

# Aging *with* and aging *into* Physical Disability

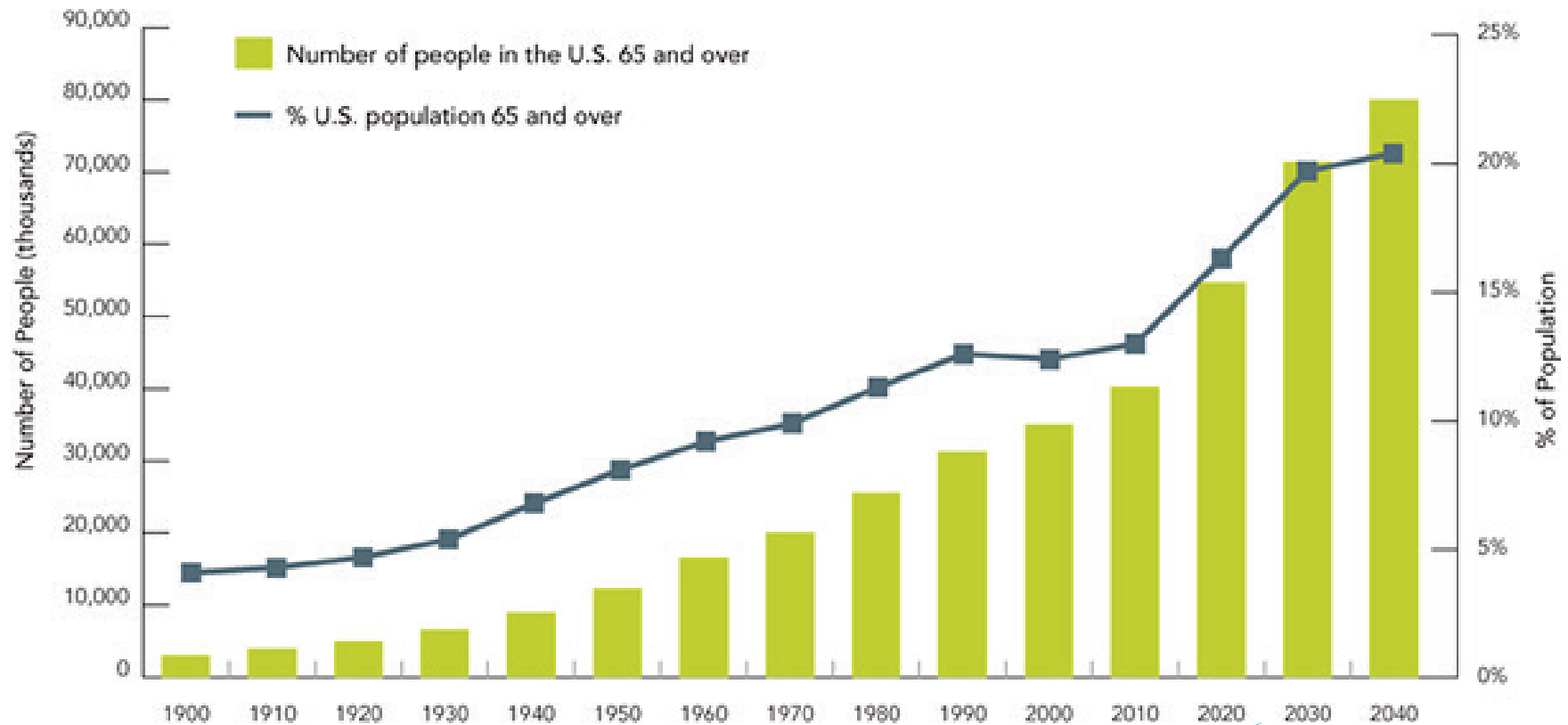
Ivan R. Molton, PhD

University of Washington, Dept. of Rehab. Medicine

Nikki Bagli, MSW, Senior Services

# We're all getting older...

**Aging U.S. Population**



- Currently 12.4% of US Population are >65 (37.3 million)
- By 2030, expected to be 20.4% (71.5 million)

# Older adults are only the same in that they're so different

- Older adults show more intergroup variability than do younger adults in almost all areas
  - Cognitive abilities
    - Crystallized intelligence
    - Complex reasoning and problem-solving
  - Emotional functioning
    - Depression, anxiety, happiness



We see the most variability in  
**physical functioning** and  
capability



# Aging *into* Disability

- Increasing age is associated with greater risk of disability due to
  - Osteoarthritis
  - Osteoporosis
  - COPD
  - Coronary Heart Disease
  - Peripheral vascular disease
  - Dementia
  - Diabetic Complications
    - Peripheral neuropathy
    - Limb loss
  - Bone frailty



# What about those aging *with* disability?



# Aging “*with*” disability

- In 2010, 29.5 million Americans aged 21-64 (16.6% of the working age population) reported physical disabilities
- 260,000 individuals with SCI
- 350,000 individuals with MS
- 100,000+ individuals with CMT
- 177,000 individuals with post-polio syndrome
- Each year, 1.7 million TBI’s



# Aging *with* disability.

- *Those* with disability are living longer...
- Example: SCI
  - In 1940, average life expectancy post-SCI was 18 months
  - In 2005, average life expectancy with SCI is approximately 85% of normal (~68 years)
  - This means that in the past 50 years
    - survival for persons with SCI has increased 2000% percent
    - survival for the nondisabled population has increased only 30%

## Aging among traditional rehab populations: A diverse group with similar needs.

- Spinal Cord Injury
  - Average age now ~ 40 years
  - 40% are over age 45
  - Average age at onset increased from 28.7 to 38.0 from 1973
- Multiple Sclerosis
  - Mean age 49-53 years
  - 42% over the age of 65
- Post-polio syndrome
  - 90% are over the age of 55
- Cerebral Palsy
  - Death in childhood is now rare (about 2%)
  - 86% live past age 50

# Aging “with” versus aging “into” disability

## Shared challenges, shared needs

### Aging “*into*” disabilities

- Osteoarthritis
- COPD
- Vascular dementia
- Coronary artery disease
- Osteoporosis
- Diabetes (complications)
  - limb loss
  - peripheral neuropathies

- Problems with balance
- Risk of falls
- Chronic pain
- Risk for infections
- Risk for fractures
- Need for caregiver support
- Cognitive impairment
- Depression/withdrawal
- Changes in vision/hearing
- Mobility limitations

### Aging “*with*” disabilities

- Spinal cord injury
- Traumatic brain injury
- Neuromuscular disease
- Multiple sclerosis
- Developmental disabilities
- Post-polio syndrome

# Common goals:

- Research:
  - Identify key health conditions and ameliorate their impact
  - Understand trajectories of ability and disability across the lifespan
  - Describe protective and risk factors for disease and disability progression
- Intervention
  - Develop interventions and evidence based practices to maximize function, participation, and community living

# Silos and barriers to collaboration

- Separate funding and policy streams  
(e.g., NIH, ACL)
- Lack of capacity building and cross-training
- Jargon & Terminology
  - “Multiple Chronic Conditions” or “Secondary Health Conditions,”
  - “Disability” or “Frailty”

## Different philosophies

“For the disabilities system, aging is a success; for the aging network, disability is a failure.”

Ansello, E. (2004). Public policy writ small: Coalitions at the intersections of aging and lifelong disabilities. *Public Policy and Aging Report*, 14(4), 3-6.



Unique needs and challenges of  
those aging *with* disability

or:

*What does the gerontologist  
need to know?*

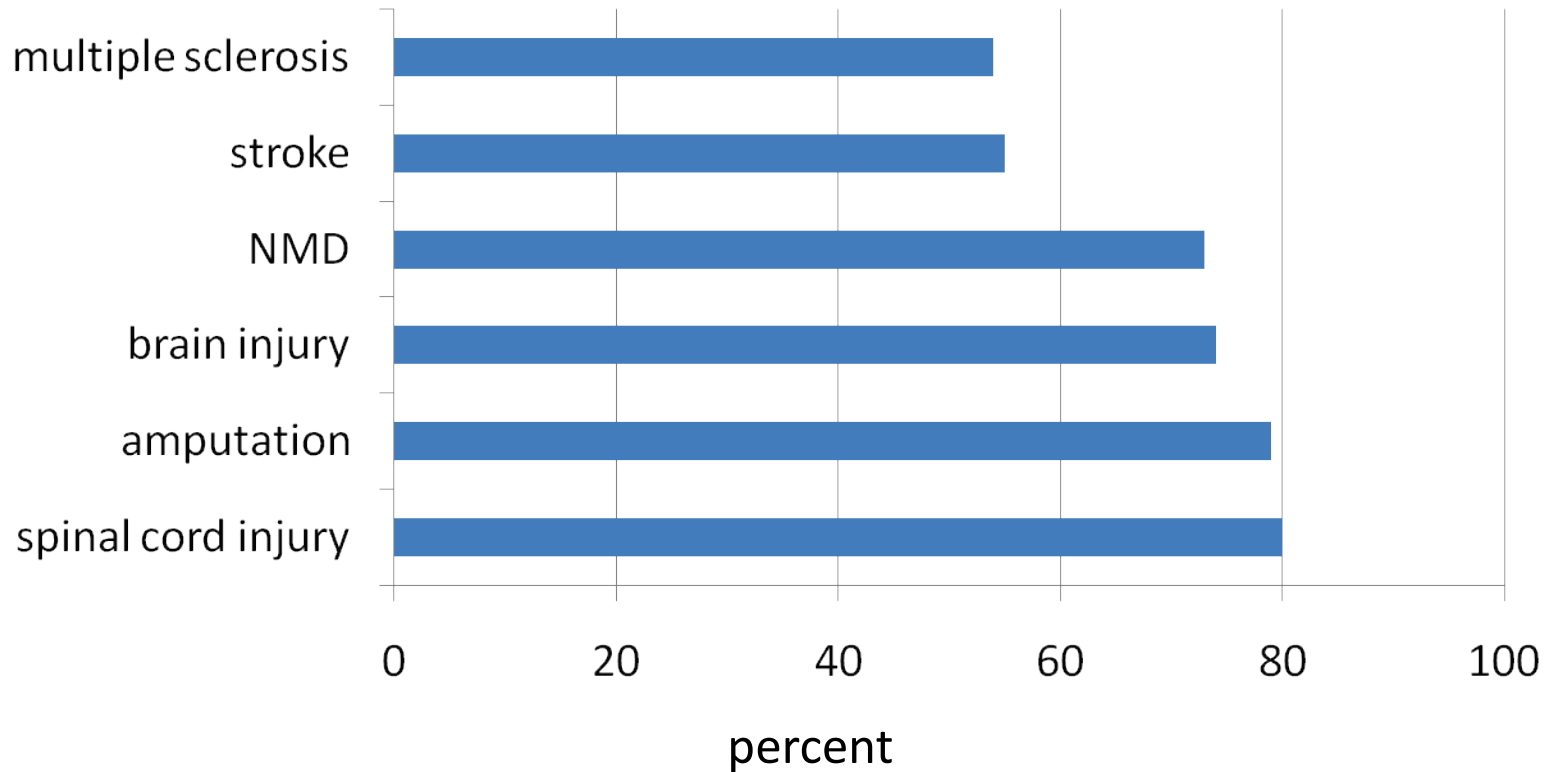


For people with long-term physical disability, increasing life expectancy is offset by increases in new troublesome health conditions and greater functional disability.

