MEETING SENIORS' MENTAL HEALTH CARE NEEDS IN BRITISH COLUMBIA

A RESOURCE DOCUMENT

BRITISH COLUMBIA
PSYCHOGERIATRIC ASSOCIATION

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Purpose of this Document

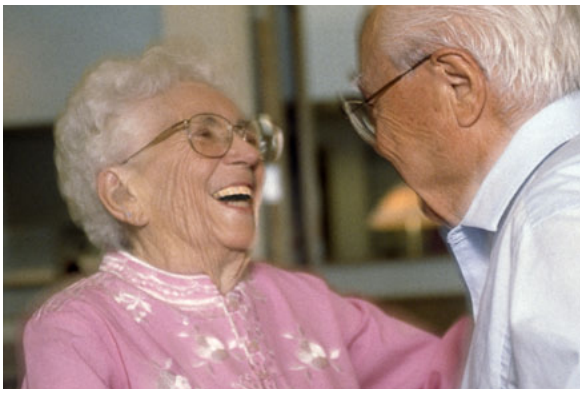
This document is intended as a resource for those in the province involved in providing care to seniors, including planners, program managers, policy makers, mental health and other health professionals. It also serves as a resource and reference document to help care-providers facilitate seniors' capacity to remain in their homes as long as possible, which in turn could help alleviate the pressures on residential care beds, hospital beds and emergency rooms.

In alignment with B.C.'s *"Healthy Minds, Healthy People – A Ten-Year Plan to Address Mental Health and Substance Use in British Columbia"*, this document provides evidence based/best practices for enhancement of the quality of seniors' mental health services. *"Meeting Seniors' Mental Health Care Needs: A Resource Document"* also addresses the implications of new trends and initiatives for the mental health care of seniors, reflecting emerging "best practice".

This resource is the result of a project which included a number of literature reviews and the results of focus groups (comprised of family caregivers and health care providers) who responded to questions around the role of mental health services, and dementia-related issues. The Meeting Mental Health Care Needs of Seniors in British Columbia Advisory Committee provided ongoing expert advice and feedback in the development of the resource document (please see list of committee members at the beginning of this document).

The resource document is organized into nine major chapters, plus a detailed bibliography and resource references, followed by an Appendix containing background information on the Role of Seniors' Community Mental Health in Dementia Care.

Please note: information contained within this resource document should not be interpreted as standards or guidelines but as reference information for planning senior mental health care.



Chapter I

I. Senior's Mental Health and Mental Health Promotion

The Significance of Mental Health Promotion

There is recognition that the concept of mental health is distinct from mental illness and that each is on a separate continuum. Mental health is not simply the absence of mental illness, but rather, as conceptualized by Keyes (2007)[1], mental health is on a continuum, with "flourishing" at one end and "languishing" at the other, and is conceptually distinct from mental illness. A person with a mental illness can have better (flourishing) or worse (languishing) mental health as can a person without a mental illness.

Positive Mental Health (Public Health Agency of Canada, 2009)

"The capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice, interconnections and personal dignity."

(Canadian Institute for Health Information. p. 3)[2]

The World Health Organization suggests that by promoting positive mental health, some of the negative outcomes of mental health problems can be modified even if other risk factors for mental illness remain (Friedli, 2009)[3].

[1] Keyes, C., (2007) Promoting and Protecting Mental Health as Flourishing: A Complementary Strategy for Improving National Mental Health. *American Psychologist*. 62, 95-108.

[2] Canadian Institute for Health Information, *Improving the Health of Canadians: Exploring Positive Mental Health*. (Ottawa: CIHI, 2009)

[3] Friedli, L. (2009) Mental health, resilience and inequalities. Prepared for the World Health Organization.

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Positive mental health enables people to realize their fullest potential and to cope with life transitions and major life events[4] (WHO, 2004).

Mental health is shaped by determinants of health that are intertwined, interact, and that can enhance or threaten an individual's or a community's health status (WHO 2004). The determinants of mental health include not only factors related to actions by individuals, such as behaviours and lifestyles, coping skills, and interpersonal relationships, but also social and environmental factors like income, social status, education, physical health, employment, housing and working conditions, access to appropriate health services, and in the community, building design and the level of social and civic participation. Many of these factors, as well as gender and ethnicity, are beyond the control of the individual.

Mental Health Promotion

"…is a process of enabling individuals and communities to take control over their lives and improve their mental health. It seeks to increase self-esteem, coping skills and capacities, and family and community supports, as well as to modify the broader social and economic environments that influence mental health."[5]

(Canadian Institute for Health Information, 2009, p. 4).

The aim of mental health promotion is to foster individual, social and environmental qualities that promote and support mental health, and to change those that do not[6] (Herrman, 2001). Promoting mental health requires multi-sectoral and multi-level mental health promotion interventions to reduce the risk factors for poor mental health and to enhance the protective factors (WHO, 2004). Factors, based on an evidence review, that protect seniors' mental health and that place their mental health at risk, are identified below (Mentality, 2004)[7].

[4] World Health Organization (2004). *Promoting mental health: concepts, emerging evidence, practice: summary report.* Available: http://www.who.int/mental_health/evidence/en/

[5] Canadian Institute for Health Information. (2009).Improving the Health of Canadians: Exploring Positive Mental Health. Ottawa: CIHI. p. 4

[6] Herrman, H. (2001). *The need for mental health promotion.* New Zealand Journal of Psychiatry, 35(6): 709–715.

[7] Mentality (2004) Literature and Policy Review for the Joint Inquiry for Mental Health and Well-Being in Later Life. Available: http://www.seniorspolicylens.ca/Root/Materials/Litandpolicyreview-Fulltextofreport%5B1%5D.pdf

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Mental Health Protective Factors

- Increased involvement and empowerment promotes mental well-being, through improving a sense of self-worth and reducing levels of isolation.
- Purpose, participation and meaningful activity are protective factors for mental health across the life course and in later life.
- Physical activity is a key element in the promotion of mental health in later life.
- Social support is a significant protective factor for mental health.
- Opportunities for seniors to have input into areas that affect them (programs, services, social relationships) support mental health.
- Seniors who remain productive and maintain or create new social networks do better than do those who disengage from society and social commitments.
- Use of new technologies such as the internet and also videophones can promote mental health in later life. Key underpinning principles seem to be creating and sustaining social networks, learning new skills and maintaining contact with family members, many of whom are dispersed geographically.
- Spirituality and religious belief have a positive influence on mental health in later life. Salient themes reflect the importance of individual and social support, sense of purpose and being able to let go of one's worries and responsibilities. There is also a sense that coming to terms with mortality is aided.
- An extensive social network is protective against onset of dementia (REF).

Mental health promotion (MHP) implies the creation of individual, social and environmental conditions that are empowering and enable optimal health and development. Such initiatives involve individuals in the process of achieving positive mental health and enhancing quality of life. It is an enabling process, done by, with and for the people (Jané-Llopis, Katschnig, McDaid & Wahlbeck, 2007, p. 13).[8]

[8] Jané-Llopis E., Katschnig H., McDaid D., and Wahlbeck K. (2007). Commissioning, interpreting and making use of evidence on mental health promotion and mental disorder prevention: an everyday primer. Lisbon.

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Mental Health Promotion Interventions

The Victorian Health Promotion Foundation (Vic Health) framework for the promotion of mental health and well-being states that Mental Health Promotion Intervention strategies should focus on four intermediate outcomes:

- Strengthening Individuals;
- Strengthening Organizations;
- Strengthening Communities; and
- Strengthening Society.

Mental Health Promotion Strengthening Individuals

Windle et al. (2008)[9] carried out a systematic review of the effectiveness and cost-effectiveness of public health interventions to promote seniors' mental well-being (i.e., different types of exercise, different types of health promotion programs, psychological interventions, computer use, gardening, support groups and volunteering). They concluded that that (1) exercise, (2) regular health promotion home visits, and (3) psychological interventions (e.g., cognitive training, control-enhancing interventions, psycho-education, relaxation and supportive interventions) are effective in promoting seniors' mental health.

Their work led to the following National Institute for Health and Clinical Excellence (NICE) recommendations[10] in Great Britain for all those involved in promoting senior's mental health, focusing on practical support for everyday activities.

- Offer regular sessions that encourage older people to construct daily routines to help maintain or improve their mental well-being. The sessions should also increase their knowledge of a range of issues, from nutrition and how to stay active to personal care.
- Offer tailored, community-based physical activity programmes. These should include moderate-intensity activities (such as swimming, walking, dancing), strength and resistance training, and toning and stretching exercises.

[9] Windle, G., Hughes, D., Linck, P., Russell, I., Morgan, R., Woods, B., Burholt, V., Edwards, R., Reeves, C., Yeo, S. (2008). Public health interventions to promote mental well-being in people aged 65 and over: systematic review of effectiveness and cost-effectiveness. University of Wales, Bangor. Available: http://www.nice.org.uk/nicemedia/live/11999/42401/42401.pdf

[10] Available: http://www.nice.org.uk

- Advise older people and their carers how to exercise safely for 30 minutes a day on 5 or more days a week, using examples of everyday activities such as shopping, housework and gardening. (The 30 minutes can be broken down into 10-minute bursts.)
- Promote regular participation in local walking schemes as a way of improving mental well-being. Help and support older people to participate fully in these schemes, taking into account their health, mobility and personal preferences.
- Involve occupational therapists in the design of training offered to practitioners.
- Involve seniors and their carer to identify the support they need.

Pinquart & Sorenson (2001)[11] carried out a systematic review to assess the effectiveness of psychotherapeutic and psychosocial interventions on the mental health of seniors with mental health problems. Interventions examined were cognitive behavioural therapy, reminiscence, psychodynamic approaches, relaxation, supportive interventions, control enhancement, psycho-educational treatments, activity treatments, and efficacy of training in cognitive skills. Outcomes included depression, subjective well-being, life satisfaction, morale and self-esteem. Their findings include:

- Seniors believe that they benefit from psychosocial and psychotherapeutic interventions – they reported significant improvements in psychological well-being across studies.
- Relaxation interventions are the most effective psychosocial interventions – they had greater impact on seniors' mental health than supportive treatments, psycho-educational interventions, activity promotion and cognitive training.
- Control-enhancing interventions and cognitive behaviour therapy had an above-average impact on self-reported measures of psychological well-being compared with reminiscence, miscellaneous therapies, supportive interventions, psycho-educational interventions, activity promotion and cognitive training.
- Individual interventions, compared to group interventions, were associated with significantly greater improvements in self-reported psychological well-being.
- Interventions with nursing-home residents, compared to interventions in the community, were associated with significantly greater improvement in self-reported psychological well-being.
- Therapists with advanced degrees and either professional experience or special geriatric experience, were more effective than those with advanced degrees but no special geriatric training, or those with no advanced degree.

[11] Pinquart M, Sörensen S. How effective are psychotherapeutic and other social interventions with older adults? *Journal of Mental Health and Aging 2001*;7(2):207-43.

Brodaty et al. (2003)[12] have carried out a meta-analysis of interventions (excluding respite) targeting caregivers of people with a dementia, for their effect on mental health. They reported that:

- Interventions that (a) involved people with a dementia and their caregivers, (b) were more intensive and (c) were modified to the caregivers particular needs (e.g., teaching skills), were more likely to succeed.
- Successful interventions also included practical support, structured individual counselling and consistent, long-term, professional support.

Peacock and Forbes (2003)[13] conducted a systematic review to investigate the effectiveness of interventions designed to enhance the well-being of caregivers of seniors with dementia living in the community. Interventions reviewed were: education, case management, psychotherapy and computer networking. Outcome measures included: institutionalization of the care recipient, death of the care recipient, perceived behaviour disturbances in the care recipient, caregiver depression, caregiver strain, caregiver stress and use of formal services.

Positive findings indicated that:

- Case management increased the likelihood of using formal services
- Psychotherapy for caregivers delayed institutionalization of the care recipient,
- The use of computer networking improved decision-making confidence,
- Education interventions that included training in coping skills, in addition to information on dementia, were more effective than those that offered education alone

There are a variety of broad initiatives, while not specifically focused on mental health, nevertheless contribute to the positive mental health of individual seniors. The self-management component of British Columbia's *Chronic Disease Management Model* promotes seniors' mental health by empowering participants to manage their health conditions. *Early Stage Dementia Support* groups provided by the Alzheimer Society of British Columbia promote the mental health of participants through opportunities for social connection, peer support and development of coping skills.

[12] Brodaty H, Green A, Koschera A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *J Am Geriatr Soc*; 51(5):657-64.

[13] Peacock SC, Forbes DA. (2003) Interventions for caregivers of persons with dementia: a systematic review. *Can J Nurs Res*; 35(4):88-107.

Chapter I

Mental Health Promotion Strengthening Organizations

Organizations that serve seniors can strengthen their capacity to promote seniors' mental health by:

- Ensuring that seniors' and their caregivers have input into planned and existing programs is solicited and acted upon
- Supporting resident and family councils in long term care facilities
- Ensuring that staff have the appropriate education and skills to the promote mental health of seniors
- Incorporating recommendations from the Dementia Service Framework
- Implementing the Seniors Mental Health Policy Lens (MacCourt, 2008)[14], a critical lens, recommended in the Mental Health Commission of Canada *Guidelines for Comprehensive Mental Health Services for Older Adults in Canada (*MacCourt, Wilson & Tourginy-Rivard, 2011)[15], that is designed to facilitate seniors' involvement in program and policy development and to identify any unintended negative effects on them.

The *Age Friendly Primary Care Guide* (WHO, 2004) was developed specifically to strengthen the age-friendliness of primary health care organizations. It has been designed to guide primary health care organizations to modify management and clinical services, staff training and the physical and social environments to better fit the needs of their older patients (e.g., removal of physical barriers, increasing respect, removal of ageist policies; appropriate means of communication and information packaging and targeting, etc.).

How services to seniors are delivered can impact seniors' mental health. For example, seniors and their caregivers repeatedly report that having too many service providers in their homes can be stressful. Similarly, it is stressful when there are too many different support workers, undermining the confidence that comes from trust.

The rate of depression in residential care facilities is very high, and at least in part affected by the social environment – the organization of care, consistency in staff, and availability of opportunities for control, social engagement and emotional support. The *CCSMH Guidelines,*

[14] MacCourt P. (2008). *Promoting Seniors' Well-Being: A Seniors' Mental Health Policy Lens Toolkit,* Victoria, British Columbia: British Columbia Psychogeriatric Association. Available: http://www.seniorspolicylens.ca/Root/ToolkitPage2.html

[15] MacCourt, P., Wilson, K. & Tourigny-Rivard, M. (2011) Guidelines for Comprehensive Mental Health Services for Older Adults in Canada Prepared for the Seniors Advisory Committee to the Mental Health Commission of Canada. To be released October 2011 www.mhcc.ca

the *Dementia Service Framework* and *Best Practices in Facility Design* can all provide direction on strategies to improve long term care environments and promote mental health. As well, models of care, such as the *Eden, Gentle Care* etc., can be implemented.

ProMenPol Project (2009)[16], funded by the European Commission, has developed a manual to enable the implementation of Mental Health Promotion programs in senior's residences[17] in a planned and systematic way.

Mental Health Promotion Strengthening Communities

Federal and provincial Healthy Aging strategies can contribute to seniors' mental health through their initiatives, particularly those related to exercise and social inclusion. The Age Friendly Community movement (WHO, 2007)[18] promotes seniors mental health through the development of supportive physical and social environments that facilitate exercise, social connection, and respect for seniors. *Addressing the Mental Health Needs of Older Adults in Age-Friendly Communities: A Guide for Planners* has been designed for planning and advocacy groups involved in developing age-friendly communities to help them to: (1) understand mental and substance abuse problems among seniors, (2) know the key components of addressing geriatric mental health in an age-friendly community, and (3) assess how well their community is meeting the mental health needs of its older residents (Williams & Friedman, 2010)[19].

Mental Health Promotion Strengthening Society

Collective action by society is needed to promote the mental health of all seniors, including those with, or at risk, of mental health problems. This requires policies and programs in government and business sectors including education, labour, justice, transport, environment, housing, and welfare, as well as specific activities in the health field relating to the prevention and treatment of ill-health (WHO, 2004).

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[16] ProMenPol (2009). lA Manual for Promoting Mental Health and Wellbeing: Older Peoples Residences .

[17] Residences are defined as: 'permanent' homes for people, whether this is a nursing home or other residential facility. It also includes older people who live at home and avail of some form of supportive service.

[18] World Health Organization. (2007). Global Age-friendly Cities: A Guide. Geneva: World Health Organization Press.

[19] Williams, K. and Friedman, M. (2010). Addressing the mental health needs of older adults in "Age-friendly Communities": A guide for planners. Geriatric Mental Health Alliance of New York. Available: http://www.mha-nyc.org/media/1251/agefriendly.pdf

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"Ageism", discrimination on the basis of age, is a problem that cuts across Canadian society and permeates our political processes (e.g., inter-generational conflict evident in debates about pensions and health care costs), the media (negative portrayal of seniors in commercials, movies), education (lack of gerontological content in curriculum of health and allied professions relative to size and needs of the seniors' population), health care systems, and the employment and voluntary sectors. To address the double stigma of aging and mental illness, the Mental Health Commission of Canada is launching a national anti-stigma campaign.

Low income is a structural barrier that influences seniors' mental health – ensuring that programs directed at seniors, medications and related needs (e.g., continence supplies, eye glasses), dental care, transportation and various levels of housing are affordable is important.

Transportation is a major concern for seniors, related to cost, distance from public transportation, and access to private transportation, weather etc. Transportation/mobility "has been linked to health and quality of life in a myriad of ways, including enhanced social functioning, engagement in life, independence, and access to health and other needed services." (New York Academy of Medicine, 2009, p, 39[20])

Lack of housing has a detrimental effect on seniors' physical and mental health. Seniors who are homeless or recently homeless and lack social supports are especially prone to depression, dementia, and other mental health problems[21]. The same study also noted that mental health conditions may threaten a senior's stable housing due to, for example non-payment of rent because of cognitive challenges. Mental health promotion benefits the entire population and populations at risk of mental ill health. As well, it works to improve the mental health of people living with mental illness and to challenge the stigma and discrimination associated with mental illness (WHO, 2004).

[20] New York Academy of Medicine (2009). Age-friendly New York City. Retrieved December 20, 2009 from http://prtl-prd-web.nyc.gov/html/om/pdf/2009/pr386-09_report.pdf.

[21] US Dept of Health and Human Service. (2003). Homeless and elderly: Understanding the special health care needs of elderly persons who are homeless. Office of Minority and Special Populations in the Bureau of Primary Health Care.

Chapter II

II. Best Practice Approaches in the Provision of Seniors Mental Health Care

The Significance of Principles and the Key Elements of Best Practice

While a service or program must ultimately reflect demonstrable evidence of quality, it must also be recognized there is no one best service system that is appropriate in all situations. What is "best" in one community may not be "best" for another community with different demographics, resources or other factors. Services and programs must reflect local variations, the potential for innovative responses, as well as more general standards for efficacy, efficiency and quality. Services and programs should be informed by the best available evidence from the academic literature and from the experiential knowledge of those who deliver the services and those who use them. All programs, old as well as new, should have goals and objectives that are stated, achievable and measurable. Appropriate evaluations should be done regularly to ensure that each program continues to meet the local needs, as well as the stated goals and objectives. Where standard evaluations for needs, processes and outcomes are established, it is possible to compare British Columbia practices to Canadian and world standards. The information will also improve local programs and practices.

Psychogeriatrics *is concerned with mental illness in elderly people*

Chapter II

Principles to Help Guide Best Seniors' Mental Health Care Practices

The following principles are based on the BC Psychogeriatric Association's Principles of Psychogeriatric Care and the input of the Working Group that assisted in the development of this Resource Document:

Principle 1: Care is Person-Centered

- Maintain the dignity of seniors and treat them with respect.
- Involve the person in care planning and be culturally sensitive.
- Be sensitive to the complex and unique ethical issues that arise in the context of decision making about care for older persons, especially those with significant mental health issues.
- Ensure the physical and social environment in which care is provided is therapeutic and shifts focus from tasks to relationships.
- Develop and foster a culture of caring across the spectrum of care that acknowledges the need for meaningful life (rather than just living), promotes optimal mental health and recognizes people's relational needs and prevents alienation, anomie and despair that many seniors feel.
- Ensure that all those caring for seniors with mental health problems are educated about person-centred principles and are supported in implementing them.
- Ensure community and residential staff who work with seniors, regardless of their discipline or job, have the skills and knowledge needed to provide informed and competent services, and are supported to maintain them.

Principle 2: Care is Goal Oriented

- Involve seniors in realizing their own personal care and life goals.
- Utilize methods of care that help seniors/clients manage their symptoms and build on their strengths.
- Reduce distress to the senior and the family.
- Improve and/or maintain functioning.
- Mobilize the individual's capacity for autonomous living.
- Maximize and maintain independence at the highest level possible.
- Work towards recovery and maximized quality of life.

Principle 3: Care is Accessible, Responsive and Flexible

- Provide information and help that is user-friendly and readily available and accessible to the public, seniors, families/caregivers and service providers.
- Provide responsive services that listen to and understand the problems and acts promptly and appropriately.
- Remove geographical, cultural, financial, political and linguistic obstacles to obtaining information about services and care.
- Expand psychogeriatric outreach to rural and remote communities. This expansion should include more consultations by a broad range of disciplines using technology as appropriate (e.g., telehealth).
- Provide individualized service to each person wherever most appropriate (e.g., residence, hospital).
- Ensure access to secondary and tertiary services.
- Define and formalize links for transitions between acute care, facility care and community-based services.
- Develop and adopt competencies expected of professionals working with seniors and ensure all staff caring for this population has the necessary skills.
- Respond to reasonable expectations from clients, families and those providing service and anticipate and respond to changing demographics.

Principle 4: Care is Comprehensive

- Develop preventive interventions, including strategies for maintaining wellness, and early interventions for mental health disorders. Incorporate this information into specific training programs for both informal and formal caregivers.
- Take into account all aspects of the person's physical, psychological, social, financial and spiritual needs.
- Make use of a variety of professionals, resources and support personnel to provide a comprehensive range of services in all settings, including the community, facilities and acute care.
- Implement a bio-psychosocial model of care that considers the whole person and addresses biological, psychological, social and environmental needs of the population being served.
- Develop a team approach; regardless of the size of the community, that utilizes a variety of disciplines and skills in a collaborative manner.

- Ensure family members are included as part of the care team.
- Ensure all care teams, regardless of size, attend to team dynamics and functioning and include education and quality improvement as part of their mandate.
- Ensure nonmedical community service providers, such as police, service clubs and volunteers, who assist seniors in various ways are also part of the larger care team.
- Develop and establish clear lines of authority to handle crisis response/emergency services including intensive at-home care services such as respite, home support and added care as needed in urgent, time-limited situations.

Principle 5: Care is Senior Focused and Specific

- Recognize that the needs of seniors with mental health problems are qualitatively different from those of mentally well seniors and different from those of younger people with a mental health problem and design appropriate and relevant services specifically for this population.
- Identify the unique service needs of seniors with mental health problems (outpatient and inpatient) and develop plans for meeting those needs with adequate and appropriate resources.

Principle 6: Programs and Services are Accountable to the Public, Clients and Families

- Accept responsibility for assuring the quality of the service delivered and ensure that seniors, families/caregivers and service providers are involved in a process of planning, monitoring and evaluating programs for seniors.
- Incorporate relevant evaluation strategies and research findings to determine optimal methods of service delivery.
- Be aware of and utilize evidence based service delivery and treatment methods.
- Formally evaluate tertiary services for seniors to assist in further planning and/or development of these resources.
- Develop ways to track indirect work, including telephone consults, discussions about cases with other professionals and educational sessions.
- Develop and utilize standardized quality improvement criteria, including access criteria, discharge criteria, case loads, staffing benchmarks and outcomes.
- Employ a variety of methodologies and approaches, to monitor and evaluate the clinical effectiveness of all programs and innovations in the provision of care.

- Support local accreditation and program evaluation of seniors' mental health care services.
- Ensure all those providing care to seniors with mental health challenges have access, and are supported in implementing best practice guidelines.
- Encourage and support research on mental health and aging, service delivery models and programs.

Principle 7: Services Work Together to Build Capacity for Seniors Care

- Recognize that families/informal caregivers provide the majority of care to seniors with, or at risk of, mental health problems.
- Recognize that family physicians and community health workers are the basic infrastructure of the mental health care system for seniors.
- Recognize that voluntary sector, private sector, police, and others provide vital support to seniors with mental health challenges and to their families.
- Ensure that families/caregivers have the necessary support, knowledge and skills to manage persons with challenging behaviours.
- Support family physicians in early detection and intervention of mental illnesses.
- Facilitate collaboration between mental health services and government and non-government/voluntary agencies in the development and delivery of programs that support seniors' mental health.
- Collaborate with other services to ensure continuity of care and coordination among all levels of services.

Key Elements and Approaches to Care

A number of care elements and approaches to care for seniors are required in the mental health care system, regardless of the community size or location, service sector or the type of care provider.

The following sections of the Resource Document are organized into Key Elements and Approaches to Care, and present examples of best/leading practices related to mental health service delivery and program planning for seniors, as well as linkages to other relevant reference documents.

Chapter II

- Education for Seniors, Family, Informal and Formal Caregivers
- Family/Caregiver Support
- Creating Supportive Environments
- Integration and Continuity of Services
- Collaboration and Partnerships: Building Capacity
- Quality Improvement and Evaluation

These care elements and approaches, including those pertaining specifically to dementia, are discussed in the following sections of this Resource Document.

Chapter III

III. Mental Illness Among Seniors

The Significance of Risk Factors and Seniors Mental Health

Many seniors maintain good health, including mental health, well into old age, have adequate social support and are resilient. However, age-related changes, often cumulative, place many seniors at risk for mental health problems and can, for example, increase the risk of social isolation and vulnerability to depression. Changes associated with normal aging include the following:

- Physical (e.g., visual and hearing deficits, mobility limitations);
- Cognitive (e.g., processing speed, memory); and
- Social (e.g., bereavement, caregiving, diminished social opportunities, relocation).

Chronic diseases, often co-occurring, can also have physical, cognitive and social impacts on seniors, sometimes complicated by the side effects of medications and other treatments.

Over and above the foregoing, there are some seniors in B.C. who face additional challenges to their mental health, for example, low income seniors, caregivers, seniors whose first language is not English, seniors who are refugees, seniors without children nearby, and First Nation seniors. The impact of environmental factors on a senior's mental health is clear: "psychiatric illness and psychological disturbances in old age cannot be separated from the physical, psychological, social and environmental context within which that illness emerges" (Sadavoy, 2007, p. 810)[22].

Seniors with or without mental health problems may experience challenges to their mental health and well being associated with normal aging, chronic diseases and with issues related to low income, housing and transportation needs. The impact of these stressors, which are often co-occurring and cumulative, may exacerbate seniors' psychiatric symptoms/illness and may be accompanied by substance use problems. Additionally, seniors with mental health and substance use problems experience the double stigma of aging and mental illness.

[22] Sadavoy, J. (2009). An integrated model for defining the scope of psychogeriatrics: The 5 Cs. *International Psychogeriatrics*, 21:5, 805-812

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Seniors with Mental Health Problems

…is a general term used to describe people over the age of 65 years who have emotional, behavioural or cognitive problems which interfere with their ability to function independently, which seriously affect their feelings of well-being, or which adversely affect their relationships with others. These problems have a variety of bio-psychosocial determinants and methods of treatment and care. "People under the age of 65 who have conditions more commonly seen in elderly people, such as early dementia, are included in this group".[23]

Included in this population are:

- Seniors who develop mental health or substance use problems in their older years or who have recurrent conditions, such as anxiety or depression.
- Seniors with long standing chronic, serious psychiatric disorders who develop age-related conditions/diseases/complications.
- Seniors presenting with complex intertwined psychiatric and cognitive, physical, functional and/or social conditions, which cannot be differentiated and diagnosed by primary care physicians.
- Caregivers of seniors with a substance use, mental health problem or illness related to their caregiver role.
- Some younger adults who have age-advancing disorders (e.g., developmentally challenged adults, Huntington's Disease) and that may receive care through the same service system, including residential care, as do seniors, (e.g., acquired brain injury).

Seniors Mental Health Services and Dementia

Dementia is a syndrome caused by a range of illnesses. Most are currently incurable, and cause progressive, irreversible brain damage. They include Alzheimer's disease (the most common cause), vascular disease, frontal lobe dementia and Lewy Body disease. Symptoms of dementia can include memory loss, difficulties with language, judgment and insight, failure to recognize people, disorientation, mood changes, hallucinations, delusions, and the gradual loss of ability to perform all tasks of daily living. In 2011 approximately 61,000

[23] B.C. Ministry of Health Services and Ministry Responsible for Seniors (1992). Services for elderly British Columbians with mental health problems: (A planning framework). Victoria, Province of British Columbia.

