

Disability Experience and Measurement

Lois M. Verbrugge, M.P.H., M.A., Ph.D.
Population Studies Center, Institute for Social
Research, University of Michigan



Abstract

Top themes of international research on disability in the past three decades are discussed: disability dynamics, buffers and barriers for disability, disability trends, and disability among very old persons. Each theme is highlighted by research examples. Turning to measurement, I discuss traditional measures of disability, new longer and shorter ones, and composites like disability-free life expectancy, noting their merits. Contemporary models of disability are presented, ranging from visual images to formal theories. The lecture ends on how scientists can facilitate movement of disability science into health care practice and policy.

Topics

Experience

Measurement

Models

What is Disability?

In brief:

Difficulty doing tasks/roles on one's own

Due to health

Lasting for awhile

Traditional Measures of Disability

ADL

Personal care activities such as dress, bathe, eat, get in/out of bed, use toilet, walk across a room

Called "(basic) activities of daily living"

IADL

Household management activities such as use phone, take medications, manage money, shop for groceries, prepare meals

Called "instrumental activities of daily living"

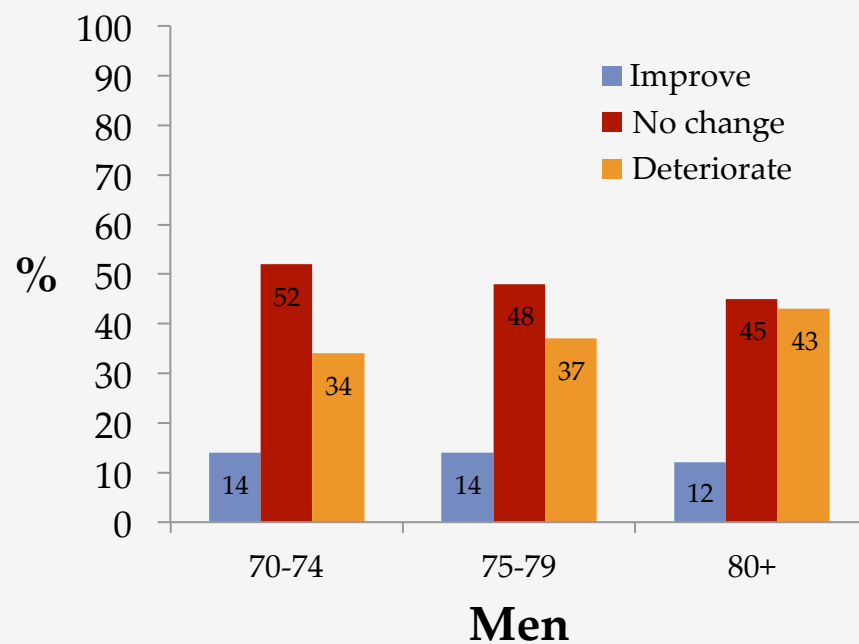
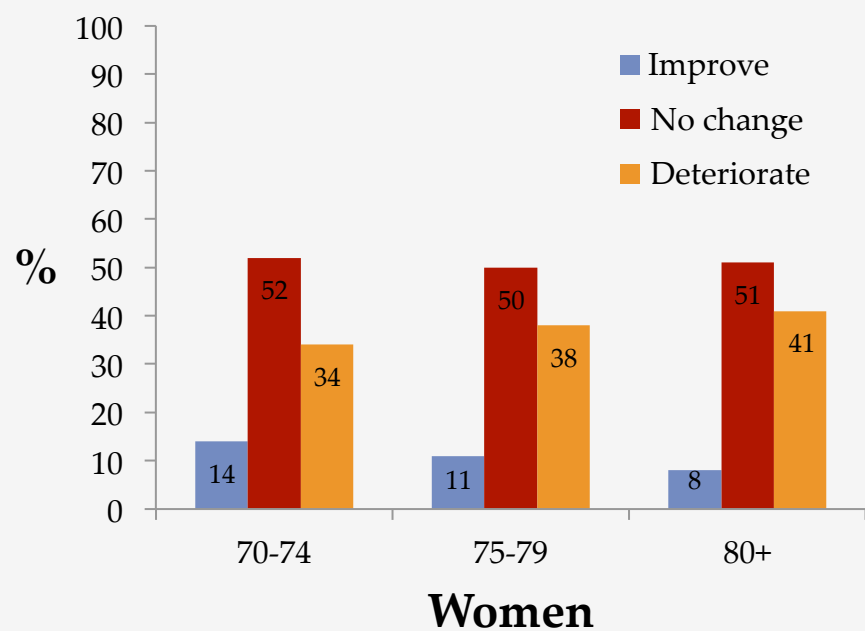
EXPERIENCE

...

1

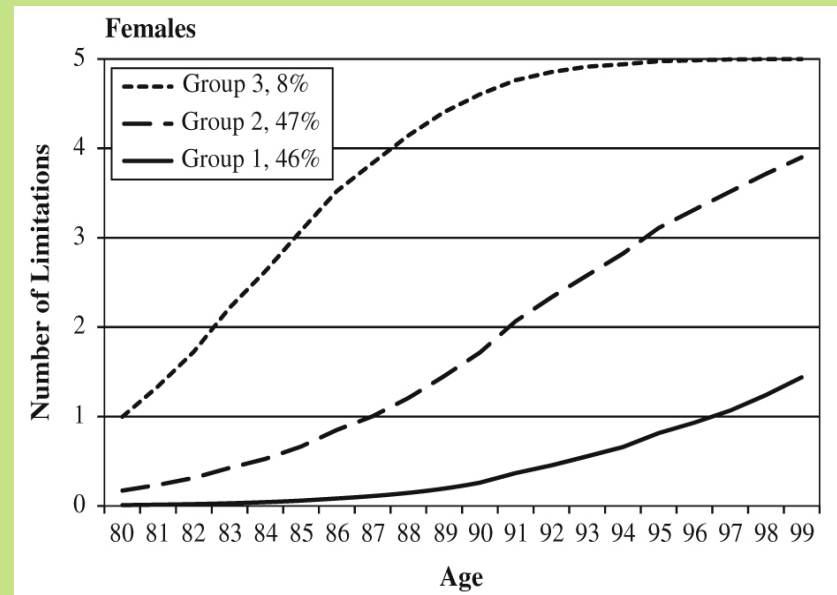
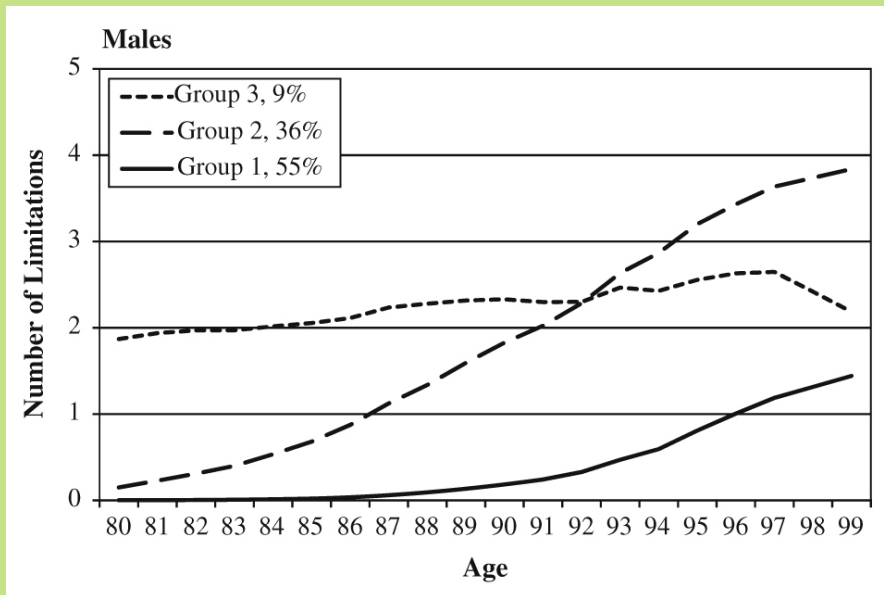
Disability Dynamics

Change in ADL/IADL disability, 1986–1990 (ages 70+)



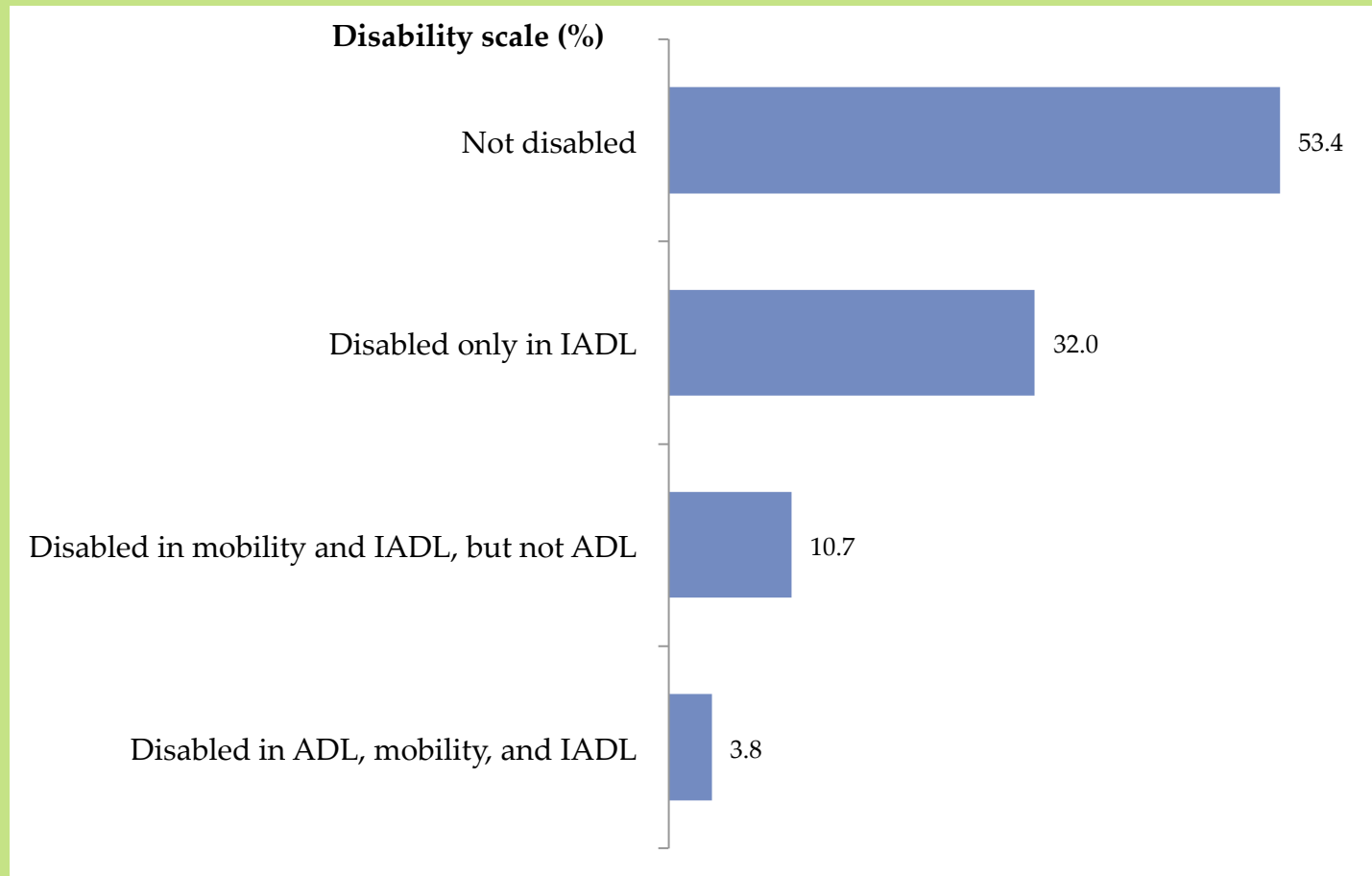
BE Holstein, P Due, G Almind & K Avlund (2007). Eight-year change in functional ability among 70- to 95-year-olds. *Scandinavian Journal of Public Health*, 35:243-249.

