

Supports For Family Caregivers Of Elders



Research Memorandum No. 517

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Foreword

The 2014 General Assembly enacted Senate Concurrent Resolution 102 that directed the staff of the Legislative Research Commission to collect information about services and supports for family caregivers of elders in Kentucky. Staff conducted interviews with family caregivers about their needs and identified policies, resources, and programs that help family caregivers. Legislative Research Commission staff would like to acknowledge the assistance of persons with Kentucky state agencies, in particular, the Department for Aging and Independent Living, caregiver professionals, advocates, interest groups, and family caregivers.

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Contents

Summary	v
Chapter 1: Background And Study Description	1
Aging Population	1
Family Caregivers	2
Description Of The Report.....	3
Organization Of The Report	4
Chapter 2: Kentucky Policies, Resources, And Programs That Help Family Caregivers	5
Adult Day Care And Alzheimer’s Disease Respite Program	5
Area Disability Resource Market.....	6
Family Caregiver Support Program	6
Health Promotion And Disease Prevention Programs	6
Homecare Program	6
Kentucky Institute For Aging	6
Kentucky State Health Insurance Assistance Program.....	7
Legal Aid And Advocacy Resources	7
Long-Term Care Ombudsman Program	7
Nutrition Program For The Elderly.....	7
Office On Alzheimer’s Disease And Related Disorders.....	7
Personal Care Attendant Program.....	8
Public Guardianship Program	8
Senior Centers	8
Veterans Affairs Caregiver Support.....	8
Federal Resources, Policies, Programs, And Legislation For Family Caregivers	8
Family And Medical Leave Act.....	8
Older Americans Act	9
Public Health Service Act.....	9
Chapter 3: Supports Used By Kentucky Family Caregivers	11
Summary Of Responses	11
Responses To Specific Needs	11
Designation As Caregivers	11
Training.....	11
Respite Services	12
Medical Leave Policies.....	12
Delegation Of Tasks To Nonmedical Aides	12
Relevant State Policies.....	13
Chapter 4: Kentucky Family Caregivers: Recommendations.....	15
Improving The Integration Of Family Caregivers In Transitional Care.....	16
Increasing Support For Area Agencies On Aging And Independent Living...	16
Enhancing Employment Policies For Caregivers	17
Delegating Health Maintenance Tasks	18

Changing The Allocation Of Medicaid Funds Spent On Long-Term Care18
Reducing Shortages Of Home Health And Personal Care Aides19
Summary19

Figure

Figure 1A 5-Year Percentage Change In Population Projections1

Appendices

Appendix A: Long-Term Care Forum Questions21
Appendix B: Family Caregiver Interview23
Endnotes25

Summary

The 2014 General Assembly enacted Senate Concurrent Resolution 102 that directed the staff of the Legislative Research Commission (LRC) to collect information about services and supports for family caregivers of elders in Kentucky. Staff conducted interviews with family caregivers about their needs and identified policies, resources, and programs that help family caregivers.

As a part of this effort, LRC staff developed a short questionnaire that was used to conduct interviews with family caregivers and added questions to those posed at long-term care forums conducted by the Department of Aging and Independent Living in each area development district. Family caregivers across the state were identified through self-referral, referral from Area Agency on Aging and Independent Living staff, and service providers.

The questionnaire asked for information about current use of services by family caregivers and the need for services, including legal designation as caregiver, training, respite services, medical leave policies, delegation of tasks to nonmedical aides, and relevant state policies.

This report presents the following conclusions.

- Individuals aged 65 and older are projected to comprise 20 percent of Kentucky's population by 2030, an increase of 321,415 seniors. Approximately one-fourth of those seniors will be aged 80 and older.
- Approximately 735,000 Kentuckians are caregivers helping their family members to age in a home setting rather than in an institutional setting.
- The majority of seniors indicate a preference to age in a home setting rather than in an institutional setting.
- In the future, there will be fewer children to care for more aging parents. The pool of family caregivers is likely to expand to include other family members, close friends, neighbors, and other nonrelated people.
- Aging in a home setting with appropriate supports for seniors and family caregivers may be more cost effective than nursing home care. Kentucky's Medicaid program pays approximately \$48,000 per year for a nursing home bed compared to \$15,000 for in-home supports.
- Kentucky ranks low nationally compared to other states on indicators of supports for family caregivers such as respite care, family and medical leave, and home health and personal care services.
- Kentucky spends approximately 81 percent of all long-term care dollars on nursing home care and the remainder on supports to help seniors age at home. The growth of the senior population may outpace available Medicaid funds without a redistribution of spending. The Department for Aging and Independent Living has indicated plans to improve this

distribution by increasing services available under the Medicaid waiver for home- and community-based services, which could help family caregivers provide care.

- Some spousal caregivers may feel that they have no other option than to admit their spouse into a Medicaid-funded nursing home to protect financial resources for themselves. If the eligibility for home-care services were given the same consideration of resources as nursing home care, more seniors may be able to care for their spouses in a home setting.
- Caregivers are often not included in transitional care planning when their family members are discharged from a hospital stay. The family members may experience relapses in illness or deterioration of health that leads to nursing home admission or hospital readmission. Transitional care includes coordination and communication between the patient, health care professionals, and caregivers about necessary post-hospital care. Inclusion of family caregivers in transitional care planning could help more seniors recover from hospital stays and remain in their homes.
- Delays in home-care services for seniors sometimes result from an extended time period between an assessed need for services, a determination of eligibility for services, and delivery of service. Delays in services such as assistance with medications, nutrition management, and personal care can result in rapid health declines, hospitalizations, and nursing home admissions. Presumptive eligibility at the time of the assessed need for home-care services could expedite service delivery and help caregivers keep their family members healthy at home.
- There are shortages of personal care and home health professionals, particularly in rural areas. These in-home caregivers provide services essential for some caregivers to help their family members to stay in their homes.
- Family caregivers for seniors are often stressed emotionally, physically, and financially. Improved supports for family caregivers could help more seniors stay in their homes.
- Transportation assistance for seniors to make health care appointments and perform household errands is not consistently available across the state. Most caregivers provide all transportation needs for their family member.
- Since 2009, the budget for the Department for Aging and Independent Living has decreased by 27 percent. Nonetheless, the Area Agencies on Aging and Independent Living provided 55,834 family caregivers with supports such as respite care and caregiver training in fiscal year 2014 and additional services for seniors that help family caregivers provide care such as homemaker services and home-delivered meals.
- Many family caregivers do not receive any state-funded supports. They are often unaware that services exist or cannot afford services that are available. There are waiting lists for most state-funded services and supports for seniors and family caregivers. More support for the Area Agencies on Aging and Independent Living could help more caregivers provide care for their family members.

