

**Building Research Capacity to Examine  
Home- and Community-Based Supports and Services**

**Background Paper  
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## 1.0 Introduction

Nova Scotia like many other provinces is moving forward with plans to enhance their publicly funded home care program. Part of these developments include expanding services to support the independence of older adults who have health difficulties and functional impairments, prevent long term care placement as well as substitute for long term care. This policy approach is largely being done with the growing recognition that people want to remain at home and that care at home may be more cost effective than institutional alternatives. However, to what extent do we understand that home care is cost effective? Is there any evidence that examines the efficacy of different provider models? What do we understand about whether home supports are meeting the needs of older adults and caregivers in ways that support quality of life or are satisfactory to the users?

This paper is a synthesis of a targeted review of published research and grey literature (1995-2014) that demonstrates current knowledge about home supports intended to help older adults remain at home (see Appendix A and B for search terms and databases used). Home supports are here understood as an array of non-medical programs and services provided in the home and community setting to help older adults with chronic care needs maintain their independence and prevent or delay long term care placement. Such services are typically provided in, or supported by, publicly funded home care programs. Primarily the focus of home supports was on homemaking, personal care and respite services, and for community-based supports those included in this review were limited to adult day programs and meals on wheels. While the studies may have varied in exactly how 'older adults' was defined, all shared a baseline of <65 years. The review was undertaken with a dual focus on effectiveness of supports and services from the individual (client/caregiver) perspective and system (agency) perspective. While special attention was paid to the 'cost-effectiveness' of home- and community-based supports, the review also considered studies which examined other outcomes such as quality of life or satisfaction. Before presenting a review of the literature, Section 2 provides an overview of the context of home care and Section 3 offers some insight into how key studies have approached understanding costing and cost effectiveness in home care.

## 2.0 Context

More than 1.4 million Canadians receive publicly funded home supports and services and an estimated 500,000 receive privately funded services, eight out of ten of which are older adults (Canadian Home Care Association, 2013; Canadian Institute for Health Information, 2007). Across Canada home support services vary in eligibility, what is offered and how much is offered, and who is paying for what. Each province and territory provides a funded needs assessment and case managers in which coordination of service occurs (Health Council of Canada, 2012). This is not always the case for service implementation. With the exception of Ontario, Manitoba, Quebec, Prince Edward Island and the three territories, provincial plans cover professional care, and personal care and homemaking service fees are based on income. Subsidization for other supports (adult day programs, respite, and meal delivery) is typically available in most provinces (Health Council of Canada, 2012).

Recently in Canada there has been an increasing policy emphasis on community-based non-institutional supports and services for older adults with long term care needs. There is growing consensus by public, government and industry stakeholders concerning the benefits of initiatives that support 'aging in place'. However, there is also a lack of readily accessible evidence-based knowledge on the actual efficacy and effectiveness of home supports for frail seniors with chronic care needs in Canada, and recognition of individual and systems-level barriers to the implementation and take-up of home- and community-based supports (Carstairs & Keon, 2009). Such barriers include the fiscal challenge faced by provincial governments as a result of population aging and projected increases in the demand for long term care; a challenge felt acutely by the Atlantic provinces in which the dependency ratio is expected to double by 2030 and triple by 2050 (Blomqvist & Busby, 2012).

Public spending in Canada on home care was estimated at \$5.6 and 6.3 billion in 2007 (Hermus, Stonebridge, Theriault, & Bounajm, 2012). In 2012 Nova Scotia had the fifth highest home care expenditure per capita at \$203.89, a dramatic shift considering the province had the least per capita for home care at \$25.10 in 1994-1995 (CIHI, 2007). Despite the large number of Canadians receiving home supports, there is a lack of legislative framework (CHCA, 2011). There are no standards legislated federally as home supports and services are considered separate and identified as extended services (Canadian Healthcare Association, 2009). The absence of an integrated health care strategy makes it difficult to evaluate the actual effectiveness of chronic home support programs and services for older adults and their caregivers. Another difficulty is that some of the leading approaches to home care blur the definitions of home- and community-based supports and services and institutional care, creating challenges for policy makers (Kane, 1995). A notable example of this can be found in respite programs which may involve the use of short stay beds in residential facilities.

In a 2007-2008 study of the characteristics and needs of individuals, primarily older adults, waiting for residential long term care in Toronto, Ontario, Williams et al. (2009) adopted the UK established balance of care (BoC) model which integrates the experiences of senior leaders and frontline case managers from across the care continuum, and focuses on the access to appropriate and cost-effective community-based care (supply) rather than the assumption the aging population automatically means a greater need for more beds (demand). The strength of this model can be found in the development of evidence-based benchmarks and attention to the need to account for changes introduced by local settings and different service configurations, in lieu of a homogenous one size fits all approach. This research had three major findings. First, many people waiting for long term care could safely and appropriately be cared for at home, and that one fifth of older adults on a placement list for long term care had only mild to moderate levels of need. Second, that caregivers are the "glue" holding home and community care packages together – monitoring client needs, coordinating services and providers and promoting social connection. Third, lighter instrumental activities of daily living such as routine transportation, nutrition and housekeeping play a determining role in successful care delivery (Williams et al., 2009).

