



## Funding Request for the Illinois Family Care Act

### Executive Summary

In 2004, Illinois passed the [Family Caregiver Act](#)<sup>1</sup> to meet the growing challenges associated with caregiver stress and fatigue. The goal of the Act was to support family (unpaid) caregivers so they may remain in their caregiver role, allowing their care recipients to remain in the community and out of institutional settings. While the Act was passed with bipartisan support<sup>2</sup>, the Act has never been funded. A 2020, collaboration between the National Alliance for Caregiving and AARP resulted in a detailed study on the impact caregiving has on family caregivers. Not only did the number of unpaid caregivers increase between 2015-2020 by more than 20%<sup>3</sup>, the study identified many areas of stress and burnout, and the survey contributed to a growing body of literature suggesting the importance of a robust family support program that helps caregivers continue in their role while experiencing decreased levels of stress and depression. As can be expected, the COVID-19 pandemic only elevated the stressors on all caregivers. Area Agencies on Aging currently receive federal funding to support caregivers through the Older Americans Act, but the funding levels are stagnate and are not meeting the needs of the growing population of those who are aging and need the care provided by family members. There is no state funding for the Illinois Family Caregiver Act.

Many states<sup>4</sup> have shown that state funding for caregiver services, coupled with existing federal funding prevents unnecessary institutionalization of care recipients thereby saving Medicaid dollars. When caregivers are cared for, they can remain in their caregiving role longer. One of the most exciting demonstrations of state funding for Caregiver Services is in Washington State, where \$11.9 million in state funding works in concert with a little over three million dollars of federal Title III E funding. They have been able to successfully demonstrate a \$20 million dollar savings in Medicaid dollars by delaying nursing home placement by 21+ months through supportive services to their caregivers.<sup>5</sup> The savings is in part due to the use of an evidenced based assessment tool designed to measure caregiver stress on several dimensions. It then

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<sup>1</sup> 320ILCS 65/5(2) Family Caregiver Act

<sup>2</sup> House sponsors: Sidney Mathias, Patricia Reid Lindner, James Meyer, Thomas Holbrook, William Delgado, Lovana Jones, Careen Gordon, Lisa Dugan, William Grunloh, John Bradley, Brandon Phelps, Naomi Jakobsson, William Davis, Linda Chapa LaVia, Rosemary Kurtz, Jack Franks, Robert Rita, Charles Jefferson. Senate Sponsors: Mattie Hunter, Jacqueline Collins, Iris Martinez.

<sup>3</sup> AARP and National Alliance for Caregiving: Caregiving in the United States 2020. May 2020

<sup>4</sup> A survey by AgeOptions in September of 2019 revealed that Alaska, Arizona, Georgia, Hawaii, South Carolina, Washington, West Virginia, Wisconsin and Wyoming are provided with some state funding for caregiver support

<sup>5</sup> Washington State Dept. of Social and Health Services Expanding Eligibility for the Family Caregiver Support Program in SFY 2012

targets services and interventions specifically to those stress points. Service is subsequently provided to those with moderate to high level stress. Instead of providing caregivers with only the limited services currently offered (mainly, respite), the number of “tools” in the toolbox are increased and support the specific needs of each caregiver—delaying the caregiver’s consideration of nursing home placement of the care recipient.

- For example, in one situation a woman was being cared for by a daughter and son-in-law. The situation caused such great stress that the couple considered placing their mother in a nursing home. The tailored assessment tool revealed this stress point and proposed the counseling services to assist the couple to work through the conflict productively while continuing to care for their loved one.
- In another situation, a caregiver wife had not been trained in how to manage her husband’s dementia. They were constantly in conflict because she routinely corrected him when his memory failed him. In this case, the tailored assessment resulted in a suggestion of Dementia Care training to decrease the tension and conflict as the wife learned methods to improve her reaction to her husband’s symptoms.

Without an evidenced based in-depth assessment, the caregiver specialists would have likely offered limited interventions to the caregivers described above. They would not have understood the true stress points. The concept of tailoring the intervention specifically to the situation is the key.

**Request:**

**We request state funding for the Illinois Family Care Act which will strengthen the aging network’s ability to support family caregivers. This system would be implemented through the existing network of Area Agencies on Aging who *are already* administering the federal Family Caregiver dollars. Cost : \$6 million.**

**100% of funds will go towards expanding existing services that will almost double support for:**

- Evidence-based assessments that tailor interventions to caregivers’ unique needs
- Support services and respite care that provide temporary relief to caregivers
- Hands-on caregiver training, education and stress relief programs
- A wide range of other support for Grandparents & others raising children
- Saves Medicaid dollars by delaying costly nursing home placement

## Analysis of Opportunity - Issues to be Addressed

According to a recent AARP Illinois Caregiving Survey, **half** of registered voters over the age of forty (40) are providing care to an adult loved one. <sup>6</sup>A robust family caregiver support program is critical for the **1.5 million** caregivers in Illinois who are providing 1.24 billion hours of unpaid work annually. The care provided by family members keeps older adults from needing more intense and costly care in the form of nursing home placement. **In fact, in Illinois, the care provided by family caregivers is estimated to be worth a whopping 17.3 billion dollars!** <sup>7</sup>Since 52% of adults over 65 will need some form of long-term care in their lifetimes, it is imperative that family caregivers are supported through a robust Family Caregiver Support Program (FCSP).

The older adult population in Illinois is projected to reach increase by 76% by 2030 (an increase of 648,129)<sup>8</sup>. As the population of older adults continues to grow, so will the need for family caregivers, as the majority of older adults prefer to receive care in their homes in the community versus in institutional settings.

