The Impact of Caregivers

California’s long-term services and support system for older adults and adults with disabilities relies, in part, on an unpaid family and friends workforce. California’s 6.5 million informal caregivers provide an estimated $127 billion in “free” care.(5) This client army contributes over 30% of the care provided to those in need. If this care was not provided, many of these older adults and adults with disabilities would be institutionalized, placing a burden on our nation’s long-term care facilities. Nationally, the estimated costs for these unpaid services are twice what the government spends annually on professional home care and nursing home care combined.(6)

Although most caregivers willingly undertake the role and intend to provide excellent care, the nearly 24/7 responsibility for caring shows, including increasingly complex medical interventions and physical assistance, takes its toll:

• More than 1 million California caregivers report moderate or serious distress levels.(7)
• The one-third of California caregivers who live with their care recipients spend an average of 36 hours a week providing care.(8)
• 45% to 70% of family caregivers have clinically significant symptoms of depression with about a quarter to one-third meeting the diagnostic criteria for major depression.(9)
• 67% of caregivers spend more than half of their income on caregiving expenses.(5)
• 70% of working caregivers suffer work-related difficulties due to their caregiving role.(2)

Despite their enormous contributions, caregivers receive little support or education to prepare them for the daunting task of caring for older adults with cognitive impairments (e.g., dementia), psychological issues (e.g., depression, anxiety, and post-traumatic stress disorder), or physical disabilities (e.g., diabetes, hypertension, arthritis). Less than 20% of California’s caregivers report having received training on how to be a caregiver. Caregivers often feel as if their needs are invisible to physicians, other health professionals, and information needed to ease their burden and help them with their caregiving responsibilities.

Taking Action to Prevent Abuse by Caregivers

The California Elder Justice Coalition (CEJC) believes that California can lead the way in supporting caregivers. CEJC’s Blueprint for Improving California’s Response to Elder Abuse, Neglect, and Exploitation calls for the following:

1. Hold abusive caregivers accountable. In some instances, caregivers provide care for the wrong reasons. Some caregivers are driven by anger, resentment, or the desire to get back at a family member. So it is important to hold abusive caregivers accountable. This is done by: (a) providing legal safeguards and supports so that caregivers who abuse or neglect older adults are held responsible; (b) ensuring that legal protections are in place to protect older adults and their families; (c) promoting the use of caregiver assessments to identify and respond to high risk situations; (d) ensuring that professionals who work with older adults (e.g., physicians, nurses, social workers, care managers) receive training to help them spot the warning signs of elder abuse and how to report it. This training includes identifying the signs of elder abuse and neglect, understanding the role of caregivers and how to recognize the warning signs.

2. Increase funding for California Caregiver Resource Centers and Caregiver Programs sponsored by the Area Agencies on Aging to expand their adult protective services and to reduce cases of victimization, burden, depression and resentment, and all of which are warning signs of abuse or neglect.

3. Ensure that professionals who work with older adults (e.g., physicians, nurses, social workers, care managers) receive training to help them spot the warning signs of elder abuse and how to report it. This training includes identifying the signs of elder abuse and neglect, understanding the role of caregivers and how to recognize the warning signs.

4. Promote the use of caregiver assessments to identify and respond to high risk situations. Caregiver assessment refers to a systematic process of gathering information about caregiving situations to identify caregivers’ strengths, problems, and needs. Assessments should ask questions that yield evidence about the warning signs of abuse and neglect. California could require that Title III-E Family Caregiver Support Programs develop a uniform performance-based assessment tool for counties to use.

5. Make abuse prevention programs accessible in every county. This includes: (a) ensuring that legal protections are in place to protect older adults and their families; (b) promoting the use of caregiver assessments to identify and respond to high risk situations; (c) ensuring that professionals who work with older adults (e.g., physicians, nurses, social workers, care managers) receive training to help them spot the warning signs of elder abuse and how to report it. This training includes identifying the signs of elder abuse and neglect, understanding the role of caregivers and how to recognize the warning signs.

6. Hold abuse prevention programs accountable. In some instances, caregivers provide care for the wrong reasons. Some caregivers are driven by anger, resentment, or the desire to get back at a family member. So it is important to hold abusive caregivers accountable. This is done by: (a) providing legal safeguards and supports so that caregivers who abuse or neglect older adults are held responsible; (b) ensuring that legal protections are in place to protect older adults and their families; (c) promoting the use of caregiver assessments to identify and respond to high risk situations; (d) ensuring that professionals who work with older adults (e.g., physicians, nurses, social workers, care managers) receive training to help them spot the warning signs of elder abuse and how to report it. This training includes identifying the signs of elder abuse and neglect, understanding the role of caregivers and how to recognize the warning signs.

