

# Aging with a Physical Disability

## RRTC: Lessons Learned

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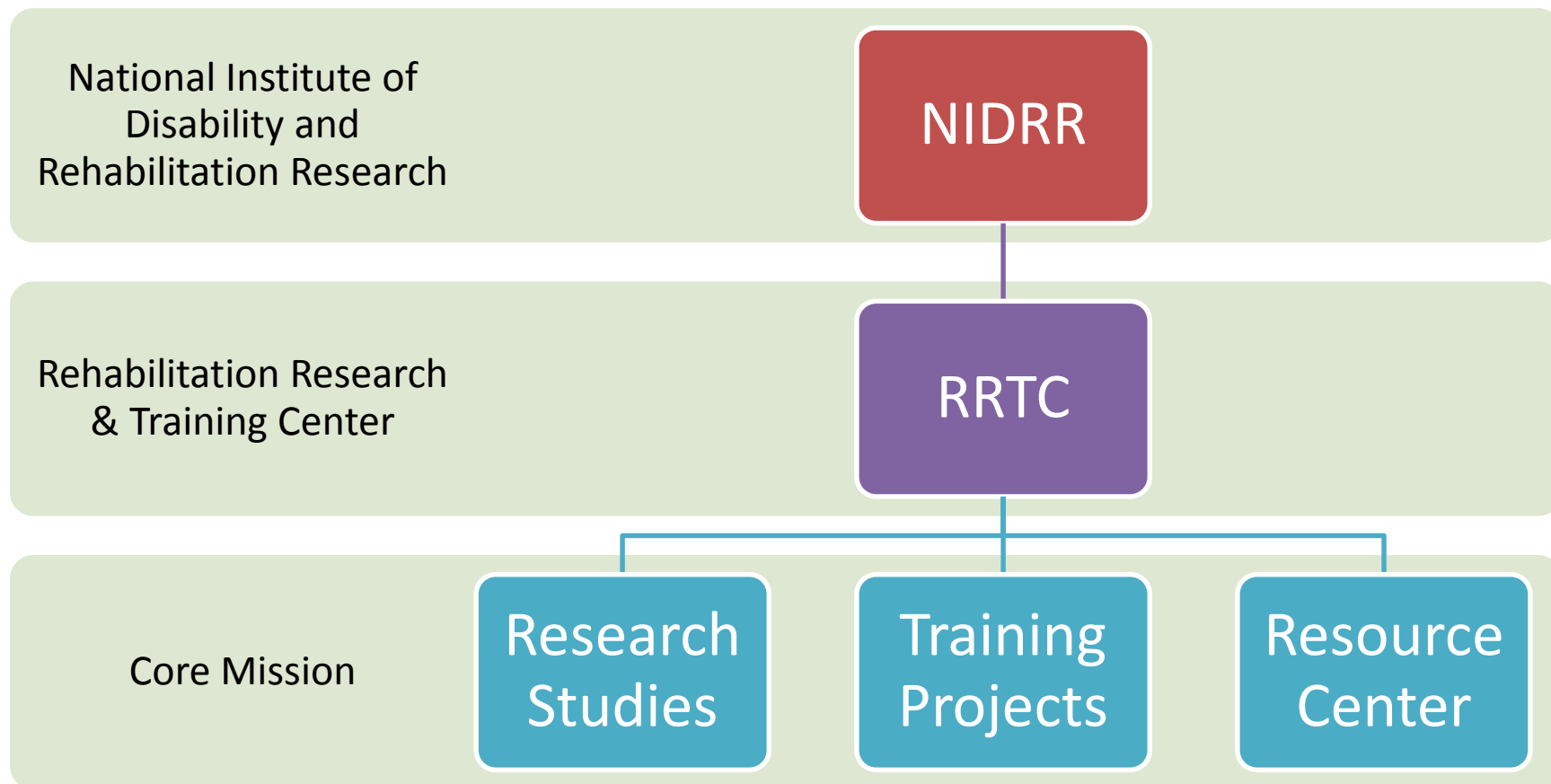
# Thank you



- Our entire team
- Advisory board
- All of our participants

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# What is an RRTC?



# Promote Healthy Aging for People with Long-term Physical Disability

## Research Studies

- Learn more about secondary conditions
- Establish better measures
- Test new interventions

## Training Projects

- Train & educate new researchers and providers

## Resource Center

- Share our findings
- Answer questions
- Connect people with resources

# Presentation Overview

- Our survey
  - Who participates?
- Defining healthy aging
- Components of healthy aging:
  - Physical: Prevent new conditions & injuries
  - Social: Social support, social roles
  - Psychological: Resilience
- Where do we go from here?

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# Our Survey

	Not at all	A little bit	Somewhat	Quite a bit	Very much
5. I am satisfied with how much work I can do (include work at home)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I am satisfied with my ability to work (include work at home)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am satisfied with my ability to do regular personal and household responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I am satisfied with my ability to perform my daily routines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Focus Groups

‘I see my legs getting weaker and weaker especially my left leg that I’ve always referred to as my good leg because it hasn’t been in the brace and I think it’s been doing all the work’ . . . that I couldn’t even use crutches anymore. . . . (F: PPS: 65)

. . . And when I got up, it was the end. I couldn’t drive anymore, I couldn’t walk anymore, and there was only one thing to do, and that was to sit’ (F: PPS: 93).



# Focus Groups

I do a lot of different things. They're not as physically demanding as the other things that I used to do. So, it's changing your outlook toward your activities and finding a replacement that's suitable but that you still get a lot of enjoyment from. (F:PPS: 65)

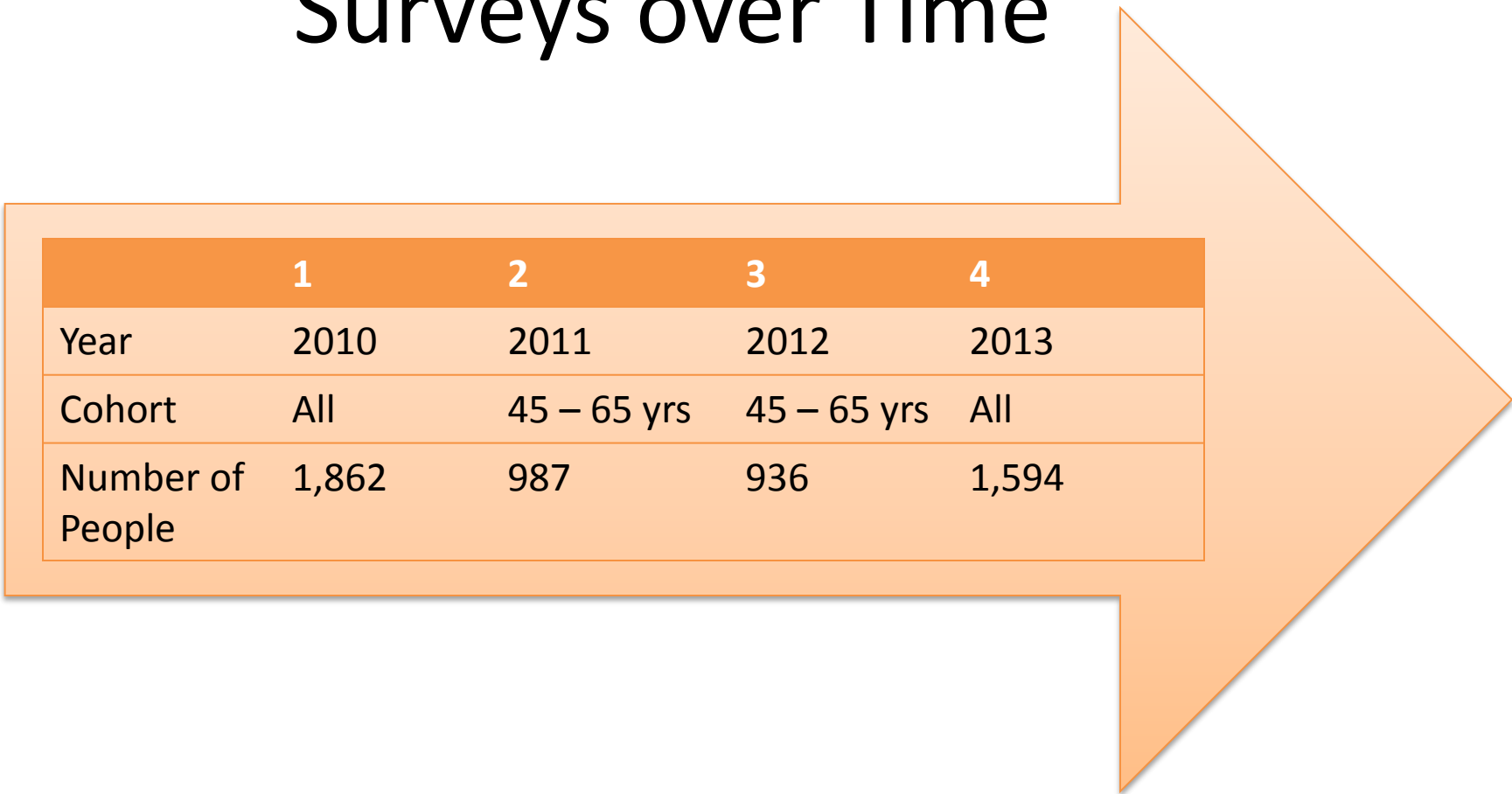
It took a long time for it to sink into my head why I was being told to use a cane. All my life I'd worn a brace so why would I need a cane? It took 2 years. Then it finally was kind of like a bell went on – conserve energy, sleep better, less pain, this vicious circle and I finally started to use one. (F:PPS: 65)

# Our Survey



- Over 6,000 surveys filled out in the last 5 years
- Over 4,000,000 questions answered.
- About 4,000 calls to collect missing data.

# Surveys over Time

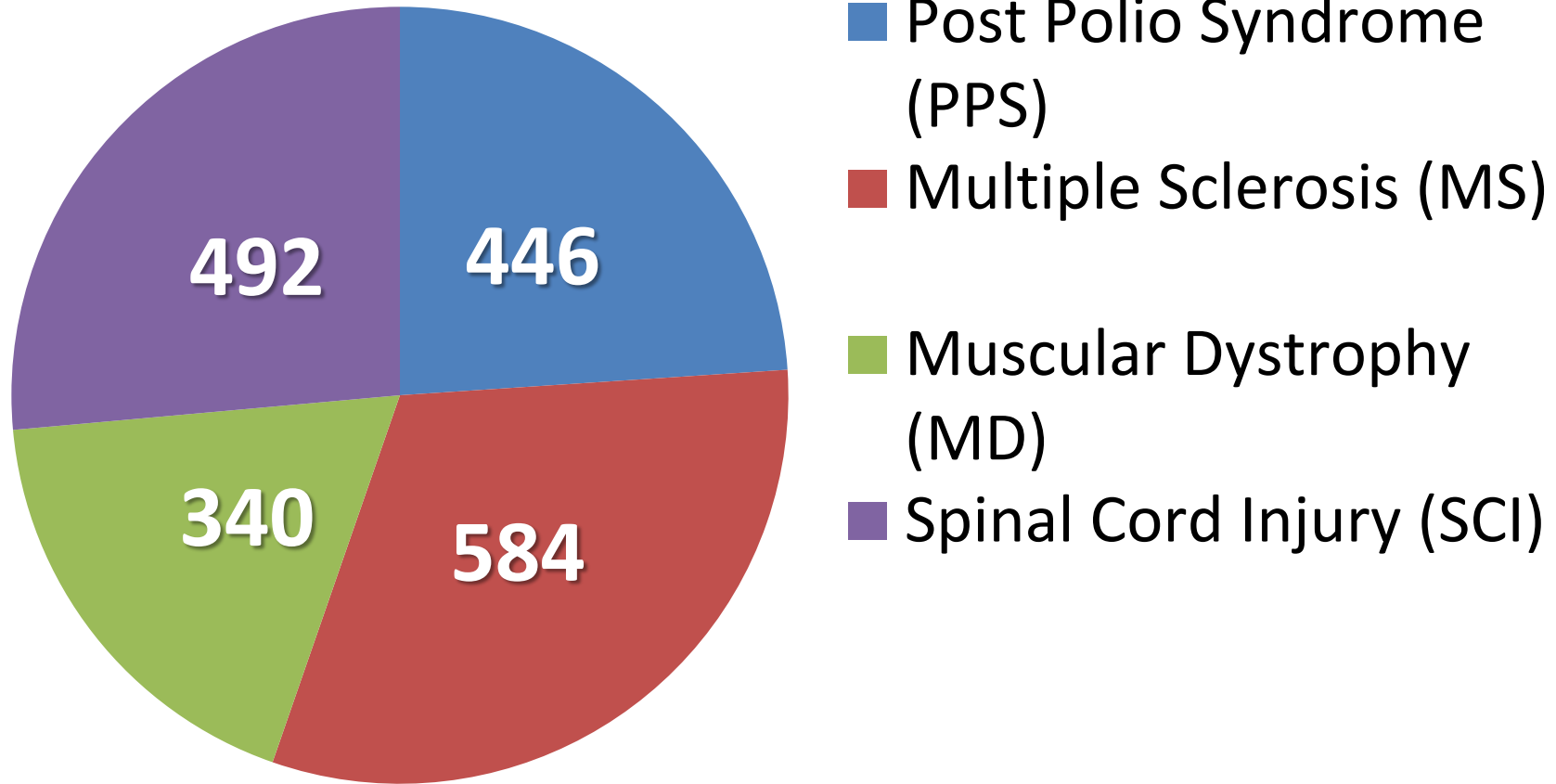


	1	2	3	4
Year	2010	2011	2012	2013
Cohort	All	45 – 65 yrs	45 – 65 yrs	All
Number of People	1,862	987	936	1,594