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British Columbians were expected to be suffering from dementia, about 57,000 over 65 years of age (Source: Primary Health Care – Registry, 2009/10. ASIR: Age Standardized Incidence Rate, ASPR: Age Standardized Prevalence Rate & ASMR: Age Standardized Mortality Rate). By the year 2021, 81,000 people in B.C. are projected to be suffering from a Dementia and may be suspected or diagnosed at the mild cognitive impairment level; the biomarkers identified at this stage become increasingly important in tertiary and quaternary care. Mild cognitive impairment may then progress to the dementia stage with the recognition of functional deficits beyond memory complaints.

In the mild stages of dementia, comprehensive assessment with a bio-psychosocial, functional approach becomes the basis for all diagnostic considerations and care plans. Patient goals should be identified and frame interventions as much as possible. At this stage issues of driving are important to start exploring, as well as advanced planning (powers of attorney, representation agreements over health, end of life planning and wills). Early patient and caregiver education is essential, and referrals to the Alzheimer's Society and to educational services within the community are important components of care. Medications to treat depression may be used, and medications to slow down the downward deterioration in function (with cholinesterase inhibitors) may also be considered.

In the middle stages of dementia patients will start manifesting behavioural problems; assessment of the origins of those behavioural problems is essential, again with a bio-psychosocial, functional and environmental approach. Care planning, starting with behavioural approaches before considering medications, is essential. If patients and families have not been referred to Home and Community Care by this point it would be appropriate to do so for support services. Caregiver support through the Alzheimer's Society and Health Unit services becomes even more important. Caregivers' goals, abilities and capacities should be assessed and taken into account in care planning. All health care providers need to focus on the quality of life of the patients and should prepare the caregivers for eventual palliative care. In the palliative stages of the dementia journey, quality of life becomes the predominant focus.

Seniors' mental health services in the community must be timely, available and flexible. Care provided by community mental health for patients with dementia and their caregivers must be either collaborative or integrative within the system, must be interdisciplinary, and must work across transitions. A case manager must be identified for coordination and continuity of care.

Communication with patients with dementia and caregivers and within the service system must be a priority. Without good communication, services and care providers may find themselves at cross-purposes, thus undermining the effectiveness of care and causing increased distress for both patient and family members.

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Recovery in Dementia

Recovery in dementia refers to maximizing a patient's function and quality of life, including provision of meaningful activities, as well as support for caregivers so caregivers have satisfaction with their role and have respite services offered to reduce their stress levels. Adams[24] (2009) reviewed the literature on a recovery model approach to nursing of people with dementia and suggested that there was a convergence of ideas between recovery and the promotion of well being for people with dementia. In a national health services document 2010, a recovery model of dementia is discussed.

"Dementia may signal the end of life, but it is not immediately fatal. If people are to make the most of the lives that are left to them, then it is living with, rather than dying from dementia that is critical. As with people of all ages who develop other terminal physical illnesses, the challenges become one of living as valued and meaningful a life as possible:

- Doing the things that you value for as long as possible;
- Preserving a sense of personhood;
- Celebrating who you are and what you have achieved in life;
- Leaving a legacy for future generations (the gift of history);
- Preparing advanced statements regarding likes, dislikes, preferences so that others know when you are unable to tell them."[25]

The Seniors Advisory Committee of the Mental Health Commission of Canada has developed Guidelines for Comprehensive Mental Health Services for Older Adults in 2011. In supporting the need for a recovery model, including dementia, these Guidelines state: "It should be underscored that the concept of recovery is rooted in the importance of choice, hope, respect, empowerment and individualized and person-centred care philosophies that are consistent with ideal dementia care."[26]

[24] Adams, T, 2010, The Applicability of Recovery to Nursing People with Dementia.

[25] Recovery is for All, Hope Agency and Opportunity in Psychiatry, a position statement by consultant psychiatrists, South London and Maudsley NHS Foundation Trust, December 2010.

[26] MacCourt, P., Wilson, K and Tourgny-Rivard, M (2011). Guidelines for Comprehensive Mental Health Services for Older Adults, prepared for the Seniors' Advisors Mental Health Commission of Canada

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The Role of Seniors' Mental Health Services in Dementia Care

For patient and family centeredness we must look first at the needs of the patients, and then define services that should be in the community in order to meet these needs. If the needs cannot be met, that also needs to be documented and dealt with patient by patient in a systems approach. We should be looking at cognitive, behavioural or medical complications requiring mental health assessment and interventions underlying the reasons for referral, including type and quality of caregiver support, both formal and informal. Formal caregiver support is always part of the mental health role whenever mental health is involved.

Seniors' mental health also needs to be involved at the community level in emergency or urgent responses. It is important to try to prevent emergencies that require patients to go into the Emergency Departments of hospitals because we are aware that unwarranted hospitalizations can have negative outcomes. Seniors' mental health services in the community must be timely, available and flexible. In the diagnosis of early dementia, awareness of gaps in services is important; service providers should advocate to fulfill needs not met because of these gaps.

Care provided by community mental health for patients with dementia and their caregivers must be either collaborative or integrative within the system, must be interdisciplinary, and must work across transitions. A case manager must be identified for coordination and continuity of care.

Caregivers and other family members must be treated with respect and trust, and they must be involved not only in care planning but also in systems planning. One of the tasks of the mental health team is to encourage caregivers to be involved in systems planning issues. Many professionals and some caregivers believe that seniors' caregivers need to have a voice in suggestions for what services need to be developed for their loved ones with dementia. They also want to be involved in the actual service development planning and in quality improvement processes once services are up and running.

The Role of Seniors Community Mental Health Services

Throughout the dementia journey there is no one caregiver, no one discipline and no one service that can provide all the necessary care. Trite as it may sound, teamwork and good communication between the various service providers are essential.

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Patients typically are referred to seniors' community mental health services at any age when there is a question of "Is this dementia or is this depression?" If community mental health makes the diagnosis of mild cognitive impairment or dementia in someone less than 65, in most cases it would be appropriate to refer them to a neurologist or a geriatrician for medical follow-up and potential research involvement or quaternary care if there is a strong genetic component. Patients less clearly definable within a geriatric mental health mandate are those younger than 65 with conditions such as brain injury with chronic cognitive impairment, developmental disabilities and neuropsychiatric patients with components of dementia. Seniors' mental health should do consults on those under 65 with geriatric psychiatry needs, but each health authority should define the role of adult mental health and/or neuropsychiatry for outpatient/outreach assessments for these populations.

Seniors' mental health services should also offer consultations to young adult mental health service patients who are turning 65 or are over 65 and who the young adult services teams have followed. These patients include those with schizophrenia and manic depressive illnesses when they begin to suffer from cognitive impairment. There should be a discussion between the young adult and seniors' mental health teams about which team is most appropriate to follow these patients on an ongoing basis and which patients need only a consult from seniors' mental health. It would only be appropriate to refer to seniors' mental health for ongoing follow-up if dementia or major interacting medical disorders need to be sorted out along with their psychiatric problems.

If mental health passes on the care of a patient to a neurologist or a geriatrician, or back to the family physician without further follow-up, clear communication should be given to the patient and the caregiver that this is occurring, with advice about how and when they may again contact and be followed by mental health. This advice will help the patient and caregiver avoid a sense of abandonment by mental health.

Ideally, all patients over 65 would be seen first by primary care and referred by primary care physicians. Should they first be seen by home and community care staff and referred to mental health, an attempt should be made to connect with a primary care physician or nurse practitioner for ongoing comprehensive primary medical care. Family self-referrals also are valuable and must be considered within the intake process, but always, if there is a family physician involved, mental health should discuss with the family the importance of maintaining connections with the family physician and ask them to speak to the family physician and request further collateral information. Mental health can then enable a collaborative care model by working with the primary care physician or nurse practitioner to do a biopsychosocial functional comprehensive assessment, make a diagnosis and suggest or discuss such issues as advance planning and driving. The objective of collaboration

with primary care is to develop a common care approach that may include medications and appropriate referrals for community resources. The primary care practitioner can then determine how much or how often mental health needs to be involved in a supportive role. In some circumstances primary care may be asking for consultation only. In other circumstances they may be asking for follow-up by mental health, especially when there are complicated caregiver issues, medical/legal issues such as potential neglect or abuse or a need for incapacity assessments. Complicated behavioural problems requiring significant ongoing team management might also be requested.

In the case of patients with dementia who are suspected of self-neglect or of neglect or abuse by others, it is especially important that seniors community mental health work collaboratively with primary care in any assessment or management.

Local Capacity

The role of seniors' community mental health in dementia care is not only dependent on what the primary care practitioners may need help with, but also on what other services are available or what capacity the community has to support people with dementia. In all communities mental health should have core services, both direct and indirect, for patients with dementia and their families. But in larger communities, or communities with more resources available, the role will be dependent upon the local capacity components. Local capacity could refer to whether or not there are neurologists or geriatricians within the community, whether or not this is an urban or rural area, whether or not there are diversity issues like multicultural factors involved in terms of population planning, or whether or not there are family physicians in the community who feel comfortable with dementia care and who take the lead in dementia care within the community. In larger communities it is likely that geriatricians or neurologists will see early cognitively impaired patients for diagnoses and that family physicians will do the follow-up until clear mental health problems or caregiver stress require the involvement of seniors' mental health services. However, clear identification of mental health issues may lead to earlier referrals to mental health services, including for caregiver support.

Direct Care

Core care for seniors' mental health includes seeing patients when asked, doing comprehensive mental health assessments in collaboration with primary care, making differential diagnoses and probable diagnoses, developing common community care plans, doing incapability assessments when required for finance or person, and being involved with

assessments of self-neglect, neglect or abuse when the community requires this. Core services should also see mental health working and communicating collaboratively within the community, not only with primary care (family physicians and home and community care), but also with residential care and acute care. In-reach to acute care and participation with discharge planning should be provided when needed.

Core care should also involve referral for caregiver education or treatment of caregivers when they suffer from anxiety or depression. Direct care providers in mental health must remember that a recovery model is possible and necessary when approaching dementia care, so psychosocial rehabilitation is essential.

Seniors' community mental health service providers should participate with other service providers in shared patient records. They should support prevention and health promotion either by doing it themselves or by helping develop curricula with other partners.

Indirect Care

Indirect care can be provided by seniors' mental health services in many forms and means. Shared or collaborative care, case discussions with primary care and education for primary care practitioners are examples of indirect care. Public education as requested or education for staff in residential care facilities and hospitals regarding community care are other examples. Indirect care also includes protocol development around dementia care, advocacy for seniors' services when gaps in the system are recognized and solutions identified, program evaluation and quality improvement to incorporate research evidence into practice and give feedback to all team members.

Personnel

Community geriatric mental health teams usually involve either a family physician, a psychiatrist or a geriatric psychiatrist, as well as an RN or RPN, a social worker, an OT and a secretary, as well as consults by Pharmacy. Neuropsychological assessments should be accessible for complex cases. It is also suggested that trained life skill workers be attached to seniors' mental health teams in order to truly work on supporting patients and caregivers in a recovery model. Equally important is consideration of the advisability of having community geriatric psychiatry clinical nurse specialists, particularly for residential care, connected with both home and community care and mental health.

The concept of patient navigator, someone who expedites patient access to services and resources in order to improve continuity and coordination of care in the provision of services,

is a new and useful organizational tool. However, the specific role of patient navigator needs to be defined, either within existing roles in primary care or mental health or specific to the patient, such as a family member. Whoever is identified as the one person to be the navigator should be seen as the single point of contact to ensure continuity of care without duplication or conflicting approaches.

Working with Tertiary Care

Tertiary care is changing over time and need not solely be defined as "beds." In fact, tertiary may refer to special populations with very special problems. These special populations include clinics for patients with frontotemporal or Lewy Body dementia, individuals with dementia plus addictions or early onset dementia or patients with severe behavioural problems in facilities. Although sometimes some of these patients may need inpatient services of a tertiary nature, they may also need "tertiary" care within the community, and this may mean a second opinion or super-specialist care. It is important to recognize that tertiary care really involves specialized staffing needs, purpose-built facilities when facilities are required and specialized skills of health care professionals.

Conclusion

Seniors' mental health services must meet the needs of both patients and families. They must work collaboratively in the whole system to support primary care and to educate others with respect to the specialized mental health needs of patients with dementia and their family caregivers. They must advocate for evidence-based individual patient care as well as recognize and report service gaps in the system. At all times mental health professionals must listen carefully to the patient who has dementia and to the caregiver and must provide a person-centred compassionate, competent approach to care. For background information on the Role of Seniors' Community Mental Health in Dementia Care see Appendix A.

Chapter III

Prevalence of Mental Illnesses Among Seniors

B.C.'s population is aging. As the population ages, so too will the number of seniors with mental health problems and illnesses.

- In 2009/10, 7.8 per cent of the B.C. population was between 65 - 75 years of age and 7.0 per cent are 75+.
- The proportion of the population aged 65+ is projected to increase by 25.9 per cent to 18.6 per cent of the total population over the next ten years with increased prevalence of chronic conditions and increased frailty[27].
- Currently, one in four seniors is believed to have a significant mental disorder (Bartels, 2003)[28], and the number of seniors with major psychiatric illnesses is predicted to more than double by 2030 (Jeste et al., 1999)[29].
- Mental illness is estimated to occur in 25 per cent of seniors (Bartels, 2003)[30] and expected more than double by 2030 (Jeste et al., 1999)[31].
- Research indicates that in the community 15 per cent of seniors have a depression, while in long term care facilities the prevalence reaches 44 per cent (CCSMH, 2006)[32]. Men over 80 years have the highest suicide rates in Canada (MDSC, 2009)[33].
- Anxiety occurs in 5 - 10 per cent of seniors (Bryant, Jackson, & Ames, 2008)[34].
- Alcohol problems occur in 6 - 10 per cent of seniors (Seeking Solutions, 2004 as cited in CAMH Healthy Aging Project, 2006)[35].

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[27] Ministry of Health Services (2010). Delivering Effective, Integrated System Of Primary And Community Care Policy Paper to Provide Background and Context for Strategy , September, 2010, p.5

[28] Bartels, S.J. (2003). Improving the system of care for older adults with mental illness in the United States. *American Journal of Geriatric Psychiatry*, 11, 486-497.

[29] Jeste, D.V., Alexopoulos, G.S., & Bartels S.J. (1999) Consensus statement on the upcoming crisis in geriatric mental health: research agenda for the next two decades. *Archives of General Psychiatry*, 56, 848–853.

[30] Bartels, S.J. (2003). Improving the system of care for older adults with mental illness in the United States *American Journal of Geriatric Psychiatry*, 11, 486-497.

[31] Jeste, D.V., Alexopoulos, G.S., & Bartels S.J. (1999) Consensus statement on the upcoming crisis in geriatric mental health: research agenda for the next two decades. *Archives of General Psychiatry*, 56, 848–853.

[32] Canadian Coalition for Seniors' Mental Health (CCSMH) (2006). *National Guidelines for Seniors' Mental Health: The Assessment & Treatment of Depression*. Toronto, ON: CCSMH.

[33] Mood Disorders Society of Canada. (2009). *Quick Facts: Mental Illness and Addiction in Canada*. 3rd Edition. Guelph, ON: MDSC.

[34] Bryant C, Jackson H & Ames D. (2008). The prevalence of anxiety in older adults: Methodological issues and a review of the literature. *Journal of Affective Disorders*, 109(3), 233-250.

[35] CAMH Healthy Aging Project. (2006). *Responding to Older Adults with Substance Use, Mental Health and Gambling Challenges: A Guide for Workers and Volunteers*. Toronto: Centre for Addiction and Mental Health.

- Persistent psychotic disorders, including schizophrenia and delusional disorder affect 1-2 per cent of seniors (Schizophrenia Society of Canada, n.d)[36].
- Bipolar disorder is estimated at less than 1 per cent among seniors (CCSMH, 2006)[37].
- Delirium is experienced by almost 50 per cent of seniors admitted to acute care hospitals (CCSMH, 2009a)[38].

Access to Assessment and Other Services

Seniors who appear to be "at risk", particularly those who self-neglect, who exhibit compromised decision making and executive functioning, severe memory impairment, poor judgment and/or significant delusions, are often referred to elderly mental health services for assessment. The situations presented are generally very complex, and there may be disagreement about the appropriate response for the client. Assessment is sought to provide capability for investigation of clinical, ethical, legal and practical issues, for improving communication and sharing of information amongst all service providers and caregivers, and for clarifying of each person or service's roles and responsibilities for the senior. Access to specialized assessment resources for seniors can be challenging both in areas with low senior populations (due to distance) and in well resourced urban areas with high senior populations (due to high demand).

Caring for seniors with dementia is not only dependent on what the primary care practitioners may need help with, but also on what other services are available or what capacity the community has to support people with dementia. In all communities mental health should have core services, both direct and indirect, for patients with dementia and their families. But in larger communities, or communities with more resources available, the role will be dependent upon the local capacity components. Local capacity could refer to whether or not there are neurologists or geriatricians within the community, whether or not this is an urban or rural area, whether or not there are diversity issues like multicultural factors involved in terms of population planning, or whether or not there are family physicians in the community who feel comfortable with dementia care and who take the lead in dementia care within the community. In larger communities it is likely that geriatricians or neurologists will see early

[36] Schizophrenia Society of Canada. (n.d.). *Information for Service: Providers: Schizophrenia and Substance Use*. Available: http://www.schizophrenia.ca/SSC_for_service_providers.pdf

[37] Canadian Coalition for Seniors' Mental Health (CCSMH) (2006). *National Guidelines for Seniors' Mental Health: The Assessment & Treatment of Depression*. Toronto, ON: CCSMH.

[38] Canadian Coalition for Seniors' Mental Health (CCSMH). (2009a). *Delirium in Older Adults: A Guide for Seniors and their Families*. Toronto, ON: CCSMH.

cognitively impaired patients for diagnoses and that family physicians will do the follow-up until clear mental health problems or caregiver stress require the involvement of seniors' mental health services. However, clear identification of mental health issues may lead to earlier referrals to mental health services, including for caregiver support.

Mental Health Risk Factors

Risk factors for poor mental health among seniors have been identified as follows[39]:

- In late life, seniors may be challenged by a number of risk factors (e.g., age discrimination, negative stereotyping, isolation, low income and poor physical health), often experienced in combination, which can result in mental distress and vulnerability to mental health problems
- Bereavement, financial strain and long-term caring are risk factors that are highly pertinent to late life.
- Caregivers, particularly of seniors with a dementia, have an increased risk of suffering from high levels of stress and of incidence of depression.
- Losses associated with late adulthood are varied (e.g., bereavement, loss of physical capabilities such as sensory acuity, mental ability (memory or cognition) and mobility, and lessening of support if partner develops a dementia) are, often operating on multidimensional levels, and are key risk factors for poor mental health.
- Reduced confidence, motivation, pleasure and reward, along with altered hopes and expectations, may accompany losses in a senior's role and status, (e.g., when children relocate, or on retirement).
- Poverty reduces access to nutritious food, appropriate housing, health care needs (e.g., medication) and social opportunities, which affects morale.
- Women in comparison to men are at a greater risk for isolation, due in part to living longer, and towards the end of life, often are alone.
- Older women may experience the cumulative effects from mental health problems (e.g., anxiety, depression, eating disorders and self harm) at earlier life stages.
- Suicide rates are higher among men than women: older men aged 75 and over "have the highest incidence of suicide, which is 11 per cent higher than the rates for all males aged 15 and over". (Mentality, 2004, p. 35).

[39] Mentality (2004) Literature and Policy Review for the Joint Inquiry for Mental Health and Well-Being in Later Life. Available: http://www.seniorspolicylens.ca/Root/Materials/Litandpolicyreview-Fulltextofreport%5B1%5D.pdf

Chapter III

Risks Related to Elder Abuse

Elder abuse is a practice area where issues of capability are often raised and is increasingly recognized as an area for concern.

Elder Abuse

"A single or repeated act, or lack of appropriate action, within any relationship where there is an expectation of trust which causes harm or distress to an older person. It can be of various forms: physical, psychological/ emotional, sexual, financial or simply reflect intentional or unintentional neglect."

(World Health Organization, 2002).[40]

"*RE: ACT*", a Vancouver Coastal Health Authority (VCHA) initiative has created an "Act on Abuse" manual to help guide front line care workers and staff in dealing with suspected cases of abuse, neglect and self-neglect of vulnerable adults[41].

The manual provides:

- An overview of the Adult Guardianship Legislation and the role of Designated Responders to suspected cases of abuse, neglect or self-neglect of a vulnerable adult.
- Information, responder processes, screening and assessment tools etc. that help staff deal with suspected cases of abuse, neglect or self-neglect.
- Information on working with Police and the role of VCHA.
- Assessment tools for use in assessing possible abuse situations

"*RE: ACT"* has also developed interactive education and support materials for health care providers who serve Aboriginal communities, to enable them to respond to complex situations of abuse and neglect[42].

Nationally, the "NICE (National Initiative for the Care of the Elderly) Elder Abuse Knowledge to Action Project" has created a Tool Kit[43] that includes practical evidence informed tools for detection, intervention and prevention of elder abuse. These have been incorporated into the "*RE: ACT"*.

[40] World Health Organization, The Toronto Declaration on the Prevention of Elder Abuse, 2002, cited in S. Carstairs and W. Koehn (2009) *Special Senate Committee on Aging*, p. 24.

[41] Available: http://www.vchreact.ca/manual.htm

[42] Available: http://www.vchreact.ca/aboriginal_manual.htm

[43] Available: http://www.nicenet.ca/files/Tool_Kit_Summary_April_2011.pdf

Chapter III

Assessing Seniors' Mental Capability

Many seniors with mental illness, particularly those with a dementia or a delusional disorder, may come to the attention of health authorities as they appear to be living "at risk", either from themselves or from others. Seniors' mental health services are often asked to assess the capability of these seniors to make autonomous decisions about their lives, and there are legal and clinical guidelines for carrying out capability assessments.

Protection from financial, physical or psychological abuse is absolutely necessary for seniors who are potentially vulnerable because of physical or mental frailty. The *Representation Agreement Act* enables adults to plan ahead for a time when they may become incapable of making their own decisions[44].

Part 3 of the *Adult Guardianship Act* promotes a coordinated community response (e.g., Community Response Networks) and designates health authorities (including the provincial health authority) and Community Living BC to receive reports and to investigate situations of abuse, neglect or self-neglect of vulnerable adults; the *Health Care (Consent) and Care Facility (Admission) Act* establishes a hierarchy of substitute decision makers and conditions for obtaining consent for health care when an adult is incapable of making their own decisions; and the *Public Guardian and Trustee Act* provides the Public Guardian and Trustee (PGT) with powers in the investigation of financial abuse.

In addition, the PGT may investigate the personal and health care decisions made by (a) a representative under a representation agreement, or (b) a decision-maker or guardian if there is reason to believe the representative, decision-maker or guardian has failed to comply with his or her duties. Health Authorities each have a designated formal systems in place for responding to potential abuse and neglect.

Health Authorities are "Designated Agencies" responsible for investigating situations of abuse, neglect and self-neglect of adults who are unable to seek support and assistance on their own due to restraint, physical handicap, illness, disease, injury or any other condition that affects decision-making ability. The *Adult Guardianship Act* (Part 3) gives designated agencies enhanced powers to intervene in emergencies and to investigate situations in which vulnerable adults are living at risk. The *Adult Guardianship Act* applies to abuse, neglect or self-neglect in a public place, the adult's home, a care facility or any other place except a correctional facility.

[44] Public Guardian and Trustee of British Columbia provides Information in Spanish, Vietnamese, Chinese and Punjabi. Available: www.trustee.bc.ca

There are clear guidelines as to how to proceed when a senior is determined to be incapable, in part or wholly, under the Act. The UBC Department of Family Medicine has developed a case based curriculum and facilitator guide, *Care for Elders* (Silberfield & Fish, 1994)[45] that focuses on how to carry out incapability assessments.

When capability is marginal, as is often the case when the senior has a dementia, the appropriate response is much less clear. In determining that a senior requires assessment of capability, and carrying out the assessment, it is important to recognize that both the ratings of risk and safety and the resulting action believed to be required are value-laden. (Silberfeld & Fish, 1994[46]). Risk is a subjective notion and may be assessed differently by each observer on the basis of personal values and personal tolerance for ambiguity (Clemens, Welte, Feltes, Crabtree & Dubitzky, 1994[47]). Although health care professionals are trained to base their decisions on knowledge, technical criteria and objective data, and to avoid personal biases and subjectivity, a lack of clarity about roles and responsibilities in these situations may allow personal and professional values to creep into decision-making (Clemens & Hayes, 1997[48]). This is problematic as the values of seniors and health care professionals differ in relation to their age and life-experiences (Egri & Ralston, 2004[49]), the professional values inculcated into the training of health care disciplines (Kane, Bershadsky & Bershadsky, 2006[50]), and the values and goals of health care organizations that influence the decisions health care professionals make (Clark, 1997[51]).

- It is important that health care professionals are able to recognize and make explicit their personal and professional values and how they contribute to their decision-making.

[45] Silberfeld, M., & Fish, A. (1994). *When the mind fails: A guide to dealing with incompetency.* London: University of Toronto Press Inc.

[46] Ibid.

[47] Clemens, E., Wetle, T., Feltes, M., Crabtree, B., & Dubitzky, D. (1994). Contradictions in case management: Client-centred theory and directive practice with frail elderly. *Journal of Aging & Health*, 6(1), 70-88.

[48] Clemens, E., & Hayes, H. (1997). Assessing and balancing elder risk, safety and autonomy: decision-making practices of health care professionals. *Home and Health Care Services Quarterly*, 16(3), 3-21.

[49] Egri, C.P., & Ralston, D.A. (2004). Generation cohorts and personal values: a comparison of China and the United States. *Organization Science*, 15(2), 210-220.

[50] Kane, R., Bershadsky, B., & Bershadsky, J. (2006). Who recommends long-term care matters. *The Gerontologist,* 46, 474-482.

[51] Clark, P. (1997). Values in health care professional socialization: implications for geriatric education in interdisciplinary teamwork. *The Gerontologist, 37*(4), 441-451.

- At Harvard University, to assist medical residents to orient them to seniors' lives and values, a "Council of Elders" has been established where they can present ethical dilemmas in caring for older adults, resulting in innovative interventions. (Katz, Conant, Inui, Baron & Bor, 2000[52])

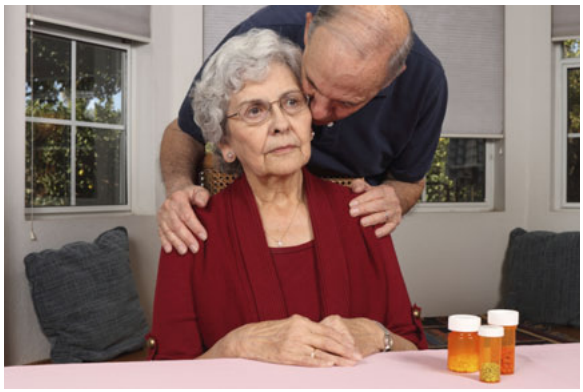
In dealing with situations where, in the eyes of the health care professional, a senior is at significant risk but not clearly incapable, professionals may experience considerable distress about how to proceed. Adding to this, where capability is marginal there are frequently differences of opinion about how to proceed between the professional and family/caregivers, and amongst the different service providers' involved. Protocols need to be in place to ensure clear communication and conflict resolution as needed and to provide health care professionals with access to third party professional support to address the ethical dilemmas and moral distress that some client situations can present.

Advocating for Seniors

Advocacy helps vulnerable people obtain services and benefits and to have a voice in their treatment. Advocacy is defined as action taken on behalf of an individual (including one's self) or a group of individuals to promote and defend needs, rights and interests. Advocacy seeks to ensure vulnerable individuals have access to the services and benefits to which they are entitled and a voice in the treatment decisions that affect them. Vulnerable individuals include those who have been socially marginalized and those with moderate or severe mental or physical disabilities who face structural and attitudinal barriers to service and participation.

The spectrum of advocacy ranges from individual advocacy to systemic advocacy. Individual advocacy helps people speak out, exercise their rights and obtain access to help services they or their relatives need. Here, advocacy attempts to redress a power imbalance and/or to respond to abuse, neglect, isolation and discrimination. At the other end of the spectrum, system advocacy promotes the needs of an identifiable population by influencing law, regulation, policy, practice, guidelines and/or service delivery.

[52] Katz, A., Conant, L., Inui, T., Baron, D., & Bor, D. (2000). Council of elders: creating a multi-voiced dialogue in a community of care. *Social Science & Medicine, 50*(6), 851-860.



Chapter IV

IV. Substance Use by Seniors

The Significance of Substance Use and Seniors Mental Health

Many people think that problematic alcohol and drug use is only an issue for youth and young adults, but people of any age can struggle with substance use issues. A simple definition for problematic substance use is that "a problem exists when the use of substance(s) results in negative consequences for the person, and the person continues to use the substance(s) despite these negative consequences. Negative consequences may affect physical health, environment, relationships, spirituality, legal status or other areas of the person's life."[53] Substances that can cause problems include alcohol, prescription and over-the-counter medications and illicit drugs. There is a growing awareness among researchers and people who provide care and assistance to seniors, that older adults' substance use problems are commonly unrecognized or misdiagnosed.[54, 55]

The combination of the increase in life expectancy as well as the large cohort of those born between 1946 and 1964 (the 'baby boomers') marks a significant aging of Canada's population. As the general population continues to age, it is anticipated that there will be increasing numbers of older adults at risk for developing substance-related problems, and as such, an unprecedented influx of older adults with substance use issues into the health care system.[56] Understanding the unique needs of older individuals is of increasing importance, yet research on how best to support older adults with substance use problems continues to be relatively limited.[57]

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[53] Centre for Addiction and Mental Health. (1998). Choosing to Change: A client-centred approach to alcohol and medication use by older adults. Toronto: Centre for Addiction and Mental Health.

