

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

NAMI Convention, Denver CO

July 8, 2016



# About the Alliance

- 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.



# Report Sponsors

This research was made possible through grant funding from:

- Allergan
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# Advisory Committee Members

This research was reviewed by an independent advisory committee:

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# 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

# 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
- 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 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



## 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

## Female Care Recipients

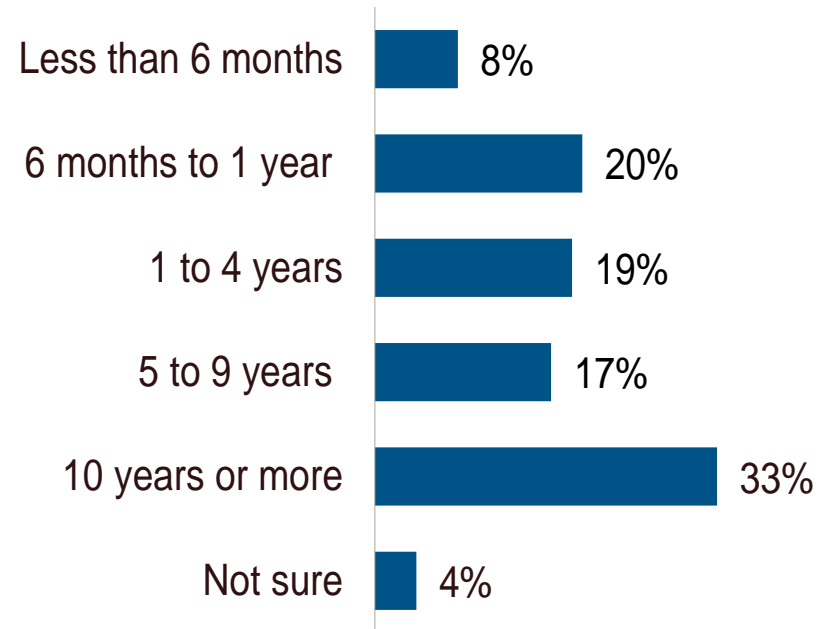
- 49% of care recipients were female
- 27% had diagnosis of depression vs. 18% of males
- 14% had diagnosis of anxiety vs. 7% of males
- 23% had a substance abuse issue
- 19% had been arrested
- 16% had been homeless

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]?*

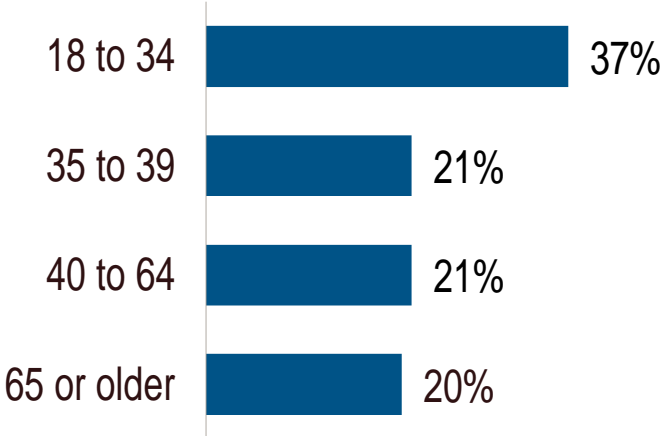
(n=1,601)



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)



