NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD

Coordinating Center on the Economics of AD/ADRD Prevention, Treatment, and Care

First Annual Meeting

Welcome and Consortium Overview

Julie Bynum, MD
Principal Investigator, NBER Coordinating Center on the Economics of AD/ADRD
Margaret Terpenning Professor of Internal Medicine, University of Michigan Medical School

John Phillips, PhD
Acting Deputy Director, Associate Director of Population and Social Processes Branch, & Program Officer, Division of Behavioral and Social Research (BSR) at the National Institute on Aging (NIA)

NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD

NBER Coordinating Center on the Economics of AD/ADRD Prevention, Treatment, and Care

First Annual Scientific Meeting
June 2025

The NBER Coordinating Center on the Economics of Alzheimer's Disease / ADRD is funded by the National Institute on Aging, part of the National Institutes of Health

Opening Remarks: Why create a Coordinating Center on the Economics of AD/ADRD?

John W. R. Phillips, Branch Chief, Acting Deputy Director, Program Official

Charlie Le, Program Analyst

David Braudt, Project Scientist

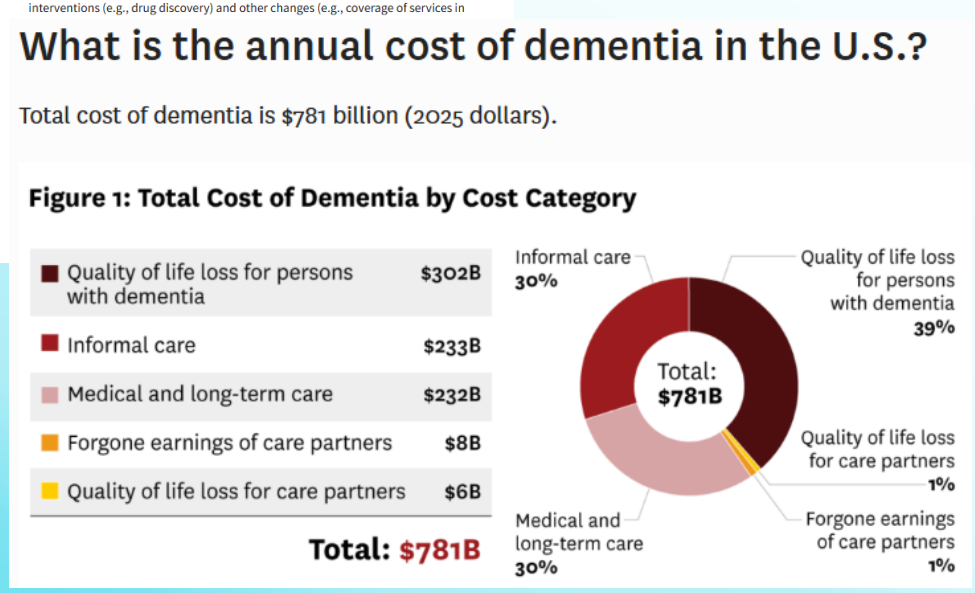
Division of Behavioral and Social Research, National Institute on Aging

NBER Coordinating Center on the Economics of AD/ADRD

June 12, 2025

Why focus on the Economics of AD/ADRD?





- Recent NIA-supported research estimates the annual cost of dementia in the UAS at $781b
- National Plan to Address Alzheimer's Disease (NAPA) - prevent future cases and better meet care needs for those facing the disease
- NAPA goals feed ***NIA's AD/ADRD Research Implementation Milestones*** that include topics ripe for analysis by economists (e.g., quasi-experimental designs/Natural Experiments)

Why create a *Coordinating Center* on the Economics of AD/ADRD?

- Advance economic research on AD/ADRD by supporting a ***consortium of research projects*** examining:
  - the development and diffusion of treatment/care innovations
  - payment and treatment models for care, care quality and access for people living with dementia (PLWD) and their caregivers
  - economic factors influencing disease progression

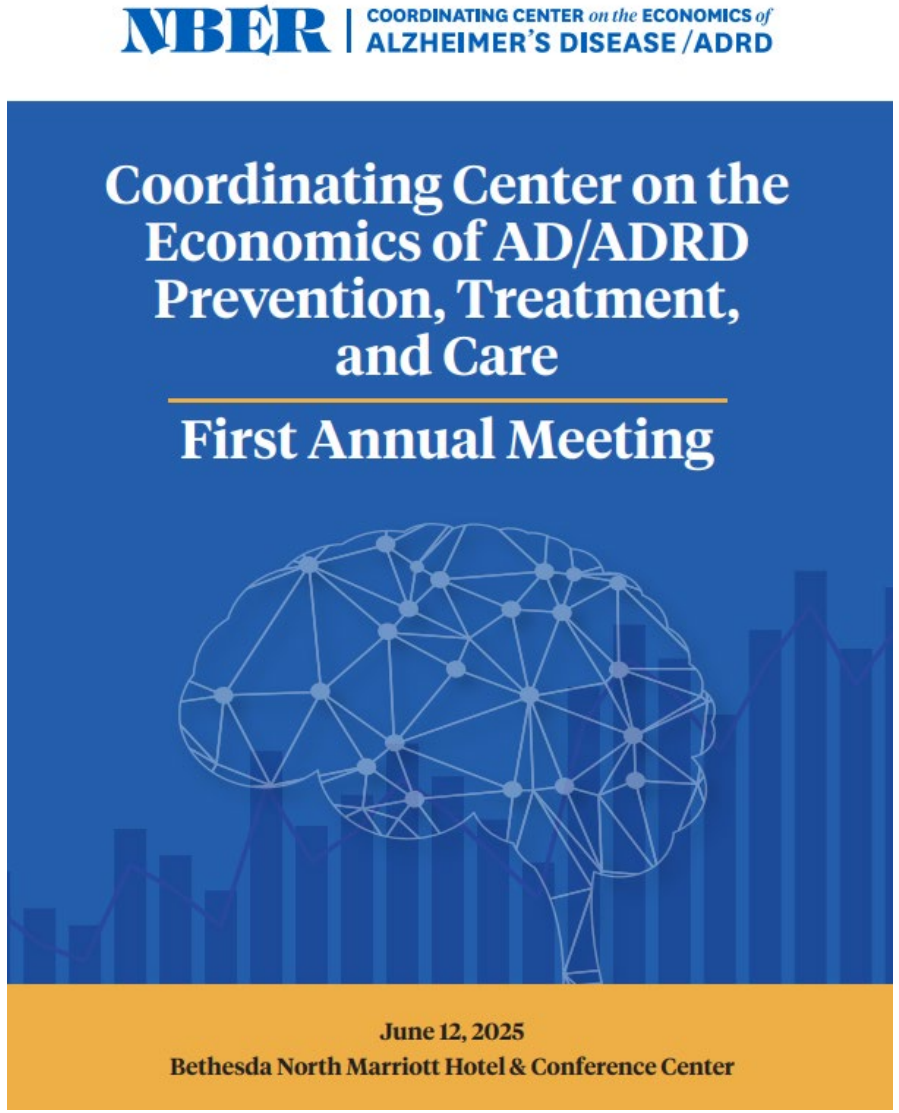
- Establish a ***Center*** to coordinate a network of researchers/projects working towards creating an evidence base for enhancing AD/ADRD prevention, treatment, and care:
  - develop strategic directions for AD/ADRD economic research
  - support new research projects based on strategic directions
  - exploit opportunities for collaboration/synergies across consortium
  - disseminating results to stakeholders

Center Goals

Funded by NIA as part of Consortium for Economic Research on AD/ADRD

- Coordinate research supported by the Consortium (R01| R56) and its initiatives in economics of AD/ADRD
- Expand network of researchers by funding early career grants and annual research project awards
- Engage advisory members from research, industry, and policy communities
- Disseminate findings including through an annual conference and other outreach

NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD



Center & Consortium Overview

What We Do

Consortium Grants

- 5 Larger scale, independently funded, five-year projects (R01/R56 grants)

Center Activities

- Research Project Core

- 5 one-year Research on the Economics of Alzheimer's Disease/Dementia (READ) awards
- 5 two-year Early Career-READ awards

- Translation Core

- Stakeholder Engagement Core

Who We Are

Coordinating Center MPIs

- Rhoda Au (Boston University)
- Julie Bynum (University of Michigan)
- Kathleen McGarry (UCLA)

NBER Team

Rose Li and Associates, Inc.

NIA Collaborators

Orientation to the Day

Schedule in Brief

9:45 Keynote: Courtney Van Houtven

Coffee Break

10:45 NIH Director Comments

11:15 Research Panel – Caregiving/LTC

Lunch

1:20 Research Panel – Medical Care

Coffee Break

2:40 Research Panel – Detection/Causes

3:45 Keynote: Amitabh Chandra

Housekeeping

- Teams and Recording
- Use of Microphones
- Breaks
- Restrooms
- Wi-Fi: MarriottBonvoy_Conference
  - Password: NBER202

Keynote: Caregiving Challenges to Individuals and Families Dealing with Alzheimer's Disease and Related Dementias

Courtney Van Houtven, PhD
Duke University School of Medicine | Duke-Margolis Institute for Health Policy

NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD

Department of Population Health Sciences
Duke University School of Medicine

Duke | MARGOLIS INSTITUTE for Health Policy

Caregiving Challenges to Individuals and Families Facing Alzheimer's Disease and Related Dementias

Courtney Harold Van Houtven, PhD | Professor

Disclosure

Research advisory boards and technical panels:

- U Penn Population and Aging Resource Center
- National Alliance for Caregiving
- NIH-funded project “The United States Cost of Dementia Model” (Zissimopoulos, PI)

Paid consulting:

- NIH-funded planning grant “STepped Exercise Program for Knee Osteoarthritis: The STEP-KOA Study (Allen, PI) (2024)
- National Academy of Sciences, Engineering and Medicine (2023)

Grants:

- National Institutes of Health
- PCORI
- Arnold Ventures
- Rosalynn Carter Institute for Caregivers
- Veterans Affairs

Case Study

Department of Population Health Sciences
Duke University School of Medicine

Aging in Place



- Forcing a conversation to obtain preferences
- Preference to remain at home
- Emotional and logistical tradeoffs

Outline

- Landscape of caregiving for people living with ADRD
- Economics of caregiving
- Directions: Healthcare, research, and policy

Caregiving Landscape

Department of Population Health Sciences
Duke University School of Medicine

Backbone of LTC: Informal Care

- Over **24 million caregivers** provide help to older adults in the U.S.
  - 75-90%+ of older adults in community settings rely on caregivers

- Disproportionate effort for **dementia caregivers**
  - Caregiving most intense to older adults with ADRD in community settings
  - And from spouses or daughters or who live with the care recipient

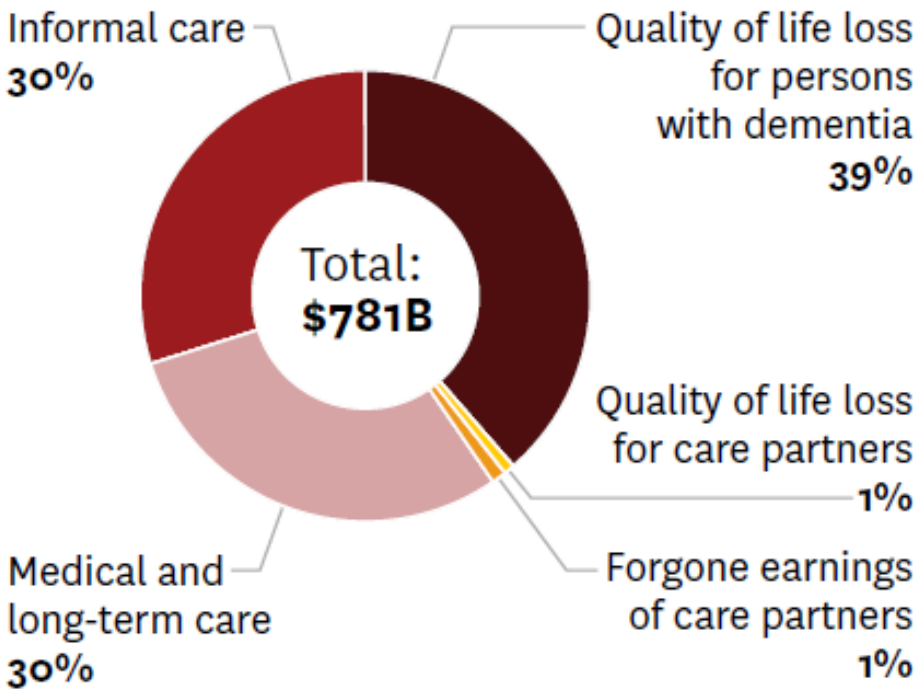
Source: Wolff et al., 2025; Van Houtven et al., 2022.

Economic Burden of Dementia

5.6 million Americans live with dementia

Figure 1: Total Cost of Dementia by Cost Category

Quality of life loss for persons with dementia	$302B
Informal care	$233B
Medical and long-term care	$232B
Forgone earnings of care partners	$8B
Quality of life loss for care partners	$6B
Total:	**$781B**



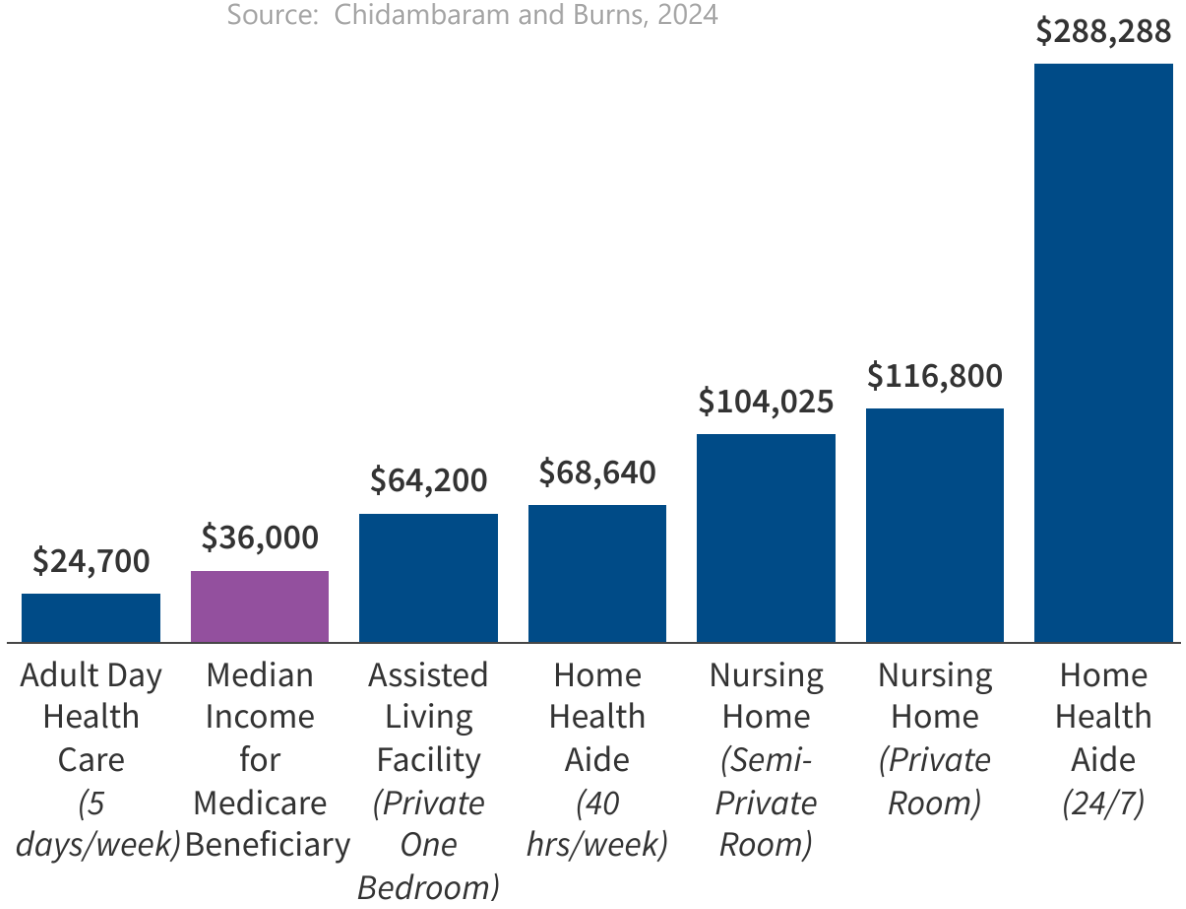
Sources: USC Schaeffer Center for Health Policy & Economics, 2025; Gruber and McGarry, 2023

Insurance Gaps

Long-Term Services and Supports Are Extremely Expensive and Not Generally Covered by Medicare

Annual costs of common long-term services and supports (LTSS) in the US compared with the median income for a Medicare beneficiary, 2023

Source: Chidambaram and Burns, 2024

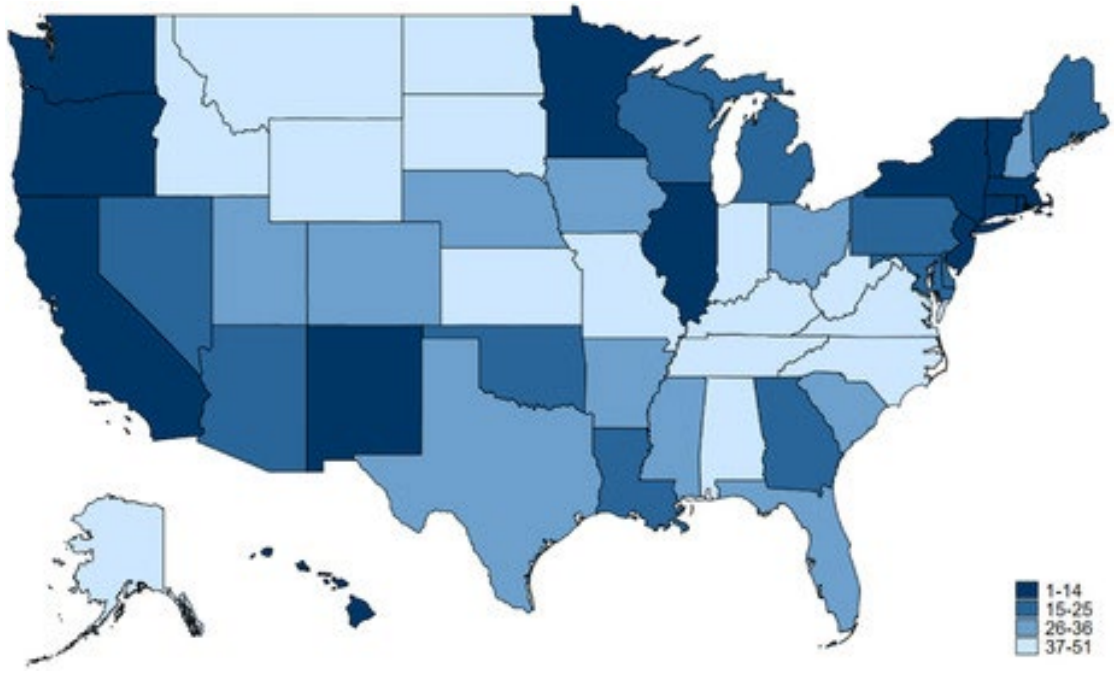


- <20% older adults have LTC insurance
  - Medicaid: 10%
  - Private LTC insurance: 10%
  - VA: 1%

Policy Context: Few Supports for Caregivers in U.S.

