



## 08: Community Services

### Introduction

As a caregiver, it is challenging to help the care recipient. The person you care for may need help finding mental health services in addition to practical help such as personal care, cooking, shopping, transportation, finances, and paperwork. It is often difficult to find the time and energy to make it all happen, and still attend to the other parts of your life. Learning how to access the available support in your community can relieve some of the pressure.

### Background: Mental Health Caregivers and Community Services

In a recent study, mental health caregivers reported dissatisfaction with the number (51%) and quality (46%) of mental health community services in their care recipient's area. The problem was most acute in rural areas where services were sparse and remote. Studies of caregivers of adults with mental illness have found that:

- One in four caregivers say they have difficulty finding services.
- Caregivers experienced trouble in finding or arranging the following:

- day or treatment programs (64%);
- peer support (58%);
- case management (49%);
- in-patient treatment (48%); and,
- substance abuse treatment (45%).

Often it is the caregiver who becomes the advocate and has the most knowledge about the care recipient's situation, but this can come at the price of personal sacrifice and lack of work-life balance. One in three caregivers (34%) reported barriers to talking with providers about their own needs for self-care. More than a third wanted, but could not get, respite services (39%).<sup>28</sup>

### Finding Needed Services

**Services for the care recipient:** If you are a caregiver looking for services, there are mental health advocacy organizations such as the National Alliance on Mental Illness (NAMI) and Mental Health America (MHA) that can help. Advocacy organizations often have staff and volunteers who also happen to be caregivers. They may know the local resources and be able to help you open doors. It can be comforting to have someone standing with you who understands the system and has provided care.

<sup>28</sup> National Alliance for Caregiving (2015) *On Pins & Needles: Caregivers of Adults with Mental Illness*.



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Many caregivers rely on their family doctor or other health care providers to find services and support. Health care providers, however, may not be versed in the range and quality of specific community mental health programs available in your community. They may not have any information about services that would support caregivers and families. Because of our fragmented health and social service system, care recipients and caregivers often fall through the cracks.

In a recent study, mental health caregivers indicated the need for policy support to help make services available and easy to navigate. Specifically, they asked for mental health coverage parity (31%) and care navigator services (30%).<sup>29</sup>

### Mental Health Services and Supports

Mild to moderate symptoms of mental illness may be treated by one main provider, although more serious conditions often require a multidisciplinary approach. If your care recipient lives in an area short on mental health professionals, routine treatment can be delivered through a local health clinic, with additional expert care as needed through tele-health or psychiatric consultation. Mental health care may involve the following:

- **Assessment and diagnosis:** Effective mental health care requires ongoing assessment, care planning, and diagnosis as the care recipient's needs change and the underlying condition(s) become clear.
- **Psychotherapy:** A range of individual, group and family therapies are effective to help people with mental health conditions change their patterns of thinking, feeling, and behavior. Once the person you care

for has a diagnosis, consider researching therapies found to be effective for the specific condition. When searching for a therapist, examine their credentials in providing those specific therapies. Living in a rural area does not need to be a barrier to a given therapy because therapists are often available through tele-health. (A word of caution: check with the care recipient's health insurer to find out whether tele-health is a covered benefit.)

- **Medication:** Psychiatric medication may be an important part of stabilization and recovery. Some people with mental health conditions require continued medication while, for others, medication is only needed at certain points or not at all. Effective prescribing practices achieve a balance between managing symptoms and minimizing side effects. Be patient as it can take weeks to determine whether the medication is working.
- **Service brokering and system navigation:** Obtaining the services and support the care recipient needs can be a daunting task. If the person you care for goes to a mental health agency or health clinic, a service broker (which can be a case manager, care coordinator, or social worker) may be assigned to arrange care, health coverage, income support, and other needs. If you feel the care recipient needs help communicating their needs to the service broker, ask to be included in a visit. If the person you care for is willing to involve you, he/she may need to complete a 'consent to release information' form.

<sup>29</sup> Ibid.



