



# THE SCHOOL OF PUBLIC POLICY

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## MASTER OF PUBLIC POLICY CAPSTONE PROJECT

Improving Caregiver Supports through System Integration

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## Capstone Executive Summary

Integration is a near-universal problem in all modern systems. From computer science to business, engineering, and healthcare, systems today are more complex than they ever have been, and fragmentation is more of a concern than ever. In human services, fragmentation is also a concern, and some sectors have taken steps to address their fragmentation issues through integration initiatives. Researchers, in recognizing problems on the world stage have not been left out of the discussion, and numerous integration frameworks exist in the academic literature.

In Alberta, caregivers, their care recipients, and service providers alike have expressed frustrations at the fragmentation of the 'system' intended to support informal caregivers. While a range of supports exists, connecting caregivers with the right supports, in the right place, at the right time has proved difficult. This paper uses Alberta's caregiver supports system as a case study on how to make integration real, creating a support system out of siloed, fragmented services. A one-day event facilitated by the University of Calgary's School of Public Policy brought together service providers and leaders in the caregiver support community, guiding them through a prioritization exercise on the path to achieving integration. The paper analyses and presents five participant-generated work packages through which the sector could move towards greater integration.

The paper concludes by drawing general findings on the process of understanding and implementing integration with recommendations for not just caregiver supports, but other sectors as well.

## **Introduction**

### **The Integration Problem**

Despite significant research supporting best practices in social support provision, actual delivery of services in Canada remains fragmented (Taylor, Quesnel-Valle, 2017). Although supports are generally available to the people who need them, many people have difficulty navigating and gaining access to systems they experience as fragmented (Bergman et al. 1997). Governments around the world have identified the need for increased integration of care, both in health and social services (Carstairs and Keon, 2009; Philippon, & Braithwaite, 2008).

“Integration” has become a buzzword with government and non-government organizations alike, but definitions of what integration means are inconsistent or non-existent across jurisdictions and sectors (Kodner, 2009). The result is that leaders want services to be more integrated but may not know what integration really means, or how to achieve it (Armitage, Suter, Oelke, & Adair, 2009). Stories abound from both support service users and providers about people falling through the cracks, in many cases resulting in harm or death (Anderssen, 2015; Cowan-Levine, 2017; Kwok, 2012; Ravenscroft, 2005).

### **Caregiver Supports Case Study**

This paper uses caregiver supports in Alberta as a case study on integration challenges in a real environment. Its focus is on informal caregivers to adults 55 years of age and older.

Informal caregivers of older adults experience a range of positive and negative effects throughout their caregiving journey, and 35 percent of people over the age of 45 will experience these challenges and rewards. Informal caregivers, defined as those who provide a range of support to older adults outside of the formal care system, provide at least 70% of all care to seniors in the community (Carstairs & Keon, 2009). It was estimated in 2009 that the formal Canadian healthcare system would have to spend 25 billion dollars to replace the contributions of informal caregivers (Chappell, Liu, & Hollander, 2009). Recent numbers have been estimated as high as 66.5 billion in replacement value, owing to the aging population and increasing prevalence of chronic illnesses (Fast, 2017). Informal caregivers are critical to the function of the formal health care system, despite working largely outside of it. One of the biggest drivers towards the recognition of fragmentation as a significant policy issue, and integration as a proven solution, is the growing older adult population and changing health needs.

### **The Aging Population and Increased Prevalence of Chronic Diseases**

Canada and many OECD countries are experiencing a historic shift in population demographics. People over 65 make up larger parts of the population than ever before, and life expectancies have increased twenty years in the last century (Calbrese, 2017; Greenber, Normandin, 2011). Alberta now has 575'000 people over the age of 65 and is projected to have twice that amount within 20 years (Government of Alberta, 2018). Older adults today are healthier and more financially prepared than in past generations, however, this historic shift in population has brought with it a drastic change in the demand for healthcare (Russell, 2017).

Healthcare needs have changed since the inception of Canada's health system, chronic conditions and frailty are more dominant issues for Canadians, owing in part to an aging population, better understanding of chronic diseases, and policy aimed at keeping people living in their communities (Van Duijn et al. 2018; Verma et al., 2014). In 2010, chronic diseases accounted for 9 out of ten deaths in Canada (World Health Organization (WHO), 2011). The majority of Canadians report living with one or more chronic conditions, and this number climbs to three quarter in people over 65 (CIHI, 2011). Canada spends a large amount of its budget on health services, with mediocre results (Canadian Institute for Health Information (CIHI), 2017; Conference Board of Canada, 2012). Over half of Canada's healthcare budget is spent on chronic diseases, while focused on hospital and physician-centred care, and health-only services. This focus means that the system relies heavily on caregivers to provide most of the community-based care. The costs of the system, and its reliance on caregivers will continue to grow as the population continues to age (Public Health Agency of Canada (PHAC), 2011). As the reliance on caregivers and no-health services increases, some research has recognized the benefits of investing in these supports (Dutton et al., 2018, pp. 70; Bradley et al. 2016; Ruben et al. 2016)

