# GERIATRIC SERVICES CAPACITY ASSESSMENT

# DOMAIN 5 - CAREGIVING

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# INTRODUCTION

## Purpose

The Geriatric Services Capacity Assessment was developed to help health plans and health systems, including community providers, hospitals, and other health care delivery organizations, evaluate their current ability to meet the needs of geriatric adults and to identify strategic opportunities for improvement.

*Geriatric-competent care focuses on providing care and support for maximum function and prevents or eliminates barriers to integrated, accessible care.*

## Serving Senior Medicare-Medicaid Enrollees

Medicaid provides health coverage to more than 4.6 million low-income seniors, nearly all of whom are also enrolled in Medicare. Medicaid also provides coverage to 3.7 million people with disabilities who are enrolled in Medicare. In total, 8.3 million people are enrolled in both Medicaid and Medicare, which accounts for more than 17 percent of all Medicaid enrollees. Many of these beneficiaries have complex care needs; they have a significant impairment in physical functioning (some difficulty with two or more activities of daily living) and/or severe impairment in cognitive functioning. Health organizations must adapt to adequately meet the needs of this growing vulnerable population.

*Medicare-Medicaid Enrollee Population*

- *59 percent are elderly*
- *Compared to other Medicare beneficiaries, Medicare-Medicaid enrollees have:*
  - *More chronic conditions*
  - *More cognitive and other functional limitations*
  - *Lower income*

## How to Use This Tool

Inherent in geriatric-competent care is the need to engage the individual in defining their care goals and needs. Establishing geriatric-competent care within a health plan or health system affects all functional areas of the plan or system, from direct care delivery to contract and payment modifications to management systems to the inclusion of a full range of home- and community-based care options and supports. As such, all key functional areas in the organization should be represented in the completion of the Tool.

# 5 CAREGIVING

There is no single definition of caregiving used across organizations, government entities, and the health care industry. Generally, a caregiver is an individual who is responsible for attending to the daily needs of another person unable to manage independently for him or herself.

There is a distinction between paid caregivers, which include home and community based workers who are trained and compensated for their services (see **Domain 3 - Long Term Services and Supports**), and individuals and resources a consumer can access through personal associations and relationships typically developed in the community, independent of formal services. These resources are usually sustainable and available to the consumer after formal services have ended. They may include relationships with family members, partners, friends, neighbors, community and civic organizations, or others who provide assistance to the consumer. Individuals who provide this care are often referred to as "informal caregivers" or "natural supports" and are usually not paid.

Caregivers provide physical, emotional, and often financial support to the individual requiring assistance due to illness, injury, disability or frailness. Informal caregiving is vital to consumers remaining in the least restrictive setting. The geriatric population often has an increased need for assistance related to chronic conditions or functional decline. A reality that is not often considered is that an older person may provide caregiving services to his or her spouse, sibling, friend (who also may be an older person), adult child, or grandchild without much, if any, external support. Providers interacting with older individuals will want to understand the natural supports the person has or can mobilize and the caregiving responsibilities the consumer has for others.

## 5.1 Older Adults as Recipients of Informal Care

The elderly are often in need of caregiving services from relatives, partners, friends, and community members. These "unpaid" services are vital for the geriatric consumer to live in the least restrictive setting possible. People supporting the older adult in this way are valuable sources of information and assistance to providers. Caregiving for consumers with certain conditions (e.g., Alzheimer's disease) may require more intensive support and involvement in the consumer's life.

### 5.1.1 Is the IDT aware of what needs are being met through the natural supports of the geriatric consumer and by whom, and what services are provided through more formal provisions of care by hired workers?

Elderly consumers may need informal caregiving for a short-term, long-term, or indefinite period of time. These natural supports cover a wide range of activities and goods including, but not limited to:

- Assistance with activities of daily living, including walking, bathing, dressing, eating, and toileting
- Assistance with instrumental activities of daily living, including shopping, food preparation, housekeeping, laundry, and using the telephone or computer
- Assistance with monitoring symptoms and administering medication
- Emotional and social support
- Finding and accessing services, including housing and medical supports
- Behavioral support, including communicating effectively and recognizing and responding to behavioral expressions in persons living with dementia (e.g., wandering, aggression, and hallucinations)
- Financial assistance, including managing bills and/or direct financial support

### 5.1.2 Are informal caregivers noted as part of the medical record?

Recognizing the importance of natural supports for the geriatric consumer, organizations with geriatric capacity will enhance care coordination by including the consumer's informal caregiver(s) in their records as resources of information and support to the older person. It is also important that this information is routinely verified and updated. Caregivers who are not local may also need to be included in the decision-making process and should be included as appropriate.

### 5.1.3 Are informal caregivers a part of the consumer's IPC?

Relatives, partners, and friends serving as informal caregivers are often the best resource for information on the consumer's day-to-day physical and mental status. Organizations with geriatric capacity involve informal caregivers in the IPC, with the geriatric consumer's permission, in order to fully ascertain the consumer's functional, mental, and emotional capacities and needs. Consumers may also designate informal caregivers to be involved in IDT-

related communications and assessments – see 1.3.1.7 and 1.4.4 (**Domain 1 – Relational-based Care Management**) for more information.