Chapter 1

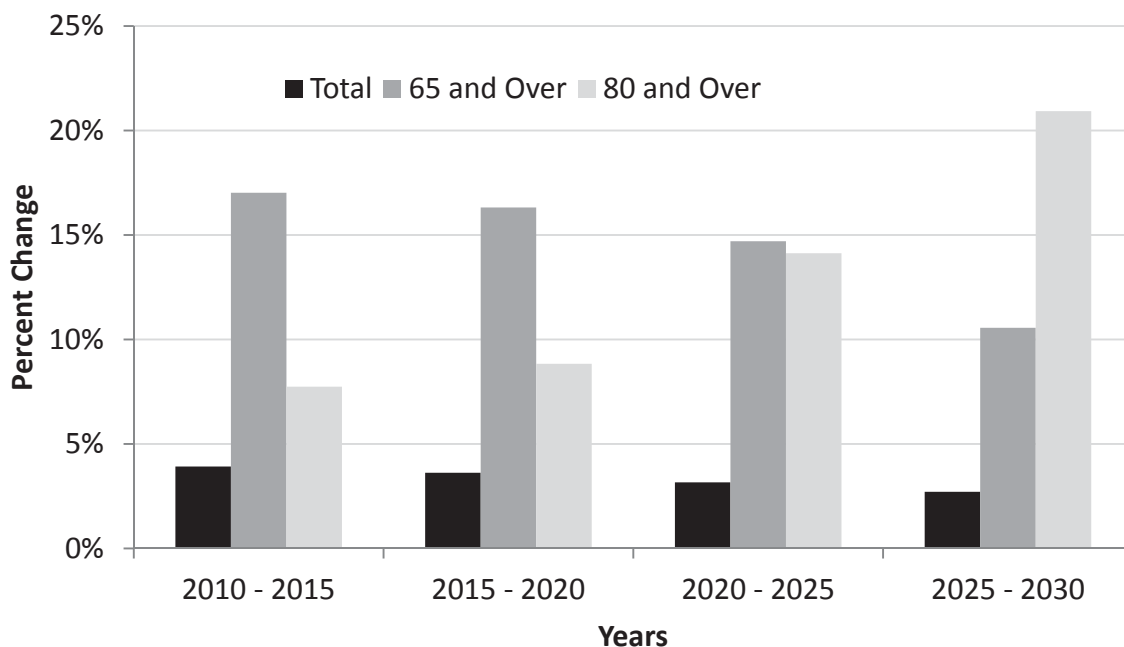
Background And Study Description

Ageing Population

The population of the United States is projected to grow older for the next several decades. By 2030, one-fifth of the US population is expected to be 65 years or older. In part, this increase is due to the 76.4 million baby boomers born in the United States from 1946 to 1964 who are becoming seniors. People also are living longer. The average life expectancy at birth in the US in 1940 was approximately 60 years, compared to approximately 79 years in 2010. The average life expectancy in Kentucky was 76 years in 2010.¹

Figure 1.A shows that between 2010 and 2025, the number of Kentuckians aged 65 and older is projected to increase by approximately 15 percent every 5 years, and the number aged 80 and older is projected to increase by 20 percent between 2025 and 2030. The total number of Kentuckians aged 65 and older is projected to increase from 578,227 to 998,084 between 2010 and 2030.²

Figure 1.A
5-Year Percentage Change
In Population Projections



Source: LRC staff calculations.

Longer life expectancy is a positive indicator of the health and well-being of a population, but the health and well-being of older individuals varies considerably. For instance, approximately 57 percent of Kentuckians aged 65 and older are able-bodied, approximately 80 percent indicate that they receive sufficient social and emotional support, and 31 percent report that their health is very good. However, approximately 38 percent of Kentuckians aged 65 and older have four or more chronic health conditions such as diabetes, heart disease, arthritis, and hypertension.³ Also, the number of seniors with Alzheimer's disease is projected to increase by 28 percent from 67,000 in 2014 to 86,000 in 2025.⁴ Longer life expectancy means that more people will spend more years in the age range in which complex and chronic health care needs are more common.

Family Caregivers

As defined by the Older Americans Act, a family caregiver is “an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction.”