Supports for caregivers vary widely, including counselling, medication management, respite, transportation and more. Caregiver supports can be provided by governments, health authorities, not-for-profit organizations, and private companies (Covenant Health, 2016). In Alberta, these supports are available, though consistently providing the right amount of support to the right caregiver, at the right time has proved difficult. Caregivers find it difficult to enter the caregiver support system and navigate once within it



(Brémault-Phillips et al. 2016; Keefe 2011; Parmar, 2015; Samaha, Nickel, McFarlane, O'Brien, Lim, 2018). The difficulty of building a system of wrap-around support lies not in the types of supports available, nor the ability of caregivers to self-advocate, but instead in the lack of ability of the various parts of the system to work together effectively. The caregiver supports sector is a complex environment with a broad range of service providers, funding sources, subdivisions, clients, and types of support needed. The complexity derives from two domains, complexity of service providers, and the complexity of caregiver needs. Service providers operating in the caregiver supports sector provide a range of generally issue-specific supports. Service providers for older adults living in the community must balance funding constraints, strict mandates, high caseloads, organizational structures, and services that span across health and social services. Caregivers are equally complex, and many manage to support their care recipient with transportation, cooking, cleaning, emotional support, healthcare, finances, and more while simultaneously managing their own lives. This unfortunately leads many caregivers to experience their role as burdensome (for a review of the effects of caregiving, see appendix A). Alberta's caregiver support providers are as varied as the caregivers themselves. Service providers include not-for-profit social services organizations, the provincial government in the forms of Alberta Health Services (AHS), Ministry of Seniors and Housing, Family and Community Support Services, municipal governments, Primary Care Networks and other family physicians, and private-for-profit organizations. Services are delivered online, by telephone, or in hospitals, care centers, doctor's offices, caregiver's homes, or community "hubs".

The School of Public Policy brought together service providers within the caregiver supports sector for a facilitated event aimed at drawing out both positive examples of integration in action, and priorities for the sector to tackle on the road to better integration and client service. This paper presents the results of this event and some recommendations for both Alberta's caregiver support system, and other human service systems as well.

### **Background of the Fragmentation Problem**

The complexity of services and number of service providers involved in delivering them has led to a fragmentation problem that is recognized in many sectors. These sectors include homelessness (Guerrero, Henwood, & Wenzel, 2014; Rosenheck et al., 2001; Streim, 2017), health care (Martin et al., 2016), vocational education (Grubb, & McDonnell, 1996), as well as crisis intervention (Douglas, & Lurigio, 2010). As well as within sectors, the challenges of fragmentation are evident across multiple sectors (Van Duijn, Zonneveld, Montero, Minkman, & Nies, 2018). In human services, system fragmentation has been linked with failure to meet client needs, wasted resources (staff time, financial resources, supplies, etc.), bottlenecks in service, long wait times, and lower user satisfaction (Banks, 2004; Ramagem et al., 2011).

In the social services sectors, system fragmentation has perhaps been best studied by the homelessness sector. One example is the homeless-serving sector in Los Angeles, which recently underwent a process of system integration. People experiencing homelessness require a wide range of coordinated services from affordable housing, mental health therapy, job training, financial supports, food security and more (Streim, 2017). Prior to the initiative towards integration, these services were

geographically scattered. In some cases, there were multiple organizations providing the same service in the same area, or conversely, clients had to travel long distances to obtain services. People would have to visit multiple several locations and organizations for each individual support (job training, housing, health care, food), with no coordination between. Additionally, funding was given out in fragmented pieces, despite public and private organizations sharing the same goal of keeping people housed (Streim, 2017). This fragmentation created difficulty for service users in accessing supports, gaps in service, service duplication, poor outcome tracking, lower efficiency, and higher costs (Guerrero at al., 2014; Streim, 2017). Following an integration initiative, researchers observed more efficiency, less redundancy, higher user satisfaction (reported as not having to take inappropriate training, less travel, and less stress), and better service user outcomes (higher permanent housing retention and shorter stays in transitional housing) (Streim, 2017).

The caregiver-serving system is not immune to the trend towards fragmentation and shares some striking similarities to issues identified in the homeless-serving sector above. Caregivers, and the care recipients they care for, often require a broad range of supports from different organizations and sectors in the form of transportation, health, housing, food, cleaning, mobility, decision-making, and more (Turcotte, 2013). System integration is especially beneficial for these groups and is being increasingly recognized as a solution to modern fragmentation problems (Fisher & Elnitsky, 2012).

### **Integration as a Solution to Fragmentation**

While system integration is unlikely to be a “silver bullet” to solve all these challenges, it has nonetheless been repeatedly proposed and demonstrated to improve

client satisfaction, quality of care, service outcomes, and system efficiency in health and social services (Armitage, Oelke, Suter, & Adair, 2009; Fine, Pancharatnam, & Thompson, 2005; Guerrero et al. 2014; Hebert, 2012; Hwang, Chang, LaClair, Paz, 2013; MacAdam, 2008; Priest, 2012; Rosenheck et al., 2001; Streim, 2017). The caregiver supports sector, far from immune to fragmentation, was picked out by a Special Senate Committee in 2009 as likely to benefit from integration. Integration, the committee found, would allow the sector to better address the needs of community-dwelling older adults with chronic health conditions, improve financial sustainability, and make necessary support services more accessible (Carstairs & Keon, 2009; MacAdam, 2008).

