

# Caregivers of Adults with Severe Mental Illness: Results of a National Study

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# About the National Alliance for Caregiving

- ➔ Non-profit coalition of over 50 national organizations focused on family caregiving issues
- ➔ Established in 1996 to support family caregivers and the professionals who work with them
- ➔ NAC Activities:
  - Conduct research and policy analysis;
  - Develop national programs;
  - Strengthen state and local coalitions;
  - Increase public awareness;
  - International work and awareness.



# About the National Alliance on Mental Illness

- ➔ NAMI (National Alliance on Mental Illness) is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness
- ➔ **We educate.** NAMI's provides education and support from trained peers
- ➔ **We listen.** NAMI's HelpLines provide free information, referral and support
- ➔ **We lead.** NAMI is a leading voice on issues that impact people living with mental health conditions and families

*On Pins &  
Needles:  
Caregivers of  
Adults with  
Mental  
Illness*

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# Advisory committee members

## This research was reviewed by an independent advisory committee:

- Richard C. Baron, MA, Director of Knowledge Translation Activities, Temple University
- Sita Diehl, MA, MSSW, Director of State Policy and Advocacy, National Alliance on Mental Illness
- Tamar Heller, Ph.D., University of Illinois at Chicago
- Karen Hirschman, Ph.D., University of Pennsylvania
- Carol Levine, Director of Families and Health Care Project, United Hospital Fund
- Victor Molinari, Ph.D., University of South Florida
- Debbie Plotnick, MSS, MLSP, Vice President for Mental Health and Systems Advocacy, Mental Health America
- Rosalyn Roker, MBA, MA, University of South Florida
- Donna Wagner, Ph.D., New Mexico State University
- Kelly Niles-Yokum, MPA, Ph.D., University of La Verne

# Methodology

- **Conducted in partnership with the National Alliance on Mental Illness and Mental Health America**
- **Quantitative online interviews with 1,601 caregivers ages 18 or older**, currently providing care or cared in the year prior
- Targeted, non-probability-based design provides an **in-depth look** at a pre-identified population
- **Findings may underestimate challenges** as respondents were typically more educated and wealthier than the general public

# Facts about mental illness

- Mental illnesses are health conditions that affect a person's:
  - Mood
  - Thinking
  - Behavioror a combination of these



- About one in five adults experience a mental health condition; one in 24 has a serious mental illness
- Mental illness can strike at nearly any age, but the majority of chronic mental illness occurs by age 24
- Mental illnesses can affect your ability to relate to others and function each day
- About one in five disability recipients (SSI/SSDI) lives with a psychotic or mood disorder

# *On Pins & Needles: The big picture*

- **8.4 million Americans** care for an adult with an emotional or mental health issue\*
- Caregivers have typically **provided care for 8.7 years**, while caregivers of an adult care for 4 years on average (any condition).
- Most care recipients (58%) are between 18-39 years; **most caregivers (45%) are parents caring for an adult child**, though other relationships can be impacted
- The main conditions requiring care are **bipolar disorder (25%), schizophrenia (25%), depression (22%), and anxiety (11%)**

\*from [Caregiving in the U.S. 2015](#), National Alliance for Caregiving and AARP Public Policy Institute



# Who are the caregivers?

- Most caregivers in sample were female (80%)
- They usually are caring for a relative (88%)
- Nearly half are caring for an adult son or daughter
  - Nearly all provide IADLs—only 18% assist with ADLs
- Most are between the ages of 45 and 64 (average age is 54.3 years old)
- 65% had a college education or more advanced degree
- 46% had a household income of \$75,000 or more
- 24% lived in rural areas

# Whom are they caring for?

- Average age of care recipient is 46.3 years old, but most are under age 40
- Almost half live in same household as caregiver (45%) or within 20 miles (27%)
- Three in ten have an alcohol or substance abuse issue
- Almost half are financially dependent on family and friends

