TOWARDS SOCIAL SERVICES SYSTEM INTEGRATION: A REPORT FROM ALBERTA'S ELDER CARE SUPPORT PROVISION COMMUNITY

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SUMMARY

Family caregivers are a significant unpaid labour force that provides at least 70 per cent of all care to seniors in the community. Recent estimates place the value of family caregiver labour as high as $66.5 billion. While a wide range of public and private services are generally available to support family caregivers, many potential clients have difficulty both gaining access, and navigating those services once they have gained access. In this sense, they experience a highly fragmented system of social support provision. As the population of older adults living in their communities grows, and with it the demand for family caregivers' support, policy attention has become increasingly focused on integration as a solution to the fragmentation challenge.

Recognizing the fragmented family caregiver support services system the School of Public Policy (SPP) organized a day-long stakeholder policy dialogue event that brought together multiple stakeholders from different sectors (government and non-government). In organizing the stakeholder dialogue and in line with a well-developed scholarly literature, we framed the problem of fragmentation as a structural issue caused by, among other factors, divergent mandates, competitive funding models, disjointed assessment processes and a lack of co-ordination as clients transition within the system. Similar to other researchers, we saw integration as the solution to fragmentation along these dimensions. Our assumption in convening the stakeholder policy dialogue was that opportunities to integrate would be found in organizational structures, joint services, shared client assessments and co-ordinated planning. In the course of the facilitated discussions, we found that for any progress to be made on

these structural issues, stakeholders needed first to share experiences, learn about each other and develop their knowledge of services outside their own experience. Thus, close contact and human relationships were the foundations of both knowledge transfer and structural efforts at integration. The dialogue event itself acted as a space where researchers, practitioners and clients met and interacted with each other and where tacit and explicit knowledge merged[1] in the co-development of recommendations for better service integration. During the event, the stakeholders discussed and set priorities for integration that focused on five potential work packages. These were: 1) creating space for dialogue between caregiver support service providers, 2) achieving formal recognition for caregivers, 3) creating a central repository of caregiver support services, 4) shifting the culture (i.e., the values and language) surrounding caregivers and 5) developing standards of care for the caregiver support services sector. The collaborative space (1) that social support providers envisioned during the stakeholder dialogue, along with the ambitious projects (2-5) they prioritized for action inside that space, were practical, implementable enactments of integration. In this way, the stakeholders saw integration as emerging from common projects that built a community as much as they tackled real service delivery problems.

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[1] Tacit knowledge refers to personal and context-specific knowledge that is difficult to formalize and communicate whereas explicit knowledge refers to knowledge that can be transmitted in formal and systematic language (Polanyi 2012).

INTRODUCTION

Governments around the world have identified the need for increased integration in both health and social service provision (Fraser 2019; Glasby 2017; Pearson and Watson 2018; Philippon and Braithwaite 2008). The English National Health Service (NHS) has recently changed its focus from one on 'accountable care systems' to one on 'integrated care systems' reflecting a need to breakdown barriers among services provided across sectors. This shift comes in response to the growing population with complex medical conditions receiving care and support from a wide range of siloed health and social care providers (Ham 2018).

More than 175 definitions of "integration" are available within the social and health services literature (Armitage et al. 2009, 4). In this paper, we define integration as the co-ordinated delivery of social support services to family caregivers of older adults. Lack of integration "among stakeholders, policies, government, community members, agencies and other service providers" is arguably the key cause of many wicked[2] social problems (Turner and Krecsy 2019). 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 (van Duijn et al. 2018). In the social services, system fragmentation has been linked to failures 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). Although research has developed a range of best practices in social support provision, actual delivery of services in Canada remains fragmented (Taylor and Quesnel-Valle 2017). While a wide range of services are generally available, many potential clients have difficulty both gaining access to systems, and navigating those systems once they have gained access (Bergman et al. 1997). Evidence from both support service users and providers suggests clients routinely fall through the cracks, resulting in harm or even death (Anderssen 2015; Cowan-Levine 2017; Kwok 2012; Ravenscroft 2005). A key challenge here is that while policy-makers and practitioners across jurisdictions and within a range of health and social service sectors want services to be more integrated, they may not have a clear idea of what integration is or how to achieve it (Armitage et al. 2009). This briefing paper reports on recent efforts within a specific social services provision community to reach consensus on what integration is and generate meaningful action plans for achieving it.

WHAT IS THE PROBLEM AND HOW BIG IS IT?

The [Family Caregiver Alliance](#)[3] defines family caregivers as "any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a

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[2] The term "wicked" problem, first proposed by Rittel and Webber in 1973, refers to complex social system problems that are ill-formulated and are continually evolving with many causal levels and no single solution that applies in all circumstances (Rittel and Webber 1973).

