



Navigating Older Adult Care:

A Stakeholders and Systems Perspective

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Abstract

In the next few decades, our aging population will place an unprecedented demand for home and community care supports and healthcare resources. Members of the baby boom cohort will reach 65 years of age in the next ten years, and older seniors, those 80 years plus, will increase rapidly between 2026 and 2045. This research considers how we might better prepare and meet the needs of a growing older adult population by asking: 1) what community-based alternatives for older adult care exist, 2) what might promote health and wellbeing among older adults, and 3) how do

we create resilience in the healthcare system. This project applied qualitative research and design methods to illustrate stakeholder perspectives and experiences of older adult care and various system inputs and enablers. Findings indicate a desire for alternative models of care that leverage the strengths of both government and community, that represent values of respect and dignity, and that enable the needs and preferences of older adults to be met regardless of residential, social and economic differences.





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Thank you to all the individuals who contributed to this project in some way — it takes a community of interested and caring people to make a difference.

And finally, to my husband, children and family for your love and support.



Dedication

Many years ago, I made a choice between doing a masters degree or pursuing professional coach training. I chose the latter and went out on my own to design and develop a business. It was the best decision of my life at the time and yet I always knew I would eventually pursue a masters degree. I just needed life and experience to unfold in such a way that the right program and time would come. Behind all these choices and decision points, were two caring individuals, my parents. They were my superstar advisors and guides along the way. This work is dedicated to them for their encouragement and support in all my ambitions and dreams.

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Introduction

A number of factors have culminated to create a sense of immediacy and heightened sensitivity towards caring for our most vulnerable citizens. Institutionalized care, such as long-term care facilities, have been in the spotlight during the pandemic. The gaps and barriers for care have been magnified under the current circumstances and older adults living in long-term care have by far been disproportionately impacted by the COVID-19 disease. Families, caregivers and the healthcare system in general, have endured emotional, mental and physical burdens during the course of the pandemic. Although community-based services have adapted during the pandemic to offer virtual seniors services (e.g., *Seniors Resources and Supports During COVID-19 | Red Book by HPL, n.d.*), there is a need to look at systemic issues that either prevent or create resilience in our healthcare and local community systems. Specifically, this research project explores what community-based alternatives for older adult care might exist that can be leveraged to better serve the needs of older adults, promote health and wellbeing, and support the notion of aging in place. Within this scope, opportunities to build a resilient healthcare system may surface. This research project runs parallel to significant changes underway in Ontario's healthcare system and an unprecedented time in our recent history with the COVID-19 pandemic.

Overshadowing all the various elements of the care system, is a more silent factor, that

is ageism. Similar to racism, it has been less prominent in our public discourse until significant events such as the pandemic brought the issue to bear on our collective consciousness. Issues such as age discrimination, lack of affordable housing and insufficient home care supports, among others, were acknowledged in a Maclean's article (*Frangou, 2020*) with a statement by Dr. Vivian Stamatopoulos,

"People don't want to think about the elderly because it's sad," she says. Or they don't think about older adults at all because they just don't see them. Seniors are often isolated from the general population because our communities are not designed to be age-friendly."

This message was further reinforced in an article written by Sharon Butala (2018), where she shared, "Currently, the aged are viewed as a large, coherent group, even though we range in age by easily thirty years, as well as by class, education, and political and religious ideas" (*para. 5*). Thus, although this project considers community-based alternatives for care, the mechanism to arrive at suitable strategies and solutions must include an awareness of society's unconscious biases and find ways to be inclusive of a wide range of needs, interests and capabilities within our aging population.

Additionally, with more recent technological and biomedical advances, people are living



Context

longer and are more capable of managing their health and needs at home or within the community. Yet, funding models and care models have not adequately adjusted or kept pace with longer life spans (Persaud, 2019). Change in the health and community care landscape has been incremental, and unexpected events, like the current pandemic, have accelerated the need to respond, adapt and change. And so, an opportunity presents itself to seek out community-based alternatives and leverage what already exists. This is instrumental in facilitating better conditions for living well and sustainably for our aging population.

This project does not attempt to analyze this entire system; but rather, probes for various perspectives about care, the current system, and the future of older adult care. Identifying

the alignments and opportunities between the various stakeholders perspectives is valuable in analyzing where the gaps may be most experienced by a particular stakeholder group, how unique roles of each stakeholder group influence behaviours, and possibly identify new or targeted solutions. By approaching this complex issue with systemic design principles (Jones, 2014), this research project aims to contribute to recent and future planning for older adult care by offering a collection of insights and a call to action. Some of the ideas expressed may support existing and new models of care, others are more intentionally positioned to influence how we approach this complex issue. Ideally, the people most impacted and the actors instrumental in facilitating older adult care will change the prevailing attitudes, conditions and levers within the current system.

The issue of older adult care is a complex one that is often hidden from everyday life. However, for the many who have been or currently are caregivers, the systemic issues associated with older adult care are magnified through a number of encounters: navigating options for assistance and care, communicating with health providers, transitions between care settings, or advocating on behalf of a loved one. The challenges and frustrations that caregivers and older adults experience are now revealed, and the impact of COVID-19 has raised attention to a number of issues including: adequate support for caregivers, insufficient staffing, long-term care costs, a patchwork of eldercare delivery models and funding allocations for home and community care (Powell, 2020). Almost daily, there are devastating reports in the news about outbreaks and deaths in long term care, along with the plight of our health human resources to manage this crisis. What the news may not reveal, is the complexity of the system in which caregivers, providers, older adults and other stakeholders must navigate. There are no quick fixes, and lags in the system often exacerbate seemingly obvious problems to address, such as staffing shortages. The pandemic may have been the wildcard we did not foresee, but an aging population and the associated demands on society are certainly well documented through a number of key initiatives and reports: The World Health Organization's (WHO) proposal, *Decade for Healthy Aging 2020*, (*Decade of*

Healthy Ageing (2020-2030), n.d.); the National Institute on Aging's report (2020) *National Seniors Strategy*; and Ontario's Senior Secretariat report (2013) *Independence, Activity and Good Health: Ontario's Action Plan for Seniors*.

There continues to be an increased demand on Ontario's healthcare system, particularly in the home and community care sector, to meet the growing needs of the aging population. According to The Ontario Caregiver Association, there are over 3.3 million caregivers in Ontario and 72% of those who receive care are over the age of 65 ("*Caring for a Senior*," n.d.). In addition to older adults receiving formal care, there is also a population of older adults who might need some minimal assistance to manage in their home or information and options to stay connected, active and socially engaged in their community. In this sense, we can begin to understand that there is a wider range of support or care that older adults may want or need. Therefore, in considering the spectrum of care needs among older adults and the needs of caregivers in general, understanding the entire system in which older adults live and access support or care can potentially show opportunities for appropriate intervention and change. Healthcare and community care is a complex system in which three levels of government play a role, multiple communities exist, and a significant number of providers and services are interconnected.

Within the past two decades, there have been a number of policy directions and strategies influencing the Ontario healthcare system. Back in 2007, Ontario introduced reforms to community care, implementing the Aging at Home Strategy (AHS). A report prepared by Peckham et al. (2018) suggests, “policy change aimed at building up community care options has been hard to achieve” (p. 31). The report highlights the various policy changes with each successive government and ultimately concludes that despite the desired aim of the AHS, the dominance of mainstream approaches to care (i.e., hospitals, doctors, medical professions) has led to contradictory policy outcomes, noted by an imbalance of resources often failing to meet local needs. Fast forward to 2018, when the new progressive conservative government came into power, Premier Doug Ford announced in October 2018 that they would take immediate action to end hallway medicine and fund 6,000 new long-term care beds. (*Ontario’s Government for the People Taking Immediate Action to End Hallway Health Care | Ontario Newsroom, 2018*). Once again, the healthcare system would come to grips with policy directions and legislative changes that are still unfolding today.

Within the following year, several announcements and legislative changes came into effect. Most notably, Ontario Health Teams (OHTs) were introduced and a number

of changes were enacted through Bill 175 Connecting People to Home and Community Act, 2020 (*Connecting People to Home and Community Care Act, 2020, n.d.*). OHTs have a purpose: to better integrate and coordinate care at a local level. As shown in Figure 1 (as seen on the following page), care will be coordinated and delivered with a “one team” approach.

From a systems level, the recent announcement of an additional thirteen Ontario Health Teams (*Ontario Announces 13 New Ontario Health Teams | Ontario Newsroom, 2020*), bringing the total number to 42, will lead, in theory, to better integrated and coordinated care; but this is only one part of the total picture, as Home Care Ontario (2019) recommends Ontario Health Teams will need to “integrate and utilize home care to end hallway healthcare in Ontario.” Their report points to a number of recommendations as to where in the system fundamental change needs to occur by making a case that care in the home needs to be expanded, efficiently used, and supported through technological advances. Effectively, when Ontario Health Teams deliver on their responsibility to coordinate care, ease transitions, and support navigation of the system, patients and specifically older adults in Ontario should have a better care experience.

While health system transformation is underway, a global pandemic took grip of the

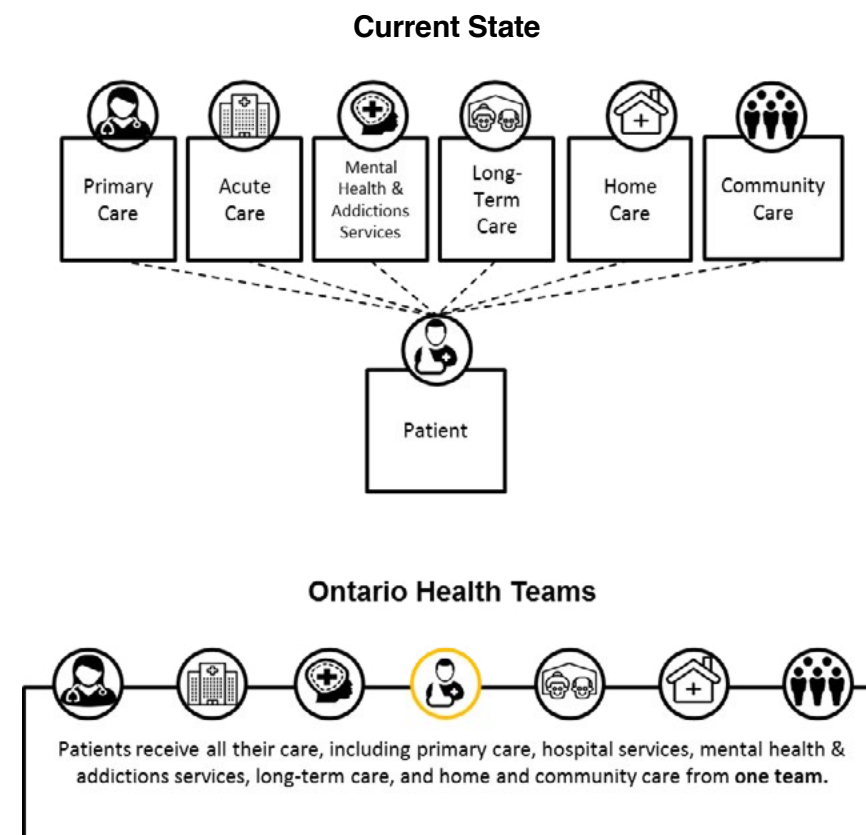


Figure 1. Ontario Health Teams Model (Government of Ontario, n.d.)

healthcare system and our daily lives in early 2020. We have read daily reports on the number of positive COVID-19 cases and deaths of residents in long-term care homes, as well as the devastating impact of isolation as a result of limited contact with carers, loved ones and fellow residents.

During the early stages of the pandemic, the impact for older adults living alone at home within their community was not well represented in the weekly media reports; however, more

reports have since offered insight into the impacts of COVID-19 lockdowns. A report by CBC (Ryan, 2020) shared:

When the initial COVID-19 lockdown cut off seniors from family and friends, as well as many organized community support programs, that brought a level of social isolation that has been associated with a decline in memory and thinking, a physical decline due to less exercise, and changes in mood as well.

