



# ON PINS & NEEDLES

*Caregivers of adults with mental illness*



February 2016



Conducted in partnership with



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## I. Executive Summary

This report outlines findings from the research study *On Pins and Needles: Caregivers of Adults with Mental Illness*. This is a study of 1,601 caregivers ages 18 or older who provide care to an adult with serious-to-moderate emotional or mental health issues, from data collected in September 2015. The purpose of this study is to describe the experiences and challenges of this targeted subset of *caregivers*. While much research on mental illness has been done from the perspective of the person with mental illness (in our study, the care recipient), as well as mental health care providers, this study aims to fill the gap in understanding from the perspective of a key piece of the care team – the unpaid caregiver.

It is estimated that at least 8.4 million Americans provide care to an adult with an emotional or mental health issue<sup>1</sup>. Prior research has shown that these caregivers are especially vulnerable, as they face complex, high burden care situations, resulting in higher caregiver stress and strain<sup>2</sup>. This study builds on prior research to better understand these mental health caregivers' unique perspectives and experiences.

Mental health caregivers are 54 years old, on average, though most are ages 45 to 64 (54%). They typically care for a relative (88%), most often an adult son or daughter (45%), parent (14%), or spouse (11%). Their care recipient is 46 years old, on average, though most are 18 to 39 years old (58%). They are providing 32 hours of care each week, more than the typical U.S. caregiver (24 hours of care weekly)<sup>3</sup>. They have been providing care for a long time, 9 years on average, longer than the typical U.S. caregiver (4 years). About half of caregivers report that their care recipient lives with them, in their household (45%), more so than the typical U.S. caregiver (34%).

About half of caregivers report that their loved one is financially dependent upon their friends and family (49%<sup>4</sup>). Mental health caregivers of adult children are in an especially unique situation – most say their son or daughter is financially dependent on friends and family (64%), but few have plans in place for someone to care for their son or daughter when they can do so no longer (32%). These parent caregivers say their caregiving role has made their own health worse (62%). As they continue to age and provide care, they may be forced to rely on others. However, only 35% say their adult son or daughter can rely on other friends and family to help. This group may be especially likely to need additional services or support to alleviate the current burden and to prepare for their

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<sup>1</sup> This is a minimal prevalence projection based on national estimates of caregiving prevalence from *Caregiving in the U.S. 2015*

<sup>2</sup> *Caregiving in the U.S. 2015*

<sup>3</sup> All figures in this paragraph referencing the typical U.S. caregiver of an adult are from *Caregiving in the U.S. 2015* and refer to caregivers who provide care to an adult for any reason or condition.

<sup>4</sup> Financial “dependence” is defined as the caregiver rating 4 or 5 on a 5-point scale, where 1 is not at all dependent and 5 is completely dependent.

adult child's future care within the formal mental health care system or by other unpaid caregivers.

Half of caregivers say it is difficult to talk to others about their loved one's mental or emotional health issues (48%), pointing to the ongoing stigma that surrounds mental illness and, by extension, the unpaid caregiver. About half of mental health caregivers report feeling alone and 63% say they have less time for themselves than they would like, due to caregiving.

This combination of stigma and isolation has implications on the caregiver's well-being: 74% report feeling high emotional stress. This emotional burden and constant feeling of being "on pins and needles" and yet, isolated, can lead to physical health impacts for the caregiver. About four in ten say they find it difficult to take care of their own health. Just one in three report having excellent or very good health (33%), far lower than 48% of U.S. caregivers generally<sup>5</sup>. Half report that caregiving has made their health worse.

Service and support for the caregiver's own health, both physical and emotional, is important, as this study shows these caregivers are an integral and often the only source of unpaid help for adults with mental or emotional health issues. Half report being the only unpaid caregiver for their loved one in the twelve months leading up to the survey.

It is important to note that all information reported on diagnosis, medications, and treatment reflect the opinions of the caregiver, and not necessarily the adult with mental illness (the care recipient). Not all caregivers are convinced their loved one has received an accurate diagnosis for his or her mental health issues. About four out of ten feel their loved one continues to search for an accurate diagnosis, a search that has been ongoing for 7 years (median). While 62% of caregivers feel that an accurate diagnosis has been made, it took 8 years (median) for that diagnosis to be reached.

Even once a diagnosis is made, caregivers still face issues with medications, commonly taken by care recipients (82%). Over half say it is difficult to find the right drug and dose (54%), and only 36% feel their loved one's medication is effective in managing his or her condition. Three in ten say they have difficulty getting their loved one to adhere to his or her medication – that is, taking the right dose at the right time. This supports prior research that has documented this frustration with both medication efficacy and compliance among patients and healthcare professionals.

Often caregivers indicate they have trouble finding the needed services for their loved one's care. One in four caregivers say their care recipient needs, but has difficulty finding, even the first line of care: a medical provider who understands mental health (22%) or a mental health professional (28%). Once a care professional is found, services are not always available in the care recipient's local community. Among those

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<sup>5</sup> *Caregiving in the U.S. 2015*

who need it, a majority of caregivers report experiencing trouble in finding day programs or treatment (64%) or peer support (58%) for their loved one. About half have difficulty arranging a case manager (49%), in-patient treatment (48%), or treatment for substance abuse (45%).

Given the difficulty of finding these kinds of providers and programs, many caregivers say they feel dissatisfied with the amount (51%) and quality (46%) of mental health community services in their loved one's area. Mental health caregivers of an adult who lives in a rural area are especially likely to note issues with service access and quality in their loved one's community. These caregivers of rural-dwelling recipients may be making up the service shortfall themselves – they provide 41 hours of care each week, significantly more than those who care for an adult who lives in a suburban or urban setting (29 hours a week).

Mental health caregivers often report difficulty in navigating the care system and interacting with providers. About half report being told by a healthcare provider or professional that the provider was unable to speak to them, the caregiver, about their loved one's condition (54%). Over half say they were included in care conversations less often than they felt they should have been (55%). Further research is needed to understand the causes of this perceived exclusion.

While existing organizations in the mental health space are providing training and information to their members, few mental health caregivers not affiliated with one of these organizations have had any sort of mental health caregiving training or education (39%). These unaffiliated caregivers often rely 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 be limiting caregivers' own ability to learn about their loved one's condition. Given the service system that caregivers face, perhaps it comes as no surprise that caregivers most want policy support that would help with care access and navigation – both mental health coverage parity (31%) and care navigator services (30%).

## **Policy Recommendations**

With these unique challenges facing mental health caregivers, we recommend 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 issues with that of medical health issues. This may include providing education for providers, caregivers, and patients about state and federal parity laws and what health care benefits 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, vocational, educational, and peer supports.
- Ensure patient access and reimbursement for appropriate medications to treat mental illness, including access to a full-range of medication and coverage for prescribed medications that work for an individual without overly-restrictive "fail first" policies.
- Provide assistance for 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 patients and their families.
- Include caregivers as part of the health care team, in ways that allow them to understand their loved one's diagnosis without limiting the patient's independence. Policies and practice should fully include individuals, families, providers, and supports (such as the Open Dialogue model).
- Educate and provide resources for caregivers of those with mental illness, 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 in caring for a loved one with mental illness.
- Work to reduce the stigma of mental illness through public awareness campaigns. Individuals with mental illness and their families continue to feel isolated, which prevents them from reaching out to find resources and supports.

The findings in this report illustrate how mental illness can impact not only an individual patient, but the family caring for that patient. Policymakers, health care providers, insurers, and other stakeholders in medical and behavioral health should continue to work towards a coordinated system of care that supports wellness for those managing mental illness.

## II. Detailed Methodology

This report – *On Pins and Needles: Caregivers of Adults with Mental Illness* – is based on quantitative online interviews with 1,601 caregivers ages 18 or older, who were currently providing care or had done so in the year prior to the time of survey, for an adult with serious-to-moderate emotional or mental health issues.

The sections below describe, in detail, the study purpose, the questionnaire and sample design, data cleaning and weighting, and response rate. There is also a section describing the *Caregiving in the U.S. 2015* data, which are presented throughout this report.

### A. Study Purpose

The purpose of this study is to provide an in-depth look at the unique issues and challenges facing those who provide unpaid care to an adult who has a serious-to-moderate emotional or mental health issue. This study was commissioned by the National Alliance for Caregiving. The findings are based on data collected in September 2015.

The core areas that we examined in this study include the following:

- Basics of the Caregiving Situation
- Diagnosis Process and Main Mental Health Condition
- Medication
- Information Sources
- Use of Services and Local Availability
- Financial, Legal, and Harming Issues
- Caregiver Stress and Well-being

The main goal of this report is to outline the overall findings from *On Pins and Needles: Caregivers of Adults with Mental Illness* – that is, to describe the experiences and challenges of this targeted subset of caregivers – caregivers of an adult with serious-to-moderate emotional or mental health issues. We also present key comparisons from the recent nationally-representative *Caregiving in the U.S. 2015* where appropriate<sup>6</sup>.

Past research has covered issues around mental illness from the perspective of the person with mental illness (in our study, the care recipient), as well as with mental

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<sup>6</sup> These comparisons draw on data about general caregivers of an adult with any kind of condition or illness, as well mental health caregivers (those caring for an adult with emotional or mental health issues with unknown severity).

health care providers and professionals. This study aims to fill the gap in understanding from the perspective of a key piece of the care team – the unpaid caregiver. All questions and data reported in this study represent the perspective of the caregiver, as he or she navigates the challenging task of caring for a loved one with serious-to-moderate mental illness.

It is estimated that at least 8.4 million Americans provide care to an adult with an emotional or mental health issue<sup>7</sup>. Prior research has shown that these caregivers are especially vulnerable, as they face complex, high burden care situations, resulting in higher stress and strain<sup>8</sup>. This study builds on this prior research to better understand these mental health caregivers' unique perspective and experiences.

## B. Research Design

The research design of this study is based on achieving the key goal of conducting online interviews with caregivers of an adult with serious-to-moderate mental illness. *On Pins and Needles: Caregivers of Adults with Mental Illness* utilized a non-probability online survey design, with three different sample sources.

One of the main reasons for this targeted study design, as opposed to a probability-based design, was the difficulty of finding qualified caregivers among a general population sample. The national prevalence of caregiving for an adult (with any condition, not specific to mental illness) is about 17 percent and it is estimated that roughly 20 percent of those caregivers provide care to an adult with an emotional or mental health issue of any severity<sup>9</sup>. Therefore, in a general population sample of all Americans, roughly 3% would qualify for this study. Requiring these caregivers to be providing care to a loved one with *serious* or *moderate* mental health issues further limits the eligible survey population.

Therefore, to maximize the ability to conduct online interviews with these difficult to find caregivers, *On Pins and Needles: Caregivers of Adults with Mental Illness* utilized a targeted, non-probability based design. The use of a targeted, non-probability based design presents the first of two key study limitations: results are not generalizable to either the general population or to the full population of caregivers of an adult with serious-to-moderate mental illness. Rather, the results must be interpreted as a targeted, in-depth look at a pre-identified population.

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<sup>7</sup> This is a minimal prevalence projection. Based on national estimates of caregiving prevalence, it is estimated that 40 million Americans provide care to an adult. Among those caring for an adult, their main care recipient has an emotional or mental health issue 21% of the time (some caregivers provide care to multiple people, severity of emotional or mental health issues is unknown). Projecting 21% onto the 40 million caregivers of adults in the United States yields a minimal prevalence estimate of 8.4 million caregivers of an adult with emotional or mental health issues. *Caregiving in the U.S. 2015*

<sup>8</sup> *Caregiving in the U.S. 2015*

<sup>9</sup> *Caregiving in the U.S. 2015*

The decision was also made to conduct the study online, which presents the second study limitation: results are biased toward those with internet access. Existing data show that younger, more educated, and higher income<sup>10</sup> people more often have internet access. Accordingly, those who completed this study had high income levels (shown in this report in Section III: I: Respondent Profile). The median household income level among mental health caregivers in this study was \$71,400, much higher than past research has shown for caregivers of all adults (regardless of condition; \$54,700) or caregivers of adults with mental illness (unknown severity; \$48,900)<sup>11</sup>.

However, this bias toward higher income caregivers suggests that *On Pins and Needles: Caregivers of Adults with Mental Illness* may be underestimating the difficulties that caregivers of adults with serious-to-moderate mental illness face, as income and education levels often make it easier to navigate care systems and afford paid services, and therefore, minimize caregiver burden<sup>12</sup>.