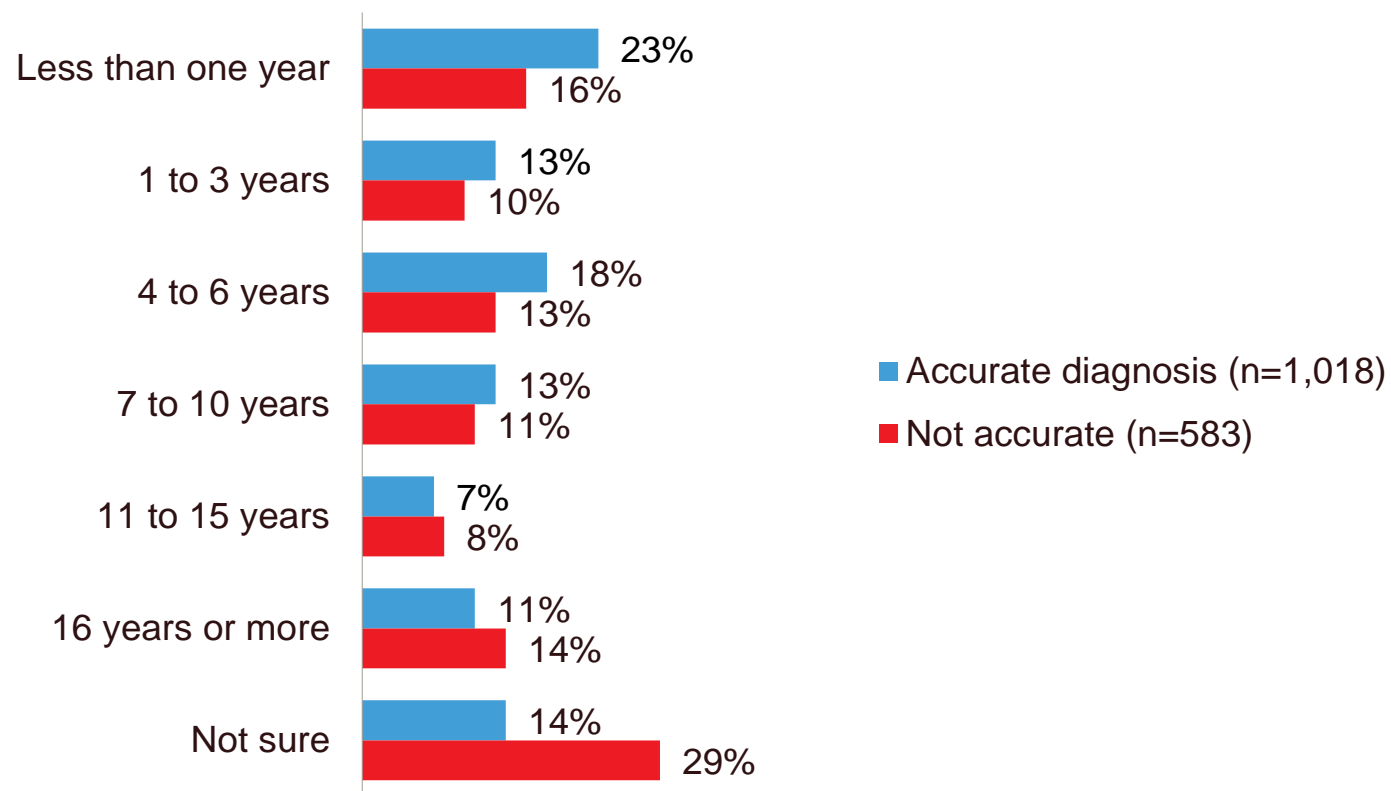
# Challenges: Time to Diagnosis

-Where families have an accurate diagnosis, it took 11.8 years on average to get there

-4/10 caregivers feel unsure that their loved one has 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?*



## Example: Time to Diagnosis

“He developed schizophrenia in his early teens. It took years for anyone to make the correct diagnosis, despite the fact that I paid out of pocket for multiple evaluations. We were only fortunate enough to get help when I asked a friend, a psychiatrist, to find someone for my son. We were referred to a resident who was wonderful and helped us to deal with the diagnosis. She is now in private practice and still sees my son at a reduced rate.”

