



# **From Caregiver to Caregiver: The Wisdom and Insights of Former NFCSP Caregivers**

*Final Report*

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**Administration for Community Living  
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## I. Introduction

In 2016, the Administration on Aging (AoA), which is part of the Administration for Community Living (ACL), funded an outcome evaluation focused on the collection of survey response data from a nationally representative sample of National Family Caregiver Support Program (NFCSP) caregivers, a matched comparison group of caregivers that do not receive NFCSP services, and a sample of care recipients. The objectives of the outcome evaluation were to:

- *Help ACL understand which kinds of services are most helpful for caregivers and identify any unmet needs of caregivers and gaps in support for them;*
- *Identify any NFCSP resources, organizational characteristics, and implementation practices that appear to contribute to positive outcomes for caregivers receiving the key NFCSP services of respite and/or caregiver training/education and for their care recipients;*
- *Assess the impact of services on the ability of caregivers to continue to provide home-based caregiving as needed; for example, by examining the relationship between self-reported caregiver measures of physical and mental well-being and the amount of caregiver services received; and*
- *Examine the relationship between NFCSP client outcomes and key processes and characteristics of the Area Agencies on Aging managing and/or providing NFCSP services.*

During the course of the 12-month data collection period for the outcome evaluation, some caregivers (CGs) were deemed “ineligible” to complete the final interview because their care recipient (CR) had passed away. However, a portion of these individuals expressed an interest in telling their story. As part of the Office of Performance and Evaluation (OPE) Support Contract, the New Editions team conducted a small, retrospective study of bereaved caregivers from the NFCSP outcome evaluation. This study gathered information on the service components/needs of bereaved caregivers who agreed to participate in a telephone interview. The results and conclusions from this study aim at affording local service providers, Area Agencies on Aging (AAAs), State Units on Aging (SUAs), and AoA insights for supporting individuals at all stages of the caring process.

### A. Questions of Interest for ACL

Key questions for this task include the following:

- *What were the circumstances that directed/led caregivers to services?*
- *What supports, either formal or informal, were caregivers receiving?*
- *How did the caregiver’s support needs evolve over the course of the caregiving experience?*
- *What supports were caregivers offered or did they need after their care recipients passed away? If none were offered, what did they need?*

## B. Population

The population frame for this study was NFCSP caregivers included in the outcome evaluation who did not complete 12-month interviews (Nov 2017-Jan 2018) because their care recipient passed away prior to the end of the measurement period. The eligible sample size is 46 individuals, however only eight individuals agreed to participate in the study.

## II. The Role and Importance of Family Caregivers

As individuals age and begin to experience declines in their health, family members and friends commonly assume greater roles in making treatment decisions and providing other supports to the care recipient. In many cases, these family and friends take on the role of caregiver, performing tasks that direct-care workers would otherwise provide such as assisting with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Institute of Medicine [IoM], 2008). As defined in the 2016 reauthorization of the Older Americans Act (OAA), a 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 (2016, 2018).*

Informal caregiving occurs across a broad variety of settings in which the person receives care, and often requires caregivers to coordinate between multiple specialty providers; assist in transition in and out of hospitals, homes, and rehabilitation centers; and frequently continues up to placement of the recipient in a nursing home or in end-of-life care (Liu, Kim, & Zarit, 2015; Health and Medicine Division [HMD], 2016). Typical tasks include shopping, food preparation, housekeeping, transportation, and the administration of medication, as well as feeding, dressing, bathing, and assisting the care recipient in toileting. However, for high-need recipients, caregivers may also be called upon to perform medical and nursing tasks or make care decisions, with over three-quarters (77%) having reported navigating the care network on their care recipient's behalf, and nearly a quarter (23%) being responsible for making all care decisions for their loved one (HMD, 2016b).

The role of informal caregiver is one that individuals may assume gradually as they recognize a recipient's need for support, or they may be suddenly required to step into the caregiving role following a crisis event such as a heart-attack or stroke (HMD, 2016a). While there are common trends in the experiences of informal caregivers, there are numerous variables that affect the trajectory for the provision of long-term informal care. As care recipients become increasingly frail or impaired, the caregiving role expands accordingly. If the periods of disability experienced by recipients are episodic, caregiving may occur in high demand over a short period, or may ebb and flow with the recipient's needs (Gitlin & Wolff, 2012; Zarit & Zarit, 2015; HMD, 2016).

Over 72 percent of all caregivers using NFCSP are female (ACL, 2017a). There is evidence to suggest that caregiving tasks vary by gender, with female caregivers more likely to assist in the most difficult physical tasks such as bathing and dressing, while male caregivers are more likely to help in areas of finance and care coordination (HMD, 2016b). Nationally, the average age of caregivers is 49 years, with 48 percent of caregivers falling between the ages of 18 and 49, and 19 percent above the age of 65 (AARP & NAC, 2015). Most caregivers using NFCSP identify as

White (74 percent), followed by Black or African American (18 percent), and 10 percent of caregivers identify as Hispanic or Latino. Over 95 percent of caregivers care for a relative or a loved one, with 42 percent caring for a spouse and 45 percent providing care to a parent or in-law (ACL, 2017a).

There are far more informal caregivers in the United States than direct-care workers. Current estimates indicate that the aging U.S. population is rapidly outpacing the availability of informal caregivers, increasing dependence on an already strained direct-care workforce. By 2030, the number of people 65 years or older is expected to double, and the number of potential family caregivers is projected to drop from seven to four per adult aged 65 or older (IoM, 2008; Centers for Disease Control and Prevention [CDC], 2018). As of 2015, there were an estimated 43.5 million informal caregivers providing supports to adults or children in the U.S. Approximately 39.8 million of these caregivers provide care to adults with a disability or long-term illness (AARP & NAC, 2015). The majority of caregivers (78 percent) provide care and support to a single adult, 13 percent for two adults, and nine percent for three or more adults (ACL, 2017a).

### **III. Impacts of Family Caregiving**

Care recipients generally report a high degree of satisfaction with the supports and care received from family and friends, and informal caregivers are broadly viewed as more responsive and in-tune with recipients' needs than paid assistance (IoM, 2008). This view is further validated by evidence indicating that informal caregiving, and family participation in care more broadly, may improve care outcomes for the care recipient, including reduced usage of emergency services and delayed placement in institutionalized care (Miller & Weissert, 2000; Liu et al., 2015). The availability of family caregivers is associated with: shorter hospital stays; lower risk for depressive symptoms; improved care recipient satisfaction; and, in some cases, a reduced rate of mortality following a significant health shock that required hospitalization (Picone, Sloan, Chou, & Taylor, 2003; Allen, Hutchinson, Brown, & Livingston, 2014).

While care recipients experience significant positive benefits of informal care, the significant demands of providing supports to loved ones can produce detrimental physical and emotional effects on family caregivers. These effects are dependent on factors such as the extent of the recipient's disability and/or health conditions, the duration of care provided, the level of oversight and attention involved in care, and the living arrangement between the recipient and the caregiver, such as cohabitation (Schulz & Sherwood, 2008; Liu et al., 2015). Conditions requiring high intensity and high frequency care, such as dementia, are linked with the most negative caregiver outcomes with respect to higher rate of physical illness, and increased incidence of depression and stress (Schulz & Sherwood, 2008; Vitaliano, Zhang, & Scanlon, 2003; Liu et al., 2015). Evidence suggests that older caregivers, caregivers with a spousal relationship to the recipient, and female caregivers are most likely to report low ratings of emotional well-being; a key factor in these associations is caregiver perception of how much the recipient is suffering (Schulz & Sherwood, 2008).

It is important to note that there are also positive effects of caregiving. Caregivers report that aiding the recipient often instills a sense of confidence, provides them with the tools to address emotionally difficult situations, strengthens the bond between caregiver and care recipient, and

gives the caregiver peace of mind with respect to the quality of care and assurance of recipient needs being met (Liu et al., 2015; HMD, 2016). Negative psychological outcomes can coexist with positive outcomes, and are not mutually exclusive; the increased stakes of the relationship may actually strengthen the known benefits of supportive relationships in living longer and healthier lives, as opposed to those living in relative social isolation (Schulz & Sherwood, 2008).

Caregiving can be a time-intensive responsibility, and its impact felt more broadly in the social interactions of caregivers. Caregivers commonly report limitations on their time and energy for maintaining social networks and participating in activities that caregivers enjoy, including reduced participation in visiting with friends and family, attending religious services, and going out for dinner or entertainment (HMD, 2016a).

Caregiving can also have financial implications for the provider. Nationally, sixty percent of caregivers were employed at some point during 2015 while providing care; over half of these caregivers were employed full-time. Seventy percent of working caregivers report work-related difficulties as a product of juggling the competing roles. Sixty-one percent of working caregivers report having to rearrange their work schedule, decrease their hours, or take unpaid leave from work in order to provide adequate care to their loved one (AARP & NAC, 2015). The financial burden of caregiving is exacerbated by a decline in work-life productivity and a loss of wages. Reports from 2010 indicate that 10 million caregivers over the age of 50 lost an estimated \$3 trillion in wages, pensions, retirement funds, and benefits (MetLife, 2011). Women are more likely to experience these strains, and leave the workplace at higher rates than men in order to focus on their caregiving role. Long-term caregiving is also linked to higher rates of poverty and lower rates of higher educational attainment (Gardiner, Brereton, Frey, Wilkinson-Meyer, & Gott, 2013). Financial and scheduling burdens of caregiving contribute to increased stress and negative emotional outcomes for caregivers (Schulz & Sherwood, 2008; Gardiner et al., 2013).