- Minimal federal policies
  - Older Americans Act – funds caregiver trainings for caregivers of older adults
  - "Credit for Caring" – non-refundable tax credit introduced in Congress March 11, 2025
  - RAISE Act National Caregiver Strategy

State ranking: Alignment with RAISE ACT Recommendations, 2022

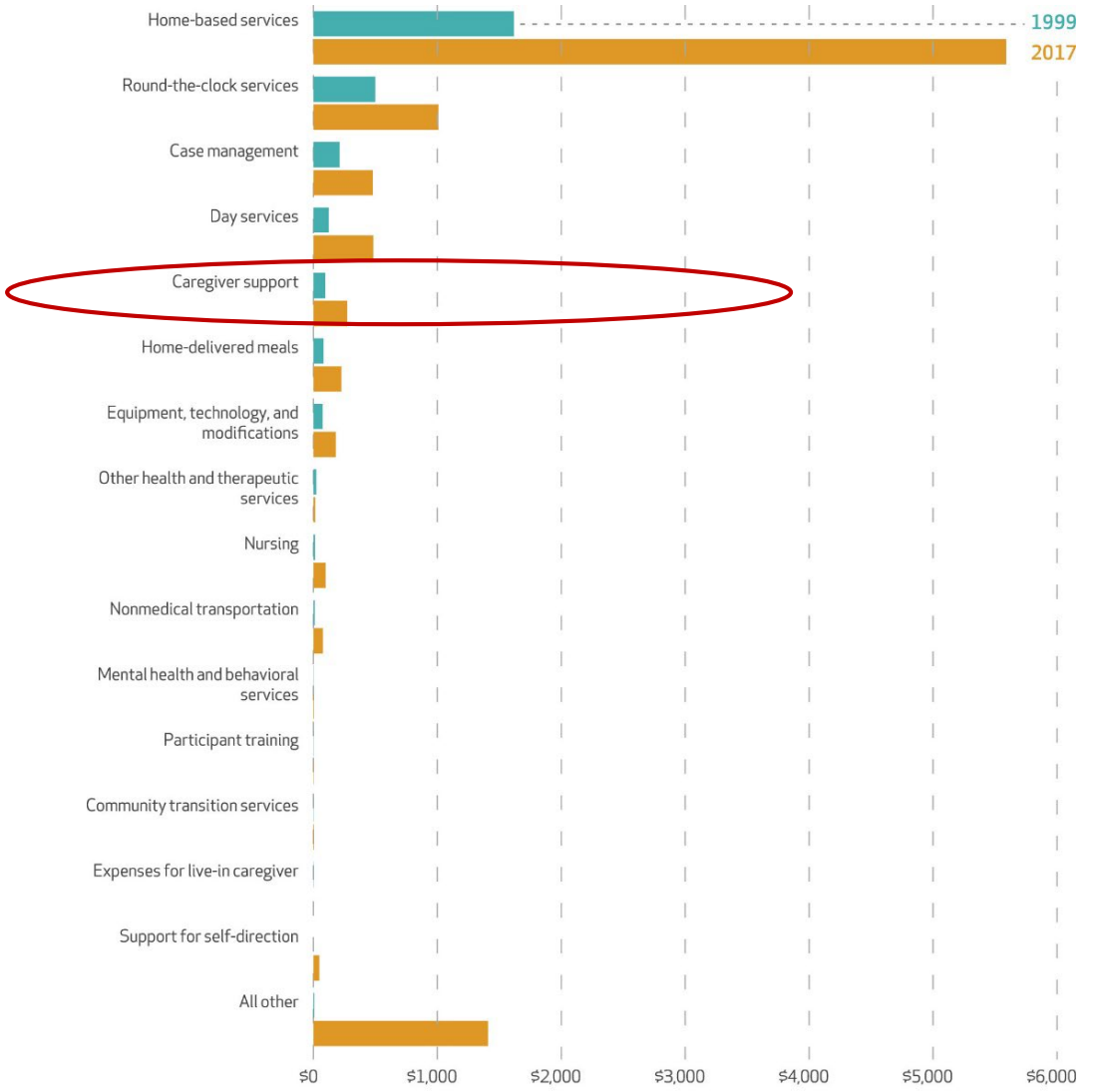


Source: Miller, KEM et al., 2022

Policy Context: Few Supports for Caregivers in U.S.

- Medicaid waivers - support for caregivers growing but remains relatively small

- Indirect policies
  - ACA-Medicaid Expansion
  - State paid leave
  - Tax laws (EITC)
  - Disability Policy
  - Retirement Policy
  - Labor Policy (predictive scheduling laws)

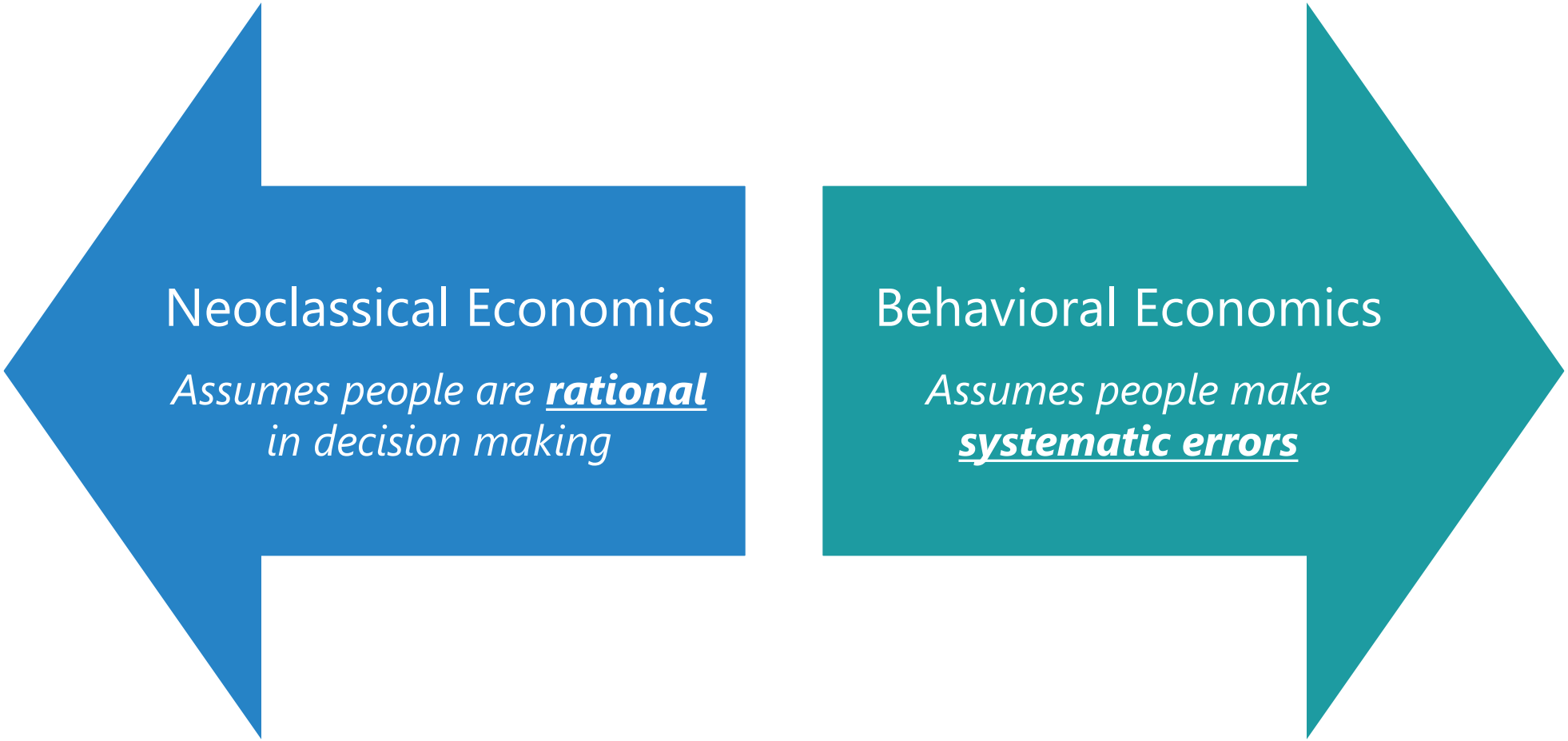


Source: Skira et al, 2022

Economic Theory and Family Caregiving

Department of Population Health Sciences
Duke University School of Medicine

Economic Frameworks for Informal Care



Neoclassical Economics and Caregiving

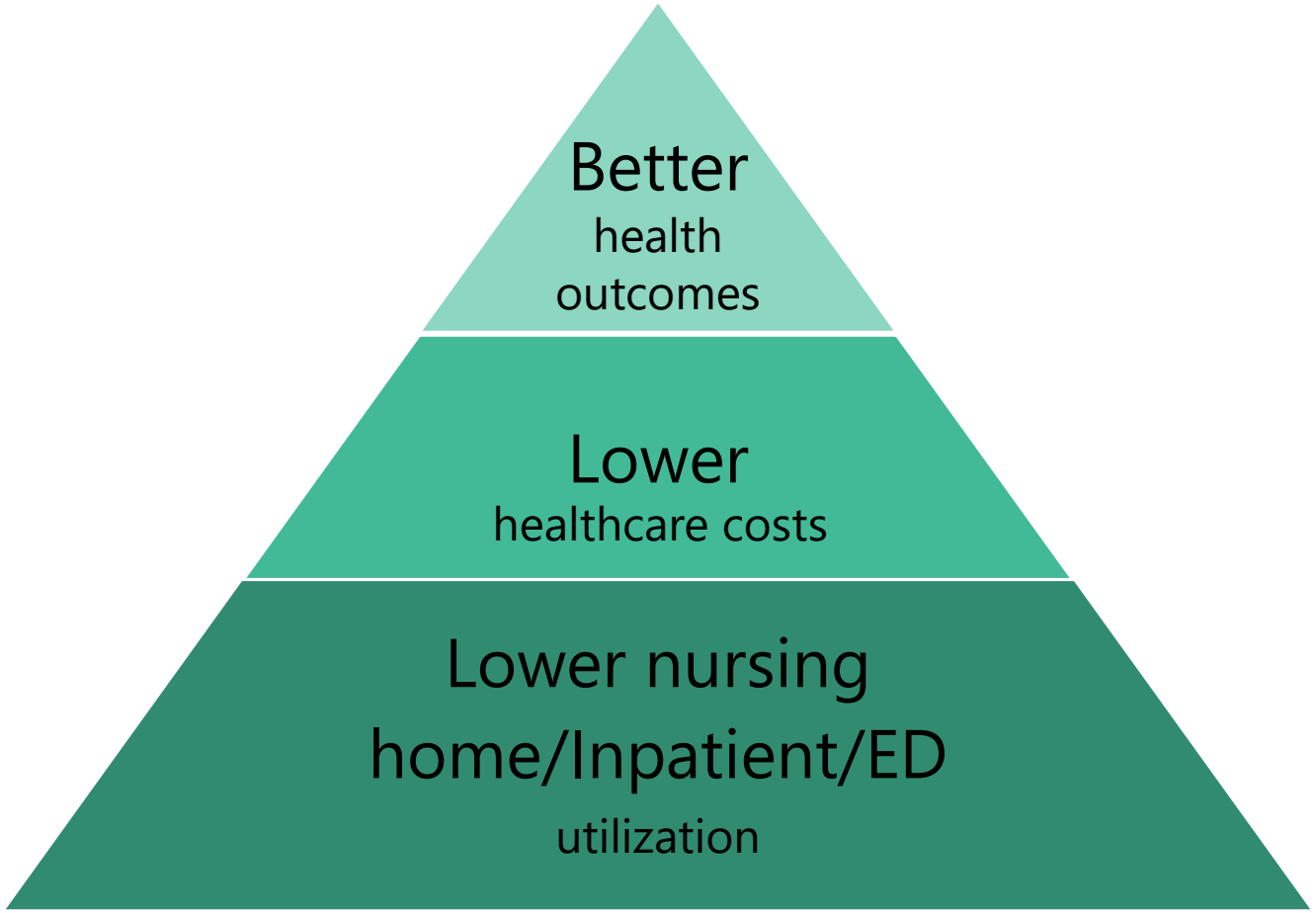
Utility Maximization of parent and child

- Household production model for adult children
  - Child **incorporates health of parent (h*t)** into her utility maximization problem (Becker) and consumption, leisure, and informal care choices, faces budget constraint
- Grossman (1972) model on demand for health for parents
  - Parent makes investment in health – including choice of medical care, M, subject to budget and health investment constraint
  - Parent **takes informal care as given** (a part of M)
  - Assume different return on investment for different decisions about M
    - Added value of different types of M unknown and depends on preferences, quality

Result: Informal care and parent's health care use are co-produced

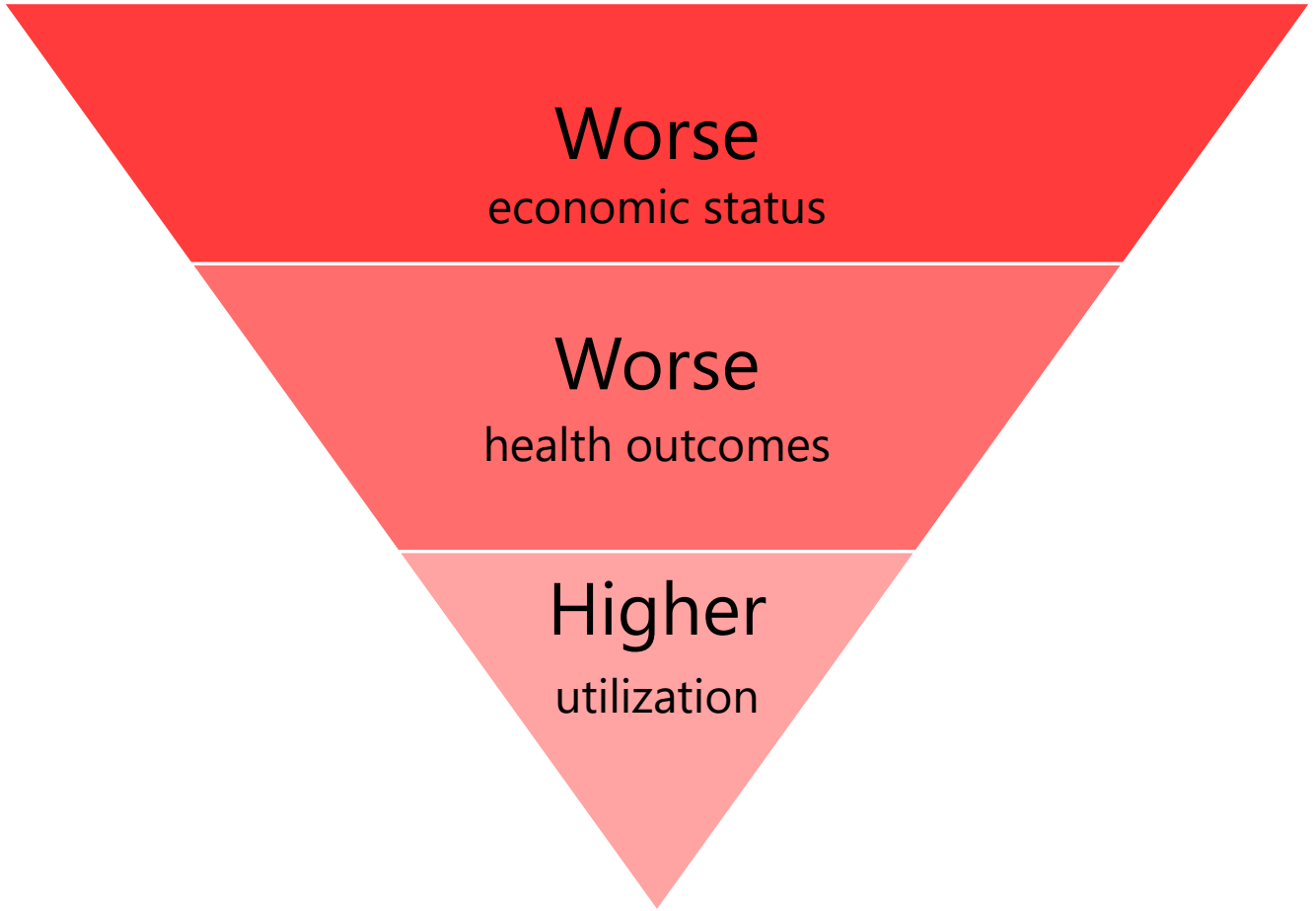
Sources: Van Houtven, 2000; Van Houtven and Norton JHE 2004

What is Broken? Effects on Care Recipients



Sources: Jacobs et al., 2024; Van Houtven and Norton, 2004, 2005; Coe et al., 2019

What is Broken? Effects on Caregivers



Sources: Van Houtven, Coe, Skira 2013; Fahle and McGarry, 2017; Maestas, Messel, Truskinovsky, 2023; Jacobs et al.,; Coe and Van Houtven, 2009; Coe et al., 2018; Kolodziej et al, 2022, ETC

What is Broken, cont?

