THRIVING AT HOME

A LEVELS OF CARE FRAMEWORK TO IMPROVE THE QUALITY AND CONSISTENCY OF HOME AND COMMUNITY CARE FOR ONTARIANS

FINAL REPORT OF THE LEVELS OF CARE EXPERT PANEL
JUNE 2017
Message from the Minister of Health and Long-Term Care

Our government is committed to providing greater consistency and transparency in home and community care services. One of our commitments in *Patients First: A Roadmap to Strengthen Home and Community Care* was to establish a levels of care framework for home care with the goal of ensuring that Ontarians with similar needs can expect to receive equitable and consistent high-quality care across the province.

In August 2016, we established the levels of care expert panel to provide evidence-informed policy recommendations and operational advice related to the design, implementation and evaluation of a levels of care framework.

I would like to thank the expert panel for their report *Thriving at Home: A Levels of Care Framework to Improve the Quality and Consistency of Home and Community Care for Ontarians*. The recommendations of this report provide valuable guidance as our government continues to accelerate the shift to more consistent and transparent service delivery in home care, further improving client outcomes and contributing to the sustainability of Ontario’s health care system.

I would like to extend my appreciation to the members of the levels of care expert panel, co-chaired by Dipti Purbhoo and Irfan Dhalla, for their time, dedication and commitment.

Over the coming months, the ministry will engage clients, caregivers and delivery partners about these recommendations. The ministry will work with Local Health Integration Networks (LHINs) and Health Shared Services Ontario (HSSOntario) to develop an implementation plan that includes piloting the framework at a small number of LHIN demonstration sites. The ministry will also engage with Francophone and Indigenous communities to ensure the levels of care framework is responsive to their unique needs and determine a process to develop a levels of care framework for children and youth, as recommended by the expert panel.
The government has been advancing a number of initiatives that complement the expert panel’s report, including:

- The *Patients First Act, 2016*, that enables greater coordination of health care service delivery and development of partnerships that enable greater collaboration.

- The Statement of Home and Community Care Values developed in collaboration with the Patient and Caregiver Advisory Table and the ministry. The ministry is working with sector partners to embed the statement into the daily operations of the sector.

- The development of caregiver supports including new caregiver training and education programs, tools and resources, and a commitment to establish a caregiver organization that will coordinate supports and information resources for Ontario caregivers.

- Quality standards (e.g., wound care, dementia care, and palliative care) to support clinicians and care providers in providing high-quality and consistent care.

- A review of home care indicators that will support the levels of care framework and also benchmark progress in order to result in better home and community care for Ontarians.

I look forward to further review of the expert panel’s report with our health care partners as well as with those receiving care, their caregivers and advocates. Together, we can continue to build a system that puts patients first, improving their health care experiences and outcomes.

Yours sincerely,

Dr. Eric Hoskins
Minister of Health and Long-Term Care
Dear Minister Hoskins,

We are very pleased to submit the report of the Levels of Care Expert Panel.

In our deliberations we focused specifically on the kinds of supports Ontarians need with day-to-day activities to be independent and thrive at home. We recognize that caregivers – family members and friends – will continue to be a key source of day-to-day support for people who need care at home. However, individuals and caregivers sometimes need help from the health care system, and some will need more help than others.

We recommend a levels of care framework, and an approach to assessment and care planning, that will help home and community care providers work together with individuals and their caregivers to identify their needs and determine the type and amount of services to meet those needs. Our levels of care framework focuses on the functional needs of adults who need home and community care for several weeks or longer which, given the large number of adults who need help with functional needs, was where we felt a levels of care framework would have the greatest benefits.

Our panel felt strongly that children and youth who need home and community care would be best served by a distinct and separate framework that recognizes their unique needs.

Our proposed framework will help ensure that regardless of where people live in Ontario there is consistency in the way people are assessed, and in the process used to determine the amount and type of care that each individual might receive. We believe that, if our recommendations are implemented, everyone will have a better understanding of, and more confidence in, the home and community care system. Most importantly, we believe that a levels of care framework can be an important foundation to improve the quality of home and community care in Ontario.

Our recommendations reflect the best available evidence as well as the real-world experience of Expert Panel members who included people who receive services, caregivers and health service providers.

We would also like to acknowledge the many people who provided expertise and advice to inform our work.

We are both grateful for, and honoured by, the opportunity to provide this advice to you. We remain available, as needed, to answer any questions about our recommendations, and to advise on their implementation.

Yours sincerely,

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BACKGROUND

THE NEED FOR HOME AND COMMUNITY CARE

- Amar, age 84, has chronic obstructive pulmonary disease, congestive heart failure, macular degeneration and a history of colon cancer. He can feed and dress himself, but his vision is poor and he is only able to walk short distances. Amar has a colostomy that is well managed but, with his loss of vision, he is finding it harder to empty and change the ostomy bag. His 75 year-old wife is his caregiver. She is still able to do housework, shop, prepare meals and do the banking, but she does not want to assist with his ostomy care, nor does she feel she would be able to assist him with bathing and toileting if that becomes necessary. She herself is becoming more frail, and often feels exhausted.

- Ross, age 27 years, has complete quadriplegia as a result of a diving accident three years ago. After a lengthy rehabilitation, Ross now lives with his parents in a three-bedroom bungalow outside the city that was modified to be wheelchair accessible. Ross receives home care assistance to help him dress, transfer to/from his electric wheelchair and help with showering. He also gets help with exercise two or three times a week from a physiotherapist. His parents do the shopping and prepare his meals, but rely on community supports for transportation. Ross is planning to return to school in the fall to complete his post-graduate degree in psychology. He has applied for attendant services to help him while he is at school.

As these profiles\(^1\) illustrate, many people need support to live independently and thrive in their own homes. Families and friends are usually the greatest source of this support, but there will often be times when individuals and their caregivers\(^2\) need more help to be able to remain at home and have a good quality of life.

That’s where home and community care comes in.

\(^1\) The scenarios are composites of actual cases described by care coordinators.

\(^2\) Caregivers are family members, friends and neighbours who provide care to individuals who need care and support at home, and who may also need home and community care services.
For many Ontarians, the right place to receive health care and social support is close to home. Services provided in the home and community help people with health care needs to thrive and to stay independent and connected with family and friends. Between April 1, 2015 and March 31, 2016:

- About 560,000 Ontarians received home care services provided by the province’s Community Care Access Centres (CCACs). They received a total of 28.7 million personal support and homemaking hours, 6.9 million nursing visits and 2.1 million nursing hours, 1.7 million therapy visits (physiotherapy, occupational therapy, speech language therapy, social work) and 1.9 million case management visits.\(^3\)

- About 675,000 Ontarians received just under 1.17 million visits and services from Ontario’s 661 community support service agencies, which provide meal services, transportation, caregiver support services, home maintenance and repair services, friendly visiting and other services.\(^4\)

It is important to note that these numbers do not include individuals who would benefit from home and community care provided by CCACs or community support service agencies, but who have not yet been referred, or do not know about the services.

While many people benefit from home and community care now, the current system can seem arbitrary, difficult to understand, and frustrating to navigate. It also often feels disconnected from primary care.

In 2015, the Expert Group on Home and Community Care, led by Gail Donner, issued *Bringing Care Home*, a report that highlighted the fact that there is “too much variability in access and too little accountability for outcomes” and called on government and the home and community care system to make a paradigm shift to a person- and family-centred system.

In response to that report, Ontario made delivering “better coordinated and integrated care in the community, closer to home” one of the four pillars of its *Patients First: Action Plan for Health Care* (2015). In the same year, Ontario launched *Patients First: A Roadmap to Strengthen Home and Community Care* (Roadmap); a three-year, 10-step plan - with timelines - to improve the quality, consistency and integration of home and community care.

As one of its first steps in implementing the Roadmap, the Ministry of Health and Long-Term Care (ministry) focused on the levels of care framework.