Predicted no. ADL limitations by age and gender (ages 80+)



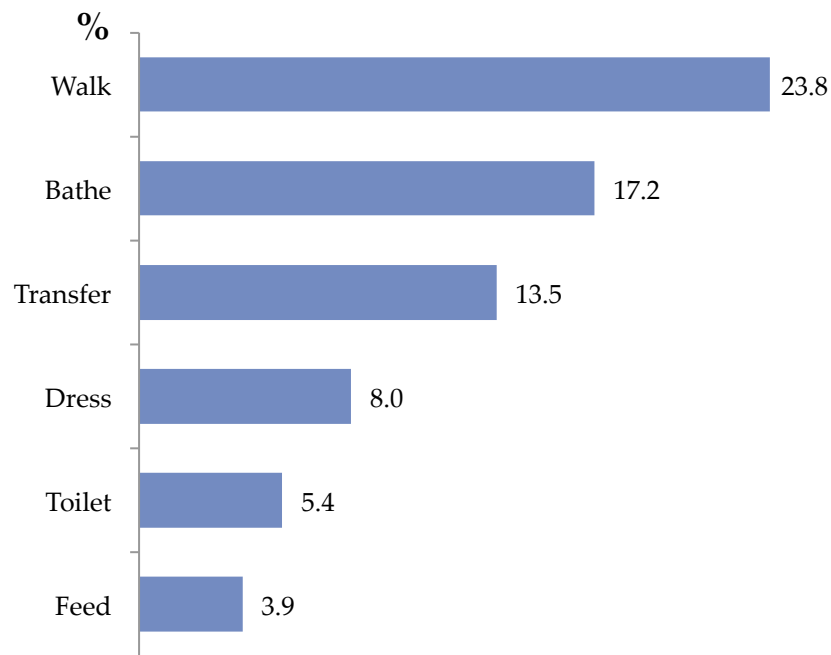
Z Zimmer, LG Martin, DS Nagin & BL Jones (2012). Modeling disability trajectories and mortality of the oldest-old in China. *Demography*, 49:291-314.

Hierarchical functional status, 1990 (ages 65-85)

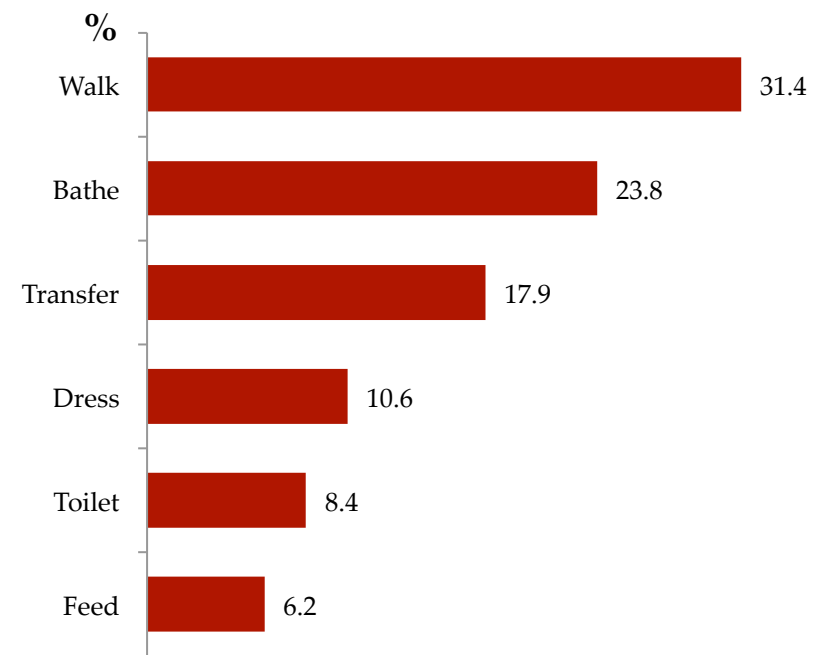


N Hoeymans, EJM Feskens, GAM van den Bos & D Kromhout (1996). Measuring functional status: cross-sectional and longitudinal associations between performance and self-report (Zutphen Elderly Study, 1990-1993). *Journal of Clinical Epidemiology*, 49:1103-1110.

Onset of specific disabilities, 1984 to 1990 (ages 70+, w/o disability in 1984)



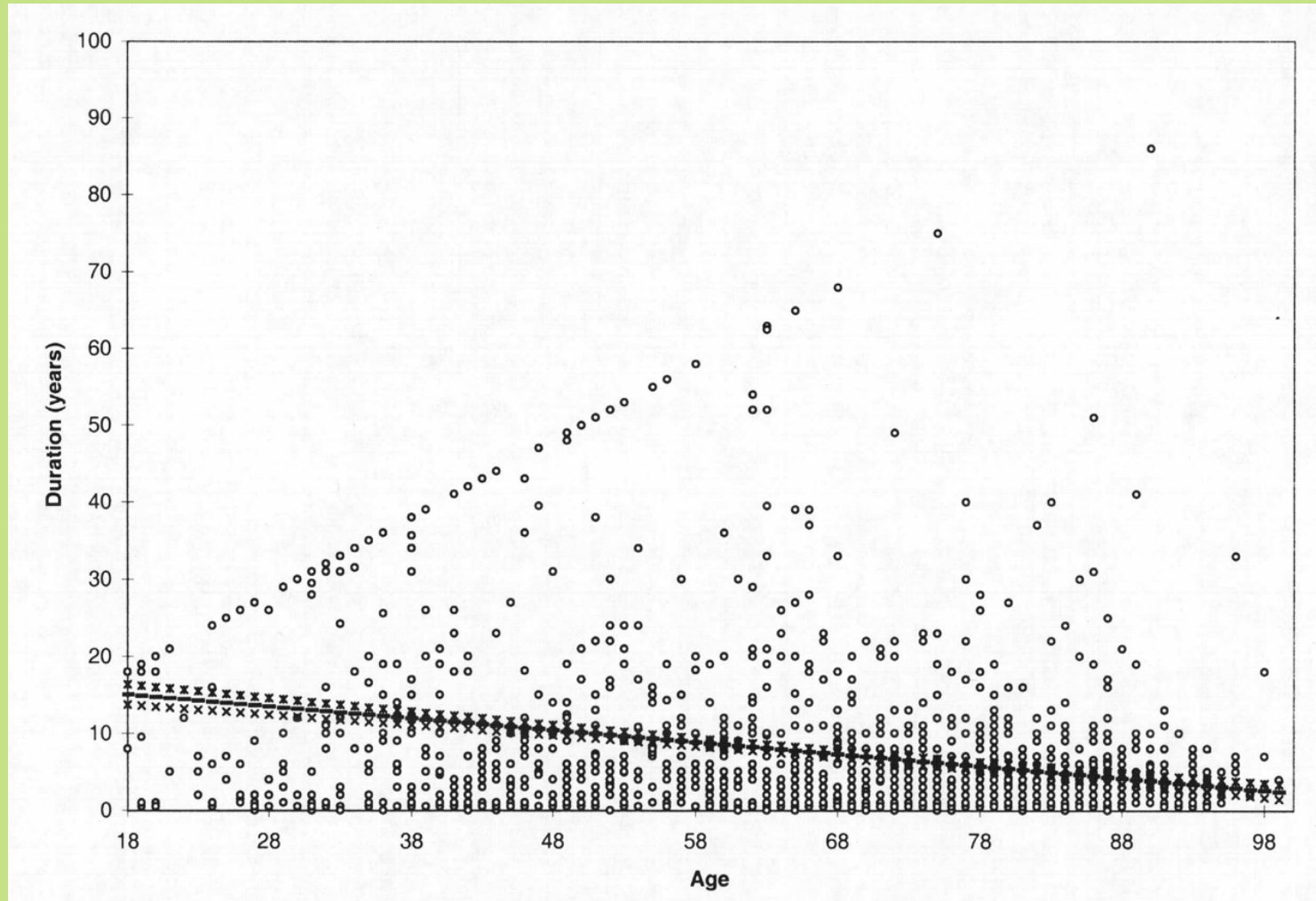
Men



Women

DD Dunlop, SL Hughes & LM Manheim (1997). Disability in activities of daily living: patterns of change and a hierarchy of disability. *American Journal of Public Health*, 87:378-383.

Duration of Bath disability by current age



L Verbrugge & L Yang (2002). Aging with disability and disability with aging. *Journal of Disability Policy Studies*, 12:253-267.

2 Buffers and Barriers

There are Many!

Medical care and rehabilitation

Medications and therapeutic regimens

Lifestyle changes

Activity modifications

Environment: built, physical, social

Assistance: special equipment, personal help

Psychosocial features and coping

Social attitudes and policies

Activity Modifications

How



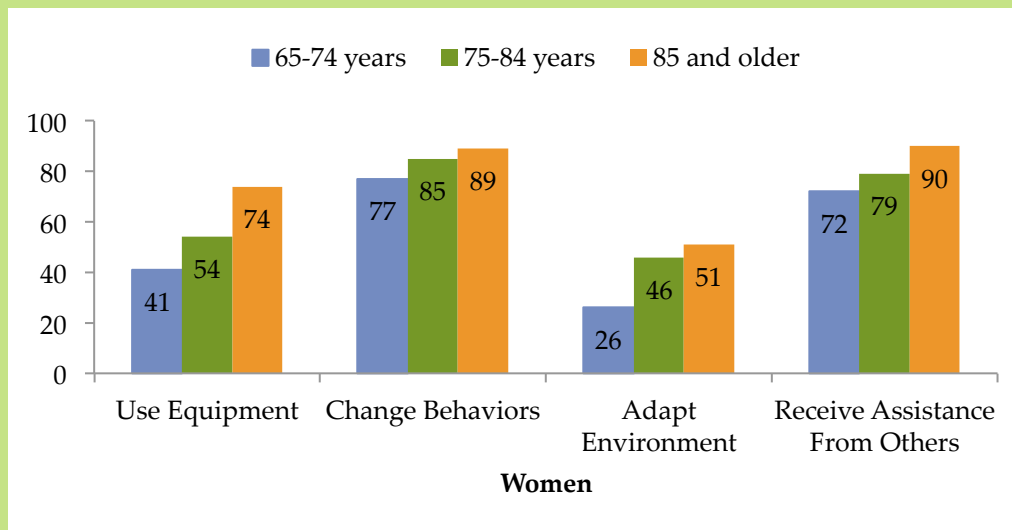
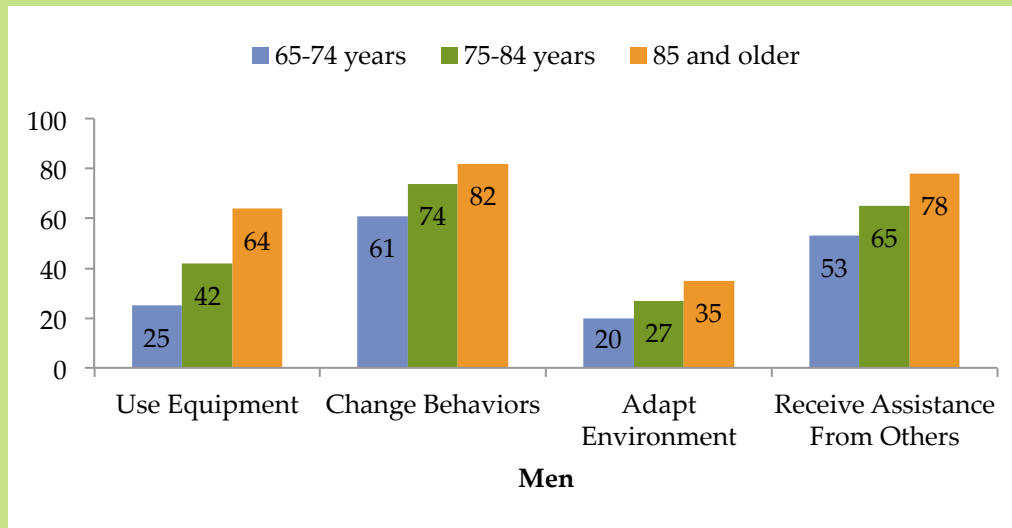
How long



