

# OLDER AMERICANS BEHAVIORAL HEALTH

## Issue Brief 12: Caregivers as Partners and Clients of Behavioral Health Services

### Introduction

The Substance Abuse and Mental Health Services Administration (SAMHSA) and the Administration for Community Living's (ACL's) Administration on Aging (AoA) recognize the value of strong partnerships for addressing behavioral health issues among older adults. This Issue Brief is part of a larger collaboration between SAMHSA and AoA to support the planning and coordination of aging and behavioral health services for older adults in states and communities. Through this collaboration, SAMHSA and AoA are providing archived Issue Briefs and Webinars, particularly in the areas of suicide, anxiety, depression, and alcohol and prescription drug use and misuse among older adults and are partnering to get these resources into the hands of aging and behavioral health professionals.

This Issue Brief explores the behavioral health needs of informal caregivers, defined as “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” including both medical and behavioral health conditions. These individuals may be primary or secondary caregivers and live with or separately from the person receiving care.<sup>1</sup> Informal caregivers, who are typically not paid, are distinct from formal caregivers—providers who are paid workers or volunteers associated with a formal service system (such as a home health agency).

This Issue Brief will:

- Describe the characteristics of caregivers including an estimate of the numbers of caregivers in the United States and explain who they are, what they do, and the impact that caregiving has on their health and well-being, such as an increased risk for mental illness and substance misuse;
- Describe special issues related to caregivers of people with behavioral health conditions;
- Highlight evidence-based interventions to decrease common caregiver problems, such as depression, anxiety, and anger, and to improve coping and problem-solving skills;
- Suggest key actions that aging network and behavioral health providers can take to address the behavioral health needs of caregivers; and
- Provide information about caregiving resources, including the National Family Caregiver Support Program (NFCSP).

### Caregiving: An Overview

Care provided by family members and friends is the backbone of long-term care services in the United States. A substantial increase in informal caregiving began in the 1950s when individuals with mental illness were deinstitutionalized. Later, those with developmental and physical disabilities also began to be deinstitutionalized and moved to less restrictive community-based settings.<sup>2</sup> In addition, the growth of the older adult population and aging in place have contributed to the increase in the number of caregivers in the United States. These changes have resulted in a larger role for family members and friends to provide care for their loved ones, including older adults with physical and behavioral health conditions.

### Statistics about Caregiving in the United States

- In 2009, 65.7 million people (31% of all households) reported being a family caregiver to an adult or a child with special needs:<sup>3</sup>
  - 72% care for an older adult who is age 50 or older and more than 60% of these care recipients are older than 65<sup>3</sup>
  - 32% care for someone with a mental health or emotional concern<sup>3</sup>
- More than 15 million care for someone with Alzheimer's disease or other dementia.<sup>4</sup>
- Caregivers spend an average of 20.4 hours per week providing care.<sup>3</sup>
- The care provided by caregivers is valued at \$450 billion.<sup>5</sup>
- Caregivers are predominantly women (66%) with an average age of 48.<sup>3</sup>
- 86% care for a relative, most often a parent (36%).<sup>3</sup>
- 34% of caregivers report taking care of two or more people.<sup>3</sup>

Several trends are beginning to change the demographics of caregiving, including an increase in the number of men—husbands and sons—serving as caregivers and the number of individuals who are sandwiched between caring for their parents and their children at the same time. The number of grandparents caring for grandchildren is also on the rise. In addition, an increasing number of family members, especially spouses and parents, are caring for wounded service men and women. Many wounded service members have behavioral health conditions such as Post-Traumatic Stress Disorder and/or Traumatic Brain Injury.<sup>6</sup>

The important work of caregivers augments the care provided by the health care and long-term services systems. Caregiver assistance may range from occasional help to full-time care. Caregiver tasks range from simple to complex and may include assistance with activities of daily living such as personal care (e.g., bathing, dressing) and instrumental activities of daily living such as managing medications, paying bills, and grocery shopping. Complex assistance may include wound care, administering injections, and other medical tasks.

