

Behavioral Health is Essential To Health



Prevention Works



Treatment is Effective



People Recover

Overview

Background and Purpose

- **On Pins & Needles: Caregivers of Adults with Mental Illness**
- **Community Inclusion From the Perspective of Caregivers of People with Psychiatric Disabilities**

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
- Main conditions requiring care: bipolar disorder (25%), schizophrenia (25%), depression (22%), and anxiety (11%)



On Pins & Needles: Caregivers of Adults with Mental Illness

Gail Hunt
National Alliance for Caregiving
President & CEO

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NAMI
Director of Policy & State
Outreach



Partners

- **National Alliance for Caregiving**
 - *Non-profit coalition of over 50 national organizations*
 - *Established in 1996 to support family caregivers and the professionals who work with them*
 - www.caregiving.org/
- **National Alliance on Mental Illness (NAMI)**
- **Mental Health America (MHA)**

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

- 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

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

Who are they caring for?

- Average age: 46.3 years old. 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

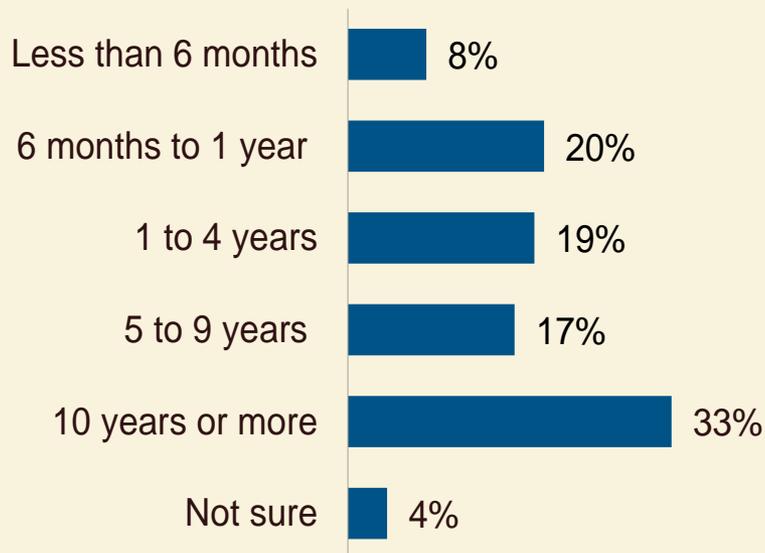
Care Recipients

- Gender:
 - *51% male*
 - *49% female*
- Diagnoses:
 - *25% bipolar disorder*
 - *25% schizophrenia*
 - *22% depression*
 - *11% anxiety*
 - *28% substance abuse issue*
- 32% had at least 1 arrest (45% males, 19% females)
- 21% homeless 1 month or longer (25% males, 16% females)

Duration of caregiving

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

(n=1,601)