How often



Self-care and personal assistance for functional limitations, 1990 (ages 65+)



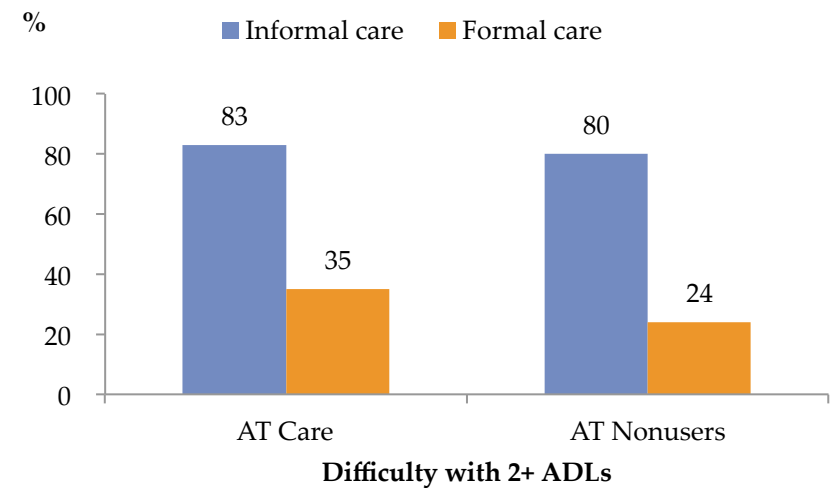
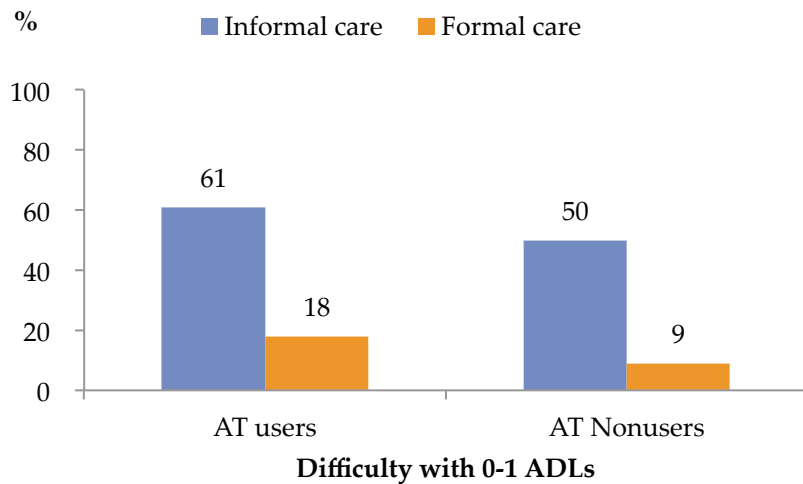
JE Kincade Norburn, SL Bernard, TR Konrad, A Woomert, GH DeFries, WD Kalsbeek, GG Koch, & MG Ory. (1995). Self-care and assistance from others in coping with functional status limitations among a national sample of older adults. *Journal of Gerontology: Social Sciences*, 50B: S101-S109.

Interaction of street conditions and functional status on outdoor mobility disability (ages 45+)



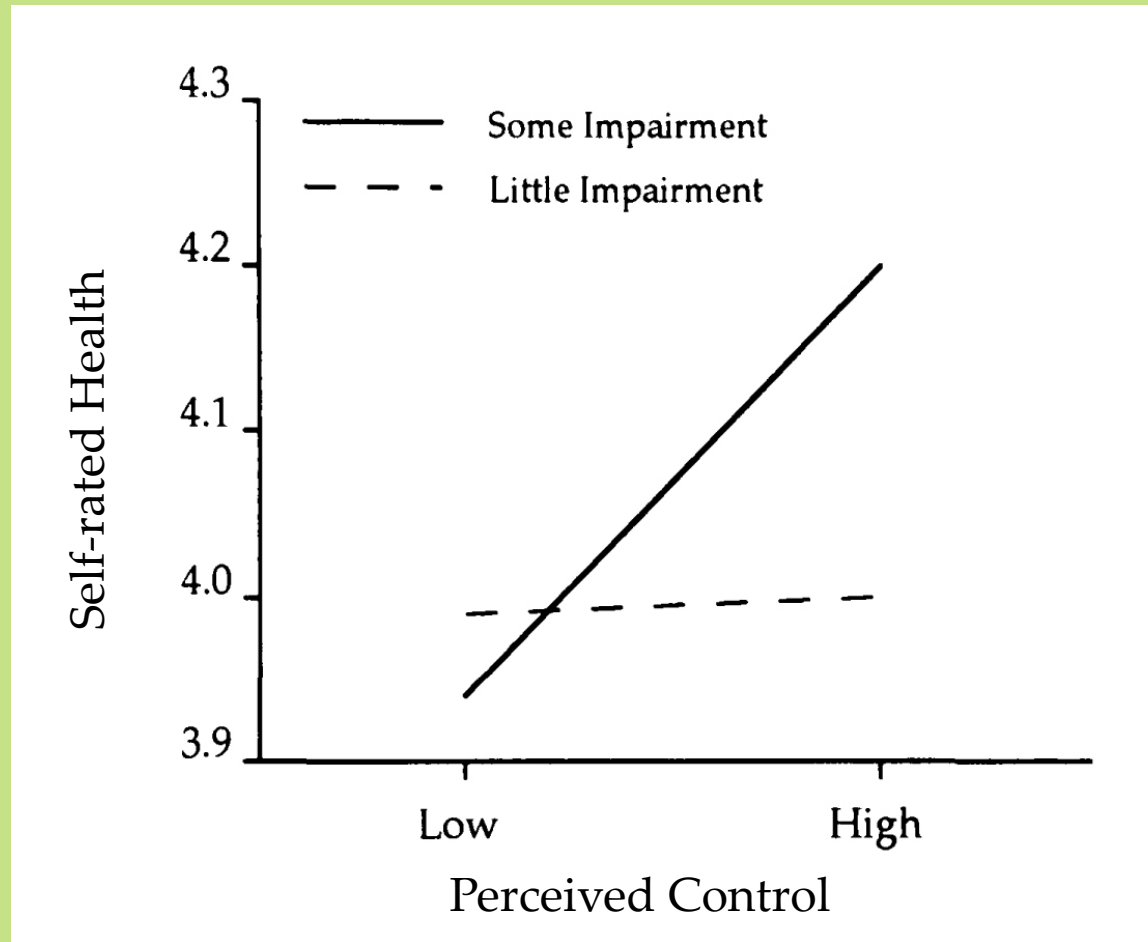
P Clarke, JA Ailshire, M Bader, JD Morenoff, & JS House. (2008). Mobility disability and the urban built environment. *American Journal of Epidemiology*, 168:506-513.

Personal care for assistive technology users and nonusers, 1994-1995 (ages 65+)



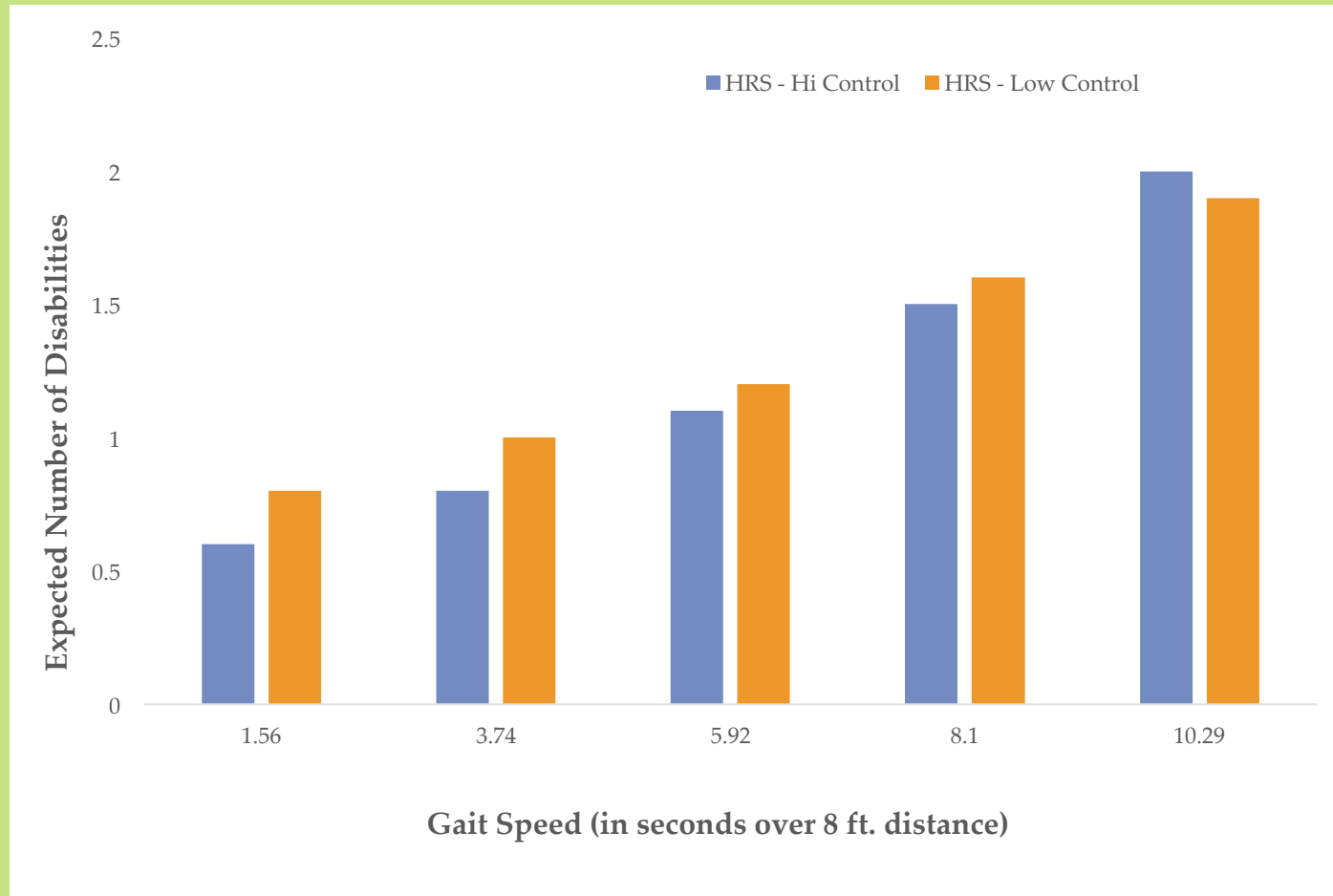
EM Agree, VA Freedman, JC Cornman, DA Wolf & JE Marcotte (2005). Reconsidering substitution in long-term care: when does assistive technology take the place of personal care? *Journal of Gerontology: Social Sciences*, 60B:S272-S280.