# “Secondary Health Condition”

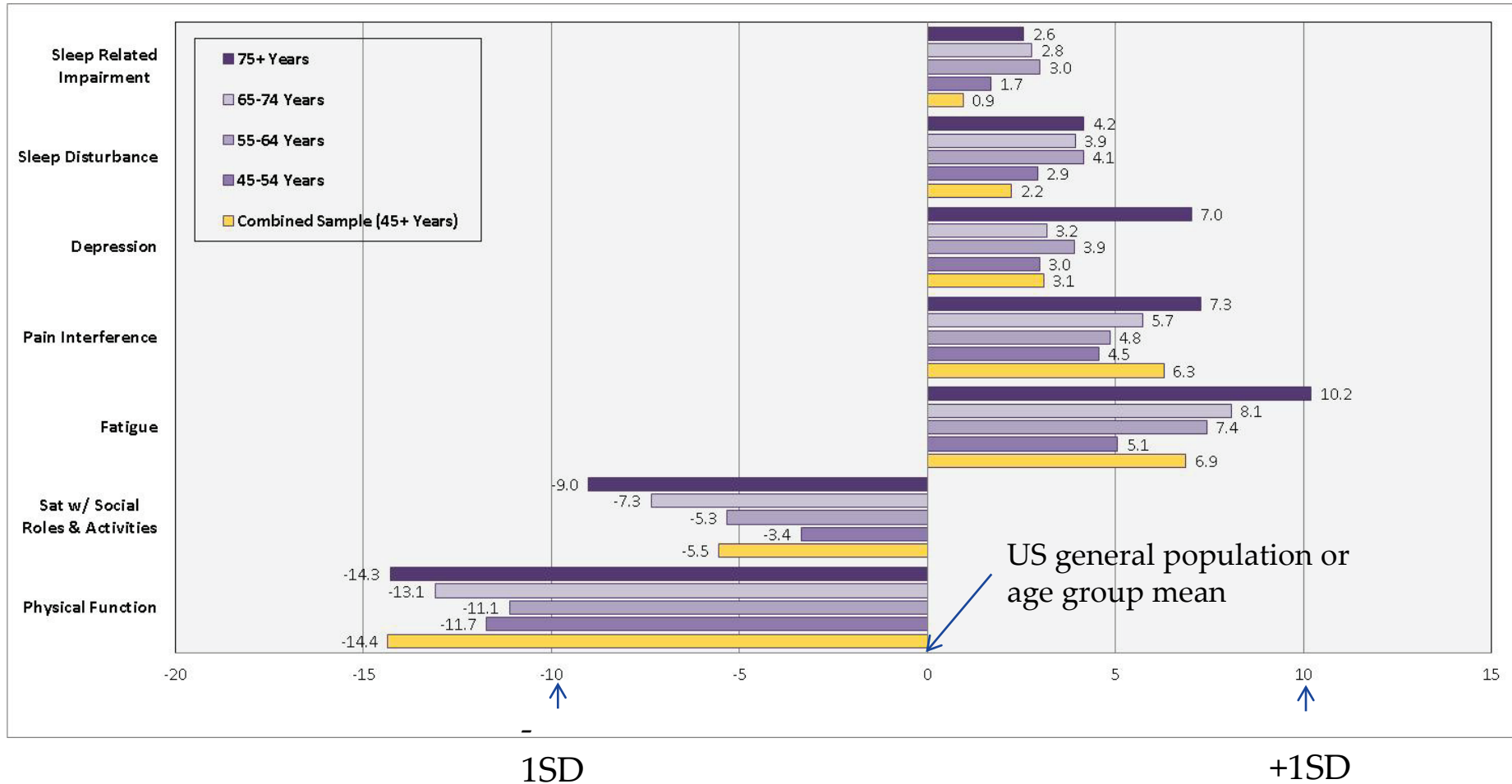
- A difficult term and a long standing debate.
- Increased weakness
- One recent definition: a “physical or psychological health condition whose development or trajectory is influenced by the presence of a disability or impairment.”
- Increased fatigue
- Worsening balance
- Increased spasticity
- Persistent pain
  - SCI Model Systems SIG on Aging, 2011
- New sensory changes
- New sleep disturbance
- Depression

# Secondary conditions: Chronic Pain



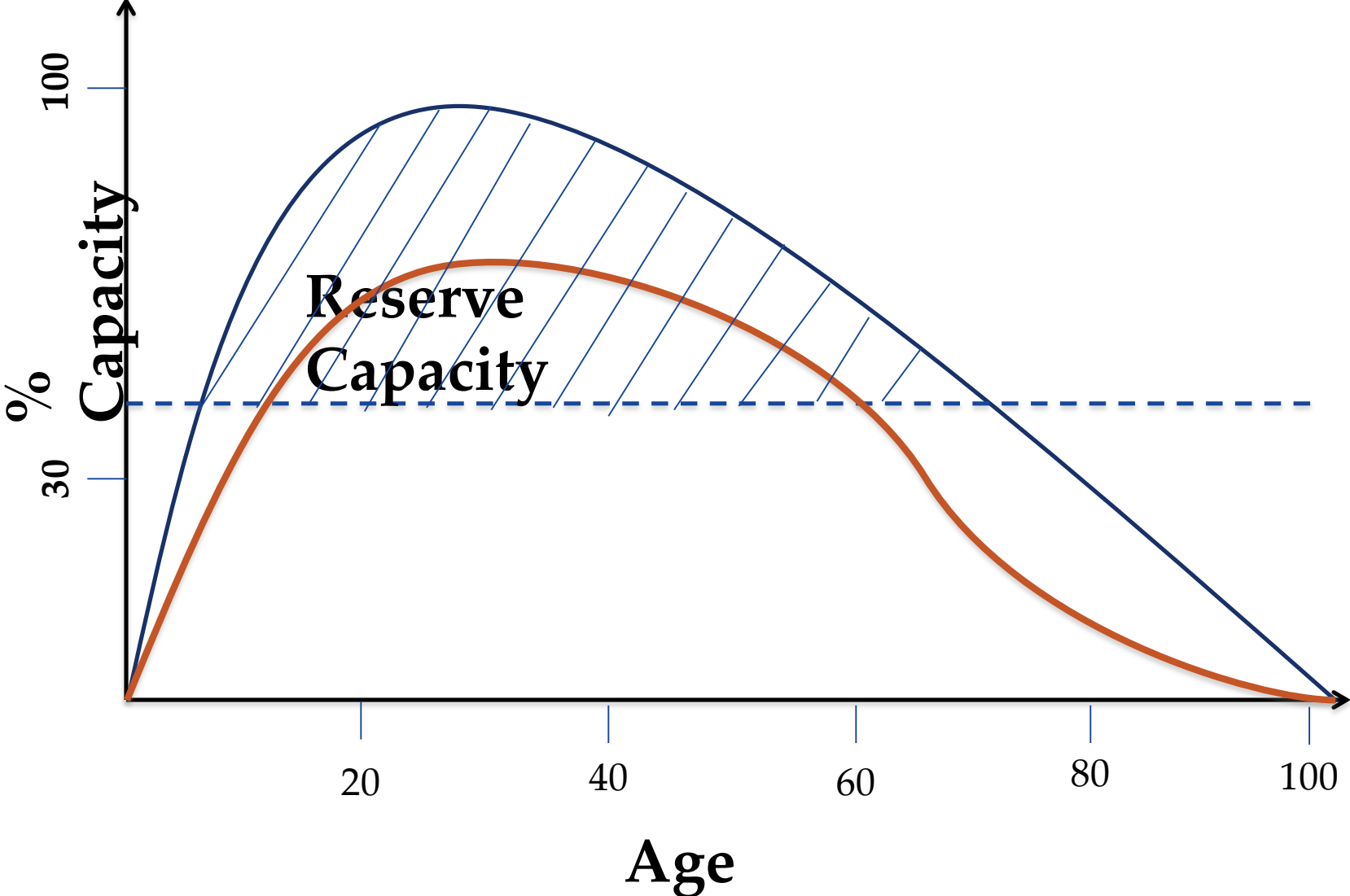
About 30% report pain as “severe and chronic”

# Troublesome symptoms in adults aging with disability: Comparison to national norms



There is emerging evidence  
for a decreased margin of  
health in adults aging with  
disability.

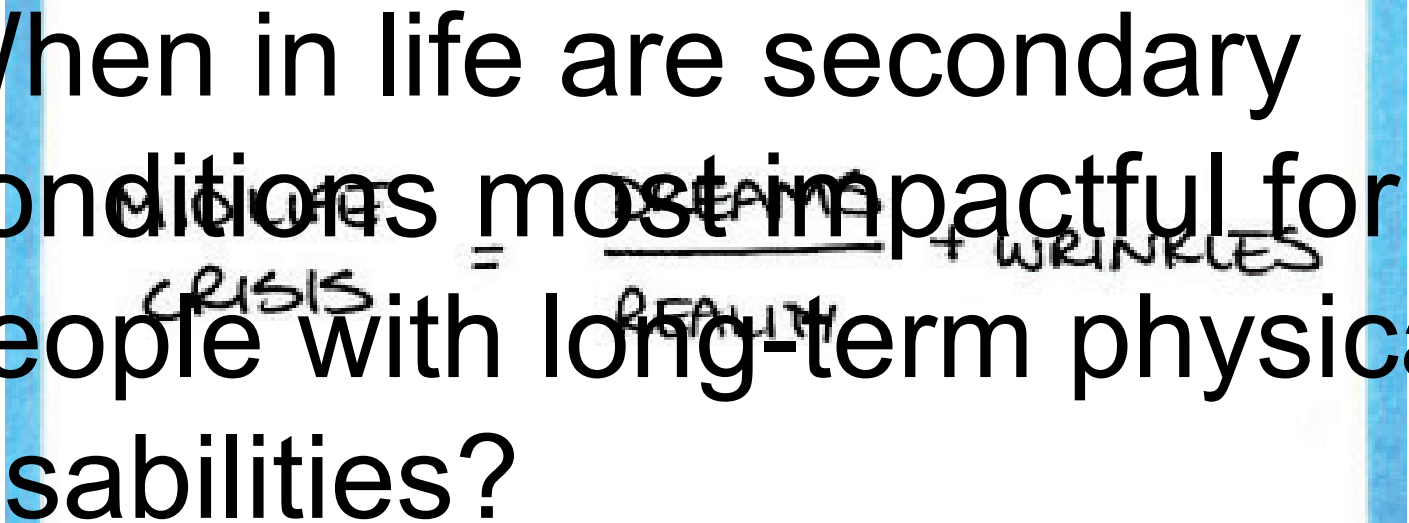
Theoretical model of reserve capacity.