While there is not an official count of caregivers for the elderly, approximately 735,000 Kentuckians are responsible for the care of a family member who is either chronically ill, has a disability, or is no longer able to care for himself or herself.⁵ The vast majority of family caregivers are adult children caring for an aging parent or spouses caring for aging spouses. Women (18 percent) are more likely to report being caregivers than men (7 percent). Persons with poverty-level incomes are more likely to report being caregivers than those with incomes higher than the poverty level.⁶

Most seniors with some chronic illnesses and disabilities receive long-term care in institutional settings such as nursing homes. Others may have conditions for which short-term care is needed and provided in residential treatment facilities. However, research has shown that for many seniors, remaining in a home setting may be more cost efficient than entering institutional care. The annual median rate for nursing home care is \$73,000 for a semi-private room and \$80,300 for a private room, compared to \$44,370 for full-time private in-home care.⁷ The Kentucky Medicaid cost for nursing home care is approximately \$48,000 annually, compared to \$15,000 for home care.⁸

As the population of citizens aged 65 and older increases, there will be proportionally fewer potential family members to serve as caregivers. The average number of children expected to be born to a Kentucky woman has fallen since the baby boom period, from 3.68 children in 1960 to 1.95 children in 2012.⁹ There will be fewer children to care for more aging parents. The pool of caregivers is likely to expand to include other family members, close friends, neighbors, and other nonrelated people.

The need for family caregivers is likely to be proportionally higher in rural areas compared to urban areas of Kentucky. The projected median age in 2030 in urban areas of Kentucky is less than 40 years, compared to more than 43 years in rural areas primarily because younger people are moving out of rural areas.¹⁰

Regardless of the setting—in the home or in an institution—being responsible for care creates emotional and economic stress for families. Stress increases when family members are responsible for providing the majority of that care. Research shows that many family caregivers experience financial, physical, and emotional difficulties due to their caregiving.¹¹

Description Of The Report

With its legislation in 2014, the General Assembly directed LRC staff to

1. identify policies, resources, and programs available for family caregivers and identify additional innovative and creative means to support family caregivers to continue to provide in-home support for older adults;
2. interview family caregivers about their needs, including the designation of caregivers, training, respite services, medical leave policies, delegation of tasks to nonmedical aides, and relevant state policies;
3. compile an inventory of the resources available to family caregivers; and
4. identify possible legislative and administrative actions to support family caregivers.

To address items 1, 3, and 4, staff conducted Internet searches; reviewed recent literature on family caregivers; and consulted with relevant state agencies, advocacy groups, and experts. Staff took a twofold approach to address item 2. The Department of Aging and Independent Living (DAIL) was conducting public forums in each of the 15 area development districts (ADDs) on community needs for long-term care services for the elderly and individuals with disabilities. Two questions related to family caregivers were added to the forum questions (see Appendix A). Study staff attended at least one forum in each ADD to take notes and conduct follow-up interviews with participating family caregivers. The forums ranged from about 7 to 70 attendees. The vast majority of attendees at the sessions were individuals employed in long-term care services, including employees from nursing homes, home health care agencies, personal care programs, state agencies, and local community agencies. Some of the attendees from the long-term care industry were family caregivers as well. Some attendees had experience as family caregivers but were not employed in long-term care services. The Bluegrass ADD forum had already been completed before this study started.

Additionally, because there is not an available list, staff identified family caregivers across the state through self-referral, referral from Area Agency on Aging and Independent Living (AAAIL) staff, and service providers. This type of sampling is a common qualitative sampling strategy where participants are identified according to preselected criteria relevant to a particular research question. While not a representative random sample of family caregivers in Kentucky, the results provide insight into the needs of family caregivers in addition to that gleaned from the literature and service providers. Identified family caregivers were interviewed by telephone using the Family Caregiver Survey questionnaire (see Appendix B).

Staff identified 21 family caregivers willing to be interviewed. Of those interviewed, 10 were caring for a parent or parent-in-law, 8 were caring for a spouse, and 3 were caring for a sibling or other relative. The average age of persons receiving care was 78, and the conditions of those being cared for ranged from acquired and traumatic brain injury to Parkinson's disease to

Huntington's disease, though most had Alzheimer's disease or dementia. Those interviewed had been caregivers from 1 to 30 years, with the average length of time being 12 years.

Organization Of The Report

Chapter 2 presents information on Kentucky policies, resources, and programs that help family caregivers and on federal policies, resources, programs, and legislation for family caregivers. Chapter 3 presents a summary of responses to questions posed at the long-term care forums and the interviews with family caregivers. Chapter 4 presents a discussion of recommendations made by family caregivers and at the long-term care forums for improving supports for family caregivers.

Chapter 2

This chapter describes state and federal policies, resources, and programs that are either specifically targeted to assist family caregivers or are targeted to help seniors but also assist family caregivers to provide care.

Kentucky Policies, Resources, And Programs That Help Family Caregivers

The Department for Aging and Independent Living in the Cabinet for Health and Family Services is the administrative agency for statewide programs and services for Kentucky's elderly population and their caregivers. The community sources of information and services for older adults and those who care for them are the Area Agencies on Aging and Independent Living located in each of the 15 ADDs.

The majority of programs administered by DAIL are state funded, federally funded under the Older Americans Act, and state and federally funded under Medicaid or Medicaid waivers. The Medicaid waivers that include services for the elderly are the Acquired Brain Injury/Acute, Acquired Brain Injury/Long-Term Care, Home and Community Based, Michele P., and Supports for Community Living. Eligibility for each Medicaid waiver program is based on specific criteria such as age and disability as well as income. The consumer-directed option permits those eligible for Medicaid waiver services to select their own providers for nonmedical services, which allows more flexibility and control to help them remain in their homes. Family caregivers may assist individuals with provider and service choices that can help the caregiver as well.

Kentucky ranks 30th (out of 39 states that provided data) in total expenditures for the aging, disabled, and caregiver population.¹² Waiting lists exist for almost all DAIL programs. In 2014, the number of individuals waiting for some program or service was more than 13,000, with the majority waiting to receive home-delivered meals. To alleviate waiting lists, DAIL permits cost sharing for services in the form of copayments that are based on household income.¹³

Many of the 735,000 Kentucky caregivers for the elderly and disabled do not receive services funded by the state. Sometimes, other resources are available for family caregivers through local governments, community organizations, private and nonprofit agencies, religious organizations, and state and national associations.