[54] SAMHSA. (2003). Get connected! Linking older adults with medication, alcohol, and mental health resources. Rockville, MD: Centre for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration.

[55] Centre for Addiction and Mental Health – Healthy Aging Project. (2008). Improving our response to older adults with substance use, mental health and gambling problems. Toronto: Centre for Addiction and Mental Health.

[56] Johnson, P.B. & Sung, H. (2009). Substance abuse among aging Baby Boomers: Health and treatment implications. *Journal of Addictions Nursing*, 20 (3):124-126.

[57] Centre for Addiction and Mental Health – Healthy Aging Project. (2008). Improving our response to older adults with substance use, mental health and gambling problems. Toronto: Centre for Addiction and Mental Health.

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Alcohol is the substance most commonly used by seniors (Health Canada, 1999a). According to a Health and Welfare Canada report (1992), 22 per cent of those over the age of 65 drink four or more times a week (Baron & Carver, 1997). Some of the warning signs of excessive drinking in this age group include confusion, forgetfulness, anxiety, depression, sleep problems, injury from falls, decrease in the effectiveness of medications, conflict or withdrawal from family and friends, and improper eating habits accompanied by weight loss (Addiction Research Foundation, 1993a). These signs of intoxication or of prolonged use can be misattributed to aging[58].

- Early-onset drinkers comprise approximately two-thirds of older problem drinkers, and late-onset drinkers comprise one-third.
- Early-onset drinkers often have a history of treatment for alcohol use, and have less social support, while late-onset drinkers often develop problem use patterns as a reaction to loss or stress, and tend to have supportive social networks.
- Prescription drug use is more prevalent among those 65 and over than among younger cohorts.
- The prescription medications most commonly used are heart medication, blood pressure medication, pain relievers and benzodiazepines.
- Approximately 20 per cent of seniors use over-the-counter pain relievers in addition to their prescribed pain relievers.
- Men consume larger quantities of alcohol, but women may be at greater risk of becoming dependent on prescription medications.
- Less than 1 per cent of Canadian seniors report using illicit drugs.

The baby-boomer generation with long histories of alcohol and other substance use/misuse will present a challenge for health care providers through the increase in the number of seniors using drugs and/or other substances. The National Survey on Drug Use and Health (NSDUH) (SAMHSA, 2009)[59] states "It has been predicted that by the year 2020, the number of persons needing treatment for a substance use disorder will double among persons aged 50 or older as the baby boom generation moves into adulthood" (p. 1). Although alcohol use is prevalent within this population, the use of marijuana and prescription medications such as benzodiazepines is increasing. Colleran & Jay (2002)[60] state:

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[58] This section was prepared by Bonnie Tateham, RN, BScN, MN, GNC(c)

[59] Substance Abuse and Mental Health Services Administration (SAMHSA), (2009). The NSDUReport. Retrieved May 10, 2011, from: http://oas.samhsa.gov/2k9/168OlderAdults.htm

[60] Colleran, C. & Jay, D. (2002). A few things you should know. In C. Colleran & D. Jay, *Aging & Addiction: Helping Older Adults Overcome Alcohol or Medication Dependence*. Center City, MN: Hazelden.

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"Addiction is the same disease regardless of which drug is used: alcohol, mood-altering medications, or illicit drugs" (p. 6). Diagnosis may be difficult as the signs of substance abuse may be confused with symptoms of aging and of other health problems, such as diabetes, dementia, Parkinson's disease, dehydration, or depression". Signs of alcohol and/or other substance abuse may present differently in seniors and may include:

- Memory problems/confusion/anxiety
- Delirium/dementia
- Depression/hostility
- Lack of self care/change in appearance
- Loss of interest in hobbies or activities
- Isolation
- Chronic health complaints
- Weight loss/malnutrition
- Sleep problems/disturbances
- Ataxic gait/falls/bruising
- Urinary incontinence

(Canadian Centre on Substance Abuse (CCST), 2011[61]; Hazelden, 2010[62]; Shilling McCann, 2003[63])

In 2007, the Canadian Centre on Substance Abuse[64] (CCSA) estimated that up to 20 per cent of individuals, 60 years of age and older, experience issues related to problematic substance use. Age-related changes in physiology (e.g., that alter metabolism) is one of the factors that researchers attribute to increased risk for substance use problems among older

[61] Canadian Centre on Substance Abuse, (2011). Working to reduce alcohol and drug related harm. Available: http://www.ccsa.ca/Eng/Topics/Populations?Seniors/Pages/Seniors/Overview.aspx?print=t

[62] Hazelden (2010). Hazelden says older adults deserve recovery from alcoholism, addiction too. Available: http://www.hazelden.org/web/public/pr100614.page?printable=true&showlogo-true&call

[63] Shilling McCann, J.A., (2003). Handbook of Geriatric Nursing Care (2nd Ed.), (pp. 22-29). Philadelphia, PA: Lippincott Williams & Wilkins.

[64] Canadian Centre on Substance Abuse. (2007). The essentials of... Seniors and substance abuse. Retrieved: October 15, 2011, from: http://www.cnsaap.ca/SiteCollectionDocuments/PT-Essentials%20of%20Seniors%20and%20Substance%20Abuse-20071101-e.pdf

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adults[65,66]. For example, relative to youth, older adults' blood alcohol levels will be higher after consuming similar levels of alcohol. Accordingly, alcohol (and other drugs) may be experienced as more potent and/or less predictable as people age[67,68].

Another factor contributing to an understanding of older adults' increased risk for problematic substance use is the misuse of over-the-counter and/or prescription medication. Misuse[69] refers to:

- Erratic (over and/or under) use of medication, including: 'double dossing'[70] to compensate for missed doses or intentionally skipping doses;
- Taking too much medicine or taking medicine when one does not need to, such as taking medicines to feel good or "high;"
- Using outdated medicine;
- Using another person's medicines; and,
- Taking medicine while drinking alcohol.

Further, evidence suggests that compliance with directions for use decreases with the greater number of medications an individual takes[71,72]. The CCSA has also identified that while older adults represented roughly 13 per cent of the population in 2007, this group consumed more than 40 per cent of all medications – including 50 per cent of all psychoactive medications prescribed. Because psychoactive medications, in particular, may rapidly produce

[65] Wu, Li-Tzy, Blazer, D.G. (2011). Illicit and nonmedical drug use among older adults: A review. *Journal of Aging and Health*, 23(30) 481-504.

[66] Healthwise Staff. (2010). Substance abuse in older adults. HealthLink BC. Retrieved: November 4, 2011, from: http://www.healthlinkbc.ca/kb/content/special/ug4806.html

[67] Healthwise Staff. (2010). Substance abuse in older adults. HealthLink BC. Retrieved: November 4, 2011, from: http://www.healthlinkbc.ca/kb/content/special/ug4806.html

[68] Wood & Piotrowski. (2008). Elderly populations, treatment issues. Encyclopaedia of Substance Abuse, Prevention, Treatment & Recovery.

[69] Healthwise Staff. (2010). Substance abuse in older adults. HealthLink BC. Retrieved: November 4, 2011, from: http://www.healthlinkbc.ca/kb/content/special/ug4806.html

[70] Double dossing refers to taking double the medication than what is prescribed at one time, in order to make up for missing the previous timeframe for taking the medication. For example, when an individual, who is prescribed medication to be taken in a 15 mg dose once each with breakfast and dinner, takes 30 mg at dinner only.

[71] Wood & Piotrowski. (2008). Elderly populations, treatment issues. Encyclopaedia of Substance Abuse, Prevention, Treatment & Recovery.

[72] Healthwise Staff. (2010). Substance abuse in older adults. HealthLink BC. Retrieved: November 4, 2011, from: http://www.healthlinkbc.ca/kb/content/special/ug4806.html

psychological and physical dependence, these medications have great potential for inducing problems[73].

The baby boomers, in particular, are understood to be at further increased risk of substance-related problems because of this generation's early and continuing positive attitude towards alcohol and the recreational use of illicit drugs[74,75,76]. U.S. researchers have observed that as baby boomers have aged, many have continued their illicit drug use, notably the use of marijuana,[77] at relatively high levels and often in conjunction with elevated alcohol use. As such, this generation is distinguished from previous and older aging cohorts; whereas older adults of previous cohorts typically ceased or "matured out" of illicit drug use, the baby boomers have not[78]. Researchers anticipate increasing problems with substance use among this cohort[79] arising from, or in relation to complications of, the misuse of medications, illicit drugs and/or alcohol[80].

Consideration of these risks (changes in physiology, high levels of consumption of prescription medications, misuse of medications, increased acceptance of recreational and illicit drug use) among others, contributes to the expectation that the percentage of older adults living with substance-related problems is expected to increase significantly by the year 2020.[81,82]

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[73] Wu, Li-Tzy, Blazer, D.G. (2011). Illicit and nonmedical drug use among older adults: A review. *Journal of Aging and Health*, 23(30) 481-504.

[74] Johnson, P.B. & Sung, H. (2009). Substance abuse among aging Baby Boomers: Health and treatment implications. *Journal of Addictions Nursing*, 20 (3):124-126.

[75] Wu, Li-Tzy, Blazer, D.G. (2011). Illicit and nonmedical drug use among older adults: A review. *Journal of Aging and Health*, 23(30) 481-504.

[76] Canadian Centre on Substance Abuse. (2007). The essentials of... Seniors and substance abuse. Retrieved: October 15,2011, from: http://www.cnsaap.ca/SiteCollectionDocuments/PT-Essentials%20of%20Seniors%20and%20Substance%20Abuse-20071101-e.pdf

[77] SAMHSA. (2011). The National Survey on Drug Use and Health Report: Illicit drug use among older adults. The Centre for Behavioural Health Statistics and Quality, Substance Abuse and Mental Health Services Administration. Retrieved on October 15, 2011, from: http://www.oas.samhsa.gov/2k11/013/WEB_SR_013_HTML.pdf

[78] Johnson, P.B. & Sung, H. (2009). Substance abuse among aging Baby Boomers: Health and treatment implications. *Journal of Addictions Nursing*, 20 (3):124-126.

[79] Canadian Centre on Substance Abuse. (2007). The essentials of... Seniors and substance abuse. Retrieved: October 15,2011, from: http://www.cnsaap.ca/SiteCollectionDocuments/PT-Essentials%20of%20Seniors%20and%20Substance%20Abuse-20071101-e.pdf

[80] Seeking Solution Project. (2004). Best practices: An introduction. Retrieved on October 19, 2011, from: http://www.agingincanada.ca/Seniors%20Alcohol/BP.htm

[81] Wu, Li-Tzy, Blazer, D.G. (2011). Illicit and nonmedical drug use among older adults: A review. *Journal of Aging and Health*, 23(30) 481-504.

[82] Gfroerer, J., Penne, M. Pemberton, M. & Folsom, R. (2003) Substance abuse treatment need among older adults in 2020: The impact of the aging baby-boom cohort. Drug and Alcohol Dependence, 69(--):127-135.

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Some researchers identify a distinction between early and later onset of problematic substance use.[83,84,85] Older adults with early onset problematic substance use issues may have a wide range of medical and/or psychiatric problems that could require more intensive, integrated treatment and monitoring.[86,87] These individuals are more likely to be estranged from family and/or have limited social support.

Research indicates that later onset substance use problems may be related to individuals' psychosocial circumstances.[88,89,90] These may include experiences of loss, such as:[91]

- Death of spouse, friends, and other family members;
- Loss of job – and related income, social status, and, sometimes, lowered self-esteem – as a result of retirement;
- Loss of mobility (trouble using public transportation, inability to drive, problems walking);
- Impaired vision and hearing, insomnia, and memory problems;
- Declining health because of chronic illness;
- Separations from children and loss of home as a result of relocation; and,
- Loss of social support and interesting activities.

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[83] Roe, B., Beynon, C., Pickering, L., & Duffy, P. (2010). Experiences of drug use and ageing: health, quality of life, relationship and service implications. *Journal of Advanced Nursing*, 66 (9):1968-1979.

[84] Wu, Li-Tzy, Blazer, D.G. (2011). Illicit and nonmedical drug use among older adults: A review. *Journal of Aging and Health*, 23(30) 481-504.

[85] Finfgeld-Connett, D.L. (2005). Self-management of alcohol problems among aging adults. *Journal of Gerontological Nursing*, 31(5): 51-58.

[86] Wu, Li-Tzy, Blazer, D.G. (2011). Illicit and nonmedical drug use among older adults: A review. *Journal of Aging and Health*, 23(30) 481-504.

[87] Centre for Addiction and Mental Health – Healthy Aging Project. (2008). Improving our response to older adults with substance use, mental health and gambling problems. Toronto: Centre for Addiction and Mental Health.

[88] Wood & Piotrowski. (2008). Elderly populations, treatment issues. Encyclopaedia of Substance Abuse, Prevention, Treatment & Recovery.

[89] Centre for Addiction and Mental Health – Healthy Aging Project. (2008). Improving our response to older adults with substance use, mental health and gambling problems. Toronto: Centre for Addiction and Mental Health.

[90] Canadian Centre on Substance Abuse. (2007). The essentials of... Seniors and substance abuse. Retrieved: October 15, 2011, from: http://www.cnsaap.ca/SiteCollectionDocuments/PT-Essentials%20of%20Seniors%20and%20Substance%20Abuse-20071101-e.pdf

[91] SAMHSA. (2003). Get connected! Linking older adults with medication, alcohol, and mental health resources. Rockville, MD: Centre for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration.

These, among other life stressors, combined with a lack of positive and effective coping skills alternative to substance use, positively correlate with later onset problems.[92,93,94] This group is more likely to have social supports than early onset individuals, but it may also be more difficult to detect substance use issues where there is no previous history of problems.[95]

There are a number of factors that contribute to the 'invisibility'[96] of problematic substance use among older adults. One area of consideration is a reluctance or avoidance on the part of family members and/or other caregivers to acknowledge problematic substance use, particularly where older adults experience later onset substance use problems. Some other considerations contributing to the invisibility of older adults' substance use problems include:[97]

- Insufficient knowledge and limited research data accessible to health care providers working in time limiting service settings;
- Complications in diagnosing substance use problems due to symptomologies (such as memory problems/confusion/anxiety, sleep problems) that mimic other medical and/or behavioural conditions;
- Reluctance on the part of older adults to reveal problems due to shame about what may be regarded as a private matter; and,
- Ageist and/or other discriminatory attitudes of younger adults and/or service providers.

There is limited research discussing effective supports for older adults with problematic substance use issues. The Seeking Solutions Project, an initiative involving seniors' groups, addiction services, and health and community agencies across Canada, developed a best

[92] SAMHSA. (2003). Get connected! Linking older adults with medication, alcohol, and mental health resources. Rockville, MD: Centre for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration.

[93] Canadian Centre on Substance Abuse. (2007). The essentials of... Seniors and substance abuse. Retrieved: October 15,2011, from: http://www.cnsaap.ca/SiteCollectionDocuments/PT-Essentials%20of%20Seniors%20and%20Substance%20Abuse-20071101-e.pdf

[94] Centre for Addiction and Mental Health – Healthy Aging Project. (2008). Improving our response to older adults with substance use, mental health and gambling problems. Toronto: Centre for Addiction and Mental Health.

[95] Wood & Piotrowski. (2008). Elderly populations, treatment issues. Encyclopaedia of Substance Abuse, Prevention, Treatment & Recovery.

[96] SAMHSA. (2003). Get connected! Linking older adults with medication, alcohol, and mental health resources. Rockville, MD: Centre for Substance Abuse Treatment, Substance Abuse and Mental Health Services Administration.

[97] Canadian Centre on Substance Abuse. (2007). The essentials of... Seniors and substance abuse. Retrieved: October 15, 2011, from: http://www.cnsaap.ca/SiteCollectionDocuments/PT-Essentials%20of%20Seniors%20and%20Substance%20Abuse-20071101-e.pdf

practices series identifying positive strategies and approaches for working with older adults experiencing substance use problems.

Specifically, the Seeking Solutions Project's *Best practices: Guiding principles*[98] identifies 10 key principles useful for supporting older adults experiencing substance use problems, alcohol use problems in particular. The Seeking Solutions Project suggests that service providers and others seeking to support older adults with substance use issues should consider the following principles:

1. **Build trust** – Take time to build rapport and be available to support older adults in their goals (this may be through encouraging their participation in health and recovery oriented activities, or accompaniment to initial meetings with new service providers or support groups).

2. **Be flexible and accessible** – Become aware and address common service barriers such as admission and discharge policies, lack of attentiveness to limitations of services (including lack of modifications for individuals with difficulty hearing or difficulty with memory in addition to physical accessibility issues).

3. **Understand and respect the older adult** – Recognize and build upon the older adult's life experience in treatment and health care planning. Acknowledge the individual's needs for independence and control over their own life. Be attentive to the language one uses and the assumptions or behaviours that may suggest negative attitudes about the substance using older adult.

4. **Take a "whole person" approach** – When helping an older person, look to the positive aspects of a person and there circumstances. Take into account all aspects of the physical, psychological, social, financial and spiritual needs of the individual, rather than exclusively focusing on their substance use issues.

5. **Recognize the diversity of older adults' needs** – Older adults have the same psychological needs as younger generations, including the need to be valued, wanted, needed and appreciated. While age defines who is an older individual, older adulthood is inclusive of a very broad range in age, from those who are in their 60s to those in their 80s and older. They are individuals who live in urban, rural, remote settings, with or without partners, families and/or other social connections. They are racially, ethnically, religiously/spiritually diverse. Older women and older men may face different issues.

[98] Seeking Solutions Project. (2004). Best practices: Guiding principles. Retrieved, November 10, 2011, from: http://www.agingincanada.ca/BEST_2.PDF

Accordingly, individuals will have different ideas, expectations about aging, alcohol and drug use, as well as other issues.

6. **Actively reach out** – Many older adult experiencing substance use problems may also be isolated because of physical, psychological, social and/or economic condition(s). Offering outreach, doing home visits or telephone support are some ways to offer connection with services and help get an individual reconnected to the community. Recognize that transportation can be a problem. Look for ways to address transportation issues when developing programs. Seek opportunities to reach individuals rather than expecting the individual to find you.

7. **Understand age and other relevant differences** – The needs of older adults experiencing substance use problems can be quite different from those of older adults without substance use problems. Older adults' needs are also different from those of younger adults with substance use problems. Recognize differences among individuals, this may include being flexible in ones expectations and program requirements. Consider the needs of the specific individuals in the development of resources materials.

8. **Be an advocate** – Older adults may have experienced being overlooked or ignored. It is important to encourage older adults to speak on their own behalf, and at times it will be necessary to speak on behalf of an older person in order to get their needs recognized and addressed at an individual or system's level. For example, various services, including hospitals, long-term care facilities, and substance use services, may have policies that create barriers to older individuals' access to the help they need. Advocate on behalf of older adults to get such policies removed and/or to address stereotypes and stigmatization that may arise in service settings.

9. **Foster common and realistic expectations** – Recognize that substance use problems and options for treatment exist on a continuum. It may be beneficial to encourage people to openly discuss personal and/or professional understandings about the nature of substance use problems. It also may be useful to encourage caregivers and/or other service providers to understand the limitations of focusing on any one type of treatment, particularly when the approach does not seem to be helping an individual.

10. **Work with others** – Draw on the skills of a variety of community resources, professionals, and support services to provide a comprehensive range of community-oriented services for the older adult. Work towards collaboration and inter-agency cooperation. Strive to work as part of a team. At a minimum, ensure that those working with older adults also have other resource people to gain support from.

Chapter IV

It is important for those supporting the older adult with substance use problems to promote the belief that change is possible for the individual and other older adults in similar circumstances.

In *Improving our response to older adults with substance use, mental health and gambling problems* (2008),[99] the Centre for Addiction and Mental Health (CAMH), Healthy Aging Project, highlights many of the same principles for improving the response of service providers to older adults with substance use problems. In addition, this resource guide highlights specific tools for identifying substance use problems in older adults; provides an overview of treatment options and services; and, includes specific information sheets on alcohol and medications (among others) for older adults.

Seniors presenting to hospitals with fractures, malnutrition, failure to thrive, or other issues may have underlying addiction issues and should be tested for history, or complications of alcohol or other substance use. Often these clients will have withdrawn from social situations and their addiction may not be noticed until they present to hospital. Withdrawal and isolative behaviours may also be exacerbated by widowhood; 'empty nest' time, when the client feels alone and neglected; or when friends pass away. These feelings of despair and loneliness increase substance use creating increased health problems related to use. The Canadian Network of Substance Abuse and Allied Professionals reports:

> "Canadian estimates indicate that between 6 and 10 per cent of seniors who drink have alcohol-related problems (Spencer, 2003). When medication issues are included, it is believed that up to 20 per cent of seniors experience difficulties due to alcohol and/or medication misuse (D'Agostino, Barry, Blow& Podgorski, 2006).
>
> Older adults are also more at risk for a number of adverse consequences of substance use because of changes in body composition (less body water and more fat stores) and function (reduced organ efficiency, greater sensitivity of the central nervous system to substances). Other factors in the life experiences of older adults may contribute to a greater vulnerability to the misuse or abuse of substances (CSAT, 2005; Holloway, 2001; Levinson & Aldwin, 2001, as cited in the Canadian Network of Substance Abuse and Allied Professionals, 2007, p. 1)[100].

[99] Centre for Addiction and Mental Health – Healthy Aging Project. (2008). Improving our response to older adults with substance use, mental health and gambling problems. Toronto: Centre for Addiction and Mental Health.

[100] Canadian Network of Substance Abuse and Allied Professionals, (2007). The essentials of... Seniors and substance abuse. Available: http://www.cnsaap.ca/SiteCollectionDocuments/PT-Essentials%20of%20Seniors%20and%20Substance%20Abuse-20071101-e.pdf

Seniors experience the complications of substance use more rapidly than do younger users, and have more severe issues with withdrawal. According to the Substance Abuse and Mental Health Services Administration (Drug Addiction, 2003)[101], "The initial treatment of older addicted adults often requires more intensive medical support than is necessary in younger patients". (SAMHSA) recommends that addiction treatment programs incorporate features designed to address the specific needs of older adults" (Drug Addiction, 2003)[102].

Some seniors with significant long-term substance use may have a history of poverty, marginal lifestyles and impaired relationships with family resulting in a limited support network. Some of these seniors may be hard to house. They may also be reluctant to enter any form of seniors' housing facility, and if admitted may not fit well with other residents. British Columbia has a number of residential resources for seniors who are using substances. Substance use may increase seniors' vulnerability to abuse by others.

Access to Seniors Substance Use Services

Services for seniors experiencing problematic substance use issues in B.C. are created and delivered through the regional health authorities, and as such, services vary between regions. One B.C. region has a centralized intake service through which seniors may access Adult Mental Health and Addictions Services. It is called the Senior's Outreach Resource Team (SORT). SORT assists seniors with addiction, neglect, abuse (physical or financial), or disabilities, to remain in their homes by providing daily check-ins, medication administration, counselling and nursing care. This organization, was formerly known as Elderly Outreach Services (for seniors with disabilities, neglect or abuse issues) and Victoria Innovative Seniors Treatment Approach, commonly known as VISTA (for seniors age 55+ with alcohol and other substance use/misuse).

Another region has older adult counsellors accessible through Community Clinics. These counsellors work with older adults to discern their needs for support. Another B.C. region runs a Strategies and Actions for Independent Living (SAIL) program through which community health workers conduct assessments with older adults to determine support and/or treatment needs.

One regional hospital focuses on older adult psychiatry and retains a number of beds slated for those with addictions issues. The Victoria Community Medical Detox Unit is a 21-bed medical

[101] Drug Addiction, (2003). Trends in treatment: Substance abuse in older adults. Available: http://www.drug-addiction.com/senior_treatment.htm

[102] Ibid.

detox facility serving clients age 19-72. Clients are in treatment for approximately 7 days. Counselling and assessments are provided. Referrals to further treatment facilities, outpatient counselling, SORT, housing or placement are undertaken during the client's stay. Financial workers are available to assist clients with their eligibility for further treatment options.

The *Healthy Minds, Healthy People: A Ten Year Plan to Address Mental Health and Substance Use in British Columbia* (2010) recognizes seniors increased risk of isolation, loneliness and depression. It is acknowledged that seniors with depression are at particularly high risk for problems with alcohol (and other drugs as the population ages).

The *Healthy Minds, Healthy People* plan highlights the need for opportunities for seniors to maintain and/or develop social connections. It also recognizes the importance for seniors to be meaningfully engaged in their communities. The B.C. provincial government, in partnership with municipal governments and other organizations, will promote opportunities, including workforce, learning and volunteer opportunities, through the use of the *Seniors in British Columbia: a Healthy Living Framework*.

Recognizing that brief interventions and advice in frequently accessed health care settings, such as primary care, effectively reduces alcohol consumption in seniors. B.C. also aims to improve routine screening protocols during primary care interventions with seniors in order to reduce substance-related harms.

Problematic substance use can be a long-standing or recently developed issue in the life of an older adult. Problematic substance use can lead to: a deterioration in an individual's health, family and social stability; a reduced ability to cope with daily life situations; and, ultimately a loss of independence. Substance use problems in the lives of older adults are often overlooked, unrecognized and/or misdiagnosed. Problematic substance use among seniors is anticipated to become an increasing health and service issue as the Canadian population ages.

There is limited current research available to inform people or services seeking to improve supports for older adults experiencing substance use problems. Key considerations for supporting seniors with problematic substance use issues identified in the literature include 10 principles highlighted in the work of the Seeking Solutions Project's *Older Adults and Alcohol Best Practices Information Sheets* (2004).[103] This research is also supported by the research of the Centre for Addiction and Mental Health's Healthy Aging Project (2008).

[103] Seeking Solutions Project. (2004). Older Adults and Alcohol Best Practices Information Sheets. Retrieved on November 10, 2011, from http://www.agingincanada.ca/Seniors%20Alcohol/BP.htm

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The *Healthy Minds, Healthy People: A Ten Year Plan to Address the Mental Health and Substance Use in British Columbia* recognizes that seniors may be vulnerable to substance use problems and highlights particular actions for reducing potential substance related harms for seniors. In B.C. the specific services for individual experiencing problematic substance use, including specialized programs for seniors, are developed and delivered through regional health authorities.

Chapter V

V. Education for Seniors, Family, Informal and Formal Caregivers

The Significance of Education and Training

Knowledge is the cornerstone of senior mental health care. It is essential everyone involved, from the client, families/caregivers to the specialized professional, have knowledge appropriate to the kind and level of involvement. Education must, therefore, be available and be geared to the specific needs of the particular individual.

Building capacity to support seniors' mental health by primary care providers, long-term care/residential care facilities, and other non-mental health providers, requires continuing education on: promoting mental health, signs and symptoms of mental health problems, early identification of mental health conditions, treatment, and appropriate timing for referral to mental health services. Supports to frontline services can also be provided through education and additionally, through case consultation, co-case management and case transfers for treatment and management of complex presentations/situations.

A comprehensive and integrated system provides information about mental health and mental illness that is sensitive to diversity in culture, language, and supports efforts to increase health literacy among seniors, family/caregivers and the public in general. Information can be shared by a variety of mediums/methods, and individualized as required.

Education for clients, family and other informal caregivers should provide a basic understanding of what is happening with the senior experiencing mental health problems, and how to manage challenging behaviours. Education for service providers requires a more specialized and detailed focus. The planning, development and implementation of strategies, policies and programs for education and training of service providers should follow a logic that is based on identifying the knowledge and skill sets that are needed by each type of service provider, establishing competency standards and ensuring that appropriate education and training are available.

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Given the aging population and the complexity of seniors with mental health problems, it is imperative that family/caregivers and professional and non-professional service providers have the necessary knowledge and skills appropriate to their responsibilities. In the long-term care sector there is a growing body of evidence showing that geriatric mental health training and education has positive effects on the quality of life for residents (by facilitating staffs' understanding of residents disease and treatment needs), and on the job satisfaction and working conditions of staff (Cassidy & Sheikh, (2002)[104], Brodaty, Draper & Low (2003)[105].

British Columbia has a provincial framework for dementia education, developed through a partnership with the Alzheimer Society of British Columbia, Interior Health Authority, Northern Health Authority, Vancouver Coastal Health, Vancouver Island Health Authority, and the University of British Columbia, Division of Community Geriatrics, Department of Family Practice and Division of Geriatric Psychiatry, Department of Psychiatry. The *Dementia Education Framework*[106] is intended to guide dementia education in B.C. and encompasses a vision, foundational principles and concepts, recommendations for leadership, a structure for sustainability, a comprehensive action plan for phase two, and expected long term outcomes. It is based on an international literature review, an inventory of educational resources within health authorities, surveys and focus groups, a provincial learning needs assessment, consultations and a Dementia Ethics workshop.

