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"A Vital Christian Presence in Social Work"

CAREGIVER/FAITH BASED ORGANIZATION COALITIONS: AN INNOVATIVE MODEL FOR MENTAL HEALTH CAREGIVING

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Partnerships between caregivers and faith-based organizations can offer opportunities to build support systems for adults with mental illness. This workshop will explore the strength of such collaborations. Participants will learn: (1) the benefits of this approach; (2) the steps to developing caregiver/faith-based coalitions; and (3) implications for social work practice.

Introduction

Mental disorders are common in the United States and internationally. An estimated 26.2 percent of Americans ages 18 and older — about one in four adults — suffer from a diagnosable mental disorder in a given year. When applied to the 2004 U.S. Census residential population estimate for ages 18 and older, this figure translates to 57.7 million people. In addition, mental disorders are the leading cause of disability in the U.S. and Canada for ages 15-44. Many people suffer from more than one mental disorder at a

given time. Nearly half (45 percent) of those with any mental disorder meet criteria for 2 or more disorders, with severity strongly related to comorbidity (NAMI, 2006). As a result, the impact of mental illness not only affects the individual, but the family as well. In short, mental illness is a *family disease* and impacts the family at every level.

Caregiver Support & Stress

Mental illness can erode the foundation and the structure of the family, especially for families with person with a chronic mental illness. As the person with mental illness progresses through their illness, oftentimes you see changes in roles and relationships within the family unit. Out of necessity, family members assume non-traditional roles of caregivers for their loved one suffering from a mental illness. A Caregiver is defined as supportive services provided to those who have difficulty solving their problems and meeting their own needs. (Zastrow, 2003). The caregiver is responsible for providing basic living needs including housing, food, financial and emotional support, medication compliance and sometimes personal care for their loved one. It is not unusual that they become the decision-maker for their loved one with chronic mental illness. Over time, the caregiver may be placed in a position that their lives are dictated by the current mental health status of their family member. In addition, they often experience increased financial expenses associated with caring for their loved one.

As the illness becomes chronic and progresses, families see further changes in their relationship with their loved one. The stress of frequent hospitalizations and/or noncompliance can become overwhelming. The caregiver often experiences frustration with the assumption of increased responsibility with limited control. Both the caregiver and person suffering from the chronic condition live with anger regarding the loss of their

lives “before” the illness. A caregiver in a healthy family structure typically is the parent. However, in families with mental illness, the caregiver’s role may become displaced. It is not unusual for a child or spouse to assume the role of caregiver for their parent or wife/husband.

Each time the person experiences a relapse in their treatment, the family structure is changed. This intensifies the cost of caregiving. With frequent hospitalizations, the home may be replaced with a shelter, group home or alternative living situation. The person living with a chronic mental illness may become transit, wandering from place to place with limited or no contact with their family. An estimated one-third of the approximately 600, 000 Americans who are homeless on any given night have serious mental illness (U.S. DHHS, 2003). As a result, they may require support from public and private mental health service delivery systems.

Caregiving vs. Case management

With the introduction of various formal systems of mental health delivery, the role of caregiver is redefined. The role of caregiving is no longer provided by the family or loved one but incorporated in the role of the case manager. The case manager becomes the constant figure in the client’s life. The definition of case management is a “procedure to plan, seek, and monitor services from different agencies and staff on behalf of a client” (Zastrow, 2003) becomes more animated. Additionally, according to Frankel and Gelman (1998) “it is not enough to insure that adults with serious mental disorders have their prescriptions filled; many need continuing support in taking them. Sometimes, the difference between living independently and institutionalization depends on medication.” The primary issue for person with mental illness is housing and basic living

Day treatment, job training, education and socialization programs are secondary (Frankel and Gelman, 1998). Case managers are trained to facilitate individuals in obtaining the resources and support necessary to effectively manage their mental illness.

In order to provide the best care in health settings, The Joint Commission on Accreditation for Hospitals and the National Institute for Mental Health Community Support Program recommends the following major components of case management in mental health: 1) assessment, 2) planning; 3) linking; 4) monitoring; 5) advocacy. (Joint Commission on Accreditation of Hospitals, 1976) (Turner and TenHoor, 1978). Assessment includes the assessment of the client's current and future potential with focus on strengths as well as weaknesses and needs. In planning, the worker focuses on developing an individualized plan which includes linking and providing clients with 24 hour services/activities. Services are monitored continuously with the client and evaluated for modification, compliance and the need for intervention as an advocate for equality in access, delivery and provision of services (Johnson and Rubin, 1983).

While the above-mentioned model to case management ensures that mentally ill clients have the resources they need to manage their illness, it lacks a connection to the community and may overlook the role of family members in the helping process. Rapp and Goscha (2004) offer a collaborative approach to case management. They state that two of the active ingredients of effective case management are "natural community resources are the primary partners" and "work is in the community." A natural resource that is often ignored in the community is the participation in faith-based activities and partnering with family networks.

