



## 7. Care for select conditions

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## Key messages for citizens

- Care for people with mental health or substance use problems is delivered in many types of places (e.g., community mental health and addictions organizations and hospitals specializing in mental health and addictions) and by many types of health professionals (e.g., psychologists and social workers).
- Care for people with work-related injuries and diseases often takes place in familiar healthcare settings (e.g., physician offices and hospital clinics), but is financed by employers (directly or through premiums), with eligibility for funding determined by the Workplace Safety and Insurance Board.
- Cancer care – from diagnosis to treatment and follow-up – occurs primarily in hospital-linked regional cancer centres.
- End-of-life care takes place in a wide variety of places (e.g., home, hospices, hospitals and long-term care homes) and regional palliative care networks are starting to bring more consistency to what patients, families and caregivers can expect with such care.

## Key messages for professionals

- A range of programs – from information and advice (e.g., Connex-Ontario) and community services (e.g., counselling and therapy services) to hospital-sponsored programs, and outreach programs – are available to individuals facing mental health or substance use problems.
- Eligible workers with work-related injury and disease have their care paid for by the Workplace Safety and Insurance Board according to its own fee schedule.
- Regional cancer centres act as local hubs for the diagnosis and treatment of cancer while Cancer Care Ontario supports province-wide programs (e.g., breast cancer screening) and linkages to primary care and other parts of the health system.
- The Ontario Palliative Care Network and regional palliative care networks, as well as many resources (e.g., Learning Essential Approaches to Palliative Care) and supports (e.g., specialist palliative care teams), are available to professionals engaged in palliative care.

## Key messages for policymakers

- Many government ministries (e.g., health and long-term care, children and youth services, education, and correctional services) and stakeholders are involved in operationalizing and implementing the province's 2011 strategy for transforming mental health and addictions care.
- The Workplace Safety and Insurance Board, which is financed by employers and governed by the Ministry of Labour, coordinates and pays for care for work-related injury and disease.
- Cancer care takes place in an almost fully parallel sub-system to the rest of Ontario's health system, with Cancer Care Ontario, an arm's-length agency, overseeing and funding cancer care in 14 regional cancer programs.
- Key 'pieces' of end-of-life care are in place – nursing and personal support workers providing palliative home care services, primary-care providers delivering palliative care with the support of specialist palliative care teams, and interprofessional palliative care teams providing care in residential hospices, palliative care units, and hospitals – but without any consistency in what can be expected from one community or region to the next.

...

In the second of four chapters focused on using the building blocks to provide care, we examine care for select conditions. We consider four conditions or groupings of conditions that are handled in unique ways in the health system, namely mental health and addictions, work-related injuries and diseases, cancer, and end of life. As with care by sector (the focus of the previous chapter), care for select conditions can be described in two ways: 1) by the policies that govern care, the programs and service provided as part of that care, the places where care is provided, and the people who provide the care (i.e., by the 4Ps); and 2) by the governance, financial and delivery arrangements within which care is provided (i.e., the building blocks). We again focus primarily on the former and secondarily on the latter.

Before describing care for these select conditions, however, some background is necessary. First, the assertion that care for these conditions is handled in unique ways requires some justification, if only briefly. Care for

people with mental health or substance use problems is delivered in many types of places (e.g., community mental health and addictions organizations and hospitals specializing in mental health and addictions) and by many types of health professionals (e.g., psychologists and social workers), some of which are rarely accessed by those not living with such problems. Care for people with work-related injuries and diseases is typically governed by the Ministry of Labour and funded by the Workplace Safety and Insurance Board (WSIB), not by the Ministry of Health and Long-Term Care. And while there are features shared with care for automobile accident-related injuries, care for people with work-related injuries and diseases has more unique attributes. Cancer care takes place in a sub-system almost fully parallel to the rest of Ontario's health system, with an arm's-length government agency – Cancer Care Ontario (CCO) – playing a unique role in many key governance, financial and delivery arrangements. End-of-life care – or the palliative care of which it is a part – is unique in how it cuts across sectors. As yet, however, end-of-life care lacks the coordination and integration that are the goals for what are arguably the sub-systems of care for those living with mental health or substance use problems, work-related injury and disease, or cancer.

Second, the points of intersection with the six sectors described in the previous chapter need to be acknowledged. People facing challenges related to mental health or addictions, for example, may live in supportive housing (and receive an array of assisted services as part of home and community care), rely on a primary-care team for comprehensive and continuous care, and be admitted to an acute-care hospital for reasons related to their physical and/or mental health. People who are living with a work-related injury or disease or who are no longer receiving cancer care (with the latter's situation sometimes called 'survivorship in the community') do not stop needing care for other conditions. In addition, end-of-life care and palliative care more generally draw significantly on home and community care as well as primary care, may draw on significant specialty input, and may take place in acute specialty care settings plus in long-term care homes.

In the past decade or two, cancer care has been alone in being singled out for significant attention (in no small part because of concerns about wait times and quality in cancer care in the early 2000s), but this is starting to change. Both mental health and addictions and palliative care are increasingly being moved to centre stage. We will address these two groupings

of conditions next and last in this chapter, respectively. In Chapter 10 we describe the reforms that led to how care for these four conditions is currently supported, and in Chapter 11 we discuss what has been learned about whether these reforms and our current approach to care are improving the patient experience and population health while keeping the amount spent per person manageable.

## Mental health and addictions

The boundaries of the mental health and addictions field can be difficult to define. While children and youth may exhibit concerning behaviours and face significant challenges but not have a formal diagnosis of mental illness, they may still be cared for by mental health and addictions professionals (and as such are considered in scope for this chapter). On the other hand, adults with Alzheimer's disease may share certain signs or symptoms with those experiencing mental illness or addiction, but are often cared for by family physicians, geriatricians or neurologists instead of mental health and addictions professionals (and are considered out of scope for this chapter). Moreover, many behaviours (e.g., gambling) and substances (e.g., alcohol, tobacco and prescription opioids) may be legal, but can lead to impairment and distress (e.g., problem gambling and alcohol, tobacco or substance use disorder) and hence be treated as addictions by mental health and addictions professionals. The full range of substance use problems and addictions are considered in scope for this chapter. We use the phrase 'mental health or substance use problems' to capture challenges that have not necessarily resulted in a formal diagnosis of mental illness or addiction (and, for lack of an inclusive short term, we include in 'substance use problems' challenges such as problem gambling, even though they involve behaviours, not substances).

The key players in care for mental health and addictions have shifted dramatically over the last few decades and depend on whether the focus is adults (18 years of age or older) or children and youth, and whether the focus is the general population and those at risk of mental health and or substance use problems (for whom efforts to reduce stigma or screen for depression or anxiety may be appropriate), those with mild to moderate mental health or substance use problems, or those with severe and persistent mental illness or addiction. For adults with severe and persistent

mental illness or addiction, community mental health and addictions organizations (e.g., local branches of the Canadian Mental Health Association – Ontario Division and community agencies represented by Addictions and Mental Health Ontario), and hospitals specializing in mental health and addictions, could be said to be the key players. For children and youth exhibiting concerning behaviours, lead agencies are now available in each region to provide a ‘way in’ to the children- and youth-focused community mental health organizations (which are represented by Children’s Mental Health Ontario) and hospital-based services. It is much more difficult to identify key players for adults with mild to moderate mental health or substance use problems, although we return below to the many places where care for such adults can be accessed.

## Policies that govern care for mental health and addictions

The key policies that govern care for mental health and addictions are (Figure 7.1):

- 1) the *Mental Health Act, 1990*, which established rules for involuntary admissions to psychiatric facilities;
- 2) the *Homes for Special Care Act, 1990*, which established requirements for the housing and support services provided to people with serious mental illness as a ‘non-institutional’ (i.e., community living) alternative to care in what were then commonly called psychiatric facilities;
- 3) the *Substitute Decisions Act, 1992*, which established provisions for the naming of powers of attorney and statutory guardians for those found to be mentally incapable of personal care or managing property;
- 4) the *Health Care Consent Act, 1996*, which established rules with respect to consent to treatment (and situations of emergency treatment), admission to a care facility (including crisis admissions) and receipt of personal assistance services, rules for when a person lacks the capacity to make decisions about such matters, and rules for such a person to contest a decision made for them to an independent provincial tribunal (Consent and Capacity Board);<sup>(1)</sup> and
- 5) *Bill 168, Brian’s Law (Mental Health Legislative Reform), 2000*, which modified assessment and committal criteria for seriously mentally ill people to enable earlier intervention by their families and health professionals, and to enable their treatment in the community rather than in a psychiatric facility.

As well, select policies attempt to prevent addictions, such as the *Smoke-Free*

Many policies that govern care in the broader health system also apply to mental health and addictions, such as the:

- 1) *Regulated Health Professions Act, 1991*, which provided the legislative framework for the self-governance of the many regulated health professions providing care for mental health and addictions (e.g., registered nurses, physicians, psychologists and social workers);
- 2) *Public Hospitals Act, 1990*, which governs the private not-for-profit hospitals where those with mental illness or addiction may be treated; and
- 3) *Local Health Systems Integration Act, 2006*, which established Local Health Integration Networks (LHINs) to plan, fund and integrate care, including the care delivered by community mental health and addictions organizations and by hospitals providing care for mental health and addictions (with the funding provided under the terms of multi-sectoral accountability agreements or hospital service accountability agreements, respectively).

