



**COLLABORATIVE RESEARCH GRANT INITIATIVE:  
MENTAL WELLNESS IN SENIORS AND PERSONS WITH DISABILITIES**

**Supports and Barriers to Independent Living and Mental Wellness in Seniors and Persons with Disabilities**



Alberta Mental Health  
Research Partnership Program



**Alberta Health  
Services**

**Building Healthy Communities through Collaboration and Learning:**

**Greg Wells, Ph. D., Psychology Instructor Red Deer College  
Scott Oddie, Ph.D., Rural Health Research Chair**

**Jacqueline Egg, Disability and Community Service Instructor, Red Deer College  
Val Trotter, Administrator, Bethany Care Society, CollegeSide  
Arron Service, Ph.D., Research & Evaluation Manager, AHS-DTHR  
Student Team Members: Heather Cardwell , Katrina  
Mundell, Peggy MacKenzie, Dylan Smibert & Danielle Nederlof**



# Table of Contents

<b>Introduction</b>	<b>3</b>
<b>Inclusion Criteria for Literature Reviews</b>	<b>4</b>
<b>Review Process</b>	<b>5</b>
<b>Synthesis Results</b>	<b>6</b>
<b>Barriers to Independent Living</b>	<b>7</b>
<b>System Barriers</b>	<b>7</b>
<b>Adequacy of Resources</b>	<b>7</b>
<b>Fragmentation of Services</b>	<b>8</b>
<b>Policy Issues</b>	<b>9</b>
<b>Environment</b>	<b>9</b>
<b>Quality of Service Barriers</b>	<b>10</b>
<b>Attitudes of Health Professionals to Mental Health Problems</b>	<b>10</b>
<b>Lack of Involvement of Individuals in Decision-Making</b>	<b>11</b>
<b>Inappropriate Treatment</b>	<b>11</b>
<b>Not Adequately Addressing Community Barriers</b>	<b>11</b>
<b>Lack of Consideration for Cultural Perspectives on Mental Health</b>	<b>12</b>
<b>Lack of Knowledge by Mental Health Professionals of Physical Impairment</b>	<b>12</b>
<b>Individual / Family Caregiver Barriers</b>	<b>12</b>
<b>Individual</b>	<b>12</b>
<b>Family Caregivers</b>	<b>13</b>
<b>Societal Barriers</b>	<b>13</b>
<b>Effective and Suggested Interventions</b>	<b>15</b>
<b>Individual / Family Caregiver Interventions</b>	<b>16</b>
<b>Summary</b>	<b>18</b>
<b>References</b>	<b>19</b>
<b>Appendix 1 – Databases Used</b>	<b>26</b>



## Introduction

Independent living is popularly conceptualized as the ability to do things on one's own, and the main indicator of the concept is often whether one lives on one's own in the community. Inherent in this view is the implication that those who reside in facility-based care have necessarily failed in the realization of independent living. A more encompassing view of independent living, and the one that will guide this report, is that the concept refers to having adequate access to the necessary resources and assistance which allow for self-determination in directing the course of one's life and active participation in making choices about matters of personal concern. In this context independent living can be seen as a defining contributor to overall quality of life, and indeed as a fundamental human right.

There are, of course, differences between individuals and between groups with regard to what constitutes independent living and with regard to what barriers are faced in achieving it. For example, seniors, persons with disabilities and those with mental health concerns each have unique independent living needs and experiences – and each group faces distinct challenges. Moreover, the fact that these groups are not mutually exclusive means that there are also additional sub-groups with their own experiences, challenges and issues. In order to promote a conceptualization of independent living which takes into consideration individual needs, abilities, preferences and goals, it is important that this diversity be acknowledged and explored. The purpose of this report is to consider the unique challenges that seniors and persons with disabilities, who also have mental health concerns, face in realizing independent living, and to explore strategies for meeting these challenges.



## Inclusion Criteria for Literature Review

Research into mental health and wellness is, of course, a vast and multifaceted enterprise which remains so even when limited to elderly or disabled populations. For example entering “depression” and “aging” as combined search terms in a single database “Psych Info” yielded over 700 peer-reviewed articles. Entering “mental health” and “disability” in this same database resulted in over 500 articles. The body of research focusing on independent living is also very large. For example, entering “independent living” with “seniors” and with “disability” produced 656 and 363 articles respectively. To narrow the literature search to a manageable level it was decided that the following inclusion/exclusion criteria would be used:

First, the review was limited to peer-reviewed research articles dealing with some aspect of independent living. Second, only articles where participants were expressly identified as seniors or as having a disability were included. Seniors were identified as adults over age 65. Persons with disabilities were generally defined as those experiencing identified physical or developmental performance limitations. This included those with acquired or congenital physical or developmental disabilities. Third, to be included in the review it was necessary that participants either be identified as having a diagnosed psychiatric disorder, or that a dependent variable expressly measuring a mental health outcome be present. Thus, studies looking at, for example, the efficacy of technological innovations in facilitating activities of daily living such as grocery shopping, bathing etc. – although certainly relevant to mental well-being - were excluded unless they explicitly measured a mental health outcome.



## Review Process

Preliminary to the literature review process, health professionals, academics and students on the team brainstormed research questions in the context of the Request for Proposals and their clinical and academic expertise. This exercise led to the identification of nine initial research questions:

- What are the barriers to independent living?
- How is a physical disability a barrier to accessing mental health services?
- Does residency in long term care become a barrier to accessing mental health services?
- What are the barriers to independent living related to service access?
- How can services be better integrated and coordinated to facilitate independent living?
- How can continuity of care from crisis to other services be better integrated and coordinated?
- What safeguards mitigate risk and improve the safety of individuals transitioning across services?
- What services, programs, and/or models of support are most effective in enhancing independent living and mental wellness?
- What interventions prevent negative mental health outcomes?

These questions were then allocated to student researchers on the team who used them for guidance in searching electronic databases for relevant research articles. A follow-up meeting with the research team then took place where these initial search results were reviewed by students in the context of clinical practice and academic expertise. Health professionals and academics on the team also searched and submitted relevant articles. Due to the multidisciplinary nature of research in this area a wide variety of electronic databases, from the areas of medicine, nursing, psychology and other social sciences, and social work were included (see Appendix 1).



## Synthesis Results

During the research teams' review of the student generated literature, it became apparent that many articles contained elements pertaining to more than one of these questions, and that there were two key emergent themes: Barriers to Independent Living and Interventions to Enhance Independent Living. It is in the context of these two broad themes that the following review is organized.

A review of the literature revealed four distinct themes with regard to barriers to independent living: System Barriers; Quality of Service Barriers; Individual/Family Barriers; and Societal Barriers. System barriers refer to challenges posed by the system providing service and support program delivery to the population of interest. Quality of Service Barriers refers to challenges to independent living resulting from various factors related to the adequacy of services received. Individual/Family Barriers refer to a variety of challenges involving the behaviour and attitudes of the individuals themselves or their family members/informal support network. Finally, Societal Barriers refer to broader failures of accommodation and recognition in society. Research pertaining to each is described below. While it is felt that delineation of barriers to independent living into these categories is useful, it is also recognized that these are not entirely independent but rather there exists a dynamic interplay between them.



# Barriers to Independent Living

## SYSTEM BARRIERS

Canada's "system" for meeting the health and wellness needs of its residents is complex and difficult to define, encompassing, as it does, such a wide array of programs providing or funding varied services and supports. Among the services and supports which are provided are screening and diagnosis, illness prevention, health promotion, intervention/treatment, and rehabilitation for all manner of physical and mental health concerns. Program goals are diverse, and services take place in many different settings, including hospitals, community health clinics, residential homes, supportive living facilities and long-term care facilities. Programs are provided and/or funded by all levels of government and by the private sector. While Canada's health care system is often referred to as universal, this is an oversimplification. While many services are funded by public means, many others, such as dental care and vision care are not. Of particular relevance to the present paper, many mental health services provided outside hospitals and medical clinics are not publicly funded. The very complexity of this system makes it difficult to navigate, particularly for vulnerable individuals experiencing some of the very problems the system exists to address. Several system barriers were identified in the literature. These include: Adequacy of Resources, Fragmentation of Service, and Policy Issues.