As the pandemic continues into 2021, a report (*Araneta, 2021*) confirms the unintended consequences of trying to keep our seniors safe:

Seniors were lonely long before the COVID-19 pandemic, experts say, but isolation and [ageism](#) may have exacerbated the problem. The pandemic now means seniors can't connect with friends or family members, whether that be seniors in independent living situations or in-care facilities.

Fortunately, this has mobilized a number of municipalities, community agencies and organizations to consider how to provide the necessary social connection and health support needed by older adults living within the community. For example, the United Way Greater Toronto and the City of Toronto developed the Community Coordination Plan, "designed to be agile and iterative to meet the urgent needs of vulnerable people during the COVID-19 pandemic" (*COVID-19, 2020*). This includes resources for seniors with a number of agencies offering modified services and virtual activities. The COVID-19 pandemic has surfaced some very real and challenging issues faced by older adults and their families. It has also enabled us to think differently as to how care is delivered and received. These circumstances warrant further consideration for community-based alternatives for care; and also provide an opportunity to learn and

consider how to sustain efforts to better serve the needs of older adults.

Within the healthcare system and specifically, home and community care service delivery there are a number of programs and services to help individuals with activities of daily living (ADLs) and often these are coordinated and accessed through care coordination and referrals. Outside of formal care delivery a number of housing or community living options exist; some with models of care that have options for older adults to be socially connected and have some of their care needs met. One such example is OASIS (*Craig, 2018*), a unique program founded by Christine McMillian who is 88 years of age. The program was developed by the seniors living in the building. This alternative model offers a means for old adults to remain healthy and connected within their own homes and community.

There are likely a number of older adults who feel isolated, did not plan for future care needs, or are suddenly in need of care or alternative living options. These difficulties are compounded by caregivers, who are overwhelmed and unfamiliar with how to navigate the system. These programs and alternative means of support and care might not be the first thing they would look for or consider, and only if they are located in a community where such programs exist. There is

still more to be done in creating a better system for older adult care and addressing the local needs of an aging population. As reported in a local news post (*MacAlpine, 2020, para. 3*), authors of a new study of aging discovered:

Canadian seniors want to enjoy healthy lives of high quality in the midst of familiar, physical and social surroundings well into their golden years. Seniors want to choose, not just be told, where they will live and their type of living arrangements.

As Ontario's healthcare transformation unfolds and new strategies take foot, we need to be mindful, as Rayner and Howlett, 2009 (as cited by *Pekman et al, 2018, p. 33*) suggest, "initiatives are not implemented in a vacuum. Historical factors impact implementation and decisions are made in a context that has deep-rooted models, practices, and established actor/institutional networks." In light of historical government initiatives, new collaborative models that are being implemented today,

and the current context we are living in, a consideration of where to intervene in the system (*Meadows, 2008*), to elicit change becomes highly relevant, as well as understanding the various perspectives, worldviews and beliefs. The report by Pekman et al. gives us a hint as to what might be getting in the way.

There is a lot of noise and distraction to systematically address the number of factors mentioned, and although the pandemic has shown the plight of our most vulnerable seniors and those who care for them, it is hard to digest or comprehend that there is no quick and easy solution. A comprehensive set of interventions guided by imaginative or novel ways of thinking will be required to influence our notions of older adult care and further transform systems of care. So to begin, we must first ask and understand what various stakeholders think, feel and know, as a starting point for change.



Methodology

Literature Review and Environmental Scan

Sources of information came from a number of entities and organizations within the community care and healthcare system. Initial key search terms included: care, models, older adults, primary care, community based healthcare, seniors care, healthcare in Ontario, home and community care, models of older adult care, and community-based alternatives. Throughout the course of the research, new search terms evolved to include systems and models of care for the elderly, community alternatives for aging in Ontario, and often, new sources of information became known in the process or appeared in the media.

Secondary sources of data included government and organizational reports, social media, newspaper articles, as well as blogs and white papers from a variety of associations; and more specifically, published journals. These sources were useful in scanning current and emerging issues and trends. Daily media reports on the impact of the COVID-19 pandemic on long-term care, the acute care system, and our everyday life ran the course of this research and continues today.

From the environmental scan and literature review, five categories of stakeholders were identified: 1) older adults who may have direct

or indirect experience of care or caregiving, 2) family members or informal caregivers, who might assist an older adult, parent or relative, 3) providers who work for an organization facilitating care and education, 4) primary care physicians (family physicians), and 5) health system leaders, who are often involved in governance, planning and administration at provincial, regional or organizational levels.

Reflection

The complexity of this topic revealed a great deal of information and research, and it was often overwhelming recognizing the vast and deep knowledge that already exists within this domain. I was reminded that qualitative research is not necessarily about having a large sample to draw statistical data from but rather a small but representative sample that could provide a deep understanding of interests, beliefs and behaviors underlying a research domain. This was a helpful reframe when considering the academic and research collaborations and experts that already exist within the field and particularly within the GTHA such as MIRA. The rigorous process of preparing the application to the Research Ethics Board (REB) furthered my appreciation for human-centred design research and the privilege that comes with conducting this type of research.

Recruitment

To develop an understanding of individual perceptions, attitudes and experiences about the topic of older adult care, and specifically, awareness of community-based alternatives for older adult care in the Greater Toronto Hamilton Area (GTHA), it was determined that a survey questionnaire and semi-structured interview would be used to gather the data. The aim for these methods was to bring the voice of each represented stakeholder group forward and identify where misalignments between the various perspectives may exist. Through the process, insights might be found that indicate suitable leverage points for systemic change. The methods chosen for this research involved human participants and therefore an application to the OCAD University Research Ethics Board was required and was approved in September 2020. All participant activities were conducted over a period of six weeks.

Survey methods

Using Survey Monkey, an invitation and link were distributed by email from a pre-populated contact list and through organizational representatives, who had agreed or offered to participate and distribute the survey invitation. The survey link was also posted on social media sites, LinkedIn, and Facebook. Upon accessing the survey, participants read a preamble outlining the purpose of the survey, terms of participation and confirmed their consent before they could proceed to the survey questions.

The survey was open for three weeks (Sept. 29 to Oct. 19, 2020). Survey questions were developed to explore stakeholder perspectives on: 1) current perceptions of older adult care, 2) perceptions of pros and cons of current models and systems, and 3) awareness of and perspective on alternative models of care.

For each open text question, responses were colour coded to create clusters of related words and phrases. After reviewing question summaries (all responses), data was filtered to show responses for each stakeholder group. This was later compared with corresponding interview questions and data themes.

Interview Methods

Participants were recruited for in-depth interviews by an email invitation and shared this information through their own network. Upon receiving an email response, interested participants were then sent a consent form and calendar invitation for a scheduled interview. Interviews were scheduled for 20-40 minutes, including a preliminary introduction and consent procedure and conducted within a maximum of 45 minutes. Interviews took place over the Zoom platform with both audio and video recordings. Notes were taken to augment recordings. Interviews were conducted while the online questionnaire was open and were scheduled up to November 6, 2020.

Analysis

Approach

Survey and interview data combined revealed a number of themes. Where there was an opportunity to compare data across questions probing at the same construct, this was done. Interviews were conducted to understand each stakeholder’s perception, knowledge and experience of older adult care. By “perception”, I mean the concerns and expectations related to older adult care; as well as their associated feelings and ideas as to what alternatives may exist, and what innovations and critical uncertainties will shape the future of older adult care. The qualitative data from the interviews was analysed using inductive thematic analysis, as described further below. Audio recordings of each interview were transcribed by listening to each recording and

manually entering responses into a spreadsheet. Filler words were excluded and lengthy details about personal stories were paraphrased. To ensure accuracy of these events and details, audio recordings were reviewed as needed. Therefore, transcription did not entail a line-by-line format typical for coding (Gale et al., 2013) however, the majority of raw data was captured including key quotes and significant details.

Interview responses were organized by each question (in rows) and also for each interviewee response (in columns) with a total of four data sheets for each stakeholder group. This was set up similar to a user response analysis (Kumar, 2013, p. 144). In addition to responses for each interview question, specific comments about COVID-19 or the pandemic were noted, along with other comments and the researcher’s

own interpretations. The sentiment (attitude, emotion) of each interview was also initially interpreted and furthermore, supported by key quotes or remarks. Expressed ideas were summarized across for each interview question and also for each individual interviewed within the stakeholder group. Once all the data and initial interpretation was documented, key ideas were clustered according to colour coded sticky notes representing each stakeholder group and each numbered question.

After grouping all the stakeholder sticky notes for an identified question, a theme was noted on a large yellow sticky note. Overall, this provided a visual pattern of stakeholder ideas grouped under one to five themes for each interview question.

Key themes and ideas were then further analysed by developing a series of system

maps and diagrams. This approach considered stakeholder perceptions of older adult care and the broader system in which care is accessed and delivered, then narrowed to map community-based alternatives for care and the sectors in which alternatives (alternative models) may exist or how each sector’s role is perceived. Through this approach, the findings were visualized and could be contextualized and understood as a whole.

Results

There were 75 total responses for the survey, with a 76 percent completion rate.

Interview data

Eighteen interviews were completed between Oct. 6-Nov 6, 2020. The following table shows the number of interviews conducted for each stakeholder group:

Stakeholder	Older Adult	Family member/ Caregiver	Provider	Health System Leaders	Primary Care Physician
Number interviewed	5	4	4	5	0

Table 1. Number of interviews conducted for each stakeholder group

The recruitment strategy succeeded in general, despite a challenging time to engage people and particularly primary care physicians, given the impact that the pandemic has had on

their work and home life. For those who volunteered to participate, they were fully committed and the majority were able to respond to all of the interview questions.



Figure 2. Data Grouping and worksheets

Question	Theme 1	Theme 2	Theme 3	Theme 4	Theme 5
1	Person-centred, support independence	Access and choice for care	Values in care	Proactively meet a range of needs	Support in home
2	Fragmented	Frustrating	Downstream care		
3	Opportunity, Learn & Contribute	Person-Centred Path of care			
4	Flexible funding models	Invest upstream	Voice at the table	Qualities and interactions of care	
5	Upstream Focus	Attitudes toward aging	Invest with action	Home and community	
6	The when, how and where of care	Preference of options for residence	Attributes of alternatives		
7	Innovate in service delivery model	Leverage tech to enable connection and service	Vibrant community and partnering		
8	Managing health Inclusion and Respect	Capacity to meet demand	Stability and sustainability		

Table 2. Interview themes for each interview question

In total, 22 interview themes emerged (Table 2) grouped according to the original interview questions (listed in Appendix A).

During and after theming interview data, corresponding survey questions and responses

were cross-referenced and identified by stakeholder category when possible.

Within each phase of the analysis, a number of insights and critical questions emerged. Insights were ordered and clustered, recognizing that

each stakeholder group shared knowledge and perspectives determined by their experience or relationship with the system of care: either by function or role, needs and expectations. It became evident that the various notions of older adult care and the language used to describe models of care was at the core of this research project.

Results from the data were organized by first considering how stakeholders understand and perceive current models and systems of care, followed by considering responses for community-based care and alternatives, along with themes for older adult care. And finally, integrating findings that addressed prerequisites for change and the future of older adult care.

Perceptions of the Current Models and Care System

Current Model of Care

Survey respondents were invited to select a description for the current model of older adult care.

There were 56 responses, with 68 percent of the responses selecting “Fragmented,” as shown in Figure 3 below. Responses in the “Other” category were generally negative, suggesting that the current model is “focused on optimizing the system rather than citizens needs,” “woefully underfunded,” “sometimes disgraceful,” and one response wondered if there is a model.

Q6 How would you describe the current model or older adult care?