Education for Clients and Caregivers

Most education for clients and family/caregivers is related to dementia and provided by the Alzheimer Society of BC (ASBC). *First Link* is intended to ensure that people affected by dementia get information and access to support and education as soon after the diagnosis as possible. Family physicians and community service providers also play a part in educating clients and family/caregivers as part of the care provided. The Canadian Mental Health Association provides education to seniors with mental illness and their family/caregivers. Specialized education and coaching is provided by mental health services to family/caregivers who are attempting to care for people with very challenging behaviours.

[104] Cassidy, E. L. and Sheikh, J. I. (2002). Preintervention assessment of disruptive behaviour problems: a focus on staff needs. *Aging and Mental Health*, 6, 166–171.

[105] Brodaty, H., Draper, B. and Low, L. F. (2003). Nursing home staff attitudes towards residents with dementia: strain and satisfaction with work. *Journal of Advanced Nursing*, 44, 583–590.

[106] Available: http://www.alzheimerbc.org/getdoc/1f230200-0ee6-4aef-a056-1e3b9e6d4cb7/DementiaServiceFramework_PDF.aspx

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Education for Future Nurses and Physicians

The National Initiative for the Care of the Elderly (NICE), in collaboration with the federal *Geriatric Education and Recruitment Initiative*, has developed core competencies[107] in the care of seniors required by medical students[108], general psychiatry trainees[109] and non-medical inter-professional undergraduates[110] prior to graduation. The Pikes Peak model for geropsychology training (Knight, Karel, Hinrichsen, Qualls, & Duffy, 2009)[111] makes recommendations for training and delineates attitude, knowledge, and skill competencies for professional geropsychology practice. The Canadian Gerontological Nurses' Association (2010) has developed competencies and standards for nurses in the gerontological field[112].

A number of educational initiatives are taking place across the province that provide family physicians and other health care professionals with education related to seniors and mental illness. For example, RE: Act in Vancouver Coastal Health Authority (VCHA) has developed an *Act on Abuse*[113] manual to help guide front-line care workers and staff in dealing with suspected case of abuse, neglect and self-neglect of vulnerable adults. Interior Health's *Phased Dementia Pathway*[114] has been created to identify, inform and implement "promising practices" (evidence-informed practice) aimed at addressing the "clinical pinch points" or areas of concern and need as identified by persons with dementia, their caregivers and clinicians. An offshoot of the *Alzheimer's Drug Therapy Initiative (ADTI)*[115] is the development of the *BC Dementia Education Project*[116], created to provide physicians with education about recognition, diagnosis and management of cognitive impairments. The Geriatric Emergency Network Initiative (GENI) is designed to teach all emergency nurses about caring for seniors in Emergency Departments[117].

[107] *A core competency is fundamental knowledge, ability, or expertise in a specific subject area or skill set.*

[108] Developed in collaboration with the Canadian Geriatrics Society.
Available: http://www.nicenet.ca/files/CGS_Competencies.pdf

[109] Developed in collaboration with the Canadian Academy of Geriatric Psychiatry.
Available: http://www.nicenet.ca/files/CAGP_Competencies.pdf

[110] http://www.nicenet.ca/files/NICE_Competencies.pdf

[111] Knight, B. G., Karel, M. J., Hinrichsen, G. A., Qualls, S. H., & Duffy, M. (2009). Pikes Peak model for training in professional geropsychology. *American Psychologist*, 64, 205–214

[112] Avialable: http://www.cgna.net/Standards_of_Practice.html

[113] Available: http://www.vchreact.ca/manual.htm

[114] Available: http://www.interiorhealth.ca/health-services.aspx?id=328

[115] Available: http://www.health.gov.bc.ca/pharmacare/adti/#redirect_notice_display_301

[116] Available: http://ipcme.med.ubc.ca/Page879.aspx

[117] Available: http://www.acgnn.ca/geriatric_emergency_nurse_initiative.html

Education for Home Support and Residential Care Providers

In British Columbia home support workers and residential care aides, at least in the public sector, receive some training in dementia care, but very little about other mental illnesses. Respondents in a Canadian Mental Health Association (2002) study, *Supporting Seniors' Mental Health in Home Care*[118], have recommended that: "staff have increased knowledge in the areas of: seniors' mental health needs; behavioural management; strategies to increase and promote seniors' independence; the use of assessment tools and skills; recognition of the early stages of depression; management of depression; and alcohol and substance abuse among seniors. Communication skills were also identified as particularly critical for home care staff." (p. 27)

Education for Primary Care Service Providers

One of the roles of elderly mental health care providers is to build capacity in the primary care system so that seniors with, or at risk of mental illness receive optimal care at the front lines. These services are provided as formal presentations, and less formally through case conferencing, consultations, and coaching. In order to carry out this role, senior mental health clinicians need advanced knowledge and skills in, for example, seniors' mental health, management of specific mental health problems and illness, behaviours management, pharmacological and non-pharmacological approaches and consultation skills. Each discipline also needs to pursue specialized knowledge related to seniors' mental health in their own field so that they can bring a strong discipline perspective inside and outside of the senior mental health service.

Education for Staff in Long Term Care Settings

Integrating elderly, chronically mentally ill individuals into home and community care residential facilities raises issues of the lack of staff knowledge and skills.

- Staff in mental health residential care facilities need appropriate gerontological training and education to assist them to provide care for aging residents with long-standing mental illnesses.

[118] *Canadian Mental Health Association (2002). A Policy Guide: Supporting Seniors' Mental Health Through Home Care*. Prepared by Parent, K., Anderson, M. and Huestis, L.

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- Staff in long-term care facilities need appropriate training and education in mental illness to assist them to provide care for residents with mental illnesses.

Beyond training and education, service providers need support to implement the knowledge gained. The *International Psychogeriatric Association Task Force* on Mental Health has resulted in a review of the best available evidence that supports best practice for geriatric mental health education and training for staff working in long-term care (Moyle, Hsu, Lieff & Vernooij-Dassen (2010)[119].

[119] Moyle, W., Hsu, M., Lieff, S. & Vernooij-Dassen, M. (2010) Recommendations for staff education and training for older people with mental illness in long-term aged care. *International Psychogeriatrics*, 22:7, 1097–1106. (p.1104)

Chapter VI

VI. Family and Caregiver Support

The Significance of Supporting the Caregivers

At present, the majority of seniors with dementia, depression or other mental health problems are cared for at home by family caregivers with the support of family physicians and a variety of home support services. The needs of the majority of these informal caregivers, and the people they are caring for, have been well reviewed and documented in B.C. in the Dementia Services Framework, through reviews of home and community care services (B.C. Ministry of Health Services and Ministry Responsible for Seniors, 1999)[120] and the respite care services (B.C. Ministry of Health Services and Ministry Responsible for Seniors, 1995)[121], and by the Family Caregiver Network of BC (2010)[122].

These families/caregivers often require emotional support, particularly during times of transition. The Alzheimer Society of British Columbia plays a vital role in the provision of emotional support and education for families/caregivers of people with a dementia. *Shaping the Journey* is an education series for people with dementia and their care partners developed to explore the journey ahead in a positive, informative and supportive environment[123].
The Canadian Mental Health Association (2002) has recommended that the family caregiver of seniors with a mental illness "is recognized and supported, that policies should encourage [home support] staff to recognize and value the role of family caregivers, involve them in decision making where appropriate, and where possible provide supports to address their mental health needs" (p. 5)[124]. See Literature Review-B for Family/Caregiver Support for more discussion.

[120] B.C. Ministry of Health Services and Ministry Responsible for Seniors (1999). Community for Life: Review of Continuing Care Services in British Columbia. Victoria, B.C..

[121] B.C. Ministry of Health Services and Ministry Responsible for Seniors (1995). For I and Mine…Respite Services in British Columbia: Report of the Respite Advisory Committee. Victoria, B.C..

[122] Available: Family Caregivers' Network Society (2010). Supporting Family Caregivers An Action Plan for British Columbia. Prepared for the B.C. Ministry of Health Services Home and Community Care Branch. p.19

[123] Available: http://alzheimerbc.org/We-Can-Help/Dementia-Education.aspx

[124] Canadian Mental Health Association (2002). A Policy Guide: Supporting Seniors' Mental Health Through

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The vision for the future, articulated by the BC Family Caregivers' Network Society is that family caregivers "are recognized, valued, and supported as partners in care, and that policy and practice is shaped by the guiding principles of respect, choice and self-determination."[125]

Caregivers Contributions

Family and friends are a vital resource to seniors and to the health care system. They provide 75 - 85 per cent[126] of care to seniors, many for more than three years.[127] The amount of care per month they provide to seniors in the community with a dementia is 63 hours, and to seniors without a dementia, 44 hours[128]. It is estimated that if informal caregivers in Canada were paid for all the care they provide at the same rate of pay as home healthcare providers, the cost would be $25 to $26 billion.[129] Family and friends continue to provide informal care after institutionalization.[130]

Caregivers Challenges

The care provided by family and friends to seniors is a benefit to seniors and a substantial saving to the health and social service system, but does not come without risks to the well-being of caregivers themselves. Caregivers often experience physical and psychosocial symptoms (e.g., depression, stress, burden, fatigue, feelings of anger, guilt, grief and loss, frustration, loneliness, isolation, and decreased well-being and life satisfaction) as well as

Home Care. Prepared By Parent, K., Anderson, M. and Huestis, L.

[125] Family Caregivers' Network Society (2010). Supporting Family Caregivers An Action Plan for British Columbia. Prepared for the B.C. Ministry of Health Services Home and Community Care Branch. p.5

[126] Angus D.E., Auer L., Cloutier, J.E., Albert T. *Sustainable health care for Canada*. Ottawa, Queen's University of Ottawa Economic Projects. Ref Type: Report. 1995; 9. Chappell N.L. Social support and the receipt of home care services. *Gerontologist* 1985; 25(1):47–54.

[127] Health Canada. (2002). National Profile of Family Caregivers in Canada - Final Report. www.hc-sc.gc.ca

[128] Canadian Study of Health and Aging Working Group. Patterns and health effects of caring for people with dementia: The impact of changing cognitive and residential status. Gerontologist 2002;42(5):643–52.

[129] Hollander M., Liu G. & Chappell N. (2009). *Unpaid caregivers in Canada: Replacement cost estimates.* Retrieved from http://www.hollanderanalytical.com/Hollander/Reports_files/HRSDC_Unpaid_Caregivers_Fin.pdf.

[130] Keating N., Fast J., Dosman D,. Eales J. Services provided by informal and formal caregivers to seniors in residential continuing care. *Can J Aging* 2001; 20(1):23–45.

financial strain[131, 132, 133] which may jeopardize their mental and physical health, limit their self-care and social activities[134], and thereby undermine their capacity to provide care[135].

Some caregivers are more likely to experience negative impacts related to caregiving than others. Caregivers who are seniors themselves, many of whom are providing care to a spouse[136], are likely to experience their own age and health related challenges[137]. Almost one third of those caring for someone with a dementia experience depression[138], and negative psychological and health outcomes have been associated with low levels of social support[139]. Among employed caregivers, one in four faces challenges at work (e.g., increased absenteeism for illness and caregiving responsibilities, with implications for themselves (e.g., future pension income) and for their employers[140].

Support for Caregivers

Clearly, it is in the best interest of seniors, their family and friends who care for them, and of Health Authorities, to support informal caregivers. Caregivers require practical support (e.g., services for those whom they care), information and education, and emotional support.

[131] Fast, J., Williamson, D., and Keating, N. (1999). "The hidden costs of informal elder care". Journal of Family and Economic Issues, 20(3): 301–326.

[132] Sawatzky, J. and Fowler-Kerry, S. (2003). "Impact of caregiving: listening to the voice of informal caregivers". *Journal of Psychiatric and Mental Health Nursing*. 10: 277-286.

[133] Shillington, R. (2004). *Policy options to support dependent care: The tax/transfer system*. Halifax: Healthy Balance Research Program.

[134] Keating, N., J. Fast, J. Frederick, K. Cranswick, and C. Perrier (1999) *Eldercare in Canada: Context, Content and Consequences*. Ottawa: Statistics Canada.

[135] Keating, N., J. Fast, J. Frederick, K. Cranswick, and C. Perrier (1999) *Eldercare in Canada: Context, Content and Consequences*. Ottawa: Statistics Canada.

[136] Stobert, S., & Cranswick, K. (2004). Looking after seniors: Who does what for whom? *Canadian Social Trends*, 74, 2-6

[137] Guberman, N., J. Keefe, P. Fancey, D. Nahmiash, and L. Barylak (2001) Screening and Assessment Tools for Informal Caregivers: Identifying Services to Meet the Needs of These Potential Clients. *Rehab and Community Care Management* Spring: 24-26.

[138] Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canada. *Can J Aging* 1994; 13(0714–9808):470–87.

[139] Canadian Study of Health and Aging Working Group. Patterns and health effects of caring for people with dementia: The impact of changing cognitive and residential status. *Gerontologis*t 2002;42(5):643–52.

[140] Duxbury, L, Higgins, C., Schroeder, B. (2009). Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada.

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Reduction in the burden of caring has been shown to be associated with the use of adult day programs and caregiver support groups[141]; in home respite[142]; psycho-educational caregiver groups[143]; and, individual counselling for caregivers[144,145]. Caregivers who participated in a B.C. study report, however, that benefits to them are compromised by: (1) difficulty in accessing services (e.g., location, hassle factors, transportation and cost issues); (2) the general inflexibility of when and how services are provided (e.g., business hours, weekdays, set times, require planning), and (3) lack of services available "on demand" or in crisis[146]. The *Caregiver Policy Lens*[147], developed through extensive consultations with caregivers, service provider and managers, and policy makers about the support needs of caregivers, can be used to guide program development and to assess programs and services for any unintended negative impacts they may have on caregivers.

Addressing Caregiver Support Needs and Risk Factors

Caregiver support groups, disease/condition-specific organizations and health authorities participated in a survey carried out by the Family Caregivers' Network Society (2010) in 2009. The following areas for improvement in caregiver support in B.C. (rank ordered to reflect the most frequently cited) were identified:

- Respite services – availability, flexibility and cost
- Awareness (both for caregivers and healthcare professionals) of programs and services available to support family caregivers
- Availability, flexibility and ease of access to home support, respite, facility admission, navigating the healthcare system
- Sufficient services for large geographical areas, support and services for isolated caregivers or caregivers in small communities

[141] Dupuis, S., Epp, T., & Smale, B. (2004). Caregivers of persons with dementia: roles, experiences, supports, and coping: a literature review. *Murray Alzheimer Research and Education Program*: University of Waterloo.

[142] Cohen, C., GAP Committee on Aging. (2000). Directions for research and policy on schizophrenia and older adults: summary of the GAP Committee Report. *Psychiatric Services*, 51(3), 290-302.

[143] Kennet, J., Burgio, L., & Schultx, R. (2000). Interventions for in-home caregivers: a review of research 1990 to present. *Handbook on Dementia Caregiving: Evidence-Based Interventions for Family Caregivers*: 61-125.

[144] Brannstrom, B., Tibblin, A., & Lowenborg, A. (2000). Counseling groups for spouses of elderly demented patients:a qualitative evaluation study. *International Journal of Nursing Practice 6*: 183-191.

[145] Mittelman, M. (2005). Taking care of the caregivers. *Current Opinion in Psychiatry*, 18(6), 633-639.

[146] McGee, P., Tuokko, H., MacCourt, P. & Donnelly, M. (2005). Factors affecting the mental health of older adults in rural and urban communities. *Canadian Journal of Community Mental Health, Vol. 23, No. 2, Fall*: 117-126.

[147] http//www.CaregiverToolkit.ca

- Unique supports for caregivers of people with mental illness, dementia, multicultural groups, working caregivers
- Knowledge of healthcare professionals on caregiver issues and specific diseases, increase referral to caregiver support organizations
- Travel and transportation to programs and services. (The importance of travel and transportation was elevated in importance in more isolated or rural areas) (p. 19).[148]

The Caregiver Risk Screen is a Canadian screening and assessment tool that has been designed to identify caregivers at risk and the level of urgency required for intervention[149]. Findings from an Interior Health Authority project have demonstrated that caregivers' abilities to provide care and cope with caregiving were enhanced[150] when case managers identified and addressed the needs of caregivers of seniors with dementia proactively, using strategies that: a) targeted and enhanced caregiver skills, knowledge and abilities to provide dementia and self care; and b) provided genuine relief of burden.

Several studies and research groups internationally have identified the key features and components of interventions and programs for caregivers that increase the likelihood of successful outcomes[151, 152].

The Rosalynn Carter Institute for Caregiving has identified common factors that characterize interventions with the most positive impact on family caregivers, as follows:

- Contact with a helper over time;
- Contact with a helper who has specific intervention protocols to follow;
- Interventions and care plans tailored to the caregiver's specific needs;
- Multi-component interventions that include a combination of knowledge, skill building, problem solving and counselling;
- Interventions with higher intensity (e.g., greater frequency and duration);

[148] Family Caregivers' Network Society (2010). Supporting Family Caregivers: An Action Plan for British Columbia. Prepared for the B.C. Ministry of Health Services Home and Community Care Branch. p.19

[149] Guberman, N., Keefe, J., Fancey, P., Nahmiash, N., & Barylak, L. (2001). Screening and assessment tools for informal caregivers: Identifying services to meet the needs of these potential clients. *Rehab and Community Care Management, Spring,* 24-26.

[150] Antifeau, E. (2009). *Sustainable caregiving community project: Final report.* British Columbia: Interior Health. Retrieved from: http://www.interiorhealth.ca/health-services.aspx?id=812

[151] Cameron, M., Massuch, L., & Wishart, D. (2008). *Research-based recommendations for effective caregiver interventions*, University of Michigan.

[152] Zarit, S. H., & Femia, E. E. (2008). A future for family care and dementia intervention research. Challenges and strategies. *Aging & Mental Health*, 12(1), 5-13.

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- Using a combination of home-visiting, telephone follow-up, internet and tele-health technology to deliver; and
- Programs developed and implemented locally and involving agency collaboration[153].

Providing proper care to seniors requires an understanding of the particular challenges associated with any health condition. The literature for interventions for caregivers of seniors is largely information pertaining to seniors with dementia. Caregivers for seniors with conditions such as stroke, cancer, and Parkinson's disease have received less attention in the published literature, although there are a handful of promising studies (Schulz, Martire, & Klinger, 2005[154]; Lee, Soeken, & Picot, 2007[155]; Mason et al., 2007)[156] that speak to specific interventions in these populations. A recent synthesis by Eagar et al (2007)[157] points out that the literature they reviewed did not identify any major differences between caregivers of seniors with different illnesses with the exception of the need for caregivers of people with dementia for support and practical assistance to deal with the emotional strain of challenging dementia-related behaviours. A review of effective interventions to support caregivers of seniors can be found in the British Columbia Psychogeriatric Association *Resource Manual* (www.caregivertoolkit.ca)[158].

Much caregiver information, education and psychosocial support is provided through the voluntary sector. The Interior Health Region Phased Dementia Pathway[159] provides evidence-based information about the caregiver experience and related needs, and, detailed directions for care providers as to how to meet the needs of the person with a dementia. The Alzheimer Society of BC proactively provides information and individual support through the *First Link* program, as well as psycho-educational support groups.

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[153] The Rosalynn Carter Institute for Caregiving. *Evidence-based resources.* Avaialable http://www.rosalynncarter.org/what_makes_caregiver_programs_effective/

[154] Schulz, R., Martire, L. M., & Klinger, J. N. (2005). Evidence-based caregiver interventions in geriatric psychiatry. *Psychiatric Clinics of North America*, 28(4), 1007-1038.

[155] Lee, J., Soeken, K., & Picot, S. J. (2007). A meta-analysis of interventions for informal stroke caregivers. *Western Journal of Nursing Research*, 29(3), 344-356.

[156] Mason, A., Weatherly, H., Spilsbury, K., Golder, S., Arksey, H., Adamson, J., et al. (2007). The effectiveness and cost-effectiveness of respite for caregivers of frail older people. *Journal of the American Geriatrics Society*, 55(2), 290-299.

[157] Eagar, K., Owen, A., Williams, K., Westera, A., Marosszeky, N., England, R., et al. (2007). *Effective caring: A synthesis of the international evidence on carer needs and intervention.* Bepress. Retrieved from http://works.bepress.com/keagar/26

[158] http//www.caregivertoolkit.ca

[159] Available: http://www.interiorhealth.ca/health-services.aspx?id=328

Front line staff working in community programs and services for seniors generally have more contact with caregivers than other providers and can play an important role in supporting them. To do this successfully they need to be sensitized and educated about caregivers' experiences, coached in how to communicate with caregivers compassionately, and be provided with accurate information about the conditions of those they care for so that they can model effective care. Front line staff who often develop close relationships with care recipients and caregivers, may require guidance in setting appropriate boundaries, emotional support and constructive supervision.

Professional counselling may be required for caregivers who are experiencing mental health symptoms as a result of their caregiving role. Senior mental health clinicians may also be required to provide specialized and individualized education and coaching to caregivers of seniors with challenging behaviours related to dementia and other mental illnesses.

Practical support, opportunities for skill building, psychosocial support, and the availability of respite, are essential to empowering caregivers of seniors with mental health problems and illnesses.

The Importance of Volunteers

Volunteers, mentors and peer counselors increase the range of services mental health agencies can provide. They provide helpful services that are often unrecognized and, therefore, undervalued, perhaps because this work is by definition "work without remuneration". Candy stripers and hospital auxiliary volunteers are familiar figures in the acute care setting. Many communities also have a number of volunteer services available for seniors, such as transportation services, delivery of Meals on Wheels and companionship through friendly visiting. Hospice volunteers provide support to seniors with dementia and their families at end-of-life. Not only is volunteer work beneficial to the recipients, but the volunteers themselves also benefit in various psychological or personal ways from the experience.

Mentoring and self-help are often provided through groups that meet for the purpose of mutual aid, support and personal growth (e.g., stroke support groups). A mentor acts as a role model to provide help or give advice to a person with a mental illness or other life management problem. Self-help or mutual aid groups are available in most communities, often organized for individuals with a similar problem, such as a mood disorder. The aim of mentoring and self-help is to provide help in coping or managing through mutual efforts, rather than professional interventions.

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Peer counselling, in which experiences are shared as peers helping peers, is a variation on the volunteer/mutual aid theme. Senior Peer Counselling of British Columbia is an incorporated non-profit society that provides training for seniors to help other seniors by providing emotional support, guidance and empathy to at-risk seniors troubled by loneliness, depression, isolation or grief.

Volunteers, mentors and peer counselors who work with people with mental health problems should always be recognized for the important role they play and require ongoing support in their work from professional service providers which enable them to feel acknowledged and well informed about the nature of seniors mental health problems and needs.

Chapter VII

VII. Creating Supportive Environments

The Significance of Supportive Home, Assisted Living and Long Term Care Environments

This section focuses on supportive environments that seniors with, or at risk of, mental health problems require in order to support their mental health in their own homes, in independent and assisted living, or in facilities. Homelessness is also discussed. Housing is recognized as a critical determinant of health. The concept of supportive environments goes beyond the physical environment in which a person lives to also consider the psychosocial milieu. The following comment seems particularly relevant:

Supportive Environments

"A healing and therapeutic person-centred approach and milieu is important. This is the context for the delivery of individual care. It is a matter of the physical and the social aspects of care. In the physical, there are many aspects – architecture, interior design (i.e., color, pictures, furnishings, etc.), but also access to a garden, to pets and to people. The social side is founded on the relationships among staff, visitors and volunteers. Creating and maintaining an environment with a positive outlook, mutual respect and communications is demanding work. Like a parent's work, it is ongoing, always changing and often unrecognized. But it is evident."[160]

The majority of seniors with mental health problems live in their own homes or in long term care facilities. Family, friends and/or home and community care (e.g., home support services) generally provide practical supports for individuals living in their own homes. Home and community care also provides long-term care (facility) housing.

[160] Communication from Margaret Neyland, senior, retired nurse and seniors' advocate.

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Home and community care services (in-home and facility) have evolved from the acute care model. This model often did not lend itself to the promotion of optimal mental health. It was not person-centred because the focus was on physical care and the daily routines of staff with respect to clients/residents. The client's "person-hood" was often underemphasized and individual strengths and abilities were overlooked.

While adult mental health programs have historically included housing for the younger population in their mandate, seniors' residential housing is primarily the responsibility of home and community care services. Access by seniors with mental health problems to residential housing is an important management issue. An important role of seniors' mental health services is to provide home and community care services, including consultation regarding mental health aspects of both program development and individual care.

Those who have grown old with mental illness that first developed in younger age, may continue residing in mental health residential facilities with specialized seniors mental health services provided to help maintain them as required.

Adequate levels of home support and respite care should be available in order to facilitate seniors remaining at home as long as possible. An expansion of the range of services provided to clients in their homes and in facilities is thus required so that psychological, spiritual and social needs are identified and addressed. This will necessitate the inclusion of a wide variety of disciplines to provide care, train staff and develop programs.

Mental health expertise should be provided to agencies and facilities to help them develop the appropriate environment and culture and design programs to meet the needs of psycho-geriatric clients.

Supportive Environments for Seniors Living in the Community

Most seniors prefer to remain in the familiar environment of their own home. For seniors with mental health challenges, as with other seniors, the housing needs to be appropriate to the senior's physical limitations. Remaining well at home also requires that Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL), as well as cleaning needs, be met independently or with informal and/or formal support. For those living alone, the mental health risks of loneliness and social isolation related to depression, is also a factor affecting aging at home. Safety issues (e.g., fire, wandering, vulnerability to criminals) for seniors with significant cognitive impairments must be addressed to maintain them safely in their homes. The importance of supporting seniors to remain where they are most comfortable cannot be understated.

Evidence from a 2001 Health Canada study of the cost-effectiveness of home care has shown that seniors who receive supportive care in their homes make less use of more expensive health care interventions, such as visits to doctors, emergency rooms, and acute-care hospitals, and are older when they seek admission to long-term care facilities[161] .

One of the main reasons that seniors leave their homes to enter institutions is due to declines in functional status, and this is especially true of seniors over age 85 (Gonyea, 2005).[162] Another reason is environmental challenges in the home that, in the face of physical challenges, are difficult to negotiate (e.g., stairs, doorways too small for wheelchairs) (Iwarsson (2005)[163]. Other factors affecting the accessibility, safety, security and usability of home settings include a lack of finances for out-of-pocket expenses, such as assistive devices (Chappell, Havens, Hollander, Miller, and McWilliam 2004[164]; Oswald , Wahl, Schilling, Nygren, Fänge et al. 2007)[165].

Desirable Home Care Policies and Practices

Chapman, Keating & Eales (2003)[166] have identified the provision of client-centred community-based care through home care supports as a major factor that facilitates aging at home. The way in which home support services are provided can impact on seniors' mental health. The Canadian Mental Health Association interviewed seniors, family members, providers, volunteer agencies, researchers, home care organizations and government officials in Canada (including B.C.) regarding the role home care does, and can play, in meeting seniors mental health needs. Their report, *Supporting Seniors' Mental Health through Home Care: A Policy Guide* (2002)[167], articulates the key "system features", summarized below, that should be addressed through policy and operationalized in practices in the home care system in order to promote seniors' mental health.

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[161] Marcus Hollander, *Unfinished Business: The Case for Chronic Home Care Services, A Policy Paper,* August 2003.

[162] Gonyea, Judith G. (2005). "The Oldest-Old: Challenges for Public Policy." In Robert B. Hudson (ed.), *The New Policy of Old Age Politics*. Baltimore, Maryland: The John Hopkins University Press.

[163] Iwarsson, Susanne. (2005). "A Long-Term Perspective on Person-Environment Fit and ADL Dependence Among Older Swedish Adults." *The Gerontologist*, Vol. 45, No. 3, 327-336.

[164] Chappell, Neena, Betty Havens, Marcus J. Hollander, Jo Ann Miller, and Carol McWilliam. (2004). "Comparative Costs of Home Care and Residential Care." *The Gerontologist*, 44, 389-400.

[165] Oswald, Frank, Hans-Werner Wahl, Oliver Schilling, Carita Nygren, Agneta Fänge, Andrew Sixsmith, Judith Sixsmith, Zsuzsa Széman, Signe Tomsone, and Susanne Iwarsson. (2007). "Relationships between Housing and Healthy Aging in Very Old Age." *The Gerontologist*, Vol. 47, No. 1, 96-107.

[166] Chapman, Sherry Anne, Norah Keating, and Jacquie Eales. (2003). "Client-centred Community-based Care for Frail Seniors." *Health and Social Care in the Community*, 11(3): 253-61.

[167] Available: http://www.camrose.cmha.ca/data/1/rec_docs/158_smhhc_polguide.pdf

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Access to Home Care Services

- To provide seniors and their family caregivers with the information they need to access appropriate services, policies should allow and encourage home care organizations to act as information clearinghouses.
- To ensure that seniors and family caregivers receive the assistance they need to navigate the health and social service systems, policies should support home care organizations taking on, or expanding the scope of their coordinating role.
- Policies should also support home care organizations in assuming the role of identifying and addressing the issues, gaps and barriers that are preventing seniors from accessing services that would enhance their mental health.