Constraints on Learning and Choice (Asymmetric information)

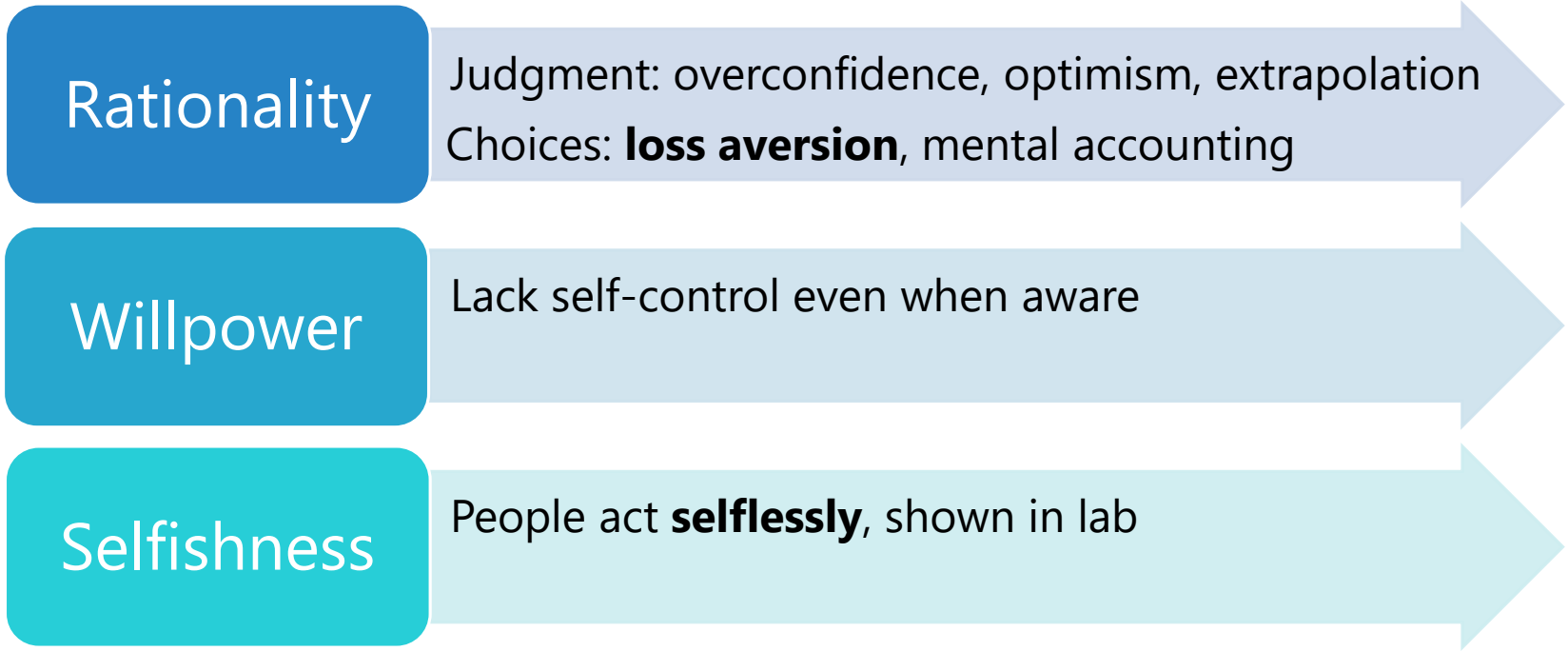
- Initial: Lack of alternatives
- Over time:
  - Older workers may not be able to re-enter work
  - Injury may be fleeting or long-term
- Duration uncertainty: affects spend down, when to trigger a LTC insurance policy
- Externalities: Co-workers, neighbors

How should preferences be weighted?

- Dynamic preferences and cognitive decline
- Ethical and emotional tensions for many reasons
- Autonomy vs. Safety Tradeoffs

Behavioral Economics and Caregiving

"The standard economic model of human behavior includes three unrealistic traits—unbounded rationality, unbounded willpower, and unbounded selfishness—all of which behavioral economics modifies."



Source: Thaler and Mullainathan, 2008

So What is Broken?

Behavioral failures in LTC planning

Why don't families plan?

- Before dementia: Present bias, ambiguity aversion, ostrich effect
- With dementia: Present bias

- Denial, complexity, planning a luxury

Changing sense of self

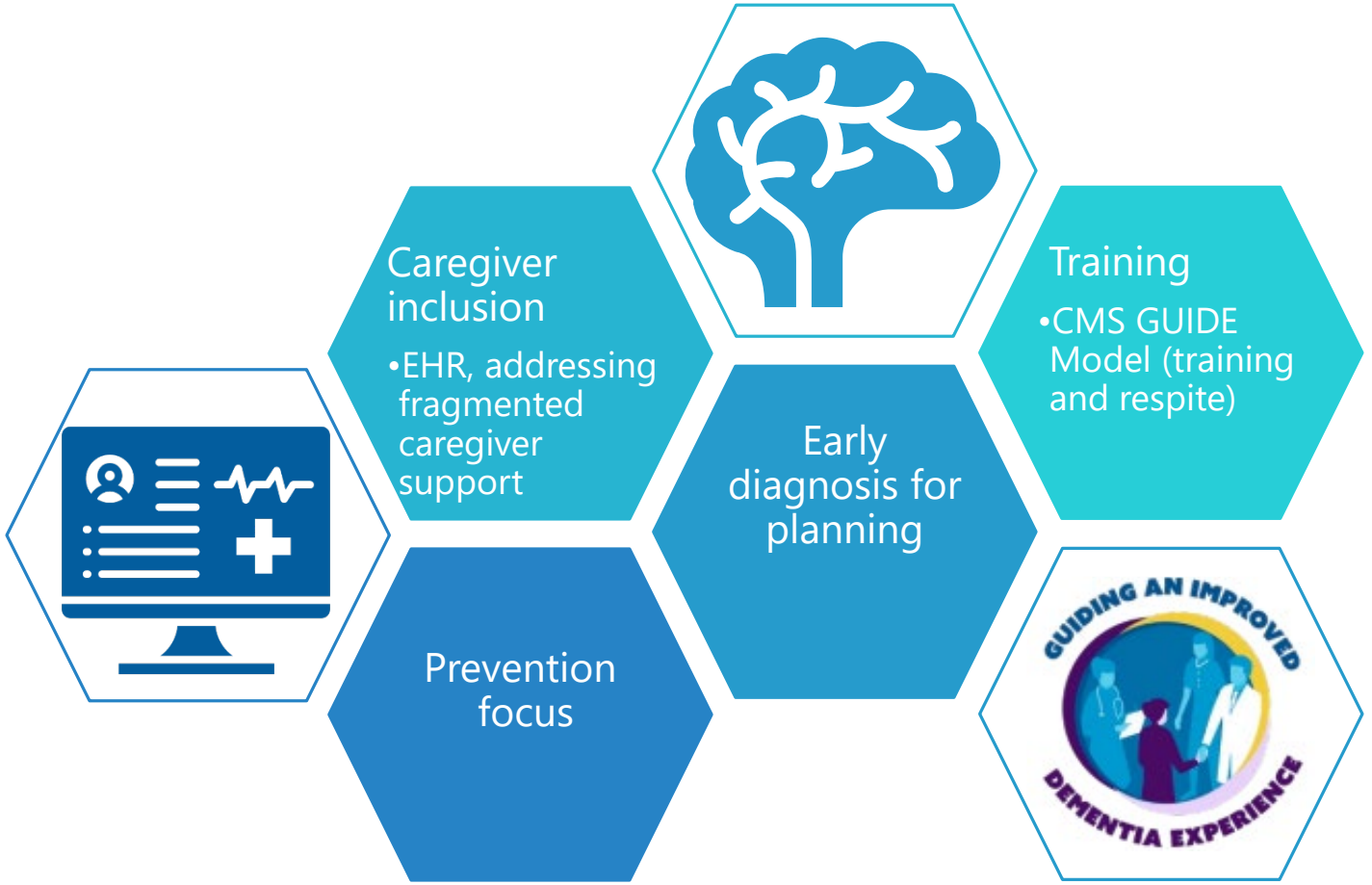
- Disconnect between intentions and actions
- Principle-agent theory
  - How to represent preferences of PLWD? And one's own?

Directions:
How can we minimize losses and maximize gains to caregivers?

Department of Population Health Sciences
Duke University School of Medicine

Healthcare System Role

- Early diagnosis for optimal planning, management
  - value of information exists even in absence of effective treatments
- Invest in standardized means of identifying caregivers in EHR
  - Include in healthcare team
  - Expand effective trainings



Source: Couch et al., 2022

Researcher's Role to Inform Policy

- **Build theoretical models** that better incorporate the interdependence of caregiver and care recipient utility and uniqueness of dementia
  - Anguish to caregivers, lack of choice, and tradeoffs understudied
  - Emotional toll of conflicting preferences, dynamic preferences
  - Utility weights…how to incorporate utility of the healthy spouse
    - Whose preferences matter most?
  - How can behavioral economics principles be applied in dementia care and caregiving interventions/policies

Researcher's Role to Inform Policy, cont.

- Caregiver policies still scant. Must study **spillovers:**



HCBS as a Caregiver Support Policy

Study 1: Holding private LTC insurance

Private LTCI helps **potential** caregivers whether the adult child ultimately becomes a caregiver or not

Adult children of parents invoked to buy LTCI due to state price subsidies on policies were no more likely to become a caregiver but more likely to work full time and not live with parent(s).

Source: Coe et al., 2023;; Shen et al, 2024

HCBS as a Caregiver Support Policy

Study 2: Causal effect of family care, formal care, or combination of both

Care team matters for care recipient outcomes
Receiving **both formal and family care** better for both physical and mental health of older adults with care needs, compared to only receiving family care. Receiving formal care only does not affect care recipient outcomes compared to receiving family care only.

Source: Coe et al., 2025

Future Directions: Keep digging into HCBS questions

- **What is the right mix of home care team?**
- Why does the care team matter? Task specialization? Preserving family caregiver health?
  - Why might it not? Too many unmet needs? No net gain hours of care?
- What are the monetary and shadow costs and benefits of these components and how do they vary by care provider?
- States moving to expand paying family in Medicaid waivers
  - Family involvement benefits care recipients but **how about caregivers**?
- Considering both "benefit and cost" and "family preferences" perspectives will truly assess value of HCBS investment in "aging in place" initiatives

Sources: Coe et al., 2019; Coe et al., 2025

Future Directions: Use International Lessons

- Learn from other countries who have more generous LTC benefits

  Gateway to Global Aging Project (Lee, Knapp) aims to enable causal research on public LTC policies



  - Tracked LTC benefits 1992-2025 in 25 U.S. States and over 16 European countries
  - Massive variation in coverage and generosity
    - In-kind benefits, cash benefits, 24-hour care benefits, service vouchers
- What are these systems' effects on care recipients and caregivers? Which ones are most effective in Europe?
- Apply eligibility criteria to U.S. case to identify best way to expand U.S. LTC benefits

https://g2aging.org

Future Directions: Include Full Caregiver Effects in LTC Policy Reform Models

Example: Medicare for All proposal. Home care to 15 million beneficiaries at cost of $4 billion. Cost of the proposed bill ***did not include a single caregiver cost****.*

- Incorporating caregiver spillovers would more accurately project the societal benefits and costs of LTC policy proposals
- Such information vital to policy makers, who strive to have a complete calculation of LTC policy choices on public budgets, the LTC workforce, health systems, and health outcomes
  - Specific applications: What does a given policy that centers "aging in place" (e.g., GUIDE model) really mean to the costs of LTC?

Source: Goda and Van Houtven, 2025; Konetzka, 2014

Closing

Case Study: Aging in Place

7 years after the LTC discussion: dementia

- Dad's preferences changed as dementia changed him
- Diabetes and dementia don't go well together

Then falls increased, cascade of ED visits

- Brother on constant call, difficult to find new job
- I flew in every 6 weeks

February: home hospice, paid home care

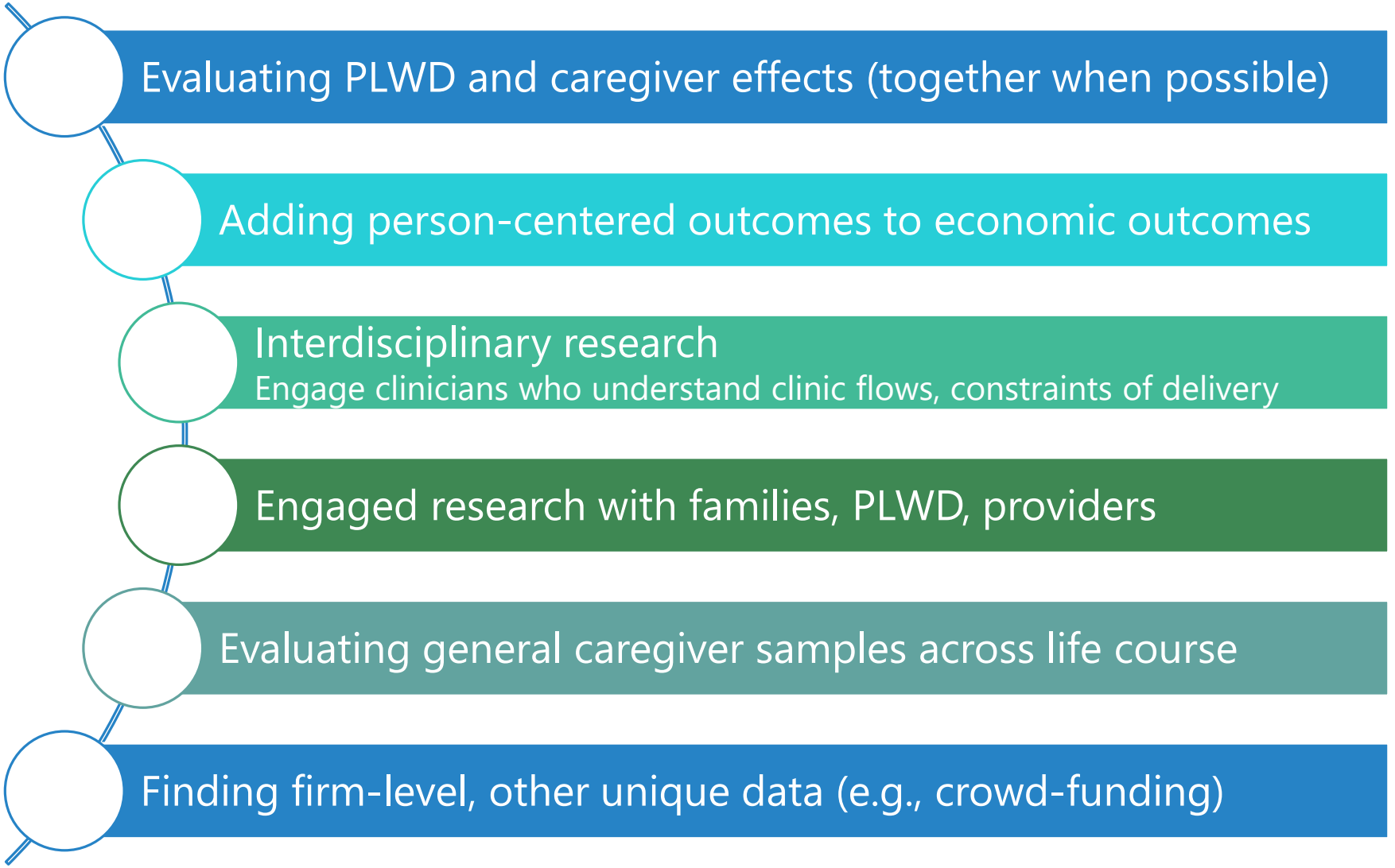
- He hated it anew every single time an aide arrived

Mid-May: final fall, died 10 days later in a home-like hospice.



Directions for Caregiving in ADRD Economics Research

Build evidence through:





Thank You!

courtney.vanhoutven@duke.edu
Bluesky: @chvanhoutven

Acknowledgements

- Edward Norton
- Norma Coe
- Meghan Skira
- Tamara Konetzka
- Gopi Shah Goda
- Jing Guo
- Jennifer Wolff
- Josephine Jacobs
- Katherine Miller
- Kasey Decosimo
- Paul Dennis
- Valerie A. Smith
- Susan N. Hastings
- Nina Sperber
- Megan Shepherd-Banigan
- Brystana Kaufman
- Ingo Kolodziej
- Wenhan Zhang
- Nathan Boucher
- Judith Vick
- Caroline Sloan
- Cara McDermott
- Ngoc Dao
- Yang Wang
- David Knapp
- Jinkook Lee

This work was supported by a grant from the National Institute on Aging [1RF1AG072364-01].