# Characteristics of male care recipients

- Comprise 51%
- 35% had schizophrenia vs. 14% for females
- 33% have a substance abuse issue
- 45% had at least 1 arrest
- 25% had been homeless

# Characteristics of female care recipients

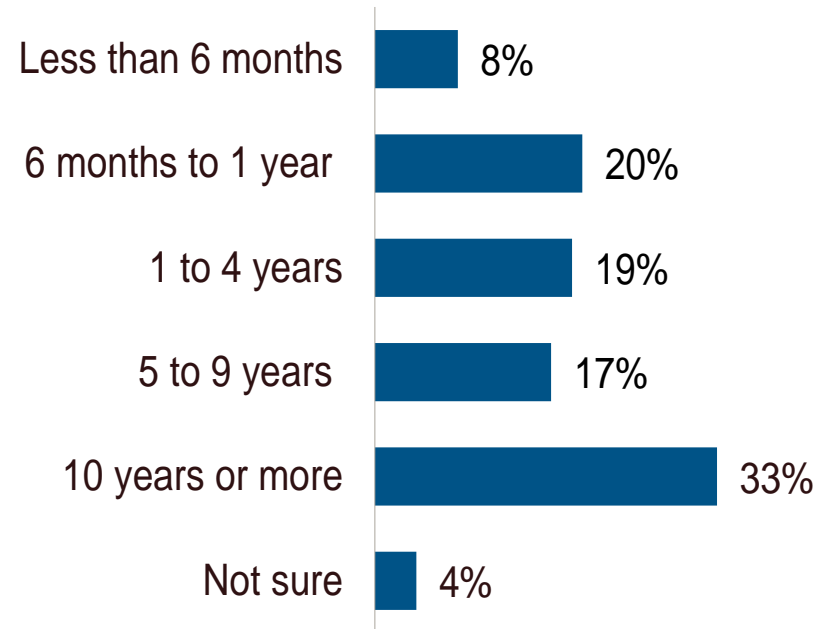
- 49% of care recipients were female
- 27% had diagnosis of depression vs. 18% of males
- 14% had diagnosis of anxiety vs. 7% of males
- 23% had a substance abuse issue
- 19% had been arrested
- 16% had been homeless

One-third of caregivers have cared for 10 years or more

## Figure 2: Duration of Care

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

(n=1,601)

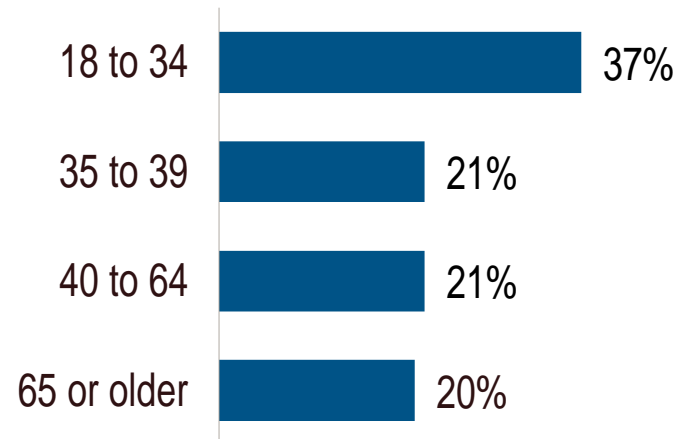


The majority of people receiving care were between 18-39 years old

## Figure 5: Care Recipient Age

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

(n=1,601)