# Why do these symptoms and conditions matter?

- Troublesome secondary symptoms and new medical comorbidities represent
  - Threats to participation
  - Threats to independent living
  - Risks for premature retirement
  - Contribute to reduced quality of life

When in life are secondary conditions most impactful for people with long-term physical disabilities?



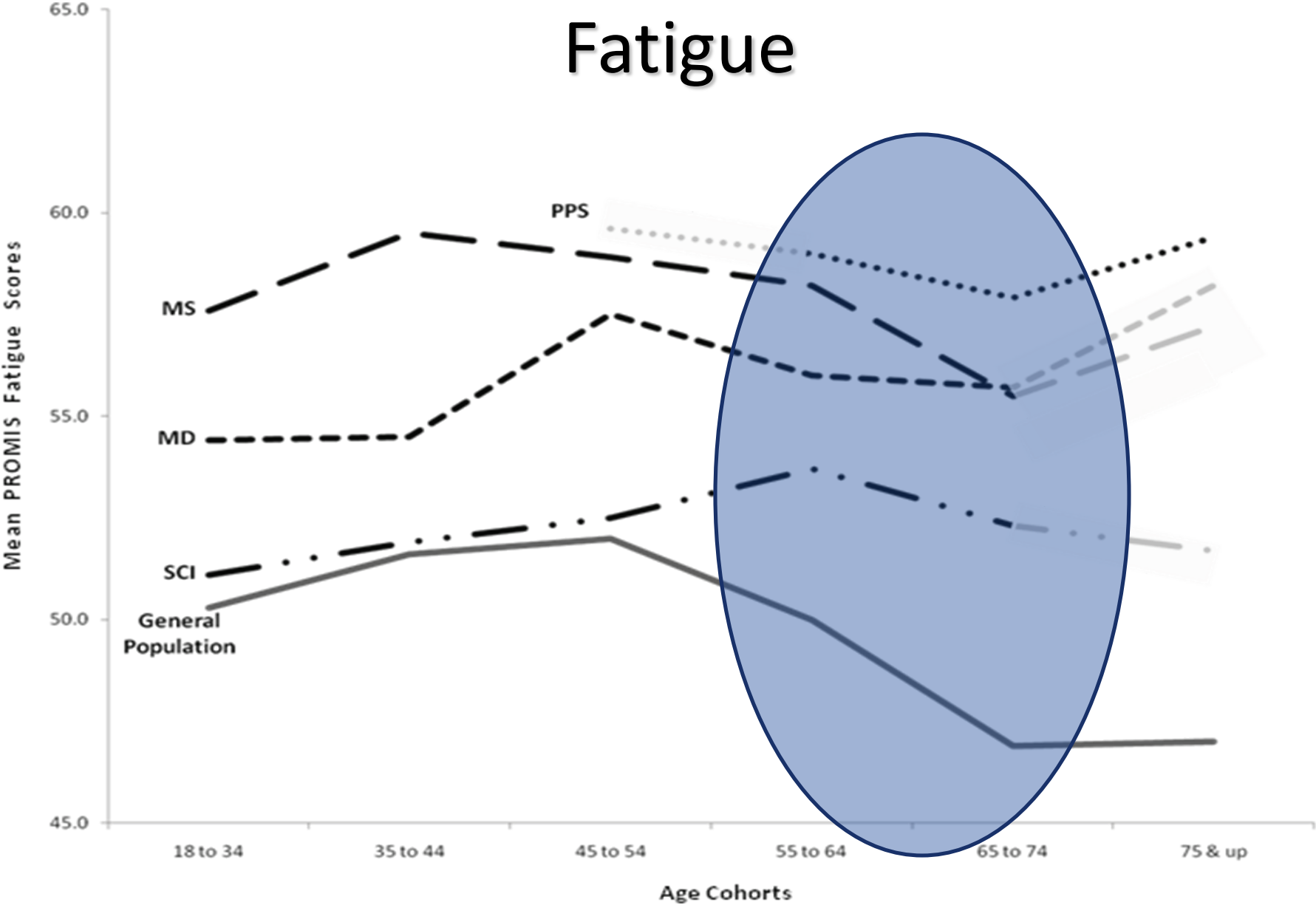
**MIDDLE AGE – RUBBER MEETS ROAD**



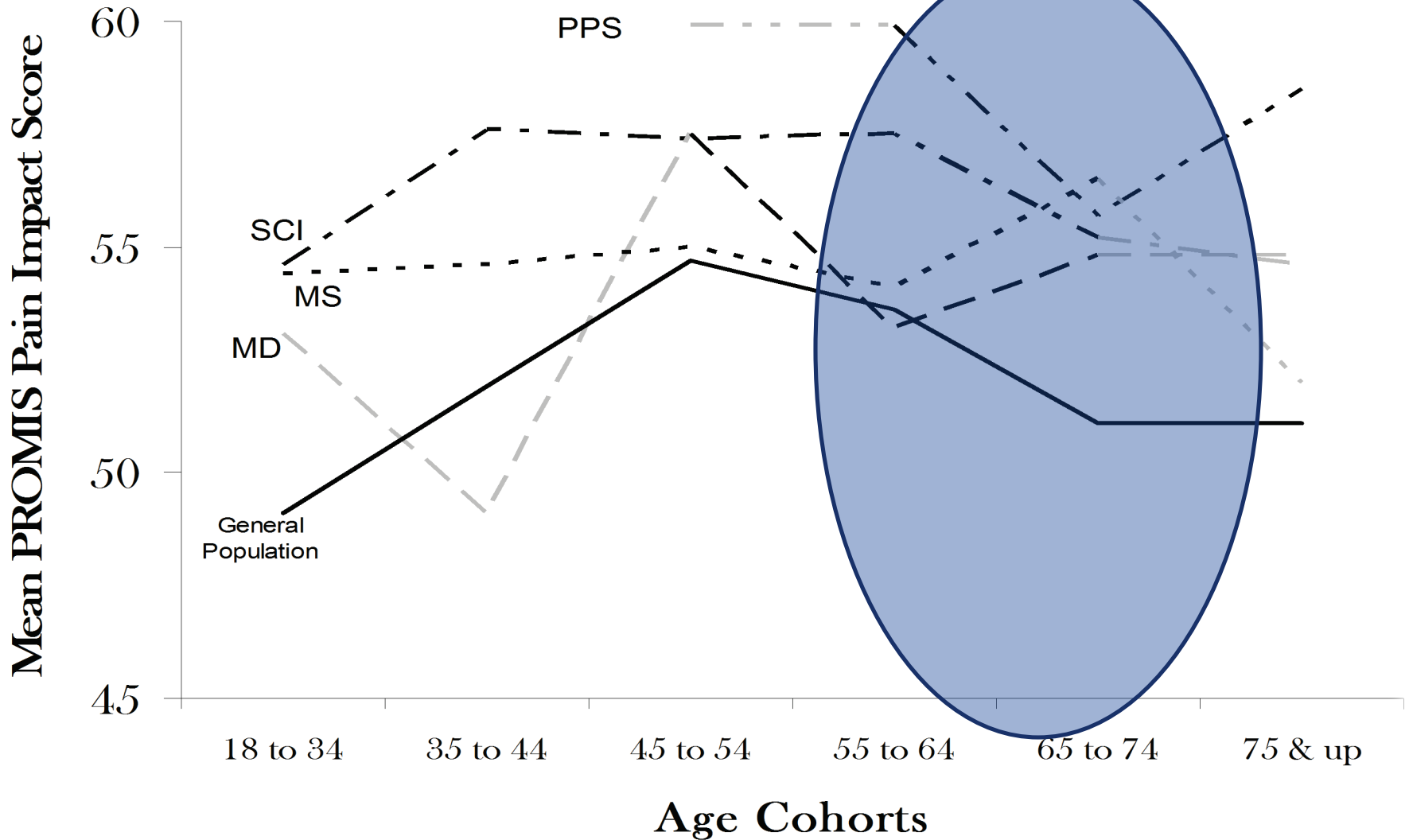
- In *nondisabled* people, 45-64 is a stressful time
  - Peak financial burden, parenting demands, pre-retirement planning, more “daily hassles”
- In people with disability, there is all of this plus worsening 2ndry health conditions, declining health, earlier involuntary retirement

- In persons with disability, middle-age is associated with
  - Highest rates of depression
  - Highest rates of falls and fall-related injuries
  - Highest rates of pain and pain interference
  - Highest levels of fatigue

# Fatigue



# Pain interference



# So where's the “retirement bonus?”

- This age group may be associated with
  - Highest levels of expectations for performance
  - Onset of new secondary health conditions
  - For some disabilities, ongoing degeneration
  - *Involuntary* decreases in work, associated with financial pressures
  - Harder time doing valued activities

# What factors make it easier?

- Access to good health care
- Personal “resilience”, or ability to bounce back from adversity
- Treatment of secondary health conditions
- Physical exercise (within reason)
- **Support from family and friends**
- **Ability to stay in the workforce**

# Social support in older adults

- Older adults have smaller, more selective social networks than do younger adults
- This probably involves intentional selection of closer partners (i.e., “social trimming”)
- Older women tend to receive support from larger and more empathetic sources than do older men
- Bereavement is a real issue: over the age of 65, 51% of women and 13.6% of men have lost a spouse