Interaction of perceived control and ADL/IADL limitation on self-rated health (ages 80+)



VH Menec & JG Chipperfield (1997). The interactive effect of perceived control and functional status on health and mortality among young-old and old-old. *Journal of Gerontology: Psychological Sciences*, 52B:P118-P126.

Personal Control and Disability (ages 65+)



P Clarke & J Smith (2011). Ageing in a cultural context: cross-national difference in disability and the moderating role of personal control among older adults in the United States and England. *Journals of Gerontology, Series B: Psychological Sciences and Social Science*, 66(4): 457-467.

3 Disability Trends

Trends in physical and sensory functions, and disability, 1997-2010 (ages 40-64 and 65+)

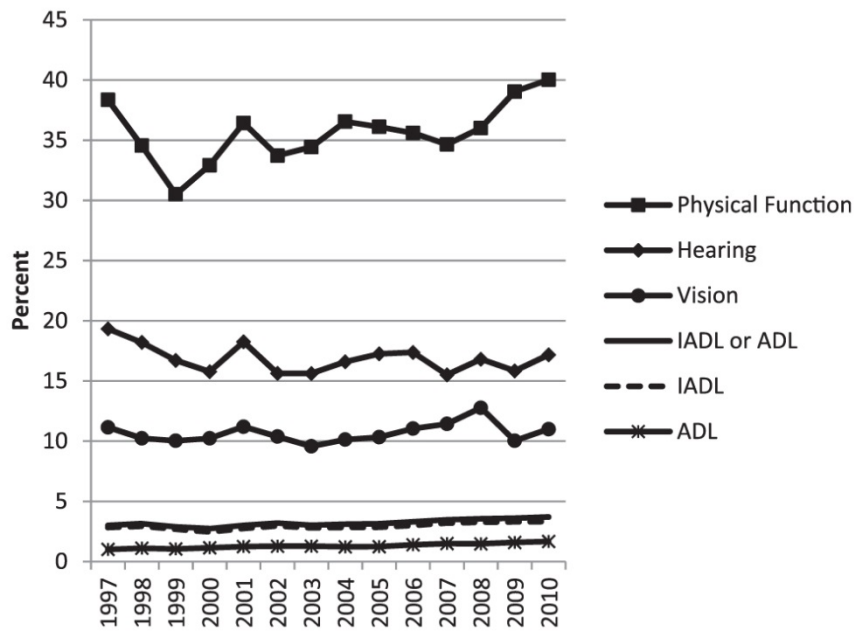


Fig. 1. Limitations, ages 40-64.

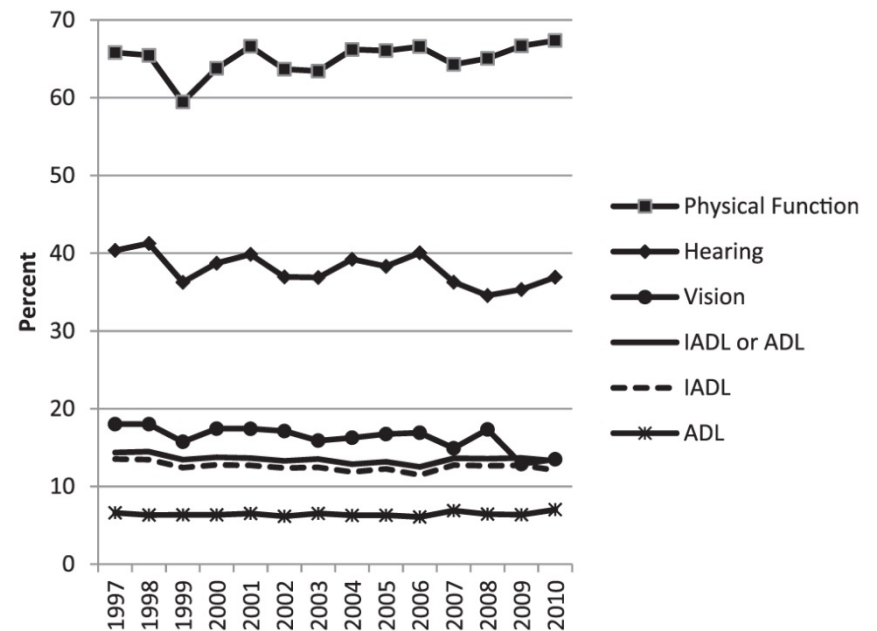
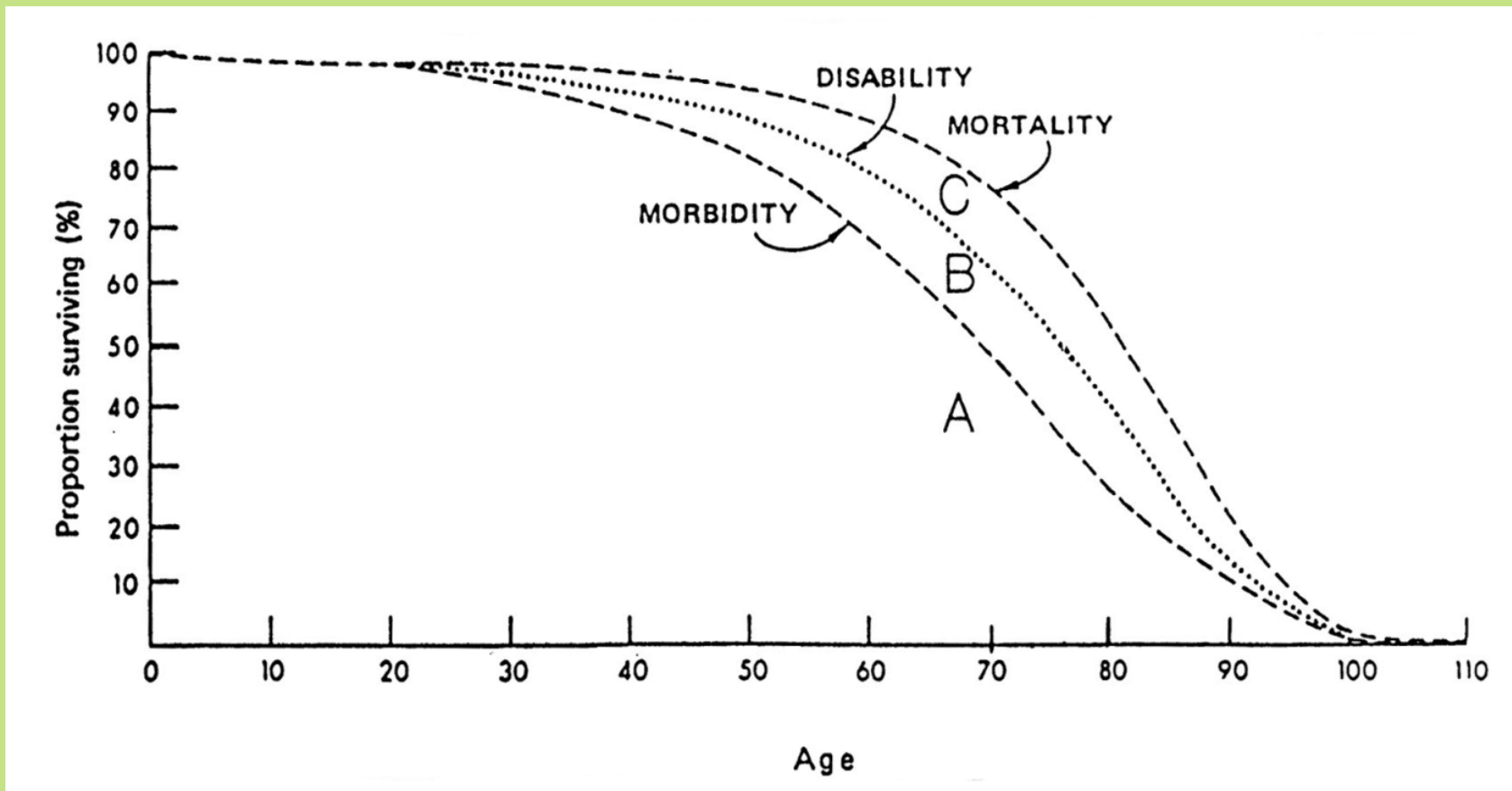


Fig. 2. Limitations, ages 65+.

LG Martin & RF Schoeni (2014). Trends in disability and related chronic conditions among the forty-and-over population: 1997-2010. *Disability & Health Journal*, 7:S4-S14.

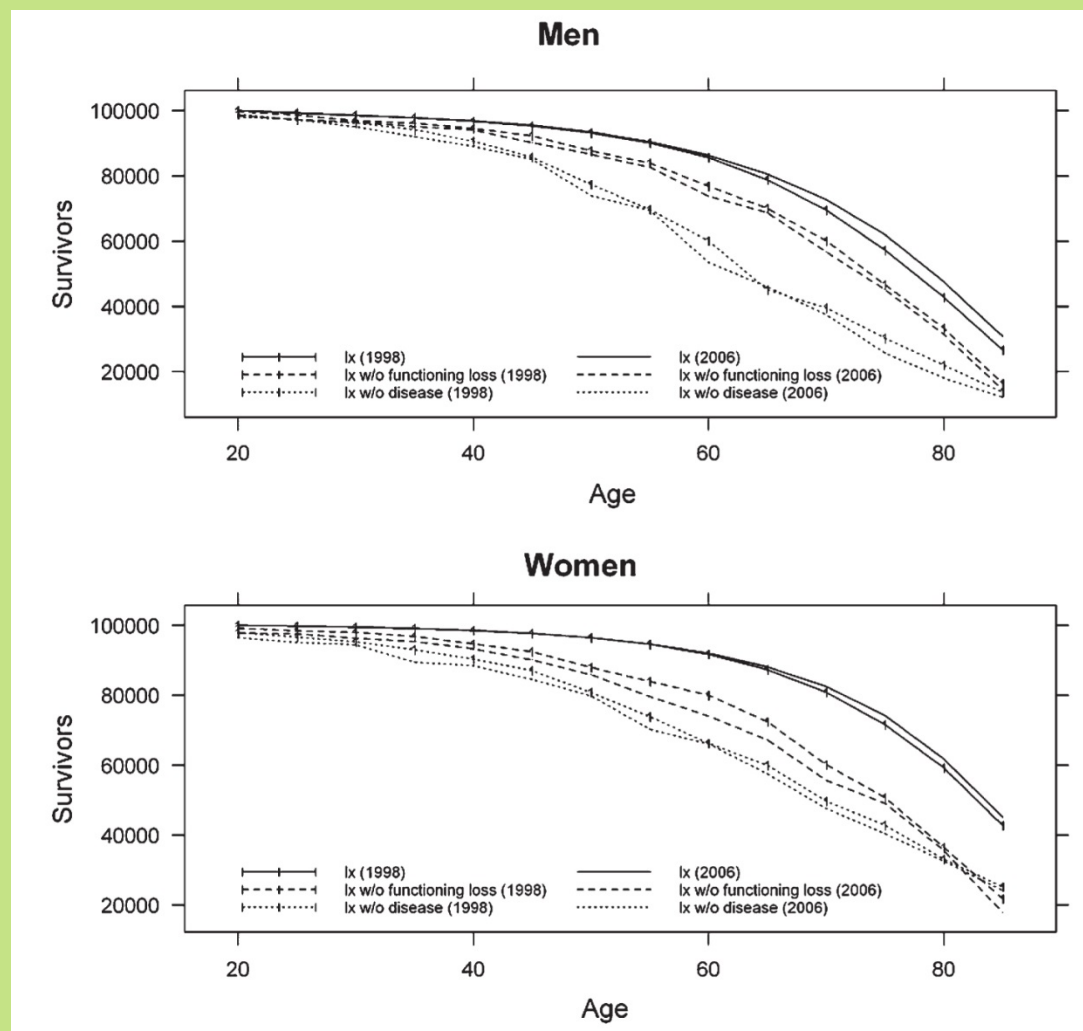
Survival curves of morbidity, disability, and mortality



Each curve shows probabilities of “surviving” (being free of) the event up to given ages. Zone A is well. Zone B is ill (morbidity) but not disabled. Zone C is ill and disabled.

