



## 01: About Mental Health Caregiving

### Introduction

As many as 8.4 million Americans act as caregivers to adults with emotional or mental health conditions.<sup>1</sup> Studies have shown that mental health caregivers often have a heavier burden of care and higher stress levels than the typical family caregiver.<sup>2</sup>

To investigate the experiences and hurdles encountered by these “mental health” caregivers, the National Alliance for Caregiving (NAC) partnered with Mental Health America (MHA) and the National Alliance on Mental Illness (NAMI) to survey caregivers of adults with mental health conditions. The purpose of this national study was to understand experiences, and identify challenges, that occur to this specific group of caregivers. In September 2015, the study collected data from 1,601 adult caregivers who provide care to a friend or family member with a mental health condition such as depression, bipolar disorder, schizophrenia, or other conditions. The resulting report, *On Pins & Needles: Caregivers of Adults with Mental Illness*, was published in 2016.

<sup>1</sup> Hunt, GG; Greene, R; Whiting, CG (2016). On Pins & Needles: Caregivers of Adults with Mental Illness. National Alliance for Caregiving, pp. 26-27. [http://www.caregiving.org/wp-content/uploads/2016/02/NAC\\_Mental\\_Illness\\_Study\\_2016\\_FINAL\\_WEB.pdf](http://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf)

<sup>2</sup> National Alliance for Caregiving (2015). Caregiving in the U.S. <http://www.caregiving.org/caregiving2015/>

<sup>3</sup> Ibid.

<sup>4</sup> National Alliance for Caregiving (2015). On Pins & Needles: Caregivers of adults with mental illness. p. 5.

### Findings

According to the study, the average mental health caregiver is roughly 54 years old, falling in the majority category of caregivers who are aged 45 to 64 years old.<sup>3</sup> The most common type of mental health care is the one provided to a family member (88%) or, more specifically, to an adult son or daughter (45%). The average mental health care recipient was around 46 years old, despite the fact that most care recipients fell in the 18 to 39 age category (58%). The typical mental health caregiver provided an average of 32 hours of care per week, over a 9-year caregiving journey.<sup>4</sup> These results indicate that mental health caregivers address their care recipient's needs for more hours a week and more years on average than the typical family caregiver.

Approximately 45% of mental health caregivers live with the care recipient, and nearly half of them report that the recipient is financially dependent upon them. Parent caregivers of adult children with mental health conditions report higher levels of stress and burden compared to other family caregivers. These caregivers also report that caregiving-related tasks have made



# 01: About Mental Health Caregiving

their own health worse (62%). This can also be attributed to the fact that a majority of these caregivers have no plans in place for someone else to care for their adult child in the event that they can no longer do so (68%).<sup>5</sup> In addition, 65% reported that there is no other family member or friend for their adult child to rely on for assistance. The above statistics are also higher compared to numbers reported by family caregivers of adults with other medical conditions. These troubling statistics further increase the need for additional services or supports necessary to assist mental health caregivers and to provide options for care recipients in the event that their main, or sole, caregiver is unable to care for them.

More than eight in ten caregivers (82%) indicated that the person they care for manages his/her mental health condition with medications. Many reported difficulties in getting the care recipient to take medications. Likewise, about four in ten caregivers (40%) did not think, or were not sure, that the care recipient's mental health symptoms were diagnosed accurately. The caregivers who believed the care recipient had an accurate diagnosis (62%) indicated that it took an average of 11.8 years for the diagnosis.

Roughly half of all mental health caregivers found it difficult to converse with others regarding the care recipient's mental health condition. In addition, half of these caregivers reported feelings of loneliness and helplessness: 63% said that because of caregiving, they felt there was not enough time to tend to themselves.<sup>6</sup> As stated above, mental health caregivers reported higher levels of stress and burden. Feelings of despair and isolation were a factor in higher

stress levels and could lead to negative health outcomes. Forty percent (40%) of mental health caregivers reported finding it difficult to take care of their own health, and more than half reported that caregiving made their health worse.<sup>7</sup> These results highlight the need for additional services and support for mental health caregivers. Addressing the health and overall well-being of caregivers is not only important to the caregivers but to the person(s) they care for.

Twenty-five percent (25%) of mental health caregivers also indicated they had trouble finding the needed services for their family member's care. Because services were not always available in the care recipient's local community, most caregivers reported experiencing difficulties in finding day treatment (64%) or peer support (58%) for the care recipient.<sup>8</sup> Furthermore, mental health caregivers reported difficulty in navigating the care system and interacting with providers. Roughly half of caregivers reported being told that the health care provider or professional was unable to speak to them about their care recipient's condition (54%).<sup>9</sup> Existing organizations in the mental health space are providing training and information to their members. Few of the mental health caregivers not affiliated with one of these organizations, however, had any sort of mental health caregiving training or education (39%). These unaffiliated caregivers often relied on doctors or health care professionals (74%), or general internet searches (38%) for information. Given their own perceived lack of inclusion in care conversations, such strong reliance on health care professionals may have limited the caregivers' own ability to learn about

<sup>5</sup> Ibid.

<sup>6</sup> Ibid.

<sup>7</sup> Ibid.

<sup>8</sup> Ibid., p.6

<sup>9</sup> Ibid.



# 01: About Mental Health Caregiving

their care recipient's condition. Given the service system challenges that caregivers faced, perhaps it comes as no surprise that one of the areas that caregivers wanted addressed was policy support to facilitate care access and navigation — both mental health coverage parity (31%) and care navigator services (30%).

## Policy Recommendations

Acknowledging the unique challenges facing mental health caregivers, the report recommends the following:

- **Integrate mental and behavioral health questions into all health care assessments and provide screenings** at all health care check-ups for the patients and their family caregivers.
- **Encourage treatment parity for mental health conditions with that of other medical health conditions.** This may include providing education to providers, caregivers, and patients about state and federal parity laws, and the health care benefits that should be covered under a patient's health plan or insurance, such as clinical treatment, health care services, or medications.
- **Provide access** to a full array of high-quality behavioral and mental health services across the continuum of care, as well as access to community inclusion, and vocational, educational, and peer support.
- **Ensure patient access and reimbursement for appropriate medications** to treat mental health conditions, including access to a full-range of medications and coverage for prescribed medications that work for an individual without overly-restrictive “fail first” policies.
- **Provide assistance to both caregivers and patients in navigating the mental health system**, with active outreach to caregivers to offer information and care coordination. County or state behavioral health entities, as well as health insurers, can play a key role in providing navigation assistance to caregivers, patients, and their families.
- **Include caregivers as part of the health care team** in ways that allow them to understand their care recipient's diagnosis without limiting the patient's independence. Policies and practices should fully include individuals, families, providers, and supports (such as the Open Dialogue model).
- **Educate and provide resources for the caregivers of persons with mental health conditions**, especially around issues of stress and caregiver health. Education should include information about services and supports, such as short-term respite, one-to-one support, day programs, and residential services. In addition, peer support for caregivers can alleviate the isolation and stigma that many family caregivers have expressed while caring for a care recipient with mental illness.
- **Work to reduce the stigma of mental health conditions through public awareness campaigns.** People with mental health conditions and their families continue to feel isolated, which prevents them from reaching out to find resources and support.