Selected References

- Wolff JL, Cornman JC, Freedman VA. The Number Of Family Caregivers Helping Older US Adults Increased From 18 Million To 24 Million, 2011-22 [published correction appears in Health Aff (Millwood). 2025 Mar;44(3):373. doi: 10.1377/hlthaff.2025.00186.]. *Health Aff (Millwood)*. 2025;44(2):187-195.
- Van Houtven CH, Konetzka RT, Taggert E, Coe NB. Informal And Formal Home Care For Older Adults With Disabilities Increased, 2004-16. Health Aff (Millwood). 2020 Aug;39(8):1297-1301. doi: 10.1377/hlthaff.2019.01800. Erratum in: Health Aff (Millwood). 2022 Sep;41(9):1357.
- The Cost of Dementia in 2025. United States Cost of Dementia Research Team, USC Schaeffer Center for Health Policy & Economics. Available at: https://schaeffer.usc.edu/research/the-cost-of-dementia-in-2025/
- Gruber J and McGarry K. Long-term Care in the United States. National Bureau of Economic Research., Nov. 2023. doi: 0.3386/w31881
- Chidambaram P and Burns A. 10 Things About Long-Term Services and Supports (LTSS). Kaiser Family Foundation, July 8, 2024. Available at: https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/.
- Reaves EL, Musumeci M. Medicaid and Long-Term Services and Supports: A Primer. 2015. March 20, 2023. https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/
- Cohen R, Cha A, Terlizzi E, Martinez M. Demographic variation in health insurance coverage: United States, 2019. 2021. National Health Statistics Reports.
- Goda G, Van Houtven CH. Expanding in-home care coverage is a needed evolution of Medicare. 2024. Brookings Institute. Available at: https://www.brookings.edu/articles/expanding-in-home-care-coverage-is-a-needed-evolution-of-medicare/
- Miller KEM, Stearns SC, Van Houtven CH, Gilleskie D, Holmes GM, Kent EE. The Landscape of State Policies Supporting Family Caregivers as Aligned With the National Academy of Medicine Recommendations. Milbank Q. 2022;100(3):854-878.
- Skira MM, Wang S, Konetzka RT. Trends In Medicaid Home And Community-Based Services Waivers For Older Adults. Health Aff (Millwood). 2022 Aug;41(8):1176-1181.
- Jacobs JC, Lo J, Van Houtven CH, Wagner TH. The impact of informal caregiving on U.S. Veterans Health Administration utilization and expenditures. Soc Sci Med. 2024 Mar;344:116625. doi: 10.1016/j.socscimed.2024.116625. Epub 2024 Jan 24. PMID: 38324974.
- Van Houtven CH, Norton EC. Informal care and health care use of older adults. J Health Econ. 2004 Nov;23(6):1159-80. doi: 10.1016/j.jhealeco.2004.04.008. PMID: 15556241.
- Coe NB, Guo J, Konetzka RT, Van Houtven CH. What is the marginal benefit of payment-induced family care? Impact on Medicaid spending and health of care recipients. Health Econ. 2019 May;28(5):678-692. doi: 10.1002/hec.3873. Epub 2019 Mar 18. PMID: 30887623; PMCID: PMC6528172.
- Coe NB, Skira MM, Larson EB. A Comprehensive Measure of the Costs of Caring for a Parent: Differences According to Functional Status. J Am Geriatr Soc. 2018 Oct;66(10):2003-2008. doi: 10.1111/jgs.15552. Epub 2018 Sep 17.
- Richard H. Thaler and Sendhil Mullainathan. "Behavioral Economics." The Concise Encyclopedia of Economics. 2008. Library of Economics and Liberty. Available at: http://www.econlib.org/library/Enc/BehavioralEconomics.html
- Couch E, Belanger E, Gadbois EA, DePasquale N, Zhang W, Wetle T. "I know that my role is going to change": a mixed-methods study of the relationship between amyloid-β PET scan results and caregiver burden. Aging Clin Exp Res. 2023 Feb;35(2):387-397. doi: 10.1007/s40520-022-02314-6. Epub 2022 Dec 9. PMID: 36484946; PMCID: PMC9735001.
- Centers for Medicare and Medicaid Services. Guiding an Improved Dementia Experience (GUIDE) Model. Available at: https://www.cms.gov/priorities/innovation/innovation-models/guide
- Dennis PA, Stechuchak KM, Van Houtven CH, Decosimo K, Coffman CJ, Grubber JM, Lindquist JH, Sperber NR, Hastings SN, Shepherd-Banigan M, Kaufman BG, Smith VA. Informing a home time measure reflective of quality of life: A data driven investigation of time frames and settings of health care utilization. Health Serv Res. 2023 Dec;58(6):1233-1244. doi: 10.1111/1475-6773.14196.
- Van Houtven CH, Stechuchak KM, Dennis PA, Decosimo K, Whitfield CL, Sperber NR, Hastings SN, Shepherd-Banigan M, Kaufman BG, Smith VA. Is more care recipient time at home also a family caregiver-centered quality of life measure? J Am Geriatr Soc. 2024 Oct;72(10):3098-3108. doi: 10.1111/jgs.19115. Epub 2024 Aug 13.
- Coe NB, Goda GS, Van Houtven CH. Family spillovers and long-term care insurance. J Health Econ. 2023 Jul;90:102781. doi: 10.1016/j.jhealeco.2023.102781. Epub 2023 Jun 12.
- Coe NB, Sun C, Van Houtven CH, Basu A, Konetzka RT. Home-Based Care Outcomes: Does the Care Provider Matter?. Health Econ. Published online April 28, 2025. doi:10.1002/hec.4972
- Konetzka RT. The hidden costs of rebalancing long-term care. Health Serv Res. 2014 Jun;49(3):771-7. doi: 10.1111/1475-6773.12190. PMID: 24831192; PMCID: PMC4231570.

Questions?

Coming Up at 10:45 AM

NIH Director Comments

NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD

Comments from the NIH Director

Jay Bhattacharya, MD, PhD

The NBER Coordinating Center on the Economics of Alzheimer's Disease / ADRD
is funded by the National Institute on Aging, part of the National Institutes of Health

Coming Up at 11:15 AM

Research Panel 1: The Economics of Caregiving for People Living with Alzheimer's Disease

Research Panel 1: The Economics of Caregiving for People Living with Alzheimer's Disease

NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD

Long Term Care in the United States and Around the World:

Caring for those with Low Cognition

Gopi Shah Goda, Brian McGarry, Kathleen McGarry, James Gluzman

*We gratefully acknowledge financial support from the National Institute on Aging, part of the National Institutes of Health.

The NBER Coordinating Center on the Economics of Alzheimer's Disease / ADRD is
funded by the National Institute on Aging, part of the National Institutes of Health

Overview of International Long-Term Care Project

- Take a collection of developed countries with similar problems and different systems – what can we learn from each other after standardizing measurement and analysis approaches?

- Countries: Canada*, Denmark, England, Germany, Italy, Japan, Netherlands, Singapore, Spain, United States

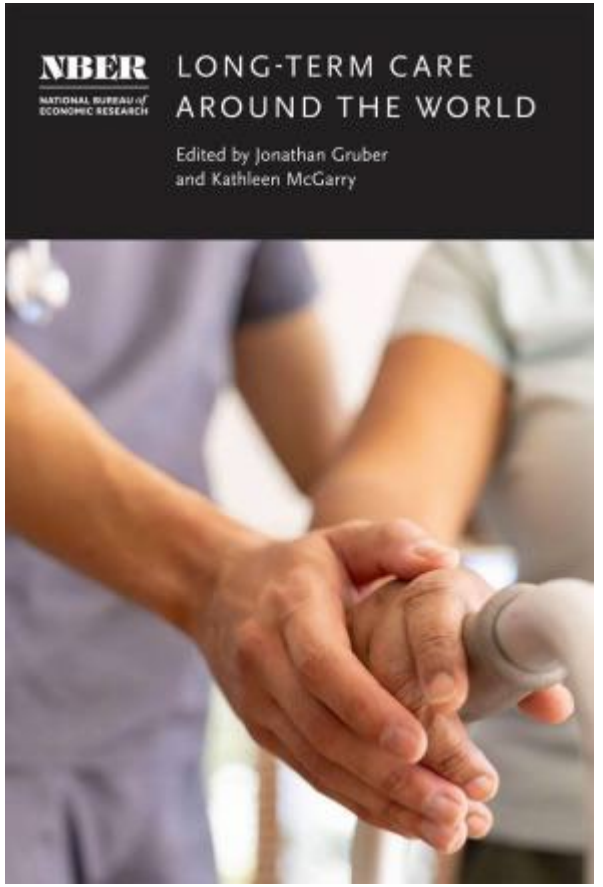
- Modeled after the successful NBER International Social Security Project

* Canada in Round 1 but not in Round 2

Round 1: Long-Term Care Around the World

- Summarized landscape of each country's LTC program
  - Population dynamics and aging
  - Public coverage programs – eligibility, types of services covered
  - Funding mechanisms

- Costs of care
  - Total costs as fraction of GDP
  - By funding source (public vs. private) and type of service (home care vs. nursing home care)
  - Informal care – relative prevalence and measurement of costs



Round 2: Care for Populations with Low Cognition

- Prevalence of low cognition and overlap with inability to perform ADLs
  - Attempt to identify those with cognitive scores low enough that care/supervision might be required
  - Based on scores on cognitive battery relative to an absolute threshold, rather than diagnoses of dementia
- Care receipt and costs by type for population with low cognition relative to other groups
- With some exceptions, similar source of data from HRS and sister surveys (ELSA, SHARE)
  - Attempt to use pooled data in 5-year period before Covid-19 pandemic (e.g. HRS 2016 and 2018 waves); some countries used post-pandemic data and some went back further in time

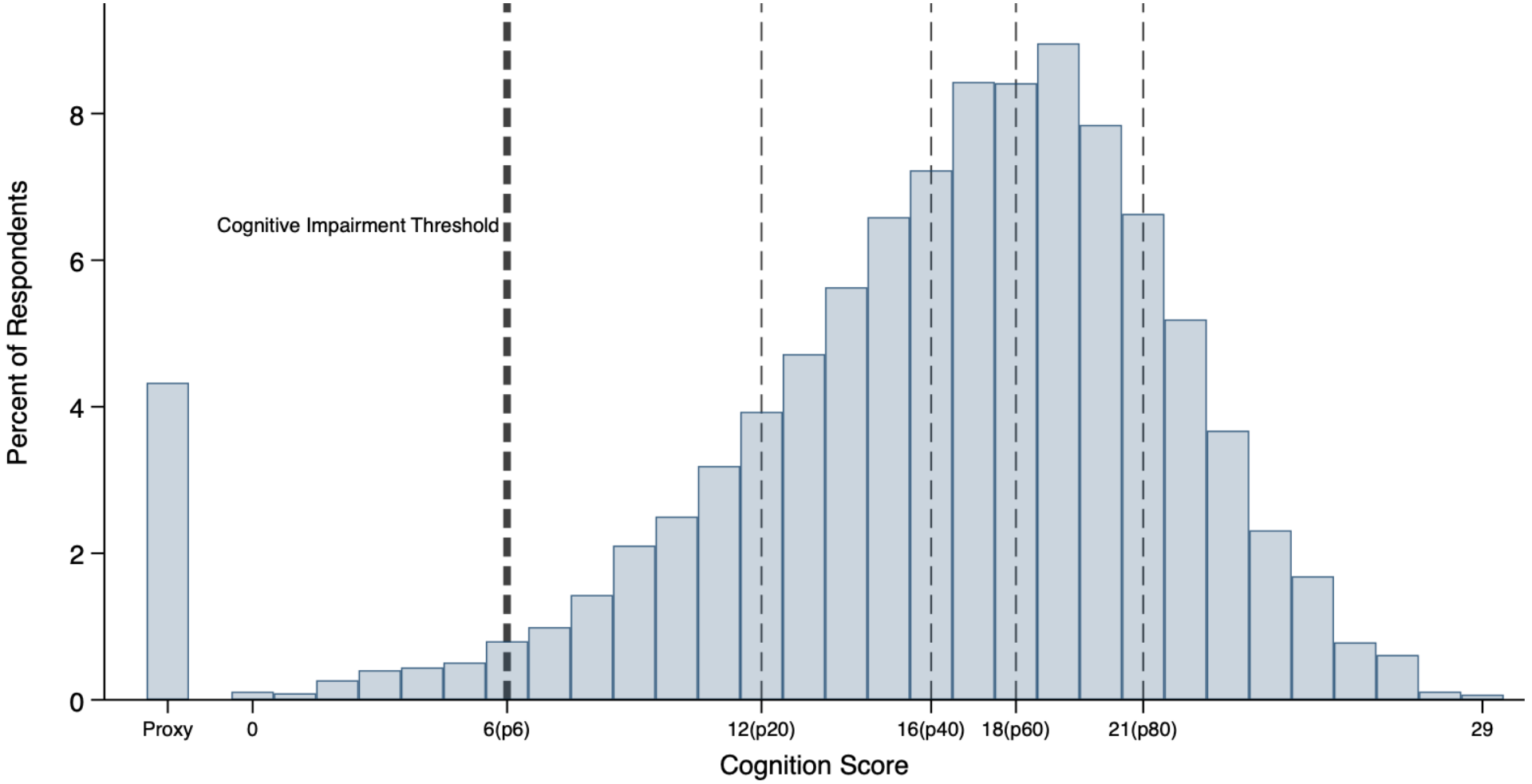
Measuring Cognition with Survey Data

- Assess cognition using survey questions that are generally comparable across countries (components of MMSE)
  - Used: Serial 7s, immediate and delayed word recall, date naming
  - Available in HRS but not used for comparability: self-rated memory, numeracy, animal naming, quantitative number series

- Threshold for low cognition: score of 6 or lower (out of 29)

- Proxy respondents – classify as low cognition based on reason for proxy interview

Distribution of Cognitive Scores (U.S.)



NBER | COORDINATING CENTER on the ECONOMICS of ALZHEIMER'S DISEASE /ADRD

Notes: 2016 and 2018 HRS, ages 65+, using sample weights that include nursing home residents.

Presence of ADLs among Population with Low Cognition (U.S.)

	Cognition Scores 0-6 and Proxy (low cognition)	Cognition Scores 7+ and Proxy (other)	Total
0-1 ADLs	2.88%	84.80%	87.68%
2+ ADLs	3.91%	8.41%	12.32%
Total	6.79%	93.21%	100.00%

Notes: 2016 and 2018 HRS, ages 65+, using sample weights that include nursing home residents.

57% of those with low cognition also have 2+ ADL limitations

Distribution of Costs by Impairment (U.S.)

	0 - 1 ADLs & Score 7+	2+ ADLs & Score 7+	Low Cognition Score 0 - 6	Total
		Formal Care		
Total (Billions $)	13.5	29.2	49.79	92.49
Per capita ($)	344	6,922	16,206	1,985
		Informal Care		
Total (Billions $)	65	32.5	47.3	144.8
Per capita ($)	1,654	7,704	15,396	3,108
		Nursing Home		
Total (Billions $)	24.3	24.9	73	122.2
Per capita ($)	618	5,902	23,761	2,623
		Total Costs		
Total (Billions $)	102.8	86.6	160.09	359.49
Per capita ($)	2,616	20,528	52,108	7,717
N	14,887	1,757	1,475	18,119
Population (millions)	39.3	4.2	3.1	46.6

NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD

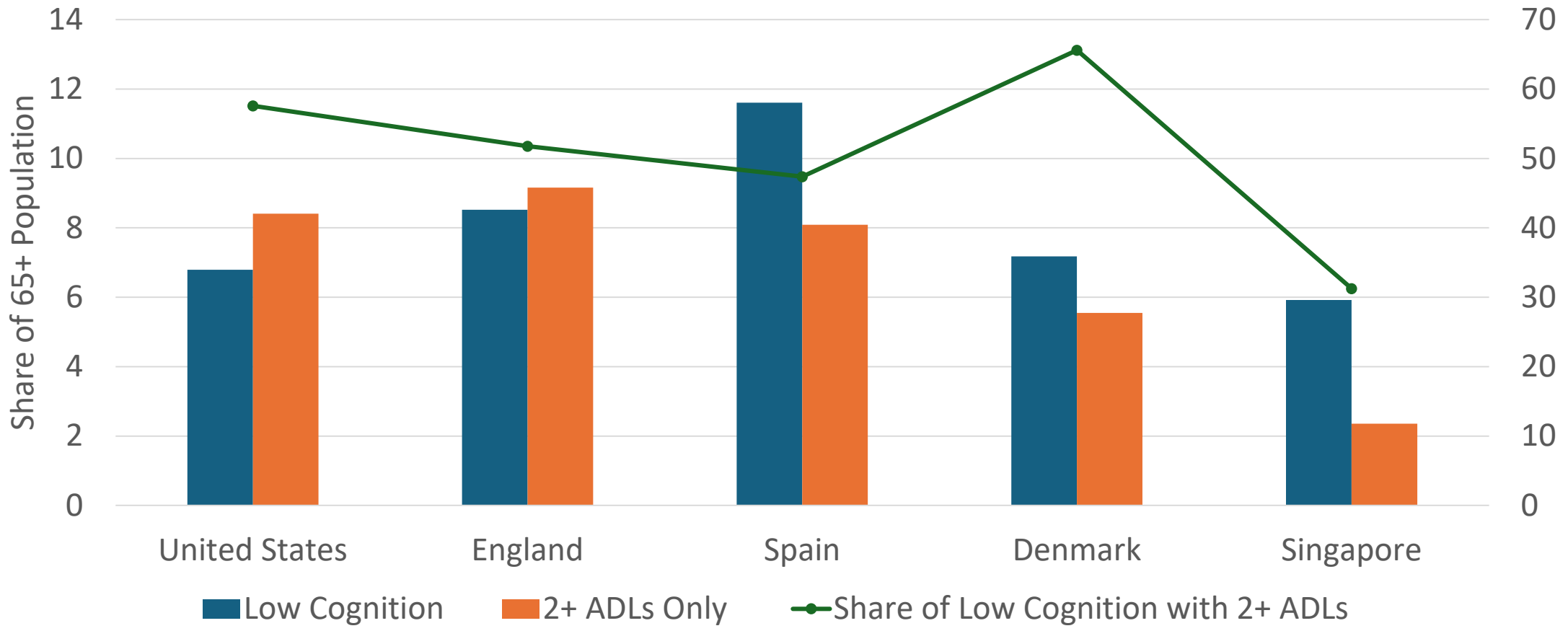
Notes: 2016 and 2018 HRS, ages 65+, using sample weights that include nursing home residents.