Within age-related policy and research there is growing recognition of the significant role family and friend caregivers play in helping older adults to maintain their independence (McWilliam et al., 2014). The 2012 General Social Survey identifies approximately 8.1

million Canadian family and friend caregivers for someone with a long term health condition, disability or aging needs, 54% of which are women and 44% between the ages of 45-64 years. The significant contribution family and friend caregivers make to the care of individuals with long term care needs should not be underestimated, particularly in light of research which shows that the long duration and intensity of caregiving can come at a cost to caregivers (Henningsen, 2012). And yet, there is a surprising lack of research-informed understanding of caregivers' contributions to the effectiveness of home supports, or if the specific outcomes of caregiver interventions are being met, and if so, how they are being met and what implications these interventions for understanding the effectiveness of home supports (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012).

When examining existing research and knowledge about home supports it is important to also consider which client and caregiver needs are being or are not being met. Comprehensive tools to assess the needs of caregivers, such as the C.A.R.E. Tool (Keefe, Guberman, Fancey, Barylak, & Nahmiash, 2008) have shown success. However, it is more often the case that caregiver assessment is relegated to a couple of questions on the client assessment tool such as the Resident Assessment Instrument Home Care (RAI-HC) tool (Morris, Fries, Frijters, Hirdes, & Steel, 2013; Stolle, Wolter, Roth, & Rothgang, 2012). The limited attention given to caregivers as clients in their own right presents barriers to understanding caregiver need and whether and how it is being met.

### 3.0 Approaches to Understanding Costs and Cost Effectiveness

A number of researchers have presented the idea of using home and community based services as a means of reducing health care costs and proactively organizing the health care system for the influx of older adults expected to overwhelm the health care system (Stuart & Weinrich, 2001; Brazil, Bolton, Ulricksen & Knott, 1998; Hollander, Miller, MacAdam, Chappell, & Pedlar, 2009; Hollander, Chappel, 2007; Chappell, Havens, Hollander, Miller, & McWilliam, 2004). Many researchers have attempted to view the cost effectiveness through analyzing the reduction of hospitalizations and or emergency room visits (Brazil et al., 1998; Thorpe, Van Sleath, & Thorpe, 2010), cross comparisons between long term care facility costs and home and community based services (Chappell et al., 2004) and intervention based savings such as fall prevention programming to reduce hospitalizations due to falls. Yet, few studies consider the direct and indirect costs of family caregivers and their potential cost-saving contribution to the system (Fast et al, 2013). Since the fragmented system is difficult to analyze and understand, these analyses have shed little light on the question of whether savings have actually been achieved (Chappell & Hollander, 2013).

Variations in how effectiveness is defined contribute to the challenge in understanding the value of home supports. One of the most common and prominent ways of defining the effectiveness of home supports and community programs is in terms of cost. According to Chappell and Hollander (2013, p. 96) cost effectiveness analyses “measure the costs and consequences of programs in comparable units. In cost-effectiveness analysis, no attempt is made to place monetary value on the quality of outcomes. The result, therefore, is a determination of the relative cost per unit; an example of this would be cost per year of life gained”. Therefore, if comparing two separate interventions, the cost effectiveness could be the analysis of comparing the impact that each intervention had on the life years saved at a

given cost. Other economic evaluation terms are cost-minimization analysis, cost-utility analysis and cost-benefit analysis. Although each is different, economic evaluation approaches all attempt to find alternatives for both cost and consequence (Chappell & Hollander, 2013, p. 96).

### 3.1 Comparing the Costs of Home & Facility Based Care

The *National Evaluation of the Cost-Effectiveness of Home Care* (NECHC) study led by Hollander and Chappell (2001) provides an example of a well-known Canadian program of research on cost-effectiveness. This study was comprised of 15 interrelated sub-studies, in which 6 focus on the cost-effectiveness of home care as a substitute for residential long term care and 9 focus on home care compared to acute care. They identified several “key issues” in doing a study on the cost-effectiveness of home care. Foremost among which were *sustainability* (otherwise it can be an add-on cost), and the *actual comparative costs of home care versus residential care*, including comparisons made across home care and institutions by level of care. In one sub-study conducted in British Columbia they found that home care costs less than residential care for comparable, if not improved, quality of care.

Unsurprisingly, costs were highest for clients requiring higher levels of care and that service/hospital utilization is greatest just before entry into care, at which point it drops significantly (Hollander & Chappell, 2001). Two other sub-studies led by Hollander, Chappell, Havens and McWilliam examined the costs and outcomes of home care and residential long term care across two sites (Winnipeg and Victoria/Gulf Islands), 200 home care clients and 200 residential care clients (Hollander & Chappell, 2001). Clients and families kept diaries about costs of informal care (use of a proxy for those with cognitive impairment). The studies, which included both ‘non-professional’ community based care and medical supports, found that home/community based clients had comparable levels of satisfaction and quality of life as facility-based clients (Hollander & Chappell, 2001).

