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ELDER CAREGIVING STUDY

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LWVWA Study Committee
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Jeanne Cullen, LWV Thurston County
Jody Disney, LWV Thurston County
Mary-Jo Giamberardini, LWV Thurston County
Tricia Grantham, LWV Pullman
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Karen Tvedt, LWV Thurston County, Study Chair

LWVWA Reading Committee
Mary Lynne Courtney, LWV Bellingham/Whatcom County
Janet Hyre, LWV Thurston County
Ann Murphy, formerly LWV Spokane Area, and newly LWV Clark County, Reading Committee Chair

Technical Reviewers
Dana Allard Webb, Program Manager, Home & Community Services, Aging & Long-Term Support Administration, Department of Social & Health Services (DSHS), Olympia, Washington
Eric Erickson, Executive Director, CDM Caretaking Services, Vancouver, Washington
Nancy Field, Health Care Consultant, Sequim, Washington

Copy Editor
Linda Green

Formatting
Sue Bredensteiner

LWVWA Liaisons
Dee Ann Klein and Shelley Kneip

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Dedication
This study is dedicated to the many courageous elders who deal with chronic physical and mental issues that interfere with the day-to-day activities most people take for granted. You continue to contribute to your families and communities. For some of you, this is despite the challenges of pain, loneliness, depression and isolation. The professional, personal and financial sacrifices of family and paid caregivers are also acknowledged and appreciated.

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List of Abbreviations and Acronyms

AAA	Area Agencies on Aging
AARP	American Association of Retired People
ACL	Administration for Community Living in DHHS
ADL	Activities of Daily Living
ADRC	Aging and Disability Resource Centers (service of the AAAs)
ALTSA	Aging and Long-Term Support Administration in DSHS
APS	Adult Protective Services
ASPE	Assistant Secretary of Planning and Evaluation in DHHS
CAPABLE	Community Aging in Place-Advancing Better Living for Elders
CDPAP	Consumer Directed Personal Assistance Program
CLC	Community Living Connections
CMS	Centers for Medicare and Medicaid Services in DHHS
CSRA	Community Spousal Resource Allowance
DHHS	U.S. Department of Health and Human Services
DOH	Washington State Department of Health
DSHS	Washington State Department of Social and Health Services
FCSP	Family Caregiver Support Program, DSHS, ALTSA
HCA	Washington State Health Care Authority
HCBS	Home and Community-Based Services
IP	Individual Provider (Home Care Worker)
KFF	Kaiser Family Foundation
LTSS	Long-Term Services and Support (sometimes LTC, LTCS)
LWVWA	League of Women Voters of Washington State
MAC	Medicaid Alternative Care
MTD	Medicaid Transformation Demonstration
OAA	Older Americans Act
OFM	Washington State Office of Financial Management
RCW	Revised Code of Washington
SEIU 775	Service Employees International Union 775
SHIBA/SHIPS	State Health Insurance Programs (SHIBA in Washington State)
SNAP	Supplemental Nutrition Assistance Program (Basic Food)
TCARE	Tailored Caregiver Assessment and Referral
TFD Cares	City of Tacoma – Tacoma Fire Department Cares Program
TSOA	Tailored Supports for Older Adults

Executive Summary

This study focuses on caregiving in Washington state and specifically caregiving for vulnerable adults 60 years of age or older who reside in their own homes and communities. The League of Women Voters of Washington authorized the study at its May 2023 convention. The study was completed in three phases: Phase I: Preliminary review of research and data; Phase II: In-depth interviews with elders, family caregivers and paid caregivers; and Phase III: Follow-up literature review and interviews with administrators in the field of elder caregiving.

Changes in the population in Washington state are consistent with the long-term global and national trend toward growth in the proportion of the population 60 years of age and older. This trend is expected to continue for the foreseeable future, creating both challenges and opportunities. While old age is frequently associated with disability and illness, elders are a source of "wisdom, perspective and experience," contributing to society as family members, citizens, workers and volunteers.[1]

For more than four decades, Washington state has been a leader in prioritizing home and community-based care for elders. In ratings by national organizations, it is ranked highly and according to state estimates, the state saved nearly $5 billion in tax dollars from 1999 to 2020 by focusing on home and community-based care rather than nursing homes.

Given growth in the number of elders and corresponding caregiver shortages in coming years, this report demonstrates the need to do more to prepare for the caregiving needs that accompany aging. The elder caregiving system is heavily reliant on family caregivers, primarily women, who often struggle to meet the demands placed on them. And the current shortage of paid caregivers promises to get worse over the next few years and decades.

The workgroup identified five overarching areas of concern that threaten Washington's ability to respond to elder caregiving needs now and in the future.

1. Most elders want to remain independent in their own homes and communities but frequently lack the resources to do so should they become unable to care for themselves without help. Further exploration is suggested about what it takes for elders to remain in their homes. This might include early retirement planning and savings, positive health practices such as promoting social connections, attention to community infrastructure including housing and transportation, and state and local planning for healthy aging that addresses alignment of infrastructure and services.
2. Elders and their families face challenges negotiating the elder care system, including accessing information about the complex system of long-term care. Improving access might involve examining ways to streamline and better coordinate the system, along with making information and support more readily available to elders and their families.
3. Washington's system of elder caregiving relies heavily on family caregivers who themselves are challenged by conflicting demands, lack of respite care, and short and long-term costs. It may be time to reevaluate Washington's heavy reliance on family

caregivers, including examining the personal costs for caregivers and making support such as respite care more readily available.

4. There is a lack of paid caregivers to meet current and projected needs. This is a serious challenge expected to get worse in coming years. In 2020, there were six working aged people 25-65 years to each elder 75 years and older. Estimates are that by 2030, the ratio of workers to elders 75 and over will be 4:1. This is expected to drop to 3:1 in 2040 and 2050.[2]

   Recruitment and retention of paid caregivers is hampered by inadequate compensation and benefits, challenging work conditions, immigration policies, infrastructure issues such as lack of transportation, housing, and child care, and barriers to training and continuing education, especially in-person training.

5. The system works better for the very poor who are eligible for Medicaid and the reasonably well-off who can pay privately. And yet, affluent elders and elders who are Medicaid recipients experience difficulties accessing and retaining care. Caregiving is even more challenging for lower and middle-income elders who lack the resources to pay for it. And, when these elders turn to Medicaid for assistance, they encounter issues with spousal asset limits and Medicaid Estate Recovery (repayment for Medicaid services).

> "There are only four kinds of people in the world: those who have been Caregivers; those who are currently Caregivers; those who will be Caregivers; and those who will need Caregivers."
>
> Rosalyn Carter

Chapter 1: Results of Interviews with Elders, Family Caregivers and Paid Caregivers

Phase I of this study consisted of a review of data and research from federal and state sources. This provided the basis for in-depth qualitative interviews with elders, family caregivers and paid caregivers during Phase II. Chapter 1 summarizes the results of these interviews including the stories interviewees told. Detailed information about research design and approach is included as Appendix A. Appendices B and C provide additional information about the study sample and questions.

Elder Interviews

The small sample of elders interviewed represents a range of circumstances and needs. One interviewee in her 60s lives by herself in permanent supportive housing, pays 30% of her Social Security disability income in rent and has Medicaid health coverage. She is happy to be housed but wishes for a place with fewer rules. Most of her days are spent watching television and playing games on her computer. She said, "I'm constantly lonely despite having a dog. And I've had multiple young caregivers over the past year who spend much of their time on their phones. While I get angry about lack of control, I worry about ending up in a nursing home."

Another interviewee is a man in his 70s, a retired engineer, who has Parkinson's and lives with his wife. His wife drives him to appointments. He spends much of his day in his "smart" room, which is equipped with two laptops where he is building a radio. He is also building a windmill-run generator in his garage. While he characterizes his care as ideal, he wishes his children would visit more often and that he could get more help so his wife could take breaks and a trip. He says he worries about current tax laws and the potential of leaving his wife without enough money to continue their current lifestyle should he need nursing home care. He contemplates the possibility of divorce to protect assets for her.

The desire for independence was a theme across interviews. Elders expressed the desire to make choices about caregivers, their need for respite care, and the value of pets. Difficulties noted included loneliness, access to information, negotiating long-term care services and support, need for care that is affordable and responsive, and access to post-surgical care. One reviewer said, "the best scenarios for eldercare are no money or quite a bit of money. In between people have more difficulty getting care and depend on family more."

Service providers and other professionals expressed concerns that people are living longer but not living with the quality of life they expected. They also noted worries about elders who are depressed, live alone, drink alcohol to excess, take multiple medications, are in abusive situations, and are themselves caretakers.

These professionals spoke about the need to involve elders and their families in establishing rapport and trust. Often this is precipitated by a crisis. Planning requires assessing an elder's ability to make decisions for themselves—all of which can be very time-consuming.

Family Caregiver Interviews

Seventeen family caregivers were interviewed, 12 of whom were over the age of 60. Eleven identified as female and six as male. The interviewees were generally well-educated and relatively affluent. Most had graduated from college and a majority had incomes over $75,000 a year. Eight provided care for their mothers, four for husbands, three for wives, and one each for a friend and mother of a partner. One of the four people caring for their husbands also cared for her adult children who have disabilities.

> Siblings in their 60s who care for their mother said: "Our father made us promise that we will always take care of our mother and never put her in a nursing home."

Care Provided

Many family caregivers interviewed reported that they provide care seven days a week, 24 hours a day. Several have done so for the past 10 or so years with limited respite. Part-time care was more common for caregivers who don't live with the person they care for. Such caregivers are likely to oversee paid caregiving, finances, medical care and shopping. In one situation, siblings take 24-hour shifts relieved somewhat by a part-time caregiver. One caregiver noted difficulties retaining paid caregivers because they quit for full-time work and better pay.

Care and Compensation

Dementia was the most frequently noted reason care is needed, and many caregivers reported helping with all daily activities such as bathing, dressing or feeding (*See Appendix D,* Activities of Daily Living*)*. Most family caregivers were not compensated for the care provided. One son said he wishes he could be paid. He had to quit his job and is worried about how expensive care is (one parent is in nursing care, the other lives in the family home). He is the oldest son in a Korean family and his family and friends expect him to take care of his parents.

Effects on Caregivers

Most family caregivers said they found the caregiving relationship emotionally rewarding. One husband said he is setting an example for his children, that "love at its core is a decision to unite yourself with God through loving another." Some caregivers noted that they missed intimacy and companionship and were lonely and unable to pursue their own activities. One daughter says it's hard when her mother doesn't recognize her, another caregiver wishes for a full day off, "a float tank day," while another noted conflict with her siblings over their mother's care.

Help Received and Needed

Family caregivers described getting help from paid caregivers, housekeepers, yard workers, health-care providers, and friends and neighbors. Not knowing where to turn for information and support was a frequently noted difficulty. Several indicated that they still need help with questions, negotiating the elder caregiving system, and access to respite care. Some discussed challenges encountered during COVID restrictions. One husband shared that his wife died because he was unable to visit her to make sure she was hydrated. While not all caregivers found support groups a good fit, others mentioned finding caregiver and Parkinson's support groups, a tennis group, a Bible study group and a community action program helpful.

Challenges Faced

Caregivers discussed dealing with emotional difficulties, isolation and resentment as well as health issues. One wife noted that the stress has affected her cognitively. She said, "I am having a hard time keeping track of things and can't remember anything if I don't write it down." Others talked about issues with home maintenance, lack of sleep, weight gain, physical injuries, financial difficulties and inability to travel. Adult children said that it is hard to achieve their own goals, including the need to delay moving or starting a family. One caregiver noted, "I made a pact with myself and my children that there would be no guilt or blame. We would provide the best care we could under the circumstances."

Sustainability of the Caregiving Situation

Several caregivers indicated that they are aware that as their loved one declines, they will need more outside help and perhaps even placement outside the home. Most family caregivers expressed challenges balancing their caregiving responsibilities with the needs of their own immediate families.

Summary

Without the support of family caregivers, millions of elders would find themselves with no choice but to move to more costly facility-based care. Family caregivers generally find aspects of caregiving rewarding. And yet, these interviews reveal that caregiving exacts emotional, physical, financial and social costs on caregivers. And family caregivers reported that it is often difficult to get the help they need. Financial issues were frequently mentioned including worries about not being able to be gainfully employed, costs associated with paid caregiving, and potentially, the impacts of Medicaid Estate Recovery should Medicaid services be required (see Chapter 4 for more about Medicaid Estate Recovery).

Paid Caregiver Interviews

> "I love spending time with my clients, hearing their life stories and helping them with their daily needs. It's also hard to see a client reaching the end of their life and saying goodbye. It can be a privilege and challenge to support clients' loved ones through the process."

Eleven paid caregivers were interviewed, reflecting a cross-section from urban to rural communities across Washington state. Most described caregiving as their career. A few noted working multiple jobs to augment their income. Motivations for working as a caregiver were helping elders remain in their homes, honoring the dignity and value of elders, and making a positive impact in someone else's life.

Education and Training

Paid caregivers noted completing state mandated training and learning from their grandmother and patients. Some expressed concerns about not being paid to attend training, training being online rather than in person, trainers not being adequately trained, and lack of a career ladder.

Challenges

Paid caregivers discussed challenges about losing clients, watching clients decline, having clients who need more care than is authorized, and lack of substitute caregivers. One worker talked about how every day is different, and how moment by moment, it's a challenge to "meet them where they are." Another said it's impossible not to worry about clients, especially elderly clients who live alone. Worry and exhaustion were noted. While overall, interviewees expressed feeling safe, several indicated that they were aware of caregivers who had experienced verbal and physical abuse. Several caregivers noted that difficult family members had caused problems, e.g., fights, drug usage, and racial slurs. One male worker said that getting past stereotypical ideas about toileting and cleaning had been hard for him. An immigrant woman said she is uncomfortable providing personal care for male clients.