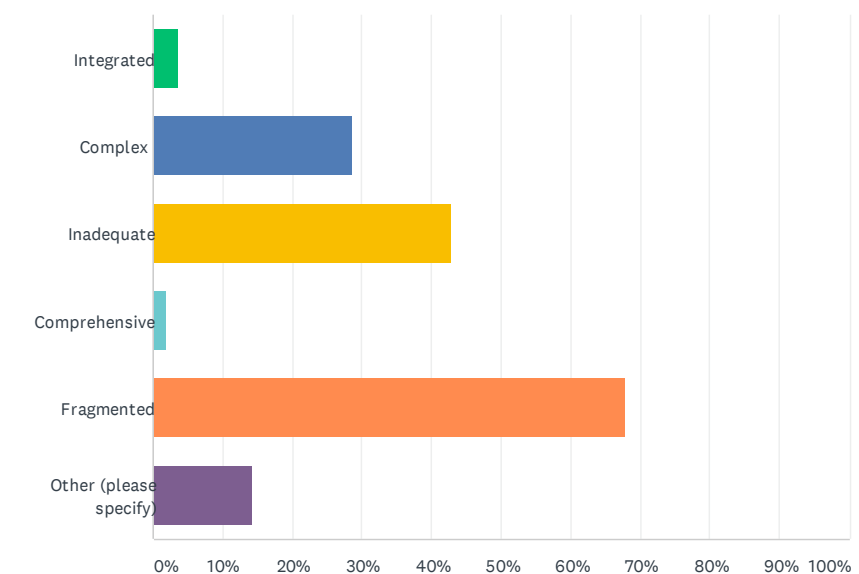


Figure 3. Survey response for describing the current model of older adult care

Interview results generated similar themes: frustrating, fragmented, and downstream focused (see Table 2). Words such as: confusing, reactive, mediocre, vague, and comments about relationships with providers or provincial ministries, described the frustrating experience that primarily older adults and family members have, although similar remarks were also evident among providers and health system leaders. “Fragmented” was described as a lack of integration or a disconnection, and was more pronounced among providers and health system leaders. Lastly, the same two groups of

stakeholders suggested that the current model and system’s focus of care is downstream, focused on institutional care, with paternalistic or patriarchal tendencies and provider focus.

Gaps, barriers and challenges in care

Perceptions of the gaps, barriers and challenges associated with current models of care and the system were identified through the survey data. Phrases with similar meaning were grouped for each area (gaps, barriers, challenges), although there was some overlap in the data for all three areas.

Gaps	Barriers	Challenges
Needs of an individual and quality, customized or appropriate level of support	Affordability (for the individual), financial ability	Provider focused system, Time to provide quality care
Level of need and service available — limited support or care for individuals living at home	Access (to care) Criteria for in-home care funding	Rationing of care (reduce length of visit for task due to less funding and more demand) Prominent role of hospitals drawing resources from other sectors
Lack of integration or transition in care between providers, geography or within the continuum of care	Managed by different “players”	Cooperation (in best interest of client)
Staffing — lack of available staff for number of people needing care in nursing homes	Long term planning (government level)	Lack of priority or political will Not enough trained staff for range or complexity of needs
Knowledge of what is available, individuals seeking information	Awareness, lack of information, systemic barriers (i.e., race, class, anti-elder bias)	Isolation, sense of community, cultural needs or expectations

Table 3. Summary of perceptions of gaps, barriers and challenges

“Lack of funding, lack of integration of services. Most in-home services are geared to physical barriers rather than cognitive. And because of severe rationing of services, there is a very high bar of illness or impairment before services can be accessed, putting extreme pressure on families and driving people to try to access long-term care.”

Survey Respondent

Perceptions of care models

Survey and interview questions also invited respondents to offer their perceptions of what is working well within current models and systems of older adult care. Four aspects emerged as favourable, 1) once connected to the system, there are good programs and services, 2) specialized geriatric care, 3) adequacy and availability of basic service (i.e., emergency care), 4) home health care and services. Although data revealed some positive perceptions, limits or gaps accompanied the responses. For example, a respondent shared,

“Services are available if one is persistent, knows where to look, and connected to healthcare professionals who take a personalized approach. The LHIN care coordinators have been very helpful for coordination of services. Specialized geriatric assessment clinics and community-based nurse practitioners are excellent resources but stretched thin.”

Another respondent stated,

“I expect there are things that are working well. I just get the sense that there is not a systemic view of older adult care in society. If you’re living independently you’re on your own until there’s an acute need and then you and your family have to have a thick skin, time, and hopefully private resources to navigate and be successful.”

With some favourable references reported in the data, there were equal or larger needs expressed for improvements of current models and systems of older adult care.

Mapping the current care system

To better understand what might be driving these perceptions, the following system map (see Figure 4) shows some of the patterns that occur in relation to the Ontario Ministry of Health’s 2019-2020 estimated budget (Financial Accountability Office of Ontario (FAO),

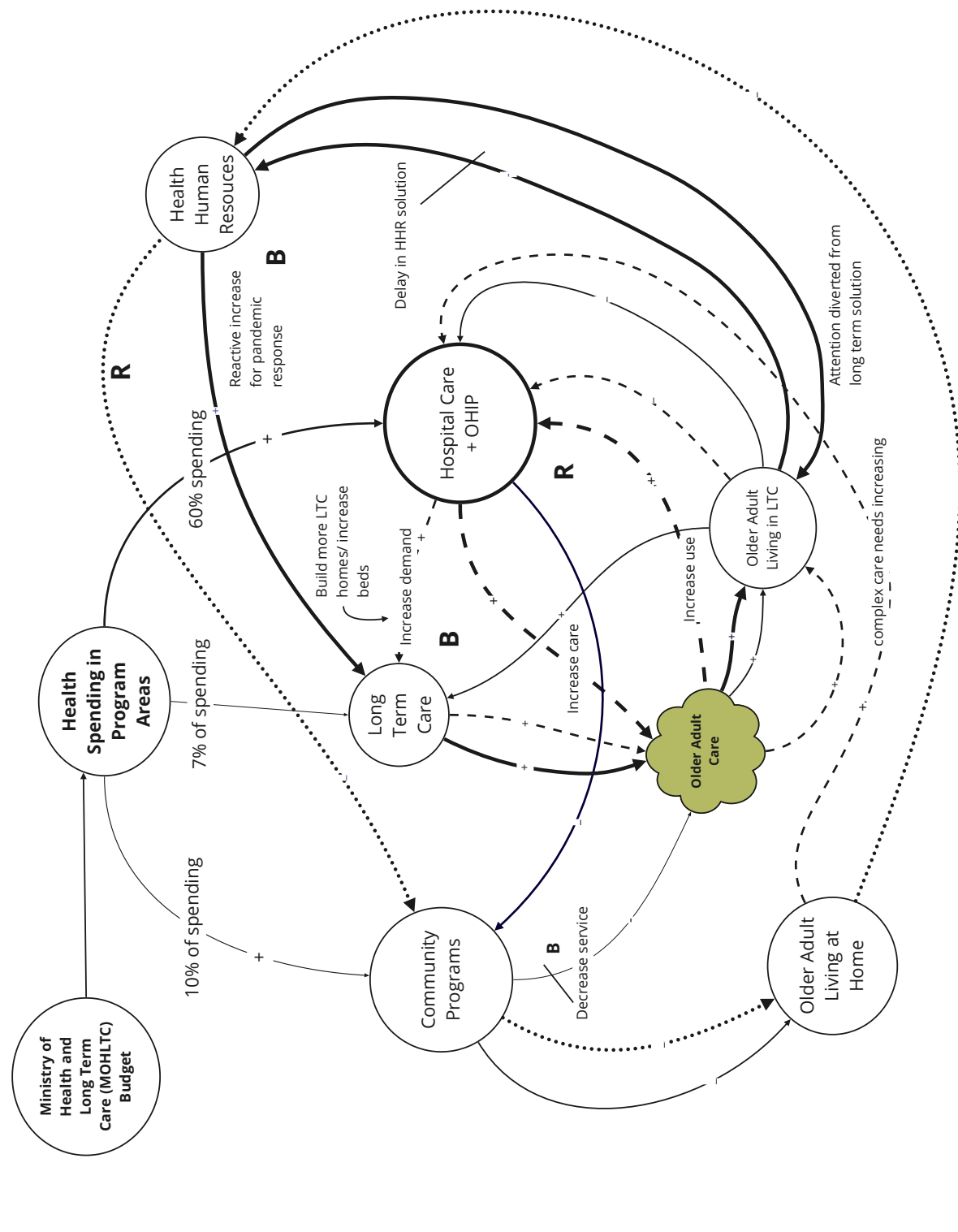


Figure 4. MOH spending influence on older adult care

R Reinforcing Loop Thick dashed loop: Limits of Growth Archetype Dotted loop: Tragedy of the Commons Archetype
B Balancing Loop Medium dashed loop: Fixes that Fail Archetype Heavy solid loop and line: Shifting the Burden Archetype

2019). The causal loops show the effects of spending for community programs, long term care, as well as hospitals and OHIP. This map shows the system's "stock" (Meadows, 2008) as older adult care, which means levels of care may increase, or decrease, or stay relatively stable over a period of time, depending on what is happening in the system.

As shown by a larger circle and thicker line, the MOHLTC estimated budget allocates 60 percent of spending to hospitals and OHIP, while a smaller portion of spending (ten percent) flows to community programs and seven percent to long term care. Although spending is directionally positive to all three program areas, the effect (capacity) to provide care for older adults by community programs is proportionately less. Over time, as care needs for older adults increase, and if funding does not keep pace for community programs, capacity is reduced leading to a reduction or limit of services for older adults by community programs. The delay to transfer adequate funding to the community perpetuates the use of emergency and primary care intervention. These elements of MOLTC spending: community programs, older adult care and hospitals + OHIP are in a balancing loop with a delay, which can result in older adults seeking care delivered through hospitals when their care needs cannot be met in the community. This system structure is producing a pattern of behaviour (archetypes) that is problematic (Meadows, 2008) and shown

in Figure 4 with a thick dashed loop, as the archetype "Limits of Growth" which shows a reinforcing (positive) loop between older adult care and hospitals + OHIP. This results in an overuse of the acute healthcare system.

The medium dashed loop represents an older adult living at home with escalating care needs. When these needs cannot be met by community care services, the demand for care shifts to primary and hospital care. If an older adult cannot return home with adequate support, the burden of care is then shifted to institutional care, typically in the form of alternative level of care (ALC) beds in hospitals. As ALC is costly, there is a push to transfer ALC patients to long term care settings (or home) creating a demand for more long term care beds and "the fix" as in, build more beds, is justified. Rather than investing (spending) in more intensive supports in the community, policy decisions to build capacity with long term care beds, although in the long run may increase care for older adults, cannot effectively alleviate current care pressures in the system. Older adult care levels remain relatively stable, and care costs continue to rise as the population grows older with more demands on systems of care. This system behaviour is described as an archetype called, "Fixes that Fail" when the goals of each actor in the system are not aligned.

The impact of COVID-19 within congregate settings (long term care residences) has required an immediate response to increase the number

of health human resources in these care settings, (shown in Figure 4 as a heavy solid loop and line) temporarily diverting human resources from other providers in the system. In addition, there are a number of historical factors at play: the government has intervened with subsidies for beds in long-term care, and budgets for staffing and training have not kept pace to support the complex care needs of residences in these settings. In addition, as families have not been able to provide care for an aging parent (shifts in culture and lifestyle, and currently, inability to enter facilities due to quarantines), they have lost control of caring for their parents and have to rely on staff and institutions to fill the gap. The pandemic has shown that work conditions for staff have deteriorated against a backdrop of “signal denying policies” (Meadows, 2008) that haven’t considered how to restructure the entire care system. This is another pattern known as “Shifting the Burden,” noted as a balancing loop. As the situation stabilizes in a congregate setting, temporary resources are taken away and we are again left with a situation where there is not adequate staff for long term care and a diversion from investing or planning for long term solutions.