### Adequacy of Resources

At the most basic level, of course, accessing mental health services requires that these services are available in the first place. Their availability hinges on the funding of necessary resources for delivery – particularly staffing, facilities, and operational costs – being present. A recent assessment of expenditures on mental health found that Canada has a rate of public mental health spending below that of most developed nations (Jacobs et al. 2008). It has also been found that the gap between the need for mental health services and the use of these services is greatest for low SES groups (Steele, Dewa, & Lee, 2007). To the extent that seniors and persons with disabilities are often low SES groups (Yamaki & Fujiura, 2002) the lack of publicly funded mental health services presents a significant financial barrier to accessing these services.

Inadequate funding of mental health services results in inadequate resources in terms of providers, infrastructure, and availability. Numerous studies point to staff shortages at all levels of the mental health system, from frontline care, to mental health providers, to specialists as a key system barrier to accessing care (American Geriatrics Society, 2003).

A related system issue is the alarmingly high rate of staff turnover among health care workers. A recent Canadian study found that 20% of new nursing graduates leave the profession within the first three years of employment (Rondeau & Wagar, 2006). Exacerbating resulting staff shortages is a continuing trend toward earlier retirement within the nursing profession and an increasingly older population in need of care (Rondeau & Wagar, 2006). Staff shortages are especially acute in rural health care environments (Sullivan, Parenteau, Dolansky, Leon, & LeClair, 2007; Morgan, Semchuck, Stewart, & D'Arcy, 2002), with one recent study reporting that nearly 50% of Canadian rural nurses intend to retire within the next five years, (Kuing, Thomlinson, Curran, Nahachewsky, Macleod, Stewart & Pitblado, 2003).

High levels of work-related stress undoubtedly contribute to the high rate of attrition in the nursing profession (Chang, Hancock, Hoanson, Daley & Jackson, 2005). In a comparison of workplace stress in various occupations, Statistics Canada found healthcare workers to exhibit the highest levels, with 45% reporting high daily work stress (Statistics Canada, 2007). In long term care, a key

---

setting for delivery of mental health services to older and disabled Canadians, these problems are particularly acute (Morgan et al. 2002).

Other resource related barriers include the reported inadequacy of community based services (AGS, 2003; Choi, Ranson, & Wiley 2005; Hemmings, 2008; Horowitz, Reindardt, Boerner & Travis, 2003; Sirey, 2008) the lack of community mental health centers (Sivis, McCrae, & Demir, 2005) and low levels of service usage (Cole, McCusker, Sewitch, Ciampi & Dyachenko, 2007). The range of possible community mental health services is very broad including assessment, referral, rehabilitation and education, screening, crisis intervention, counselling, consultation, and case management. Services take place in a variety of settings and target both care recipients and family care providers. However, the availability and adequacy of these services varies greatly from region to region. Rural regions, in particular, have been identified as lacking appropriate mental health facilities and services.

A lack of access to adequate housing is also a fundamental barrier to independent living for seniors and persons with disabilities facing mental health challenges. Being able to access adequate housing is recognized as a basic human right and as essential to successful recovery from mental illness (Browne, Hemsley, & St. John, 2008). Moreover, it has been noted that the lack of such access makes the achievement of other key quality of life outcomes such as meaningful social relationships and fulfilling leisure pursuits much more difficult (ibid). A large proportion of Canadians experiencing mental health problems lack housing altogether or live in poor housing conditions that lack adequate support (CMHA, 2004). Despite this, Canada lacks a comprehensive strategy addressing the affordability and availability of housing for those with mental health challenges and, indeed, provincially and federally, there has been a trend toward withdrawal of provision of social housing (Bryant, 2003). A related housing barrier concerns individuals with disabilities and mental health challenges transitioning from facility based care to community living. Although the right to live in one's community is widely recognized as fundamental to independent living, inadequate support for planning this transition, a lack of supportive/supported housing, and a lack of community services continue to present barriers to returning to the community and hence to independent living (Durbin, Goering, streiner, & Pink, 2004; Greenberg, Fontana, & Rosenheck, 2004; Joyce et al. 2004).

A lack of services for family caregivers is another important barrier that has been identified (Parish & Lutwick, 2005). These caregivers play a crucial role in mental health delivery to seniors and persons with disabilities and this role is a stressful one with caregivers reporting high levels of physical and psychological problems (Beach, Schultz, Yee & Jackson, 2005; Chappell & Reid, 2002). Clearly then, programs designed to provide support for caregivers are crucial, and the lack of availability of such services is a major barrier.

### **Fragmentation of Services**

Ideally, the many elements of the health care system should operate as a co-ordinated whole. In reality, however, services are fragmented and there is a lack of coordination within different elements of the system such as acute care and long-term care, and between health care and other supportive services such as housing and transportation (Alkema, Wilber & Enguidanos, 2007; Hall, Higgins, Parkes, Hassiotis, & Samuels, 2006; Herrman, Trauer, & Warnock, 2002; Maitland, Tsakanikos, Holt & Bouras, 2006). While fragmentation of services and supports within the mental health care system presents challenges in and of itself, those also requiring service provision from the broader health care or social system are particularly affected. As just one example, substance abuse problems are commonly associated with traumatic brain injury, and yet many of these individuals receive inadequate substance abuse treatment because such treatment and rehabilitation services are frequently offered through different programs (Krahn, Farrell, Gabriel, & Deck, 2006). Alkema et al. (2007) note that service fragmentation is the outcome of multiple competing forces including varied consumer needs, divergent perspectives on appropriate care,

---

different types of providers, programs under different bureaucratic authorities, the absence of an integrated information system, different regulations from various levels of government, and divergent regional service areas and capacities. As these authors point out, this fragmentation leads to gaps and redundancies in service, cost inefficiencies, and understandable frustration for all stakeholders. In short, fragmentation of services results in seniors, persons with disabilities and their caregivers having difficulty navigating the system and accessing services, presenting a clear barrier to independent living including transitions from facility-based care and community-based care.

## Policy Issues

It is widely accepted that best-practice in the treatment of mental health problems requires the exploration of non-pharmacological treatment approaches prior to drug treatments (Ruckdeschel & Katz, 2004). In reality, however, pharmacological interventions are typically used as an initial approach (Ruckdeschel & Katz, 2004). This is especially the case for elderly individuals experiencing dementia, where the administration of anti-psychotic and anti-depressant medications is often the first-line of treatment despite an elevated risk of adverse drug reactions in this population (Ballard & O'Brien, 1999; Ballard et al., 2001).

This is of particular concern as the efficacy of these medications for this population is not well-established, with recent review articles noting generally positive reported treatment outcomes in the literature but also a dearth of randomized controlled trials (Schneider, Dagerman, & Insel, 2006; Thompson, Herrmann, Rapoport, & Lanctôt 2007; Bains, Birks, & Dening, 2002). In general, it may not be so much that effective treatment policies fail to exist, but rather that there are systemic barriers to their implementation. It has been noted, for example, that there are established clinical practice guidelines, consensus statements, and decision-making algorithms for managing depression in older adults (Eil, 2006) and in persons with disabilities (Kroll, Jones, Kehn, & Neri, 2006), but it seems that the health system itself presents a barrier to their implementation (Eil, 2006). As discussed above, there is a lack of coordination and collaboration among care providers. This is compounded by shortages of health practitioners with training in geriatric mental health (Ayalon, Arean, & Bornfeld, 2008; Bartels et al., 2002). High turnover of care providers and staff have also been shown to be significant obstacles to the coordination and continuity of care (Drainoni et al., 2006). Economic barriers also interact with system barriers as inadequate or discriminatory financing of mental health services for older adults may deter care (Bartels et al., 2002).

## Environment

Due to mobility challenges, seniors and persons with disabilities have unique access issues for health care services in general. These challenges are widely recognized in primary care and, by legislation, facilities providing such care are architecturally accessible to all users. Similarly, mass transit policy and practice regarding access to primary care facilities accommodates those with mobility problems. Services targeting mental health concerns, however, are less likely to consider mobility issues with regard to architecture and transportation, resulting in unique barriers for seniors and persons with disabilities who are experiencing such concerns (Nosek, Hughes, & Robinson-Whelen, 2008). Seniors and persons with disabilities living in rural areas are especially vulnerable in this respect, as local mental health services and/or adequate public transportation in such areas are often insufficient or lacking entirely.

