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McMaster Health Forum

For concerned citizens and influential thinkers and doers, the McMaster Health Forum strives to be a leading hub for improving health outcomes through collective problem solving. Operating at regional/provincial levels and at national levels, the Forum harnesses information, convenes stakeholders and prepares action-oriented leaders to meet pressing health issues creatively. The Forum acts as an agent of change by empowering stakeholders to set agendas, take well-considered actions, and communicate the rationale for actions effectively.

About citizen panels

A citizen panel is an innovative way to seek public input on high-priority issues. Each panel brings together 10-14 citizens from all walks of life. Panel members share their ideas and experiences on an issue, and learn from research evidence and from the views of others. The discussions of a citizen panel can reveal new understandings about an issue and spark insights about how it should be addressed.

About this summary

On November 8, 2014, the McMaster Health Forum convened a citizen panel on how to improve care and support for unpaid caregivers in Ontario. The input from the citizen panel will help to guide the efforts of policymakers, managers and professional leaders who make decisions about our health system. This summary highlights the views and experiences of panel participants about:

- the underlying problem;
- three possible options to address the problem; and
- potential barriers and facilitators to implement these options.

The citizen panel did not aim for consensus. However, the summary describes areas of common ground and differences of opinions among participants and (where possible) identifies the values underlying different positions.

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Summary of the panel

Panel participants discussed challenges related to improving care and support for unpaid caregivers in Ontario. During the deliberations, the following four challenges were consistently raised: 1) caregivers' heavy burden can cause anxiety about its impact on their own and other's health; 2) financial and employment impacts of caregiving are substantial; 3) many caregivers don't know about available services or how to access them; and 4) caregivers' roles are not fully recognized or supported.

Participants reflected on three options (among many) for improving care and support for unpaid caregivers in Ontario: addressing the economic security of unpaid caregivers (option 1); engaging and supporting unpaid caregivers (option 2); and providing tailored training and supports to unpaid caregivers who care for older adults with complex conditions (e.g., dementia) (option 3). Several values-related themes emerged during the discussion about these options, with two emerging with some consistency: 1) competence (i.e., educating and training unpaid caregivers to provide optimal care, but also to clearly define the scope of duties of unpaid caregivers versus other healthcare providers); and 2) empowerment (i.e., supporting unpaid caregivers to become strong advocates for their loved ones and for themselves, and equipping them with practical tools to manage the complex care needs of their loved ones).

When turning to potential barriers to improve care and support for unpaid caregivers in Ontario, participants focused on five key barriers: 1) a universal and equitable system to financially support unpaid caregivers may not be sustainable; 2) new tax measures to increase financial assistance will most likely face resistance from taxpayers; 3) deteriorating community cohesiveness; 4) many unpaid caregivers are already stretched too thin to be engaged meaningfully in decision-making processes; and 5) many unpaid caregivers lack access to family doctors. Participants then turned to two key factors that could facilitate efforts to bring about change: 1) advocacy activities targeting health system-leaders and elected officials to implement the necessary policies, programs and services; and 2) activities to promote public dialogue and support experiential learning to build sensitivity to the needs of older adults and their unpaid caregivers.



“It’s the little bit healthier old, helping the little bit less healthy old.”

Discussing the problem: What are the most important challenges to improving care and support for unpaid caregivers?

Panel participants began by reviewing the findings from the pre-circulated citizen brief, which highlighted what is known about the underlying problem – shortfalls in the care and support available to unpaid caregivers – and its causes. They individually and collectively focused on four challenges in particular:

- caregivers’ heavy burden can cause anxiety about its impact on their own and other’s health;
- financial and employment impacts of caregiving are substantial;
- many caregivers don’t know about available services or how to access them; and
- caregivers’ roles are not fully recognized or supported.