Another pattern or “trap” as defined by Meadows (2008) as “Tragedy of the Commons” is apparent in the current health spending context. The dotted loop shows that there are less health human resources flowing

into community programs, which reduces service to older adults living at home, which reduces access to health human resources as they are acquired into long-term care institutions and hospitals. The level of care in the system remains status quo, while the common resource, health human resources, is diminishing as each actor in the system competes for this resource. In the case of the COVID-19 pandemic, many health care workers became sick and also shouldered the burden of care when families and co-workers were unable to support them. Also, health-care workers earn less in community than in long term care settings and hospitals (Jeffords, 2021), and this further creates strain in the community to adequately serve older adults living at home. In summary, Figure 4 shows a number of structures that perpetuate downstream care, high use of costly hospital care and reinforcement of institutional care, aligning with some of the gaps, barriers and challenges as noted in the themes.

The next map (see Figure 5) attempts to show the complexity of older adult care as recognized by stakeholders, including entities and their relationships. It is not an exhaustive representation of the system in which care occurs but rather highlights key entities, interactions and experiences described in the data.

The known entities that stakeholders referenced in the data, including the favourable aspects like specialized services, show a health system

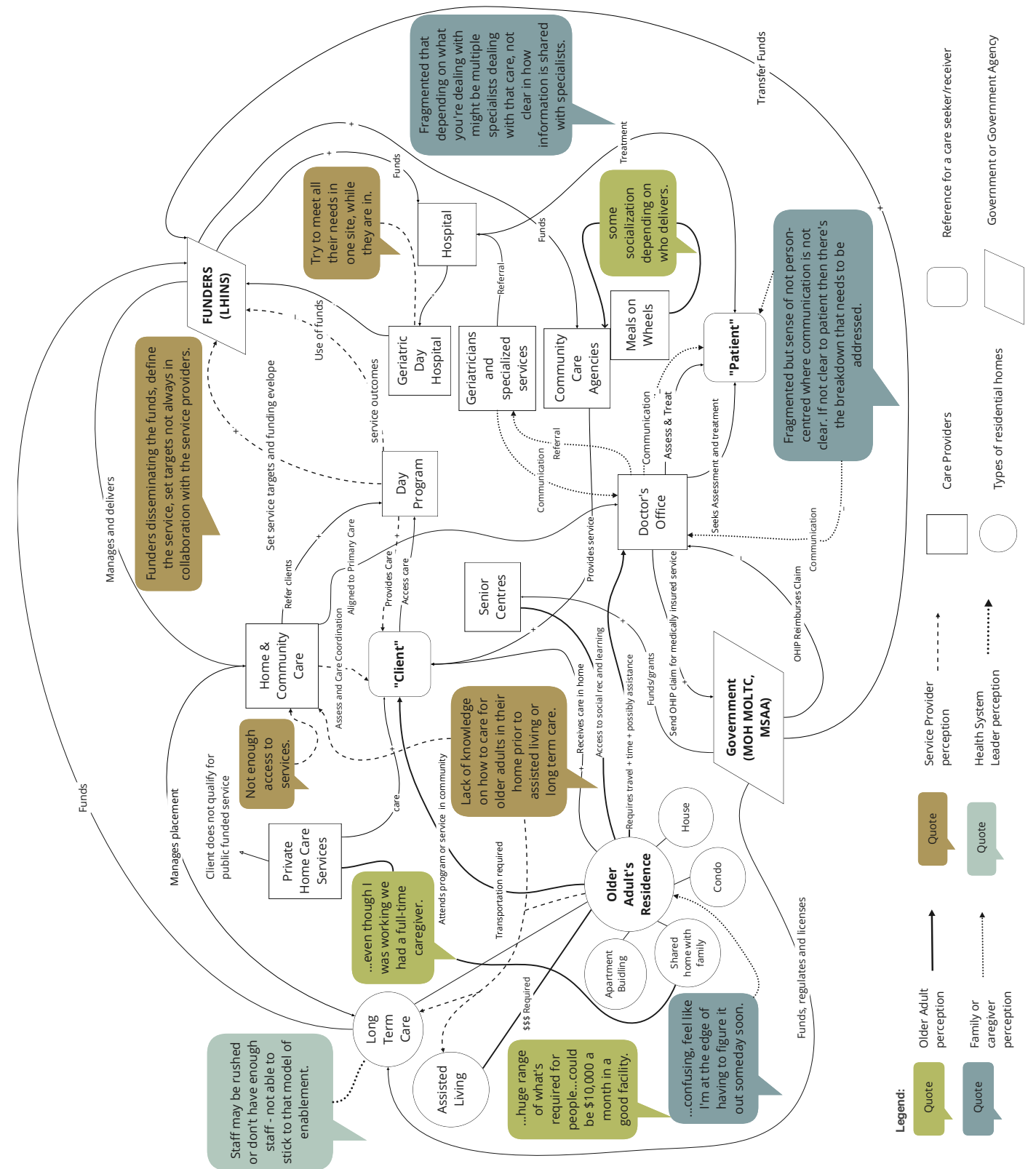


Figure 5. Older Adult Care System as represented from the data

that covers the basics and a number of programs and services that may be accessed when needed. There are causal loops among providers and funders in the system and point to two service users, either a “client” or “patient”. Family members expressed frustration with numerous points of care: at the doctor’s office, upon hospital discharge, or navigating the system for needed support and services to maintain their parent’s ability to live at home. The descriptor “patient”, shows that the relationship between physicians and older adults is primarily regarded as a function of assessment and treatment with another separate channel in which the family doctor may facilitate referrals or receive referrals for community-based care. Communication is the primary barrier (dotted line) within this relationship of care and can be shown to be a reinforcing feedback loop. In this dynamic, the older adult may also be a “client” for a variety of providers, but as expressed by a family member, “...many appointments where Mom is retelling her story, I get frustrated when I hear Doc say, “ I don’t know what they are doing.” The family doctor may not know who is involved and what they are doing, and the patient or family member is retelling their story or providing details of those interactions. There were other remarks suggesting that current care models are fragmented and reactive and that there is no anticipation of what older adults may need.

As reflected in collected quotes, some older adults and family members try to anticipate

future care costs or needs but have very limited understanding of the system; in particular, where to get information and address concerns about financial aspects of care. There was also a sense that if resources are not available within the community, then older adults are destined for assisted-living or long term care residences, which may not exist within their neighbourhood or be aligned with their current lifestyle interests and daily activities. The disconnect between home and community care services and individuals having adequate knowledge to care for someone at home is shown in Figure 4 with dashed lines. All stakeholders shared a common theme that there is inadequate knowledge and incentives to provide care at home. Individuals who remain living at home may need to purchase additional care through private home care services. All stakeholders recognize that community programs and services exist but may be limited by their mandate or funding.

The connection between funder (LHIN) and provider (Day Program) is represented as a dashed balanced loop (see Figure 4) as funding, service standards and measures may not be mutually determined. Although day hospitals that provide outpatient care may meet a number of needs, these programs alone can not adequately support individuals to live well or independently at home unless they are connected with a network of community resources, services and providers. Day hospitals

and day programs serve older adults who meet criteria for this level of care, and often help caregivers and clients navigate a complex system of care.

Community-Based Alternatives for Care

All responses related to the notion of older adult care, its meaning and goals, were themed and informed ideas about community-based alternatives for care and sectors (government, community and private) where care may be supported, facilitated and accessed.

Themes for Older Adult Care:

1. Person-centred, living well and maintaining independence

Older adult care was often described from an individual focus, with notions of living well, maximizing independence and maintaining health. Support, respect and enablement were concepts embedded within this theme. All stakeholder groups were represented in this theme.

2. Access and choices for care

Access to care and receiving care when needed was identified as being important to respondents, along with having choices and options available in the community. This was quoted by one respondent as “having appropriate care available, being fully informed of choices.” Another survey respondent shared, “Older adults who want to stay at home but

need assistance have very few services available to them. The system is very cumbersome to navigate and frustrating for the clients.” This statement captures both a preference for where an individual receives support and the broader challenges associated with accessing services and care. This theme was reflected by older adults and closely associated with the ideas of maintaining independence and functioning in Theme 1, person-centred care.

3. Integrating values

Words such as compassion, safety, and dignity defined this theme, as well as cultural expectations and norms. This was described by one interview participant (*Family 3*) as, “take care of those who took care of us.” A survey respondent pointedly stated, “Care versus Cure.”

This theme was more apparent among the family stakeholder group and related to community and societal values around aging and care.

4. Proactively meet a range of needs

This theme included ideas about the provision, level of care and assistance that someone may want or need. This theme also suggests there are many types of needs, as represented in this survey response:

Identification of key acute and preventative medical needs, assessment of social and medical supports, assessment of ability to meet one’s financial needs. Prioritization of self-identified goals. Support in

understanding advance care planning. Teaching about lifestyle, both physically and mentally...

Similar to Theme 2, access and choices for care, interview comments and survey responses suggest that various needs of care are met at various levels within the system. Ideas within this theme were contributed by providers, health system leaders and older adults.

5. Support in home

Older adult care was also attached to the idea of where one lives or receives care. Retirement settings and long-term care homes were often mentioned and the associated resources, human or programs, that offer care. Also reflected in the responses was an individual's

ability and the idea of living as independently within their home and community as possible, until a person would require living in an institutionalized setting. The aim here, as reflected in this statement: "...looking after people to the greatest degree possible in their home and community and having a bias towards that arena of care and only resorting to institutionalized care if absolutely necessary." (HS Leader 1) The voice of health system leaders and older adults was most present within this theme and also connected to Theme 1, person-centred care.

Exploring community-based alternatives

The next phase of analysis considered responses to the core research question inquiring about alternatives for older adult care: do alternative

models exist, what sector they may fall within, why they might work, and what community-based alternatives come to mind. Survey data revealed that 39 out of 56 (69.7%) respondents selected yes to the question: Do you see an alternative model of care? The graphic in Figure 6 shows where these alternative models might fall.

Responses were varied for "a mix", including comments about leveraging the strength of each and working together. This suggested that the government has oversight and leadership; whereas, the community should manage and operationalize care. Notably, respondents did not choose the private sector for an alternative model to fall within but rather referenced options for private sector involvement like: homecare monitoring and maintenance, innovation and technology, and private delivery. The idea that government, community and private sector all have a role to play is summarized in this response: "I believe all (govt, private, community) have to come together to provide a comprehensive alternative for older adult care."

The following model (see Figure 7) represents some of the primary roles and functions that each sector may contribute for alternative models of care as well as some of the opportunities where overlap exists.

During the interviews, participants were asked to consider community-based care and what

alternatives come to mind. Alternatives were not readily mentioned other than commonly known programs or services such as: senior discounts, senior community centres/programs, and Meals on Wheels. Figure 8 shows some of the community-based programs or services that were recognized by stakeholders.