### C. Questionnaire

*On Pins and Needles: Caregivers of Adults with Mental Illness* was designed to explore topics unique to mental health caregivers and their recipients. It was drafted by Greenwald & Associates, with input from National Alliance for Caregiving, National Alliance on Mental Illness (NAMI), and Mental Health American (MHA). The full questionnaire can be found online at <http://www.caregiving.org/mentalhealth>.

This study conducted 1,601 quantitative online interviews with caregivers ages 18 or older, who were currently providing care or had done so in the year prior to the time of survey, for an adult with serious-to-moderate emotional or mental health issues. Caregivers were defined as those who self-identified as providing unpaid care, as described in this question:

*At any time in the last 12 months, have you provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.*

Caregivers were only eligible for this study if the severity of the emotional or mental health issue(s) of the adult care recipient were moderate or serious. The caregiver must have indicated their loved one had an emotional or mental health issue, such as anxiety, bipolar disorder, depression, or schizophrenia. In keeping with other research

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<sup>10</sup> File, Thom and Camille Ryan, "Computer and Internet Use in the United States: 2013," American Community Survey Reports, ACS-28, U.S. Census Bureau, Washington, DC, 2014.  
<http://www.census.gov/content/dam/Census/library/publications/2014/acs/acs-28.pdf>

<sup>11</sup> *Caregiving in the U.S. 2015*

<sup>12</sup> *Caregiving in the U.S. 2015*

on caregiving, to qualify, the caregiver must also assist their loved one with at least one Activity of Daily Living (ADL) or Instrumental Activity of Daily Living (IADL)<sup>13</sup>.

#### D. Sample

*On Pins and Needles: Caregivers of Adults with Mental Illness* utilized a blended sample from three sources, in order to effectively target caregivers of adults with serious-to-moderate mental illness: 1) An independent, online non-probability sample from Research Now<sup>®</sup>. 2) Mental Health America's national email distribution list. 3) National Alliance on Mental Illness local email distribution lists.

The first sample source was Research Now<sup>®</sup> e-Rewards<sup>®</sup> Consumer Ailments Panel. Research Now<sup>®</sup> maintains one of the industry's most comprehensive and deeply-profiled online survey panels. Panel members are recruited through a controlled mix of both online and offline methods through invitation only. For this project, Research Now<sup>®</sup> targeted known caregivers of someone with a mental or emotional illness from their e-Rewards<sup>®</sup> Consumer Ailments Panel. Caregivers were targeted if their panelist profile indicated they were a caregiver for someone with anxiety, bipolar disorder, depression, other neurological/mental health condition, and schizophrenia. A total of 253 Research Now<sup>®</sup> panelists completed the study.

The second sample source was Mental Health America's (MHA) national email distribution list, yielding a total of 207 caregivers who completed the study. Greenwald & Associates generated 31,000 custom links for MHA, which were inserted into customized email text and mailed to the national email distribution list.

The third component of the sample was the National Alliance on Mental Illness (NAMI) local email distribution lists, resulting in 1,141 caregivers completing the study. Greenwald & Associates created a generic survey link for NAMI along with a list of frequently asked questions about the study effort. This generic link and list of questions were placed on a survey landing page, hosted on the NAMI website. An email was then sent to the local email distribution lists directing potential respondents to the NAMI landing page, who were then redirected to the Greenwald & Associates survey platform. Because no unique identifiers were used in the survey link, the survey platform utilized browser cookies to prevent duplication of respondents.

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<sup>13</sup> Activities of Daily Living (ADLs) include helping the care recipient with: bathing or showering, getting to and from the toilet, getting in and out of beds or chairs, dressing, dealing with incontinence or diapers, or feeding them. Instrumental Activities of Daily Living (IADLs) include helping with: arranging or providing transportation, shopping, housework, preparing meals, managing finances, giving medicines or injections, or arranging services.

## E. Fielding

The questionnaire was programmed and hosted by Greenwald & Associates using mobile optimized online survey software, allowing respondents to more easily take the survey on a mobile device, like a tablet or smartphone. It must be noted that smartphone ownership and use of mobile devices to access the internet are more common among male, racial/ethnic minorities, and lower income groups<sup>14</sup>. This study utilized research best practices to optimize the questionnaire for mobile device administration to avoid bias as a result of device, though the sample sources, especially those from Mental Health America (MHA) and National Alliance on Mental Illness (NAMI) were predominately female, White, and highly educated (see Section III: I: Respondent Profile).

Six in ten took the survey on a desktop computer (63%), while 37% used a mobile device (smartphone or tablet). The average length of the interview was 19.2 minutes (Research Now<sup>®</sup> 13.2 minutes, MHA 20.0 minutes, NAMI 20.4 minutes). The online interviews were conducted between September 3 and September 30, 2015.

## F. Data Cleaning

After fielding, data were reviewed for quality purposes. Respondents were removed from the analysis if they did not fit the study population definition. Reasons for removal from analysis included:

- The reason for care was something other than a mental or emotional health issue
- Care was provided more than 12 months prior to survey (but not within the 12 months leading up to and including the time of survey)
- The main reason for care was a substance abuse issue without presence of a mental health issue
- Only monetary support was provided without providing hands-on care (ADLs and IADLs)
- Care was paid as part of employment or job description
- Care was provided as part of volunteering or community leadership role to many people in an institutional setting

Additionally, data were reviewed for quality issues such as straight lining, speeding, or inconsistent results. Finally, data across the three samples were reviewed for duplication, to ensure that no one caregiver took the survey multiple times. Finally, due to an overwhelming response from the NAMI sample in a short time frame and the

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<sup>14</sup> Blumberg, SJ, Luke JV. "Wireless substitution: Early release of estimates from the National Health Interview Survey, July-December 2014. National Center for Health Statistics. June 2015. <http://www.cdc.gov/nchs/nhis.htm>

skewed nature relative to the other samples (see III:H), a random sample of 100 white women with graduate degrees were dropped from the final analysis. A total of 255 completes were removed from the final results.

The final result was a total of 1,601 online interviews conducted with caregivers of an adult with serious-to-moderate emotional or mental health issues.

**Figure 1: Completion Rate by Sample Source**

	All Samples	Research Now	MHA	NAMI
Survey starts (click ins)	4,095	1,003	898	2,194
Terminates (not qualified during survey process)	1,279	587	384	308
Drop-offs	829	110	258	461
Initial completes	1,856	302	248	1,306
Completes after cleaning	1,601	253	207	1,141
Completion rate (Initial completes divided by survey starts)	45.3%	30.1%	27.6%	59.5%

### G. Weighting and Margin of Error

Caregivers from each sample source are weighted such that each sample provides an equal share of the combined total.

Other methods for weighting the 1,601 mental health caregivers were explored, with the intent to make respondents demographically representative. Weighting benchmarks or demographic targets for caregivers of an adult with mental health issues could have been surmised from *Caregiving in the U.S. 2015*, but the lack of indication about the severity of the care recipient’s condition limited the comparability of the populations. Therefore, this alternative weighting was abandoned, given the lack of a reliable demographic profile of the true population of caregivers of an adult with serious-to-moderate mental health issues.

The sample used for this project was non-probability based sample, which means traditional estimates like margin of error do not apply. However, if a project were completed with a comparable number of mental health caregivers using a probability-based sample, we would expect a margin of error of plus or minus approximately 2.4 percentage points at the 95% confidence level. This means that 95 times out of 100, a difference of greater than roughly two and a half percentage points would not have occurred by chance. Subgroup analyses would have a larger margin of error.

## H. Caregiving in the U.S. 2015 Supplement

To bolster analysis, this report folds in results from *Caregiving in the U.S. 2015*<sup>15</sup>. *Caregiving in the U.S. 2015* was sponsored by the National Alliance for Caregiving and AARP Public Policy Institute and utilized a national, probability-based, online panel to achieve two goals. First, to estimate prevalence of caregiving for someone of any age within both the U.S. population and households; and second, to describe the characteristics, roles, and needs among caregivers who provide care to an adult age 18 or older.

Out of the 1,248 caregivers of adults surveyed in *Caregiving in the U.S. 2015*, 252 reported their adult care recipient had an emotional or mental health issue, though no severity of that mental health issue was indicated.

Where appropriate, this report – *On Pins and Needles: Caregivers of Adults with Mental Illness* – presents key comparisons to the full 1,248 caregivers of adults and findings about the 252 caregivers of an adult with mental illness.

## I. Reading This Report

This report – *On Pins and Needles: Caregivers of Adults with Mental Illness* – aims to provide insight into the experiences and perspectives of the caregiver. It is not intended to represent clinical evaluations of health care or behavioral health providers or professionals, nor is it intended to capture the experiences of the person with mental illness, the care recipient or patient. This study fills the gaps in existing knowledge by gathering information from the perspective of the caregiver, to help further the existing research and to advocate for policy and support on behalf of the caregiver.

The main figures present results for all 1,601 mental health caregivers. All numbers have been weighted and rounded. In addition, “don’t know” or “refused” responses are not always presented in figures. For these reasons, data in some figures will not add to 100 percent. The results for multiple response questions may also add to greater than 100 percent.

The n sizes shown in each table or graphic represent the unweighted number of respondents who answered each question. To signal key differences between subgroup findings, the report uses a superscript letter next to a numerical result indicates that it is significantly higher than the numerical result in the column designated by that letter.

All demographic information about the caregivers is in reference to their current situation if currently caregiving, or their situation at the time they last provided care if not a current caregiver.

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<sup>15</sup> For more detail about *Caregiving in the U.S. 2015*, including full methodological description, see <http://www.caregiving.org/caregiving2015/>

For the sake of brevity, we refer to the study respondents as “caregivers” or “mental health caregivers” interchangeably throughout the report; both of which refer to the same study population – that is, adults age 18 and older, who provide unpaid care to an adult who has serious-to-moderate mental or emotional health issue(s).

## III. Detailed Findings

### A. Basics of the Caregiving Situation

#### Prevalence

It is estimated that at least 8.4 million Americans provide care to an adult with an emotional or mental health issue<sup>16</sup>. The nationally-representative study *Caregiving in the U.S. 2015* found these 8.4 million caregivers are especially vulnerable, as they face complex, high burden care situations, resulting in higher stress and strain. *Caregiving in the U.S.* found that mental health caregivers are more likely to face emotional stress and physical strain. They are less likely to feel they had a choice in taking on care. These caregivers more often report financial strain, as well as difficulty finding affordable care services in their loved one’s community.

#### Current versus Past Care

More than eight in ten mental health caregivers in this study were currently providing care for their loved one (83%), while 17% were not currently providing care, but did so in the 12 months prior to the survey<sup>17</sup>. This supports findings from *Caregiving in the U.S. 2015* that found caregivers of adult with a mental health issue were more often currently providing care than caregivers of an adult without these issues.

#### Duration of Care

Caregivers of an adult with a mental or emotional health issue have been in their role for an average of 8.7 years. In contrast, caregivers of an adult with *any kind* of condition or illness spend less time providing care: 4 years on average<sup>18</sup>.

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<sup>16</sup> This is a minimal prevalence projection. Based on national estimates of caregiving prevalence, it is estimated that 40 million Americans provide care to an adult. Among those caring for an adult, their main care recipient has an emotional or mental health issue 21% of the time (some caregivers provide care to multiple people, severity of emotional or mental health issues is unknown). Projecting 21% onto the 40 million caregivers of adults in the United States yields a minimal prevalence estimate of 8.4 million caregivers of an adult with emotional or mental health issues. *Caregiving in the U.S. 2015*

<sup>17</sup> The survey was conducted in September 2015.

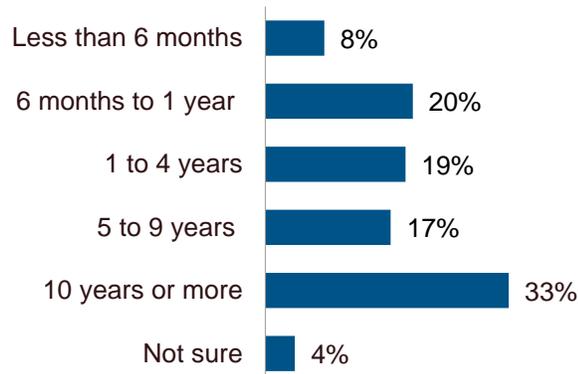
<sup>18</sup> *Caregiving in the U.S. 2015*. This supports findings from the same study that found mental health caregivers had been providing care longer (5.0 years on average) than caregivers of adults without these issues (3.7 years on average).