Supervision

Paid caregivers employed by agencies generally spoke positively about the supervision they receive. Some said their supervisor checks in with them regularly and that they feel comfortable taking conflicts to their supervisor. One worker noted that their official supervision is through Consumer Direct[3] which works better for some workers than others. (As indicated in the endnote, while Consumer Direct manages employment-related activities for individual providers, the client is the managing employer.)

Income and Benefits

Caregivers employed as union members expressed more satisfaction with their compensation and benefits than non-union members. Several outlined the benefits they receive through Service Employees Internation Union (SEIU) 775 including getting a pair of shoes each year. One caregiver said she has access to a retirement plan but is not taking advantage of it. A worker who is a refugee seemed not to know about the union.

Another caregiver shared that when her client spent an extended period in the hospital during COVID, she had to supplement her income by working in a nursing home. A couple of caregivers noted that loss of a client can result in periods of time without enough hours of work to qualify for health insurance (80 hours a month). In one very difficult scenario, a worker talked about having a car accident on her way home from seeing a client. This caused her to lose two months of work and medical coverage for her family.

Summary

Paid caregivers consistently said they are motivated by caring and connecting with clients. Most expressed concerns about working conditions, e.g., compensation, benefits, training and respect for their chosen profession. Lack of stability in employment and benefits is a major challenge and sends the message that their work is not valued.

Chapter 2: Current and Projected Caregiving Needs

Demographics and Need for Long-Term Care

While aging brings with it increased risk of illness and disability, elders contribute economically and socially to all residents in Washington. AARP estimates that in 2018, Washingtonians 50 years and older contributed $205 billion to the state's Gross Domestic Product and paid $15 billion in state and local taxes. They also averaged 720 hours devoted to caregiving and 33 hours volunteering in 2018.[4]

Every day until 2030, 10,000 baby boomers will turn 65.

Nationally by 2034, the percentage of those 65 and over is expected to exceed that of children under 18.[5] The 75 and older population will grow from 7% in 2023 to 13% of Washington State population by 2050; elders 85 and older will increase from 1.7% to 5.5% of the population during the same period.[6]

Racial and ethnic minority populations are likely to see even larger increases. The 2020 Profile of Older Americans, an annual summary of statistics about elders in the United States, finds that as compared to a 29% increase in non-Hispanic white elders from 2019 and 2040, racial and ethnic minority populations 65 and over are expected to grow by 115%. Hispanic elders are expected to increase by 161% while non-Hispanic minority populations will increase as follows: African American 80%; American Indian and Alaska Native 67%; and Asian American 102%.[7]

A study conducted by the Urban Institute for the federal Assistant Secretary of Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services (DHHS) finds that 70% of adults who live to age 65 will develop long-term care needs before they die. Forty-eight percent will receive some paid care.[8] Black elders have a greater probability of experiencing moderate to significant disabilities in their later years. And while Hispanic and Black elders are more likely to live with extended family, they also have a greater likelihood of experiencing unmet long-term services and support needs. [9]

Special Vulnerabilities for Elders

- **Food Insecurity.** While lower than the national average, 28% of Supplemental Nutrition Assistance Program households in Washington are headed by someone 60 years and older. This has increased by 69% since 2013. During the same period, the overall SNAP caseload declined by 14%.[10] According to AARP, many eligible elders choose not to apply for SNAP or are not aware that they may be eligible for assistance.

- **Homeless or Unstably Housed.** While elders 65 and older are a small percentage of the homeless and unstably housed in Washington State (5,927/187,751 or 3.2%), this number more than doubled from 2017 to 2022 (from 2,445 to 5,927).[11]
- **Adult Protective Service Reports and Investigations have Increased**. The Aging and Long-Term Support Administration in the Washington Department of Social and Health Services investigates reports of abuse, abandonment, neglect, exploitation and self-neglect of vulnerable adults in Washington. The goal of APS is to promote lives free of harm while respecting individual choice. Protective services may include emergency shelter, food, medical care, personal assistance, counseling and more.[12] From 2005 to 2023, reports to APS increased 371% and investigations increased 310%. In 2023, 66,716 allegations were investigated by the administration. The most common allegations were financial exploitation (30.7%); self-neglect (18.5%); mental abuse (16.9%); neglect (12.6%); and physical abuse (11.6%). While 19% of alleged perpetrators were unknown at intake, 50% were identified as family or household members.[13]

Need for Long-Term Care

Another study completed by DHHS found that more than half of adults develop serious disabilities after they reach 65 and must use some paid long-term services and support, such as home care or nursing home care. Older adults who earned relatively little over their lifetimes are most likely to develop a need for long-term services and receive paid services, but the risk of needing care and receiving paid services is high across the lifetime earnings distribution.[14] These findings highlight the need for better planning by families and policymakers. Women will likely need a longer period of care (3.7 years vs. 2.2 years for men).[15]

The need for long-term care begins with an individual losing the ability to complete one or more of the daily living activities. *See Appendix D.* This can be the result of chronic disease, an accident, aging, or illness. A decision not to live independently can be affected by social network, loss/overwork of caregiver, physical abilities, caregiver availability, costs, and facility availability.

Tipping points may include the death of a partner, a bad fall, onset of dementia, a serious illness, loss of eyesight, inability to drive, loss of housing, a partner being unable to lift, and/or change in insurance. Assistive methods can help compensate for loss in one or more daily living activities and allow an elder to continue living independently. Examples of assistive devices include grab bars, raised toilet seats, and ramps. Assistive support might include bill autopay, grocery delivery, or Uber. Once these assistive strategies no longer meet an elder's needs, caregivers may be needed.

For people 65 and over in Washington State who receive care, 19.6% have ambulatory difficulties, 12.7% have difficulty living alone, and 8.3% have cognitive impairments.[16]

Preferences and Misconceptions

> “Most Americans underestimate the risk of outliving their financial resources in retirement or experience economic hardship stemming from large, unanticipated health and long-term care costs in later life.”

Elder Preferences and Concerns

In 2021, the DHHS Office of Planning and Evaluation issued a report showing more than 50% of adults develop serious disabilities after age 65. Based on the data, individuals, families, and policymakers need to better plan for long-term services and support (LTSS). Unfortunately, “most Americans underestimate the risk of outliving their financial resources in retirement.”[17]

AARP’s 2021 Home and Community Preferences Survey finds that approximately 75% of those 50 years and older want to stay in their own homes or communities for as long as possible. If they experience illness or disability, 2/3 prefer a combination of help from family and paid caregivers in their own homes.[18]

Many elders worry this may not be possible. In a 2021 AARP member opinion survey:

- 65% of Washington state respondents said they were concerned about the ability to age in their own homes;
- 59% worried about being able to pay for long-term care;
- 77% said that ensuring Social Security for the future was a top concern;
- 75% were concerned about consumer fraud and identity theft; and
- 25% lacked high speed internet.[19]

Those surveyed expressed concerns, including about becoming a burden on family members or others (62%). Other worries included:

- Needing to live in a nursing home or assisted living (58%);
- Being unable to remain in their own homes (57%); and
- Lacking support from family or friends as the daily tasks of life get more difficult (50%).

Half have discussed end-of-life plans with family and have a will: younger, Hispanic and Black respondents are less likely to have a will. Only 43% of respondents had a designated power of attorney for health care and finances; and only 12% reported having long-term care insurance (Black respondents were more likely at 26%).[20]

Misconceptions about Medicare and Long-Term Care

Medicaid, a joint federal-state program, provides health care including long-term care for individuals with limited income and resources. On the other hand, Medicare offers federal health coverage for individuals 65 and older as well as younger people with disabilities. Medicare does not cover long-term care except in limited circumstances.

A 2021 long-term readiness study[21] involving a nationally representative survey of adults 50 and older found that about half of those interviewed believed that Medicare covers long-term care. Women were more likely to think it does (52% vs. 40%).

In the same study, Black and Hispanic respondents were more likely than White respondents to say they have given significant thought to how they will live independently if they need assistance (51% and 38% vs. 23%).

Awareness of Resources

The National Poll on Healthy Aging asked more than 4,000 adults over 50 about their awareness and use of Area Agencies on Aging (AAAs) and State Health Insurance Assistance Programs (SHIPS) for help negotiating Medicare.[22]

- Only 7% of respondents were familiar with and had used Area Agencies on Aging; 26% were familiar with such agencies but hadn't used them; 67% were not aware of the agencies.
- Respondents 65 and older were more familiar with these programs as compared with younger people; 37% were familiar with AAAs, as compared to 29% of those 50-65. Thirty-one percent (31%) of the older group was familiar with SHIPs versus 20% for younger respondents.
- The researchers noted that the poll demonstrates that there is a gap between the services that are available and what older adults know about their choices.

Other Trends Influencing the Need for and Affordability of Care

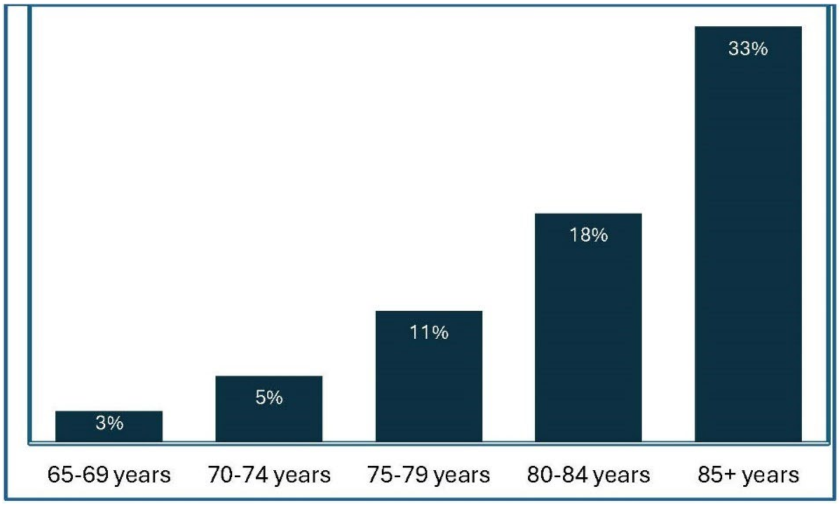
Trends expected to influence need for and affordability and availability of care include dementia risk, elders aging without close family members, immigration policies, technological innovations, and involvement of private equity firms in the long-term care market.

Dementia and Aging

The risk of dementia increases with age and typically results in greater caregiving needs for elders. This includes increased nursing home care use. Elders from 65-69 years have a 3% risk of dementia. The risk increases to 5% for elders 70-74, 11% for 75-79, 18% for 80-84, and 33% for those 85 and older. The risk of dementia is higher for women, and Black and American Indian Medicare recipients.[23] [24]

In Washington, average Medicaid Long-Term Services and Support (LTSS) expenditures are dramatically higher for elders 65 and over who have a dementia diagnosis, i.e., $557 vs. $43 a month. For elders aged 65-69, the average per month cost for an elder with dementia is $926. This compares to $37 a month for an elder 65-69 without dementia. For purposes of this analysis, LTSS includes institutional, e.g., nursing home care as well as non-institutional (home and community-based) services authorized by DSHS for beneficiaries 65 and older.[25]

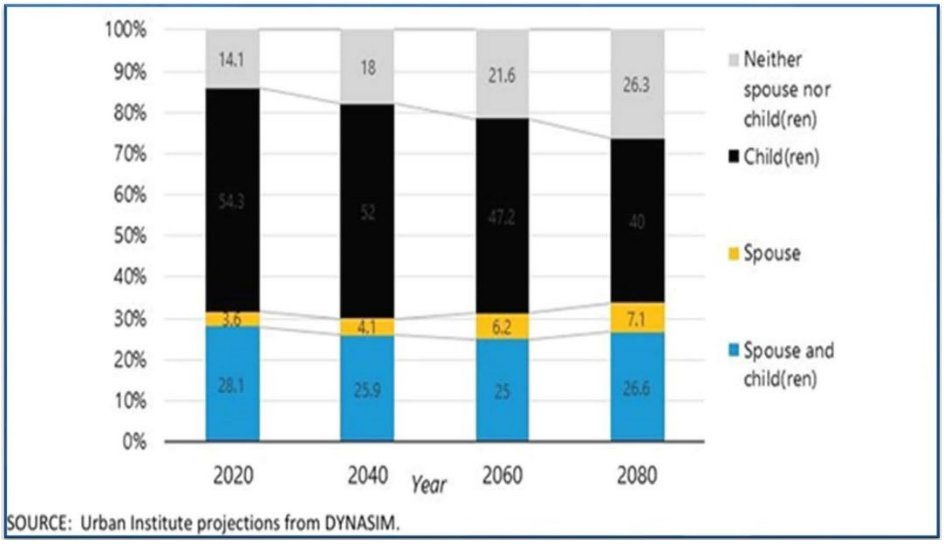
Figure 1: Risk of Dementia Increases with Age Among 2018 Washington State Medicare Beneficiaries Age 65+ (Dementia Risk—DSHS Research & Data Analysis Division. Oct. 2023)[26]



Elders Without Close Family Members

In future decades, more elders are likely to age alone without close family members including a spouse or children. This relates to declining fertility rates and marriages. This will change the availability of informal family care creating a "care gap." As shown in Figure 2, DHHS finds that among older people with significant long-term care and support needs, approximately 26% will not have a spouse, partner, or child in 2080, compared with about 14% in 2020. Increased life expectancy for men may partially offset increases in the number of elderly single adults.[27]

Figure 2: Projected Composition of Potential Care Networks at Ages 65 and Older, People with Significant Long-term Needs, 2020-2080 (%). The number of elders without a surviving spouse or child is expected to grow steadily.[28]



SOURCE: Urban Institute projections from DYNASIM.