### **Defining Integration**

Definitions of integration abound. A literature review by Armitage et al. (2009, p. 4) found over 175 definitions and concepts of integration focused on health or social services. Integration is often discussed alongside system cost, patient experiences, and is most often coupled with concepts such as continuity and coordination across services (Gillies, Shortell, Anderson, Mitchell, & Morgan, 1993). Additionally, integration can take different forms, from linkage, in its least comprehensive form, where specialized services and general services operate separately, to coordination, where different services provide care independently, with coordination and communication between, to full integration, where all aspects of a system are seamless and synergistic (Leutz, 1999, Van Duijn et al. 2018). The lack of an agreed-upon definition of integrated care strongly suggests that implementation, evaluation, and comparison problems exist, and sector-specific or geographic-specific considerations are important. Making

recommendations for integration real are, it seems, very much a matter of local context and relationships. Indeed, integration is relationship-based, requires trust and experience, and the barriers to accomplishing it exist at multiple levels of the system, from financing (MacAdam, 2008) to organizational culture (Kodner, 2009), regional variation, conflicts in mandate (Hollander & Prince, 2008), or provider relationships (Taylor-Robinson et al., 2012).

This paper uses Kodner and Spreeuenberg's definition of integration as a coherent set of methods and models "designed to create connectivity, alignment and collaboration within and between the cure and care sectors" with the goal of enhancing "quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long-term problems cutting across multiple services, providers and settings quality of care" (2002, p.3). This definition is useful as it is relevant to the population in question, patient-centered, and broad enough to be easily adapted to different social service sectors while respecting their unique aspects. It does not limit itself to healthcare services only and strays from healthcare-dominated terminology such as "diagnosis" and "rehabilitation", which may themselves exclude non-healthcare services.

With these factors in mind, as well as the lack of consensus on what integration is, a range of researchers have sought to provide policy-makers and practitioners with frameworks for understanding integration and putting integration into action.

### **Models of Integration**

The following section begins by introducing criteria for selecting a model of integration that will be most appropriate to the caregiver supports sector. It then reviews some of the more established models of integration applying those criteria to the models, and so selecting a particular framework to guide discussions at the facilitated event.

1. **Flexible to multiple systems/jurisdictions** – Integration is a process that requires an understanding of the relationships and unique context of the sector and location. The model must allow for this flexibility by providing a structure which is not restrictive. Additionally, due to the nature of caregiver supports, it must allow for cross-sectoral integration as supports in this sector are through health and social service systems.

2. **Built from a person-centered lens** – The goal of integration is broad, and many have connected better system integration with more resource efficiency. However, from the perspective of caregivers, care recipients, and service providers, the desire for more integrated services is driven by the desire for a better service. While integration may offer cost-savings, or more efficiency, and these benefits should not be ignored, the main driver is the goal of serving people better, and the framework should recognize this reality.

3. **Involves many sectors and organizations** – Caregiver supports are provided by several organizations, with different structures, mandates, policies, and funders. Frameworks which focus on single-organization integration would not be suitable to the caregiver support system due to this.

4. **Well-cited in academic literature** – This event offers the opportunity to engage with an academic framework of integration and bridge the gap between academia, and direct practice. As such, the chosen framework should be well-cited in the academic literature and provide structure based on research practices and academic expertise.

5. **Avoids a focus on hospitals and physicians** – Caregivers require supports from both health and social services in the community. Physicians and hospitals are a necessary part of caregiver supports, however integration must involve all parts of the care team, and the framework should recognize this necessity.

### **A Review of Major Frameworks of Integration**

#### **Hollander-Prince Framework (Hollander & Prince, 2008)**

Hollander and Prince present a 3-tiered framework for the integration of services. This framework was generated through interviews and focus groups with care providers, as well as a literature review to address gaps in health care services for four populations: the elderly, persons with disabilities, persons with chronic mental health conditions and children with special needs. These populations are those who typically require ongoing care and may have one or more informal caregivers involved in their care. The first tier is the philosophical and policy pre-requisites, which included beliefs in the benefits of the system, and commitments by the entire sector to a full range of services, psychosocial model, and evidence-based decision-making. The next tier contains ten best practices split into five administrative best practices and clinical best practices. This tier includes shared philosophy displayed in policy, highly coordinated or

shared funding, administration, information systems, entry system, assessment, case management, and the inclusion of families. Finally, the third and most “on the ground” tier is the inclusion of linkage mechanisms across population groups, hospitals, primary health care, and social and human services. These linkage mechanisms include some recommendations specific for community-based care, including physician consultations in the community, cross-sectoral planning with community agencies, and co-location of community and hospital staff.

### **Evaluation of the Hollander-Prince Framework**

- 1. Flexible to multiple systems/jurisdictions** – Hollander and Prince’s framework is flexible across multiple dimensions, the three tiers allow for change at many levels of the system with only the requirement for hospitals, primary care, and social services.
- 2. Uses a person-centered lens** – While there is no explicit mention of person-centered care, the framework aims to improve quality of care and system efficiency. The authors mention the need to address common complaints and experiences of care recipients throughout their analysis.
- 3. Involves many sectors and organizations** – Although the model does mention the need for better inclusion of community and human-service organizations, most of the framework is centered around health-specific services including physicians, hospitals, and primary care facilities.
- 4. Well-cited in academic literature** – Since the frameworks’ conception in 2008, it has been cited somewhat frequently in academic literature, both in Canada and



internationally (MacAdam, 2008; Strandberg-Larsen, 2011). The article has 59 citations in Google Scholar.