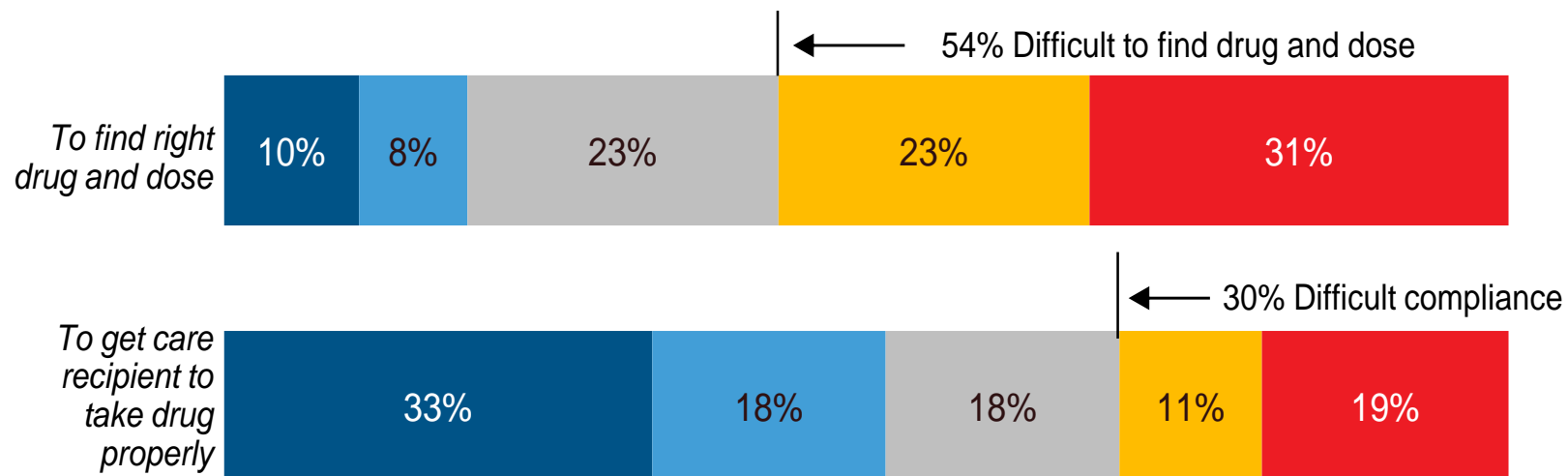
# Challenges: Medication Management

**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)

■ 1 - Not at all difficult ■ 2 ■ 3 ■ 4 ■ 5 - Very difficult



## Example: Medication Management Challenges

“Right now my son finally has the right "cocktail". It took us almost four years and three suicide attempts before getting to this point. Accessing his medication is now easy, but not so for many years!”

“My son happens to have a very good psychiatrist at the moment who has convinced my son that medication will keep him functional. It has made a huge difference in our lives. The doctor gives him therapy which has been unusual. It has given my son a new lease on life.”

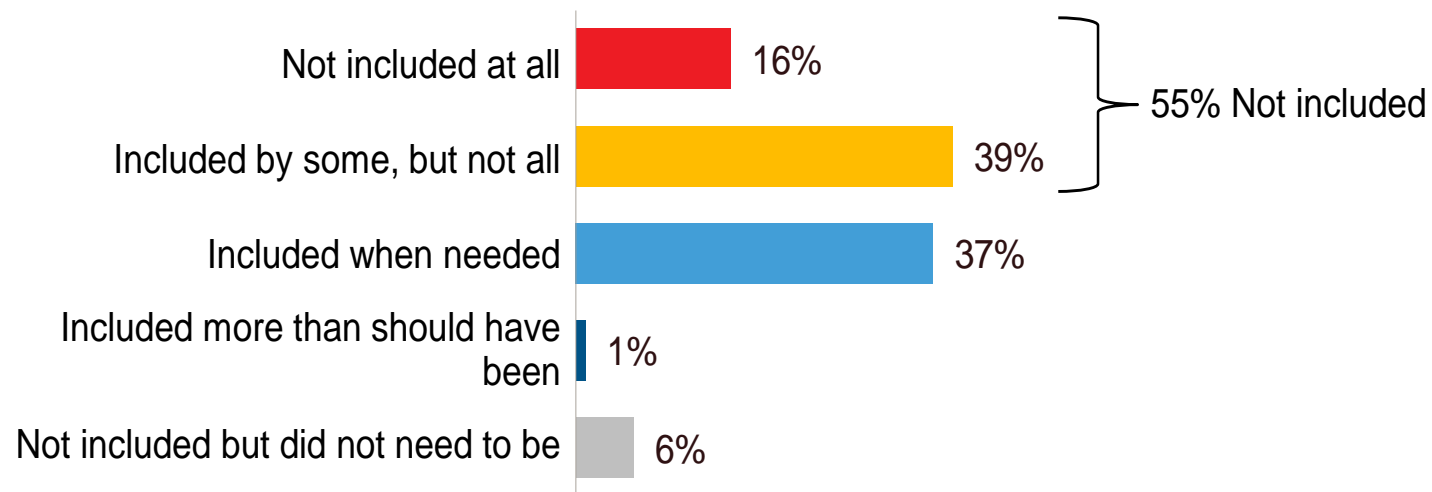


# Challenges: Caregivers often feel excluded from conversations with healthcare providers

## 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)



Example:  
Caregivers often  
feel excluded  
from  
conversations  
with mental  
health  
healthcare  
providers