The NECHC program of research examined home care services that included medical and nursing home care, and not simply supports designed to help people maintain their independence at home. More recently, Chappell and Hollander (2011) reaffirmed their understanding of home care, including non-medical home supports, as a cost-saving alternative to nursing home care. However, they also note that, “the fact that home care costs less than institutional care is a necessary but not sufficient condition for cost-effectiveness. Value for money in the broader healthcare system can only be achieved if home care is part of a larger integrated system of care delivery that allows for cost-effective trade-offs” (2011, p. 14).

### 3.2 Caregiving & Cost Effectiveness

A discussion of the cost-effectiveness of supports and services to maintain older adults at home cannot be complete unless the inclusion of costs by family and friends are considered. Yet, few studies do so. Caregiving includes time spent with the care receiver (e.g., providing personal care, meals, homemaking, attending appointments, supervision), on behalf of the care receiver (e.g., managing finances, coordinating appointments), travel to and from the care receiver and monitoring the care receiver. This could mean less time

for other activities that contribute to the caregiver's health and wellbeing (Fast et al., 2013). A recent synthesis of findings on the economic costs of care to family and friend caregivers found that 1 in 4 Canadians is a family/friend caregiver, and that caregiving across the life course is a "normative experience" the time devoted to caregiving has short and long term economic consequences including employment consequences (Fast et al., 2013). These caregivers can also incur out-of-pocket expenses including fees for respite services, day support, and household help (Fast et al., 2013). A clear definition of services is essential to understanding those hidden costs and with them the actual cost-effectiveness of home supports and community-based care for older adults.

In addition to including the cost to caregivers is understanding the cost-effectiveness of supports targeted towards caregivers. A review conducted in the UK (Picard, 2004) offers some insight as to possible outcomes<sup>1</sup> with a view to understanding: 1) the effectiveness of services in delaying residential and nursing home care admissions; 2) whether carers had access to effective services to support them in sustaining their caregiving role. Pickard (2004) defines outcome measures for family and friend caregivers of older adults as: caregiver burden, caregiver well-being, caregiver physical health, and caregiver emotional health. Client outcomes are similarly defined and include measures of physical and emotional health, client satisfaction with services, and rates of admission to institutional care, hospital admissions and other service utilization rates. Measures of effectiveness include: reductions in caregiver burden; reductions in caregiver mortality; reductions in caregiver unmet needs for support; increase in caregiver physical or emotional health and well-being; increase in caregiver social interaction; increase in caregiver satisfaction with services; increase in caregiver employment (Pickard, 2004). The final measure of effectiveness reflects recognition of the oft-overlooked price of caregiving detailed by Fast et al. (2013). Despite the common assumption that home supports offer a less costly alternative to residential long term care, the major findings from Pickard (2004)'s review suggest that the total costs of community-based home supports may actually exceed those of residential care, particularly when the costs to caregivers are taken into account.

#### 4.0 Review of the Literature on Home Supports and Community-Based Services

Much of the published research brings together home supports and in-home professional services such as nursing under the umbrella term 'home care'. This makes it difficult to understand the effectiveness of non-medical supports and services specifically or to separate its effect/contribution to the maintenance of the older adult.

In a comparison of data collected on adults who were using government subsidized homecare in 1994 and 2003, Statistics Canada observed that in 2003 recipients of home care spent fewer days in hospital, despite the fact that a smaller percentage of people who needed home care were actually receiving it (35% compared to 46%). In 2003 more people were utilizing nursing care and personal care than in 1994 (52% compared to 39%) and less people were receiving housekeeping services (33% compared for 51%) (as cited in Canadian Healthcare Association, 2009).

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<sup>1</sup> Many of the studies reviewed involved an examination of dementia-specific care.

The way in which services are available and offered in publicly funded programs is inconsistent so it can be difficult to address effectiveness. Typically in-home services include personal care, homemaking, home-delivered meals and respite (Xu, et al., 2010; Li, 2006; Li, et al., 2012; Tang & Lee, 2010). These services are the focus of this review. Others that are acknowledged as a part of the support system, but not always considered in their own right are: transportation, home modification, assistive devices, senior lunch, helpline users, senior centers and visitation services (Tang & Lee, 2010; Li, 2006). Despite the important role they play in maintaining an older adult at home, these are usually not part of, or supported by, publicly funded home care programs. The following section outlines key studies that offer some insights in the effectiveness of in-home supports.

#### *4.1 Homemaking, Housekeeping & Personal Care*

In-home supports such as homemaking are valued by both older people and their carers as forming an essential part of a cost-effective community care package that can delay institutionalization and contribute to reductions in caregiver stress. In a UK review of the literature on cost-effectiveness of in-home supports Picard (2004) cites several studies (conducted prior to and following community care reforms introduced in the UK) that indicate that receipt of home supports can enable people to remain in the community for longer (e.g., Davies & Fernandez, 2000; Levin et al., 1989; Twigg, 1992; Whitby & Joomratty, 1990). One notable study reviewed found that the provision of in-home care such as heavy homemaking increased the length of stay in the community by 93% for recipients (Davies & Fernandez, 2000). However, Picard (2004) also cautions that these findings do not necessarily suggest that in-home supports are a cost-effective way of reducing caregiver burden and that such supports should be considered in relation with interventions for caregivers.

