



Respite for Caregivers of Adults with Mental Disorders

Introduction

Beginning in the 1950's, the United States began a movement toward deinstitutionalization of individuals with mental illness, and later those with developmental disabilities. Those who were once segregated from the general population and placed in long-term psychiatric institutions, were now living in community environments that were meant to be less restrictive, such as community care facilities, group homes, or the homes of family members and loved ones. This policy shift resulted in a more direct role for many family members of individuals with mental illness, that of caregiver.

While the movement toward less restrictive environments, community living, and consumer choice took positive steps toward encouraging independence and individualized options, these changes also resulted in significant challenges for consumers and family caregivers in accessing the needed resources to support healthy and successful community living. In addition, while policy changes over the last several decades have increasingly mandated the civil rights of individuals with physical and mental disabilities, the stigma associated with mental disorders continues to be a challenge for consumers and families.

As a result of increased reliance on family caregivers, a documented need for respite for family caregivers of this population arose. Despite this need, a review of the literature on respite care between 1967 and 2002, found only 21 papers related to respite care for those with severe mental illness (SMI) and their family caregivers and none at all after that date (Jeon, Brodaty, O'Neill, & Chesterson, 2006). Respite care for this population is currently described in the literature and on the internet as an alternative to psychiatric hospitalization or as crisis intervention to provide overnight placement in a therapeutic setting. The respite is focused on the needs of the care recipients rather than on family caregivers.

However, because of the unique nature of their respite needs, this fact sheet will focus on respite for family caregivers of individuals with mental health issues who are between the ages of 18 and 60. Mental health related conditions, such as serious emotional disturbance among children and youth, and Alzheimer's and other dementias, will not be addressed in this fact sheet, as they are addressed elsewhere ([ARCH Fact Sheet 34. Respite for Families with Children Experiencing a Serious Emotional Disturbance](#); [ARCH Fact Sheet 55. Respite for Persons with Alzheimer's Disease or Related Dementia](#)).

This fact sheet is meant to assist state agencies, Lifespan Respite grantees and their collaborators, and respite providers by

increasing their understanding of the unique needs of this population and their family caregivers. Such insight and direction will help State Lifespan Respite programs and others develop strategies to increase respite quality, access, and capacity for this population through partnerships with community-based services and enhanced provider recruitment and training efforts. It is also intended to offer resources for family caregivers seeking to expand respite opportunities for themselves and others.

Mental Health Problems in the US

Prevalence and Common Disorders

Mental disorders are “health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning” (U.S. Department of Health and Human Services, 1999b). The U.S. Surgeon General estimates that 26.3% of American adults aged 18 and older have a diagnosed mental health disability and 6% of adults have a serious mental illness (Kessler, et al., 2005; National Institute of Mental Health, 2008).

Some of the most common disorders among adults in the United States are mood disorders (9.5%) such as major depressive disorder, dysthymic disorder, and bipolar disorder; anxiety disorders (18.1%) such as social phobia, post-traumatic stress disorder, and generalized anxiety disorder; and personality disorders (9.1%) such as avoidant personality disorder, borderline personality disorder, and antisocial personality disorder (National Institute of Mental Health, 2010).

A unique population includes those with co-occurring disorders. The prevalence in the US of persons with intellectual/developmental disabilities and a co-occurring mental illness is estimated to be over 3 million (North Carolina START, 2010).

The Impact of Mental Disorders on Health, Employment, and Interpersonal/Social Relationships

Mental disorders can have a significant impact on an individual’s health and well-being, employment, and social and familial relationships. Individuals with mental disorders are five times more likely to experience a co-occurring health condition such as diabetes, heart disease, or cancer, as compared to those without mental disorders (Parks, Radke, & Mazade, 2008).

Mental disorders are the leading cause of disability in the United States among those 15-44 years of age (World Health Organization, 2008). The main burden of illness is concentrated in about 6% of the population (1 in 17) that has a serious mental illness (Kessler, et al., 2005). Estimates suggest that mental disorders in the United States cost approximately \$193 billion annually in lost wages alone (Kessler, et al., 2008).

Individuals with mental illness often become the focus of family life (Mental Health America, 2010). Those with mental disorders can experience impaired functioning in their interpersonal relationships (Robinson, Rodgers, & Butterworth, 2008). Evidence suggests that some mental disorders are associated with marital dissatisfaction (Whisman & Bruce, 1999) and the likelihood of marital breakdown (Mendlowicz, 2000; World

Health Organization, 2008; Kessler, et al., 1998).