Thirty-two percent of caregivers report that they care for someone with emotional or mental health issues.<sup>3</sup> Caregivers often have to respond to rapidly changing needs and situations. They play an even greater role in managing symptoms, ensuring adherence to medication and other treatment regimens, and serving as home-based care coordinators and personal advocates for care recipients. In addition, those caring for older adults with serious mental illness assume supportive functions because of the scarcity of community-based housing alternatives and mental health services.<sup>7</sup>

In addition to providing medical and social support, those providing care to someone with behavioral health conditions must also manage the stigma that is often associated with many mental and substance use disorders. Guilt is often reported by these caregivers, and there is a growing need for explaining to caregivers that a mental disorder is not related to or caused by family behavior. Many caregivers of those with severe mental illness are parents who have been providing care for many years and are aging themselves.<sup>8</sup> They are concerned about who will assume responsibility for their care recipient when they are no longer able.

## The Impact of Caregiving

The impact of providing informal care differs depending on the caregivers' responsibilities. Many caregivers report positive experiences such as a sense of satisfaction and relief knowing that their loved ones are being cared for appropriately. They find caregiving rewarding and a way to give back.

However, caregiving can also have a negative impact on the health and well-being of informal caregivers. Some of the most common mental health problems reported by caregivers include depression, anxiety, and stress. In addition, many report high rates of guilt, sadness, dread, worry, and other negative experiences, as well as distress from witnessing the suffering of their relatives. Health-related concerns include fatigue, sleep disturbances, and risk of illness and injury. Secondary strains are work-related productivity loss, financial strains, relationship stress, loss of time for self-care, and overall reduced quality of life.<sup>9</sup> Some caregivers experience caregiver burnout with symptoms of severe tension, irritability, anger, fatigue, disturbed sleep, and difficulties thinking clearly and making decisions. These symptoms may be a precursor to Major Depressive Disorder.

Studies have found varying degrees of negative experiences resulting from caregiving:

- Women are more likely to report high stress due to caregiving.<sup>3</sup> Likely reasons for this include women spend more time providing care and take on more complex tasks.
- Caregiving can result in increased use of alcohol especially when caregiving impedes the caregiver's social interaction with family or friends or when the caregiver has negative feelings about caregiving.<sup>10</sup> Other correlates of alcohol use in caregivers are depression and anxiety. More than one-third of spousal caregivers report using alcohol as a coping strategy for the stresses of caregiving.<sup>11</sup> Medications may also be used by some caregivers as a coping strategy; this use could lead to misuse and/or abuse by some if certain psychoactive medications such as antianxiety medications (benzodiazepines) and opioid analgesics are overused by caregivers.
- Caregivers of those with emotional/mental health problems are more likely to report general health decline.<sup>12</sup>
- Spouses of individuals with mental illness are at high risk for developing a depressive disorder.<sup>13</sup>

## Caregiver Assessment

Assessment of caregivers is an important first step in supporting care recipients, caregivers, and their families. The Family Caregiver Alliance (FCA) has defined caregiver assessment as “a systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources and strengths of the family caregiver. It approaches issues from the caregiver’s perspective and culture, focuses on what assistance the caregiver may need and the outcomes and support the family member is seeking and needs to maintain the caregiver’s own health and well-being.”<sup>1</sup> Although the assessment approach needs to be tailored to each service setting and program, all caregiver assessments should:

- Identify the primary caregiver and other family members/friends who are involved in arranging, coordinating, or providing care;
- Improve caregivers’ understanding of their role and what they need to know to carry out tasks;
- Give practitioners information to work with the caregiver to develop a care plan with measurable outcomes for caregivers; and

- Address services available for the caregiver and provide appropriate and timely referral for services.

FCA has identified seven categories that should be assessed when working with caregivers:

1. Context of caregiving (How would you describe your caregiving experience?);
2. Caregiver’s perception of the care recipient;
3. Caregiver’s values and preferences;
4. Well-being of the caregiver;
5. Consequences of caregiving;
6. Caregiver’s skills, abilities, knowledge, and gaps; and
7. Potential resources.<sup>14</sup>

The FCA website provides an outline of areas to assess and possible questions to ask for each category. [FCA Assessment](#).