Older adults interviewed all lived within their own homes, either alone, with a spouse, or with another family member within their community. Relationships that an older adult may or may not have with a particular community-based service or support were described as attending, connecting, and seeking referral and treatment. For older adults interviewed, care was associated with residential care buildings or programs and with services like Meals on Wheels or day programs. Providers interviewed did not mention clear community-based alternatives other than considering how people can be supported in community or their current living environment and what support can be put in place to prevent reactive moves to residential or institutional care. For example, one provider suggested there is "not enough mental health support in the community; if you want to see a social worker [it] has to be with a goal in mind, no ongoing support." This disconnection to these services and supports is represented on the map with a dashed line. Notably, not all community-based services and neighbourhood resources are shown but rather the associations that represent a large

Q12 Does this alternative model fall within:

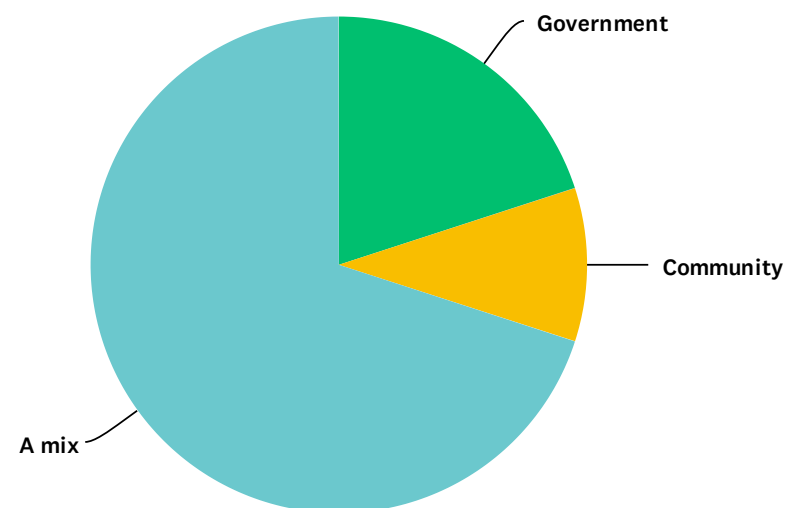


Figure 6. Survey response showing what sectors alternative models of care fall within

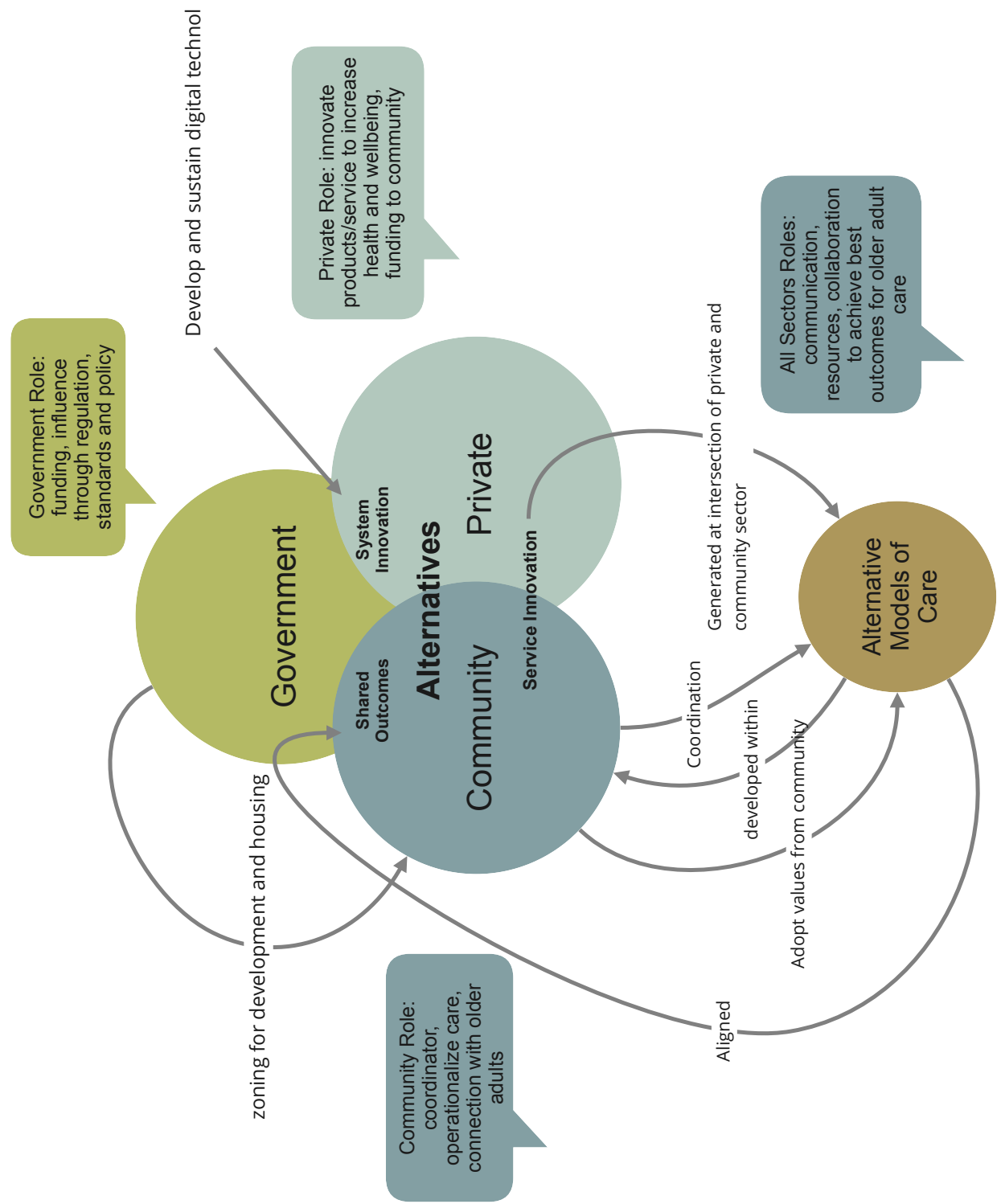


Figure 7. Alternative models of care and suggested roles for government, community and private sector

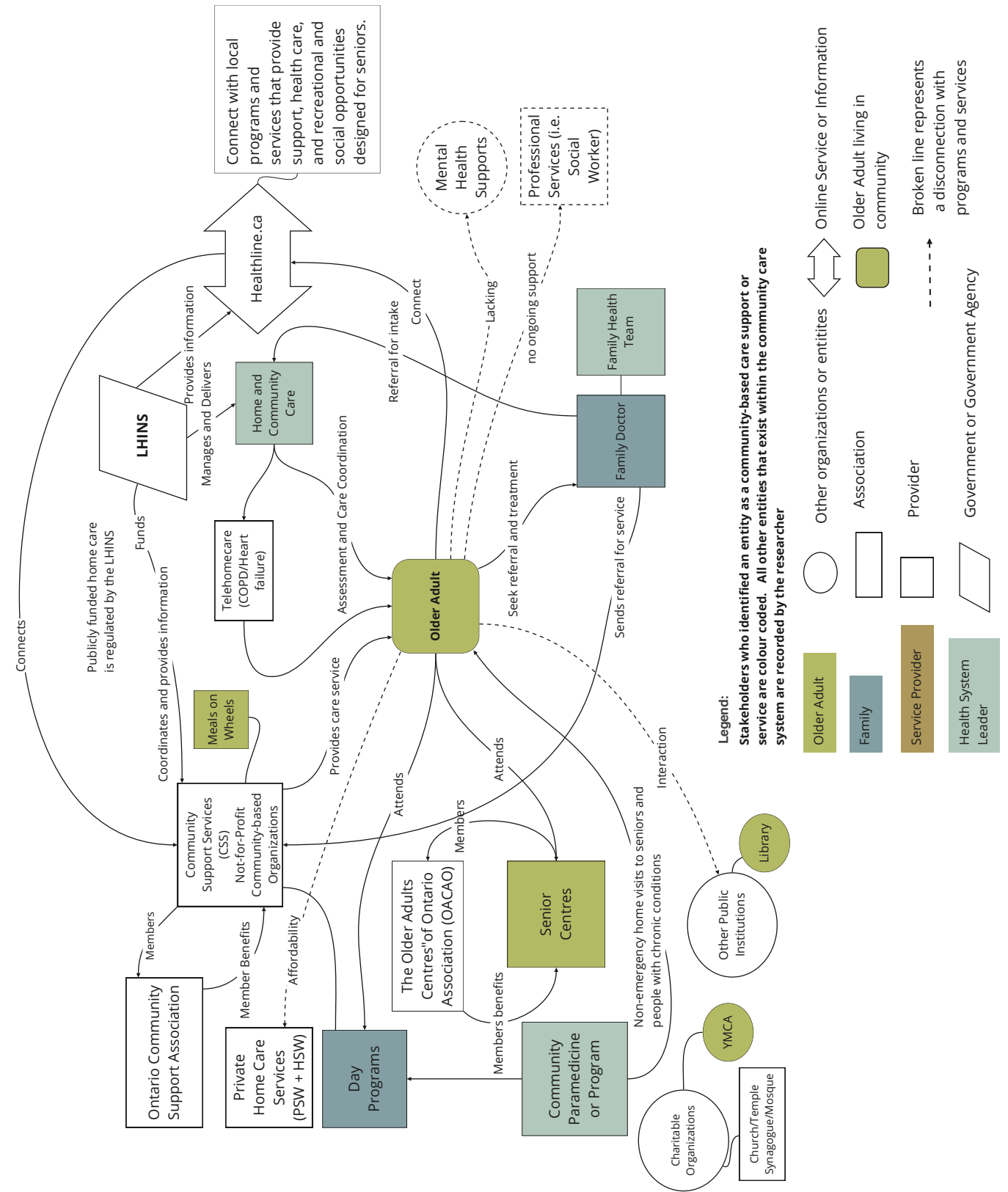


Figure 8. Community-based programs and services recognized by stakeholders

number of not-for-profit organizations. Associations were not mentioned in the primary data collected; however, they are included to show their role within the community-based care system.

Although there was recognition that a number of programs and services exist within the community, there was a sense that important features and considerations were lacking. An interviewee explained, “There are no organizations or private companies that are interested in our generation.” This reflection points to a perceived gap and possible opportunity to explore why public and private services are not fully engaging with this market. Similarly, this older adult offered some ways in which older adults and youth could be more engaged for mutual learning and contribution through public institutions and other services.

Respondents and participants described features or aspects of programs and experiences that should be considered in alternatives. The attributes most desired for alternatives include: learning, creative, stimulating activity (mental, physical), contribution, connection, and inter-generational. Other suggestions were that alternatives need to include discounts and services that increase health and wellness. Ideas were also shared as to what, where and how alternatives for older adult care should occur:

- Treatment in doctor’s office rather than a clinic located outside of someone’s community

- Paramedicine
- Integrative care community
- “How To” guidance tools and information

A number of preferences for living within the community or type of residence were shared by stakeholders:

- live in age friendly community/ walkable community
- shared accomodation with student, other older adult, renter
- gated community
- congregate housing
- shared home with funding attached to shared household

Some of these ideas referred to examples or models that already exist, such as shared accommodation between students and older adults (Ayerst, 2018) or models of care in Denmark (Stuart & Weinrich, 2001).

The primary research began to shape how older adult care is perceived, whether or not community-based alternatives may exist in models or approaches within existing systems or structures, and also as entities. Furthermore, stakeholders identified attributes that should be associated with activities and models of care, as well as the various roles and relationships that the government, community and private sector might or should play when considering alternatives for care. Some of the home and community-based delivery models represented

in the literature such as those shared within The Conceptual Framework Supporting Future Long-Term Care Provision in Care in Canada (An Evidence Informed National Seniors Strategy for Canada - Third Edition, 2020) were not identified, with only a few references and alternate living options mentioned.

The map and description in Figure 9 represents a number of ideas and desired relationships and connections that stakeholders held for community-based alternatives. This map builds upon community based programs and services already recognized by stakeholders (see Figure 6).

The green ellipse represents an older adult living in a home and community of choice and within an Age Friendly community, reflecting a common preference among stakeholders. The living options are represented within the ellipse, with considerations for better design for multi unit buildings and developments that integrate homes (new builds or rezone) geared toward older adults within existing neighbourhoods or infrastructure. This is most desired to enable close proximity to familiar places, stores and everyday conveniences, as well as, support everyday interactions within public life. There were a number of references by stakeholders suggesting that interactions and learning should occur in the built environment and through public institutions. These include building curriculum into primary and elementary school programs to reduce stigma about elderly,

facilitating knowledge sharing, and providing older adults the opportunity to help young children with reading and other activities. Additionally, public institutions, like universities, may facilitate connections across generations with co-housing options for students and older adults. The map also indicates a desire to strengthen services that are inclusive of “seniors” facilitating health promoting behaviours and learning to embrace and adopt new technology. The map indicates that charitable organizations can encourage older adults patronage through discounts on membership fees, and generally facilitate health promoting behaviours and engagement.