---

## QUALITY OF SERVICE BARRIERS

### Attitudes of Health Professionals to Mental Health Problems

A number of articles cited attitudes of primary care health professionals toward mental illness as a key barrier to accessing effective mental health services (e.g., Ell, 2006; Epstein et al., 2008). Those with both medical conditions and psychological concerns frequently reported their perceptions that primary care physicians viewed mental health concerns as secondary and relatively unimportant. Several authors noted that the attitudes of primary care professionals in this context may reflect adherence to a biomedical model of care. From this perspective, health is seen as the absence of physical disease, and mental phenomena are viewed as separate and secondary to physical problems (Wade & Halligan, 2004). In essence, it is argued that adherence to the biomedical model by primary health care providers presents an access barrier to receiving mental health services, in that it discourages comprehensive consideration of psychological symptoms. Where mental health symptoms are observed, they are often seen as merely a manifestation of the physical symptoms (Reynolds III, 2003). In fact, mental health issues often exacerbate negative physical health outcomes (Raue & Meyers, 1997; Sivilis et al., 2005; Cohen et al., 2003) making the treatment of these essential to physical rehabilitation.

In discussing attitudes of primary care workers toward mental health problems it should also be emphasized, of course, that these workers are not immune from general societal stereotypes about mental illness which may impact their professional interactions with those experiencing mental health problems. It has been demonstrated in a number of studies that health professionals hold such views and that this impacts their consideration of mental health options (Bahm & Forchuk, 2008; Kroll et al., 2006; Pelletier, Rogers & Dellario, 1985; Leigh, Powers, Vash, & Nettles, 2004).

Another potential quality of care barrier results from a lack of caregiver knowledge/training about mental health problems, issues, and treatment. Of those seeking help for mental health problems, three-quarters will see a general practitioner and one-quarter will see a psychiatrist (Lillis, Mellsop & Emery, 2008). Although family physicians are often relied upon for treatment of anxiety and depression, they commonly report a lack of confidence in their ability to provide effective care due to inadequate skills and training in mental health problems (Ell, 2006; Epstein, 2008; Choi, 2008; George, Davison, McCabe, Mellor & Moore, 2007). For many seniors and persons with disabilities, family physicians are their first point of contact, and, as noted in its 2005 report on mental health programs and policies in Canada, the Standing Senate Committee On Social Affairs, Science And Technology reported that “many family physicians lack sufficient knowledge, skills and motivation to manage patients with mental illness and addiction, to accurately screen for mental disorders, or to navigate the appropriate referral pathways to access the more specialized mental health and addiction system.” Inadequate knowledge and training regarding mental health issues is not, of course, limited to family physicians. Other health care professionals and paraprofessionals, many with considerably less formal education and training than family physicians, also regularly interact with seniors and persons with disabilities. One cross-sectional investigation of 353 long-term care personnel including nurses, social workers, activity personnel and personal care attendants for example, reported that the latter group, relative to the others, were more likely to view depression as inevitably co-morbid with dementia, lacked knowledge regarding the symptoms of depression, and lacked awareness of the efficacy of treatment for depression (Ayalon et al., 2008). Other studies have similarly reported a lack of recognition of mental health issues by health care staff in long-term care (Raue & Meyers, 1997; Ruckdeschel, 2004; Bagley et al. 2000; Boyle et al. 2004).

Generally speaking, there are effective strategies for managing mental health issues of older adults and persons with disabilities. These strategies extend from community (Marshall & Lockwood, 2008) to primary (Kates, Crustolo, Farrar, & Nikolaou, 2001; Reynolds III, 2003) and continuing care settings (Molinari, 2003). However, much evidence indicates that mental health issues, and

---

especially depression, are not well detected or treated (Bagley et al., 2000; Boyle et al., 2004; Choi, 2009; Cohen, 2003; Cole, 2008, Epstein, 2008; Palinkas et al., 2008; Sivis, 2005).

### **Lack of Involvement of Individuals in Decision Making**

Another quality of service barrier referred to in the literature is a lack of involvement by care recipients with regard to decision making related to their care (Corrigan, 2002). Of course, individuals will vary greatly with regard to their desire and capability to actively and safely participate in care decisions. Nevertheless, this is an area where adherence to the goals of independent living requires that care recipients be given every opportunity to contribute. To the extent that the traditional biomedical model assumes that the role of those receiving treatment is simply to comply with, rather than contribute to, treatment directives (Wade & Halligan, 2004), it clearly denies individuals self-determination in their care. Thus, while acknowledging that appropriate care may, on occasion, require care providers to play a governing role in care decisions, it is important to acknowledge the importance to independent living of allowing care recipients, to the greatest degree possible, the opportunity to actively contribute to their care.

### **Inappropriate Treatment**

Psychoactive medications are, of course, an integral part of mental health treatment for seniors and persons with disabilities and their efficacy is well established. Despite widespread erroneous beliefs by physicians and others that members of these populations are poor candidates for drug treatment, there is ample evidence to the contrary (e.g., Snowden, Sato, Kersten, & Roy-Byrne, 2003). Moreover, it is accurate to say that the benefits of medications in the context of both the relief of symptoms in care recipients and in terms of reduced burden for care-providers are important contributors to independent living. Nevertheless, there is the potential for misuse of these medications, and there is evidence that they are frequently used for purposes of control and convenience rather than treatment, as in the case of so-called “chemical-restraints” (Hughes, 2008).

While non-pharmacological intervention is recognized as the appropriate first line of treatment for many mental health concerns, and while care recipients and their family members prefer this type of treatment, in reality, pharmacological treatment is often the initial approach, without consideration of alternatives (Douglas, James & Ballard, 2004). The effectiveness of non-pharmacological approaches in the treatment of disorders such as depression and anxiety, as well as in the management of dementia is well established.

Of course, the appropriate approach to the treatment of mental health problems is very complex, with great variation between individuals with regard to responsiveness to particular treatment modalities and with regard to patient treatment preferences. Certainly, medication may often be the most appropriate and effective treatment option. To the extent that effective alternatives to medication are available and preferred by recipients, however, lack of consideration of these alternatives represents a barrier to independent living.

### **Not Adequately Addressing Communication Barriers**

Effective communication is vital to accessing quality mental health care and communication barriers are many-fold (e.g., Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001; Burgio et al., 2001). Seniors and persons with disabilities may have trouble conveying and/or receiving adequate information regarding their needs, varying from technological limitations (such as requiring that appointments be made by phone), to insufficient size or clarity of print on written instructions, to knowledge of communication strategies for persons with dementia, to a structured power dynamic that doesn't provide adequately for patient input and control over treatment decisions.

---

## **Lack of Consideration for Cultural Perspectives on Mental Health**

Among the key barriers identified by a recent Canadian study, examining mental health services access in ethnic seniors (Sadavoy, Meier, & Ong, 2004) was a dearth of ethnically knowledgeable mental health professionals; lack of mental health knowledge/skills among workers in ethnospecific social agencies; and negative attitudes toward mental illness held by ethnic seniors and their families.

## **Lack of Knowledge by Mental Health Professionals of Physical Impairment**

As noted above, a key barrier to independent living for seniors and persons with disabilities is lack of knowledge of mental health issues by primary health providers. At the same time, it has been reported that an important additional barrier faced by seniors and persons with disabilities is that their physical health symptoms and concerns, and the bearing they may have on mental health concerns, are not adequately taken into consideration by mental health professionals who often lack knowledge of physical impairment or the physical/cognitive changes of aging (Pelletier, Rogers & Dellario, 1985).

## **INDIVIDUAL / FAMILY CAREGIVER BARRIERS**

In accordance with a view of seniors and person with disabilities being active participants in their own mental health care, it is important to consider the potential barriers resulting from individual and family caregiver factors. The degree to which individuals or their family members adhere to stereotypical views of mental health will clearly impact their willingness to seek and receive mental health care.

### **Individual**

Among today's cohort of elderly people for example, there is a common view of mental illness as a flaw in character (Eil, 2006). Psychological symptoms are often "masked" in reports to health care providers, and an emphasis placed on physical symptoms. Similarly, it has been found that persons with disabilities are reluctant to admit to psychological symptoms as a result of having internalized negative stereotypes about mental illness (Wagenaar, Mickus, Luz, Kreft & Sawade, 2003).