One in three mental health caregivers have provided care for ten years or more. There are some mental health caregivers who are relatively new to their role – with nearly three in ten caring for less than a year.

**Figure 2: Duration of Care**

Q14. How long have you been providing/did you provide care to your [relation]?

(n=1,601)



**Profile of “New” Caregivers vs. Experienced Caregivers**

- Mental health caregivers who have provided care for less than a year – that is, “new” caregivers – are different than their counterparts who have been providing care for a decade or longer.
  - “New” caregivers are caring for a variety of loved ones: an adult child (27%), parent (18%), non-relative (15%), or sibling (10%). Their loved one’s emotional or mental health issues are equally likely to be moderate (47%) as they are to be serious (53%). Compared to their more experienced counterparts, “new” caregivers are more often caring for someone with depression (32% vs. 11% among experienced caregivers) or anxiety (13% vs. 8%).
  - Experienced mental health caregivers are typically caring for an immediate relative, like an adult child (68%) or spouse (14%). Their loved one typically has *serious* mental health issues (65%). They are more often caring for someone with schizophrenia (34% vs. 14% “new” caregivers) or bipolar disorder (33% vs. 21%).

**Help with Activities**

Nearly all mental health caregivers help with Instrumental Activities of Daily Living (IADLs), which includes arranging or providing transportation, shopping, housework, preparing meals, managing finances, giving medicine or injections, or arranging services. Fewer than one in five assist with Activities of Daily Living (ADLs, 18%), which includes personal care activities like bathing or showering, getting to and from the toilet,

helping them get out of beds or chairs, dressing, dealing with incontinence or diapers, or assisting with feeding.

The relatively low rates of assistance with ADLs may be due to the young age of the care recipients in this study, who are usually 42 years old (median care recipient age). In contrast, *Caregiving in the U.S. 2015* found that 59% of caregivers of adults help with ADLs, but the care recipients in that study were 30 years older (median care recipient age of 73 years old).

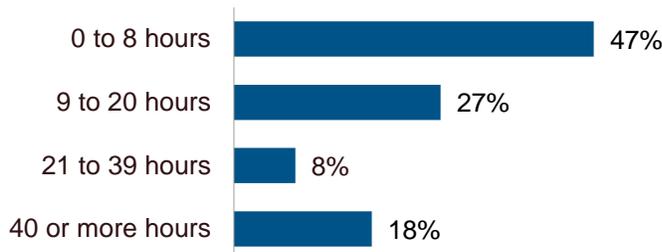
### Hours of Care

Mental health caregivers spend an average of 31.8 hours a week assisting their loved one, higher than the average U.S. caregiver who provides 24.4 hours of care weekly<sup>19</sup>.

**Figure 3: Hours of Care Provided**

Q15. About how many hours do/did you spend in an average week, helping your [relation]?

(n=1,601)



Nearly one in five spend more than 40 hours a week, the equivalent of a full-time position, providing care to a loved one. Groups especially likely to be full-time caregivers include those caring for a spouse/partner (34% vs. 16% all other relationships), co-resident caregivers (31% vs. 7% of those who do not live with their recipient), and sole caregivers (22% vs. 14% of those with other unpaid help).

### Profile of Rural Caregivers

- Mental health caregivers whose recipient lives in a rural area spend more time providing care each week (see Figure 4, next page). These caregivers of rural-dwelling adults with emotional or mental health issues also are less likely to be satisfied with the availability and quality of care services in their loved one's community, suggesting that these unpaid mental health caregivers find themselves taking on greater hours of unpaid care to fill the gaps in mental health services available.

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<sup>19</sup> All caregivers of adults, *Caregiving in the U.S. 2015*

**Figure 4: Hours of Care and Services by Rural Residence of Recipient**

	Caregivers of Recipients who live in...	
	Rural (n=343) A	Not rural (n=1,258) B
Average hours of care provided	40.7 <sup>B</sup>	29.0
<b>Satisfaction with:</b>		
Amount of services	11%	17% <sup>A</sup>
Quality of services	13%	19% <sup>A</sup>

Caregivers in rural areas reflect on their challenges in service access:

*“[I need] more affordable community and mental health services in a rural area.”*

*“We live in a rural area where there is very poor inpatient care and a dearth of day programs and assisted housing where he can learn to live a life not completely dependent on parents.”*

*“I am having difficulty navigating the system, due to being in a rural area, with a scarcity of resources. I just had to send my son out of state for treatment. No one should have to do this!”*

### Age and Relationship

Among mental health caregivers, half are caring for a male (51%) and half are caring for a female (49%). Among all caregivers of adults nationally, most care recipients are female (65%)<sup>20</sup>, suggesting that when it comes to caring for an adult with serious-to-moderate mental illness, that adult is more often male.

Mental health caregivers are 54.3 years old on average, though most are between the ages of 45 and 64 (54%, see III: I: Respondent Profile for more detail).

Mental health caregivers are caring for a loved one who is 46.3 years old, on average<sup>21</sup>. The majority of care recipients are under age 40 (58%, see Figure 5 next page). As with caregivers generally in the United States<sup>22</sup>, these younger recipients are most commonly the adult son or daughter of their caregiver.

<sup>20</sup> *Caregiving in the U.S. 2015*

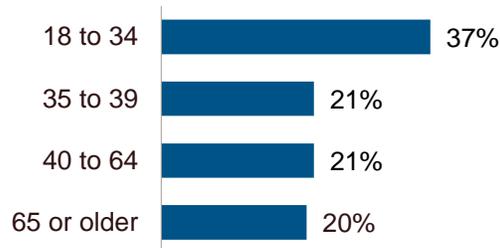
<sup>21</sup> This supports findings from *Caregiving in the U.S. 2015* that found care recipients' with mental health issues were younger by 8 years, on average, than recipients without these issues.

<sup>22</sup> Among all caregivers of adults age 18 to 49 in *Caregiving in the U.S. 2015*, 32% are the adult son or daughter of their caregiver, the most common relationship among these youngest recipients.

**Figure 5: Care Recipient Age**

Q13. How old is/was your [relation]?

(n=1,601)



Mental health caregivers are most often caring for a relative (88%), with nearly half caring for an adult son or daughter (45%). One in seven care for a parent (14%), 11% help a spouse, and 9% care for a sibling. Just 9% assist a non-relative with his/her serious-to-moderate emotional or mental health issue.

**Figure 6: Relationship of Care Recipient to Caregiver**

Q12. Who are you caring/did you care for?

	Caregivers (n=1,601)
<b>Relative</b>	<b>88%</b>
Adult Child	45
<i>Son</i>	30
<i>Daughter</i>	15
Parent	14
Spouse/Partner/Companion	11
Sibling	9
Grandparent/Grandparent-in-law	2
Parent-in-law	2
Aunt/Uncle	2
Nephew/Niece	1
Cousin	1
Brother/Sister-in-law	1
Grandchild	<0.5%
Other relative	<0.5%
<b>Non-relative</b>	<b>9%</b>
Friend	7
Neighbor	1
Other Non-Relative	*
Decline to respond	3%

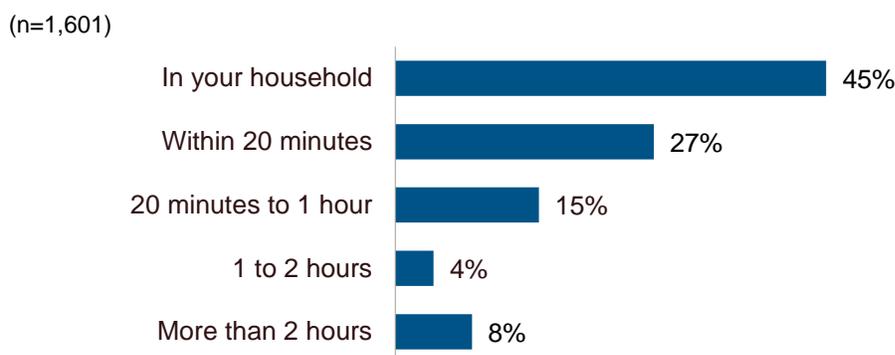
Among all caregivers in the U.S., more provide care to a non-relative (15%). However, the greater the needs of the recipient, the more often caregiving falls on the shoulders of a relative. High burden caregivers in the U.S. generally – that is, those providing the greatest hours of care and doing the most activities for their loved one – are more often a relative (90%)<sup>23</sup>.

### Residence of Care Recipient

Almost half of mental health caregivers say their recipient lives in their household (45%), a co-residence rate more common than caregivers in the U.S. generally (34%)<sup>24</sup>. More than one in four mental health caregivers say their loved one lives very close by (within 20 minutes).

**Figure 7: Caregiver Distance from Care Recipient**

Q17. How far away does/did your [relation] live currently/at the time you last provided care?



Among mental health caregivers of an adult child, most co-reside or live within 20 minutes of their son or daughter (74%). Half of caregivers whose care recipient is financially dependent<sup>25</sup> on family and friends report their loved one lives in their household (52%).

Among mental health caregivers who do not live with their care recipient, about half (52%) report their loved one lives alone, while 45% live with someone else. Two percent of care recipients are homeless<sup>26</sup>.

<sup>23</sup> The “burden” of care is a simplified version of the Level of Care index, which is created by combining caregiver hours of care and assistance with ADLs and IADLs. *Caregiving in the U.S. 2015*

<sup>24</sup> *Caregiving in the U.S. 2015*

<sup>25</sup> Financial dependence is defined rating 4 or 5 on a 5-point scale, where 1 is not at all dependent and 5 is completely dependent. See Figure 25 for financial dependence question results.

<sup>26</sup> At the time of survey for current mental health caregivers, or at the time the caregiver last provided care to their loved one (if not a current caregiver). As reported in a later section, 21% of mental health caregivers report their loved one has *ever* been homeless for a period of a month or longer.

### C. Care Recipient Condition

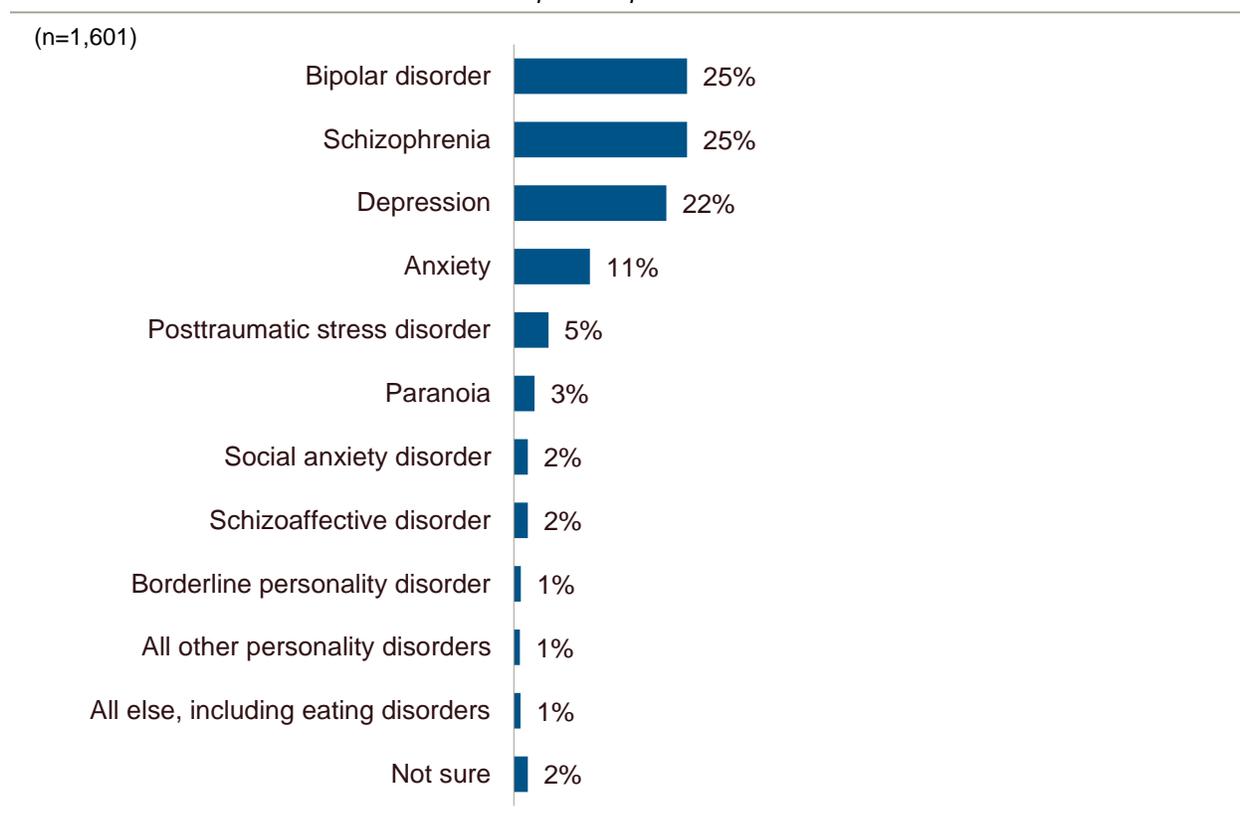
Nearly six in ten say they care for an adult with a serious emotional or mental health problem (58%), while 42% feel their care recipient’s mental health issues are moderate.