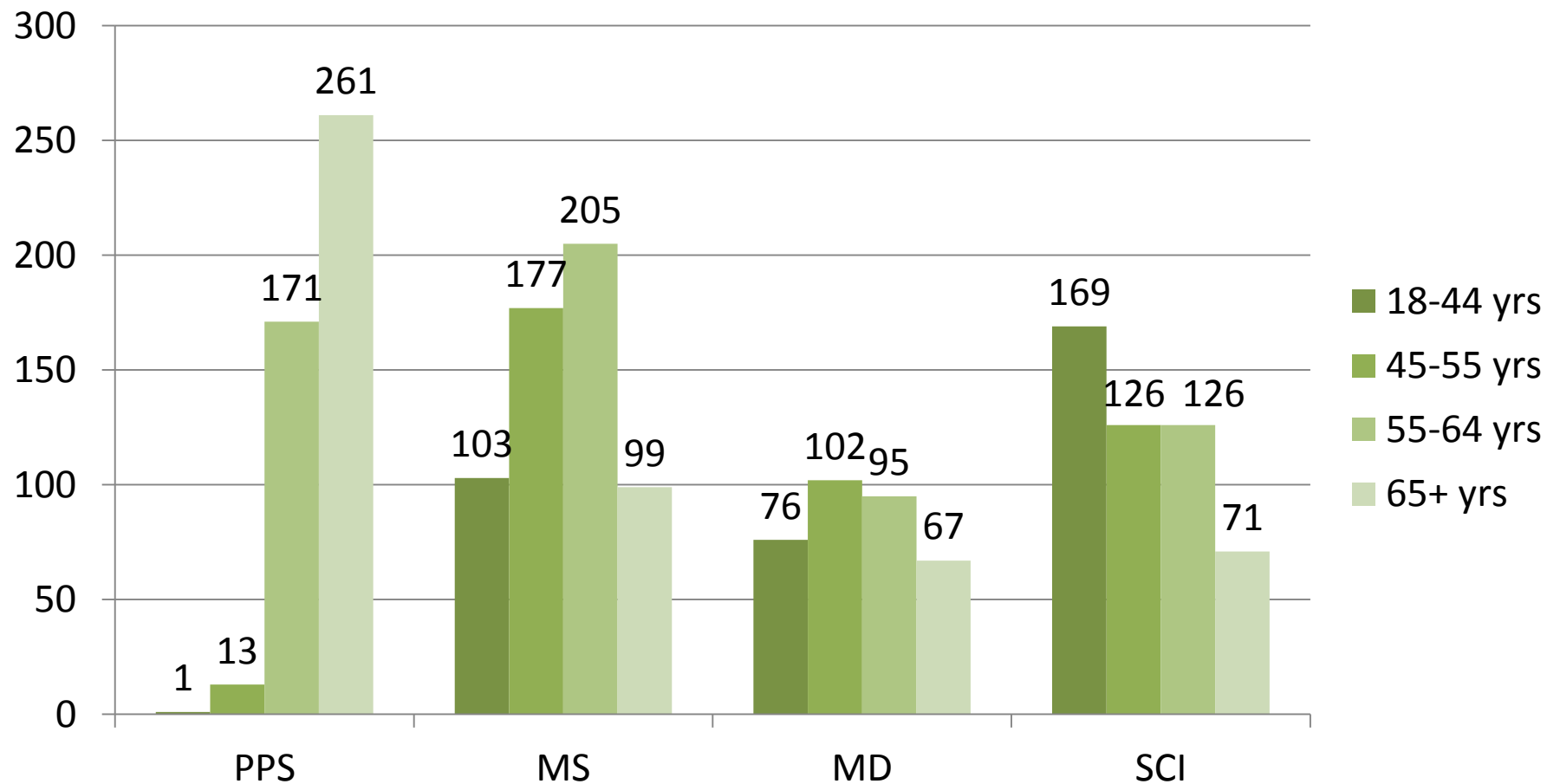
# Who participates in our survey?



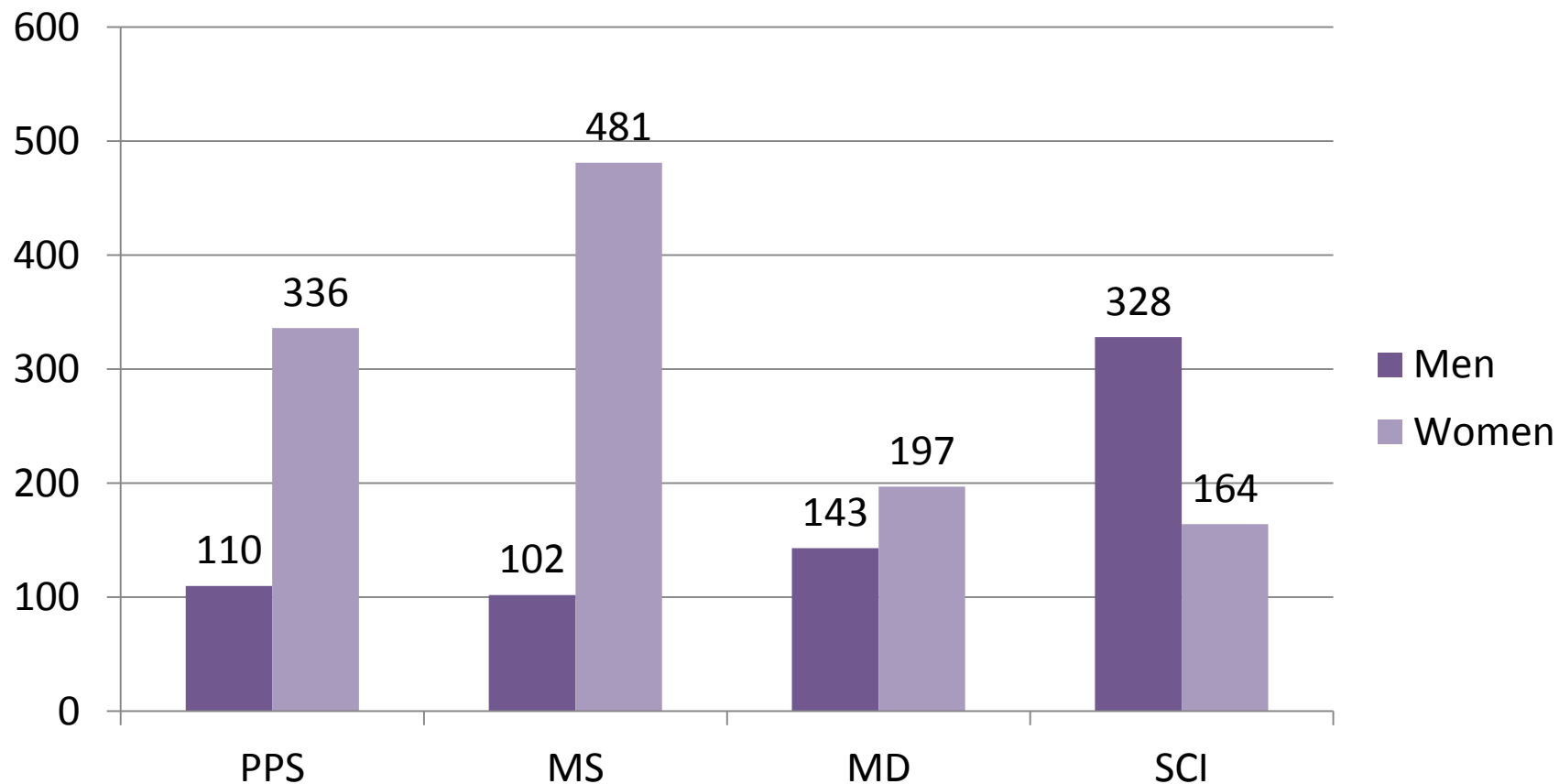
# Who participates in our survey?