#### **IV. The OAA and NFCSP**

In 1965, in response to gaps in community supports for older persons, Congress passed the Older Americans Act (OAA), which established federal grants for community planning and social services, research projects, and training for personnel in the fields of aging and disability (Administration for Community Living [ACL], 2017a). In addition to establishing the Administration on Aging (AoA) to administer its grant programs, the OAA is considered the primary vehicle for the organization and delivery of social services to older Americans and their caregivers (ACL, 2017b).

The National Family Caregiver Support Program (NFCSP) was established in 2000 to provide grants to states and territories to fund support programs to assist informal caregivers in caring for a recipient in the home (ACL, 2017c). The NFCSP provides grants for five types of services: (i) informational resources to caregivers about available services; (ii) assistance to caregivers in accessing services; (iii) individual counseling, support groups, and caregiver training; (iv) respite care; and (v) supplemental services, on a limited basis (ACL, 2017c). NFCSP directs State Units on Aging (SUAs) to work in partnership with Area Agencies on Aging (AAAs) to provide comprehensive information on the array of services provided through NFCSP funding, as well as those state programs that fall outside of its scope.

Individual counseling and support group programs funded through the NFCSP vary by state, in part because the ACL does not impose programmatic requirements. Not all support groups or counseling programs provided through AAAs receive funding through the NFCSP, as AAAs may incorporate existing local services instead of creating new programs from the ground up. Some AAA programs may provide grief management or end-of-life counseling, and family counseling. The NFCSP also funds trainings, including evidence-base interventions to help caregivers attend to the stress of caregiving (Link, 2015/2016). Respite care programs provide trained caregivers to attend to a recipient's needs and perform care activities, in either a planned or emergency capacity, providing temporary relief for the primary caregiver to attend to their own needs. These services are primarily provided in a home setting, but can also occur through adult day care centers and overnight residential facilities (ARCH National Respite Network and Resource Center, 2018).

In 2016, with a budget of slightly over \$150 million, NFCSP provided support services to over 190,000 individual caregivers. This included 61,989 caregivers who received respite services, as well as 120,100 individuals who received counseling. The ACL further reached nearly 20 million caregivers with their informational services, and provided nearly 1.2 million contacts to caregivers seeking services through its access assistance program (ACL, 2017a; ACL, 2018). In 2016, an evaluation by the ACL of NFCSP implementation found that NFCSP is the primary or only source of caregiver support provided through AAAs in nearly 75 percent of service areas. Results also indicated that, in states which had established caregiver programs prior to the NFCSP, the number of caregivers served increased substantially after implementation (The Lewin Group, 2016).

## V. Bereaved Caregivers

The reach and efficacy of NFCSP services noted above assumes typical caregiving conditions and experiences, and gaps in the supports provided may exist as recipients' health decline and in the period following the death of the care recipient. The ACL is currently evaluating how caregivers interact with NFCSP services in order to help their network better serve family caregivers. In the course of the outcomes evaluation, the ACL encountered family caregivers whose caregiving was ended by the loss of their care recipient. The ACL recognized an opportunity to gain retrospective insight into the caregiving experience, which might provide an opportunity to refine programs, shape outreach, and better understand the evolving needs of family caregivers, particularly as their recipients' progress into the end-of-life phase of care. This expansion of the outcomes evaluation also provides an opportunity for caregivers to share with current and future caregivers the wisdom gained through their experiences. Demographic data from a sample of 46 caregivers whose care recipient passed away during the course of the ACL's NFCSP outcome evaluation are presented below to contextualize the population of interest.

Caregivers from this sample were predominately female (85 percent), and between the ages of 47 and 88, with a mean age of 69 years. Half (50 percent) of caregivers reported having a spousal relationship with the care recipient, and 41 percent responded that they were caring for a parent. Of the 19 children caring for an aging parent, 18 were the daughter of the recipient. Eighty-three percent of caregivers identified as White, 15 percent as Black or African American, and two percent reported another racial identity. Nearly a quarter (24 percent) of bereaved caregivers reported current full- or part-time employment. Respondents report caring for the recipient for an average period of seven years, with answers ranging from one year of care to a period of 25 years.

What social and economic factors enable or predispose caregivers, particularly bereaved caregivers, to utilize supports and services represents a gap in the currently available literature. Informal caregivers are more likely than non-caregivers to be of a low socioeconomic status and to have a lower educational attainment. Twenty percent of Americans with a high school education or lower will take on the caregiving role in their lifetime, compared with 15 percent of college graduates and 16 percent of postgraduates. In addition, 47 percent of caregivers have an annual household income under \$50,000, with a median income of \$54,700. For African American and Hispanic caregivers, the frequency of household income below \$50,000 increases to over 61 percent (AARP & NAC, 2015). Informal caregivers also appear to be at a higher risk for certain health risk behaviors, including substance abuse, sleep problems, poor diet, and smoking (Vitaliano et al, 2003; HMD, 2016b). Furthermore, it is understood that caregivers participate in fewer social activities and are less engaged in their own health care and wellbeing (HMD, 2016a; HMD, 2016b; Gitlin & Wolff, 2012).

Caregivers who exhibit health risk behaviors associated with stress stand to benefit from programs which reduce the burden of care, or alleviate some of the expectations that caregivers may feel are placed on them. Trainings and education on providing care and accessing the health care delivery system can help equip a caregiver without prior health care experience to better handle the medical realities and needs of their care recipient. Support groups and respite care both serve to increase a caregiver's opportunities for social interaction and recreation. Finally, assistance in coordinating and balancing the caregiver's health needs helps to ensure that caregivers do not neglect themselves in the course of caring for their loved one (Adler et al., 2016; HMD 2016b). The full impact of these services in addressing utilization of services is presently unclear, as is the perspective of bereaved caregivers on the need for these supports, or other similar services.

End-of-life care is an especially complicated period for caregivers, both in terms of the increased physical demands of caregiving and in the emotional impacts of providing care to a dying loved one. There are relatively few studies on the end-of-life phase of caregiving, and those that exist indicate that caregiving demands become more urgent and intensive during this period (Schulz & Sherwood 2008; Chi, Demiris, Lewis, Walker, & Langer, 2015; HMD, 2016b). During this time, caregivers continue to report high levels of burden and stress, but also report a greater degree of meaning or purpose experienced as a product of providing care (HMD, 2016b; Nielsen, Neergaard, Jensen, Bro, & Guldin, 2016). Approximately 70% of all deaths in recipients with terminal conditions involve chronic, deteriorating conditions such as cancer, dementia, or organ failure, confronting the caregiver with a loved one's deterioration and the uncertainties of the future (Nielsen et al., 2016).

Losses during this period of illness are most likely to cause grief, and caregivers are most at-risk for psychological distress during this time. During bereavement, there is significantly increased incidence of depression, anxiety, and complicated grief; a condition characterized by intense yearning for the deceased and impairment of daily life lasting for more than six months after the death (Chi et al., 2015; Nielsen et al., 2016). There is some evidence to suggest that caregiving during the period antecedent to the recipient's death may help transition out of the grief period more quickly and with lower stress levels than non-caregivers, but there is not extensive support for this effect in the literature and this effect, dubbed "forewarning" or "anticipatory grief", is not well-understood (Nielsen et al., 2016).



## VI. Access and Usage of Support Services by Bereaved Caregivers

There is a paucity of literature on the usage of support services by caregivers in the periods leading up to and immediately following a recipient's death. The statistics presented below are drawn from the sample of 46 bereaved caregivers identified during the ACL's NFCSP outcome evaluation. In this sample of caregivers, nearly 48 percent reported receiving respite care in the 6 months prior to the recipient's passing, at nearly 10 hours each week on average. In the 6 months prior to the recipient's death, only 17 percent of these caregivers report receiving caregiver education, counseling, or support group services. One interpretation of the data would suggest that the increased demands during this period of care incite a greater need for time away from the caregiving environment, but a barrier to seeking emotional and social supports. It is important to note that these questions had an approximately 30 percent non-response rate, and may not be fully generalizable.

Contrary to the intuitive expectation that a sudden loss is more difficult to cope with, in 2016 Nielsen et al. found that prolonged periods of anticipatory grief indicated greater risk for complicated grief and post-loss depression, suggesting that prolonged decline is a significant factor in predicting difficult bereavement. A low preparedness for death, defined loosely as the lack of a strong network of social supports, was also strongly linked to difficult bereavement; given the extremely low utilization of counseling and support group services by the sample of bereaved caregivers in the months leading up to the recipient's passing, it is possible that that caregivers are poorly equipped to handle the death of their loved one, and may need additional supports in this area to better cope with their loss (Gitlin & Wolff, 2012; Chi et al., 2015; Nielsen et al., 2016).

## VII. Unmet Needs of Bereaved Caregivers

As discussed earlier, bereaved caregivers exhibit a low utilization of support group and individual counseling services in the months leading up to the recipient's death. These services are integral to a caregiver's preparedness for bereavement, and a low usage is predictive of complicated grief and depression (Garrido & Prigerson, 2014; Nielsen et al., 2016). However, these services may already be provided under the NFCSP, and low utilization is suggestive instead of secondary barriers to access, such as the high demands of end-of-life caregiving leaving little time for a caregiver to seek out personal supports, or a general low-attractiveness of these services. It may therefore be necessary to increase educational supports to caregivers in planning for the inevitability of end-of-life care, and instituting programs to help caregivers actively identify their own needs as they develop (Garrido & Prigerson, 2014; Aoun et al., 2015; Nielsen et al., 2016).