#### Main Emotional or Mental Health Issue

The most common primary emotional or mental health issues cited by caregivers are bipolar disorder, schizophrenia, and depression<sup>27</sup>. Other commonly mentioned issues include anxiety, posttraumatic stress disorder (PTSD), and paranoia.

**Figure 8: Main Emotional or Mental Health Issue of Care Recipient**

Q19. What is/was the main emotional or mental health issue your [relation] has/had, for which he/she requires/required care?



While these are self-reported data from caregivers and not intended to represent clinical diagnoses, certain conditions are more common among certain subgroups of recipients, reflecting population-level demographics in mental health diagnoses. Caregivers of male recipients are more likely to report their loved one has schizophrenia (35% vs. 14% of those caring for a female recipient), while those caring for a female recipient more

<sup>27</sup> This is self-reported by the caregivers and represents the caregiver’s perception of what their loved one’s main emotional or mental health issue is. This is not intended to be representative of nor indicative of an official diagnosis by a care professional.

often report depression (27% vs. 18% of male recipients) or anxiety (14% vs. 7% of male recipients).

As expected, caregivers who say their loved one has schizophrenia or bipolar disorder more often describe their loved one’s condition as serious, while those whose loved one has anxiety or depression more often describe the issue as moderate.

**Figure 9: Severity of Condition by Reported Main Issue**

	Schizophrenia (n=550) A	Bipolar (n=455) B	Depression (n=249) C	Anxiety (n=148) D	Other (n=199) E
Serious	77% <sup>BCDE</sup>	58% <sup>CD</sup>	46% <sup>D</sup>	34%	66% <sup>CD</sup>
Moderate	23	42 <sup>A</sup>	54 <sup>ABE</sup>	66 <sup>ABCE</sup>	34 <sup>A</sup>

It is also estimated that 74% of care recipients who have an emotional or mental health issue also have some sort of short-term or long-term physical condition<sup>28</sup>.

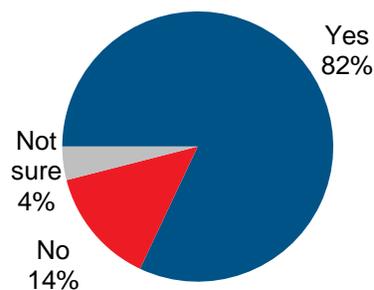
### Prescription Medication

More than eight in ten indicate their recipient manages their emotional or mental illness with a prescription medication (82%).

**Figure 10: Prescription Medication Taken by Care Recipient**

Q23. *Is/Was your [relation] taking any prescription medication(s) to help manage his/her mental or emotional illness?*

(n=1,601)



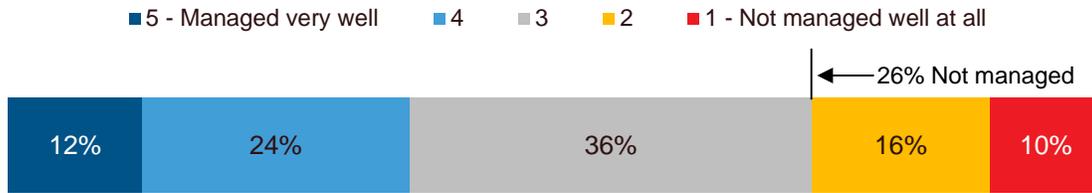
Of the mental health caregivers who report their recipient takes a prescription medication, one in four feel their loved one’s condition is not managed well with that medication (26%) and only 36% feel the condition is managed well (see Figure 11, next page).

<sup>28</sup> Among all caregivers of adults with any sort of mental or emotional health issue (severity unknown) from *Caregiving in the U.S. 2015*

### Figure 11: Medication Management of Condition

Q25. And how well do/did you feel your [relation]'s condition is/was managed with his/her medication?

Caregivers of someone taking prescription medication (n=1,338)



### Difficulty with Medication

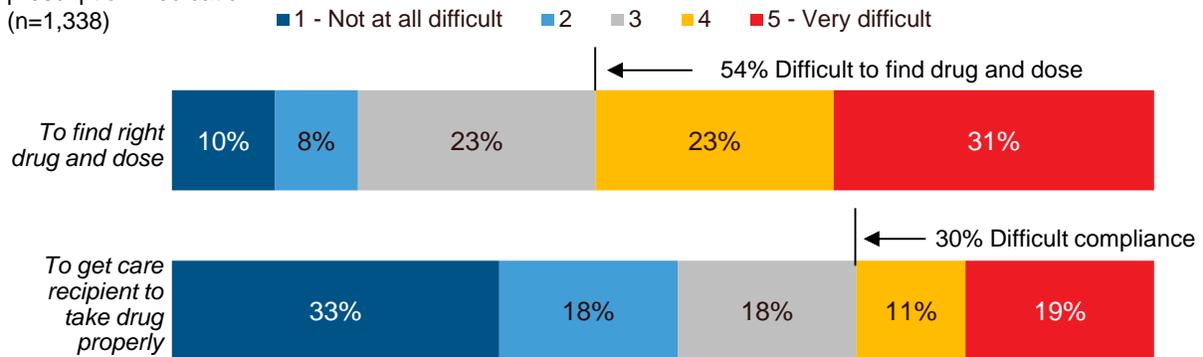
More than half of mental health caregivers report they have had difficulty finding the right drug and dosage for their recipient (54%), while three in ten say it is difficult to get their loved one to take their medication as prescribed.

### Figure 12: Search for and Compliance with Prescription Medication

How difficult is/was it to...

Q24a. find a specific drug and dosage that you feel works/felt worked for your [relation]'s mental health issue(s) /  
Q24b. get your [relation] to take his/her medication as prescribed (the right amount at the right time)?

Caregivers whose recipient takes prescription medication (n=1,338)



Those caring for an adult child more often report difficulties in getting their loved one to take his/her medication (31% vs. 15% caring for a spouse/partner). Mental health caregivers whose recipient has schizophrenia (34%) or bipolar disorder (33%) are also especially likely to report compliance difficulty, more so than those caring for someone with depression (20%).

Prior research done on medication compliance and efficacy among people who have mental health conditions shows that caregivers are not alone in their frustration with the

search for and compliance with medication<sup>29</sup>. Many caregivers express their own experience with the often imperfect science of prescription therapy for mental illness:

*“Right now my son finally has the right “cocktail.” It took us almost four years and three suicide attempts before getting to this point.”*

*“It has taken us a long time to get to this point, where my son somewhat willingly takes his medication that I give to him every day. If I don't give it, he doesn't remember to take it.”*

*“{We need} consistent care in [the] search for the right medicine. Guessing and sending him home for the family to deal with the side effects is not safe. One week of hospitalization or [a] 15 minute psychiatric visit is not adequate to observe his symptoms or the effect of the medicine.”*

## D. Diagnosis and Service Needs

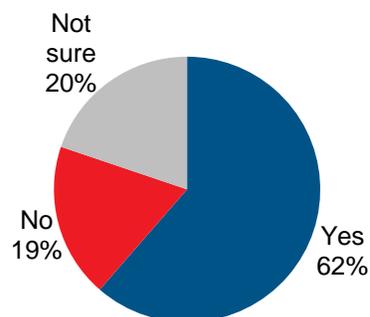
### Journey to Accurate Diagnosis

About four in ten mental health caregivers do not think (20%) or are not sure (19%) that their recipient's mental health issues have been diagnosed accurately, reflecting the often difficult time practitioners and recipients can have in the diagnostic process.

**Figure 13: Accurate Diagnosis of Mental Health Issues**

Q21. Do/Did you feel your [relation]'s mental health issues have been/were accurately diagnosed?

(n=1,601)



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<sup>29</sup> Manschreck, TC and RA Boshes. “The CATIE Schizophrenia trial: results, impact, controversy.” Harvard Review of Psychiatry, 2007 Sept-Oct; 15(5): 245-58.

<http://www.ncbi.nlm.nih.gov/pubmed/17924259>

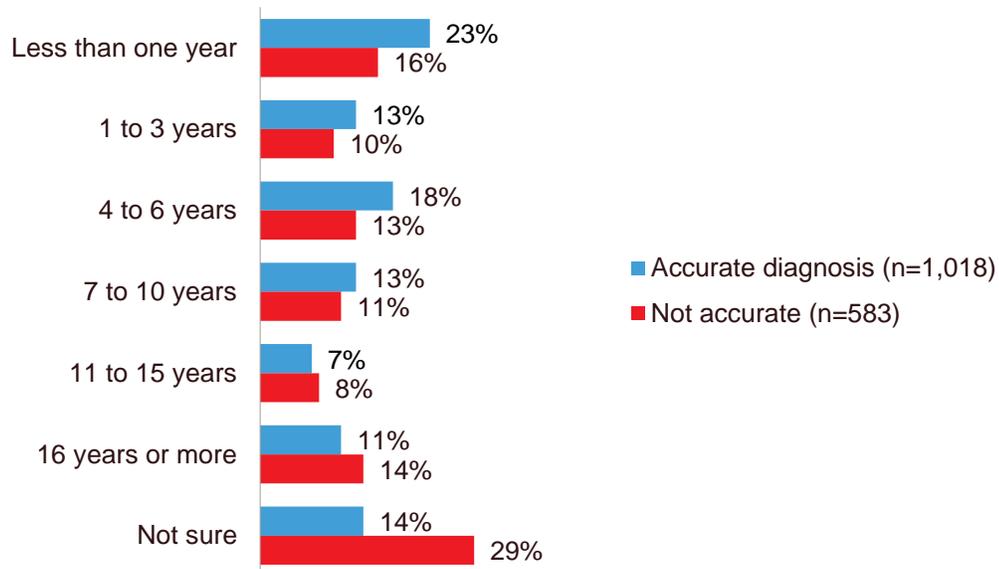
Rush, A. John et al. “Acute and Longer-Term Outcomes in Depressed Outpatients Requiring One or Several Treatment Steps: A STAR\*D Report.” The American Journal of Psychiatry, November 2006; 163(11): 1905-17. <http://ajp.psychiatryonline.org/doi/abs/10.1176/ajp.2006.163.11.1905>

While 62% of mental health caregivers do believe their loved one's mental health issues have been accurately diagnosed, it took an average of 11.8 years to get that diagnosis and, most commonly, 8 years (median). More than one in ten says it took 16 years or longer (11%), to get to a diagnosis that the caregiver feels was accurate.

Those caregivers who feel their loved one's issues remain a mystery have faced a similarly long battle to diagnosis, on average 11.8 years, with a common search length of 7 years (median). Three in ten are not quite sure how long their loved one has been searching for an accurate diagnosis.

**Figure 14: Time to Diagnosis**

*Q22. [If Accurate]: How many years did your [relation] display symptoms of an emotional or mental health issue before you felt he/she was accurately diagnosed/[If Not Accurate]: How many years has/did your [relation] been trying/try to get an accurate diagnosis for his/her emotional or mental health issues?*



## Alcohol or Substance Abuse Issues

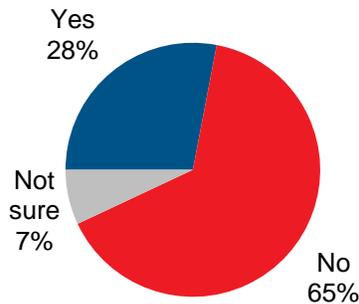
Three in ten mental health caregivers report that their loved one has an alcohol or substance abuse issue (28%)<sup>30</sup>.