## Formal Caregiver Assessment Tools

- **Zarit Burden Inventory**—This 22-item self-report assessment of burden is used by many aging agencies.
- **Caregiver Self-Assessment**—This questionnaire was developed to help physicians measure caregivers’ distress and their need for supportive services; the physician can then make appropriate referrals to community resources.
- **Perceived Support Scale**—This brief instrument measures social support or perceptions of help received from others as a means to cope with stress.
- **Perceived Benefits of Caregiving Scale**—This 11-item scale identifies the benefits of caregiving as a way of coping with stress.

## The National Family Caregiver Support Program (NFCSP)

**The National Family Caregiver Support Program (NFCSP)**, established in 2000, provides grants to states and territories based on their share of the population ages 70 and older to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.

In 2010, more than 700,000 caregivers received services through NFCSP. These services helped caregivers better manage their responsibilities while ensuring that their loved ones remained in the community for as long as possible. Services include access assistance, counseling, peer support, training and respite care. More information is available at [NFCSP](#).



# Caregiver Interventions: Caring for the Caregiver

Most interventions designed for caregivers have targeted caregivers of people with Alzheimer's disease or other types of dementia. Few interventions are designed specifically for caregivers of older adults with mental or substance use disorders. However, interventions can be adapted for and applied to caregivers of people with behavioral health conditions because the overall goals are the same. These goals are to enhance knowledge and skills of caregiving and self-care, increase coping skills, manage stress and symptoms of depression and anxiety, and assist with caregiving role and tasks. These interventions include education, care management, respite such as adult day services for the care recipient, and support groups. However, the evidence of effectiveness of these interventions is not as strong as other interventions.

**Individualized caregiver interventions** are one-on-one meetings between a clinician and the primary caregiver. Many individualized caregiver interventions exist that address a variety of problems. These interventions target behavioral health symptoms in caregivers, most commonly depression. Others train caregivers in skills related to managing care recipient problems, such as disruptive behaviors in dementia or pain in patients with cancer. Careful assessment of the caregiver must be completed before implementing any intervention because the intervention focuses on the specific needs of the caregiver. For many approaches, building coping and problem-solving skills and increasing the rate of enjoyable activities for the caregiver and/or care recipient are either the explicit goals or the primary components of the intervention. Interventions also often focus on stress reduction through environmental modification.<sup>9</sup>

**Psychotherapy and counseling** through cognitive behavioral therapy (CBT) can

improve symptoms of depression and anxiety in caregivers. CBT for caregivers can be delivered in as few as eight individual or group sessions.<sup>15</sup>

**Psychoeducational skill building** is the most widely studied approach for addressing caregiving distress (e.g., depression management, anger management, care recipient behavior management). These programs emphasize building skills to manage common emotional and/or behavioral problems and provide basic support and education on caregiving and diseases.<sup>16,17,18</sup> Examples of these programs include:

- Savvy Caregiver;
- Progressively Lowered Stress Threshold Model; and
- Coping with Caregiving.

More information about these and other evidence-based programs for caregivers can be found at [Caregiver Interventions](#).

**Multicomponent interventions** combine two or more approaches into one intervention package. Two examples of evidence-based multicomponent interventions are the *New York University (NYU) Caregiver Intervention and Resources for Enhancing Alzheimer's Caregiver Health (REACH) II*.

During the two individual and four family counseling sessions of the *NYU Caregiver Intervention—Enhanced Counseling & Support Intervention*, caregivers learn ways to manage patient behaviors and/or promote family communication and receive education about community resources. The intervention includes support groups, education and ad hoc counseling to manage crises, changes, and transitions. Studies have found that caregivers in the *NYU Caregiver Intervention* had significantly fewer depressive symptoms after the intervention than did control subjects. These effects were sustained for

more than 3 years after baseline, were similar across genders and care recipient severity levels, and were sustained after nursing home placement or death of the care recipient. This intervention has also been shown to delay nursing home placement for care recipients with Alzheimer's disease. Improvements in caregivers' satisfaction with social support, response to patient behavior problems, and symptoms of depression collectively contributed to the intervention's beneficial impact on nursing home placement.<sup>19,20</sup>