Box 1: Key features of the citizen panel

The citizen panel about improving care and support for unpaid caregivers in Ontario had the following 11 features:

1. it addressed a high-priority issue in Ontario;
2. it provided an opportunity to discuss different features of the problem;
3. it provided an opportunity to discuss three options for addressing the problem;
4. it provided an opportunity to discuss key implementation considerations (e.g., barriers);
5. it provided an opportunity to talk about who might do what differently;
6. it was informed by a pre-circulated, plain-language brief;
7. it involved a facilitator to assist with the discussions;
8. it brought together citizens affected by the problem or by future decisions related to the problem;
9. it aimed for fair representation among the diversity of citizens involved in or affected by the problem;
10. it aimed for open and frank discussions that will preserve the anonymity of participants; and
11. it aimed to find both common ground and differences of opinions.

We review each of these challenges in turn below.

Caregivers' heavy burden can cause anxiety about its impact on their own and other's health

The discussion initially focused on the substantial burden placed on the shoulders of unpaid caregivers, the anxiety it can induce for them, and the impact of this anxiety on their own and other's health. Participants highlighted that this burden and anxiety often occurs because caregivers: 1) frequently provide care to multiple people and to both dependent children and aging family members (not just the latter); 2) increasingly provide complex (and specialized) care; 3) have limited access to informal support due to changing family structures and a deteriorating community cohesiveness; and 4) are getting older and must manage their own health conditions. Each of these challenges is discussed in turn below.

Many unpaid caregivers are providing care to multiple people. As one participant pointed out, many caregivers must provide care to their aging parents while also taking care of their own children. This is particularly complex when these children have physical or developmental disabilities. Once these children become adults and leave the school the system, the full responsibility for care often shifts to the parents. The parents are then 'caught in the

middle' because their own parents are aging and they have to provide care to them as well. Performing these many roles can put a severe strain on caregivers and can result in burnout, anxiety and deteriorating health.

Participants then focused on the wide range of roles that they must play as unpaid caregivers, some of which involve providing complex (and specialized) care. Examples of the many roles played by caregivers that were identified by participants included:

- providing emotional support;
- providing physical care;
- providing transportation or accompaniment to medical appointments;
- managing medication, test results and paperwork;
- making appointments and coordinating care;
- making legal and financial arrangements; and
- housekeeping, paying bills and completing income tax forms.

These multiple roles constitute a significant burden on the shoulders of unpaid caregivers.

A few participants emphasized that unpaid caregivers increasingly need to take care of older adults with complex care needs (e.g., older adults with multiple chronic health conditions, Alzheimer's and other dementias). In addition, they also expressed concern that specialized care is often handed off to unpaid caregivers (e.g., giving shots for treatments). These participants emphasized that there needs to be more education and time spent on training caregivers to provide care to older adults with complex care needs, especially when they are expected to perform tasks that are usually performed by healthcare providers.

Several participants also pointed out that unpaid caregivers have limited access to informal support. Some participants talked about changing family structures (i.e., people having fewer children, older generations no longer living with or even near their children) making it more difficult, and sometimes impossible, for unpaid caregivers to lean on their children or siblings to share the burden of providing care to aging parents. Referring to the changing family structures, one participant indicated: "We're not family-centric like we used to be. I grew up in a house with three generations." In addition, one participant said that "many caregivers are incidental caregivers," meaning that they step up to provide care to an older adult who has no immediate family member to rely on.

Other participants spoke of deteriorating community cohesiveness, which makes it difficult for those in need of care to seek help from neighbours and community members when they need it. One participant said that there used to be strong and cohesive community networks, but this sense of community has been lost over the years. "There used to be a community of

families where people were concerned with each other and provided care when needed.” According to a few participants, the deteriorating community cohesiveness seems to be particularly salient in urban areas where people seem to stick to themselves. As a few participants pointed out, this may explain why people are increasingly looking to governments to address their problems instead of looking to the community.

Unpaid caregivers are also getting older and must manage their own health conditions. As one participant said: “It’s the little bit healthier old, helping the little bit less healthy old.” Several participants pointed out the challenge of managing their own health conditions (and most often neglecting them) when caring for someone else. Many participants indicated that uncertainties about their own health and their capacity to provide care generated a lot of anxiety. As one participant noted: “What frightens me about this is that I have chronic illnesses myself, and if I fall flat on my back tomorrow then there is nobody there for me or those I provide care to.” Another participant agreed and expressed concern that unpaid caregivers may not have someone to take care of them if something went wrong. “Do we have a caregiver waiting to help us when we’re down and out?”