**Figure 15: Alcohol or Substance Abuse Issue**

Q20. Does/did your [relation] have an alcohol or substance abuse issue?

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(n=1,601)



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Caregivers who feel their loved one has not yet received or who are unsure if their loved one has received an accurate diagnosis of his or her mental health issues more often report their care recipient has an alcohol or substance abuse issue (34%), compared to 24% of caregivers who feel an accurate diagnosis has been reached.

Other groups more likely to have a substance abuse issue, as reported by the caregiver, include care recipients with a serious mental health issue (34% vs. 20% moderate) and male recipients (33% vs. 23% female recipients).

## Confidentiality and Caregiver Involvement

About half of mental health caregivers have had a healthcare provider or professional say they were unable to speak with them, the caregiver, about their loved one's condition (54%).

About four in ten caregivers say they are included in care conversations about their loved one when needed (37%), though over half say they were included less than they felt they should have been (55%, Figure 16 next page).

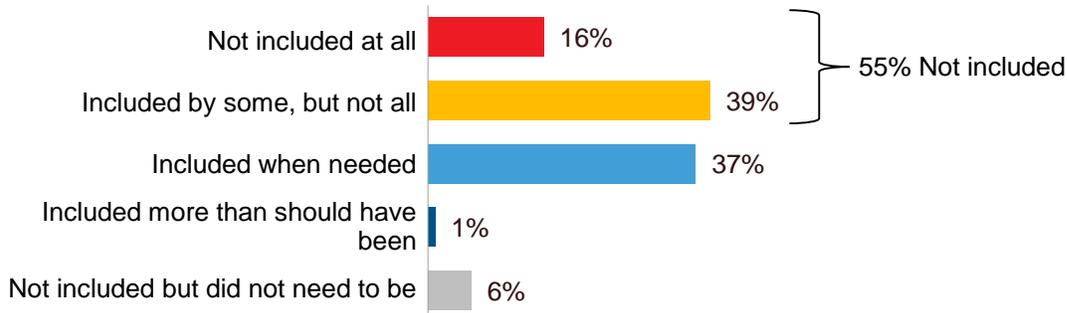
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<sup>30</sup> As noted in II: Detailed Methodology, this indicates co-morbidity of substance abuse issues along with the main mental health issue. If the only issue present was substance abuse, the caregiver was removed from the study.

**Figure 16: Conversations with Care Providers**

Q33. To what extent do/did you feel care providers have/had included you in conversations about your [relation]'s care?

(n=1,601)



Those caring for an adult child are especially likely to say a healthcare provider or professional was unable to speak with them (77%), more so than those caring for a spouse/partner (37%), other relative (37%), or a non-relative (28%). Parents caring for an adult child are more likely to say they feel left out of care conversations (69% vs. 46% of all other caregivers). More research is needed to tease out the reason for the relationship between parental caregiving and feelings of being left out of care conversations. These may be real omissions from the care team due to privacy issues, a desire for independence on the part of the adult child, or perhaps perceptions by either the provider or adult child that the parent may be, rightly or wrongly, a contributing factor to the mental health issue.

The struggle to find an accurate diagnosis can be frustrating for caregivers, especially when they feel left out of the care conversations:

*“Before my daughter had her first break, she had been diagnosed with a serious medical condition. To this date, we have not been able to determine if the diagnosis...is PTSD. Since she lives alone, it is difficult to truly know how well she is doing.”*

*“She was on a lot of psych meds that I didn't know what they were for. I did know she was psychotic when she didn't take her [medication], but no one ever said for what illness she was taking [medication]. I had to guess that maybe she was bipolar. The one thing that would have helped was knowing exactly what I was dealing with.”*

*“My father refuses to seek treatment, diagnosis and denies he has any problems. How do you help someone like that?”*

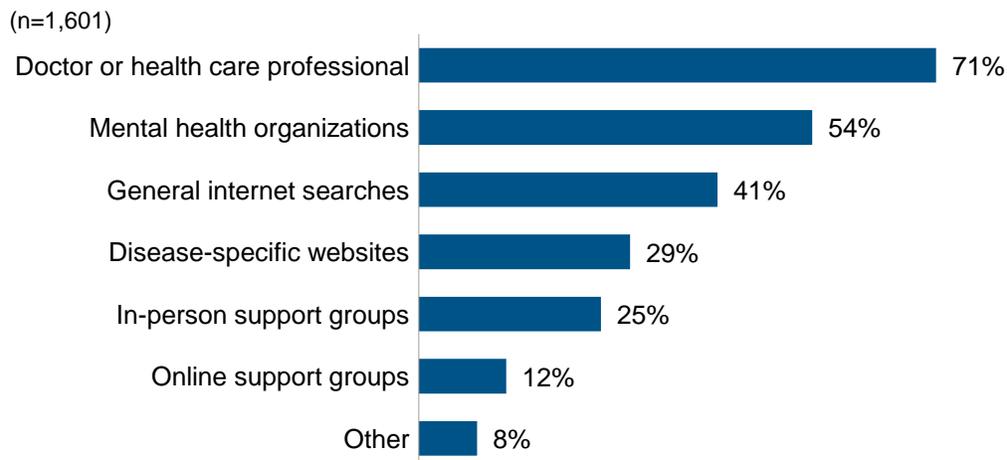
## E. Services

### Care or Support Services Utilized

Seven in ten mental health caregivers have turned to a health care professional for help or information about caring for their loved one (71%). Four in ten use general internet searches, while 29% go to disease-specific websites.

**Figure 17: Help and Information Sources**

Q30. Where do/did you go for help or information about caring for your [relation]'s emotional or mental health condition?



The use of mental health organizations as a source for caregiving information is fairly high (54%), though this is a result of including caregivers who were affiliated with both Mental Health America (MHA, 53%) and National Alliance on Mental Illness (NAMI, 84%), each of whom are more likely than the independent sample to turn to one of these organizations (24%). The high levels of reliance upon mental health organizations among caregivers who are affiliated with these organizations suggests that providers can and should refer caregivers to these organizations, as they have become a trusted resource among their respective memberships.

The top sources of help among the independent sample are a doctor or health care professional (74%), general internet searches (38%), and disease specific websites (23%). Approximately one in ten of the independent sample mental health caregivers use in-person (13%) and online support groups (11%), while 8% have not gotten any help (percentages not shown in Figure 17 above).

### Caregiver Education or Training

Six in ten caregivers say they have had education or training on how to care for their loved one (61%), while 39% have had no education or training. Again, the affiliated sample from MHA (68%) and NAMI (75%) are more likely to have had this type of

training. Just four in ten from the independent sample have had any kind of mental health caregiver education or training (39%).

*Caregiving in the U.S. 2015* found that caregivers of an adult with mental health issues were more likely to want help or information with managing their loved one’s challenging behaviors (24% vs. 9% of caregivers of adults without mental health issues), as well as help with managing their own emotional and physical stress (53% vs. 40% among caregivers of adults without mental health issues). Programs for caregiver education or training could focus on these areas of behavior and stress management.

When asked what they need or want for support, mental health caregivers in this study often reflect a need for training or education:

*“[I need] education on how to deal with this situation and guidance on what I can do to best help my son.”*

*“Families of people with serious mental illness need the tools to learn about what their loved ones are facing and to help them support, without enabling, their loved ones to overcome their illnesses.”*

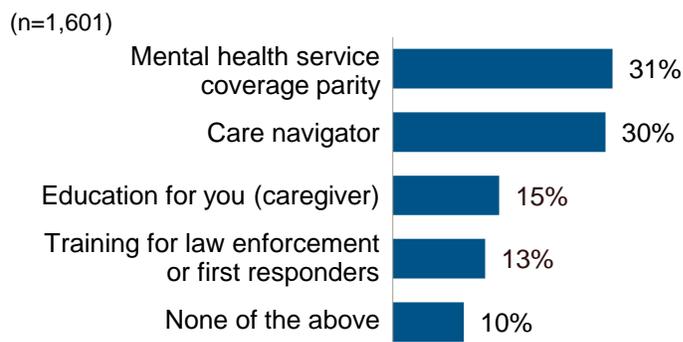
*“[I need help with] how to deal with the ups and downs of manic episodes and to help prevent or deal with violent outbursts or actions.”*

## Policy Support

The two most helpful policies accordingly to mental health caregivers involve help with accessing services and navigating the care system. Three in ten say it would be helpful to have health insurance plans to cover mental illness at similar levels as they cover medical care (31%), while 30% would most prefer a care navigator to help figure out the mental health care system and service providers.

**Figure 18: Most Helpful Policies or Programs to Caregiver**

Q52. Which of the following policies or programs would be/have been most helpful to you as a caregiver?



Despite recent legislation such as the Patient Protection and Affordable Care Act of 2010, caregivers still perceive mental health service coverage parity to be lacking. Further research is needed to determine why and how caregivers experience coverage issues related to mental and behavioral health services for their loved ones. Possible explanations could include that: care recipients are not insured, recipients are insured but through non-parity legislated plans<sup>31</sup>, caregivers and/or care recipients do not understand the level of coverage in their insurance plans, or caregivers want greater service access rather than coverage equity.

As might be expected due to their lesser amounts of prior training and education, the independent sample is more likely to want mental health caregiver education (25% vs. 10% of the combined MHA and NAMI samples), demonstrating that continued outreach and support by these kinds of organizations to mental health caregivers is key.

In addition, *Caregiving in the U.S. 2015* found that caregivers of an adult with mental health issues found two policy supports especially appealing, more so than caregivers of adults without mental health issues. Caregivers of those with mental health issues were especially likely to want respite services (39%) and discussions with providers about their needs for their own self-care (34%).

Mental health caregivers often mention care system navigation as a way to better help their loved one:

*“Navigating the system to get ALL the services needed for a mentally ill family member is a difficult process. A very disjointed system that needs to be improved! It is sad that caregivers need to learn as they go -if they even can navigate it to begin with!”*

*“[I need a] case manager who organizes and oversees my daughter's mental health care with collaboration with her other medical providers.”*

*“I need help navigating thru the mental health system, especially for a daughter who refuses services.”*

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<sup>31</sup> “PPACA expands the reach of federal mental health parity requirements to three main types of health plans: qualified health plans as established by the ACA; Medicaid non-managed care benchmark and benchmark-equivalent plans; and plans offered through the individual market.” Sarata, Amanda K. “Mental Health Parity and the Patient Protection and Affordable Care Act of 2010”. Congressional Research Office. December 28, 2011. <http://www.ncsl.org/documents/health/MHparity&mandates.pdf>

### Services Utilized and Needed by Care Recipient

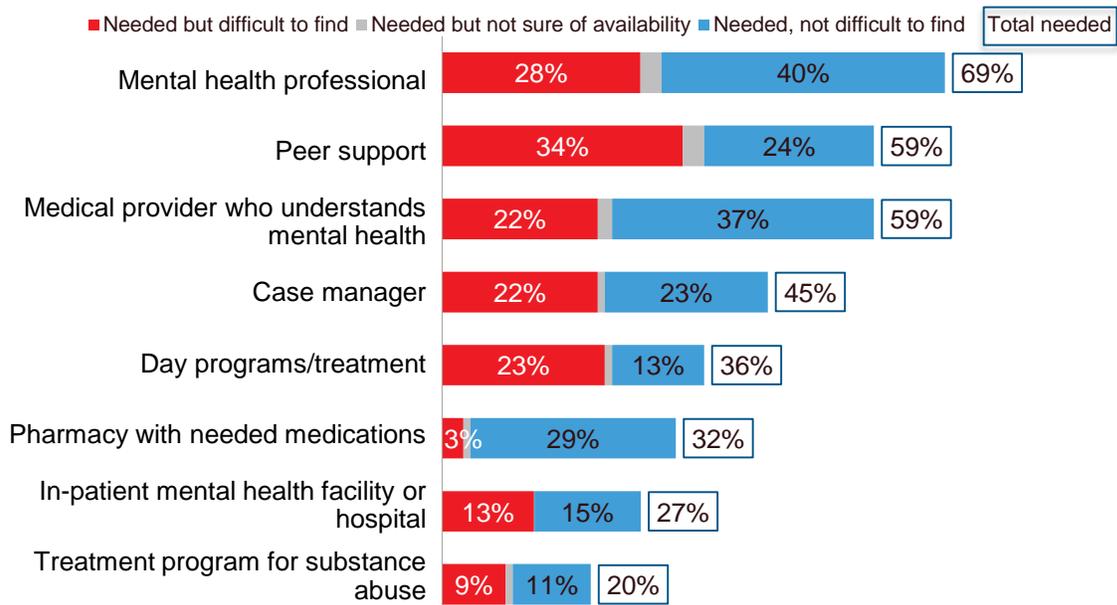
Almost seven in ten say their loved one needs a mental health professional (69%), while six in ten feel their care recipient needs peer support (59%) or a medical provider who understands his/her mental health issues (59%). About half feel their loved one needs a case manager (45%). One in three report their care recipient needs day programs or treatment (36%) and a pharmacy that has needed medications (32%). Fewer say the adult they care for needs in-patient treatment (27%) or substance abuse treatment (20%).