One tool that has been developed for this purpose in Australia is the Carer Support Needs Assessment Tool (CSNAT), which facilitates the assessment of caregiver need for supports in the physical, psychological, social, practical, financial, and spiritual domains of palliative home care (Aoun et al., 2015). The tool takes a screening approach designed to identify the supports and services a caregiver needs to (i) continue providing care to the recipient, and (ii) care for their own wellbeing and emotional wellness. One of the key dimensions of success for the CSNAT were high reports of increased caregiver awareness of their emotional needs in the end-of-life phase of care, coupled with a broadly reported sense of empowerment and validation in seeking social and counseling supports (Aoun et al., 2015). Another key outcome from the implementation of the

CSNAT was increased integration of the family caregivers with the broader medical care team, which decreased perceptions of social isolation, and increased reports of self-care among caregivers (Aoun et al., 2015).

While there is a scarcity of literature documenting the effects of specific disease diagnosis and progression, as well as the relationship between caregiver and recipient, on the utilization of support services, certain trends in physical and emotional demands are recognized. The prolonged periods of decline common to cancer and dementia diagnoses are linked to both higher physical demands in caregiving, and greater emotional strain and stress on the caregivers (Vitaliano et al., 2003; Schulz & Sherwood, 2008; Kim et al., 2018). Evidence also indicates that older caregivers, and those with a spousal relationship to the recipient, are at increased risk for stress and related physical and mental health conditions (Schulz & Sherwood, 2008; Kim et al., 2018).

The results of this study of bereaved caregivers will help identify gaps in existing services, as well as provide insight in how caregiver perceptions of services provided throughout the caregiving trajectory, including during end-of-life care, affect utilization. These results will help shape our understanding of family caregiving, and the preparatory work and supports that caregivers require to cope with bereavement in a healthy manner.

## VIII. Methodology

This small, qualitative study of bereaved caregivers included a potential pool of 46; the final number who self-selected and agreed to be interviewed was eight. The study aimed to examine and understand the bereaved caregivers' usage of the caregivers support services and any identified gaps in services provided. The research team initially developed an interview guide protocol (see **Appendix I**) based on the literature review and analysis of aggregated characteristics of caregivers (CG) with a deceased care recipient (CR) included in the outcome evaluation but who did not complete 12-month interviews. Through these interviews, we aimed to gather information on the service components/needs of bereaved caregivers who agreed to participate in a telephone interview. The information gathered is intended to afford local service providers, Area Agencies on Aging (AAAs), State Units on Aging (SUAs), and the Administration on Aging (AoA) insights for supporting individuals at all stages of the caring process.

Westat, the contractor responsible for conducting the outcome evaluation, notified bereaved caregivers about the bereaved caregiver study opportunity and ten bereaved caregivers notified Westat of their interest in participating in the study. Lewin then notified each of the caregivers in writing about the study along with expectations: 60-minute telephone interview, ensure confidentiality, participation is optional, expect a call within one week of letter receipt to schedule the interview, and a \$50 gift card upon completing the interview. Lewin then contacted the bereaved caregivers to schedule interviews. Through this outreach process, one of the caregivers decided not to proceed and another caregiver was not reachable. Lewin conducted eight interviews with caregivers who granted permission. All interviews were recorded, as permission to record was granted by each caregiver. During the interviews, one individual from the research team conducted the interview according to the semi-structured interview guide protocol and another individual was listening to the interview and taking notes. Lewin adapted each interview protocol in order to avoid redundancy in information already accounted for and available from the Westat data. Subsequent

to conclusion of all interviews, Lewin partnered with a transcription service entity, FEM, Inc., to have each of the telephone recordings transcribed.

## A. Qualitative Data Analysis – Stratifications

Stratifications for the qualitative data analysis were based on the literature review and include the following:

- *Caregiver relationship to care recipient*
- *Caregiver gender*
- *Caregiver age*
- *Rural vs. urban setting*
- *Social Determinants of Health (SDOH) of caregivers – education level, socioeconomic status, and health status*
- *Living arrangement of caregivers and their care recipient*
- *Length of time caregiving/length of time receiving services*
- *Types of services received through the NFCSP*
- *Types of services received through other state or local entities*
- *Access to services – including information provided about or transportation to services*
- *Perception of available services*

## IX. Coding and Analysis

Upon receipt of interview transcripts from FEM, Inc., Lewin coded each interview transcript in the ATLAS.ti 7.0 (ATLAS) software, a dedicated qualitative analysis tool which allows for desired information to be extracted from the collected data and analyzed for trends and other predominant themes or interrelations. Lewin utilized grounded theory and constant comparative methods in order to develop the themes used to compare output from each interview. Each theme was categorized and assigned a main tier code. Each tier code was then structured in a nesting format for comparison at multiple levels of granularity. Lewin ensured that each interview transcript was reviewed by two individuals to ensure consistency of method and analysis. **Appendix II, Exhibits 1 - 5** detail the codes and definitions used during analysis in ATLAS.

## X. Results

### A. Demographic Data

The participants in the NFCSP Bereaved Caregiver Study were recruited as part of a volunteer sample of limited size. To estimate generalizability of the results of this study, researchers compared demographic data collected through the interviews of eight caregivers against population data published by the National Alliance for Caregiving and the AARP (2015). All demographic data collected for the purpose of this study is included in **Table 1**.

**Table 1 – Demographic Data of Caregivers and their Care Recipients**

Field	Study Sample	Population
CG Race	100% White	62% White
CG Gender	100% Female	75% Female
CG Age	67.6 Years	49.2 Years
CG Employment	75%	60%
Years as CG	4.5	4
CR Race	100% White	No data
CR Gender	37.5% Female	65% Female
CR Age	79.6 Years	69.4 Years

### B. Services Accessed by Caregivers

Based on the results of the interviews conducted, caregivers had a tendency to access a similar array of services while providing care to their loved ones. The most commonly accessed services were respite care and informational/educational opportunities.

- Respite Care: 7 caregivers
- Informational/Educational: 6 caregivers

Services with a moderate degree of access included home health care, individual counseling, support groups, and non-care companionship services.

- Home Health Care: 5 caregivers
- Individual Counseling: 5 caregivers
- Support Groups: 4 caregivers
- Non-Care Companionship: 3 caregivers

The least accessed services included transportation, financial aid, nutritional programs such as Meals on Wheels, and supplemental services (one caregiver received assistance setting up her husband's Emergency Response System (ERS)).

- Transportation: 2 caregivers
- Financial Aid: 2 caregivers
- Nutritional Programs: 2 caregivers
- Supplemental Service: 1 caregiver

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*“I was going through all of the different services, Medicare plans, prescription plans that were available in the area, and I came across this one and I thought, oh, okay, this sounds really interesting and I don't know all that much about it. So, I called and found out that my husband would fit into the program perfectly, and so we began doing all the paperwork getting him eligible for it. They were just wonderful. That's how I found out.”*

*“But, they had that and they even offered somebody to come, like an art person, a craft person. They had somebody to maybe come and exercise with the person. This was over and above the homecare, which is what that one woman did and it was explained to me that a lot of people regard the homecare people and let's back up, before my mom needed hospice, people regard the homecare people as maid service and it was explained to me that that's not what it is, they can do some light things but they're there to, like companionship, to help with bathing but they're not there to scrub the woodwork and do all that, just light stuff.”*

*“I took one at a visiting nurse association on how to do safe transfers. As a caregiver, how do you help someone go from a chair to sitting to standing? And they had some equipment that they showed, like some kind of a belt that you can put on someone that you can hold them from behind safely. Ramps, how to use portable ramps, where to buy portable ramps. So the training stuff was good. I never used any support groups or counseling, but the information stuff, yeah, I got a great use of that.”*

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### C. NFCSP Services vs. Non-NFCSP Services

The sources through which these services were provided and accessed also varied between caregivers. A multitude of the services utilized by caregivers were funded through the NFCSP. There were a total of 17 reported instances of service accessed through NFCSP-funded programs, with a median 2.5 NFCSP services accessed per caregiver within a range of 0 to 4 services. The most common services to access through the NFCSP were:

- Informational/Educational: 5 caregivers
- Support Groups: 3 caregivers

Services provided through a hospice program were the next most common for caregivers to access. There were 11 reported instances of services provided through local hospice programs, with a median 0.5 services accessed per caregiver within a range of 0 to 4 services. The most common services to access through the hospice were:

- Individual Counseling: 5 caregivers
- Respite Care: 3 caregivers

Volunteer and community-organized services experienced a median level of access among this sample. These programs include support groups organized through churches and social media, and companion and respite services provided by volunteer organizations. There were 7 reported instances of services accessed through these programs, with a median of 1 service accessed per caregiver across a range of 0 to 2 services. The most volunteer services accessed through volunteer or community programs were:

- Support Groups: 3 caregivers
- Respite Care: 2 caregivers
- Non-Care Companionship: 2 caregivers

One caregiver accessed several services through the Programs of All-Inclusive Care for the Elderly (PACE), which provides comprehensive medical and social services to certain frail, community-dwelling elderly individuals, most of whom are dually eligible for Medicare and Medicaid benefits.<sup>1</sup> The services accessed through this program included:

- Home Health Care
- Respite Care
- Transportation
- Individual Counseling

Only one caregiver reported accessing services through stand-alone, private pay programs. These programs include any not provided through NCFSP funding or affiliated with a hospice or hospital. The services accessed through these private pay programs were:

- Home Health Care
- Respite Care
- Cleaning Service

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*“I was able to get like someone to clean [my mother’s] house every other week. But again, that was private pay. And so basically, everything I did was mainly private pay.”*

*“It was hard because we were forced to put [my husband] on Medicaid. Some places don’t take Medicaid and some places don’t like to if they can find them a better paying customer.”*

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<sup>1</sup> Information related to the PACE program can be accessed here:  
<https://www.medicaid.gov/medicaid/ltss/pace/index.html>

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*“[A representative from the AAA] brought me a book on Alzheimer’s care and it was supportive and had great suggestions. Often they weren’t helpful because every person is so different. They were helpful; there was a lot of good helpful things. But, the one thing, Alzheimer’s people just, it seems they’re always changing just when you get one thing down then they change and you have to approach things in a different way.”*

*“I could contact them, anytime, 24/7, but they did have a nurse on call always. She or he would come at least once during the week and I usually saw one on the weekends. They had a young gal come in and bathe him, because he didn’t want me doing it and he got very irritated towards the end if I was doing it, so that really helped.”*

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## **D. Circumstances Leading to Service Access**

Caregivers reported accessing services at every stage in the care process. When caregivers were proactive about seeking help with their role, caregivers report that their first steps were often to seek information through online resources and AAAs to better understand their loved ones’ illnesses, as well as what support options were available to them. However, these caregivers were of the minority.