### 5.1.4 Do IDT staff regularly consult consumers about their options to share protected health care information with caregivers?

Organizations with high levels of geriatric capacity and expertise with caregiver involvement regularly consult consumers about sharing health information with family and non-family caregivers. IDT staff must understand their role in protecting the consumer's Protected Health Information (PHI) under Title II of the Health Insurance Portability and Accountability Act as well as the necessary steps to facilitate sharing PHI with the consumer's appointed caregiver or caregivers should the consumer choose to do so. See question 7.2.4 for more information on the role of HIPAA in an organization with geriatric capacity.

### 5.1.5 Are IDT staff trained to watch for, and report, problematic caregiver relationships, such as abuse, neglect, and exploitation?

In addition to identifying potentially problematic interactions and relationships, staff will want to be knowledgeable and comfortable to respectfully address concerns with the consumer and others as appropriate. Organizations with geriatric expertise have reporting guidelines for staff to follow in the case of a problematic caregiver relationship.

### 5.1.6 Are staff aware of an older consumer's back-up plan to provide replacement caregiving in case of an emergency and resources that staff may contact to assist the consumer if needed?

When an informal caregiver is unexpectedly unable to provide help, the consumer's physical and mental health may be at risk. Organizations with geriatric capacity maintain listings of resources available to consumers during such emergency periods. Substitute caregiving services are necessary to ensure that a consumer is not placed in a more restrictive care setting due to a temporary lapse in informal caregiving services.

### 5.1.7 Are staff aware of respite care available for consumers' informal caregivers?

Respite care is the planned provision of a short period of rest or relief for informal caregivers who routinely provide caregiving services to an individual. It may help the caregiver avoid burnout and therefore continue providing services for a longer period of time, allowing the consumer to remain in a less restrictive care setting. Respite care may be provided by paid home health aides or personal care assistants in the home, or the care recipient may temporarily receive care in a setting outside the original residence. Some examples of respite care include[1]:

[1] Alzheimer's Association: Respite Care: https://www.alz.org/care/alzheimers-dementia-caregiver-respite.asp

- In-home care services: this can include a range of services offering companionship to the consumer, assistance with bathing, dressing, toileting and exercising, homemaker or maid services, and skilled care services to help with medication and other medical services.
- Adult day centers: these are designed to be a safe and social environment for the consumer with activities led by trained staff. Transportation and meals are often provided.
- Residential facilities: these facilities offer short-term, overnight accommodations for the consumer that can allow for the caregiver to take an extended break or vacation.

Additional sections in this Tool related to informal caregiving that may be useful to review include the following:

- Domain 1 – Relational-based Care Management
  - 1.1.3 – Involving older consumers, families, and caregivers, in care planning and implementation to ensure a consumer-centered focus
  - 1.7.6 – IDT collaborating and providing resources to the caregiver or family member to assist with care transitions
  - 1.11 – Interacting with caregivers
- Domain 2 – Highly Responsive Primary Care
  - 2.3.4 – Consumer and caregiver training in medication administration
- Domain 4 – Alternate Living Arrangements
  - 4.7 – Living with a family member or friend

## 5.2 Older Adults as Providers of Informal Care

Older adults are not only on the receiving end of caregiving. Increasingly, older adults provide informal caregiving services to their elderly spouse/partner, relatives, and friends. Longer lives and changes in family demographics such as grown children living distances from their elderly parents and/or working hours that make offspring less available to assist older parents, requires older people to look for non-family alternatives for assistance. Spouses or life-long partners often compensate for each other's functional limitations. In other situations, an older person may be providing caregiving to children or a disabled person(s). These types of caregiving relationships may greatly impact all involved, including the geriatric consumer.

### 5.2.1 Are IDT staff aware of consumers' roles as caregivers to an elderly partner, family member, friend, or neighbor?

Organizations with geriatric capacity ensure that their staff identify the caregiving services that older adults provide to partners, relatives, and friends. Routine assessment of caregiving roles allows the IDT a holistic picture of the consumer's physical, emotional, and social well-being.

### 5.2.2 Are IDT staff trained to assess the effect of caregiving on the geriatric consumer's physical, emotional, and financial status?

Caregiving often requires an enormous physical and emotional commitment to the care recipient. An older caregiver faces additional burdens due to poor health, functional or mental decline or disability. Organizations with geriatric capacity may use formal assessment tools and train their staff to recognize potential harmful effects of being a caregiver, including:

- Chronic stress, frustration, loss of self-identity, lower levels of self-esteem, constant worry or feelings of uncertainty
- Depression
- Physical and mental exhaustion
- Increased alcohol, tobacco, or substance use
- Hostility and threats of harmful behavior toward the care recipient
- Increased health problems and functional limitations that make caring for others more difficult
- Decreased self-care, including less frequent preventative health behaviors, missed doctors' appointments and prescription refills, poorer diet and exercise habits

### 5.2.3 Are the consumer's caregiving responsibilities noted as part of the consumer's IPC?

Organizations with geriatric expertise recognize the effect being a caregiver has on the consumer's physical and mental health. The IPC takes into consideration the limitations that this responsibility places on the consumer's ability to attain IPC goals.