[3] https://www.caregiver.org/

broad range of assistance to an older person or an adult with a chronic, disabling or life-limiting condition." This heterogeneous group (Eales et al. 2015), represents a significant unpaid labour force that provides the vast majority of care not only to older adults but to citizens of all ages with chronic health conditions or physical and cognitive disabilities (Abdelmoneium and Alharahsheh 2016; Stacey et al. 2016; Williams et al. 2016). The lifespan value of a family caregiver's time to support a child diagnosed with autism spectrum disorder is approximately $5.5 million higher than for a child without autism (Dudley and Emery 2014). Estimated annual costs of care per person with late-onset dementia are $8,064 for a formal care system and $23,436 for family caregivers (Harrow et al. 2004). It was estimated in 2009 that the formal Canadian health-care system would have to spend $25 billion to remunerate the contributions of family caregivers (Hollander et al. 2009). More recent estimates have seen this replacement value number climb as high as $66.5 billion as the general population ages and the prevalence of chronic illness increases (Fast 2018).

Family caregivers of older adults experience a range of positive (Cohen et al. 2002) and negative effects (Keating et al. 2014; Schulz and Sherwood 2008) throughout their caregiving journey, and 35 per cent of people over the age of 45 will experience these challenges and rewards. They provide at least 70 per cent of all care to seniors in the community (Carstairs and Keon 2009). Family caregivers are critical to the function of the formal health-care system, despite working largely outside of it. Indeed, one of the biggest drivers of policy conversations recognizing fragmentation as a significant issue, and integration as a proven solution, is the growing older adult population and its changing health needs.

Although social support services have been shown to improve the subjective wellbeing of caregivers, reduce their burden and act as a source of respite (Goeman et al. 2016; Kurz et al. 2005; Thompson et al. 2007), evidence suggests these services are rarely accessed. This is especially true for those caring for people with Alzheimer's and other forms of dementia. While there are other factors, fragmented systems of care and support are major factors in lowering utilization. Family caregivers' use of social support services ranges between 4.8 per cent and 14.0 per cent (Chow et al. 2000; Gräßel et al. 2010; Jang et al. 2010). Our own research has shown family caregivers' frustration with, and inability to navigate, the fragmented social support system (authors, under review). Indeed, family caregiver support services were singled out by a special Senate committee in 2009 as particularly 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 and Keon 2009; MacAdam 2008).

HOW DID WE APPROACH THE PROBLEM?

We report on the experiences and perspectives of Alberta's family caregiver support community at a day-long stakeholder policy dialogue event hosted by the University

of Calgary's School of Public Policy (SPP). That event – *How to Make the 'System' Real* – was convened as part of the SPP's mission to find practical solutions to global policy problems using community-centred and community-driven techniques. The term "stakeholder" refers to "individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavor" (Deverka et al. 2012). A stakeholder policy dialogue is defined as an organized gathering of stakeholders, focused on a specific policy topic and structured by particular consensus-building methods (van Asselt Marjolein and Rijkens-Klomp 2002). In this sense, consensus-building is the main objective, with stakeholders co-developing joint policy recommendations that reflect the needs and perspectives of all participants (Susskind 1999; Susskind et al. 2003). In recent years, attention to stakeholder policy dialogues has increased due to: 1) calls for more transparent democracy to enhance the legitimacy of decisions and policies (Fung and Wright 2001), 2) a rise in the number of educated citizens in contemporary societies (Irwin 2002), 3) an increased appreciation for non-traditional policy stakeholders' views, knowledge and expertise (Fischer 2000) and 4) disappointment with the results of an exclusive reliance on scientific and expert knowledge in policy-making (Jasanoff 2009).

Our stakeholder policy dialogue event originated in the family caregiver support community's own desire to better understand and accomplish integration. It was designed as a space for different stakeholders to move away from talking about integration, and towards making both it, and the concept of a system of care, real. It also created a platform to merge explicit and tacit knowledge or, in other words, to integrate research and practice. Throughout the day, participants engaged with a theoretical model of integration and co-developed multiple ambitious policy recommendations to help address the fragmentation challenges they identified in their daily work. In this way, this briefing paper uses the specific experiences of Alberta's family caregiver support community to draw out broader lessons for achieving integration.

Forty-five participants from different stakeholder groups across Alberta participated in our policy dialogue event. We identified event participants as policy- and decision-makers, service delivery providers (both governmental and not-for-profit community organizations), researchers, boundary spanners or leaders in the field, using both snowball and purposeful sampling approaches based on our experience with, and connections into, the caregiver support community. We recruited 45 stakeholders from the government of Alberta (N=7), Alberta Health Services (N=13), research/academic institutions including the University of Alberta and University of Calgary (N=8), NGOs such as the Alzheimer Society and Kerby Centre (N=16), and Covenant Health (N=1).