- 5. Avoids a focus on hospitals and physicians** – As noted above, the framework discusses healthcare specifically, and though it mentions community-based services and non-health supports, the focus is on health-only services like hospitals, primary care clinics, and physicians.

### **The Kodner and Spreeuwenberg Framework (Kodner & Spreeuwenberg, 2002)**

The Kodner and Spreeuwenberg framework provides 5 streams of focus which, together can bring a loosely-associated system towards more integrated services.

**Funding** – Stating that form follows financing, this stream focuses on the way money is spent on both social and health services. Pooled funding and capitation are specifically mentioned by Kodner and Spreeuwenberg.

**Administrative** – The way government regulatory and administrative functions are structured can eliminate program deficiencies and ease the transition between programs and sectors.

**Organisational** – Vertical and horizontal networking, both formal or informal intersectoral relationships and co-management of programs comprise this stream of the framework.

**Service Delivery** – The method of service delivery and management including staff training and practice approaches are included in this stream.

**Clinical** – Shared understanding of patient needs, common language, uniform assessments, the use of agreed-upon practices and standards define this stream of the framework.

### **Evaluation of the Kodner and Spreeuwenberg framework.**

1. **Flexible to multiple systems/jurisdictions** – The framework gives a list of areas for discussion; these areas can be understood through many different realities. This framework allows for discussing integration within the Alberta/Canadian context as well as organization-specific contexts.
2. **Uses a person-centered lens** - The framework was built on a person-centered focus and mentions this goal specifically. While the model offers potential cost-saving outcomes, it stems primarily from a desire for higher quality care for patients.
3. **Involves many sectors and organizations** – The framework begins by recognizing that true integration occurs where many organizations and sectors interact. This focus can be seen throughout the framework, which focuses on the way organizations work together regardless of their sector or unique circumstances.
4. **Well cited in academic literature** - The framework has been used extensively and recently since its inception and has been discussed in multiple jurisdictions including Canada (Cameron, & Gignac, 2008; MacAdam, 2008), Europe (Leichsenring, 2004; Shaw, Rosen, & Rumbold, 2011), and Australia (Davies et al. 2008). It has been cited 842 times according to Google Scholar.

5. **Avoids a focus on hospitals and physicians** – The framework is primarily focused on health-care organizations; however, it does not make specific reference to healthcare institutions. Although the framework leans towards a healthcare environment it is general enough to be adaptable to non-healthcare environments.

### **Minkman’s Developmental Model for Integrated Care (DMIC) (Minkman, 2012)**

Minkman’s model was developed in the Netherland as a response to integration challenges in post-stroke services. The model was developed through a literature review and Delphi-style questionnaire involving professionals with experience in research and integrated care programming. The model contains 89 unique elements which are grouped into nine “clusters”. These 9 clusters are “quality care, performance management, interprofessional teamwork, delivery system, roles and tasks, patient-centeredness, commitment, transparent entrepreneurship” (p. 3). In addition to these nine clusters, Minkman describes a four-phase implementation process. These phases are initiative and design; the experimentation and execution; expansion and monitoring; and consolidation and transformation.

### **Evaluation of the DMIC**

1. **Flexible to multiple systems/jurisdictions** – The DMIC framework provides specific categories and phases, however it allows systems to self-identify where they are in the process and define their own goals and plans to move forward. It has been tested both in Europe and Canada and shown to be successful.

2. **Uses a person-centered lens** – The model does not see person-centered care as a defining goal, however one of the clusters is “patient centredness”. The model does include patient centred care as a goal of integration, but not a key goal.
3. **Involves many sectors and organizations** – The model makes no explicit reference to any group or sector as part of the implementation, allowing it to involve different groups and organizations as needed.
4. **Well-cited in academic literature** – Minkman’s DMIC has been cited consistently in the literature, and the framework has been used and tested academically in different sectors. It has been cited 60 times in Google Scholar.
5. **Avoids a focus on hospitals and physicians** – The model makes no specific mention of health-care facilities or physicians, diverting instead to the sectors own definitions and requirements.

### **PRISMA (Hébert, Durand, Dubuc, & Tourigny, 2003)**

The PRISMA model is a Canadian model designed to support impaired adults living in the community who are accessing multiple services. Key to this model is the creation of a joint governing board between social and healthcare leaders. The board then allocated funding to ensure a single point of entry, and case management services, uniform assessments and service plans. While this model would ensure access to services for clients, it does not substantively look at the way in which service providers interact with each other and simply layers a single point of entry and case management onto the existing system of care. As this event is primarily a chance for service

providers to look inward at the way the system interacts and collaborates, this model was determined to not be a suitable candidate, despite its promising outcomes.