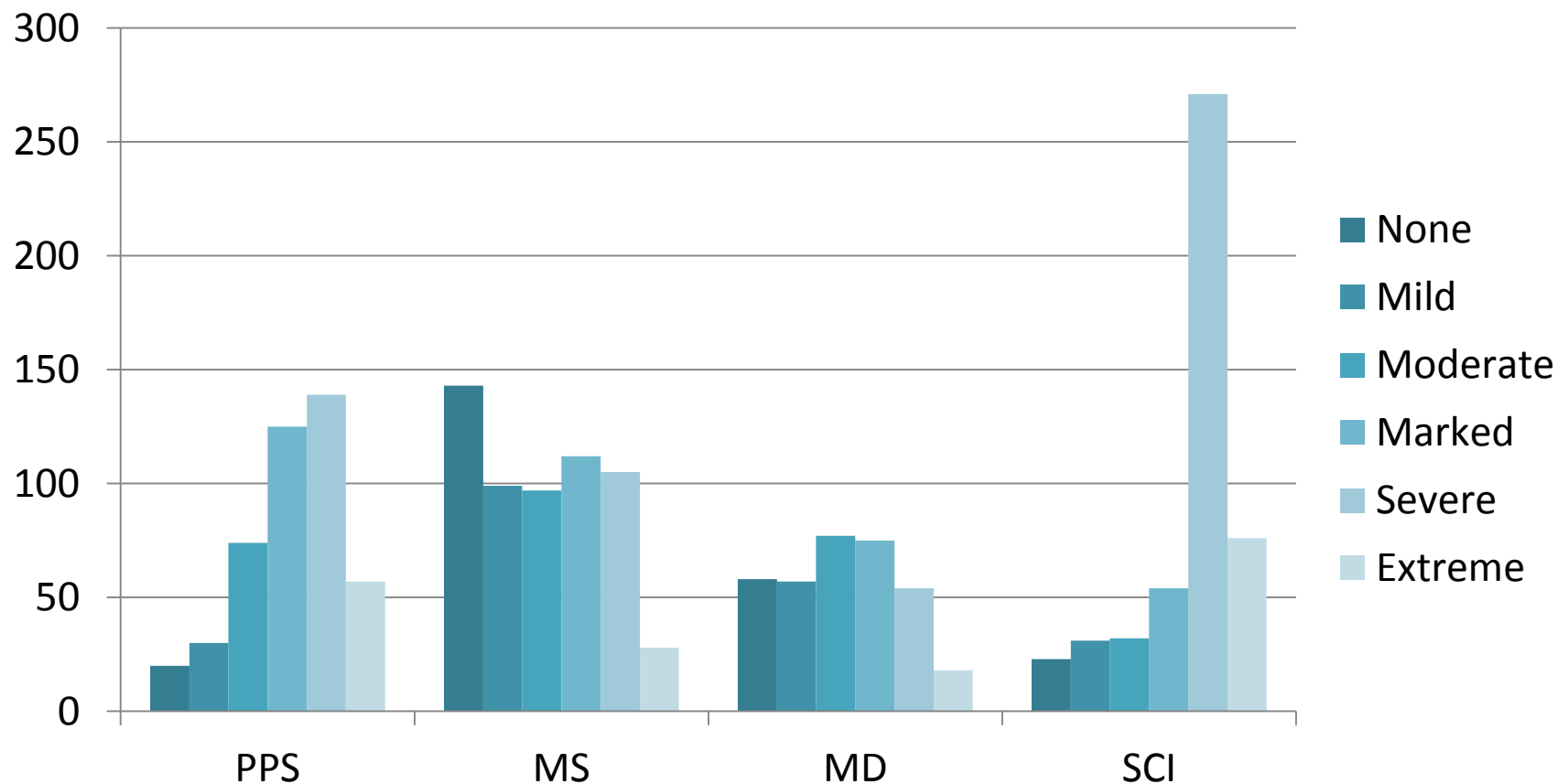
# By Age



# By Gender

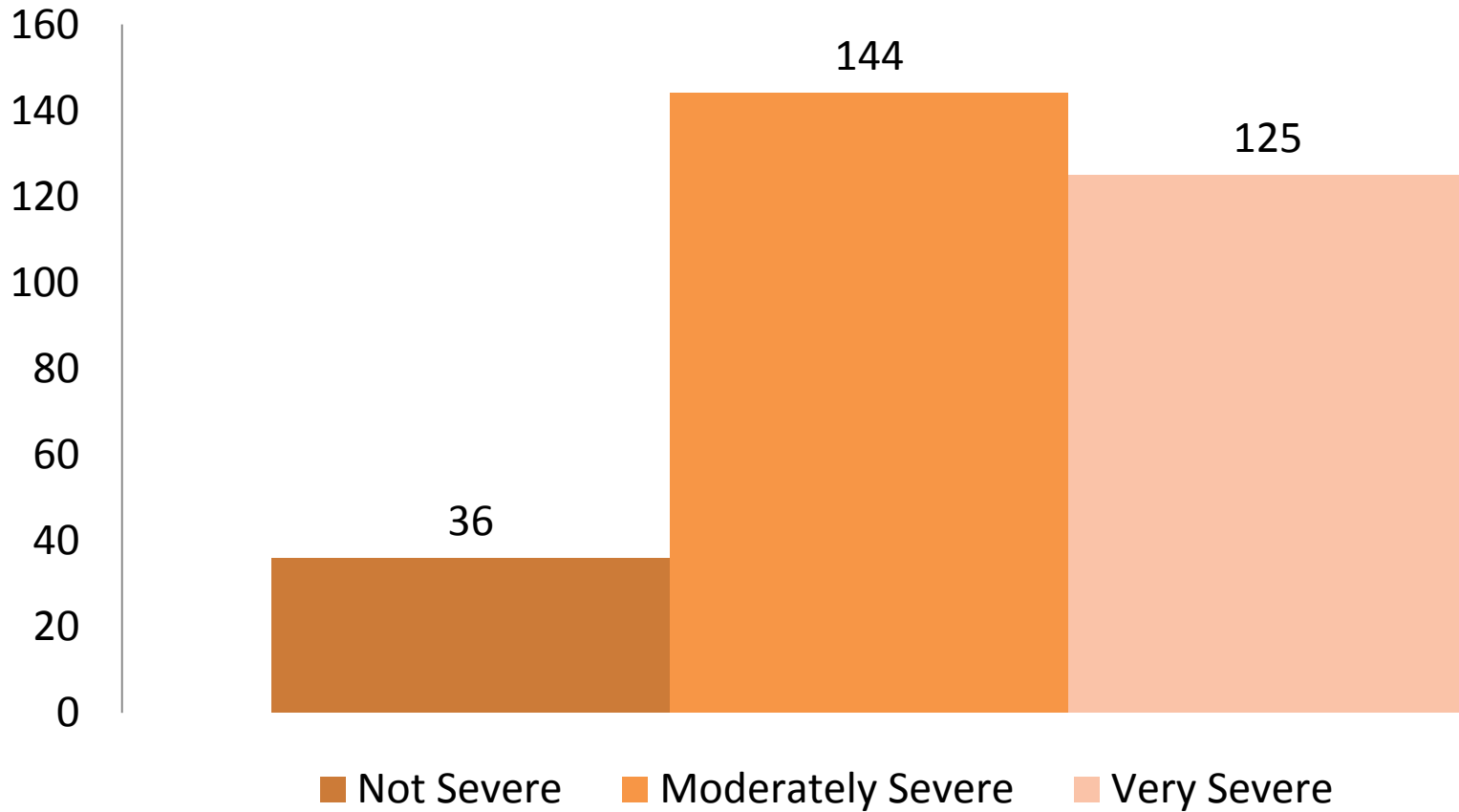


# By Mobility

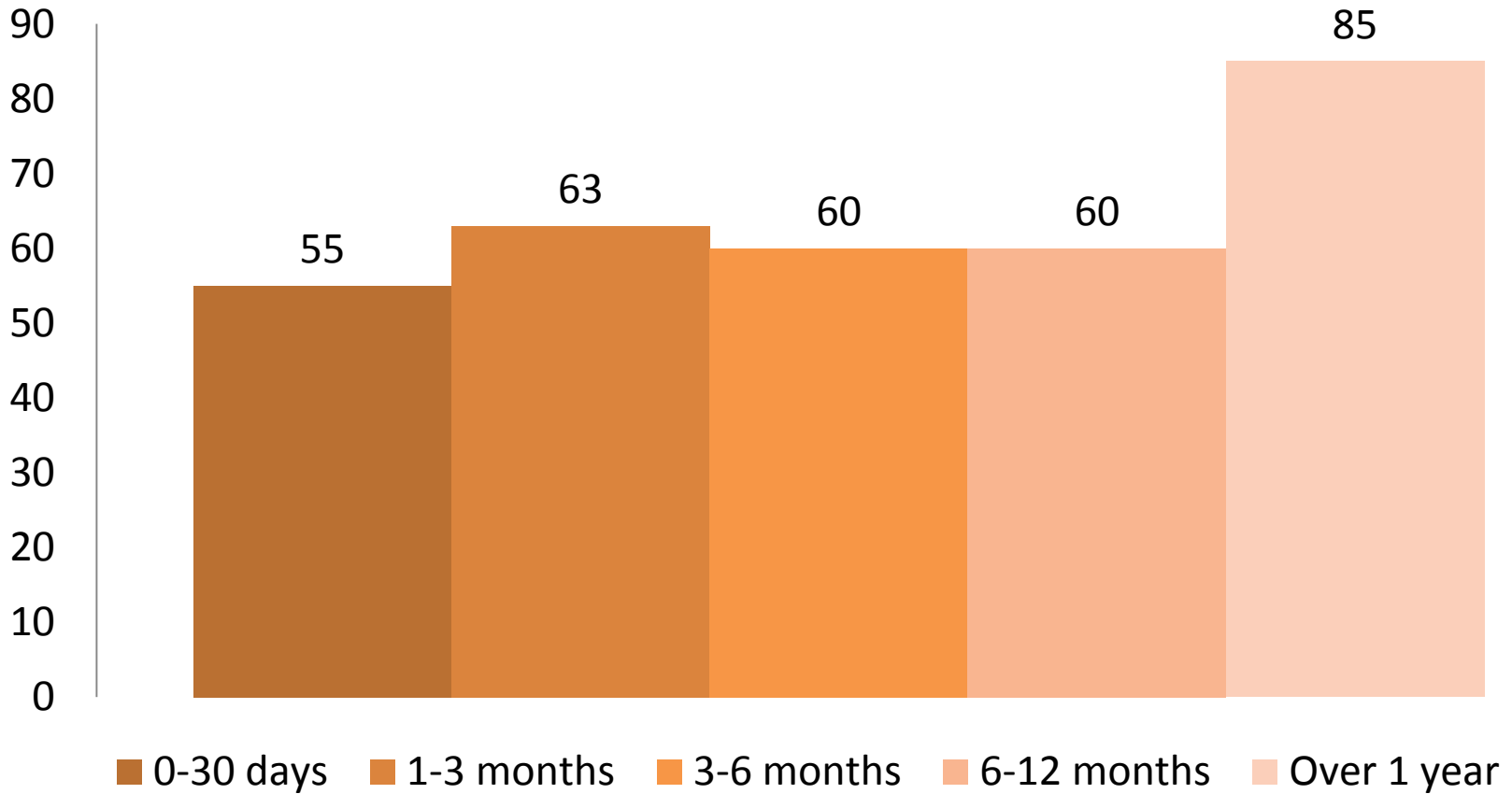




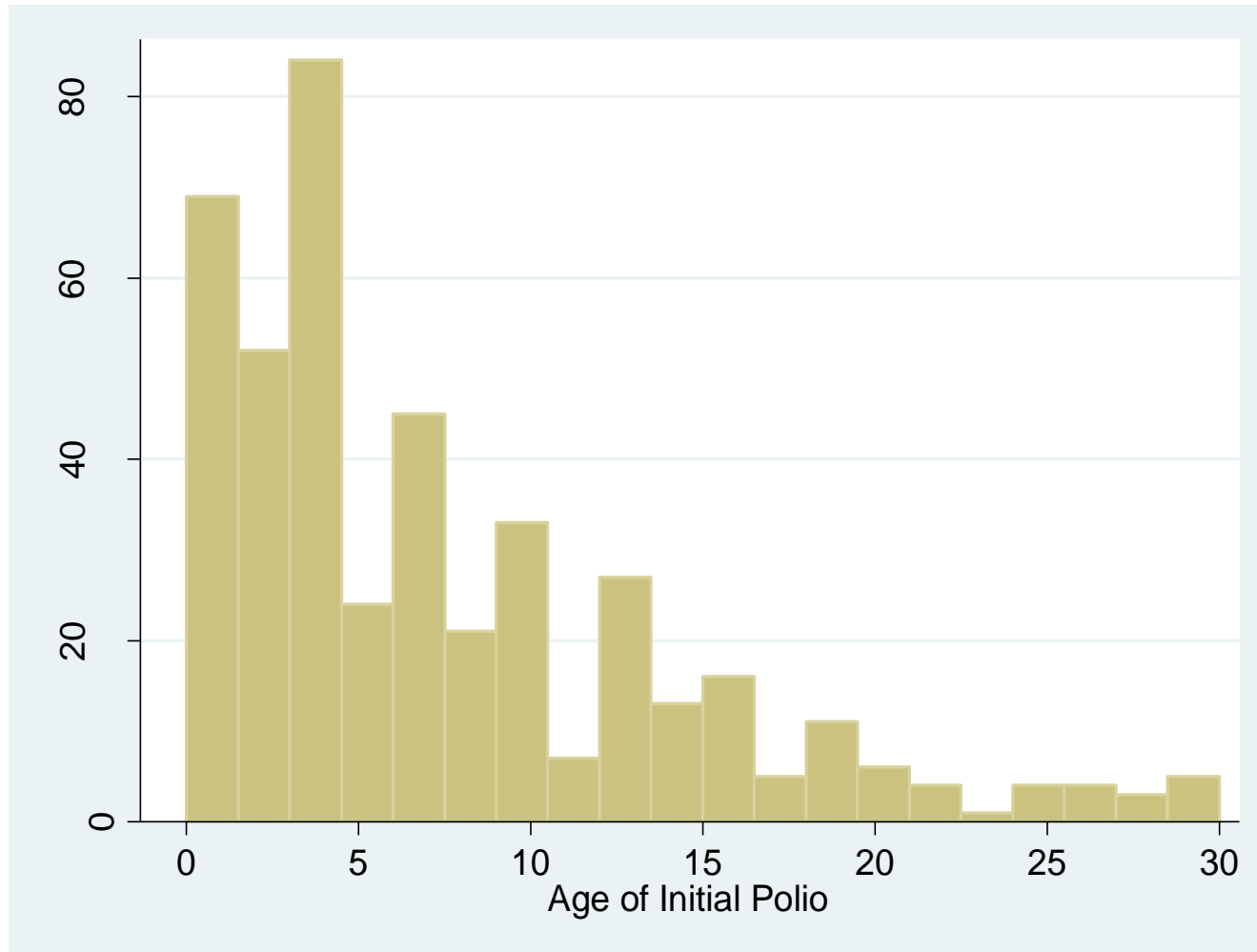
# How severe was your initial polio?



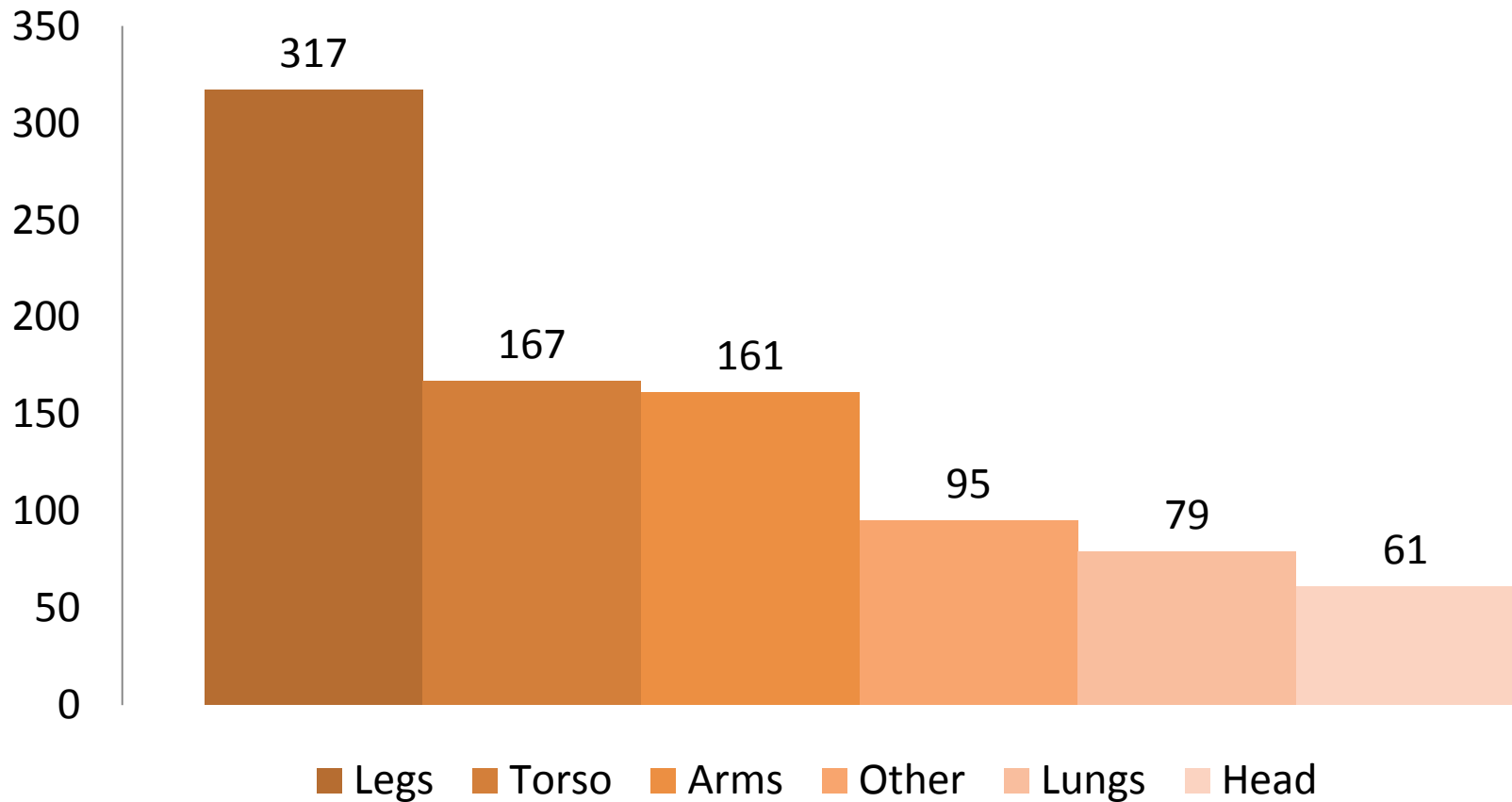
# How long did your initial polio last?