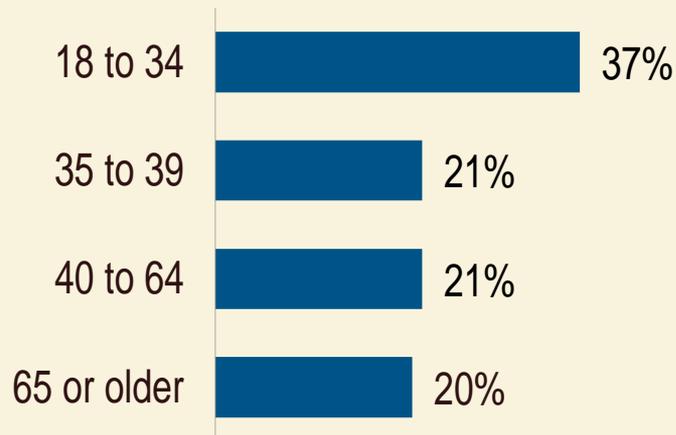


One-third of caregivers have cared for 10 years or more

Care Recipient Age

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

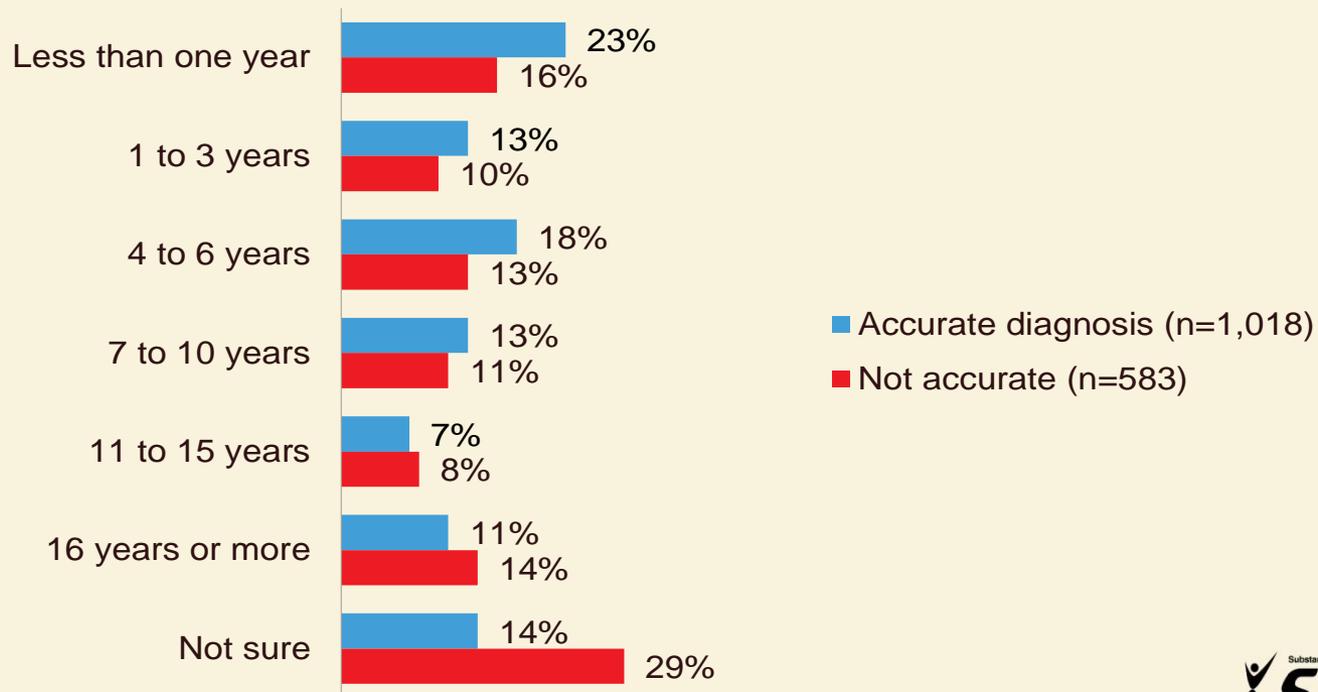
(n=1,601)



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

Challenges: 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.

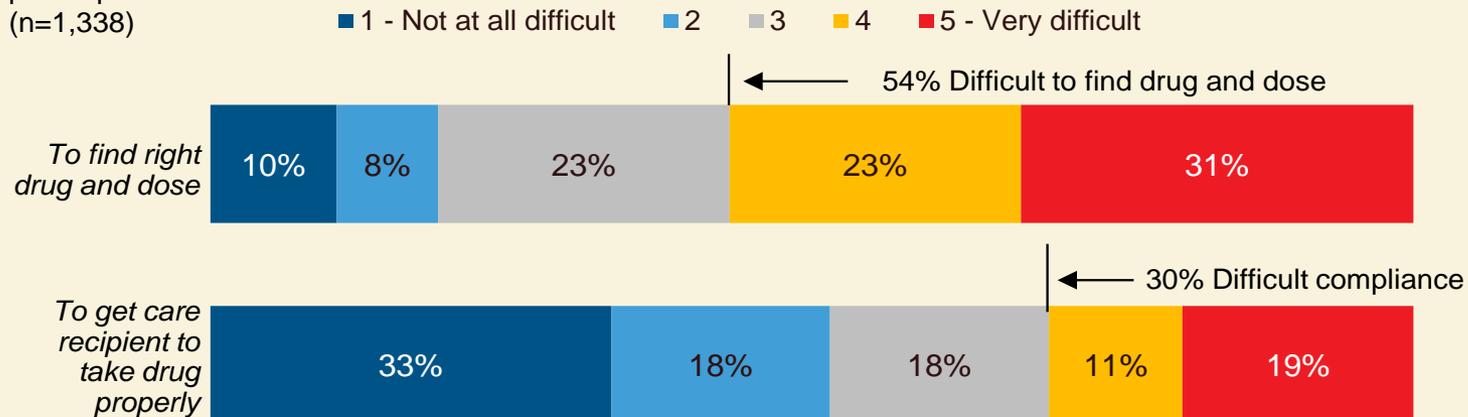
We were only fortunate enough to get help when I asked a friend, a psychiatrist, to find someone for my son. We were referred to a resident who was wonderful and helped us to deal with the diagnosis. She is now in private practice and still sees my son at a reduced rate.”