Additional Findings

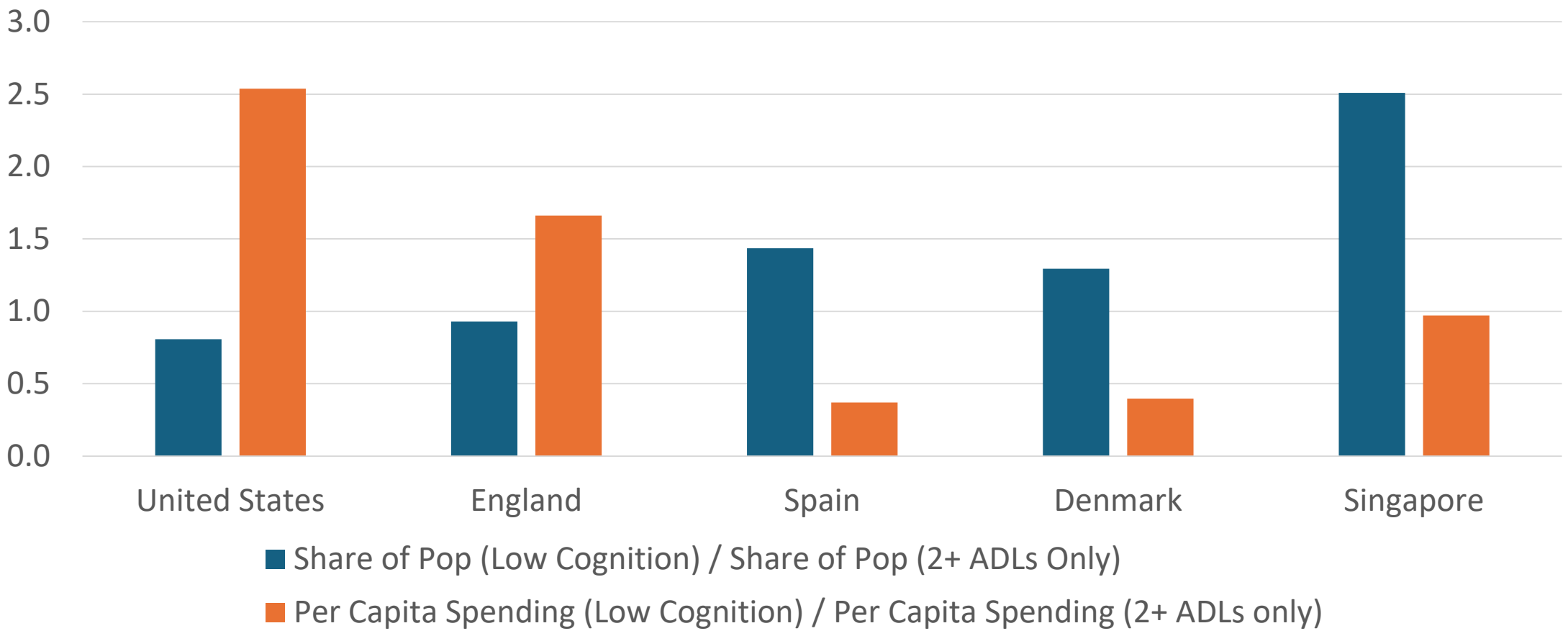
- Consistently strong relationship between low cognition and care utilization after controlling for age and demographic factors
  - Unpaid and paid care: low cognition associated with smaller increase in care than ADLs alone on extensive margin; bigger increase on intensive margin
  - NH care: low cognition associated with much larger increase in care on extensive margin

- Medicaid coverage associated with higher paid home care/nursing home care, less unpaid care

Presence of Low Cognition and 2+ ADLs



Spending on Low Cognition Relative to Spending on Population with 2+ ADLs



Thank you!

Market Changes in the Stability of Home Health Care Services:
Evidence of Minimum Wage Eligibility and Overtime Protections

Katherine E. M. Miller, PhD [a, b, c]
Liisa T. Laine, PhD [a, b, d]
Norma B. Coe, PhD [a, b]

a. Department of Medical Ethics & Health Policy, University of Pennsylvania
b. Leonard Davis Institute of Health Economics, University of Pennsylvania
c. Center of Innovation to Accelerate Discovery and Practice Transformation, Durham VA Health Care System
d. Wharton School, University of Pennsylvania

Background



Background



Background



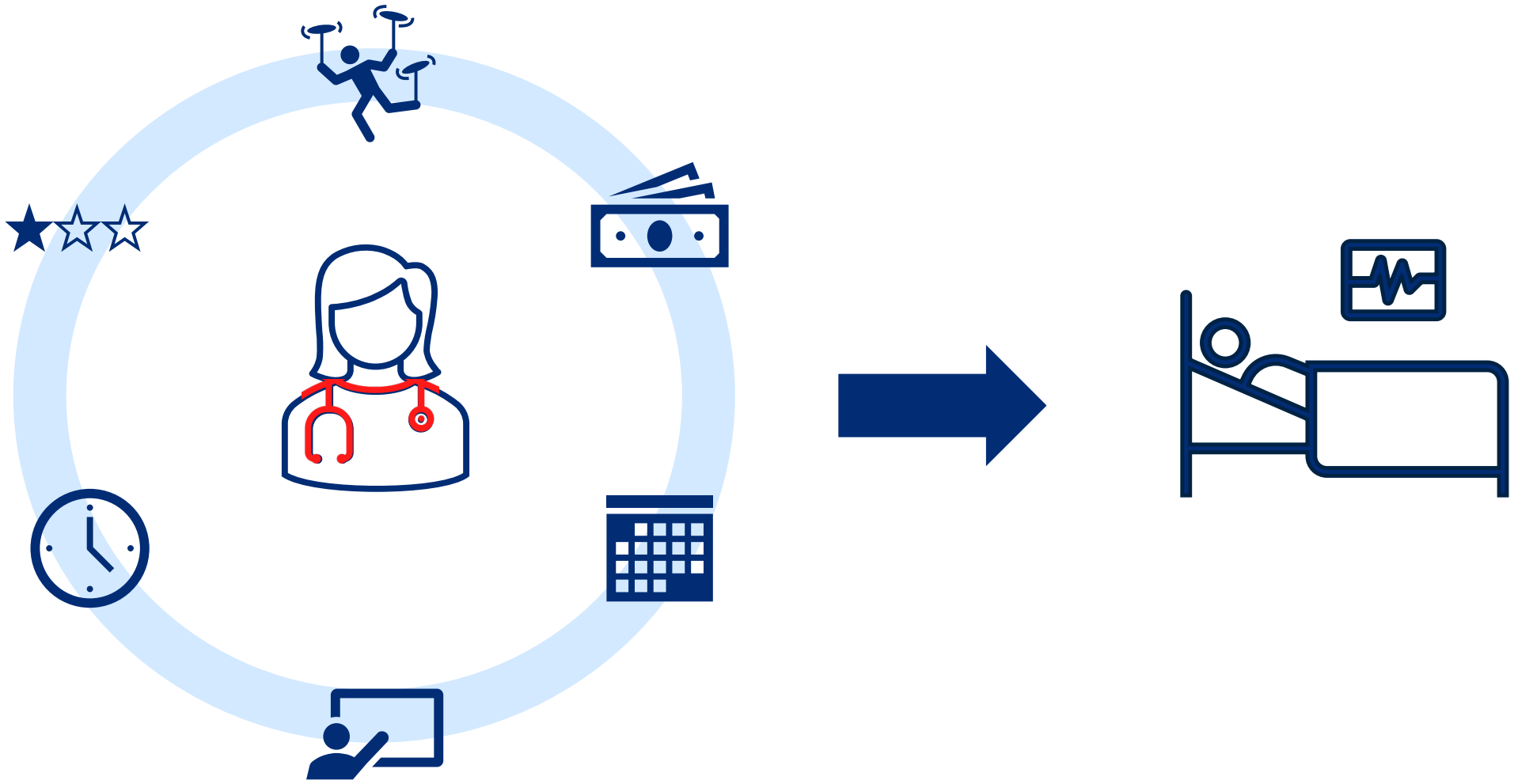
Background



Background

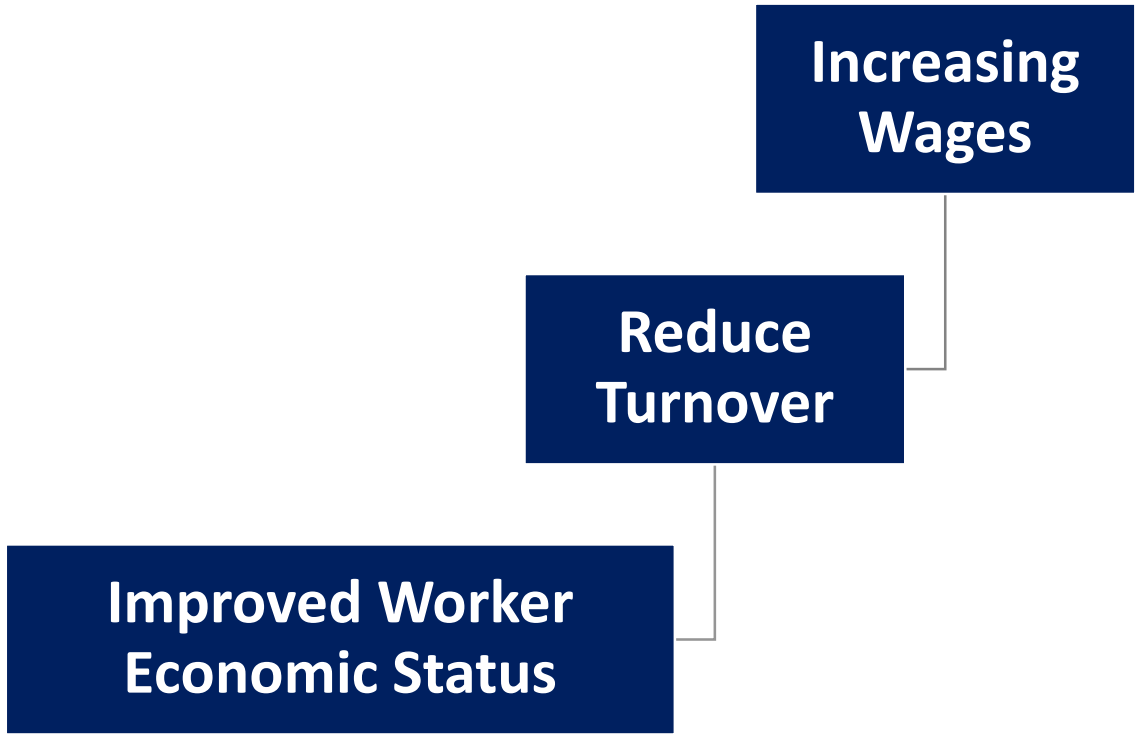


Background



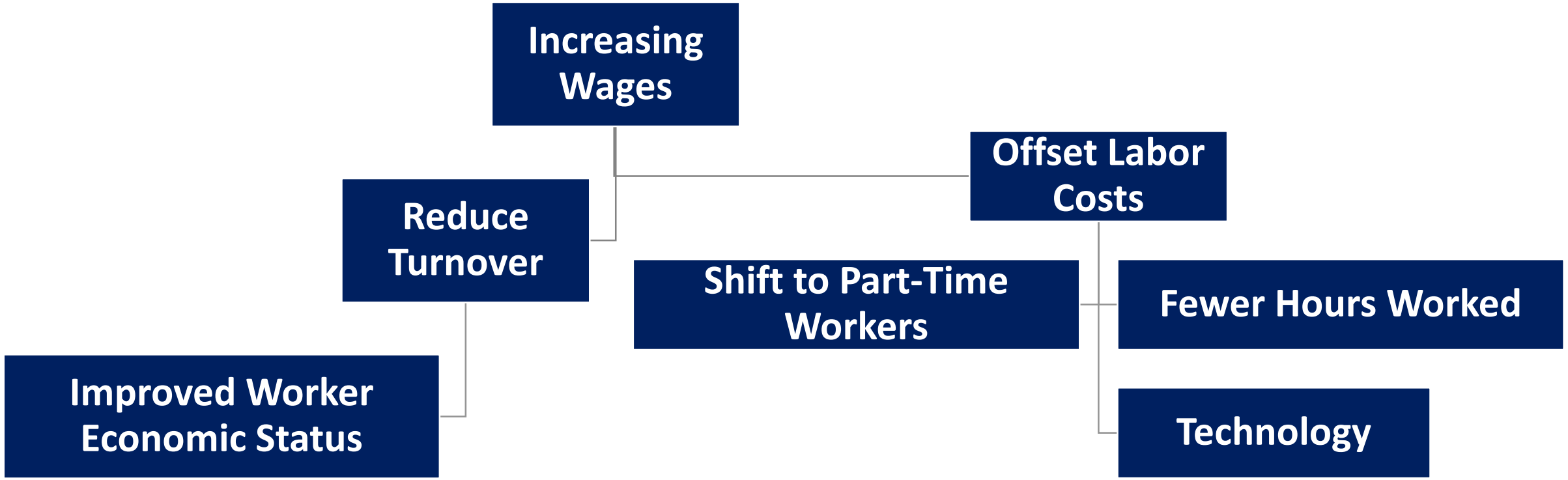
Background

- Minimum Wage Increases:



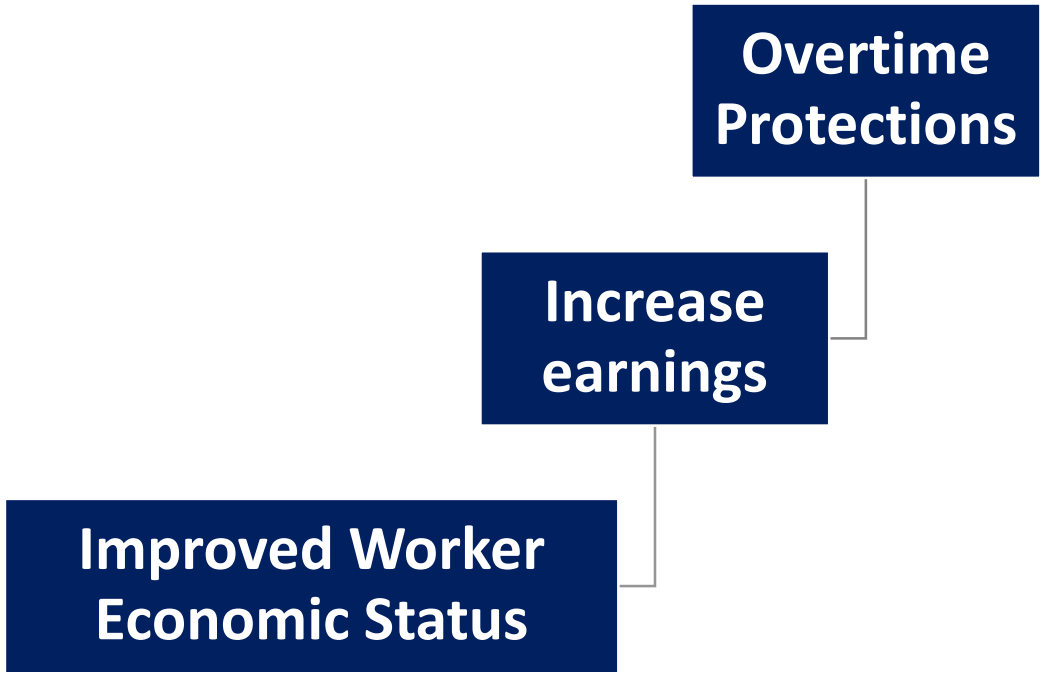
Background

- Minimum Wage Increases:



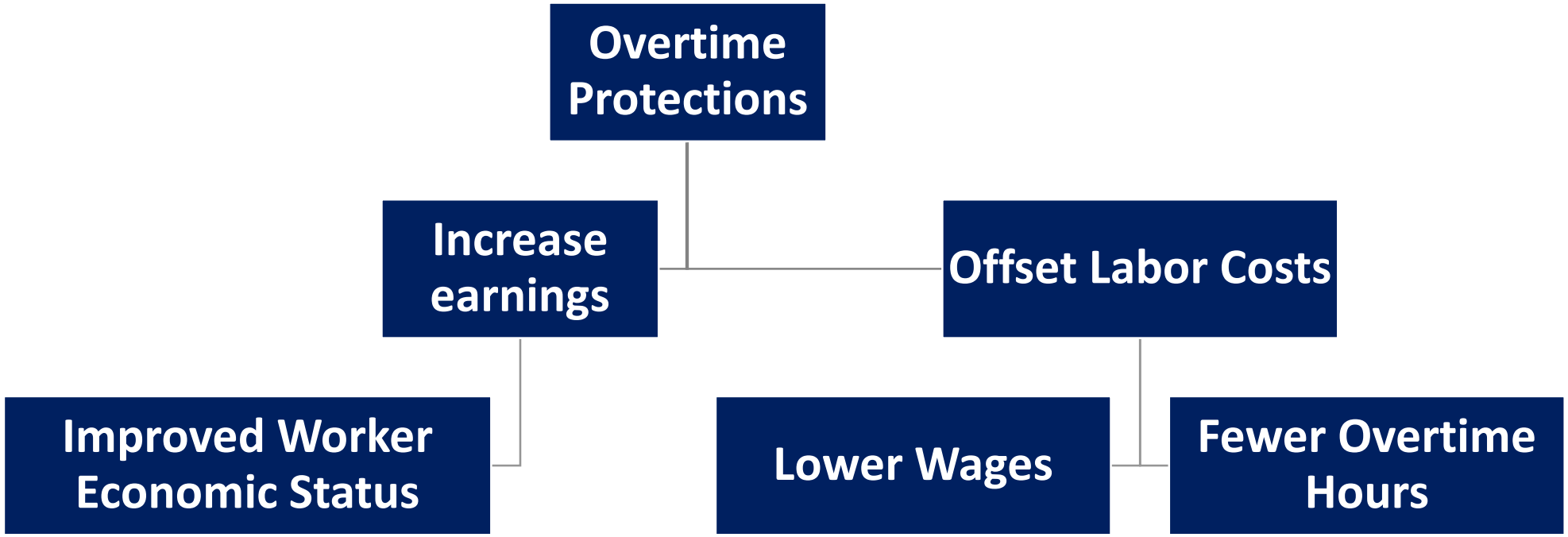
Background

- Overtime Protections:



Background

- Overtime Protections:



Background

- Minimum Wage Increases
  - Higher weekly earnings among low-wage workers
  - Fewer layoffs and separations
  - Negative employment effects
    - Reduced hiring

Neumark, David, and Shirley, Peter. 2022. "Myth or measurement: What does the new minimum wage research say about minimum wages and job loss in the United States?" Industrial Relations 61: 384– 417. https://doi.org/10.1111/irel.12306

Jardim, E., M. C. Long, R. Plotnick, E. van Inwegen, J. Vigdor, and H. Wething (2022, May). Minimum-wage increases and low-wage employment: Evidence from seattle. American Economic Journal: Economic Policy 14 (2), 263–314.