# How old were you during your initial polio?



# Where did you experience weakness during your initial polio?



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# What do we mean by “healthy aging?”



# Defining Healthy or 'Successful' Aging

- THEN:
  - Focus on physical function or longevity
  - Remaining free of medical conditions and disability
  - Does not account for adaption to decline in function

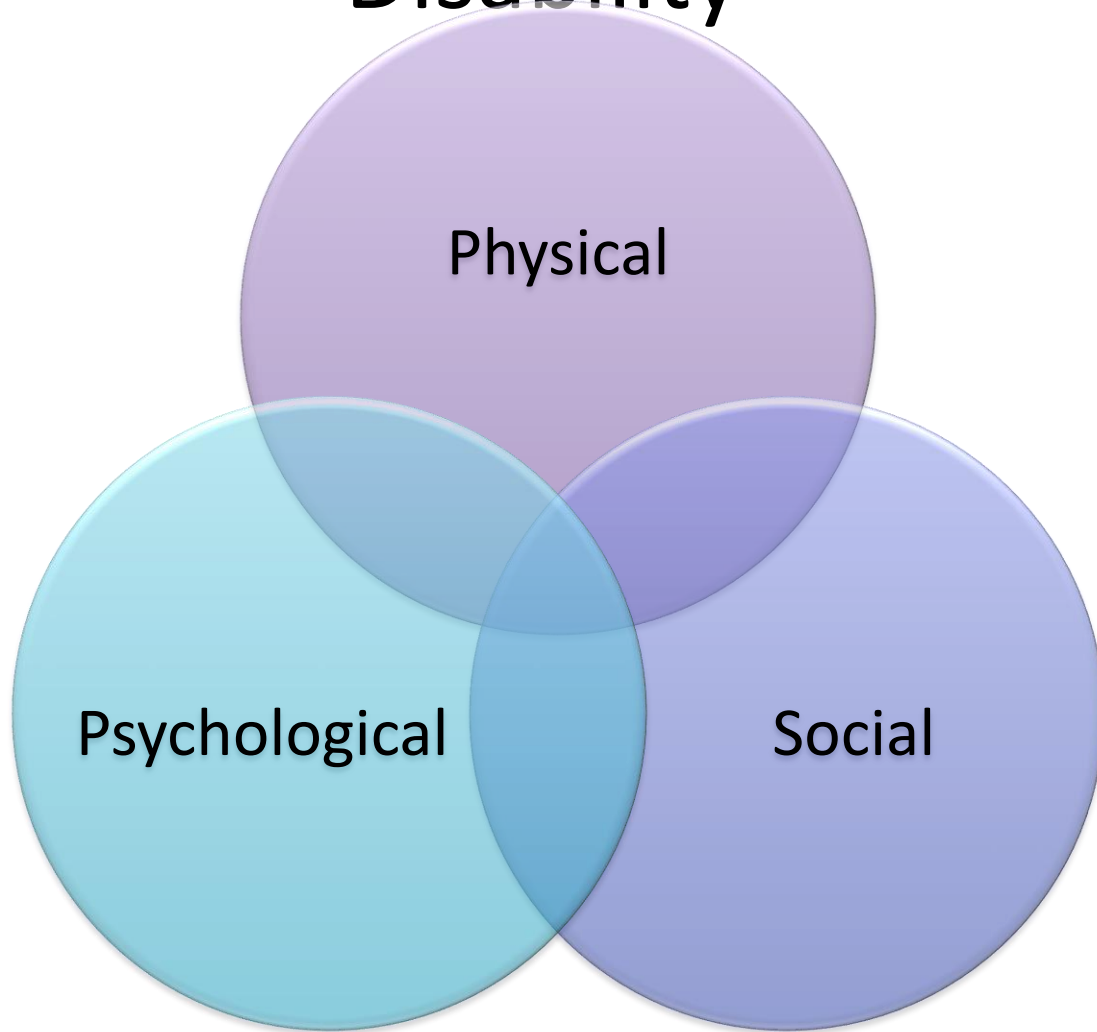
# Defining Healthy or 'Successful' Aging

- NOW:
  - Include psychological and social components
  - E.g. engaging in meaningful activities, quality of life





# Model of Healthy Aging with Physical Disability



- *“...invoke adaptive psychological and social mechanisms to compensate for physiological limitations to achieve a sense of well-being, high self-assessed quality of life, and a sense of personal fulfillment even in the context of illness and disability”*



**Physical**

**Prevent New  
Conditions &  
Injuries**



**Psychological**

**Emotional vitality,  
resilience, coping**



**Social**

**Engaging in  
life**

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# Physical Component

## Prevent or Reduce Conditions & Injuries



# Prevent or Reduce Conditions

## Reducing the Impact of Secondary Conditions



# What are secondary conditions?

- Problems that may not be directly caused by your condition.
- Sometimes “secondary” problems can be even more difficult to manage than the original disability itself.
- May be overlooked by health care providers or coverage from health insurance companies.