Effective Communication and Involvement in Decision-making

- To ensure that clients are active participants in the planning and delivery of their care, policies must reflect a client-centred model and support the integration of the model into clinical and home support services by front line staff.
- To enhance communication with, and accountability to the community, policies should encourage the recruitment and participation of seniors and family caregivers not only in the governance structure of home care organizations and/or advisory groups, but also in ongoing care planning and identification of required supports.

Flexible Services

- To ensure that services remain client-centred, policies must recognize mental health needs as well as medical needs and support the principle of flexibility in care plans and time assigned to tasks.

Enhanced Role for Home Support Services

- To ensure that the mental health needs of seniors are considered in resource allocation decisions, policies must recognize the value of home support services and give consideration on how they can be maintained in an efficient and effective manner.

Services that Address Social Isolation

- To ensure the key mental health issue of socialization is addressed, home care organizations should identify options for meeting this need and ensure that these options are incorporated into service delivery planning.

Skilled Workforce

- To ensure home care staffs have adequate knowledge of the factors affecting mental health, training in mental health issues should be made explicit in staff development plans and be incorporated into continuing education curricula.

Continuity of Care

- To ensure continuity of care is maintained, operational policies and structures must maximize staff retention (e.g., salary and benefits policies) and encourage and support staff in developing and sustaining relationships with clients (e.g., scheduling policies).

Supporting Family Caregivers

- To ensure the family caregiver role is recognized and supported, policies should encourage staff to recognize and value the role of family caregivers, involve them in decision-making where appropriate, and where possible provide support to address their mental health.

A second guide, *Supporting Seniors' Mental Health: A Guide for Home Care Staff* (Anderson, Parent & Huestis, 2002) focuses on providing tools and checklists to assist the front-line practitioner to support the mental health needs of seniors.

Kane (2005)[168] points out that a dual focus is needed in policies designed to enable seniors living in the community: assistance to maintain living at home, and assistance to remain involved in their communities. Age Friendly community guides can assist in developing communities that support seniors[169]. Several communities in British Columbia (as well as in other parts of Canada and internationally) are using community-wide age friendly approaches to facilitate good person-environment fit for seniors by addressing issues such as increased accessibility in stores and banks, and volunteer assistance with snow shoveling and yard work.

[168] Kane, Rosalie. (2005). "Connecting the Dots: Public Health, Health Care, Health Policy, and Successful Aging." *The Gerontologist*, Vol 45, No. 2, 274-79.

[169] World Health Organization. (2007). Global Age-friendly Cities: A Guide. Geneva: World Health Organization Press.

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Models of All Inclusive Care to Support Seniors in the Community

A number of models have been suggested to integrate personal, medical and support services to seniors that are applicable to seniors with, or at risk of, mental health problems. Models of all-inclusive care are centred around a day-centre where seniors receive some meals, personal care, medication supervision and activity opportunities. Transportation is also provided. Support is provided in the home (including help with dressing in the morning and getting to bed at night) on days the senior is too unwell to attend the day-centre (Ontario Coalition of Senior Citizens Organizations (2004)[170].

Two models identified by the Ontario Coalition of Senior Citizen Organizations (2004)[171] are **PACE** and **Choice**.

PACE – (Programs of All-Inclusive Care)

- PACE is a model of all-inclusive care that was created by On Lok Senior Health Services in San Francisco. PACE provides medical and long-term care services to both inpatients and outpatients. Seniors in the programs must live within a geographical area close to the PACE centre. Participants can receive services in their home or at the centre, depending on their health and circumstances. Seniors have many options: transportation services, attending recreational and educational programs, having meals at the centre or at home, supervision of medication, benefiting from social work services and personal support services, and others.

CHOICE – (Comprehensive Home Option of Integrated Care for the Elderly)

- CHOICE is the Canadian version of the PACE program, located in Calgary. CHOICE helps seniors to live in dignity and with autonomy. The average participant is 81 years old. Seniors receive a flexible range of health care options and social supports, and these services can change, as the seniors' needs change (thus the term "services follow the senior"). There is a monthly charge to participants.

[170] Ontario Coalition of Senior Citizens Organizations (2004). Seniors Health and Housing Crossroads: Exploring Alternatives to Long-term Care Facilities. Prepared by D. Kucharska.

[171] Ibid.

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Assisted Living[172]

Assisted Living (AL) in B.C. was conceived as a social model of housing that increased choice, provided the possibility of aging in place and reduced the demand for publically funded complex care placement. Intended to fill the gap between living independently and living in a care facility, assisted living generally includes senior housing with hospitality services, assistance with personal care, opportunities for socialization, and around-the-clock emergency response.

Under the 2002 B.C. *Community Care and Assisted Living Act,* residents must be able to direct their own care and initiate a complaint. The only time when an AL setting is able to accommodate a cognitively impaired resident is if the client is accompanied by a caregiver who is responsible for 24 hour supervision of the impaired resident and will make the necessary decisions on his/her behalf. Another exception is listed under Section 37 of the *Mental Health Act* – when the resident is required (under the terms of the *Mental Health Act*) to live in AL instead of the mental health facility, as long as the resident is able to make decisions around ADLs (*Community Care and Assisted Living Act*).

Behavioural evictions are the second (to financial) most common type of eviction from AL. For seniors, inappropriate behaviour may begin or exacerbate with the progression of dementia, as a result of addictions, or because of the poor fit of environment to the client's personality. Specialized mental health services are often asked to assess residents at risk of eviction and to make suggestions about behaviour management and modifications to the social environment.

Licensed Dementia Housing

Recognizing that some individuals with a dementia can be managed in settings similar to assisted living, licensed dementia housing is emerging in B.C. as an alternative when long-term care placement is deemed premature. One example is Brentwood House, a formally licensed dementia housing facility operated in a private public partnership between the Vancouver Island Health Authority and Beacon Community Services Vancouver Island. A set of standards, congruent with "personhood" and recovery philosophies, guide the care provided, and facilitate a supportive environment for residents:

- Reassuring and familiar environment;

[172] This section is a summary from Silvester, A. (2008). *Tenancy Management in Assisted Living Settings in Vancouver Island Health Authority*, unpublished Master Thesis, University of Victoria

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- Inclusion of personal preference and choice;
- Maintenance and development of relationships;
- Knowledge of a person's past to inform the present;
- Promotion of abilities and maintenance of mobility;
- Continual evaluation and innovation; and
- Staff and family members seek opportunities to facilitate joy.

Poilievre (2010)[173] reports that a comparison between Brentwood House residents and similar people living in the community indicated (1) that the Brentwood House residents retained a higher level of function; (2) experienced a higher quality of life, and (3) that many of the clients living at home moved to residential care. Additionally "anecdotal staff reports are that less medications are being used, and residents are less anxious. Family members are also satisfied with the care and experience less stress than family members of comparable residents in the community" (MacCourt, 2010[174] as cited in Poilevre, 2010, p. 45).

"Hard to House" Seniors and Homelessness[175]

The term *hard-to-house* refers to the population whose multiple diagnoses impede their ability to secure housing because they are deemed problematic by housing providers (Gurstein & Small, 2005)[176]. Problematic behaviour may include aggressiveness, visual appearance or lack of social skills that are difficult or offensive to housing providers and other tenants. Anucha (2003)[177] reports that individuals who are hard-to-house often lack a good social support system; they do not know how or may not want to look for help, as they may feel disillusioned with the system.

[173] Poilievre, T. (2010). Licensed Dementia Housing: A New Model of Residential Care in British Columbia (2010). Prepared for Home and Community Care Ministry of Health Services.

[174] The evaluation report is available at: http://www.beaconcs.ca/pdfs/housing/BrentwoodHouseEvaluation2009.pdf

[175] Reproduced from Silvester, A. (2008). *Tenancy Management in Assisted Living Settings in Vancouver Island Health Authority*, unpublished Master Thesis, University of Victoria, p. 34-35.

[176] Gurstein, P. & Small, D. (2005). From housing to home: Reflexive management for those deemed hard-to-house. *Housing Studies*, 20(5), 717-735.

[177] Anucha, U. (2003). *Research report for Canada Mortgage and Housing Corporation. Where do they come from? Why do they leave? Where do they go? A study of tenant exits from housing for homeless people.* Toronto, ON: University of Toronto, Center for Urban and Community Studies. Available: http://ftp.cmhc-schl.gc.ca/chic-ccdh/Research_Reports-Rapports_de_recherche/eng_unilingual/RR_Homeless.pdf

The Ontario Coalition of Senior Citizens Organizations (2004) forum on seniors housing and health, report that seniors experiencing severe mental health and addiction problems have great difficulty in finding and keeping decent affordable housing, due to stigma and often, low income. Some factors contributing to seniors becoming homeless were identified as the lack of services for recognizing and dealing with problems such as:

- Seniors with a history of severe mental illness
- Seniors who have experienced mental health problems all their lives who may not have been diagnosed or treated
- Mental health issues that become mental health illnesses, e.g., mild depression which untreated becomes severe
- Seniors with addictions (Ontario Coalition of Senior Citizens Organizations, 2004, p. 45)

In 2009 the Mental Health Commission of Canada (MHCC) implemented a national research project in five cities to find the best way to provide housing and services to people who are living with mental illness and homelessness. A '*Housing First*' approach is being used which focuses on first providing people who are homeless with a place to live, and then any other assistance and services they may require. When completed, the findings may be useful in addressing homelessness with seniors.

Supportive Environments in Long Term Care

Supportive social environments are an important determinant in psychosocial and health outcomes for seniors with mental health challenges living in long term care settings. A supportive environment includes physical design concepts as well as the social environment and organizational setting. A supportive long-term care environment can maintain and enhance the well being and quality of life of all residents, including those with mental health challenges.

In spite of the effort of many committed people working in long term care, there are continued criticisms about these care environments in relation to their institutional physical design and features, to their cultures of care, to the way care is delivered, to limited activity programs, to inadequate staff numbers and training and to the co-housing of seniors who have very challenging behaviours with frail seniors. In part, the deficiencies in long term care environments can be attributed to their evolution from the acute care model rather than

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from an understanding of the importance of residents' bio-psychosocial and spiritual needs (Eliopoulos, 2010)[178].

The International Psychogeriatric Association's Task Force on Mental Health Services in LTC Homes was formed in recognition of the very high prevalence of mental illness in long term care facilities (particularly depression and dementia) and the high incidence of very challenging behaviours. Its tasks included: "(1) to gather information and share views from diverse countries and settings about how best to restore or ensure good mental health in LTC settings; and (2) to support and strengthen mental health services in the LTC sector" (Conn & Snowdon, 2010, p. 1023)[179]. The task force has identified the ideal long term care environment.

The Ideal Long-Term Care Environment

"One where residents retain self-esteem, with opportunities for choice and (as far as possible) for controlling their own lives in a home-like environment, where staff show respect for residents, and vice versa. The ideal LTC home ensures there is ongoing education of staff, residents and families concerning matters affecting mental health and ensures staff (including doctors) work as a team, coordinating and communicating – and involving relatives and residents in discussions. To make this possible they need time and adequate funding. In the ideal LTC home, staff and residents and visitors feel confident and content – and, if they don't, someone is taking remedial action (Conn & Snowdon, 2010, p. 1024)."

Long Term Care Facility Design

Long term care facility design can impact the mental well-being of residents, particularly those with dementia. Marshall (2001, cited in Fleming & Purandare, 2010[180]) asserts that design factors can compensate for disability, maximize independence, reinforce personal identity, enhance self esteem/confidence, demonstrate care for staff and welcome relatives and the local community. She recommends that facilities:

[178] Eliopoulos, C. (2010). Cultural transformation in nursing homes [Guest editorial]. I*nternational Journal of Older People Nursing*, 5, 1–2.

[179] Conn, D. & Snowdon, J. (2010) Guest Editorial: Optimizing mental health in long-term care homes. *International Psychogeriatrics* (2010), 22:7, 1023–1024.

[180] Fleming, R. & Purandare, N. (2010). Long-term care for people with dementia: environmental design guidelines *International Psychogeriatrics* (2010), 22:7, 1084–1096.

- Be small in size
- Control stimuli, especially noise
- Enhance visual access, i.e. ensure that the resident can see what they need to see from wherever they spend most of their time
- Include unobtrusive safety features
- Have rooms for different functions with furniture and fittings familiar to the age and generation of the residents
- Have single rooms big enough for a reasonable amount of personal belongings
- Be domestic and home-like
- Have scope for ordinary activities (unit kitchens, washing lines, garden sheds)
- Provide a safe outside space
- Provide good signage and multiple cues where possible, e.g., sight, smell, sound
- Use objects rather than colour for orientation (Fleming & Purandare, 2010[181], p. 1085)

In a review of evidence to support these recommendations, Fleming and Purandare (2010)[182] found strong evidence for: "using unobtrusive safety measures; varying the ambience, size and shape of spaces; providing single rooms; maximizing visual access to important features and providing for stimulus control with the periodic availability of high levels of illumination" (p. 1093).

A number of models designed to create care cultures that provide person-centred care in home-like environments to optimize residents' quality of life and to improve the quality of care have been developed, examples of which are the Eden Alternative[183] (being implemented in Providence Care facilities in Vancouver Coastal Health Authority), the Green House program[184] and the Wellspring program[185]. Seniors with a dementia in a care facility using the Eden Alternative model, compared to a facility not using the model, experienced less boredom and less helplessness (Bergman-Evans, 2004)[186]. The impacts of these very promising and intuitively appealing models await formal evaluation.

[181] Fleming, R. & Purandare, N. (2010). Long-term care for people with dementia: environmental design guidelines *International Psychogeriatric*s (2010), 22:7, 1084–1096.

[182] Ibid.

[183] See http://edenalt.com

[184] See http://ncbcapitalimpact.org

[185] See http://WellspringProgram.org

[186] Bergman-Evans, B. (2004). Beyond the basics: effects of the Eden Alternative model on quality of life issues. *Journal of Gerontological Nursing*, 30(6): 27-34.

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Guidelines for Provision of Care in Long Term Care Facilities

In order to facilitate supportive environments for seniors with dementia living in care facilities, the Alzheimer Society of Canada (2011)[187] has developed evidence based *Guidelines for Care: Person-Centred Care of People With Dementia Living in Care Homes*. A framework is provided for strengthening the capacity of care home staff to implement person-centered care by influencing the culture of care and encouraging recognition of each resident's individuality, reproduced below. Implementing person-centred care would support the mental health of any long-term care resident, not only those with a dementia.

- Ensure that people who work in care homes understand what a person-centred philosophy of care means and are able to put it into practice.
- Ensure that relationships and interactions with people with dementia are respectful.
- Focus on maintaining, supporting, and/or restoring the independence of the person living with dementia.
- Develop strong bonds with family members of people with dementia and engage them in activities whenever possible.
- Provide quality care to all residents with dementia regardless of their cultural background, age or mental ability.
- Anticipate the needs and reactions of people with dementia and adjust individual, social and environmental factors to reduce negative behaviours.
- Encourage and support persons with dementia to make choices in keeping with the person's lifelong values, preferences, and interests. (Alzheimer Society of Canada, 2011, p. 3)[188]

The Canadian Coalition for Seniors Mental Health (2006)[189] has developed evidence-based *National Guidelines for Seniors' Mental Health: The Assessment and Treatment of Mental Health Issues in Long Term Care Homes* that include specific organization and systems recommendations intended to improve the physical and social environments of long term care homes (LTC homes). (In the document supporting discussion can be found for each guideline as well as the level of evidence available to support the guideline).

[187] Alzheimer Society of Canada (2011) Guidelines for Care: *Person-centered care of people with dementia living in care*. Available: http://www.alzheimer.ca/english/care/framework.pdf

[188] Alzheimer Society of Canada (2011) *Guidelines for Care: Person-centered care of people with dementia.* Available: http://www.alzheimer.ca/english/care/executive-summary.pdf

[189] Canadian Coalition for Seniors Mental Health (2006) *National Guidelines for Seniors' Mental Health: The Assessment and Treatment of Mental Health Issues in Long Term Care Homes.* Toronto. Available htpp://www.ccsmh.ca

- LTC homes should develop the physical and social environment as a therapeutic milieu through the intentional use of design principles.
- LTC homes should have a written protocol in place related to staffing needs specific to the care of older residents with mood and/or behavioural symptoms.
- LTC homes should have an education and training program for staff related to the needs of residents with depression and/or behavioural concerns. Ideally, dedicated internal staff would be available to provide leadership in this area, including the development and delivery of best practices.
- LTC homes should have a written protocol in place related to the administration of medication by para-professional staff.
- LTC homes should have a written policy in place regarding the use of restraints.
- LTC homes should obtain mental health services from local practitioners or multidisciplinary teams, with interest and expertise in geriatric mental health issues.
- Administrators and managers within LTC homes should be prepared to advocate with local, provincial, and national policy makers and funding agencies to promote the health and well-being of older residents.
- LTC homes should have a process in place that ensures adherence to the ethical and legislative rights of the older resident.
- LTC homes should ensure adequate planning, allocation of required resources and organizational and administrative support for the implementation of best practice guidelines.
- LTC homes should monitor and evaluate the implementation of best practice recommendations.

Chapter VIII

VIII. Collaboration for Seniors Services

The Significance of a Collaborative, Integrative Continuum of Care

Collaboration is a key component of seniors mental health services. Seniors with multiple and complex needs require an array of health and social/community services with specific services requiring changes over time as the nature and intensity of their needs fluctuate. In addition to health needs, seniors with complex needs have the same needs and aspirations as other seniors. Likewise, they are affected by the determinants of mental health (i.e., social and environmental factors like income, social status, education, physical health, employment, housing, transportation and working conditions, access to appropriate health services, and in the community, building design and the level of social and civic participation) (WHO, 2004)[190].

Creating a comprehensive and integrated seniors' mental health system is a shared responsibility. It requires the community, private and voluntary sector, health and mental health services, and all levels of government to work together in order to support seniors with and without mental health problems, sustain their caregivers, and avoid crises. Creating this system demands partnerships, collaboration, and mechanisms in place: inter-and cross-sectorally, ensuring that seniors can access the appropriate services in timely manner. In short, the system must be collaborative and integrative – combining and coordinating diverse elements into a whole.

In a collaborative, integrated approach to care, the care providers (which may include health professionals and community supports) are jointly responsible for a patient's care and exchange of clinical information and services (ranging from hospital to community services) to deliver optimal all-systems patient care. The level of intensity of the collaborative model depends on the severity of health and mental health needs and may change throughout the course of an individual's life as needs and community resources change. Care plans are often joint, representing the whole of the person's care needs. The continuum of care is described below followed by a discussion of the importance of collaboration in seniors mental health.

[190] World Health Organization (2004). Promoting mental health: concepts, emerging evidence, practice: summary report World Health Organization, Department of Mental Health and Substance Abuse in collaboration with the Victorian Health Promotion Foundation (VicHealth) and the University of Melbourne. Geneva.

Chapter VIII

The Roles of Primary, Secondary, Tertiary and Other Services

The major components of the health care system are traditionally defined as primary, secondary and tertiary. Also included in this discussion are crisis response/emergency services for seniors.

The Primary Service System

- Family Physicians and other primary care service providers can manage many problems without direct consultation from specialists. Family physicians and community health workers (e.g., nurses, rehabilitation therapists, social workers, psychologists, homemakers, support workers) are the basic infrastructure of the mental health care system for seniors. In order to enable providers in the primary care system to care for an increasing number of seniors with complex high level needs, additional specialized training and supports are needed.
- The primary service system is commonly the point of entry to all subsequent services that may be provided through the secondary and tertiary systems. Often it is the family physician who first sees the individual experiencing problems. In certain circumstances, the family physician may want to try sequential or stepped care management strategies[191] prior to involving other resources which may be needed to provide care or support for the person or family caregivers.
- Best practices in the primary care system depend on knowledgeable clinicians, co-ordination and collaboration among caregivers and service providers with as much integration and continuity of service flow as possible.

The Secondary Service System

The secondary service system supports the primary service system by providing specialized care by professionals who have specific training in geriatric mental health, psychiatry or geriatric psychiatry. Secondary services are provided in a variety of settings (e.g., seniors' homes, residential care, inpatient services). They provide indirect services, such as consultation to professionals, and specialized education to informal and formal care providers. Direct services, such as assessing the client and/or assisting with ongoing care and treatment, are also provided. It is essential that the primary system continue to provide ongoing overall medical and supportive care and that consultation and liaisons are maintained between the primary and secondary service system providers.

[191] Von Korff, M., Katon, Wayne, MD, Unutzer, Jurgen, MD, MPH, Wells, Kenneth, MD, Wagner, Edward H., MD: Improving Depression Care Barriers, Solutions, and research needs, *The Journal of Family Practice*, 50:6 (2001).

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The secondary system delivers care for (and only needs to care for) a small percentage of older clients with mental health problems (perhaps 10 to 15 per cent of those who are ill or about 3 per cent of the population as a whole). It is believed that the secondary system is presently not seeing a high percentage of those who genuinely need their services because resources are limited, especially in rural areas. Secondary resources may need to be assessed in relation to the local capacity (e.g., characteristics of seniors' population, availability of expertise in primary service system, community resources to support seniors, etc). Shared care and other forms of collaboration can maximize secondary resources.

Components of the Secondary System[192]

a) Outpatient/Outreach Community-based Seniors Mental Health Teams

Seeing seniors in their home (including nursing homes) and providing services outside formal offices or clinics is the essence of outpatient/outreach community-based services. Multidisciplinary community outpatient/outreach mental health teams, whether hospital or community-based, constitute the foundation of the secondary system. Individual clinicians in very small towns or remote areas can be successful if they work as a team even though they may not be organizationally connected. For instance, a family physician consulting with a community nurse regarding care for a senior with mental health problems may well be the foundation of a psychogeriatric support system in an area that is too small to have a specific psychogeriatric mental health team. Defined linkages to regional secondary services in larger health authority communities, and outreach by more resourced communities to those less resourced, needs to be developed. Teams can, therefore, vary from this basic two-person liaison to sophisticated teams with four or five disciplines working in an ideal interdisciplinary format. Outpatient/outreach elderly mental health teams require access to specialized:

- Physicians (family physicians, geriatricians, psychiatrists, geriatric psychiatrists);
- Registered nurses and registered psychiatric nurses;
- Social workers;
- Rehabilitation therapists (occupational therapists, physical therapists);
- Psychologists;
- Life skill/support workers;
- Administrative support.

[192] In this document components of the secondary services refer to specialized mental health services for seniors.

These individuals would constitute the core team members. In addition, it is important that the client, their family, the client's family physician and other community health service professionals are considered partners in care and that there is collaboration amongst them. Case management issues (i.e., accountability and responsibility) should be defined among the collaborating professionals.

Other team members needed for occasional consultation may include pharmacists, neurologists, Licensed Practical Nurses, health care aides and life skills and home support workers trained for psychogeriatric care. Access to lawyers, ethics consultants, nutritionists and staff from the Office of the Guardian and Public Trustee should be available as needed. In keeping with general community mental health principles, clients should be seen wherever it is appropriate to see them – within their own home, within an outpatient team environment, in a long-term care facility, at a day program or in hospitals.

The role of the multidisciplinary community mental health outreach team includes:

- Assessment (including collection of collateral information);
- Recommendations for care;
- Direct care[193] (assessment, treatment, case management, follow up);
- Indirect care[194] (consultation to other care providers, e.g., shared care);
- Capability/competency assessments or at-risk assessments as required;
- Consultation regarding program development or environmental approaches to care;
- Collaboration and partnerships[195] with the primary care service system;
- Education and training for formal and informal caregivers; and
- Research and evaluation.

Models of service delivery can be developed with more direct or more indirect care as is appropriate for an individual community, based on knowledge of the local seniors' population, resources and community capacity.

In 2004 the Ontario Ministry of Health and Long Term Care, Mental Health and Rehabilitation Reform Branch, defined a specialized geriatric mental health outreach team's program

[193] Direct care/consultation – Consultation in which one professional, or team of professionals, upon referral, sees and individual and makes recommendations to the consulter

[194] Indirect care/consultation – Consultation in which one professional service provider discusses a case with another professional without the second professional seeing the individual

[195] See Appendix 1.1 Collaboration and Partnerships: Building Capacity

policy and accountability framework:[196] "Specialized geriatric mental health outreach teams are located in a variety of organizational settings, including community agencies, teaching hospitals and community hospitals. Services are time limited and geared to the needs of the senior experiencing serious difficulties due to complex, age-related or mental health problems, their families and service providers within community and long term care settings. It is estimated that only 3 per cent of seniors have problems that require specialized services. Services at this level include specialized ambulatory services – outreach teams, specialized inpatient services, complex continuing care and geriatric rehabilitation."

Outreach/outpatient programs may not have the resources to deliver all core functions and services; however, it is expected that through a shared care approach, all core functions and services will be locally available. Regional decision-making determines how resources will be aligned to deliver core functions.

b) Inpatient Elderly Mental Health Care Services

Health authorities should consider the following points concerning the provision of specialized inpatient mental health services for seniors:

- The service design should take into consideration the size of the community local capacity (e.g., the professionals and programs that support seniors) in that community.
- The recommended range of services includes:
  - Family practice services;
  - Psychiatry services;
  - Geriatric psychiatry services geriatric medicine services; and
  - Inpatient medical and psychiatric geriatric assessment and treatment services (e.g., short-stay assessment and treatment units).
- The development of clear, measurable admission criteria and protocols for access is needed.
- Program development should be informed by a recovery model philosophy and ensure that psychosocial rehabilitation needs are met, along with biological assessment and treatment, whether elderly people with mental health needs are located in general medicine or psychiatry beds.

[196] Ontario Ministry of Health and Long Term Care, Mental Health and Rehabilitation Reform Branch defined a specialized geriatric mental health outreach team's program policy and accountability framework.

- Medical consultants, as needed, should be accessible for specific case problems. (e.g., geriatricians, specialists in internal medicine, neurology and cardiology, etc.)
- Care protocols, clinical path models and/or practice guidelines should be defined for assessment and treatment.
- Discharge criteria and planning, with connections back to the community and appropriate involvement of family/caregivers, are essential.
- Quality improvement activities, including utilization processes, should be in place.
- Integration between outpatient/outreach and inpatient care is essential. This could be facilitated in several ways, such as having the outpatient/outreach and inpatient care connected by being at the same site or by having clear protocols in place for accessing individual services. Another model could have the case manager of the outpatient outreach team act as the continuous case manager through inpatient admissions and back to the community.
- Liaison with home and community care services/nursing homes and the family physician for discharge planning and arranging of supports is essential and should be considered as part of the continuum of integrated care across several different spectrums, such as outpatient/inpatient, acute care/home and community care/nursing home and specialist/family physician care.

c) Outpatient Clinics

An outpatient clinic is very similar in form and function to an outpatient/outreach team, the only difference being that clients come to the clinic rather than being served in their residence. Generally, outpatient clinics, located in hospitals, have a major role in follow up of discharged inpatients.

d) Outpatient Electroconvulsive Therapy

Electroconvulsive Therapy (ECT) may be offered by hospitals on an outpatient basis for both acute or maintenance ECT treatment. The scientific evidence regarding the efficacy of the treatment has been firmly established in the professional literature. ECT has a higher success rate for severe depression than any other form of treatment. It can be life saving and produce dramatic results and is particularly useful for people who cannot take antidepressants due to problems of health or lack of response. A patient who is very intent on suicide, and who could not wait three weeks for an antidepressant to work, would be a candidate for ECT.

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e) Inpatient Geriatric Psychiatry (Consult) Services

Formally constituted consult/liaison services give care providers access to expert advice and second opinions. These services consist of consultation to acute care hospital inpatient programs or liaison with them around psychiatric or geriatric psychiatric problems. Typically, a psychiatrist sees the client and gives an opinion. Most often the client's psychiatric needs are treated where they are receiving care. Occasionally, the psychiatrist may facilitate the transfer of the client to a psychiatric unit. Teams may be created to perform the consult/liaison service. Teams may include nurses, social workers or rehabilitation therapists along with physicians.

Consult/liaison services may include indirect consultation – discussing cases without seeing clients – or education for staff about how to identify psychiatric illness or how to manage challenging behaviours. In smaller hospitals, the outpatient/outreach team may undertake the role of the geriatric psychiatry consult liaison service. Geriatric psychiatry consult/liaison services also provide to service providers in the community, including nursing homes, access to expert advice, and second opinions.

The Tertiary Care System

The tertiary service system delivers care for individuals needing more than what secondary care can provide. The most complicated of cases need secondary or tertiary services. Ideally, referrals to tertiary care should always be made by a secondary resource.

Components of the Tertiary Care System

a) Inpatient Tertiary Elderly Mental Health Care Services

Although only a small number of tertiary services are needed, these services are vital to the overall functioning of the system. Without them, incredible pressure on the secondary and primary system can develop. To address this, given the planned closing of Riverview Psychiatric Hospital, there are community-based psychogeriatric programs in each Health Authority.

Tertiary inpatient services require highly specialized, trained staff and programs to provide care for people whose behaviours or complicated disorders are beyond the capacity of secondary staff and resources. Tertiary inpatient services require clear, measurable admission criteria and protocols for access. Discharge criteria and planning, with connections back to the community and appropriate involvement of family/caregivers and service providers, are essential.