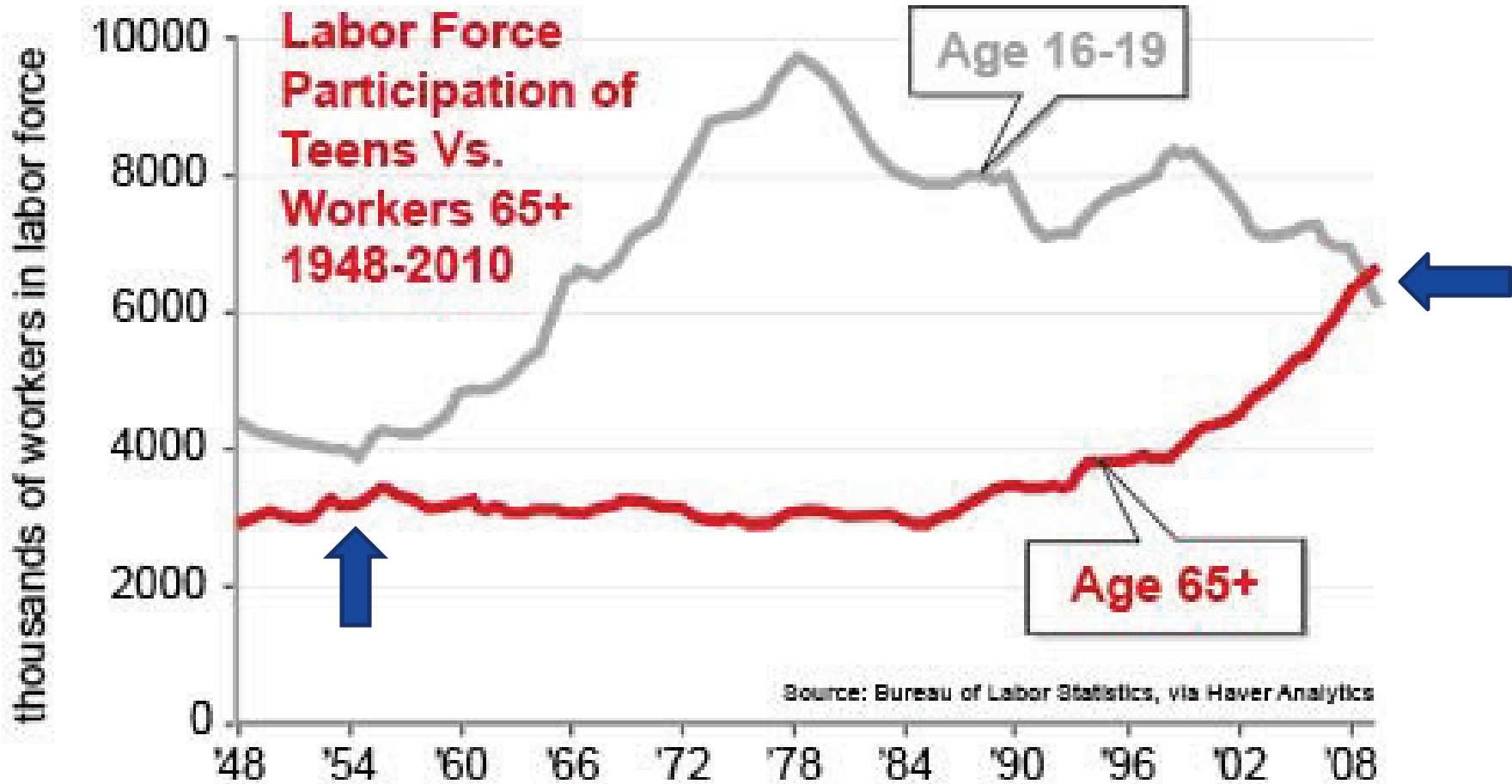
# Social support and disability

- Individuals aging with disability have unique social support needs
- At least in SCI, most individuals rely on their spouses to fulfill the majority of these needs
  - (41% of men with SCI report that their wife is their “only” source of support)
- Individuals with disabilities are less likely to marry, and have higher than average divorce rates (21%)
- Individuals aging with disability report that their caretakers are also aging

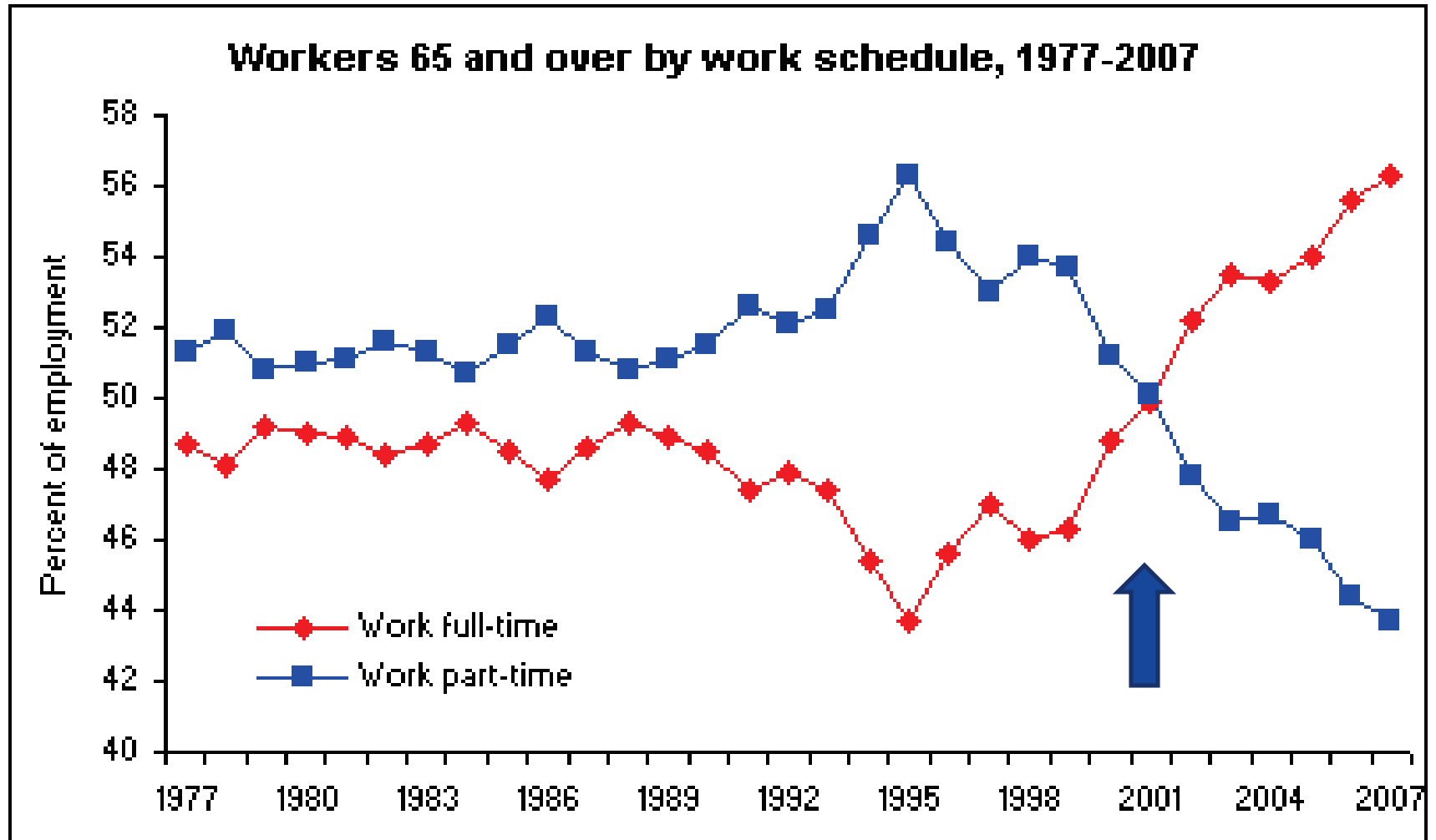


# What about employment?

# Older workers now outnumber teens in the workforce



# More older workers are full time employees



# Employment in those with disabilities

- 78% of people with disabilities are not in the workforce
- Higher for people of color
- Most people with disabilities would prefer to work
- Most people with disabilities can work

# Rates of employment

- In persons with MD, 32-40% maintain employment.
- Average age to stop working with CMT is 46
- 30% of those with MS maintain employment
- For people with SCI,
  - about 60% were employed before accident
  - only about 30% are employed 5 years later.

# Barriers to employment for people aging with a disability in the US

- Irrational subsidy system
- Necessity of close access to rehab care
- Functional limitations associated with the primary disability
- Functional limitations associated with secondary conditions such as pain, fatigue, cognitive changes
- Social and environmental access issues
- Lack of vocational rehabilitation and related services

# “Successful Aging”: a troublesome notion

# A brief history of the “successful” aging concept

- First used by social scientists in the 1960’s and 1970’s to describe the “best adapted” older adults
- Initially, a slew of terms
  - Positive aging
  - Healthy aging
  - Successful Aging
  - Productive Aging
  - Elite Aging



## What elements make up “successful” aging?

- Not clearly established
  - Maintained physiological function
  - The absence of disease
  - Longevity
  - Physical activity
  - Emotional vitality
  - Intact cognitive function

# Similarities between models

- Almost all models of successful aging emphasize
  - Maintenance or preservation of functional capacity
  - Physical activity
  - Social Engagement
  - Freedom from chronic illness
  - *“Low probability of disease and disease-related disability” and “a high level of physical and cognitive function”.*



# What's wrong with this picture?

- “Low probability of disease and disease-related disability” and “a high level of physical and cognitive function”.
- 26 of 29 published definitions of “successful” aging note the absence of major chronic conditions or disability as necessary

# What's wrong with this picture?

- Over age 65, 2/3rds suffer from multiple chronic conditions contributing to physical disability
- These individuals utilize 65% of the US healthcare budget
- Only 10-12% of the world population over 75 would meet this criteria
- Such models do not account for accommodations and adaptations

## How do older adults define successful aging?

- Most older adults report themselves to be “aging successfully” despite not meeting objective health criteria
- When asked to create their own definition, older adults emphasize
  - Free time
  - Time spent with family/friends
  - Greater psychological resilience
  - Better everyday function

What about successful aging for those with long-term physical disability?

- ***“Low probability of disease and disease-related disability” and “a high level of physical and cognitive function”.***
- 67 year old woman with Relapsing/Remitting multiple sclerosis
  - Mild cognitive impairment
  - Difficulties in ambulation
- Regardless of her level of community engagement, life quality, satisfaction, and activity, she has “failed” at aging

# Successful aging in Disability

- In one study of participants with MS, successful aging was described in terms of
  - Maintained social engagement
  - Effective and accessible health care
  - Maintaining independence at home
  - Ability to communicate effectively with ones caregivers



What should a mode of successful aging in Disability include?