Adult Day Care And Alzheimer's Disease Respite Program

The Adult Day Care and Alzheimer's Disease Respite Program provides supervision and care to eligible people aged 60 and older and individuals with Alzheimer's disease or a related disorder of any age to provide caregivers temporary relief from caregiving duties. Adult day care centers are community-based programs that provide social activities, transportation, meals and snacks, personal care, and therapeutic activities. The adult day care centers in Kentucky range from 4 to 50 attendees. There are two models of adult day care in Kentucky: the health model that provides

medical services and the social model that provides supervision and socialization. In Kentucky, there are approximately 111 adult day care centers operating under the health model and 24 operating under the social model.¹⁴ Adult day care centers are operated primarily as nonprofit entities. In fiscal year 2014, programs administered by DAIL and offered through the 15 AAAILs funded adult day services for 359 individuals.¹⁵

Area Disability Resource Market

The area disability resource market is a website administered by DAIL that provides information on services and programs that are available in each of the AAAIL areas for older Kentuckians and their caregivers. The website is <http://chfs.ky.gov/dail/areaagenciesonaging.htm>.

Family Caregiver Support Program

The Family Caregiver Support Program provides support services, including assistance in gaining access to services, caregiver training in the areas of financial literacy, health, and nutrition; and provides information to caregivers about respite care, in-home services, and support groups.¹⁶ In FY 2014, 55,834 individuals received assistance under this program administered by DAIL and offered through the 15 AAAILs.¹⁷

Health Promotion And Disease Prevention Programs

Health promotion and disease prevention programs provide benefits counseling, home injury prevention information, medication management counseling, rehabilitation information, mental and physical health screenings, and nutrition counseling.¹⁸ These services can help family caregivers provide care. In FY 2014, 5,502 individuals received assistance under these programs administered by DAIL and offered through the 15 AAAILs.¹⁹

Homecare Program

The Homecare Program is a state funded program, administered by DAIL and offered through the 15 AAAILs, that assists family caregivers and providers to help adults who are at risk of institutionalization remain in their homes by providing daily supports and services. To be eligible for this program, individuals must be 60 or older and unable to perform at least two activities of daily living. The homecare program provides a variety of social services, including assessment and case management, homemaker services, and respite for family caregivers. The program also provides home-delivered meals and nutrition education. In FY 2014, 5,855 individuals received social services, 2,516 individuals received home-delivered meals, and 3,245 individuals received nutrition education.²⁰

Kentucky Institute For Aging

The Kentucky Institute for Aging, established by the General Assembly, operates in collaboration with DAIL to address the preference of older Kentuckians to avoid institutionalization and to advise the secretary for the Cabinet for Health and Family Services on policy matters related to the aging population in Kentucky.

Kentucky State Health Insurance Assistance Program

The Kentucky State Health Insurance Assistance Program provides information, counseling, and assistance to seniors and their caregivers regarding health insurance coverage. The program is aimed at educating and assisting seniors and their caregivers, particularly Medicare beneficiaries, in making informed decisions. This program also informs seniors and their caregivers about preventive health services that can help avoid medical complications. The program is administered by DAIL and offered through the 15 AAAILs.

Legal Aid And Advocacy Resources

Legal services are available through the AAAILs and are provided by the Access to Justice Foundation Legal Helpline for Older Kentuckians and by four regional Legal Service Corporation programs. These organizations help older Kentuckians and their caregivers understand the rules of Social Security, Social Security Insurance, Medicare, Medicaid, and other benefits programs. They help with consumer protection, contract law, and consumer lending issues.

Long-Term Care Ombudsman Program

The Long-Term Care Ombudsman Program advocates on behalf of all individuals and their caregivers who are participating in the long-term care system. Ombudsmen assist with reinforcing and exercising residents' rights, facilitating the complaint process, and resolving concerns of residents and their caregivers. The ombudsman program is administered by DAIL and offered through the 15 AAAILs.

Nutrition Program For The Elderly

The Nutrition Program for the Elderly provides one meal per day either in a dining setting or through a home-delivered meal, which can assist caregivers in providing care. The program also includes nutrition education and counseling. In 2014, 20,635 individuals received meals in a dining setting, 6,581 received home-delivered meals, 226 received nutritional counseling, and 21,968 received nutritional education.²¹ This program is administered by DAIL and offered through the 15 AAAILs.²²

Office On Alzheimer's Disease And Related Disorders

The Office on Alzheimer's Disease and Related Disorders was established by the General Assembly and is housed in the Cabinet for Health and Family Services to oversee information and resources related to policy and services affecting individuals with dementia and their caregivers and families. The Alzheimer's and Related Disorders Advisory Council, also established by the General Assembly, is a community group that identifies ways to help Kentuckians with memory loss and their families. The council reports to the Office on Alzheimer's Disease and Related Disorders.

Personal Care Attendant Program

The Personal Care Attendant Program enables eligible adults with significant disabilities to hire employees to assist with domestic, personal, and transportation needs. These services help family caregivers assist adults at risk of being institutionalized to live in their own homes and communities. In FY 2013-2014, 353 individuals received services under this program administered by DAIL and offered through the 15 AAAILs.²³

Public Guardianship Program

The Public Guardianship Program provides legal assistance by a court-appointed person who assumes the responsibility of guardian for an adult who has been declared legally disabled by the court and is unable to care for personal needs or manage his or her financial resources. A guardian may be a friend or family member who is willing to care for the individual. Waiting lists are not allowed for this program by state law. The program is administered by DAIL.

Senior Centers

There are more than 200 senior centers throughout Kentucky with at least one in each county. The role of senior centers is to connect older individuals to community services, social activities, information, health programs, and other resources. Senior centers can help family caregivers obtain information on services and remain socially active, particularly when the caregivers are seniors as well. Senior centers are administered by local governments but may receive some state and federal funds.