Questions arise as to whether or not some of the tertiary long stay clients could be managed in other facilities, such as long-term care facilities with special care environments. Each Health Authority needs to address this question, taking into consideration that appropriate care would require additional staffing with specialized training. The capacity for tertiary services depends on resources, particularly staff, being locally available.

b) Rural and Remote Community Outreach

Seniors in rural and remote communities are entitled to the same mental health care as other British Columbians. These services can be provided by the outreach community-based mental health teams in better resourced communities by means of tele-health and video-conferencing and visits as needed.

c) University Research/Teaching Clinics

University teaching clinics, such as the UBC Alzheimer's Clinic and Movement Disorders Clinic, are primarily research focused. Tele-health and video conferencing technologies may support access to these services by remote communities. These research/teaching clinics, as well as other university programs, not only offer opportunities for research, but also provide education for many of the professional care providers.

Crisis Response/Emergency Services

Crisis response/emergency services need to be available for seniors. Crises or emergencies can occur with clients being treated in any part of the service system – primary, secondary or tertiary care. In fact, it would be expected that the majority of crises would occur where the majority of clients are treated within the primary system and that most would be minor and could be handled within the primary system of care. If the crisis is more serious, this may be the point at which a client is introduced to the secondary system for the first time.

It is important to note that seniors need medical assessment in crises because of the very high prevalence of medical/psychiatric co-morbidities presenting as emergencies. Ideally, the family physician should be involved in all assessments. However, crisis staff personnel must be trained to identify medical problems in psychiatric emergencies in seniors or know how to quickly obtain a medical assessment quickly. It is equally important that community and hospital staff work together to ensure that a continuum of community services are available for seniors who present in emergency departments.

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As with the mental health system as a whole, the structures, which are appropriate for treatment of mental health emergencies in seniors, depend on the size of the community and availability of trained personnel. It is important that the protocols and environments of response/emergency services are senior and dementia-friendly, accommodating their special needs.

Components of Crisis Response/Emergency System

Care service components required to provide for the urgent/emergent assessment and crisis interventions needed by seniors are:

- Crisis lines staffed by trained volunteers,
- Mobile crisis outreach by first-line responders,
- Walk-in crisis stabilization services for assessment and access to follow-up care, community crisis stabilization services at home or elsewhere where 24-hour observation, support, intensive case management, assistance and connection with follow-up services is provided,
- Hospital-based psychiatric emergency services which provide specialized emergency mental health assessment, treatment and management services to seniors referred via a hospital emergency department. These services are able to detain and treat seniors on an involuntary basis.

Building a Comprehensive and Integrative System

Seniors receive support and services from a wide range of sources. Support and services may come from different health care programs (e.g., day care, chronic care, continuing care, mental health) in different sectors (e.g., acute, community, residential care); from municipalities (seniors' centres, Handi Dart); non-profit (e.g., CNIB, Alzheimer Society of BC); from the voluntary (e.g., Meals on Wheels) and private sector (e.g., retirement homes). Finding and coordinating this array of services so that they form a whole and seamless experience for seniors can often be a daunting task for seniors, their family/caregivers and service providers. Efforts to build alignment and collaborative practices across the spectrum of seniors' mental services and other services to seniors are an ongoing priority from all perspectives.

One model that provides a basis for planning comprehensive service delivery for seniors' mental health services is described in a tiered model of psychogeriatric service delivery: An evidence-based approach by Brian Draper, Henry Brodaty and Lee Faye Lau (International

Journal of Geriatric Psychiatry 2006, 21:645-653). This model outlines seven tiers of management intensity that increase with the increased severity of patients' mental disorder.[197]

Tier 1:
There is no mental disorder but primary prevention activities are supported through primary care and non-medical support systems.

Tier 2:
Selective prevention for risk factors for mental health disorders is provided to patients with behavioural or psychological symptoms of dementia (BPSD). Education, training and prevention therapies support psychogeriatric services.

Tier 3:
Management of mild mental disorders but not dementia with BPSDs is provided through education of caregivers and staff in primary care and liaison with psychogeriatric services. Management also includes options for environmental modifications, activity programs, psychotherapy and pharmacotherapy.

Tier 4:
Management of moderate mental disorders and patients with dementia with moderate BPSD's is achieved through psychogeriatric consultation for both pharmacotherapy and behavioural management in collaboration with primary care in a shared care model.

Tier 5:
Case management of complex mental disorders, (including dementia with BPSDs such as aggression or agitation), is provided by multidisciplinary psychogeriatric outreach teams in community or institutional settings, where caregiver stress is evident.

Tier 6:
Management of severe mental disorders, primarily dementia with severe psychosis or severe BPSD, is provided in psychogeriatric or neurobehavioural units, or in dementia specific nursing homes.

Tier 7:
Management of extreme mental disorders is provided by intensive, specialized, psychogeriatric units; (the incidence of cases would be rare).

[197] *A tiered model of psychogeriatric service delivery: An evidenced-based approach* by Brian Draper, Henry Brodaty and Lee Faye Lau (International Journal of Geriatric Psychiatry 2006, 21:645-653)

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The authors suggest that "the boundaries between tiers are not distinct and movement between tiers is not necessarily stepwise." This model would start with Public Health and move through primary care, then community mental health services and on to residential and/or inpatient services. Since clear connections between the tiers would be necessary, the role for the community mental health team would have to be flexible in order to support patients in and out of the various tiers.

Collaboration across Sectors

Addressing the mental health needs of seniors with, or at risk of, mental health problems and illness demands the efforts of more than the mental health system alone. Families and other informal caregivers, the formal primary care system, municipal and provincial government organizations/services, nongovernment organizations (e.g., Alzheimer Society of BC) provide most of the support to these populations and have important roles to play. The mental health service system has a vital role in building capacity to support and care for seniors through education and individual and program consultation.

Health authorities can contribute to building capacity in communities to support seniors through collaboration with organizations outside the health sector. The Age Friendly Community (AFC) Model is one vehicle for promoting mental health through multi-sectoral collaboration. The AFC model provides a framework to strengthen communities that utilizes the expertise of seniors, and involves the business, voluntary, health and education sectors, as well as all levels of government. The approach is flexible, builds on local capacity, and can be adapted to local concerns, resources and characteristics. The needs of all seniors, including those who are vulnerable and those who are marginalized, are considered. The bottom-up and multi-pronged approach utilized in implementing the AFC Models contribute to the mental health and well-being of seniors participating in the process as well as to community and social cohesion.

B.C.'s Healthy Aging plan focuses on healthy eating, physical exercise, smoking cessation, fall prevention and social inclusion and also provides possibilities for collaboration. For example, there is evidence that physical exercise contributes to mental health promotion, prevention of mental health problems and recovery from depression.

Partnerships with municipalities could be undertaken to ensure their programs accommodate the needs of seniors with functional, mental health or other limitations. Fear of falling is a source of significant anxiety for seniors – partnerships between the fall community and the mental health community could be effective in the early detection and treatment of anxiety.

Senior Peers provide emotional support and lay counselling to seniors – seniors mental health services can play a role in training and supervising them as well as providing consultation as needed. The B.C. Dementia Service Framework, a partnership with all health authorities and the ASBC, makes a number of recommendations for collaborations between the community and health services and within health services to better support and address the needs of people with dementia and their family/caregivers.

Educating the public, community organizations and other stakeholders about mental health and mental illness so they can better meet the needs of the people they serve is another area for collaboration. For example, Mental Health First Aid (sponsored by the Mental Health Commission of Canada[198]) is a program that will teach people how to recognize the signs and symptoms of mental health problems, provide initial help, and guide a person towards appropriate professional help. The *Alzheimer's Drug Therapy Initiative* (ADTI)[199] is research collaboration between the Government of British Columbia, the Alzheimer Society of B.C., the University of British Columbia, the University of Victoria's Centre on Aging, drug manufacturers, clinical experts, researchers and practicing clinicians which has resulted in education for family physicians about cognitive impairment. There is a role for collaborating with educational institutes to ensure that they have psychogeriatric content in their health related programs.

Collaborations with community groups can lead to creative ways of meeting seniors needs. In Northern B.C., partnerships have been developed with organizations in a number of communities to provide seniors with non-medical support services – Instrumental Activities of Daily – such as social outreach, transportation, housekeeping and other supports needed by seniors in order to enhance their quality of life and allow them to live in their homes for as long as possible[200]. For example, in Prince George, the Council of Seniors has partnered to provide these supports. Partnerships with the ASBC are fruitful. ASBC and health authorities have developed *First Link*. In this program a protocol is in place for family physicians to trigger a contact between the ASBC and a person newly diagnosed with a dementia. The dementia support groups that ASBC offers to people with dementia and their family/caregivers are a valuable resource to our clients.

[198] Available: http://mentalhealthcommission.ca

[199] Available: http://www.health.gov.bc.ca/pharmacare/adti/#redirect_notice_display_301

[200] Projects are part of a research project by BC Home and Community Care Research Network (HCCRN) in partnership with the University of Northern BC (UNBC) School of Social Work, Northern Health's Primary Health Care Integrated Health Network and Home & Community Care, United Way of Northern British Columbia, the Centre for Healthy Aging at Providence Health Care (Vancouver), and the School of Population and Public Health (UBC).

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Collaboration within the Health Sector

The Canadian Collaborative Mental Health Initiative (2006) (CCMHI) was created to improve mental health care in the primary health care setting through interdisciplinary collaboration, including collaboration among health care providers, consumers and caregivers.

Examples of positive practices in collaborative mental health for seniors among the CCMHI initiatives include: interdisciplinary mental health team partnering with a community interdisciplinary team; mental health case manager on site with family physician practice; nurse practitioner and psychogeriatric outreach team members co-visit with consumers in their homes; centres for seniors' health with integral stakeholders co-located; support worker/navigator assigned to facilitate access to resources; geriatric mental health teams supporting family physicians; direct care liaison team to transition consumers from complex care to long-term care; rural outreach team collaborating with university psychiatry program; seniors outreach services; interdisciplinary training programs; and innovative senior peer programs. For descriptions of each project, see the CCMHI *Collaborative Mental Health Care in Primary Health Care: A Review of Canadian Initiatives Volume II Resource Guide* (2005).[201]

Better practices to enhance and develop collaborative activities in primary health care by policy makers, providers and other key stakeholders have been identified by CCMHI as follows[202]:

- Successful collaborative relationships between primary and mental health care providers require preparation, time and supportive structures, ideally building on pre-existing clinical relationships.
- Co-location of collaborative services is important for both providers and consumers.
- The pairing of collaboration with treatment guidelines or treatment protocols for patients with major depression (versus minor depression) appears to offer important benefits over either of these interventions alone.
- The inclusion of systematic follow-up as part of the study protocol was one of the most powerful predictors of positive clinical outcomes in studies of collaborative care for depression.
- Efforts to increase medication adherence through collaboration were a common and important component of many successful studies, but a clear relationship between adherence and clinical outcomes could not be discerned.

[201] Available: http://www.ccmhi.ca/en/products/documents/05b_CanadianReviewII-EN.pdf

[202] Craven, M. and Bland R. Better Practices in Collaborative Mental Health Care: An Analysis of the Evidence Base. Can J Psych 2006:51(Suppl 1, May). For discussion of each of these better practices, see p. 21: http://www.ccmhi.ca/en/products/documents/Overview4_BetterPractices_EN.pdf

- In the treatment of depression, collaboration alone has not been shown to produce skill transfer or enduring changes in primary health care physician knowledge or behaviours. Service restructuring, specifically designed to support changes in the practice patterns of primary health care providers is also required.
- Enhanced patient education about mental disorders and their treatment was a component of many of the studies with good outcomes. Education was more likely to be provided by someone other than the primary care physician.
- Collaborative interventions that are established as part of a research protocol may be difficult to sustain long-term without ongoing funding.
- Consumer choice about treatment modality may be an important factor in treatment engagement in collaborative care (e.g., having the option to choose psychotherapy versus medication).

An analysis of Canadian collaborative mental health care initiatives has resulted in the identification of a number of strategies to facilitate shared care (CCMHI, 2006)[203]. The most prominent solutions to overcoming challenges are[204]:

- Developing key partnerships with community resources;
- Having flexible structures that accommodate the needs of the community;
- Having designated planning days or team meetings;
- Implementing strong orientations for new team members;
- Working closely with key stakeholders to ensure that the initiative goals are achieved;
- Developing formal communication strategies;
- Designating a coordinator who has clearly defined roles and responsibilities; and
- Reviewing the partnership agreement and recommitting to the purpose, objectives, and service delivery methodologies with all of the key stakeholders. (p. 7-8)

CCMHI (2006)[205] has developed a Toolkit, informed by an inter-professional expert panel, to support health providers and planners to coordinate and implement collaboration between mental health and primary care services for seniors.

[203] For a comprehensive discussion of the themes and trends as they relate to previous research and best practices, refer to Volume I of the report *Collaborative Mental Health Care in Primary Health Care: A Review of Canadian Initiatives*. (Pauzé, Gagné and Pautler, 2005).

[204] http://www.ccmhi.ca/en/products/documents/05b_CanadianReviewII-EN.pdf

[205] Available: http://www.ccmhi.ca/en/products/toolkits/documents/EN_CompanionToolkitforSeniors.pdf

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Age Friendly initiatives and the provincial Healthy Aging strategies related to physical activity and social isolation, while not explicitly focusing on mental illness, do promote mental health. Municipalities offer seniors recreational opportunities while colleges and universities offer learning opportunities: collaboration with them can sharpen the focus on mental health promotion and facilitate development of programs for seniors with mental illness. Fruitful partnerships between health authorities and the Alzheimer Society of BC (ASBC) have led to *First Link*[206] and to education programs for individuals with a dementia, their caregivers and for all levels of health care providers.

Partnerships between health authorities and the research community (e.g., COACH; ASBC grants to improve dementia care) can ensure that practice is informed by relevant evidence. Voluntary associations such as the Canadian Coalition for Seniors Mental Health and the British Columbia Psychogeriatric Association and similar organizations bring together diverse stakeholders to promote the mental health of seniors through, for example, practice support and advocacy.

Integrated Care

There may be both overlaps and gaps in the care of seniors with complex needs, often resulting in premature or unnecessary and costly interventions. Therefore, various attempts have been made to reorganize service delivery to address these issues. In Great Britain, the National Framework for Older People standards aim to "ensure that older people receive person-centred care, regardless of organizational and professional boundaries between health and social care" (DoH, 2001 as cited in Davey, Levin, Ilffe & Kharicha, 2005)[207].

Many jurisdictions (including B.C.) have established a single entry point system, with case management provided for continuing care in the community and for admissions to long-term care institutions. However, gaps remain between medical and social care, acute and continuing care, and community and institutional care (Johri, Beland & Bergman, 2003)[208]. In response, integrated care approaches are being introduced with the intent of improving continuity of care and health and satisfaction of patients while simultaneously decreasing hospital and nursing home costs (Hébert, Raîche, Dubois, Gueye, 2010)[209].

[206] Available: http://www.alzheimerbc.org/We-Can-Help/First-Link.aspx

[207] Davey, B., Levin, E., Ilffe, S. & Kharicha, K. (2005) Integrating health and social care: implications for joint working and community care outcomes for older people. *Journal of Interprofessional Care*, Vol. 19, No. 1: 22-34.

[208] Johri, M., Beland, F. & Bergman, H. (2003) International experiments in integrated care for the elderly: a synthesis of the evidence *International Journal of Geriatric Psychiatry*: 18: 222–235.

[209] Hébert, R., Raîche, M., Dubois, M-F., Gueye, N.R., Dubuc, N., Tousignant, M., & The PRISMA Group (2010). Impact of Prisma, a coordination-type integrated service delivery system for frail older people in Quebec (Canada): A quasi-experimental study. *Journal of Gerontology: Social Sciences*, 65B (1), 107–118.

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Integrated Care

"…is defined as 'discrete set of techniques and organizational models designed to create connectivity, alignment, and collaboration within and between the cure and care sectors at the funding, administrative and/or provider levels" (Kodner, 2006 p 385)[210].

Leutz describes three forms of integrated care (1999, as cited in Kodner, 2006):

- ***Linkage***, in which health and social care providers attempt to work together more closely, within their respective operating rules and separate funding streams;
- ***Coordination***, which involves the rebalancing of the system through purpose-built structures and mechanisms to bridge gaps between services and users, and also help to address mandates and other areas that may not be clear, improve communication and improve the quantity and quality of the lack of information-sharing;
- ***Full Integration***, which combines responsibilities, human and physical resources and funding from multiple sectors within one structure, thus creating "bundled financing, global management and unified service delivery" (Kodner, 2006, p. 385).

Examples of fully integrated models of care are SIPA[211], a community-based, primary-care-led, case-managed health system for the frail elderly in Quebec, and PACE[212] an American program that provides acute and long-term care services which are coordinated by, and largely organized around, an adult day health centre. The PRISMA[213] model is a coordinated model of integrated care in Quebec. Results from a review of these programs suggest that full integration makes a difference to services and to outcomes for seniors and their caregivers: there is a "somewhat positive pattern of results in terms of service access, utilization, costs, care provision, quality, and health status and client/corer satisfaction" Kodner, 2006, p. 388)[214]. Four key elements that appear to account for the successful impact of these service initiatives were identified as:

[210] Kodner, D. (2006). Whole-system approaches to health and social care partnerships for the frail elderly: an exploration of North American models and lessons. *Health and Social Care in the Community.*

[211] For a description of SIPA see: Bergman H., Béland F., Lebel P., Contandriopoulos A.-P., Tousignant P., Brunelle Y., Kaufman T., Leibovich E., Rodriguez R. & Clarfield M. (1997) Care for Canada's frail elderly population: fragmentation or integration. *Canadian Medical Association Journal* 157, 1116–1121.

[212] For a description of PACE see: Eng C., Pedulla J., Eleazer P., McCann R. & Fox N. (1997) Program of all-inclusive care for the elderly (PACE): an innovative model of integrated geriatric care and financing. *Journal of the American Geriatrics Society* 45, 223–232.

[213] For a description of PRISMA see: Hébert R., Durand P., Dubac N. & Tourigny A. (2003) PRISMA: a new model of integrated service delivery for frail older people in Canada. *International Journal of Integrated Care*.

[214] Ibid.

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- Umbrella organizational structures guide integration on the strategic, managerial and service delivery levels, encourage and support effective joint working, ensure efficient operations, and maintain overall accountability for service, quality and cost outcomes.
- Case-managed, multidisciplinary team care allows for the effective evaluation and planning of client needs, provides a single contact or entry point into the healthcare and social service systems, packages and coordinates services, and triages or allocates clinical responsibility.
- Organized provider networks joined together by standardized referral procedures, service agreements, joint training, shared information systems, and even common ownership of resources enhance access to services, provide seamless care and maintain quality.
- Financial incentives promote prevention, rehabilitation and the downward substitution of services, as well as enable service integration and efficiency (Kodner, 2006, p. 389).

In B.C. there is a variety of integrated care approaches being implemented that may provide direction to those planning mental health services to seniors. There are a number of innovations across the province that integrate services at different levels and in different ways to increase collaboration among services and service providers, and with the community sector, while at the same time reducing overlaps and increasing efficiency. Shared care models across the country provide examples of collaboration between family physicians and seniors mental health services that facilitate early identification and effective treatment of seniors with mental health challenges.

The Seniors Advisory Committee of the Mental Health Commission Guidelines for Comprehensive Mental Health Services for Older Adults state that there is a need for modification of usual practices and relationships to achieve an accessible, integrated and seamless comprehensive mental health system relevant to local conditions and able to provide core functions in services. Further, they state that:

> "Service components do not make a system of care in an integrated mental health service system. Formalized collaborative relationships are required between all components (across and within sectors) with clear mechanisms for accessing each other's programs/services/skills. Service providers working front-line services for seniors, including family physicians, look after the majority of seniors with mental health problems and illnesses living in the community. These service providers must have skills in early identification of mental illness in late life, including dementia. While the majority of seniors begin their journey towards recovery and well-being with their family physician or other front-line service providers, it is important to acknowledge that the front-line service system cannot manage all mental health

problems alone; collaboration amongst care providers in the mental health system is needed; Outreach programs may not have the resources to carry out all the roles and services described, however models of service delivery can be developed with more direct or more indirect care, as is appropriate, for an individual community. While other programs provide overlapping services, activities will need to be coordinated and formal linkages between the services established. Local community capacity should determine the most appropriate model – collaboration with local community resources should ensure that all core functions and services are locally available".[215]

Service personnel from all systems should collaborate to provide client-centred care for an individual case. This may range from client conferences all the way to integrated teams.

Some health authorities may choose to have shared staffing between various health sectors. For example, physicians may work with mental health teams and with other programs or facilities in a community. Other health authorities may choose to establish effective communication links between separate staff. No matter what system is adopted, the key is working together to solve client/family problems, improve access to care and allow for creativity as a means of directing client care operations.

New systems of care (e.g., SIPA[216] in Quebec), using integration of care as a central tenet, have been developed to care for "frail" seniors in North America.

The Canadian College of Family Practice and Canadian Psychiatric Association have jointly developed a model of shared care between family physicians and psychiatrists to improve continuity of client care, stretch scarce psychiatric resources and improve family physicians' skills in assessment and treatment of clients with psychiatric problems. The concept of "shared care" across disciplines and between formal care providers and families is being pursued in communities and regions across the country.

[215] MacCourt, P., Wilson, K. and Tourgny-Rivard, M (2011). *Guidelines for Comprehensive Mental Health Services for Older Adults*, prepared for the Seniors' Advisors Mental Health Commission of Canada.

[216] For a description of SIPA see: Bergman H., Béland F., Lebel P., Contandriopoulos A.-P., Tousignant P., Brunelle Y., Kaufman T., Leibovich E., Rodriguez R. & Clarfield M. (1997) Care for Canada's frail elderly population: fragmentation or integration. *Canadian Medical Association Journal* 157, 1116–1121.

Chapter IX

IX. Quality Improvement and Evaluation of Seniors Mental Health Services

The Significance of Focus on Improvement

It is recommended that all services for mental health care for seniors should have defined quality improvement (QI) processes to improve their performance on an ongoing basis. To facilitate comparison between current and optimal levels of quality, a standard framework for describing services should be adopted to help compare types and amounts of services. It is also recommended that regular reports be compiled of services available for seniors with mental health problems using a standard template.

Quality Improvement (QI):

An organizational philosophy that seeks to meet clients needs and exceed exceptions with a minimum of effort, rework and waste, by using a structured process that selectively identifies and improves all aspects of care and service on an ongoing basis

(Berwick & Godfrey, 1990)[217]

A standard problem list is useful in the planning, monitoring and evaluation of services. Consistent use of a standard form would help to identify the problem and frequency that the service or program encounters. Changing trends or patterns in referral can then be accommodated with service or program changes, thus ensuring that services are effectively organized and deployed.

The attainment of personal goals as an outcome measure (for clients and families) should also be encouraged. These goals will vary and be unique from one person to another, but they will help provide both subjective and objective measure of service quality. A tool that can be used

[217] Berwick DM, Godfrey AB et al. *Curing health care: New strategies for quality improvement.* San Francisco: Jossey-Bass, 1990.

to provide insight and information about personal goals and the degree to which services help in their achievement is the Goal Attainment Scale (GAS)[218].

All professional services for mental health care for seniors should work towards being accredited. The use of standardized accreditation models and processes allows comparisons across regions, provinces or countries.

Quality Improvement focuses on:

- Systems rather than individuals;
- Improving mean functioning rather than punishing outliers;
- Interdisciplinary team problem-solving; and
- Data, rather than opinion or tradition to drive decision-making.

The following is a summary of the key elements of quality improvement methodology[219] that can guide quality improvement efforts in seniors' mental health.

Quality improvement methodology consists of four key steps:

Step One: *Identify*

The goal of the first step, ***identify***, is to determine what to improve. This may involve a problem that needs a solution, an opportunity for improvement that requires definition, or a process or system that needs to be improved upon. Examples of problems or processes that are commonly identified include unavailability of drugs, lost laboratory reports, and wait times. This first step involves recognizing an opportunity for improvement and then setting a goal to improve it. Quality improvement starts by asking these questions:

- What is the problem?
- How do you know that it is a problem?
- How frequently does it occur, or how long has it existed?
- What are the effects of this problem?
- How will we know when it is resolved?

[218] Heavlin, W., Lee-Morrow, & Lewis, V. (1998). The psychometric foundations of goal attainment scaling. *Community Mental Health Journal* 18:3:230-41.

[219] Retrieved April 2010 from http://www.reproline.jhu.edu/english/6read/6pi/pi_advances/piadvances3.htm

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Step Two: *Analyze*

Once we have identified areas for quality improvement, the second step is to ***analyze*** what we need to know or understand about this opportunity for improvement before considering changes. The objectives of the analysis stage can be any combination of the following:

- Clarifying why the process or system produces the effect that we aim to change
- Measuring the performance of the process or system that produces the effect
- Formulating research questions, such as the following:
  - Who is involved or affected?
  - Where does the problem occur?
  - When does the problem occur?
  - What happens when the problem occurs?
  - Why does the problem occur?
- Learning about internal and external clients through the tools available

To reach these objectives, this step requires the use of existing data or data collection. The extent to which data are used, depends on the quality improvement approach chosen. A few techniques to analyze problems include:

- Clarifying processes through flowcharts or cause-and-effect analyses
- Reviewing existing data
- Collecting additional data

Step Three: *Develop*

The third step, ***develop***, uses the information accumulated from the previous steps to explore what changes would yield improvement. Hypotheses, tentative assumptions used to test consequences, are formulated to identify which changes, interventions, or solutions would reduce the problem and thus improve the quality of care. Hypotheses are based on people's knowledge and belief about the likely causes and solutions of the problem. It is crucial to remember that at this point, the hypothesis remains a theory, as it has not yet been tested.

Step Four: *Test and Implement*

This step, ***test/implement***, builds on the first three. A hypothesis is tested to see if the proposed intervention or solution yields the expected improvement. Because interventions that prove to be effective may not yield immediate results, allowing time for change to occur is important in the testing process. The results of this test determine the next step.

Different Approaches to Quality Improvement

Many approaches to quality improvement exist; deciding on which one to use depends on the circumstances. Some problems are simple and can be resolved rapidly, while others involve core processes and require extensive research. The approaches can be visualized along a continuum of complexity of increased time, resource allocation, and group participation. Along this continuum, there are four points that represent four approaches to quality improvement. They are not the only points along the continuum of complexity, but they do illustrate how quality improvement approaches differ.

1. ***Individual problem solving*** occurs when an individual identifies an apparent problem, recognizes his or her ability to fix it, and feels empowered to make necessary changes. Although teamwork is an essential part of quality improvement, the QA Project has learned from experience that the simpler or more urgent improvement needs do not necessitate lengthy team-based approaches. The hallmark of individual problem-solving is its use to address problems that are not interdependent, meaning that one person can make and implement the decisions necessary to address a problem. Individual problem-solving tends to require little time or data and is methodologically the least complex of the approaches. It is evident in organizations where each individual recognizes the overall goal of delivering quality care and acts accordingly when needs arise that he or she can personally address.

2. ***Rapid team problem solving*** is an approach in which a series of small incremental changes are tested in a system for improvements in quality. This approach can be used in any setting, although it generally requires that a team has some experience in problem solving and/or seeks a mentor for help in quickly managing this approach. This approach is less rigorous in terms of time and resources required because it relies largely on existing data and the team's understanding of the cause(s) of the problem and likely solutions. Teams are ad hoc and disband once the desired level of improvement has been achieved.

3. ***Systematic team problem solving*** is often used for complex or recurring problems that require detailed analysis. The mainstay of this approach is a detailed study of the causes of problems and then the development of appropriate solutions. This detailed analysis often

involves data collection, and therefore often requires more time and resources. Although systematic team problem solving can be used in any setting, its in-depth nature makes it most appropriate when the ad hoc team is able to work together over a period of time.

4. Process improvement is the most complex of the four approaches because it involves a permanent team that continually collects, monitors, and analyzes data in order to improve a key process over time. It is generally used in organizations where permanent resources are allocated to quality improvement. This permanent team can use more than one approach, for example, forming ad hoc teams to solve specific problems. Process improvement is often used to assure the quality of important services in a health facility or organization.

In sum, experience with quality improvement has rendered it a simpler, more robust methodology, and the application of QI methodology to a wide range of settings has become more clear. The settings include both clinical and nonclinical environments, with the approaches ranging from individual problem solving to core-process improvement by permanent teams. In all of these approaches, the methodology and principles remain unchanged, though their different aspects are stressed differently.

Uptake of Improvements and Innovations

"Buy in" and commitment from all who are affected by planned changes is required, once the need for improvement is identified. Dissemination plans can be developed with the input of all stakeholders to publicize and promote the necessary changes, but diffusion through social influence, a more subtle approach, is also important to effectively implement quality improvements.