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\(^3\) Data provided by Health Shared Services Ontario. March 2017.

\(^4\) Data provided by Health Data Branch, Ministry of Health and Long-Term Care. March 2017.

What is a Levels of Care Framework?

A levels of care framework is a consistent process of working with individuals and their caregivers to: assess their needs, determine their level of care based on those needs, and develop a care plan to meet those needs. A levels of care framework can help ensure greater consistency and transparency in home and community care across the province. A levels of care framework will give everyone – individuals who need services, individuals receiving services, their caregivers and service providers – a better understanding of how people are assessed, and the type and amount of home and community care services they may be eligible to receive.

In 2016, the ministry:

- developed a discussion paper that described the purpose and proposed elements of a levels of care framework
- invited public consultation on levels of care through three workshops and a dedicated email address (200 organizations and individuals responded in person or by email)
- summarized the in-person and email feedback from the public consultations in Reporting Back on What We Heard (November 2016).

In the summer of 2016, the ministry also appointed the Levels of Care Expert Panel.

THE LEVELS OF CARE EXPERT PANEL

The Levels of Care Expert Panel (Expert Panel) is a group of individuals with wide-ranging expertise in home and community care. It includes people who receive home and community care, caregivers, care coordinators, service providers, physicians, researchers, and experts in evaluation and quality improvement. Expert Panel members share a deep commitment to high quality patient-centred care, and to enabling people who need home and community care and their caregivers to be partners in their care.

The Expert Panel was not asked to make recommendations related to resources, funding or how the home and community care system should be organized; however, the Expert Panel recognizes that many of its recommendations have implications for these issues.

TASKS

The Expert Panel was asked to:

- Develop and recommend a levels of care framework that would group individuals who need home and community care into care levels based on their functional, clinical, social, cognitive and other needs, and to provide typical examples of individuals at each level, including client profiles and care plans
- Provide advice on eligibility criteria and service ranges for each level of care
- Provide advice on tools to help assign individuals to care levels and allocate services
- Recommend how the levels of care framework will take into account issues related to clinical quality, including how it will use the quality standards developed by Health Quality Ontario
- Provide advice on best practices for assessments and reassessments to inform the development of an assessment policy
- Provide advice on an approach to maximize transparency about the levels of care framework, as well as the consistency and quality of home and community care in Ontario.
GOALS AND PRINCIPLES

To guide its work, the Expert Panel identified goals, principles, and enablers (see Figure 1).

Figure 1: Goals, Principles, and Enablers

**EXPERT PANEL’S VISION OF HOME AND COMMUNITY CARE**

Enable people to maximize their independence and thrive in their own homes and communities.

**GOALS OF A LEVELS OF CARE FRAMEWORK**

- **Patients First**
  - Individuals and their caregivers partner with providers to develop and implement a care plan.
  - The care plan focuses on what is most important to the individual and caregivers.

- **Equitable Care**
  - Providers, policy makers and funders provide equitable access to high quality care across the province.
  - Inequities are addressed by adopting leading practices and strategically allocating resources.

- **High Quality Care**
  - Individuals and caregivers understand what to expect from home and community care.
  - Providers consistently deliver high-quality care consistent with the best available evidence.

- **Confidence and Trust**
  - Assessment results, and the care plan, are available to individuals and caregivers.
  - Individuals can request reviews of decisions about their care level, and their care plan.

**GUIDING PRINCIPLES FOR A LEVELS OF CARE FRAMEWORK**

- **Inclusive**
  - Will respond to the needs of all individuals who seek home and community care.

- **Transparent**
  - Will be user-friendly and understandable.

- **Evidence-Informed**
  - Will reflect available evidence regarding service needs.

- **Nimble**
  - Will be able to respond to changes in care models, practices, and technologies.

- **Fiscally Responsible**
  - Will set realistic care levels that can be sustainably resourced.

- **Population-Specific**
  - Will be tailored to reflect and meet the needs of a specific population.

- **Needs-Based**
  - Will respond to individuals’ assessed functional, medical, and social care needs.

- **Flexible**
  - Will support individualized care by engaging individuals and families in care planning.

- **Responsive**
  - Will enable individuals to move between levels of care as their needs change.

**KEY ENABLERS**

- **Integration, Collaboration & Technology**
  - Service integration, information sharing, and smooth transitions across the health care continuum (e.g., primary care, home and community care, specialized services, hospital care, long-term care).

- **Competence & Consistency**
  - Professional development and training to enable home and community care staff to effectively provide consistent person- and family-centred care.

- **Enablement Focus**
  - Focus on enabling/empowering individuals to maximize their ability to function independently, and improve their health and quality of life.

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Ministry of Health and Long-Term Care. Levels of Care Discussion Paper. Toronto, ON; 2016. (Available upon request from the Ministry of Health and Long-Term Care, Home and Community Care Branch).
**METHODOLOGY**

The Expert Panel’s work builds on the foundation laid by *Bringing Care Home, the Levels of Care Discussion Paper and Reporting Back on What We Heard*. To develop its recommendations, the Expert Panel:

- reviewed literature and rapid reviews related to levels of care frameworks and approaches used in other jurisdictions — particularly Japan, Australia, France and the Netherlands — to learn from their experiences
- attended three ministry-sponsored levels of care workshops with more than 150 stakeholders (people receiving care, caregivers, service providers)
- reviewed submissions from key experts, organizations and researchers
- reviewed relevant data on home and community care services in Ontario and where available from other provinces (see Appendix B)
- reviewed and analyzed different assessment tools and approaches, focusing specifically on the interRAI suite of tools, which are widely used in the home and community sector in Ontario
- held a half-day focus group with 20 care coordinators to develop client profiles that would help explain each level of care
- held a day-long development session with 118 people (people receiving home and community care, caregivers, service providers) to discuss different client profiles, where the clients would “fit” in terms of level of care, and the care plan and services that people at each level of care might require (for more detail see Appendix C).

To inform the framework, the Expert Panel:
- identified the key factors that affect the amount of support individuals need to thrive at home
- considered the number of hours of personal support currently provided in Ontario as well as in other jurisdictions
- discussed key issues with experienced care coordinators
- identified the other supports required for effective implementation of a levels of care framework.

Note: In the process of developing the proposed framework, the Expert Panel found very little research assessing the impacts of different intensities and types of home and community supports on health outcomes. Without high-quality evidence to guide them, the Expert Panel provided their expert advice on the range of hours of personal support (i.e., service intensity) that people at each level might need to thrive at home. While the Expert Panel recommended a starting point, more research is needed to help make necessary adjustments to the framework over time.

**ORGANIZATION OF THE REPORT AND RECOMMENDATIONS**

The report is organized into three main sections:

- the proposed framework
- the assessment process
- other supports/activities required to successfully implement the framework and the assessment process.

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7 interRAI is an international collaborative of health researchers in over 30 countries which promotes evidence-informed clinical practice and policy decision-making through an integrated comprehensive assessment system.
WHERE WE WANT TO BE: Ontarians who need home and community care and their caregivers work with home and community care coordinators to assess their functional needs, and identify the level of care they need to be independent and thrive at home. As their needs change, they are able to move between levels of care. At any time, they and their caregivers know their level of care and the services they may be eligible to receive.

THE EXPERT PANEL RECOMMENDATION #1: FRAMEWORK

i. The ministry adopt the proposed levels of care framework to guide the delivery of supports that meet the functional needs of adults who need home and community care services for several weeks or longer and their caregivers, and ensure the framework is applied consistently across the province.

ii. The ministry work with Francophone and Indigenous communities to ensure the framework is responsive to their needs, and adapt the framework as necessary.

GUIDE TO THE PROPOSED FRAMEWORK

Functional Needs. The seven-level framework is designed to help identify and meet the functional needs of adults who require home and community care services for a longer period of time and their caregivers. The Expert Panel focused on this group because:

• Problems with ADLs and IADLs are the main reasons people need home and community care.