Immigration Policies

Immigration policies in the United States influence the number of direct care workers available to meet elder caregiving needs. In 2021, 19% of home care workers (paid caregivers and home health aides) were U.S. citizens by naturalization. Thirteen percent were not U.S. citizens.[29] A bill introduced in Congress during its 2021-2022 session (but failed) would have established a mechanism for eligible aliens who worked as essential workers during the COVID-19 emergency to apply for and obtain permanent resident status.[30]

In a 2024 Commentary, Brookings Institution argues that one of the best strategies for increasing caregiver supply is through expanded pathways for legal immigrants.[31] Brookings argues for a special visa category for frontline care workers and a citizenship path for immigrants who work with seniors. They also advocate for worker protections for immigrant caregivers.

Technology and Artificial Intelligence (AI)

“Technology like artificial intelligence will never replace person-to-person care,” according to the Alzheimer’s Society, United Kingdom, “but used in the appropriate circumstance, could enhance care and support people affected by dementia to live at home for longer and avoid crisis situations.[32]

Technological innovations promise a shift in caregiving needs and approaches toward an artificial-intelligence-based approach that emphasizes preventive care and wellness, underscoring the importance of early intervention in health and social management. Among probable uses for AI for in-home care are real-time alerts for improved safety, wearable health technology, and remote monitoring technologies.[33] Technology is also likely to influence dementia care as discussed in Chapter 5.

Private Equity Firms

> "As the home care industry booms, the nation's largest health insurance companies and private equity firms are looking to cash in by buying up a growing share of what has historically been a highly fragmented and competitive field."
>
> *Wall Street Journal*

A *Wall Street Journal* article in September 2024, describes insurance and equity firm interest in the home care industry.[34] In addition, *Forbes* reports that home health and personal care is the industry with the highest projected job growth over the next decade with the addition of more than 804,000 jobs (a 22% increase). As noted, paid caregivers are a subset of the workers in the home health and person care industry. Contributing to this growth is the aging population, increased focus on home-based services and advances in medical technology.[35]

Private equity firms, investment groups that buy and manage private or public companies before selling them, find the home care industry lucrative. Private equity ownership creates opportunities for firms to maximize profits through cost cutting, control over prices, and other financial mechanisms.[36]

And, regardless of economic fluctuations, the demand for health and social services is constant. By the end of 2022, nearly 6% of the nation's 8,500 home care agencies were owned by 37 private equity companies with prices for in-home care for the elderly rising by 11.4% from June 2023 to June 2024.[37]

In 2023, 24 states passed 36 bills dealing with health system consolidation, competition and related issues.[38] And, in early 2024, a joint request for information was issued by the Department of Justice, DHHS, and the Federal Trade Commission. This request sought public comment on the effects of transactions in health care that involve private equity funds or alternative asset managers, health systems or private payers. While expressing belief in health-care market competition, the request notes, "Recent research suggests that transactions conducted by private equity funds have adversely affected patients, health-care workers, and other stakeholders in some cases including through worse patient outcomes and higher costs for care."[39]

April 22, 2024, Medicaid final rules were issued requiring that states ensure that within six years at least 80% of Medicaid payments for home care services go to workers’ wages. The rule also calls for greater transparency in company ownership and expenditures.[40]

Chapter 3: Family and Paid Caregivers

This chapter addresses caregivers including types and characteristics of caregivers and the work they do. Federal code defines caregiver as a family member or other individual who provides compensated or uncompensated care to an elder in any setting.[41] As noted, this study focuses on family caregivers and paid caregivers who care for vulnerable elders in their own homes.

Family Caregivers

> "I love my mother. I have been caring for her for over 20 years. The time needed to invest in dealing with her affairs has been ever increasing as have been the tasks as she ages and declines. I am so exhausted with her needs. I want to float in a tank where no one can reach me."
>
> Interview with a family caregiver

Who Is a Family Caregiver?

In 2021, Washington had 820,000 family caregivers. They provided approximately 770 million hours (or about 88,000 years) of unpaid care valued at an estimated $16.8 billion in 2021.[42] An AARP survey of 704 Washingtonians 45 and older discovered that 67% were providing care for an adult relative or friend or had done so in the past. Of these, 75% were also employed at another job.[43] Nearly half of those surveyed said being a caregiver had had a major impact on their financial situation, and more than half said they felt emotionally stressed because of their caregiving responsibilities.[44]

> In one family with six grown children, each spends a day and night each week with their 92-year-old mom. Puerto Rican by ethnicity, they are committed to caring for their mother until she passes. Their own children have informed them not to expect this kind of care in their old age.

Two-thirds of all caregivers are women. Care is something people do out of love or obligation. However, that does not mean it's not costly. At least 53 million people are family caregivers in the United States. Family caregivers reflect the diversity of America's communities, and people can assume family caregiving responsibilities at any stage of life.[45]

Family caregivers form the backbone of our nation's system of long-term care. According to one study, only 13% of people who need long-term care (elderly and non-elderly) receive paid care.[46] Family caregivers support diverse communities with a wide breadth of needs:

- Older adults and disabled people of all ages may need assistance with bathing, toileting, dressing, and eating (also known as activities of daily living, ADL) or with services such as grocery shopping and meal preparation, getting to medical appointments, home maintenance, or multiple medication management.
- People with chronic health conditions such as cancer, diabetes, and arthritis may need assistance navigating complex health-care systems, managing symptoms and medication side effects and maintaining a good quality of life.
- Adults and children with intellectual disabilities or developmental disabilities may require assistance with ensuring that their basic needs are met while their rights are respected and protected. They may also need assistance with accessing and coordinating the support needed for health, well-being, independence, and opportunities for community inclusion, integrated employment, and self-determination. Whether an individual with disabilities lives with a family caregiver or in their own home, parents and other family members often provide medical, behavioral, financial, and other daily supports beyond what most families provide, and they provide this assistance across the lifespan of the person with intellectual or developmental disabilities.[47]

In recent years, attention has been given to measuring the financial impact of family caregiving such as lost wages, reduction in workforce participation, and out-of-pocket costs that caregivers often incur for meals, transportation, medical supplies, toys, educational tools, home modifications, and more. Family caregivers sacrifice an estimated $522 billion (about $1,600 per person in the U.S.) in wages each year due to caregiving, and associated productivity losses cost employers an estimated $33 billion annually.[48]

The Cost of Caregiving

> "My wife and I have had to move in with our parents to care for them. At this point because of the financial weight of this decision and the time necessary for supporting my parents, we cannot see ourselves being able to afford a family of our own in our early 30s."
>
> Interview with a family caregiver

Without adequate resources, family caregiving often affects caregivers' own physical and emotional health and well-being, contributing to financial strain. These negative consequences are felt most acutely by women. Women make up nearly two-thirds of family caregivers and leave the workforce three times more frequently than men to provide this care.[49] Family caregivers provide an average of 18 hours of unpaid care per week, a commitment frequently overlooked by policymakers. According to one estimate, in 2017, the value of unpaid care provided to elders by family members was $470 billion nationally.[50]

If compensated at the state minimum wage $16.28 per hour, unpaid caregivers would earn an extra $15,238 annually. Family caregivers in Washington may receive payment if the person they care for qualifies for Medicaid providing they are not their spouse. *See Appendix E.*

Policy Approaches and Trends

While the federal Family and Medical Leave Act allows eligible employees to take unpaid leave for medical or family reasons, some states including Washington have implemented paid leave laws. These provisions vary from state to state, e.g., Maine's new family leave law provides up to 12 weeks of paid leave per calendar year compared with 16 weeks in Washington. In addition, new approaches to family caregiving compensation are becoming more common. Oklahoma provides up to $3,000 annually in tax credits. Utah offers direct payments for caregiving work through Medicaid as does Washington.

A new proposal from the Centers for Medicare and Medicaid Services (CMS) would authorize Medicare payments to health-care professionals to train family caregivers in a range of activities from managing medications to helping with daily activities. This would support states in rolling out more effective and nimble training and certification processes. Louisiana has created a new trust fund that will place 12% of any excess revenue in a given budget year into an account to be used for home and community-based needs. AARP supports a family caregiver tax credit, integrating caregivers into Medicare, and ensuring a high standard of care.[51]

And finally, the Washington Cares Trust Fund, initiated in July 2023, is an innovative public long-term care insurance program designed to be available to pay for needed care, including care provided by family caregivers.

Summary

Without the support of family caregivers, millions of elders would find themselves with no choice but to move to more costly nursing homes and other institutional and congregate settings.[52] More than half of all family caregivers (53%) feel they currently have no choice about taking on the role of caregiving.[53] Importantly, the burden of caregiving primarily impacts women and disproportionally affects families of color. For example, Black, American Indian and Alaska Native children are more likely to live with grandparents.[54] The effects of our caregiving policies weigh most heavily on women from disadvantaged and under-resourced communities already overwhelmed with economic challenges, poorer health outcomes, and lack of systems support.

Paid Caregivers

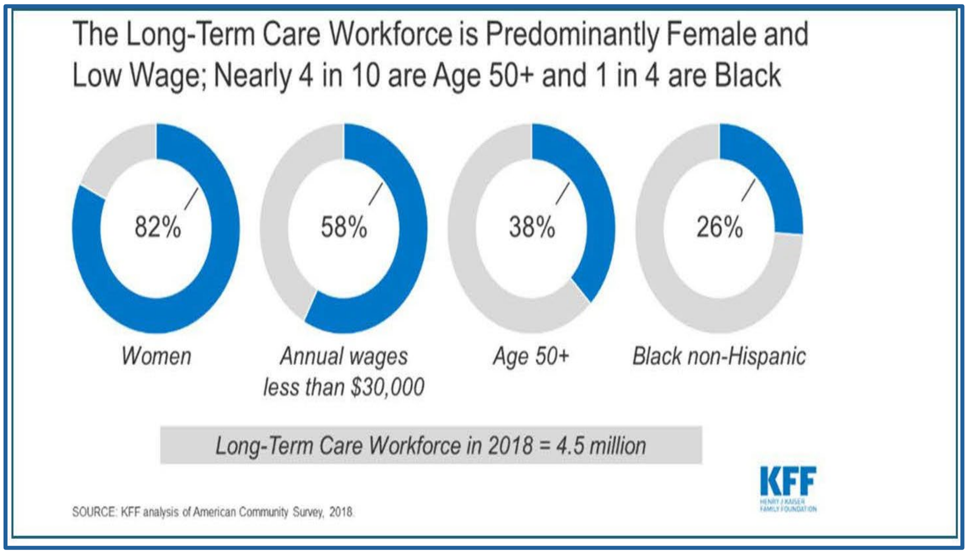
> "Care workers, disproportionately women of color, are among the lowest paid in our country and often have to rely on public benefits despite working complex and demanding jobs."
>
> White House Executive Order, 2023

The White House issued an Executive Order on April 18, 2023,[55] to address the need for direct care workers across the long-term care system stating that they are disproportionately women of color and among the lowest paid workers in the U.S. More than half of workers leave their jobs each year and 75% of long-term care providers report being unable to accept new clients due to lack of caregivers. Eight million long-term care job openings are anticipated in the next decade.[56]

What Do We Know About Paid Caregivers? Home care workers, which include paid caregivers along with home health aides, and some nursing assistants, support more than 9.8 million older adults and people with disabilities living in homes. The home care workforce grew from 1.4 million in 2014 to more than 2.9 million in 2023. Wages increased from 2022 to 2023 but remain low.[57] [58]

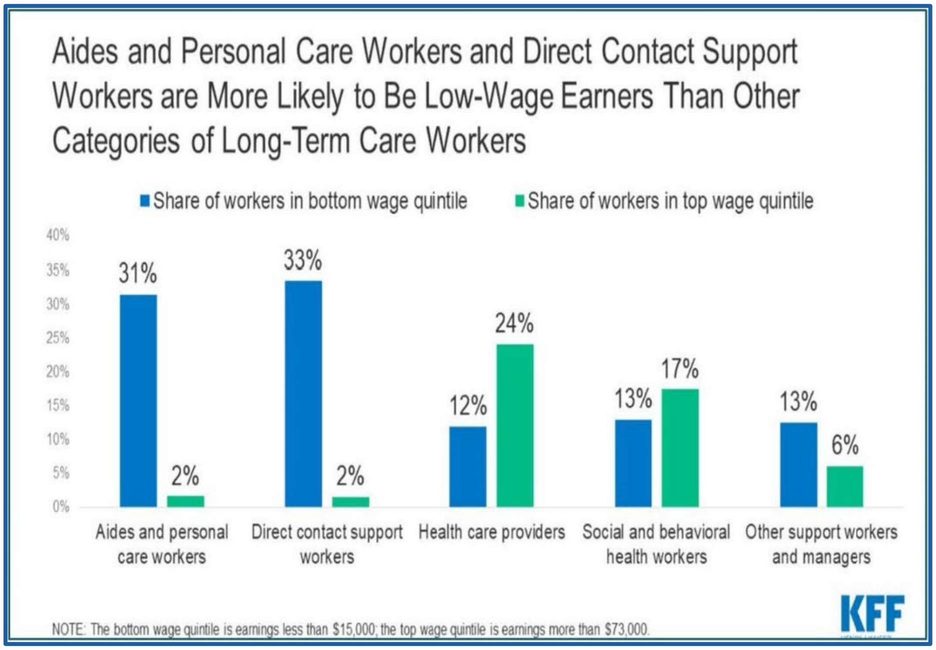
- Most paid caregivers work part-time, and their hourly wages are dependent on the geographic region in which they work, ranging from a low of $8.76 in Louisiana to a high of $17.45 in Massachusetts.[59] Overall, home care worker median hourly wages grew from $12.69 in 2014 to $16.13 in 2023 (adjusted for inflation).[60]
- A study completed by PHI, a non-profit organization focused on improving long-term care through quality jobs, finds that home-care workers are primarily women, people of color and immigrants. By sex, 84% of workers are female and 16% male. Thirty-three percent are White, 27% Black, 26% Hispanic and 9% Asian or Pacific Islander. Immigrants are 32% of the home care workforce. The median age for workers is 47. Home care workers assist clients with daily activities and commonly provide companionship, respite care, and transportation.[61]
- A substantial number of paid caregivers in Washington state are unionized through SEIU 755. While caregivers reported ongoing concerns about their work, they noted that wages and benefits have improved in recent years.