### **Services Intégrés pour les Personnes Âgées Fragiles (SIPA) (Béland et al., 2006)**

SIPA, or the Integrated Services for Frail Elders, is a program out of Quebec which was informed by an analysis of various experiments from around the world. The framework contains several characteristics. It is centred on community-based primary care services, a local organization which has responsibility for the health and services of older people in that area, the integration of health and social services through shared services, case management, rapid needs-based responses, and ongoing assessment of service quality, among others.

#### **Evaluation of SIPA**

1. **Flexible to multiple systems/jurisdictions** – SIPA was designed and implemented within Quebec and was designed to include services which are unique to Quebec, especially CLSCs (local community service centers). While the model could likely be adapted to other circumstances, it appears the program was not designed with cross-jurisdictional adaptation at its forefront.
2. **Uses a person-centered lens** – The model remains heavily invested in cost-savings and does not explicitly use a person-centered lens. The model does evaluate patient experiences, but does not focus on improving these metrics, but maintaining them while generating system efficiencies and better outcomes. There is no specific mention of patient engagement or desires in the model.

3. **Involves many sectors and organizations** – The model involves many different organizations from different sectors, though these are largely healthcare organizations such as long-term care facilities, hospitals, and CLSCs.
4. **Well-cited in academic literature** – The article is well-cited, with 88 citations since being published. It has been cited in Canada and internationally.
5. **Avoids a focus on hospital and physicians** – The model remains firmly rooted in health care facilities and relies heavily on health-care services with only limited mention of other community-based social service organizations.

**Program of All-inclusive Care for the Elderly (PACE) (Eng, Pedulla, Eleazer, McCann, & Fox, 1997)**

Originally piloted in 1973 in San Francisco, and eventually expanded across the United States, the PACE programs aim to provide integrated services to older adults to keep them living in their communities. Key aspects of the PACE program are collaboration between multidisciplinary teams, and a single point of delivery for the full continuum of healthcare services. The PACE model was innovative in part because it bridged between the two major funding programs in the U.S., Medicare and Medicaid using an interdisciplinary team.

**Evaluation of PACE**

1. **Flexible to multiple systems/jurisdictions** – PACE is beneficial largely because it integrated services provided by both Medicaid and Medicare. Because these funding models are unique to the United States, PACE has limited benefits in jurisdictions where healthcare funding is administered differently.

2. **Uses a person-centered lens** – The framework mentions patient experiences as an outcome, though the primary focus is on cost-savings and the patient experience is not a central concern of the framework.
3. **Involves many sectors and organizations** – PACE involves a wide range of healthcare services but is limited to services eligible under the Medicaid and Medicare program.
4. **Well-cited in academic literature** – The article is very well-cited, with over 400 citations since being published. It has been cited mostly in the United States, though it has been cited internationally.
5. **Avoids a focus on hospital and physicians** – The model remains firmly rooted in health care facilities and relies heavily on health-care services with only limited mention of other community-based social service organizations.

### Choosing a Model

	<b>H+P</b>	<b>K+S</b>	<b>DMIC</b>	<b>SIPA</b>	<b>PACE</b>
<b>Flexible and Adaptable</b>	Yes	Yes	Yes	No	No
<b>Person-Centered</b>	No	Yes	Yes	No	No
<b>Cross-Sectoral</b>	No	Yes	Yes	Yes	No
<b>Well Cited</b>	No	Yes	No	No	Yes
<b>Includes Non-Healthcare</b>	No	Yes	Yes	No	No

*Table 1 Analysis of Integration Models*

Based on the analysis of the above models, the Kodner and Spreeuwenberg model was chosen as the foundation for the event as it offers the most flexible and adaptable structure, it is well cited, offers guidance on the integration of both health and

non-health services, and is founded upon the goal of person-centered care. The model best suits the needs identified by caregivers and services providers in the caregiver support sector.

### **How to Make the ‘System’ Real: A Roundtable Session for Alberta’s Support Services for Caregivers of Seniors.**

The University of Calgary’s School of Public Policy’s mission is to find practical policy solutions to global policy problems. To generate actions to better integrate caregiver support, the School of Public Policy put on a one-day engagement roundtable for service providers and leaders in the caregiver support sector. The event was an opportunity for people to engage with “integration” as more than rhetoric and make it real. Participants engaged with a model of integration, and generated multiple, ambitious policy recommendations to help address integration challenges in Alberta’s caregiver support system.

The event was attended by over 40 professionals representing more than 20 organizations across Alberta including AHS, GOA, the Alzheimer’s Society of Alberta, University of Alberta, University of Calgary, the City of Calgary, and more. The event included speakers on topics of integration initiatives in British Columbia, the experience of a caregiver navigating with Alberta’s system, and some current initiatives. The participants were then given the opportunity to engage with the chosen model through a structured workshop. The room was divided into five streams, each containing one of the areas identified in the Kodner and Spreeuwenberg framework identified above as most appropriate. Participants self-selected themselves into one of the five: funding, administrative, organizational, service delivery, and clinical. They then engaged in a



short, facilitated brainstorming discussion to collect and debate their ideas. This process was repeated twice, giving participants the opportunity to engage in three of the five streams from the model.