• The volume of home and community care provided in Ontario is heavily weighted towards people’s functional needs: the 560,000 Ontarians who received CCAC services in 2015-16 received 28.7 million personal support and home making hours compared to 2.1 million nursing hours.

• Adults who needed home care services for more than six months (known as long-stay) made up less than half of CCAC service users (i.e., 37.7 per cent of the total home care population and 45.3 per cent of all active users of CCAC services) but they accounted for 90 per cent of all personal support worker services - at a cost of $884 million.

Functional needs refer to a person’s ability to perform:

- activities of daily living (ADLs), such as personal hygiene, bathing, eating, toileting, and moving from a bed to a chair.

- instrumental activities of daily living (IADLs), such as home maintenance, preparing meals, shopping for groceries or clothing, banking, and taking medications.

Expert Panel members recognize that other populations, such as children and youth, also need person-centred home and community care. However, they would benefit from their own levels of care framework that meets their unique needs.

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8 Data provided by Health Shared Services Ontario. March 2017.
9 Ibid.
• Adults who need care for a short time (known as short-stay) have usually been discharged from hospital after surgery or treatment, and they mainly need nursing care and rehabilitation services. If they do need help with functional needs, it will be for a very short period of time. While the framework can be used with short-stay adults, the Expert Panel feels it will have the greatest impact and be most useful with adults who need ongoing help with their functional needs.

• 85 per cent of individuals who received personal support services through CCACs needed those services for more than six months.10 For those individuals, their services cost an average of $717 a month, compared to $371 for the seven per cent who required care for 60 days or less, and $1,006 for the eight per cent who required end-of-life support.11

• The more that home and community care services can help people manage ADLs and IADLs, the more likely it is that individuals can live independently at home, and the less likely they are to move to a long-term care facility or be admitted to hospital.

Note: The functional need profiles in the framework describe the ADL and IADL needs of an individual at each level. They are not intended to capture all aspects of an individual’s health, social, cognitive and mental health needs. The Expert Panel recognizes that people who need home and community care often need clinical health services like nursing, medical care, physiotherapy, occupational therapy, social work, dietetics, speech language therapy, and mental health services. These other needs are assessed by the care coordinator as part of the overall comprehensive assessment, and will be included in the broader care planning process.

The Expert Panel believes that the provision of these services should be guided by evidence-based clinical care standards. The panel agreed that:

• Health Quality Ontario should continue to provide leadership over the next few years in developing quality standards for clinical conditions
• Individuals who can physically attend clinics and outpatient services should receive their clinical services in those settings if they exist in their regions
• Individuals who, due to their physical health condition, cannot attend clinics and outpatient services should receive clinical services in the home.

10 Analyses provided by Health Analytics Branch, Ministry of Health and Long-Term Care. March 2017.
11 Data provided by Health Shared Services Ontario. March 2017.
Intensity of Functional Supports. The seven-level framework will give people receiving services and their caregivers a clear understanding of how much support they may be eligible to receive at home or in the community, based on need. Figure 2 sets out the Expert Panel’s proposed seven-level framework and describes the criteria of need for each level. The descriptions – that is, the combinations of functional needs, strengths and impairments that would put someone at a certain level – are based on Expert Panel experience and advice, and take into consideration the descriptions used in the interRAI IADL-ADL Functional Hierarchy Scale. The Expert Panel modified the interRAI descriptions to include other factors that, in their expert opinion, were vital to identify the functional needs of individuals at each level, such as the need for bathing support and caregiver respite.

Range of Support Hours. The Expert Panel established a range of support hours for each level. The ranges are broad enough that care coordinators can take into account the intensity of the person’s support needs, as well as any modifiers that could increase the need for support, such as cognitive impairment or multiple health conditions.

The framework ensures that the process of determining a person’s level of care and amount of service is not mechanistic. It reflects the person’s holistic needs and circumstances and is determined based on a combination of standardized assessment process and clinical judgment. The process of determining a person’s level of care requires clinical expertise.
### Figure 2: Proposed Levels of Care Framework

<table>
<thead>
<tr>
<th>LEVEL OF CARE</th>
<th>FUNCTIONAL NEED PROFILE*</th>
<th>TOTAL SUPPORT HOURS PER MONTH*****</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The person is independent in terms of personal care (ADLs) but needs assistance with some IADLs, such as home maintenance and meal preparation. The person does not need personal support but may benefit from community support services such as assistance with transportation or home maintenance, as well as education, exercise and socialization programs.</td>
<td>community support services only; no need for personal support</td>
</tr>
<tr>
<td>2</td>
<td>In addition to the needs at Level 1, the person may need assistance with medication management and help or supervision with some personal care activities, such as bathing (e.g., getting in and out of the tub). Individuals at this level do not need assistance every day. They may also benefit from community support services, and from some assistive devices (e.g., cane, walker).</td>
<td>up to 12 hours</td>
</tr>
<tr>
<td>3</td>
<td>In addition to the needs at Level 2, the person needs assistance with most IADLs and may need assistance with ADLs such as bathing, moving around in the home, and dressing. Individuals at this level may need assistance every day. They may also benefit from community support services, assistive devices, and caregiver coaching programs.</td>
<td>up to 32 hours</td>
</tr>
<tr>
<td>4</td>
<td>In addition to the needs at Level 3, the person needs additional help with transferring and toileting. Individuals at this level may need assistance once or twice per day. They may also benefit from community support services, assistive devices, caregiver respite, and caregiver coaching programs.</td>
<td>up to 56 hours</td>
</tr>
<tr>
<td>5</td>
<td>In addition to the needs at Level 4, the person needs extensive assistance with personal hygiene and bathing, and may need help with eating. Individuals at this level may need assistance two or three times per day. They may also benefit from community support services, assistive devices, caregiver respite, and caregiver coaching programs.</td>
<td>up to 84 hours</td>
</tr>
<tr>
<td>6</td>
<td>In addition to the needs at Level 5, the person needs extensive help with eating and locomotion, and may need two people to assist with transferring. Individuals at this level may be unable to leave their bed, or may spend extensive periods of time in a chair. They may need assistance three or more times per day. They may also benefit from community support services, assistive devices, caregiver respite, and caregiver coaching programs.</td>
<td>up to 120 hours</td>
</tr>
<tr>
<td>7</td>
<td>The person needs assistance with all IADLs, needs extensive help with all ADLs, and cannot be left alone for long periods of time. Individuals at this level may be unable to leave their bed, or spend long periods of time in a chair. They are experiencing exceptional circumstances, such as nearing end of life, awaiting crisis placement to long-term care, a short-term emergency, or a caregiver who is ill or hospitalized. They need frequent assistance throughout the day. They may also benefit from community support services, assistive devices, caregiver respite, and caregiver coaching programs.</td>
<td>above service hours in level 6</td>
</tr>
</tbody>
</table>

Notes to the Framework:
- * Based on Expert Panel advice, taking into consideration the interRAI IADL-ADL Functional Hierarchy Scale.
- ** For the purposes of this framework, a month is equal to 4 weeks.
- *** Individuals who do not need the offered level of support at the time of the assessment are still eligible to receive it at a later date.
KEY FEATURES OF THE FRAMEWORK

Assessment based on total functional needs. A person’s level of care is determined based on what he or she cannot do independently, regardless of who assists them with these activities. The level of care reflects the person’s total functional needs. For example, people may have high functional needs but relatively few unmet needs because family and friends are able to assist with a lot of ADLs and IADLs. When assessing a person’s level of care, the care coordinator will consider what the individual cannot do for him or herself, regardless of whether someone is providing assistance. When planning care and deciding how much home care service the person will need, the care coordinator will consider the capacity of caregivers to assist with ADLs and IADLs, as well as any distress that caregivers may be experiencing.