Veterans Affairs Caregiver Support

Veterans Affairs provides benefits and services for veterans as well as services directed specifically for family caregivers of veterans. The services offered by Veterans Affairs include adult day health care centers, home-based primary care, home hospice care, homemaker and home health aides, home telehealth, respite care, skilled home care, a support line, and support coordinators.

Federal Resources, Policies, Programs, And Legislation For Family Caregivers

Family And Medical Leave Act

The federal Family and Medical Leave Act (FMLA) guarantees up to 12 weeks in a 12-month period of job-protected unpaid leave for a worker's or family member's serious health needs. The FMLA does not cover all workers and does not cover all familial relationships. To qualify, a worker must have worked at least 1 year and must have worked at least 1,250 hours in the past year, approximately 24 hours per week.²⁴

The FMLA provides limited assistance to family caregivers of older persons because it applies only to a caregiver's children, parents, or spouse. Other family members are not included.²⁵

Older Americans Act

The Older Americans Act provides oversight to and funding for states to provide services to seniors and their caregivers. The Act specifies that DAIL and the AAAILS should focus on providing services to economically needy older individuals with few social supports, with severe disabilities, with limited English proficiency, who are at risk for institutional placement, or were living in rural areas. In 2014, Kentucky received a \$17.5 million allocation for meals and nutrition services, supportive services and preventive health, and the Family Caregiver Support Program.²⁶

Programs and services in Kentucky offered under the Act include the Adult Day Care and Alzheimer's Disease Respite Program, the Area Disability Resource Market, the Family Caregiver Support Program, health promotion and disease prevention programs, legal aid and advocacy resources, the Long-term Care Ombudsman Program, the Nutrition Program for the Elderly, Personal Care Attendant Program, and social services such as case management and assessment services.

Public Health Service Act

Under the Public Health Service Act, the Lifespan Respite Care Program provides respite care services for family caregivers. Since 2009, Congress has appropriated \$2.5 million per year for this program. Eligible agencies in 30 states have been awarded grants to develop respite programs or build on respite program foundations.²⁷ Kentucky has not applied for a grant, primarily because a 25 percent state match is required.²⁸

The Alzheimer's Disease Supportive Services Program is also under the Public Health Service Act. This program supports state efforts to expand, create, and deliver supportive services for those with Alzheimer's disease and related disorders and their families. Kentucky has received a grant from this program.²⁹

Chapter 3

Supports Used By Kentucky Family Caregivers

The 2014 General Assembly in Senate Concurrent Resolution 102 directed LRC staff to interview family caregivers about their needs, including the designation as caregivers, training, respite services, medical leave policies, delegation of tasks to nonmedical aides, and relevant state policies. This chapter presents the results of these interviews.

Summary Of Responses

The responses were fairly consistent across the area development districts. The tasks that family caregivers most commonly reported performing include health care coordination tasks (doctor and specialist appointments, transportation to and from appointments, and medication management and administration); medical and nursing tasks in the home (catheter monitoring and upkeep, diabetes management, treatment of staph infections, and wound care); personal care activities (bathing, cooking, cleaning, dressing, household chores, and mobility assistance); and financial management and planning.

Services mentioned as most used by family caregivers included adult day care, information and resource sharing, referrals to services, respite services, support groups, and training and education.

Many caregivers reported seeking information on programs and services on their own, whether through the Alzheimer's Association, churches and parish nurses, home health and hospice providers, Internet research, local AAAILs, local police departments, long-term care call centers, pamphlets at health care provider offices, support groups, veterans groups, and workshops.

Responses To Specific Needs

Designation As Caregivers

Legal designation as a caregiver was not a major issue for family caregivers. However, a few caregivers mentioned that it might be helpful to have a legal designation when attempting to access health information for their family member.

Training

None of the family caregivers interviewed reported that they received training in health or medical tasks, including medication administration, medication management, or wound care; or in physical or personal care, such as bathing, cleaning, clothing, feeding, or assisting with mobility. Several of those interviewed were previously or were still employed in a health care-related field. Those individuals reported using their career training in their daily caregiving tasks

noting that they would not have known how to properly care for their family member without that professional training. Those without health care backgrounds reported relying on unofficial observations of medical or nursing tasks during hospital stays and home health visits.

Some of those interviewed noted a need for caregiver training and education such as recognizing signs of abuse, neglect, and exploitation; care for illness and disease; wound care; medication monitoring and administration; basic emergency care such as CPR, the Heimlich maneuver, and recognizing signs and symptoms of stroke and medication interactions; providing personal care, including bathing, cleaning, feeding, clothing, and mobility assistance; and creating a safe home environment. Also mentioned was the need for training on programs such as Medicare, Medicare Replacement Plans, Medicaid, Medicaid waivers, supplemental insurance, and workplace leave options. A number of caregivers mentioned the need for community education, information, and training regarding financial and legal planning.

Respite Services

Most caregivers mentioned the need for breaks from the demands of caring for an elderly family member, even for shorter periods of time to be able to run basic errands such as going to the bank, grocery, or pharmacy. Many of the caregivers interviewed reported using respite services provided by their local AAAILS, others reported using adult day care services. However, problems with access included limited hours allotted, limited slots available, and long waiting lists. Other challenges to getting respite included lack of transportation to such services and the cost of private sitters.

Medical Leave Policies

The majority of Kentucky caregivers interviewed were no longer working. Some explicitly mentioned they either quit or retired early in order to provide full-time care. Some caregivers suggested that while workplace leave policies could have helped, without affordable respite services to provide care for their family member while they worked, they still would have had to stop working in order to provide that care.

