologne or heavily scented products, and encourage participants to do likewise
- Try to avoid holding workshops in rooms with poor ventilation, especially if the room has been cleaned with harsh chemicals

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Environment

- Arrange furniture so that there is plenty of room for a person using a mobility aide to navigate, and leave a few empty spaces at tables to make room for people using wheelchairs or scooters
- Try to minimize external noises: fans, traffic, simultaneous classes, etc.

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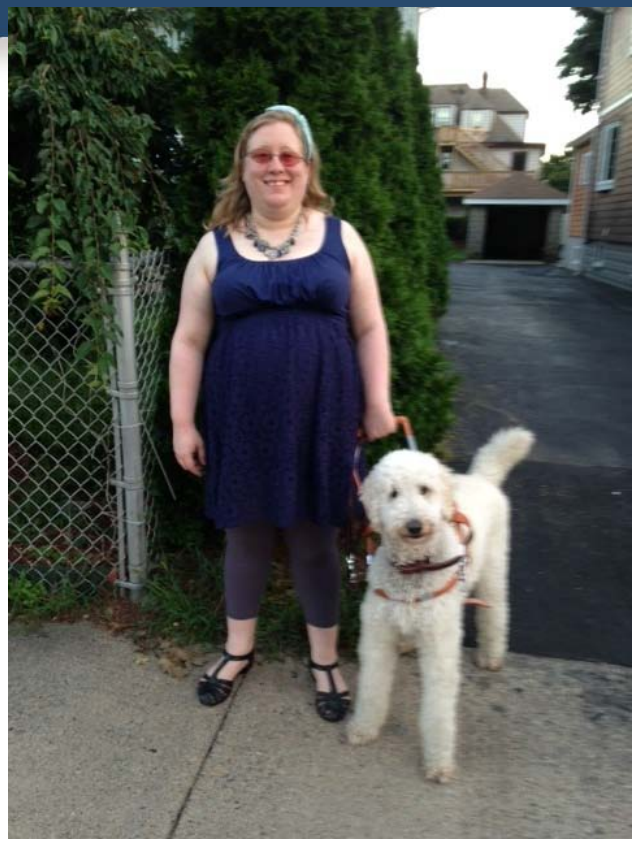
Service Animals



- Make sure staff know that service animals are welcome at the workshop
- Not all service dogs are the same size or breed, and not all disabilities are visible
- Check for trash cans near relief areas
- Do not distract, pet, feed, or interact with a service animal

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Etiquette

- Use “People First Language”
- Do not single people out publically
- Do not make assumptions about preferred format or means of communication – ask them
- Do not ask personal questions without being invited to do so
- Keep an open mind and have fun!

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Making inclusivity part of how you do your job

- Inclusivity is not a special way of doing things – incorporate it into your usual processes
- Communications access shouldn’t be a surprise cost – make it part of your budget every time
- Look for tax breaks or corporate sponsorships

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Resources

- Planning Accessible Meetings and Events: Guidelines to Accommodate All Participants http://www.mass.gov/eohhs/docs/dph/com-health/healthy-aging/accessible-events.pdf
- Massachusetts Facility Assessment Tool (MFAT) http://www.mass.gov/eohhs/gov/departments/dph/programs/community-health/health-disability/ada-compliance/the-massachusetts-facility-assessment-tool.html
- Tax Incentives for Businesses - http://www.ada.gov/taxincent.htm
- Accessible Print Materials: Accessible Publication Style Guide http://www.ohsu.edu/xd/research/centers-institutes/institute-on-development-and-disability/research/upload/Accessible-Publications-Style-Guide.pdf

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Oregon County Resources

NAME

Disability Prevalence:

*According to Oregon Office on Disability and Health 2013 Annual Report on the health of Oregonians with Disabilities utilizing 2011 BRFSS Data.