Challenges: Medication Management

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)



Example: Medication 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!”

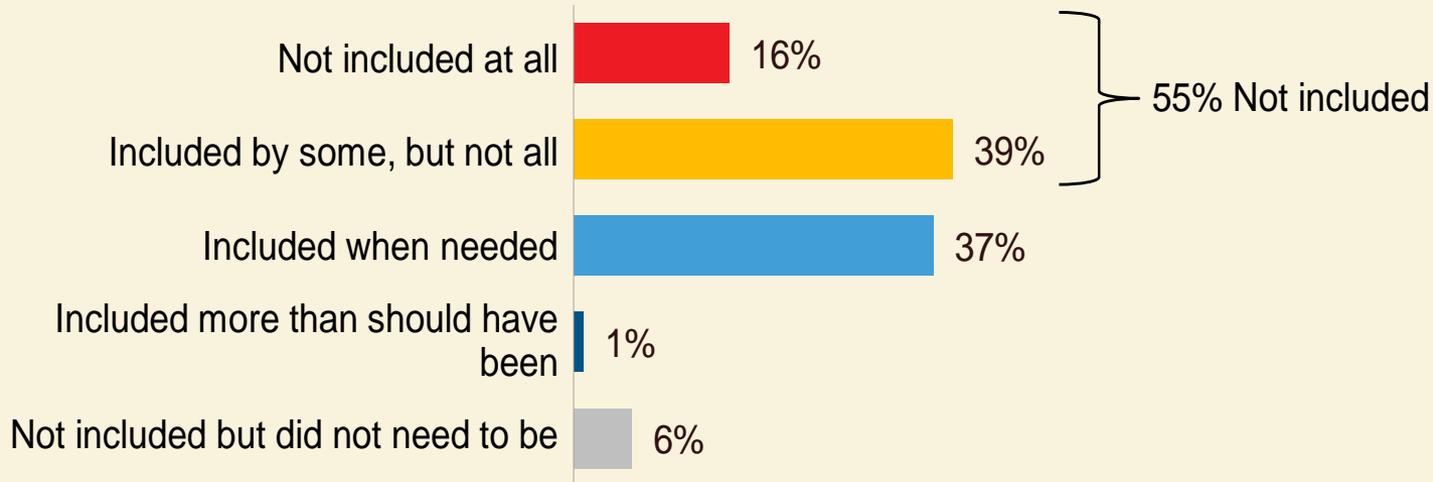
“My son happens to have a very good psychiatrist at the moment who has convinced him that medication will keep him functional. It has made a huge difference in our lives. The doctor gives him therapy which has been unusual. It has given my son a new lease on life.”

Challenges:

Caregivers often feel excluded

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

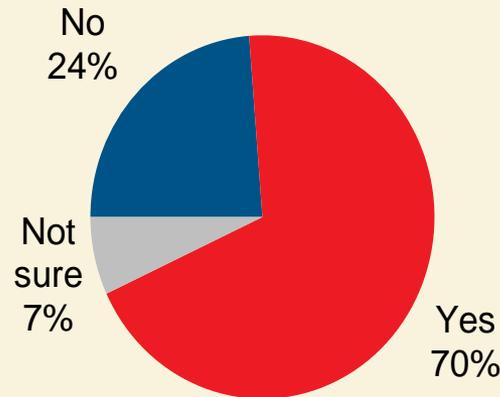
(n=1,601)



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

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: The 'business of care'

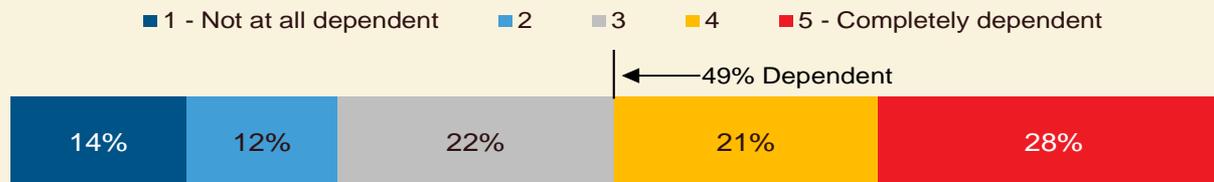
Q41. How time consuming is/was it for you to help your [relation] with his/her care paperwork or finances?