In addition to individual differences in adherence to stereotypes about mental illness, there are a number of other individual qualities which may present barriers to care. For example, certain personality characteristics may be associated with willingness to accept treatment for mental health problems or with the likelihood of treatment being effective. For example, Trait Optimism has been found to be linked to adherence to "homework" recommended in cognitive behavior therapy (Scheier, & Carver, 1992). Importantly, the relationship of such enduring traits to mental health is something health professionals not primarily involved with mental health treatment may not be aware of, presenting an additional potential barrier to independent living.

Coping style is also an important factor. A number of studies have shown that individuals with an emotion-focused coping style are more likely to deny mental health symptoms, and are less willing to actively seek help or participate in treatment strategies than those with problem-focused styles (e.g., Ortega & Alegria, 2005). Several studies have found age differences in the frequency of such coping styles with elderly individuals considerably more likely to rely on passive emotion-focused coping styles (Blanchard-Fields, Stein, & Watson, 2004).

Self-efficacy is another key personal factor that may present a barrier to care. Self-efficacy is a domain-specific concept referring to the degree of belief that an individual has it in their ability to

---

successfully perform particular tasks (Bandura, 1995). The degree to which one believes he or she has the capability to deal successfully with mental health challenges, such as maintaining a medication regimen or successfully completing an intervention strategy, varies greatly between individuals and may present a key barrier to effective mental health care. While self-efficacy is highly domain specific a number of studies have shown that elderly people are less self-efficacious when it comes to a variety of capabilities related to mental health (Blazer, 2002). Thus, to the extent that elderly individuals or persons with disabilities may have lower levels of self-efficacy related to mental health management domains, this may present another important barrier to independent living.

## Family Caregivers

The fact that family caregivers are often the key mediators of mental health care for seniors and persons with disabilities is often under appreciated. The degree to which individuals are able to maintain independence and successfully cope with mental health challenges often depends largely on the physical and mental well-being of family care providers (Montgomery, Rowe, & Kosloski, 2007; Spruytte, VanAudenhove, Lammertyn, 2008). Numerous studies have shown that family caregivers are overburdened, and experience high levels of stress and burnout (e.g., Beach et al., 2000). As a number of studies have shown, family caregiver burden has a clear impact on quality of care and the degree to which caregivers are vulnerable to the stress of providing care varies greatly by individual depending on coping style, personality, and self-efficacy. To the extent that these characteristics impact the quality of caregiving, they present barriers to independent living in seniors and persons with disabilities.

The degree of family caregiver knowledge about effective caregiving also presents a potential barrier. For example, inadequate knowledge of effective ways of communicating with individuals with Alzheimer's Disease contributes to agitated behavior and decreased motivation/ability to successfully carry out activities of daily living (Gitlin, Corcoran, Winter, Boyce & Hauck, 2001). Also, as with individuals themselves, the degree to which family caregivers adhere to stereotypes about mental illness will impact whether individuals seek or receive treatment for mental health concerns. It has been found, for example, that family members' negative attitudes toward mental illness are a key factor in refusal of mental health services in long-term care settings (Wagenaar et al., 2003).

As will be discussed below, it is clearly essential to the realization of independent living in seniors and persons with disabilities that family caregivers be adequately supported and that their knowledge and well-being be a target of intervention strategies. In order for such strategies to be effective, however, there needs to be an awareness of caregiver support services such as adult day programs and a willingness to accept that accessing such services is appropriate. As has been pointed out, these two factors, as much as the availability of services *per se*, present the greatest barriers to family caregiver support (Montgomery, Rowe, & Kosloski, 2007).

Finally, in discussing the importance of family caregivers to independent living it is important to acknowledge that there are many seniors and persons with disabilities within the various systems of care (facility, community care/programs) who do not have access to this source of support. The absence of family support presents an additional barrier to independent living and these individuals, in particular, may be in need of compensatory support.

## SOCIETAL BARRIERS

Considerable evidence attests to the pervasiveness of societal stigmas concerning aging, disability, and mental health. Negative attitudes and discriminatory behaviour associated with categorization into each of these groups is well documented. As these groups are not mutually exclusive, those who are physically disabled and/or elderly and also experiencing mental health concerns are obliged

---

to deal with an aggregate of stigma. Societal stereotypes of aging, disability, and mental health problems, which involve labels such as helpless, powerless, and vulnerable, negatively influence how individuals within these groups are treated by others. To the extent that such beliefs result in one being patronized, ignored, mocked, and discriminated against, they may also influence one's self-image and mental well-being. In other words, the stigma of disability, aging, or mental illness may exacerbate existing mental health concerns. Certainly it is possible that the high rates of psychological distress experienced by those with physical disability may, to some extent, reflect an outcome of the stigma associated with disability.



## Effective and Suggested Interventions

Clearly there is a need to increase and redirect resources in accordance with identified barriers. Directing funds toward improved training and retention of care professionals should clearly be a priority. As mentioned, professional caregivers experience high levels of stress and burnout which impact quality of care and present a barrier to independent living. Accordingly, there is great potential benefit in directing funding toward the establishment of effective interventions and practices aimed at improving quality of care through stress reduction. A number of such interventions, designed to reduce stress in professional providers of geriatric and mental health care, have received empirical support (e.g., Finnema et al., 2005; Mackenzie & Peragine, 2003; Coogle, Parham, Jablonski, & Rachel, 2007).

Funding directed toward improved quality of service must recognize the need for education and skill development for health professionals to enhance knowledge of mental health priorities in seniors and persons with disabilities. This should necessarily include interventions directed toward attitude change. To the extent that the professional caregiver attitudes toward aging, disability, and mental health impact quality of service and ultimately are a barrier the ability of individuals to live independently, interventions targeting attitude change have potential benefit.

Beyond attitudinal barriers to effective care provision, there is a clear need to address professional care provider short-comings in awareness and training with regard to the unique mental health needs of seniors and persons with disabilities. Clearly, education initiatives elucidating these needs are desirable. A number of effective interventions targeting the enhancement of communication skills and conflict resolution have been developed. For example, Ripich, Wykle, and Niles (1995) demonstrated improvement in quality of care and attitudes toward patients with Alzheimer's Disease following a communication skills training program for Nursing Assistants.

As mentioned above, self-efficacy enhancement interventions can be effective in reducing stress. They also play a key role in the utilization of learned skills. Numerous investigations, in a variety of domains, have demonstrated that knowledge improvement alone is often insufficient to effect behaviour change. Thus, psychoeducational initiatives which target, for example, simultaneous skill development and self-efficacy enhancement (e.g., Mackenzie and Peragine, 2003) are most likely to be successful in improving the quality of service provision.

There is also a need for mental health professionals from a variety of ethnic backgrounds, and for others to be more adequately trained in cultural sensitivities. Ethnic specific social service agencies also need to be better trained in mental health issues. Specialized education programs geared toward ethnic minorities are also needed to increase awareness of available services and to reduce the stigma associated with mental illness (Sadavoy, Meier, & Ong, 2004).

As mentioned, there are a plethora of community based mental health services and supports that have been implemented to varying degrees in different jurisdictions (e.g., Lawn, Smith & Hunter, 2008; Melis et al., 2005; Storfjell et al., 2008). The availability and quality of such services obviously varies greatly from region to region, and clearly there is a need for enhancement of services in areas where these are lacking. At the same time, however, it is important to identify and support those services which are most effective in maximizing the independence of seniors and persons with disabilities facing mental health challenges (Field & Jett, 2008).