Delegation Of Tasks To Nonmedical Aides

Medication management and administration was frequently mentioned as a source of concern—one caregiver was managing 16 prescriptions, medications, dosages, and interactions for the person she was caring for and had no training to help guide her.

Caregivers also reported concern over the transition from institutional care, as in a hospital or nursing facility, to the home without adequate home health services. The gap between these levels of care was a source of anxiety, as was the lack of education or training in home-based care. Some caregivers mentioned the lack of home health care services and the associated steep costs.

Several caregivers reported periodically using inpatient services, such as assisted living facilities, hospitals, and skilled nursing facilities, when the intensity and level of needed care increased.

When their family member returned home, some individuals qualified for the transitional services through the AAAILs; some used home health services; and others employed private sitters, personal care aides, and case managers.

Relevant State Policies

Transportation concerns were commonly mentioned. Though there are some public transportation programs, they are difficult to access in rural areas. In addition, increases in demand can increase wait times. Few of the caregivers had access to public transportation. Most provided all transportation themselves. Those who did access public transportation services used public transit and taxis.

There was repeated mention of difficulties accessing services and a marked lack of services in rural areas. Some mentioned that caregivers were not aware of, could not afford, or could not find services. The need to alleviate waiting lists, increase the number of people served, and expand existing services was often mentioned.

Many caregivers reported that the lack of awareness of services was a major challenge. The majority sought out information on programs and services on their own, whether through the Alzheimer's Association, churches, Internet research, home health and hospice providers, local AAAILs, pamphlets at health care provider offices, support groups, or veterans groups. Caregivers suggested that there is a need for a central hotline, information hub, resource center, or resource guide that could provide information on services, instructions on how to access them, and referrals to those programs. When asked to elaborate, some described a telephonic or web-based hotline that could provide consultation; others pictured a resource guide for seniors and caregivers who are less technologically savvy; and some discussed the possibility of a central point of contact, case manager, or care coordinator filling this role.

Caregivers also mentioned the need for more support groups and mental health care to combat the emotional toll of providing care, including strains on familial relationships, empathy fatigue, caregiver guilt, and maintaining healthy work/caregiver balance. Several caregivers reported having attended support groups, including Alzheimer's Association and AAAIL support groups. Of those who did not attend support groups, some mentioned the desire to find a support group but lacked the awareness or knowledge of where to find such services. They also expressed the need for respite in order to take advantage of support groups.

No caregivers reported personal use of counseling or mental health care services, though some expressed interest in gaining access to those services. There were repeated concerns over cost, with one person detailing an account of attending therapy a few times but the expense led to a dilemma: "Between his meds and my sanity, his meds are going to win."

Some caregivers reported making modifications to their homes to accommodate the aging relative, including elevated toilet seats, handrails, hospital beds, ramps, tub benches, walkers, or walk-in showers. Most used personal funds and savings accounts to pay for modifications, though some reported using funds from the home care program, Medicare, and the Veteran's Administration.

While the number of Kentucky family caregivers interviewed is small, the responses are consistent with national surveys of family caregivers. More than one-half of family caregivers nationally report negative impacts on their family, their personal health and well-being, and stress levels as a result of time, energy, and resources allocated to providing care. The AARP Public Policy Institute scorecard that ranks states on multidimensional performance and outcome measures of long-term care services and supports systems ranked Kentucky last. The states that comprised the lower ranks of the scorecard are primarily in the South, where poverty and disability rates are among the highest in the nation.³⁰

Chapter 4

Kentucky Family Caregivers: Recommendations

In addition to the services used or needed, Kentucky family caregivers were asked about recommendations they had for improving the long-term care system. A commonly repeated recommendation was to increase awareness and education about the services that are already in place. The disconnected, fragmented nature of the long-term care system was a frequent source of complaint. Some suggested the need for a statewide directory of resources outlining available services, relevant eligibility criteria, and connections to the program or department that administers the program. This suggestion indicates that some caregivers may be unaware of the Area Disability Resource Market website or that the website is inadequate. Many caregivers mentioned the need for more training for caregivers in basic health, medical, and personal care activities.

Another common suggestion was to increase the amount of funding for and availability of respite services. Those who used respite services expressed a need for more hours. Of those who did not know of, qualify for, or use respite services, most expressed interest in or need of these services. Requests for increased funding for adult day care in particular were common to provide caregivers with respite during work hours.

Some of those interviewed discussed needing help to manage the financial toll that caregiving had placed on their families. They mentioned having to deplete their assets in order to qualify for services or earning too much to qualify for some services but not enough to live without fear of financial hardship.

Through the course of this study, staff contacted state agencies, caregiver professionals, advocacy and interest groups, and caregivers, and conducted research on state and federal programs. The following discussion of ideas and their possible ramifications for Kentucky is based on the information gleaned from those sources and from topics discussed at the ADD forums, considering that Kentucky has in place some policies and programs geared toward aiding family members responsible for the care of elder relatives.

The following ideas are discussed:

- Improving the integration of caregivers in transitional care
- Increasing support for Area Agencies on Aging and Independent Living
- Enhancing employment policies for caregivers
- Delegating health maintenance tasks
- Changing the allocation of Medicaid funds spent on long-term care
- Reducing shortages of home health and personal care aides

Improving The Integration Of Family Caregivers In Transitional Care

One action to address Kentucky family caregiver requests for more education and training is to improve the integration of family caregivers in transitional care. “Transitional care is a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location. Representative locations include (but are not limited to) hospitals, sub-acute and post-acute nursing facilities, the patient’s home, primary and specialty care offices, and long-term care facilities.”³¹ While many seniors rely on family caregivers to help them navigate transitions and coordinate their care when they return home, family caregivers often are not recognized by providers or integrated into the transitional care process.³²

Integration of the family caregiver into the transitional process requires a paradigm shift that challenges the notion of patient confidentiality. Sharing patient health care information with even close family members of patients is often viewed as a breach of professional ethics.³³

The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that serves to protect personal health care and medical information. Health care providers and facilities sometimes reference HIPAA when declining to share health care information with family caregivers. However, the US Department of Health and Human Services has clarified that unless a patient has specifically stated that no information is to be shared with a particular individual, a health care provider can share information with a family caregiver about treatment for an illness.³⁴ Training for patients, family caregivers, and health care providers on what medical information may be safely shared and when it can be shared could considerably improve the transitional care process.