Tang and Lee (2010) identify homemaking (or housekeeping) and personal care as crucial in assisting older adults to maintain independence and live at home. Through a telephone survey of older adults identified as vulnerable and currently using at least one support, Tang and Lee (2010) identified that there are five services directly related to ones perceived ability to age in place, which are: 1) adult day; 2) housekeeping; 3) senior lunch; 4) helpline users; 5) personal assistance. Both housekeeping and personal assistance were associated with the highest need for aging in place from those currently using the service or who have used the service in the past. Service availability and utilization of these services is often linked to rurality but interestingly Li, (2006) shows that a significant number of caregivers in urban areas identify both personal care and homemaking as an unmet need (33%, 31%) when compared to those living rurally 24%, 22%. Despite the recognized importance of these support services, no studies were uncovered that examined the effectiveness of these services specifically in terms of maintaining independence and preventing long term care placement. Studies that did were situated in relation to receipt of professional services (Chappell & Hollander, 2013; Hollander & Chappell, 2001; Lum, Ruff & Williams, 2005).

#### *4.2 Caregiver Support*

Family caregivers make a significant contribution to the maintenance of an older person's situation. As previously described they are often the "glue" holding the home and community



care package together (Williams et al, 2009). Since institutionalization is largely due to caregiver burden and caregiver depression (Keefe & Manning, 2005), efforts taken to address caregiver burden are expected to have impact on placement outcomes. To remain within the scope of the targeted review only those studies that addressed caregiver support within the context of in-home supports. The series of studies discussed below examine caregiver satisfaction via a consideration of different aspects of home support, such as interactions with home support workers, and safety and security. Satisfaction is also viewed through the lens of rates of institutionalization.

A thematic review of the literature on caregiver satisfaction with home support (and home support workers) notes the significance of the preservation of autonomy and a person-centred focus to caregiver satisfaction (Byrne, Sims-Gould, Martin-Matthews, & Frazee, 2012). Developing relationships based on trust are central to satisfaction and should involve the client and caregiver's expectations of the home care worker's skills during the period of adjustment to the introduction of home support services (Soodeen, Gregory, & Bond, 2007). Listening, interaction with the home care worker and recognition and validation were identified as important to a person-centred focus (Byrne et al., 2012). However, there are some situations in which care is non-negotiable and efforts to preserve autonomy are necessarily limited, such as situations where safety is involved (Byrne et al., 2012).

Caregivers also identify safety and security as a significant part of the service satisfaction. In both a community service (adult day) and a one on one in home support, respite can give a sense of security that their loved one is safe (Gaugler, 2013; Soodeen et al., 2007). Often the caregiver has difficulty feeling comfortable with both taking their loved one out due to physical or cognitive impairment, but also feels very uncomfortable with leaving the care receiver at home alone.

Caregiver support has been found to delay institutionalization as caregivers initiating institutional placement is largely due to caregiver burden and caregiver depression (Keefe & Manning, 2005). A large study of 4,761 caregivers of persons with dementia were followed for a three year period looking at duration of supports and their long term use outcomes using a Cox proportional hazards model (Gaugler, Kane, Kane, & Newcomer, 2005). Outcomes of this study show that the utilization of home and community based services do not directly relate to the availability of the services. Utilization does show evidence of delaying institutionalization when implemented earlier on (Gaugler, et al., 2005) but people are either lacking in knowledge of what is available (Tang & Lee, 2010) or for unknown reasons are simply not accessing services in the areas which caregiver identify as a gap (Li et al., 2012).

A longitudinal study that included 406 caregivers of spouses with Alzheimer's disease by Mittelman, Haley, Clay and Roth (2006) examined institutionalization placement and found significance in placement reduction when ongoing caregiver support was provided. The focus was on utilization of six individual/family counselling sessions, ongoing caregiver support, group participation and continuous availability of telephone counselling to address if these supports lead to institutional delay (Mittelman et al., 2006). Over the 9.5 years a questionnaire was administered at baseline, every four months for the initial year, and then

at 6-month intervals until the end of the study. Results measuring the effects of the interventions collectively showed that overall there was a 28.3% reduction in the rate of institutionalization.

### 4.3 Respite

There are three primary types of respite services; in home attendants, adult day programs and short stay beds in facilities (Chappell, 2012). Regardless of the type of respite service, the benefit to the caregiver directly impacts the success of the older adult aging in place. A study by Ashworth and Baker (2000) assessed the three types of respite care in a general way focusing on the costs and benefits. The results showed that while all types of respite care were beneficial, requesting and accepting assistance was difficult for a number of reasons. The caregiver viewed respite as a sign that they were not good at their job, a failure, or having difficulties with trust. The caregivers also said they were critical of professional care when considering the type of care they believed they could provide (Ashworth & Baker, 2000).