Dube, A., T. W. Lester, and M. Reich (2010). Minimum wage effects across state borders: Estimates using contiguous counties. The Review of Economics and Statistics 92 (4), 945–964

Portugal, P. and A. R. Cardoso (2006, 09). Disentangling the Minimum Wage Puzzle: An Analysis of Worker Accessions and Separations. Journal of the European Economic Association 4 (5), 988–1013

Ruffini, Krista, Worker Earnings, Service Quality, and Firm Profitability: Evidence from Nursing Homes and Minimum Wage Reforms (October 1, 2022). Review of Economics and Statistics, Forthcoming, Available at SSRN: https://ssrn.com/abstract=3830657 or http://dx.doi.org/10.2139/ssrn.3830657

Background

- Minimum Wage Increases
  - Higher weekly earnings among low-wage workers
  - Fewer layoffs and separations
  - Negative employment effects
    - Reduced hiring

- Overtime Protections
  - Decreased overtime hours
  - Decreased wage rates
  - Ambiguous effect on total earnings

Brown, Hamermesh. Wages and Hours Laws: What Do We Know? What Can Be Done? RSF: The Russell Sage Foundation Journal of the Social Sciences. 2019-01-01 2019;5(5):68. doi:10.7758/rsf.2019.5.5.04
Barkume A. The Structure of Labor Costs with Overtime Work in U.S. Jobs. ILR Review. 2010-10-01 2010;64(1):128-142. doi:10.1177/001979391006400106
Hamermesh, D. S. and S. J. Trejo (2000). The demand for hours of labor: Direct evidence from
california. The Review of Economics and Statistics 82 (1), 38–47.

Background: Fair Labor Standards Act – 2015 Home Care Worker Final Rule

- January 1, 2015, home care workers became eligible for minimum wage and overtime pay protections
  - Home care workers are defined as home health aides, personal care attendant, certified nursing assistant (CNA), provider, or caregiver.

Background: Fair Labor Standards Act – 2015 Home Care Worker Final Rule

- January 1, 2015, home care workers became eligible for minimum wage and overtime pay protections
  - Home care workers are defined as home health aides, personal care attendant, certified nursing assistant (CNA), provider, or caregiver.

- Department of Labor's Wage and Hour Division
  - January 1 to June 30, 2015
  - July 1, 2015 to December 31, 2015

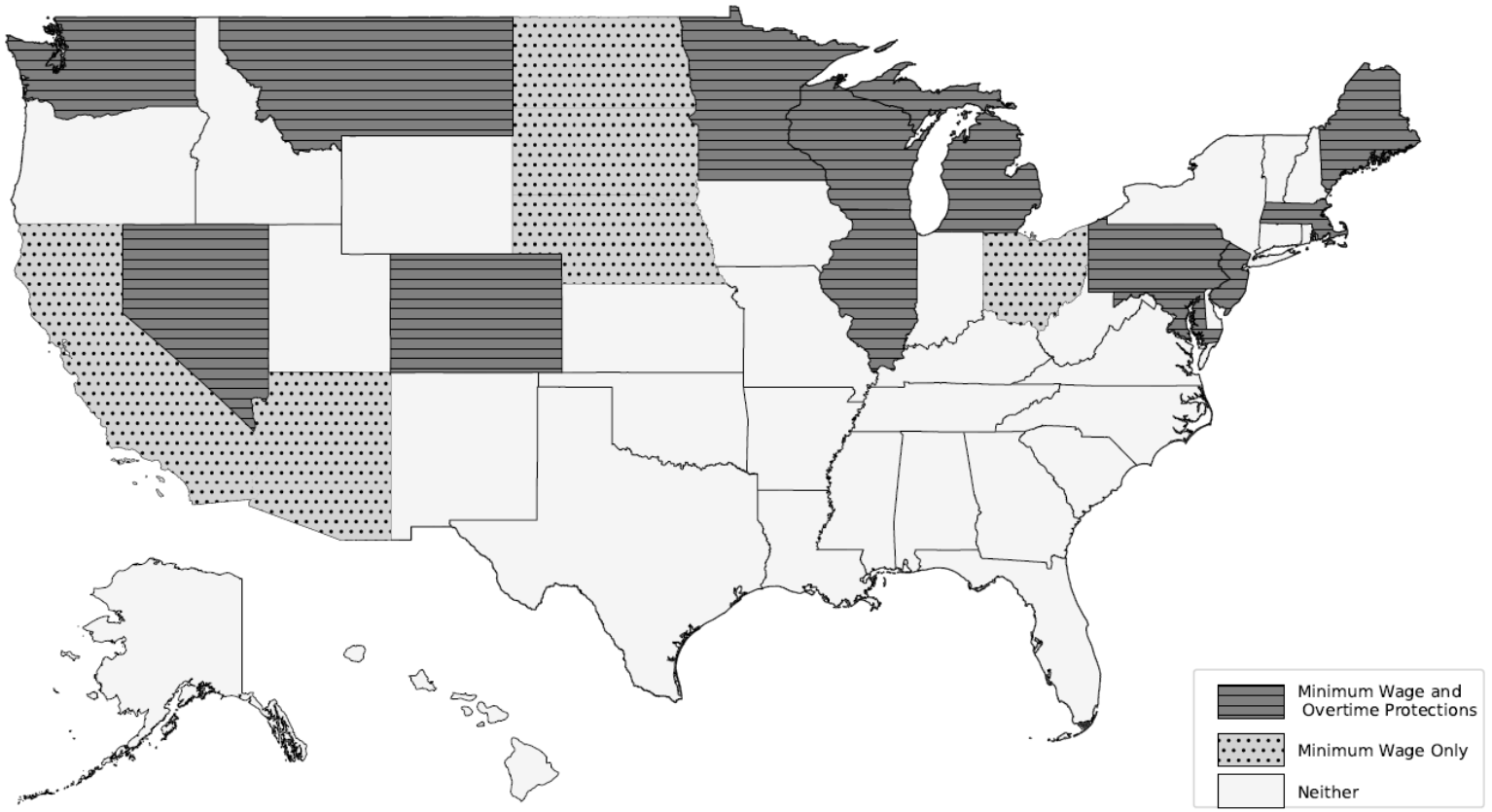
Research Objective

- To examine the effect of the minimum wage eligibility and overtime protections on home health and personal care aide turnover rates.

- To examine the effect of the minimum wage eligibility and overtime protections on home health and personal care aide distribution of hours worked and overall income.

Background: State-level Employee Protections

- State-level Expansion of minimum wage and overtime protections to direct care workers



Empirical Approach

Data Sources

- Quarterly Workforce Indicators, 2013-2018
  - County-level turnover rates per quarter per year, 2013-2018

Data Sources

- Quarterly Workforce Indicators, 2013-2018
  - County-level turnover rates per quarter per year, 2013-2018

- Area Health Resource File
  - Total population estimate
  - Estimated population aged 65 or older
  - Rural-Urban Continuum Code (2013)
  - Percent of fee-for-service Medicare beneficiaries with Medicare Advantage
  - Percent of the population living in poverty
  - Unemployment rate
  - Percent of 18–64-year-old adults without health insurance

Data Sources

Primary Analysis

- Quarterly Workforce Indicators, 2013-2018
  - County-level turnover rates per quarter per year
- Area Health Resource File
  - Total population estimate
  - Estimated population aged 65 or older
  - Rural-Urban Continuum Code (2013)
  - Percent of fee-for-service Medicare beneficiaries with Medicare Advantage
  - Percent of the population living in poverty
  - Unemployment rate
  - Percent of 18–64-year-old adults without health insurance

Secondary Analysis

- American Community Survey, 2013-2018
  - Worker occupation and industry
  - Individual-level demographic characteristics
  - Geographical region indicators

Sample

Treatment

- Women with a high school level of education working in the home health care industry

Comparisons

- Workers with a high school level of education working in the animal slaughtering and processing industry **(upper bound)**
- Women with a high school level of education working in the child day care industry **(lower bound)**

Empirical Strategy

- Event-study Difference-in-Difference Approach

$$(1) \qquad Y_{qtcs} = \sum_k \beta_k \mathbb{I}[t - E_c = k] + \beta W'_{tcs} + \gamma_t + \delta_q + \lambda_c + \epsilon_{ct}$$

Y_{qtcs} = turnover rate at each quarter (q) in each year (t) for each county (c) in state (s)

W'_{tcs} = vector of time-varying county-level controls (percent of population 65+, Medicare Advantage penetration, percent in poverty, unemployment rate, percent of 18–64-year-old adults without health insurance) for each year t (2013-2018) for county c in state s.

γ_t = vector of year t fixed-effects

δ_q = quarter-of-the-year fixed effects to control for cyclical trends (i.e., 1st quarter, 2nd quarter, 3rd quarter, or 4th quarter)

λ_c = industry-specific, county-level fixed effects to control for time-invariant, county-specific differences within each industry

Empirical Strategy: Worker Outcomes

- Difference-in-Difference Approach

$$(1) \qquad Y_{it} = \beta_1 Post'_t + \beta_2 Treatment_i + \beta_3 (Post'_t \, x \, Treatment_i) + \beta_4 W'_{it} + \epsilon_{ct}$$

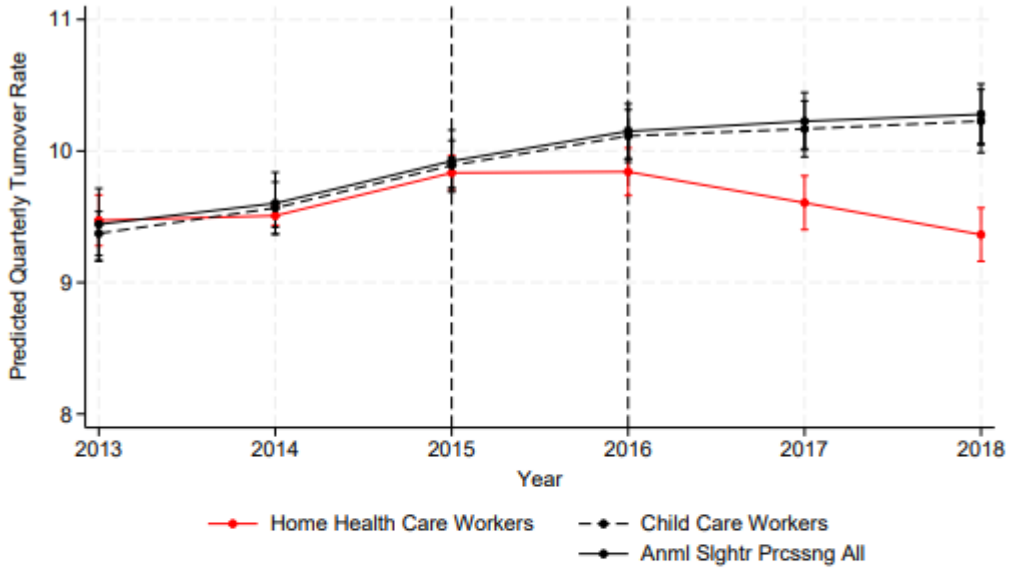
  - Y_{it} = worked multiple jobs, worked any overtime, wages for person i at time t.
  - $Post'_t$ = vector of an indicator for year t = 2015 and an indicator for years t = 2016-2018.
  - $Treatment_i$ = indicator of treatment group for person i
  - W'_{it} = vector of individual level controls (age, sex, race, ethnicity, marital status, geographic region, years since Medicaid expansion).

Results

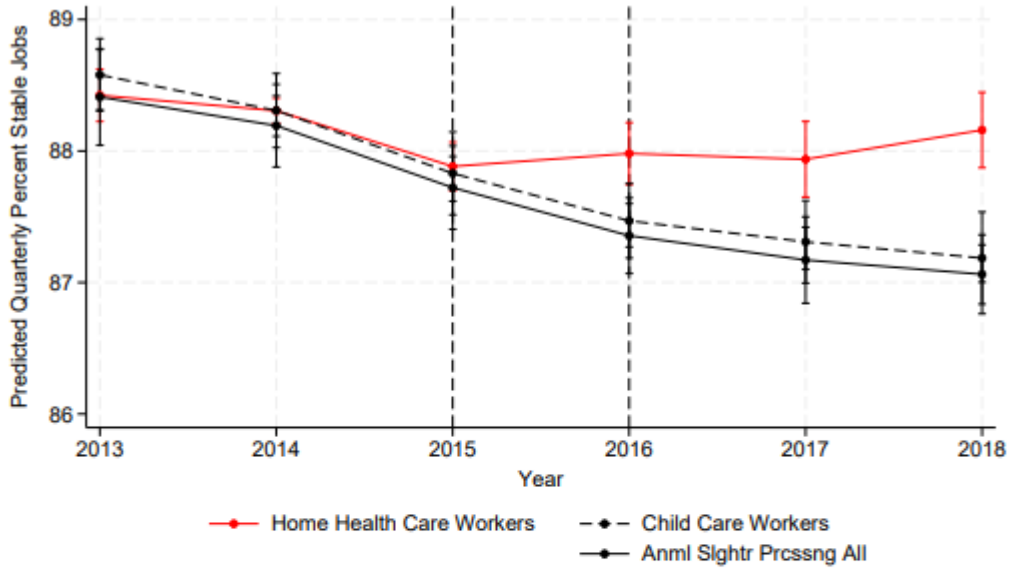
Descriptive Statistics: County Characteristics

	Home Health Care (N=2228)	Child Day Care (N=1532)	Animal Slaughtering and Processing (N=236)
Turnover Rate, mean (SD)	11.04 (2.83)	9.47 (2.44)	5.94 (2.55)
Percent of Stable Workers, mean (SD)	87.04 (3.77)	88.21 (3.78)	92.17 (3.84)
Employed Workers, mean (SD)	367.15 (800.15)	259.56 (296.49)	258.29 (144.25)
Number of Home Health Agencies, mean (SD)	17.57 (56.82)	23.51 (67.66)	33.69 (127.06)
Percent of Medicare Advantage Penetration Enrollees, mean (SD)	27.54 (13.14)	29.97 (13.51)	21.39 (12.42)
Unemployment Rate, 16+, mean (SD)	6.15 (1.57)	5.85 (1.42)	5.63 (1.60)
Percent of the Population 65+, mean (SD)	15.15 (3.79)	13.81 (3.38)	14.93 (2.98)
Percent Persons in Poverty, mean (SD)	16.17 (5.74)	14.52 (5.70)	17.70 (6.40)
Percent of Persons Aged 18-64 without Health Insurance, mean (SD)	16.95 (6.54)	15.61 (6.20)	19.77 (6.07)
Rural-Urban Continuum Code 2013, mean (SD)	2.35 (1.48)	1.62 (0.76)	3.63 (1.94)

Primary Results: Labor Force Participation



(a) Predicted Quarterly Turnover Rate.



(b) Predicted Quarterly Percent of Stable Jobs.

Figure 4: Predicted Quarterly Turnover Rates and Percent of Stable Jobs

Notes: Figure 4A plots the model adjusted predicted values of the quarterly turnover rates among home health care workers compared to child day care and animal slaughtering and processing workers. Figure 4B plots the model adjusted predicted values of the quarterly percent of stable jobs among home health care workers compared to child day care and animal slaughtering and processing workers. The reference period modeled is 2014. See Section 4.6.1 for more information on the specification of the model.