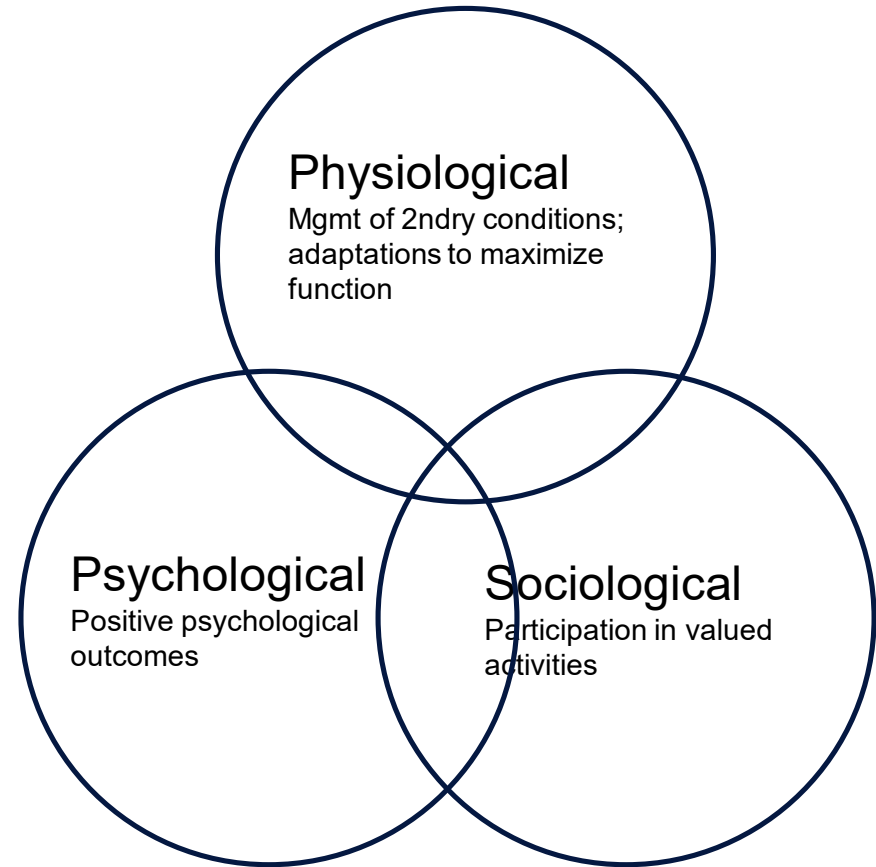
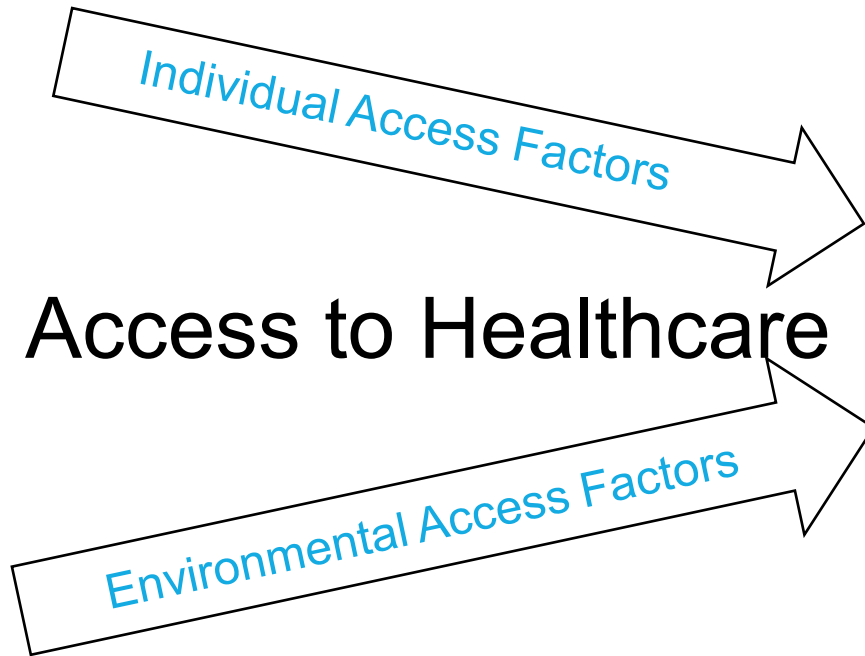
- 6 UW Focus Groups; Older individuals with disability asked to define “successful aging”
- Tools to manage secondary Conditions
- Maintenance of valued activities with adaptations
- Access to healthcare
  - Physical and transportation barriers
  - Limited access to assistive tech
  - Limited access to specialists

# A model of “Successful Aging” with a disability

- Maintain participation in important activities
- Stay socially connected
- Use assistive devices or technologies to enhance quality of life
- Adjust expectations for performance to physical health
- Stay in a chosen work area, with reasonable accommodations
- Get good access to medical, and rehab care

Modified model from Young, Frick, & Phelan (2009)

## Domains of successful aging



There is a need for community based, evidenced health promotion programs for adults aging *with* as well as *into* disability.

# For older adults, many options

The screenshot shows the website for the National Council on Aging (NCOA). At the top left is the NCOA logo with the text "National Council on Aging". To the right is a search bar with a "GO" button. Below the logo is a navigation menu with tabs: "Enhance Economic Security", "Improve Health" (selected), "Public Policy", "Get Involved", "News", and "Events". The breadcrumb trail reads: "Home > Improve Health > Center for Healthy Aging > About Evidence-Based Programs". On the right, there is a "CHANGE TEXT SIZE: A A A" link.

The main content area is titled "Center for Healthy Aging" and includes a sub-menu with "About Evidence-Based Programs", "Offering Evidence-Based Programs", "Resource Library", "Grantee Resources", and "About the Center". The "About Evidence-Based Programs" section is active, featuring a "SHARE:" button with icons for Facebook, Twitter, and Print, and a "Print" link. The text describes evidence-based programs as proven ways to promote health and prevent disease among older adults. It mentions the Center's support for expanding and sustaining these programs through collaboration with national, state, and community partners. The goal is to help older adults live longer and healthier lives. The Center houses two national resource centers: the National Chronic Disease Self-Management Education (CDSME) Resource Center and the National Falls Prevention Resource Center.

On the left side, there is a sidebar with a "Center for Healthy Aging" header and several links: "Chronic Disease", "Falls Prevention", "Physical Activity", "Behavioral Health", and "Self-Management Alliance". Below these links is a section titled "Annual CDSME and Falls Prevention Resource Centers Meeting" with the subtitle "Making Our Vision a Reality". The meeting dates are "April 28-30, 2015" in "Arlington, VA", and there is a link to the "Agenda" and "Presentations".

On the right side, there is a "Getting Started" section with a sub-section "Evidence-Based Health Promotion 101". The text states: "This presentation by Marcia Ory gives an overview of evidence-based programming including what it is, why it's important, how to find the right program for your agency, and how to measure success." Below this is an "Online Training" section with a green header and an image of a stack of colorful books and a computer mouse. The text below the image reads "Introduction to Health".

At the bottom right, there is a call-to-action box with the text "I want to sign up" and "Get the latest news on health, economic security, and advocacy for older adults." Below this is a "SIGN UP" button.

### Title III-D Highest Tier Evidence-Based Health Promotion/Disease Prevention Programs

PROGRAM	WEBSITE/ CONTACT	PROGRAM GOALS & TARGET AUDIENCE	PROGRAM DESCRIPTION	DELIVERED BY	TRAINING REQUIREMENTS	PROGRAM COSTS	KEY WORDS
<b>A Matter of Balance (MOB)</b>	<a href="http://www.mainehealth.org/mob">www.mainehealth.org/mob</a>	<ul style="list-style-type: none"> <li>Reduce fall risk and fear of falling</li> <li>Improve falls self-management</li> <li>Improve falls self-efficacy and promote physical activity</li> <li><b>Target Audience:</b> Adults 60+ who are ambulatory, able to problem solve, concerned about falling, interested in improving flexibility, balance and strength and have restricted their activities because of concerns about falling</li> </ul>	<ul style="list-style-type: none"> <li>8 weekly or twice weekly sessions</li> <li>2 hours per session</li> <li>8-12 group participants</li> <li>Emphasizes practical coping strategies to reduce fear of falling and teach fall prevention strategies</li> <li>Structured group intervention activities include group discussion, problem-solving, skill building, assertiveness training, videos, sharing practical solutions and exercise training</li> </ul>	<ul style="list-style-type: none"> <li>2 coaches (volunteer lay leaders) teach the class to participants</li> <li>Guest therapist visit (1 session for 1 hour)</li> </ul>	<ul style="list-style-type: none"> <li>Master Trainers: 2-day training and on-going updates</li> <li>Coach/Lay leader training: 8 hours and attend annual 2.5 hour training update</li> </ul>	<ul style="list-style-type: none"> <li><b>Licensing Cost:</b> None. Everything is included in the training fee</li> <li><b>Training Cost:</b> <ul style="list-style-type: none"> <li>Master Trainer session open to anyone (includes all materials): \$1,500 per Master Trainer plus travel</li> <li>Group training available at an agency's location upon request: <ul style="list-style-type: none"> <li>a) 11-15 attendees: \$16,000* plus \$220/person for materials</li> <li>b) 16-20 attendees: \$18,500* plus \$220/person for materials</li> </ul> </li> <li>* plus travel, meals and lodging for 2 Lead Trainers</li> </ul> </li> <li><b>Post-training Materials Cost:</b> <ul style="list-style-type: none"> <li>Coach Handbook: \$20</li> <li>Participant Workbook: \$13</li> <li>Guest Therapist Handbook: \$6</li> <li>DVD (Fear of Falling and Exercise: It's Never Too Late): \$164.76/set</li> <li>A Matter of Balance DVD: \$11.00</li> <li>A Matter of Balance Lay Leader Model CD-ROM for Coaches: \$2.00</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>fall prevention</li> <li>group setting</li> <li>self-management</li> <li>health promotion</li> </ul>
<b>Active Choices</b>	Contact person: Cynthia M. Castro, Ph.D., Program Developer and Trainer, <a href="mailto:cync@stanford.edu">cync@stanford.edu</a> , (650) 498-7281	<ul style="list-style-type: none"> <li>Physical activity program that helps individuals incorporate preferred physical activities in their daily lives</li> </ul>	<ul style="list-style-type: none"> <li>6-month telephone-based individualized program that provides remote guidance and support and</li> </ul>	<ul style="list-style-type: none"> <li>Trained activity coach/peer counselor/facilitator who monitors progress, modifies exercise strategies</li> </ul>	<ul style="list-style-type: none"> <li>Facilitator training and certification (recommended, but not required): <ul style="list-style-type: none"> <li>8-hour minimum workshop</li> <li>Assigned reading and written test</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li><b>Licensing Cost:</b> None. One time purchase of Active Choices Manual.</li> <li><b>Training Cost:</b> <ul style="list-style-type: none"> <li>Minimum \$1200. Costs vary depending on organization,</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>telephone-based</li> <li>physical activity</li> <li>self-management</li> <li>health promotion</li> </ul>