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



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

(n=1,601)



Examples: 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!”

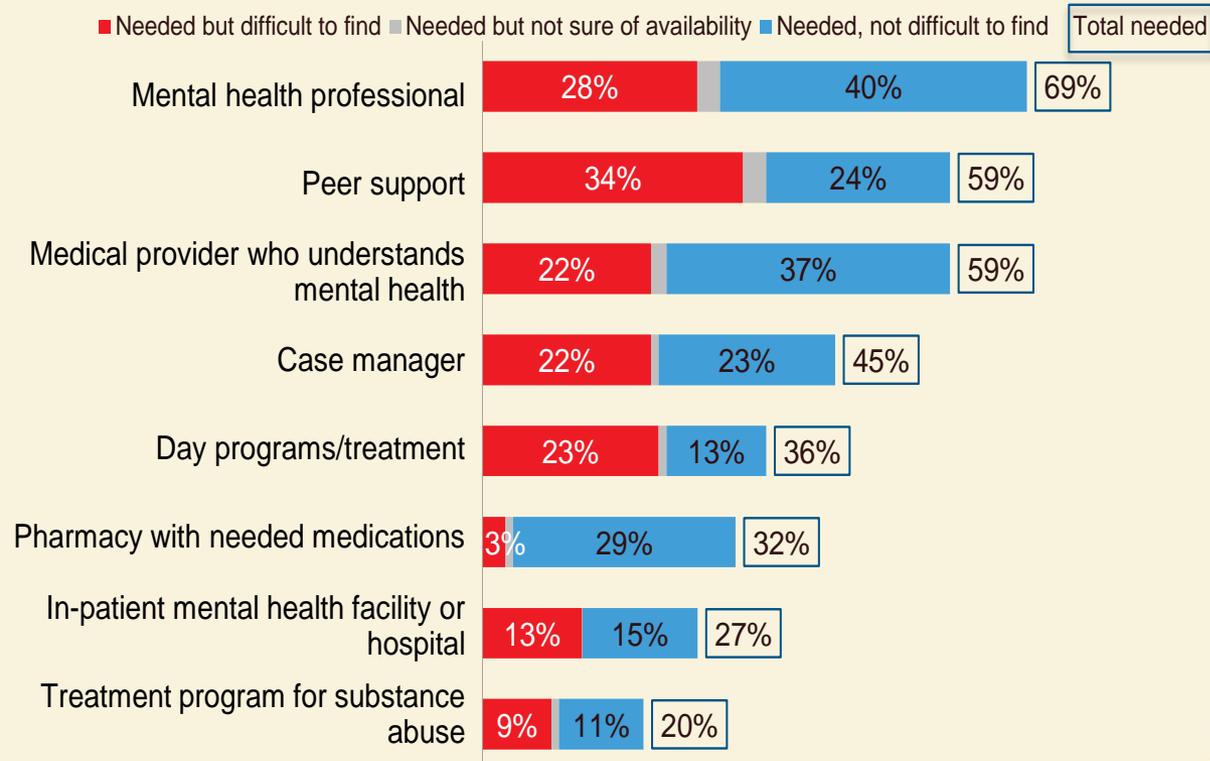
Other challenges

- **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?

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.”

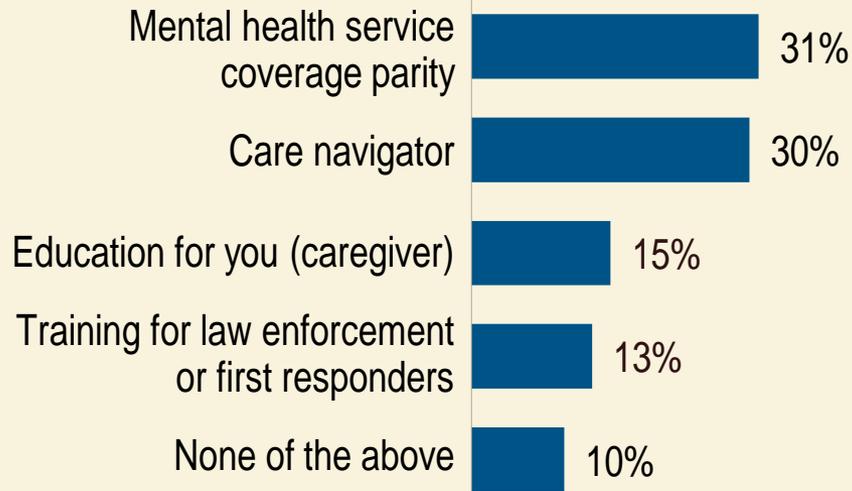
Other findings

- Many caregivers express concern for the future, yet only half have made plans for their loved one's care
- 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?