The College of Physicians and Surgeons of Ontario, whose role is defined by the first of these three policies, addresses issues such as the appropriate prescribing of opioids.(3)

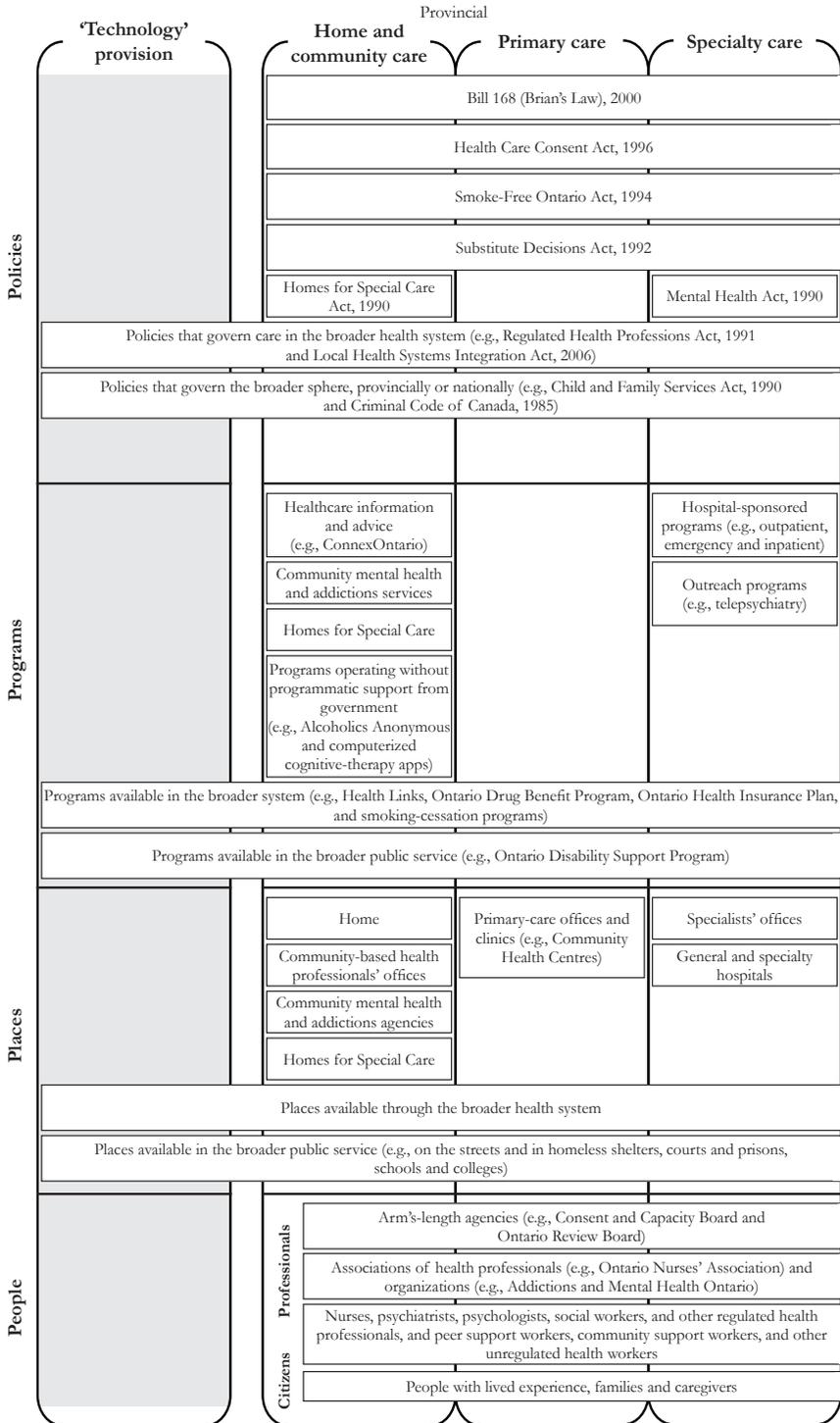
Policies that govern the broader public sphere – provincially or nationally – can also be highly relevant to mental health and addictions. Examples of provincial policies include the:

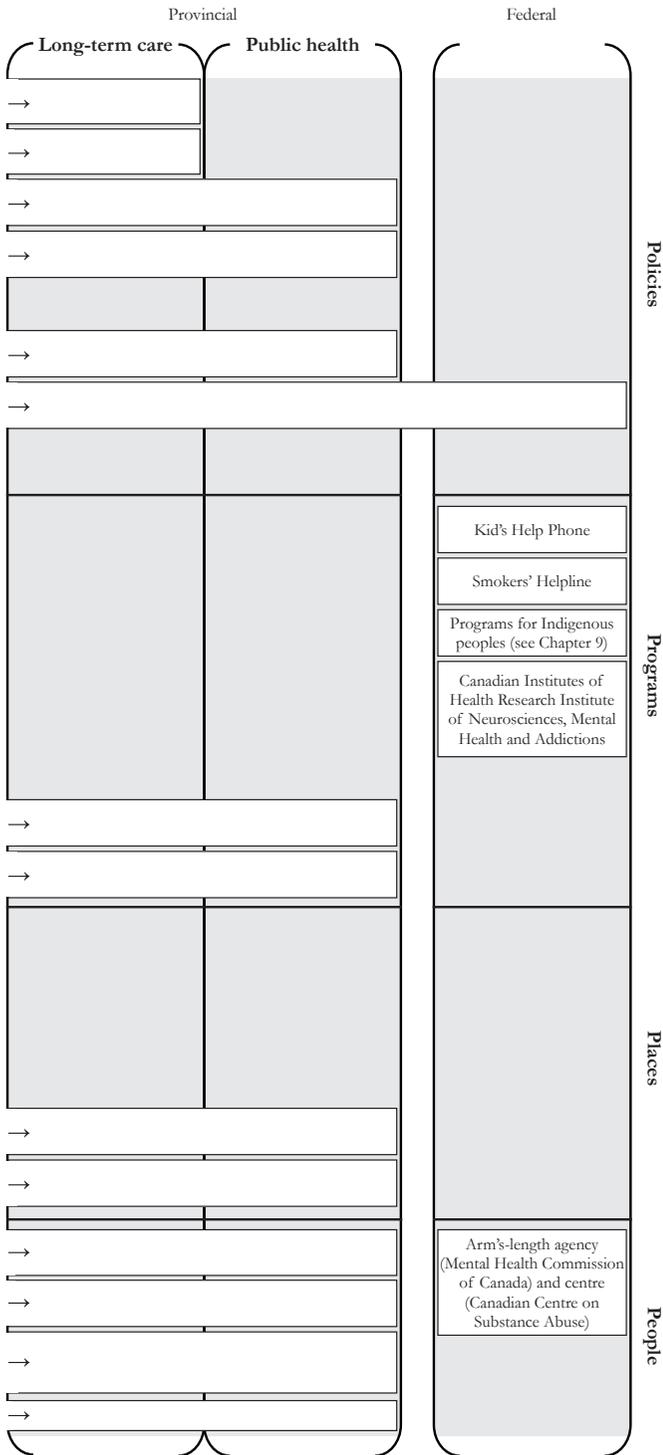
- 1) *Child and Family Services Act, 1990*.(4) which established the terms under which services can be provided to children and youth from birth to 18 years of age (including those exhibiting concerning behaviours and facing significant challenges with or without a formal diagnosis of mental illness);
- 2) *Ontario Disability Support Program Act, 1997*, which established the terms under which people living with mental illness or addiction may receive social assistance; and
- 3) *Liquor License Act, 1990*.(5) which established terms for the sale and possession of alcohol.

Examples of federal policies include the:

- 1) *Criminal Code of Canada, 1985*.(6) which established rules for finding a person to be not criminally responsible or unfit to stand trial for

Figure 7.1: Mental health and addictions care





criminal offences on account of a serious mental illness, as well as the independent provincial tribunal (Ontario Review Board) that annually reviews the status of such persons;(7) and

- 2) *Controlled Drugs and Substances Act, 1996*,(8) and amendments to it (such as Bill C-2, 2015),(9) which make it difficult to offer supervised injection services as a harm-reduction strategy for those living with addiction.

## Programs constituting care for mental health and addictions

Care for mental health and addictions – particularly publicly funded programs and how they are accessed – is in a transformative period, with the strategy for going forward articulated in ‘Open Minds, Healthy Minds: Ontario’s Comprehensive Mental Health and Addictions Strategy’ (released in 2011 with an initial focus on children and youth, and expanded in 2014 to include adults).(10) The action plan for care for children and youth is documented in a 2012 report entitled ‘Moving on Mental Health: A System that Makes Sense for Children and Youth’ (11) and significant progress has already been made in creating and supporting pathways to care, defining core services to be available in communities across the province, establishing (as noted above) a lead agency that can serve as a ‘way in’ to the full range of available services in each defined geographical area (much like Community Care Access Centres or CCACs do for home and community care and for long-term care), creating a new funding model for these agencies, and building a legal framework for these agencies.(12; 13) Similar work for adults, such as defining core services, is now being undertaken by the Mental Health and Addictions Leadership Advisory Council, which is a time-limited (three-year) body created by the Government of Ontario in 2014 to advise the Minister of Health and Long-Term Care on the implementation of Ontario’s mental health and addictions strategy. (14)

A wide range of programs are available in the mental health and addictions sub-system (Figure 7.1):

- 1) healthcare information and advice, including telephone helplines specific to mental health, drug and alcohol, and problem gambling concerns (ConnexOntario), and for healthcare in general (Telehealth Ontario), and an online tool that can be used to locate healthcare services, including mental health services for children and youth (Health

- Care Options);(15; 16)
- 2) children and youth mental health services, which include targeted prevention, brief services, counselling and therapy services, family/ caregiver skill building and support, specialized consultation and assessment, crisis support services, intensive treatment services, and secure treatment;(17)
  - 3) community mental health and addictions services for adults, which can range from mental health promotion (e.g., stigma reduction), mental illness and substance abuse problem prevention (e.g., needle-exchange and other harm-reduction services) and early identification and information/referral (e.g., client-navigation services) to peer support (e.g., people with lived experience as part of team-based care), counselling and therapy services, psycho-social intervention (e.g., case management and family intervention), intensive treatment (e.g., assertive community treatment and intensive case management), and crisis services (e.g., mobile crisis response), as well as social determinants support services (e.g., supportive housing);(14; 18; 19)
  - 4) Homes for Special Care, which provide long-term and permanent residential care for people with severe and persistent mental illness who require supervision or need assistance with activities of daily living;(20)
  - 5) hospital-sponsored programs, which provide care on an outpatient, day treatment, emergency and inpatient basis, consultative and educational support to community-based agencies and providers,(21) and a range of specialized services (including justice-related services, like forensic services) that are typically for adults with severe and persistent mental illness or addiction;(22-25) and
  - 6) outreach programs to provide – at a distance – clinical and support services to adults, children and youth, healthcare providers and organizations in rural, remote and underserved communities (Ontario Psychiatric Outreach Program, which is provided by six university psychiatry programs, and Ontario Child and Youth Tele-Psychiatry Program, which is provided by the Child and Parent Resource Institute and several partners in southwestern Ontario, the Hospital for Sick Children for central Ontario, and the Children’s Hospital of Eastern Ontario for southeastern Ontario).(26; 27)

While clarity is currently lacking in what the core services should look like for adults living with different levels of complexity in their mental health or substance use needs, this issue is a current focus for the Mental Health and Addictions Leadership Advisory Council, as are complementary issues

like better integration in services, improved transition across services, and more robust performance measurement.(14; 28)

Some programs in the sub-system are volunteer-driven (e.g., Alcoholics Anonymous, Gamblers Anonymous, and Narcotics Anonymous, as well as Al-Anon Family Groups for friends and families of problem drinkers) or more generally operate without programmatic support from government (e.g., self-help support, such as computerized cognitive-therapy apps, and the workplace supports and awareness-raising initiatives funded by many companies). Many programs can be accessed by self-referral and are free of charge. Several system-wide programs also play key roles, including Health Links (which targets clients with complex needs, including mental health or substance use problems), the Ontario Drug Benefit (ODB) Program (which covers the cost of drugs for eligible individuals), the Ontario Health Insurance Plan (OHIP, which remunerates both family physicians and psychiatrists providing care for people at risk of, or living with, mental health or substance use problems), and smoking-cessation programs. Programs are also available in the broader public service that can support those living with mental illness or addiction (e.g., Ontario Disability Support Program).