Following the discussions, the facilitators wrote the potential actions onto five boards. Participants were given 3 dots each and placed the dots on the action items which they felt should be prioritized. The top priority issue from each section was identified and released to participants as part of a follow-up survey. The survey asked participants to clarify their understanding of the priority issues, identify practical actions which could be taken to address the issue, and identify the groups/organizations who ought to be responsible for taking those practical actions.

### **Results of Stakeholder Engagement Event – Prioritizing Needs and Developing “Real” Solutions**

#### **Reviewing the Framework:**

While the Kodner and Spreeuwenberg framework provided a useful structure for the event and encouraged participants to think and discuss solutions at different levels, participants moved beyond the structure as discussions grew deeper. The prompts and streams gave participants a foundation upon which to build solutions at different levels of the system. Participants seemed to identify with the examples provided under each stream. As discussions developed, however, people seemed to feel trapped by the streams, but a deeper analysis of those discussions and responses to the follow up survey has shown that the participants’ thinking had moved beyond the framework. Participants identified issues which joined and passed between multiple streams. As

well as the issues, the collaborative projects that participants generated flowed between and around the boundaries of the five streams. As such, this analysis moves away from the Kodner and Spreeuwenberg structure, as its usefulness to the event was key, but limited to providing a springboard for discussions. What follows focuses on how the participants understood the key issues, and the solutions they offered, whether they fit with the framework or not.

While there was frustration expressed in the conversations there were also some big collaborative ideas. Some ideas appeared more significant than others, but all gave the sector the opportunity to do integration through meaningful, collaborative work. The results of the post-event survey are discussed below: In total, twenty-six participants responded to the survey. Ten (38.5%) participants finished the survey completely, sixteen (68.5%) participants partially completed the survey.

### **Recognizing Caregivers**

The first issue participants agreed upon was that “caregivers are not recognized in the formal system/there is no ‘caregiver support system’”.

Participants split their responses to this issue among two paths: some focused on the lack of explicit recognition for the contributions and needs of caregivers, while others noted that service providers (health service organizations, government ministries, community organizations, etc.) often allocated funding and services to caregivers based on the needs of the care recipients and not the caregivers themselves. Despite the divergence in the desire for change between focusing on more formal recognition and focusing on more separation between caregivers and care recipients in funding and

services, participants from both camps viewed law and policy change as the solution to their prospective problems.

Participants who wanted changes in law and policy, in either direction, identified the government of Alberta as the party responsible for change. While it is true that the government has control over many of laws and policies related to health, viewing the province as responsible seems unlikely to help the caregiver community, in its current fragmented state, draw together. Participants have a significant amount of expertise with caregivers and articulated this experience by listing several issues and opportunities with the current system that could be addressed in law. Asking the government to make this change eliminates the opportunity for the true experts to collaborate and ensure the change fits with the needs of the system. A shift in law and policy requires a concerted effort from the sector, not only to get onto the government's radar, but to ensure that the changes are desirable after the need for legislative change is recognized. Most participants felt the government should take on this responsibility, but if the sector took this on, the opportunity for integration is even greater. Most participants agreed that effective law change can be accomplished in 1-3 years.

### **Creating a Central Repository**

The second issue participants identified was that "There is no central repository for caregiver resources".

The desire for a central repository appeared in many discussions across different streams. Participants stated that services for caregivers are not well organized and there is not always adequate knowledge among even service providers. This creates a

system that doesn't see caregivers as a priority and makes services difficult to access. Participants who viewed this saw the development of a central "hub" as the solution.

Two trends developed for how participants felt the development of a central repository should be created. The first group of participants advocated for collaborative development, suggesting that organizations across the province should work together to develop and maintain a central repository in an agreed-upon location and format. A second group of participants viewed this task as the responsibility of a single organization which ought to lead development and maintenance.

While this is no doubt an important part of working together, the development of a central hub is not a new concept, and resource guides, directories, websites, and databases abound with varying degrees of accuracy, completeness and accessibility. Given that integration requires the building of trust, relationships, and agreement, the first suggestion of collaborative develop seems to offer the greatest potential for furthering integration in the system. As with a group effort to create law and policy change for caregiver recognition, the collaborative creation of a central hub could well serve as a community-building task that brings the sector together. A task that can provide a chance not only for people to get to know and trust each other, but also to engage in work towards achieving the other priorities identified during the event such as shifting cultural norms and creating collaborative spaces. Passing such a task onto others would forego these community building opportunities.

### **Creating Space for Health and Social Service Dialogues**

A third priority was the need to “Create space for dialogues between the social and health sectors”. Participants felt that this concept could form a stepping stone towards co-located services, more integrative practice between primary care, home care, and community-based service providers.

Participants wanted more dialogue, meetings, and coordination between the two sectors, especially between health authorities and community-based service providers. These dialogues could involve discussions of individual cases, organizational practices and policies, gaps, and opportunities for collaboration.

It is perhaps here that the benefits of these meaningful work packages are most salient. Participants offered a range of both informal and formal means to come together, and solutions ranging from mandated committees to email chains were offered. While dialogue certainly appeared to be important to the participants, what that dialogue was directed towards and accomplished was perhaps even more important. This is to say, creating space for dialogues requires a pragmatic reason for dialogue. This suggests that instead of simply creating space for dialogue, the practical work packages identified through the event are the projects around which productive, trust-building, integrative dialogue can take place. Having community-driven goals to work on will give dialogue sessions the foundation they need to generate meaningful change and see the community building itself into an integrated rather than siloed system.