Figure 3: Long-Term Care Workforce (Kaiser Family Foundation, 2018)



SOURCE: KFF analysis of American Community Survey, 2018.

Figure 4: Direct Contact Workers More Likely to Be Low-Wage Workers (Kaiser Family Foundation)



NOTE: The bottom wage quintile is earnings less than $15,000; the top wage quintile is earnings more than $73,000.

Types of Paid Caregivers

Paid caregivers are either private pay or public pay. Private pay is when an individual pays the caregiver or agency directly. Public pay is when the caregiver is paid through a government program. Direct private pay rates vary the most but do not include caregiver benefits, e.g., health insurance. Most publicly funded agencies compensate employees for training and offer health care and retirement benefits. Benefits at private pay agencies are generally less robust.

Pay and often health benefits end when a client is hospitalized or dies although an agency can place another client with the caregiver. Annual pay for caregivers varies depending on employer, union affiliation, and hours worked. At the current starting wage for union employers, a full-time caregiver would make approximately $45,000 a year.

- Family and non-family caregivers of Medicaid recipients can be paid for the care they provide through the Consumer Directed Personal Assistance Program administered by Consumer Direct Care Network Washington.
- Veterans can receive additional funds to pay for a caregiver through the aid and attendance program. Family and non-family members of veterans can be paid for the care they provide through the Program of Comprehensive Assistance for Family Caregivers program. Training is available from the county Area Agency on Aging.
- Individual Providers. Family and non-family members can choose to become certified as an individual provider. *See Appendix E.* Individual Providers are certified as home-care aides. Some are grandfathered out of being certified or do not need to because of their relationship or hours of care provided. If they are not a spouse caring for a spouse, and they are serving a Medicaid recipient, they can be paid by Medicaid. As an individual provider, they are affiliated with Consumer Direct Care Network Washington. The current wage range is $21.44 to $24.34. See Appendix E for home-care aide training.
- Agency caregivers are certified as home-care aides. They too can be grandfathered out of being certified individual providers or do not need to be certified because of their relationship or hours of care provided. The support they receive varies by agency. They can have their training compensated and receive health care and retirement benefits. Agencies reimbursed by Medicaid typically follow the wages above while private agencies may have higher pay and fewer benefits. Agencies can be union or non-union.

Challenges and Possibilities

When asked what motivates them to work as caregivers, paid caregivers interviewed for this study uniformly talked about caring and connecting with their clients, supporting them to be as independent as possible, making a positive impact, and having flexible schedules. Most inspiring was their commitment to clients often choosing to stay connected with families even after the death of their family member.

Caregivers also expressed concerns. A majority said there was a lack of adequate compensation, benefits, and respect for their chosen profession. They were concerned with the system itself including burn-out, recruitment to maintain and grow the caregiver workforce, and lack of in-person training. Comments included, “This work can be fraught with physical risks, including injury with lifting, emotional stress, and violence, including sexual assault.” “There is a broad range of challenges from the often-temporary position of caring for the dying, injured, and aging, along with disabilities and mental health struggles."

According to the Kenan Institute, few jobs were affected by COVID-19 as much a direct care workers, leaving an already challenged industry with "historic staffing shortages."[62] This article argues that these shortages relate to the difficult nature of care work including challenging hours and low-wages. Second jobs are common for caregivers and a tight labor market has offered easier jobs with better compensation.

Among the recommendations included in the White House Executive Order are improved caregiver compensation, better connections between workers and Medicaid beneficiaries, access to health care and behavior health services for caregivers, expanded training pathways and learning opportunities for caregivers, and development of materials that explain the employment rights of noncitizen workers who are legally eligible to work.[63]

Summary

Estimates indicate that Washington elders 65 and older will nearly double by 2040 (increasing from 1.2 million to nearly 2 million people).[64] The ratio of workers 25-54 years to elders 75 and over is expected to drop from six to one in 2020 to four to one in 2030.[65]

The data is convincing--avoiding a full-blown crisis in caregiving will require a commitment to recruiting and retaining caregivers. This means making it a career with professional recognition, significant improvements in compensation and benefits, stability of employment, better work conditions, and improved training requirements and opportunities for continuing education.

Chapter 4: State and Federal Policy and Programs

This chapter provides context about elder caregiving in Washington including from the historical perspective and state and federal policy and programs. The first section, Washington State History: Rebalancing, focuses on Washington's long-term strategy of prioritizing home and community-based services. The second section addresses the role of Medicaid in funding long-term care and how spousal transfer of assets and Medicaid Estate Recovery create disincentives for elders in accessing services through Medicaid. The final section discusses Washington state priorities and programs and how these relate to federal programs.

Washington State History: Rebalancing

Washington State Emphasis on Home and Community-Based Care

> Washington state DSHS saved $4.9 billion from June 1999 to June 2020 by rebalancing $$ from nursing homes to community-based care.

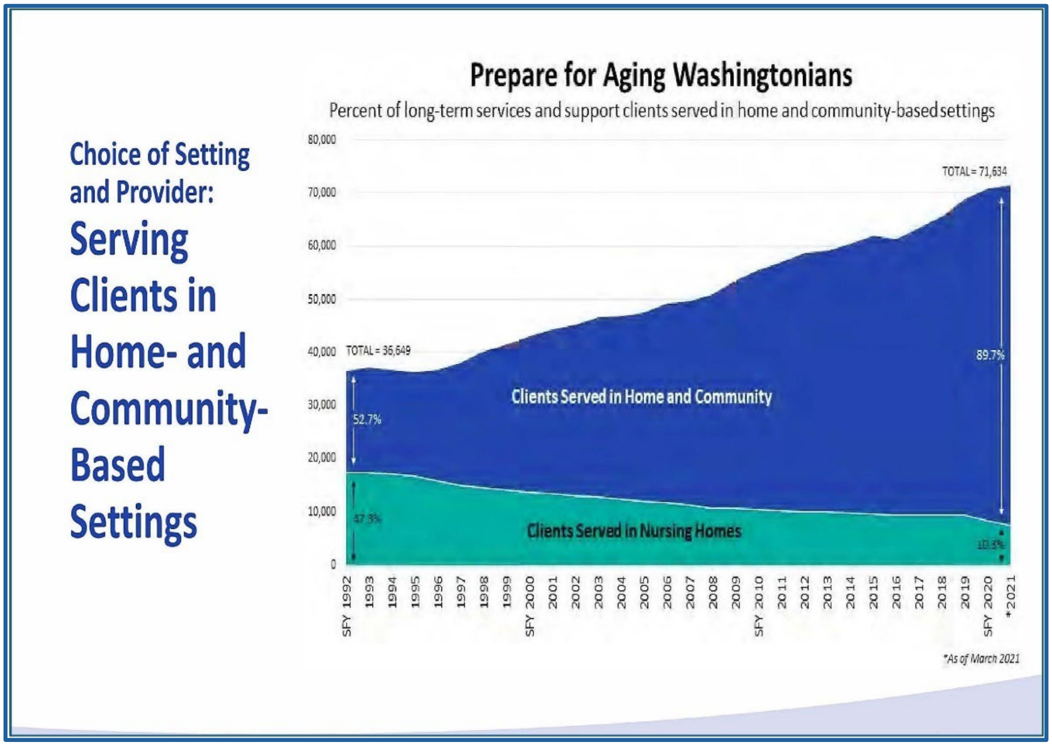
Rebalancing away from nursing homes to home and community-based care saved Washington state $4.9 billion from June 1999 to June 2020.[66]

Responding to increased demand for publicly funded long-term care, rapidly growing costs for facility-based care, and inadequacy of community alternatives, Washington formed a task force in 1981 to examine long-term care.[67] In 1984, steps were taken to control the growth of nursing homes[68] and in 1995, the legislature authorized limits on nursing home use through diversion and voluntary relocation. The 1996 State Long-Term Care Options Program Strategic Plan called for further expansion and quality improvement in home and community services.[69] Included was a proposed reduction in the nursing home caseload from 15,000 in 1996 to 12,000 in 2003.

This emphasis is reflected in current patterns of service delivery and Medicaid expenditures in Washington. According to Aging and Long-Term Services Administration, in 1992 the state served 52.7% of clients in home and community-based settings; by March 2021, this had risen to 89.7%.[70] See Figure 5.

Similarly, Kaiser Family Foundation finds that of Medicaid enrollees in Washington who used any long-term services and support in 2021, 9% received only institutional care while 91% used home and community-based support. By comparison, seven states including Arkansas, Florida, Louisiana, Maine, Mississippi, Nebraska, and Tennessee served 40% to 50% of LTSS enrollees in institutional settings.[71]

Figure 5: Serving Clients in Home- and Community-Based Settings (DSHS. 2023)



Choice of Setting and Provider:

Serving Clients in Home- and Community-Based Settings

Medicaid, Medicaid Estate Recovery, and Spousal Transfer of Assets

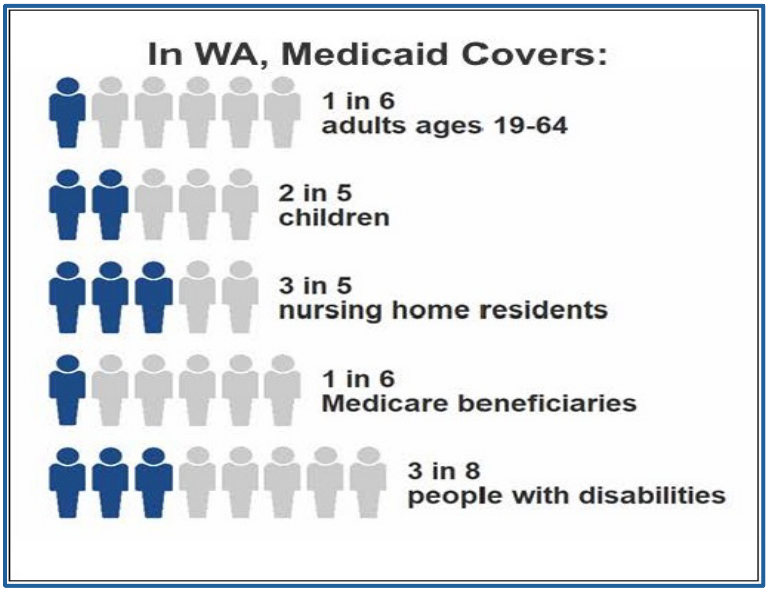
> As one elder care adviser said, "Once there's a crisis that requires placement in a facility, for most elders, it's only a matter of time until their funds are gone, and Medicaid becomes the only option for paying for long-term care."

Medicaid was signed into law in 1965 along with Medicare. Jointly funded by Federal and state governments, Medicaid provides health coverage for low-income people.[72] All states, the District of Columbia, and U.S. territories have Medicaid programs and must follow Federal requirements. However, they do have flexibility which results in variations in Medicaid coverage across the country. Medicare, on the other hand, provides federal health coverage for individuals 65 years and older as well as younger people with disabilities. It does not cover long-term care except in limited circumstances.

Nationally, Medicaid is the primary source of long-term care funding. In 2022, Medicaid paid for more than half of the $415 billion spent on long-term care in the United States.[73] While only

14% of Washington State Medicaid enrollees are elderly and disabled, this population accounts for 40% of state Medicaid expenditures, and Medicaid covers the costs for 60% of nursing home residents in Washington.[74]

Figure 6: Medicaid in Washington State (Kaiser Family Foundation, Aug. 2024)



While Medicare provides health-care services for elders 65 years and older (and people under 65 with long-term disabilities) its coverage for long-term services is limited to a maximum of 100 days of rehabilitation following a qualified hospital stay. On a limited basis, Medicare will cover home health services for those who are homebound and in need of skilled nursing services. As noted in Chapter 2, Kaiser Family Foundation finds that 40% of adults incorrectly believe Medicare will cover long-term care for low-income elders including home and facility-based care.[75]

While 8.9% of the Washington state budget is spent on long-term care (2023-25 biennium), elders must spend their savings down to $2,000 to be eligible for Medicaid-funded long-term care services.

Medicaid clients receiving long-term care services in Washington are likely to be more diverse than two decades ago, receive in-home and community-based care as their first service, get more than two years of services (51%), and receive care that is more costly if they have a dementia diagnosis.[76]

Medicaid Estate Recovery

Prioritization of home and community-based care in Washington State was accompanied by Medicaid Estate Recovery. This is the process the state uses to seek reimbursement for long-term care and other medical services provided to individuals. Since estate recovery was implemented in 1987, the age at which individuals become subject to estate recovery was reduced from 65 to

55 years, asset exemptions were reduced, and the services subject to estate recovery broadened.[77] These changes were at least partially required by federal Medicaid rules.

> Estate recovery disproportionately impacts low-income and families of color who are less likely than more affluent families to avoid recovery through estate planning. As one family caregiver of color said, "We couldn't afford paid caregivers. The required spend-down would have meant losing our income from the small properties our parents worked to acquire over their lifetimes and earned income from. We believed we would lose everything."

Under current state regulations, recovery is deferred while there is a surviving child under 21 or who is blind or disabled; until the death of a surviving spouse; or if the estate is the sole income-producing asset and income is limited or recovery would cause undue hardship for a qualified individual. Certain properties owned by American Indians/Alaska natives are not subject to estate recovery.