Services and Supports for those with Mental Disorders

With appropriate treatment, many individuals with mental illness can learn to cope or recover (Mental Health America, 2010). Unfortunately, research suggests that a large proportion of adults with mental disorders in the United States delay or do not receive treatment for their disorders (Wang, Lane, Olfson, Pincus, Wells, & Kessler, 2005).

START: Systemic, Therapeutic Assessment, Respite, and Treatment –

START is a national model for crisis prevention, intervention and respite for adults with developmental disabilities and co-occurring mental illness or challenging behaviors. It was developed in 1989 to help coordinate care for such individuals. Planned and crisis respite services are key components of the program. Significant reduction in emergency service use, increases over time in planned supports/service use, and satisfaction with service experiences for individuals and their families have been demonstrated by this model. In a comparative analysis of the TN -START demonstration project in Chattanooga, Tennessee conducted in 2007, findings included significant cost savings when compared to individuals who did not receive services through the TN -START program in Tennessee .

For more information, visit the Center for START Services, Institute on Disability/UCED, Concord, NH.
http://iod.unh.edu/Projects/start/description_history.aspx Phone: 617.469.7391.

The START Model has been used in 13 states. For contact information for these programs, see <http://www.iod.unh.edu/Projects/start/locations.aspx>.

Among the reasons reported for not receiving mental health treatment include cost or insurance issues, not feeling a need for treatment, feeling that they could handle the problem on their own, and concerns regarding the stigma associated with mental health problems (Substance Abuse and Mental Health Services Administration, 2006).

Studies show that people who have a dual diagnosis of mental illness and intellectual/developmental disability are at greater risk for institutionalization than people diagnosed with an intellectual/developmental disability alone.

In addition, overuse of community emergency departments and long stays in psychiatric facilities have been documented in this population (North Carolina START, 2010).

Caregivers of Adults with Mental Disorders

Much of the responsibility for caring for individuals with mental health problems falls on family members. Estimates suggest that nearly one-third to two thirds of those with long-term mental disorders currently live with family members (Dyck, Short, & Vitaliano, 1999). Approximately 800,000 adults with co-existing developmental and intellectual disabilities and mental illness in the U.S. live with (and rely upon) their families (Beasley, 2001). These family caregivers provide practical assistance as well as emotional support (Shah, Wadoo, & Latoo, 2010). The role of family caregiver for an individual with mental illness may be taken on by numerous individuals, including parents, spouses, siblings, an adult, or young children..

Because the needs of an individual with a mental disorder change as their condition changes, caring for such individuals is not a static process (Shah, et al., 2010).

Common Challenges and Stressors Faced by Family Caregivers

The research literature on family caregivers of individuals with mental disorders has identified two types of burden experienced by these individuals: objective and subjective burden. Specifically, objective burden refers to disruptions in family relationships, economic stressors, limitations on social and work activities, negative effects on the caregiver's health, and the burden of common caregiving tasks, such as navigating the mental health, medical, welfare, and sometimes the criminal justice systems. In contrast, subjective burden relates to the psychological and emotional stress of caregiving (Huey, Lefley, Shern, & Wainscott, 2007; Shah et al., 2010).

Further, evidence suggests that some differences may exist in the experiences of caregivers depending on the mental disorder of the care recipient. According to a recent review of the literature by Shah, Wadoo, and Latoo (2010), caregivers of individuals with mood disorders commonly experience significant distress, significant difficulties maintaining social activities, decreased income, strained marital relationships, poorer physical health, and greater health service utilization. In one study, primary caregivers of

bipolar disorders were at high risk for developing sleep problems and chronic conditions, such as high blood pressure. However, the caregivers were less likely to see a doctor for their own health issues (Perlick, et al., 2007).

Some suggest that the families of individuals with schizophrenia may suffer some of the most significant caregiver effects, including fear, anger, mourning, disbelief, loneliness, demoralization, desperation (Huey, et al., 2007) guilt, loss, helplessness, vulnerability, cumulative feelings of defeat, anxiety, and resentment (Shah et al., 2010). These feelings can be exacerbated by the unpredictable behaviors of a loved one with mental health problems, such as reactions of violence, volatile mood swings, alienation, abusive language, and appearing normal one minute and on the edge the next (McKeague, 2003).