<b>Chronic Disease Self-Management Program (CDSMP)</b>	<i>Refer to Stanford Suite of Self-Management Programs below for community-based, Spanish and online versions</i>						<ul style="list-style-type: none"> <li>• physical activity</li> <li>• chronic condition</li> <li>• group setting</li> <li>• self-management</li> <li>• health promotion</li> </ul>
<b>Chronic Pain Self-Management Program (CPSMP)</b>	<i>Refer to Stanford Suite of Self-Management Programs below for community-based program details</i>						<ul style="list-style-type: none"> <li>• physical activity</li> <li>• chronic pain</li> <li>• chronic condition</li> <li>• group setting</li> <li>• self-management</li> <li>• health promotion</li> </ul>
<b>Diabetes Self-Management Program (DSMP)</b>	<i>Refer to Stanford Suite of Self-Management Programs below for community-based, Spanish and online versions</i>						<ul style="list-style-type: none"> <li>• diabetes</li> <li>• chronic condition</li> <li>• group setting</li> <li>• medication management</li> <li>• self-management</li> <li>• health promotion</li> </ul>
<b>EnhanceFitness</b>	<a href="http://www.projectenhance.org/EnhanceFitness.aspx">www.projectenhance.org/EnhanceFitness.aspx</a>	<ul style="list-style-type: none"> <li>• Improve the overall functional fitness and well-being of older adults</li> <li>• <b>Target Audience:</b> Sedentary older adults wishing to maintain and/or improve their physical functioning and stay socially connected</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing 1 hour, 3 times/week group physical activity</li> <li>• Focused on 4 areas:               <ul style="list-style-type: none"> <li>- Stretching and flexibility</li> <li>- Low impact aerobics</li> <li>- Strength training</li> <li>- Balance</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Certified fitness instructor</li> </ul>	<ul style="list-style-type: none"> <li>• Attend a 1.5 day EnhanceFitness New Instructor training</li> <li>• Be a certified fitness instructor by a nationally recognized organization</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Licensing Cost:</b> <ul style="list-style-type: none"> <li>- Basic package fee, including licensing fee: \$3,000</li> <li>- \$500 per new site for the first year</li> <li>- Renewal fee: \$50 per site</li> </ul> </li> <li>• <b>Training Cost:</b> <ul style="list-style-type: none"> <li>- Master Trainer training: \$2,000</li> </ul> </li> <li>• <b>Online Data System Fee (optional):</b> Data Entry System for data management and report creation is \$200/year for each data entry user</li> </ul>	<ul style="list-style-type: none"> <li>• physical activity</li> <li>• chronic condition</li> <li>• self-management</li> <li>• health promotion</li> </ul>
<b>EnhanceWellness</b>	<a href="http://www.projectenhance.org/EnhanceWellness.aspx">www.projectenhance.org/EnhanceWellness.aspx</a>	<ul style="list-style-type: none"> <li>• Maintain or increase the health and functional status of community-based older adults with chronic conditions</li> <li>• <b>Target Audience:</b> Older adults with one or more chronic conditions, excluding dementia</li> </ul>	<ul style="list-style-type: none"> <li>• 6 month individualized program, along with regularly scheduled optional support group meetings and evidence-based workshops such as Chronic Disease Self-Management Program (CDSMP) and Matter of Balance (MOB)</li> </ul>	<ul style="list-style-type: none"> <li>• A nurse practitioner and/or social worker work with the participant to develop a health action plan and provide support and encouragement to the participant in achieving the goals of that plan</li> </ul>	<ul style="list-style-type: none"> <li>• Provider training in EnhanceWellness training</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Full Program Cost (program licenses, SS Services, with training limited to Licensee employees, access to web-based data management program (WellWare) and one copy of the Program Materials):</b> <ul style="list-style-type: none"> <li>- Complete package fee: \$6,000 for one site; \$1,000 for each additional site, same licensee</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• chronic conditions</li> <li>• physical activity</li> <li>• self-management</li> <li>• health promotion</li> </ul>

# Were people with physical disabilities included in this evidence base?

- Much of the evidence base for these interventions has systematically excluded those aging with long-term physically disabling conditions
  - Studies have required participants to be
    - “ambulatory”
    - “without a chronic health condition that limits participation”
    - “not wheel-chair bound”



# Evidence-Based Wellness Programs

Nikki Bagli, MSW  
Senior Services

# What is an Evidence-based Program?

- Based on scientific reasoning, behavior change theory, and program planning
- Proven effective in achieving desired outcomes
- Improves health status
- Employs a process of planning, implementing, and evaluating programs adapted from tested models or interventions

# Evidence-Based Programs Developed and Disseminated at Senior Services



# Health Enhancement Program Study\*

- Northshore Senior Center, 1998
- Objective: Increase health and functioning of frail older adults using a self-management, senior center-based approach
- 201 participants 70+ recruited through medical practices
- 100 in intervention group

\* Leveille SG, et al. (1998). Preventing disability and managing chronic illness in frail older adults: A randomized trial of a community-based partnership with primary care. *Journal of American Geriatrics Society*, 46:1-9.

# Health Enhancement Program Study

- Outcomes
  - Intervention group showed less decline in function
  - Hospitalized participants decreased by 38%
  - Inpatient hospital days was significantly less (72%) (33 days)
  - Significantly higher levels of physical activity and senior center participation
  - Significant reductions in the use of psychoactive medications

 **ENHANCE  
WELLNESS**

Poll: Has your doctor ever told you to do something you know would be good for you, but you don't do it?



# Features of ENHANCE WELLNESS

- Individualized and participant-driven
- Social Worker and/or Registered Nurse
- Motivational Interviewing
- Health Behavior Stages of Change
- Participant directed action planning
- Self-management support
- Standardized tests for pre and post outcomes

# Participant Questionnaire

---

## I) Rating of Health

---

19) In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

---

## J) Confidence about Doing Things

---

20) For each of the following questions, please fill in the circle which corresponds to your **confidence** that you can do the tasks regularly at the present time.

**How confident are you that you can:**

A) Do gentle exercises for muscle strength and flexibility 3 to 4 times per week (range of motion, using weights, etc)?

- Not at all confident Extremely confident
- 0  1  2  3  4  5  6  7  8  9

B) Talk to your doctor about things that concern you?

- Not at all confident Extremely confident
- 0  1  2  3  4  5  6  7  8  9

C) Control your chronic health condition so that it does not interfere with the things you want to do?

- Not at all confident Extremely confident
- 0  1  2  3  4  5  6  7  8  9



# Motivational Interviewing

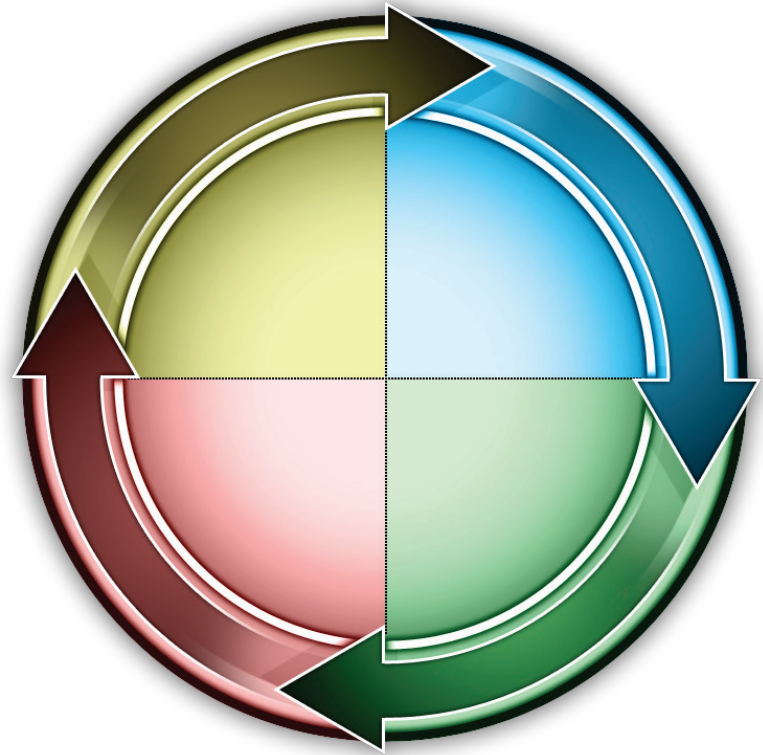
A collaborative, client centered, goal-directed, communication style that engages intrinsic motivation within the client in order to change behavior.



# Health Behavior Stages of Change

## Health Behavior Stages of Change

- Pre-contemplation
- Contemplation
- Preparation
- Action
- Maintenance



**Participant**  
Engman, Hans

**Type**  
Six month review

[Back to Plans Summary](#)

**Enter Questionnaire**

<a href="#">A) Health Problems</a>	Partial
<a href="#">B) Social Activity</a>	Complete
<a href="#">C) Alcohol Use</a>	Complete
<a href="#">D) Smoking</a>	Complete
<a href="#">E) Feelings</a>	Complete
<a href="#">F) Physical Activity</a>	Complete
<a href="#">G) Nutrition</a>	Complete
<a href="#">H) Falls</a>	Complete
<a href="#">I) Rating of Health</a>	Complete
<a href="#">J) Confidence</a>	Complete
<a href="#">K) Recent Health</a>	Complete
<a href="#">Vital Stats</a>	Complete

**Review Questionnaire**

● [Current Issue Summary](#)

[Finish Later](#)

**Questionnaire**  
**Current Issue Summary**

**List of all Issues and Measures sort by severity:**

[Print the Current Issues Summary](#)

**Social Activity**

- ✔ Close relative or friend contacts: 6 per month
- ✔ Social calls or visits: 4 per week

**Smoking**

- ✔ Number of cigarettes smoked per day: None

**Feelings**

- ✔ PHQ-9 Severity: 13 out of 27 (moderate depression)
- ❗ PHQ-9 Diagnosis: Minor depressive syndrome
- ❗ PHQ-9 Difficulty: Somewhat difficult
- ✔ Goldberg Anxiety Scale score: 3 out of 9

**Exercise**

- ✔ RAPA1: 7 out of 7 (active)
- ✔ RAPA2: 3 out of 3 (both strength and flexibility activity)

**Nutrition**

- ❗ Nutrition Screening Initiative score: 5 out of 21
- ✔ Weight Satisfaction: Maintain weight
- ❗ BMI: 33.8 (Overweight)

**Medication**

- ✔ Use of prescription medications: 3 prescription(s)
- ❗ Use of psychotropic medications: 2 prescription(s)

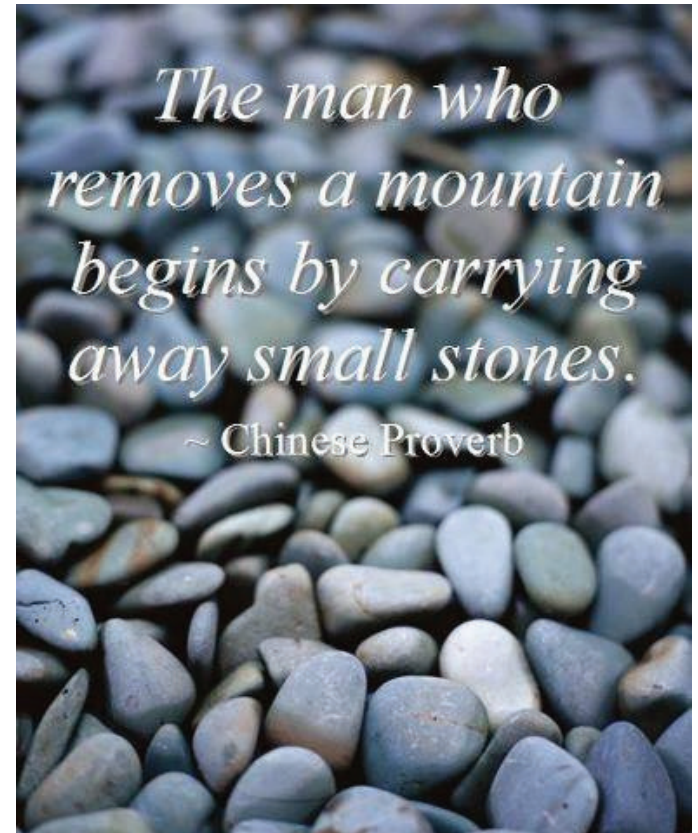
**Health Self-Management**

- ❗ Confidence to exercise: 6 out of 9 (0-low, 9-high)
- ✔ Confidence to communicate with physician: 8 out of 9 (0-low, 9-high)
- ✔ Self-rating of health: Very good
- ❗ Confidence to control condition: 4 out of 9 (0-low, 9-high)

**Alcohol**

## Goals are:

- Something the client wants to do
- Achievable
- Specific
  - ✓ What
  - ✓ How much
  - ✓ When
  - ✓ How often
  - ✓ Confidence level of 7 or more



*Success begets success!*

# EnhanceWellness Menu



# EnhanceWellness Service Process

Referral by Staff/Health Care Provider/Self



Contact by EW Staff



First Visit



Second Visit



Six Month Graduation

# Data Management



Online Data Entry System for Evidence-Based Programs

Home EnhanceWellness

Welcome, Dorothy Gale  
[My Profile](#) | [Logout](#)

- EnhanceWellness Menu
- [EW Participants](#)
  - [EW Groups](#)
  - [Healthcare Providers](#)
  - [EW Program Forms](#)

Search

[Go!](#)

[Advanced Search...](#)



## Program Activity

Tools to enter program data into the system. Users can enter participant demographics and questionnaires, vitals, encounters, group activity and health coverage.