- Of non-institutionalized persons needing assistance with personal care needs, two-thirds depend solely on family and friends for assistance.
- Another 25% supplement family care with services from paid providers.
- Only a little more than 5% rely exclusively on paid services. Family caregivers are frequently under substantial physical, psychological, and financial stress. Unrelieved by support services, this stress may lead to premature or unnecessary institutionalization of the care recipient or deterioration in the health and family circumstances of the caregiver.

Maintaining work and family life while providing care for an older adult loved one requires balancing multiple roles and responsibilities simultaneously. **AARP's survey found that in Illinois, 49% of family caregivers are currently working, and 12% are raising children, all while providing support for aging family members.** The responsibility of caring for an aging loved one is not easy, and 70% of caregivers report feeling emotional stress. Two-thirds of working caregivers report conflicts between work and caregiving, requiring them to rearrange their work schedules, work fewer than normal hours, or take an unpaid leave of absence. For this population, caregiver support services have the added benefit of allowing family caregivers to remain active members of our workforce.

When family caregivers don't receive the support they need, everyone suffers. In FY 2020, there were 20,800 reports of elder abuse and neglect in Illinois. Of these reports, 75% indicated the abuser as either the spouse, child or other relative. Almost one in five victims

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<sup>6</sup> *Family Caregiving in Illinois: A Survey of Registered Voters Age 40 and Older*. AARP March 2019

<sup>7</sup> *Valuing the Invaluable: 2019 Update*. AARP Public Policy Institute, November 2019

<sup>8</sup> IDoA 10/15/19, *A Tsunami of Senior: Guiding CCPAC to better serve the tidal wave of boomers and beyond through effective counsel to IDoA and Providers*, Barb McConnell, Ed.D.

was age 86 or older; 42% suffer from independent living difficulties.<sup>9</sup> Victims may suffer from some form of dementia or physical impairment, often suffering from multiple disabilities which make them dependent on others for care. Additionally, depression and emotional problems related to stress leads to poor health outcomes for family caregivers.

Those caring for a close relative, such as a spouse or parent, are at an even higher risk of declining health, and as the number of hours the caregiver provides increases, their health declines. Caregivers supporting a family member with chronic health conditions such as Alzheimer's disease or a long-term physical condition report higher levels of emotional stress.

The COVID-19 pandemic has increased stress levels amongst all caregivers but perhaps especially so in the African American community. 51% of African American caregivers report spending more on caregiving as a result of COVID-19. Additionally, 33% say they are spending a lot more time on caregiving since the pandemic began and 37% report worsened physical health to some extent because of the pandemic.<sup>10</sup>

The Illinois Family Caregiver Act, which was passed 16 years ago, has remained unfunded, leaving caregivers to rely on the limited services that are provided through federal funding. Despite the increased population of older adults and number of people who provide unpaid care for them, federal funding has remained stagnant, while the number of people over the age of sixty has increased by 26% in Illinois since 2010<sup>11</sup>. In addition, since those who are age 85 and over are increasing rapidly<sup>12</sup> these older adults may have greater needs than in the past due to advanced age and increased frailty. The number of people over the age of sixty who are in poverty increased 25% to 231,776 and the number who are minority increased 87% to 724,981! In effect, funding has decreased due to inflation as the need for services grows.

Additionally, provider agencies, funded by the Older Americans Act to provide services and programs for caregivers, lack the tools needed to intervene. Area Agencies on Aging are equipped with a network of agencies and staff who are dedicated to serving older adults and their caregivers, but they lack the resources to provide the comprehensive care that would make a real difference in the length of time of caregiver is able to continue in their role. Family caregivers who provide unpaid care are a mainstay of the long-term care system and this Act recognizes that the hours put in by family caregivers is what postpones or even helps avoid institutionalization of care recipients.

Illinois receives just over \$6.5 million under the Federal Older Americans Act and a total of 55,336 caregivers are served under the program. We know that in 2018 201,200 "units" of service were provided<sup>13</sup> to those caregivers but due to scarcity of funding, in most cases, we

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<sup>9</sup> Adult Protective Services of Illinois: Annual Report 2020

<sup>10</sup> Caregiving Out-Of-Pocket Costs Study 2021, AARP Research, June 2021

<sup>11</sup> IDoA 10/15/19 A Tsunami of Seniors: Guiding CCPAC to better serve the tidal wave of boomers and beyond through effective counsel to IDoA and Providers Barb Mc Connell, Ed.D.

<sup>12</sup> IDoA, NAPIS data 2018

<sup>13</sup> IDoA, NAPIS data 2018

do not have detailed data on exactly what services are provided *or* on how the services provided to the caregivers makes a real difference in the length of time they are able to continue in their caregiver roles or in the quality of their experiences. The Illinois Caregiver Resources Centers are local organizations designated to serve caregivers. The primary services at their disposal are respite care which is in short supply, home delivered meals, and evidenced-based caregiver training programs such as Powerful Tools for Caregivers and Savvy Caregivers. The Community Care Program is a great resource for those who are eligible but for those who fall outside of income or needs guidelines the resources are scarce. Another tool we are missing is an evidenced based assessment tool to assist Care Coordinators in pinpointing the most critical needs of the caregivers to help sustain them in their roles.

### **In Conclusion**

Funding for the Illinois Family Care Act in the amount of \$6 million will strengthen the aging network's ability to support family caregivers. These programs are implemented through the existing network of Area Agencies on Aging who *are already* administering the federal Family Caregiver dollars.

100% of funds will go towards expanding existing services that will almost double support for:

- Support services and respite care that provide temporary relief to caregivers
- Hands-on caregiver training, education and stress relief programs
- Counseling and evidence-based assessments that tailor interventions to caregivers' unique needs
- A wide range of other support for Grandparents & others raising children
- Saves Medicaid dollars by delaying costly nursing home placement