Of the 6% of adults ages 18 and 64 years who experience a severe mental illness (SMI) such as schizophrenia, major depression and bipolar affective disorders, their family caregivers are more likely to be older parents, mostly mothers. Typically, older family caregivers have provided many years of intense caregiving and are now dealing with their own age-related health issues. Moreover, they may have concerns about the care recipient's future living situation following their own death, and may be especially mistrustful of the mental health care system (Jeon, et al., 2006).

Other care recipient variables are associated with psychological distress among family caregivers, including physical impairments, functional impairments, cognitive impairments, behavioral disturbances, and concern about suicide attempts (Shah et al., 2010). The intensity of caregiver burden and responses may also be influenced by the duration of illness, symptom intensity, duration and frequency of hospitalizations and relapse, and the relative's attribution (Huey et al., 2007; World Federation for Mental Health, 2010). Furthermore, data indicate that caregiver burden increases when caregivers have greater contact with consumers and when consumers live with their families (Schulze & Rössler, 2005).

Among the most notable concerns of caregivers of individuals with severe mental illness are access to specialist services, availability of ancillary services such as respite care, eligibility for financial assistance, and therapeutic support for themselves (Edwards, Higgins, Gray, Zmijewski & Kingston, 2008). Many of these family caregivers experience common thoughts and feelings, including denying the warning signs regarding their loved ones illness, worrying what other people will think because of the stigma associated with mental disorders, or wondering what caused their loved one to become ill (Mental Health America, 2010).

Most families are ill prepared to cope with their loved one's mental illness (Mental Health America, 2010). The stress of caregiving can make it difficult to manage the symptoms of a

Respite care is, to my knowledge, almost non-existent for people with a serious mental illness...When it becomes important is when you're exhausted, you need to get away, you need to have a break. We had our son living under our roof until he was 29, and we became exhausted. We booked a holiday, but had to keep cancelling our holiday because as soon as he thought we were going away, he would get worse or things would happen.

Family Caregiver of an adult with mental illness from a study on how respite has been utilized, perceived and experienced by stakeholders (Jeon et al., 2006)

mental disorder and may lead to missed work, lost free time, strained relationships with those who may not understand the situation, and physical and mental exhaustion (National Institute of Mental Health, 2009). Caregiver stress can also have an impact on the care recipient. In fact, one study suggests that if a caregiver is under a great deal of stress, the consumer has greater difficulty following their treatment plan (Perlick, et al., 2004). Caregivers of individuals with severe mental illness may experience emotional challenges when the consumer does not comply with their treatment (Polio, 2001).

Historically, families of those with mental illness often were inappropriately blamed for their loved one's disorder. Consequences of these old assumptions continue to be felt by many families (Huey, et al., 2007). Some family caregivers continue to experience a sense of being left out of key decisions regarding their loved one's care. While the consumer or care recipient remains the key focus of most health and social service efforts, family caregivers are an essential part of the care team. Studies have shown that when family caregivers are included in the decision-making process regarding care for their loved ones, significant benefits accrue.

Such involvement may not only help the caregiver to remain involved, but evidence suggests that family interventions have repeatedly demonstrated reductions in illness

relapse, negative symptoms, and inpatient service utilization (Barbato, 1998). In addition, evidence suggests that family members can play an important role in reducing the risk of suicidal behavior (Huey et al., 2007).

Family therapy and other programs that involve and support families early in the treatment process have been found to reduce illness relapse and decrease stress and disruption in the family (McEvoy, et al., 1999). When possible, a family approach to support may be beneficial for the consumer, as well as his/her caregivers.

Respite for Caregivers of Individuals with Mental Disorders

Increasing attention in recent years has focused on the important role of family caregivers and the resources needed to help them maintain or improve their health and

availability, provision and flexibility for this population. A majority of the caregivers interviewed said they had no knowledge of potentially available respite care services or had no knowledge of how respite could help. This was especially true of family caregivers from culturally or linguistically different backgrounds. Family caregivers needed respite care when their ill relative was unwell, but not seriously ill enough to be admitted to an inpatient setting. If respite was not provided when it was most needed, they were not likely to consider using respite later. In addition, mistrust of the mental health system on the part of family caregivers and care recipients (fear of respite leading to institutionalization), led to mistrust about available respite services.