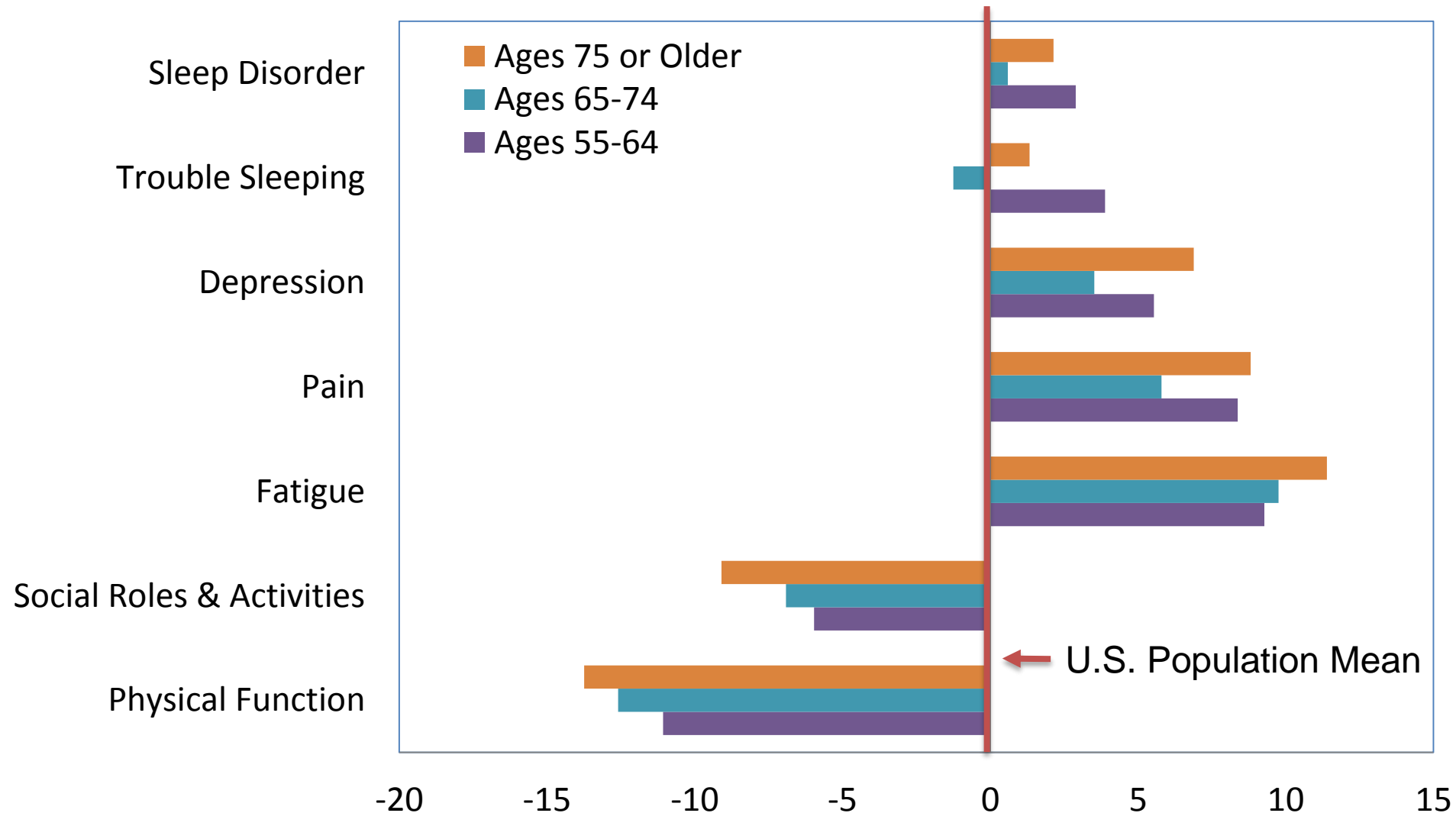


# Secondary Conditions

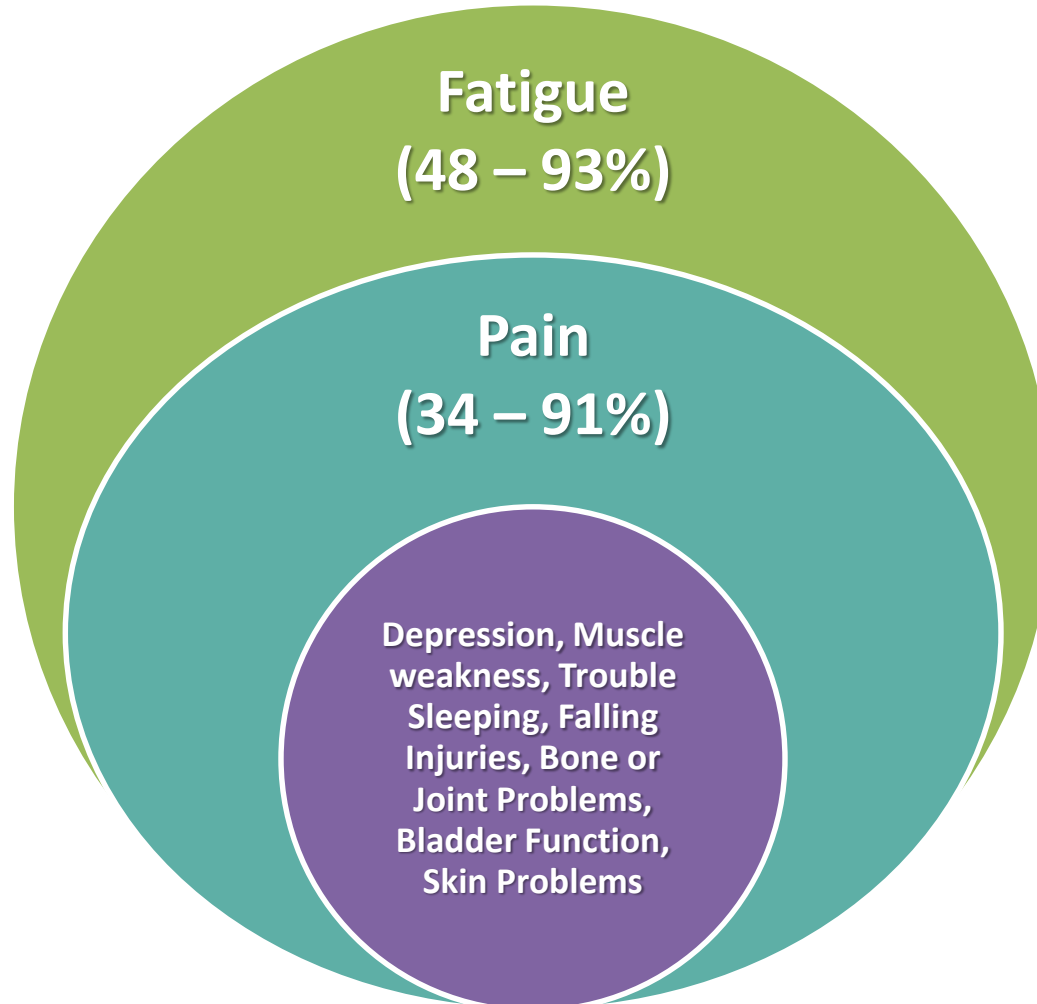




# Secondary Conditions for PPS

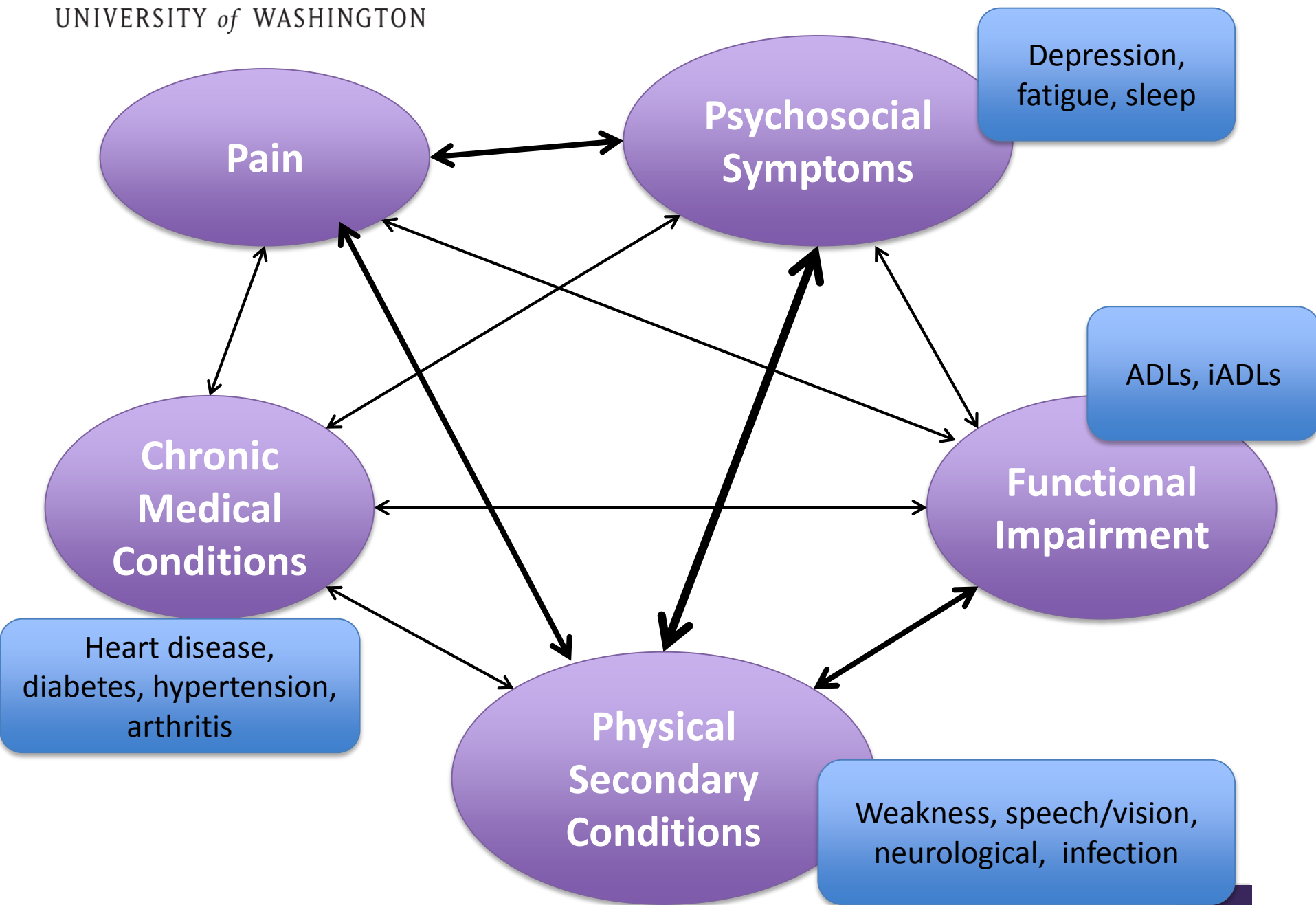


# What else do we know: Secondary Conditions



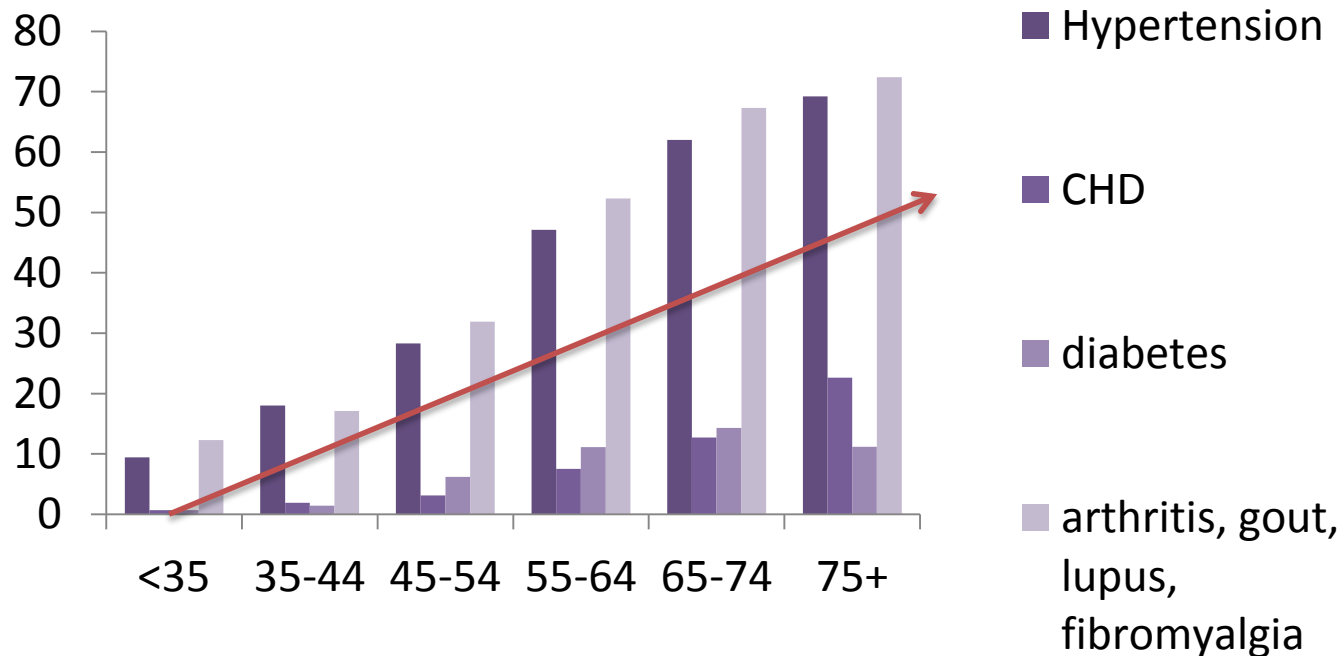
# What is the impact of secondary conditions?

- How do secondary problems relate to one another?
- How do they impact people's ability to live their lives to its fullest?
- Are there differences across age groups?



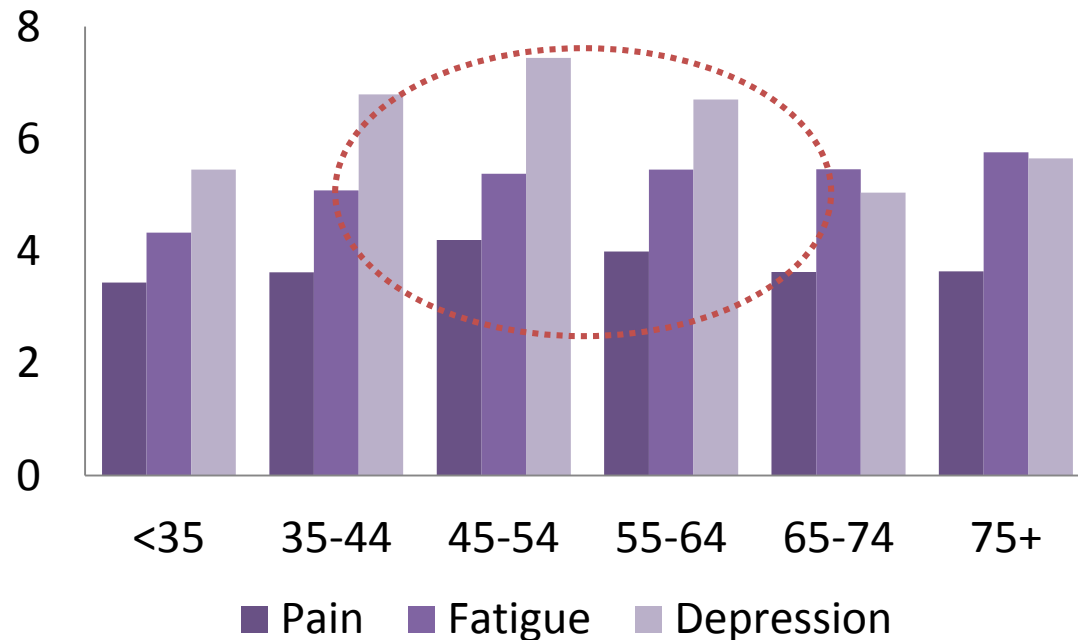
# What happens with age?

- Older age is associated with
  - More chronic medical conditions
  - Greater physical secondary conditions
  - Greater functional impairment



# It's not just an uphill battle...

- Middle age associated with:
  - Greater psychosocial symptoms
  - Greater pain



# Prevent New Injuries

## Falls

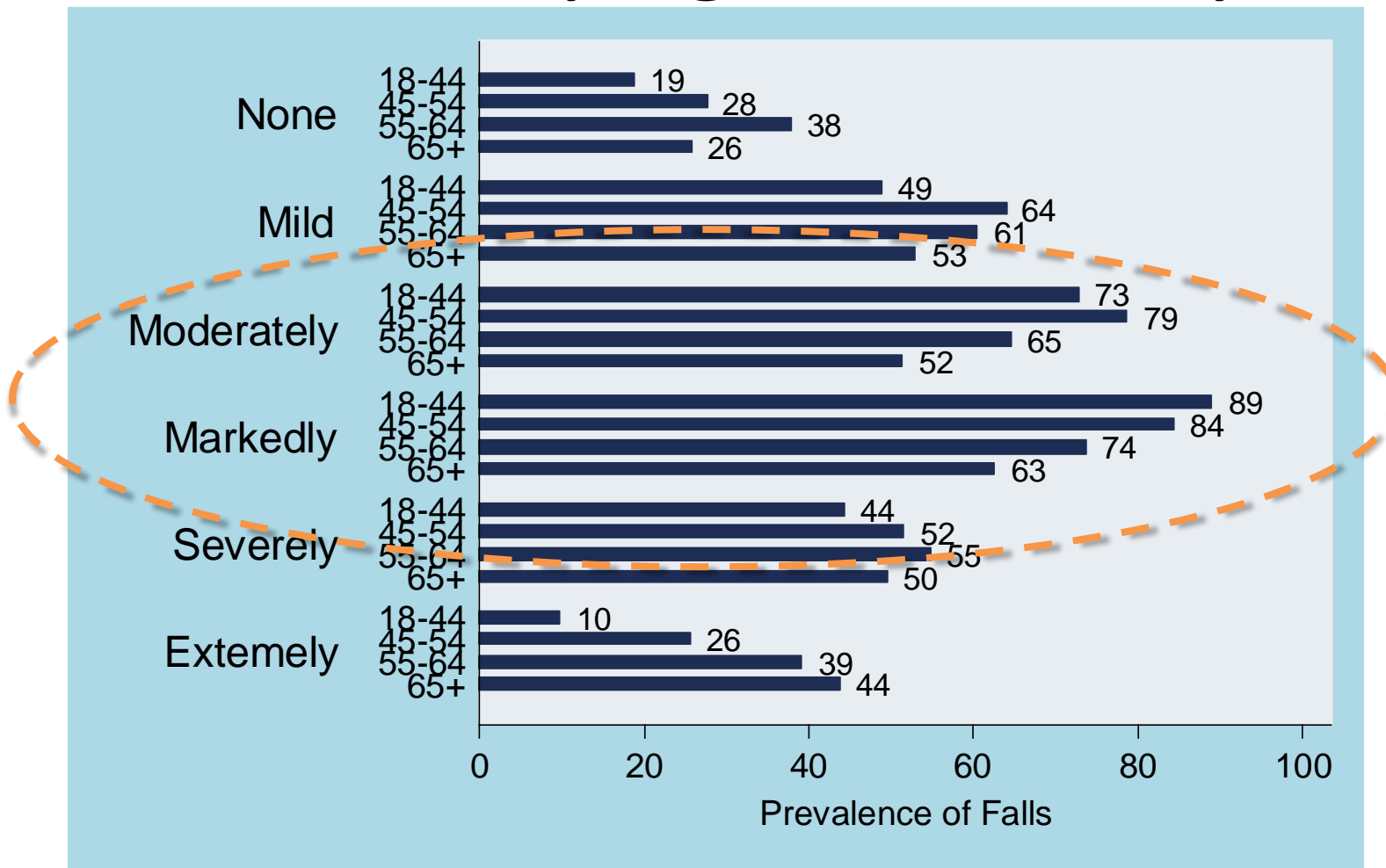


# Why Falling Matters

- One in three adults age 65 and older falls each year.
- In 2010, about **21,700** older adults died from unintentional fall injuries.
- Older adults are hospitalized for fall-related injuries **5 times** more often than injuries from other causes.
- People 75 or older who fall are **4–5 times** more likely than those age 65 to 74 to be admitted to a long-term care facility for a year or longer.
- Falling may lead to fear of falling and limiting valued activities.