Programs in the mental health and addictions sub-system are often supported by the capacity building, policy advocacy and other activities of the Mental Health Commission of Canada, which developed and implements Canada's first mental health strategy with provincial partners,(29) and the Canadian Centre on Substance Abuse.(30) For children and youth, the programs are complemented by the Kid's Help Phone,(31) which is operated by an independent national organization. For smokers, the programs are complemented by the Smoker's Helpline, which is operated by the Canadian Cancer Society.(32) For Indigenous peoples, the programs are also complemented by federal government programs (see Chapter 9).

## Places and people involved in care for mental health and addictions

The places where care for mental health or substance use problems is provided include a person's home (e.g., where they may access telephone helplines, self-help apps, telepsychiatry, and supportive housing), the offices of community-based health professionals (e.g., psychologists and social workers), community mental health and addictions agencies, Homes for Special Care, primary-care offices and clinics (including Community

Health Centres), specialists' (e.g., psychiatrists and psychologists) offices, and general and specialty hospitals (outpatient clinics, emergency rooms, and inpatient wards), as well as in a variety of other settings where people at risk of, or living with, mental health or substance use problems can be found (e.g., on the streets and in homeless shelters, in courts and prisons, and in schools and colleges) (Figure 7.1).

The people involved in care for mental health and substance use problems include those living with mental health or substance use problems themselves (who are often referred to as people with lived experience) and their families and caregivers (who may be supported by organizations such as the Mood Disorders Association of Ontario, the Schizophrenia Society of Ontario, and Parents for Children's Mental Health, among others), as well as a broad range of regulated health professionals (e.g., nurses, psychiatrists, psychologists and social workers) and unregulated health workers (e.g., peer support workers and community support workers). People with lived experience increasingly play formal roles in the governance and delivery of care for mental health or substance use problems. The health professionals are represented by their respective professional associations (e.g., Ontario Nurses' Association), and the agencies for which they work are represented by member associations such as Addictions and Mental Health Ontario.<sup>(24)</sup> Some citizens and professionals are members of arm's-length agencies like the Consent and Capacity Board and the Ontario Review Board (both described above),<sup>(33)</sup> as well as programs like the Ontario Centre of Excellence for Child and Youth Mental Health (at the Children's Hospital of Eastern Ontario), Provincial Systems Support Program (at the Centre for Addictions and Mental Health), and Gambling Research Exchange Ontario (which support evidence-informed practice and policy in their respective areas of focus).<sup>(34; 35)</sup>

## **Governance, financial and delivery arrangements in care for mental health and addictions**

Governance, financial and delivery arrangements (i.e., the building blocks) are another lens through which mental health and addictions can be described. The governance arrangements that are particularly salient to the sub-system have been addressed under 'policies' above. One key financial arrangement for mental health and addictions care is the funding provided by the Ministry of Children and Youth Services and the Ministry

of Education (for children and youth) and the Ministry of Health and Long-Term Care (for adults), with the latter providing funding directly (e.g., for ConnexOntario and Homes for Special Care), through LHINs (e.g., for community mental health and addictions agencies and hospitals) or through system-wide programs (e.g. OHIP and Underserved Areas Program).(28) Proportionately smaller contributions are made by other government ministries (e.g., advanced education and skills development, attorney general, community and social services, community safety and correctional services, and municipal affairs and housing). The second key financial arrangement is the mix of out-of-pocket payments (e.g., for psychologists and social workers in private practice) and payments by private insurance plans, employee-assistance programs, and other sources, although many services – particularly those for people with severe and persistent mental illness and addiction – have no fees.(28)

In terms of delivery arrangements for adults needing care for mental health or substance use problems, as of 2015 there were more than 300 community-based mental health and addictions agencies (36) and 71 hospitals with a psychiatric-facility designation under the *Mental Health Act, 1990*, of which four – Centre for Addiction and Mental Health (Toronto), Ontario Shores Centre for Mental Health Sciences (Whitby), the Royal Ottawa Mental Health Centre (Ottawa), and the Waypoint Centre for Mental Health (Penetanguishene) – are specialty hospitals.(21) Care for children and youth can be accessed through lead agencies in 31 service areas across the province, and is provided in over 260 mental health and addictions agencies (including 90 accredited children’s mental health centres), 17 hospital-based (outpatient) children’s mental health programs, and one child and youth mental health facility (Parent Resource Institute, which is located in London).(37)

## Work-related injuries and diseases

Care for people with work-related injuries and diseases was deemed by government to be a collective responsibility in 1914 – long before the same was done for other types of care.(38) The idea is that employers, through a compulsory no-fault liability insurance scheme, should bear the costs when an injury or disease was clearly work-related, such as a severed limb or broken back among those working in construction, or mesothelioma

(a cancer of the lining of the lungs or abdomen) among those working in an asbestos mine. Workers could reasonably argue that they bear these costs collectively given the costs effectively represent part of their total compensation package. The costs include income replacement (i.e., regular payments to partially offset lost earnings) or survivor benefits (in the case of work-related fatalities) and healthcare, as well as industry-specific health and safety information for employers, help and support for workers to return to work, and regulatory enforcement by the Ministry of Labour. A broadly analogous scheme has been put in place for automobile injuries, although here the costs are assumed by drivers with automobile insurance.

The key player for work-related injuries and diseases is the WSIB, which was called the Workers' Compensation Board until 1998. The WSIB operates under government legislation, is fully financed by employers and earned investment income (although legislation mandates that it will be fully financed only by employers by 2027), and governed by an independent board of directors (representing employers, workers and others).(39) At one time the WSIB played a fairly passive role as the payer of bills submitted by providers (e.g., physicians) and organizations (e.g., hospitals) providing care to eligible workers, but more recently it has played a more active role in commissioning care to achieve better health and return-to-work outcomes (and a network of providers and organizations has evolved to meet this demand).

Four key features of the WSIB sub-system warrant mention as context to what follows: 1) a determination of work-relatedness is key to coverage and hence can be contentious; 2) the historical focus on physical injuries has left a legacy of unevenness in attention to mental health; 3) the long latencies and multifactorial nature of most work-related diseases has left a legacy of unevenness in coverage of such diseases; and 4) incentives for under-reporting work-related injuries and diseases means that many costs can be covered by the publicly funded health system that is the focus of the rest of the book. One other point worth noting is that the URLs for WSIB webpages can be many lines long, so to save space we have opted to provide in the reference list the URL for the WSIB home page rather than for the specific webpage we are referencing.

## Policies that govern care for work-related injuries and diseases

The key policies that govern care for work-related injuries and diseases are the:

- 1) *Occupational Health and Safety Act, 1990*,(40) which established the contemporary standards for making workplaces safe and healthy (thereby preventing work-related injury and disease), including the rights and duties of all parties in the workplace, procedures for dealing with workplace hazards, and enforcement mechanisms; and
- 2) *Workplace Safety and Insurance Act, 1997*,(41) which set the terms for the no-fault liability insurance scheme (including the role of the WSIB and the independent agencies – Office of the Employer Advisor, Office of the Worker Advisor, and Workplace Safety and Insurance Appeals Tribunal – that complement the WSIB) and established the industries that are exempt (e.g., banks, insurance companies, law firms, real estate agencies, private schools, and health clubs), the two types of participating employers (i.e., schedule 1 employers that contribute to and are covered under the collective liability scheme and schedule 2 employers that self-insure the benefit-compensation and administration costs incurred by the WSIB), how benefits are determined, how the experience-rated premiums are calculated for employers, and the WSIB's service-delivery model.

Roughly three quarters of the workforce is covered by the WSIB, either through schedule 1 or schedule 2 employers (Table 7.1).