In the same study, respite providers expressed their belief that individuals with mental illness should be included in mainstream respite

services as the need for respite for this population would be no different from that of people with other disabilities. At the same time, respite providers acknowledged problems concerning the inappropriateness of certain respite facilities

(such as nursing homes and day care centers) for this population; respite care workers' lack of knowledge and skills in dealing with people with a mental illness, and the stigma of having a family member with a mental illness (Jeon, et al., 2006).

While existing state information indicates that respite is available in many states, other information suggests that respite for family caregivers of individuals with mental health

If their behavior is out of control or unmanageable or very difficult, then it would be hard to find a place that would be able to cope with the person. I think people with mental illness when stabilized, may not want to go into a strange environment, which could de-stabilize them and make them feel unwanted.

View of Respite Provider from a study on how respite has been utilized, perceived and experienced by stakeholders (Jeon, et al., 2006)

well-being, including respite. Respite is a resource that provides short-term care to allow family caregivers to take a break from their regular caregiving duties. However, respite services may be unavailable, inaccessible, unused, or unaffordable to a majority of caregivers, especially caregivers of adults with mental health issues.

One study of respite for older family caregivers of individuals with severe mental health conditions found limited respite care

conditions is especially limited. A statewide survey of family caregivers in Delaware found that respite was in shortest supply for individuals with mental illness and behavioral disorders, as compared to those with other conditions. Only 18% of such individuals in need were receiving respite (Delaware Caregiver Support Coalition, 2005).

Much of the caregiving and respite literature to date has focused on the needs of caregivers of individuals with developmental disabilities and dementia/Alzheimer's disease. Only limited research has focused on the needs of caregivers of individuals with a variety of mental health challenges. Additional research is warranted to understand the needs of family caregivers of those with mental illness.

Federal and State Respite Resources

Increasingly, government policy has acknowledged the important role that the public sector has in sustaining family caregiving. There are several important federal and state respite resources that could be of particular use to family caregivers of adults with mental health issues.

Federal Respite Resources

There are three primary federal programs related to respite for family caregivers, (1) the National Family Caregiver Support Program (NFCSP), (2) the Home and Community-Based (HCBS) Medicaid Waiver Program, and (3) the Lifespan Respite Care Program (LRCP).

Descriptions of these programs are discussed elsewhere in more detail (ARCH Fact Sheet 2 (2011): [Building Blocks for Lifespan Respite: Federal Funding for Adult's and Children's Respite](#)).

Lifespan Respite Care Program. Under the Lifespan Respite Program, grants have been distributed to states and the District of Columbia to improve the availability and quality of respite services across the lifespan. This effort is important to family caregivers of those with mental illness because the program is charged with addressing the respite needs of those with conditions who have limited access to appropriate respite services. These grants include several model programs for addressing the needs of family caregivers of individuals with mental disorders.

New Hampshire Lifespan Respite Program

The New Hampshire Department of Health and Human Services, Special Medical Services, supports the Lifespan Respite Care (LRC) project in collaboration with the Bureau of Elderly and Adult Services, Bureau of Developmental Disabilities, Bureau of Behavioral Health, Division of Children and Youth, National Alliance on Mental Illness, New Hampshire Family Voices, and the College of Direct Support. The goal of the project is to increase availability of trained respite providers for New Hampshire residents. They have focused on training providers to work with individuals with Serious Emotional Disturbance (SED). Program objectives include the (1) choosing direct support training modules appropriate to respite care providers, modifying them to meet the project needs, (2) developing training modules to serve populations with SED and the Traumatic Brain Injured (TBI) , (3) developing a marketing campaign to recruit and train providers, (4) designing and implementing a coordinated registry providing access to fully trained respite care providers, (5) instituting a pilot targeting a specific population with SED based upon the model of New Hampshire Division of Children, Youth and Families (DCYF) Adoptive Care Respite Pilot. (US. Department of Health and Human Services, Administration on Aging, 2010b)

Medicaid Home and Community Based Services (HCBS) Waiver Program. The HCBS Waiver Program is an important source of federal matching funds for those in need of long-term services and supports. States have the option to apply for a waiver to implement the HCBS program, which allows them to use Medicaid funding for non-medical expenses such as respite. The majority of states and the District of Columbia offer respite through their HCBS waiver program. From a current ARCH survey which is underway, it was found that while many state home and community-based Medicaid waivers cover conditions such as Traumatic Brain Injury, only two states, Colorado and Montana, have home and community-based Medicaid waivers that support respite for adults ages 18-64 with Serious Emotional Disturbance and mental illness.