[EW Participants](#)

[EW Groups](#)



## Program Management

Tools to assist in managing the EnhanceWellness program. Download program forms, and enter and edit site, staff, mentor, and healthcare provider information.

[Program Forms](#)

[Healthcare Providers](#)

[EW Affiliate](#)



## Reporting

Reports on program data.

[Reports](#)



## Assistance

Questions, comments, issues, and suggestions can be submitted to Project Enhance here. Find resources to assist in using the system.

[Requests](#)

[Resources](#)

# What results does ENHANCE WELLNESS produce?

In older adults, studies show that the program reverses functional decline:

- 72% decrease in hospital days
- 35% decrease in psychoactive drugs
- 11% decrease in depression
- 18% decrease in physical inactivity



# Most frequent target areas in EnhanceWellness

Top Issues Selected	Maintained	Improved	Maintained/Improved
1. Exercise	34%	48%	82%
2. Nutrition	31%	46%	77%
3. Feelings	26%	59%	85%
4. Health Self-Management	36%	46%	82%
5. Social Activity	31%	55%	85%

# EnhanceWellness Dissemination

- 90's – King County; 2000's – other states
- Affiliates purchase license
- Affiliate staff trained in EnhanceWellness process and motivational interviewing; Counselor Manual
- WellWare - online data entry system for participant and program data

# States with EnhanceWellness Sites

- Colorado
- Indiana
- Massachusetts
- Missouri
- New Jersey
- South Carolina
- Washington

# Who is an average EW participant?

- ❑ Female (74%)
- ❑ White (81%)
- ❑ Age 60+ (84%)
- ❑ Very Low Income (42%)
- ❑ High BP (64%)
- ❑ Arthritis (62%)
- ❑ Depression/Anxiety (40%)



# Questions?

Dr. Sabine Thomas

Senior Director, Health and Wellness

206-268-6736 [sabinet@seniorservices.org](mailto:sabinet@seniorservices.org)

Paige Denison

EnhanceFitness National Trainer

425-830-2819 [paiged@seniorservices.org](mailto:paiged@seniorservices.org)

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

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

# Adapting EnhanceWellness

Ivan Molton

University of Washington

# Adapting the Program

- Rationale
- Stakeholder engagement
- Program modifications
- Methods
- Challenges
- Preliminary Data
- Participant Feedback

# Rationale

Partner with a large non-profit community service organization, already delivering an intervention to older adults endorsed by the National Council on Aging, and test the utility and efficacy of this intervention in people aging with long-term physical disability (LTPD). If proven efficacious, testing the project in a real-world setting allows for more efficient dissemination.



# Stakeholder Engagement

- Focus groups with consumers
- Advisory board meetings with researchers, community providers
- Two-day training for community providers on:

Medical Aspects of Disability | Secondary Conditions |  
Employment & Benefits | Sexuality and Disability |  
Legal Issues | Ableism | Cognition | Assistive  
Technology | Physical Activity and Falling Concerns



# Program Modifications

- Eligibility criteria
  - Age ( $\geq 45$ )
  - Living in King County
- Meeting locations
- Program length
- Physical therapist consult

# Methods

- 120 adults with MS, MD, PPS or SCI
- Separate research outcomes collected pre- and post-program.
- Inclusion Criteria:
  - Minimum age 45
  - Self-reported physician diagnosis of MS, MD, SCI or PPS
  - Living in King County, WA
  - Able to read and understand English
- Exclusion:
  - Active suicidal ideation
  - Use of mechanical ventilator to breathe or speak
- Two thank you payments of \$50 for completion of research surveys

# Methodological Challenges

- Outcome measures
  - Fatigue
  - Physical Activity
  - Self-efficacy
  - Psychotropic medication use

# Enrollment To Date

- 54 Enrolled
- 36 Complete
- Waitlist in place since the beginning;  
significant interest in the program

# Case example

- 61 yo woman with MS, living alone, income=\$18,000
- Goal Topic: **Falling**
  - Task 1: re-start yoga practice
    - Task 1 barriers: heat, out of shape (confidence level “10”)
  - Task 2: Register for the matter of balance workshop at the North Shore Senior Center
    - Task 2 barriers: timing/schedule (confidence level “10”)
  - Task 3: purchase a non-slip bath mat
    - Task 3 barriers: gross mold, cost (confidence level “10”)

# Participant Goals

- Address:
  - Physical activity, socialization, strength & endurance, organization, maintaining independence, downsizing, weight loss, smoking & alcohol cessation, decreasing falls...
- Examples:
  - To create balance in my life
  - To be more social and write more
  - To lose 10 lbs., become agile and build muscle
  - To feel more sexy (???)



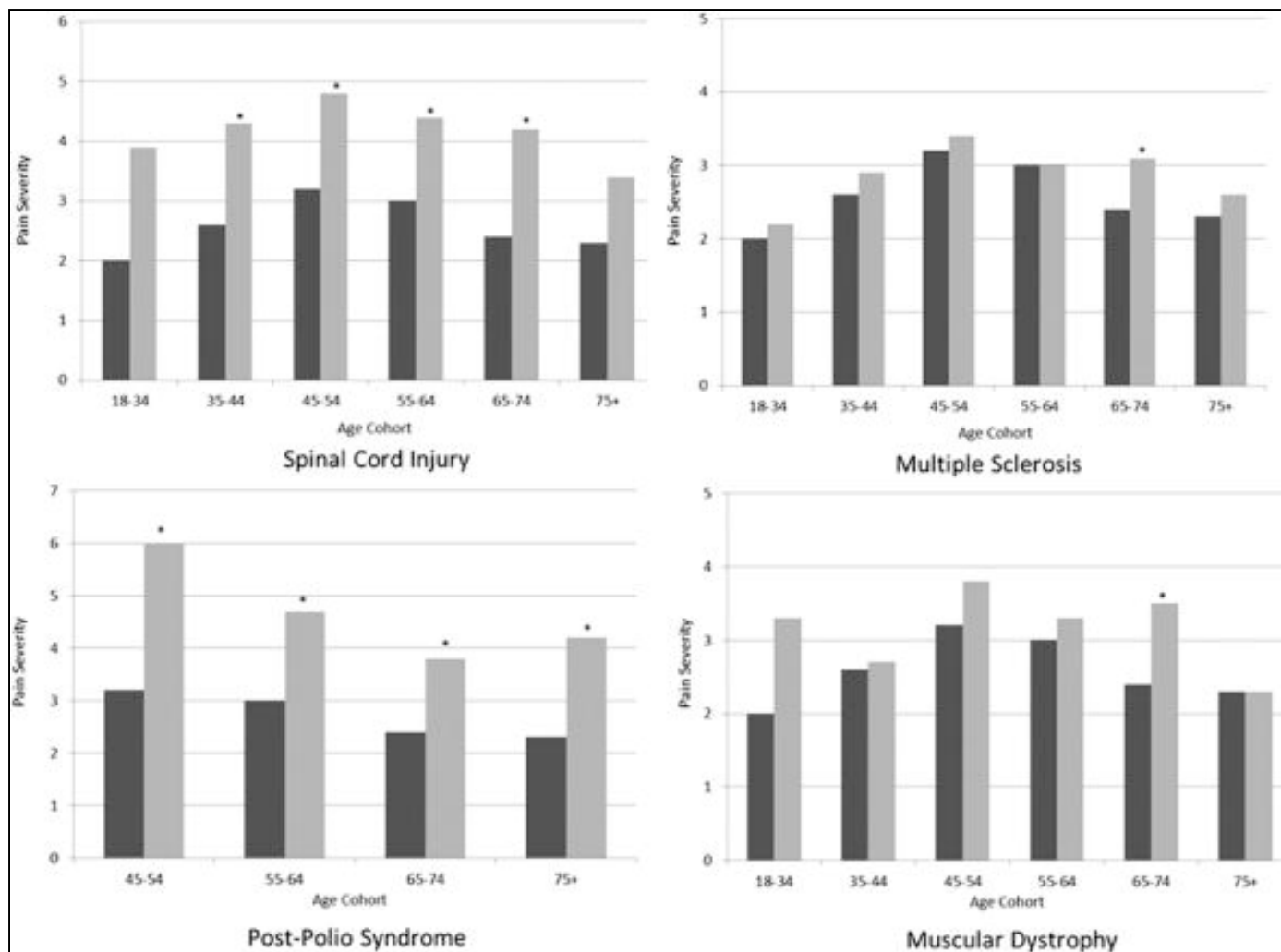
# Preliminary Results

- Mean age: 64 (range 57 – 79)
- 26 with MS, 4 with SCI, 5 with PPS
- Primarily female (67%), with at least a college degree (60%) and identified as White/Caucasian (94%)