In 1993, Federal law mandated states to implement estate recovery programs although states have flexibility as to which services are subject to estate recovery and may establish hardship exemptions. In recent years, there have been attempts to change Federal law governing estate recovery, due to concerns about how estate recovery disproportionately impacts low-income and families of color who are less likely than more affluent families to have the resources to avoid recovery through estate planning.[78]

Also concerning are stories that fears about losing the family home through estate recovery can act as a barrier to elders receiving needed long-term services and support. This can lead to increased hospitalization costs that may have been prevented if services had been provided earlier.

From July 2022 through June 2023, $23,606,111 (nearly two million a month) was collected by the Office of Financial Recovery under Medicaid Estate Recovery; the July 2023 through June 2024 total was slightly more at $23,854,339. Information about the number of recoveries and costs of making these recoveries was requested, but the Office of Financial Recovery said this information is not readily available. In its Report to Congress, the Medicaid and State Children's Health Insurance Program (CHIP) Payment and Access Commission questions the cost effectiveness of estate recovery.[79] This is an area for further examination in Washington state.

Consistent with Governor Inslee's Executive Order 21-05, Reducing Intergenerational Poverty in Washington,[80] DSHS and the Health Care Authority proposed changes to what is covered by Medicaid Estate Recovery. This proposal did not move forward as DSHS-request legislation.

However, Senate Bill 5318,[81] sponsored in 2023 by Senators Nobles, Kuderer, Nguyen and C. Wilson would have modified lien provisions and recovery prior to the death of certain individuals. The bill failed to pass the legislature in 2023 and 2024.

At the federal level, Rep. Jan Schakowsky from Illinois has again introduced the Stop Unfair Medicaid Recoveries Act of 2024 (which failed to pass in 2023). This legislation is "to repeal the federal mandate requiring state Medicaid programs to go after families and estates for repayment of Medicaid long-term care services." The Act is endorsed by Justice in Aging, Center for Medicare Advocacy, National Consumer Voice for Quality Long-Term Care, National Health Law Program (NHeLP), and Families USA.[82]

Washington state officials say they are now waiting to see what happens at the federal level. California, however, recently passed legislation limiting Medicaid estate recovery to the minimum required under Federal law.[83]

Spousal Transfer of Assets

In Washington state, all assets of a married couple are considered owned jointly. This is true regardless of the long-term Medicaid program for which an elder is applying and regardless of whether one or both spouses are applicants. There is, however, a community spouse resource allowance which protects a larger amount of a couple's countable assets for the non-applicant spouse of a nursing home Medicaid or a Medicaid waiver applicant, i.e., home and community-based services. The person requiring care is considered the "institutionalized" spouse.

Another policy that can potentially contribute to the impoverishment of a family system is the current Washington rule regarding spousal transfer of assets. In 2024, the Washington state community spouse resource allowance is $68,301 and the 2024 federal limit is $154,140. "Increasing the community spouse resource limit to the federal maximum community spouse resource standard for Medicaid is a fair and compassionate policy that would benefit many low-income families. The current limit is too low and forces many spouses to live in poverty or spend down their assets to qualify for assistance. By raising the limit, the state would allow more spouses to keep a reasonable amount of resources and maintain their dignity and quality of life. This policy would also reduce administrative costs and complexity for the state and applicants. The state should adopt the federal CSRA as soon as possible."[84]

Examples of how this works:

- The total combined resource value is $80,000. That amount is divided in half to $40,000. If the new total (half of the combined total) is below the state maximum, then up to the state maximum ($68,301) is allowed for the community spouse to keep.
- Total combined resource value is $350,000. This is divided in half ($175,000). If the new total is over the federal maximum, then the federal limit is applied, $154,140 in 2024. The community spouse would be allowed to keep this asset amount.

- Total combined resources are $150,000; divided in half, $75,000. If that is between the state and federal standards, then the allowance is half of the combined total. The amount the community spouse can retain is $75,000.

Adopting the Federal allowance of $154,140 for Washington Medicaid eligibility for nursing home and home and community-based programs would lessen the financial burden on the spouse trying to maintain their home. This would require a change to the Washington Administrative Code (WAC 182-513-1363) that addresses "transfer of assets for clients applying for or receiving long-term care."[85]

Federal and State Programs and Priorities

Federal: Older Americans Act and National Support for Family Caregivers

The Older Americans Act was passed by Congress in 1965 to improve the availability of services for elders. The Act authorized grants for community planning and social services, research and development projects, and personnel training in the field of aging.[86] The Act serves as the major vehicle for organization and delivery of social and nutrition services to elders and their caregivers. Services are provided nationally through 56 state agencies, 618 area agencies, nearly 20,000 service providers, and 281 Tribal organizations and one Native Hawaiian organization representing 400 Tribes. The Administration for Community Living oversees implementation of the Act at the national level.

The Administration for Community Living 2022 National Strategy to Support Family Caregivers was created to support family caregivers of all ages, from youth to grandparents, regardless of where they live or what caregiving looks like for them and their loved ones.[87] The strategy was developed jointly by the advisory councils created by Recognize, Assist, Include, Support & Engage and the Supporting Grandparents Raising Grandchildren Act, with extensive input from the public, including family caregivers, and the people they support. The intent is to give family caregivers a voice in setting policy and advocacy for adequate funding. The strategy will be updated to evolve with the caregiving landscape.

Washington State Plan on Aging-2023-2027[88]

Washington State's Aging and Long-Term Support Administration administers federal programs under the Older Americans Act and has adopted several initiatives that align with the Administration on Community Living strategies. These are reflected in Washington's 2023-27 State Plan on Aging. It supports the choice and independence of older adults through an array of long-term services and support. By partnering closely with Washington's thirteen Area Agencies on Aging, tribal partners, and contracted service providers, ALTSA coordinates work toward implementation of the State Plan on Aging.

Three of the objectives in the State's Strategic Plan are particularly relevant to this study. They include:

1. The first objective under Goals/Strategic Plan (2023-2025) is to serve individuals in their own home or in community-based settings. At the core of Washington's long-term support network are the area agencies on aging and local service providers. They are contracted by the state to carry out several long-term care efforts within their planning and service areas. Many providers are funded in part by Older Americans Act or Medicaid. Non-Medicaid support services offered to eligible caregivers include but are not limited to:

   Community Living Connections, a collaborative approach to caregiver resource information and assistance that involves state and federal agencies; the Family Caregiver Support Program and kinship care; the Washington Cares Long Term Trust Fund; and person-centered care transition supports

   Those services funded through Medicaid begin with an assessment of an individual's functional and financial eligibility for long-term care. The ability to access information on available long-term services and support throughout the state is essential for individuals to get needed assistance. The Community Living Connections No Wrong Door initiative provides Washington residents with access to local private pay and/or publicly funded long-term care options. It also includes a management information system for providers to document services delivered. These programs use person-centered concepts and practices to promote choice, independence and safety of older Washingtonians when planning for future needs.

2. Person-centered planning is "a process for selecting and organizing the services and support that an older adult with a disability may need to live in the community" The second Strategic Plan objective is to develop and expand approaches to serve older adults (55 plus), Medicaid recipients and caregivers. The success of this action will be measured by evaluating the diversion or delay of individuals' need for more intensive Medicaid long-term services and support, emphasizing support for family caregivers, and increasing the proportion of family caregiver/care receiver pairs by three percent compared to individuals enrolled in the Tailored Supports for Older Adults by December 2025.

   Recognizing that unpaid caregivers are the backbone of our state's long-term care system, two programs were introduced in 2017 to support unpaid family caregivers or individuals who currently do not have an unpaid caregiver while also improving their own well-being. These programs were created under the auspices of the Medicaid Transformation Demonstration Program. They include the following:

   - *Medicaid Alternative Care:* The care receiver must be 55+ and the caregiver must be 18+ in age. It requires that the care recipient currently be eligible for Medicaid. The care receiver must require help with some activities of daily living such as bathing, assistance with walking, medications, transfers, etc. The maximum allotment in a six-month period is $5,064.

- *Tailored Supports for Older Adults:* The care receiver must be 55+ and the caregiver must be 18+ in age. Medicaid eligibility is not a requirement and income and resources can be above the Medicaid guidelines. As with Medicaid Alternative Care, the care recipient must require assistance with basic activities. Currently, the maximum allocation to cover the services needed is $5,064 for a six-month period, which can be extended through an exception to rule approved by the DSHS staff. In Planning and Service Area 11, consisting of five counties in eastern and northeastern Washington, including Spokane, this funding is typically used to cover the cost of in-home care hours provided through a licensed home-care agency and personal emergency response system.

Three additional programs intended to support clients and caregivers are noteworthy including:

- *The Family Caregiver Support Program*: A service available to unpaid caregivers of adults needing care who reside in Washington. Seventy percent of services are funded by the state. Assistance includes help finding local resources and caregiver support groups and counseling. Respite care can be authorized but is limited due to a lack of funding. The T-Care (Tailored Caregiver Assessment and Referral) tool is used to determine the unique needs of the unpaid caregiver. Depending on income and resources, a contribution toward the cost of care can be required which can be a deterrent to receiving services in some situations. Agency support service providers recommend that large employers and insurance companies be educated about the needs of family caregivers and encouraged to support them through adoption of supportive organization policies.
- *Assistive Technology:* AI has been implemented in the state through several programs and pilots. The Roads to Community Living Demonstration Project allows clients and caregivers to access assistive technology and training to improve functional capabilities while transitioning from residential settings back into the community. Washington has partnered with Trualta, a free family caregiver training platform at wacaregivingjourney.com that provides online education and social forum for unpaid caregivers. During the pandemic, this became a crucial tool offering quick lessons on personal care, injury prevention, dementia, and caregiver wellness, among other topics.
- *The Washington Cares Trust Fund*: An innovative state program that provides another source of funding for future elder care needs. Started in July 2023, Washington Cares is a public long-term care insurance program into which working Washingtonians contribute a small percentage of their income (0.58% of gross wages). When care is

needed, an earned benefit of up to $36,000 (adjusted up to inflation) can be accessed for services including for care provided by family members. This payroll contribution is mandatory for certain classifications of workers. Care needs are evaluated to determine if assistance is required with three or more activities of daily living. These may include mobility, personal hygiene, eating and medication, and cognitive functioning.

3. Workforce development is the third objective in the state's strategic plan. This includes increasing participation in Home Care Aide training among local high schools, skills centers, and tribal schools. It also designs and deploys resources to increase worker retention and bring greater visibility to the vital work of direct care workers through education and outreach. One group in the state, Caregiver Careers Washington, has launched a campaign with messaging that promotes "Caregiving is HEART work!" The website[89] includes information on different types of caregiver roles, caregiver stories, and FAQs regarding employment requirements and benefits. It is intended to professionalize, recruit and retain caregivers to respond to the ever-growing need in our state for long-term care.

   Registration, training and certification are essential to the onboarding of paid caregivers in the state's long-term care system. The Department of Health's Office of Health Professions is responsible for the necessary vetting of individuals who wish to be employed as home care aides and other related positions. A backlog of applicants has developed over time. Senate Bill 5278 was passed in 2024 to reduce barriers to the home care aide certification process. The Department of Health is currently working on a pilot project designed to reduce delays between training and testing for home care aides by integrating the two to allow applicants to test where they train. There is a provision to allow remote testing within training programs immediately or shortly after completion. This rule change helps to address the challenges due to travel time in rural areas of the state.

Chapter 5: Proven Models and Promising Innovations

For every dollar spent on medical care in Europe, $1.76 is spent on social services. By contrast, 56 cents is spent on social services in the U.S. for every dollar spent on medical care.

The American Health Care Paradox by Bradley and Taylor highlights the difference between social service spending in Europe and the U.S.[90] In this chapter, existing models of elder care and caregiving strategies are presented from around the world, the United States, and in Washington state. Differences between prevailing social systems and how elder care is supported are examined. Observations about what is working including the promise of artificial intelligence (AI) and technology are discussed. [91]

Overview

Models of elder care with similar elements exist throughout the world and are adapted to suit the cultures of individual communities and their contexts. Elements recurring in many of these successful models include a person-centered approach, use of an interdisciplinary team analysis for care planning, focus on care transitions, care management and the integration of medical social care.[92]

Europe and other first world nations are ahead of the United States in developing both models of care and strategies of caregiving for elders. As with other critical safety system supports, care for the elderly in the European Union is enshrined as one of the pillars of social rights.[93] This approach allows elder care to be shifted from being the sole responsibility of families or a single individual to being shared with the state; alleviating much of the care burdens that women experience.[94] Other pillars of social rights include paid family leave and child care which further lessen the burden. Additionally, housing, healthcare, food security, and long-term care complete the pillars of support.[95] A systematic safety net as used in European countries is more likely to prevent the all-too-common financial devastation experienced by families in the United States, especially women, to qualify for needed Medicaid benefits.

In the United States eldercare is directed primarily through families and social service supports. Elders on their own, without family or other support systems, can rapidly deteriorate clinically and land in overburdened emergency rooms, with nowhere to go. This has been the case in Washington state, especially in under-resourced communities where elders languish when services are lacking.[96] For every dollar spent on medical care in Europe, $1.76 is also spent on social services. Contrast this with the United States where only 56 cents is spent on social services for every dollar spent on medical care.[97]

As previously discussed in Chapter 2, private equity concerns in the home health care arena are growing[98] but less is known about those investments in home care itself. Europe and other countries rely on universal healthcare which is usually paid for by single payor systems[99] with low administrative overhead like our Medicare system in the U. S. Recognition of the cost-effectiveness of social services as comprising much of the care most people really need regardless of age, and which results in reduced medical care has been demonstrated resulting in improved elder outcomes.[100]

In the context of caregiving, when social services connect elders and their families to caregiving support, housing, food services, and child care, misplaced reliance on medical care is reduced. This requires a shift in our funding of an adequate social safety net and the political will to make this shift. However, some signs of progress have been made with the passage of the Affordable Care Act, and with it, the demonstration that healthcare is a right not a privilege.