Based on an exhaustive systematic review of the literature on the spread and sustainability of innovations in health service delivery and organization carried out for Britain's National Health Service, the interrelated key areas that influence the spread and success of initiatives for improving health services were identified:

- The attributes of the innovation
- The adoption process as engaged in (or not) by individuals
- Communication and influence (including the impact of opinion leaders)
- Champions, (boundary spanners and designated change agents)
- The inner (organizational) context (including structural determinants of innovativeness, receptive context for change in general, absorptive capacity for new knowledge, and tension for a particular change)

- The outer (extra-organizational) context (including inter-organizational collaboration and networking, prevailing environmental pressures such as external competition, particular policymaking contexts and streams, and proactive linkage initiatives)
- The nature of any active dissemination campaign (which incorporates the general principles of social marketing and knowledge construction)
- The nature of any active implementation process (which incorporates the general principles of effective management in a changing environment. (Greeenhalgh, Robert, Bate, Kyriakidou & Peacock, 2004, p. 321)[220]

Considerations in Evaluating Services

This section begins with some factors to consider in conducting program evaluation, followed by an overview of the effectiveness of senior mental health services.

Canada's population is aging and a disproportionate number of people over the age of 65 suffer from mental illness, particularly from dementia and depression. This vulnerable population often faces concurrent social, physical, intellectual, functional and environmental challenges, in addition to mental health needs. It is essential to ensure that the limited mental health resources available to seniors are adequately meeting their needs and those of their families and of the community. In the first part of this section, evidence about the effectiveness of services is provided. In the second part, factors to consider when evaluating services are presented.

It is self-evident that senior mental health services in British Columbia must be evaluated to ensure they are effective. However, this can be challenging given the diversity of mental health services, ranging from specialized psychiatric inpatient units to community outreach programs, and the lack of systematic evaluations of these services. Further, there may be limited resources (e.g., time, expertise, planning) to devote to evaluation. Issues of privacy and confidentiality related to collecting, sharing and analyzing data from multiple sources are challenging to address. Following, are general considerations to take into account when evaluating services.

[220] Greeenhalgh, T., Robert, G., Bate, R., Kyriakidou, O. & Peacock, R. (2004) How to Spread Good Ideas: A systematic review of the literature on diffusion, dissemination and sustainability of innovations in health service delivery and organizations. London, NCCSDO.

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To evaluate any program it is important to have a clear idea of the program's role: without identifying specific, measurable goals, outcome evaluation becomes difficult and the validity of the results may come into question. When evaluating program or patient outcomes, one must also identify from whose perspective those outcomes are being measured; the care provider, the patient, the patient's family and the community all have an interest in, and a perspective on the outcomes of a given health care service (Happell, 2008)[221].

The decision to use self-reporting, professional reporting, performance-based measures, objective data (such as hospital admission rates or length of stay) or a combination of these, will depend on the way in which the outcome data is to be used, as well as on the clinical setting and on the feasibility of administering the test or collecting the data. Having patients identify and/or prioritize variables to be measured and making use of multidisciplinary collaboration in selecting or designing an outcome assessment tool can help maintain a relevant focus to the evaluation; the variables clinicians use to make judgments may differ from those variables which influence patients' self-perception.

One of the problems cited, both in evaluating individual services and in attempting to compare different programs, is the lack of consistent and clearly defined outcome criteria, without which meaningful outcome evaluation is impossible (MacDonald, 2005)[222]. Commonly selected variables include hospital and long term care facility admission rates; caregiver and referring agent satisfaction; caregiver stress or burden; patient physical, cognitive and functional impairment; quality of life and cost. One of the easiest variables to measure and to document quantitatively is hospital and long-term care admission rates, but these are as much related to the ability and the availability of a caregiver in the community as they are to the involvement of a geriatric psychiatry service.

Most senior mental health programs serve primarily elderly people living in the community, which means relying on informal caregivers, often spouses or children to evaluate the effectiveness of these programs. It is necessary to recognize the tremendous impact of psychiatric illness or dementia on the patient's family or caregiver, and to measure caregiver outcomes in addition to patient, program and system outcomes.

[221] Happell, B. (2008). "Determining the effectiveness of mental health services from a consumer perspective: Part 2: Barriers to recovery and principles for evaluation." *International Journal of Mental Health Nursing* 17(2):123-130.

[222] MacDonald, A. (2005). Evaluation of service delivery. In Draper, B., Melding, P. & Brodaty, H. [Eds.] *Psychogeriatric Service Delivery: An International Perspective*. Oxford University Press.

Chapter IX

In a review of evidence-based health care in old-age psychiatry, it has been noted that there is a tendency for drug studies to focus on younger adults and, even if seniors are included, studies involve uncomplicated patients, seldom seen in real clinical settings. It is also noted that nondrug therapy is seldom analyzed (Banerjie & Dickinson (1997)[223]. The importance of looking at effectiveness, not just efficacy in therapies, and support the Cochrane Collaboration efforts in this regard is stressed.

Clearly more research in all aspects of mental health care for seniors is required. It has been argued that the evaluation of old-age mental health services is best achieved by the construction of relatively simple models from an array of complex knowledge (Harrison & Sheldon, 1994)[224]. Perhaps a simple place to start in British Columbia, is to be able to define our own present practices in common language so we can begin to cross-compare amongst ourselves and with the "written evidence".

Service Effectiveness – What we know

A synthesis report on the effectiveness of senior mental health services, prepared for the World Health Organization Health Evidence Network (HEN)[225], provides some direction for planners. Draper and Low (2004)[226] have synthesized evidence covering all aspects of care for seniors with mental disorders, covering effective treatments, models of care and different service delivery settings. The overall quality of the evidence was rated using a hierarchy that has four levels of evidence (Level I-IV)[227]. In reviewing the findings, it is important to note that weak evidence is not proof of ineffectiveness but more likely due to a lack of controlled studies. The key findings from this systematic review follow, and readers are directed to Draper and Low (2004)[228] for detailed program descriptions and findings for each of the studies that support their results.

[223] Banerjie, S. & Dickinson, E. (1997) Evidence based health care in old age psychiatry. *Int'l J Psychiatry in Medicine*, 257:3, I.283-292.

[224] Harrison, S. & Sheldon, TA. (1994). Psychiatric services for elderly people: Evaluating system performance. *International Journal of Geriatric Psychiatry*, 9:259-272.

[226] HEN, initiated and coordinated by the WHO Regional Office for Europe, is an information service for public health and health care decision-makers.

[226] Draper B, Low L (2004) What is the effectiveness of old-age mental health services? Copenhagen, WHO Regional Office for Europe (Health Evidence Network report.
Available: http://www.euro.who.int/document/E83685.pdf

[227] Ibid.

[228] Draper B, Low L (2004) What is the effectiveness of old-age mental health services? Copenhagen, WHO Regional Office for Europe (Health Evidence Network report.
Available: http://www.euro.who.int/document/E83685.pdf

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The World Psychiatric Association (WPA) and World Health Organization (WHO) consensus statement on the organization of care in old-age psychiatry supports a model of senior mental health services that features multidiscipline, comprehensive and integrated service delivery to a defined catchment area (Wertheimer, 1997)[229].

Although senior mental health service models have not been evaluated, Draper and Low (2004)[230] suggest that factors identified in effective models of general elderly care, can provide some guidance. These factors, (a single entry point system, case management, geriatric assessment, a multidisciplinary team and financial incentives to encourage less expensive community-based care), with the exception of the latter point, are also identified in the WPA and WHO consensus statements. The following evidence-based findings (see explanation of the levels in the table below) are examples of what we have learned about effective approaches.

Effectiveness of Community Based Service Delivery

- The effectiveness of day treatment for seniors with mental illnesses has not yet been adequately studied. The existing evidence, (Level IV), suggests that day hospitals may improve mental health outcomes, particularly for depression (Draper & Low, 2004, p. 9)[231].
- There is good evidence (Level I) that multidisciplinary elderly mental health outreach teams are more effective than usual care in the management of depression, dementia and other mental disorders in seniors. Key factors in effective community treatment include multidisciplinary teams, an individualized case management approach with ongoing care rather than just assessment, home-based assessments to improve attendance and caregiver education (Level III-2). There is evidence (Level IV) that community senior mental health services are more effective in managing depression in seniors than are adult mental health services (Draper & Low, 2004, p. 11)[232].

[229] Wertheimer J. Psychiatry of the elderly: a consensus statement. *International journal of geriatric psychiatry*, 1997, 12:432-435.

[230] Draper B, Low L (2004) *What is the effectiveness of old-age mental health services?* Copenhagen, WHO Regional Office for Europe (Health Evidence Network report. Available: http://www.euro.who.int/document/E83685.pdf

[231] Ibid, p. 9.

[232] Ibid, p. 9.

- There is good evidence (Level II) that integrated community senior mental health care following discharge from hospital plays an important part in preventing readmission of seniors with mental illness, and in maintaining them in the community (Draper & Low, 2004, p. 11)[233].
- There is good evidence (Level II) that collaboration between specialist and primary care is effective in identifying and managing late-life depression (Draper & Low, 2004, p. 12)[234].
- There is limited evidence (Level IV) that most seniors treated on general psychiatric wards achieve global improvements and have positive discharge outcomes (Draper & Low, 2004, p. 12)[235].
- Most seniors treated in acute geriatric psychiatry units for depression (Level III-2 evidence) and for BPSD (Level IV evidence) have good outcomes post-discharge, mediated over the long term by the adequacy of post-discharge follow-up (Draper & Low, 2004, p. 12)[236].
- There is some evidence (Level II) that delirium prevention programs by medical services have modest effects for seniors, mainly for intermediate risk patients without co-morbid dementia. There is little evidence that medical services are effective in treating other mental disorders (Draper & Low, 2004, p. 13)[237].
- There have not been enough evaluation studies to determine the effectiveness of combined old age mental health and geriatric medical wards in improving seniors' the mental health (Draper & Low, 2004, p. 13)[238].
- There is Level II evidence for the effectiveness of interventions by CL services on non-mental health outcomes such as length of stay and costs, but only Level IV evidence for mental health outcomes (Draper & Low, 2004, p. 14)[239].

[233] Ibid, p. 11
[234] Ibid, p. 12
[235] Ibid, p. 12.
[236] Ibid, p. 12.
[237] Ibid, p. 12.
[238] Ibid, p. 12.
[239] Ibid, p. 14.

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Effectiveness of Long Term Institutional Care

- Evidence indicates that purpose-built community based residential facilities have advantages over long-term psychogeriatric wards for less dependent patients with dementia and chronic schizophrenia, but it is unclear whether they are suited for patients with very severe aggressive behavioural disturbances (Draper & Low, 2004, p. 14)[240].
- There is good evidence (Level I) that elderly mental health outreach services provide effective services to long-term residential care. Key factors are a liaison-style with a strong educational component, including treatment guidelines and possibly emotional support and/or supervision of the nursing staff. The evidence for the effectiveness of acute treatment using a consultative model is weaker, at Level II (Draper & Low, 2004, p. 15)[241].

Designation of Levels of Evidence

I	Obtained from a systematic review of all relevant randomized controlled trials
II	Obtained from at least one properly designed randomized controlled trial
III-1	Obtained from well-designed pseudo-randomized controlled trials (alternate allocation or some other method)
III-2	Obtained from comparative studies (including systematic reviews of such studies) with concurrent controls and allocation not randomized, cohort studies, case-control studies, or interrupted time series with a control group
III-3	Obtained from comparative studies with historical control, two or more single arm studies, or interrupted time series without a parallel control group
IV	Obtained from case series, either post-test or pre-test/post-test

Source: Draper B, Low L (2004) *What is the effectiveness of old-age mental health services?* Copenhagen, WHO Regional Office for Europe (Health Evidence Network report; http://www.euro.who.int/document/E83685.pdf, accessed 23 July 2004), p. 27.

[240] Ibid, p. 14.

[241] Ibid, p.15.

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2. Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities, British Columbia Mental Health Services, February 2002.

3. Developing a national consensus on the accessibility needs of older adults with concurrent and chronic, mental and physical health issues: A preliminary framework informing collaborative mental health care planning. Canadian Journal on Aging, 28/(2), 97-105, Linda Horgan, Ken LeClair, Martha Donnelly, Geri Hinton, Penny MacCourt and Sarah Kreiger-Frost.

4. Ontario Ministry of Health and Long Term Care, Mental Health and Rehabilitation Reform Branch defined a specialized geriatric mental health outreach team's program policy and accountability framework.

5. www.mentalhealthcommission.ca

6. Guidelines for Comprehensive Mental Health Services for Older Adults, prepared for the Senior's Advisors Mental Heath Commission of Canada 2011 by Dr. Penny MacCourt and Kimberly Wilson from the CCSMH.

7. www.dementiajourney.ca

8. Adams, T. 2010, The Applicability of Recovery to Nursing People with Dementia.

9. Recovery is for All – Hope Agency and Opportunity in Psychiatry, a position statement by consultant psychiatrists, South London and Maudsley NHS Foundation Trust, December 2010.

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Buffett, C, Ciliska, D. & Thomas H. (2007) Assessing Applicability and Transferability of Evidence. Prepared for the National Collaborating Centre for Methods and Tools (NCCMT), McMaster University.

This document presents a tool to assist public health managers and planners in decision-making about program priorities for their community. It provides a process for determining whether an intervention identified elsewhere could work with similar expected outcomes in other jurisdictions.

Contact: ciliska@mcmaster.ca School of Nursing, McMaster University
Suite 302, 1685 Main Street West Hamilton, ON L8S 1G5.
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Fax: (905) 529-4184

World Health Organization (2004). *Promoting mental health: concepts, emerging evidence, practice: summary report.*
Available: http://www.who.int/mental_health/evidence/en/

This document is comprised of an extensive review and evaluation of interventions aimed at promoting seniors' mental health.

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  Available: www.ccsmh.ca.
- Alzheimer's Society of Canada, 2011, *Guidelines for Care: Person-centred care of people with dementia living in care homes,*

The guideline is a summary of the 'most promising guidelines' for person-centred care intended to strengthen the capacity of care home staff to ensure a person-centred philosophy in care and to increase the potential for knowledge integration. Research evidence has been supplemented by expert advice from leading clinicians, people with dementia, family members and professionals.

http://www.alzheimer.ca/english/care/framework.pdf

Client Centred Care

Registered Nurses Association of Ontario (RNAO), 2006, *Client Centred Care*
www.rnao.org/Page.asp?PageID=1212&SiteNodeID=155&BL_ExpandID=

Recommendations for recognition, diagnosis and longitudinal management of cognitive impairment and dementia in seniors

Cognitive Impairment in the Elderly – Recognition, Diagnosis and Management (2007)
B.C. Ministry of Health Guidelines and Protocols Advisory Committee (GPAC).

This guideline summarizes current recommendations for recognition, diagnosis and longitudinal management of cognitive impairment and dementia in seniors. It includes a guide for people with dementia and their family and an interdisciplinary supplement.

Available from: http://www.bcguidelines.ca/pdf/cognitive.pdf

Best Practices

Mental Health Promotion

The Victorian Order of Nurses has developed a document, *Reach Up, Reach Out: Best Practices in Mental Health Promotion for Culturally Diverse Seniors*, that discusses best practices in mental health promotion for culturally diverse seniors, derived from an environmental scan, a literature review and focus groups. It includes a compilation of projects from around the world which share a focus on providing the tools needed to sustain and improve seniors' mental health.

Available: http://www.von.ca/en/special_projects/reachup_reachout.aspx

VON Canada, 2004, *Learning to Listen – Listening to Learn: A New Way of Caring for Caregivers: Caregiver Support Best Practice Manual for Community Health Care Providers*, www.von.ca/en/caregiving/default.aspx.

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The Centre for Addiction and Mental Health (CAMH) has developed a guide to responding to addiction issues among seniors, CAMH Healthy Aging Project. (2006). *Responding to Older Adults with Substance Use, Mental Health and Gambling Challenges: A Guide for Workers and Volunteers*. Toronto: Centre for Addiction and Mental Health.

Available: http://www.camh.net/Publications/Resources_for_Professionals/Older_Adults/responding_older_adults.pdf

Health Canada (2002). Best Practices for the Treatment and Rehabilitation for Seniors With Substance Use Problems Developed with funding from Health Canada this document synthesizes the best available research and expert evidence about the treatment and rehabilitations of seniors with substance use problems, and includes issues related to the accessibility and provision of services.

Available: http://www.hc-sc.gc.ca/hc-ps/pubs/adp-apd/treat_senior-trait_ainee/index-eng.php

Bridging aging and women abuse

This toolkit, available on-line, provides practical tools and resources for service providers working with older women experiencing abuse.

www.nicenet.ca/files/LowResolution_Eng_ToolKit2%5B1%5D.pdf

Policy Tools

A principle based policy tool to assess policies related to respite care.

VON Canada, 2004, *Respite as Outcome: Guiding Principles for Good Practice*, www.von.ca/en/caregiving/default.aspx

Policy guide to support seniors' mental health through home care

The Canadian Mental Health Association (2002), based on a national study (that included British Columbia) to examine the place of home support in promoting and supporting seniors' mental health, developed *Supporting Seniors' Mental Health through Home Care: A Policy Guide*, which identifies the key system features that need to be in place to optimize home support role in supporting seniors' mental health.

Available: http://www.camrose.cmha.ca/data/1/rec_docs/158_smhhc_polguide.pdf

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Seniors' mental health policy lens

The Seniors' Mental Health Policy Lens (SMHPL) is an analytical tool developed as a best practice in policy design through a grant from the Public Health Agency of Canada and sponsored by the BC Psychogeriatric Association. The SMHPL has been designed to promote and support the mental health and well-being of all seniors.

MacCourt P. & Tuokko H. (2005) Development of a Seniors' Mental Health Policy Lens: An Analytical Tool to Assess Policies and Programs from a Seniors' Mental Health Perspective. *Canadian Journal of Community Mental Health*, Vol. 24(2), 35-53.

Available: www.seniorspolicylens.ca

Best practice models in continuing care for seniors

Prepared on behalf of the Federal/Provincial/Territorial Committee (Seniors) for the Ministers Responsible for Seniors (1999), this document describes community-based and facility-based initiatives continuing care for seniors in all provinces and territories, and identifies features of best practice models of continuing care.

Available from: http://www.phac-aspc.gc.ca/seniors-aines/publications/pro/caregiving-soins/innovations

Best practices for organizing service delivery systems for persons with ongoing care needs and their families

This model extends or combines best practices for service delivery systems that currently exist or have existed in Canada. The Continuing Care Model outlines the 10 best practices for organization care delivery systems for persons with ongoing care needs.

Hollander, Marcus and Michael J. Prince, 2007, "Organizing Healthcare Delivery Systems for Persons with Ongoing Care Needs and Their Families: A Best Practice Framework," *Healthcare Quarterly,* 11(1) 2008: 44-54, www.longwoods.com/content/19497

Implementing best practices for specialty geriatric mental health outreach services

Elements of knowledge exchange that are needed to implement best practices for speciality seniors mental health outreach in order to achieve shared care, education, and program and systems development, are identified within existing and developing models of program delivery.

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Best practice guidelines for mental health promotion programs

The Centre for Addiction and Mental Health (2010) has developed *Best practice guidelines for mental health promotion programs: Older adults 55+*. The document discusses risk and protective factors for mental health and provides examples of mental health promotion interventions.

Available: http://knowledgex.camh.net/policy_health/mhpromotion/mhp_older_adults/Pages/default.aspx

The role of home support in supporting seniors' mental health

The Canadian Mental Health Association (2002), based on a national study (that included British Columbia) to examine the place of home support in promoting and supporting seniors' mental health, has developed *Supporting Seniors' Mental Health: A Guide for Home Care Staff*, that provides tools and checklists to facilitate home support staffs' capacity to support seniors' mental health.

Available: http://www.camrose.cmha.ca/data/1/rec_docs/158_smhhc_polguide.pdf

Canadian best practice portal

The Public Health Agency of Canada provides a portal to effective community interventions related to (among other topics) seniors' mental health promotion. The site includes:

- A catalogue of best practice systematic review sites;
- A searchable database of interventions; and
- Resources to inform public health planning, chronic disease prevention and health promotion activities.

Available: http://www.phac-aspc.gc.ca/ncfv-cnivf/cbpp-pcpe/

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The Age-friendly principles, developed by the World Health Organization, are designed to serve as a guide for community-based primary care centres to modify management and clinical services, staff training and environments to better meet the needs of seniors.

Available: http://www.seniorspolicylens.ca/Root/Materials/Towards%20age%20friendly%20primary%20care.pdf

Strategic framework for addressing mental heath and addictions among seniors

Canadian Mental Health Association, Ontario. (2010). *Mental Health and Addictions Issues for Older Adults: Opening the Doors to a Strategic Framework*.

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Partnering with patients and families to design a patient and family centered health care system

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Includes a literature review of *Best Practices for Family-Centered Care*, a discussion paper *Caring Together: families as partners in the mental health and addiction system*.

Centre for Addiction and Mental Health, 2004, *Best Practices for Family-Centered Care*, www.camh.net/Care_Treatment/Community_and_social_supports/Social_Support/FCCI

Collaboration between mental health and primary care services

The Canadian Collaborative Mental Health Initiative (CCMHI) (2006) provides an on-line resource for those establishing collaborative initiatives between mental health and primary care services. There are a variety of toolkits, including a planning and implementation toolkit for health care providers and planners, and a toolkit for best practices in collaborative seniors' mental health. Descriptions of programs are provided.

Bibliography and Resources

Available: http://www.ccmhi.ca/en/products/toolkits/documents/EN_CompanionToolkitforSeniors.pdf

The CCMHI has also produced a comprehensive annotated bibliography of research publications (2000-2004) related to the integration of mental health and primary health care. Over 800 relevant articles found in journals and grey literature were reviewed. The annotated bibliography provides a discussion and summary of key themes.

Available: http://www.ccmhi.ca/en/view_practices.html

B.C.'s primary health care charter

The Primary Health Care Charter (the Charter) sets the direction, targets and outcomes to support the creation of a strong, sustainable, accessible and effective primary health care system in B.C.

Available: http://www.health.gov.bc.ca/library/publications/year/2007/phc_charter.pdf

Age-friendly community guides

The World Health Organization and the Federal/Provincial/Territorial Ministers Responsible for Seniors have developed age-friendly community guides to facilitate communities that support healthy and active aging.

World Health Organization. (2007). Global Age-friendly Cities: A Guide. Geneva: World Health Organization Press

Available: http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf

Federal/Provincial/Territorial Ministers Responsible for Seniors (2006) Age-friendly Rural and Remote Communities: A Guide

Available: http://www.phac-aspc.gc.ca/seniors-aines/alt-formats/pdf/publications/public/healthy-sante/age_friendly_rural/AFRRC_en.pdf

B.C. Dementia service framework

Dementia Service Framework Working Group. (2007). *Dementia service framework*.

Available: http://www.alzheimerbc.org/getdoc/1f230200-0ee6-4aef-a056-1e3b9e6d4cb7/DementiaServiceFramework_PDF.aspx

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Mental Health Commission of Canada

Mental Health Commission of Canada. (2009). *Toward Recovery and Well-being: A framework for a mental health strategy for Canada*. Calgary: MHCC.

Available: http://www.mentalhealthcommission.ca

Canadian Institute for Health Information (CIHI)

The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization in Canada that collects and maintains datasets from across Canada using data from governments, regional health authorities, hospitals and physicians. They produce a wide variety of reports relevant to health care system planning.

Available: http://secure.cihi.ca/ews/en/index.jsp

National Initiative for the Care of the Elderly (NICE)

The aim of NICE is to improve the care of seniors by ensuring good research is implemented in practice. NICE operates through a network of Theme Teams that review evidenced-based literature to develop user-friendly, interdisciplinary, team-based tools. They then work to disseminate these tools into practice, thus moving research into practice. Themes include seniors' mental health.

Available: http://www.nicenet.ca/

Special Senate Committee on Aging

Carstairs S. & Keon WJK. (2009). *Special Senate Committee on Aging Final Report. Canada's Aging Population: Seizing the Opportunity*. The Senate: Ottawa.

Available: http://www.parl.gc.ca/Content/SEN/Committee/402/agei/rep/AgingFinalReport-e.pdf

Alzheimer Society of Canada (2010) *Rising Tide: The Impact of Dementia on Canadian Society* is a report released by the Alzheimer Society that provides statistics about the projected economic and social costs of dementia in Canada.

Available: http://www.alzheimer.ca/english/rising_tide/rising_tide.htm

Appendix A

Appendix A: Background Information on the Role of Seniors' Community Mental Health in Dementia Care

Introduction

A review of the Mental Health Guidelines for Seniors in B.C. 2002[242] revealed that there was no specific role defined for mental health professionals in dealing with dementia. Clearly, since dementia is both a psychiatric illness and a neurological illness, a role should be defined. Further, a multitude of carers are required to provide appropriate care over the course of the illness. To prepare for defining this role and to get a wide perspective on the issue, some literature on psychogeriatric outreach teams and psychogeriatric mental health services in general was reviewed; in addition, input was sought from two caregiver groups organized by the Alzheimer's Society and three focus groups of health care professionals from all Health Authorities provided insights.

The information was analyzed; the role of community mental health in dementia care was defined, and then reviewed by members and the Board of the B.C. Psychogeriatric Association and an Advisory Committee with wide stakeholder support. Their suggestions are incorporated in the definition.

Prevalence of Dementia

In 2011 approximately 61,000 British Columbians suffered from dementia, about 57,000 were over 65. By the year 2021, 81,000 people in B.C. will suffer from a dementia, a 33 per cent increase from 2011 in ten years.[243]

The Role of Seniors Community Mental Health in Dementia Care

The goal of seniors mental health care is summarized in the 1988 federal document *Guidelines for Comprehensive Services to Elderly Persons with Psychiatric Disorders*: "The aims of geriatric management and treatment include the reduction of stress to the patient and family, the improvement and maintenance of function and the mobilization of the individual's capacity for autonomous living. These should be the goals for all patients whether living at

[242] *Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities*, British Columbia Mental Health Services, February 2002

[243] *Centre for Applied Research in Mental Health and Addictions (CARMHA)*, Simon Fraser University, B.C., 2006.

home or in institutions: A degree of autonomy should be possible in all settings. Independence should be maximized and maintained at the highest levels that can be reached."[244]

This goal is just as relevant in 2011 as it was in 1988. Also, the principles of elderly mental health care as defined by the B.C. Psychogeriatric Association and explained in the *Guidelines for Elderly Mental Health Care Planning for Health Authorities* in 2002 for B.C. are equally relevant.

Principle 1 – Client and family centred

Principle 2 – Goal oriented

Principle 3 – Accessible and flexible

Principle 4 – Comprehensive

Principle 5 – Specific services (recognizing elderly needs).

Principle 6 – Accountable

Further principles worth consideration include:

- collaborative or integrated care
- evidence informed care
- culturally competent care.

All of these principles are appropriate for care for patients with dementia throughout the system, and they are particularly appropriate with respect to the role of seniors' community mental health in dementia care.

The 2002 *BC Guidelines*[245] document stated that the role of community mental health outreach includes:

- Assessment (including collection of collateral information);
- Recommendations for care;

[244] *Guidelines for Comprehensive Services to Elderly Persons with Psychiatric Disorders* (1988): National Department of Health and Welfare, Ottawa, page 14.

[245] *Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities*, British Columbia Mental Health Services, February 2002.

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- Direct care (treatment, case management, follow up);
- Indirect care (consultation to other care providers, i.e., Shared Care);
- Competency assessments, or at risk assessment as required;
- Consultation regarding program development or environmental approaches to care;
- Education and training for formal and informal caregivers;
- Research and evaluations.

"Models of service delivery can be developed with more direct or more indirect care as is appropriate for an individual community, and local community capacity should determine the most appropriate model."

What is new since then is a greater emphasis on integrative or more collaborative models of care in which primary care is seen as being central while specialized care is designed to support primary care and therefore individual patient and caregiver needs.

A consensus framework on accessibility to care for seniors with concurrent and chronic health needs in collaborative mental health care was defined by Horgan and others in 2009.[246] Three areas defined in this framework were:

Caregiver Factors:
These focused on the need to support caregiver health, complex coordination of services for the senior that affect the caregiver and inclusion of the person with dementia and the caregiver in planning for community services.

Personal Factors:
These focused on the mobility of the senior and their caregiver, the need for awareness of resources and the need for good communication within the system.

System Factors:
These again emphasized the need to include seniors and diverse cultural groups in defining services, to have broad stakeholder representation in planning, to actively link supports within and outside the health care system in supporting seniors and their caregivers, and to avoid service fragmentation through better collaboration.

[246] Horgan, L., LeClair, K., Donnelly, M., Hinton, G., MacCourt, P. and Kreiger-Frost, S. (2009). Developing a national consensus on the accessibility needs of older adults with concurrent and chronic, mental and physical health issues: A preliminary framework informing collaborative mental health care planning. *Canadian Journal on Aging*, 28/(2), 97-105.

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All of these factors within this framework seem to be addressing the needs of patients with dementia most specifically, and therefore should influence the role of community mental health in dementia care.

In 2004 the Ontario Ministry of Health and Long Term Care, Mental Health and Rehabilitation Reform Branch, defined a specialized geriatric mental health outreach team's program policy and accountability framework:[247] "Specialized geriatric mental health outreach teams are located in a variety of organizational settings, including community agencies, teaching hospitals and community hospitals. Services are time limited and geared to the needs of the senior experiencing serious difficulties due to complex, age related or mental health problems, their families and service providers within community and long term care settings. It is estimated that only 3% of seniors have problems that require specialized services. Services at this level include specialized ambulatory services – outreach teams, specialized inpatient services, complex continuing care and geriatric rehabilitation."