#### 4.3.1 In-Home Respite

Quality of life of caregivers is a strong predictor of the success of an older adult aging in place and the utilization of a respite service can be an essential part of a caregiver's quality of life (Bartfay & Bartfay, 2013). It offers caregivers a break from their responsibilities which can offset feelings of burden. In-home respite is commonly accepted as a productive way to address caregiver burden and protect and improve caregivers' quality of life. A recent study in two home care sites in Alberta examined the impact of enhanced respite offered to caregivers who receiving publicly funded respite services and were assessed as having an "at-risk" caregiving situation and could benefit from having access to enhanced supports, as compared with caregivers who were assessed as "at-risk" but did not receive enhanced supports (Henningsen, 2012). The study, which involved 79 caregivers of persons with and without dementia, found that for those that received AHS-funded respite there were noted decreases in Caregiver Risk Screen score (33%) and Zarit Burden test score (41%). Further, 86% of the caregivers that participated and received AHS-funded respite rated the intervention as 8 out of 10 or higher (indicating satisfaction), and those that received additional respite hours reported a reduce in stress (Henningsen, 2012).

However, research exists that challenges unexamined relations to the supposed benefits of respite; as, for instance, in a meta-analytic review and quantitative analysis of the effect of different types of professional dementia home care interventions by Schoenmakers, Buntinx and De Lepeleire (2010). This study noted a relationship between respite and an increase in caregiver distress, although it found that home care was experienced positively and did help to reduce caregiver burden, albeit in a non-significant way. Another interesting research finding was that a psychosocial intervention was associated with a decrease in depression; multidisciplinary case management appeared to produce a greater, although also insignificant, decrease.

### 4.3.2 Adult Day

Adult day programming as another source of caregiver respite is significant to the overall wellbeing of the caregiver. Schacke and Zank (2006) found when measuring the effect that adult day programming has on caregiver stress for caregivers caring for someone with dementia, outcomes included: having the ability to cope with behavioural problems of the care receiver, a decrease in stress where related to a restriction of their own person needs such as regeneration and social participation, and finally a reduction in stress where related to role conflicts such as family obligations and their job. Findings from the implementation of a comprehensive, multidimensional, caregiver stress measure with 77 caregivers suggest that adult day will neither eliminate caregiver stress nor address all areas of caregiver stress, but where it is effective (as listed above), it is significant.

The level of effectiveness of respite programs like adult day is increased when used in coordination with other services and caregiver supports. Adult Day Services Plus (ADS Plus) is a U.S. program designed to address the well-being of caregivers with dementia, increase the utilization of the service and delay or decrease institutionalization which added psychosocial caregiver support to an existing adult day service (Gitlin, Reeve, Dennis, Mathieu, & Hauck, 2006). ADS Plus is a stress process model which targets the primary stressors of caregiving, behavioural problems of care recipients and the overall health of the caregiver. The measures included a short 10 item assessment measuring caregiver depression, the Zarit Burden Interview, the Memory and Problem Behaviors scale, Perceived Change Index, and six items from the National Institute of Health multisite Resources for Enhancing Alzheimer's Caregivers' Health initiative (Gitlin et al., 2006). Assessments were followed up at 3, 6 and 12-month timelines. The short term effects of ADS Plus were that caregiver participants showed a significant decrease in depression and memory and problem behaviour self-efficacy; reported more confidence, overall change for the better and caregiver burden showed a marginal effect but not statistically significant at the 3 month follow up. The statistically significant long term effects of the ADS Plus program were a reduction in levels of depression and memory and problem behaviour efficacy (Gitlin et al., 2006).

It should also be noted that utilization of adult day services does not always lead to a decreased chance of institutionalization. A longitudinal study that examined the use of adult day services by 218 clients with Alzheimer's disease at three month intervals over 48 months using Cox proportionate hazards models found that the risk of placement in a nursing home facility increased significantly, especially for males (McCann et al., 2005). Factors other than caregiver burden may be involved, such as a tendency to institutionalize (McCann et al., 2005). For this reason, there are limits to using service utilization and hospitalization as measures of effectiveness.

### 4.3.3 Short Stay Bed

A 1998 study on the effectiveness of rehabilitative day hospital care on community-based home care patients was conducted with 177 individuals receiving home care in a rural area. Participants were randomized into two groups. One group was offered a 2-month period of rehabilitation and medical care in a day hospital, while the second group was offered

treatment in home care. Both groups were examined at the start of the study and then again, 2, 5, and 12 months later. Indicators of effectiveness included use of health services, subjective health, symptoms, satisfaction with care and physical functioning, measured by the Katz ADI Index. Results showed that day hospital care affects the quality of life of older people as indicated in improvements of patients' views of their own health, but that it does not clinically significantly improve physical functioning or reduce use of health services.

#### *4.4 Other Recognized Initiatives that Maintain an Older Person to Live Independently*

Other services and programs that are part of a support system to maintain independence and prevent long term care placement can include: transportation, home modification, assistive devices, senior lunch, helpline users, senior centers, visitation services and fall prevention initiatives. Since the focus of this review is on supports that may be available or supported through publicly funded home care programs, we reviewed evidence pertaining to meal delivery programs.