LM Verbrugge (1991). Survival curves, prevalence rates, and dark matters therein. *Journal of Aging and Health*, 3:217-236. Figure adapted from KG Manton & BJ Soldo (1985). Dynamics of health changes in the oldest old: New perspectives and evidence. *Milbank Quarterly/Health and Society*, 63:206-285.

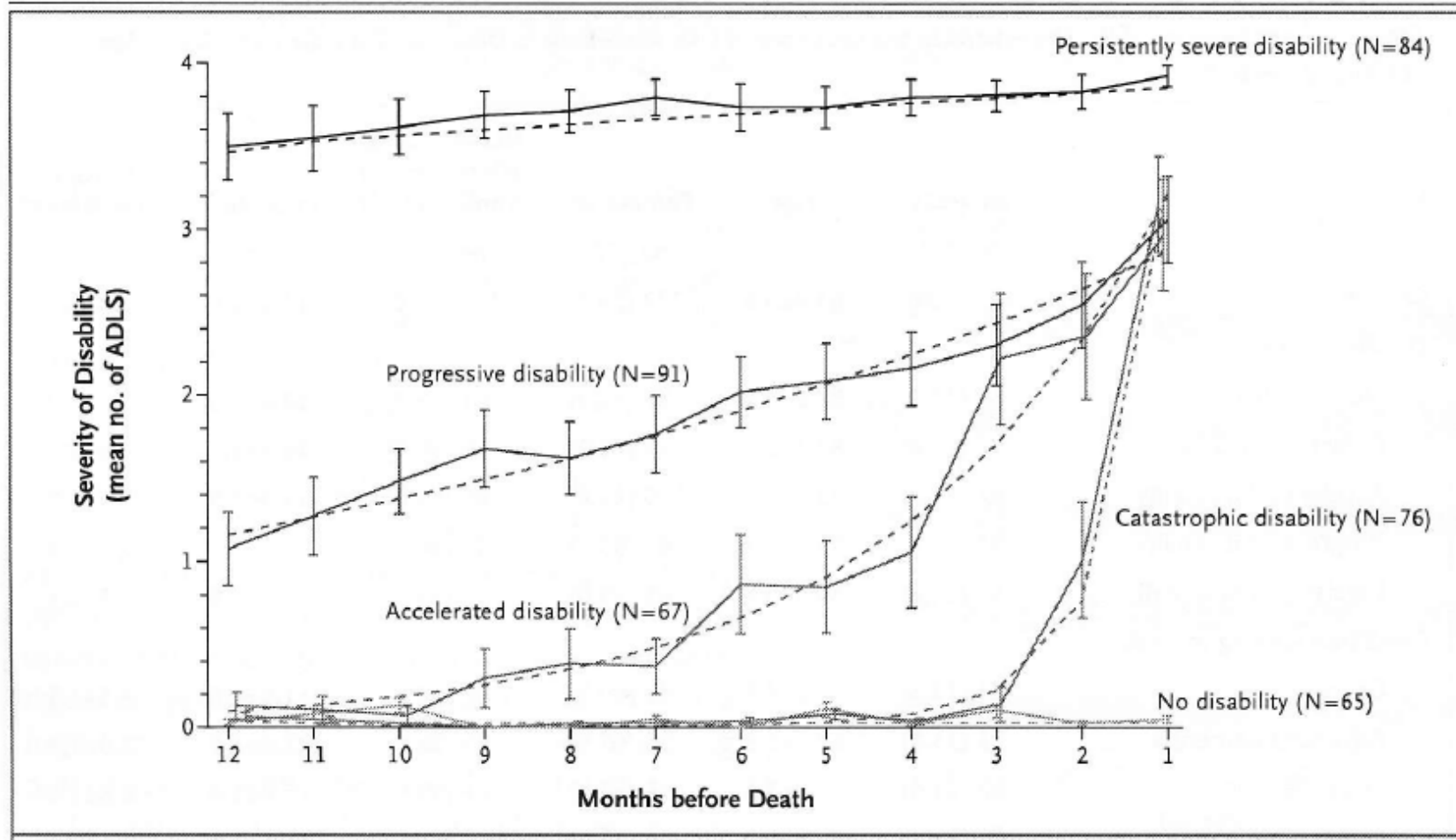
Survival curves of disease, mobility limitation, and mortality, 1998 and 2006 (ages 20+)



EM Crimmins & H Beltrán-Sánchez (2010). Mortality and morbidity trends: is there compression of morbidity? *Journal of Gerontology: Social Science*, 66B:75-86.

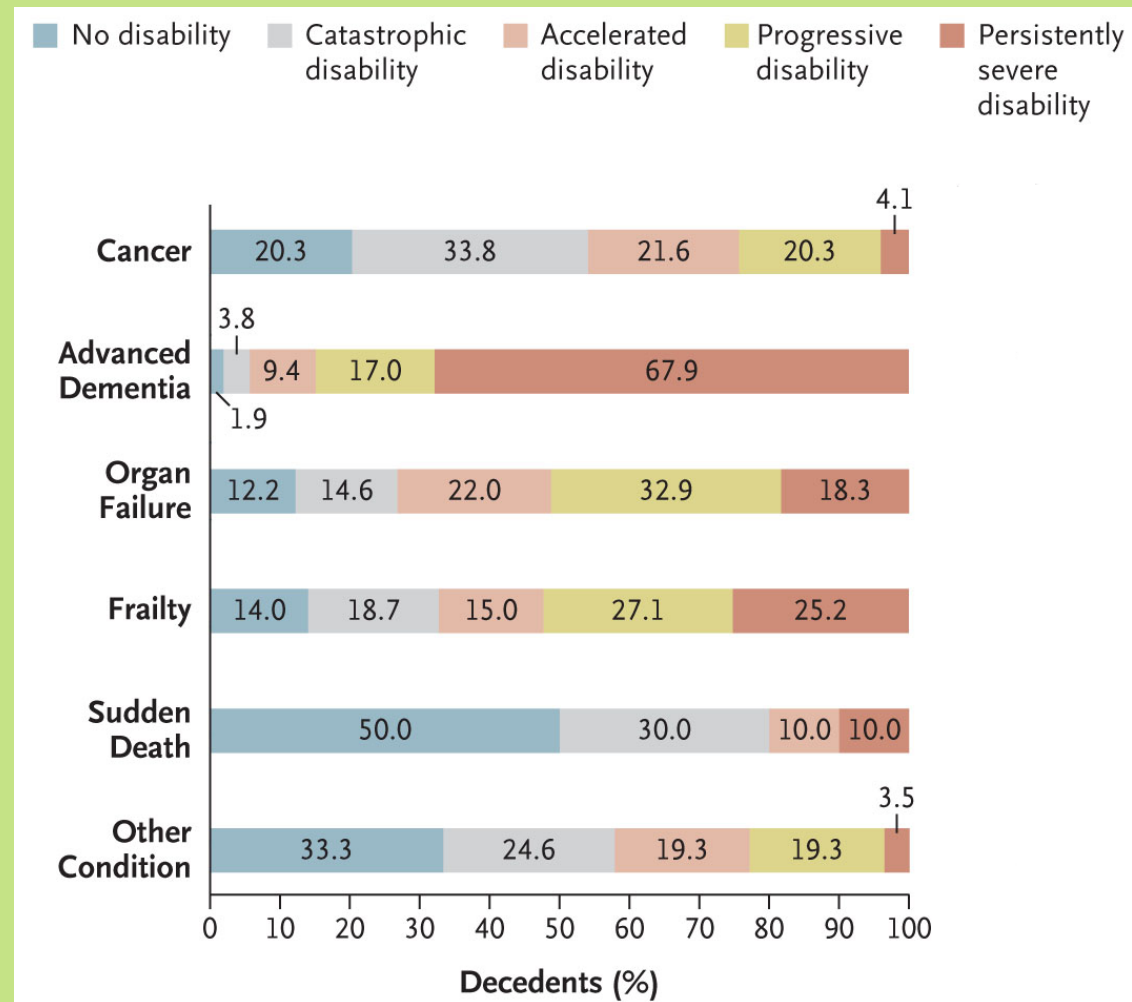
4 Very Old Persons

Disability trajectories in last year of life (ages 70+)



TM Gill, EA Gahbauer, L Han, & HG Allore (2010). Trajectories of disability in the last year of life. *New England Journal of Medicine*, 362:1173-1180.

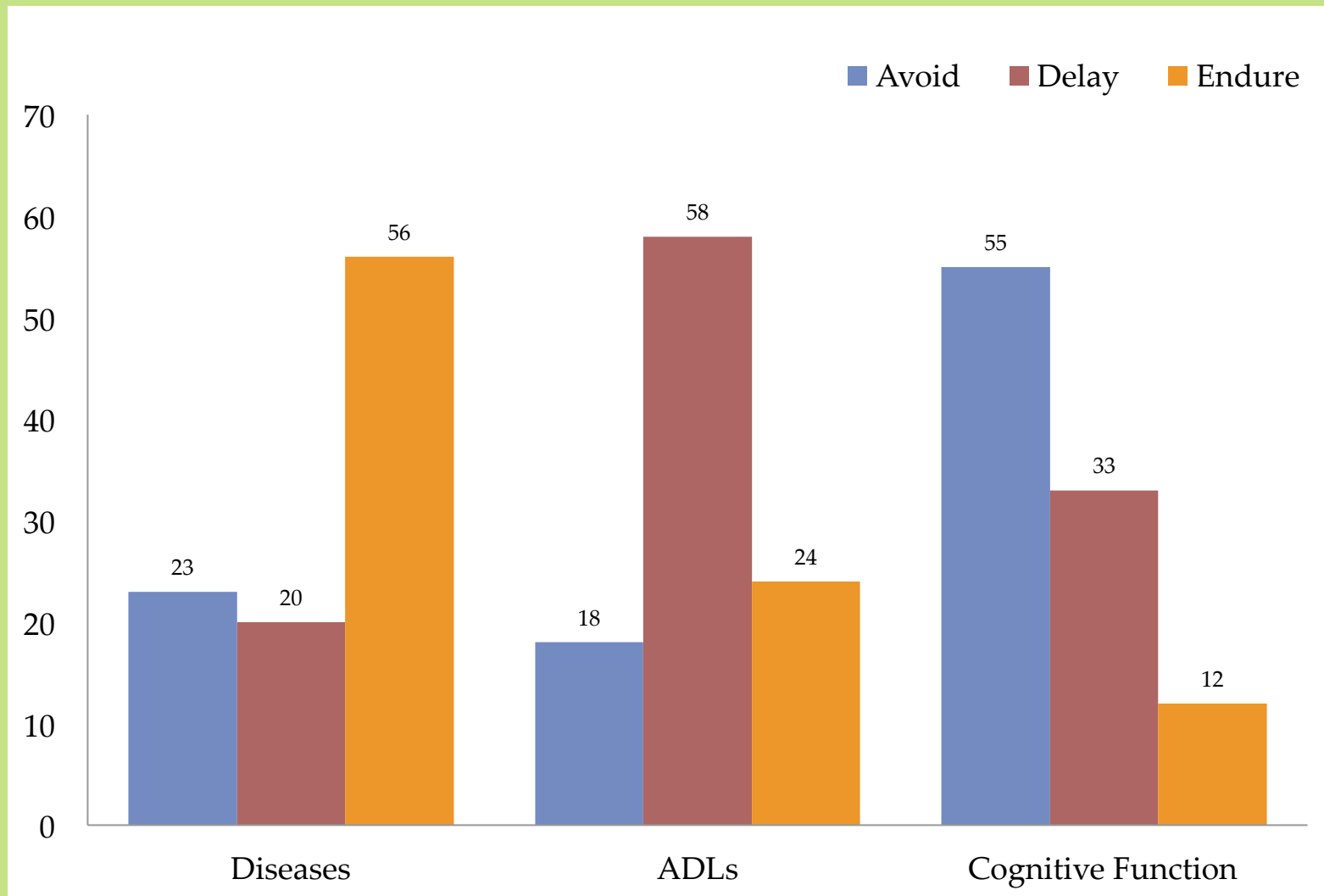
Disability trajectories in last year of life, by cause of death



Values in bars are percentages of decedents with each disability trajectory.