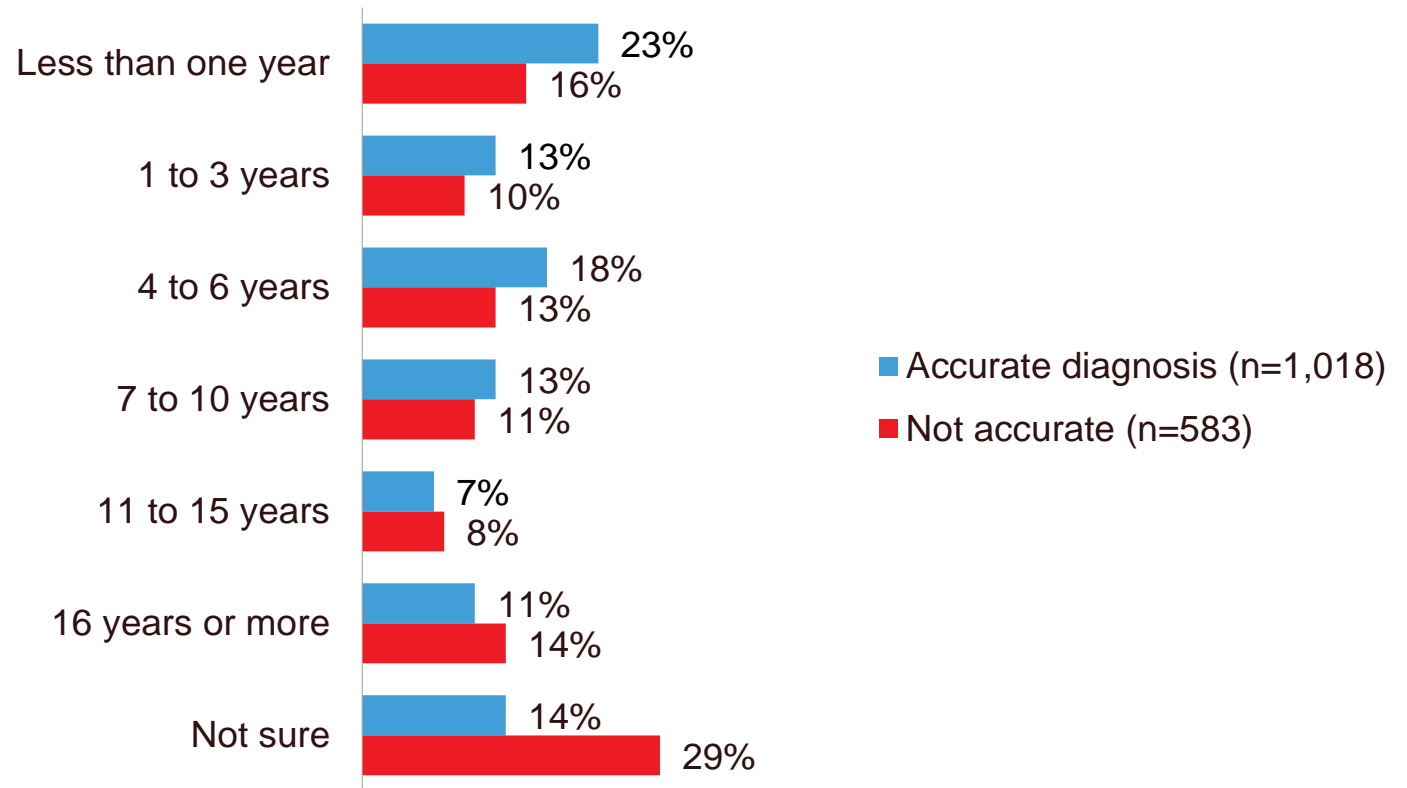
# Challenges: Time to diagnosis

-It took an average of 11.8 years to get to an accurate diagnosis

-4 in 10 caregivers feel unsure of 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?