Outreach/outpatient programs may not have the resources to deliver all core functions and services; however, it is expected that through a shared care approach, all core functions and services will be locally available. Regional decision-making determines how resources will be aligned to deliver core functions.

One model that provides a basis for planning comprehensive service delivery for seniors' mental health services is described in *A Tiered Model Of Psychogeriatric Service Delivery: An Evidence-Based Approach* by Brian Draper, Henry Brodaty and Lee Faye Lau (International Journal of Geriatric Psychiatry 2006, 21:645-653). This model outlines seven tiers of management intensity that increase with the increased severity of patients' mental disorder.[248] (NOTE: This model is referenced and described in Section VIII Collaboration for Seniors Services, "Building a Comprehensive and Integrative System". The Vancouver Island Health Authority (VIHA) has adapted this model for their own use. Their adaptation is seen in Appendix A –Vancouver Island Health Authority's Adaptation of the Tiered Model.)

In *Toward Recovery and Well-Being: A Framework for a Mental Health Strategy for Canada* (2009), the Canadian Mental Health Commission defined eight strategic directions for its transformation agenda. Two of those directions are particularly relevant to the role of community mental health. The first strategic direction identified is actively engaging people living with mental health problems and illnesses and their families in decision-making at

[247] Ontario Ministry of Health and Long Term Care, Mental Health and Rehabilitation Reform Branch defined a specialized geriatric mental health outreach team's program policy and accountability framework.

[248] *A tiered model of psychogeriatric service delivery: An evidenced-based approach* by Brian Draper, Henry Brodaty and Lee Faye Lau (International Journal of Geriatric Psychiatry 2006, 21:645-653)

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all levels; the second important strategy is improving pathways to recovery and well-being because the "current mental health system is a tangle, which is often difficult to navigate. Innovative approaches are needed to provide an integrated continuum from promotion to specialized care that can meet people's needs across the lifespan and bridge the public, private and voluntary sectors. Everyone should be able to benefit from timely and equitable access to the right programs, treatments, services and support."[249]

The Seniors Advisory Committee of the Mental Health Commission has developed *Guidelines for Comprehensive Mental Health Services for Older Adults* in 2011. In supporting the need for a recovery model, including dementia, these Guidelines state: "It should be underscored that the concept of recovery is rooted in the importance of choice, hope, respect, empowerment and individualized and person-centred care philosophies that are consistent with ideal dementia care."[250] The Guidelines also point out that there is a need for modification of usual practices and relationships to achieve an accessible, integrated and seamless comprehensive mental health system relevant to local conditions and able to provide core functions in services.

A care program approach (CPA) for psychiatry for seniors defined by consultant psychiatrists in the United Kingdom has seven summary headings and sub-headings as follows:

1. **Summary of Need**:
   - This includes metal health, physical health, relationship, occupation and education, activities of daily living, accommodation, finance, ethnicity/culture, religious/spirituality/guiding values, child need and risk, fear, access to care and consideration of these questions: does the patient need continuing care services? What is the patient's fair access to care? What are the eligibility criteria?

2. **Summary of actions/interventions**:
   - By whom, how often and what type

3. **Unavailable care service**:
   - Any needs not met due to lack of resources

4. **Medications**:
   - Prescribing and supplying medication, regular monitoring and treatment of any side effects and the impact on physical health

[249] www.mentalhealthcommission.ca

[250] MacCourt, P., Wilson, K. and Tourgny-Rivard, M (2011). *Guidelines for Comprehensive Mental Health Services for Older Adults*, prepared for the Seniors' Advisors Mental Health Commission of Canada.

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5. **Contingency Plans**:
   - Contingency planning prevents a crisis by developing arrangements to be used at key points in the care program

6. **Crisis Plans**:
   - Early warning signs/relapse indicators
   - The nature of service response to a crisis/out of hours; responding includes any particular risks, which should be taken into account in a crisis

7. **Diagnosis/problem type**:

The Dementia Journey

The dementia journey[251] starts at the pre-diagnosis phase where public education and knowledge translation are key. Dementia may be suspected or diagnosed at the mild cognitive impairment level; the biomarkers identified at this stage become increasingly important in tertiary and quaternary care. Mild cognitive impairment may then progress to the dementia stage with the recognition of functional deficits beyond memory complaints.

In the mild stages of dementia, comprehensive assessment with a biopsychosocial, functional approach becomes the basis for all diagnostic considerations and care plans. Patient goals should be identified and frame interventions as much as possible. At this stage issues of driving are important to start exploring, as well as advanced planning (powers of attorney, representation agreements over health, end of life planning and wills). Early patient and caregiver education is essential, and referrals to the Alzheimer's Society and to educational services within the community are important components of care. Medications to treat depression may be used, and medications to slow down the downward deterioration in function (with cholinesterase inhibitors) may also be considered.

In the middle stages of dementia patients will start manifesting behavioural problems; assessment of the origins of those behavioural problems is essential, again with a biopsychosocial, functional and environmental approach. Care planning, starting with behavioural approaches before considering medications, is essential. If patients and families have not been referred to Home and Community Care by this point it would be appropriate to do so for support services. Caregiver support through the Alzheimer's Society and Health Unit services becomes even more important. Caregivers' goals, abilities and capacities should be

[251] www.dementiajourney.ca

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assessed and taken into account in care planning. All health care providers need to focus on the quality of life of the patients and should prepare the caregivers for eventual palliative care.

In the palliative stages of the dementia journey, quality of life becomes the predominant focus. After the patient dies, grief support for caregivers may well be needed.

Caregiver Focus Groups

Introduction

Two caregiver's groups with twelve caregivers from across the province were organized by the B.C. Alzheimer's Society. Six of the participants were form the Lower Mainland and six from the other health authorities, including rural areas.

The caregivers were asked:

1. *Have you or your loved one had contact with mental health regarding Alzheimer's or dementia experiences in the past five years?*
2. *Can you name any positive or negative experiences?*
3. *Is there anything that you could suggest that would improve care?*

The participants were eager to share their stories in order to have the voices of their loved ones heard. These stories were then divided into two categories, stories about difficulties they had dealing with mental health professionals with their loved ones, or stories about positive experiences with mental health professionals caring for their loved one. Finally, their suggestions for improved care were summarized as a description of ideal care for mental health patients with dementia.

Caregivers' Description of Ideal Care for Patients with Dementia

1. The family physician, who has been seeing the patient for years, is aware of issues around dementia and is attentive to the patient with dementia and their caregivers.
2. The professionals working in mental health provide care, which early on (and always) is:
   - Supportive of patient and caregiver concerns, never discounting them;
   - Flexible;
   - Prepared (with previous notes having been obtained and read);
   - Empathetic;

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- Compassionate;
- Easy to understand in terms of speech;
- Respectful of the dignity of the person;
- Respectful of the real experts (the caregivers);
- Professional;
- Collaborative with family members;
- Relationship-based with the relationship based on trust;
- Patient with those who have dementia and yet willing and able to gently probe to hear their words;
- Knows about resources;
- Knows about alternatives to medications and how to offer these to family members.

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3. The system:
    - Recognizes that patients and caregivers are central;
    - Is cohesive;
    - Gives directions to caregivers;
    - Has clear systems and communication;
    - Provides follow-up (not just assessment);
    - Inspires confidence in the patient and the caregiver that help will be given appropriately;
    - Allows caregivers to open up and discuss their concerns freely, giving them permission to be open and frank;
    - Recognizes the need to speak to the caregiver or relative when the patient refuses services;
    - Involves the NGO's, like the Alzheimer's Society or Canadian Mental Health Association;
    - Involves caregivers in research where appropriate and available;
    - Involves caregivers in planning of the system.

Health Care Professionals Focus Groups

Three focus groups of health care professionals from all Vancouver Coastal Health (VCH), three from Vancouver Island Health Authority (VIHA), eleven from the Fraser Health (FH), eleven from the Interior Health Authority (IHA) and four from the Northern Health (NH) – provided insights.

The health care professionals had many concerns about care for patients with dementia and many suggestions for improvement. Their ideas were grouped into ten themes[252].

[252] See Appendix 2 for excerpts or summaries of all the ideas that were suggested

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Theme 1 Needed Based Services	i. Age cut offs ii. Needs iii. Stigma iv. Streams of dementia
Theme 2 A Complete/Continuum/Care	i. Type of care ii. Personnel iii. Continuum iv. Prevention
Theme 3 Risk and Incapability Assessment	i. Risk ii. Incapability assessment
Theme 4 Place of Care	i. Community ii. Facility care iii. Role/Urban
Theme 5 Nature of working together: Collaboration/Integration/Other	i. Collaboration ii. Integration iii. Other
Theme 6 Information Sharing	i. Computer systems. ii. Access to medical records
Theme 7 Communication	i. Patient care ii. Across transitions iii. System wide
Theme 8 Education	i. Professionals ii. Families
Theme 9 Creating systems to navigate for the patient and the system	i. Patient navigation ii. Systems forms iii. Redesign concerns iv. Family and patient involvement
Theme 10 Tertiary	i. Diagnosis and system management ii. Staffing according to needs of patients. iii. Facility design iv. Specialized care

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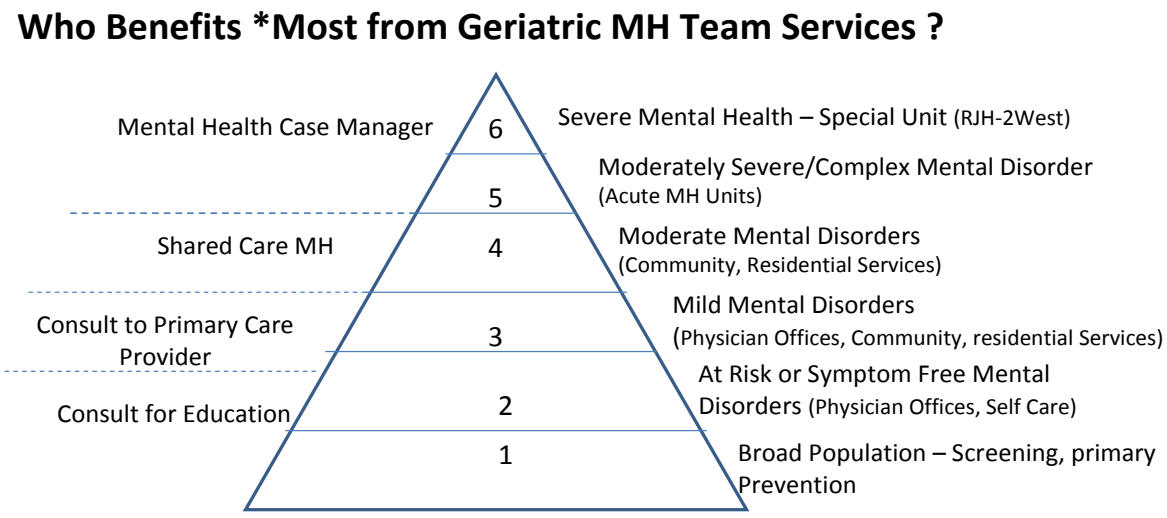
Vancouver Island Health Authority's (VIHA's) Adaptation of the Tiered Model



Population Characteristics:
6. Severe psychosis/depression, Agitated, psychotic with delirium, Chronic schizophrenia, severe BPSD (1% Dementia).
5. Specialist Case Managed – Severity in symptoms/living context eg. Major depression, suicide risk, Chronic schizophrenia, Paranoid Psychosis, Dementia with BPSD of agression/agitation Risk from Residential Services
4. Moderate Dementia BPSD (20%) – Community/Residential services managed – physical/social pharmacotheraphy/Behavior management
3. Dementia – mild BPSD, medication consultation for depression/anxiety
2. Mild cognitive Impairment, Dementia no BPSD (39%), symptom free mood/psychotic disorders

*Reference: Draper, B., Brodaty, H., Lau, L.(2006). A tiered model of psychogeriatric service delivery: an evidence based approach.
This modification is from VIHA

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Health Care Professionals' Focus Group Themes

Theme 1 – Needed Based Services

(i) ***Age Cut Offs:***

1. Should there be an age cutoff and how should you determine it?
2. Should traumatic brain injuries over 65 be part of geriatric mental health teams as they have cognitive impairment?
3. Is it appropriate to take patients over 65 from young services of patients with chronic, severe, persistent mental illness, like schizophrenia or manic depression, or just if they become demented or frail physically? Sometimes fresh eyes can be very helpful.
4. There is some ambiguity around acute brain injury, neuropsychiatry and geriatric psychiatry, especially around frailty. Who should see who?

(ii) ***Needs:***

1. For patient/family-centeredness we should be placing the needs of the patients at the center and then highlighting what services should be in the community in order to meet those needs. If the needs cannot be met, that needs to be documented and dealt with.
2. We shouldn't be looking at dementia severity, but complications with severity requiring a mental health assessment and intervention, and that must include caregiver strain because caregivers keep people in the community longer.
3. Formalized caregiver's support as part of the mental health role.
4. Care is not always available when needed and mental health at times has to fill the gaps.
5. The availability of housing is an important issue when one is looking at community mental health needs.
6. There is a need for emergency response or urgent responses to solve crises and prevent patients going into Emergency.
7. Systems are overwhelmed and therefore services may not be available or beds in hospital in long-term care when needed.

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8. Core means to meet the mental health needs of a patient and the caregiver. It means timely access; it means availability of outreach; it means flexibility of hours and workers.
9. Mental health teams tend to have an emphasis on complex dementia, those with severe behavioural problems.
10. There is a gap in the diagnosis of early dementia, (especially seen by caregivers) and their lack of services because they don't fit the mandates at home, and community care, or mental health.
11. There is a care gap between home care and when they don't need a bath, but they do need guidance in life skills.
12. All slightly different systems so therefore the client is core. The client needs assessment and the client and family need education.

(iii) ***Stigma:***

1. Dementia is a mental illness, even though some argue that it is not.
2. There may be some guilt associated with dementia now that there is such a heavy emphasis on positive aging, and mental health promotion and trying to prevent cardiovascular problems, which may lead to earlier dementia.

(iv) ***Streams of Dementia:***

1. In VIA it is defined there are three streams of patients with dementia:
    a. Complicated by BPSD's or personality disorder or family dynamics, who are best seen in consultation with geriatric psychiatry.
    b. Complicated by medical health problems, who are best consulted by geriatric medicine.
    c. Early dementia or MCI where collaborative care is essential in primary care.

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Theme 2 – A Complete/Continuum/Care

(i) *Type of Care:*

1. Interdisciplinary is a must.
2. Avoid the consultation and disappearance approach.
3. Assessment usually of dementia with behavioural problems.
4. Need for biopsychosocial functional assessment.
5. Treatment obviously involves drug and counselling – for individual and family, as well as day programs for activities like the Bright Spot in Vancouver, or mild cognitive impairment, or early dementias or day centres run for more than mild dementias.
6. Who will deal with biomarkers in the future like doing the LP's to diagnose early dementia?
7. Psychosocial rehabilitation with activation.
8. Home and community care referrals seem to be increasing and it may be that people are living longer and getting into more severe problems at home.
9. Want psychiatric clinical neuro specialist position in the community.

(ii) *Personnel:*

1. Geriatric nurses in Emerg are a great idea to assist with overall community care.
2. Life skill workers assist with IADL's. Once ADL support is needed, usually the patient is heading towards facility care.
3. Is it time to think about community memory clinics, which would be collaborative?
4. Want psychiatric clinical nurse specialist position in the community.

(iii) *Continuum:*

1. The role of primary mental health in community has to be considered as part of a continuum of care: Primary, secondary, tertiary and mental health care.

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(iv) ***Prevention:***

1. A lot teams respond to crisis only, but the crises need to be prevented.
2. Diagnosis of dementia, paranoid, BPSD's but the consultations are often late. It would be nice to see more integration with the health unit to do prevention and more education.

Theme 3 – Risk and incapability assessment

(i) ***Risk:***

1. Risk assessments and negotiations for care are important mental health interventions. Sometimes mental health act is needed, including extended leave with provisions for accepting care back in the community and this involves long follow up or follow through, and in fact it may be for years.
2. There is a very important role for mental health in dementia for those who are living at home at risk and sessional GP's attached to mental health care are very helpful.
3. Risk assessments need to be collaboratively with home and community care.
4. What is tolerable risk?

(ii) ***Incapability Assessment:***

1. Complex capacity assessments need to be done by mental health, but simple ones could be done by primary care, either physicians or with home and community care.
2. How intrusive can you be in forcing care and that brings us back to capacity?
3. Incapability assessments.

Theme 4 – Place of care

(i) ***Community:***

1. Community mental health must see patients in their own homes in the community, but must also serve long-term care facilities to support their staff.

(ii) ***Facility Care:***

1. It is very important for mental health to work very closely with residential care to provide education, or service, or both.
2. More rapid response to long-term care facilities is needed.

(iii) ***Rural/Urban:***

1. The place is important in how to affect the role, rural versus urban, geography, staffing, and staff education.

Theme 5 – Nature of Working Together: Collaboration/Integration/Other

(i) ***Collaboration:***

1. Get rid of the silos and focus on the patient and primary care where others collaborate to support them.
2. Collaborative is a must.
3. Co-location can be extremely helpful.
4. Despite co-location, collaboration may not occur, so collaboration is really key.
5. Virtual collaboration and continuous collaborative engagement should be the models of community mental health services for seniors.
6. Collaboration with police, fire etc. may be necessary, especially with dementia hoarding.
7. Need for focus on collaborative care with physicians and older adult services.
8. Need to help family physicians diagnose MCI, differentiate tests of dementia, deal with caregiver strain or needs or depression and connect with Alzheimer's Society first link.
9. It is essential to collaborate and it was felt that most mental health workers in home and community health care workers do collaborate with primary care, none of them together; however, there is often a lack of communication about that.
10. Collaborative model constitution of primary care. Co-management of different patients for education. Increasing the expertise in primary care. Supporting long-term care facilities.
11. We work at the front lines collaboratively.

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(ii) ***Integration:***

1. Victoria is integrating mental health with home and community care and has a transition team that is like an ACT team so that outreach and inpatient are connected.
2. Integrating services to meet biopsychosocial functional needs of the patient in primary care and patients at the center and mental health and home and community care, geriatric medicine, and all the rest, supporting the basic patient/caregiver/primary care dyad.
3. Family physicians now have better fee-for-service possibilities and the new divisions may assist in integration as well.
4. The word "integration" has some negatives. There is a sense of needing to be careful that there is a careful look at human resources planning before adopting anything called integration that may further dilute resources in poorly resourced areas.
5. Is there a need for a dementia care team involving home and community care, mental health, primary care and the Alzheimer's Society?
6. What does integration really mean? We hear about it. We don't know what it means.

(iii) ***Other:***

1. **Resource** to primary care and family.
2. **Links** to NGO's like Alzheimer's Society and CMHA are important.
3. **Bridges** are needed between and among primary care, mental health, pharmacy, home and community care and tertiary care.
4. Now getting away from case management because of few staff, therefore more consultation in assisting in care planning with acute care. Therefore **partnerships** to get people back in to the community, especially at transitions. Only following complicated dementias.
5. In a rural area **limited resources have forced us to work together**. The doctors tend to refer earlier states of dementia for diagnosis. There is limited education for caregivers. There is the use of wellness centres, which decreases the stigma of dementia.

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Theme 6 – Information sharing

(i) ***Computer Systems:***

1. Computer systems can assist or defeat good care.
2. Develop a shared document, like chronic disease management, a tracking tool, including powers of attorneys and risk factors, like the Depression Flow Sheet used in primary care. If this was created, education regarding use of the document will be a must. It is possible that with better shared documentation, emergency visits could be avoided.
3. Shared documents should have needs assessments, financial, functional, social, housing care in it and with shared document there should be joint planning where there is an identification of potential crisis points and solutions.
4. Freedom of Information Act can prevent access to information.

(ii) ***Access to Medical Records:***

1. There are real problems with medical records and this is an issue that somehow needs to be sorted out for transitions and for ease of care.

Theme 7 – Communication

(i) ***Patient Care:***

1. There is an intense need for better communication.
2. There are pockets of good practice, but better communication is needed, like a hub and a spoke model.

(ii) ***Across Transitions:***

1. Now shorter case management. Communication with acute care not really good because of different systems of communication. Therefore community mental health does not go into acute often.

(iii) ***System Wide:***

1. Communication within health authorities needs to be improved because within health authorities, some don't even know what the left hand and the right hand are doing.

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2. In rural areas there may be no educators for case managers in home and community care to help decide when to refer cases. Now in the Interior they are moving to integrated, primary care, home and community care, mental health and aboriginal health, but communication about how to do the integration is very much needed. The psychiatrist now is being used to access specialized beds in continuing care, and therefore not available to do other things.

Theme 8 – Education

(i) ***Professionals:***

1. Family physicians need more education regarding capacity assessments. In fact, family physicians may know more about function from day to day and would be ideal candidates to do capacity assessments if they were educated.
2. Mental health should lead education of acute care, emergency care, residential care, and within the community.

(ii) ***Families:***

1. Mental health education in family and children not living with a parent and working in partnership with the Alzheimer's Society, but remember in remote communities there may be no Alzheimer's groups so it may be mental health or home and community which needs to do the education.

(iii) ***Specific Problems:***

1. Addictions plus dementia can be difficult. There is a need for education.

Theme 9 – Creating systems to navigate for the patient and the system

(i) ***Patient Navigation:***

1. System navigation regarding mental health issues is essential.
2. How do you slice up a pie for an individual team between service, education, service support development and advocacy?

(ii) ***Systems Forum:***

1. No forum to network to solve problems.
2. There is a need to look at broader systems issues.
3. At the systems level, look at whether or not individual needs of patients with dementia are being met and try to problem solve as to how to fill in the gaps.

(iii) ***Redesign Concerns:***

1. Redesign can shake up working agreements.
2. It is important for a program to understand the impact on patient care during redesign and the impact on relationships that presently exist before the redesign.

(iv) ***Family and Patient Involvement:***

1. Seniors need to be more involved in planning of systems.

Theme 10 – Tertiary

(i) ***Diagnosis and Symptom Management:***

1. Tertiary means special populations, frontotemporal, Lewy Body, dementia plus addictions, early onset.
2. Patients' behaviours in facilities affect other patients in the facility and we need to consider the effect on other patients of behavioural problems.
3. Tertiary is a needs resourced definition and not just a severity of illness definition.

(ii) ***Staffing According to Needs of Patients:***

1. Tertiary means staffing needs. There is a small proportion of the population that is in need of specialized facility care with specialized staffing levels.

(iii) ***Facility Design:***

1. We need purpose built facilities for dementia in order to truly improve quality of life.

(iv) ***Specialized Care:***

1. Tertiary care is specialized care. Everyone was asked to look at the Broadty Model from Australia.
2. There are often long-term care facility beds filled with people who have tertiary needs.

Appendix A

Stories About Positive / Negative Experiences

Stories about positive experiences

- Access to mental health is important. The Alzheimer's Society is very helpful to support caregivers until mental health is accessed. Having a central intake number where families can phone by themselves and do not need a referral from a doctor is a very positive thing.

> *The family doctor didn't really know where to go, but she referred us to mental health so mom got assessed. She then had a doctor who fully understood Alzheimer's and was really willing to learn all she can.*

> *I expressed need for more support with mental health social workers, who were very helpful. They helped strategize and they were aware of my needs and helped me met my needs.*

- But I was involved with the Early Onset Dementia Support Group through the Alzheimer's Association and it was a group particularly focused on supporting the early dementia and their spouses had a separate group. It was really appropriate.
- I was part of a caregivers' project. I answered questions regarding stress and health issues and loss and awareness of grief and it really brought my awareness up in relating to my health issues and the fact that I needed more respite and I needed to be more involved with my own fitness and activities and so it encouraged me to do that.
- I could recommend that earlier contact or awareness of mental health for supporting caregivers is helpful. I also made use of the clinical psychologist, but the support through the mental health social worker was really excellent.
- I had a very positive experience when my mother was referred to a psychiatrist. She'd had a rare interaction with a heart medication, which was diagnosed by the psychiatrist.
- She ended up in a facility and she is doing very well now. She can't remember anything, but she's happy.

Appendix A

- My mother finally got referred to a very good facility. She is not taking any antipsychotics and her disease has certainly progressed since she was admitted.
- I took her home, which was against medical advice. She actually had a good year.
- I asked for hospice for however long she had left. They brought a hospital bed to me and everything that I needed and I had her home exactly one week before she passed away.

Stories about difficult experiences

- I'm pretty sure the neurologist's notes, the hospital notes and everything went to mental health before they contacted me. I tend to think that medical teams and mental health teams are going to do all the organizing for the caregiver. I wasn't coping well. I really needed help. It would be nice if the case manager was very understanding of that. In this case the case manager did not seem to know what was in the notes.
- The family doctor didn't fully understand what was happening. I started losing confidence.
- My mother is now in a funded bed on a secure floor. I guess social services has taken it all over. I don't know whether it was the intent of mental health to push us to the side. It almost seems that way on reflection.

> *The biggest failing as far as mental health goes, and my only complaint now is, that we only ever heard from them I think once or twice. I'm sure the case manager is overworked, but I saw her and she said she had assessed my mom again, but she didn't have the numbers and hadn't discussed it with us. So I think as far as mental health goes, once they are assessed and in the program, it's like we're forgotten. We're not in the loop.*

- When I did contact mental health, it was a long conversation. They helped calm me. You almost have to know what needs to be done before you make contact.
- I found that the doctors were not understanding anything about mental health resources or being able to connect people with mental health.
- Everything was fragmented. It's almost like the fragmentation was like Alzheimer's itself. That's kind of how we felt with mental health and the communication with doctors and the social workers. You know all sorts of different people were interacting, but nobody was really connecting.

Appendix A

- I was dealing with the GP and then we were referred to a geriatric psychiatrist. He was excellent in creating a positive relationship with my husband, but I felt very left out because I really felt I needed more support and information.
- The frustrating part came relating to having the time organized for me to go to a support group, as my husband was not amenable to day care or other programs. He wasn't comfortable with somebody coming in. He needed some activity. We now have *First Link* happening. It would have been helpful if that had been there at the time.
- The psychiatrist totally ignored the input from the families. The outcome was negative. There wasn't even a diagnosis. The person just didn't have the time for the person with dementia.
- I had a rather unhappy experience. Our family doctor treated her for depression for a couple of years, but with the wrong medication. We finally went to a psychiatrist and he referred us to an assistant nurse and she came out and said she had Alzheimer's without really giving thought to how it might affect her. When we got home I found her in a state. I took her to Emerg and they said it was just Alzheimer's and gave her a prescription. I had to take her back to Emerg and they in fact said she had been trying to commit suicide with a bottle of aspirins and she had to go on dialysis.
- The psychiatrist doctor was very blunt. She had to go into a mental hospital, which wasn't in our hometown. We stayed there ourselves for three months. We finally were able to take her home but with home care there were different people all the time. She didn't want any help and she told them she didn't want to see them again.
- The facility wanted to use antipsychotics for chemical restraint and my mother had had very bad reactions to these. We ended up in Emerg because of quetiapine poisoning. I was eventually sent to a psychiatrist because I was having trouble accepting that my mother should be "treated." The psychiatrist came with an assistant who distracted my mother while the psychiatrist spoke with me, which I felt was really ironic. They were trying to shut me up, not create a care plan for my mother. My mother was transferred to acute care because she was evicted from her care facility because I refused to agree to the drugs suggested.
- My mother was in assisted living, withdrawing from activities, lashing out verbally at people. The doctor never diagnosed her with Alzheimer's. I thought she had dementia caused by hardening of the arteries. I had to go away so I put her in a care facility and when I got back she was not responsive. Because she had been angry they tended to ignore her so she didn't get care.
- I took her for respite care, she walked in but she came out in a wheelchair.

Appendix A

- My wife went for a driver's test at age 80 and was told she had Alzheimer's and couldn't pass the test. There was no psychiatrist in our town. The neurologist saw her and didn't suggest any particular medication. He apparently had asked my mother without me present, if she would take Aricept and she had said no. I wish she had been able to see a psychiatrist in the first place.

- My mother-in-law was referred to the Geriatric Outreach Team. We were very disappointed. The psychiatrist never talked to us alone. He asked all these questions about her past, with all three of us in the room and I found this very frustrating because in order to set him straight we had to say that mom didn't know what she was talking about in effect. In the end nothing happened. We got a short letter, less than a page long, saying she had no psychiatric disorder. She had dementia. End of story. It seemed really dismissive, but they were saying, "Well you're on your own now." I have a psychology degree and I was horrified with all of this.

- I guess I'm mostly disappointed in these facilities when they know that they have dementia and they have difficulty. I suppose it's a shortage of help. Whatever it is, but they don't give them the care that they need. If they angry or if they are not, you know submissive and quiet and sweet, just shoved into the background and not given the care that they need. It's the happy ones that get all the attention and that's probably just a normal human reaction.

> *The case manager had a strong accent and it was sometimes a little bit difficult for my husband to understand and so I needed to somehow interpret without being offensive.*