Conclusions

Older Americans are the fastest growing segment of the population, and California is home to the largest number of older adults in our country. Let’s celebrate the spirit of caregivers who give of themselves without expectation of remuneration or recognition/helps thousands of elders stay in the community. Let us support them and through them the nearly 24/7 responsibility for caring shows, including increasingly complex medical interventions and physical assistance, takes its toll:

• More than 1 million California caregivers report moderate or serious distress levels.(7)
• The one-third of California caregivers who live with their care recipients spend an average of 36 hours a week providing care.(8)
• 45% to 70% of family caregivers have clinically significant symptoms of depression with about a quarter to one-third meeting the diagnostic criteria for major depression.(9)
• 67% of caregivers spend more than half of their income on caregiving expenses.(5)
• 70% of working caregivers suffer work-related difficulties due to their caregiving role.(2)

For more information, please contact the California Elder Justice Coalition at info@elderjusticecal.org. Or visit our website at: http://elderjusticecal.org

References


Illustrations

This figure is an illustration of the importance of caregivers to our aging population.
The Intersection of Elder Abuse and Caregiving

Despite their enormous contributions, caregivers receive little support or education to prepare them for the daunting task of caring for older adults with cognitive impairments (e.g., dementia), psychological issues (e.g., depression, paranoia), and multiple chronic conditions (e.g., diabetes, hypertension, arthritis). Less than 25% of caregivers report having received training on how to be a caregiver. Caregivers often feel as if their needs are invisible to physicians, health systems, and policy makers.

It is in every wonder that, there are two studies show that as many as 475 of family caregivers of people with Alzheimer’s are more likely to engage in abusive behaviors (1) (2) (3) (4) (5) (6) (7) (8) (9) (10) (11)

One in ten older Americans are believed to experience abuse each year in the United States, according to the National Institute of Justice (1) (2). As few as or as many as 21% are aware of the problem and are not sure how to respond. Unfortunately, the elder justice system (e.g., Adult Protective Services, Long-term Care Ombudsman, law enforcement) need education about programs available to support caregivers.

Increase funding for California Caregiver Resource Centers and Caregiver Programs sponsored by the Area Agencies on Aging of California (AAAC) and Explorations calls for the following:

1. Design and run a public awareness campaign to help caregivers realize that resources are available, identify as caregivers (many caregivers do not identify with this label), and help them identify the “tipping points” (warning signs for abuse, neglect, or exploitation).

2. Increase funding for California Caregiver Resource Centers and Caregiver Programs sponsored by the Area Agencies on Aging of California (AAAC) and Explorations calls for the following:

3. Ensure that professionals who work with older adults (e.g., pharmacists, nurses, social workers, care managers) receive training to help them spot the warning signs of elder abuse and how to report it.

4. Hold abusive caregivers accountable. In some instances, caregivers provide care for the wrong reasons. Some are incapable of providing good care and others are pressed into providing care. In some instances, predatory individuals use their role to exploit those in their care. Caregivers may need help to screen and monitor caregivers, and remove if abuse occurs.

Conclusion

Older Americans are the fastest growing segment of the population, and California is home to the largest number of older adults in our country. Let’s celebrate the spirit of caregivers whose giving of themselves without expectation of renumeration or recognition helps thousands of older adults to stay in the community. Let us support them and through them older adults in need, and guide with dignity and respect in the Golden State.

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References

6. According to the National Institute of Justice, (1) (2) The one-third of California caregivers who live with their care recipients spend an average of 36 hours a week providing care. (7) 45% of family caregivers have clinically significant symptoms of depression with about a quarter to half meeting the diagnostic criteria for major depression. (8)
7. 67.1% of caregivers had full hold down part-time or full-time jobs. (2)
8. 700 working caregivers suffer work-related injuries, burnout, burden, depression and resentment, all of which are warning signs of abuse or neglect. California could require that Title III family Caregiver Support Programs develop a uniform performance-based assessment tool for counties to measure.
9. CEJC Policy Brief:
10. Designed by: Eden Ruiz-Lopez, Project Manager of the National Center on Elder Abuse (NCEA)