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

(n=1,601)



Public Policy Solutions

- Provide assistance for both caregivers and care recipients 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 adults with mental illness, especially around issues of stress and caregiver health.
- Educate about HIPAA: Develop and disseminate model training for providers, lawyers, care recipients and families on appropriate communication of health information to support people living with mental illness.

Solution: National Mental Health Family Caregiver Support Program

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

Solution: CARE Act

AARP model state legislation

Care, Advise, Record, Enable (CARE)

- Family caregiver name requested upon admission to hospital or rehab
- The family caregiver notified if relation is to be discharged
- The hospital or rehabilitation facility must provide an explanation and live instruction of caregiver tasks

Now enacted in 34 states

Caregiver Resources

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

On Pins & Needles: Caregivers of Adults with Mental Illness



Report available at:

www.caregiving.org/mentalhealth



Challenges and Solutions for Mental Health Caregivers

**Richard Baron, MA, Temple Collaborative for
Community Inclusion of Individuals with
Psychiatric Disabilities (TU Collaborative)**

**Debbie Plotnick, MSS, MLSP, Mental Health
America (MHA)**



Why ask caregivers about community inclusion

Among the eight policy recommendations in the Pins and Needles study is one that explicitly refers to community inclusion and a number of its domains:

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.

What is Community Inclusion

- **Housing**
- **Employment**
- **Friendships and Intimate Relationships**
- **Education**
- **Health and Wellness**
- **Spirituality and Religion**
- **Recreation**
- **Civic Engagement**

Summer 2016 Caregiver Survey

More than 450 respondents answered 10 questions and provide 1000's of comments

- Parents (largest number)
- Adults caring for a parent
- Adults caring for a sibling
- Adults caring for a spouse
- Mental Health Professionals
- People reporting their own lived experience

Far More Challenges than Solutions

| | Uninvolved | Minimally Involved | Involved | Very Involved |
|--|------------|--------------------|------------|---------------|
| Competitive Employment | 62% | 18% | 11% | 8% |
| Recreational Activities | 42% | 41% | 13% | 4% |
| Religion of Choice | 52% | 25% | 15% | 8% |
| Friendships Unrelated to Services | 28% | 45% | 21% | 6% |
| Community Events | 49% | 39% | 8% | 3% |
| Housing of Choice | 45% | 22% | 21% | 12% |
| Educational Supports and Opportunities | 48% | 29% | 15% | 8% |
| Health and Wellness | 26% | 44% | 22% | 9% |
| Family Supports | 13% | 33% | 29% | 25% |
| Healthy, Meaningful Intimate Relationships | 45% | 31% | 17% | 8% |
| Overall (Answer to Q1) | 18% | 36% | 26% | 20% |

Challenges by Domain: Housing

- Residing with caregiver on-going challenges:
 - *“My adult son 47, has always lived with us, his parents. He is quite isolated... We are in our early 70’s and worry about housing for him in that his only sibling lives [abroad].”*

Challenges by Domain: Housing

- Living independently often put people between the proverbial rock and hard-place:
 - *“ Sometimes the only choices are within a segregated mental health setting or an unsafe community setting.”*

Challenges by Domain: Employment

- Even though research shows that employment is one of keys to recovery, Caregivers described their loved ones
- “lacking skills training,” “not having a high school diploma or GED,” and as having “no job training or experience.”
- Also cited: uneven job history, and criminal records, as well as job application process as impediments.