### **Creating a Culture Shift Among Government and Funders**

The final priority issue which participants identified was “Create a space for funders and government ministries to meet and explore a culture shift”. Participants

were asked what the term culture shift meant to them. A shared definition of “culture shift” proved difficult for participants to agree upon.

One group of participants responded that a culture shift would mean that government ministries and funders recognize the value and importance of caregivers. This definition appears to align with, if not duplicate the goal of recognizing caregivers through law and policy change.

Another group of participants stated that it should mean a shift in how funding is allocated to move away from a competitive model and towards a model that creates more opportunities for collaboration. Again, this appears to align with, if not duplicate the ask for more space for dialogue.

Others still, explained that ‘culture shift’ meant, for them, moving away from the acute, disease-curing medical model and towards a more holistic, community-based, social model of care. Participants suggested that further research was needed in this area. While this may constitute a noble and meaningful action, its contribution to the integration of the existing system is less clear.

Participants identified the government of Alberta as a key player in culture change. Participants also mentioned Alberta Health Services and community stakeholders as groups who could complete these actions. Most participants felt that this priority could be addressed within a 1 to 3-year timeframe.

## **Standards of Care**

The priority issue participants identified within the service delivery stream was the need to “Develop standards of care and evaluation criteria/indicators for caregiver

support providers”. Participants identified that there is a need to ensure that all caregivers are receiving appropriate and effective services across geographic boundaries. These standards can serve to ensure that caregivers are receiving consistent and effective services across the province. Some participants discussed the challenges of providing an equal quality and quantity of services in rural areas.

Like changing law and policy, the project of developing standards of care presents another work package, albeit a significant one, for the service provision community to take on. There is no doubt that both the process of generating these standards with, in the words of one participant “equal participation by government, not-for-profit health and social service providers, for-profit agencies, and people with lived experience of caregiving” and the standards themselves will move the sector towards the trust and relationships that underpin integration.

Participants already began brainstorming a range of criteria during the event. As one participant explained, standards of care should seek to “acknowledge caregivers, communicate in a timely manner, provide system navigation and access to resources, assess and meet caregiver needs, assess and address caregiver stress”.

### **Moving Towards Integration**

This paper has presented integration as a structural issue. Fragmentation is a problem of divergent mandates, competitive funding models, disjointed assessment processes, a lack of transition, etc. Researchers of the past have seen the solution to fragmentation as integration through the lens of organizational structures, joint services, shared assessments, coordinated planning, etc. When presented with these ideas,

participants connected with these concepts, but quickly diverged away from the structural recommendations of the framework and instead generated their own initiatives through conversations and relationship building. The act of bringing service providers together to share experiences, learn about each other, and develop their knowledge of services is the foundation upon which the structural aspects identified in so many of the frameworks above are built. Joint services cannot exist without trusting relationships, coordinated planning cannot exist without agreement between providers. The event provided participants with the opportunity to set agreed-upon goals for the sector to work on together. Not only will the results promote system integration, but so will the process.

While this paper has spent a significant amount of time viewing and presenting integration as a structural issue, with frameworks, joint programs, shared planning, co-location, and more as the solution, what came out of the event is that these structural concepts aren't the pathway to real integration, because they cannot be done without some necessary preconditions. It is very likely that any other model, if used at the event would have generated equally promising integrative actions. Instead of structural elements, trust, agreement, and collaborative relationships are the necessary preconditions to integration, in whatever form it may take. The collaborative work packages that participants generated in the event provide the opportunity for the caregiver support sector to developing these preconditions with a firm goal in mind. The lesson for other complex human service sectors is that the meaningful work is the source of these preconditions, not frameworks and structures plucked from the research. The frameworks and research will set the stage, but the people make the



play. Other sectors looking toward integration should focus less onto choosing the right framework, and put more effort into developing collaborative, trusting relationships, through self-created goals to be successful.

## **Appendix A: Caregiving in Canada**

The General Social Survey administered by Statistics Canada contains information on caregiving in Canada. The GSS doesn't separate data based on the age of the care recipient, however over 13 million Canadians can expect to provide care to someone, and 8.1 million Canadians over the age of 15 provided care to somebody in the past 12 months according to the GSS (Sinha, 2013, pp. 4). 3.5 Million people cared for multiple care recipients, and more recent data shows that 1 million caregivers were themselves over the age of 65 (Employer Panel for Caregivers, 2015).

Caregivers provided care for people with a diverse range of needs and diagnoses. Aging was the most common reason care recipients needed care (28%), followed by cancer (11%), cardiovascular disease (9%), mental illness (7%), and Alzheimer's disease or dementia (6%) (Sinha, 2013, pp. 5). Types of support provided were equally diverse. Transportation was the most common type of support at 73%, followed by Household work, home maintenance, scheduling, managing finances, helping with medical treatment, and providing personal care (Sinha, 2013, pp. 6). Most care was provided in the care recipient's home (Canadian Association of Retired Persons, 2016; Sinha, 2013, pp. 7). For middle-aged caregivers, many were balancing caregiving responsibilities with work or childrearing, and caregiving was likely to cause some level of disruption with work, especially when more hours of caregiving were reported (Sinha, 2013, pp. 7).