TM Gill, EA Gahbauer, L Han, & HG Allore (2010). Trajectories of disability in the last year of life. *New England Journal of Medicine*, 362:1173-1180.

Disease, disability, and cognition pathways for centenarians



JA Ailshire, H Beltrán-Sánchez & EM Crimmins (2015). Becoming centenarians: disease and functioning trajectories of older U.S. adults as they survive to 100. *Journals of Gerontology: Medical Sciences*, 70: 193-201.

MEASUREMENT

...

Traditional

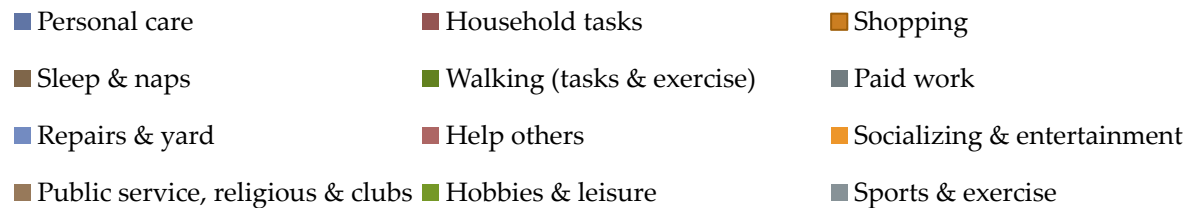
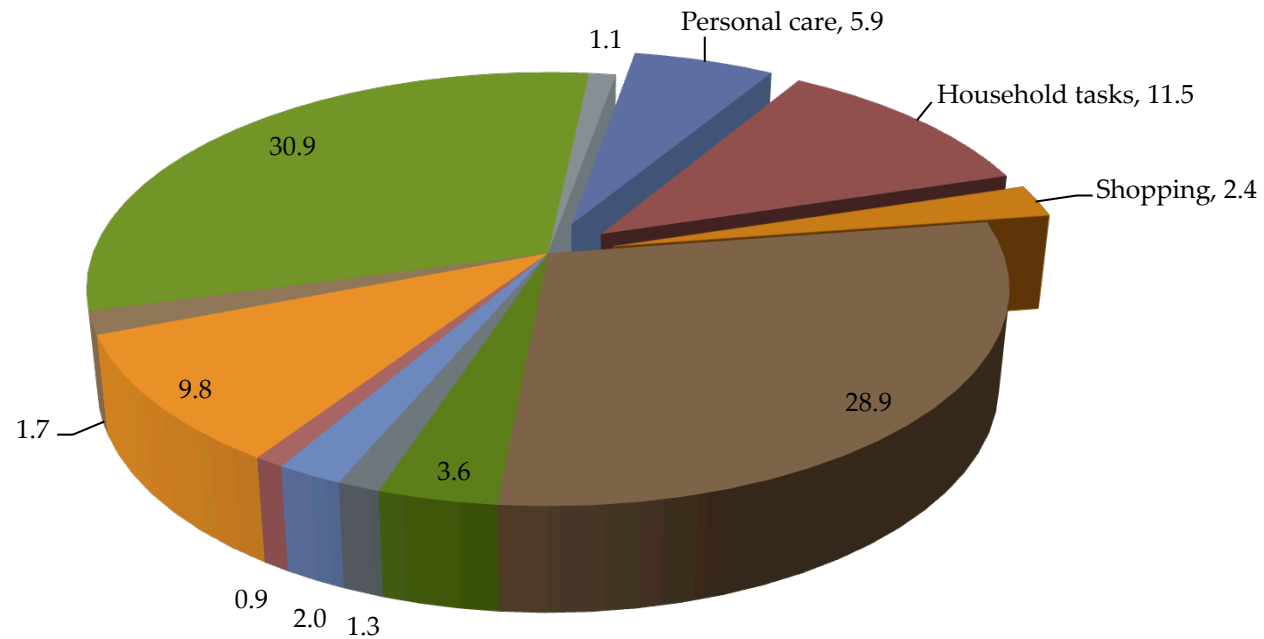
ADL Personal care activities such as dress, bathe, eat, get in/out of bed, use toilet, walk across a room

IADL Household management activities such as use phone, take medications, manage money, shop for groceries, prepare meals

Contemporary concerns

- On one's own, or with help
- Narrow coverage of activities

Activities of Older Adults, 2001 (ages 70+)



Source: Unpublished output (LM Verbrugge & X Liu) from the Consumption and Activities Mail Survey, Health and Retirement Study.

More Activities

"By yourself, and without using any special equipment, how difficult is it for you to:

- Go out to things like shopping, movies, or sporting events?"
- Participate in social activities such as visiting friends, attending clubs and meetings, going to parties?"
- Do things to relax at home or for leisure (reading, watching TV, sewing, listening to music)?"

(Responses: not at all; only a little; somewhat; very; can't do at all; do not do this activity)

Source: Adult Health Status & Limitations module, 2015 National Health Interview Survey (NHIS).



More Answers

For ADLs, people are asked about equipment assistance (devices or home modifications), personal assistance, current difficulty on one's own, and frequency changes in past year.

Severity of disability is scored as a hierarchy:

Fully able (no difficulty, no eqpt, no freq change, no pers ass)

Successful accommodation (use eqpt and no difficulty)

Activity reduction (reduced freq and no difficulty)

Difficulty (even if eqpt or reduced freq)

Assistance from others

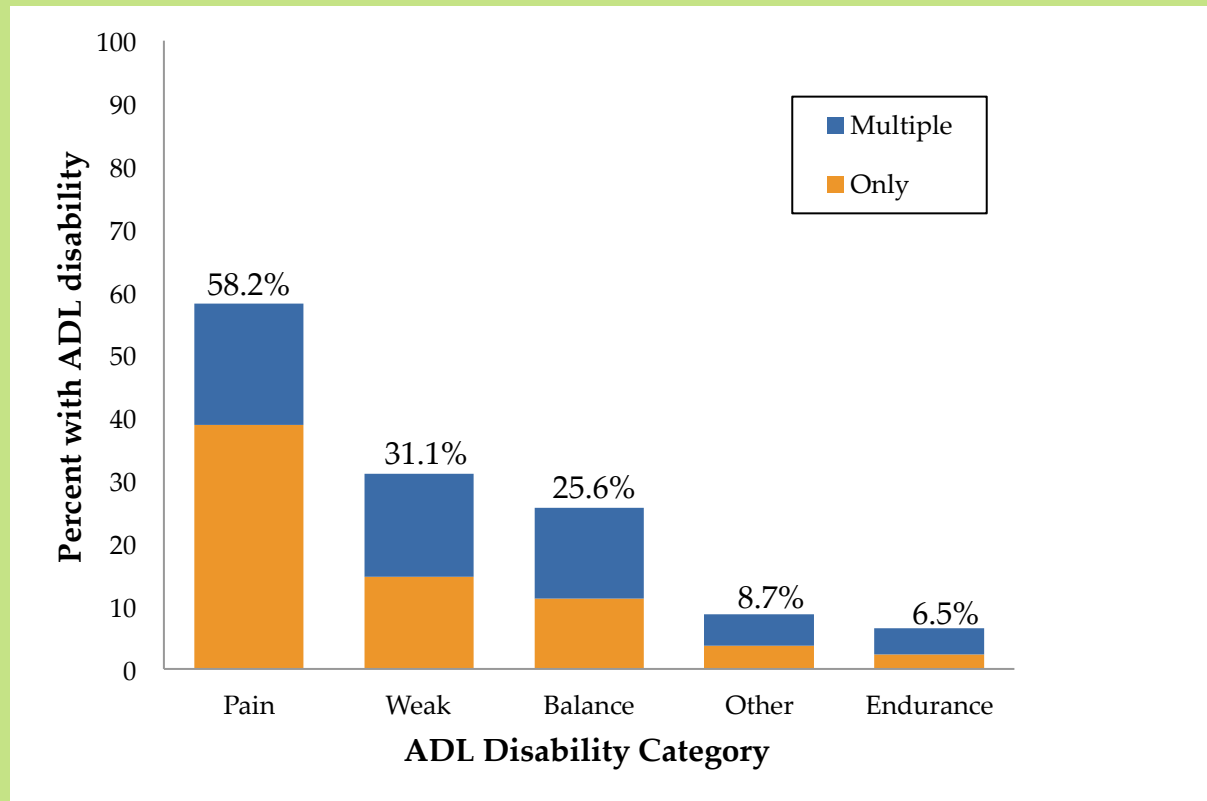
Nursing home

Source: National Health and Aging Trends Study (NHATS).

VA Freedman, JD Kasper, BC Spillman, EM Agree, V Mor, RB Wallace & DA Wolf (2014). Behavioral adaptation and late-life disability: a new spectrum for assessing public health impacts. *American Journal of Public Health*, 104(2):388-e94.



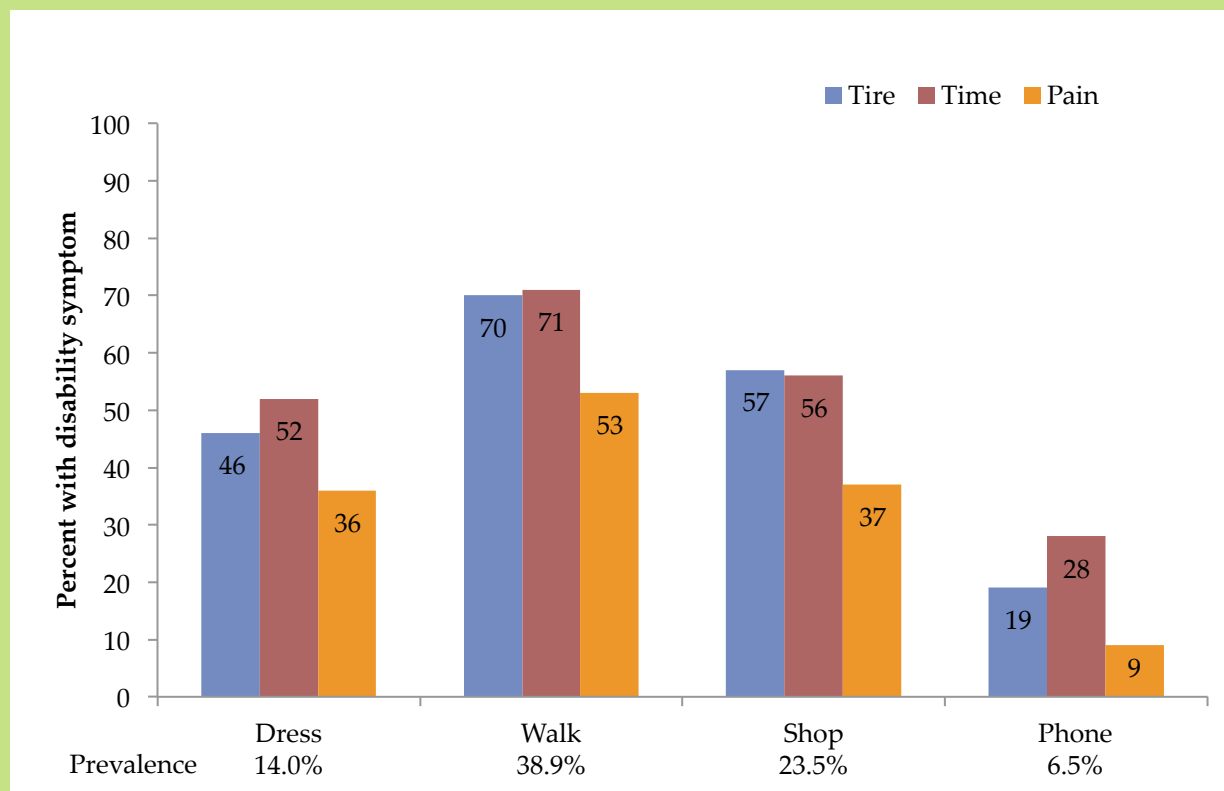
More Aspects (Disability Symptoms)



Percent of women with ADL disabilities (ages 65+) who have symptoms when doing the tasks. Orange for just this symptom, blue for multiple ones. Data from Women's Health and Aging Study.