A strategy for addressing inadequate housing to support the independent living needs of seniors and persons with disabilities experiencing mental health challenges is also clearly essential. This must include consideration of the complexities of transitioning between home settings such as individual capacity and desire as well as the community support available to meet care needs (Nishita, Wilber,

---

Matsumoto, & Schnelle, 2008). Indeed, it is vital to the success of transition to community living initiatives that adequate support programs and services be available. It has been suggested by the CMHA (2004) that funding should be targeted toward supporting individuals with mental health challenges in their own homes rather than toward services tied to facility based care. It should be emphasized, however, that what constitutes one's "own home" is not necessarily a private dwelling. Indeed, it has been shown that semi-autonomous living units for seniors are often associated with higher perceived autonomy, sense of security and quality of life than private dwellings (Bilsen, Hamers, Groot, & Spreeuwenberg, 2008; Cheek, Ballantyne, Roder-Allen, & Jones, 2005). As mentioned, home-based services for mental health needs are often inadequately covered by public health care. To the extent that home-based care offers considerable cost-saving (Hay et al., 2002), and to the extent that individuals express a clear preference for home-based care over facility care (Soodeen, Gregory & Bond, 2007), it clearly also makes sense to allocate additional funds to the enhancement and maintenance of such services, including funding directed toward research and development of assistive technology and home modification initiatives. Another promising direction involves the extension of cognitive-behavioural therapy to home-care settings (Diefenbach, 2008).

Support services such as respite, adult day programs, support groups, and psycho-educational programs designed to ease the burden on family caregivers are becoming increasingly available. Within services targeting seniors or persons with disabilities, however, there is a need for a broadening of services, perhaps in co-ordination with services currently offered by mental health organizations, to address the unique needs of the family members of those experiencing mental health concerns. To the extent that available mental health programs are not being accessed due to a lack of knowledge of availability and/or the belief that accessing such help reflects a failure of care (Montgomery et al., 2007) there is a need for educational and counselling initiatives targeting family caregivers.

Fragmentation of care services is clearly a barrier that needs to be addressed. Co-ordination and integration of primary care, mental health care in the community, and long term care, as well as the coordination of these with other assistive services such as transportation and housing is essential to independent living and mental well being (Crawford, de Jong, Freeman & Weaver, 2004). According to Alkema et al. (2007) successful integration of services requires change in a number of areas, including consumer-directed care, linkages between services that provide consumers with the ability to connect with all services from any entry point, better collaboration between aging and disability networks, integrated information systems, and collaboration between and within different levels of government.

## **INDIVIDUAL / FAMILY CAREGIVER INTERVENTIONS**

There is a considerable and growing literature on effective evidence-based non pharmacological interventions for maximizing independence and quality of life for seniors and persons with disabilities (Cohen-Mansfield, 2005; Collins & Benedict, 2006; Cott, Dawson, Sidani & Wells, 2002; Cress, Buchner, and Prohaska, 2004; Edwards, Gardiner, Ritchie, Baldwin & Sands, 2008; Mihaliko, Wickley, & Sharpe, 2006; Robinson, Hughes, Taylor, Hall & Rehm, 2007). While much of the research regarding the effectiveness of these interventions is preliminary, there is great promise.

As mentioned earlier, there are a number of individual factors that make some caregivers more vulnerable to the effects of stress and burnout. Caregiver stress impacts quality of care and ultimately is a crucial determinant of independent living in seniors and persons with disabilities. It is, therefore, of great potential benefit to explore stress reduction interventions targeting these factors. While some individual contributors to stress and burnout, including such personality characteristics as trait optimism or neuroticism, are not particularly amenable to change, others are modifiable. One such factor that holds great promise is caregiver self-efficacy. Several studies have demonstrated that this can be enhanced through intervention and that doing so is effective in reducing family

---

caregiver stress (e.g., Gitlin et al., 2001; Huang, Shyu, Chen, Chen, & Lin, 2003). Blazer (2002) proposes a number of ways in which self-efficacy enhancement in old age may promote quality of life and psychological well-being. A wide variety of other effective stress management, social skills training, and coping strategies have also been identified in the literature (e.g., Abeles & Victor, 2003; Belle et al., 2006; Burker, Evon, Sedway, & Egan, 2005; Coon, Thompson, Steffen, Sorocco & Gallegher-Thompson, 2003; De Boer, 2007; Gaugler et al., 2003; Reich & Zautra, 1991).

Addressing stigma/attitudes about mental health, disability, and aging is a very broad undertaking (Hickie, 2004). Public education/awareness initiatives clearly should be part of any strategy to combat negative attitudes. The effectiveness of such campaigns in changing views on, for example, smoking behaviour or impaired driving are quite well established. It is also clear, however, that educational campaigns are often not sufficient. Initiatives based on Gordon Allport's (1954) premise that direct contact between groups is an important means by which attitude and behaviour change can be affected have had demonstrated success.

One relevant application of this premise can be found in intergenerational programs. These occur in a great many contexts and with a number of different populations, but essentially involve older and younger individuals working together on mutually beneficial goals. One key aim of these programs is to reduce negative stereotypes that these groups may hold about each other. The effectiveness of these programs in accomplishing this has been demonstrated in a number of studies. For example, Newman, Faux, & Larimar (1997) found children to hold more positive views toward aging and older adults following an intergenerational program involving older adults volunteering in elementary school classrooms. While few studies have considered the use of such programs with seniors with mental health challenges, there have been several studies looking at the potential impact of such programs on both older participants with dementia and on the attitudes of younger adults and children (Jarrott & Bruno, 2003; Xaverius & Mathews, 2003).

Another approach that seeks to reduce negative stereotypes through contact is Community Service Learning (CSL). Considerable research attests to the potential effectiveness of CSL programs in reducing the stigma associated with mental illness. CSL refers to a structured approach to education whereby students apply course related knowledge and critical thinking skills to engage in meaningful volunteer opportunities. Numerous studies have provided evidence that, in addition to the usefulness of such programs in fostering positive student self-perceptions and behaviour, they also have the potential to reduce negative stereotypes. For example, a study by Lundy (2007) found students to have more emotional empathy following participation in a CSL program where they volunteered in organizations such as assisted living facilities.



## Summary

As outlined above, barriers to independent living in seniors and persons with disabilities are multifaceted and daunting. Numerous barriers exist at the system, caregiver and individual levels. Moreover, despite the delineation above, it is recognized that a dynamic interplay exists between barriers and thus an integrated approach to overcoming these is necessary. Service fragmentation clearly needs to be addressed, as do capacity issues related to adequacy of training and information dissemination. While the barriers are many, numerous strategies for combating them also exist. While conclusive evidence as to the efficacy of these strategies is lacking in some areas, there is nonetheless considerable promise that barriers can be minimized and the capacity for self-determination in seniors and persons with disabilities experiencing mental health challenges can be improved.



## References

1. Abeles, N. & Victor, T. (2003). Unique opportunities for psychology in mental health care for older adults. *Clinical Psychology: Science and Practice*, 10, 120 – 124.
2. Alkema, G. E., Wilber, K. H., & Enguidanos, S. M. (2007). Community- and facility-based care. In J. A. Blackburn & C. N. Dulmus (Eds.). *Handbook of gerontology: Evidence-based approaches to theory, practice, and policy*. Hoboken, N.J. : John Wiley & Sons.
3. Allport, G.W. (1954). *The nature of prejudice*. Cambridge, MA: Perseus Books.
4. American Geriatric Society. (2003). The American Geriatrics Society and American Association for Geriatric Psychiatry recommendations for policies in support of quality mental health care in U.S. nursing homes. *Journal of the American Geriatrics Society*, 51, 1299-1304.
5. Ayalon, L., Areal, P. & Bornfeld, H. (2008). Correlates of knowledge and beliefs about depression among long-term care staff. *International Journal of Geriatric Psychiatry*, 23,356-363.
6. Bagley, H., Cordingly, L., Burns, A., Mozely, C.G., Stutcliffe, C., & Challis, D., et al (2000). Recognition of depression by staff in nursing and residential homes. *Journal of Clinical Nursing*. 9, 445-450.
7. Bahm, A., & Forchuk, C. (2009). Interlocking oppressions: The effect of a comorbid physical disability on perceived stigma and discrimination among mental health consumers in Canada.. *Health & Social Care in the Community*, 17(1), 63-70.
8. Bains, J., Birks, J. S., & Dening, T.D. (2002). Antidepressants for treating depression in dementia. *Cochrane Database of Systematic Reviews*, Issue 4. No.: CD003944
9. Ballard, C. G. & O'Brien, J. T. (1999) Pharmacological treatment of behavioural and psychological signs in Alzheimer's disease: How good is the evidence for current pharmacological treatments? *British Medical Journal*, 319, 138–139.
10. Ballard, C. G., O'Brien, J., James, I., et al (2001) *Dementia: Management of behavioural and psychological symptoms*. Oxford: Oxford University Press.
11. Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York, NY: W.H. Freeman & Company.
12. Bartels, S.J., Dums, A.R., Oxman, T.E., Schneider, L.S., Areán, P.A., Alexopoulos, G. S., & Jeste, D. V. (2002). Evidence-based practices in geriatric mental health care. *Psychiatric Services*, 53, 1419-31.
13. Beach, S. R., Schultz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology and Aging*, 15, 259-271.
14. Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., et al.[REACH II Investigators]. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine*, 145, 727–738.
15. Bilsen, P. M. V., Hamers, J. P., Groot, W., & Spreeuwenberg, C. (2008). Sheltered housing compared to independent housing in the community. *Scandinavian Journal of Caring Sciences*, 22(2), 265-274.
16. Blanchard-Fields, F, Stein, R., & Watson, T. L. (2004). Age differences in emotion-regulation strategies in handling everyday problems . *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 59, P261-P269.