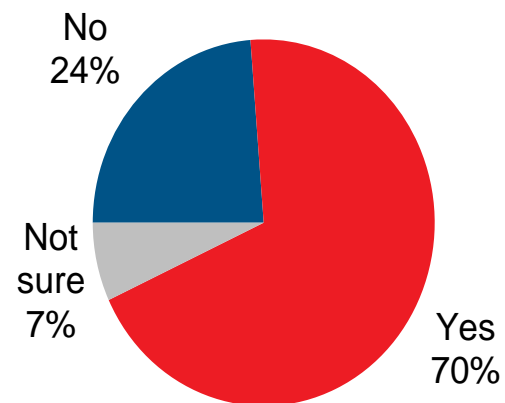
“Caregivers are often overlooked and the importance of the role they play in the wellness of their loved one is underestimated. An educated, healthy and supported caregiver is critical. The need for MH services is first and foremost, yet families also need their own support in the community.”

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)



Examples:  
Care  
recipients  
often  
discharged  
“too early” or  
“too quickly”

“My son was often discharged from the hospital before he was stable on medicine.”

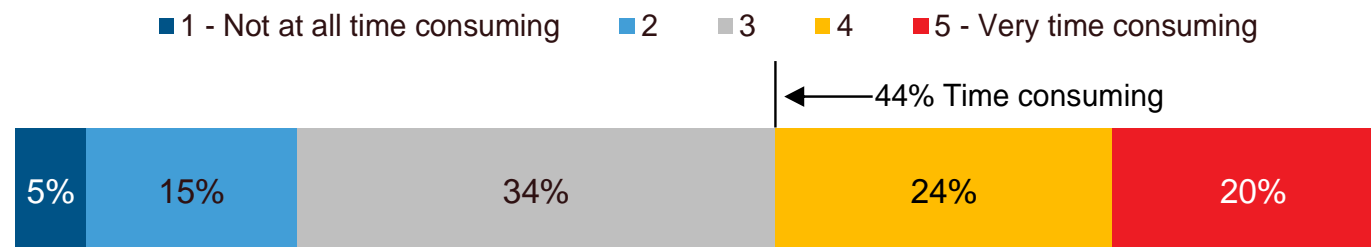
“We have been turned away from local hospitals twice while my son was psychotic and seeking help, because there was no psychiatrist on staff and no available beds. At one hospital a staff member advised me to take my son home and call police if he got worse. This was terribly inappropriate for a medical problem.”

# 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?

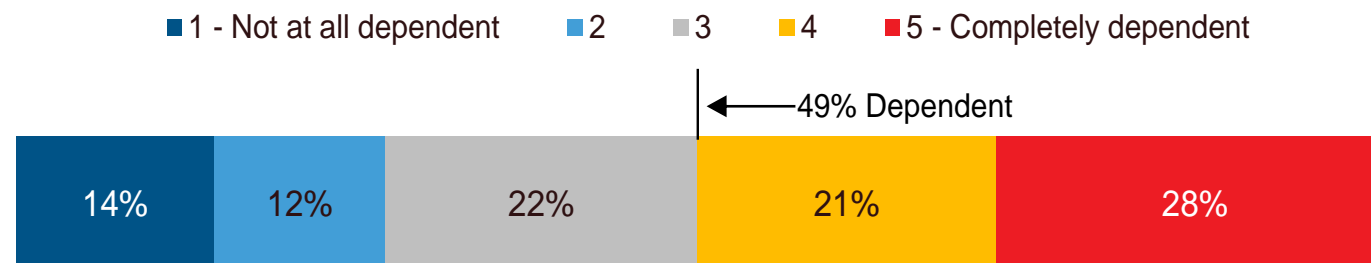
Those who manage recipient's finances  
(n=1,361)



## Figure 25: Care Recipient's Financial Dependence

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

(n=1,601)



## Examples: The “business of care”

“I would love to be able to spend time with my relative just visiting, socializing, and enjoying his company. Instead, we spend our time trying to get him into programs, doing paperwork, and generally trying to navigate the system, mostly with little success.”