### **Positive Effects of Being a Caregiver**

According to a health report published in Statistics Canada, data in 2009 shows that 95 percent of caregivers experienced some positive experiences due to their caregiving role. The first group of positive aspects are personal benefits, these include feelings of mastery, learning new skills, a sense of accomplishment, increased life satisfaction, higher self esteem, and personal growth (Mackenzie, & Greenwood, 2012; Li and Loke, 2013; Lloyd, Patterson, & Muers, 2016; Pysklywec, Plante, and Demers, 2018; Turner, & Findlay, 2012; Yu, Cheng, & Wang, 2018). The second group of benefits are between the caregiver and the care recipient, caregivers valued the opportunity to repay the care recipient, and to fulfil societal expectations, caregivers also reported relationship improvements. The final group of benefits caregiving reported were outside the direct caregiver/care recipient relationship, caregivers reported gaining a better understanding of life's purpose and meaning, as well as improvements in relationships with their family, friends, professionals, and larger social structures such as faith, race, social class, etc. (Pysklywec, Plante, and Demers, 2018)

The literature on the positive aspects of caregiving identifies many benefits caregivers receive because of their caregiving journey. Public policy should seek to recognize that caregiving can be beneficial, and that caregiver supports should not only aim to alleviate caregiver burden but enhance the benefits.

### **Negative Effects of being a Caregiver**

Caregivers may experience negative effects, broadly defined as “caregiver burden”. Mosquera et al. (2016, p. 1062) define caregiver burden as “a negative reaction to the impact of providing care on the carer’s physical, psychological, emotional, social and financial situation”. Caregivers supports must exist within many

domains as well as cross and coordinate between them. Caregivers are more likely to report burden if the care recipient is experiencing depression, cognitive impairment, dementia, anxiety, psychosis, sleep disturbances, and other neuropathic/cognitive disorders (Mosley, Moodie, and Dissanayaka, 2017; Vitaliano, Young, & Zhang, 2004).

**Caregiver Mental and Physical Health Burden.** Caregivers are more likely than non-caregivers to experience mental and physical health problems including depression, anxiety, worry, isolation, overall health decline, increased medication use, and reduced resistance to viruses (Mahoney et al, 2005; Pinguart & Sorensen, 2003; Saban, Sherwood, DeVon, & Hynes, 2010; Vitaliano, Young, & Zhang, 2004). In 2012, most Canadian caregivers who cared for their parents, and about a third of caregivers caring for a grandparent experienced at least one symptom of distress or worry (Turcotte, 2013). 1 in 4 caregivers reported experiencing more than four negative symptoms of caregiving. This burden may persist even after the death of the care recipient (Caputo, Pavalko, and Hardy 2016; Family Caregiver Alliance 2016)

**Social Burden.** Verma, Sayal, Vijayan, Rizvi, & Talwar note that the overall responsibility and time requirements associated with caregiving can lead to “restricted social engagements and sacrificing family relationships” (2016, p.387). Other population research adds that caregivers changed their social activity due to their caregiving responsibilities, including a reduction in visiting friends, attending religious services, recreational activities, and volunteer work (National Academies of Sciences, Engineering, and Medicine (NASEM), 2016). These social impacts can contribute to other negative outcomes such as increased stress, isolation, and other mental health challenges.

**Financial Burden.** Keating, Fast, Lero, Lucas, and Eales (2014) describe three “domains” of financial costs that many caregivers experience as they balance many competing responsibilities, care labour costs, employment restrictions, and out-of-pocket expenses. Caregivers spend an average of 17 hours caring per week (CIHI, 2018) and 1.2 million full-time workloads combined. Most caregivers reduced or ended their employment due to this responsibility (Fast, 2015; Fast et al. 2014). U.S. data estimates that the lifetime loss of caring for a parent was US\$324,044 for women and US\$283,716 for men (MetLife Mature Market Institute (MMMI), National Alliance for Caregiving (NAC), and Center for Long Term Care Research and Policy (CLTCRP), 2011).

**Other Effects.** Research suggests that it is the burden and stress of caregiving, not caregiving itself that is associated with higher mortality rates for the caregiver (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010; Perkins et al., 2012). Boerner, Schulz, & Horowitz (2004) add that more positive caregiving experiences are associated with intensified grieving after the loss of the care recipient, demonstrating that the effects of caregiving do not end with the passing of the care recipient.

Caregiver burden has negative effects not just for the caregiver, but also the care recipient, and is associated with premature institutionalisation of the care recipient and elder abuse (Bédard, Pedlar, Martin, Malott, & Stones, 2000; Sheilds, 2010; Wolf, 1998). Caregivers experience a wide range of negative effects across many domains. The integrated prevention and treatment of caregiver burden through both domain-specific and comprehensive supports has benefits not only for the caregiver but also the care recipient, the healthcare system, and society (Etters, Goodall, & Harrison, 2008;

Sorensen & Conwell 2011). Even though supports are available these benefits are not being maximized due to a system that is difficult to access and move around within.

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