







### *Caregiver Burden*

The caregiving burden is multidimensional and includes direct care of a loved one and disruption in the family's life and activities (Sales, 2003). Caregiving responsibilities negatively impact the caregivers' quality of life, as well as physical and mental health (Rees, O'Boyle, & MacDonagh, 2001; Smerglia, Miller, Sotnak, & Geiss, 2007). A meta-analysis by Pinquart and Sorensen (2003) demonstrated that individuals caring for elderly adults are more likely to experience depression, stress, and poor general health compared to non-caregivers. Activity restriction is a mediator between the caregiving burden and depressive symptoms, indicating that caregivers' mental health is negatively affected by the constraints that providing care places on their lives (Nieborer et al., 1998).

Caregivers, particularly parents, of people with mental illness face the challenge of providing extended caregiving. Mental illnesses often emerge in adolescence or young adulthood and thus require long-term support (Aschbrenner, Greenberg, Allen, & Seltzer, 2010). Additionally, family members and caregivers can experience stigma associated with their loved one's mental illness. Stigma by association includes social exclusion, blame for the individual's conditions, and not being taken seriously, and is associated with emotional distress in the caregiver (Sanden, Stutterheim, Pryor, Kok, & Bos, 2014).

### *Advocacy and interventions at the relationship level*

To provide effective care and to cope with the difficulties of caregiving and stigma by association, supports can benefit caregivers. In a qualitative study of caregivers who experienced depression, three main interventions that participants felt would be especially beneficial were support groups, respite care, and financial aid (Ramsay, Walker, Ramsay, Compton, & Thompson, 2010). Support groups allow caregivers to connect with each other and share stories. However, caregivers often have difficulty in finding time to attend such groups. Respite care, where a loved one can be watched for a limited time, gives the caregivers an opportunity for rest and personal time. The downsides to respite programs are that they can be far away, especially for caregivers living in rural areas, and are not always affordable. Finally, financial assistance provides caregivers some relief from financial strain, especially when the caregiver cannot work due to the needs of their loved one. Financial assistance often is based upon complex eligibility criteria and application processes that can be difficult to navigate (Ramsay et al., 2010). Advocating for policies that provide easier access to these services could ease the burden on caregivers and lessen the strain on both caregivers and their loved ones. Once again, this would involve advocacy for distance-delivered programs.

### **Mental Health Advocacy and the Community**

Although most mental health services are provided at the community level, there are limitations to mental health advocacy at this level that create barriers to effective implementation of interventions. These factors include, but are not limited to, trust, community norms, needs unique to diverse populations, licensing laws, and the availability of emergency and safety services. This section outlines ways in

which each of these factors influences mental health services at the community level. The section concludes by describing how being mindful of these factors can increase community-level access to mental health services.

### *Trust and norms*

In delivering mental health interventions, trust is a factor in ensuring the success and sustainability of a program. Since trust is relational and built over time, we are often dependent on those individuals in communities who are already trusted as sources of support and collaboration when advocating for enhanced access to community-level resources. In Project UPLIFT, described above, the model is to use a person from the targeted population as a co-facilitator, but these individuals must be carefully selected because their presence in the group influences the participation of others in their community, either positively or negatively. The previously cited study by Ramsay and colleagues (2010) highlights issues surrounding trust associated with mental health care at the community level. Caregivers in this study stressed the need to have someone they know to help them cope with the stress of caregiving because they were concerned with issues of confidentiality (Ramsay et al., 2010), revealing a tension between wanting to get help and feeling uncomfortable accessing it. Other caregivers raised concerns over the use of computer technology, which indicates that these technological methods may not always provide the best way to make interventions accessible to hard-to-reach populations. To enhance access to mental health services in communities, we should recognize that who and what method of interaction is trusted may look different within and across communities. To reach people and provide them with resources in a way that is meaningful to them, we need to advocate for recognizing the norms of each community and for incorporating these norms into our programs. Creating resources that are consistent with community norms helps make them more accessible.