Care planning based on unmet functional needs. The care coordinator will determine the type and amount of supports to be provided, and will use the person’s unmet functional needs to develop the care plan. At this stage, all current and possible sources of support for the individual will be taken into account. For example, having a caregiver who can provide some help with ADLs and IADLs may reduce an individual’s need for personal support, while having a distressed caregiver may increase the need for respite care. Some of a person’s unmet needs can also be met with effective use of assistive devices and technologies. For example, having a mechanical lift that helps with transfers may meet some of the person’s needs and reduce the amount of personal support required. Community support services, such as adult day programs and respite programs, may also be used to meet someone’s unmet functional needs.

Use of modifiers to determine service needs within a level. To determine how many hours of service people assessed at a certain level will receive, the care coordinator will look at factors or modifiers that might affect a person’s needs. The care coordinator will also assess the caregiver’s capacity and level of distress. Modifiers identified by care coordinators that justify an individual’s level of service should be recorded in the electronic record. This information will support regular review, and can be used to help ensure greater equity and transparency in how resources are allocated across the province.

Monthly versus weekly hours. To give individuals and caregivers more flexibility, the framework has established monthly rather than weekly support hours. This approach allows individuals and caregivers to determine when in the month they need support rather than having to fit to a fixed schedule.

Modifiers that May Affect Needs

Complex social issues such as:
- low income
- unstable housing
- living alone
- complex family dynamics

Complex health issues such as:
- a mental health condition (e.g., depression) or an addiction
- significant cognitive impairment (e.g., dementia)
- multiple medical conditions

Caregiver availability and capacity
- lack of caregiver
- distressed caregiver

Home and community care services complement the support provided by caregivers. For many individuals who need help to live independently and thrive at home, caregivers (family members, friends, neighbours) are their primary source of care and support. However, some individuals will not have caregivers nearby or their family members may only be able to assist with certain aspects of care. Some caregivers may themselves be frail, have health conditions or be experiencing distress. **Under the proposed levels of care framework, caregiver capacity will be part of the assessment and will be a factor in determining the type and amount of care provided.**

Note: The Expert Panel believes it is essential to: determine whether the proposed framework is appropriate for use with Francophone and Indigenous communities; and to adapt it as required to ensure it is responsive to their needs.

### OTHER SERVICES THAT ARE PART OF THE FRAMEWORK

In addition to the support hours, at all levels in the framework:

- Individuals and caregivers have a **care coordinator** responsible for working with them to understand their goals and preferences, assess their needs, develop a care plan to meet their needs and achieve their goals, arrange and coordinate their services, and work with the other members of the care team.

- Care coordinators help individuals and caregivers access the **appropriate community support services and other programs**. Individuals and caregivers are aware when they will be asked to pay for part or all of these services.

- Individuals and caregivers are receiving regular **primary care**. If they do not have a regular primary care provider, they are connected with one. Individuals who have significant difficulty getting to the primary care office should receive primary care at home. In the proposed framework, many people in levels 5, 6 and 7 may need primary care at home.

- Individuals have access to **comprehensive specialized geriatric assessment and dementia supports**, depending on their needs.

- A common list of **assistive devices** is available and is recommended based on need. Individuals and caregivers are aware when they will be asked to pay for part or all of an assistive device.

- Individuals will also have **access to the appropriate rehabilitative programs either at home or in their community** to address their needs.

- All caregivers have access to **coaching and education programs** as needed.

“In Ontario, 3.3 million men and women are family caregivers, and 48 per cent are caring for a parent or in-law. Almost 850,000 of these caregivers provide more than 10 hours of care a week, including transportation, domestic tasks both indoors and out, scheduling appointments, managing finances and providing personal care.”

*Bringing Care Home, Expert Group on Home and Community Care, 2015*
Alma is in her 80s. She has heart failure and has become more frail with age. Alma is generally able to manage her ADLs and most IADLs on her own. She is careful to take her time, and uses equipment and aids to maximize her safety. She is no longer able to safely lift larger dishes in and out of the oven so she now prepares very simple meals using a toaster oven. Because she no longer drives, Alma is not able to visit with her friends and family as much as she would like, and admits to being a little lonely. Although she tries to walk around the neighborhood every day, she avoids walking during the winter months because she is afraid of falling. She is no longer able to garden, do small home repairs (e.g., change a light bulb) or anything other than very light housekeeping. **Alma is at Level 1.** She doesn’t need help with ADLs but she could benefit from help with some IADLs, such as home maintenance. Her daughter, Cathy, who lives close by with her adult son, is able to help with home maintenance. The care coordinator arranges transportation so she can do some shopping on her own.

As Alma continues to become frailer, she starts to need help with some ADLs and more IADLs. Cathy now helps her with her morning routine, including showering three times a week. Cathy ensures that Alma has everything she needs within easy reach, helps style her hair, and stays nearby in case she needs other help. Alma continues to do most of the day-to-day housekeeping, Cathy does the laundry and grocery shopping once a week, and a cleaner comes in once a month to do the heavier cleaning. At this stage, **Alma is at Level 2.** The care coordinator arranges for some assistive devices to make showering easier, and homemaking each month to help with Alma’s needs. Because Cathy is able to assist with showering, Alma receives personal support only when Cathy goes on vacation. At the suggestion of her care coordinator, Alma starts to go to a day program.

A year passes, and Alma now needs more help with ADLs and struggles to manage her medications and finances. She is still able to help with day-to-day housekeeping but can no longer manage it on her own. In addition to helping Alma with her morning and evening routine and showers three times a week, Cathy does the grocery shopping and laundry, helps with the dishes and helps Alma manage her finances and medications (i.e., by filling her dosette each week). Alma has fallen twice while getting dressed and needs assistance with dressing. **Alma is now at Level 3.** Cathy is able to help in the morning but not in the evening. To help Alma and relieve some of Cathy’s responsibilities, the care coordinator increases the amount of personal support. The personal support services are timed to help with Alma’s evening routine. Alma continues to go to the day program.

As time passes, Alma is more reliant on Cathy for considerable help with ADLs and for most IADLs. She needs much more help getting dressed, and she also needs assistance with cleansing after toileting. Cathy still does her grocery shopping and laundry once a week, manages her medications (tracks and fills prescriptions, fills dosette weekly) and manages Alma’s finances. She also does some of the cooking. **Alma is now at Level 4.**
The care coordinator increases the number of hours of personal support so someone can come and help with both the morning and evening routine, and arranges for “Meals on Wheels” on the days when Alma is not at the day program. She also makes arrangements for respite care when Cathy goes on holidays and for occasional weekends.

Over time, Alma continues to become frailer. She needs significant help to manage most ADLs. She now showers twice a week, and needs Cathy or a personal support worker to provide weight-bearing support to help her get in and out of the shower, settle her on her bath chair and wash herself. To maintain her balance, Alma has to lean heavily on someone during her morning and evening care routines, and needs help getting out of bed and when she moves from place to place in her home. She spends long periods of time in her chair. Alma is generally able to feed herself as long as the food is prepared and placed within reach. In terms of IADLs, Alma is now only able to plan meals and take her medications. Alma is now at Level 5. The care coordinator arranges for more personal support to assist with the morning and evening routine as well as one additional visit most days to help with mobility and reduce the risk of a pressure injury that Alma might develop if she stays in one position too long. Because Cathy is finding it difficult to manage home maintenance as well as look after her mother, the care coordinator arranges for someone to do some minor repairs on the house. Alma is no longer able to go to the day program so the care coordinator arranges for a friendly visiting service to give Alma social stimulation. Alma is no longer able to visit her physician, and so Alma’s care coordinator arranges for primary care and laboratory testing to be provided in the home.