SG Leveille, LP Fried, W McMullen & JM Guralnik (2004). Advancing the taxonomy of disability in older adults. *Journal of Gerontology: Medical Sciences*, 59A:86-93.

Tire/Time/Pain



Disability symptoms for U.S. community dwellers ages 55+ with ADL/IADL disabilities

LM Verbrugge & P Sevak (2004). Disability symptoms and the price of self-sufficiency. *Journal of Aging and Health*, 16(5): 688-722.

Short Set

"Because of a health problem,

- do you have difficulty seeing, even if wearing glasses?"
- do you have difficulty hearing, even if using a hearing aid?"
- do you have difficulty walking or climbing steps?"
- do you have difficulty remembering or concentrating?"
- *do you have difficulty (with self-care such as) washing all over or dressing?"*
- using your usual (customary) language, do you have difficulty communicating, for example, understanding or being understood by others?"

(Responses: no, no difficulty; yes, some difficulty; yes, a lot of difficulty; cannot do it at all)

Source: United Nations Statistical Division, Washington Group on Disability Statistics.

JH Madans, ME Loeb & BM Altman (2011). Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. *BMC Public Health*, 11 (Suppl 4):54.



One Question

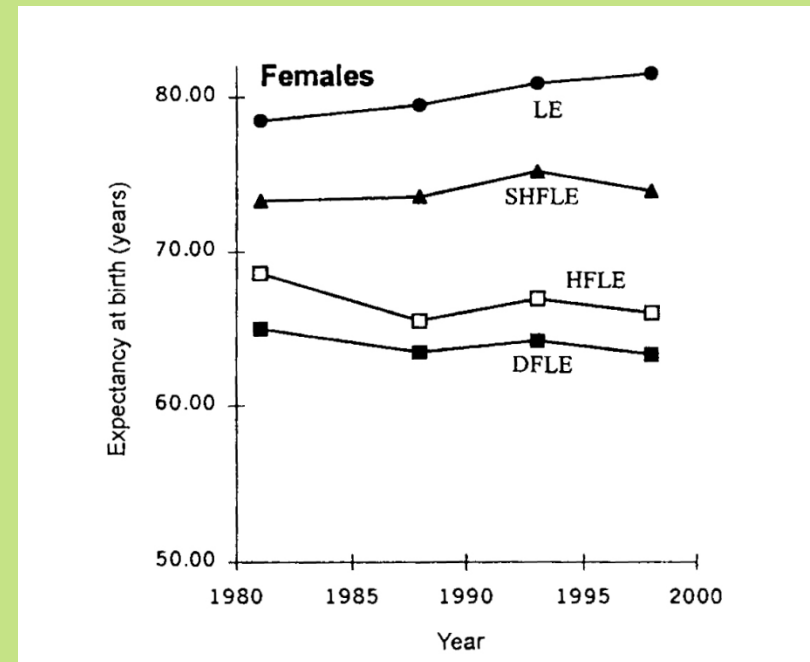
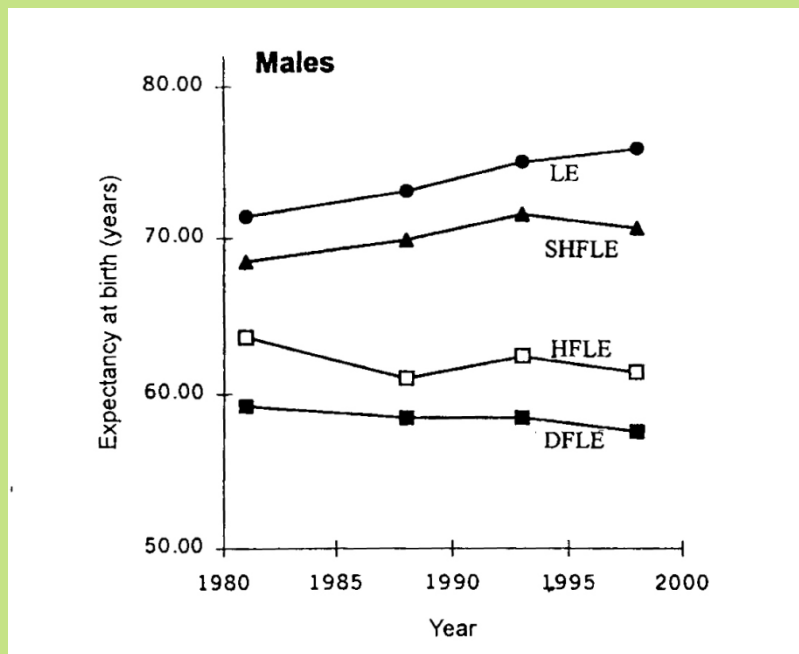
"For at least the past six months, to what extent have you been limited because of a health problem in activities people usually do?"

(Responses: severely limited; limited but not severely; not limited at all)

Global Activity Limitation Indicator (GALI), Joint Action European Health & Life Expectancies Information System (JA: EHLEIS).

H van Oyen, J van der Heyden, R Perenboom & C Jagger (2006). Monitoring population disability: evaluation of a new Global Activity Limitation Indicator (GALI). *Social and Preventive Medicine*, 51:153-161.

Disability-Free Life Expectancy



Trends in disability-free life expectancy (DFLE), handicap-free life expectancy (HFLE), severe handicap-free life expectancy (SHFLE) and total life expectancy (LE) at birth, by sex, Australia, 1981 to 1998.

P Davis, CD Mathers & P Graham (2003). Health expectancy in Australia and New Zealand. Pp. 391-408 in J-M Robine, C Jagger, CD Mathers, EM Crimmins & RM Suzman (eds.) *Determining Health Expectancies*. Chichester, England: John Wiley & Sons Ltd.

More But Less

More coverage and less burden (respondent, survey agency, analysts, end users)



The current winners are:

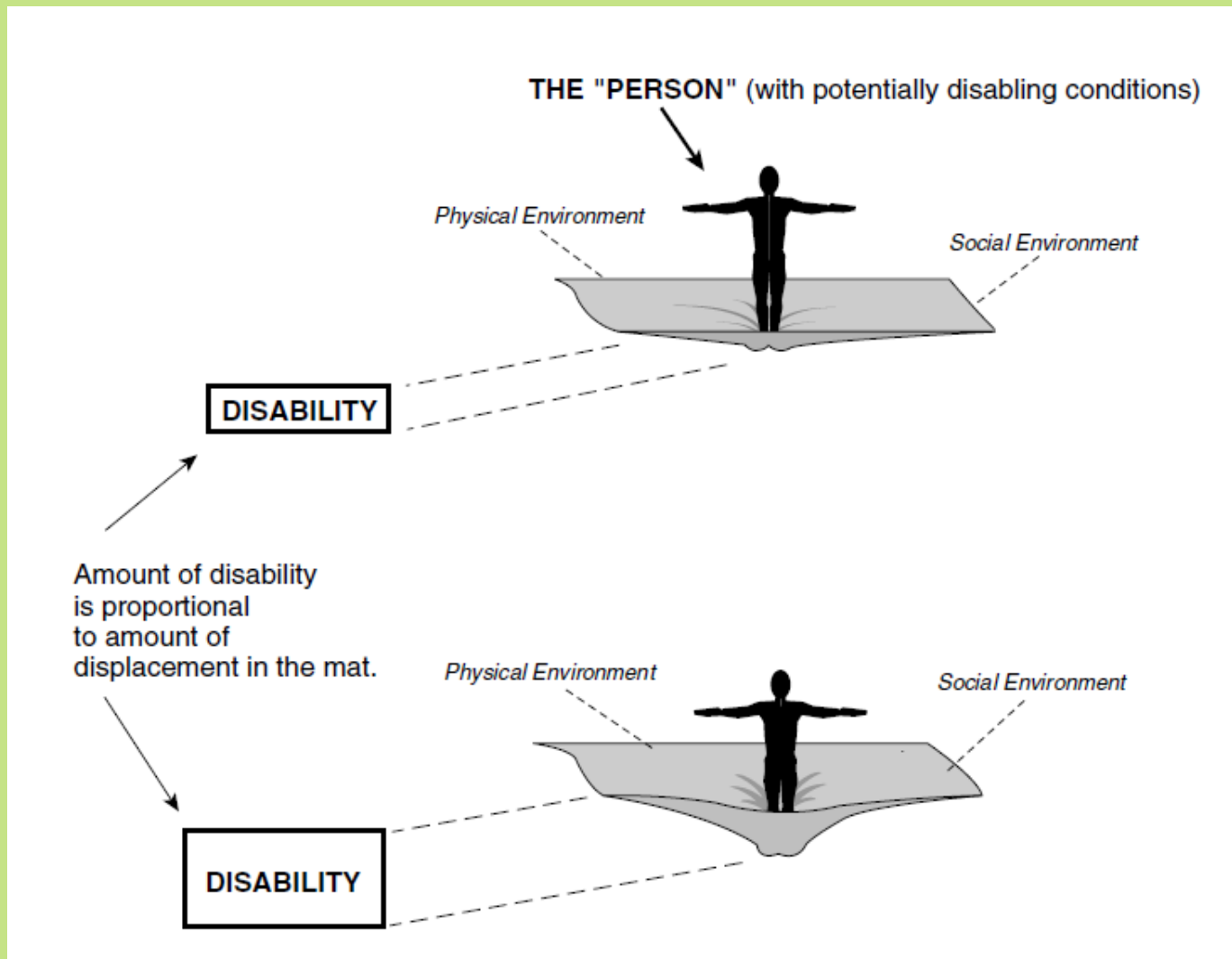
GALI (broad coverage, low burden)

and

DFLE (succinct for end users; analyst burden)

MODELS

Visual Image



- EN Brandt, Jr. & AM Pope (1997). *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*. Washington, DC: National Academy Press.