Challenges by Domain: Employment

- Other caregiver reported challenges
 - Jobs without “growth potential.”
 - Disclosure being a “double-edged sword.”
 - Number one reason caregivers gave for their loved ones’ lack of involvement in competitive employment were attributed to the illness.
 - Symptoms, medication side effects, difficulties finding or keeping a job, “coworker discomfort,” and conversely that the “person feels uncomfortable around co-workers

Challenges by Domain : Friendships and Intimate Relationships

- Caregivers attributed challenges to their loved ones' behaviors and perceived appearance:
 - *“My son finds it impossible to make friends. Often his behavior is "odd" and it put a strain on his social skills.”*
 - *“...He has never had an intimate relationship. Few women can tolerate his "weirdness.”*

Challenges by Domain: Education

- Caregiver's own words;
 - *“Asking for supports to be put in place during high school was not supported by school staff because her IQ and test scores were “too high” yet she clearly needed additional support in some subjects, and with managing her mental illness.”*
 - *“My child was bullied at school, not so much by other children -- but by staff and teachers. She has been victim to some dreadful verbal abuse by teachers.”*

Challenges by Domain: Health and Wellness/Recreation

Caregivers cite illness, lack of money, lack of interest:

- *“...hard to focus on physical wellness when so much energy needs to go into the management of the mental illness.”*
- *“Participating in health and wellness beyond doing home exercise also requires interaction with others.”*
- *“There are many wellness activities/groups and programs that are simply unaffordable and out of reach to her.”*

Challenges by Domain: Religion of Choice

- While participating in religious life is reported to be very important and has positive effects for recovery, caregivers and consumers didn't always find welcoming environments:
 - *“We have attended Church and heard from pastors that there is no such thing as mental illness, and people should not be taking pills and expecting to get better, they just need a better relationship with the Lord; (explain that to your mentally ill young person).”*
 - *“The church thinks if I had more faith I'd be "healed".”*

Barriers cited by Caregivers

- **Transportation/Location:** “X can’t drive,” or “we need transportation.”
“We are in a rural area.”
- **Financial:** Any combination of income, financial difficulties, can’t afford
- **Access to Services:** these included any kind of clinical and support services (including peers and support groups, case management).
- **Stigma or Discrimination:** This included direct references to stigma and discrimination as well as impactful actions “she got fired because of her bipolar” or “the school would not honor her IEP”
- **Physical Issues:** co-morbidities, age, being physically in prison or jail, and, in a lot of cases... pain.

Caregivers reported being impacted

| | Not Impacted | Minimally Impacted | Impacted | Highly Impacted |
|-----------------------------|--------------|--------------------|------------|-----------------|
| Recreation | 10% | 27% | 37% | 27% |
| Religious Activities | 44% | 26% | 16% | 14% |
| Employment | 23% | 26% | 27% | 24% |
| Friendships | 15% | 26% | 30% | 29% |
| Family/Community Gatherings | | | | |
| Ostracized | 34% | 24% | 23% | 19% |
| Overall | 3% | 20% | 36% | 42% |

Impact on Caregivers

“ She's fine ... I have no socialization!”

“...It exhausts me and burns me out as it is now. I'm out of work because of the stress of this situation.”

Caregiver recommendations

- Don't give up be educated:
 - *Get loved ones out of the house and into the community when possible.*
 - *Keep looking for opportunities and don't give up.*
 - *Continue to offer to take loved ones to events and encourage other friends and family to do the same.*
 - *Become informed of support services available in the community for both the person needing help and for caregivers*

More Caregiver Recommendations

- A caregiver walks a fine line between support and encouragement. If you push too much it just sets back the trust you have worked for.
- **STAY CONNECTED.** Make sure you are reaching out often and continuously.

Show your love and willingness to listen, always.

Caregivers Policy Recommendations

- People to fully participate as community members.
- Services that engaging, holistic, address trauma, and that don't end when crises abate
- Services that go beyond clinical improvement
- Education for employers and coworkers, and educators so people can stay in school and be employed.
- Understanding about difficult symptoms and the attendant side effects of medication

More Caregiver Policy Recommendations

- Compassion from teachers and other school personnel, clergy, and the public.
- Support for caregivers (such as respite for people caring for adults, not just kids).
- Education to better help their loved ones be more involved in life, including information about what community resources exist for recreation, health and engagement.
- Policy makers and legislators to address issues related to poverty; lack of transportation; community services that are ineffective, scarce, or hard to access; and the unavailability of housing, and unsafe housing.
- More people to step forth as “exemplars,” demonstrating recovery and showing that “people with mental illnesses are not scary.”

For More Information

- **Please contact:**

- *Debbie Plotnick at Mental Health America,
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- *Rick Baron at the Temple Collaborative:
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- **To download the complete report: visit:**

<http://www.mentalhealthamerica.net/sites/default/files/Community%20Inclusion%20from%20the%20Perspective%20of%20Caregivers%20FINAL.pdf>

[Or Click here](#)

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