One day, Alma suddenly becomes very short of breath and calls 911. In the hospital, she has some tests and it becomes clear that she has had a heart attack and, as a result, her heart failure is now significantly worse. Alma now feels that her quality of life is poor and, although she wants to continue to take medications for symptom control, she doesn’t want any more laboratory tests. She does however want to return home. She now finds it difficult to even stand and spends all her time either in the bed or in a geri-chair. Her physician anticipates that she will likely live for just a few more months. After she is discharged home, she is given a bed bath once a day and is hand-fed a diet of pureed meals. She now uses incontinence garments and needs several visits daily from a personal support worker. Alma is now at Level 7. At this stage, the care coordinator arranges for more intensive palliative care and continues to provide respite care for Cathy.
ASSESSMENT, REASSESSMENT AND CARE PLANNING

WHERE WE WANT TO BE: Individuals and their caregivers are active partners in assessing their functional and health care needs, setting their health goals and developing a care plan. They are able and supported to participate in a standardized, culturally accessible and sensitive assessment, reassessment and care planning process that also involves their primary care provider. They have confidence and trust in the assessment and care planning process, understand and have been provided with the assessment results and the care plan, and are able to request a reassessment of their level of care and care plan.

Assessments are based on a combination of standardized tools, clinical judgment, and input from the person and caregiver. Care planning takes into account the individual and family’s goals and preferences, the services the person is eligible to receive (based on his or her assessed level of care), existing supports, any unmet functional needs, as well as the person’s medical, cognitive and social needs. Every effort is made to ensure the care plan is flexible enough to meet both the individual’s and caregiver’s needs, and that it is centred around what is most important to the individual and their caregiver.

All members of the care team know and understand their roles in the care plan.

THE EXPERT PANEL RECOMMENDATION #2: ASSESSMENT AND REASSESSMENT

i. The ministry should establish a standardized, person-centred, culturally sensitive assessment process that includes:
   - an accessible easy-to-use self-assessment tool for individuals and caregivers
   - an initial formal, standardized comprehensive assessment of the person and caregiver that uses both the interRAI suite of tools and clinician judgment. This assessment should cover:
     - ADLs and IADLs
     - caregiver capacity/burden
     - other factors or modifiers (e.g., social issues, medical complexity, cognitive impairment, mental health) that may affect the individual’s functional support needs, level of care, and other health and social needs
   - a plain language accessible summary of the assessment results and recommendations that is shared with the person and, with the person's consent, their caregiver, primary care provider and other health care providers
   - ongoing informal assessments of the individual’s needs, and the caregiver’s capacity, by all members of the care team in the course of providing services
   - check-in visits (in person or by telephone) by the care coordinator for an individual assessed at level 4 and above at least every six months (or more frequently depending on the complexity of the person's and family's needs)
   - a formal reassessment
     - at least every 12 months, and
     - whenever the person’s functional needs or the caregiver’s capacities change significantly
     - when the family requests a reassessment
     - when a reassessment is requested by any member of the care team
     - when the home and community care coordinator determines it is necessary.
ii. The ministry should work with interRAI, Health Shared Services Ontario, and the Local Health Integration Networks to optimize the assessment process and create a shared interRAI platform, including:

- refining current assessment tools to support the framework, making them shorter, easier and faster to use
- developing a short standardized assessment tool that care coordinators can use during check-in visits and follow-up calls
- identifying triggers for a formal reassessment.

iii. To harmonize assessment across the home and community sector, the ministry should ensure consistent use of the same tools, and provide the resources, training and support to enable community support services agencies to adopt the updates to the interRAI CHA.

THE EXPERT PANEL RECOMMENDATION #3: PERSON- AND FAMILY-CENTRED CARE PLANNING

i. The ministry should promote a person- and family-centred care planning process that ensures:

- individuals and their caregivers are partners in care planning, which is based on their identified goals, the person’s needs, caregiver capacity, community supports and other resources, and the roles of team members
- the care team is empowered to identify innovative ways to meet people’s needs, such as more effective use of assistive devices and programs in the community
- the care plan is shared, with the individual’s consent, with the person and caregivers, the person’s primary care provider and/or specialist, and others in the person’s care team
- the care plan is revised based on any change in the person’s or caregiver’s needs and the results of any reassessment.

ii. Individuals and their families should have the right to request a review of their assessment and any element of the care plan.
THE IMPORTANCE OF ASSESSMENT AND REASSESSMENT

Because the functional and health care needs of individuals receiving home and community care can change quickly over time, ongoing assessment should be an integral part of providing care. According to a recent interRAI analysis, about seven in ten people in Ontario experienced a health decline within six months of their initial RAI-HC assessment - including loss of ADL or IADL function that placed them at higher risk of being admitted to hospital or a long-term care home. Regular reassessments help ensure good quality care and reduce the risk that changes in need will go undetected. However, the ongoing assessment process needs to be manageable for individuals, caregivers and care coordinators.

Informal reassessments by interdisciplinary team members. All members of the care team need to be alert to any changes they notice in the person or caregiver and to share that information with the care coordinator and other members of the care team. To develop a culture of ongoing informal assessment, it will be important to empower personal support workers, as well as other members of the care team, and ensure they have the training and skills to:

- recognize early signs of change in a person’s ability to perform ADLs and IADLs or in their energy, mood and cognition
- recognize any changes in a caregiver’s health and capacity
- report the changes to other members of the care team.

Any significant change should be a trigger for a formal reassessment.

Formal reassessments. Regular formal reassessments are essential to high quality care. The Expert Panel recommends, as a minimum standard: an annual formal reassessment by the home and community care coordinator for all individuals receiving home and community care; and check-in visits every six months (or more often depending on the complexity of their needs) for people at level 4 or higher.

CONSISTENT USE OF VALID ASSESSMENT TOOLS

The goal is to have efficient tools to support the initial assessment, informal ongoing assessments, and formal reassessments. These tools should help to:

- identify a person’s level of care and plan appropriate care
- reduce administrative burden for care coordinators, individuals and caregivers
- ensure consistency within and across regions in Ontario.

As part of implementing the levels of care framework, it would be beneficial for all home and community care providers to use the same tools and scales. The interRAI assessment tools are currently in use in all CCACs and in about half of the province’s community support service agencies. During its consultations, the Expert Panel heard that, while the interRAI tools have many strengths, they may not be sensitive to the needs of all populations and can be burdensome, especially if repeated unnecessarily (e.g., by two care coordinators working for different organizations). Members of the Expert Panel also learned that Belgium had developed a way to allow members of the care team to update only those sections of the interRAI tool related to needs that have changed (rather than re-administering the full interRAI assessment). It may be worthwhile for Ontario to explore the potential to use a similar approach to support the reassessment process.

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The interRAI suite of tools has scales and indicators that can enhance the assessor’s ability to tailor care to the individual’s unique needs. For example:

- The interRAI IADL-ADL Functional Hierarchy Scale is a potentially useful tool in identifying an individual’s level of care. The IADL-ADL Functional Hierarchy Scale aligns well with the proposed levels of care framework because both support a proportionate increase in personal support services based on a person’s functional needs (as measured by capacity to perform IADLs and ADLs). The higher a person’s IADL-ADL Functional Hierarchy Scale score, the more support the person is likely to need.
- The interRAI home care assessment can generate clinical assessment protocols (CAPs) that address a wide range of issues (e.g., mental health needs, rehabilitation potential, functional status, medical symptoms, caregiver supports) and identify specific problem areas (e.g., pressure ulcers) as well as which individuals are most likely to benefit from more attention to specific aspects of their care.

“The importance of clinical judgment arises from a comprehensive geriatric assessment [is] central to the development of care plans for older adults living with frailty. These efforts highlight the importance of trained interprofessional teams and robust clinical assessment process, rather than over-reliance on the use of tools to inform clinically appropriate levels of care.”