Financial and employment impacts of caregiving are substantial

Participants generally agreed that the financial and employment impacts of caregiving are substantial. Participants talked about the challenges of maintaining employment while juggling caregiving responsibilities. A few participants described instances where employers ‘gave people grief’ for taking days off to care for a loved one, thus creating a tense working environment. Others indicated that people often gave up jobs because their loved one required constant care, but also because they simply could not afford to pay for outside help. One participant talked about a vicious cycle for unpaid caregivers. “[It’s] cyclical because if you can’t afford [the home and community care services], you have to leave your job and then you are stuck in an unpaid situation that has financial impacts on the patient and caregiver.”

Several participants also emphasized the significant out-of-pocket expenses associated with caring for a loved one. They pointed out that many home and community care services are not covered by the health system, that drugs are only partially covered, and that caring for older adults requires frequent and expensive travel to medical appointments (which can be significant for those from rural and remote areas).

Participants also expressed frustration with the very narrow eligibility criteria and limited scope of existing assistance programs. They pointed out that existing supports include flexible employment programs (i.e., the provincial Family Medical Leave program), employment

insurance (i.e., the federal Compassionate Care Benefits program), and income tax benefits, which are only available to those who are employed. Such programs appear inadequate since many unpaid caregivers must leave their jobs to provide ongoing care to their loved ones. Talking more specifically about the provincial Family Medical Leave program, one participant complained that it is an unpaid leave and only relevant for those who have been able to sustain a job. A second participant pointed out that using income tax credits to provide financial assistance to unpaid caregivers was not effective since there is a long delay between when support is needed and when taxes are submitted and processed. Thus, participants were quite concerned that current policy efforts to support unpaid caregivers fell short in addressing their economic security. They called for more flexibility and adaptability of existing assistance programs to fully meet the needs of unpaid caregivers.

Many caregivers don't know about available services or how to access them

Participants generally agreed that there was a lack of awareness about available services and how to access them. They indicated that unpaid caregivers usually do not know where to turn for help, which can be quite frustrating. As one participant said: “That’s the rub – if you don’t know about it, how are you going to access it.”

One participant gave the example of the Guide to Programs and Services for Seniors in Ontario, which provided a comprehensive listing of existing programs and services. However, most participants indicated that they were unaware that such a guide existed. As one participant indicated: “I didn’t even know this existed when I needed it.” While hard copies of this guide may be ordered, it is also available in online format, which appeared to be problematic for many participants. As one participant noted: “Everything is online because they assume you’re going online even though many older people don’t have a computer, let alone internet.”

While agreeing about the general lack of public awareness about existing services, one participant emphasized that unpaid caregivers are rarely calling for help or seeking help. As one participant said: “We do a very poor job of telling people that we need help.” A second participant explained this behaviour by a lack of time, since caregivers are being caught up in the demanding job of providing constant care to a loved one. “As a caregiver, when do you have time to sit in front of a computer to find what’s available when you have care to provide and pills to organize and give?”

Box 2: Profile of panel participants

The citizen panel aimed for fair representation among the diversity of citizens likely to be affected by the problem. We provide below a brief profile of panel participants.

- **How many participants?**
10
- **Where were they from?**
Regions covered by the Hamilton Niagara Haldimand Brant Local Health Integration Network (8), the North East Local Health Integration Network (1), and the North Simcoe Muskoka Local Health Integration Network (1)
- **How old were they?**
25-44 (10%), 45-64 (30%), 65 and older (60%)
- **Were they men, or women?**
Men (50%) and women (50%)
- **What was the educational level of participants?**
40% completed high school, 10% completed community college, 40% completed a bachelor's degree/post-graduate training or professional degree, and 10% completed postgraduate training
- **What was the work status of participants?**
10% working full-time, 20% working part-time, 50% retired, 10% homemakers, and 20% disabled (one participant identified their work status as both homemaker and disabled, hence the ratings do not add up to 100%).
- **What was the income level of participants?** 10% earned less than \$20,000, 10% between \$20,000 and \$40,000, 30% between \$40,000 and \$60,000, 10% between \$60,000 and \$80,000, 10% more than \$80,000, and 30% preferred not to disclose their income.
- **How were they recruited?**
Selected based on explicit criteria from the AskingCanadians™ panel

Caregivers' roles are not fully recognized or supported

Participants generally agreed that the role of unpaid caregivers is not fully recognized or supported in the health system. This situation resulted in a lack of coordination and sub-optimal communication between patients, unpaid caregivers and healthcare providers.