However, mental health caregivers indicate there are some gaps in care or support services that their loved one needs in his/her area or community. Among all mental health caregivers, one in three indicate that peer support programs are needed but difficult to find (34%). Over one in four indicate it is difficult to find a mental health professional in their care recipient’s area or community (28%).

**Figure 19: Service Needs and Availability**

Q34. Select any care or support services you feel your [relation] needs/needed. /  
 Q35. Which have been/were difficult to find in his/her area or community?

(n=1,601)



Among those who do need it, access to a variety of treatment and support services is problematic, with nearly two out of three who would need day treatment or programs reporting they are difficult to find (64%). Over half of those who want peer support for their loved one have difficulty finding it (58%), while about half have trouble finding case managers, in-patient treatment, and substance abuse treatment.

**Figure 20: Most Difficult to Find Services**

Service needed	% Difficult to Find <i>Among those who need it</i>
Day programs/treatment	64%
Peer support	58%
Case manager	49%
In-patient treatment	48%
Treatment for substance abuse	45%
Mental health professional	41%
Medical provider who understands mental health issues	37%

Caregivers often express the difficulty in finding adequate services for their loved one’s mental health care, with descriptions of their difficulties verging on despair:

*“[I need] services for caregivers that respect the privacy and autonomy of those cared for.”*

*“[I need] health care services and rehab facilities that [have] qualified and committed clinicians caring for the patients. My daughter has spent time in insurance-approved holding facilities where there were no qualified clinician[s] overseeing what was being done for my daughter or anyone else for that matter.”*

*“I’ve found very few resources especially in my county for my daughter. It is virtually impossible to find the correct type of therapy she needs and it is not covered by her medical insurance.”*

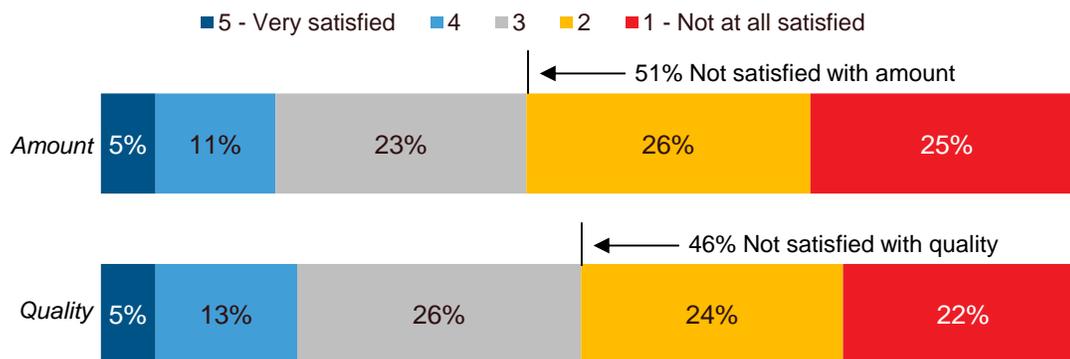
## Service Satisfaction

Reflecting the difficulty mental health caregivers report in finding care or support services in their care recipient’s community, very few are satisfied with the amount (16%) or quality (18%) of mental health services in their loved one’s area. About half are not satisfied with the amount (51%) or quality (46%)<sup>32</sup>.

**Figure 21: Amount and Quality of Community Services**

Q36a. How satisfied are/were you with the amount... / Q36b. How satisfied are/were you with the quality...  
...of community services for people with mental health issues in your [relation]’s area?

(n=1,601)



As mentioned prior, mental health caregivers whose loved one lives in a rural area are especially likely to have an issue with the amount (11% satisfied vs. 17% non-rural) and quality (13% satisfied vs. 19% non-rural) of community mental health services.

When looking at the combination of these two aspects of services, four in ten caregivers are unhappy about both amount and quality of services available.

**Figure 22: Satisfaction with Amount and Quality of Services Combined**

	% of Caregivers (n=1,601)
Not satisfied with Amount and Quality	40%
Not satisfied with Amount, but satisfied with Quality	2%
Satisfied with Amount, but not Quality	1%
Satisfied with both Amount and Quality	11%

<sup>32</sup> *Caregiving in the U.S. 2015* also found service access to be an issue among caregivers of those with mental health issues, with 31% reporting it was difficult to find affordable services in their loved one’s area, more than the 23% of caregivers who found service access difficult when caring for an adult without emotional or mental health issues.

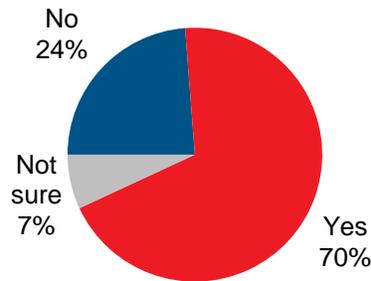
## Hospitalization

Seven in ten caregivers report that their loved one has ever gone to an emergency room, hospital, or other facility due to an urgent or crisis mental health situation (70%). Among those who report their loved one has gone to a facility in crisis, 70% feel their loved one was sent home too early or quickly.

**Figure 23: Early Discharge in Crisis Situation**

Q38. Of all the times your [relation] went to an emergency room, hospital, or other facility due to an urgent mental health issue, do you feel he/she was ever sent home too early or too quickly?

Caregivers whose recipient had crisis visit (n=1,256)



This means that among all mental health caregivers, 49% say their loved one has gone to a facility in a mental health crisis situation, only to be discharged too soon.

## F. Care Recipient Vulnerability

### Managing Paperwork and Finances

Navigating the healthcare system in the United States is often difficult, but the patchwork and disparate mental health system can require caregivers to actively manage the “business of care.” Eight in ten mental health caregivers help their loved one manage his or her finances or paperwork, helping with forms, bills, payments, or health insurance (82%). Of those who assist with this, 44% find it time consuming.

**Figure 24: Time Spent Managing Paperwork or Finances**

Q41. How time consuming is/was it for you to help your [relation] with his/her care paperwork or finances?

Those who manage recipient’s finances (n=1,361)



Those who help their loved one with paperwork or finances are more likely to say a care navigator would be most helpful in their role as a caregiver (32% vs. 24% of those who do not help with the business of care).

This supports findings from *Caregiving in the U.S. 2015* that found that caregivers of an adult with emotional or mental health issues more often help their loved one manage his or her finances (63%), more so than caregivers of adults without mental illness (51%).

### Financial Dependence

Half of mental health caregivers say their care recipient is financially dependent (completely or significantly) on family or friends (49% rating 4 or 5 on a 5-point scale).

**Figure 25: Care Recipient’s Financial Dependence**

Q43. How financially dependent is/was your [relation] on his/her family or friends?

(n=1,601)



Those whose recipient has a serious emotional or mental health issue is more often financially dependent (58% vs. 39% moderate). This reliance of the care recipient on family and friends for financial support may create financial difficulties for the caregiver. Caregivers of those with mental illness more often report feeling high levels of financial strain, more so than caregivers who provide care to an adult without mental health issues<sup>33</sup>.

Issues of financial dependence and issues in securing financial assistance are often top of mind among mental health caregivers, as they attempt to navigate the complex care system with limited resources:

*“We have always found support for our daughter but it isn't always covered by insurance. This is an expensive journey. We feel lucky but financially stressed. I lost my job in December and my husband's insurance that we have now is really awful. I do wish there was an patient navigator who could help us understand more about Medicaid options...Social Security benefits...living options, creating wills and estate and trust planning to support her properly when we can't...”*

<sup>33</sup> One in four caregivers of an adult with mental health issues report feeling high financial strain as a result of caregiving (25% rating 4 or 5 on a 5-point scale), as compared to 16% of caregivers caring for an adult without mental health issues. *Caregiving in the U.S. 2015*

*“Having him able to qualify for supplemental security income so that his care is not entirely financed by me.”*

*“More financial assistance and caregiver help. I was it and other children in the family did not help.”*

### Arrest

Almost one in three mental health caregivers report that their loved one has been arrested (32%). Caregivers of certain groups of care recipients more often report their loved one having been arrested. This includes caregivers of those with substance abuse issues (59% vs. 20% no substance abuse), caregivers of those with schizophrenia or bipolar disorder (43% vs. 15% of those with depression or anxiety), and those caring for males (45% vs. 19% female).

### Homelessness

One in five caregivers say their care recipient has been homeless for a month or longer (21%). Caregivers of certain groups of care recipients more often report their loved one having been homeless, like caregivers of those with substance abuse issues (38% vs. 12% no substance abuse), caregivers of those with schizophrenia or bipolar disorder (28% vs. 11% of those with depression or anxiety), and those caring for males (25% vs. 16% female).

### Recipient Self-Harm and other Concerns

Two-thirds of mental health caregivers are concerned that their loved one would attempt to die by suicide (65%). Those caring for someone with a serious mental health issue are more likely to be concerned about suicide (73% vs. 53% moderate), as are those caring for someone with a substance abuse issue (79% vs. 58% no substance abuse). The younger the care recipient, the more often the caregiver is concerned about suicide.

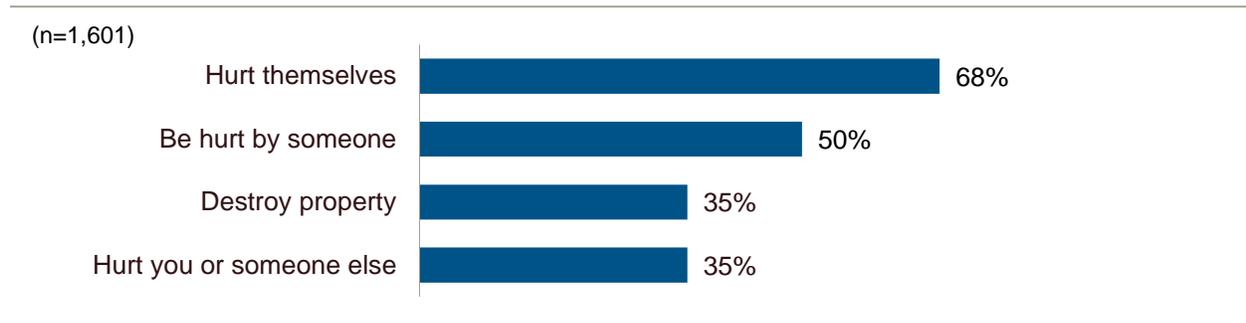
**Figure 26: Concern about Suicide by Care Recipient Age**

	Age of Care Recipient			
	18-34 (n=744) A	35-49 (n=382) B	50-64 (n=265) C	65 and older (n=210) D
Caregiver concerned about suicide	81% <sup>BCD</sup>	71% <sup>CD</sup>	55% <sup>D</sup>	40%

Similarly, 68% fear their loved one will hurt themselves. Another major concern among mental health caregivers is victimization – that their loved one will be hurt by someone else (50%). Fewer caregivers express concern over their loved one destroying property or hurting another person.

**Figure 27: Caregiver Concerns**

Q53. Have you ever been concerned that your [relation] would do any of the following?



As with concerns about suicide, caregivers of younger recipients, of those with a substance abuse issue, and of those with a serious condition each are more likely to show concern about both self-harm and victimization.

Mental health caregivers whose recipient has a history of arrest are more often concerned about both victimization (70% vs. 41% no history of arrest) and self-harm (74% vs. 66%). Likewise, caregivers of a loved one who has ever been homeless for a period of a month or longer show greater concern about victimization (69% vs. 45% no history of homelessness) and self-harm (77% vs. 66%).