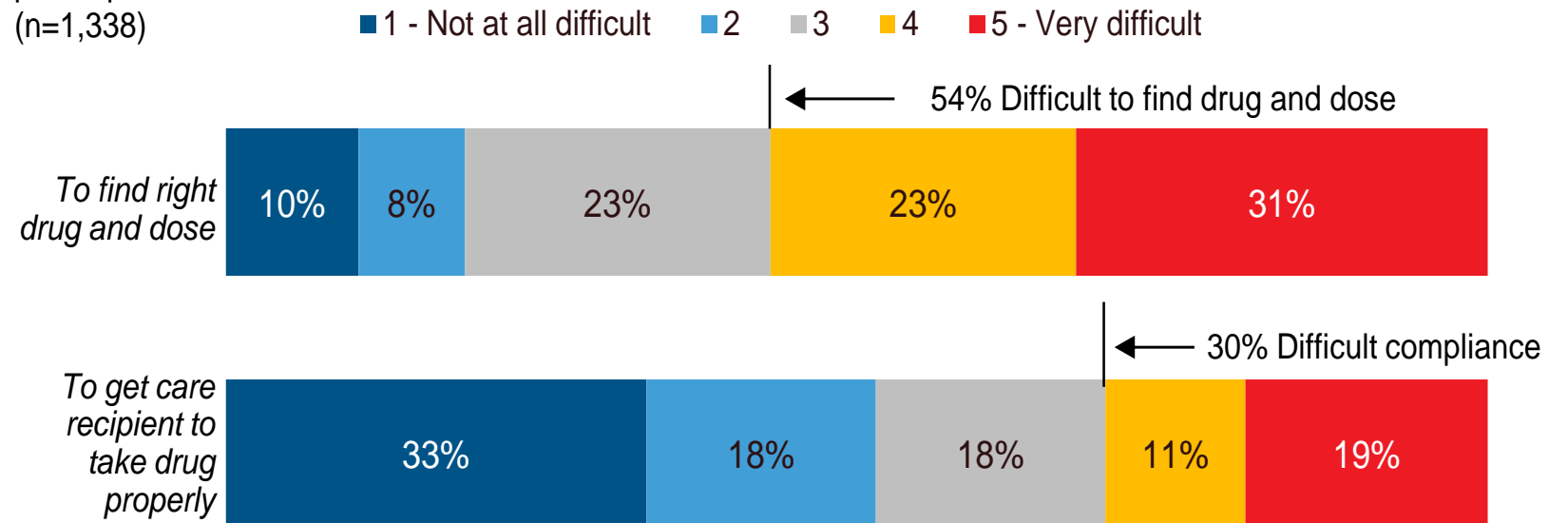


# Challenges: Managing medications

**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)





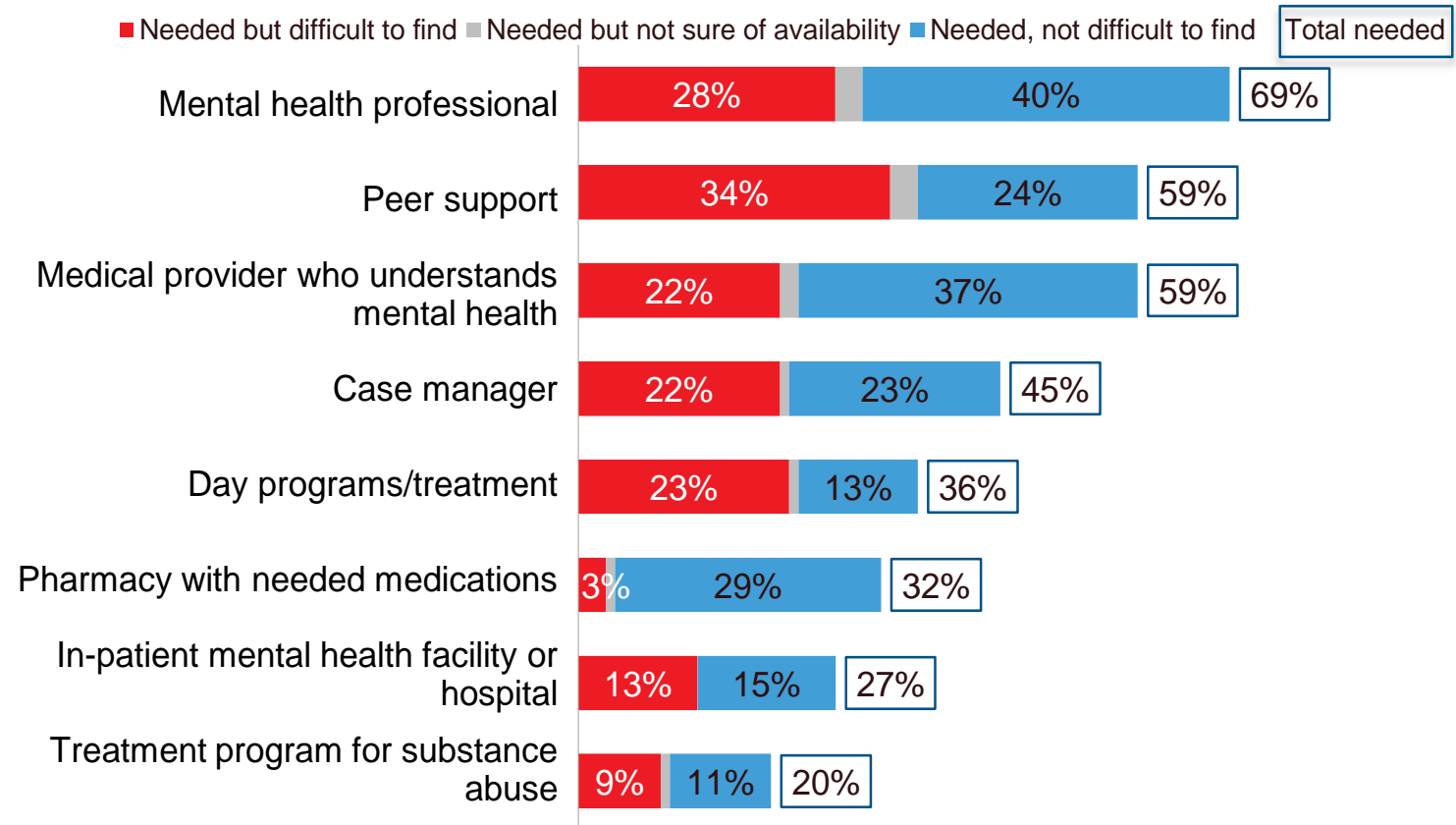
# Challenges: Access to mental health services

## 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)



# Challenges: Amount and quality of community services

**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?*



# Challenges: Arrest, homelessness and harm

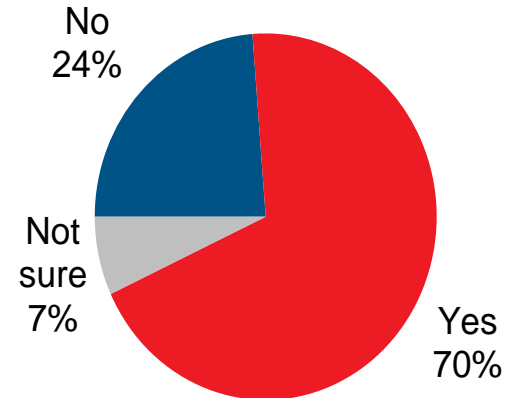
- **Arrest:** About one in three report their care recipient has been arrested (32%)
- **Homelessness:** One in five caregivers report their care recipient has been homeless for a month or longer (21%)
- **Self-Harm and Suicide:** Two-thirds of mental health caregivers are concerned their care recipient will self-harm (68%) or die by suicide (65%)
- **Victimization:** Half of caregivers are worried their care recipient will be hurt by someone else (50%)
- **Other Harm:** 35% of caregivers are concerned that their care recipient will destroy property; 35 % of caregivers are also concerned they or someone else will be hurt by their care recipient

Challenges:  
Care recipients  
often  
discharged  
“too early” or  
“too 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)