##### 4.4.1 Meal Delivery Programs

The usage of meal delivery programs such as Meals on Wheels can help to support aging in place successfully. The utilization of home delivered meals has been found to have a positive impact on intake patterns and contribute to an increase in overall nutrition and improved food security (Frongillo & Wolfe, 2010). Additionally, a meals on wheels program was much more likely to have an impact on older adults living alone (Frongillo & Wolfe, 2010). Nutrition deficiency can lead to an array of debilitating circumstances that can have effects such as fatigue, energy reduction and falls. Many older adults are undernourished and although receiving meals on wheels may not change the assessment of undernourished to nourished, research suggests that the inclusion of such meal supports can have a significant reduction of falls leading to hospitalizations (Luscombe-Marsh, Chapman, & Visvanathan, 2013). An empirical study in Australia examined the effects of a Meal on Wheels (MOW) program that classified 250 older adults as either receiving MOW and being undernourished or not receiving MOW and being undernourished, and then compared both groups to a well-nourished group (Luscombe-Marsh, Chapman & Visvanathan, 2013). Both groups (under nourished receiving MOW and undernourished not receiving MOW) were similar when looking at weight loss and frequency of falls in comparison to the well-nourished older adults. However, when compared with the well-nourished subjects, it was only the non-MOW group who actually had a statistically greater frequency of falls that lead to hospital admissions and longer hospital stays. Those receiving MOW, even when considered undernourished, were observed to have fewer incidences of falls resulting in hospital admissions than those not receiving the meals (Luscombe-Marsh, Chapman & Visvanathan, 2013).

#### 5.0 Home Supports & Integrative Care Model Implementation

When considering cost effectiveness from a systems perspective, the concept of a systematic home and community based service procedure is essential (Hollander et al., 2009; Hollander & Chappell, 2007). Attention to benefits to the client as well as the effectiveness in monetary savings at a systems level is central to programs that are situated

within a coordinated services approach (i.e., all home and community based services, long term care facility services, community interventions, hospitals) (Hollander, Miller, MacAdam, Chappell, & Pedlar, 2009; Stuart & Weinrich, 2001; Lum & Aikens, 2009; Li, Phillips, & Weber, 2009).

### *5.1 Integrated Care Models*

Chappell and Hollander (2013) suggest that for home care to be cost-effective an integrated system of care is needed. However, they also identify a lack of agreement about what integrated care means or what services are included. In their review of the literature on integrated models of care for the frail elderly, Béland and Hollander (2011) note the existence of two types of care delivery: community-based cooperative models and large-scale centralized models. Integrative care models can also look different depending on which services are included (i.e., community-based cooperative models and large-scale centralized models) (Beland & Hollander, 2011). Drawing on Kodner (2006), MacAdam (2008) identifies four elements key to integrated care: umbrella organization structures, organized provider networks, financial incentives, and perhaps most important, multidisciplinary case management.

Research on the relationship between community support services and the well-being of seniors in supportive and social housing in Toronto, Canada, conducted by Lum, Ruff and Williams (2005) documented patterns of community support service use by seniors and analyzed the impact of support services on functional independence, social connectedness, physical and mental well-being and use of formal emergency services. The findings of this study, which included interviews with 226 older adults, suggest that services are most effective when they were integrated and managed around individual need and that minimal levels of services were used.

The following section examines two models of integrated care. One model was developed in Denmark and adapted for use in the rural Ontario community of Deep River, while the second model is currently in use in the US. As briefly described below, the perceived effectiveness of the models should be understood within the jurisdictional context of their implementation.

#### 5.1.1 Denmark Model of Integrated Care

In the mid 1980's an innovative integrated model of care for older adults in Denmark emerged as a promising example of integrated care (Stuart & Weinrich, 2001). Denmark's model focused on the coordination and usage of existing and some new supports and services such as; homemaking, personal care, caregiver support, respite, home meal delivery, long term care facilities, hospitals and an in home security service. Of the 275 Danish municipalities participating in this model of care, within the first 12 years there were many proven cost effective markers, for example: the growth of the Danish long term care expenditures levelled off, expenditures dramatically decreased in the over 80 population, and Denmark dropped a percentage of the gross domestic product (Hollander et al., 2009; Stuart & Weinrich, 2001). In a comparative study with the United States using the international comparative policy analysis, Denmark showed dramatic positive results (as

stated above) while the US expenditures continued to increase and deficits in access and quality of care remained unchanged (Stuart & Weinrich, 2001). When looking at per capita expenditures between the 1985-1997, Denmark's costs increased by 8% for integrated care services with people over 65 years of age, while the United States increase was 67% during the same period. Furthermore, while the expenditures of the over 80 population decreased in Denmark by 12%, they increased by 68% in the United States (Hollander et al., 2009; Stuart & Weinrich, 2001). These dramatic results have been a great source of interest and have led to Canadian consideration.