For older adults who have moderate complex care needs, community paramedicine was mentioned by health system leaders as an great example of what can be done to bring care into someone’s home and minimize the use of acute care resources. The various day programs and home care services are highly valued with a theme that early access to help (i.e., physical, medical, social, mental etc.), when needed through collaborative means and within community-based resources/services/ providers would be optimal.

The costs of private care and services are perceived as a barrier and, although shown on the map, were not regarded as viable options for those who cannot afford it. In a desired state, older adults can access private care and services that are affordable and accessible.

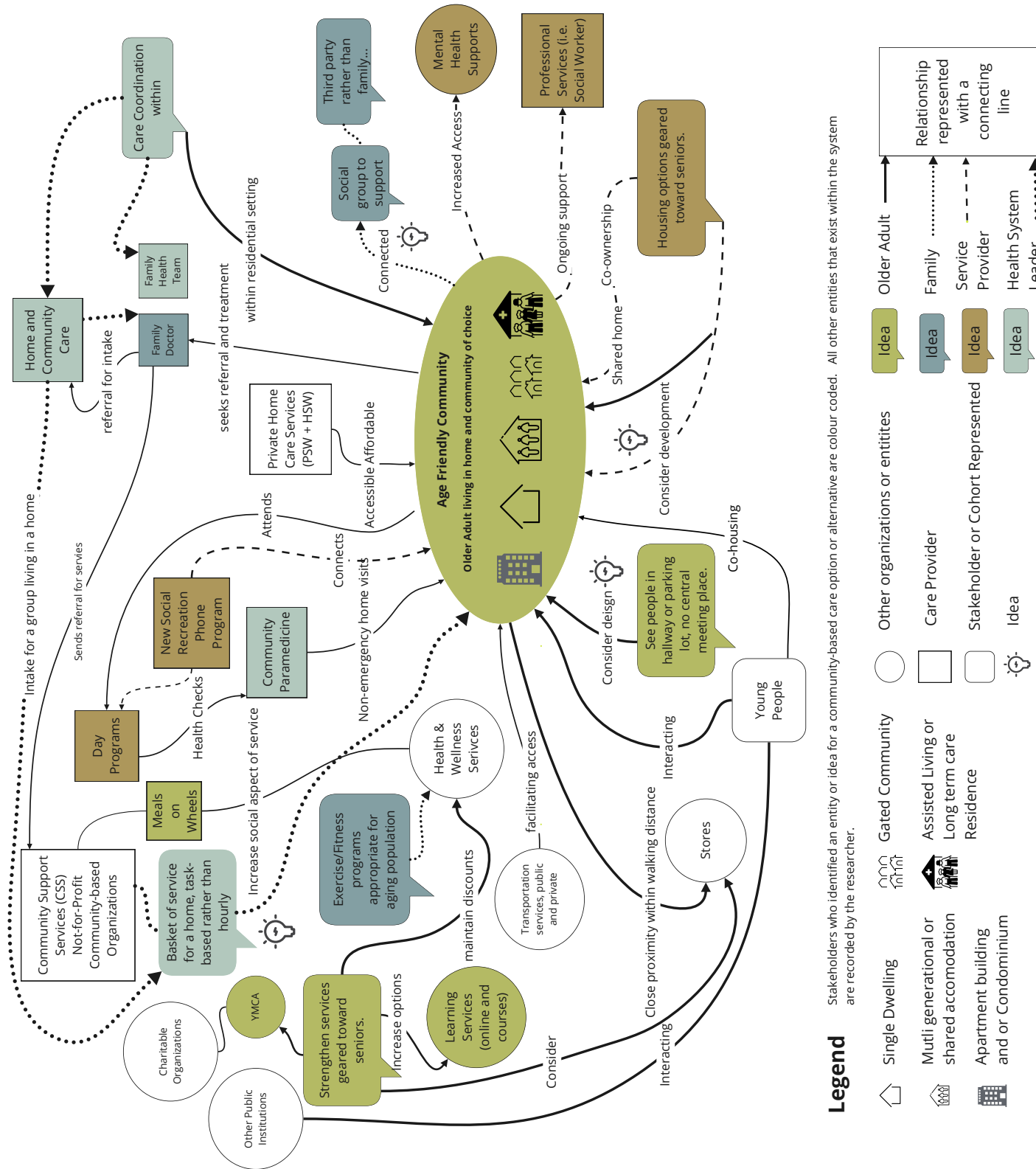


Figure 9. Ideas and desired relationships for community-based supports and care

There were also suggestions that care be delivered and managed directly by the providers within the community, with care coordination occurring at the sites of direct care provision or within the living environment. There is also recognition that some professional services are attached to existing day programs and services and when that ends, individuals do not have ongoing support and access to these professionals. Therefore, research participants would like to experience direct and ongoing connection to professional services without an intermediary, and as well, increased access to mental health services. Ideas suggested by health system leaders considered how care might be bundled as a basket of services with cost based on provision of tasks rather than time either for an individual or a group of older adults living in one home. Several ideas also supported “ownership” for health through the engagement of peer support to navigate care and facilitate better health management. This would reduce some of the conflicts that caregivers or family experience being involved in a loved one’s care. These ideas are shown in direct relationship with an older adult or their living environment. Overall, the map shows a number of direct relationships with older adults and suggests a more dynamic and interactive experience living within the community.

Prerequisites for Change

New inquiries and questions emerged after theming the data about stakeholder perceptions of what needs to be present

and come together to create a better system of care, as well as, stakeholder perspectives about prerequisites for change and levers for change.

“There has to be impetus from the healthcare system to respect and treat older people just as important as everyone else.” (Family 1)

Some of the inquiries are addressed in the synthesis and findings of this report, and others are considerations for future research.

These inquiries and questions (see Table 4) were also informed by the themes (see Table 2) that emerged from inviting interview participants to share their ideas for innovations and uncertainties that may shape the future of older adult care. Of particular note, all ideas represented in the data suggest how technology must be focused on the user; for providers that it must be integrated, for older adults it needs to be user-friendly, and in essence technology is seen as a “connector.”

In summary, the process of analysing the data was both interesting and dynamic and also iterative and challenging. Each system map provided key discoveries and insights that informed the synthesis and findings, and also formed the basis for future considerations. The possibility to better serve the needs of older adults through community-based alternatives began to take shape while discovering leverage points in the care system to create change.

Discussion — Shifting Perspectives

The design research process began with an exploration, seeking to understand and make sense of both the context and the stakeholders' experience. The stakeholders interviewed and survey respondents were in a sense, "reactive informers" (Sanders, 2008), engaging in this research project as subjects or users in the system. A scan of the literature provided both expert opinions and academic reviews about the various care models and issues associated with older adult care; further defining what is, with some suggestions as to what might be. Human-centred design and systemic design is the space between understanding reality and shaping reality — it's the space in which the insights emerged. The insights have the potential to shift perspectives and facilitate a rich dialogue creating a shift from an expert mindset to a participatory mindset with key stakeholders engaged as "active co-creators" and partners. This is a key consideration, as the Province of Ontario seeks to modernize and transform healthcare, and more specifically, as health system planners and providers develop strategies to meet the care needs of older adults, now and into the future.

To help frame the findings, and facilitate future discussion and a shift in perspective, insights were synthesized into a diagram describing notions of care (see Figure 10) and a framework for evolving alternatives for care (see Figure 11). First, I will discuss notions of care as these inform attitudes and behaviours across the various sectors of care.

Notions of Older Adult Care

Insights are reflected in a simplified diagram (see Figure 10) to show the connections between two notions of care, neither is right or wrong but reflective of how older adult care might be described, what it means to an individual, and how it is identified in the system.

As the perceptions of older adult care were explored, data revealed a number of value-based and rich descriptions of what older adult care ought to be, as one respondent shared, "It means tailored to an aging population with varying needs and complexities. It ought to be celebrated, invigorating and positive thereby enabling well-being at every age and stage." While other responses suggest older adult care as, "inadequate," "a hit and miss situation!" "frightening," "hard," "overwhelming and underserved." As global health and social systems have evolved, a number of policy frameworks and new models of care have been adopted to reflect a growing demand by individuals and families to be fully engaged in their care through shared-decision making and control. Throughout the literature there is reference to both patient-centred care and person-centred care, but as Barnett (2018) suggests, semantics is important:

The word 'patient' has specific, but perhaps unrecognised, connotations. When we think of 'patients' rather than 'people', there is a mental shift in the balance of power from two equal people to 'helper' (with health

Collected Data Themes	Inquiry: "What if...?"
Flexible funding models	How might the government fund the individual rather than programs? Where within the existing funding formula(s) or model (loops) can a shift be created toward individual choice? How might the government play a role as an influencer through policy, legislation and funding?
Invest Upstream	What if Inter-ministerial collaboration could facilitate a sustainable upstream approach? What are the practices within government to ensure a holistic and upstream focus?
Voice at the table — input and collaboration	What if we envision a network model of care and formed principles of engagement and governance? Might this pivot toward community-based alternatives and away from an institutional attachment for care?
Qualities and Interactions of Care	What if all organizing and planning principles begin with the notion that individuals can determine and choose their own care within their local community? What communication (channels) become critical to facilitate awareness and support? What if we develop community-based alternatives based on the notions of social proximity, intergenerational relationships, and social connection?

Table 4. Emergent inquiries for change

Notions of Older Adult Care

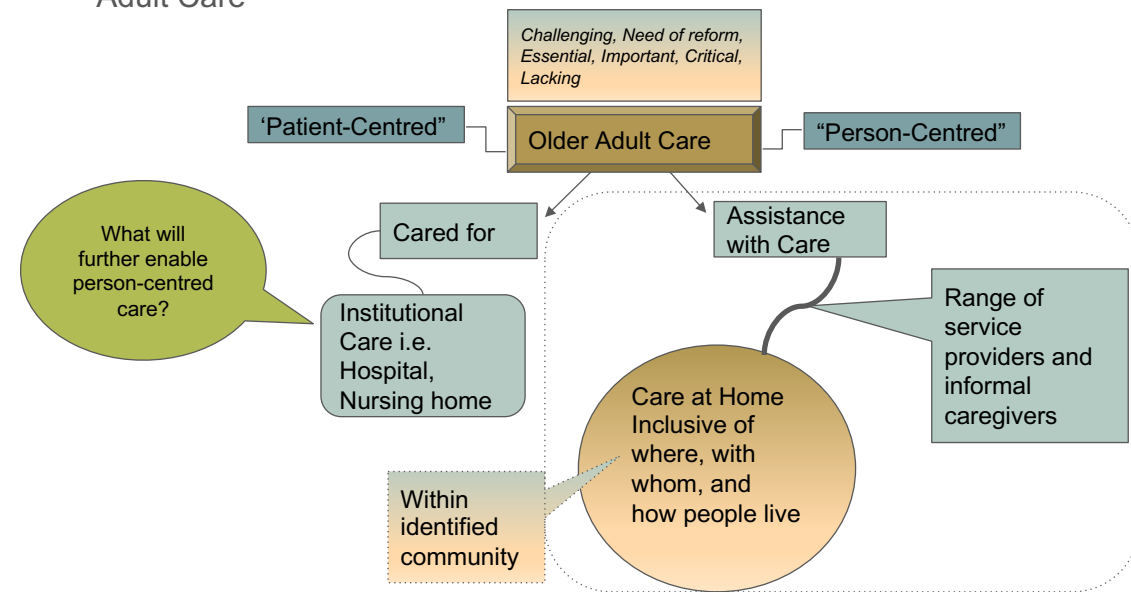


Figure 10. Notions of older adult care

knowledge, skills and experience) and 'person needing help' (needing our health knowledge, skills and experience). This unconsciously encourages a more paternalistic attitude to the person we are treating.