** Not available in county See state-wide services

Centers for Independent Living (CILS)

County Developmental Disability Services Offices

Support Service Brokerages

Disability Service Providers

Accessible Transportation Providers

Assistive Communication Devices and Language Services

Assistive Listening Devices Providers

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Handouts

- Overweight and Obesity in People with Disabilities – Oregon / US data
- People First Language
- Rising Healthcare Costs for PWD Who Are Obese
- Comparing Diabetes Rates Among PWDD
- Ways to Improve Health-Reduce Costs
- Intersection between Disability and Chronic Disease

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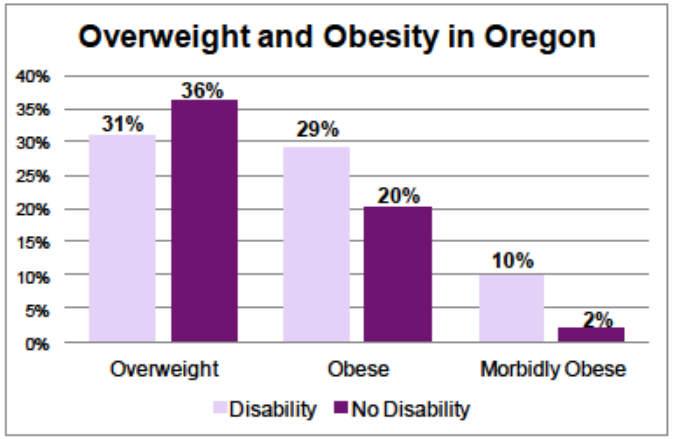
Overweight and Obesity in People with Disabilities

Overweight and obesity are both terms that describe people's body weight. People who fit these definitions may be less healthy for their height than others. Behavior, environment, and genetic factors can affect whether a person is overweight or obese. We examined obesity and overweight among Oregon adults with and without disabilities using the most recent data from a telephone survey, the Behavioral Risk Factor Surveillance System (2011). We identified the percent of the adult disability population that is overweight or obese.

Here is what we've learned in Oregon

We found that adults with disabilities are more likely than adults without disabilities to be obese but are less likely to be overweight. We also found that figures in Oregon are similar to the United States overall.

- 31% of Oregon adults with disabilities are overweight and 37% of Oregon adults without disabilities are overweight
- 29% of adults with disabilities in Oregon are obese and 20% of Oregon adults without disabilities are obese
- 10% of Oregon adults with disabilities are morbidly obese and 2% of Oregon adults without disabilities are morbidly obese



Here are some general guidelines about adult BMI numbers

A BMI between 25 and 29.9 is considered overweight

A BMI of 30 or higher is considered obese

A BMI of 40 or higher is considered morbidly obese

Created by the Oregon Office on Disability and Health
www.oodh.org

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Examples of People First Language

Say	Instead of
People with disabilities	the handicapped or disabled
he has a intellectual disability	he's mentally retarded
she has autism	she's autistic
he has Down syndrome	he's Downs
she has a learning disability	she's learning disabled
he has a physical disability	he's a quadriplegic/crippled
she's of short stature	she's a dwarf (or midget)
he has an emotional disability	he's emotionally disturbed
she uses a wheelchair or mobility chair	she's wheelchair bound she's confined to a wheelchair
he receives special education services	he's in special education
Typical kids kids without disabilities	normal or healthy kids
Congenital disability	birth defect
brain injury	brain damaged
Accessible parking	handicapped parking
she needs . . . or she uses . . .	she has a problem with . . .

The difference between the right word and the almost right word is the difference between lightning and the lightning bug. --Mark Twain

"Disability is a natural part of the human experience..."
U.S. Developmental Disabilities Act & The Bill of Rights Act, 1993

The beginning of wisdom is to call things by their right names.
--Old Chinese Proverb

If you have questions about People First Language, you should ask a person with a disability for advice or contact People First of Tennessee at (615) 713-1162.

The Arc Tennessee is a non-profit membership advocacy organization for people with intellectual and developmental disabilities. Membership is tax-deductible.
Become a member of The Arc today by visiting www.thearctn.org

The Arc
Tennessee

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From The Lund Report:

Disabled Who Are Obese Face Rising Healthcare Costs

The writer, who has cerebral palsy, discusses the difficulties faced by disabled people who require specialized medical equipment and the difficulties they face from insurance companies
By:
Heather Brooks

October 30, 2012 -- Since 1994, the obesity rates among children with cerebral palsy (CP) have doubled. This is because such children, who received inadequate nourishment in utero, or were seriously ill when very young, continue to eat nutrient-dense foods after they are out of medical crisis.

I have CP, and typify the former norm, being of low weight for a woman of my height. I am beginning to present something of a challenge to the medical profession, who are accustomed to treating bariatric patients, including those with other disabilities. Often their equipment, such as patient lifts and commode chairs, is designed for individuals much larger than I.