- 
17. Blazer, D. G. (2002). Self-efficacy and depression in late life: A primary prevention proposal. *Aging and Mental Health*, 6, 315-324.
  18. Boyle, V.L. (2004) Recognition and management of depression in skilled-nursing and long-term care settings: evolving targets for quality improvement. *American Journal of Geriatric Psychiatry*, 12, 288-295.
  19. Bourgeois, M., Dijkstras, K., Burgio, L., & Allen-Burge, R. (2001). Memory aids as an augmentative and alternative communication strategy for nursing home residents with dementia. *Augmentative and Alternative Communication*, 17, 196-210.
  20. Browne, G., Hemsley, M., St John W. (2008). Consumer perspectives on recovery: a focus on housing following discharge from hospital, *International Journal of Mental Health Nursing*, 17, 402-409.
  21. Bryant, T. (2003). The current state of housing in Canada as a determinant of health. *Policy Options*, March, 52-56
  22. Burgio, L. D., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., et al. (2001). Come talk with me: Improving communication between nursing assistants and nursing home residents during care routines. *The Gerontologist*, 41, 449-460.
  23. Burkner, E. J., Evon, D. M., Sedway, J. A. & Egan, T. (2005). Religious and non-religious coping in lung transplant candidates: Does adding God to the picture tell us more? *Journal of Behavioural Medicine*, 28(6), 513-526.
  24. Canada. Parliament. Senate. (2004). Mental health, mental illness, and addiction: Issues and options for Canada, Interim Report of The Standing Senate Committee On Social Affairs, Science And Technology. Retrieved from <http://www.parl.gc.ca/38/1/parlbus/commbus/senate/com-e/soci-e/rep-e/report3/repintnov04vol3-e.htm>
  25. Canadian Mental Health Association (2004). Housing, Health, and Mental Health. Retrieved April 19, 2009 from [www.cmha.ca](http://www.cmha.ca).
  26. Chang, E., Hancock, K., Johnson, A., Daly, J., & Jackson, D. (2005). Role stress in nurses: Review of related factors and strategies for moving forward. *Nursing and Health Sciences*, 7, 57-65.
  27. Chappell, N. L., & Reid, R. C. (2002). Burden and well-being among caregivers: Examining the distinction. *Gerontologist*, 42, 772-780.
  28. Cheek, J., Ballantyne, A., Roder-Allen, G., & Jones, J. (2005). Making choices: How older people living in independent living units decide to enter the acute care system. *International Journal of Nursing Practice*, 11(2), 52-57.
  29. Choi, N., Ranson, S. & Wyllie, R. (2008). Depression in older nursing home residents: The influence of nursing home environmental stressors, coping, and acceptance of group and individual therapy. *Aging and Mental Health*, 12, 536-547.
  30. Cohen, G., et al. (2003). Mental health problems in assisted living residents: the physician's role in treatment and staff education. *Geriatrics*, 58, 44-46.
  31. Cohen-Mansfield, J. (2005). Nonpharmacological interventions for persons With dementia. *Alzheimers Care Quarterly*, 6, 129-145.
  32. Cohen-Mansfield, J., Parpura-Gill, A., Kotler, M., Vass, J., MacLennan, B., & Rosenberg, F. (2007). Shared interest groups (SHIGs) in low-income independent living facilities. *Clinical Gerontologist*, 31(1), 101-112.
  33. Cole, M.G., McCusker, J., Sewitch, M., Ciampi, A., & Dyachenko, A. (2008). Health services use for mental health problems by community-living seniors with depression. *International Psychogeriatrics*, 20:3, 554-570.
  34. Collins, C., & Benedict, J. (2006). Evaluation of a community-based health promotion

- 
- program for the elderly: Lessons from seniors CAN. *American Journal of Health Promotion*, 21(1), 45-48.
35. Cooper, C., Regan, C., Tandy, A. R., Johnson, S. & Livingston, G. (2007). Acute mental health care for older people by crisis resolution teams in England. *International Journal of Geriatric Psychiatry*, 22, 263-265.
  36. Coogle C.L., Parham I.A., Jablonski R., & Rachel J.A. (2007). The value of geriatric care enhancement training for direct service workers, *Gerontol Geriatr Educ*, 28, 109-131.
  37. Coon, D., Thompson, L. W., Steffen, S., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia. *The Gerontologist*, 43, 678–689.
  38. Corrigan, P.W. (2002). Empowerment and serious mental illness: Treatment partnerships and community interventions. *Psychiatric Quarterly*, 73(3), 217-228.
  39. Cott, C. A., Dawson, P., Sidani, S., & Wells, D. (2002). The effects of a walking/talking program on communication, ambulation, and functional status in residents with Alzheimer Disease. *Alzheimer Disease and Associated Disorders*, 16, 81-87.
  40. Crawford, M.J., de Jong, E., Freeman, J.K., & Weaver, T. 2004. Providing continuity of care for people with severe mental illness. *Social Psychiatry and Psychiatric Epidemiology*, 30(4), 265-272.
  41. Cress, M., Buchner, D., & Prohaska, T. (2004). Physical activity programs and behavior counseling in older adult populations. *Medicine and Science in Sports and Exercise*, 36(11), 1997-2003.
  42. de Boer, M. E., Hertoguh, C. M. P. M., Droes, R., Riphagen, I., Jonker, C. & Eefsting, J. A. (2007). Suffering from dementia-the patient's perspective: A review of the literature. *International Psychogeriatrics*, 19(6), 1021-1039.
  43. Diefenbach, P. (2008). Extending cognitive-behavioral therapy for late-life anxiety to home care. *Behavior Modification*, 32, 595-610.
  44. Douglas, S., James, I., & Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment*, 10, 171-177.
  45. Drainoni, M.L., Lee-Hood, E., Tobias, C., Bachman, S.S., Andrew, J., & Maisels, L. (2006). Cross-disability experiences of barriers to health-care access. *Journal of Disability Policy Studies*, 17, 101-115.
  46. Durbin, J., Goering, P., Streiner, D.L., & Pink, G. 2004. Continuity of care: Validations of a new self-report measure for individuals using mental health services. *Journal of Behavioural Health Services and Research*, 31(3), 279-296.
  47. Edwards, N., Gardiner, M., Ritchie, D. M., Baldwin, K. & Sands, L. (2008). Effect of exercise on negative affect in residents in special care units with moderate to severe dementia. *Alzheimer Disease and Associated Disorders*, 22, 362–368.
  48. Ell, K. (2006). Depression care for the elderly: Reducing barriers to evidence-based practice. *Home Health Care Services Quarterly*, 25, 115-148.
  49. Epstein, S.A., Hooper, L.M., Weinfurt, K.P., DePuy, V., Cooper, L.A., Harless, W.G., & Tracy, C.M. (2008). *Medical Care Research and Review*, 65, 674-695.
  50. Field, M., & Jette, A. (2008). Dealing with disability. *Issues in Science and Technology*, 24(2), 85-90. *International Journal of Geriatric Psychiatry* 2005; 20: 330–343.
  51. Finnema, E., Droes, R., Ettema, T., Ooms, M. Ader, H., Ribbe, M., & van Tilburg, W. (2005). The effect of integrated emotion-oriented care versus usual care on elderly persons with dementia in the nursing home and on nursing assistants: a randomized clinical trial. *International Journal of Geriatric Psychiatry*, 20, 330-343.
  52. Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M. P., Townsend, A., & Greene, R.