Service provider response to the Levels of Care Discussion Paper

THE IMPORTANCE OF CLINICAL JUDGMENT

Assessment tools can play a critical role in helping to determine a person’s level of care; however, the Expert Panel strongly agrees with the advice from interRAI developers: the tools’ algorithms should not be used rigidly or on their own to determine an individual’s appropriate level of care, amount of service or location of care. Expert Panel members strongly encourage an assessment process that makes effective use of both assessment tools and clinical judgment. The care coordinator’s comprehensive assessment of the person and caregiver, and understanding of their goals and preferences, is critical in selecting the most appropriate level and intensity of care, and in developing an effective, individualized care plan.

ENGAGING INDIVIDUALS AND CAREGIVERS

The involvement and input of individuals and their caregivers is as important as assessment tools and clinical judgment. The initial assessment is an opportunity to start forging the respectful partnership that is the foundation for effective home and community care. The assessment helps people understand their functional and health care needs, how their needs affect their level of care and the services they may be eligible to receive.

To help engage individuals and caregivers as early as possible, the Expert Panel recommends the ministry develop an easy-to-use online self-assessment tool that would give Ontarians a sense of what services might be available to assist them – even before they complete the initial formal home and community care assessment.

The self-assessment tool would ask the individual and caregiver a series of simple questions focused mainly on the IADLs and ADLs that can determine a person’s functional needs and level of care, such as: Do you need help to get in and out of the bathtub? Do you need help with dressing? Do you need help with eating?
Open communication is key to engagement and transparency. Care coordinators should talk with individuals and caregivers about the assessment tools, why certain questions are being asked and how the information is used to help determine the appropriate level of care.

The care coordinator should also arrange support for individuals and caregivers who have unique cultural or linguistic needs, or who face barriers to completing the assessment (e.g., cognitive impairment, mental health issues, addictions).

To support communication, individuals and caregivers should be given a plain language summary of their assessment results, level of care and care plan. The interRAI assessment tools have the capacity to automatically generate a one-page personal health profile. The current personal health profile, which is designed for service providers, should be made more user-friendly for individuals and caregivers; it should also be adapted to include the CAPs as well as links to the recommendations on how to manage each of the health problems identified by the CAPs.

To ensure transparency, individuals and caregivers should have the right to request a reassessment whenever they feel that their needs have changed, and to ask for a review of any decisions related to their level of care or their care plan.

A PERSON-CENTRED CARE PLANNING PROCESS

The care planning process provides the opportunity to decide how best to use all available resources to meet a person’s and caregiver’s needs and goals. Care planning starts by understanding what is most important to the individual and their caregiver. Coordinators should work closely with all members of the care team to determine the right mix of supports, including community programs and services, for the person and caregiver.

Care plans should be adjusted any time needs or goals change. The care team should develop regular “progress reports” that are shared with the individual receiving care, his or her caregiver, and his or her primary care provider. The reports should show clearly the areas where there has been progress in meeting goals as well as those where either a different approach is required or goals need to be revisited. The reports may also be used over time to inform care plans and to help assess the effectiveness of different home and community services.

OPPORTUNITIES FOR REVIEW

To reinforce the person-centred nature and transparency of the proposed framework, individuals and families who have been part of the assessment and care planning process and who still do not agree with either the assessed level of care or the care plan should have the option of having a timely review of the decisions by, for example, the care coordinator’s direct manager. This review would be separate from, and prior to, the formal appeal process already available through the Health Services Appeal and Review Board (related to decisions about eligibility for and amount of community services).14

14 For information on the Health Services Appeal and Review Board, see: http://www.hsarb.on.ca
FRAMEWORK SUPPORTS

WHERE WE WANT TO BE: Ontario’s health system truly values and supports person- and family-centred care. Ontario’s home and community care services work as an integrated sector and develop strong partnerships with primary care. The home and community care sector has the knowledge, skills, tools, resources and capacity to implement the framework. Care coordinators have the training, clinical judgment, capacity and skills to fulfill their role. Members of the care team communicate in real time about the person’s health. Information systems developed for home and community care communicate with existing systems in other sectors, such as primary care, long-term care and hospitals, so information can be easily shared among all involved in the person’s care. The sector is committed to quality improvement and consistently works to meet standards of care.

All Ontarians are aware that home and community care services are available and know how to access them. Those needing services know what services they may be eligible to receive, and have realistic expectations of what the home and community care system can provide. They have confidence and trust in the home and community care system.

A levels of care framework and a standardized assessment process can go a long way to improving Ontarians’ access to appropriate home and community care services. However, the framework alone will not be enough to nudge the system toward consistent, transparent, high-quality home and community care. It must be supported by the right policies, training, tools, funding and other resources. For that reason, the Expert Panel recommends the ministry take a series of other steps designed to help the framework achieve its desired impacts.

CHAMPION A CULTURE OF ENABLEMENT AND PERSON- AND FAMILY-CENTRED CARE

THE EXPERT PANEL RECOMMENDATION #4: CULTURE

All ministry policies and communications, and all home and community care processes and practices continually reinforce that:

- the primary goal of home and community care is to enable people with health and functional needs to maximize their independence and thrive in their homes and communities
- individuals and caregivers are key members of the care team and active partners in care planning
- publicly funded home and community care services complement the care and support provided by caregivers to the degree that these individuals have the capacity to provide care.

Rationale

Consistent with the goals of Patients First: Action Plan for Health Care, home and community care should focus on meeting Ontarians’ needs by providing person-centred and family-centred care. Person-centred care describes an approach where home and community care services partner with other health care providers and – most importantly – with individuals and their caregivers to help achieve the individual’s and family’s goals. Services are adapted to the needs and preferences of the person receiving care.
ENCOURAGE SERVICE INTEGRATION

THE EXPERT PANEL RECOMMENDATION #5: SERVICE INTEGRATION

The ministry should continue to encourage service integration to improve the experiences of individuals who need home and community care and their caregivers, and to make the best use of resources, focusing particularly on:

• integrating home care, community support services and primary care into a cohesive system of person- and family-centred services
• improving access to and integration with specialized services (e.g., geriatrics).

Rationale

Community care access centres and community support services agencies generally deliver complementary services that support individuals and their families. Individuals may receive some services from community care access centres and be referred to community support services for others. To obtain clinical services (e.g., nursing), individuals must go to community care access centres, which also provide the bulk of personal support services.

To access both community care access centres and community support services agencies, people may be referred by their primary care practitioner, a social worker, a hospital (i.e., if they are being discharged to home) or a disability support program. Ontarians can also self-refer if they think they have unmet needs. Although there are two main streams, services – particularly community support services – are often provided by a number of different agencies and can be quite fragmented.

With the responsibility for community care access centre services being transferred to the Local Health Integration Networks (LHINs) there is an opportunity to integrate home care and community support services into a true home and community sector. LHINs should continue to advance efforts to ensure that individuals receiving home and community care have a primary care provider and are receiving regular primary care.

The Expert Panel feels strongly that, to ensure effective person- and family-centred care, home and community care must be integrated with primary care - as recommended by the Expert Group on Home and Community Care in its report, Bringing Care Home and in the government’s Patients First agenda.
REINFORCE THE CRITICAL IMPORTANCE OF CARE COORDINATION

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**THE EXPERT PANEL RECOMMENDATION #6: CARE COORDINATION**

The ministry should recognize care coordination as a critical home and community care service and work closely with Local Health Integration Networks, home and community care providers and care coordinators to:

- clearly define the role of home and community care coordinators
- identify the skills and competencies care coordinators need to work with individuals and caregivers, and primary care providers and/or specialists, to assess needs and develop care plans
- establish standards and expectations for home and community care coordinators that support the delivery of individual and family-centred care, including expectations about management and delegation of responsibilities to other health care team members (e.g., clinical managers, nurses, personal support workers, team assistants), and consistent methods of communication/collaboration with primary care providers and specialists
- develop standard professional development programs that will enhance home and community care coordinators’ skills and capacity
- help ensure that care coordinators have the right tools, technology and capacity to provide effective individual and family-centred coordination services.