I became particularly aware of this after a physical therapy session during which the therapist, unable to locate the sling ordinarily used to transfer me, substituted one with a weight capacity of 800 pounds. Many times smaller than that, I lay, rather than sat, in this sling, and nearly fell through the bottom.

Of course, those with CP are not the only people with disabilities to face obesity. The disabled, among them those who become significantly impaired later in life, through accident or injury, are 58 percent more likely to become obese. This is true for those with cognitive, as well as physical disabilities, because of the difficulty in mobility that accompanies many cognitive impediments. Collectively 36 percent of the disabled population in America is obese, as opposed to 21 percent of the population without disabilities. Obese people individually incur a cost of $1,429 each year, and, as a group, generate $147 billion annually in healthcare costs. The disabled who are obese account for $44 billion of this.

Standard wheelchairs—those made for people who weigh 300 pounds or less — cost between $5,000 and $7,000, depending on individual manufacturer-suggested retail price, and other adaptive features. Bariatric wheelchairs—those designed for people whose weight exceeds 300 pounds, and may reach 600—may cost more than $14,000. This doubling in price exists for medical equipment of all types, including:

- **Bariatric canes: $70**
- **Bariatric walkers: $300**
- **Bariatric shower and commode chairs: $1,000+**
- **Bariatric patient lifts: $2,000-$6,000**
- **Bariatric beds: $1,000-$4,000+**

These vast expenses likely arise from the need to build sturdier medical equipment designed to support more weight. It stands to reason, then, that the cost of maintaining or repairing such equipment would rise correspondingly. Many people with disabilities, whether or not they experience obesity, encounter resistance from their health insurance companies which are often unwilling to pay for the repairs, changes or replacements. As the cost increases, the insurers even hesitate more, and the larger and sturdier a piece of equipment, the more expensive it will be.

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RTC MiCL

Research and Training Center on Measurement and Interdependence in Community Living

FACT SHEET

Comparing Diabetes Rates among Adults with Cognitive Limitations to Adults with No Disabilities in the U.S.

New Information from the U.S. Medical Expenditures Panel Survey

What We've Learned

This project analyzed the most recently available data from the national 2006 Medical Expenditure Panel Survey (MEPS) to assess whether adults with cognitive limitations (i.e., an intellectual or developmental disability) experience higher rates of diabetes and other chronic diseases compared to people with no disability. We found:

- Individuals with cognitive limitations had a diabetes prevalence of 18.5% compared to 3.7% for people with no disability.
- The majority of Medicaid-supported diabetic individuals with cognitive limitations did not receive their yearly foot check, HbA1c check, eye check, or cholesterol check.
- Those with cognitive limitations and diabetes had a higher prevalence rate for six major chronic conditions (asthma, arthritis, heart disease, high cholesterol, high blood pressure, and stroke) than people who had diabetes but no disability.

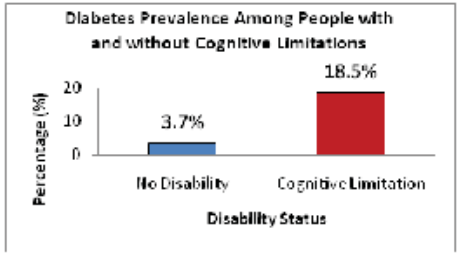
How Can We Improve Preventive Screenings and Health Services?

- Accurately identify individuals who are at risk by a) improving consumers' capacity to report health care needs and b) improving care providers' capacity to identify and report illness or disease
- Educate health care professionals on the importance of preventive care, health screenings and chronic disease management for people with cognitive limitations
- Incorporate education on how to improve health behaviors in high school curriculum for individuals with cognitive limitations

The Bottom Line

A substantial portion of adults with an intellectual or developmental disability are at risk for developing or may have already developed diabetes and other chronic conditions.

We can improve preventive screenings and health services to improve the health of these individuals and minimize the cost of their health care.