Participants pointed out three key factors contributing to this challenge: 1) a lack of respect and empathy towards unpaid caregivers; 2) unclear roles for unpaid caregivers across the full spectrum of care; and 3) a lack of proper 'training' for healthcare providers.

Participants described various experiences where healthcare providers did not engage them in conversations about treatment and care of their loved one, which was perceived as a lack of respect and empathy towards them. Speaking to their experience with a healthcare provider not acknowledging their role in providing care to a loved one during an appointment, one participant said: "As a caregiver, I was not respected and I didn't matter."

Some participants pointed to the lack of clarity about the role of unpaid caregivers across the full spectrum of

care, which is sometimes fuelled by privacy concerns among healthcare providers. Others indicated that healthcare providers often do not engage with unpaid caregivers, or share basic information, because there are concerns of privacy violations. “I can’t tell you anything because you’re not the patient.” This was seen as problematic since they are the ones providing care and often interpreting and planning the care that has been suggested by the healthcare providers. A few participants indicated that they had similar experiences despite being designated as power of attorney, and had to fight for recognition with the various healthcare providers. “I was fighting constantly with them [care providers in hospital] to get an update.” One participant offered a different perspective, having been respected during palliative care planning and extensively engaged as an unpaid caregiver.

Lastly, some participants suggested that there was a lack of training for healthcare providers who may not recognize the additional range of supports that their patients and their unpaid caregivers may need to perform their role and stay healthy.





“Caregivers exemplify the concept of radical hospitality – the giving of yourself completely without anything in return.”

Discussing the options:

How can we address the problem?

After discussing the challenges that together constitute the problem, participants were invited to reflect on three options (among many) for improving care and support for unpaid caregivers in Ontario:

- 1) addressing the economic security of unpaid caregivers;
- 2) engaging and supporting unpaid caregivers; and
- 3) providing tailored training and supports to unpaid caregivers who care for older adults with complex conditions (e.g., dementia).

Several values-related themes emerged during the discussion about these options, with two emerging with some consistency: 1) competence (i.e., educating and training unpaid caregivers to provide optimal care, but also to clearly define the scope of duties of unpaid caregivers versus other healthcare providers); and 2) empowerment (i.e., supporting unpaid caregivers to become strong advocates for their loved ones and for themselves, and equipping them with practical tools to manage the complex care needs of their loved ones). We review the themes that emerged for each option in more detail below.

Option 1 – Addressing the economic security of unpaid caregivers

The discussion about the first option touched on various approaches to address the economic security of unpaid caregivers. This option might include (but is not limited to):

- fostering a workplace culture in the province that supports flexible employment arrangements for caregivers who are working or would like to work;
- government-provided income supports for caregivers who face a financial burden in providing care (e.g., for those who meet specific needs tests); and
- making supportive housing available both to older adults and their caregivers to allow them to continue living at home or in the community.

Six values-related themes emerged during the discussion that were identified as being important for guiding efforts to address the economic security of unpaid caregivers:

- selflessness;
- inclusiveness (all those in need);
- fairness (especially towards those most in need);
- attuned to the needs of unpaid caregivers;
- innovation (in terms of economic and fiscal measures); and
- evidence-based (i.e., documenting the costs and benefits of different interventions, and building a business case).

Participants generally agreed that interventions to address the economic security of unpaid caregivers could provide much needed relief, but some shared concerns about implications of providing care on a volunteer basis. At a minimum, participants agreed that unpaid caregivers should not incur out-of-pocket expenses as a result of providing care. However, some participants struggled with the notion of providing additional financial assistance to caregivers. While such assistance could provide significant financial relief, some participants were concerned that it could create a new model of care and a different set of incentives, from doing work on a volunteer basis. Such financial assistance could create a type of ‘fee-for-service caregiving,’ which could compromise selflessness as a core value of caregiving. One participant spoke of the value of selflessness in the context of what they termed ‘radical hospitality’. “Caregivers exemplify the concept of radical hospitality – the giving of yourself completely without anything in return.”