## Programs constituting care for work-related injuries and diseases

Six categories of programs are relevant to care for work-related injuries and diseases (Figure 7.2):

- 1) WSIB services that form a part of the WSIB's service-delivery model,(42) which aims – first and foremost – to reduce the duration of claims and which includes nurse consultants (who make decisions about healthcare entitlement) and medical consultants (who interact with the worker's physician and conduct case file reviews), as well as a number of:
  - a. unregulated workers such as registration clerks (who process the initial form 6 from workers, form 7 from employers, and form 8 from health professionals), primary adjudicators (who ensure that there is a worker, an employer, proof of accident,

Table 7.1: Workplace Safety and Insurance Board coverage and claims for schedule 1 and 2 employers, 2004, 2010 and 2014

| Coverage and claims   | 2004 <sup>1</sup> | 2010      | 2014      | 10-year percentage change |
|---|-------------------|-----------|-----------|---------------------------|
| <b>Schedule 1</b>   |                   |           |           |                           |
| Number of employers   | 217,693           | 250,536   | 299,339   | 38%                       |
| % workforce covered   | 64%               | 61%       | 64%       | 1%                        |
| Workplace Safety and Insurance Board (WSIB)-covered employees | 4,022,010         | 4,009,201 | 4,431,674 | 10%                       |
| Registered claims   | 308,865           | 198,617   | 195,495   | -37%                      |
| Lost time claims by gender                                    |                   |           |           |                           |
| Female  | 26,012            | 17,967    | 15,321    | -41%                      |
| Male  | 49,466            | 28,137    | 25,237    | -49%                      |
| <b>Schedule 2</b>   |                   |           |           |                           |
| Number of employers   | 630               | 611       | 600       | -5%                       |
| % workforce covered   | 9%                | 11%       | 10%       | 10%                       |
| WSIB-covered employees  | 577,816           | 702,383   | 690,942   | 20%                       |
| Registered claims   | 42,479            | 39,781    | 38,150    | -10%                      |
| Lost time claims by gender                                    |                   |           |           |                           |
| Female  | 6,577             | 7,015     | 6,648     | 1%                        |
| Male  | 8,577             | 7,019     | 6,454     | -25%                      |

Source: Adapted from: 87; 88

Note:

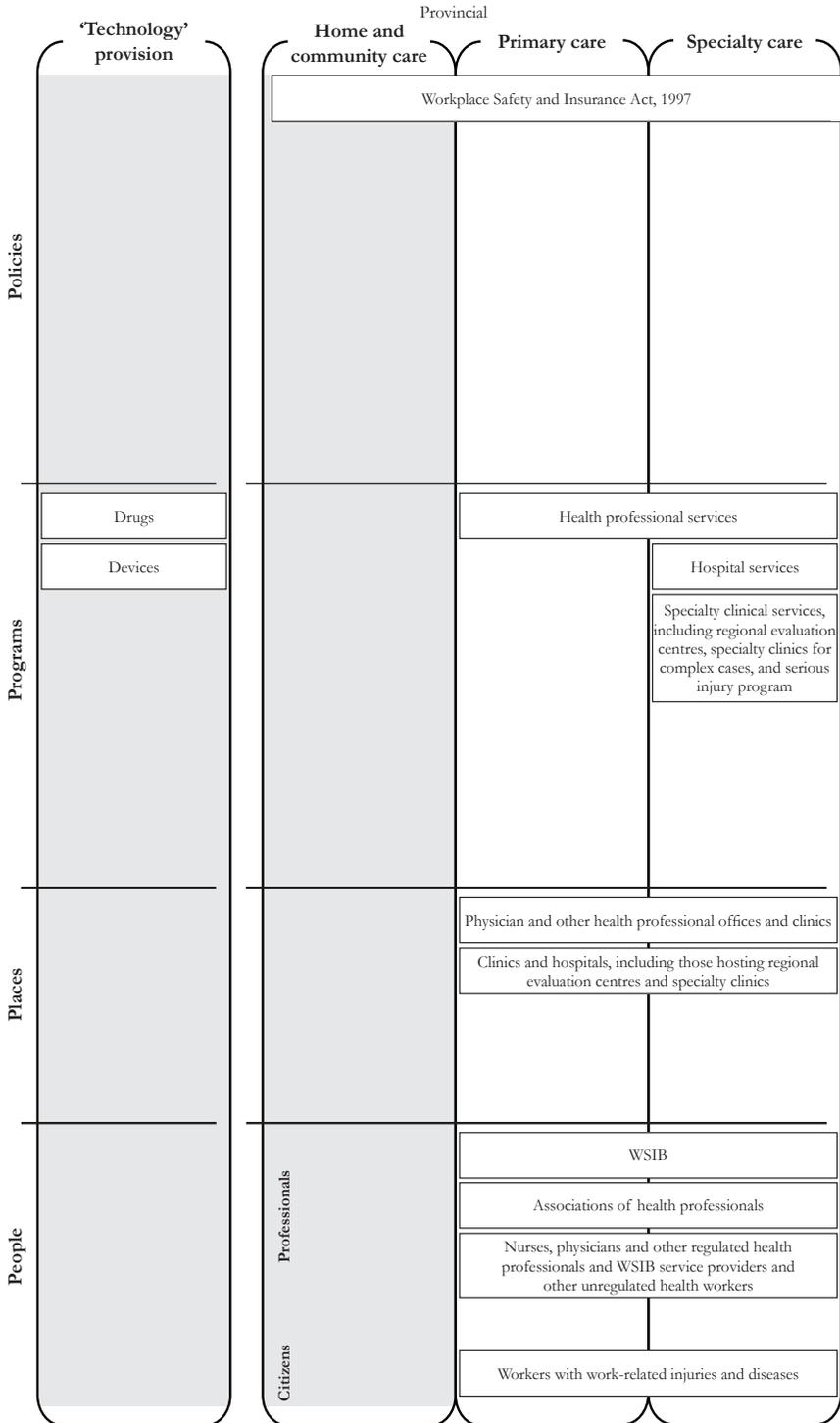
<sup>1</sup> Data for the baseline year of 2000 used elsewhere in the book were unavailable.

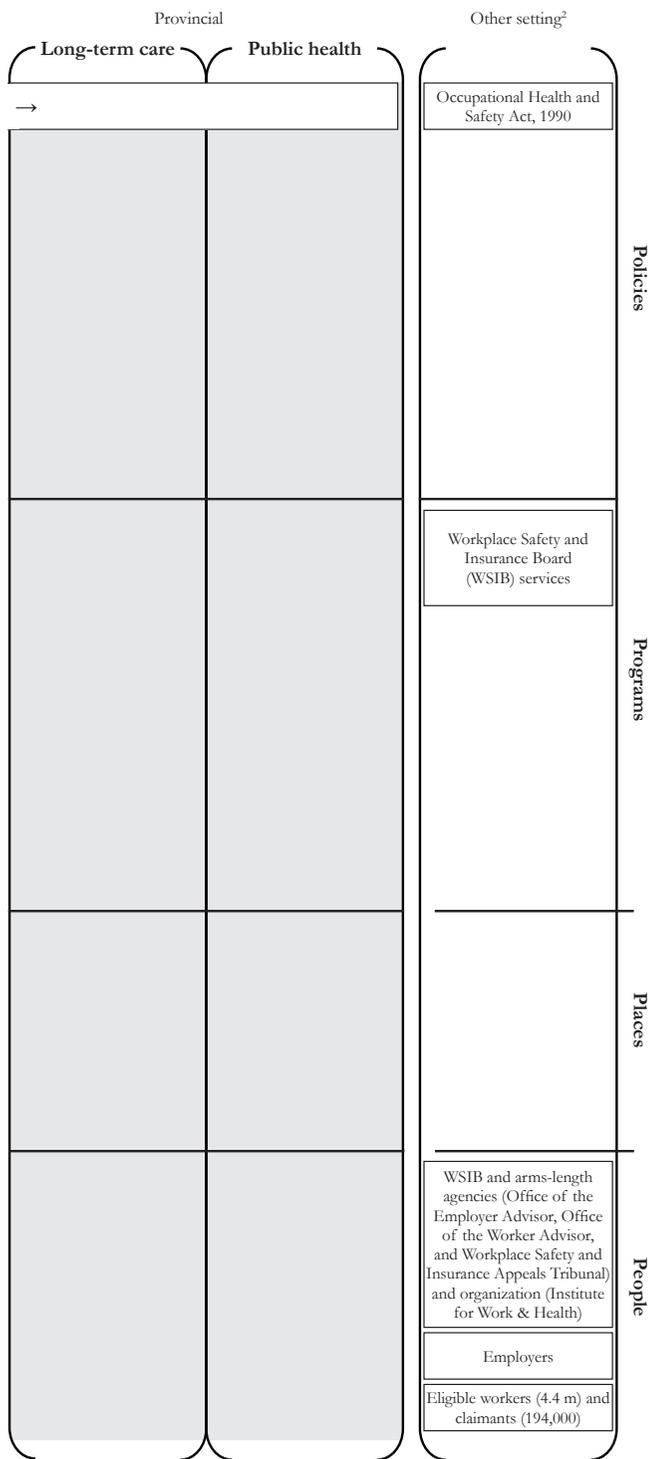
personal work-related injury, and compatibility of the diagnosis to the accident or disablement history, and hence an initial entitlement to WSIB benefits), eligibility adjudicators (who adjudicate more complex claims, alone or with the support of a nurse consultant), case managers (who assist with work re-integration, recurrences, etc.), return-to-work specialists (who act as facilitators), work-transition specialists (who provide support when the worker has not returned to suitable, available work), and employer liaison specialists (who share best practices), and

b. dedicated teams (e.g., case-management re-employment team, recurrence and work-disruption team, second-injury and enhancement fund team, mental health team, and appeals team);(43)

2) health professional services and programs, which include physician services paid via the Ministry of Health and Long-Term Care (which

Figure 7.2: Care for work-related injuries and diseases





Note:

<sup>1</sup> Unlike similar figures elsewhere in the book, the heading for the final column has been changed from 'Federal (government)' to 'Other setting' so that we could capture the workplaces, etc., that are central to this domain.

processes the service claims on behalf of the WSIB, which ultimately pays them), services delivered by physiotherapists, chiropractors and other select non-physician providers, and specialized clinical services and programs;

- 3) hospital services, which include both outpatient and inpatient care;
- 4) drugs, which includes prescription drugs listed on a drug formulary;
- 5) devices (e.g., hearing aids and medical devices); and
- 6) travel, accommodations and other healthcare-related allowances.

Healthcare constitutes the third-largest category of benefit payment, after income replacement for lost earnings and workers' pensions (Table 7.2).