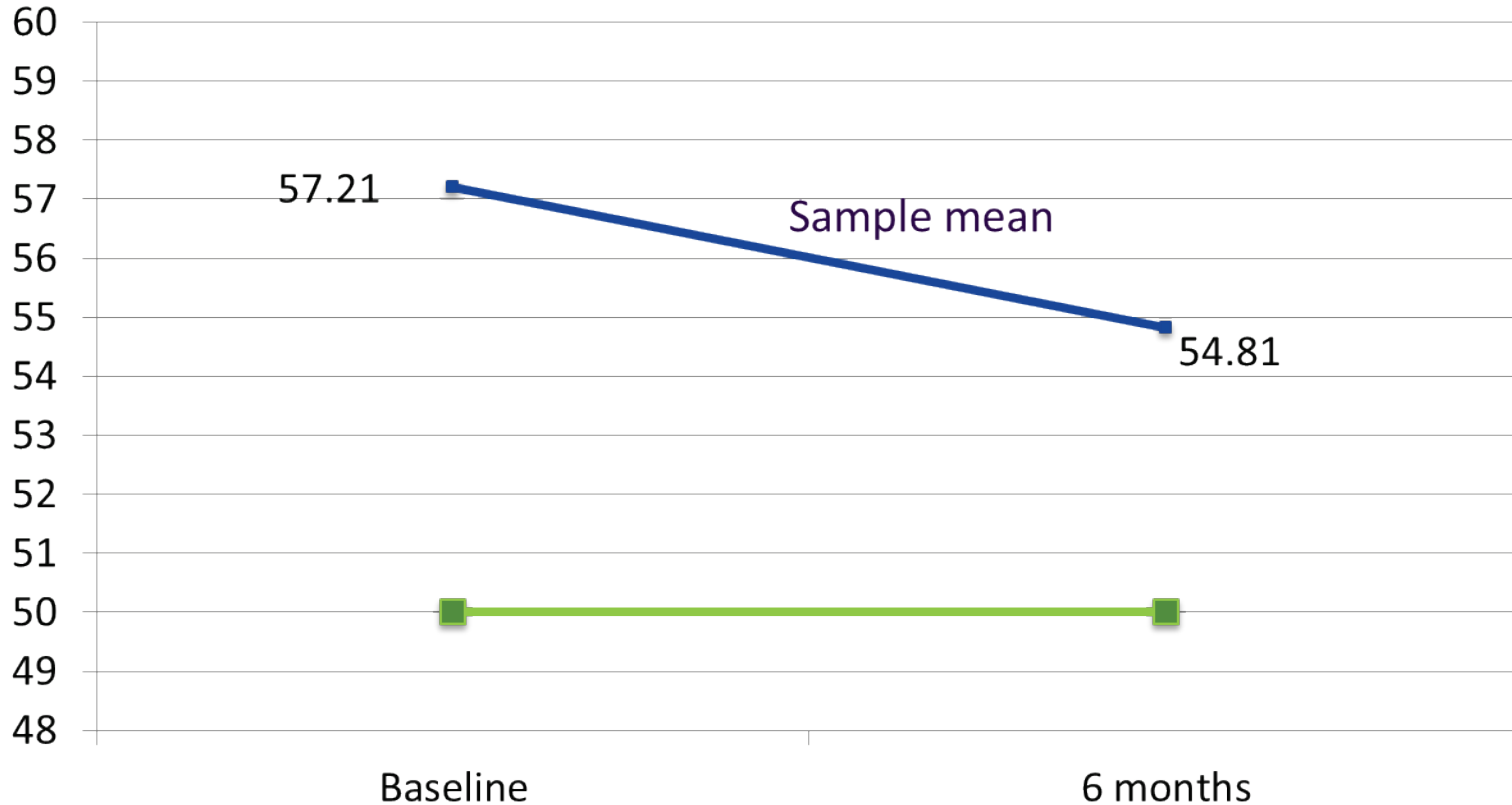
# Pain Interference

- Measured using the PROMIS Pain Interference Short Form.
- “In the past 7 days, how much did pain interfere with your day to day activities?”
- “In the past 7 days, how much did pain interfere with your ability to participate in social activities?”
  - Not at all, a little bit, somewhat, quite a bit, very much

# Pain Interference



# Preliminary Results – Pain Interference



PROMIS Pain Interference T Score:

$N = 33, t(32) = 1.98; p = .06$

# Falls Prevalence

Age	Reported falling at least once in the past 6 months				
	All (n = 1826)	MS (n = 571)	MD (n = 332)	PPS (n = 439)	SCI (n = 484)
<b>All Ages</b>	<b>977 (54%)</b>	<b>311 (55%)</b>	<b>231 (70%)</b>	<b>242 (55%)</b>	<b>193 (40%)</b>
18-44	149 (15%)	45 (15%)	42 (18%)	1 (0.4%)	61 (32%)
45-54	234 (25%)	94 (30%)	78 (34%)	8 (3%)	54 (28%)
55-64	345 (35%)	119 (38%)	67 (29%)	104 (43%)	55 (29%)
≥ 65	249 (25%)	53 (17%)	44 (19%)	129 (53%)	23 (12%)

Matsuda P N, Verrall AM, Finlayson ML, Molton IR, Jensen MP. "Falls Among Adults Aging With Disability." Arch Phys Med Rehabil. 2015.

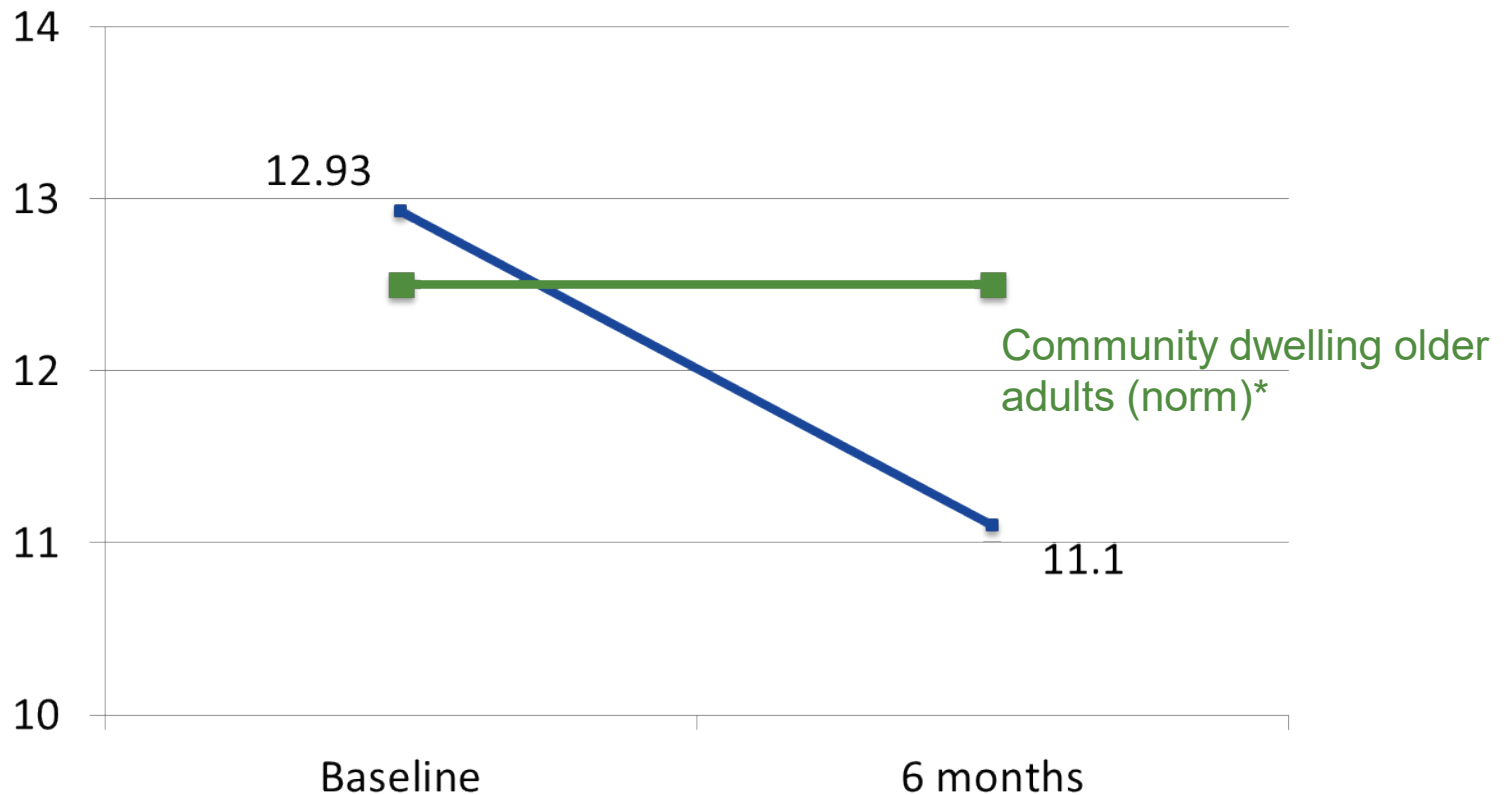
# Fear of Falling

## Falls Efficacy Scale – International (FES-I)

“For each of the following activities, please check the box which is closest to your own opinion to show **how concerned you are that you might fall if you did this activity.**”

	Not at all concerned	Somewhat concerned	Fairly Concerned	Very Concerned
1. Getting dressed or undressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Taking a bath or shower	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Getting in or out of a chair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# Preliminary Results – Fear of Falling



FES- I;

$N = 30, t(29) = 2.63, p = .01;$

\*Gertrudis IJM, Kempen JM, Yardley L, et al. (2007) "The Short FES-I: a shortened version of the falls efficacy scale-international to assess fear of falling. Age Ageing: 37(1): 45-50.

# Additional positive findings

- Increase in leisure physical activity:
  - 23.46 to 33.43,  $n=35$ ;  $p = .03$
- Increase in satisfaction with social roles:
  - 45.12 to 48.43,  $n=34$ ;  $p = .01$
- Decrease in fatigue:
  - Fatigue 10.88 to 9.68,  $n=34$ ;  $p = .02$
- Decrease in anxiety ( $n=19$ ):
  - Anxiety 9.0 to 8.0,  $n=19$ ;  $p = .05$



# Treatment satisfaction

- Treatment Satisfaction
  - Helpfulness: mean 7.67 (0 – 10 NRS)
  - Benefits outweighed the effort: 15 (42%)
  - Equaled the effort: 15 (42%)
  - Efforts outweighed benefit: 1

# Negative findings

- No significant changes in
  - Community Integration
  - Global Quality of Life
  - Sleep Disturbance
  - Depression

# Follow-up Interviews

- Qualitative interviews conducted with a random sample of 10% of all participants
  - Overall satisfaction with the program
  - Issues with access (if programs weren't nearby, it was hard to meet the goals in between visits)
  - Some programs were cost-prohibitive

# Participant Reflections

“I’m doing better than I have since I got my injury.”

(SCI)

“I don’t feel rudderless anymore.”

“I had been wanting to do this and you pushed me over the edge!”

“This program has been “life changing,”...”I’ve always taken care of others and now, I’m on the list.”

“You recognized what I needed and gave me a reason for doing it.”

# “Aging with Grace”

<https://youtu.be/HSvEs2NzmEk?t=2m55s>

# Future plans for dissemination

- Finalize manual; distribute to sites providing EnhanceWellness
- Provide web based training module on disability to EnhanceWellness coaches
- Provide ongoing supervision/training support to EnhanceWellness coaches
- National level RCT?

# Thank You

## Questions?



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



Healthy Aging RRTC



@AgingRRTC

# EnhanceWellness Citations

- Leveille SG, et al. (1998). Preventing disability and managing chronic illness in frail older adults: A randomized trial of a community-based partnership with primary care. *Journal of American Geriatrics Society*, 46:1-9.
- Phelan EA, et al. (2002). Outcomes of a Community-Based Dissemination of the Health Enhancement Program. *Journal of American Geriatrics Society*, 50:1,519-1,524.
- Phelan EA, et al., (2003). Promoting health and preventing disability in older adults: Lessons from intervention studies carried out through an academic-community partnership. *Family Community Health*; 26:214-20.
- Phelan EA, et al. (2004). Activities of daily living function and disability in older adults in a randomized trial of the Health Enhancement Program. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 59A(8): 838-843.