Involving family caregivers in the transitional process may increase the quality of patient care, increase the confidence of providers and caregivers, improve patient outcomes, and decrease hospital readmissions.³⁵

Education and training for family caregivers is also important for transitional care. Caregivers may not understand how to perform the tasks necessary to treat complex chronic health conditions. Medication errors are one of the leading reasons for preventable hospitalizations, yet caregivers often receive no training.³⁶

In October 2014, the University of Kentucky announced that the Center for Health Services Research will lead a national research project sponsored by the federal Patient-Centered Outcomes Research Institute to identify the most effective approaches for patient care transitions as they move between hospitals, nursing homes, and their homes.³⁷

Increasing Support For Area Agencies On Aging And Independent Living

Another approach for addressing Kentucky family caregiver requests for more education and training and improving respite services is to increase support for Area Agencies on Aging and Independent Living.

There are waiting lists for many services available through the AAAILs, and the same services are not available through all AAAILs. Since funding for the programs derives from several sources, including federal, state, and local dollars and consumer contributions, the ability of each AAAIL to provide services varies. For instance, some AAAILs have more staff to manage aging programs, stronger collaborations with local partners, and more sources of local funding than others. Additionally, within ADDs some counties have more resources than others.

A national comparison of state aging and disability services ranked Kentucky 34th. Kentucky scored relatively lower than other states on the availability of options for counseling services, local partnerships, targeting local populations, and assurance of quality services.³⁸

Enhancing Employment Policies For Caregivers

Nationally, family caregivers are employed at the same rate as the rest of the population. Approximately 74 percent of caregivers have been employed at some point during their time as caregivers.³⁹ Additionally, one-half of the US workforce expects to be a caregiver for an elder in the next 5 years.⁴⁰ Among US caregivers who are retired, nearly 1 in 5 reported that they left the workforce earlier than planned to take care of an elderly family member. Also, approximately 7 in 10 reported arriving late, leaving early, reducing hours, taking leave, changing jobs, or quitting because of caregiver responsibilities.⁴¹

The result is a significant financial impact on the families of caregivers. Caregivers report a loss of job security, career mobility, health plans, retirement plans, Social Security benefits, and work hours. On average, family caregivers are estimated to lose more than \$300,000 in wages and benefits across their lifetimes.⁴²

The federal Family and Medical Leave Act guarantees up to 12 weeks in a 12-month period of job-protected unpaid leave for a worker's or family member's serious health needs. The FMLA does not cover all workers and does not cover all familial relationships. To qualify, a worker must have worked at least 1 year and must have worked at least 1,250 hours in the past year, approximately 24 hours per week.⁴³ Even so, for nearly 40 percent of private-sector workers and 80 percent of low-wage workers in the US, leave would be unpaid.⁴⁴ Some states have expanded eligibility for family and medical leave to businesses with fewer than 50 employees; permitted leave for medical appointments; and expanded the definition of "family member" to include grandparents, in-laws, domestic partners, or siblings.⁴⁵ Unless states add supplemental provisions, the FMLA only covers approximately 60 percent of workers.

Some states offer paid family and medical leave to workers. Some states fund this leave through an employee-paid tax, placing no direct costs on the employer. Other states allow working caregivers to put pre-tax dollars into flexible spending accounts to help pay out-of-pocket costs for eldercare expenses regardless of whether they are a legal dependent of the caregiver.⁴⁶

Another public policy option is a type of paid leave insurance much like temporary disability insurance. Some states provide employees with full or partial income replacement while away from work for personal health care or caregiving. States have financed these programs through either employee contributions or a combination of employee and employer contributions.

Delegating Health Maintenance Tasks

Many family caregivers perform medical tasks for a family member with multiple chronic physical and cognitive conditions. These tasks include administering intravenous injections; managing nutrition and medication; providing wound care; and using and maintaining monitors, devices, and medical equipment. Research shows that family caregivers who report performing these types of nursing tasks often do so because of the prohibitive cost of hiring a health professional.⁴⁷ Allowing nurses to delegate tasks to direct care workers such as home health and personal care aides could ease some of burden on family caregivers.

As of April 2014, a Kentucky Board of Nursing opinion statement had been amended to eliminate the list of tasks that may be delegated. Instead, the board states that it is a nurse's responsibility to decide what should and should not be delegated as long as the provisions of 201 KAR 20:400 are met. This administrative regulation lists factors for a nurse to consider in making decisions as to whether a nursing task is appropriate to delegate. A task that is appropriate to delegate on one occasion may not be appropriate on another occasion.⁴⁸

Changing The Allocation Of Medicaid Funds Spent On Long-Term Care

The Medicaid Home and Community Based Waiver is a federally approved option permitting states to use Medicaid funds for some nonmedical services and supports to elderly people so that they can remain in or return to their homes. The use of this option in Kentucky is limited. Approximately 81 percent of all Medicaid spending on long-term care in Kentucky goes to institutional care, compared to the median for all states at 69 percent. The top two states, Minnesota and New Mexico, allocate only 35 percent of funds to institutional care.⁴⁹ Kentucky spends \$857 million of the total allocated for programs for the elderly on institutional care, compared to \$198 million that goes to waiver services.⁵⁰

Some ways to increase the number of seniors and their caregivers who can be assisted under the waiver are to increase the proportion of Medicaid funds allocated to the waiver, implement presumptive eligibility for services that help seniors stay at home, and raise the income or asset limits for eligibility.