HOW DID WE FRAME INTEGRATION THROUGH EXPLICIT KNOWLEDGE?

With a plethora of definitions of integration available within the social and health services literature (Armitage et al. 2009, 4), we adopted Kodner and Spreeuwenberg's (2002) comprehensive definition, taking integration to be "a coherent set of methods

and models designed to create connectivity, alignment and collaboration within and between the cure and care sectors." A range of possible integration frameworks – which is to say, theoretical models or typologies that posit integration as occurring in certain ways at certain locations subject to certain limitations – were also considered, with one developed by Dutch scholars (Kodner and Spreeuwenberg 2002) ultimately selected. Their integration framework provides five structural themes (see Box 1), which, when used as intervention points, can bring a loosely associated system toward more integrated service provision.

Theme 1: Funding – Noting that "forms follow financing", Kodner and Spreeuwenberg create a category of integration activity focused on the way service providers acquire and spend money. The authors call out pooled funding and capitation as particular integration tools in this category.

Theme 2: Administrative – The framework's administrative category focuses on government regulatory and administrative functions as structures that can eliminate program deficiencies and improve integration by easing the transition between programs and sectors.

Theme 3: Organizational – The framework's organizational category focuses on integration activity that occurs in vertical and horizontal networks, and through both formal and informal intersectoral relationships that can include co-management of programs.

Theme 4: Service Delivery – Kodner and Spreeuwenberg's framework includes a service delivery category of integration activity that focuses on the methods of service delivery and management, including staff training and practice approaches.

Theme 5: Clinical – Finally, the framework's clinical category focuses on integration activities that focus on developing common understandings of patient needs, languages and uniform assessments as well as agreed-upon practices and standards.

The Kodner and Spreeuwenberg model was selected out of a large pool of possible frameworks for the following reasons:

1. It is flexible to multiple systems/jurisdictions;

2. It uses a person-centred lens;

3. It involves many sectors and organizations;

4. It is well-cited in the academic literature;

5. It avoids a focus on hospitals and physicians.

BOX 1: CONTINUUM OF INTEGRATED CARE STRATEGIES

Funding	Administrative	Organizational	Service Delivery	Clinical
Pooling of funds (at various levels)	Consolidation and/ or decentralization of responsibilities and functions	Co-location of services	Joint training	Standard diagnostic criteria (e.g., DSM IV)
Prepaid capitation (at various levels)	Inter-sectoral planning	Discharge and transfer agreements	Centralized information, referral and intake	Uniform, comprehensive assessment procedures
	Needs assessment and allocation chain	Inter-agency planning and/or budgeting	Case/care management	Joint care planning
	Joint purchasing or commissioning	Service affiliation or contracting	Multi-disciplinary and/or interdisciplinary teamwork	Shared clinical record(s)
		Jointly managed programs or services	Around-the-clock (on-call) coverage	Continuous patient monitoring
		Strategic alliances or care networks	Integrated information systems	Common decision support tools (i.e., practice guidelines and protocols %)
		Consolidation, common ownership or merger		Regular patient/ family contact and ongoing support

Source: Kodner and Spreeuwenberg (2002)

At the event, the participants were invited to select three of the five categories identified in the Kodner and Spreeuwenberg framework as particularly interesting to them. Each of the themes was given a dedicated area (i.e., roundtable) in the event space, which participants could move to and then join a 20-minute, facilitated brainstorming discussion to collect and debate their ideas. Participants contributed to their chosen three themes over the course of an hour.

WHAT DID WE FIND?

We framed the problem of fragmentation as a structural issue caused by, among other factors, divergent mandates, competitive funding models, disjointed assessment processes and a lack of co-ordinated transition. Similar to other researchers, we saw the solution to fragmentation as integration through the lens of organizational structures, joint services, shared assessments and co-ordinated planning. The Kodner and Spreeuwenberg framework provided a useful structure to start the dialogue and encouraged participants to think about and discuss solutions at different levels. However, when we presented the framework and structural concepts to the family caregiver support community, they initially connected with them, but quickly diverged away from the structural recommendations and instead co-developed their own

initiatives through dialogue, conversations and relationship building. The prompts and structural themes gave participants a foundation upon which to build solutions at different levels of the system. As discussions developed, however, participants' ideas moved beyond the theoretical framework and into issues which joined and passed between the themes. Thus, the framework was useful predominantly as a starting point for more wide-ranging discussions among community members who saw and wanted to talk about the practical links and dependencies that elided the theoretical structures. It is our sense that a theoretical model other than Kodner's and Spreeuwenberg's would likely have generated equally promising integrative discussions. Rather than a technical focus on structural elements, a social and qualitative focus on trust, agreement and collaboration appeared to be the necessary pre-conditions for effective integration talk and action.