As this quote suggests, the labels or language used in a system of care, can continue to perpetuate attitudes and beliefs that hinder change and transformation. Similarly, patient health leaders (Campbell & Thiessen, 2020) acknowledge the unidirectional system of health and although there has been a switch from clinical-led to a patient-led system, there was still a need to adopt a more balanced approach, one that is described as a people-centred approach

as defined in the World Health Organization's *Secretariat Report (2016)*:

People-centred care: care that is focused and organized around the health needs and expectations of people and communities rather than on diseases. People-centred care extends the concept of patient-centred care to individuals, families, communities and society. Whereas patient-centred care is commonly understood as focusing on the individual seeking care — the patient — people-centred care encompasses these clinical encounters and also includes attention to the health of people in their communities and their crucial role in shaping health policy and health services. (p. 2)

Within the research data, descriptions of what older adult care means and how care should be viewed is aligned with this approach. Yet, references to ageism, silos and paternalistic behaviours were also evident in the data. Despite general references toward a people-centred philosophy, labels and everyday language of patient-centred care continue, as recent as the use of "patients" rather than people in the model of care for Ontario Health Teams (Figure 1). How the concept of care is framed and organized is important and often persists through deep rooted structures, world-views and metaphors. To transform our health-care system and influence notions of older adult care, a number of changes need to occur at all levels of a system and be inclusive of different ways of knowing and how a problem is framed (Inayatullah, 1998). Possibly we can begin to reimagine older adult care, one that does not organize care by economic and political agendas, organizational mandates, disease/health conditions or geography; but rather, by situating the person (people) at the core of all interactions, relationships, practices and systems of care.

A Framework for Evolving Alternatives for Care

The framework proposes an increased presence of community-based alternatives for older adult care: 1) infrastructure needs to be developed around that intention, 2) with a person-centered perspective at the core, and 3) enveloped

by supportive and positive societal attitudes toward aging.

The framework aims to show that person-centred care is the target or common element among all other occurrences, entities, behaviours and actions. This also serves as a compass or focal point for all actors in the system to embrace and thereby test any assumptions, actions and decisions. The framework proposed offers a reference for how stakeholders can begin to engage in designing for the future of older adult care, one that is rooted in principles and values of community and person-centred care. Through intentionality, investment can be guided toward community-based alternatives for care, which would call upon a number of sectors, communities services and neighbourhood groups to partner. This could serve to further embed the principles of age friendly communities and generate more sustainable approaches for care; while reaping economic gains and benefits.

Framework for Evolving Alternatives for Care

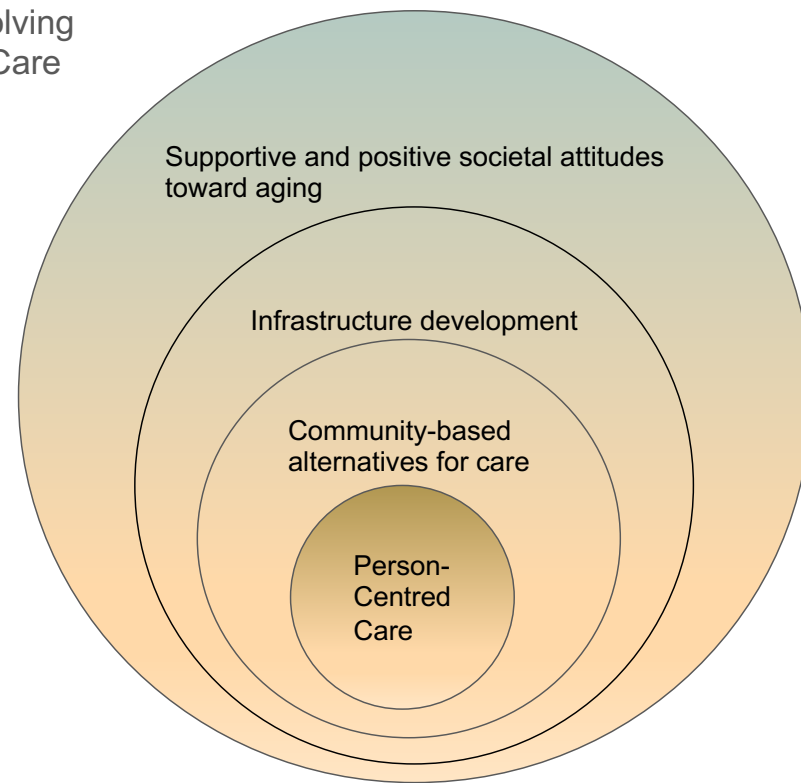


Figure 11. Framework for evolving alternatives for care

Key Findings

1. Community-based alternatives for older adults care are insufficiently acknowledged or known, except by those who are experts, researchers, and or, have extensive experience in this field. Even so, individuals (and stakeholders) might not be as familiar with community-based alternatives or models of care, unless there is a need, interest, or motivation to know. Stakeholders interviewed offered some examples of models of care and alternative living options.

Community-based care and alternative models for care are evident in the programs and services that are most recognized by providers and health leaders in the system, and for the older adults who are already using or accessing these services, namely, recreational programs, seniors centres, or day programs for people who have more complex care needs. That said, there are a number of older adults who don't require formal care and are not seeking it, what they are more concerned with is how they maintain their independence in their own home. An older adult might just need assistance for home maintenance, i.e. a paint job for high ceilings, or to access learning and maintain skills to stay connected with everyday life. With this in mind there is an opportunity for services both public and private to really consider the older adult population as a viable market segment with a unique set of needs that could be met. Also, older adults would prefer to have access to health and wellness promoting services. There

is an immense value proposition that emerges for both providers (in all forms) to serve this growing population.

2. A strong preference to delay transitions to institutional care with an overriding desire for older adults to maintain living at home in their community in contrast to system behaviours.

There is a spectrum of care needs from minimal to highly complex and as such, long-term care homes are often a reasonable choice for individuals, who have high complex care issues and needs. However, findings indicate a strong preference to delay transitions to these types of care settings with an overriding desire for older adults to maintain living at home in their community. Even as the Ontario government invests in building more homes and creating more beds, there may not be enough health human resources (staff) to provide adequate care. More so, there is no guarantee that the model of care within these settings will reflect the values and attributes of care that are most desired, unless there is sustained investment in leadership and staff training and development, and above all, ethical practices and accountability. The healthcare system appears to have a preoccupation with counting "beds" as a measure for capacity but I argue this does not equate with the meaning of care, at least not in the sense of values or attributes of care. The opportunity here, is then to consider

increasing investments in more intensive supports in the community (i.e. High Intensity Supports at Home program) or consider how existing resources can be leveraged to serve older adults and their caregivers with the means to delay moving into a long term care facility. This requires early and enhanced mobilization of knowledge, information and communication flows between a number of individuals and entities; and specifically, targeted for older adults. When people are in crisis, and or, do not have adequate support, knowledge, or finances to quickly access the products or services to be safe and healthy at home, then the move to long term care may be accelerated. To create capacity in the system, government not only needs to shift investments to home and community care but also consider rules for more focused actions. For example, in Denmark promoting awareness and access to services is achieved through The Home Prevention Act. As explained by Stuart & Weinrich (2001), “An important dimension of access in the Danish system is the letter that goes to all Danes at age 75, offering them a home visit. The Home Prevention Act mandates home visits twice a year for elders, regardless of their health status” (pp. 477). This example shows how leveraging dimensions of legislation (rules) and mobilizing resources on the ground, can better equip older adults with information and knowledge to anticipate and or meet care needs within their community. Therefore, the possibility exists to leverage new legislation in Ontario and develop a meaningful engagement

mechanism that can be carried out through an existing provider (designate) or sector partnership. This could be a public health offering (no where in the primary research was public health mentioned, although with a focus on determinants of health, such sector partners play a vital role in creating capacity and minimizing barriers for health). So rather than creating and counting “beds” the focus can shift to a number of meaningful and targeted engagements with an aim to delay unnecessary transitions to long term care homes.

3. Gaps in recognition of need (reality check by society and government) and limited awareness of what exists (individual level) perpetuate ageism and silos of care.

There are a number of ways in which we can do better as a society to be inclusive; it requires a conscious mindset to include this diverse cohort of older adults, as part of the dialogue. Two leverage points (self-organizing, paradigm) become important to consider. What became apparent was an entire shift in attitudes around what constitutes being an older adult and what that actually means in terms of contribution to society and continued opportunities for health and wellness. This therefore, translates into how care is administered and how care is embedded in our communities and not to be seen as something that is an augmented thing, but rather, caring for older adults and generating alternatives for care is actually part

of how we plan and design where people live from cradle to grave.

4. Older adults may rely more on informal and formal caregivers or providers than necessary due to a lack of understanding and engagement with alternatives for care, and or, viable housing alternatives within their local community or residence.

Alternatives will emerge when all sectors (government, community and private) can work together more collectively to establish and achieve a common outcome for older adult care in the community. Municipalities should have greater capacity and influence as to what happens at a neighbourhood level or urban community level to support care in the community, with adequate funding and influence on how the built environment is designed to support Age-Friendly Communities.

5. Forums or opportunities for engagement (multi-stakeholder, collective, diverse) to facilitate knowledge, ideas, exploration, intergenerational learning or problem-solving were not evident.

Specifically the voice of older adults — their needs to be the predominant voice in planning circles — is missing. Family, older adults and providers “on the ground”, all expressed being left out of the conversation (all aspects). There are patient and family advisory councils

(PFAC) structures for hospitals and the LHINs, which do inform the Ministry of Health (there is a ministerial PFAC as well). However, without researching this explicitly, there was limited evidence of any effective structures at a community or municipal level, where the voice of an aging population can be contributed and amplified.

To identify or imagine alternatives for older adult care, it was helpful to frame this area of exploration by first understanding how older adult care is defined and also how models and systems of care are perceived. The findings begin to thread the attributes, relationships and associations related to older adult care together, while also pointing toward some future considerations. Findings further suggest:

- Stakeholders’ perspectives align around core themes of care and point to person-centred care in one’s home and community as important.
- An integration of creativity, collaboration and quality are at the heart of facilitating older adult care and possibly generating more community-based alternatives for older adult care.
- There is a dynamic interplay between system level and individual level inputs and behaviors with technology being a vital connector in the system.



Design Principles

Below are five principles to consider in the process of design and future scenario planning for older adult care.

Ownership for Health and Wellbeing

- Shift from medical models of care or rather a system that has been primarily downstream focused with investment in health promotion and prevention — targeting all levels of behaviour (individual, community, organizational) in the system. Accelerate with incentives for individuals to engage in health promoting behaviours and for community-based alternatives to emerge through partnerships focusing on early intervention and holistic care. Tax incentives and funding for health promoting behaviours that support early intervention and planning at all levels (build collaborations between Community, Public Health and Healthcare) are critical enablers.

Integrate Tech and Human Touch

- Frustration with navigating the current system, and in particular for individuals to be aware and knowledgeable about community-based care could be mitigated through customized digital technology tools and information systems. And further enabled through mutually reciprocal partnerships that take into consideration human-to-human interactions that preserve values such as: respect, dignity, compassion and care.

- A blend of professional and peer support with tech-enabled supports to mobilize knowledge and reduce significant pain points such as navigation and communication.

Reduce Blind Spots

- Create an effective approach for older adults to be contacted directly for a mandatory health prevention visit, to share information and determine needs and support in planning for care. Key measures for this initiative could include: transparency of information, timely planning, and public health indicators. This process could yield data (leverage information systems) to better inform indicators of need and demand, minimizing knowledge, practice and funding gaps. Both government and individuals have a 360 degree view of what is critical, needed and desired.