Table 7.2: Workplace Safety and Insurance Board benefit payments by benefit category, 2010 and 2014

| Benefit category       | 2010 <sup>1</sup><br>payments<br>(\$ millions) | 2014<br>payments<br>(\$ millions) | Four-year<br>percentage<br>change |
|------------------------|--|-----------------------------------|-----------------------------------|
| <b>Schedule 1</b>      |  |                                   |                                   |
| Total benefit payments | 3,067  | 2,420                             | -21%                              |
| Loss of earnings       | 1,117  | 863                               | -23%                              |
| Workers' pension       | 701  | 596                               | -15%                              |
| Healthcare             | 497  | 452                               | -9%                               |
| Future economic loss   | 292  | 230                               | -21%                              |
| Survivor benefits      | 178  | 184                               | 3%                                |
| External providers     | 151  | 44                                | -71%                              |
| Non-economic loss      | 126  | 48                                | -62%                              |
| Other                  | 5  | 3                                 | -40%                              |
| <b>Schedule 2</b>      |  |                                   |                                   |
| Total benefit payments | 300  | 240                               | -20%                              |
| Loss of earnings       | 110  | 86                                | -22%                              |
| Workers' pension       | 61   | 52                                | -15%                              |
| Healthcare             | 65   | 59                                | -9%                               |
| Future economic loss   | 20   | 14                                | -30%                              |
| Survivor benefits      | 21   | 18                                | -14%                              |
| External providers     | 5  | 2                                 | -60%                              |
| Non-economic loss      | 16   | 6                                 | -63%                              |
| Other                  | 2  | 3                                 | 50%                               |

Source: Adapted from: 87; 88

Note:

<sup>1</sup>Data for the baseline year of 2000 used elsewhere in the book were unavailable.

Specialized clinical services, which are the largest expenditure category of healthcare benefit payments (Table 7.3), include an array of purportedly

**Table 7.3: Workplace Safety and Insurance Board healthcare benefit payments by healthcare service category, 2012 and 2014**

| Healthcare service category   | 2012 <sup>1</sup><br>(\$ thousands) | 2014<br>(\$ thousands) | Two-year<br>percentage<br>change |
|---|-------------------------------------|------------------------|----------------------------------|
| <b>Schedule 1</b>   |                                     |                        |                                  |
| Total healthcare benefits   | 457,494                             | 452,246                | -1%                              |
| Specialized clinical services and programs                              | 83,229                              | 93,025                 | 12%                              |
| Drug benefits   | 71,129                              | 61,883                 | -13%                             |
| Allowances (clothing, independent living, personal care)                | 30,706                              | 53,951                 | 76%                              |
| Hospital in/outpatient  | 36,587                              | 38,596                 | 5%                               |
| Physician services via Ministry of Health and Long-Term Care            | 39,503                              | 37,285                 | -6%                              |
| Hearing aid devices and services  | 28,860                              | 37,131                 | 29%                              |
| Reports and information   | 25,084                              | 24,841                 | -1%                              |
| Travel and accommodations   | 24,176                              | 23,700                 | -2%                              |
| Physiotherapy, chiropractic, and other select (non-physician) providers | 55,670                              | 21,675                 | -61%                             |
| Medical devices   | 20,072                              | 20,557                 | 2%                               |
| Other   | 42,478                              | 39,062                 | -7%                              |
| <b>Schedule 2</b>   |                                     |                        |                                  |
| Total healthcare benefits   | 58,488                              | 58,593                 | 0%                               |
| Specialized clinical services and programs                              | 13,160                              | 15,243                 | 16%                              |
| Physiotherapy, chiropractic, and other select (non-physician) providers | 7,091                               | 5,367                  | -24%                             |
| Hearing aid devices and services  | 3,899                               | 5,083                  | 30%                              |
| Drug benefits   | 5,860                               | 5,015                  | -14%                             |
| Hospital in/outpatient  | 3,957                               | 4,925                  | 24%                              |
| Physician services via Ministry of Health and Long-Term Care            | 5,072                               | 4,717                  | -7%                              |
| Allowances (clothing, independent living, personal care)                | 4,749                               | 4,465                  | -6%                              |
| Reports and information   | 3,892                               | 3,903                  | 0%                               |
| Travel and accommodations   | 3,579                               | 3,403                  | -5%                              |
| Medical devices   | 2,316                               | 2,558                  | 9%                               |
| Other   | 4,913                               | 3,914                  | -20%                             |

Source: Adapted from: 87-90

Note:

<sup>1</sup> Data for the baseline year of 2000 used elsewhere in the book were unavailable.

evidence-based ‘programs of care’ that aim to achieve the best functional outcomes and include specific admission criteria, program duration, treatment interventions, and outcome measures. The programs address: 1) low-back injury; 2) shoulder injury; 3) musculoskeletal injury other than

those above; 4) noise-induced hearing loss; and 5) mild traumatic brain injury.(44) Health professionals delivering these programs must register to do so, agree to adhere to the relevant program reference guide, and consent to having their contact details made available through a searchable database on the WSIB website.(45)

Specialized clinical services also include:

- 1) regional evaluation centres (in 13 locations around the province), which provide assessments (including expedited migrant worker assessments) and make recommendations about early intervention to enhance functional recovery of, and support return to work by, workers with musculoskeletal injuries (to both the WSIB and the worker's primary health professional);(46)
- 2) specialty clinics for complex cases, which provide access to care through 11 programs – amputee, back and neck, burn, function and pain, lower extremity, mental health, neurology, occupational disease, substance management, surgical, and upper extremity – operating in 15 hospitals, as well as a time-limited demonstration project (early low-back assessment service);(47) and
- 3) serious injury program, which provides the specialized services and devices needed to maximize the recovery of function and quality of life for workers with a serious or permanent disability or with specific injuries (e.g., paraplegia, blindness, major amputation or burns).(48)

## Places and people involved in care for work-related injuries and diseases

Much of the care for work-related injuries and diseases is provided in the same physician (e.g., family physician) offices and other health professional (e.g., physiotherapy) clinics as the care provided to those whose injury or disease is not work related. Even the regional evaluation centres and specialty clinics are typically just dedicated units within clinics and hospitals that provide a much broader range of services. That said, because of the separate programs of care and payment mechanisms, some offices and clinics may focus exclusively on care for work-related injuries and diseases.

The people involved in care include two types of 'clients,' namely employers (for the liability-insurance scheme) and workers (for the income replacement and healthcare benefits), as well as the broad array of regulated health

professionals (both those working at the WSIB, like the nurse consultants making decisions about healthcare entitlement, and the medical consultants interacting with the worker's physician and conducting case file reviews, and those working in the offices, clinics and hospitals where care is being provided) and unregulated workers (like those listed above as contributors to the WSIB's service-delivery model). The health professionals are, as usual, represented by their respective professional associations (e.g., Ontario Nurses' Association). Some citizens and professionals are members of the board of the WSIB, the Office of the Employer Advisor (an independent agency of the Ministry of Labour that provides free advice about managing workplace safety and insurance costs), the Office of the Worker Advisor (a second independent agency of the Ministry of Labour, which in this case provides free advice, education and representation in workplace insurance matters and occupational health and safety reprisal issues), and the Workplace Safety and Insurance Appeals Tribunal (a third independent agency of the Ministry of Labour, which provides the final level of appeal to which workers and employers can bring disputes about workplace safety and insurance), as well as independent organizations like the Institute for Work & Health (which support evidence-informed practice and policy in this domain).(49-52)

### **Governance, financial and delivery arrangements in care for work-related injuries and diseases**

The governance arrangements that are particularly salient to care for work-related injuries and diseases have been addressed under 'policies' above. The key financial arrangements for this care are the employer premiums (i.e., the source of financing), the income replacement provided to workers, and the payments made to health professionals, pharmacies and device suppliers. As noted above, most physicians bill the Ministry of Health and Long-Term Care for both providing services and completing reports, according to a fee schedule set and reimbursed by the WSIB. Some physicians and all other health professionals (including pharmacists dispensing drugs) use an electronic-billing system administered by a third party (TELUS Health), but again according to a fee schedule set by the WSIB.(45) Four preferred providers of approved healthcare equipment and supplies bill the WSIB directly.(53) As alluded to above, the WSIB is a fairly unique organization in the health system in its use of a 'commissioning' model that pays for care that meets the performance standards

outlined in service agreements (and we return to another key example in the next section). In terms of delivery arrangements for workers needing care for work-related diseases and injuries, as noted above, there are the 'usual' components of the system's infrastructure, as well as 13 regional evaluation centres and 15 hospitals hosting specialty clinics.(46; 47)

## Cancer

As noted in the introduction, cancer care takes place in a sub-system that operates almost fully in parallel to the rest of Ontario's health system. For adults, some prevention and screening, most aspects of diagnosis, virtually all aspects of treatment, and most aspects of follow-up care are coordinated by those working in the cancer sub-system. The health system's traditional sectors play comparatively smaller roles: the home and community care and long-term care sectors play a role in supporting those receiving treatment while living at home or in long-term care homes; the primary-care sector plays a role in some individually targeted cancer-prevention and screening activities, and more and more often in follow-up care (with the latter occurring as cancer care leaders increasingly recognize that it is no longer sustainable for cancer survivors to be returning indefinitely to their clinics); and the public health sector plays a role in some population-based cancer-prevention activities. For children, diagnosis and follow-up care and most aspects of treatment take place primarily in children's hospitals, although they may receive radiation therapy in a regional cancer centre.

The key player for cancer care for adults is an arm's-length government agency – CCO – that is alone among provincial health agencies in the spectrum of governance, financial and delivery arrangements that it can alter to ensure that care is well planned and coordinated, and continually improved. Established in its current form in 1997, CCO's very existence, the span of control it has been given and the size of the budget it is allocated annually (roughly \$1.7 billion, of which roughly \$800 million is provided to hospitals and other cancer-care providers) have effectively singled out cancer in a way that has not been done for other conditions.(54) The reforms that created CCO are described in Chapter 10. CCO's executive team is supported by a Provincial Leadership Council (with regional representation), a Clinical Council (with representation from across the agency), and an arm's-length advisory body called the

Cancer Quality Council of Ontario (with ‘external’ professional, patient/family and expert representation). The Pediatric Oncology Group of Ontario acts as an arm’s-length advisory body for cancer care in children.