Heterogenous Effects: Pre-existing Protections

	(1)	(2)
	Turnover Rate	**Percent of Stable Workers**
Post	0.935***	-1.313***
	(0.253)	(0.335)
Post x Pre-existing Protections	0.057	0.479
	(0.275)	(0.449)
Post x Treatment Group	-0.509*	0.885**
	(0.236)	(0.311)
Post x Treatment Group x Pre-existing Protections	-0.144	-0.337
	(0.360)	(0.512)
Covariates	Yes	Yes
Quarter of the Year	Yes	Yes
R-squared	0.007	0.023
N	14,784	14,688

Robustness and Falsification Analyses

- No evidence of treatment group among comparison groups
- No evidence of treatment group between comparison groups

- Primary analyses on dataset not restricted by sex
- Synthetic difference-in-differences approach
- Interrupted time series
- Excluded counties in California

Primary Results: Worker Outcomes

	Worked Any Overtime	Part-time 20+ Hrs	Adjusted Income	Log Income	Adjusted Wages	Log Wages
Treatment Group	-0.021	-0.195***	-6360.445***	-0.436***	-1.081***	-0.144***
	(0.013)	(0.011)	(433.673)	(0.034)	(0.308)	(0.018)
Post Period (3 levels)						
Post = 0	-ref-	-ref-	-ref-	-ref-	-ref-	-ref-
Post = 1	0.041	0.007	1469.184*	0.081	0.139	0.022
	(0.022)	(0.009)	(729.672)	(0.043)	(0.372)	(0.025)
Post = 2	0.050**	0.009	2041.088***	0.115**	0.333	0.043*
	(0.016)	(0.009)	(493.463)	(0.035)	(0.305)	(0.019)
Treatment × Post						
T=1 × Post=1	-0.042	0.010	-1179.496	-0.062	-0.015	-0.004
	(0.024)	(0.014)	(794.214)	(0.049)	(0.436)	(0.029)
T=1 × Post=2	-0.053**	0.013	-1437.335**	-0.068	-0.023	-0.018
	(0.017)	(0.012)	(537.084)	(0.038)	(0.350)	(0.022)
Individual Characteristics	Yes	Yes	Yes	Yes	Yes	Yes
State Fixed Effects	Yes	Yes	Yes	Yes	Yes	Yes
N	28,385	28,385	28,385	28,385	28,385	28,385

Heterogenous Results

- Significant and positive effect on earnings for workers in states with pre-existing protections for workers
- No evidence of heterogenous effects among workers in states with Medicaid expansion versus those without.
  - Wages are consistently higher in states that expanded Medicaid compared to those that did not expand Medicaid.

Conclusions

Policy Implications



Employers

Policy Implications



Employers



Direct Care Workforce

Policy Implications



Employers



Direct Care Workforce



Aging Population

Policy Implications



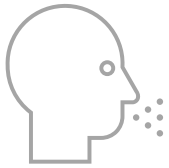
Employers



Direct Care Workforce



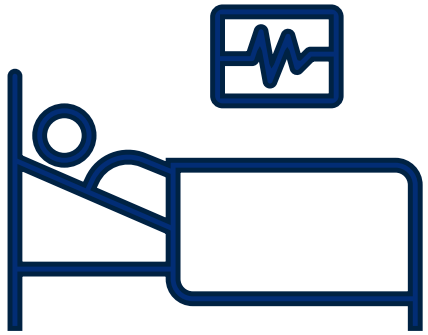
Aging Population

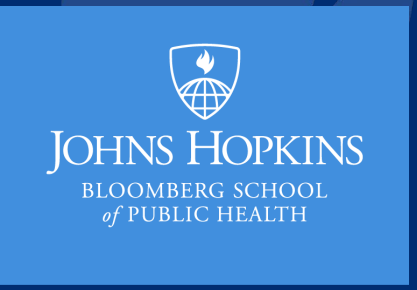


COVID-19

Next Steps

- Employers
- Direct Care Workforce
- Aging Population
- COVID-19





Thank you

NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD

Family Spillovers of ADRD

Onur Altindag, Bentley University & IZA, ERF
Jane Greve, Vive Denmark
Yulya Truskinovsky, Syracuse University & NBER

The NBER Coordinating Center on the Economics of Alzheimer's Disease / ADRD
is funded by the National Institute on Aging, part of the National Institutes of Health

Acknowledgement

This work is supported by the Johns Hopkins Economics of Alzheimer's Disease & Services (HEADS) Center — long may it live! We are grateful for their generous support. These views are our own and do not represent the opinions of the NIH or HEADS Center.

Please do not cite, quote, or circulate without the permission of the authors. Results are preliminary.

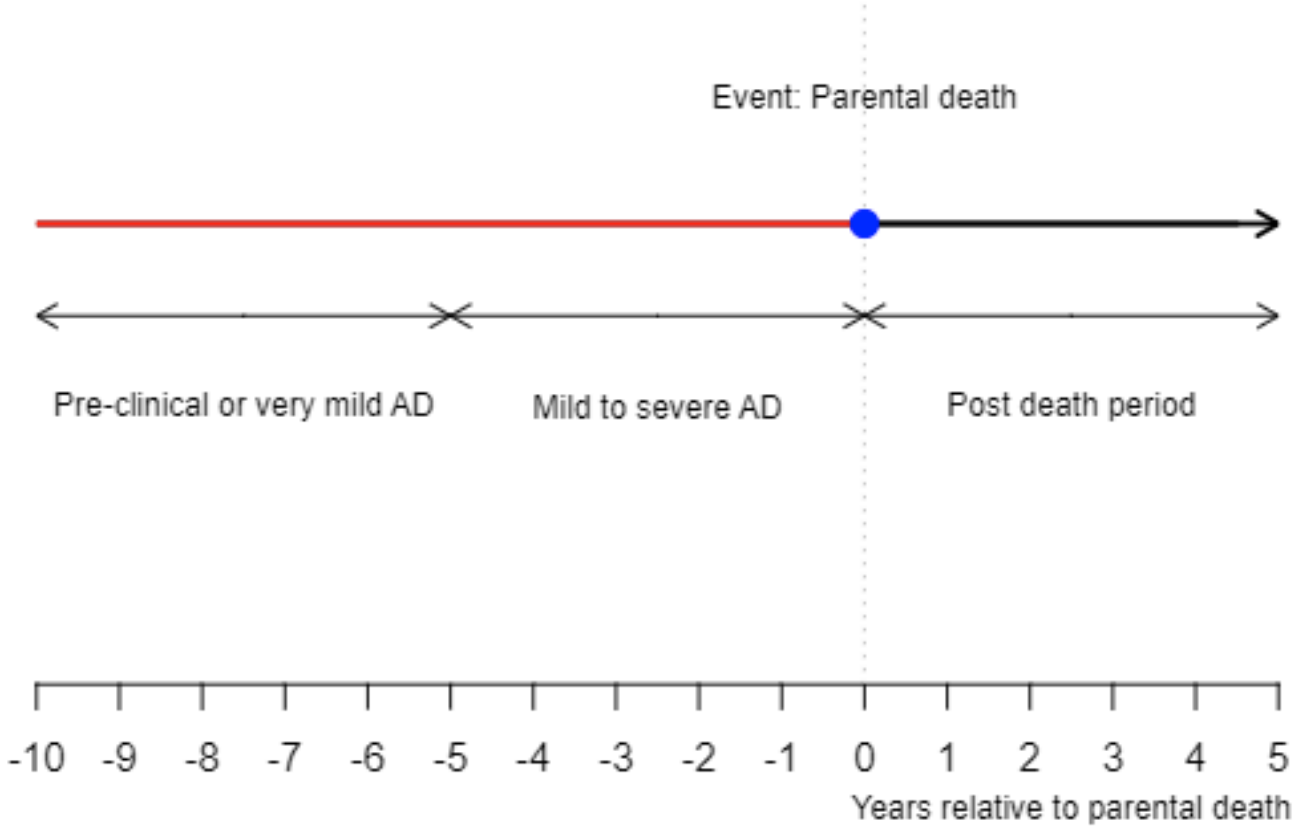
Alzheimer's disease and related dementias (ADRD)

- Prevalence is growing
  - 29.4 per 1,000 population by 2050 across OECD countries
- Disease progression and care needs impose costs on families and governments
  - Progressive, terminal illness requiring increasing levels of care
  - Family caregivers experience physical, emotional and economic challenges
- Estimating all impacts on family members is necessary for full accounting
  - Identifying ADRD in survey/administrative data
  - ADRD onset is not a "shock" -- difficult to determine when spillovers start
  - Focus is often on opportunity cost, but non-caregiving channels are important

Research question and approach

- **Objective:** Estimate the impact of ADRD on adult children
  - Health (mental and physical) and labor market outcomes
  - Explore mechanisms underlying any impacts
- **Approach:** Track adult children up to 10 years before and 7 years after ADRD-related death of a parent using linked administrative data
  - ADRD status based on ICD codes (diagnoses, medications, cause of death)
  - Capture period of accelerating care needs + any post-death recovery
  - Multiple matched comparison groups
- **Context:** Denmark is a "best-case scenario"
  - One of the highest per capita LTSS expenditures in the OECD, focus on home-based care.
  - Robust family caregiver support, including generous paid leave and cash benefits for terminally ill family members, universal healthcare

Empirical Design: Matched Event Study



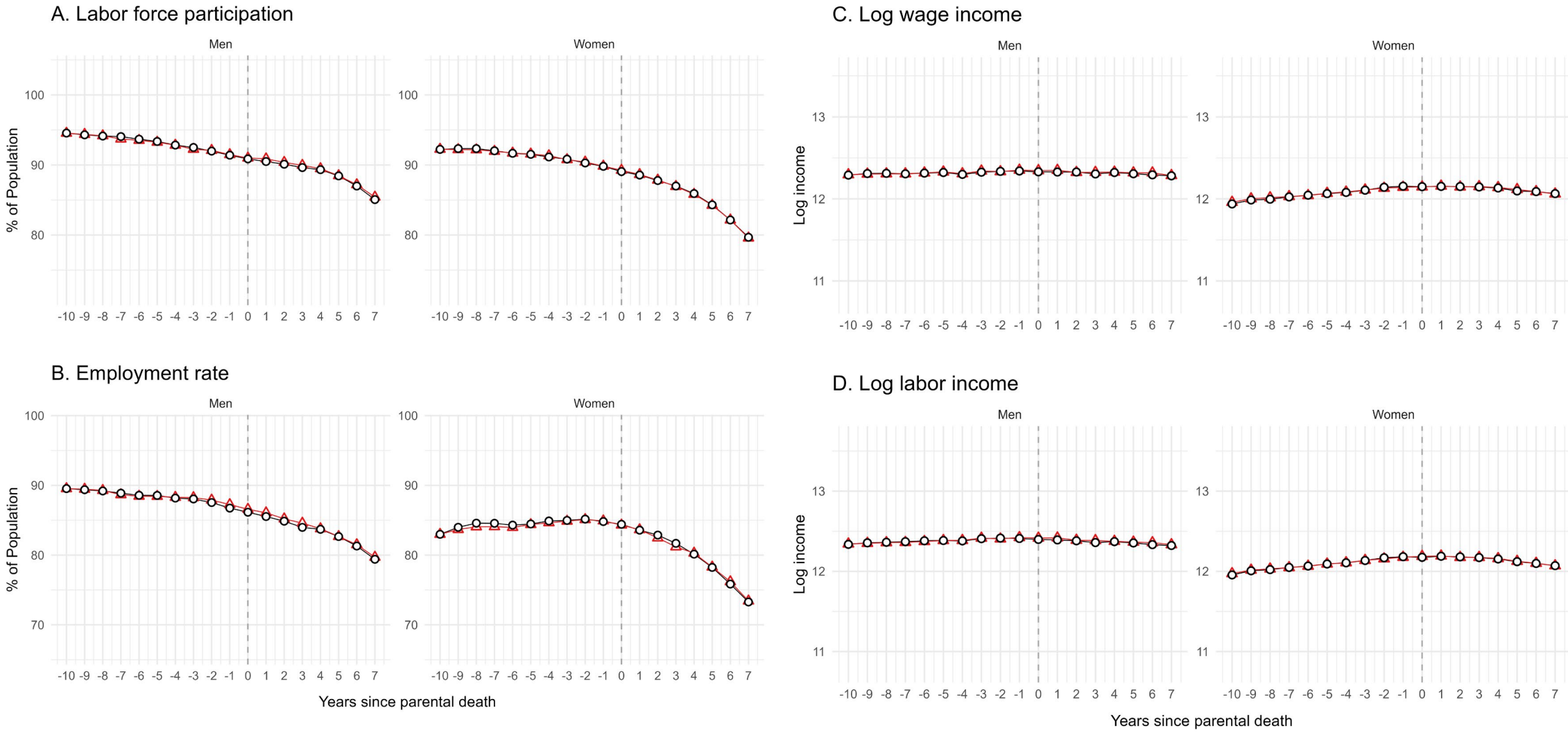
Empirical Design: Counterfactuals

- **Treatment Group 1**: Child-parent pairs where the parent died with an ADRD diagnosis between 2005 and 2011
  - ADRD indicated in in-patient or out-patient records (National Patient Registry or Psychiatric Central Registry).
  - Minimum of two anti-dementia drug prescriptions (National Prescription Registry).
  - ADRD listed as primary or secondary cause of death (Danish Registry of Cause of Death using ICD codes).
- **Treatment Group 2**: Child-parent pairs where the parent died without ADRD diagnosis
- **Placebo Controls**: Children-parent pairs where the parent did not die in the index year (but could have died any other year)

Sample Characteristics: Adult Children

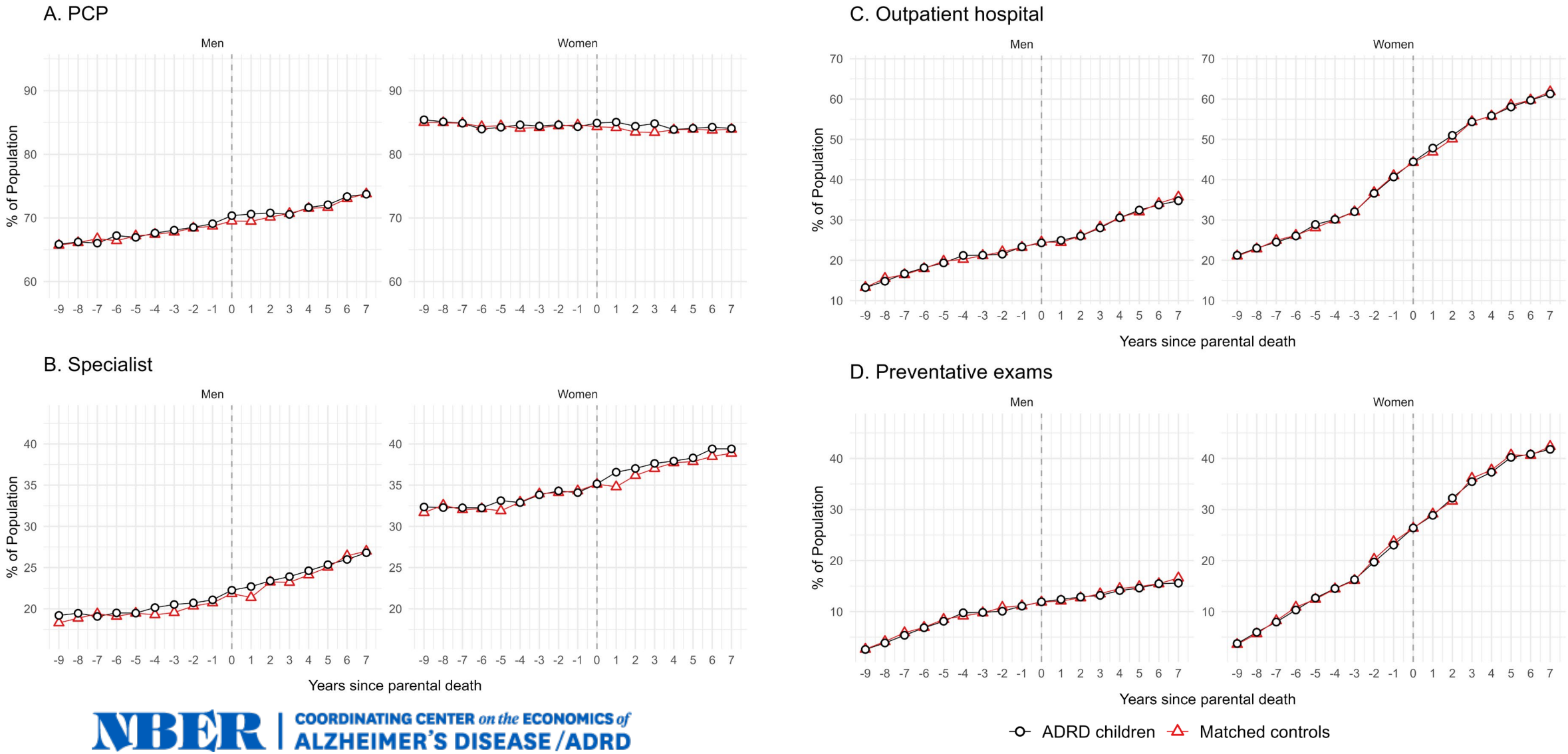
	ADRD		Other Causes	
	Mean	Placebo Mean	Mean	Placebo Mean
Demographics				
Birth year	1959.3	1959.3	1961.1	1961.1
Female (%)	50.0	50.0	49.7	49.7
Age	49.5	49.5	47.5	47.5
Socioeconomic Status				
College or above (%)	32.6	32.6	28.8	29.1
Married (%)	64.3	64.8	62.9	63.1
Number of children	2.16	2.17	2.16	2.17
Immigration Status				
Immigrant (%)	1.0	1.0	1.2	1.1
Observations	36,220	36,220	196,433	196,433