- 
- (2003). Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry*, 18, 55–62.
53. George, K., Davison, T., McCabe, M., Mellor, D. & Moore, K. (2007). Treatment of depression in low-level residential care facilities for the elderly. *International Psychogeriatrics*, 19, 1153-1160.
  54. Gitlin, L.N., Corcoran, M., Winter, L., Boyce, A. & Hauck, W.W. (2001). A randomized controlled trial of a home environment intervention: effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*, 41(1), 4-14.
  55. Greaney, M., Lees, F., Greene, G., & Clark, P. (2004). What older adults find useful for maintaining healthy eating and exercise habits. *Journal of Nutrition for the Elderly*, 24(2), 19-35.
  56. Greenberg, G.A., Fontana, A., & Rosenheck, R.A. (2004). Continuity and intensity of care among women receiving outpatient care for PTSD. *Psychiatric Quarterly*, 75(2), 165-181.
  57. Hall, I., Higgins, A., Parkes, C., Hassiotis, A., & Samuels, S. (2006). The development of a new integrated mental health service for people with learning disabilities. *British Journal of Learning Disabilities*, 34, 82-87.
  58. Hay, J., LaBree, L., Luo, R., Clark, F., Carlson, M., Mandel, D., et al. (2002). Cost-effectiveness of preventive occupational therapy for independent-living older adults. *Journal of the American Geriatrics Society*, 50(8), 1381-1388.
  59. Hemmings, C. (2008). Community services for people with intellectual disabilities and mental health problems. *Current Opinions in Psychiatry*, 21, 459–462.
  60. Herrman, H., Trauer, T., & Warnock, J. 2002. The roles and relationships of psychiatrists and other service providers in mental health services. *Australian and New Zealand Journal of Psychiatry*, 36(1), 75-80.
  61. Hickie, L. (2004). Can we reduce the burden of depression? The Australian experience with beyondblue: The national depression initiative. *Australasian Psychiatry* 12.
  62. Horowitz, A., Reinhardt, J. P., Boerner, K. & Travis, L. A. (2003). The influence of health, social support quality and rehabilitation on depression among disabled elders. *Aging & Mental Health*, 7(5), 342-350.
  63. Huang, H. L., Shyu, Y. I., Chen, M. C., Chen, S. T., & Lin, L. C. (2003). A pilot study on a home-based caregiver training program for improving caregiver self-efficacy and decreasing the behavioral problems of elders with dementia in Taiwan. *International Journal of Geriatric Psychiatry*, 18, 337–345.
  64. Hughes R. (2008). Chemical restraint in nursing older people. *Nursing Older People*, 20(3), 33-38.
  65. Jacobs, P., Yim, R., Ohinmaa, A., et al. (2008). Expenditures on mental health and addictions for Canadian provinces in 2003 and 2004. *Canadian Journal of Psychiatry*, 53, 306-313.
  66. Jang, Y. (2007). The mediating role of health perceptions in the relation between physical and mental health. *Journal of Aging and Health*, 19, 439-452.
  67. Jarrott, S.E., & Bruno, K. (2003). Intergenerational activities involving persons with dementia: An observational assessment. *American Journal of Alzheimer's Disease and Other Dementias* 18, 31-37.
  68. Joyce, A.S., Wild, T.C., Adair, C.E., McDougall, G.M., Gordon, A., Costigan, N., Beckie, A., Kowalsky, L., Pasmeny, G., & Barnes, F. 2004. Continuity of care in mental health services: Toward clarifying the construct. *Canadian Journal of Psychiatry*, 49(8), 539-550.
  69. Kates, N., Crustolo, A.M., Farrar, S. & Nikolaou, L (2001). Integrating mental health
-

- 
- services into primary care: Lessons learnt. *Families, Systems & Health*, 19(1), 5-12.
70. Kersten, P., McLellan, L., George, S., Smith, J. A. E., & Mullee, M. A. (2000). To what extent are the needs of severely disabled people met by community rehabilitation services? A follow-up study. *Disability and Rehabilitation*, 22(18), 855-861.
  71. Krahn, G., Farrell, N., Gabriel, R. & Deck, D. (2006). Access barriers to substance abuse treatment for persons with disabilities: An exploratory study. *Journal of Substance Abuse Treatment*, 31, 375-384.
  72. Kroll, T., Jones, G. C., Kehn, M., & Neri, M. T. (2006). Barriers and strategies affecting the utilisation of primary preventive services for people with physical disabilities: A qualitative inquiry. *Health & Social Care in the Community*, 14(4), 284-293.
  73. Kulig, J.C., Thomlinson, E., Curran, F., Nahachewsky, D., Macleod, M., Stewart, N., & Pitblado, R. (2003). *Rural and remote nursing practice: An analysis of policy documents. R03-2003. Ottawa: Nursing Practice in Rural and Remote Canada.*
  74. Lawn, S., Smith, A., & Hunter, K. (2008). Mental health peer support for hospital avoidance and early discharge: An Australian example of consumer driven and operated service. *Journal of Mental Health*, 17(5): 498 – 508.
  75. Leigh, I., Powers, L., Vash, C., Nettles, R. (2004). Survey of psychological services to clients with disabilities: The need for awareness. *American Psychological Association*, 49(1), 48-54.
  76. Lillis, Mellsop & Emery (2008). Diagnosing mental illness in general practice. *New Zealand Family Physician*, 35. 91-95.
  77. Lundy, B.L. (2007). Service learning in life-span development psychology: Higher exam scores and increased empathy. *Teaching of Psychology*, 34, 23-27.
  78. Mackenzie, C.S., & Peragine, G. (2003). Measuring and enhancing self-efficacy among professional caregivers of individuals with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 18(5), 291-298.
  79. Maitland, C.H., Tsakanikos, E., Holt, G., & Bouras, N. (2006). Mental health service provision for adults with intellectual disability: sources of referrals, clinical characteristics and pathways to care. *Primary Care Mental Health*, 4, 99-106.
  80. Marshall, M., & Lockwood, A. (2008). Assertive community treatment for people with severe mental disorders. *Cochrane Database of Systematic Review*, (4), CD001089. doi: 10.1002/14651858.CD001089.
  81. Melis, R., van Eijken, M., Borm, G., Wensing, M., Adang, E., van de Lisdonk, E., et al. (2005). The design of the Dutch EASYcare study: A randomised controlled trial on the effectiveness of a problem-based community intervention model for frail elderly people. *BMC Health Services Research*, 5(1), 65.
  82. Mihalko S., Wickley K., & Sharpe B. (2006). Promoting physical activity in independent living communities. *Medicine & Science in Sports & Exercise*, 38(1), 112-5.
  83. Molinari, V. (2003). Nursing Homes as Primary Care Sites for Psychological Practice. *Clinical Psychology: Science and Practice*, 10, 112–114.
  84. Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (2007). Family caregiving. In J. A. Blackburn & C. N. Dulmus (Eds.). *Handbook of gerontology: Evidence-based approaches to theory, practice, and policy*. Hoboken, N.J. : John Wiley & Sons.
  85. Morgan, D., Semchuk, K., Stewart, N., and D'Arcy, C. (2002). Job strain among staff of rural nursing homes: A comparison of nurses, aides and activity nurses. *Journal of Nursing Administration*, 32(3), 152-151.
  86. Newman, S., Faux, R., & Larimar, B. (1997). Children's views on aging: Their attitudes and values, *The Gerontologist*, 37, 412-417.
-