Community Mental Health Services Block Grant is a federal program administered by the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration that has the potential to fund respite for this population. This initiative assists states (through their state mental health agencies) in carrying out a plan for providing comprehensive community mental health services to adults with a serious mental illness and to children with a serious emotional disturbance. These grants are awarded under a complicated formula, with a minimum allocation based on 1998 funding levels. Some of the activities supported by this funding include mental health services, which must be provided only through appropriate, qualified community programs. Respite and crisis care may be included in direct mental health services provided by community programs. Funds may not be used for inpatient

services, cash payments to the intended recipients of health services, or to provide financial assistance to any entity other than a public or nonprofit private entity.

In 2007, the last time states reported on how they used their Community Mental Health Services Block Grant funds, nine states (AL, CT, IN, MA, ME, MI, MS, TN, and VT) indicated that they used some funds for respite. (Personal communication with John M. Morrow, Ph.D., Acting Director, Division of State and Community Systems Development Center for Mental Health Services, May 2011).

Unfortunately, many states also identified respite services among their unmet needs. In fact, some states identified respite as one of the services they would provide if additional funding were made available through the block grant (NASMHPD Research Institute, Inc. (2007).

Initiatives for Family Caregivers of Service Members and Veterans

The conflicts in Iraq and Afghanistan and the ever increasing number of veterans in the United States has resulted in greater attention to the needs of military service members, veterans, and their families. Among the wounds associated with military service are mental and behavioral health challenges. Just like their civilian counterparts, returning service members and veterans depend on family members for a variety of services and supports.

According to a recent study by the National Alliance for Caregiving and the United Health Foundation, caregivers of veterans serve in their role for a longer period and experience a heavier burden of care as compared to other

caregivers. Large proportions of these caregivers reported that they care for a veteran who has a mental illness such as depression or anxiety (70%) or posttraumatic stress disorder (60%). In addition, only 58% of caregivers of veterans reported that the veteran received help from other unpaid caregivers, 33% reported that they have received help from paid caregivers, and only 15% reported receiving respite services from the U.S. Department of Veterans Affairs (VA) or some other community organization within the past 12 months (National Alliance for Caregiving and the United Health Foundation, 2010). The report findings highlight the need for services and supports to assist our nation's wounded warriors and their families.

One significant initiative was recently established to assist those who care for the nation's wounded warriors and veterans:

Veterans Omnibus Health Services Act of 2010 (Public Law 111-163). In May 2010, a new federal caregiving initiative was established by Congress. The law authorizes the Veterans' Health Administration to offer several services and supports for approved family caregivers of veterans wounded since 9/11, including training in providing personal care services to the veteran, ongoing technical support, counseling, and lodging when accompanying the veteran to a VA facility. In addition, the family caregiver who is the designated primary provider of personal care services for the veteran can receive mental health services, respite care (not less than 30 days, including 24-hour per day care), medical care, and a monthly stipend. (U.S. Department of Veterans Affairs, 2011).

For additional respite supports offered to Military and Veterans, see ARCH Fact Sheet 2 (2011): [Building Blocks for Lifespan Respite: Federal Funding for Adult's and Children's Respite](#).

State Resources

From a state-by-state review of respite for adults with mental health concerns conducted informally by ARCH (still under review), it is apparent that very little state funding is currently available for respite directed to the family caregiver for this population. States that once used CMHBG or state funds are no longer doing so because of serious fiscal constraints. ARCH identified one state – South Dakota – still funding respite in a limited way for this group, but there may be others that allow limited state dollars to be used for respite or did so before recent state cutbacks.

Improving Respite for Family Caregivers of those with Mental Disorders

Evidence suggests that many family caregivers are in need of planned as well as emergency in-home supports, such as respite. Such services may help to avoid involuntary treatment (Huey, et al., 2007). However, a variety of conditions hampers successful access to and utilization of respite care for caregivers of individuals with mental health problems. These include: lack of knowledge and understanding of respite care; passive attitudes and behaviors towards respite; caregivers negative experiences with mental health services; lack of service flexibility; lack of mental health respite care focus within the healthcare system; inadequate care services and related resources; and poor support for

culturally and linguistically diverse groups (Jeon, et al. 2007).