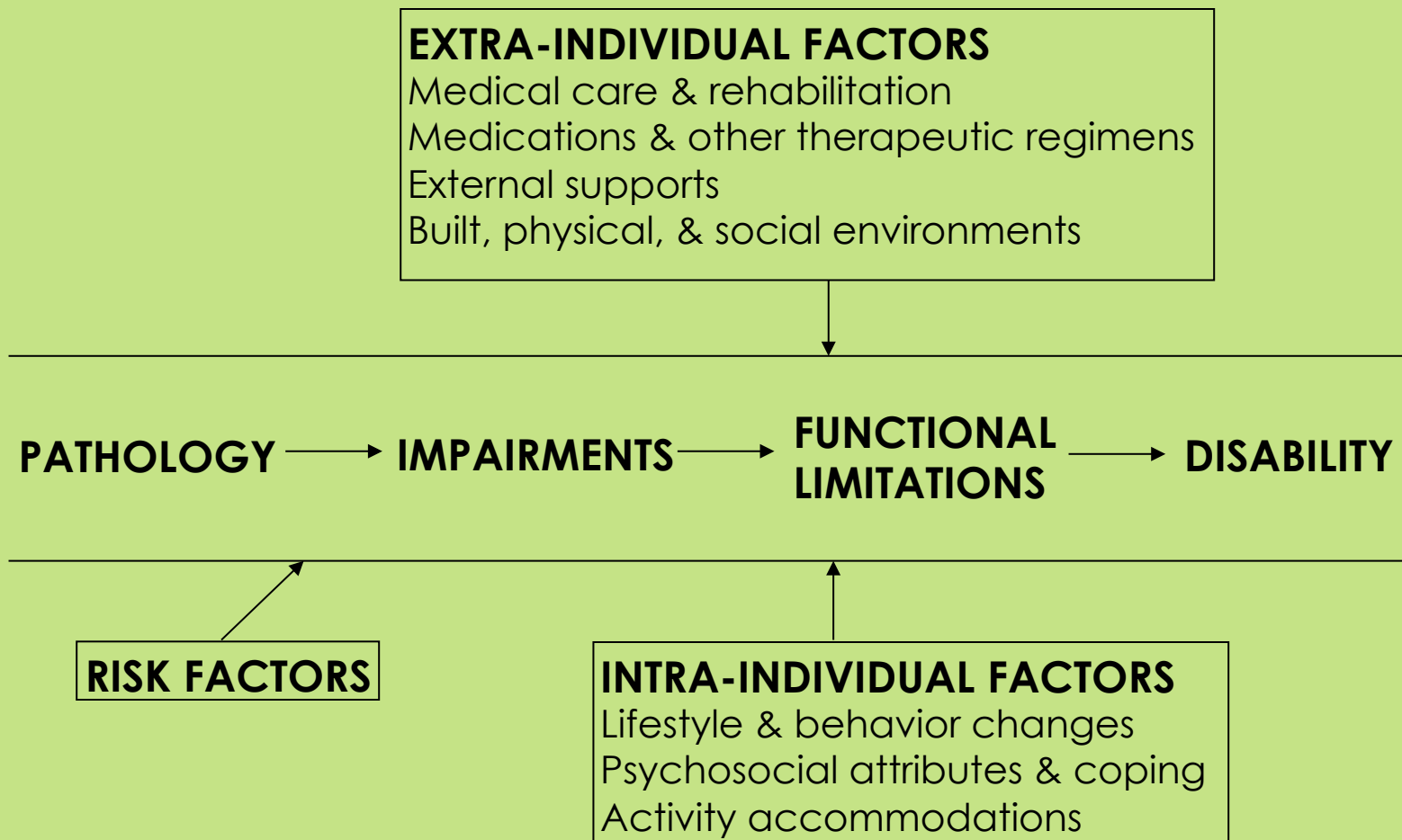
Taxonomy

Activities and Participation	ICF	ICF	Activities and Participation
d 6403 Using household appliances Using all kinds of household appliances, such as washing machines, driers, irons, vacuum cleaners and dishwashers.		d 6501 Maintaining dwelling and furnishings Repairing and taking care of dwelling, its exterior, interior and contents, such as by painting, repairing fixtures and furniture, and using required tools for repair work.	
d 6404 Storing daily necessities Storing food, drinks, clothes and other household goods required for daily living; preparing food for conservation by canning, salting or refrigerating, keeping food fresh and out of the reach of animals.		d 6502 Maintaining domestic appliances Repairing and taking care of all domestic appliances for cooking, cleaning and repairing, such as by oiling and repairing tools and maintaining the washing machine.	
d 6405 Disposing of garbage Disposing of household garbage such as by collecting trash and rubbish around the house, preparing garbage for disposal, using garbage disposal appliances; burning garbage.		d 6503 Maintaining vehicles Repairing and taking care of motorized and non-motorized vehicles for personal use, including bicycles, carts, automobiles and boats.	
d 6408 Doing housework, other specified		d 6504 Maintaining assistive devices Repairing and taking care of assistive devices, such as prostheses, orthoses and specialized tools and aids for housekeeping and personal care; maintaining and repairing aids for personal mobility such as canes, walkers, wheelchairs and scooters; and maintaining communication and recreational aids.	
d 6409 Doing housework, unspecified		d 6505 Taking care of plants, indoors and outdoors Taking care of plants inside and outside the house, such as by planting, watering and fertilizing plants; gardening and growing foods for personal use.	
d 649 Household tasks, other specified and unspecified		d 6506 Taking care of animals Taking care of domestic animals and pets, such as by feeding, cleaning, grooming and exercising pets; watching over the health of animals or pets; planning for the care of animals or pets in one's absence.	
Caring for household objects and assisting others (d650-d669)		d 6508 Caring for household objects, specified	
d 650 Caring for household objects Maintaining and repairing household and other personal objects, including house and contents, clothes, vehicles and assistive devices, and caring for plants and animals, such as painting or wallpapering rooms, fixing furniture, repairing plumbing, ensuring the proper working order of vehicles, watering plants, grooming and feeding pets and domestic animals. <i>Inclusions: making and repairing clothes; maintaining dwelling, furnishings and domestic appliances; maintaining vehicles; maintaining assistive devices; taking care of plants (indoor and outdoor) and animals</i> <i>Exclusions: acquiring a place to live (d610); acquisition of goods and services (d620); doing housework (d640); caring for others (d660); remunerative employment (d850)</i>		d 6509 Caring for household objects, unspecified	
d 6500 Making and repairing clothes Making and repairing clothes, such as by sewing, producing or mending clothes; reattaching buttons and fasteners; ironing clothes, fixing and polishing footwear. <i>Exclusion: using household appliances (d6403)</i>		d 660 Assisting others Assisting household members and others with their learning, communicating, self-care, movement, within the house or outside; being concerned about the well-being of household members and others. <i>Inclusions: assisting others with self-care, movement, communication, interpersonal relations, nutrition and health maintenance</i> <i>Exclusion: remunerative employment (d850)</i>	

156

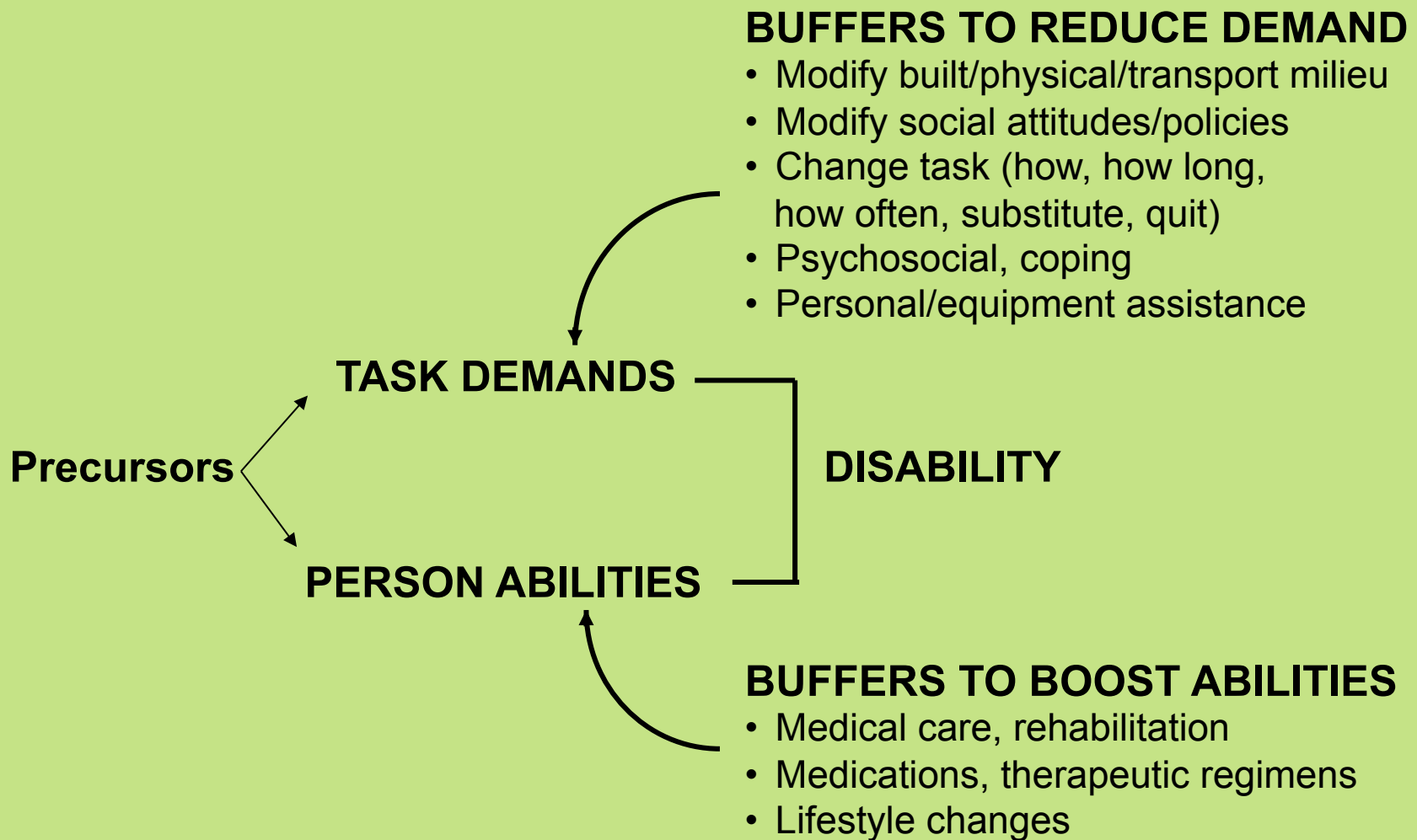
157

Disablement Process 1



LM Verbrugge & AM Jette (1994). The disablement process. *Social Science & Medicine*, 38: 1-14.

Disablement Process 2



Modified from LM Verbrugge & AM Jette (1994). The disablement process. *Social Science & Medicine*, 38: 1-14.

Formal Theory

- Population aging
- Life course
- Life-span development
- Role theory
- Exchange theory
- Person-environment theory

CONCLUSION

...

There was a crinkly old lady in Oz



*There was a crinkly old lady in Oz
Who became moody, and hungry, because
She could no longer go shopping,
So afraid was she of dropping.
Bunions so painful, sun so bright and hot, vision so fuzzy, speedy drivers in
cars.*

Oh dear!

*So the crinkly old lady in Oz
Bought online pink sneakers and a rollcart with attached umbrella [Applause!].
Now she goes out rain or shine with stability,
Stuns drivers into slowness and crosswalk immobility,
Her fridge is full, her new jumper fits nicely, and (because yesterday she stopped at
the animal society on her way home) she now has a bouncy white kitten with black
paws!*

Oh my!

Themes in Next Three Decades

- Lifetime disability experience
- People's own solutions for disability
- Population compression or expansion of disability
- Biogenetic aspects of long life

Stumbling Blocks

- Disability advocacy and disability science
- Disconnect between child/youth and midlife/older adults research
- Bringing environment into research
- Scientists in a rush

Research Does Matter

Translate disability science to healthcare practice, health policy, and public education

Importance of clear terminology, good writing, and visual display

Southeast Asia and Region



THANK YOU

...



**INSTITUTE FOR SOCIAL RESEARCH
POPULATION STUDIES CENTER**

UNIVERSITY OF MICHIGAN