Most caregivers reported that they did not ask for help soon enough in the process, and became aware of services over time as the need for support increased. This second group of caregivers was more likely to report finding out about services through support groups and hospice programs, after they had already served as caregivers for several years. Those caregivers who learned of program options later in the caregiving experience were less likely to engage with services and supports, and were more likely to report doing so only after they had already experienced extreme stress and periods of high need.

Caregivers who accessed services earlier in the experience reported feeling more supported, and reported a higher degree of satisfaction with services, compared with those who did not begin engaging with services until their recipient declined to the point of requiring hospice care.

## **E. Program Quality**

Caregiver perceptions of program quality varied widely, although these differences appear to be associated with three factors. The first, mentioned earlier, was the timing of program access. Those caregivers who accessed programs earlier in the process and were exposed to information about program availability sooner tended to have more positive perceptions of overall program quality.

The second dimension to perceptions of program quality was the source of services and supports. Those caregivers who received respite and home health services through hospice programs tended to report lower levels of program satisfaction than those who received similar services through NFCSP-funded services or volunteer programs. This dimension of program quality is partially conflated with the first, however, as those caregivers who accessed services later in their recipients’ decline were more likely to access a majority of their services through hospice.

The final factor of greatest impact on perceptions of program quality is the location in which services were delivered. Those caregivers who accessed services in rural settings were less likely to know what services were available to them, accessed fewer services, and reported lower satisfaction with the services provided. Several factors that may contribute to this effect are the tendency for rural areas with fewer people to receive lower funding for government programs, and a limited infrastructure and fewer qualified individuals to support those programs.

## F. Advice to Caregivers

The caregivers interviewed by the research team were eager to provide advice to current and future caregivers to help ease the burden and make the experience more manageable. The universal theme was clear: ask for help early and ask for it often. Caregivers who sought assistance and supports earlier in the process reported finding the experience to be more manageable than those who did not engage with services until later on in their loved one's decline.

Among the benefits cited by caregivers were having a more positive outlook and experiencing less stress, experiencing fewer interruptions in daily life and having more time to take care of their needs, and being a more effective caregiver for their loved ones. Even caregivers who described themselves as having a hard time asking for help stated that they could not imagine trying to go through the caregiving experience alone, and it was common to report a regret over not asking for help or seeking out services sooner.

The second major advice theme emerging from caregivers was also universal: find time for yourself. The literature tells us, and caregivers confirm, that the caregiving process is physically demanding and emotionally draining. Caregivers who made frequent use of respite and home health services reported more positive caregiving experiences, superior emotional and physical health, and were more likely to access some form of support group compared with those who did not use respite or waited until hospice.

### From Caregivers to Caregivers

Ask for help early and often. Don't be afraid to reach out to friends and family for support, and engage with services early on to get a feel for how the Aging Services Network can best support you and your loved one.

*“Family has baggage that comes with it, but that doesn't mean that you can't have other people who can be really helpful and supportive. My mother's best friend, who has died, her daughters so appreciated all the kind things my mother had done for their mother. And when my mother got sick, they would call and they would come and say, gee, Bev, we're going to be in town, can we visit mom, can we pick this up for your mom. And I knew...I don't think I ever called on them, but I knew if I needed them to come and help me take her to the doctor or something, they would have been there in a way that my sister, who had my conflicted feelings, maybe would not have been. So yeah, I think it's the most important thing you can do is ask and reach out to people. People really are very kind.”*

*“...Except it was more stressful. I had a lot of frustration just because I was just at times overwhelmed with everything.”*



## G. End of Life and Bereavement

A common element to all caregivers interviewed was the loss of their care recipient, but each individual's experience of bereavement was unique. It can be difficult to quantify what is meant by bereavement, because the grieving process is so different for each person. From the literature, we know that grief, as it relates to mourning, begins as soon as there is acknowledgement that the care recipient is unlikely to recover and survive. This change in outlook is generally preceded by a marked decline in the recipient's condition, and the beginning of the end of life phase.

### From Caregivers to Caregivers

Find time to focus on you. It can be difficult to find time for yourself while caring for a loved one, but taking breaks to stay active and engage socially can help you maintain your health and continue delivering the best care.

Unsurprisingly, caregivers did not continue to receive respite or home health services after the death of their loved ones. Those who were receiving companionship services – whether or not it was provided under the NFCSP – tended to report several further interactions after their recipient passed, but all discontinued these services within the first year after their care recipient's passing.

Caregivers who were already participating in a support group at the beginning of the end of life phase continued to participate, and were likely to report continuing to attend after their loved one's death. One caregiver reported joining an additional

support group specific to bereaved caregivers that she found online through social media, after her care recipient passed away. Of the caregivers who did not participate in a support group prior to their care recipient's death, none reported joining a support group after the death of their care recipient.

Conversely, caregivers universally did not engage with any individual counseling services until their recipient entered the end of life phase, typically indicated by a move to hospice care. During this time, five of the eight caregivers interviewed began seeing a grief counselor, all of which were provided by their hospice.

Caregivers who did not make use of individual counseling reported being aware that counseling services were available, but expressed a belief that counseling would not be of particular benefit to them in their grieving process. In one instance, a caregiver expressed that they were not ready to participate in bereavement related support groups or counseling due to not having fully coped with the quality of medical care provided by the hospital and their primary care physician to their care recipient prior to death.

## H. Program Quality

Caregivers reported a high degree of satisfaction with the support groups in which they participated, particularly those organized through the community such as through their local church. Caregivers did not report any negative opinions of the individual counseling services that they received, although they were less likely to claim any particular benefit compared with reports of support group performance.

### I. Advice to Bereaved Caregivers

The interviewed caregivers also offered advice to current and future caregivers regarding the bereavement period. Every single caregiver stressed the importance of having a support network to help them through their grief; all recommended keeping family and friends close and not hesitating to lean on them when needed. Many of the caregivers highlighted the importance their faith played in grief management, and the significant role their community played in supporting them.

Caregivers recommended to their peers to plan ahead and get started on estate planning early. The caregivers who reported delaying preparations of their loved one's estate emphasized that planning ahead does not mean that the caregiver is giving up on their loved one's recovery. Rather, it can actually ease the loss when it does occur, both through reducing the stress of funerary planning and through the comfort of already having executed a plan with clear direction in place.

Finally, caregivers recommended that others in their position make an effort to stay active, eat well, and get involved in their local community. By staying physically and socially active, caregivers reported more positive outlooks on the caregiving and grieving periods, as well as better overall health outcomes. Specific recommendations included returning to work, joining a gym, and getting involved in community service and volunteer organizations.

### From Caregivers to Caregivers

You aren't alone in grieving. Whether you seek out family, friends, or a community or faith group, establishing a personal support network is a healthy step in the grief process. Find those you can lean on, and who will celebrate the life of your loved one with you.

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*“I had called an elder law attorney and talked with her shortly before [my husband] died. We never really got to finish up, but I don't think even that alone would have been enough. (Inaudible) thinking about the house insurance, but as you start to think it through, there are lots of practical things that the person left behind is going to have to deal with.”*

*“After she passed? I wish I could have had... how do I put this? I wish I could have had like a list from someone as to what things to consider that might have needed to be done. She was very elderly. So what I needed to do to stop Social Security, stop her health insurance. Stop all these things that she was involved in. I think maybe something to put my hands on to say, this way, you're not going to forget anything.”*

*“I think for caregivers, I think they need more of that because they really do feel like they're out there by themselves and nobody really cares.”*

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## XI. Conclusions and Recommendations

The results outlined in the previous section provide detailed information gathered from the eight caregivers interviewed as part of this study. Based on these findings, it is clear that while the majority of caregivers accessed support services, not all of these services were funded by NFCSP, and this may be due to their lack of information surrounding service availability. Based on the feedback received, caregivers who did receive information about NFCSP services received this information late in their caregiving experience and therefore felt that this information was not tailored to their current needs, or would have been useful earlier in the process.

### From Caregivers to Caregivers

It is never too early to begin estate planning. Talking to your loved one about their wishes can be a difficult step to take, but having a plan in place will reduce the burden on you if the time comes to put it in action.

Several caregivers expressed their desire for access to disease-specific information in order to provide daily, in-home medical care for their care recipient without having to rely solely on home health care service providers. These caregivers did not feel completely prepared or confident in their ability to meet the daily medical needs of their care recipient. They expressed a desire for more medical education trainings and information on how to assist their loved one with ADLs and IADLs. Additionally, caregivers also expressed a desire for access to more frequent respite services with longer duration periods.