### *Considering diverse populations*

Within communities, there may be subpopulations that face additional barriers to accessing mental health resources. The diversity within a community must, therefore, be considered when promoting these resources. Cultural differences within a community can pose additional barriers to allowing diverse populations to access mental health resources (Morris, Popper, Rodwell, Brodine, & Brouwer, 2009). The communication or manifestation of symptoms may vary across cultural groups, thus creating a complex dynamic that can influence quality of care when the culture of the patient differs from that of the medical provider (Office of the Surgeon General, Center for Mental Health Services, & NIMH, 2001). Regarding symptoms, a review of primary care and population-based studies found that depression and anxiety disorders are associated with the presentation of somatic symptoms that cannot be explained by the methods of the healthcare practitioner (Kroenke, 2003). Furthermore, access to a support system and coping style also affect an individual's interface with the healthcare system.

Refugees and other immigrant groups are community subpopulations for consideration, especially in Georgia. As

of May 2014, Georgia ranked eighth in receiving the most refugee arrivals in the United States (Bureau of Population, Refugees, and Migration, 2015). Refugee populations often experience high levels of psychological distress as a result of displacement-related stressors (Pernice & Brook, 1996; Miller & Rasco, 2004; Gorst-Unsworth & Goldenberg, 1998). Depression rates range from 5-21% among different refugee groups (Martens, 2007; Ao et al., 2012). A recent study involving Bhutanese refugees resettled in the United States found that their annual age-adjusted suicide rate was 24.4 per 100,000; approximately double that of U.S. residents (12.4 per 100,000) (Ao et al., 2012). Furthermore, influenced by differences in social norms regarding social support for people with mental illness, many Bhutanese refugees use withdrawal and self-harming coping mechanisms to deal with stress, rather than seek out mental health services (Chase, 2012).

Despite these statistics and concerns, there is a lack of community-based mental health interventions for refugee populations. Moreover, there are circumstances faced by refugees that pose additional challenges to accessing mental health services. Language barriers limit an individual's ability to navigate their new environment and communicate with people outside of their community, particularly to identify and seek out specialized medical services. Since many adults are reliant on their children as translators, having appropriate translators can help these individuals in the resettlement process. Beyond the language barrier, the significance of a health program may be lost if a person does not share the same view on disease etiology. Translating materials and helping these individuals understand when, where, and why a program is taking place is essential. Many adult refugees are caregivers for both children and elderly family members and cannot be expected to access mental health services if they do not have support systems in place that allow them to prioritize their health needs. Transportation is also a widely recognized barrier for refugees because they often lack the financial means to buy a car and are therefore reliant on public transportation systems. Such reliance requires that we be mindful of the timing of programs and where they take place so they are accessible. To advocate for the mental health of diverse populations, we should recognize when barriers such as these limit the reach of community-level resources.

#### *Professional licensing and emergency and safety services*

Telehealth is a promising approach to delivering mental health services to underserved areas and geographically isolated populations. It allows health care providers to employ technologies, such as telephone and video conferencing, to deliver health-related services directly to patients in places where no providers are available or when it is difficult to reach patients in an effective manner. However, telehealth is not only limited to reaching patients who have access to a qualified medical facility (ATA, 2013), the practice places the burden on mental health professionals to become licensed in each state in which they have patients for whom they are providing care. For example, Georgia law states that psychologists in other states providing services to patients in Georgia must be

licensed to practice in Georgia (Representation of Services, 2004). Thus, when distance delivery takes place across state lines, there are barriers for both the patient and the psychologist. Tele-mental health also poses challenges when practiced community-to-community within a state, particularly concerning the capacity to provide emergency services to patients in need. To ensure the safety of their patients, mental health professionals practicing distance delivery services must become familiar with or advocate for emergency service referrals where their patients are located.

#### *Advocacy and interventions at the community level*

As noted, to advocate for enhanced access to mental health services at the community level, we need to consider the subpopulations within communities who face additional barriers to accessing mental health services. Language translation, culturally sensitive materials, and ease of access are relevant aspects of intervention. Engaging trusted people from the community to assist in developing intervention materials that reflect appropriate language and cultural norms is an essential step in this process. Intervention materials that reflect appropriate language and cultural norms can then be delivered throughout the community, and, with distance delivery, throughout the state of Georgia. If groups do not have access to the technology required for distance delivery, however, equipment and training will need to be provided or alternative methods explored. Advocating for access to inexpensive equipment such as throw-away telephones and training in the use of the equipment could enhance access to community-level mental health services and ease the burden on groups that are disproportionately affected by mental illness and who face barriers to seeking treatment services.