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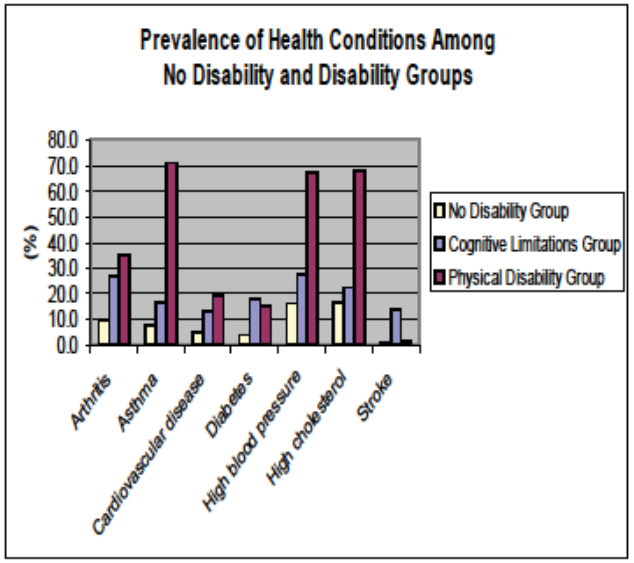
RTC MiCL

Research and Training Center on Measurement and Interdependence in Community Living

FACT SHEET

R-2

Ways to Improve Health and Reduce Costs for Adults with Physical Disabilities or Cognitive Limitations



What's the Bottom Line?

People with physical disabilities or cognitive limitations have higher prevalence rates for chronic diseases and are less likely to receive preventive services than persons with no disabilities.

This fact sheet presents policy strategies to improve the health of these individuals while reducing the related costs to Medicaid and other payors.

What We've Learned

Disease Rates

- Adults with physical disabilities or cognitive limitations have an increased risk of developing seven major chronic conditions (arthritis, asthma, cardiovascular disease, diabetes, high blood pressure, high cholesterol, and stroke).
- More than 70% of those with physical disabilities are either overweight or obese compared to 62.7% of the cognitive disabilities group and 59.7% of the no disability group.

Associated Costs

- Individuals with *cognitive limitations* ($11,487/year) had expenditures 4.8 times higher than those with no disabilities ($2,375/year).

(over)

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RTC MICL

Research and Training Center on Measurement and Interdependence in Community Living

FACT SHEET

The Intersection of Disability and Chronic Disease

Often, we use the terms "chronic disease" and "disability" together; some even use them interchangeably.

While disability and chronic disease do overlap, these terms are not synonymous and using them as such undermines the notion that ***people with disabilities can be healthy***.

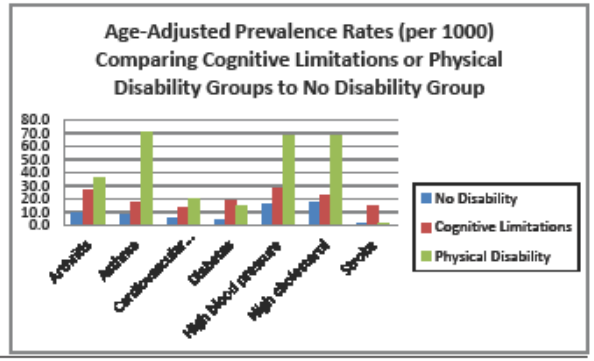
- The World Health Organization (WHO) defines chronic disease as: ". . . diseases of long duration and generally slow progression" (World Health Organization, 2011).
- The WHO defines disability as: ". . . impairments, activity limitations, and participation restrictions . . . reflecting an interaction between features of a person's body and features of the society in which he or she lives" (World Health Organization, 2011a).
- The important distinction to understand between these is that while chronic disease is integrally related to health, **the preferred conceptual framework of disability views disability as separate from health and does not integrally relate the two.**

The CDC reports that chronic diseases (such as heart disease and diabetes) are the leading causes of death and disability in the U.S. (http://www.cdc.gov/chronicdisease/).

Our research (Reichard, Stolzle, & Fox, 2011) has shown that people with disabilities have higher prevalence rates for chronic diseases than those with no disability.

- Moreover, our research has shown people with disabilities are more likely than those with no disability to experience higher prevalence rates of multiple chronic diseases.
- Other studies have found that some people with disabilities develop chronic conditions at an earlier age (DeJong, Palsbo, Beatty, Jones, Kroll, & Neri, 2002; World Health Organization, 2011b) and some people with disabilities die from chronic disease sooner after diagnosis (Capriotti, 2006).

Especially disconcerting is the fact that not only are people with disabilities more likely to be obese, but among those who are obese, people with disabilities have statistically significantly higher BMI scores than those with no disability.



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Questions and Thank You!

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