The Helping Tradition Among Faith Based Organizations

The development of social services, and the social work profession, has historical roots in religious teachings of various faith institutions. “As early as 1200 BC, religious leaders urged Jews to help the poor in their communities. Reflecting those tenets, historical Jewish documents describe charitable services that actually resemble modern-day mediation and casework.” (Berg-Wager, p. 22). Today, churches provide a variety of social services. A few primary services that would be useful when supporting adults with mental illness are: Transportation: regular transportation either for bus or cab fare (to help defray costs). Volunteer coordination to take individuals to medical appointments, church services, life skills classes and job training, shopping, pharmacy, bank, barbershop etc.; Friendship: spending time with a person with mental illness, listening to them and just being a “friend”; Recreational/Social Activities: churches have many activities where members can serve as “sponsors” to attend various meetings and activities with the mentally ill adult. Deacons, Deaconesses and other helping ministries within the church can provide support in this area; and Cash Assistance: provide cash awards to help individuals meet living expenses (i.e. paying utility, phone bill, prescriptions, bus fare etc. These services can become a useful tool in providing support and assistance for people with mental illness and their caregivers through caregiver/faith based organization coalitions.

The Benefits of Caregiver/Faith Based Organization Coalitions

The case manager’s role of working within the community to provide services can best be served by partnering two already existing systems: faith institutions and caregivers of persons living with mental illness. The case manager historically has

recognized the role of the family in a client's treatment and care. However, mental health systems fail to build a system that relieves stress and strengthen family roles, structure and maintenance.

Therefore, the creation of faith based organization coalitions can become a primary support network for mentally ill adults and their caregivers. The concept behind faith-based organizations as a model for caregiving is fostered in the rooted mission of "loving they neighbor." Additionally, a core value of most religious institutions is a commitment to social justice, respect for all persons and nondiscrimination. "Sharing the message that all persons are worthy in the eyes of God, a faith community may be the only place where a person with a mental illness truly feels accepted, valued and loved." (NAMI, 2006, p. 1).

A key component of that concept is in the investment in the neighbor's emotional and mental wellbeing as noted in Galatians 6:2. It states, "Bear one another's burdens and so fulfill the law of Christ." (Holy Bible, NIV Version,). In the spirit of spreading Christ's compassion, faith-based organizations can challenge the stigma associated with mental illness; extend non-financial resources such as shelter, meals, support program. They can also provide support through visits to their home, listen and give moral support, learn more about the illness, serve as respite for families and just open their doors to facilitate access to family and case management services.

Steps to Building Caregiver/Faith Based Organization Coalitions

Gunnar E. Christiansen, M.D., founder of FaithNet NAMI, outlined several steps for case managers to use in building support for a mental health coalition between faith congregations, case managers, caregivers, consumers and formal mental health delivery

systems. Additionally, coalitions can be a useful tool in coordinating human services between case managers and faith institutions. In fact coalitions are effective in helping case managers to increase public awareness on mental health caregiving and provide needed community networks to help people with mental illness. (Christiansen, 2006).

The first step in building a network is to gain the support of senior clergy. Use a personal story on the impact of mental illness on consumers, friends and especially caregivers. The second step is to establish a coalition of consumers, family members and human service professionals as well as representatives from participating faith institutions. Once coalition members are identified, a strategic plan should be developed; include goals, objectives and a timeline. Additionally, the coalition should identify supports within the faith community (i.e. senior clergy such as deacons as well as church members with mental illness as well as compassionate adults.

The third step is to create educational campaigns for local congregations on the causes and scope of mental illness. It is also important to educate congregations on stigma related to mental illness. To do this, customize the approach to match various faith traditions. Also use fact sheets, information kits, and bulletin inserts to educate members and potential volunteers about mental illness. Also, it is important to allow full participation of coalition members in developing and implementing the educational campaign.

Finally establish a support network for caregivers/family members. Oftentimes, family members are overlooked in the quest to provide services and support for the mentally ill adult. Family members may be concerned about their ability to provide for their loved-one. They may experience feelings of guilt, frustration and anger. A family

member may also be concerned about the financial impact of treatment and hospitalizations. Another concern of siblings is that they might develop a mental illness. Caregiver support groups provide a safe space for family members to express their feelings in a safe place. (Christiansen, 2006).

Implications for Social Work Practice

The implementations of faith based organization caregiver coalitions have several major implications for social work practices and linkages with religious institutions. First, faith-based organizations provide a natural support network that is community based and consumer driven. Within caregiver/faith based organization coalitions, mentally ill adults are empowered to become active participants in their recovery within their own community networks. Second, these coalitions can provide respite services for caregivers in a supportive environment. They also provide family members with a safe place to express their hopes, features and struggles related to their role as caregivers. Third, caregiver/faith based coalitions serve as a much needed resource for case managers who desire to implement a collaborative approach to case management. From this perspective, case managers have an important resource in linking their clients to services that are both strengths' based and empowering.

While caregiver/faith-based organization coalitions offer several positive implications for social work practice, there are some limitations to the development of such partnerships that must be explored. Faith institutions must be careful not to stigmatize individuals with mental illness as being demon possessed and only need prayer to "cure" their illness. Similarly, participants from faith-based organizations should realize that they fulfill the mission of Christ by helping "the least of these" by their

support and friendship with mentally ill adult and/or family member who participates in their coalitions. Next, case managers must be willing to work in partnership with faith-based organizations to educate them on the stigma of mental illness as well as the challenges of managing it. Finally, faith institutions that participate in these coalitions must realize that success may not be immediate, but are rewarding.

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