Build Integrative Communities that Care

- Leverage the knowledge and power of local government to generate new standards and rules for the built environment; including critical partnerships with developers, property managers and neighbourhood associations and other sector partners.
- Leverage existing actors and entities to form collaborative forums or an umbrella-type organization, where older adults and

Collectively, the findings depicted through the various maps and models, show the dynamic interplay between all entities and stakeholders. It also shows that we cannot consider alternatives to community-based care unless we understand the structures (behaviours, policy, funding etc.) that influence or quite simply get in the way of progressing toward the desired goals of older adult care. Ontario Health Teams are a new model of care that aims to support people within their community; however, community-based alternatives for care outside of the formal healthcare system are not prevalent in the minds of stakeholders sampled for this research and also not well represented in the media/news outlets. The findings suggest that the government has not mobilized sufficient action or foresight to support community-based care, rather government's inaction and lack of accountability perpetuates dependency on institutional or acute-based care for older adults.

Broadly, where and how an older adult seeks or receives care; and values such as: respect, choice, dignity, inclusion and compassion, are important and ought to permeate the philosophy, delivery and design of older adult care. We might pause to consider this question, Is aging and care coupled by values and beliefs that keep us stuck in the current paradigm? To initiate change at any level within the system of care, we should be encouraged to do the deeper work of reframing societal attitudes toward aging and then begin to reimagine older adult care from a new paradigm. The findings aim to facilitate a holistic perspective (for older adult care), with the potential for stakeholders to meaningfully engage through supportive reframes, inquiries and collaboration. This in turn, may generate new possibilities for community-based alternatives and work toward developing sustainable and resilient systems of care.

caregivers have a “voice at the table” with influence to shape care within the community. Sustained engagement in the process of creating options and solutions for local community-based care alternatives is a key measure of success.

- Adopt and refine the framework (*Figure 11*) as presented in the synthesis, in addition to evidence-informed care planning frameworks and principles.

Rise up against Ageism

- Leverage the diversity that exists within an aging population to alter perceptions and mindsets of what it means to age, pointing to a shared goal of maximizing independence, health and wellbeing within the community.
- Leverage people of influence and the founders of initiatives that provide assurance for new approaches to care and community alternatives. Use visible platforms to spread effective practices and innovative ideas; in contrast to the failures of our current system.

- Develop societal consciousness about the use of semantics and labels that reinforce stereotypes and power dynamics that support the status quo. Increased awareness of unconscious bias by using design methods for dialogue and engagement.
- Develop partnerships (across sectors, and specifically government and private sector) to consider the value proposition to meet the needs and desires of an aging population, with product and service design recognizing desired attributes of care (learning, creativity, stimulating activity (mental, physical), contribution, connection, and inter-generational) that support and sustain quality of life.



Limitations of the project

Limitations included challenges with accessing health care professionals due to busy schedules and multiple demands, as well as, the influence of the pandemic for people’s time and attention.

It was difficult to find literature specific to community-based alternatives and specifically for one region or community. Often the research pointed toward specific provider models of care and reports about specific healthcare models and services. The research in the

area of older adult care is vast and seeking information and resources for a large urban region proved challenging and difficult as often information was not readily found. The scope of this project made it impossible to capture all of the existing community programs and services across the GTHA.

Within the time constraints of this project I was not able to build a synthesis map integrating all the models and maps developed in this project.



Next Steps

As the project was designed to consider perceptions, knowledge and experiences presented by different stakeholder groups, it became apparent that commonalities exist. Yet, siloes can impede this awareness and fall short to enact levers for change and further perpetuate the status quo. No single individual or group can navigate this complex system of care adequately. We should not persist in pursuing solutions in silos, particularly when aging and care affects us all in some way. Stakeholders who participated in this project, present an opportunity for further dialogue and engagement, and the potential for participatory design options to be introduced.

A next phase proposes a collaborative effort to prepare and facilitate a “futures” workshop to enable the development of a clear set of strategies, generated through cross-sectoral and diverse representation. To initiate this work, a collaboration with interested individuals and

groups (e.g., OCAD University Strategic Foresight and Innovation community, key stakeholders) is proposed with transdisciplinary membership taking shape with a steering committee and project structure. The objective is to develop a set of future scenarios and strategies and further test the five design principles and proposed framework from this project.

As noted in the synthesis, as the provincial government continues with plans to modernize home and community care delivery, and transform healthcare, these next steps may enable a shift towards a participatory mindset with the potential for new forms of organizing and planning to emerge. Therefore, a further next step should consider the idea of a network of governing members or entities that drive purpose and action toward building and sustaining alternatives for community-based older adult care.



Future Research

To dive deeper into areas of inquiry, building upon some of the prerequisites for change, future research should consider exploring how:

1. Funding models shift the focus away from providers and programs and align more directly with the needs and preferences of an older adult. Research in this area should query existing funding formulas and consider the role of government policy and legislation in funding criteria and spending allocations.
2. Collaborating (and what processes and structures) within government ministries could facilitate a sustainable upstream approach for older adult care.
3. Ensuring the voice of older adults and other key stakeholders are embedded in all organizing structures and processes, such that current governance models are sufficiently challenged and reimagined to serve an aligned vision. This research should consider taking a deeper look at local level planning and implementation practices.
4. Developing useful tools and technology approaches and applications to yield valuable information. For example, a comprehensive and integrative map of care alternatives (GTHA, community) with the potential to be accessed through a technological app and updated live through a multi-user platform.

Conclusion

A number of insights emerged by reflecting on the current state: the differences and commonalities across stakeholder perceptions, aiming to provoke further thinking and curiosity in how we might develop approaches for community-based alternatives for older adult care.

What emerged clearly from this project, is that community-based care needs to be aligned with how older adults choose to live, where they live, and what supports already surround them.

The provision of care needs to encompass values of dignity, respect, inclusion, and compassion and should be supported with adequate funds for training and development to sustain these values regardless of where and by whom care needs are met. Issues still persist with inadequate flow of information and siloed perspectives. A lack of strong organizing principles, incentives and knowledge impede creativity and collaboration across all sectors who have a critical stake in supporting an aging population.

Reactionary behaviour at all levels (individual, community, organizational and society) is problematic, rather than proactive means to facilitate health and wellbeing within community and at home. A number of system traps (as described by the archetypes) could be influenced at higher leverage points, such as a fundamental shift in how we value older adults and care.

This project aimed to show how stakeholders are thinking about older adult care and how we accommodate for these different stakeholder perspectives and interests. By conducting a system's analysis and applying systemic design, a number of deficits, gaps and fragmentations were validated from the research. By considering all the contextual aspects for the research topic in question and using systems thinking, siloed groups are enabled to see the big picture and why intervening in one area alone will not create the necessary changes for a better system of older adult care.

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Appendix A — Interview Guide

Research to explore community-based alternatives for older adult care

Stated verbally:

Thank you for participating in this interview. The interview will take approximately 20-40 minutes. Allow me to remind you briefly of the terms of this interview. Your participation is voluntary and you may withdraw from participating in the interview at any time. You may also take a break at any time during the interview. You may decline answering any question.

The interview is confidential, meaning your privacy and content of the interview will not be shared with anyone except the researcher and primary investigator. The interviews are recorded for the purpose of accurate data collection. Before proceeding with the interview, I will ask if I have your permission to record the interview. I may take notes to augment the recording or if recording capability is disabled or permission is denied. Attributable quotes will not be used without your prior written consent.

Only in case consent was not received prior to the scheduled interview: For further information, please review the letter of consent. The interview will not proceed until the letter of consent has been reviewed and signed by you, the participant.

Do you have any questions?

Do I have your permission to record the interview? Yes/No

If Yes – say: You may choose at any time, to close your camera in the settings on the ribbon (show or explain navigation).

Let's proceed.

To verify, do you provide services, work or live within the GTHA?

Within the topic of older adult care, there are a number of interested stakeholder groups, of which group do you most identify with:

- Older Adult (65 yrs. +)
- Family Member and or Caregiver
- Service Provider
- Primary Care Physician
- Health System Leader
- Other _____

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Appendix B — Survey Questions

My research will investigate community-based alternatives for older adult care; what stakeholder perceptions exist and how these may promote or resist senior's health and wellbeing and further build a resilient healthcare system. This topic is timely given changes underway in Ontario's healthcare system, the disproportionate impact of the COVID 19 pandemic on long term care, and a growing older adult population. Your experience, knowledge and perspective, will support the development of new insights and inform this area of research.

The survey will take approximately 8-15 minutes to complete. The survey will close by Sunday, October 18th, 2020 at midnight. Participation is completely voluntary, however once submitted, survey responses cannot be withdrawn. No personal identifying information will be collected; your participation is therefore completely anonymous. You may decline to answer any question.

I sincerely appreciate you taking the time to participate in this survey. Should you have any difficulties responding to the survey or have further inquiries about the research and interviews, please contact me directly susan.wright@student.ocadu.ca

Demographic questions:

Select which group you identify with the most? (Drop down)

- Older Adult (65 yr +)
- Family Member
- Service Provider
- Primary Care Physician
- Health System Leader
- Other _____ (text line)

Do you live, work or provide services within the Greater Toronto Hamilton Area (GTHA)?

Yes No Other (please specify)



Interview Questions

1. Briefly, what does older adult care mean to you?
2. How would you describe the current model of older adult care?
3. What do you think the goal of older adult care ought to be?
4. What needs to be present or come together to create a better system for older adult care?
5. What might be the prerequisites for change in the older adult system?
6. When considering community-based care, what alternatives for older adult care come to mind?
 1. How might these influence (promote/resist) the health and wellbeing of older adults?
 2. How might these further build a resilient healthcare system?

Time permitting:

7. What innovations do you see that might shape the future of older adult care?
8. What critical uncertainties need to be considered as we look toward the future of older adult care?

Thank you so much for taking the time to participate in this research. If you are interested in the findings of this study, the final report will be accessible through OCAD University's public research repository (<http://openresearch.ocadu.ca/view/creators/>) by January 2021. You can look up my name and it will lead you to the final report of this research.

The following questions explore your perspective on older adult care.

1. Complete the following sentence with a word or phrase, “older adult care is...”
2. What does older adult care mean to you?
3. How would you describe the current model of older adult care?
4. In your perspective, how is older adult care organized or defined? (Select as many as applicable)
 - Geography
 - Health condition and/or disease
 - Organization type/Service (e.g. health, religious, community)
 - Other (please specify)
5. From your perspective, what gaps, barriers or challenges exist within the current models and systems?
6. To create a better system of older adult care, how would you prioritize the leverage points (small shift in one thing, produces big change in all things) listed below in order of most effective (1) to least effective (4)?
 - System infrastructure (e.g. Create impact restrictions, Changes taxes, Increasing services)
 - Information flows (e.g. Spread real-time high quality data on care activity, Expand communication with public reporting)
 - Organizing Principles (e.g. Create amendments that add protections for older adults, Build a network to support collaborations between agencies, Add eldercare responsibilities to all ministries)
 - Mindsets (e.g. Influence politicians to accept urgent reality of older adult care, Create opportunity for engagement and diversity)
7. Do you see an alternative model for older adult care?
8. Does this alternative model fall within:
 - Government
 - Private Sector
 - Community
 - A mix (please specify)
9. Why do you think this alternative might work better?

To complete the survey, click done (submit). Message then generates:

Thank you for taking the time to complete this survey.

If you are interested in this topic, you are invited to participate in an in-depth interview, which will facilitate a deeper discussion about the research area being explored. Please contact susan.wright@student.ocadu.ca if you wish to participate.

Findings of this study will be accessible through the OCAD University's public research repository (www.openresearch.ocadu.ca/view/creators/) by January 2021. You can look up my name and it will lead you to the final report of this research.