#### **Mental Health Advocacy and the Society**

In 2010, Healthy People 2020 added a goal to "create social and physical environments that promote good health for all" (U.S. Department of Health & Human Services (HHS), 2014, p. 3). For achieving this goal, the objectives focus on key areas and underlying factors, including economic stability, social and community context, and health and health care (HHS, 2013). In this section, we discuss some underlying factors that influence mental health outcomes at the societal level, including the distribution of wealth, stigma and discrimination, and access to health care. We also discuss how cost data may assist in advocating for interventions that may contribute to addressing these societal-level influences.

#### *Income inequality*

In the United States, income inequality has worsened over the last few decades. In 2013, the top five percent of household income accounted for 22.2% of all income, whereas in 1980, the top five percent accounted for only 16.5% (U.S. Census Bureau, 2014). Locally, a 2014 analysis of income inequality in 50 cities found that Atlanta was the most unequal city (Berube & Holmes, 2015). This is relevant because income inequality is related to worse mental health outcomes (Pickett & Wilkinson, 2015).

The relationship between income inequality and mental health exists at various levels of influence. For instance,

Burns and colleagues (2014) found that a one-point increase in income inequality at the country level corresponded with a two-point increase in the incidence of schizophrenia. In another longitudinal study at the state level, depression was related to income inequality (Pabayo, Karachi, & Gilman, 2014). However, this relationship was statistically significant only for females, not males (Pabayo et al., 2014). The authors hypothesized that a reason for the gender difference is that income inequality may contribute to the erosion of social networks and social cohesion, and women may be more likely to be influenced by these factors (Pabayo et al., 2014). With evidence supporting the relationship between income inequality and mental health outcomes at various geographic levels and for various mental illnesses, addressing income inequality may prove helpful in reducing the burden of mental health problems.

### *Stigma and discrimination*

Stigma and discrimination also influence mental health outcomes at the societal level. Individuals who have such experience have worse mental health outcomes (e.g., Bostwick et al., 2014; Soto, Dawson-Andoh, BeLue, 2011). People may be subject to stigma and discrimination based on age, gender, disability, race/ethnicity, sexual orientation, and mental health status, among others. Those who experience more than one type of discrimination are more likely to report mental health problems (Bostwick et al., 2014; Soto et al., 2011). For example, when lesbian, gay, and bisexual adults experience discrimination based on sexual orientation and race/ethnicity, they are more likely to report a mental health disorder, and the likelihood increases with the more types of discrimination they experience (Bostwick et al., 2014). Similarly, as determined in a study examining the relationship between discrimination and generalized anxiety disorder among African Americans, Afro Caribbeans, and non-Hispanic Whites, those who experienced more discrimination were more likely to report generalized anxiety disorder (Soto et al., 2011). For race-based discrimination, only African Americans reported greater levels of anxiety (Soto et al., 2011).

Stigma and discrimination related to mental health status also have effects on mental health outcomes and on disparities in health care, education, and employment outcomes (Hatzenbuehler, Phelan, & Link, 2013). Delay in accessing mental health care due to stigma and discrimination (Clement et al., 2014) or experiences of stigma and discrimination within the health care system may reduce the quality of care that individuals receive (Thornicroft, Rose, & Kassam, 2007).

### *Health care access*

Limited access to mental health care coverage is a potential consequence of stigma and discrimination. Historically, within the health care system, mental health services have not been covered equally with physical health services. This unequal access may contribute to inadequate provision of services. A study of mothers with depression found that 38% did not receive any treatment; only 35% received adequate treatment (Witt et al., 2011). Even those with access to treatment did not receive adequate services. While the 2008 Mental Health Parity and Addiction Equity Act

and the 2010 Patient Protection and Affordable Care Act (ACA) provide legislation to improve the provision of mental health care (Beronio, Glied, & Frank, 2014), monitoring and evaluating the extent to which insurance companies are complying with the new rules of parity is needed (Langheim, Shim, & Druss, 2015).

Gaining insurance coverage benefits mental health outcomes. Oregon implemented a health plan that expanded access to health care for low-income, uninsured individuals (Baicker et al., 2013). Those who received insurance coverage reported lower rates of depression than those who did not (Baicker et al., 2013). Providing access to insurance may reduce stress and the financial strain associated with accessing health care services, which could influence mental health outcomes (Baicker et al., 2013; Langheim et al., 2015).