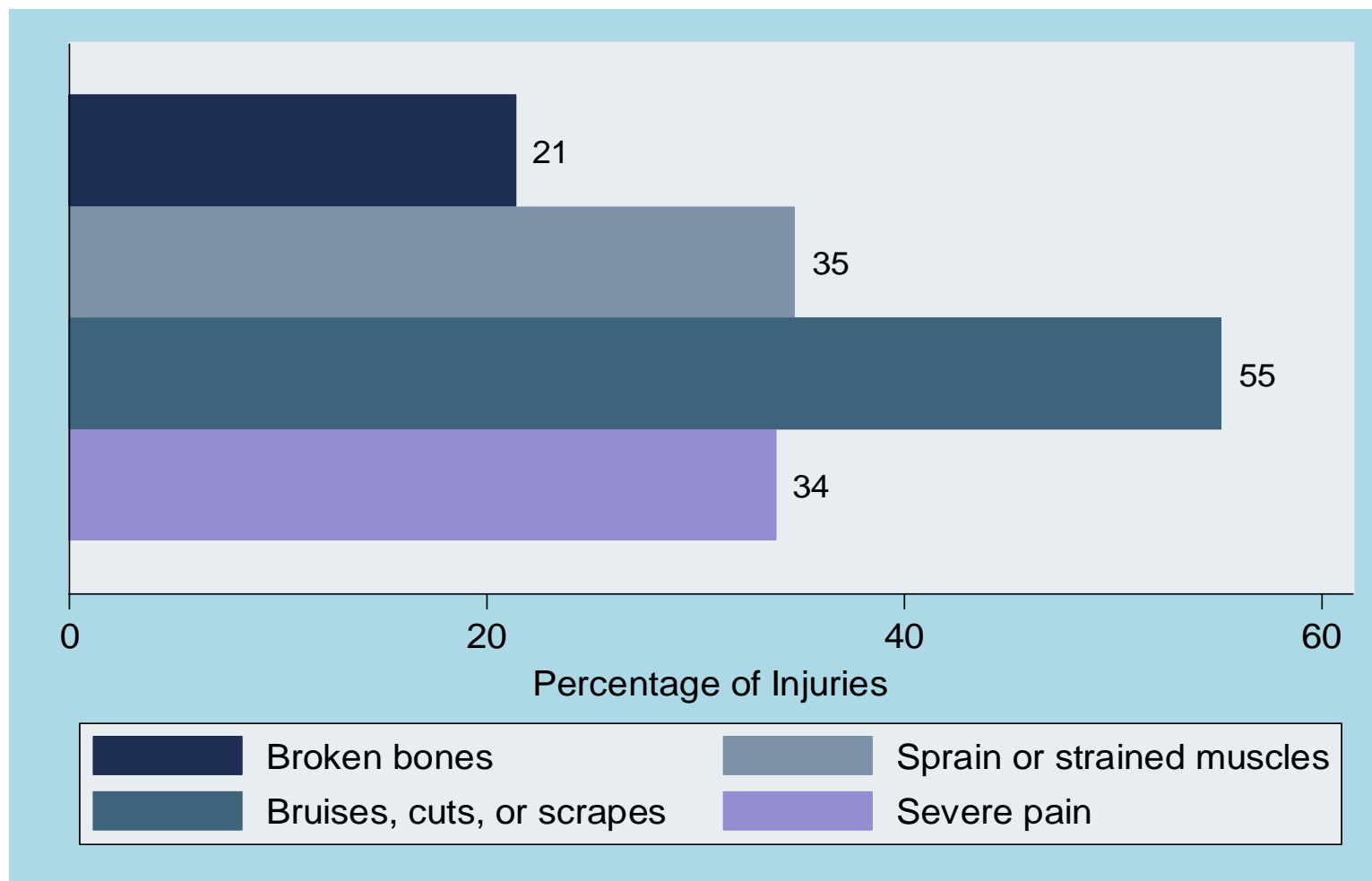


# Falls by Age & Mobility



For Everyone: PPS, MS, MD, SCI

# Types of Injuries



For Everyone: PPS, MS, MD, SCI

# Who is at risk of falling for PPS?

- Older age.
- Middle mobility levels, using devices like walkers, canes, crutch users.
- Vision trouble.



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# Social Component

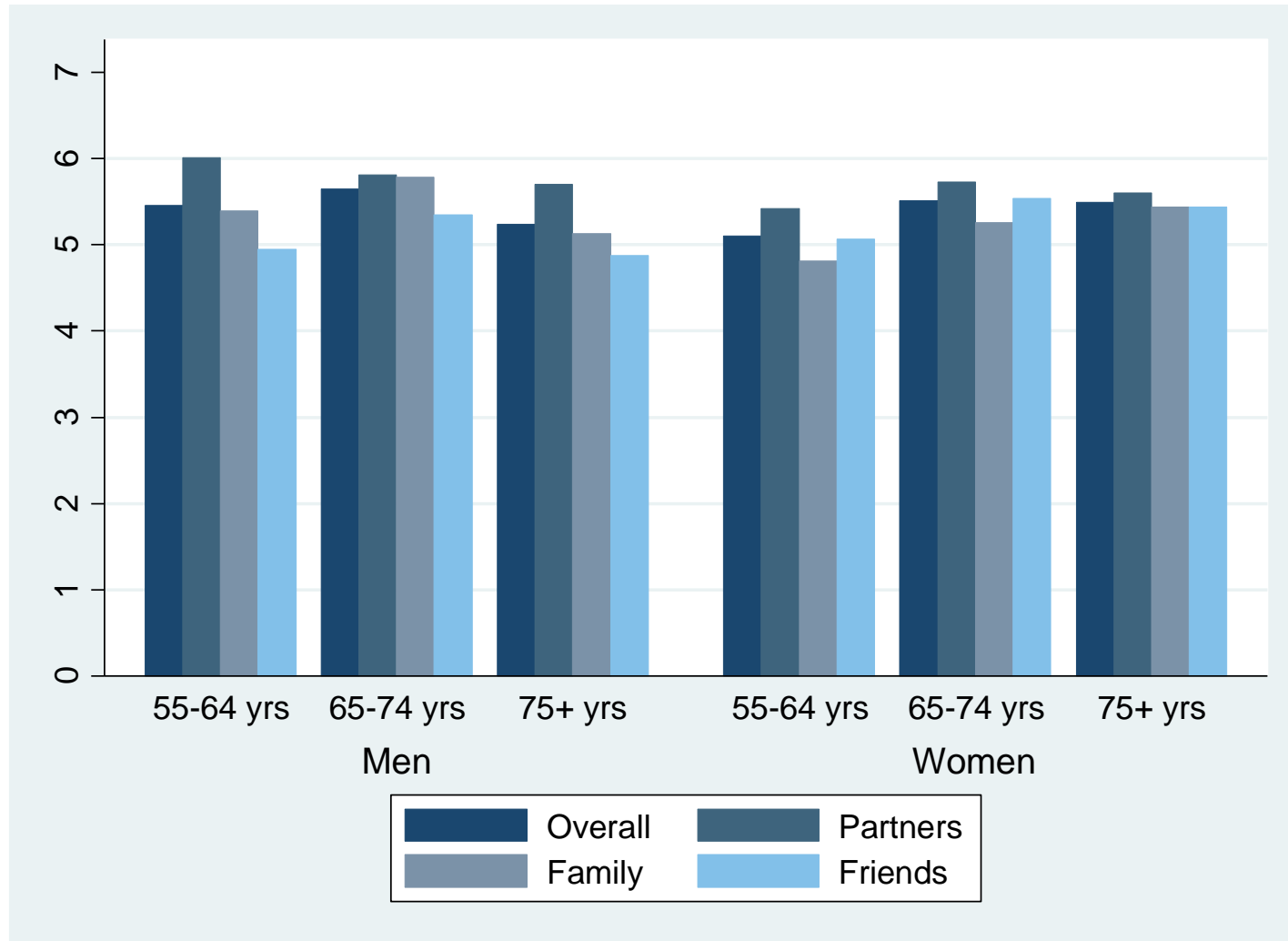
The Support of my Friends, Family, and Partners  
and my Social Place in the World.



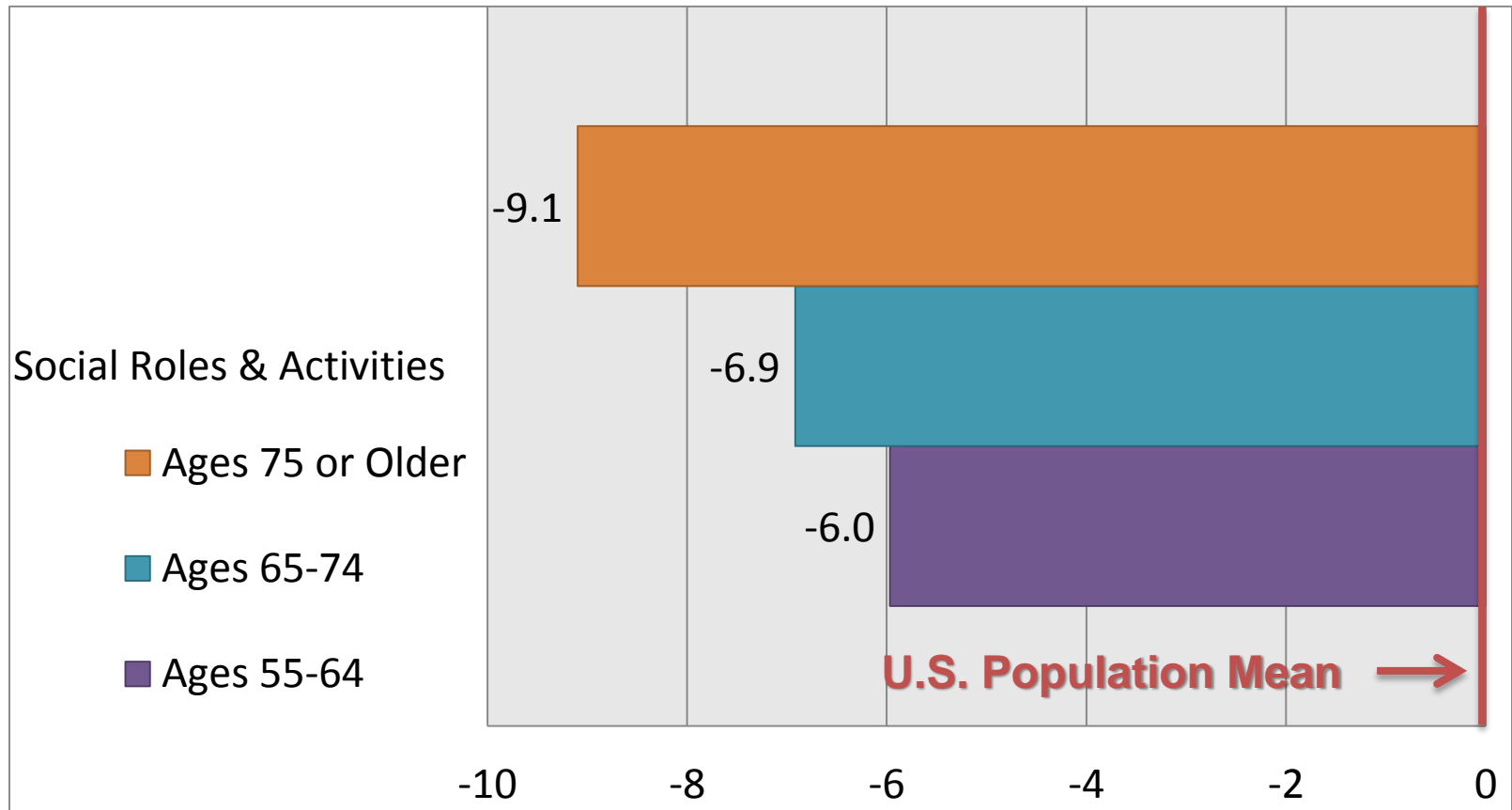
# Social Well-Being

- With age, social support networks may get smaller, but the quality of relationships get deeper.
- Social support provides resources to help us deal with chronic conditions.
- Feeling supported allows us to engage in life.

# Social Support for PPS by Age and Gender



# How happy am I with my social place in the world?



- Post-Polio Participants



# Our Findings

- Social support (especially friend support) decreases with age and is lower for men.
- Support is associated with depression.
- How do secondary symptoms interact with social life?

# Fatigue and Satisfaction with One's Social Life Over 4 Years



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# Psychological Component

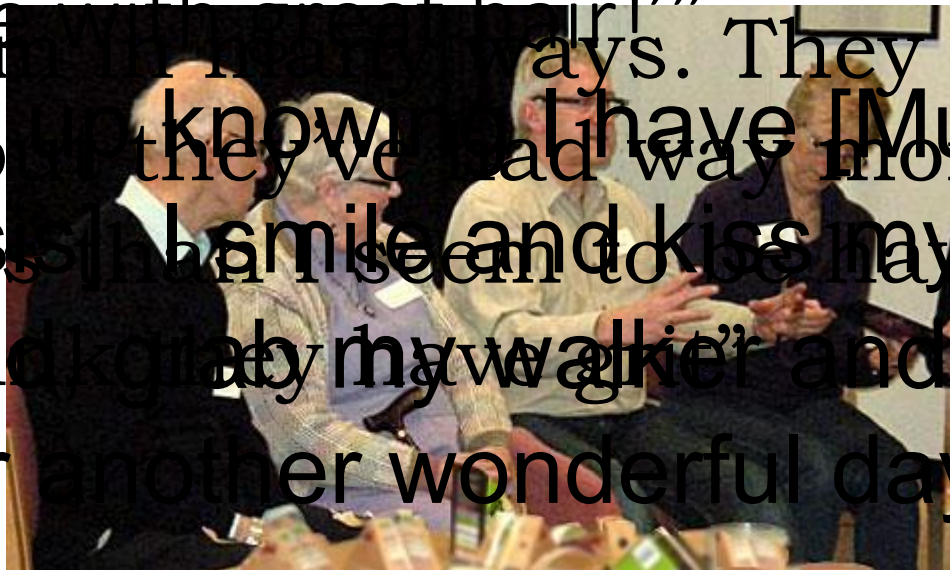
## Resilience



# Participant Comments

"I don't even think about being disabled. I like to say 'God took my legs age bracket that are in worse shape and left me with great hair!'"