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**Rationale**

Skilled care coordinators are the lynchpin of the proposed levels of care framework. Successful implementation of the framework will depend on coordinators’ ability to engage individuals and their caregivers, understand what is most important to them, assess their needs, goals and preferences, assemble the care team, develop and oversee care plans, and evaluate the impact of the care provided.

At the current time, CCAC care coordinators are regulated health care professionals such as nurses, social workers, occupational therapists, physiotherapists and speech language pathologists. In community support services, assessments are done by assessors who also have the appropriate competencies. In the Expert Panel’s view, the person’s professional designation is not as important as both the hard and soft skills required for the role.

As LHINs take responsibility for home and community care, there is an opportunity to enable care coordinators to deliver more value by: clearly defining their role; establishing competencies, expectations and professional development programs; and providing care coordinators with the right tools, technology and capacity.

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Care coordination is a service that has therapeutic benefit for the individuals and families receiving home and community care services. At the heart of care coordination is the relationship between the care coordinator and the individual and family. Care coordinators work hand-in-hand with individuals and their families – as advisors, guides and advocates – to help achieve individual and family goals.
The ministry should develop policies to guide data sharing agreements and electronic information systems that are integrated with existing systems and:

- enable all members of the care team to record and share the person’s assessment and care plan, the services provided and any changes in the person’s health or functional abilities
- reduce duplicative assessments and unnecessary administrative burden
- optimize and increase the time that providers spend providing care.

Rationale

One of the main barriers to reducing assessment burden and optimizing care is the cumbersome way that information is shared among members of the care team. To provide person-centred home and community care, the system must develop protocols and information systems that allow all members to share information in real-time. Tablet-based charting will ensure that everyone providing care in the home can record details at the time care is delivered so records are always up to date. Any system developed to support home and community care should be able to “talk” to primary care providers’ electronic medical records. Any information systems developed to support home and community care should also ensure that information is available to the people receiving care and their caregivers.

Sharing assessments and care plans within the care team and across the home care and community support services sectors can benefit people receiving care and their caregivers, and reduce the number of duplicate or redundant assessments in the health system. Currently, some health care provider organizations make assessment results and care plans available, while others do not. The Expert Panel heard that countries like New Zealand and Belgium have developed relatively seamless mechanisms for sharing assessment data between home and community care providers and primary care. Ontario should examine the innovations implemented in other jurisdictions for their applicability in this province.

One example of how an innovative information system can support integrated care in home care is the Toronto Central Integrated Palliative Care Program. Palliative care teams including palliative physicians, care coordinators, nurses, personal support workers, and hospice volunteers work together as a team to provide home-based palliative care. The program’s integrated electronic medical record allows all team members to document their care in one electronic record and have real-time access to information about the person’s care. The information system makes it easier for the team to share information, reduces duplication and enables safe, effective care.
PROMOTE QUALITY IMPROVEMENT

THE EXPERT PANEL RECOMMENDATION #8: QUALITY IMPROVEMENT

i. To evaluate the framework and ensure it is applied consistently, the ministry should work with Local Health Integration Networks, Health Quality Ontario and Health Shared Services Ontario to:
   • gather data from the standardized assessments and resource allocations
   • establish indicators of success and effectiveness, both at the individual and system levels.

ii. Local Health Integration Networks should work with home and community care professionals and organizations to ensure they meet evidence-based quality standards for clinical and rehabilitation services established by Health Quality Ontario.

iii. The ministry should invest in research to:
   • assess the impact of care provided in the home, and provide evidence to guide policies and programs
   • identify best practices in terms of the amount and type of care people need to thrive at home and maximize their independence.

Rationale

Health Quality Ontario has responsibility for establishing evidence-based quality standards for care for the province. Most of the standards Health Quality Ontario is currently producing are for specific conditions, and LHINs should ensure that clinicians who provide home and community care are supported in using these quality standards so that individuals receive the best possible care.

In the course of reviewing the literature to inform their work, Expert Panel members noted the dearth of information on best practices in home and community care, specifically the number of hours of personal support needed to optimize outcomes. Ontario could strengthen its own home and community care services, and provide a service nationally and internationally, by investing in research and evaluating the framework as it is implemented and scaled up across the province.

It will be important to evaluate how the levels of care framework is implemented, and ensure it is having the anticipated impacts in terms of: equitable access to services based on needs, high quality care, more consistent care, greater public trust and confidence in the system, and – most importantly – maximizing independence and helping individuals with functional needs thrive at home. The Expert Panel suggests that Health Quality Ontario and Health Shared Services Ontario are uniquely positioned to assist with this evaluation.
ENSURE TRANSPARENCY / EFFECTIVE PUBLIC COMMUNICATION

THE EXPERT PANEL RECOMMENDATION #9: TRANSPARENCY AND PUBLIC COMMUNICATION

i. To ensure Ontarians understand the framework, the assessment process, and the services they are eligible to receive, the ministry should establish and promote a provincial web site or portal where people can access:
   - information about home and community care services available in Ontario and what the system can provide
   - information on the framework and assessment process, including communications that explain the framework and its use that is tailored to different audiences, including individuals who need services, their caregivers and primary care providers
   - the self-assessment tool
   - links to their Local Health Integration Network’s home and community care services.

ii. To ensure public accountability, the ministry should work with Health Quality Ontario to continue to enhance public reporting on the quality of home and community care in Ontario.

Rationale

To have trust and confidence in the system, Ontarians need easy access to clear information on what the levels of care are, how people are assessed, the services they are eligible for at each level, and the ways in which they can shape and influence their care plan. They need to have realistic and reasonable expectations of what the publicly funded health care system can provide. Whenever there is a cost involved in a service – as is the case with some assistive devices – families should know up front, and receive information on any programs, such as subsidies or tax credits, which can reduce the cost.

The Expert Panel is recommending a web-based portal as a way to make information on home and community care accessible to Ontarians; however, members recognize that information will have to be available in other formats for those who do not have easy access to a computer. It will also have to be available in different languages, and presented in culturally sensitive ways. Given that some people being assessed may not speak English or French as a first language, or may have cognitive issues, the system should also explore the use of picture-based systems that people can use during the self-assessment.

The Expert Panel also acknowledges that other care providers, particularly primary care providers, would benefit from tailored communications that answer their questions about the framework, how it is used, and the home and community care services that individuals can expect to receive.
ADDRESS RELATED ISSUES BEYOND THE PANEL’S SCOPE

In the course of its work, the Expert Panel identified two issues beyond its scope that need to be addressed.

THE EXPERT PANEL RECOMMENDATION #10: OUT-OF-SCOPE ISSUES

i. The ministry should establish an Expert Panel to develop a framework for home care services for children with medically complex needs. Its tasks should include working with the adult home and community care system to ensure children are able to make a smooth transition from the paediatric to the adult system.

ii. The Ministries of Health and Long-Term Care and Community and Social Services should work together to address the home and community care needs of people in developmental services programs.

Rationale

As noted earlier in this report, the Expert Panel focused specifically on establishing a levels of care framework that meets the functional needs of adults who require home and community care for a longer period of time. Members recognized that there are other populations – including children and youth, and people currently in developmental services programs – who also need person-centred home and community care, and recommends specific initiatives to plan for their needs.
4 CONCLUSION

IN THIS REPORT, THE LEVELS OF CARE EXPERT PANEL:

• Recommends that Ontario adopt a seven-level framework to help assess the functional needs of adults who need home and community care services for a longer period of time as well as their caregivers.

• Describes a comprehensive assessment, reassessment and care planning process to support the use of the framework and makes recommendations about the type of assessment tools and the importance of using those tools consistently across the province.