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- **Emotional support:** The road to recovery can be hard. People with mental health conditions often need someone they can turn to as a sounding board or for encouragement. Mental health professionals should provide emotional support as needed. Peer support specialists are particularly helpful because they have personal experience with the recovery process. They know how hard it can be, but they also know that it gets better. Peer support specialists are often employed by mental health agencies or independent organizations.
- **Life skills and socialization:** Common symptoms of mental illness include confusion, self-doubt, loneliness, and anger. Training in social skills and stress reduction helps a person with a mental health condition build good relationships. Instruction in practical skills like budgeting and cooking can improve quality of life. Mental health agencies and peer support centers offer opportunities to help the care recipient meet others, learn healthy social interaction skills, and reduce isolation.
- **Housing support:** Decent, safe, affordable housing lays a foundation for recovery, yet without financial assistance, independent housing is out of reach for many people on a fixed income.<sup>30</sup> A recent study of mental health caregivers found that 45% of the care recipients lived with the caregiver.<sup>31</sup> Although there are advantages to living as an extended family, the situation can also be stressful. Mental health agencies often employ housing specialists to help with subsidized housing. In some communities, the waiting lists are long, but signing up is still worthwhile.
- **Supported employment:** Most people with mental health conditions want to work, and would work, given effective employment and vocational support.<sup>32</sup> Studies show that work promotes recovery<sup>33</sup> by offering financial independence, a sense of purpose, social interaction, and hope.<sup>34</sup> The two most effective models of supported employment for people with mental health conditions are Individual Placement and Support (IPS), and the Psychosocial Clubhouse. Community mental health centers may offer these programs, although Clubhouses are often independent agencies.
- **Crisis intervention:** Crisis services intervene at the breaking point. Crisis counselors stabilize, help prevent further crises, refer to professional help, and follow-up to ensure long-term recovery. A crisis response system can include 24/7 telephone counseling, mobile crisis response teams, walk-in clinics, short-term crisis stabilization units, respite services, and transportation. If the person you care for is in crisis and an immediate threat to him/herself or to others, call 911 and ask for a Crisis Intervention Team (CIT), or get to the nearest hospital emergency room as soon as possible. If your care recipient is suicidal, The National Suicide Prevention Lifeline has trained counselors who can speak with you or your care recipient 24/7 and can be reached at 1-800-273-8255.
- **Hospital and residential treatment:** Inpatient care may be necessary if the person you care for is in psychiatric crisis, is at risk of harm to self or others, or requires complex intervention.

<sup>30</sup> Cooper E, Knott L, Schaak G, Sloane L, Zovistoski A (2015). *Priced Out in 2014: The Housing Crisis for People with Disabilities*. Technical Assistance Collaborative. <http://www.tacinc.org/knowledge-resources/priced-out-findings/>

<sup>31</sup> Hunt et al (2015). *On Pins & Needles: Caregivers of Adults with Mental Illness*. p. 20.

<sup>32</sup> McQuilken M, Zahniser JH, Novak J, Starks RD, Olmos A, Bond GR (2003). *The Work Project Survey: Consumer perspectives on work*. *Journal of Vocational Rehabilitation* 18: pp. 59-68.

<sup>33</sup> Burns T, Catty J, White S, et al (2009). "The impact of supported employment and working on clinical and social functioning: Results of an international study of Individual Placement and Support." *Schizophrenia Bulletin* 35: pp. 949-958.

<sup>34</sup> Douglas D, Diehl S, and Honberg R (2014). *The Road to Recovery: Employment and Mental Illness*. National Alliance on Mental Illness. p. 3 <https://www.nami.org/About-NAMI/Publications-Reports/Public-Policy-Reports/RoadtoRecovery.pdf>



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- Most psychiatric hospital stays are brief, no more than a week or two, with specific treatment goals. In-patient mental health care may be received in the psychiatric unit of a general hospital, a privately operated psychiatric hospital, or a state psychiatric facility. It is best if the care recipient enters into in-patient care of their own accord, but when the care recipient or others are at immediate risk, involuntary commitment may be necessary. Today, many hospitals ask patients to name a caregiver to be involved in discharge planning. Designated caregivers receive information to support aftercare, which can improve outcomes.
- Residential mental health treatment is a step-down, or hospital diversion, strategy usually consisting of two to eight weeks of intensive treatment in a home-like setting. Goals include reducing symptoms, learning healthy coping mechanisms and living skills, rebuilding relationships, and preventing relapse. (A note of caution: residential treatment is expensive, and health insurance coverage can be difficult to obtain).