Participants also emphasized the need to ensure that any new program designed to address the economic security of unpaid caregivers be inclusive and fair. They also wished that such a program (and its eligibility criteria) would be flexible and adaptable in order to be attuned to

the different needs of unpaid caregivers (e.g., for lower- and higher-income caregivers, as well as part- and full-time caregivers). However, some participants doubted the possibility of implementing such programs in a “fair and equitable way” and particularly in achieving consensus on the eligibility requirements (i.e., who benefits and by how much). One participant also expressed concerns about broadening the eligibility requirements of certain programs. For example, this participant pointed out that there is already a five-year waiting list to access supportive housing. Broadening the eligibility requirements would then add more people to the waiting list and it would become even harder to access.

Several participants also called for greater innovation in the types of economic and fiscal measures, as well as flexible working arrangements, that could be implemented to support unpaid caregivers. While some participants called for more flexible approaches to claiming income tax credits that gets money into people’s hands when they need it, others emphasized that such tax measures only benefit a few. Some participants suggested the need to adopt financial assistance models like Quebec’s parental insurance plans that provide extended financial assistance to unpaid caregivers. However, a few participants similarly cautioned that such a model would only benefit those with employment status.

Box 3: Key messages about option 1

- Six values-related themes emerged during the discussion that were identified as being important for guiding efforts to address the economic security of unpaid caregivers:
 - selflessness;
 - inclusiveness (all those in need);
 - fairness (especially towards those most in need);
 - attuned to the needs of unpaid caregivers;
 - innovation (in terms of economic and fiscal measures); and
 - evidence-based (i.e., documenting the costs and benefits of different interventions, and building a business case).

Lastly, a few participants suggested the need to invest research funding to document the costs and benefits of different types of interventions to address the economic security of unpaid caregivers. Alternatively, this research could explore the implications or unintended consequences of not addressing the economic security of unpaid caregivers (e.g., high rates of no-shows to medical appointments could be due to the lack of support for caregivers in getting them there). This research evidence could then be used to build a business case for offering these types of supports to unpaid caregivers.

Option 2 – Engaging and supporting unpaid caregivers

The discussion about the second option examined various approaches to better engage and support unpaid caregivers. This option might include (but is not limited to):

- opportunities for caregivers to engage in decision-making about how care and support is organized to ensure services are aligned with the values, needs and preferences of patients and their caregivers;
- handbooks or toolkits that help caregivers identify the full range of resources available to them in their community; and
- education and supports to reduce caregiver burden and to help them cope and build resilience.

Four values-related themes emerged during the discussion that were identified as being important for guiding efforts to engage and support unpaid caregivers:

- competence (educating and training unpaid caregivers to provide optimal care and delineating the scope of duties for unpaid caregivers);
- empowerment (so that unpaid caregivers become strong advocates for their loved ones and for themselves);
- holistic care (providing care to both patients and their unpaid caregivers); and
- timeliness (of information).

Participants generally agreed about the need to offer education and training opportunities to unpaid caregivers so that they can provide optimal care. However, participants offered divergent views about the type of education and training required. Some participants suggested the need to go beyond training caregivers to cope with multiple roles and instead offer specialized training related to certain medical procedures (e.g., clean wounds, administer shots, manage medications or administer first-aid). As one participant pointed out: “I will cope better if I’m trained to better manage his care.” While admitting that nursing care is increasingly being shifted to unpaid caregivers, some participants questioned whether the scope of duties of caregivers should be expanded beyond what they are already doing. Some of these participants indicated that education could help caregivers know where to draw the line in the types of care they can safely provide.

Participants also generally agreed that education is important for empowering caregivers to become strong advocates. Specifically, they envisioned learning about how to advocate for the care required, both for the person they are providing care to and for themselves, as a core educational requirement.