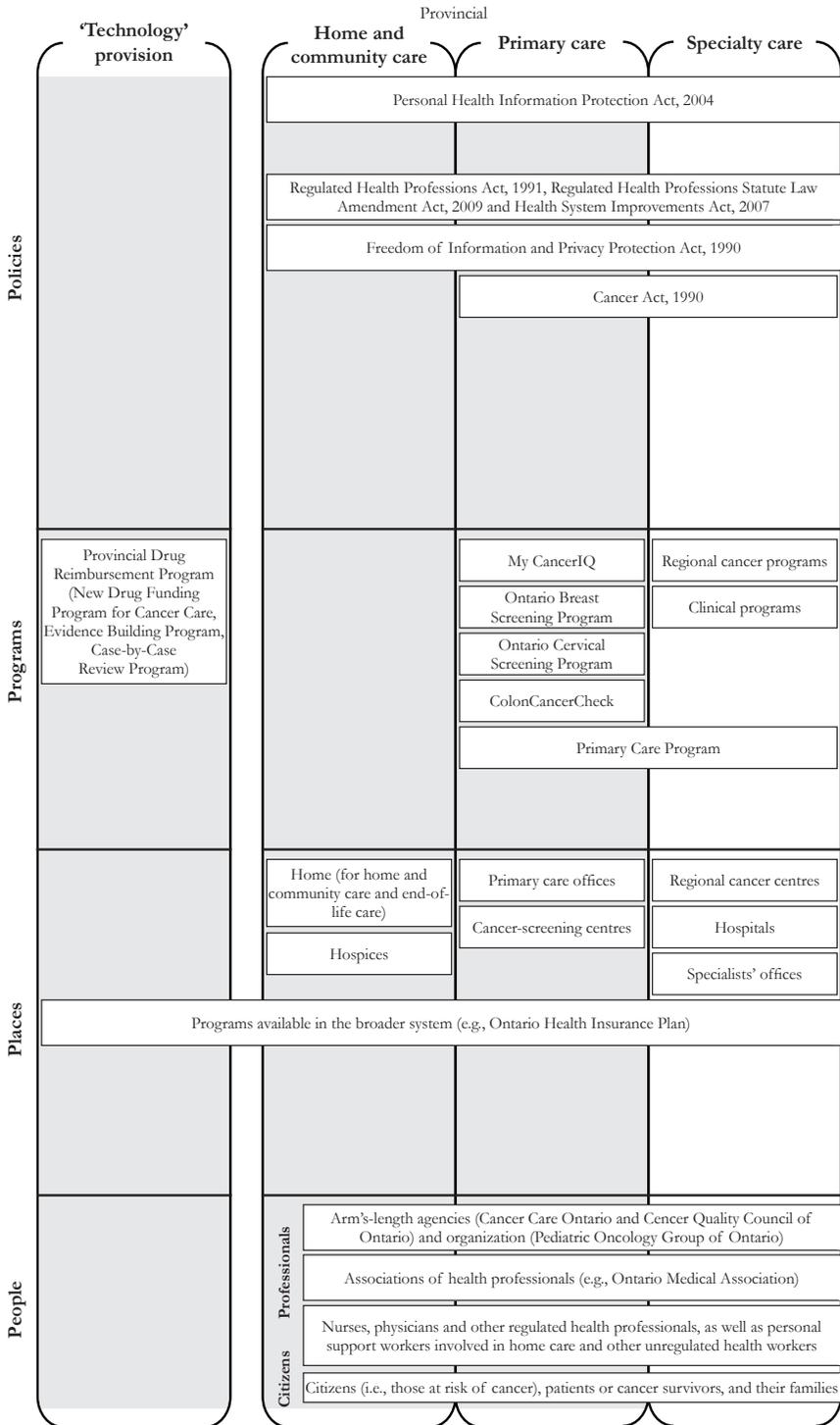
Periodically the Ministry of Health and Long-Term Care has considered (or key stakeholders have encouraged it to consider) expanding CCO’s mandate to include other ‘singled out’ conditions or groups of conditions, such as chronic kidney disease, diabetes, and mental health and addictions, or other cross-system functions. Currently, it serves such a function only for chronic kidney disease, which it does through the Ontario Renal Network (established in 2009), and for the province’s wait-times strategy and its emergency room/alternate-level-of-care strategy, which it does through the Access to Care program.(55-57) The Ontario Renal Network organizes and funds dialysis and other renal services across the province. While it is an ‘in-house’ analogue to CCO, the closest ‘external’ analogue would be the Cardiac Care Network, which operates within a narrower span of control to improve access, quality, efficiency and equity in the delivery of cardiac services.(58)

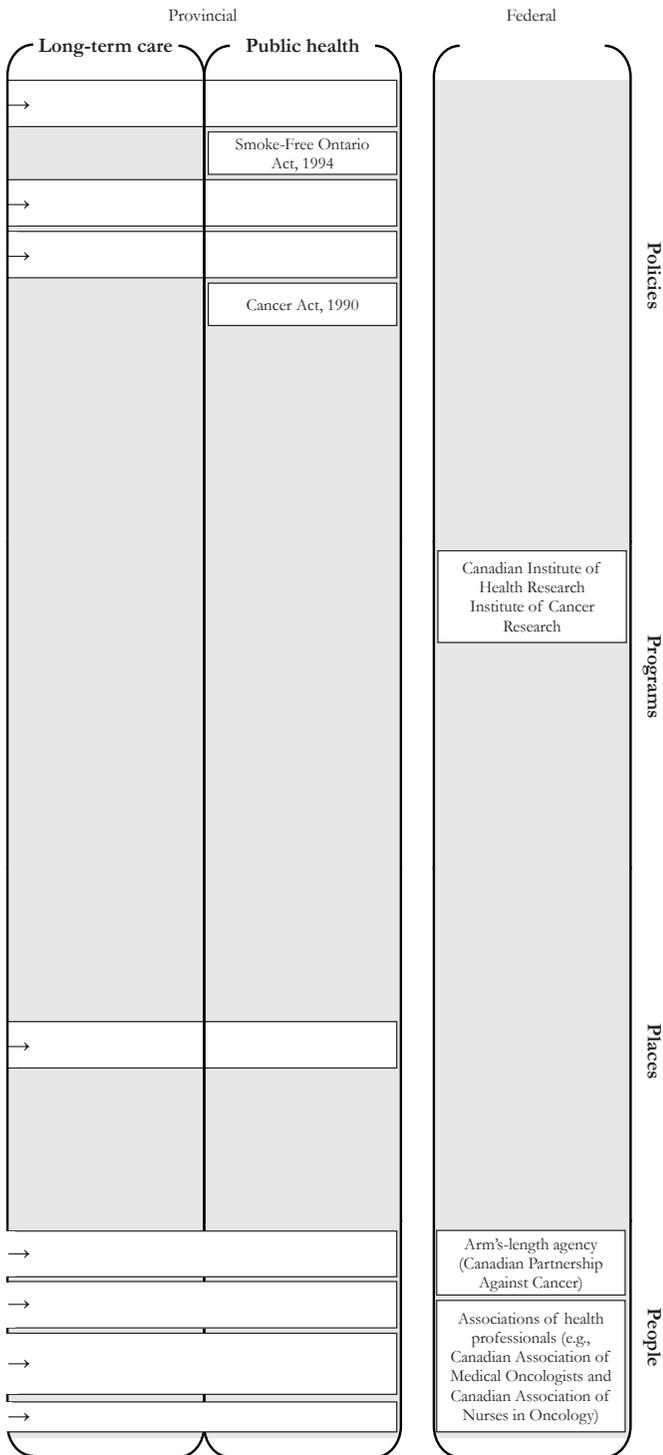
## Policies that govern cancer care

The key policies that govern cancer care (Figure 7.3) are the:

- 1) *Cancer Act, 1990*, which formalized the governance of the precursor to CCO (the Ontario Cancer Treatment and Research Foundation, first established in 1943) and its objectives (e.g., creation and operation of regional treatment centres and of laboratories, coordination of treatment, collection and reporting of data, and education of the public about cancer), but the act does not cover the wide spectrum of activities currently undertaken by CCO (which are dealt with through administrative agreements with it);
- 2) *Freedom of Information and Privacy Protection Act, 1990*, which provided individuals with the right to access their own personal health information (and to have the privacy and confidentiality of their personal healthcare information respected), but which, through later amendments, established that the head of organizations like CCO can refuse to disclose a record that contains information provided in the context of quality assessment and improvement efforts; and
- 3) *Personal Health Information Protection Act, 2004*, which enshrined patient confidentiality as an individual right by outlining rules for

Figure 7.3: Cancer care





collecting, using and disclosing personal information about individuals that protect confidentiality while also providing effective healthcare, and which reaffirmed the role of an agency like CCO as a custodian for such information (providing it with the ‘prescribed registry’ status that allows it to, for example, write to Ontarians to notify them about their eligibility for breast, cervical and colorectal cancer screening, and requiring it to be reviewed by the Information and Privacy Commissioner every three years).

As well, select policies govern efforts to prevent specific types of cancer, such as the *Smoke-Free Ontario Act, 1994*. And many policies that govern care in the broader health system also apply to cancer care, such as the *Regulated Health Professions Act, 1991*, which provided the legislative framework for the self-governance of the many regulated health professions providing cancer care (e.g., registered nurses and physicians).