"I wake up knowing I have Multiple Sclerosis. I smile and kiss my husband and say 'I have a walker' and thank God for another wonderful day."



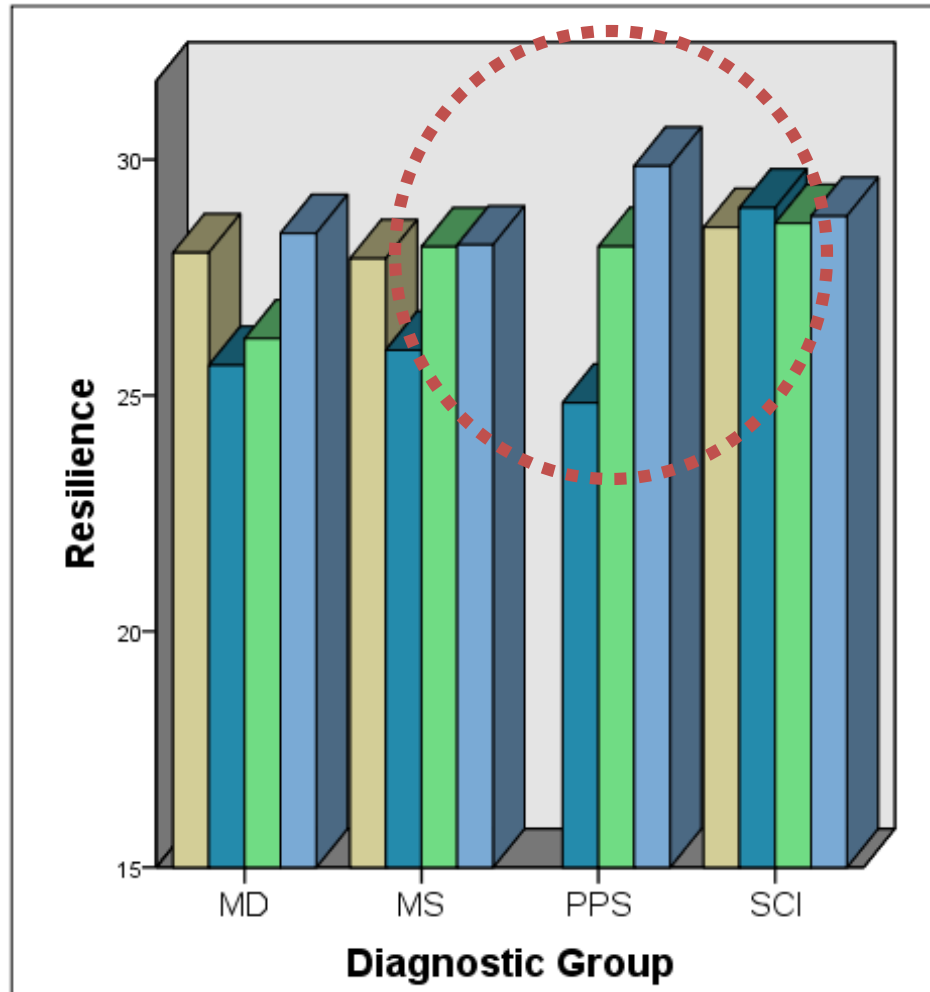
# What is Resilience?

- Adapting or thriving in the face of adversity
- A dynamic process
- A set of cognitive, behavioral, and interpersonal skills
- Grounded in genetic, biological, psychological, and environmental factors.

# What's it got to do with aging?

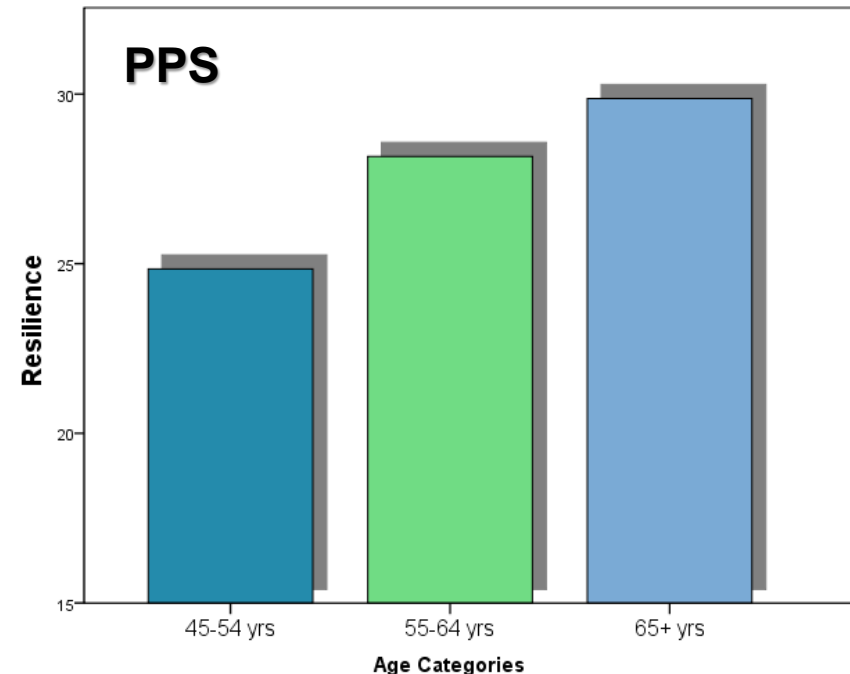
- Maintain well-being when faced with aging-associated losses
- Resilience, depression, and physical health all associated with successful aging