### Helpful Resources

There are various online tools to access services through national organizations. One resource is your local municipality. Many people don't think of the public sector as being an access point for mental illness but in fact there are many programs that may assist you. Examine the information and referral systems that can provide you with phone numbers and other information on available services. The following includes examples of services and assistance that may be of interest:

- **Eldercare Locator** provides assistance to families who are seeking programs and services in their local communities. [www.eldercare.gov/Eldercare.NET/Public/Index.aspx](http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx)
- **The National Institute of Mental Health (NIMH)** offers information on topics by condition, population, and prevention. [www.nimh.nih.gov/news/science-news/2011/support-program-can-help-caregivers-cope-with-relatives-mental-illness.shtml](http://www.nimh.nih.gov/news/science-news/2011/support-program-can-help-caregivers-cope-with-relatives-mental-illness.shtml)
- **The Substance Abuse and Mental Health Services Administration (SAMHSA)**, a federal agency, offers a confidential nationwide mental health and substance abuse services locator. Locator services are available either online or by telephone: [findtreatment.samhsa.gov/](http://findtreatment.samhsa.gov/)
- **The National Alliance on Mental Illness (NAMI)** offers various education and support programs for people with mental illness and their families. To learn more about specific programs, visit [www.nami.org/programs](http://www.nami.org/programs). To find a NAMI organization in your area, visit [www.nami.org/local](http://www.nami.org/local).
- **Mental Health America (MHA)** offers information and programs including the Peer Support Program housed within the Peer Support Center. [www.mentalhealthamerica.net/center-peer-support](http://www.mentalhealthamerica.net/center-peer-support)
- **National Family Caregiver Support Program (NFCSP)** was established in 2000 to provide support to caregivers and since that time has expanded to include a variety of caregiving situations including mental health. Through the NFCSP, money is distributed to states and territories in the form of grants to provide support to caregivers. [www.acl.gov/programs/support-](http://www.acl.gov/programs/support-)



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*caregivers/national-family-caregiver-support-program*

- **Lifespan Respite Program** is a community-based system of care for family caregivers providing care to family members of all ages. [www.acl.gov/programs/support-caregivers/lifespan-respite-care-program](http://www.acl.gov/programs/support-caregivers/lifespan-respite-care-program)
- **Aging and Disability Resource Centers** are considered 'single points of entry,' 'no wrong door,' or 'access points' to resources related to Long-Term Services and

Support (LTSS). Through person-centered counseling (PCC), individuals are assisted through the process and learn about the resources available to them. [www.n4a.org/adrcs](http://www.n4a.org/adrcs)

- **The National Association of Area Agencies on Aging** provides a wealth of information for caregivers related to housing, home and community-based services, transportation, elder law, and much more. [www.n4a.org/agingservices](http://www.n4a.org/agingservices)

### Helpful Websites

**AARP-Caregiving** [www.aarp.org/home-family/caregiving/](http://www.aarp.org/home-family/caregiving/)

**Caregiver Action Network** [caregiveraction.org](http://caregiveraction.org)

**Family Caregiver Alliance** [www.caregiver.org](http://www.caregiver.org)

**Mental Health.Gov** [www.mentalhealth.gov](http://www.mentalhealth.gov)

**National Alliance for Caregiving** [www.caregiving.org](http://www.caregiving.org)

**National Alliance on Mental Illness** [www.nami.org/Find-Support/NAMI-Programs](http://www.nami.org/Find-Support/NAMI-Programs)

**U.S. Department of Health and Human Services (HHS)**

[www.mentalhealth.gov/talk/community-conversation/services/index.html](http://www.mentalhealth.gov/talk/community-conversation/services/index.html)