South Dakota Respite for Adults with Mental Health Conditions:

Any family having a child or adult family member who has a developmental disability, a developmental delay (children only), a serious emotional disturbance, a severe and persistent mental illness, a chronic medical condition (children only), a traumatic brain injury, or a child they have adopted may be considered for respite services. Respite is available to eligible families regardless of income. There is no age limit. However, the child or adult must live with a parent or family member. Documentation of the child or adult's diagnosis must accompany the application form. Families are allotted \$550 per fiscal year \$200 per additional child or adult up to a family maximum of \$950. For more information:
Respite Care Program
Department of Human Services/Division of Developmental Disabilities
1-800-265-9684;
dhs.sd.gov/dd/respite/index.aspx

Much work remains ahead to address these barriers to care and challenges faced by family caregivers of those with mental disorders. Below are some considerations for improving respite for these family caregivers.

Combat Misinformation and Stigma

Societal misinformation and stigma associated with mental illness in the United States can have an impact on consumers and family caregivers. Natural support systems can be diminished due to the stigma associated with a loved one's mental health problems (U.S. Department of Health and Human Services,

Public Health Service, 1999b). In addition, a lack of understanding of mental health issues can make it challenging for family caregivers to find services and supports that are competent to address consumers with mental health needs.

Evidence suggests that difficulties may arise when using respite care facilities that do not specifically target consumers with mental health problems and their caregivers. Respite care workers' lack of knowledge and skills in working with mental illness, inappropriate respite care for some patients, and the stigma associated with having a loved one with a mental health problem also are barriers to respite use (Jeon, et al., 2006).

Many in the mental health advocacy arena are working diligently to address the issue of stigma through education and awareness initiatives in hopes of reducing the bias and prejudice experienced by those with mental illness and their families.

Improved Education and Training for Respite Providers

It is essential that education and training opportunities be made available to those providing respite for individuals with mental illness. Because many of the symptoms of mental disorders are behavioral, many family caregivers may be particularly concerned about leaving their loved one with a respite provider who is not educated about mental health issues. Ensuring that respite providers have specific knowledge regarding mental and behavioral health issues may make it easier for family caregivers of individuals with mental illness to utilize respite care and get a much needed break from their caregiving duties. It is also helpful for the respite providers to

understand the specific disorder of the consumer with whom they are working and receive education and training regarding techniques for appropriate management of associated symptoms and behaviors. Understanding the nuances of various mental health conditions may help a respite care provider to anticipate and avert potential challenges.

Maximize Flexibility and Consumer Control

Not all family caregivers have the same respite care needs. A great deal of diversity exists among family caregivers. They may have very different family relationships, caregiver resources and stressors, care recipient needs, and caregiving responsibilities. Therefore, a wide array of policy and programmatic options are needed to address these diverse needs. Efforts should be made to match the individual family need with available services or develop new services to meet caregiver needs (Autism PDD Support Network, 2010).

Further, some respite programs allow family caregivers to make key decisions about the type of services their loved one will receive and who will provide those services (Bueno, 2007). While some programs designate that respite must be provided by an agency provider or an independent provider who is not a family member, others allow family members, relatives, or friends to serve as providers of paid respite care (Bueno, 2007). There is a need for greater flexibility in respite services and the needs of caregivers should be recognized and addressed (Jeon et al., 2005).

In addition, all services for family caregivers must be psychologically accessible. This means that services such as respite must be seen by the consumer and the caregiver as “personally

relevant and responsive to their ideas regarding the nature of care need” (Huey et al., 2007).

Promote Culturally and Linguistically Competent Care

The U.S. population is becoming increasingly racially and ethnically diverse. According to a U.S. Department of Health and Human Services Surgeon General’s report (1999a) entitled “Mental Health: Culture, Race, and Ethnicity some important disparities exist among racial and ethnic minorities”. Specifically, minorities have less availability of, and access to, mental health services; are less likely to receive needed mental health services; often receive a lower quality of mental health care, and are underrepresented in mental health research.