*REACH II* is a multicomponent in-home individual intervention that combines caregiver education and skill-training with telephone support groups that address five areas linked to caregiver risk: safety issues, social support, care recipient problem behaviors, caregiver emotional well-being and self-care, and caregiver health behaviors. Research findings indicated that Hispanic and Caucasian caregivers in *REACH II* showed significant improvement in multicomponent quality-of-life indicators (depression, burden, social support, and self-care). African American spouse caregivers also experienced improvement. However, non-spouses did not show improvement. Prevalence of clinical depression was lower among caregivers who participated in the *REACH II* intervention than those who did not.<sup>21</sup> *REACH II* has been successfully adapted for use in local communities (e.g., by personnel in local Area Agencies on Aging), and it has been effectively adapted for use with family caregivers of persons with acquired physical disabilities (e.g., spinal cord injury).





## KEY ACTIONS

## Lessons Learned from the Field

- When reaching out to caregivers through community events, use language that caregivers can relate to such as “caring for an aging parent” or make the event’s focus disease specific (e.g., depression, Alzheimer’s disease).
- Include caregivers in the care team. Good care for older people with chronic medical and behavioral health conditions requires a care team and a focus on person- and family-centered care. This collaborative approach must integrate family caregivers into the care team, engaging them as partners in care with health and behavioral health care professionals.<sup>22</sup>
- Educate primary care providers in the community about caregiving issues and encourage them to assess and refer caregivers to appropriate community-based supportive and educational programs.

- Partner with aging and behavioral health providers to better address the needs of family caregivers especially those with behavioral health issues or those caring for individuals with mental health conditions or substance use disorders. This partnership could result in not only cross-referrals but also implementation of one or more caregiver interventions such as those described in this Issue Brief.
- Offer caregivers clear information about assistance (e.g., available services and resources, contact information, explanation of services that are NOT available).
- Provide navigation coaching by offering strategies to help the care recipient and caregiver navigate through the complex health and behavioral health care delivery systems.
- Refer caregivers to behavioral health services if needed. Caregivers who need a referral are those whose level of depression, anxiety, anger (and possible abuse), and substance misuse is affecting their capacity to function effectively and provide adequate care.



## Resources

- **ACL—Caregivers as Partners and Clients of Behavioral Health Services:** Archived webinar held February 13, 2013;
- **Alzheimer’s Association—Alzheimer’s and Dementia Caregiver Center:** Information on daily care, stages and behaviors, safety issues, legal and financial planning, and care options, 800.272.3900 (24/7 Helpline);
- **Alzheimers.gov**—The government’s free information resource about Alzheimer’s disease and related dementias; authoritative, up-to-date information from agencies and organizations with expertise including a webpage for those providing care;
- **American Psychological Association—Caregiver Briefcase:** Resource for psychologists and other health professionals to assist family caregivers through individual and organizational practice, research, teaching, and community service;
- **AoA—Alzheimer’s Disease Supportive Services Program:** Information on current projects, resources, and useful links;
- **ElderCare Locator—Caregiver Tips:** Information and a variety of suggestions by caregivers for caregivers;
- **FCA—National Center on Caregiving:** A wealth of caregiving advice, resource lists, newsletters, fact sheets, research reports, policy updates, and discussion groups;
- **FCA—Caregiver’s Guide to Understanding Dementia Behaviors:** Communication tips and explanations of behavior of people with dementia including wandering, incontinence, and agitation;
- **National Alliance for Caregiving**—A national resource on family caregiving research to improve the quality of life for families and care recipients;
- **National Institute on Aging—Caregiver Guide:** Tips on communication, personal care, home safety, driving, coping with holidays, visiting the doctor, and other topics;
- **National Family Caregiver Support Program**—established in 2000, provides grants to states and territories based on their share of the population ages 70 and older to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible;
- **SAMHSA—Alcohol, Medication and Older Adults, For Those Who Care About or Care for an Older Adult:** A web-based course for professionals and caregivers interested in preventing and reducing problems related to older adults’ misuse of alcohol and medications;
- **U.S. Department of Veterans Affairs—VA Caregiver Support Services:** Information on services and support available to family caregivers of veterans as well as information about the Caregiver Support Line and how to find local caregiver support coordinators.

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