As we know from the literature, caregivers who access support programs and individual counseling tend to report less stress and experience healthier grieving periods. It is interesting to note that caregivers who reporting accessing support groups did so exclusively through NFCSP-funded services and community-organized groups, while those who accessed individual counseling did so exclusively through their hospice program. This may suggest that caregivers are unlikely to reengage with NFCSP services once their recipient has reached the end-of-life phase or deceased, and that the immediate availability of hospice grief services makes them more appealing or accessible to caregivers. Additionally, it is important to note that some SUAs, AAAs, or service providers may have policies in place that terminate OAA service coverage when hospice care begins, which may also explain why caregivers did not return to NFCSP services.

Finally, all of the caregivers interviewed expressed their regret over not asking for help sooner. Providing information to caregivers early on in the process about the significant benefits of having a support system in place not only to aid in caring for their care recipient but also as an outlet for their own emotional well-being is critical. Additionally, those caregivers receiving information about NFCSP supports and services early in their caregiving experience were more likely to have a positive perception of NFCSP service quality. The caregivers who were not aware of the NFCSP services and supports expressed a desire to have been provided information about these services sooner or otherwise directed to these services earlier in their caregiving experience.

## A. Recommendations to ACL and the Aging Services Network

Based on the above findings and conclusions, SUAs and AAAs should aim to ensure that information is disseminated within their local communities so that caregivers may access this information early in the caregiving process. Collaborating with other community organizations or programs and long-term services and supports (LTSS) funded through state or advocacy programs may be beneficial to ensuring caregivers are supported at all phases of the caregiving experience. Such partners include, but are not limited to such as the Alzheimer’s Association, American Cancer Society, faith communities, hospitals, and health plans. AAAs may also consider the development of caregiver fact sheets that offer information about services provided within their specific communities, with links to online resources.

Many of the caregivers we spoke with expressed the need for access to respite services that included overnight or weekend care. Along with this, caregivers also stated they would appreciate the ability for longer periods of respite services. For example, in addition to offering respite services 2-3 days a week for two hours each day, perhaps offering 1-2 days a week for four hours at a time.

Expanding availability of respite services may also encourage caregivers to make use of services such as support groups and individual counseling, as well as taking the time to maintain healthy behaviors, such as balanced diet and exercise. The most commonly cited barrier to engaging in self-care activities was the demanding schedule faced by caregivers and the perception that they could not take time to focus on themselves. States and AAAs may wish to examine their menu of available respite options to ensure that they offer maximum flexibility to encourage caregiver use of underutilized services.

### From Caregivers to Caregivers

Keep busy and get involved. Other caregivers report eating well, staying active, being social, and getting involved in their community as ways to cope with their loss.

Another consideration is to enable and empower caregivers to seek advice and guidance from their peers. Several caregivers interviewed described positive experiences with seeking information and advice from other caregivers in similar situations, or with care recipients suffering from the same condition or illness. While no program currently exists, ACL may encourage AAAs and state agencies to implement programs that link caregivers so they may support one another through their similar experiences. Such agencies could apply local funding or NFCSP dollars to the development of a peer-to-peer support network. Another catalyst to drive this type of sharing and support is to encourage AAAs to maintain contact with caregivers who may wish to offer their insights and experience during structured, in-person learning opportunities, and to implement a periodic webinar or learning series to provide a platform for AAAs to share best practices and speak to their caregivers’ experience. A similar program, the Charting the LifeCourse Framework, is already implemented by the Administration on Disabilities, part of the ACL. The Framework was developed by families with experience navigating the health care delivery system in response to major life changes, and was designed to help individuals and families locate services and construct an informed plan for their care future. While it was originally developed to serve individuals with disabilities, it is a universally-designed framework and its expansion could further bridge the gap between aging and disability programs (University of Missouri, 2017).

## Appendix I: Interview Guide Protocol

### Introduction

[The goal is to make the interview with the caregiver conversational while also hitting the key points for AoA. So, while the content below is scripted, we will adjust accordingly to make the caregiver feel comfortable.]

Hi, [*insert CG name*] thank you for agreeing to talk with us today. I am [*Lewin name #1*] from the Lewin Group. I want to spend a few minutes sharing some background information with you and describing the purpose of our call. Then we can hear more from you. Okay?

Before we begin, I also want to introduce my colleague [*Lewin name #2*]. He/she will be taking notes and asking questions if I miss something important.

As part of our work with the Administration on Aging, we are speaking with bereaved caregivers like yourself. We are conducting this small study of individuals who participated in the recent “National Study of Caregivers Needs and Support.” You were part of this earlier study focused on your caregiving efforts, but were unable to finish because your [*CR title/name*] passed away.

You expressed a desire to tell your “story” and we really appreciate your willingness to speak with us today. Do you have any questions at this time?

Through these interviews, we want to understand more about the services you received and what additional services would have been helpful to you. The Administration on Aging wants to support individuals at all stages of the caring process. There are no right or wrong answers to these questions; we are interested in your perspectives and opinions.

With your permission, I would like to record today’s discussion. This will allow us to really listen to you and not worry about taking notes. We will maintain the confidentiality of our conversation. We will not share identifiable information with anyone. We will summarize what you tell us and combine with other caregiver interviews.

Do you have any questions before we begin?

May we have your permission to record the discussion? [*If yes, turn on recorder*]

## A. Identifying Gaps in Support Programs and Services

1. What supports or services were you offered while providing care to [CR title/name]?
  - a. What supports or services were the most helpful to you? *Note to Interviewers:* The subsequent response will require flexibility on our part. An example response could be: How frequently did you receive respite services? What circumstances led you to these services? How did the respite services help you? Did you need want more hours of respite services? If yes, how many more hours?
  - b. Other potential support services we are likely to hear about: support groups, individual counseling and caregiver training/education programs
2. Do you feel that you asked for help early enough in your caregiving experience? Why or why not?
3. What supports or services do you feel would have been beneficial to you, but weren't ever offered or available? When would it have been helpful to receive these services? (e.g., when my mother was discharged from the hospital). How frequently would receiving these services have been beneficial to you? (e.g., daily, monthly).
4. What supports were you offered after [CR title/name] passed away?
5. What supports or services do you feel would have been beneficial to you after [CR title/name] passed away, but weren't ever offered or available?
6. What piece of information would you like to share with current or future caregivers that would make their work as a caregiver more manageable?
7. What piece of information would you like to share with current or future caregivers that would make bereavement more manageable?
8. You are a caregiver who has experienced the death of your [CR title/name]. Given your unique experience, what are some key pieces of information that you would like to share with the Administration on Aging to make it easier for other caregivers?

## B. Use of NFCSP Services

1. The National Family Caregiver Support Program supports programs in local communities to assist caregivers like you. Some of the services include: (i) informational resources to caregivers about available services; (ii) assistance to caregivers in accessing services; (iii) individual counseling, support groups, and caregiver training; (iv) respite care; and (v) supplemental services on a limited basis.

2. When you were a caregiver did you utilize any of the services I just mentioned? (Y/N)

*If yes, which services did you use?*

- a. Please provide details about these services.
- b. How long did you use these services? Did you use them prior to or following [insert CR title/name] death?
- c. What made you stop using the services?
- d. What recommendations do you have to improve the NFCSP services that you utilized?

*If no, please explain why you did not use any of the mentioned support programs or services while you served as a caregiver. This may include any barriers or challenges you experienced with accessing services.*

3. Do you feel that your caregiver support needs changed over the course of your experience?
  - a. *If yes, how so?*
  - b. *If no, thank you.*

### C. Demographic and SDOH Information

[In advance of each caregiver interview, we will pre-populate the questions with known information from Westat]. Other information will be populated during the interview.]

1. What was your relationship to [CR title/name]? How long did you serve as a CG to [CR title/name]?
2. How long did [CR title/name] illness last prior to death? Was his/her death sudden/unexpected or gradual and anticipated? Are you comfortable sharing with me what [CR title/name] died from?
3. [Hopefully we will know gender based on existing information]. What is your gender? How old are you? What is your race/ethnicity?
4. [Hopefully we will know gender based on existing information]. What was the gender of your [CR title/name]? How old was [CR title/name] at the time of his/her death? What was his/her race/ethnicity?
5. Did you live with [CR title/name] for the entire time that you were providing care? (Y/N). If no, did you live together at all? If yes, how long did you live together?
6. What state did you live in at the time you served as a caregiver?
  - a. Would you consider this location to be a rural or urban setting?

7. During the time in which you were a caregiver, were you working for pay either full- or part-time? (Y/N)
  - a. At any point while you were a caregiver, did you feel that you needed financial assistance in order to continue serving as a caregiver?
8. What is your highest level of education?
9. We are interested in better understanding your health status during the time in which you served as a caregiver and after [CR title/name] died.
  - a. What would you consider your health status to be during the time in which you served as a caregiver? Please pick from one of the following responses: Excellent Health, Good Health, Fair Health, or Poor Health. If the CG noted to be in “Fair or Poor Health” – can you provide an explanation as to why you chose this response? If the CG noted to be in “Excellent or Good Health” – can you tell us what you did to maintain your health while being a caregiver?
  - b. What would you consider your health status to be after the passing of [CR title/name]? Please pick from one of the following responses: Excellent Health, Good Health, Fair Health, or Poor Health. If the CG noted to be in “Fair or Poor Health” – can you provide an explanation as to why you chose this response? If the CG noted to be in “Excellent or Good Health” – Can you tell us what you did to maintain your health after the passing of [CR title/name]?
10. During the time you served as a caregiver, how would you describe your emotional well-being?
  - a. Do you feel as though your emotional well-being declined as a result of [CR title/name] passing?
11. We would like to close with four general questions.
  - a. Reflecting on your caregiving experience, is there anything else you would like to share with us?
  - b. Is there anything you would have done differently?
  - c. If you have to offer advice to a new caregiver today, what would it be?
  - d. Do you have any other information that you would like to share with us?