• Highlights other resources required to support effective, consistent use of the framework and build confidence in home and community care, including: a culture of person- and family-centred care; more effective care coordination; better integration of home care, community support services, primary care and specialized services; better information systems; and more effective ways of communicating with individuals, caregivers and the public.

Implementing the levels of care framework will be a complex task. In terms of priorities, the Expert Panel suggests that the ministry focus first on creating the backbone for the framework, which includes:

• **Assessment Tools:** standardized tools to support all assessments – self-assessment, initial assessment, informal ongoing assessments, and formal reassessments – that are shorter and easier to use than current tools.

• **Information Technology and Tools:** an efficient information system that enables effective real-time communication among members of the care team, including the person’s primary care provider, and a provincial home and community care website, with information about the framework.

• **Care Coordination:** clearly defined role, competencies, tools, technology, and a standard training program for care coordinators.

Applied consistently, the proposed levels of care framework will give everyone – individuals receiving care, caregivers and service providers – a common understanding of how people are assessed and the type and amount of home and community care they may be eligible to receive. Implementation of the framework will go a long way to ensuring consistent access to home and community care services, and making the current assessment and care planning process more patient-centred, transparent and accountable.
A. LEVELS OF CARE EXPERT PANEL TERMS OF REFERENCE

Purpose
To support the design and implementation of a levels of care framework, the Ministry of Health and Long-Term Care (ministry) is proposing to establish a Levels of Care Expert Panel (Expert Panel).

The Expert Panel will provide advice and recommendations to the Minister of Health and Long-Term Care regarding the evidence-informed development and successful implementation of a levels of care framework in Ontario.

Background/Context
In May 2015, the Ministry of Health and Long-Term Care released Patients First: A Roadmap to Strengthen Home and Community Care (Roadmap), a three-year, 10-step plan to improve home and community care.

A signature initiative under the Roadmap is the creation of a levels of care framework. The objective of the levels of care framework, is to support common standards for home and community care assessment, eligibility, quality of care, and consistent service allocation across the province.

Levels of Care is a multi-faceted initiative containing a number of core project streams that consult with CCACs and LHINs, Health Quality Ontario, primary and acute care, and the research community. The process is designed to ensure the implementation is informed by evidence and experience in home and community care provision in Ontario.

Mandate
The Expert Panel will provide evidence-informed policy recommendations and operational advice related to the design, implementation, and evaluation of the levels of care framework, in particular focusing on issues related to eligibility for home care and consistent service allocation across the province.

Deliverables
The Expert Panel will provide advice and recommendations in the form of a report, on both policy and process for implementation. This report will be presented to the Minister of Health and Long-Term Care and contain advice on three project work streams that underpin the levels of care framework:

1. Levels of Care Framework: Develop and recommend a levels of care framework that will include:
   - Development of:
     - A typology that stratifies home care populations by care needs into care levels considering functional, clinical, social, cognitive and other critical factors; and
     - Exemplars for each level with client profiles and care plans to meet client needs including supported self-management
   - Recommendations/advice on:
     - Eligibility and service ranges for each care level; and
     - Tools for assigning clients to care levels and for allocation of services.

2. Quality Standards: Make recommendations about how the levels of care framework, will incorporate issues related to clinical quality, including how Health Quality Ontario’s quality standards will be used.

3. Assessment Policy: Provide advice and recommendations on best practices for assessments and reassessments to inform the development of an assessment policy.
In addition, the Expert Panel will provide advice on the development of an approach designed to maximize transparency, which will drive improvement and demonstrate success. This will include advice on the transparency of the work of the Expert Panel itself, transparency about the levels of care framework, and assessment policy, and, ultimately, transparency regarding the consistency and quality of home care in Ontario.

**Membership**

- The Expert Panel will contain a number of standing members (up to 18 members), including patients, caregivers as well as service providers, clinicians and care coordinators who are familiar with the needs of individuals who require home care.
- Broad representation and system-wide input is required to inform the full breadth of Levels of Care and achieve its full potential.
- Members will be appointed by the Minister and the constituting instruments.
B. NATIONAL COMPARISON OF HOURS OF SERVICE

As part of its research, the Expert Panel sought information on the levels of home care service provided by other jurisdictions across Canada. Four jurisdictions – Nova Scotia, Manitoba, Newfoundland and Labrador, and Nunavut – provided information directly. Information on other Canadian jurisdictions was obtained from a review conducted by the Research, Analysis and Evaluation Branch of the Ministry of Health and Long-Term Care.

<table>
<thead>
<tr>
<th>JURISDICTION</th>
<th>MAXIMUM HOURS OF SERVICE</th>
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<tbody>
<tr>
<td>Manitoba</td>
<td>55 hours of home care attendant service per week</td>
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<tr>
<td>Quebec</td>
<td>15 hours per week</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>215 hours per month for home support</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>100 hours of home support services per 28 days</td>
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<tr>
<td>Prince Edward Island</td>
<td>Three visits or 28 hours a week</td>
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<tr>
<td>Newfoundland &amp; Labrador</td>
<td>Monthly home support of $3,490 for seniors and $4,985 for adults with a disability, which can be used to pay for:</td>
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<tr>
<td></td>
<td>• 4 hours a day of personal care/behavioural support for a senior and five hours a day for an adult with a disability</td>
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<td></td>
<td>• Up to 1 hour a day for meal preparation and 2 hours a week for homemaking when a caregiver does not reside with the client; and up to 2 hours a week of homemaking when the caregiver resides with the client and there is additional homemaking requirements</td>
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<tr>
<td></td>
<td>• Respite services for caregivers living with someone who needs 24-hour care/supervision</td>
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<tr>
<td>Nunavut</td>
<td>5 hours per week for homemaking services and 2 hours per day for personal care services (e.g., bathing, dressing)</td>
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<tr>
<td>Northwest Territories</td>
<td>4 hours per month for housekeeping services</td>
</tr>
<tr>
<td>Yukon</td>
<td>35 hours per week for services such as homemaking, personal care and respite care</td>
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C. DEVELOPMENT SESSION

The Expert Panel held a “Development Session” on January 31, 2017, which was attended by 118 participants with experience receiving or providing home and community care from a variety of sectors (e.g., primary care, geriatrics), roles (e.g., personal support workers, family physicians, physical therapists, care coordinators, nurses, patients, and family caregivers), and varied lived experiences, cultural or linguistic identities, and needs.

As preparation for the meeting, participants received the ministry’s Levels of Care Discussion Paper and Reporting Back On What We Heard, as well as narrative stories or vignettes that described home and community care clients with functional needs. The vignettes were developed by a small team that the Expert Panel had assembled to assist with consultation activities, and had been previously reviewed and refined by a focus group of care coordinators from across the Greater Toronto area.

At the Development Session, the Expert Panel presented a draft framework that consisted of six levels of care reflecting client need, with increasing requirements for personal support, care coordination, community support, equipment and supplies, and caregiver support. Participants were divided into small groups, and tasked with reviewing the vignettes to ensure that they could adequately describe the kinds of individuals and their needs who would be in each of the levels, and to revise them in order to complete that task.

During the Development Session, the Expert Panel also received advice related to the overall framework. The advice and suggestions for revisions was distilled into nine themes:

1. Integrate care across the health care continuum
2. Standardize access to care across Ontario
3. Suggestions for interRAI scales and algorithms that could be used for assessment (e.g., the use of the IADL-ADL Functional Hierarchy Scale, Method of Assigning Priority Levels (MAPLe), Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS), and the Personal Support Algorithm)
4. Focus on client goals and preferences, and incorporate that into the vignettes
5. Importance of preventative and holistic approaches
6. Build-in flexibility to move between the levels of care
7. Consider caregiver/family needs and assessment
8. Construct vignettes to reflect diversity
9. Consider mental health, addictions, and cognitive issues

The Expert Panel used participants’ advice to inform the levels of care framework, and this report.