Also, CCO and its regional cancer centres effectively work under many other policies that support safe, high-quality cancer care, including the following examples: 1) an accreditation process for stem-cell transplants, which is overseen by the Foundation for the Accreditation of Cellular Therapy;(59) 2) regulations for the safe delivery of radiation therapy, which have been established by the Canadian Nuclear Safety Commission;(60) and 3) regulations for the use of drugs in clinical trials, which have been established by Health Canada.(61)

## Programs constituting cancer care

Two broad categories of programs are highly visible in cancer care, namely prevention and screening programs and diagnosis and treatment programs (Figure 7.3). The prevention and screening programs include:

- 1) MyCancerIQ ([www.mycanceriq.ca](http://www.mycanceriq.ca)) – a website that helps Ontarians understand their risk of developing specific cancers (breast, cervical, colorectal, kidney and lung cancer, as well as melanoma) and what they can do to help lower that risk;
- 2) the Ontario Breast Screening Program – an organized screening program that reminds eligible women by letter about the need for screening, and that provides, in dedicated locations across the province, either: a) mammograms every two years for women aged 50 to 74 who are at average risk for breast cancer; or b) mammograms and breast magnetic resonance imaging (MRI) every year for women aged 30 to 69 who are

- at high risk for breast cancer;(62)
- 3) the Ontario Cervical Screening Program – a screening program that reminds eligible women by letter about the need for screening and that supports family physicians and nurse practitioners to provide the Pap tests used in screening women (typically those aged 21-70) every three years;(63) and
  - 4) ColonCancerCheck – an organized screening program that reminds eligible men and women by letter about the need for screening, that supports family physicians and nurse practitioners to provide a fecal occult blood test every two years to screen Ontarians aged 50 to 74 who are at average risk of colorectal cancer (although the tests are also available by calling Telehealth Ontario), and that provides, in dedicated locations across the province: a) follow-up colonoscopy for those with abnormal fecal occult blood test results; b) flexible sigmoidoscopy every 10 years for those seeking additional reassurance (which can be provided by a physician or a specially trained registered nurse); and c) colonoscopy every 10 years for those at high risk (i.e., with one or more first-degree relatives with the disease).(64)

Two regions of the province (North West region and Hamilton Niagara Haldimand Brant region) have mobile screening coaches (i.e., buses) to screen eligible women for breast cancer (mammography), cervical cancer (Pap test), and colorectal cancer (fecal occult blood test kits).(65)

The diagnosis and treatment programs can be grouped into two sub-categories:

- 1) 14 regional cancer programs (one for each LHIN), which were established in 2005, are networks of organizations (e.g., regional cancer centre), professionals and patient/family groups, headed by a regional vice-president (who also leads the regional cancer centre), that implement provincial standards and programs for cancer care, ensure service providers meet the requirements and targets set out in their partnership agreements with CCO, coordinate care across local and regional healthcare providers, respond to local cancer issues, and work to continually improve access to care, wait times, and quality of care;(66) and
- 2) 10 clinical programs, which are provincial programs that aim to improve the accessibility, quality and safety of the cancer care being provided in the regional cancer programs – across the patient journey from diagnosis (i.e., diagnostic assessment, pathology and laboratory medicine, and cancer imaging programs) to treatment (i.e., systemic

treatment, radiation treatment, and surgical oncology programs), to recovery/survivorship, palliative care, and other points in the patient journey (i.e., patient education, oncology nursing, psycho-social oncology, and specialized services) – and that do so by monitoring quality, developing evidence-based guidance for the system, and working with organizations, professionals and patient/family groups to implement best practices province-wide.(67)

The clinical program portfolio is also responsible for McMaster University's Program in Evidence-Based Care, which develops evidence-based guidance for practice and policy decisions for all disease sites and clinical programs across the cancer-care continuum.(68)

Additionally, CCO performs a number of functions and oversees a number of initiatives that also support cancer care:

- 1) planning, which includes both long-term planning (as reflected in the four-year Ontario Cancer Plan) (69) and capacity planning;
- 2) Indigenous programming, which includes the Aboriginal Cancer Strategy, the aboriginal tobacco program, and the aboriginal cancer and prevention team;(70)
- 3) primary-care provider engagement in cancer prevention, screening, care and support, through the Primary Care Program's engagement strategy (focused initially on screening) and its provincial network (launched in 2008) of primary-care leads in each LHIN;(71)
- 4) drug-reimbursement programs, for which CCO reviews and processes requests from hospitals and regional cancer centres for reimbursement for new injectable cancer drugs (New Drug Funding Program for Cancer Care), new drugs for which clinical and cost-effectiveness data need to be collected (Evidence Building Program), and drugs for specific patients (Case-by-Case Review Program), although decisions about which drugs to pay for are informed by the pan-Canadian Oncology Drug Review and made by the government's public drug programs, which are described in Chapter 8, and the funds to pay for the drugs come from government (and are then transferred by CCO to the hospitals that dispense them);
- 5) performance improvement, which involves the use of performance monitoring (e.g., against the 21-day target set for the time from referral from a physician to an initial appointment with a cancer surgeon), performance-based funding (i.e., making some funding conditional upon achieving particular results), and public reporting (i.e., reporting

results to providers and to the public), as well as targeted initiatives with regional vice-presidents and cancer-care providers to address particular problems;(72) and

- 6) surveillance, monitoring and public reporting on patterns and trends in cancer risk factors, incidence, prevalence, mortality and survival.(73)

CCO also works in partnership with other organizations, such as:

- 1) the College of Physicians and Surgeons of Ontario, with which it co-leads the Quality Management Partnership that designs and implements provincial quality-management programs for mammography (for breast screening), colonoscopy (for colorectal cancer screening, among other purposes), and pathology (for the diagnosis and staging of cancer, among other purpose);(74) and
- 2) Canadian Partnership Against Cancer, with which it implements the national strategy for cancer control.(75)

## Places and people involved in cancer care

The places where cancer care is provided include, first and foremost, the 14 regional cancer centres and their affiliated hospitals and specialists' offices. But of course cancer care can also be provided in a person's home (e.g., where they may receive home and community care or palliative care), primary-care offices (e.g., where they may access cancer screening or comprehensive primary care, through which they may access care in a regional cancer centre, and to which they may be 'discharged' when their cancer treatment has been completed), and cancer-screening centres (e.g., those providing breast screening or colonoscopies), as well as residential hospices (for palliative care) (Figure 7.3).

The people involved in cancer care include those at risk of cancer, those being treated for or surviving after treatment for cancer (who are often referred to as cancer survivors), and those being provided with palliative care (who are often referred to as patients) and their families, as well as a broad range of regulated health professionals (e.g., nurses and physicians) and unregulated health workers (e.g., personal support workers involved in home care). The health professionals are represented by their respective professional associations (e.g., Ontario Medical Association) or by associations representing their particular area of specialty (e.g., Canadian Association

of Nurses in Oncology). Some patients and family members are involved in roles ranging from members of the Cancer Quality Council of Ontario or CCO's Patient and Family Cancer Advisory Council (who are chosen to ensure geographic diversity), to Patient and Family Advisors (who provide input into policies, programs and practices that affect care). Cancer advocacy groups, such as the Canadian Cancer Society and many disease-specific (e.g., breast cancer, prostate cancer) groups, also play important roles, particularly in education, fundraising and supporting patients and families. The Canadian Partnership Against Cancer – an arm's-length agency of the federal government – works in partnership with many of those involved in cancer care.(76)

### **Governance, financial and delivery arrangements in cancer care**

Governance, financial and delivery arrangements (i.e., the building blocks) are another lens through which cancer care can be described. The governance arrangements that are particularly salient to the sub-system have been addressed under 'policies' above. The key financial arrangement for cancer care is the funding provided by the Ministry of Health and Long-Term Care to CCO and, through it (sometimes for the achievement of particular results, as noted above), to the regional cancer centres, hospitals and other providers of cancer care. CCO (and the Ontario Renal Network that operates as a division within it), WSIB (as described earlier in the chapter) and CCACs are fairly unique organizations in the health system in their use of a 'commissioning' model that pays for care that meets the performance standards outlined in service agreements. Other financial arrangements, such as the funding for home and community care (through LHINs and then through CCACs) and for the family physicians and specialty physicians involved in providing care (through OHIP), operate in the same way as they do for the sectors described in Chapter 6. In terms of delivery arrangements, the 14 regional cancer centres and their affiliated hospitals and clinics provide the key infrastructure for cancer care.

## **End of life**

End-of-life is less commonly thought of as a condition in the way that we may think of an addiction, injury or cancer, but there is value in considering it in a way that is analogous to these other conditions. The alternatives

for a book organized in the way that we have organized this one would be to consider: 1) end-of-life care as a ‘treatment,’ as we do in Chapter 8 for prescription and over-the-counter drugs, complementary and alternative therapies, and dental services; or 2) those at the end of life as a ‘population,’ as we do in Chapter 9 for Indigenous peoples. When considered as a category of ‘treatment,’ the most appropriate term would be ‘palliative care,’ which increasingly emphasizes the importance of intervening early in the trajectory of a life-threatening condition (or a potentially life-threatening condition) and much earlier than the ‘end-of-life’ phase (that in the past was unhelpfully defined as only the remaining hours or days of life). We have adopted here a much broader conception of end of life and we use the broader term ‘palliative care.’

Palliative care, like rehabilitation care and to some extent care for mental health and addictions, can involve or take place in four of the six sectors described in Chapter 6 (i.e., home and community care, primary care, specialty care, and long-term care). The Supreme Court decision about medical assistance in dying,(77) and the resulting federal government legislation that responded to this decision, have skewed public attention to just this one potential consideration at the end of life.(78) With the legislation now passed and being implemented, attention will likely return to the state of palliative care in general and how it can be improved.

To the extent that there is a key player in palliative care, it is (or hopefully one day will be) the 14 regional palliative-care networks (sometimes called hospice palliative-care programs) that operate within the boundaries of each of the LHINs and that bring together service providers such as CCACs, home and community care agencies, family and specialty physicians, and hospitals to plan, coordinate and improve the delivery of palliative care in their region. In the March 2016 budget announcement, the government committed to establish the Ontario Palliative Care Network, a partnership among CCO, LHINs, Health Quality Ontario and other partners such as patient, caregiver and clinical representatives, to develop provincial palliative-care standards, and to support the regionally focused networks that already exist.(79) The budget announcement also committed to increasing support for caregivers, and partnering with the Ontario Palliative Care Network to provide training and support to new hospice volunteers each year. From the perspective of patients, however, the key players are likely their caregivers and the health professionals, workers or

teams involved in their care.

## Policies that govern palliative care

Broadly speaking, no provincial government policies govern palliative care specifically, however, many sector-specific or system-wide policies govern it indirectly (Figure 7.4), such as the:

- 1) *Local Health Systems Integration Act, 2006*, which established the LHINs that fund: a) the CCACs that act as the gateway to government-funded home and community care and provide information about care that is not funded by government; b) the home and community care agencies that provide nursing, personal support and homemaking services that comprise one element of palliative care; and c) the residential hospices, palliative-care units and hospitals where much palliative care is provided;
- 2) *Home Care and Community Services Act, 1994*, which established eligibility criteria for home and community care services and the maximum levels of nursing, personal support and homemaking services that can be provided to an individual, including those receiving palliative care;
- 3) *Health Insurance Act, 1990*, which governs OHIP, through which all physicians are paid, including the family physicians and specialty physicians providing palliative care;
- 4) *Public Hospitals Act, 1990*, which governs the private not-for-profit hospitals where some palliative care is provided (including care provided in palliative-care units);
- 5) *Long-Term Care Homes Act, 2007*, which governs the long-term care homes where some palliative care is provided;
- 6) *Regulated Health Professions Act, 1991*, which governs the health professions who are involved in providing palliative care;
- 7) *Cancer Act, 1990*, which governs CCO and, through it, the palliative care provided through regional cancer programs;
- 8) *Substitute Decisions Act, 1992*, which established provisions for the naming of powers of attorney and statutory guardians, for both personal care and property, for those found to be mentally incapable of personal care or managing property, which may include some individuals receiving palliative care; and
- 9) *Health Care Consent Act, 1996*, which established rules with respect to consent to treatment and receipt of personal assistance services and rules for when an individual lacks the capacity to make decisions about

such matters.