### *Advocacy and interventions at the societal level*

To make substantial changes in the societal-level factors that influence mental health, changes to policy and programs that address areas of influence are needed. Data that demonstrate the cost effectiveness and benefits of programs may help convince decision-makers about the value of these programs. Some examples of programs that have collected and provided this type of information are described below.

**Income Inequality:** Vinokur and colleagues (1991) developed an effective intervention to assist individuals who had lost their jobs. Those who participated in an employment support program that focused on reducing poor mental health outcomes had a quicker return to work and had higher wage earnings, thus reducing their income disparity. The authors estimated that this would benefit each participant by more than \$45,000 over a working lifetime, (Vinokur et al., 1991).

**Stigma and Discrimination:** In the United Kingdom, results of a national campaign to reduce stigma related to mental illnesses suggested that the benefits of the intervention outweighed the costs (Evans-Lacko et al., 2013). The authors estimated that more people with depression have the potential to access services and gain employment, providing a positive economic benefit in relation to campaign costs.

**Health care Access:** Programs like Project UPLIFT (Thompson et al., 2014) have the potential to demonstrate value due to the distance- and group-delivery format. Future innovations in health care delivery, as well as increased access to care, may demonstrate cost-effectiveness and benefits. Evaluating the cost-effectiveness and benefits of these programs could provide support for their dissemination.

Demonstrating the potential value of interventions, in addition to their effectiveness, assists in advocating for the implementation of these programs. Broader implementation of effective programs could reduce the number of people experiencing poor mental health.

## CONCLUSIONS

The social-ecological model provides a framework that outlines the dynamic interplay of influences between people and their environments (McLaren & Hawe, 2005). With a substantial proportion of the population likely to experience a mental or behavioral disorder at some point (Ferrari et al., 2013), the burden of these disorders needs to be addressed. Furthermore, the multiple and complex influences on mental health outcomes require a multi-level perspective that the social-ecological model offers.

At the individual level, people with mental illnesses experience various problems, including internalized stigma and comorbid chronic illnesses. Encouraging people with mental illnesses to be kind to themselves and develop the skill of self-compassion may reduce the negative outcomes that can result from internalized stigma. Innovative programs, such as Project UPLIFT, may reduce the impact of comorbidity by treating and preventing depression and anxiety among people with chronic illnesses (Thompson et al., 2014; Thompson et al., 2010).

At the relationship level, caregivers provide valuable support to people with mental and/or physical health conditions. However, these relationships are complex and at times are difficult for the caregiver. The spectrum of support that caregivers provide influences the burden they may experience, which can influence their quality of life and physical and mental health (Rees, O'Boyle, & MacDonagh, 2001; Smerglia, Miller, Sotnak, & Geiss, 2007). Aiding caregivers through support groups, respite care, and financial assistance may help reduce the burden they experience.

At the community level, barriers such as trust, community norms, needs of diverse populations, licensing laws, and access to emergency and safety services may contribute to the community burden of mental illnesses. Acknowledging community-level barriers and working with subpopulations, such as refugees, to understand how they view mental illnesses and mental health providers and to develop solutions to increase access to mental health services would ensure that interventions are tailored to their needs and community values.

Finally, at the societal level, influences on mental health include, among others, income equality, stigma and discrimination, and access to health care coverage. Each of these contributes to disparities among sub-populations, including those with poor mental health outcomes. Effective interventions addressing each of these factors have been developed, providing a foundation for reducing poor mental health outcomes at the societal level. Use of cost data to demonstrate their value could convince policy and decision-makers to support wider dissemination and implementation.

Each of the levels described in this review offers opportunities for advocacy and intervention. Moving forward, advocacy and interventions that are designed to have an impact across the levels of the social-ecological model have the potential to contribute to progress in

improving mental health outcomes. In Georgia, limited access to mental health services (Aron et al., 2009) and lower levels of funding for mental illnesses suggest that mental health advocacy at the various levels of the social-ecological model could help address the burden of mental illnesses in this state (National Association of State Mental Health Program Directors Research Institute, Inc., 2006).

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