As part of the initial organization for the stakeholder dialogue, a range of participants had expressed a desire to move beyond re-statements of the simple mantra that doing integration "is complicated." The facilitated discussions and dialogue gave the stakeholders the opportunity to do integration through meaningful, collaborative work. We observed the explicit knowledge of the structural framework merging with the tacit, practical knowledge of stakeholders, ultimately leading to the co-development of five priorities for action. Below, we discuss these consensus-driven priorities for integration, beginning with one capacity-building goal and following with four projects aimed at leveraging that capacity-building goal.

BUILDING CAPACITY: CREATING SPACE FOR CONVERSATION

Participants identified the need to "create space for dialogues between the social and health sectors". They felt these conversation spaces were a steppingstone towards co-located services, and a more integrative practice between primary care, home care and community-based service providers. Participants wanted more dialogue, meetings and co-ordination between the two sectors, especially between health authorities and community-based service providers. These conversation spaces were envisioned as facilitating discussions of topics ranging from individual cases to organizational practices and policies, gaps and opportunities for collaboration. Participants described a range of both informal and formal means to come together, and solutions ranged from mandated committees to email chains. While dialogue alone was clearly important to the participants, they were not imagining more meetings or emails simply to be able to talk to one another. Rather, they saw the newly created conversation spaces as the foundations of broader, pragmatic projects that would advance the caregiver support community's mission while enacting integration. That is, the committees and email chains were not to be ends in themselves, but rather jumping-off points where productive, trust-building, integrative dialogue could take place and the hard work of the projects could evolve.

PROJECT 1: SHIFTING THE CULTURE OF CAREGIVER SUPPORT

In the first of the projects aimed at leveraging the newly created space for dialogue, participants identified the need to "create a space for funders and government ministries to meet and explore a culture shift". Participants were asked what the phrase "culture shift" meant to them. A shared definition proved difficult for them to agree upon. One group explained that, for them, a culture shift involved moving away from medical, disease-oriented and acute-focused approaches to service delivery and toward a more social care, strengths- and goals-oriented, long-term and community-focused model. Those following this definition suggested that further research was needed in this area to identify best practices. Thus, commissioning, collecting, evaluating and transferring knowledge from this research became the shared work of those inhabiting the newly created conversation spaces. A second group of participants defined their intended culture shift as a move away from competitive and siloed interactions among caregiver support community members, and towards collaboration. Their hope was that through changes in the way funding is allocated in the sector and the development of the conversation spaces described above, the community would shift from competing with one another to planning with and learning from one another. For this group, then, the shared conversation spaces were, when linked to changes in the way funders approached apportioning money, the places where a new culture and community of collaboration were to be built. A third group of participants responded that a culture shift would have occurred when government ministries and funders had come to recognize the value and importance of caregivers. This definition appears to align with, and potentially duplicate, another of the major projects outlined below – that of recognizing caregivers through law and policy change. We deal with this in the next section.

Regardless of their working definition of "culture change", participants identified the government of Alberta as a key player in accomplishing it. 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 in a one- to three-year time frame.

PROJECT 2: RECOGNIZING CAREGIVERS

Throughout the facilitated discussions, participants agreed that "caregivers are not recognized in the formal system," further specifying this shortfall by noting "there is no formal legislation or policy that recognizes the contribution and financial hardship of caregivers." From this broad acknowledgment of a gap in policy, participants diverged in their preferred response to the problem. Some focused on the lack of explicit recognition for the contributions and needs of caregivers, and others noted that providers – such as health service organizations, government ministries and community organizations – often allocated funding and services to caregivers based on the needs of the care recipients and not the caregivers. The first group – interested in ensuring formal recognition of caregivers and their labour – saw legislative change and provincial law as their preferred area of policy reform. The second group – interested in

ensuring practical recognition and inclusion of caregivers in health and social services delivery – saw ministry and clinical level policy as their preferred area of reform.