[CG name], thank you so very much for talking with us today. We will mail you a \$50 gift card later this week. Would you prefer a gift card to Walmart or Amazon?



## Appendix II: Coding Methodology Exhibits

Exhibit 1 – Service/Support Code Tree

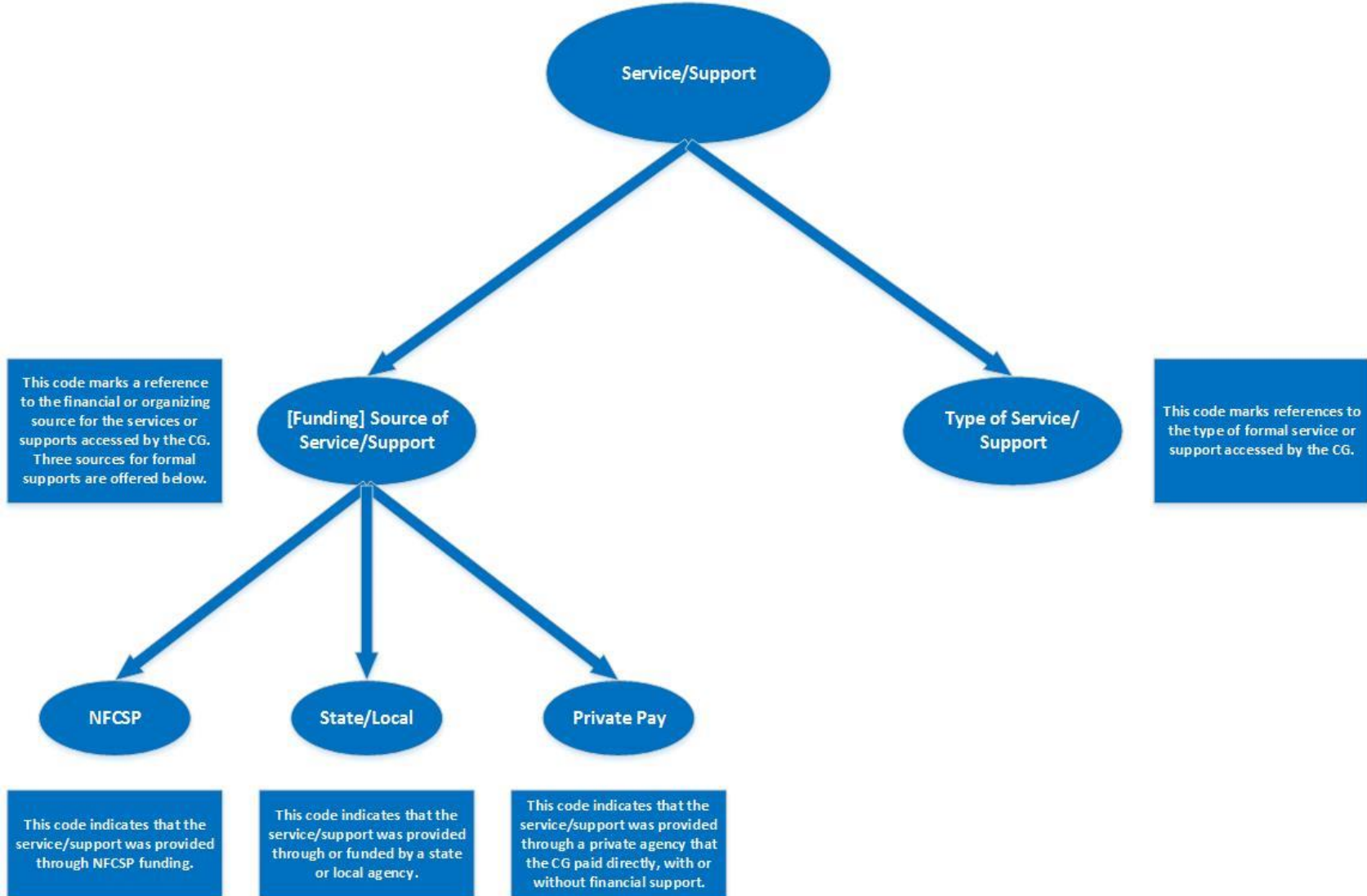