In September 2014, DAIL announced a plan to integrate services and nursing supports into the waiver program. This action would increase the proportion of Medicaid funds allocated to the waiver and help family caregivers provide care. DAIL indicated plans to file administrative regulations making these changes in the spring of 2015.⁵¹

Implementing presumptive eligibility for services that help seniors stay at home is another possibility for increasing the use of the Medicaid waiver for long-term care services and helping family caregivers. It is currently used for pregnant women to quickly start prenatal care and to reduce infant mortality. Presumptive eligibility for home care could expedite care for the elderly who are at risk of admission or readmission to the hospital or nursing home because they are not able to provide self-care. Time delays in verifying eligibility can result in seniors being admitted prematurely to nursing homes, losing their homes, and experiencing increased impairment with

longer recovery times. There is a possibility that an applicant could be determined to be presumptively eligible by an initial assessment and later found to be ineligible.

Another strategy related to Medicaid spending is to change policies on financial protection for spouses of Medicaid beneficiaries who receive waiver services. Kentucky limits the income allowance and the asset resource protections for waiver participants to near the federal minimums. In contrast, Kentuckians who are spouses of nursing home residents receive the federal maximum income allowance and asset resource protections in determining eligibility for services. Some states extend the same income allowance and asset resource protections to spouses of waiver recipients and spouses of nursing home residents. An increase in the income or asset limits could allow more waiver recipients to stay in their homes rather than enter institutions, particularly when the spouse is the caregiver.⁵²

Reducing Shortages Of Home Health And Personal Care Aides

Family caregivers can receive support in the form of training, respite care, and help with complicated medical services to the extent these services are available and affordable. Providers who assist with daily caregiving tasks can help relieve stress for caregivers and give them time to perform activities outside the home. However, Kentucky ranks 44th in the number of home health and personal care aides per 1,000 population aged 65 and older—22 per 1,000 compared to a median of 33 per 1,000 for all states and 76 per 1,000 for the top state, New York.⁵³

Summary

Kentucky family caregivers made recommendations to increase awareness and education about services, to centralize access to services, to increase access to respite services, and to assist with the financial toll that caregiving has placed on their families. In this chapter, ideas to address these recommendations and build on existing policies and programs were discussed. Improving the integration of family caregivers in transitional care and delegating health maintenance tasks could involve training and education for providers, facilities, and caregivers. Increasing support for AAAILS and changing the allocation of Medicaid funds spent on long-term care could involve a transfer of resources between programs as well as increased funding. Enhancing employment policies for caregivers most likely would involve state or federal legislative changes.

Appendix A

Long-Term Care Forum Questions

1. If you are or ever have been a family caregiver, what resources do you currently utilize and/or are particularly beneficial to help you provide care (such as informational/educational resources, referral, training, respite services, medical leave from your job, ability to perform or delegate tasks to non-medical aides, state programs, regulations, or policies)?
2. If you are or ever have been a family caregiver, what resources do you need to help you provide care (such as legal designation as a caregiver, training, respite services, medical leave from your job, ability to perform or delegate tasks to non-medical aides, changes in state policies)?

Appendix B

Family Caregiver Interview

Hello my name is I work for the Legislative Research Commission in Frankfort. We are conducting short interviews with selected family caregivers for older persons in home settings. The purpose of these interviews is to discover more about what services and resources are needed by family caregivers to help them enable their loved ones to age in a home setting. The responses to these questions will be summarized and reported to the Kentucky General Assembly. I was given your name and phone number as a current family caregiver of an older person in a home setting. Is that right? If you are a former caregiver your responses would also be helpful.

If so, are you willing tell us about your experience as a family caregiver? Your responses are completely confidential and anonymous. We will not be using names or any other individually identifying information. Your responses will be combined with the responses of other family caregivers of older persons across the state. The final report will be available early next year on the LRC website.

Confirm County of Residence:

1. First, would you briefly describe your caregiver situation? (Who are you caring for, how old, how long, only caregiver, type of care needed, are you currently employed, etc...) (If past care giver, note about how long and how long ago.)
2. I'm going to read off a list of resources that family caregivers might use or need. Please tell me if you have used or if you need each resource to help you as a family caregiver.

Such as: (Indicate response after each resource).

1. Support from other family caregivers or support groups?
2. Financial planning assistance (Medicare, Medicaid...)?
3. Legal assistance? (Designation as legal caregiver, living will, etc...)?
4. Health care training or assistance (Medication management, communication with health care providers, etc...)?
5. Perform or have delegated medical tasks (Diabetes care, administer medications, etc...)?
6. Training about or assistance with physical care (bathing, dressing, meals, housekeeping, etc...)?

7. Assistance in gaining access to services (referrals or recommendations from local or state agencies, churches, etc...)?
8. Individual counseling and/or health care for you in your capacity as a family caregiver?
9. Training to assist in making decisions and solving problems relating to their care giving roles?
10. Respite care to temporarily relieve you from your care giving responsibilities?
11. Transportation (to medical appts, etc...)?

(Just a couple more to ask about...)

12. Housing (modifications or moves for accessibility, affordability)?
 13. Medical leave or workplace flexibility from your job?
 14. Social Activities (for you or your loved one)?
 15. Home-delivered meals (Meals on Wheels...)?
3. Do you have any suggestions for changes in state policies or programs that could help you or other family caregivers?

Thank you for your time. Your responses will be very helpful to us in completing this report to the General Assembly on the needs of family caregivers.

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