Holistic Framework for an Aging Society

A more integrated approach to the care of elders is reflected by the framework below, adapted from the Frame Works Institute. The basic structure has been expanded to include policy examples from this study, providing an overview of what needs to be addressed to support healthy aging.[101]

- *Public institutes and infrastructure:* Successful adaptation to an aging society will require adjustments in all sectors of public life e.g., education, planning for retirement and financial literacy, employment, retirement, health care, transportation, urban planning, housing, etc.
- *Civic and social contributions:* Redesign social policies to facilitate the contributions of older adults and expand opportunities for lifelong learning and service allowing elders to be part of the solution rather than the problem.
- *Public spending:* Manage and spend resources more efficiently to provide for the health care and retirement income security of older adults. This should include the design of a robust system to connect caregivers and elders with existing elder resources such as in the Statewide Health Insurance Benefits Advisors model of volunteers.[102]
- *Retirement security:* Ensure retirement income security for older adults, e.g., by expanding and strengthening Social Security and rethinking policies including training to help elders become financially literate.
- *Healthcare workforce and long-term care:*
    - Improve geriatric training for all health-care workers to prepare them to meet the needs of an aging population.
    - Expand the scope of practice of health-care workers in all areas concerning elder care to alleviate some of the shortages currently experienced.

  - Lift-up the role of the home care worker with improved income and benefits.
  - Provide public insurance options for long-term care such as the previously described Washington Cares Fund.
  - Expand Medicare to cover home care.
- *Caregiver support:* Provide better institutional, social and financial support to family caregivers.
- *Research investment:* Invest in research to better understand the aging process and the economic, civic and social implications of an aging society.
- *Ageism:* Identify and call-out ageism wherever it appears; incorporate into policies, programs and practices.

Models Near and Far

Less developed countries are also implementing services or successful models that work well for elders residing in the community. An example is Brazil's Rio de Janeiro Copacabana neighborhood. After moving there in the 1950s and 1960s, many of the 6500 residents are happily aging in place due, in part, to a creative training program developed by gerontologist, Dr. Andre Kalache.[103] Doormen from each apartment building in the neighborhood are trained to become the eyes and ears for family members. The door attendants keep their eye on the residents and take care of day-to-day issues they may have difficulty with. They also connect residents with social services when necessary or requested because their training helps in identifying potential needs.

Most models seek to meet the expectations of an aging population who wish to stay in their own homes supported with wanted or needed resources as warranted. Mirroring the Copacabana neighborhood model without the paid staff, the best and most replicated is the Village-to-Village Model.[104] Known internationally, it was originally conceived in the U.S. and founded in the Beacon Hill neighborhood of Boston in 2001. It grew to become a Network in 2010 boasting 264 Village member communities as of 2024 with 64 currently in development.[105] The Villages rely primarily on member volunteers who help each other by providing transportation, support during illnesses, minor home repairs and other functions. Individual villages are very different and develop based on the needs, wants, and talents of the members.

The Village Model requires more replication in ethnically and racially diverse communities, however the model itself is much like mutual aid groups.[106] These groups tend to occur organically as need arises. The Seattle Model[107] which arose during COVID to meet the needs of queer women of color, serves the needs of group members.

CAPABLE: Community Aging in Place-Advancing Better Living for Elders

Another model with paid professional employees addressing low-income elder residents' needs is CAPABLE (Community Aging in Place-Advancing Better Living for Elders).[108] CAPABLE was developed by the School of Nursing at Johns Hopkins University. It is a person-directed home-based program that addresses function while also reining in medical expenses. The program combines Occupational Therapy, a Registered Nurse as a case manager, and a handy person for minor repairs who together with the older adult, set goals and formulate action plans.[109] It has been highly effective at improving overall health outcomes and reducing health-care costs while also addressing and improving health equity. There is an initial four-to-five-month period spent developing an individualized program per person which costs $3,000. This results in an approximately $30,000 reduction in health-care services costs in comparative populations studies.

Compared with models such as continuing care residence communities typically focused on elders who are financially well off,[110] the CAPABLE Model and others such as the mutual aid organizations previously described, focus on under-resourced and lower income populations. A model akin to the continuing care communities is the Almshouse Model[111] increasingly being reinvigorated in the United Kingdom but without the connotations of punishing the poor. The original form dates to the medieval period in the United Kingdom (circa 990) when religious institutions provided support to the poor and in that era were also primarily hospitals. Present day Almshouse Models in the United Kingdom are run by secular charity organizations with governmental support for the growing low-income, aging population. The model is again being used, modernized and expanded to include supportive care and services in the United Kingdom.

PACE: Program of All Inclusive Care for the Elderly

PACE programs[112] are primarily focused on the frail elderly on Medicare who are also eligible for Medicaid and still reside in the community. On the surface, PACE programs are extremely comprehensive, typically including an interdisciplinary team of providers who design an individualized care plan. The cost for the program is based on a capitated[113] or set fee amount from Medicaid and Medicare and although not mandated by the Centers for Medicare and Medicate Services, PACE programs are typically delivered by Medicare Advantage programs for a capitated monthly amount. An individual who is not eligible for Medicaid but has Medicare must pay the same capitated amount to participate. Medical services along with home care, adult day care, outpatient and inpatient hospital care as well as transportation are included. Social services are integral to the plans. Services are primarily delivered in an adult health-care center and in the home if required.

End of life services are part of the program. However, if hospice care is elected, the individual must disenroll from the PACE program as hospice can be seen as an equivalent comprehensive program.[114] PACE programs have a large footprint in Washington state with ten individual programs. All but three of these programs are managed by Providence, a large religious-based health-care industry provider.[115]

Medicare Advantage

Medicare Advantage plans, which are primarily owned by private insurance companies, have rapidly gained a share of the total Medicare healthcare market in Washington.[116] Similar to employer-based healthcare and operated as Health Maintenance Organizations (HMOs) or Preferred Provider Organizations (PPOS), these plans require prior authorizations for services such as specialist care and types of testing with high price tags. Additionally, some companies have a history of delaying care leading to denials of care. They also use restricted health-care networks which can limit access to healthcare providers and facilities as compared with traditional Medicare where an open network can make getting an appointment quicker if adequate numbers of providers are available.

Especially concerning as relates to marginalized and underserved communities, Medicare Advantage plans with limited approved medical providers are willing to accept Medicaid covered individuals. These individuals frequently opt for Medicare Advantage plans because they offer additional services traditional Medicare does not. These may include a basic pharmaceutical formulary, limited dental and vision care and often gym membership and other services including hearing aids. Traditional Medicare without a Medi-Gap policy to bridge the gap can be financially catastrophic for elders with limited resources who require hospitalization or specialty care.

While Medicare Advantage plans have significant potential with their greater programming flexibility, abuse exists and requires correction. Administrative costs differ for Medicare Advantage programs (10-20 percent) vs. traditional Medicare (1.5-2 percent).[117] With over 50% of the potential Medicare market, [118] the Centers for Medicare Services estimates it will pay Medicare Advantage plans 126% of the amount paid for similar enrollees in Traditional Medicare in 2024. This translates to $88 billion in expenditures from Medicare.[119] Some of these costs may not be spent on care but on marketing and administrative benefits, salaries, and redundant staffing that might be better allocated if Medicare offered the crucial vision, hearing, and podiatry most elders require.

Washington State Models

Models from around the globe and in the United States have been repeated in Washington state and have been previously described including Village to Village, CAPABLE, mutual aid groups, PACEs, continuing care communities and others. Necessarily, well-established models are adapted for the needs of the state or community they serve along with the funding available or projected which make them unique. However, the underlying frameworks typically remain the same. Washington, however, has one model serving primarily disenfranchised populations which may well be unique and with potential generalizability to other communities in search of innovative solutions to reach marginalized and complex populations.

Tacoma's program is highlighted below but other communities have CARES programs including the Clark-Cowlitz Fire Rescue, North County Regional Fire Authority in Snohomish County, Puget Sound Regional Fire Authority, and Whatcom Ground-Level Response and Coordinated Engagement program (GRACE). Provisions for the program are codified in state statute and other communities, e.g., Thurston County, are adopting the program.[120]

City of Tacoma—TFD Cares Program

The Fire Department in Tacoma provides emergency and non-emergency services to residents on the streets, in homes, emergency departments, and by phone. The expanded program began in 2012 with funding from the Legislature. The Cares Team is a non-traditional team that primarily receives referrals from first responders to address individuals who make frequent 911 calls and who have complex chronic illnesses, complex psychiatric illnesses, limited social support, or substance use disorders. The team works to identify services for the individual so that they are not using 911 services for nonemergent care and services.[121]

Meeting Caregiving Demands with Innovation—The Hogeweyk

The Hogeweyk is the outcome of an innovative and disruptive vision on living, care and well-being for people with severe dementia.[122] It is a paradigm shift from nursing home care to community care of a different sort. Within the community, the traditional nursing home has been deinstitutionalized, transformed and normalized. The Hogeweyk is just like any other neighborhood that is part of the broader society in the town of Weesp, a suburb of Amsterdam.

In The Hogeweyk you will find houses where people live together based on similar lifestyles. They can visit the pub, restaurant, theater, the supermarket or one of the many clubs offered. The concept supports unique needs, lifestyles and personal preferences. Living in The Hogeweyk puts boredom, loneliness, and hopelessness in another perspective. It focusses on possibilities, not disabilities. This community is directed, staffed and supported by trained professionals.

Looking Forward: The Use of AI for In-Home Care and Dementia

> Aaron Labbé writes: “Many of us assume that AI adoption is a daunting process for older adults. We have this image of the struggling senior citizen, which clouds the product design process, often forcing a reluctance to push AI features within products for the aging population. This notion may have been valid at one point in time. Still, it remains an ageist assumption among those of a younger generation developing this tech, as research has shown that AI adoption is rapidly increasing for people aged 65+.”

Promise and opportunity to expand and improve care for elders in their home, in purpose-built communities such as The Hogeweyk, are due to the powerful development of artificial intelligence and the influence of technology in general. The same is true for other existing care models and in support of caregivers. The coexistence of human caregiving and AI innovation will be part of the future of eldercare resulting in a better balance between technological advancement and compassion. The reality is, as detailed in Chapter 3, future needs for in-home caregivers as well as all caregivers will be difficult to meet. Inevitably, AI and other technologies will provide a sizable portion of that care, and models will evolve.[123]

The eldercare industry is on the cusp of a major transformation: on the one hand the interest in the home health-care industry by private equity which has increased year over year and has potentially one of the highest returns for services that are reimbursed by Medicare. This concern may also increasingly apply to home care along with the increasing use of AI in this market.

On the other hand, there are many in-home and family caregivers who do what they do because of their concern for the people involved, many of whom have been caregivers in their lives and who themselves will soon need care. As technology evolves, more providers and thought leaders believe that AI will dictate a revolution in elder caregiving and that the numbers of elders requiring care dictate this potential reality.

> "Before I moved in with my mother as her care needs intensified, I set up a device she was able to access with her voice to call her sisters and listen to her favorite gospel songs. It brought her a measure of control and joy to life."
>
> Interview with family caregiver

Due to these technological innovations, the upcoming decade also suggests a shift in home health care moving from a reactive model to an AI-based proactive approach. This transition emphasizes preventive care and wellness, underscoring the importance of early intervention in health and social management. [124] When providing care in the home, because of a lack of planning and often training, caregivers may only respond to patient concerns as they arise, resulting in a more reactive approach.

Taking prevention a step further involves the integration of technologies that more readily identify potential issues leading to injury. These technologies may include systems alerting caregivers when high-risk patients attempt to get out of bed, thereby preventing falls or other problematic events before they happen or monitoring heart rhythms for concerning changes. These technologies provide a potential platform on which proactive care makes progress and better supports caregivers.[125]

Technology will also influence dementia care. There are two types of robots being used in the care and treatment of the elderly: service robots and social robots. Service robots are meant to offer companionship and provide cognitive stimulation. Many of the social robots have been designed to look like humans and provide intelligent conversations, play games and initiate activities.[126] This field is expanding to include detecting robots and social robots whose objective is to express feelings and emotions to improve acceptance by dementia patients, to improve people's moods, increase social interaction, give caregivers time for themselves, and reduce symptoms.

Artificial intelligence applications will potentially represent a significant cut in annual U.S. health-care costs by an estimated $150 billion in 2026. A large part of these cost reductions would stem from changing the healthcare model from the reactive to a proactive approach, focusing on health management rather than disease treatment.[127]

Summary

Successful models currently exist. Too often, however, they serve only the very frail with limited to no resources for individuals living independently with adequate resources. The findings of this study indicate the need to adapt the eldercare system to be more inclusive by providing the financial resources necessary to achieve the needs and goals of elders without bankrupting caregivers emotionally, physically, and/or financially.

Europe's example of how a social safety net can support family caregivers provides an instructive model. A system without resilient humans adequately nurtured and prioritized by a social safety net will ultimately benefit no one. Models that recognize elders' wishes to remain in their homes supported by family and other caregivers will require adaptation of our system and importantly, additional funding.

Conclusions

For more than four decades, Washington has been a national leader in prioritizing home and community-based care for elders. In state rankings by AARP and other national organizations, Washington rates among the top ten states on indicators of quality long-term care services. And, according to state estimates, the shift away from nursing homes to home and community-based care saved the state nearly five billion in tax dollars from June 1999 through June 2020.