### 5.2.4 Are IDT staff aware of resources, including respite care, for the elderly caregiver?

Organizations with geriatric expertise ensure that consumers who provide caregiving to partners, relatives, and friends have access to respite care and other resources as explained in 5.1.6. IDT staff should be prepared to offer Alzheimer's-specific resources to caregivers, such as the National Institute on Aging's guide to "Caring for a Person with Alzheimer's Disease," national advocacy groups such as the Family Caregiver Alliance or Dementia Action Alliance, and local supports available in their communities.[2]

[2] National Institute on Aging: "Caring for a Person with Alzheimer's Disease" https://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide

## 5.3 Older Adults as Caregivers to Children

Over the past decade, elderly consumers have increasingly assumed the role of caregivers for their grandchildren.[3] This type of responsibility may also extend to other minors such as nieces or nephews. Regardless of the relationship, we refer to the older consumer in this role as a grandparent caregiver. There are many practical issues involved in caring for a child, including legal and financial issues. There are also health considerations for the older consumer who provides caregiving services and supports to children under the age of 18.

### 5.3.1 Are IDT staff aware of their geriatric consumers who have custody of children?

Organizations with geriatric expertise stay abreast of the consumer's caregiving responsibilities, specifically when the consumer is raising one or more children under the age of 18.

### 5.3.2 Are IDT staff aware of the effects on the consumer's physical, emotional, and financial well-being of raising a child or children?

In addition to challenges faced by all caregivers noted in 5.2.2 above, grandparent caregivers may have the added burden of:

- raising children on a fixed income
- finding or maintaining adequate housing
- experiencing their own health problems and functional limitations that make caring for children more difficult
- raising children who may have behavioral and emotional problems due to various factors, including an unstable home environment or history of parental drug use and neglect

### 5.3.3 Are IDT staff aware of resources available to grandparent caregivers?

Geriatric-competent organizations have general knowledge of community, financial, and legal resources available to older consumers still raising children. Staff know how to connect the older person with the right resource or a point person to assist them with their needs. Community resources may include respite care, low-cost day care, and school programs.

Financial resources may include a case manager or social worker who is informed on Medicaid, Children's Health Insurance Program (CHIP), and Temporary Assistance to Needy Families (TANF) eligibility for grandchildren under the care of an older adult. If the grandchild is mentally or physically disabled, Supplemental Security Income may pay cash benefits. Legal resources include information and support for grandparents in the following areas:

- Physical custody
- Legal custody
- Guardianship
- Adoption

[3] Livingston, G., & Parker, K. (2010) Since the Start of the Great Recession, More Children Raised by Grandparents. Pew Research: Social & Demographic Trends. September 9, 2010. Retrieved from: http://www.pewsocialtrends.org/2010/09/09/since-the-start-of-the-great-recession-more-children-raised-by-grandparents/

# APPENDIX A:
# REFERENCES AND RESOURCES

Included in this appendix are references that were utilized and consulted during the development of this Tool or augment the information contained in the assessment tool. References are links to government websites, resources provided by professional organizations, or publications in academic journals. The references are divided by domain for ease of use.

# Introduction

- **Slow medicine:**
  http://www.nytimes.com/2008/02/26/health/views/26books.html?_r=1&
- **Geriatric Competencies:**
  http://www.pogoe.org/gwiz
- **Geriatrics Competent Care Webinar Series:**
  https://www.resourcesforintegratedcare.com/Geriatrics_Competent_Care_Webinar_series

# 5. Caregiving

- **Nursing Care of Older Adults:**
  http://www.aacn.nche.edu/geriatric-nursing/aacn_gerocompetencies.pdf
- **Care of the Family Caregiver:**
  http://www.caregiving.org/pdf/resources/CFC.pdf
- **Caregiving Resources:**
  http://www.aarp.org/home-family/caregiving/
- **Kinship Care:**
  https://netforum.avectra.com/eweb/DynamicPage.aspx?Site=cwla&WebCode=Kinship14
- Alzheimer's Association: Respite Care:
  https://www.alz.org/care/alzheimers-dementia-caregiver-respite.asp
- **National Institute on Aging: "Caring for a Person with Alzheimer's Disease"**
  https://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide
- **Family Caregiver Alliance: Dementia with Lewy Bodies**
  https://caregiver.org/dementia-lewy-bodies

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This document represents one domain of an eight-part self-assessment tool. To access additional domains, or to see the tool as a whole, please visit: https://www.resourcesforintegratedcare.com/. We also welcome any feedback to RIC@Lewin.com.