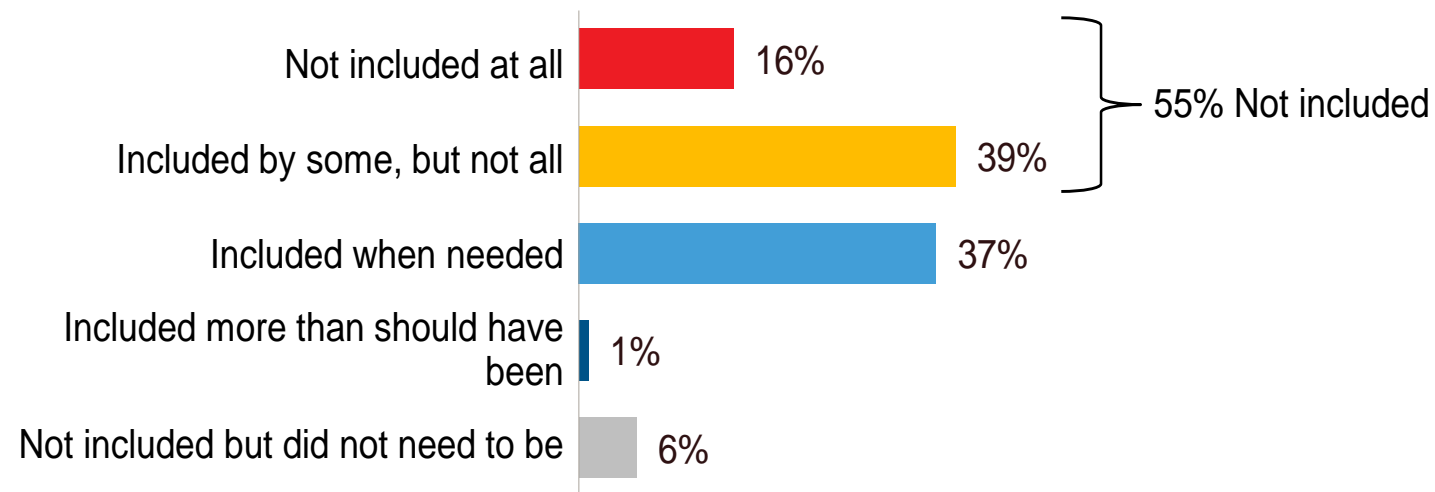


# Challenges: Exclusion from conversations with healthcare providers

**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)

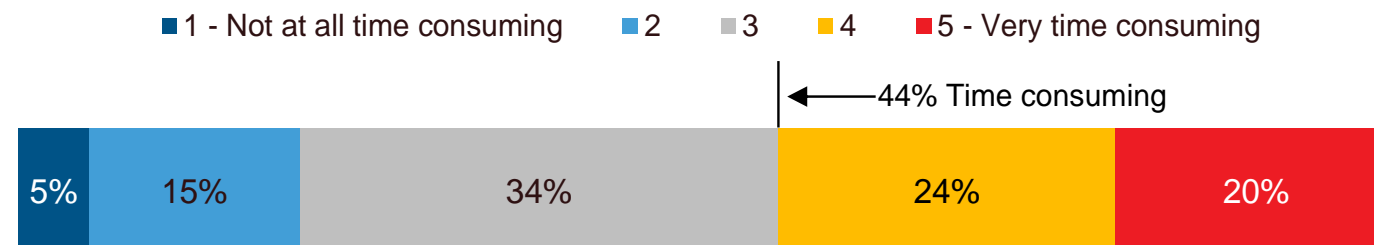


# Challenges: The “business of care”

## 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?

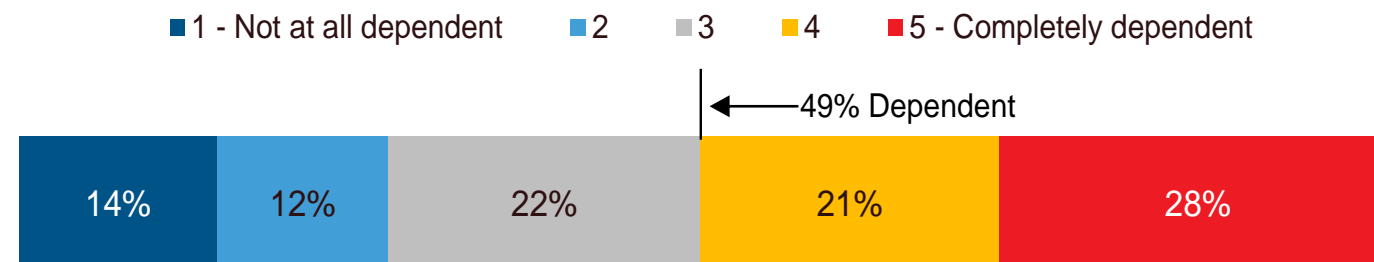
