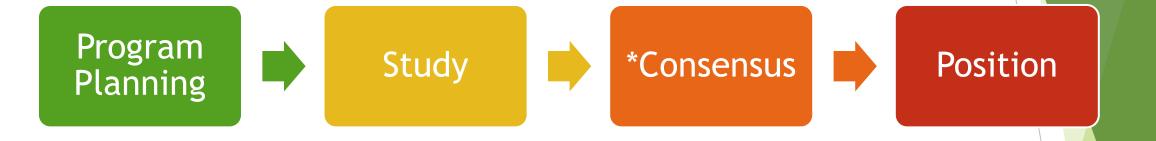


ELDER CAREGIVING STUDY https://www.lwvwa.org/eldercare



- Consensus: grass roots member agreement; meeting of the minds after discussion
- Position: developed based on results of consensus process
- > Advocacy: consistent with League positions

Elder Caregiving Study approved at 2023 LWVWA Convention

Caregiving in Washington State: What exists and what is needed to support seniors and other vulnerable adults and their caregivers.

Core Workgroup: Theresa Baker; Jeanne Cullen; Jody Disney; Mary-Jo Giamberardini; Tricia Grantham; Dick Halvorson; Karen Tvedt

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Elder Caregiving Study Scope

60 years and older living in their own homes and communities who lack the ability to care for themselves.

Study Approach: Three Phases

1

Phase I-preliminary review of research and data from state and federal sources; issues identified; explored models. 2

Phase II-33 qualitative interviews with a sample of elders, family caregivers and paid caregivers.

3

Phase III-interviews with service providers and managers; indepth interviews on key issues; additional literature review.

Elder Caregiving Study Report Overview

- Chapter 1-Results of Interviews with Elders, Family Caregivers and Paid Caregivers
- Chapter 2-Current and Projected Caregiving Needs: demographics and need, preferences and misconceptions, trends such as dementia, technology & AI
- ► Chapter 3: Family and Paid Caregivers: what do we know about family and paid or professional caregivers? Challenges and possibilities
- Chapter 4: State and Federal Policy and Programs: rebalancing and emphasis on home & community-based care; Medicaid Estate Recovery and spousal transfer of assets.
- ► Chapter 5: Proven Models and Promising Innovations: includes a holistic framework for an aging society-systems approach and models including CAPABLE (John Hopkins), PACE, Village, Cares Program (Tacoma Fire Dept)



Interviews with Elders

- Small sample of elders (5) represented a range of circumstances and needs.
- ▶ Interviewee in her 60s in permanent supportive housing.
- ▶ Interviewee a man in his 70s, a retired engineer.
- Themes across interviews:
 - desire for independence, to make choices about caregivers,
 - need for respite care,
 - value of pets.
 - difficulties included loneliness, access to information, negotiating long-term care services and support, need for care that is affordable and responsive, worries about loved ones.

Family Caregiver Interviews

- ▶ 17 family caregivers interviewed; 12 over the age of 60; 11 female, 6 male.
- Many reported providing care 7 days a week, 24 hours a day; several for 10 years or so. Part-time care common for caregivers who don't live with the person cared for.
- Most not compensated for the care provided.
- Effects on caregivers: can be emotionally rewarding; missed intimacy and companionship.
- Challenges: not knowing where to turn for information; delaying own life goals; difficulty balancing caregiving with needs of own families; isolation and resentment as well as health issues, affordability and concerns about estate recovery.

Family Caregiver InterviewsScenarios

One husband said he is setting an example for his children; another caregiver wishes for a full day off, "a float tank day" while another noted conflict with her siblings over their mother's care.

A caregiver son said 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.

Paid Caregiver Interviews

- ▶ 11 paid caregivers interviewed, reflecting a cross-section from urban to rural across WA state.
- Most described caregiving as their career; a few noted working multiple jobs.
- Motivations included helping elders to remain in their homes, honoring the dignity and value of elders, and making a positive impact.
- Challenges included losing clients, clients needing more care than is authorized, worrying about clients who live alone.
 - Worry and exhaustion.
 - Working conditions, e.g., compensation, benefits, training and respect for their profession. Lack of stability in employment and benefits.

Paid Caregiver Interviews

- We heard the following from paid caregivers:
 - ▶ I love spending time with my clients, hearing their life stories, and helping them with their daily needs.
 - Some expressed concerns about not being paid to attend training.
 - Some caregivers have experienced verbal and physical abuse.
 - Caregivers employed as union members expressed more satisfaction with their compensation and benefits than non-union members.
 - ► They noted that loss of a client can result in periods of time without enough hours of work in a month (80 hours) to qualify for health insurance.

- 1. Most elders want to remain in their own homes but frequently lack the resources to do so should they become unable to care for themselves without help.
- Early retirement planning and savings
- Positive health practices
- Attention to community infrastructure such as housing and transportation
- 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
- 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, not enough respite care and short and long-term costs.
- Reevaluate our heavy reliance on family caregivers and the costs they experience?
- Making supports 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 as the ratio of workers to elders drops significantly. Recruitment and retention hampered by:
- Compensation & benefits
- Challenging work conditions
- Immigration policies
- Infrastructure issues, e.g., transportation, housing and child care
- Barriers to training and continuing education

5. The system works better for the very poor who are eligible for Medicaid and the reasonably well-off who can pay privately. While it can be challenging elders across incomes, it can be especially challenging for lower and middle-income elders who lack the resources to pay. And, when these elders turn to Medicaid, they often encounter issues with spousal asset limits and Medicaid Estate Recovery.

Next Steps

- Local Leagues are meeting and considering consensus questions.
- Reports back to study committee by March 18.
- Study committee reviews the results and based on responses, makes recommendations to the state board about new position.
- April-target date for state Board to adopt new position, post on website. Position available for us.
- June-position ratified at Convention as part of the League's Current Program.
- Questions: Karen Tvedt, tvedtkl@msn.com



LWVWA Elder Caregiving Study

"There are only four kinds of people in this world:

- ▶ Those who have been caregivers
- ► Those who currently are caregivers
- Those who will be caregivers
- Those who will need caregivers"

From Helping Yourself Help Others: A Book for Caregivers, Rosalyn Carter with Susan K. Golant