Because of the success Denmark has had with the implementation of this type of an integrated care model, it has been adopted in the Canadian context in Deep River, a small community in Ontario (Lum & Aikens, 2009). With the Rural Network Model used as a framework for implementation, Deep River's project was able to recognize and build on the internal community capacity to use already existing services to work collaboratively and link services as well as create new services (Lum & Aikens, 2009). Deep River is a rural community and like other rural communities, they survived by working together when formal services were not available, described as the 'Belief in Community' (Skinner et al., 2008). 'Belief in Community' suggests that those living rurally work together in unity for a common goal, to take care of one another. Integrated home and community based services were provided (access to meals, personal support workers, reassurance checks/security, housekeeping, caregiver support, transportation links, adult day services and recreation/social services) (Lum & Aikens, 2009).

Not only are the home and community based supports integrated but other services such as shared speciality staff (physicians, dietician); laundry (long term care facility and hospital was completed at one location); supportive care apartments, respite beds and long term care beds were offered in one building; and continued education such as dementia care was offered collectively to each of the hospital staff, home and community support staff, and long term care staff (Lum & Aikens, 2009). A state of the art communication technology was implemented as adapted from Denmark's initiative, which consisted of a call button worn on wrist/neck and was connected to the client's phone which automatically placed a call to one of the 24/7 home support worker(s) cell phones to provide fast service with a familiar person and quite frequently eliminated the need for a hospital visit (Lum & Aikens, 2009). Because of the level of collaboration, a case manager was not necessary to achieve these results, which has been strongly suggested by other researchers as a necessity in an integrated model of care in order to manage client services (Li, Phillips, & Weber, 2009; Chappell & Hollander, 2013). The project showed an increase to overall care with a reduction in costs. A significant reduction in ER visits and long hospital stays were two major cost effective benefits of the implementation of this integrative model of care (Lum & Aikens, 2009).

#### 5.1.2 Program of All-inclusive Care for the Elderly (PACE)

Program of All-inclusive Care for the Elderly (PACE) is a well-known integrated care model in the United States. It was developed and first implemented over 40 years ago and now has 71 organizations following the PACE framework in 31 states providing services to over 18,000 seniors throughout the country (Li, Phillips, & Weber, 2009). PACE, which was

originally called 'On Lok' meaning "peaceful, happy abode" in Cantonese, was built on the foundation of offering frail elderly people the option to age in place through providing a service to enhance safety, increase overall health and well-being with in interdisciplinary web of care (Li, Phillips & Weber, 2009). PACE works within 'Adult Day Health Clinics' which is a building consisting of a typical adult day like recreation/social programming and meals but also as a health clinic with various therapies (Physiotherapy, Occupational Therapy, Recreation Therapy) offered as well as on-site physicians and other speciality services. Transportation is provided to and from the 'clinic' making for a well-rounded service to keep clients able to age in place, provides assistance to caregivers with respite and a lessening of burden in escorting their loved one to various appointments/services. Like the Denmark model and the adapted model followed in Deep River, a minimization of ER visits, hospitalizations, and preventing various health emergencies has been achieved throughout this long term program.

## 6.0 Key Message, Gaps, Limitations

The targeted review of the literature on non-medical home supports revealed that there are limited studies on the effectiveness of in home supports, and that the research that does exist is fragmented (i.e., focusing on a particular support in isolation of other supports and/or in the absence of a consideration of the contexts and systems within which the support is situated). For the most part, existing research tends to be US-based, to consider home care more generally, and include medical supports in analyses of effectiveness. While such research is valuable, it restricts understanding of the impact of social supports and human services on delaying institutionalization. Within research that examines medical and non-medical supports in tandem, assumptions concerning the superior value of medical as compared to non-medical supports are left unexamined, and the specific qualities and properties of home supports that make HCBS distinct from institutional care are more easily overlooked.

Studies that overtly privileged medical home supports were excluded from the review. The lack of published research that privileged non-medical home supports the search produced presented a challenge to conducting the review. To address this challenge studies were reviewed that may have included, but did not privilege, medical supports. These studies were diverse in the supports examined, sample sizes, methodologies, geographic foci, analyses and findings. Studies on clients and caregivers tended for the most part to be small, with the exception of Mittelman et al. (2006)'s longitudinal research. Published research on integrated care models tended to be larger, representative of a systems level perspective, and more responsive to the existence of clusters of supports and services and their coordination, sometimes at the expense of a refined understanding of the specific impact of individual supports and services.

The most obvious limitation of the current literature on HCBS concerns a lack of conceptual framework. This makes it difficult to compare the findings and learnings of the limited research that does exist. There was a noticeable absence of a theoretical framework in any of the research, even the more comprehensive studies on integrated care. Although effectiveness may have been operationalized and measured (and surprisingly this was not always the case), and a context or background to the relevance of a study on the supports(s)

provided, the guiding frameworks and/or methodological assumptions were rarely explicitly discussed. If understanding cost-effectiveness is the aim, what kind of conceptual framework is needed to understand cost-effectiveness *within the context of non-medical home supports*? The oft-cited difficulty in determining cost and cost effectiveness due to recognition of the 'hidden costs' of caregiving cannot be resolved without a consideration of what makes non-medical supports distinct.