Those who manage recipient's finances  
(n=1,361)



## Figure 25: Care Recipient's Financial Dependence

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

(n=1,601)

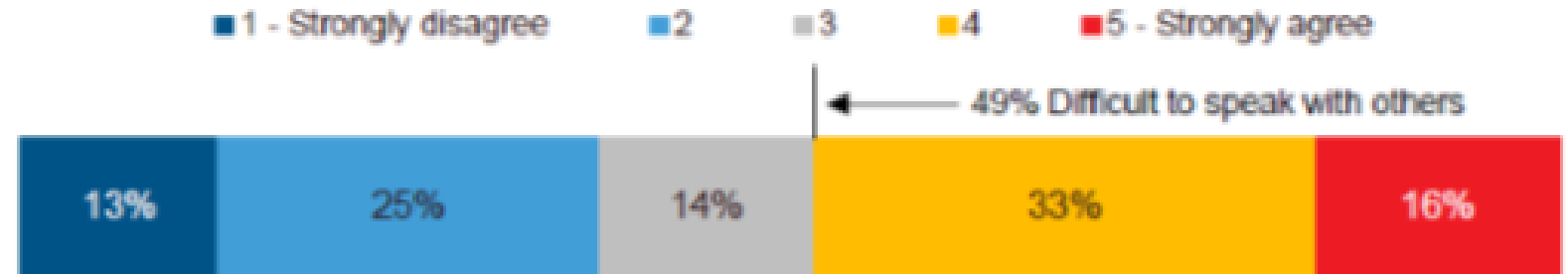


# Challenges: Stigma and caregiver emotional stress

**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?

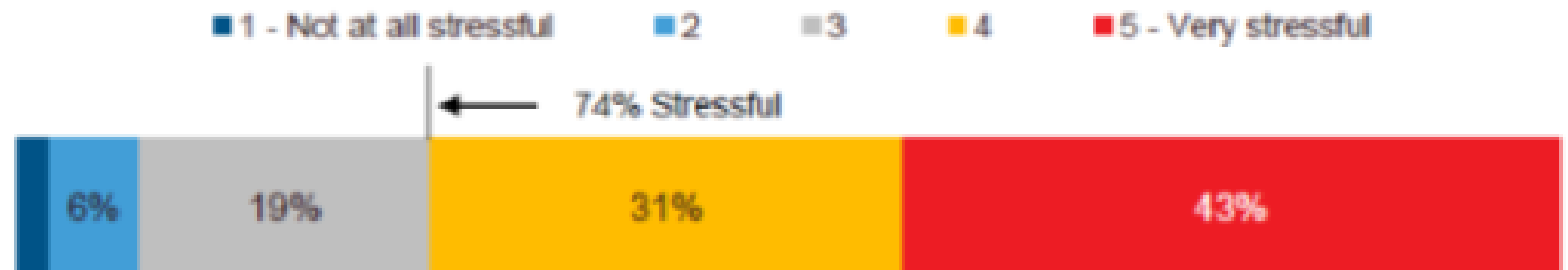
(n=1,601)