Unadjusted Trends: Labor Market Outcomes



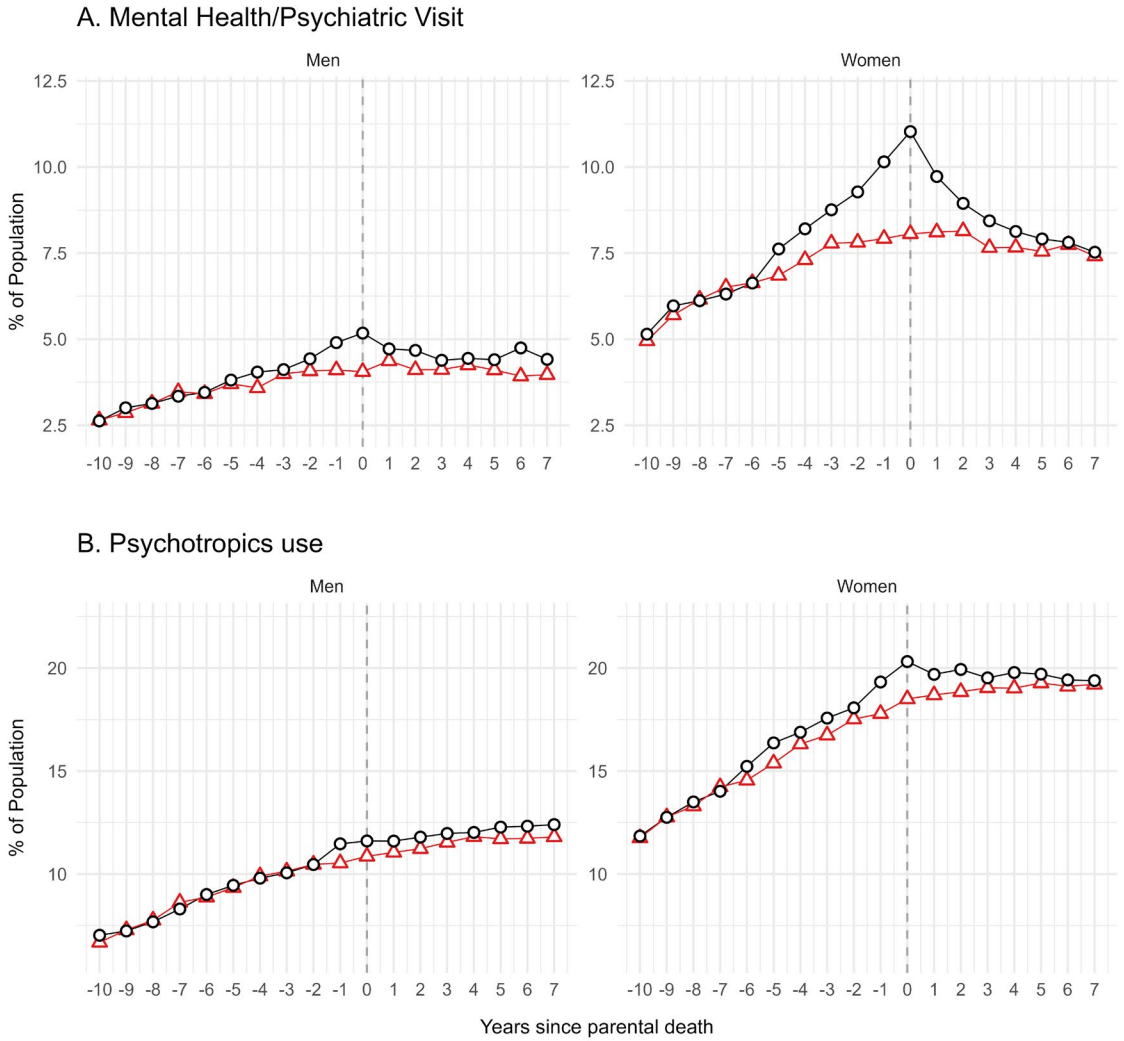
NBER | COORDINATING CENTER on the ECONOMICS of ALZHEIMER'S DISEASE /ADRD

Unadjusted Trends: Physical Health



NBER | COORDINATING CENTER on the ECONOMICS of ALZHEIMER'S DISEASE /ADRD

Unadjusted Trends: Mental Health

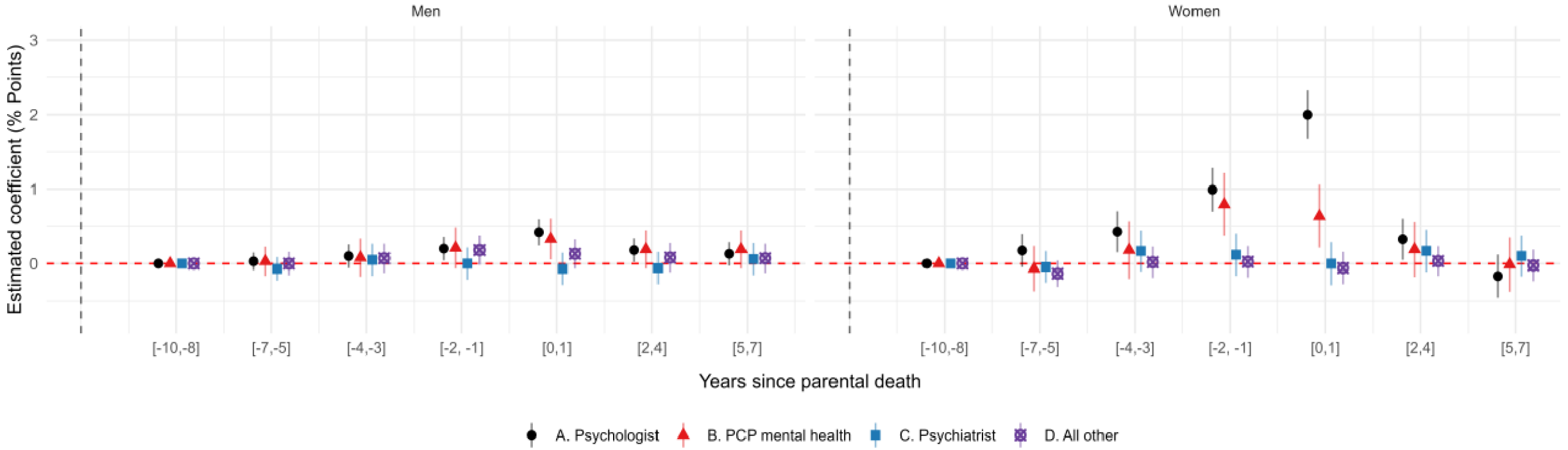


	Mental Health Visits		Psychotropic Use	
Event Years	Men	Women	Men	Women
[−10, −8]	[Reference Category]			
[−7, −5]	-0.03 (0.15)	0.05 (0.21)	-0.10 (0.19)	0.39 (0.24)
[−4, −3]	0.25 (0.19)	0.80*** (0.26)	-0.16 (0.25)	0.61** (0.30)
[−2, −1]	0.53*** (0.20)	1.71*** (0.28)	0.39 (0.27)	0.95*** (0.33)
[0, 1]	0.69*** (0.21)	2.15*** (0.29)	0.57** (0.29)	1.31*** (0.35)
[2, 4]	0.30 (0.19)	0.54** (0.26)	0.33 (0.29)	0.68** (0.35)
[5, 7]	0.48** (0.20)	0.04 (0.26)	0.52* (0.30)	0.22 (0.36)
Dependent Mean N	3.94 652,392	7.60 651,528	10.22 652,392	17.09 651,528

NBER | COORDINATING CENTER *on the* ECONOMICS *of* ALZHEIMER'S DISEASE /ADRD

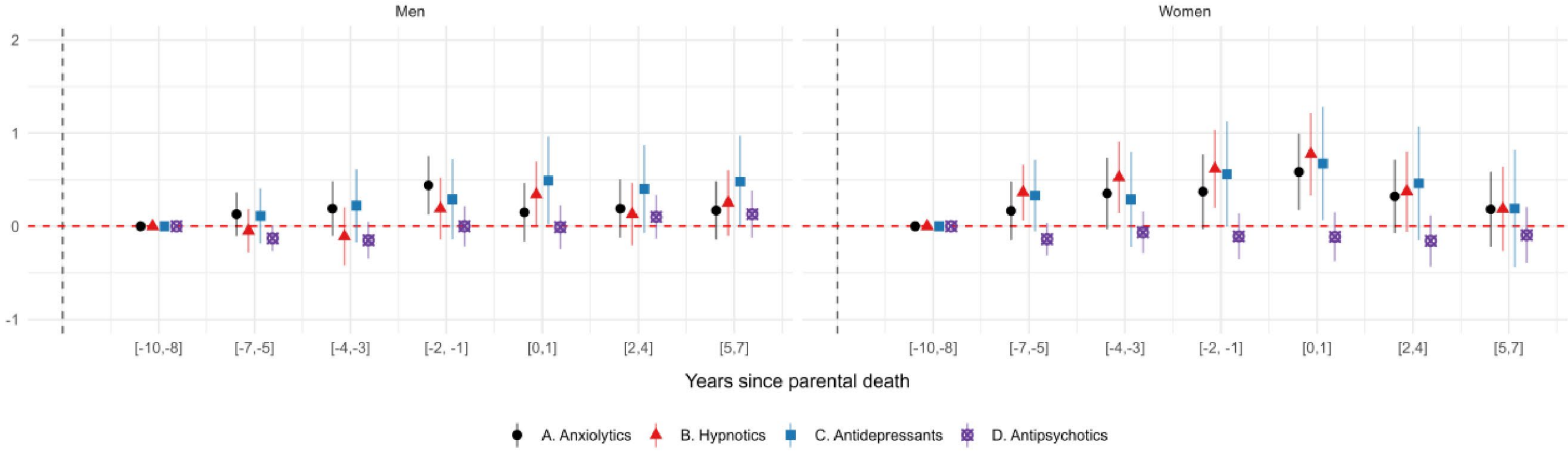
ADRD children Matched controls

Visit Type



- More frequent visits to **PCPs for mental health concerns** (!6%-!" % increase) and **psychologists/therapists**. Men: +#$ to 68%, Women: +%&–!&&%.
- No signi’ cant changes in visits to **psychiatrists** or other mental health services (e.g., **hospitalizations**).

Medication Type

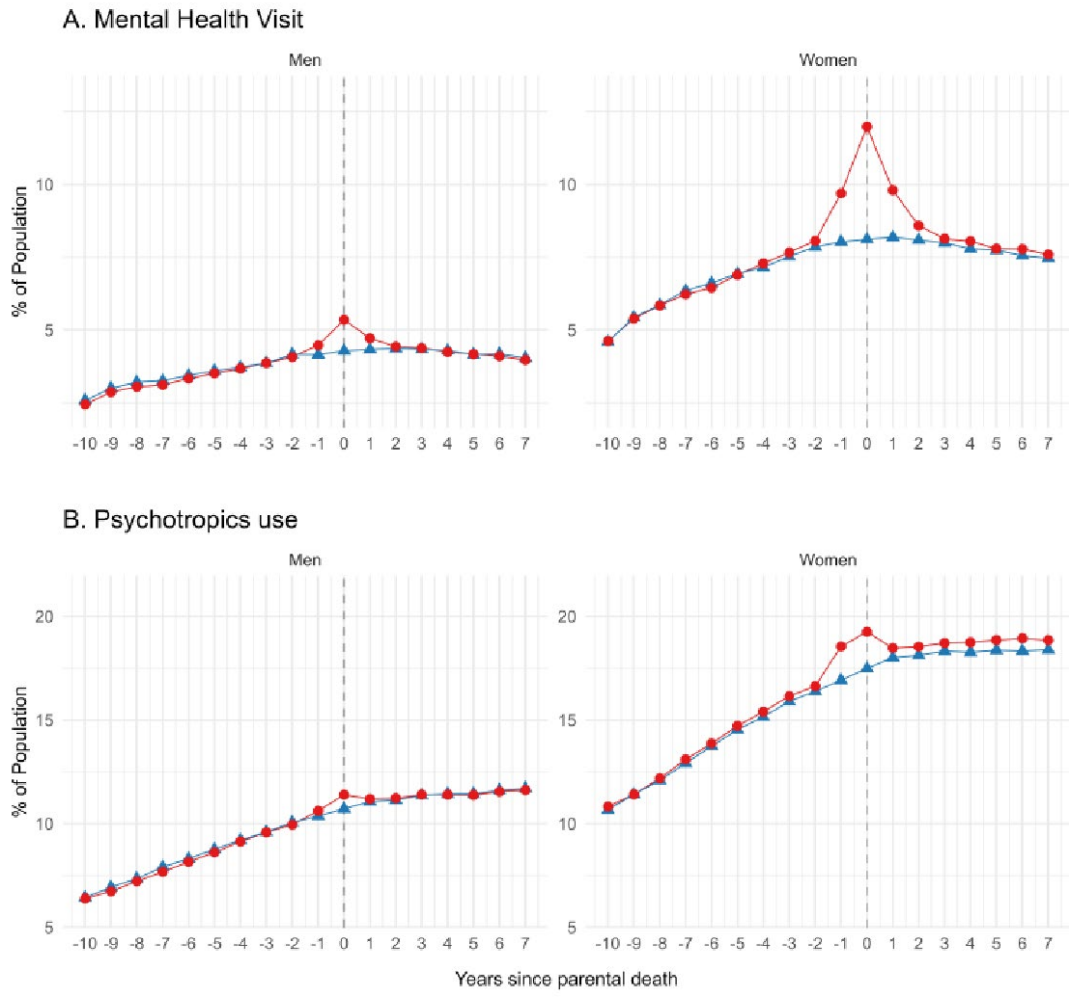


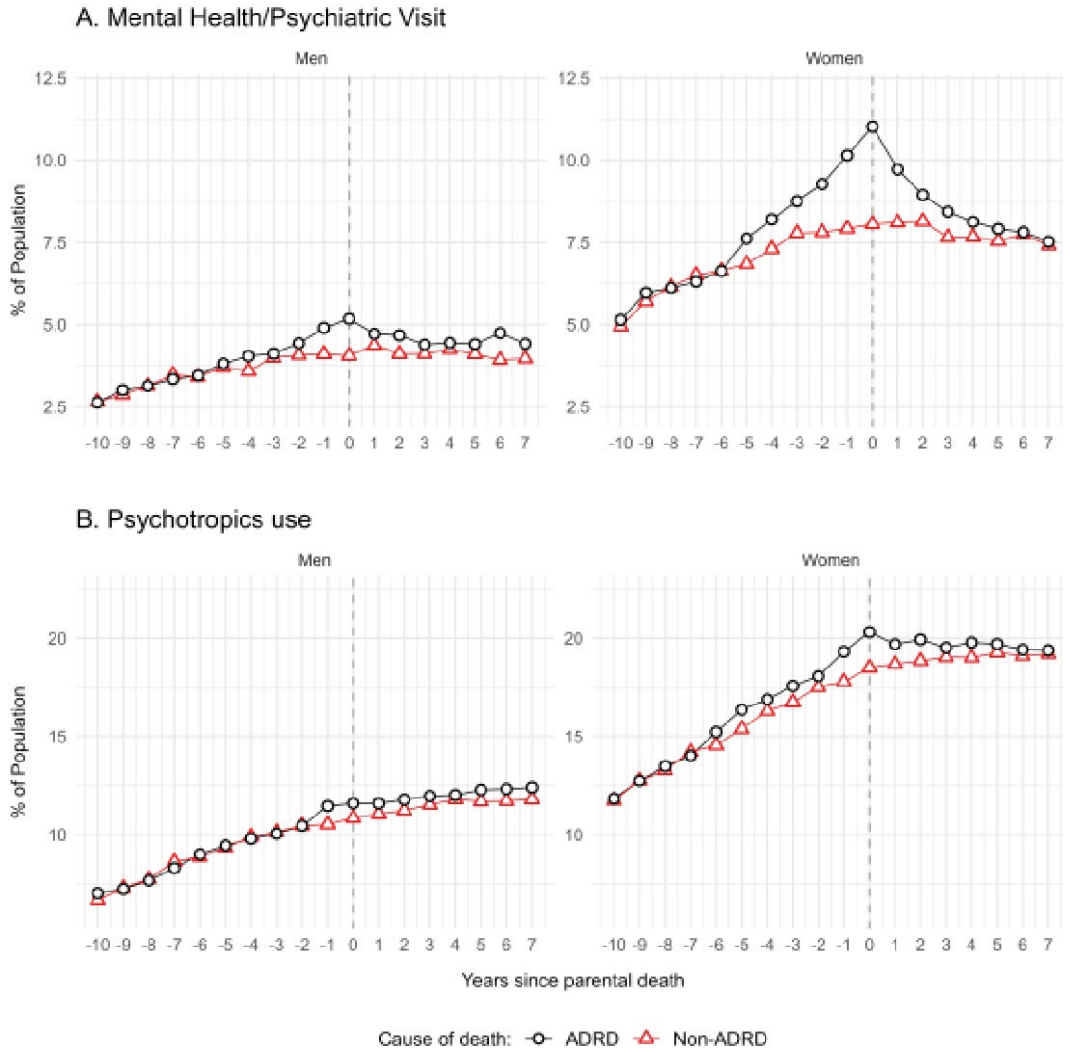
- Use of all types of psychiatric medications increases—anti-anxiety drugs, sleeping pills (hypnotics), and antidepressants—except for antipsychotics.

Subgroup Analysis

- Child's Age <50
  - Younger adult children show substantially larger increases in use of mental health care
- Sibling Status
  - Only children show larger increases in psychotropic use though estimates are noisy
- Parent partnership status
  - No clear patterns emerge

Parental Health due to non-ADRD causes





NBER | COORDINATING CENTER on the ECONOMICS of ALZHEIMER'S DISEASE /ADRD

Conclusions

- Parental ADRD leads to increased mental health care use, especially among daughters.
- Sons show similar patterns, but from a lower baseline and with smaller increases.
- Effects emerge 2–4 years before parental death, peak around the time of loss, and partially persist for up to 10 years.
- No substantial effects on labor market outcomes or use of non mental health care services
- Parental loss contributes to, but does not fully explain, the psychological burden.

Discussion

- Is there caregiving going on? We don't know
  - Survey results suggest limited caregiving among children
  - Non-caregiving channels for mental health effects
- Labor market spillovers to children can be mitigated through a robust social welfare state, publicly funded formal care
- Substantial mental health spillovers persist even in this context
- Companion paper: Spouses

Questions?

Coming Up at 1:20 PM

Research Panel 2: The Economics of Medical Care for People with Alzheimer's Disease