Exhibit 2 – Program Success Code Tree

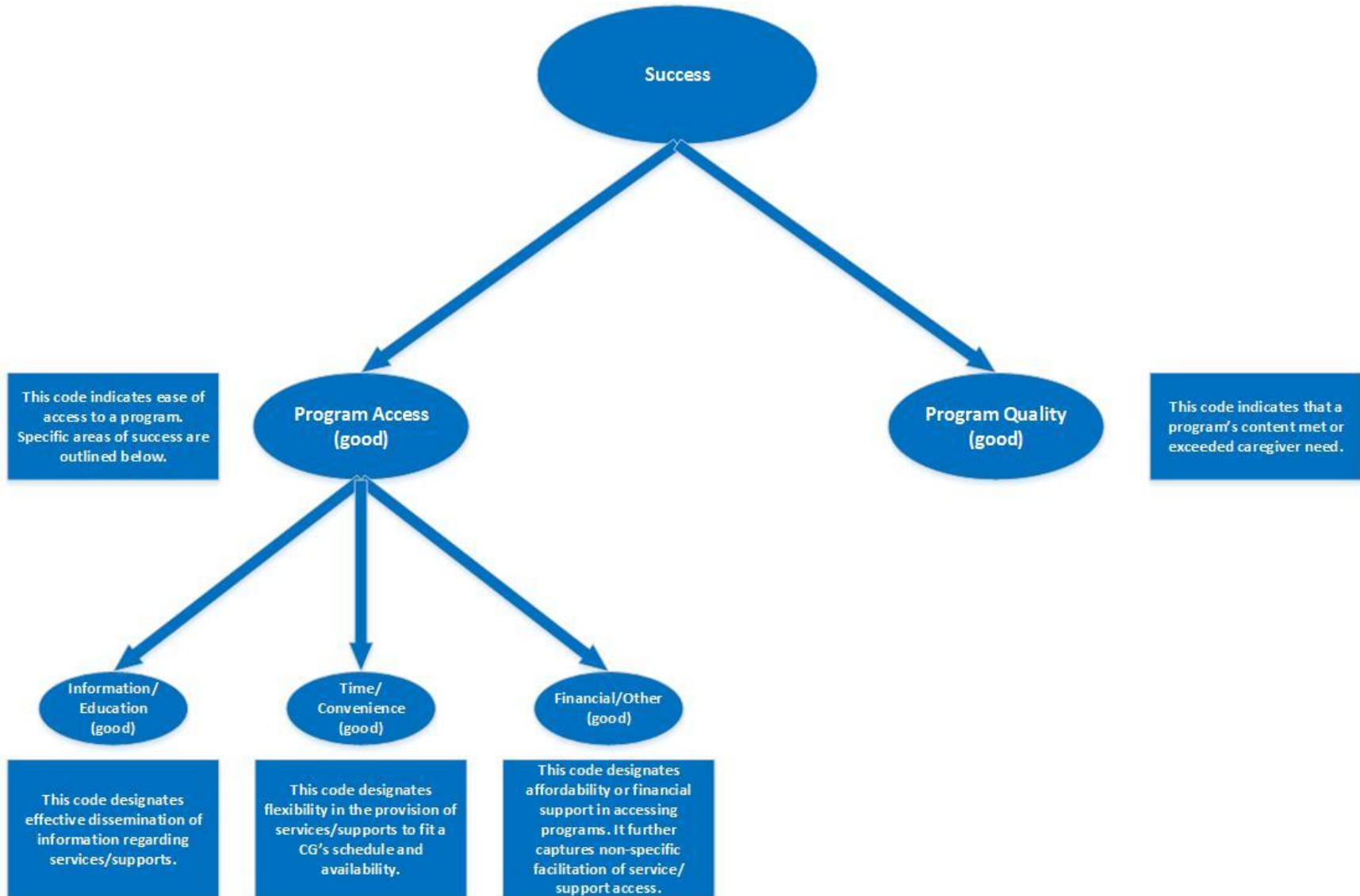


Exhibit 3 – Program Challenge Code Tree

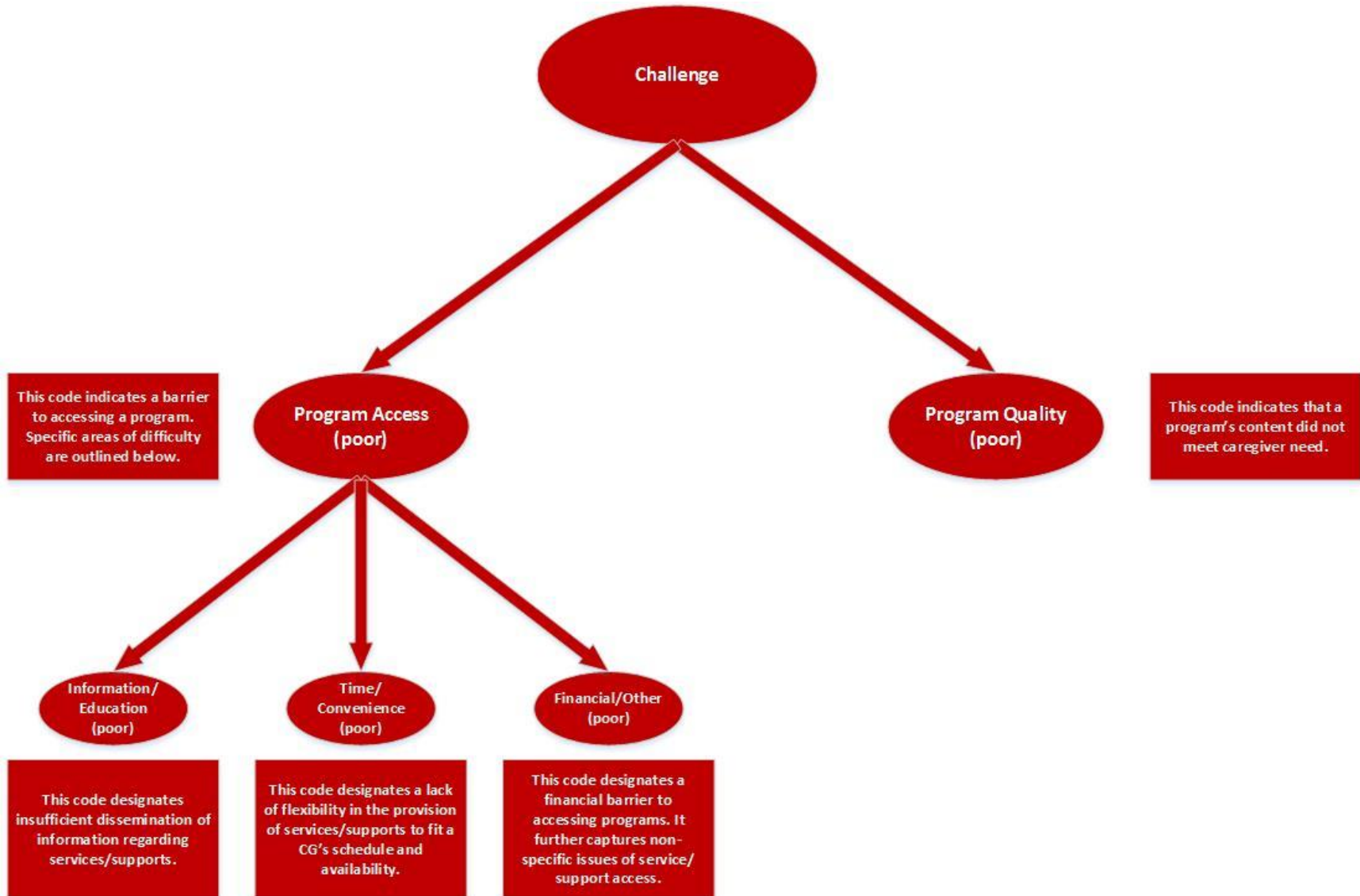


Exhibit 4 – Program Recommendation Code Tree

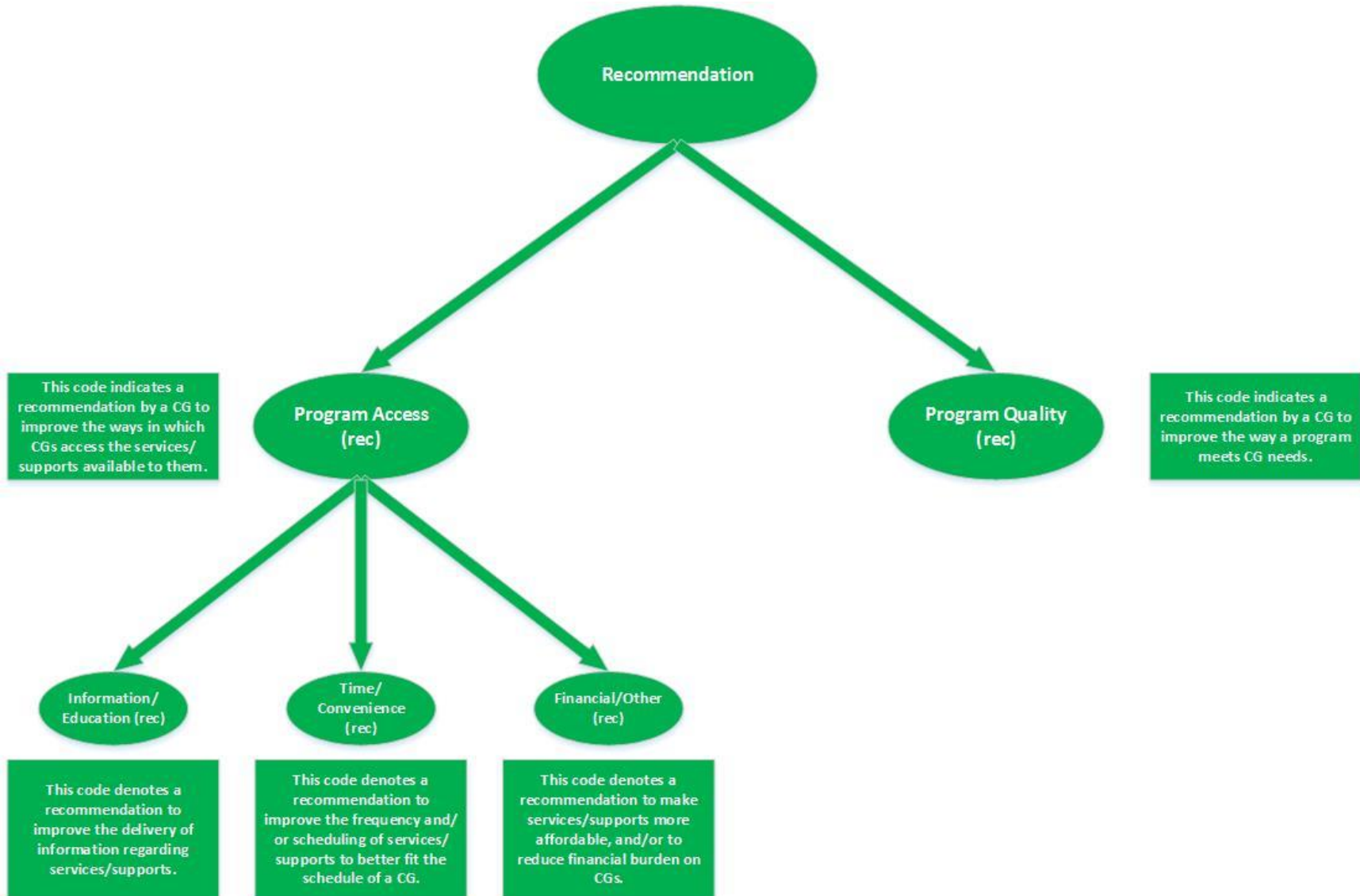
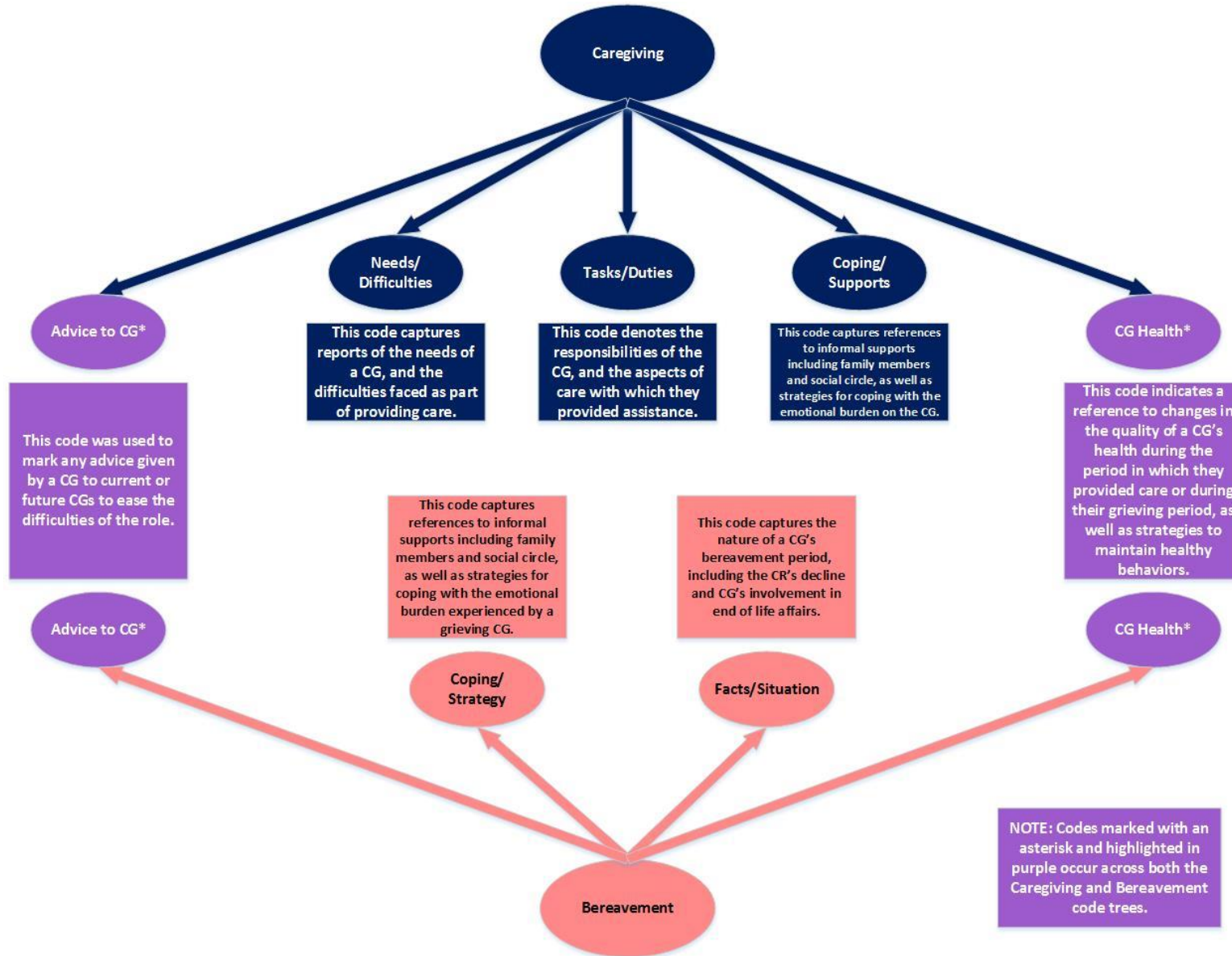