- 
87. Nishita, C.M., Wilber, K.H., Matsumoto, S. & Schnelle, J.F. (2008). Transitioning residents from nursing facilities to community living: Who wants to leave? *The American Geriatrics Society*, 56, 1-7.
  88. Nosek, M. A., Hughes, R. B., & Robinson-Whelen, S. (2008). The complex array of antecedents of depression in women with physical disabilities: Implications for clinicians. *Disability & Rehabilitation*, 30(3), 174-183.
  89. Ortega, A. N., Alegría, M. (2005). Denial and its association with mental health care use: A study of island Puerto Ricans. *The Journal of Behavioral Health Services and Research*, 32, 320-331.
  90. Palinkas, L.A., Criado, V., Fuentes, D., Shepherd, S., Milian, H., Folsom, D., & Jeste, D.V. (2007). Unmet needs for services for older adults With mental illness: Comparison of views of different stakeholder groups. *American Journal of Geriatric Psychiatry*, 15, 530 – 540.
  91. Parish, S. L., & Lutwick, Z. E. (2005). A critical analysis of the emerging crisis in long-term care for people with developmental disabilities. *Social Work*, 50(4), 345-354.
  92. Pelletier, J., Rogers, S., & Dellario, D. (1985). Barriers to the provision of mental health services to individuals with severe physical disability. *Journal of Counseling Psychology*, 32(3), 422-430.
  93. Raue, P. & Meyers, B. (1997). An overview of mental health services for the elderly. *New directories for mental health services*, 76, 3-10.
  94. Reich, J.W. & Zautra, A. J. (1991) Experimental and measurement approaches to internal control in at-risk older adults. *Journal of Social Issues*, 47(4), 143-158.
  95. Reynolds III, C.F. (2003). Meeting the mental health needs of older adults in primary care: How do we get the job done? *Clinical Psychology: Science and Practice*, 10, 109–111.
  96. Ripich, Wykle, & Niles (1995). Alzheimer's disease caregivers: The FOCUSED program: A communication skills training program helps nursing assistants to give better care to patients with Alzheimer's disease. *Geriatric Nursing*, 16, 15-19.
  97. Robinson, W., Hughes, R., Taylor, H., Hall, J., & Rehm, L. (2007). Depression self-management program for rural women with physical disabilities. *American Psychological Association*, 52(3), 254-262.
  98. Rondeau, K., and Wagar, T. (2006). Nurse and resident satisfaction in Magnet long-term care organizations: Do high involvement approaches matter?. *Journal of Nursing Management*. 14, 244-250.
  99. Ruckdeschel, K. & Katz, I. R. (2004). Care of dementia and other mental disorders in assisted living facilities; New research and borrowed knowledge. *American Geriatrics Society*, 52, 1771-1773.
  100. Sadavoy J., Meier, R., & Ong, A. Y. M. (2004). Barriers to access to mental health services for ethnic seniors: The Toronto study. *Canadian Journal of Psychiatry*; 49: 192-199.
  101. Scheier, M.F., & Carver, C.S. (1992). Effects of optimism on psychology and physical well-being; Theoretical overview and empirical update. *Cognitive Therapy and Research*, 16, 201-228.
  102. Schneider, L.S., Dagerman, K., & Insel, P.S. (2006). Efficacy and adverse effects of atypical antipsychotics for dementia: meta-analysis of randomized, placebo-controlled trials. *The American Journal of Geriatric Psychiatry*, 14, 191-210.
  103. Sirey, J. (2008). The impact of psychosocial factors on experience of illness and mental health service use. *The American Journal of Geriatric Psychiatry*, 16, 703-705.
  104. Sivis, R., McCrae, S. & Demir, A. (2005). Availability of mental health services for older adults: a cross-cultural comparison of the United States and Turkey. *Aging & Mental*

---

Health, 9, 223-234.

105. Snowden, M., Sato, K., & Roy-Byrne, P. (2003). Assessment and treatment of nursing home residents with depression or behavioral symptoms associated with dementia: a review of the literature. *Journal of the American Geriatrics Society*, 51, 1305-17, 2003.
106. Soodeen, R., Gregory, D., & Bond, J. B. (2007). Home care for older couples: "It Feels Like a Security Blanket . . .". *Qualitative Health Research*, 17(9), 1245-1255.
107. Spruytte, N., Van Audenhove, C. & Lammertyn, F. (2001). Predictors of institutionalization of cognitively-impaired elderly cared for by their relatives. *International Journal of Geriatric Psychiatry*. 16, 1119-1128.
108. Statistics Canada. (2007). Health reports; Job satisfaction, stress and depression. *The Daily*, 17(4), Retrived March 20, 2009, from <http://www.statcan.gc.ca/daily-quotidien/061017/dq061017a-eng.htm>.
109. Storfjell, J. L., Brigell, E., Christiansen, K., Mcdevitt, J., Miller, A., Snyder, M., et al. (2008). WOW specialty home care service for individuals with serious mental illness. *Home Health Care Management & Practice*, 21(1), 23-32.
110. Steele, L., Dewa, C., & Lee, K. 2007. Socioeconomic status and self-reported barriers to mental health service use. *Canadian Journal of Psychiatry*, 52(3), 201-206.
111. Sullivan, M., Parenteau, P., Dolansky, D., Leon, S., LeClair, J., (2007). Shared geriatric mental health care in a rural community. *Canadian Journal of Rural Medicine*. 12(1), 22-29.
112. Thompson, S., Herrmann, N., Rapoport, M.J., & Lanctot, K. L. (2007). Efficacy and safety of antidepressants for treatment of depression in Alzheimer's disease: A metaanalysis. *The Canadian Journal of Psychiatry*, 52, 248-254.
113. Wagenaar, D., Mickus, M., Luz., Kreft. & Sawade, J. (2003). An administrator's perspective on mental health on assisted living. *Psychiatric Services*, 54, 1664-1666.
114. Wade, D., & Halligan, P. W. (2004). Do biomedical models of illness make for good healthcare systems? *British Medical Journal*, 329, 1398-1401.
115. Xaverius, P., & Mathews, R. (2003). Evaluating the Impact of Intergenerational Activities on Elders' Engagement and Expressiveness Levels in Two Settings. *Journal of Intergenerational Relationships*, 1, 53-69.
116. Yamaki, K., & Fujiura G.T. (2002). Employment and income status of adults with development disabilities living in the community. *Mental Retardation*, 40, 132-141.



## Appendix 1 – Databases Used

### Medicine

- Ageline (Ovid)
- Allied and Complementary Medicine Database (AMED)
- Alt-HealthWatch
- CAB Abstracts (Ovid)
- CINAHL Plus with Full Text
- Evidence-Based Medicine (EMB) Reviews
- Evidence-Based Medicine (EBM) Reviews – Cochrane Controlled (Ovid)
- Evidence-Based Medicine (EBM) Reviews – Cochrane Database (Ovid)
- Health & Psychosocial Instruments (HAPI) (Ovid)
- Health & Wellness Resource Center
- HealthSTAR (Ovid)
- History of Science, Technology, and Medicine
- International Pharmaceutical Abstracts (Ovid)
- MEDLINE (Ovid)
- PILOTS (Published International Literature on Traumatic Stress)
- PubMed
- SAGE Health Sciences

### Nursing

- Allied and Complementary Medicine Database (AMED)
- Alt-HealthWatch
- CINAHL Plus with Full Text
- Health & Wellness Resource Center
- Health Source: Nursing/Academic Edition
- HealthSTAR (Ovid)
- SAGE Health Sciences

### Psychology

- Child Development and Adolescent Studies
- Health & Psychosocial Instruments (HAPI) (Ovid)
- PILOTS (Published International Literature on Traumatic Stress)
- Psychology & Behavioral Sciences Collection
- PsycINFO (Ovid)
- SAGE Psychology

### Social Sciences

- Abstracts in Social Gerontology
- Ageline (Ovid)
- Alternative Press Index
- Anthropology Plus
- Bibliography of Native North Americans
- CIP.Q. – Canadian and international periodicals
- Family & Society Studies Worldwide
- Family Studies Abstracts
- Gender Studies Database
- IBSS: International Bibliography of the Social Sciences
- Oxford Journals
- SAGE Sociology
- Social Services Abstracts
- SocINDEX with Full Text
- Sociological Abstracts (CSA)

### Social Work

- Child Development and Adolescent Studies
- Family & Society Studies Worldwide
- Family Studies Abstracts
- SAGE Criminology
- SAGE Sociology
- Social Work Abstracts
- SocINDEX with Full Text
- Sociological Abstracts (CSA)



## CONTACT INFORMATION

Alberta Health Services  
Addiction & Mental Health  
Edmonton General  
8<sup>th</sup> Floor, R Wing  
11111 Jasper Avenue  
Edmonton, AB T5K 0L4

Tel: 780.342.8800

Fax: 780.342.8801

[www.mentalhealthresearch.ca](http://www.mentalhealthresearch.ca)