The report also identifies a variety of barriers that deter minorities from reaching treatment (many of which are true for all Americans), including cost, fragmentation of services, lack of availability of services, and societal stigma toward mental illness. Racial and ethnic minorities may also face additional barriers including mistrust and fear of treatment, racism and discrimination, and differences in language and communication (U.S. Department of Health and Human Services, Public Health Service, 1999a).

Efforts must be made to develop and maintain a culturally and linguistically competent workforce of individuals to care for the needs of those with mental illness and their families. This includes respite providers and others who provide services and supports to family caregivers.

Recommended Strategies

Expanding respite options and improving respite access, appropriateness, acceptance and cultural relevance for those caring for adults with mental health issues will take the work and expertise of mental health professionals, government agencies, community providers and many others diligently working in partnership with family caregivers. There are steps that Lifespan Respite Programs, state organizations and respite coalitions, respite providers and even family caregivers can take to improve the situation.

For State Lifespan Respite Programs:

1. Grantees, charged with public education and education of family caregivers, can take the lead in bringing experts together to develop public awareness and education materials that focus on the special needs of adults with mental health issues to reduce the stigma.
2. While conducting needs assessments in your states to identify service gaps, include questions to determine the specific barriers to respite for this distinct population and work toward strategies to overcome these barriers.
3. In developing training materials to recruit and train respite providers and volunteers, seek expertise from the mental health professional community and family caregivers, to develop training modules that will result in more respite providers able to serve this population. Specifically, train providers and caseworkers to respect the dignity of the client and their family. Include family caregivers as part of the training team for professionals.

4. Offer participant-directed respite so that family caregivers have greater choice in hiring and training their own providers from their trusted communities of support.

5. Train family caregivers to recognize the warning signs of burnout and how to recognize when their loved one may be in need of additional care.

6. Develop training programs for peer mentors to assist other family caregivers. They understand what others coping with mental illness are experiencing.

For Respite Programs, Community Agencies, and Health Care Providers:

1. When looking for volunteers to assist in respite service delivery, consider reaching out to university or community college students who are pursuing careers in the mental health field or look to state professional associations to find volunteers with mental health experience.

2. Develop and use training modules that educate the respite workforce in the special needs of individuals with mental health concerns and offer additional supports to encourage respite workers to engage with this population.

3. Include family caregivers (with the appropriate consent of the consumer) as a member of the consumer's support team and encourage their input (where appropriate) in the development of individual service plans 4.

For state mental health agencies or state respite coalitions:

1. Provide information sessions for family members focused on particular mental

disorders, what to expect, and how to seek support.

2. Encourage State affiliates of mental health related organizations, such as the National Alliance on Mental Illness (NAMI) or Mental Health America (MHA), to co-sponsor educational events that allow for caregiver/care recipient feedback and input.

For Family Caregivers

1. Become involved with your state Respite Coalition and/or your State Lifespan Respite Program to share input regarding your specific respite needs.

2. If your state programs are already working on these issues, stay involved to offer your expertise and input as new respite services are developed and new providers are trained and recruited.

3. Seek support and use respite early and as often as appropriate!

Conclusion

Although caregiver stress and the need for services and supports are well documented, many family caregivers, especially those caring for adults with mental illness, do not have access to or utilize respite care. It is important that caregivers of those with mental disorders take care of themselves (National Institute of Mental Health, 2009). Research indicates that respite can be a beneficial resource for family caregivers and is associated with improved mental health and quality of life for family caregivers (Silberberg, 2001). Respite has been shown to decrease caregiver stress for individuals and families and postpones the need for institutional care for the consumer. However, given the dearth of available and

appropriate respite services for this population in particular, many challenges must be overcome to improve respite access and delivery for them.

Resources

The following resources may be helpful to Lifespan Respite Programs, respite providers, mental health consumers and their family caregivers.

Administration on Aging

www.aoa.gov

(202) 619-0724

The Administration on Aging (AoA) is the Federal agency responsible for advancing the concerns and interests of older people and their caregivers. AoA works with and through the Aging Services Network to promote the development of a comprehensive and coordinated system of home and community-based long-term care that is responsive to the needs and preferences of older people and their family caregivers. AoA is part of the Department of Health and Human Services and is headed by the Assistant Secretary for Aging, who reports directly to the Secretary. AoA administers two important programs for family caregivers, including the National Family Caregiver Support Program and the Lifespan Respite Care Program (LRCP).