Exhibit 5 – Caregiving and Bereavement Code Trees



## References

- AARP & the National Alliance for Caregiving (2015). *2015 Report: Caregiving in the U.S.* Retrieved from: <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- Adler, N. E., Cutler, D. M., Fielding, J. E., Galea, S., Glymour, M. M., Koh, H. K., & Satcher D. (2016). Addressing Social Determinants of Health and Health Disparities. *Vital Directions for Health and Health Care*. Retrieved from: <https://nam.edu/wp-content/uploads/2016/09/Addressing-Social-Determinants-of-Health-and-Health-Disparities.pdf>
- Administration for Community Living. (2017). *AGing Integrated Database (AGID)*. Retrieved from: <https://agid.acl.gov/>
- Administration for Community Living. (2017). *Older Americans Act*. Retrieved from: <https://www.acl.gov/about-acl/authorizing-statutes/older-americans-act>
- Administration for Community Living. (2017). *National Family Caregiver Support Program*. Retrieved from: <https://www.acl.gov/programs/support-caregivers/national-familycaregiver-support-program>
- Administration for Community Living. (2019). *FY2019 Justification of Estimates for Appropriations Committees*. Retrieved from: <https://www.acl.gov/sites/default/files/about-acl/2018-05/FY2019ACL-CJ3.pdf>
- Allen, J., Hutchinson, A. M., Brown, R., & Livingston, P. M. (2014). Quality care outcomes following transitional care interventions for older people from hospital to home: a systematic review. *BMC Health Services Research*, *14*, 346. Retrieved from: <https://doi.org/10.1186/1472-6963-14-346>
- Aoun, S., Deas, K., Toye, C., Ewing, G., Grande, G., & Stajduhar, K. (2015). Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial. *Palliative Medicine*, *29*(6), 508-17. Retrieved from: <http://journals.sagepub.com/doi/pdf/10.1177/0269216314566061>
- ARCH National Respite Network and Resource Center. (2018). *What is Respite?* Retrieved from: <https://archrespite.org/>
- Centers for Disease Control and Prevention. (2018). *Caregiving*. Retrieved from: <https://www.cdc.gov/aging/caregiving/index.htm>
- Chi, N. C., Demiris, G., Lewis, F. M., Walker, A. J., & Langer, S. L. (2016). Behavioral and Educational Interventions to Support Family Caregivers in End-of-Life Care: A Systematic Review. *American Journal of Hospice & Palliative Medicine*, *33*(9), 894-908. Retrieved from: <http://journals.sagepub.com/doi/pdf/10.1177/1049909115593938>
- Gardiner, C., Brereton, L., Frey, R., Wilkinson-Meyers, L., & Gott, M. (2013). Exploring the financial impact of caring for family members receiving palliative and end-of-life care: A systematic review of the literature. *Palliative Medicine*, *28*(5), 375-90. Retrieved from: <http://journals.sagepub.com/doi/pdf/10.1177/0269216313510588>
- Garrido, M. M., & Prigerson, H. G. (2014). The end-of-life experience: modifiable predictors of caregivers' bereavement adjustment. *Cancer*, *120*(6), 918-25. Retrieved from: <https://onlineibrary.wiley.com/doi/abs/10.1002/cncr.28495>
- Gitlin, L. N., & Wolff, J. (2012). Family involvement in care transitions of older adults: What do we know and where do we go from here? *Annual review of Gerontology and Geriatrics*, *31*(1), 31-64. Retrieved

from: <https://jhu.pure.elsevier.com/en/publications/family-involvement-in-care-transitions-of-older-adults-what-do-we-3>

Health and Medicine Division Committee on Family Caregiving for Older Adults. (2016). *Families Caring for an Aging America: Chapter 1 - Introduction*. Washington (DC): National Academies Press.

Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK396405/>

Health and Medicine Division Committee on Family Caregiving for Older Adults. (2016). *Families Caring for an Aging America: Chapter 3 – Family Caregiving Roles and Impacts*. Washington (DC): National Academies Press. Retrieved from: <https://www.ncbi.nlm.nih.gov/books/NBK396398/>

Institute of Medicine Committee on the Future Health Care Workforce for Older Americans. (2008). *Retooling for an Aging America: Building the Health Care Workforce*. Washington (DC): National Academies Press. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK215403/>

Kim, S. Y., Kim S. J., Kim, J. M., Kim, S. W., Shin, I. S., Shim, H. J., Cho, S. H., Chung, I. J., & Yoon, J. S. (2018). Prevalence and predictors of major depressive disorder in bereaved caregivers at 6 and 13 months. *Palliative & Support Care*, 1-6. Retrieved from:

<https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/prevalence-and-predictors-of-major-depressive-disorder-in-bereaved-caregivers-at-6-and-13-months/616DCC52180799B31FF3DDE266632839>

The Lewin Group. (2016). *National Family Caregiver Support Program (NFCSP) Process Evaluation*. Retrieved from: [https://www.acl.gov/sites/default/files/programs/2017-02/NFCSP\\_Final\\_Report-briefing.pdf](https://www.acl.gov/sites/default/files/programs/2017-02/NFCSP_Final_Report-briefing.pdf)

Link, G. (2015/2016). The Administration for Community Living: Programs and initiatives providing caregiver support. *Generations*, 39(4), 57-63. Retrieved from: <http://fsrtc.ahslabs.uic.edu/wp-content/uploads/sites/9/2016/03/Generations-ACL-Caregiver-Programs.pdf>

Liu, Y., Kim, K., & Zarit, S. H. (2015). Health Trajectories of Family Caregivers: Associations with Care Transitions and Adult Day Service Use. *Journal of Aging and Health*, 27(4), 686-710. Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5533951/>

MetLife Mature Market Institute. (2011). *the MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents*. Retrieved from: <https://www.caregiving.org/wp-content/uploads/2011/06/mmi-caregiving-costs-working-caregivers.pdf>

Miller, E. A., & Weissert, W. G. (2000). Predicting Elderly People's Risk for Nursing Home Placement, Hospitalization, Functional Impairment, and Mortality: A Synthesis. *Medical Care Research and Review*, 57(3), 259-97. Retrieved from:

[http://journals.sagepub.com/doi/abs/10.1177/107755870005700301?url\\_ver=Z39.88-2003&trfr\\_id=ori:rid:crossref.org&trfr\\_dat=cr\\_pub%3dpubmed](http://journals.sagepub.com/doi/abs/10.1177/107755870005700301?url_ver=Z39.88-2003&trfr_id=ori:rid:crossref.org&trfr_dat=cr_pub%3dpubmed)

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. B. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review*, 44, 75-93. Retrieved from:

[https://ac.els-cdn.com/S0272735816000039/1-s2.0-S0272735816000039-main.pdf?\\_tid=3cfc184b-27d7-4b41-9d82-00ab07cdd0fd&acdnat=1529257857\\_8a2d19101c56972b1dd0ff00fb54243e](https://ac.els-cdn.com/S0272735816000039/1-s2.0-S0272735816000039-main.pdf?_tid=3cfc184b-27d7-4b41-9d82-00ab07cdd0fd&acdnat=1529257857_8a2d19101c56972b1dd0ff00fb54243e)

- Older Americans Act Reauthorization Act of 2016, 42 U.S.C. § 3001 (2018). Picone, G. A., Sloan, F. A., Chou, S. Y., & Taylor, D. H., Jr. (2003). Does Higher Hospital Cost Imply Higher Quality of Care? *Review of Economics and Statistics*, 85(1), 51-62. Retrieved from: [https://www.researchgate.net/publication/24095807\\_Does\\_Higher\\_Hospital\\_Cost\\_Imply\\_Higher\\_Quality\\_of\\_Care](https://www.researchgate.net/publication/24095807_Does_Higher_Hospital_Cost_Imply_Higher_Quality_of_Care)
- Schulz, R., & Sherwood, P. R. (2008). Physical and Mental Health Effects of Family Caregiving. *Journal of Social Work Education*, 44(3), 105-13. Retrieved from: <https://www.tandfonline.com/doi/pdf/10.5175/JSWE.2008.773247702?needAccess=true>
- University of Missouri – Kansas City. (2017). *About LifeCourse*. Retrieved from: <http://www.lifecoursetools.com/about/>
- Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychology Bulletin*, 129(6), 946-72. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/14599289>
- Zarit, S. H., & Zarit, J. M. (2015). Chapter 2: Family Caregiving. In Bensadon, B. A. (Ed.), *Psychology and Geriatrics: Integrated Care for an Aging Population* (pp. 21-43). Academic Press. Retrieved from: <https://www.sciencedirect.com/science/article/pii/B9780124201231000022>