Box 4: Key messages about option 2

- Four values-related themes emerged during the discussion that were identified as being important for guiding efforts to engage and support unpaid caregivers:
 - competence (educating and training unpaid caregivers to provide optimal care and delineating the scope of duties for unpaid caregivers);
 - empowerment (so that unpaid caregivers become strong advocates for their loved ones and for themselves);
 - holistic care (providing care to both patients and their unpaid caregivers); and
 - timeliness (of information).



Several participants also called for more holistic care, which considers the needs of patients and those of their unpaid caregivers. These participants indicated that healthcare providers often strictly focus on the well-being of patients. Healthcare providers may conclude that patients are doing relatively well and that everything is fine. Yet, the unpaid caregivers who are providing ongoing care and support may still be facing burnout, stress, anxiety and/or depression. While these participants emphasized the need to design models of care that could provide care to both patients and caregivers, some participants doubted that general practitioners could take time away from patients during already short appointments to focus on the caregiver. These participants suggested that responsibility for some of this could be shifted to nurses who would be more likely to be able to connect with caregivers on an ongoing basis.

Lastly, participants emphasized the need to have access to timely information. Several participants indicated that clinics, doctor's offices or hospitals do not offer in print or online toolkits that provide readily available information about the availability of services for unpaid caregivers, who is eligible for the services, and how to access them.

Option 3 – Providing tailored training and supports to unpaid caregivers who care for older adults with complex conditions (e.g., dementia)

The discussion about the third option examined ways to provide tailored training and supports to unpaid caregivers who care for older adults with complex conditions. This option might include (but is not limited to):

- programs that provide education and support that is tailored to caregivers of people with complex conditions; and
- system navigators or coordinators who help to identify and connect both the people with complex conditions and their caregivers with the care and supports they need.

Five values-related themes emerged during the discussion that were identified as being important for guiding efforts to provide enhanced training and support to unpaid caregivers:

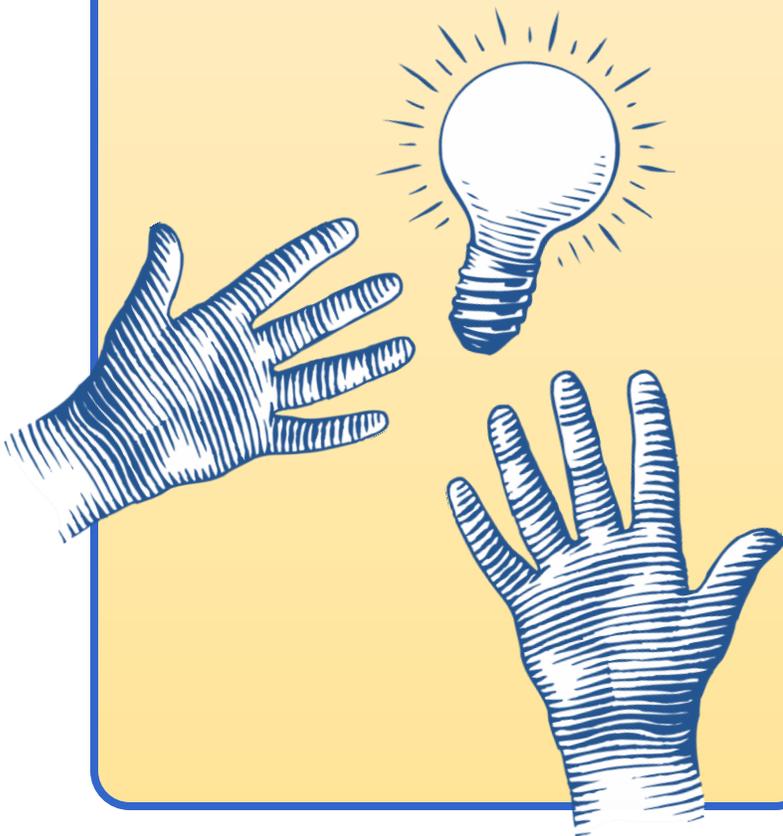
- compassion;
- collaboration (among caregivers, providers and organizations);
- solidarity (trusting relationships)
- competence (of unpaid caregivers to manage the complex care needs of their loved ones); and
- empowerment (equipping caregivers with practical tools to manage the complex care needs of their loved ones).