The diversity of studies included in the review reflects the inter/multi-disciplinary nature of the subject under investigation. The research on the integrated care models speaks to the relationality between and across different sites. Nonetheless, one should be able to understand the effectiveness of homemaking or respite without necessarily advocating for integrated care. Future research that not only produces or collects information but that integrates it would make a valuable contribution to the field. Many of the studies reviewed for this paper suggest that an examination of outcomes, measures and evaluations of the effectiveness of home and community-based supports for older adults should include a consideration of the specific nature of the conditions requiring care, particularly dementia.

This paper has provided an overview of current literature examining the effectiveness of home and community based supports and services for older adults. It highlights the importance of service integration to real and perceived effectiveness. It is clear from the literature that effectiveness was primarily understood in terms of cost-effectiveness, and that this was true even in research in which client/caregiver quality of life was the criteria of effectiveness. Much of the existing research focuses on a systems perspective, with limited attention to the coordination of services across multiple and divergent domains (local, regional, national). There was a noticeable gap in published research that privileged the client/caregiver perspective, and more broadly, a general failure to attend to individual characteristics that may be contributing factors in home and community-based supports service utilization and long term care admission. Given our learnings from the review, the following represent potential avenues for future research:

- Research that focuses on the (cost) effectiveness of non-medical home and community supports in the Canadian context (and that provides a method for addressing the distinction between non-medical and medical home care services in understanding effectiveness);
- Longitudinal research that examines utilization of non-medical home supports on client/caregiver quality of life;
- Research that focuses on non-medical home support services and their relationship to prevention or delay of long term care placement;
- Research on indicators of quality of care, quality of life and client/caregiver satisfaction within the context of in home supports;
- Research on the efficacy of different provider/delivery models of in home support services;
- Research that includes the costs of caregiving into evaluations of the (cost) effectiveness of home supports.



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## Appendix A – Search Terms

### General Search

- aging in place, health services
- aging in place, outcomes
- aging in place, policy
- client perspectives, home care
- community care, expectations
- community care, expectations, older adults
- community care, instruments of evaluation
- community care, knowledge transfer
- community care, measures
- community care, models
- community care, older adults, knowledge transfer
- community care, outcomes
- community care, outcomes, older adults
- community care, research capacity
- community care, research capacity, older adults
- community-based care, evaluation, instruments
- community-based care, evidence, effectiveness
- Hollander, home care
- home care expectations, older adults
- home care, Canada
- home care, Canada, benefits
- home care, Canada, review
- home care, community care, research capacity
- home care, empirical, Canada
- home care, evaluation, instruments
- home care, evidence, effectiveness, seniors
- home care, evidence, policy
- home care, evidence-based knowledge
- home care, expectations
- home care, instruments of evaluation
- home care, knowledge transfer
- home care, long term care, Canada
- home care, measures
- home care, models
- home care, older adults, benefits
- home care, older adults, health systems
- home care, older adults, knowledge transfer
- home care, older adults, policy
- home care, older adults, practice
- home care, outcomes
- home care, outcomes, older adults
- home care, research capacity
- home care, research capacity, older adults
- home care, seniors, knowledge transfer

- home care, supports, Canada
- innovation, home care, Canada
- system perspectives, home care

#### Systems-Level Outcomes

- home care, long term care facility waiting lists
- home care, older adults, emergency visits/hospitalizations
- home care, older adults, fall prevention
- home care, older adults, incident reports/accident reports
- home care, older adults, provider morale
- home care, older adults, rates of institutionalization
- home care, older adults, readmission
- home care, older adults, safety
- home care, residential placement
- meal on wheels, effectiveness
- meals on wheels, results
- meals on wheels, outcomes
- falls prevention, seniors
- falls prevention program, seniors
- falls prevention, seniors, Canada

#### Client Outcomes

- home care, older adults, functioning
- home care, older adults, life satisfaction
- home care, older adults, mortality
- home care, older adults, quality of life
- home care, older adults, satisfaction with care

#### Family Caregivers

- adult day care, assessment
- adult day care, evaluation
- adult day care, outcomes
- adult day care, quality of life
- adult day care, quality of life
- adult day care, satisfaction
- educational programs, family caregivers, assessment
- educational programs, family caregivers, evaluation
- educational programs, family caregivers, outcomes
- educational programs, family caregivers, quality of life
- educational programs, family caregivers, satisfaction
- home care, family caregivers, effectiveness
- home care, family caregivers, evaluation
- home care, family caregivers, outcomes
- respite, older adults, assessment
- respite, older adults, evaluation
- respite, older adults, outcomes
- respite, older adults, quality of life

- respite, older adults, satisfaction
- caregiver, respite
- support groups, family caregivers, assessment
- support groups, family caregivers, evaluation
- support groups, family caregivers, outcomes
- supports, caregiver, older adult, assessment
- supports, caregiver, older adult, evaluation
- supports, family caregivers, older adults

## Appendix B – Databases

- Ageline
- ProQuest
- Medline
- Pubmed
- Science Direct
- Article First
- Project Muse
- Google Scholar
- PsycINFO (EBSCO)
- Ageline