### Legal Responsibility and Needs

One in three caregivers has some type of legal responsibility for their recipient, such as guardianship or power of attorney (33%). About four in ten would like more information or help about legal issues (38%).

Only about one in three caregivers have plans in place for their recipient’s care if something should happen to make them unable to provide care (35%). In fact, *Caregiving in the U.S. 2015* suggests that the lack of future planning is especially common when an adult care recipient has emotional or mental health issues. Just 36% of caregivers of an adult with mental health issues report their loved one has plans in place for his or her own future care, including things like financial matters, healthcare decisions, and living arrangements; compared to 49% of caregivers of recipients without mental health issues who report their loved one has plans in place.

Many mental health caregivers express concern about the future and the care of their loved one:

*“I also worry what will happen when I die, who will help him and watch out for him.”*

*“My worst fear is that if something happens to myself or to my husband, that our son will just give up and wait to die. I would like to move to be near family...But this is impossible as my son is so severely anxious.”*

An alarming picture arises when you look at the lack of plans in place among caregivers of adult children. Nearly two out of three indicate that their son or daughter is financially dependent on family and friends. However, only half that have plans in place for their recipient’s care (32%) or have a current legal arrangement in place (31%).

**Figure 28: Financial and Legal Responsibility by Relationship**

	Caregiver Relation			
	Adult Child (n=984) A	Spouse/ Partner (n=144) B	Other Relative (n=356) C	Non-Relative (n=85) D
Recipient is Financially Dependent (4 or 5)	64% <sup>BCD</sup>	42%	36%	35%
Has legal responsibility	31% <sup>D</sup>	38% <sup>D</sup>	40% <sup>AD</sup>	13%
Has plans in place	32%	26%	40% <sup>AB</sup>	43% <sup>B</sup>
Wants more help on legal issues	43% <sup>BC</sup>	19%	35% <sup>B</sup>	44% <sup>B</sup>

**Profile of Caregivers of Adult Children without Care Plans**

- These parents caring for an adult son or daughter without any care plans in place are especially vulnerable. They are 60 years old and have been providing care for 29 hours a week for 14 years, on average.
- They are often the sole unpaid support, without whom their adult child would be reliant on the service system alone. Over half report having no other unpaid help (55%) and just 35% report their son or daughter can rely on other loved one’s to provide care.
- More than one in three would like a care navigator (36%) to help them and their child manage the mental health care system.
- This is often a solitary role – 56% feel alone – and it takes its toll on the caregiver, with 84% who report high emotional stress and 62% who say their caregiving role has made their health worse.

## G. Caregiver Vulnerability

### Presence of Other Caregivers

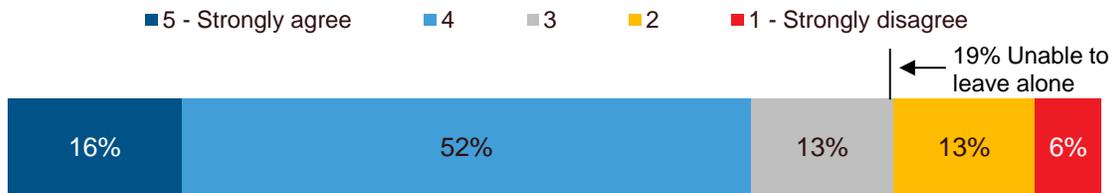
Half of mental health caregivers report that their loved one gets help from others (52%), while 48% are the sole unpaid caregiver, comparable to levels seen among all caregivers nationally<sup>34</sup>.

One in five report being unable to leave their loved one alone (19%), although most are comfortable leaving their care recipient alone (68%).

**Figure 29: Ability to Leave Care Recipient Alone**

Q29a. How much do you agree or disagree with: I am/was able to leave my [relation] alone

(n=1,601)



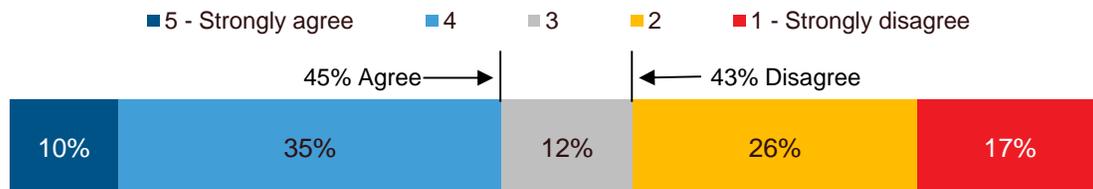
Those caregivers who have the assistance of other unpaid helpers are more likely to feel they can *not* leave their loved one alone (22% vs. 16% of sole caregivers), implying that having other people help with care may arise out of the need to keep someone with the recipient at all times.

Mental health caregivers are torn on the sentiment of whether or not their care recipient can rely on other friends and family to help him or her – 45% feel there are others available to help, while 43% feel there are not.

**Figure 30: Ability of Care Recipient to Rely on Others**

Q29b. How much do you agree with: My loved one can rely on other friends or family to help him/her

(n=1,601)



Caregivers who have the assistance from other unpaid helpers are more likely to say their loved one can rely on friends and family for help (60% agree), compared to sole

<sup>34</sup> Among all U.S. caregivers, 53% report the presence of other unpaid help. *Caregiving in the U.S. 2015*

caregivers (29%). However, those caring for someone with a serious mental health issue are less likely to agree that their loved one can rely on friends and family (37%), less so than those caring for someone with a moderate issue (56%).

Caregivers of an adult with mental health issues often feel they had no choice in taking on their role as caregiver (56%), more so than caregivers of adults without mental health issues (48%)<sup>35</sup>.

The pressure of feeling like there is no relief or that there is no one else to turn to is a common theme among mental health caregivers:

*“Something in place to give caregivers a break, a service to come in for a day or two to help, paid for by insurance.”*

*“Having a safe place I can leave her once a week or even once a month so I can go and have time for me.”*

*“[I need] help from others in the day to day care.”*

*“[I need] other people to step in and help. I felt like it was my entire responsibility before he went to an inpatient rehab program, and I was stressed and felt alone.”*

### Mental Health Stigma

Caregivers of an adult with a mental or emotional illness may face stigma surrounding their loved one’s illness. Nearly half of caregivers report that they find it difficult to talk with others about their recipient’s mental or emotional health issues (48% agree).

**Figure 31: Mental Health Stigma**

Q29c. How much do you agree or disagree with: It is/was difficult to speak with others about my [relation]’s mental or emotional health issues

(n=1,601)



<sup>35</sup> Caregiving in the U.S. 2015

Caregivers of a spouse/partner find it especially difficult to speak with others about their loved one’s mental or emotional health issues (63%), more so than all other mental health caregivers (47%).

Again, many caregivers mention the impact of stigma on both their loved one and themselves:

*“Education for the general population that would help remove the stigma of having a mental illness and would help people see that it is indeed an illness and not something the person is doing to get attention or is the result of a personal weakness.”*

*“Getting rid of the stigma associated with mental health in the work place, it has constantly been the reason my mother stops taking medication.”*

*“General education for people who don't know about caring for a sick relative, so that conversations about what I do and why might be less uncomfortable when they occur.”*

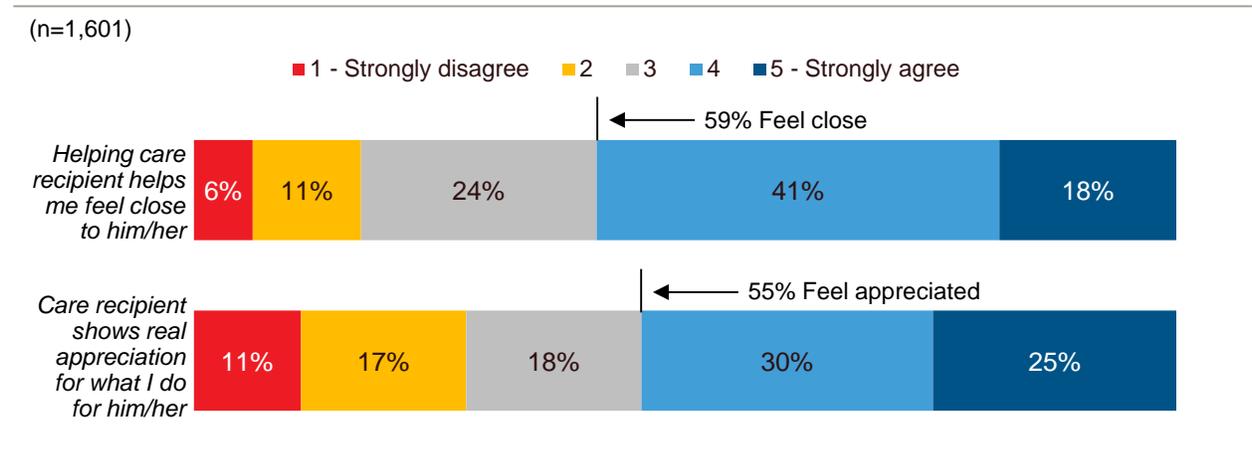
*“[I would like] to have less stigma. If my son was sick in a physical way, friends and family would ask "how is he". People who knew about his illness, never asked.”*

### Impact on Caregiver-Recipient Relationship

Caregivers do report positive aspects of caregiving. The majority of mental health caregivers report feeling closer to their recipient as a result of providing care for him/her (59% agree), while more than half feel that their loved one is appreciative of the care they give (55% agree).

**Figure 32: Appreciation of and Closeness with Care Recipient**

Q49. As a caregiver, how much do you agree or disagree with each statement?



## Caregiver Work

*Caregiving in the U.S. 2015* found that most caregivers of an adult with an emotional or mental health issue were employed while caregiving (62%), for an average of 35.5 hours per week<sup>36</sup>. Half of these caregivers report their supervisor knew they were providing care to a loved one (50%)<sup>37</sup>.

Among mental health caregivers who work in the *Caregiving in the U.S. 2015* study, 50% report they went in late, left early, or took time off from work to provide care<sup>38</sup>. Caregivers of an adult with mental illness were more likely to report receiving a warning about performance or attendance (15%) and to report giving up work entirely (10%)<sup>39</sup>. Workplace accommodations could help caregivers juggle competing demands of providing care and working. However, only 44% of working mental health caregivers reported having flexible work hours, less so than caregivers of an adult without mental health issues (55%)<sup>40</sup>.

The caregivers from *On Pins and Needles: Caregivers of Adults with Mental Illness* also reflect their concerns about work and their ability to juggle caregiving responsibilities:

*“Currently I have to take time off work and drive more than 50 miles to his mental health care provider, because the one in our town was closed.”*

*“[I need an] employment opportunity that could handle the bad days.”*

*“I am lucky that my employer is flexible when it comes to doctor’s appointments and therapy visits. I wish other people in my situation had understanding supervisors/co-workers/bosses.”*

## Caregiver Stress

Three out of four mental health caregivers say that providing care for their loved one has been emotionally stressful for them (74%, Figure 33 next page). Similarly, in *Caregiving in the U.S. 2015*, those caring for an adult with an emotional or mental

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<sup>36</sup> Concurrent employment is defined as being employed at any time in the year prior to survey while also providing care to the loved one. *Caregiving in the U.S. 2015*

<sup>37</sup> *Caregiving in the U.S. 2015*

<sup>38</sup> Comparable to the 48% of caregivers of an adult without mental health issues who went in late, left early, or took time off from work. *Caregiving in the U.S. 2015*

<sup>39</sup> 15% reported they got a warning about their performance or attendance at work, compared to just 4% of working caregivers who care for someone without mental health issues. 10% report they gave up work entirely, compared to just 5% of working caregivers who care for someone without mental health issues. *Caregiving in the U.S. 2015*

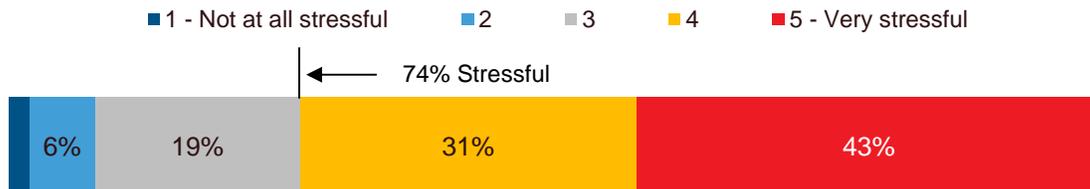
<sup>40</sup> *Caregiving in the U.S. 2015*

health issue report feeling high emotional stress (53%), more so than caregivers of an adult without mental health issues (34%). They also report high levels of physical strain<sup>41</sup>.