And yet, data and research along with interviews of elders, family caregivers, paid caregivers, and others provide reason for concern especially given growth in the number of elders as a proportion of the population and caregiver shortages in coming years. Absent ongoing and additional funding for long-term care for elders, it would be possible to experience a situation analogous to what happened with deinstitutionalization in mental health. In considering Washington's ability to respond to the caregiving needs of elders in the next few years and decades, the workgroup identified five overarching areas of concern.

1. Exploring what it takes for elders to remain independent in their own homes and communities including:
    - Early retirement planning and savings
    - Health practices including the need to address loneliness
    - Community infrastructure, e.g., transportation and housing
    - Multi-sector state planning with consideration of models from across the nation and globe
2. Addressing the complexity of the elder care system and ways it might be easier for elders and their families to learn about and negotiate the system. This might include:
    - Streamlining and coordinating within the long-term care system and encouraging public-private partnerships at the state and local levels
    - A campaign to disseminate information about the system of caregiving in Washington state
    - Providing information and support to elders and their families analogous to the state health insurance program for Medicare services
3. Reevaluating the effects of our long-term care system's heavy reliance on family caregivers including:
    - Personal costs for caregivers and especially women and less advantaged communities
    - Availability of respite care
    - Supports and incentives for family caregiving such as tax credits
4. Focusing more attention on recruitment and retention of paid caregivers to meet current and projected caregiving needs:
    - Improved compensation and benefits
    - Better work conditions including stability of employment and health care

    - Addressing barriers to working in the field including transportation, housing, child care, and issues specific to rural communities
    - Improved training and continuing education including opportunities for in-person instruction
    - Creating a career ladder associated with roles and training requirements
5. Focusing on the challenges faced by lower- and middle-income elders and their families in paying for caregiving including:
    - Revising spousal asset retention policy
    - Revising Medicaid Estate Recovery policy
    - Strengthening the Washington Cares Trust Fund, Washington's public long-term care insurance program

Appendices

Appendix A: Study Purpose, Scope and Approach

This study, *Caregiving in Washington State: What exists and what is needed to support seniors and other vulnerable adults and their caregivers?* was approved by delegates at the 2023 LWVWA convention. With population aging, increasing numbers of Washingtonians will require long-term care to meet their basic needs. As this study demonstrates, this care falls disproportionately on family caregivers, predominantly women, many of whom are employed outside their homes.

Core Workgroup. A core workgroup of LWVWA members from across the state met at least biweekly starting in July 2023 to provide ongoing leadership to the study. Workgroup members brought with them years of expertise and experience with research and public policy, health-care policy and administration, and service delivery for elders at national, state and local levels.

Study Scope. The workgroup focused its work on vulnerable adults sixty years of age or older living in their own homes who lack the functional, mental, or physical ability to care for themselves. The term "elders" is used to refer to the over sixty population. Emphasis on in-home care is consistent with current state priorities for "aging in place" and the situation most elders say they want. However, safe, quality caregiving for all vulnerable adults in need of care is critically important. Many of the study findings are relevant to younger vulnerable adults as well as elders receiving care in nursing homes and other facilities.

Approach. An iterative research process consisting of three phases was used in this study. Phase I included a preliminary review of the research and data. Phase II involved qualitative interviews informed by what was learned in Phase I. In Phase III, based on issues raised during interviews with elders, family caregivers, and paid caregivers, additional literature review was conducted along with in-depth discussions with professionals who oversee elder caregiving-related programs.

Phase I: A review of research and data from federal and state sources was done. This included review of surveys with elders and caregivers conducted by organizations such as AARP, the Alzheimer's Association and other entities working in the field of elder care. There were also informal conversations with professionals working in the field, participation in meetings such as that of the Washington Senior Citizens Lobby and the Center for Medicare Advocacy, and work group discussions.

The initial study plan included preliminary research questions based on issues highlighted during literature review and discussions. Among the issues noted were the need for more family caregiver support including respite care, low caregiver wages, an insufficient pool of paid caregivers (now and in the future), need for more caregiver incentives, concerns about Medicaid estate recovery, and difficulties accessing information about eligibility requirements and services.

Based on Phase I research, the first in-depth interviews were with elders, family caregivers, and direct care workers[1], the people currently negotiating the caregiving system.

Phase II: During Phase II, interviews were completed with a sample[128] of elders, family caregivers, and direct-care workers. Using Phase 1 results, interview protocols and scripts were developed for each group of interviewees. Interviewees were identified by reaching out within the League, communities, and organizational. Efforts were made to achieve diversity in race and ethnicity, rural vs. urban, and economic circumstances. While most of the interviews were completed by telephone, a few were done in person and via Zoom. In total, qualitative interviews were completed with 33 elders, family caregivers and paid caregivers. *Demographic summaries and interview scripts are included as Appendix B and Appendix C.*

- *Elders:* Five in-depth semi-structured interviews were completed with elders. While more would have been desirable, the prevalence of dementia, other disabilities and death resulted in elders being unavailable for interview.[129] The elders interviewed ranged from their early 60s to more than 90 years of age. Four were female, one was male. Questions for elders included: their living situation, any help they get in managing daily activities, type of care preferred, how they learn about services and supports that may be available to them, challenges they have faced in getting the care they need, and circumstances that would cause them to reconsider their living situation or the kind of care they receive.
- *Family Caregivers:* Seventeen family caregivers were interviewed including eleven female and six male caregivers. Eleven caregivers were white, one Hispanic, two Puerto Rican, two Asian, one Brazilian and one Black. Five caregivers lived in rural Washington while the rest lived along the I-5 corridor. Four caregivers cared for husbands, three for wives, eight for mothers, and one for a friend. Questions for family caregivers included: hours of care; reason for care; types of care provided; whether they received compensation; challenging and rewarding parts of being a caregiver; additional help needed and received; effects on them as a caregiver; what they would do if money were not an issue; and what they envision for the future.
- *Paid Caregivers:* Eleven paid caregivers were interviewed ranging in age from early 30s to their 60s. Ten were female and one male; six were white, two were Black, and one each were Southeast Asian, Chinese and Latino. Questions for paid caregivers included: agency employee or independent worker; length of time working as a paid caregiver; motivation for doing this work; education and training; types of care provided; areas of specialization; hardest or most challenging part of their work; safety at work; worries for themselves and/or their clients; impact of work on their well-being and health; supervision received; and adequacy of compensation. The completed interviews were reviewed for themes by

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[1] While commonly referred to as paid caregivers, “direct care workers” or “direct care professionals” are the preferred terms for addressing workers paid to care for vulnerable persons.

workgroup members as well as outside reviewers. Overarching themes that emerged from the interviews included:

- Most elders want to remain independent in their own homes and communities.
- Elders and their families face challenges negotiating the elder care system including accessing information about the complex system of long-term care.
- Washington's system relies largely on family caregivers. The majority of family caregivers are women, who themselves are challenged by lack of respite care and personal costs.
- Lack of paid caregivers to meet current and projected needs is a serious challenge expected to get worse as the population ages; caregivers reported issues with lack of adequate compensation, continuity of health-care coverage, and respect as professionals.
- While even more affluent elders and their families experience difficulties accessing and retaining long-term care, the system works better for the reasonably well off who can pay privately as well as the very poor who are clearly eligible for Medicaid.

Phase III: Informed by our qualitative interviews with elders, family caregivers and paid caregivers, a wide-range of service providers and managers were interviewed. This included local agency administrators, a senior center executive director, an assisted living facility owner, a retired physician, a retired firefighter, professionals who counsel elders and their families, a retired attorney who worked for the state, and administrators with major organizations such as AARP and the Washington Senior Lobby. In addition to learning about their work, they were asked about gaps they see in our system of caregiving and changes to caregiving and/or funding they would like to see.

More in-depth information was needed about some issues that had emerged in interviews. This included AI, the role of private equity firms, current approaches to caregiver support, union involvement, and Medicaid Estate Recovery. In addition to further literature review, workgroup meetings were scheduled with subject matter experts.

These meetings included:

- Program Manager for the Family Caregiver Support Program with the Aging and Long-term Services Administration in the DSHS.
- Chair of the Washington State Senate Health & Long-Term Care Committee.
- Public Affairs Director with SEIU 775.
- DSHS and Health Care Authority HCA staff involved with Medicare Estate Recovery.

Appendix B: Demographics of Interviewees

	Elders		**Paid Caregivers**		**Family Caregivers**	
Number of Interviews	5		11		17	
Age	61-70	1	31-40	1	41-50	1
	71-80	2	41-50	5	51-60	4
	81-90	1	51-60	3	61-70	4
	91+	1	61-70	2	71-80	6
					81-90	2
Gender	Female-4 Male-1		Female-10 Male-1		Female-11 Male-6	
Ethnicity	White-5		African American-1 Black-Caribbean-1 Chinese-1 Latino-1 Southeast Asian-1 White-6		African American & mixed race-1 Brazilian/white-1 Filipino-1 Hispanic-1 Korean-1 Puerto Rican-1 White-11	
Location	Olympia-1 Lacey-2 Renton-1 Thurston County-1		Bellingham-1 Issaquah-1 Kent/Auburn-2 Lacey-1 Lynnwood-1 Pasco-1 Tacoma-1 County-1 Rural-1 Suburban-1		Bellevue-1 Bellingham-2 Lacey/Olympia-5 Seattle-2 Tacoma-1 Vancouver-1 Rural-5	
Marital Status	Divorced-1 Widowed-1 Married-3		Single-4 Married-4 Divorced-1 Widow-2		Single-2 Married-9 Divorced-1 Widowed-5	

	Elders	**Paid Caregivers**	**Family Caregivers**
Education	Less than high school-2 Bachelors-2 Masters-1	High school/GED-5 Some college-4 Bachelors-1 Masters-1	High School-2 Bachelors-8 Masters-5 PhD-1 Unknown-1
Career/Job	Engineer-1 Housewife-1 Interior Design-1 Misc. service jobs-1 Teacher/Activist-1	Caregiving-11 (1 person also does accounting)	Engineer-1 Homemaker-1 Medical-3 Sales, Business, & Management-4 Social worker-2 Software/Tech & Training-1 State employee-1 Teacher-3 Unknown-1
Income	Less than $25,000-1 $25-75,000-2 75-125,000-1 Prefer not to say-2	<25,000-1 25-75,000-4 75-100,000-2 Hourly-$15-$24-1 Prefer not to say-3	$25-75,000-2 75,000-125,000-7 Over 125,000-2 Prefer not to say-6
Health Care	Medicaid-1 Medicare-2 Medicare Advantage-1 Medicare & Aetna-1	Private-7 (incl SEIU) Private & state-3 None-1	Apple Health (state)-1 Medicaid-1 Medicare-2 Medicare+Private-10 Private-3
Relationship (to person in need of care)	Self-5	*Provide caregiving:* Through Agency-5 Independently-2 Both agency and independently-4	Adult children and husband-1 Friend-1 Husband-3 Mother-8 Mother of partner-1 Wife-3

Appendix C: Elder Caregiving Study: Interview Script

Elders (B), Family Caregivers (C1) and Paid Caregivers (C2)

Interview done by:
Date:
Format: in person, phone, virtual

Information about Study
In June 2023, the League of Women Voters of Washington (LWVWA) approved a two-year study of caregiving for vulnerable adults. The study focuses on people sixty years of age or older residing in their own homes who lack the functional, mental, or physical ability to care for themselves without help.

The League was founded in 1920, six months after women won the right to vote. While the League is committed to democracy and voting for all US citizens, it is non-partisan, never supporting political parties or candidates for office.

However, we are political in that we study issues, researching them thoroughly through review of the literature and data, and listening to people with differing perspectives and experiences. Once we study an issue, League members participate in a consensus process during which they weigh in on statements based on study findings. The results of the consensus process determine the development of positions used for advocacy and lobbying.

The LWVWA currently has broad positions about universal access to affordable health services for all state residents and providing basic human needs for those unable to provide for themselves. With this study, we hope to educate ourselves, LWVWA membership and the public about current and projected caregiving needs and facilitate the adoption of specific advocacy positions about caregiving for vulnerable adults.

The major questions we are exploring are:

- What is the current and projected need for care? This includes learning about the preferences and experiences of elders with diverse perspectives.
- What does family and community-based caregiving look like today? This includes hearing from caregivers with diverse experiences and perspectives.
- What current funding and resources are available?
- What are the gaps and challenges identified by vulnerable elders and their caregivers?
- What are promising frameworks, models and approaches for addressing gaps and challenges?

Informed Consent: Your participation in this study is entirely voluntary. If at any point you are uncomfortable with the interview, please let us know and we will stop immediately. The interview will take approximately 45-60 minutes and notes will be taken. Insights gathered from you and other participants will be used in shaping and writing our report. While direct quotes from you may be used, your name and other identifying information will be kept anonymous. Do you agree to participate? **Before we get started, do you have any questions for me/us?**

QUESTIONS:

A. **DEMOGRAPHICS** (elders and caregivers; *voluntary participation*). *For focus groups, describe group composition. Prompts shown in italics; use interviewer discretion in the use of prompts.*

1. ***Age****-What is your age? Under 30; 31-40; 41-50; 51-60; 61-70; 71-80; 81-90; 91 or over; prefer not to say.*
2. ***Gender:*** *How do you identify your gender?*
3. ***Ethnicity****: What is your ethnic background?*
4. ***Location****: Where do you currently reside? City/county/suburban/rural*
5. ***Marital Status****: What is your marital status? Are you single, married, divorced, widowed?*
6. ***Education***
7. *What is the highest level of education you completed? High School/GED; Associate Degree; Bachelor Degree; Master Degree or higher; others; prefer not to say*
8. **Career/job***: What kind of work did/do you do?*
9. **Income**: *What is your approximate annual household income? Less than $25,000; $25-75,000; 75,000-125,000, more than $125,000; prefer not to say.*
10. **Health Care**: What is your primary source of health care insurance coverage-Medicare, Medicaid, private insurance, Military/VA benefits, other?