Both groups – those interested in changing or creating statutes, and those interested in changing operational policies – identified the government of Alberta as the party responsible for change. While it is true that the provincial government and its ministries have authority over the laws and policies shaping health and social service provision, it was unclear how focusing on the province would help the caregiver support community improve its integration. While many of the participants were not only embedded in government, but had significant expertise in policy affecting caregivers, they tended to see the government as a third party that was outside of their particular community or sphere of influence. In assigning the government the responsibility to change statutes or operational policies, the participants were effectively eliminating the opportunity for the true experts to collaborate and ensure that changes not only aligned with caregiver needs, but that they were carried forward by well-informed champions, thus increasing their likelihood of success. 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 proposed 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 – for working together on a valued project – would be much greater. Most participants agreed that effective law change could be accomplished in one to three years.

PROJECT 3: CREATING A CENTRAL REPOSITORY

Another major project leveraging improvements in dialogue capacity stemmed from the observation that "there is no central repository for caregiver resources." As a solution, participants suggested "a single hub of information that provides a place for caregivers to go to that assists in navigating the system with links to disease-specific resources". Although participants expressed significant frustration at the ineffectiveness of previous efforts to create internet-based hubs, the sense persisted that a common, well-curated, up-to-date repository of information was necessary.

The desire for a central repository appeared in many discussions across different topics during the event. Participants noted that services for caregivers are not well organized and there is not always adequate knowledge of service availability and eligibility requirements, even among service providers. In participants' eyes, this lack of co-ordination and disseminated knowledge made the system less than client-centric and difficult to access. A central hub was seen as the solution. Perspectives on how to build this hub, particularly in light of past failures, again saw the participants split into two groups. The first group 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. The second group viewed this task as the responsibility of a single umbrella 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. Resource guides, directories, websites and databases abound with varying degrees of accuracy, currency, completeness and accessibility. Given that integration requires the building of trust, relationships and consensus, the first group's collaborative development approach to creating a central repository seems to offer the greatest potential for not just achieving the technical goal of a hub, but the more wide-ranging goal of better integration across 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 leverages the newly created dialogue spaces by bringing the currently siloed parts of the caregiver support system together. Viewing the hub not as a place for siloed services to advertise their programs, but rather as a community development initiative, it becomes a meaningful work package around which integration can happen. The hub becomes a task that can provide a chance not only for people to get to know and trust one another, but also to engage in work toward achieving the other priorities identified during the event, such as shifting cultural norms. Passing such a task on to an umbrella organization – just as passing on the task of legal or policy reform to the government – would forgo these community building opportunities. Given that creating an information hub received a great support from event participants, it may present the best option as the community looks at moving forward.

PROJECT 4: DEVELOPING STANDARDS OF CARE

The final priority issue participants identified was the need to "develop standards of care and evaluation criteria/indicators for caregiver support providers". Spurred by concerns that service delivery is inconsistent across geographical areas, participants argued that "to adequately support carers, standards of care should be developed that identify the supports and wrap-around services all carers should have access to." Some participants explained that services varied widely across the province and care recipients and their family caregivers may be forced to relocate or travel to gain necessary supports. Participants identified the need to ensure that all caregivers are receiving appropriate and effective services across geographic boundaries. These standards can serve to ensure that caregivers receive 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 toward the trust and relationships that underpin integration.

CONCLUSION AND THE WAY FORWARD

We deployed a stakeholder policy dialogue to bring together different stakeholders from the caregiver support sector and used facilitated discussions that brought community members together in unfamiliar ways. The stakeholder dialogue event acted as a space where research and practice met, and where explicit and tacit knowledge were integrated to co-develop capacity building and specific program recommendations for better service integration. Through the course of the stakeholder dialogue, participants imagined a space populated by an un-siloed group of colleagues and stakeholders that could be dedicated to shifting culture, recognizing caregivers, creating a central information hub and creating standards of care. A facilitated stakeholder policy dialogue using consensus-building methods thus became an effective platform to merge research and practice and foster the co-development of policy recommendations for a wicked and widespread problem like system fragmentation.

Finding the resources to create the space for dialogue and then take on one or more of these major projects remains for the community and government to accomplish. The collaborative space that social support providers envisioned during the stakeholder dialogue, along with the ambitious work packages they prioritized for action inside that space, were practical, implementable visions of integration as an activity emerging from a community working together. Stakeholders co-developed five collaborative work packages in the dialogue, using both their personal knowledge and expertise (i.e., tacit knowledge) and building on the theoretical framework (i.e., explicit knowledge). These packages provide the opportunity for the caregiver support sector to develop these recommendations/ideas with a firm goal in mind. The lesson for other complex human service sectors is that dialogue and boundary spanning are key elements along with the frameworks and structures plucked from the research. The frameworks and research (explicit knowledge) will set the stage, but the people using their experiences and knowledge (tacit knowledge) make the play. Other sectors looking toward successful integration should put more effort into developing dialogues and collaborative, trusting relationships.

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