**Figure 33: Caregiver Emotional Stress**

Q47. How emotionally stressful would you say that caring for your [relation] is/was for you?

(n=1,601)

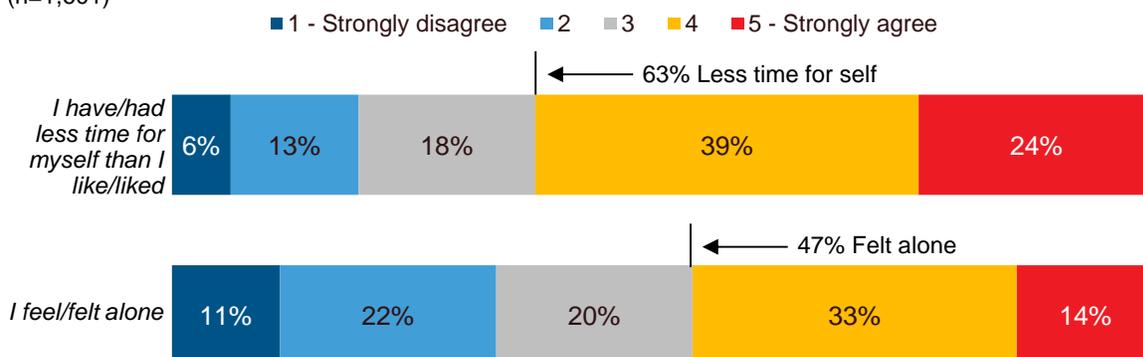


Nearly two in three indicate that caregiving has given them less time for themselves (63% agree). Nearly half say that caregiving makes them feel alone (47% agree).

**Figure 34: Time for Self and Feeling Alone**

Q49. As a caregiver, how much do you agree or disagree with each statement?

(n=1,601)



The high levels of emotional stress may be in part due to the lack of time caregivers have for themselves or as a result of feeling alone. Nearly nine in ten caregivers who report having less self-time also report high emotional stress (86%), compared to 37% of those who disagree with the statement “I have less time for myself than I like.” Similarly, 88% of those who feel alone report high emotional stress (compared to just 54% of those who do not feel alone).

<sup>41</sup> One in four (25%) of caregivers of adults with an emotional or mental health issue reported high physical strain (rating 4 or 5 on 5-point scale), compared to 18% of caregivers of adults who do not have an emotional or mental health issue. *Caregiving in the U.S. 2015*

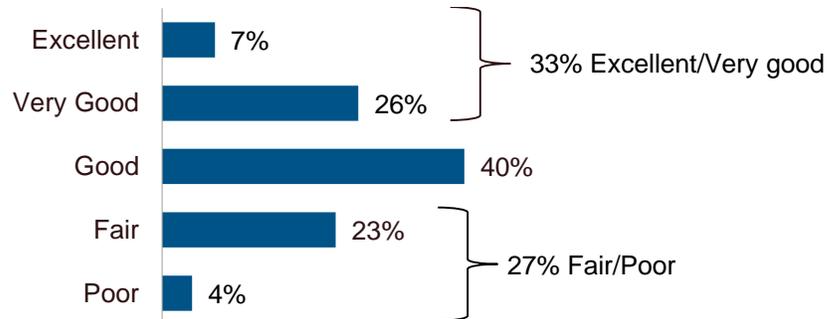
## Caregiver Health

Emotional stress and not having enough time for oneself can lead to impacts on caregiver’s physical health. Just one in three mental health caregivers describe their health as excellent or very good, while 27% say it is fair or poor.

**Figure 35: Caregiver Health**

Q50. How would you describe your health?/When you were last caregiving, was your health...?

(n=1,601)



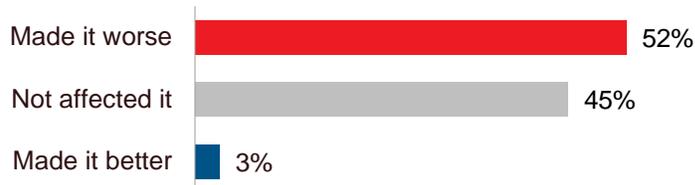
Mental health caregivers fare worse in terms of their own health than U.S. caregivers in general – 48% of whom rate their health as excellent or very good and 17% of whom rate it fair or poor<sup>42</sup>.

In fact, 52% of mental health caregivers feel their role has made their own health worse. This is in contrast to the 22% of all U.S. caregivers who feel caregiving has made their health worse<sup>43</sup>.

**Figure 36: Impact of Caregiving on Caregiver’s Health**

Q51. How would you say taking care of your [relation] has affected your health?

(n=1,601)



<sup>42</sup> Caregiving in the U.S. 2015

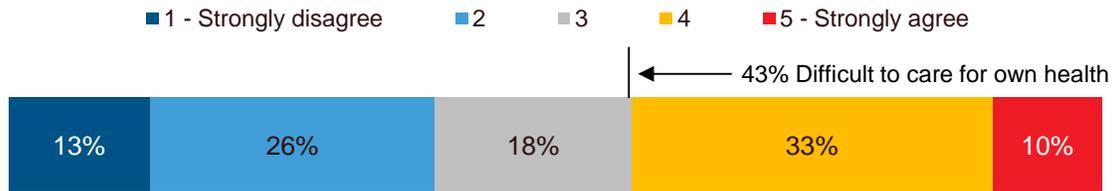
<sup>43</sup> Caregiving in the U.S. 2015

More than four in ten caregivers feel their role makes it difficult to take care of their own health (43%).

**Figure 37: Caregiver Difficulty Caring for own Health**

Q49d. As a caregiver, how much do you agree or disagree with: I find/found it difficult to take care of my own health

(n=1,601)



As might be expected, mental health caregivers who say it is difficult to care for their own health more often report that caregiving made their health worse and that their health is fair or poor.

**Figure 38: Health Status and Impact on Health by Difficulty Caring for Health**

	Difficult to care for own health (n=685) A	Not difficult to care for own health (n=610) B
Health is fair or poor	45% <sup>B</sup>	8%
Made health worse	78% <sup>B</sup>	27%

The impact that caregiving has had on their own health and stress levels is a common theme among mental health caregivers:

*“A lot of my life seems to have been put on hold for the last 8 years; I don’t get to the gym for routine exercise, it’s been more important for many years to be home outside of work hours.”*

*“I would really like someone to bring me a casserole...Casseroles seem to be reserved for people with heart problems, cancer, and accidents, yet these problems are either resolved or the person dies, bringing closure to the medical crisis. With mental illness, it never goes away and in our case has never gotten any better.”*

*“No matter how good things are you are always on pins and needles...You worry about a possible relapse, you worry about him not being able to get his medication on time, you worry he will stop taking his meds, you worry he will go back to drinking, smoking and doing drugs, you worry about him getting uncontrollably angry.”*

## H. Policy Recommendations

With these unique challenges facing mental health caregivers, we recommend 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 issues with that of medical health issues. This may include providing education for providers, caregivers, and patients about state and federal parity laws and what health care benefits 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, vocational, educational, and peer supports.
- Ensure patient access and reimbursement for appropriate medications to treat mental illness, including access to a full-range of medication and coverage for prescribed medications that work for an individual without overly-restrictive "fail first" policies.
- Provide assistance for 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 patients and their families.
- Include caregivers as part of the health care team, in ways that allow them to understand their loved one's diagnosis without limiting the patient's independence. Policies and practice should fully include individuals, families, providers, and supports (such as the Open Dialogue model).
- Educate and provide resources for caregivers of those with mental illness, 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 in caring for a loved one with mental illness.
- Work to reduce the stigma of mental illness through public awareness campaigns. Individuals with mental illness and their families continue to feel isolated, which prevents them from reaching out to find resources and supports.

## I. Respondent Profile

Mental health caregivers are typically female and 54.3 years old, on average. The comparison of the samples shows wide variation in both the profile of mental health caregivers and the profile of organizations memberships. The independent sample has greater proportions of male, younger, and racially/ethnically diverse caregivers, suggesting that these groups could benefit from greater outreach.

**Figure 39: Respondent Profile**

	Total (n=1,601)	Research Now (n=253) A	MHA (n=207) B	NAMI (n=1,141) C
<b>Caregiver Gender</b>				
Male	20%	33% <sup>BC</sup>	12%	16%
Female	80	67	88 <sup>A</sup>	84 <sup>A</sup>
<b>Age of Caregiver</b>				
18 to 34	12%	23% <sup>BC</sup>	11% <sup>C</sup>	2%
35 to 44	10	16 <sup>BC</sup>	10 <sup>C</sup>	4
45 to 54	22	21	23	21
55 to 64	32	19	35 <sup>A</sup>	41 <sup>A</sup>
65 to 74	21	16	20	26 <sup>A</sup>
75 or older	4	5 <sup>B</sup>	1	6 <sup>B</sup>
<i>Mean age</i>	<i>54.3</i>	<i>49.5</i>	<i>53.9<sup>A</sup></i>	<i>59.5<sup>AB</sup></i>
<b>Race of Caregiver</b>				
White	84%	70%	89% <sup>A</sup>	94% <sup>A</sup>
African American	9%	17% <sup>BC</sup>	7%	3%
Asian American	5%	12% <sup>BC</sup>	1%	2%
Native American	3%	5% <sup>C</sup>	3%	2%
Other	2%	1%	3%	1%
<b>Hispanic</b>				
Yes	6%	9% <sup>BC</sup>	4%	4%
No	94	91	96 <sup>A</sup>	96 <sup>A</sup>
<b>Caregiver Education</b>				
Less than high school	1%	2%	*	*
High school graduate	5	4	4%	5%
Some college	18	19	18	17
Technical school	12	14	11	11
College graduate	27	25	27	29
Graduate school	38	37	40	37

Income levels among the surveyed mental health caregivers are fairly high<sup>44</sup>. This suggest two things: 1) that the situation among mental health caregivers may be underestimated in this report, as income and education tend to allow for improved caregiving situations; and 2) better outreach may be needed among lower-income caregivers, as the majority of the surveyed caregivers came from mental health outreach organizations.

**Respondent Profile, Continued**

	Total (n=1,601)	Research Now (n=253) A	MHA (n=207) B	NAMI (n=1,141) C
<b>Children/Grandchildren in Caregiver's Household</b>				
Yes	20%	28% <sup>BC</sup>	20% <sup>C</sup>	13%
No	80	72	80 <sup>A</sup>	87 <sup>AB</sup>
<b>Care Recipient Service in Armed Forces</b>				
Yes	8%	9%	7%	6%
No	91	89	92	93 <sup>A</sup>
<b>Care Recipient Living Location</b>				
Urban/Suburban	76%	72%	76%	80% <sup>A</sup>
Rural	24	28 <sup>C</sup>	24	20
<b>Caregiver Household Income</b>				
Less than \$15,000	5%	5%	6%	4%
\$15,000 to \$29,999	10	13	8	9
\$30,000 to \$49,999	16	15	21 <sup>C</sup>	13
\$50,000 to \$74,999	22	18	23	25 <sup>A</sup>
\$75,000 to \$99,999	16	18	13	18
\$100,000 or more	30	32	29	30
<i>Median Household Income</i>	<i>\$71,400</i>	<i>\$74,100</i>	<i>\$66,800</i>	<i>\$73,700</i>

<sup>44</sup> *Caregiving in the U.S. 2015* found all caregivers of adults had a median household income of \$54,700, while caregivers of an adult with mental health issues had a median household income of \$48,900. Both of these figures are comparably lower than the current study median of \$71,400.

**National Alliance for Caregiving**

4720 Montgomery Lane  
Suite 205  
Bethesda, MD 20814  
[www.caregiving.org](http://www.caregiving.org)

**Mental Health America**

2000 N. Beauregard Street  
6th Floor  
Alexandria, VA 22311  
[www.mentalhealthamerica.net](http://www.mentalhealthamerica.net)

**National Alliance on Mental Illness**

3803 N. Fairfax Drive  
Suite 100  
Arlington, VA 22203  
[www.nami.org](http://www.nami.org)

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