B. **ELDER CARE NEEDS** *(Individual elders; as appropriate, with or without caregiver/spouse)*

1. **Tell us about your current living situation**; *Who do you live with? How is that for you? If you had a choice, would you choose this arrangement? Has your home been modified to accommodate your needs (i.e., grab bars, ramps, etc.); do you have transportation to get to medical appointments, grocery shopping, etc. Are there others coming into the house, as visitors or for other purposes? Tell me how you spend your days. Are you ever lonely?*
2. **What help do you get in managing your daily activities***? (Activities of Daily Living-essential basic self-care tasks: bathing; dressing; toileting; transferring; continence; and feeding.) Who provides help? How much help do you need? What additional help would you like? Do you pay for that care; if so, how much? Do you receive help paying for that care? If so, who provides financial help? Do you expect to need Medicaid? If so when? Do you have help managing your finances?*
3. **What type of care do you prefer?** *Family members? Paid caregivers? Friends, neighbors, other? If you could think of an ideal caregiving situation, what would that look like?*
4. **How do you learn about services and supports that may be available to you?** *How easy is it to get the information you need?*
5. **What challenges have you faced in getting the care you need?** *What were those challenges? If money were no object, what might you do differently?*
6. **What circumstances would cause you to reconsider the kind of care you receive or your living situation?** *(Tipping points might include serious illness or injury, serious fall, loss of partner/child, inability to drive or maintain house, etc.)*

Thank you for your participation and time. What you've shared with us will help guide the study and ultimately the League's ability to advocate for legislation and funding that supports vulnerable adults and their families and caregivers.
Is there anything you want to tell us that we haven't asked?

C. WHAT DOES FAMILY & COMMUNITY CAREGIVING LOOK LIKE?

C.1. FAMILY CAREGIVERS

1. ***What is your relationship with the person you cared/care for, e.g., husband, wife, sibling, friend other?***
2. **Currently or in the past, do/did you give regular care or assistance to a friend or family member?** *If so, what does/did that look like, e.g., person nearby, living with the person or long-distance caregiving, etc.? Approximately how many hours of care do you/did you provide daily/weekly? How long have you been caring for this person?*
3. **Reason person needs care**, e.g., Parkinson, Dementia, stroke, falls, chronic mental illness, etc.
4. **Tell me briefly about experiences you have had caring for vulnerable family members/friends.**
5. **What types of care do you provide?** *Physical, mental, functional (managing bills, medical appointments, grocery shopping, cooking etc.). Activities of Daily Living-essential basic self-care tasks: bathing; dressing; toileting; transferring; continence; and feeding. Are there other caregivers providing services? If so, what services do they provide?*
6. **Do you receive compensation for the caregiving you provide? If so, what are the sources?**
7. **What was/is the most challenging part of being a caregiver?**
8. **What was/is rewarding about being a caregiver?** *Relationship with the person I care for; personal satisfaction in being of service; consistent with personal/spiritual beliefs; other?*
9. **What challenges did/do you face as a caregiver?** This might include lack of support; physical challenges; inability to pursue own activities including employment; other? Missed companionship, intimacy; friendships; physical safety; dealing with drug and alcohol abuse.
10. **What additional help do you get with your caregiving responsibilities? What other help do you need?** *Who do you trust to support you with needs including health-care providers, your church, etc.? Who have you reached out to for additional help? Do other family members share responsibilities with you? Are you part of a support group? How do you learn about services and support systems that may be available to you? What training/and or support do you have? What additional training would you like?*
11. **How has caregiving affected your well-being, life choices, employment, relocation, and health (mentally, physically, emotionally)?**
12. **If money were no object, what might you do differently?**
13. **Do you have long-term caregiving plans, e.g., is the current situation sustainable?** *What tipping points would require changes in the caregiving arrangement? (Tipping points might include serious fall, onset of dementia with behavior symptoms, serious illness or injury, unable to lift person, incontinence, etc.)*

Thank you for your participation and time. What you've shared with us will help guide the study and ultimately the League's ability to advocate for legislation and funding that supports vulnerable adults and their families and caregivers. Is there anything you want to tell us that we haven't asked?

C.2-PAID CAREGIVERS- *(provides care on a regular basis, respite ok)*

1. **Do you provide caregiving through an agency or as an independent worker?**
2. **How long have you been working as a paid caregiver?**
3. **What motivates you to do this work?** *What do you enjoy about caregiving?*
4. **What education and training have you received to prepare you for the work you're doing?** *What additional training might be helpful? What are some of the challenges you face with continuing education? What prevents you from getting that training?*
5. **What types of care do you provide? Do you have particular areas of specialization?**
6. **What is the hardest or most challenging part of your work?**
7. **To what extent do you feel safe in your work as a caregiver? What do you worry about for yourself and/or your clients?**
8. **How has caregiving affected your well-being and health?** *Talk about the ways it has affected you. Are there things in your work that trigger you emotionally or physically?*
9. **To what extent are you comfortable with the supervision you receive?** *If you work for an agency, are there protocols for dealing with conflicts and difficult situations? How would you like things to be different?*
10. **To what extent is the compensation you receive adequate including wages, benefits, and retirement provisions?** *Are you a union member? If so, have you benefitted from union membership?*

Thank you for your participation and time. What you've shared with us will help guide the study and ultimately the League's ability to advocate for legislation and funding that supports vulnerable adults and their families and caregivers.
Is there anything you want to tell us that we haven't asked?

Appendix D: Activities of Daily Living

Activities of daily living is a term used in healthcare to refer to people's daily self-care activities. Health professionals often use a person's ability or inability to perform these activities as a measurement of their functional status. The concept was originally proposed in the 1950s by Sidney Katz and his team at the Benjamin Rose Hospital in Cleveland, Ohio.

The concept of activities of daily living has been added to and refined by a variety of researchers since that time. For example, many indexes now include some measure of mobility. Additionally, to be more inclusive of the range of activities that support independent living, in 1969, Lawton and Brody developed the instrumental activities of daily living. Activities of daily living are often used in the care of people with mental or physical disabilities, people with injuries, and elderly people.

They are categorized into basic, self-care tasks acquired starting from infancy, and instrumental, tasks learned throughout adolescence. A person who cannot perform such activities may have poorer quality of life or be unsafe in their current living conditions; therefore, they may require the help of other individuals and/or assistive devices. Examples of devices to aid in daily activities include grab bars, raised toilet seats, electric toothbrushes, sock pullers, grabbers, canes, walkers, electric lifting seats, shower benches, bathtub transfer benches, and ramps to replace stairs.

Basic

Basic activities of daily living consist of self-care tasks that include:

- Bathing and showering
- Personal hygiene and grooming (including brushing teeth, combing/styling hair)
- Dressing
- Toilet hygiene (getting to the toilet, cleaning oneself, and getting back up)
- Functional mobility, often referred to as "transferring", as measured by the ability to walk, get in and out of bed, and get into and out of a chair; the broader definition (moving from one place to another while performing activities) is useful for people with different physical abilities who are still able to get around independently
- Self-feeding (not including cooking or chewing and swallowing), as opposed to assisted feeding

The functional independence measure is a tool developed in 1983 that uses a 0-7 scale to rank different activities based on the level of assistance they require. A 7 on the scale means the patient is independent, whereas a 0 on the scale means the patient cannot complete the activity without assistance. The specific breakdown of the scale is shown below:

7 - Independent
6 - Modified Independent
5 - Supervision/Set-up
4 - Minimal Assist
3 - Moderate Assist

2 - Maximal Assist
1 - Total Assist
0 - Activity Does Not Occur

Instrumental

Instrumental activities of daily living are not necessary for fundamental functioning, but they let an individual live independently in a community:

- Cleaning and maintaining the house
- Managing money
- Moving within the community
- Preparing meals and cleanup
- Shopping for groceries and necessities
- Taking prescribed medications
- Using the telephone or other form of communication

Occupational therapists often evaluate Instrumental activities of daily living when completing patient assessments. The American Occupational Therapy Association identifies 12 types of Instrumental activities of daily living s that may be performed as a co-occupation with others:

- Care of others (including selecting and supervising caregivers)
- Care of pets
- Child rearing
- Health management and maintenance
- Religious observances
- Safety procedures and emergency responses

Wikipedia Activities of Daily Living taken from National Library of Medicine, National Center for Biotechnology Information.

Appendix E: Becoming a Paid Caregiver in Washington State

To become an individual provider in the home, the caregiver must:

- Be 18 years old or older.
- Pass an in-state and federal (FBI) criminal conviction background check.
- Provide picture ID and be authorized to work in the U.S.
- Successfully complete all the caregiver training requirements (see below).
- Complete an application as an individual provider Home Care Aide.

The individual needing care must be eligible for Medicaid Long Term Services and Supports before they can receive care in their home.

Individual providers can provide care to any family members, but not to a spouse, unless under the Veteran Directed Home Services.

All individual providers in this program can be represented by the SEIU 775.

Home Care Aide Training: Individual Providers may begin providing direct care after completing the 5-hour orientation and safety training. Certification requires 75 hours of basic training. Those providing care for less than 20 hours per month or for a parent do not need certification and only the orientation and 30 hours of basic training.

- Assisting with body care
- Preventing compassion fatigue
- The person-centered approach to care: treating each person as an individual with unique needs, values and preferences.
- How to work with an individual to solve problems.
- Techniques for tracking and organizing medications.
- How to support an individual and watch and report changes to their health.
- How to work with treatment and care plans.
- Motivational interviewing techniques that will help provide encouraging, non-judgmental support.
- Healthy ways to cope with difficult or tense situations; how to respond logically rather than react emotionally.
- How to assist the individual to become more involved in their healthcare.
- How to practice healthy ways to care for themselves.

In the Home of a Veteran: Aid and Attendance benefits (paid to the veteran) are available to veterans who qualify for VA pensions and the veteran meets at least one of the following criteria:

- Requires help from another person to perform everyday personal functions such as bathing, dressing and eating.
- Is confined to bed because of disability.

- Is in a nursing home because of physical or mental incapacity.
- Has very limited eyesight, less than 5/200 acuity in both eyes, even with corrective lenses, or a significantly contracted visual field.

Surviving spouses of qualifying veterans also may be eligible for this benefit.

Program of Comprehensive Assistance for Family Caregivers offers a monthly stipend to family members who serve as caregivers for veterans who need assistance with everyday activities because of a serious injury or illness sustained in the line of duty. The veteran must be enrolled in VA health services, have a disability rating (individual or combined) of 70% or higher, and need in-person care services of a minimum of six continuous months based on any one of the following:

- An inability to perform an activity of daily living
- A need for supervision or protection based on symptoms or residuals of neurological or other impairment or injury
- Or a need for regular or extensive instruction or supervision without which the ability of the veteran to function in daily life would be seriously impaired.

The caregiver must be 18 or older and a child, parent, spouse, stepfamily member, extended family member or full-time housemate of the veteran. The stipend for a caregiver is based on the region where an eligible veteran lives and is currently up to $2800 a month.

Other caregiver benefits through the program include:

- Access to health insurance and mental health services, including counseling
- Comprehensive training
- Lodging and travel expenses incurred when accompanying vets going through care
- Up to 30 days of respite care per year

Appendix F: Tax Deductions for Caregivers

1. **You can claim your parent as a dependent on your taxes if you are their caregiver, as long as you meet certain requirements:**
   - You (and your spouse if filing jointly) are not a dependent of another taxpayer.
   - Your parent, if married, doesn't file a joint return — but this doesn't apply if your parent and their spouse file a joint return only so they can claim a refund of income tax withheld or estimated tax paid.
   - Your parent is a U.S. citizen, U.S. national, U.S. resident alien, or a resident of Canada or Mexico.
   - You paid more than half of your parent's support for the calendar year.
   - Your parent's gross income for the calendar year was less than $4,700.
   - Your parent isn't a qualifying child of another taxpayer.
   - If your parent is your foster parent, they must have lived with you all year in your main home and as a member of your household.
2. **You can file as head of household for a parent who lives in your home and for whom you are the caregiver, but only if you meet certain requirements:**
   - You're unmarried or considered unmarried on the last day of the year.
   - You may claim your parent as a dependent.
   - You paid more than half of the cost of keeping up a home that was the main home for both you and your parent for more than half of the tax year. Alternatively, you paid more than half the cost of keeping up a home that was your parent's main home for the tax year (meaning your parent lived in the home), even if your parent did not live with you.
3. **You can deduct medical expenses incurred by your parents and paid by you, as their caregiver, if you meet certain requirements:**
   - If you itemize your deductions and your parent was your dependent either at the time the medical services were provided or at the time you paid the expenses, you can claim a deduction for the portion of their expenses that you paid during the taxable year, as long as it wasn't compensated for by insurance or otherwise.
   - Your medical expense deduction is limited to the amount of medical expenses that exceeds 7.5% of your adjusted gross income.
   - You can include medical expenses you paid for a person who would have been your dependent, unless one or more of the following apply:
   - They received gross income of $4,700 or more in 2023.
   - They filed a joint return for the year.
   - You, or your spouse if filing jointly, are properly claimed as a dependent on someone else's return.

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[128] A “snowball” sample was used to identify interviewees, starting with people in the immediate community and reaching out for recommendations to achieve diversity in race and cultural, income, geographic locations and circumstances. Interviews started with an interview script (see Appendix C) but used a “semi-structured” qualitative interview approach that allowed interviewers to explore responses of particular relevance.

[129] Elder interviews were augmented by several recent surveys of older adults conducted by AARP and other organizations.