“Service providers expect the caregiver to complete a large bundle of forms which one tries to do after work, in between fixing dinner, cleaning house, doing laundry - and sleep! The paperwork burden is complex and daunting!”

## Other challenges

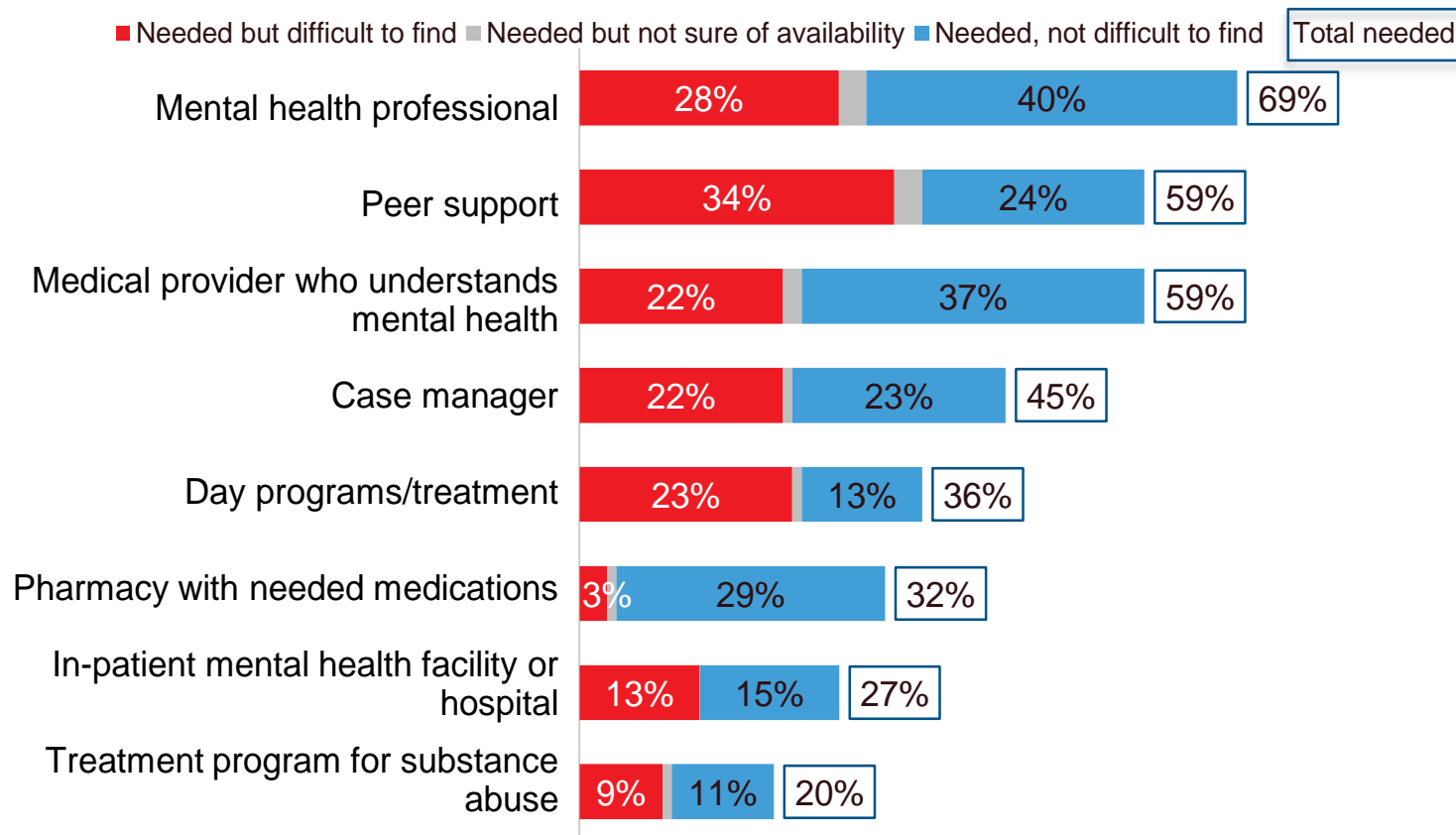
- **Arrest:** About one in three report their loved one has been arrested (32%)
- **Homelessness:** One in five caregivers report their loved one has been homeless for a month or longer (21%)
- **Self-Harm and Suicide:** Two-thirds of mental health caregivers are concerned their loved one will self-harm (68%) or die by suicide (65%)

# What social services would help with providing care?

**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)





## Examples: Needed social services

“We need services within my county. We have to travel 80+ miles round trip for a psychiatrist visit of 5 minutes!”