Several participants indicated that this option was important because it focused on one of the most vulnerable groups of caregivers, given the complex care needs of their loved ones. As a result, participants strongly emphasized the need to be particularly compassionate towards this group, and ensure that they have access to all the resources they need.

Participants also emphasized the great need for collaboration among caregivers, providers and organizations, given the complexity of care required by these patients. Some participants indicated that more intense collaboration could ensure greater continuity of care and help to build trusting relationships with healthcare providers. To achieve this, participants pointed out the need for a combination of information and communication technologies and in-person supports to facilitate information sharing across sites and providers. They also proposed the idea of a system navigator who would walk people through the set of

Box 5: Key messages about option 3

- Five values-related themes emerged during the discussion that were identified as being important for guiding efforts to provide enhanced training and support to unpaid caregivers:
 - compassion;
 - collaboration (among caregivers, providers and organizations);
 - solidarity (trusting relationships)
 - competence (of unpaid caregivers to manage the complex care needs of their loved ones); and
 - empowerment (equipping caregivers with practical tools to manage the complex care needs of their loved ones).



challenges, issues and decisions that unpaid caregivers (and the person they care for) are likely to face. The system navigator could then link them to the services needed.

Lastly, participants highlighted that this group of unpaid caregivers needed to develop strong competencies to manage the complex care needs of their loved ones, but also to be empowered to advocate for their loved ones. Many spoke about the complexity of coordinating care across multiple providers and settings, and keeping track of the complex treatments that they must manage. They emphasized that caregivers must be able to actively listen, take notes, and be empowered to ask questions when needed (and especially when information or instructions are unclear). To achieve this, a few participants indicated the need to better equip unpaid caregivers by widely disseminating and promoting the uptake of caregivers' notebooks. A caregiver's notebook is a central place to record and document important aspects of the care of their loved ones, including calls and notes from medical appointments as well as the legal, financial and insurance paperwork.



“Unpaid caregivers in Ontario need to be recognized, supported and trained.”

Discussing implementation considerations:

What are the potential barriers and facilitators to implement these options?

After discussing the three options (among many) for improving care and support for unpaid caregivers in Ontario, participants examined potential barriers and facilitators for moving forward.

Participants identified five barriers to moving forward. First, a few participants expressed concerns about the feasibility of addressing the economic security of all unpaid caregivers. They indicated that making a universal and equitable system will be very difficult to achieve, and most likely financially unsustainable. Second, a few participants stressed that any new tax measures to increase the financial assistance for unpaid caregivers will most likely face resistance from taxpayers. Third, a few participants reiterated their concerns about deteriorating community cohesiveness. These participants indicated that we cannot systematically turn to the government for solutions, and that it was essential to support greater community empowerment to address the challenges facing unpaid caregivers. Fourth, a few participants indicated that many unpaid caregivers are already stretched too thin, and they have too many competing demands to engage meaningfully in decision-

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making processes. Lastly, many participants spoke to the importance of access to a family doctor for components of each of the options. Yet many unpaid caregivers do not have a family doctor.

Participants then turned to key factors that could facilitate efforts to improve care and support for unpaid caregivers in Ontario. First, several participants suggested that people who step up to provide unpaid and ongoing care to their family members, friends and neighbours should be adequately informed and equipped, and fully recognized by the health system, in order to face the challenges of caregiving. As one participant summed up: “Unpaid caregivers in Ontario need to be recognized, supported and trained.” To achieve this, several participants highlighted the need for greater advocacy and campaigning to force health-system leaders and elected officials to implement the necessary policies, programs and services.

Second, several participants emphasized the need to promote greater public dialogue and support experiential learning to build sensitivity to the needs of older adults and their unpaid caregivers. A few participants suggested that this could be achieved by encouraging greater voluntarism among young adults (e.g., 40-hour volunteer requirement in high school before graduating) to connect them with older adults in need in the community and in institutional settings. Others indicated the need to leverage social media to help connect unpaid caregivers with other unpaid caregivers and community members, which could account for some of the lost connectivity that we have experienced in our society.



Acknowledgments

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Conflict of interest

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