**Figure 33: Caregiver Emotional Stress**

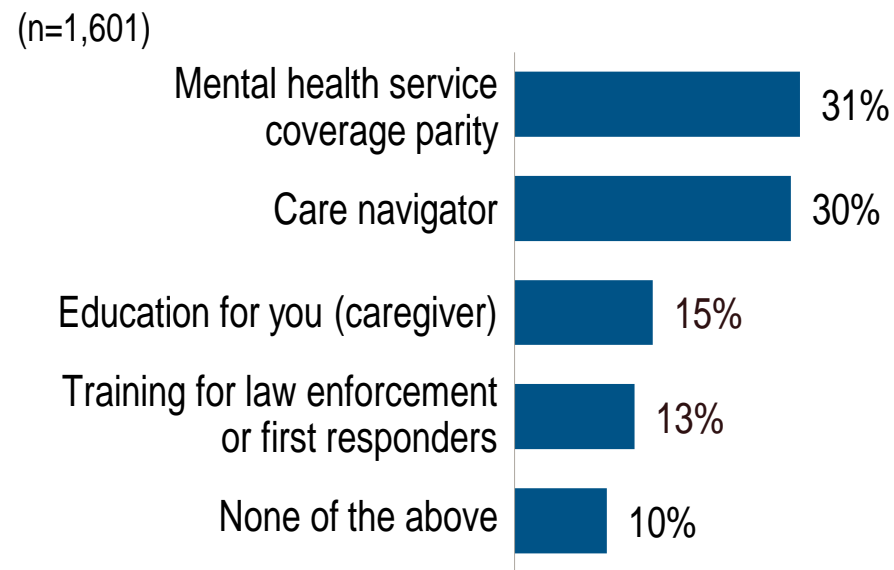
Q47. How emotionally stressful would you say that caring for your [relation]is/was for you?

(n=1,601)



# What policy solutions would best help family caregivers?

**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?*





# From the report: Public Policy Solutions

- **Screen for mental health at health care check-ups and include behavioral health questions in all health care assessments**
- **Encourage parity** for treatment of mental health conditions comparable to treatment of other health conditions
- **Provide access** to a full array of high-quality behavioral health services across the continuum of care
- **Ensure patient access and reimbursement for appropriate medications** to treat mental illness

# From the report: Public Policy Solutions

- Provide **assistance for both caregivers and patients in navigating the mental health system**
- **Include caregivers as part of the health care team**
- **Educate and provide resources** for caregivers of those with mental illness, especially around issues of stress and caregiver health
- **Work to reduce the stigma of mental illness**

# Additional solutions to support caregivers

- **Refer mental health caregivers to NAMI** or other mental health supports
- **Encourage annual mental health screening for caregivers** as a routine part of health care
- **Promote inclusion of caregivers in discharge and transition planning**
  - Ensure crisis plan is included

# Additional solutions to enhance caregiver involvement

- **Promote education of permissible communications under HIPAA**
  - HIPAA is often interpreted more rigidly than necessary
- **Promote patient signing of a release of information at multiple points in care.**  
**A release:**
  - *Never* includes psychotherapy notes
  - Can specify or limit what information is shared with a caregiver
- **Promote use of psychiatric advance directives (PADs)**

Public policy  
solution:  
Promote  
collaboration  
on caregiver  
support

- **Bring state and local aging and disability agencies together with community mental health and Medicaid agencies**
  - Most mental health services are funded through Medicaid
  - Medicaid and community mental health are often unfamiliar with caregiver support
  - Collaborate on ways to support caregivers
  - Explore Medicaid waivers to support people with mental illness and caregivers

Public policy  
solution:  
*National  
Mental Health  
Family  
Caregiver  
Support Act  
(not yet filed)*

**Ask Congress to support a National Mental Health Family Caregiver Support Program to provide:**

- **Information** on mental health services, support and coverage;
- **Navigation and assistance** to access services and supports;
- **Education** for family caregivers and peer-led **support groups**; and
- **Respite care and supplemental services.**

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Report available at:  
[www.caregiving.org/mentalhealth](http://www.caregiving.org/mentalhealth)

Thank  
you

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NAMI