American Psychiatric Association

(703) 907-7300

www.psych.org

The American Psychiatric Association is the world's largest psychiatric organization. It is a medical specialty society representing more than 38,000 psychiatric physicians from the United States and around the world. Its member physicians work together to ensure humane care and effective treatment for all

persons with mental disorders, including intellectual disabilities and substance-related disorders. Its vision is a society that has available, accessible quality psychiatric diagnosis and treatment.

American Psychological Association

www.apa.org

(202) 336-5500

The American Psychological Association is a scientific and professional organization that represents psychology in the United States. With 154,000 members, the American Psychological Association is the largest association of psychologists worldwide and its mission is to advance the creation, communication, and application of psychological knowledge to benefit society and improve people's lives. In 2010, APA developed a Family Caregiver Briefcase for Psychologists. Its purpose is to assist all psychologists in identifying and addressing the needs of family caregivers. It organizes and provides resources and information in a way that is useful to them in identifying and providing services to family caregivers.

Mental Health America

www.mentalhealthamerica.net

(800) 969-6642

Mental Health America (formerly known as the National Mental Health Association) is the country's leading nonprofit dedicated to helping all people live mentally healthier lives. With more than 320 affiliates nationwide, they represent a growing movement of Americans who promote mental wellness for the health and well-being of the nation – everyday and in times of crisis.

MilitaryHOMEFRONT

http://www.militaryhomefront.dod.mil/portal/page/mhf/MHF/MHF_HOMEPAGE

MilitaryHOMEFRONT is the U.S. Department of Defense website for official Military Community and Family Policy (MC&FP) program information, policy and guidance designed to help troops and their families, leaders, and service providers.

Military OneSource

www.militaryonesource.com

(800) 342-9647

Military OneSource is provided by the U.S. Department of Defense at no cost to active duty, Guard and Reserve (regardless of activation status) and their families. It is a virtual extension of installation services.

National Alliance on Mental Illness (NAMI)

www.nami.org

(800) 950-NAMI (6264)

From its inception in 1979, NAMI has been dedicated to improving the lives of individuals and families affected by mental illness. For three decades, NAMI has established itself as the most formidable grassroots mental health advocacy organization in the country. Dedication, steadfast commitment, and unceasing belief in NAMI's mission by grassroots advocates have produced profound changes. NAMI's greatest strength is the dedication of our grassroots leaders and members that include the families, friends, and individuals that serve to strengthen communities across the country.

National Association of Social Workers

www.socialworkers.org

202-408-8600

The National Association of Social Workers (NASW) is the largest membership organization of professional social workers in the world, with 145,000 members. NASW works to enhance the professional growth and development of its members, to create and maintain professional standards, and to advance sound social policies. In 2010, NASW

released the [NASW Standards for Social Work Practice with Family Caregivers of Older Adults](#), designed to enhance social work practice with family caregivers of older adults and to help the public understand the role of professional social work in supporting family caregivers.

National Institute of Mental Health (NIMH)

www.nimh.nih.gov

(866) 615-6464 The National Institute of Mental Health (NIMH) is the largest scientific organization in the world dedicated to understanding, treating, and preventing mental illnesses through basic research on the brain and behavior, and through clinical, epidemiological, and services research.

National Military Family Association

<http://www.militaryfamily.org/>

The National Military Family Association is an organization that speaks up on behalf of military families and empowers husbands, wives, and children to understand and access their benefits. They meet the needs of service members and their families with insightful recommendations, innovative programs, and grassroots efforts to better the quality of life for military families.

Substance Abuse and Mental Health Services Administration (SAMHSA)

www.samhsa.gov

(877) SAMHSA-7

SAMHSA was established in 1992 and directed by Congress to target effectively substance abuse and mental health services to the people most in need and to translate research in these areas more effectively and more rapidly into the general health care system. Over the years SAMHSA has demonstrated that - prevention works, treatment is effective, and people recover from mental and substance use disorders. Behavioral health services improve health status and reduce

health care and other costs to society. Continued improvement in the delivery and financing of prevention, treatment, and recovery support services provides a cost effective opportunity to advance and protect the Nation's health.

U.S. Department of Veterans Affairs

VA Caregiver Support Services

http://www.caregiver.va.gov/support_landing.asp

1-855-260-3274 (Caregiver Support Line)

The VA offers a variety of family caregiver supports for family caregivers of veterans, including respite.

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