# What does resilience look like in our participants?



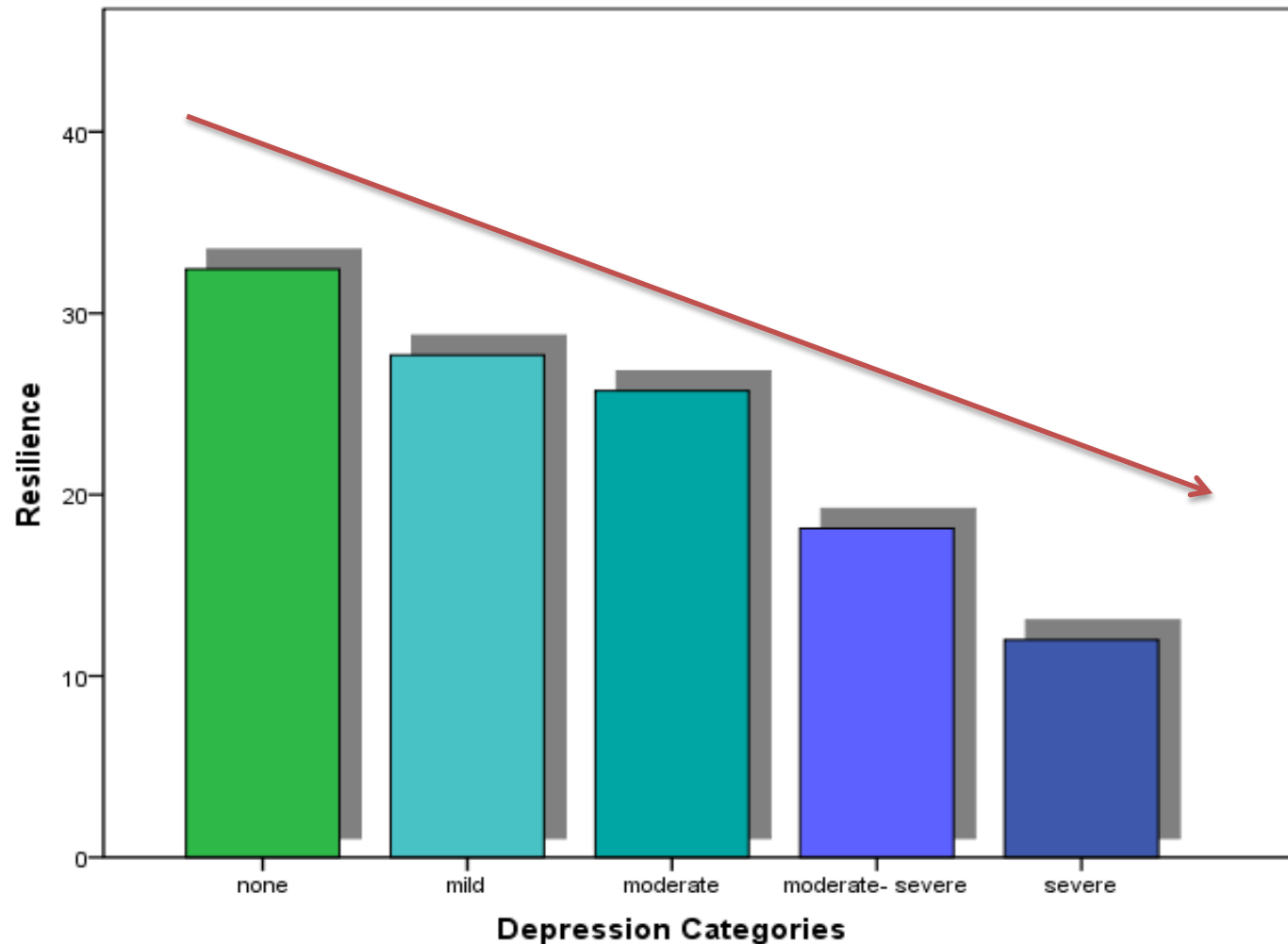
Age Categories

- 18-44 yrs
- 45-54 yrs
- 55-64 yrs
- 65+ yrs

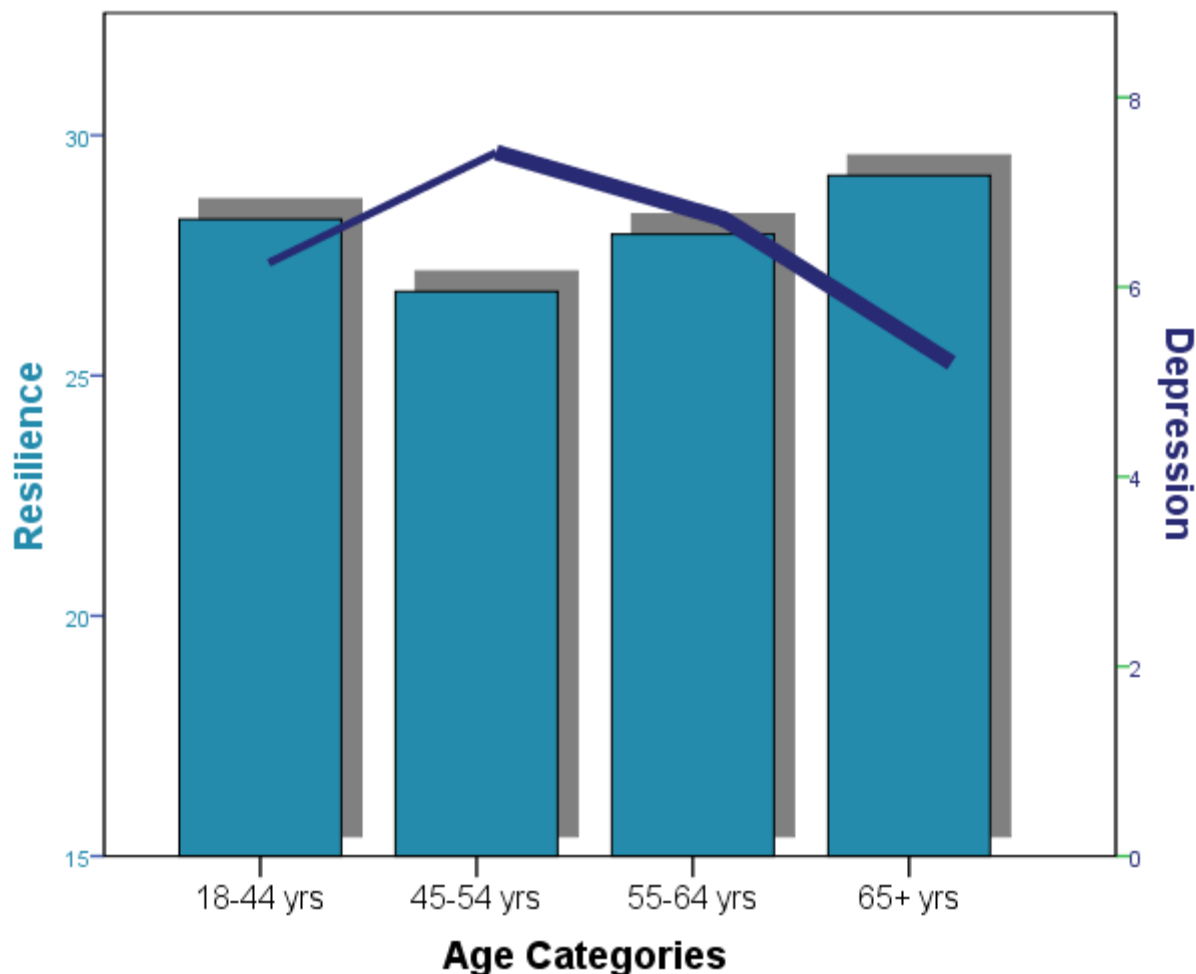




# Resilience and Depression

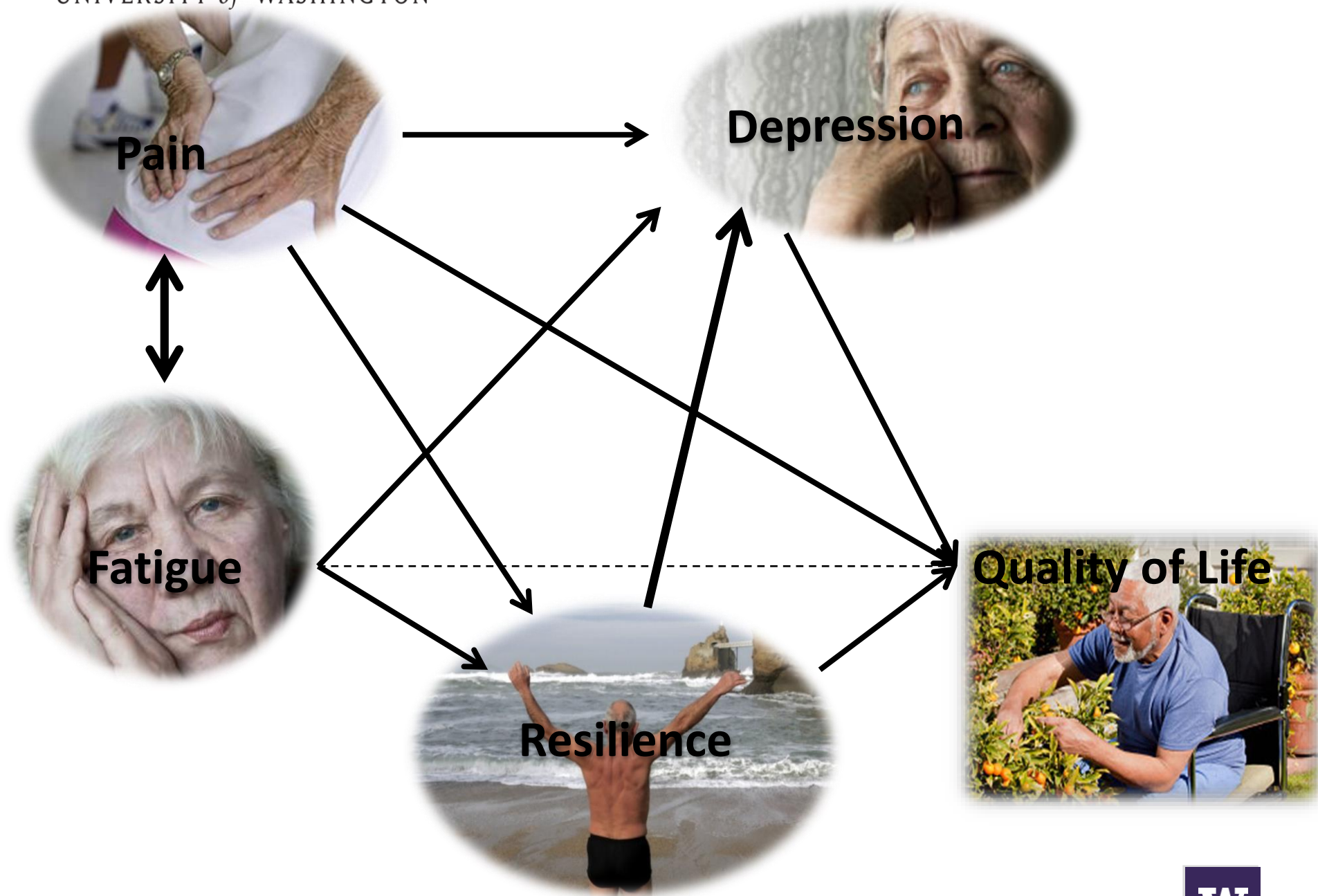


...and how do resilience and depression vary with age?



# Does resilience matter?

- How is resilience related to secondary conditions, such as pain and fatigue?
- Can it “buffer” against effects of secondary conditions on depression?
- What about quality of life?



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# Where do we go from here?

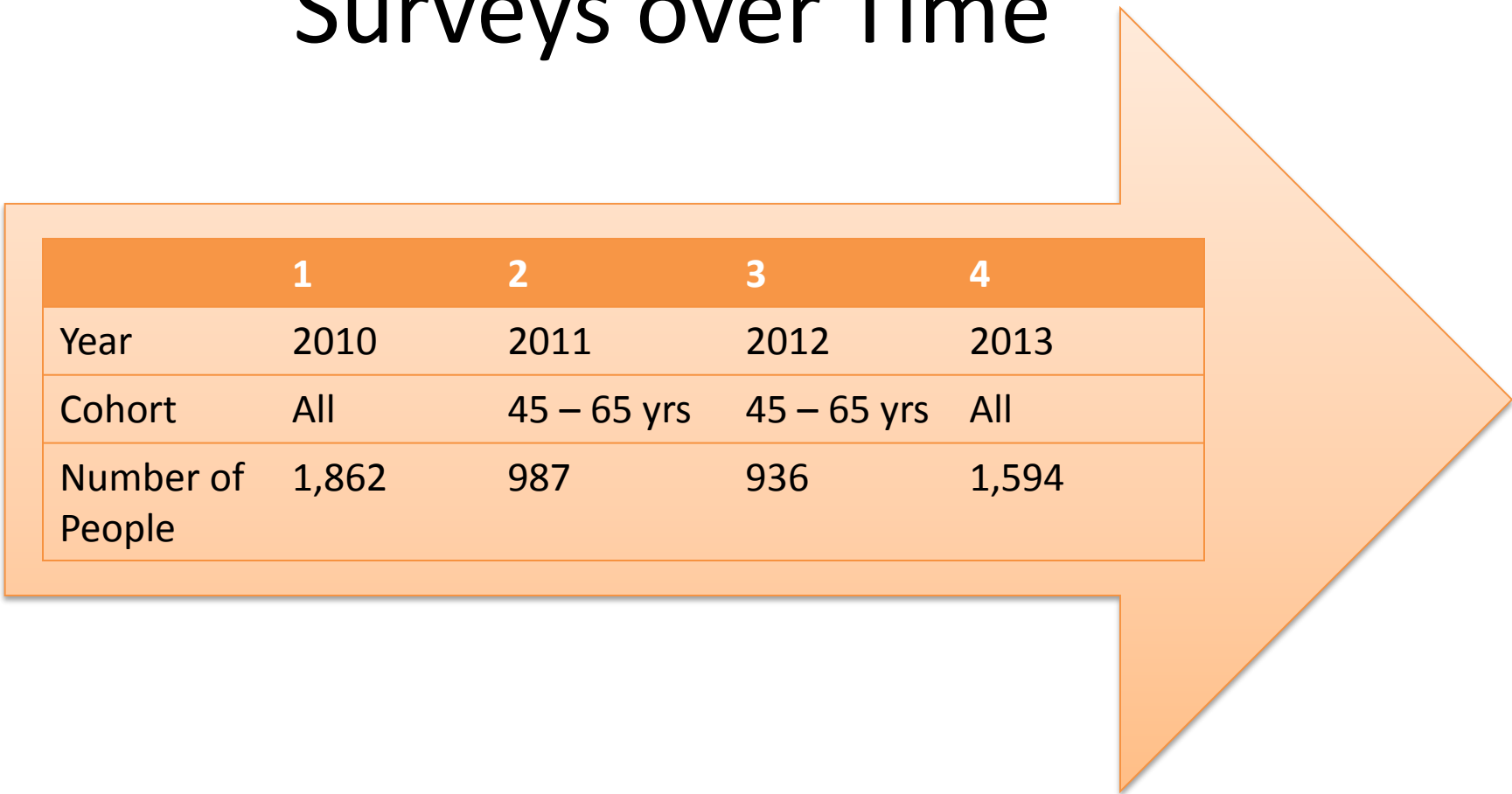




Rehabilitation Research and Training Center

- New funding
- New website
- New research
- Continue prior research (surveys!)
- Share our findings
- Answer questions / be a resource

# Surveys over Time



	1	2	3	4
Year	2010	2011	2012	2013
Cohort	All	45 – 65 yrs	45 – 65 yrs	All
Number of People	1,862	987	936	1,594



# 3 More Surveys

	1	2	3	4	5	6	7
Year	2010	2011	2012	2013	2014	2016	2018
Cohort	All	45 – 65 yrs	45 – 65 yrs	All	All	All	All
Number of People	1,862	987	936	1,594	1,800	1,800	1,800

- Open enrollment to fill in gaps in diversity – For PPS, we need Men!

# Project Enhance



# ENHANCE

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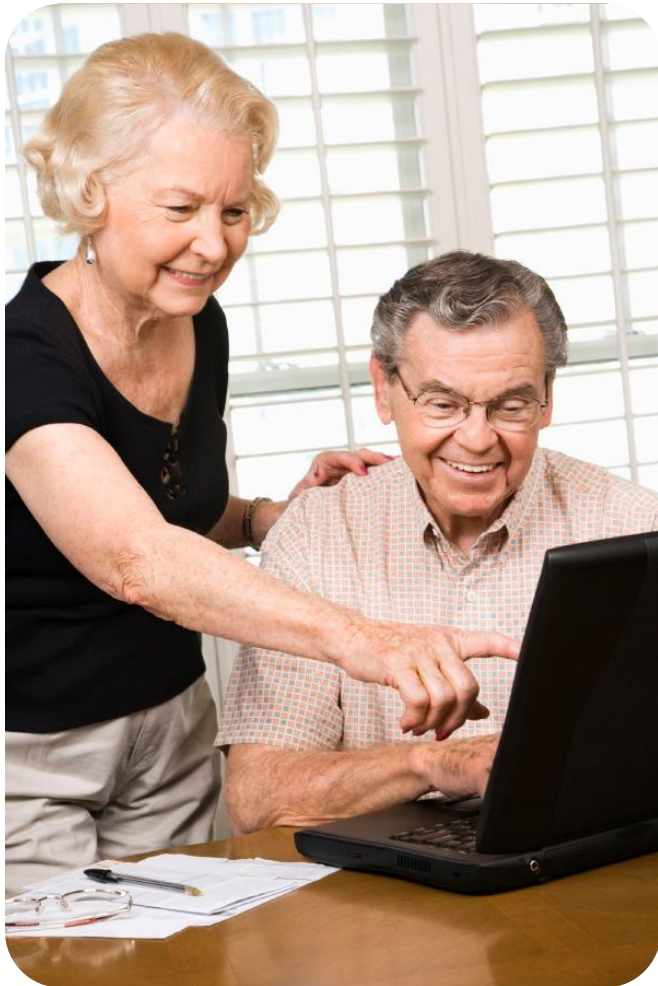
[Particip](#)



# Project Enhance

- Award winning health promotion program for older adults.
- Adapting for people with long-term physical disabilities (MS, MD, PPS, SCI).
- Work toward a health goal of your choice with a “Wellness Coach.”
- A joint study with Senior Services of King County, WA.

# Factsheets



- There is a lot of health-related information on the internet. But not all of it is good.
- Evidence-based: using the current best knowledge available.

## Aging Well with a Physical Disability Factsheets

Our factsheets are reviewed by experts and consumers (people aging with a physical disability) to make sure they are up-to-date, evidence-based, and easy to read.

"Evidence-based" means that it's using the current best knowledge available.

Please note, this information is not meant to replace the advice from a medical professional. You should consult your health care provider regarding specific medical concerns or treatments.

- [Exercise for Older Adults with a Disability](#)
- [Depression and Aging with a Disability](#)
- [Getting the Most Out of Health Care Visits](#)
- [Sleep and Aging with a Disability](#)
- [Getting Trustworthy Health Information from the Internet](#)
- [Thinking problems and Aging with a Disability](#)
- [Employment and Aging Adults with Disability](#)
- [Provider's Guide for Aging Well with a Physical Disability Factsheets](#)
- [Fall Prevention for Older Adults with a Physical Disability](#)
- [Fatigue and Aging with a Physical Disability](#)



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## New Paper: How to Age Well with Secondary Problems

### [Living with physical disability: How to age well with secondary problems](#)

**What is this research about?** It is well known that people who live with long-term physical conditions like multiple sclerosis or muscular dystrophy may experience physical problems, such as muscle weakness or trouble balancing, as a direct result of their medical condition. However, we know people experience many problems that may not be *directly* caused by their disability, but are still related to it. These problems include things like chronic pain, fatigue, depression, worsening muscle spasms, or chronic infections. These kinds of problems are called “secondary” or “secondary conditions.” In fact, sometimes “secondary” problems can be even more difficult to manage than the original disability itself. However, these “secondary” problems often don’t get as much attention from health care providers or coverage from health insurance companies.

**What did the researchers do?** We asked a large group of people living with spinal cord injury, multiple sclerosis, muscular dystrophy, and post-polio syndrome about their “secondary” problems. About 2,000 people from all over the United States answered a survey for us. We looked at how people’s answers on these “secondary” problems

# Our Findings

- Summaries of our research papers.
- “Spreading the News” A way for our findings to be available and reach more people.
- Available on our website’s “What’s New” section and also through our Facebook, Twitter, and our quarterly e-newsletter.

# Stay Connected with Us!



<http://agerrtc.washington.edu/>



Healthy Aging RRTC



@AgingRRTC



# Thank you and Questions?

For additional questions, feel free to contact us  
at [aterrill@uw.edu](mailto:aterrill@uw.edu) or [verrall@uw.edu](mailto:verrall@uw.edu).





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