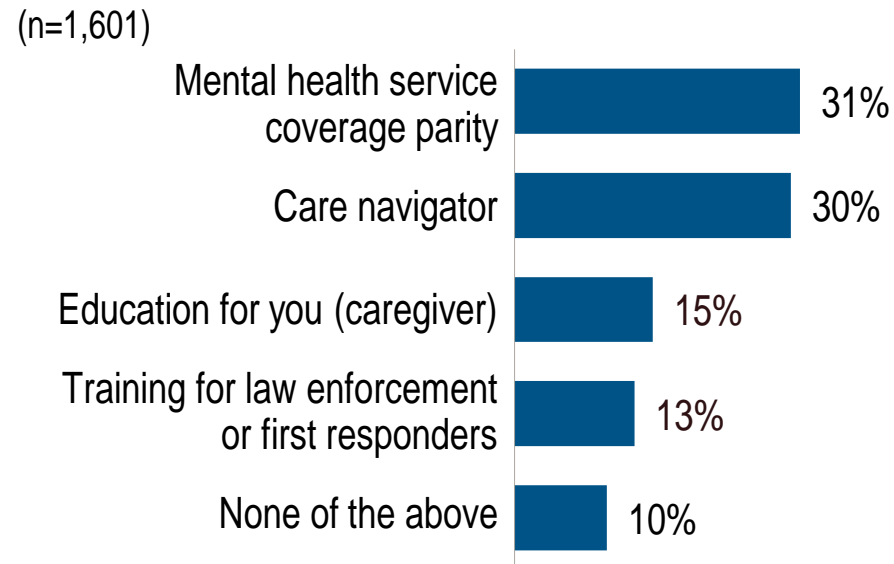
“There should be a mentor type person available for my son on a regular basis so I'm not the person who must always be "ON-CALL" 24/7; someone to teach him how to cook, balance a checkbook and clean his apartment.”

# Other findings

- Many caregivers express concern for the future, yet only half have made plans for their loved one's care
- Only 1 in 3 caregivers has guardianship or power of attorney. 40% would like more information
- 74% report that caregiving has been stressful
- 33% report their health as excellent or very good versus 27% who report it as fair or poor
- Yet, majority indicate that they feel closer to their relative (59%) and he/she appreciates the care they provide (55%)

# 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?*



# Public Policy Solutions

- **Integrate mental and behavioral health questions into all health care assessments,** and provide screenings.
- **Encourage treatment parity** for mental health issues with that of medical health issues.
- **Provide access** to a full array of high-quality behavioral and mental health services across the continuum of care.
- **Ensure patient access and reimbursement for appropriate medications** to treat mental illness.

# Public Policy Solutions

- Provide **assistance for both caregivers and patients in navigating the mental health system.** County and state providers can help.
- **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.**

Public Policy  
Solution:  
*Comprehensive  
Mental Health  
Reform bills  
H.R. 2646  
S. 2680*

## **Educate providers and caregivers about HIPAA:**

Develop and disseminate model training for providers, lawyers, patients and families, including family caregivers, on appropriate communication of health information to support people living with mental illness.

Public Policy  
Solution:  
*National  
Mental Health  
Family  
Caregiver  
Support Act  
(not yet filed)*

- **National Mental Health Family Caregiver Support Program**
- **National Mental Health Caregiver Technical Assistance Center:** Training, curricula and technical assistance
- **Grants to organizations for family caregivers of adults with mental illness to provide:**
  - **Information** on mental health services, supports, coverage;
  - **Navigation and assistance** to access services & supports;
  - **Education** for family caregivers, family caregiver support groups.

## Caregiver Resources

- National Family Caregiver Support Program
- Life Span Respite Program
- VA Caregiver Program
- Aging & Disability Resource Centers
- Local Caregiver Coalitions



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## Report Findings



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

Thank  
You

For more information,  
the full report is available at  
[www.caregiving.org/mentalhealth](http://www.caregiving.org/mentalhealth)