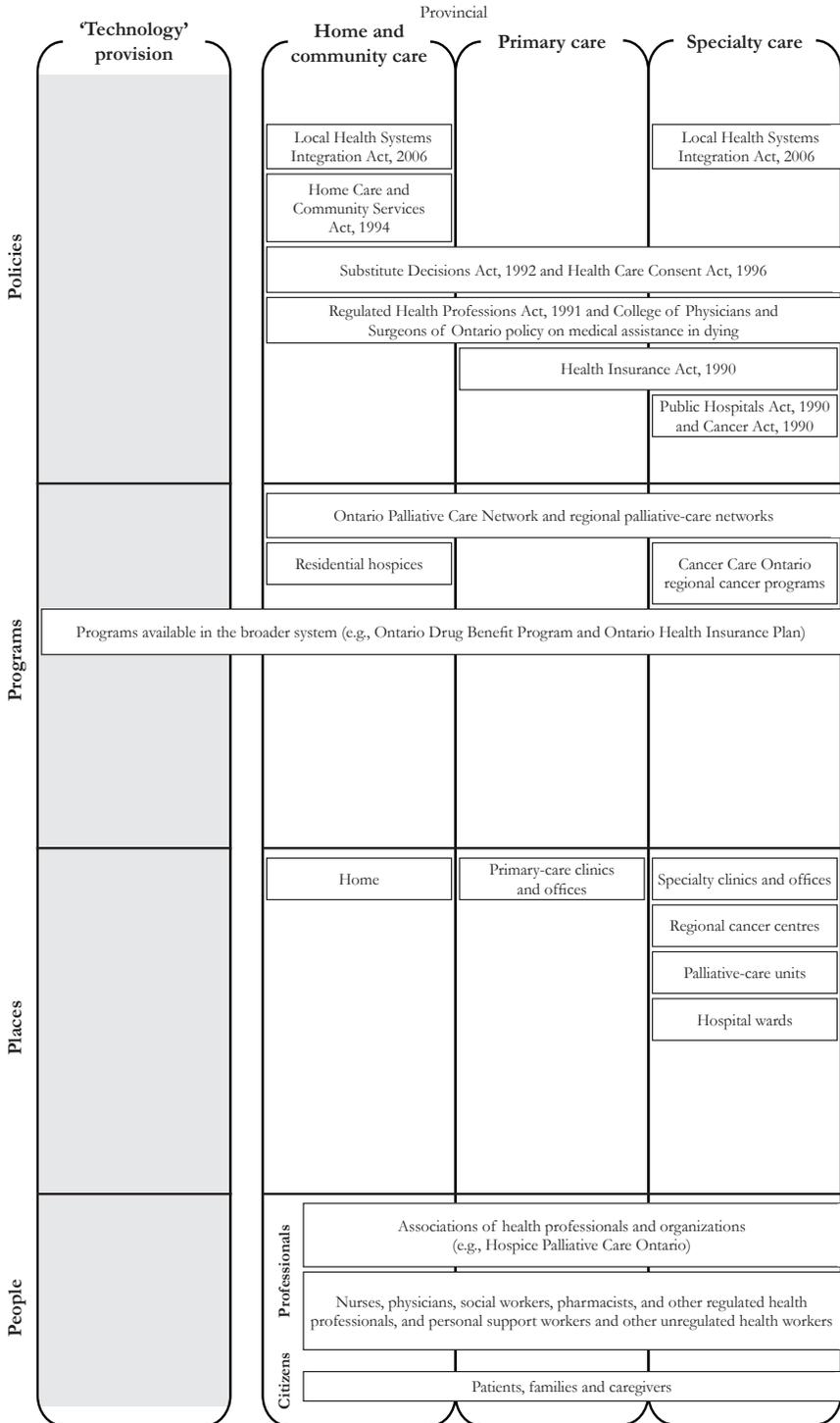
The last of these policies specifies that even when an advance care plan is in place (as would ideally be for all citizens) or a do-not-resuscitate order is in place (as could be for some patients at the end of life), decisions about treatment and services cannot be made without informed consent, which means that health professionals need to discuss care options with patients or their substitute decision-makers.(80) Support for advance care planning is available through [www.advancecareplanning.ca](http://www.advancecareplanning.ca).

The aforementioned federal government legislation stipulates that five conditions must be met by a patient for medical assistance in dying: 1) be eligible for health services funded by the federal or provincial government (which excludes visitors to Canada); 2) be at least 18 years old and mentally competent (i.e., capable of making healthcare decisions for oneself); 3) have a 'grievous and irremediable' medical condition (the definition of which includes being at a point where natural death has become reasonably foreseeable); 4) make a request for medical assistance in dying that is not the result of outside pressure or influence; and 5) give informed consent to receive medical assistance in dying.(78) The College of Physicians and Surgeons of Ontario has developed a policy to guide physicians in providing medical assistance in dying.(81)

### Programs constituting palliative care

The two provincial programs most directly related to palliative care are: 1) the 14 palliative-care networks that plan, coordinate and improve the delivery of palliative care in their region (or will do so as they become as fully functional as the Champlain Hospice Palliative Care Program in Ottawa and the Erie St. Clair Hospice Palliative Care Network in southwestern Ontario); and 2) the 39 residential hospices (with somewhere in the range of 300 beds), of which four are privately funded (and all of which rely in significant part on fundraising), that provide care for patients in the last weeks or months of life who either cannot be cared for or do not wish to be cared for at home (Figure 7.4).(82) In the same budget announcement noted above, the Government of Ontario committed to funding 20 new residential hospices across Ontario and to increase funding for existing residential hospices.(79) As noted above, home and community care agencies, hospitals and long-term care homes, as well as regional cancer programs, also provide palliative care, and many have formal programs.

Figure 7.4: Palliative care





Hospitals may provide such care in a palliative-care unit, on a ward, or on an outpatient basis.

Several system-wide programs also play key roles, including the ODB Program (which covers the cost of drugs for eligible individuals) and OHIP (which remunerates both family physicians and specialists providing palliative care-related telephone and case management, and home, hospital and long-term care home visits).(83) The Palliative Care Facilitated Access program, which is administered by the Ontario Medical Association and funded by the Ministry of Health and Long-Term Care through the ODB Program, allows the ODB Program-eligible patients of registered physicians to access essential palliative care medications (84) more easily than is usually the case under the Exceptional Access Program. Also, the cancer sub-system provides many supports to palliative care for those with cancer.

The federal government administers the Compassionate Care Benefits program that allows eligible Ontarians to receive Employment Insurance benefits if they need to be away from work for up to 26 weeks to provide care or support to a family member who has a significant risk of death within 26 weeks.(85) The benefit can be shared among family members involved in providing care or support.

## Places and people involved in palliative care

The places where palliative care may be provided include a person's home (whether that be in a private residence, retirement home, correctional centre, long-term care home or someplace else), offices and clinics (for those who are mobile), residential hospices (typically for patients with less complex needs in the last days or weeks of life), palliative-care units (which may be located in hospitals or complex continuing-care facilities and are for patients with acute or complex needs), and hospitals (typically in a general medical unit if there is no palliative-care unit or if there is no available bed in a palliative-care unit), among others (Figure 7.4). A report by Health Quality Ontario found that, of those receiving palliative care services in 2014-15, less than half (43%) received palliative home care services in their last month of life, about one third (34%) received a home visit from a physician in their last month of life, and nearly two thirds (65%) died in hospital.

The people involved in palliative care include the patients themselves, their families and caregivers, and the regulated health professionals and unregulated health workers providing palliative care. These professionals and workers can draw on many educational supports, including the Learning Essential Approaches to Palliative Care courses and workshops. Some common configurations of these professionals and workers include nurses and personal support workers providing palliative home care services, family physicians providing palliative care alone or with the support of a specialist palliative care team (acting in a consultation and/or shared-care model) and/or nurse-led Palliative Pain and Symptom Management Services, and the interprofessional teams providing palliative care (or consultations about palliative care) in residential hospices, palliative-care units, and hospitals. However, there is little standardization of such models of care and significant unevenness in access to them across the province. Both the health professionals and the organizations where they work may be represented by associations (e.g., Hospice Palliative Care Ontario).

### **Governance, financial and delivery arrangements in palliative care**

The governance arrangements that are salient to palliative care have been addressed under ‘policies’ above, the financial arrangements operate in the same way as they do for the sectors described in Chapter 6, and the delivery arrangements include the 14 palliative-care networks that plan, coordinate and improve the delivery of palliative care and the many home and community care agencies and offices/clinics, the 39 residential hospices, the 21 palliative-care units, and the many hospitals that provide palliative care.

## **Conclusion**

The unique approaches used in the care of the four conditions or groupings of conditions addressed in this chapter can be seen, in a manner that is somewhat comparable to the division of labour among the six sectors comprising Ontario’s health system, as either integral to a well-functioning system that accommodates diversity of care needs, or a reflection of an unhelpful siloing of care in the system, depending on your perspective. As we will return to in the book’s concluding chapter, tough questions can (and perhaps should) be asked about why we care for mental health

and addictions so separately from 'physical health' (particularly given the numbers of Ontarians living with both mental and physical health challenges),(86) why we care for injuries and diseases so differently when they happen to be work-related (which includes buying preferential access to care), why we only organize cancer care as an almost entirely separate sub-system (and sometimes ask CCO to take on a delivery role for other prioritized conditions or issues), and why we have come so late to the game of standardizing models of palliative care and ensuring equitable access to these models. The answers may either reassure us or lead us to continue the push for integrated care that the LHINs have been empowered to pursue.

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