

Don't smoke,  
Don't be poor,  
Read before signing:

*Linking health literacy and legal capability*

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CLEO CENTRE FOR  
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## **A note to readers:**

The links (URL's) to the websites referenced in this book were correct as at April 6, 2015. However, as information on the internet changes frequently, we cannot guarantee that the links or the content of the websites will remain accurate.

## Executive summary

This report provides an overview of community health information and promotion practices in Ontario. We identify promising practices and ideas from the health sector, draw parallels to similar work by public legal education and information (PLE) providers in Ontario, and identify some opportunities and strategies for building upon or adapting learnings from the health sector into PLE thinking and practices.

Vulnerable communities face hurdles when it comes to getting information and help in both the health and justice sectors. However, systemic approaches used by the health information and promotion sector to address the literacy challenges and needs of vulnerable people have led to significant improvements in access to health information in Ontario over the past 30 years. In contrast, the justice sector has moved far more slowly in recognizing systemic barriers faced by vulnerable people who need access to legal information.

For this project, CLEO conducted a review of literature about health literacy and health information practices. Our goal was to identify practices from the health information and promotion sector that could be incorporated into PLE work to expand the reach of PLE to vulnerable communities and improve their legal capability – or their ability to deal with legal problems.

One major observation flowing from our research is that in the health information and promotion sector there has been universal recognition that “social determinants of health” – the economic and social conditions that affect individuals and communities – influence a person’s ability to become health literate. Acknowledgment of the role of social determinants has led to major improvements in the ground-level and systemic development and distribution of accessible health information materials in Ontario and elsewhere. It has also influenced the development of statistical measures to test health literacy and identify which communities were at risk of low health literacy.

In contrast, the emerging concept of legal capability is still primarily framed on a general level, in other words, reflecting the population at large. There has been no specific recognition of the social and economic barriers that may interfere with the ability of people in vulnerable communities to access and use legal information. Moreover, there currently is no standard means for measuring legal capability in the Ontario or Canadian populations.

In Part 1 of this report, CLEO summarizes existing approaches to health literacy and legal capability and contrasts them, noting the gaps that exist. Our overall recommendation for trying to close the gaps: systemically address social and economic barriers to improve access to legal information. Doing this involves three related tasks:

1. compiling a universal list of the social determinants of civil justice analogous to the social determinants of health and promote research on how societal factors compromise peoples' ability to identify and deal with legal problems in their lives.
2. developing or recommending statistical measures to help assess legal capability
3. building a detailed definition of legal capability that explicitly addresses the needs of vulnerable communities

In Part 2 of this report, CLEO provides an overview of the ways in which the identification of social determinants of health and resulting health literacy principles have shaped and improved access to health information for vulnerable communities in Ontario and elsewhere. Specifically, we explain how consideration of the impact of social determinants have led to building robust health information interventions by highlighting the importance of locating, targeting, and tailoring approaches to delivering information to specific vulnerable communities.

We draw parallels with similar PLE initiatives in Ontario and identify some opportunities for PLE providers to incorporate or build upon existing successful practices in the health information sector.

In Part 3 of this report, we summarize our findings about health information practices and flesh out strategies and opportunities to incorporate these findings into both wider thinking about access to justice and front-line PLE work. The wide-spread acceptance in the health information and promotion sector that social determinants directly affect the ability of people to access health information has led to sweeping changes in the distribution of health information over the past three decades. Whether these strategies succeed in the justice sector will hinge, in our view, on highlighting and promoting the links between social determinants, access to legal information, and building personal and legal capability within vulnerable communities.

We are mindful that our comparison of health promotion with PLE in Ontario is influenced by the fact that the publicly funded health system is far better resourced than the justice system. This difference in funding levels is not within the purview of our paper to address. However, we hope our research will help open and shape a wider dialogue about the effect of social determinants on the ability of vulnerable communities in Ontario and Canada to access and understand legal information.

## Part 1: Health literacy and legal capability

Through an extensive literature review, we examined how health professionals define, measure, achieve, and evaluate health literacy – and how that compares with existing concepts of legal literacy and legal capability.

Literacy in general (referred to as “general literacy” in this paper) and health literacy are clearly related, as literacy is a necessary component of health literacy (Canadian Council on Learning *Healthy* 9).<sup>1</sup> Thus, the literature on health literacy also addresses concepts of general literacy, as we will discuss in the following section.

### 1.1 Defining general literacy

The scope of what is included in general literacy is continually evolving. In the past, general literacy was measured as a binary outcome with a focus on the ability to read prose. That is, one was either literate or illiterate (Rootman and Gordon-El-Bihbety 12).<sup>2</sup>

However, in recent years, tests for literary proficiency have focused on literacy as a continuum of skills. Thus, general literacy is now measured across a wider spectrum (Statistics Canada *Building* 12; Ronson and Rootman 172).

As a result, general literacy is increasingly seen as an “active and broad-based learning process” (UNESCO *Literacy for Life* 151). In Canada, general literacy ability is currently evaluated based on a matrix that includes four areas or “domains”:

- **Prose literacy** – the ability to understand and synthesize information in text from sources like editorials, news stories, brochures, and instruction manuals.
- **Document literacy** – the ability to find and use information located in different sources like job applications, maps, tables, and charts.
- **Numeracy** – the ability to manage mathematical demands, for example, navigating the checkout aisle in a grocery store or negotiating a vehicle purchase.
- **Problem solving** – the ability to engage in goal-directed thinking where routine solutions are not immediately obvious. For example, the problem solver may have a goal, but not immediately know how to attain it (Statistics Canada and OECD 14).

Given the breadth of the concept of general literacy, definitions in the literature vary in terms of focus and scope. The following are examples of commonly used definitions:

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<sup>1</sup> The Expert Panel, a panel convened in 2006 by the Canadian Public Health Association, which conducted the first Canada-wide research on health literacy, found that some researchers feel that health literacy is nothing more than literacy in a health context, while others believe that they are completely separate and different concepts. The Expert Panel attributed this to the fact that current health literacy measurement tools are not completely satisfactory, as will be discussed further in this paper. In the view of the Expert Panel, the reality is that health literacy likely lies somewhere in the middle. See Rootman and Gordon-El-Bihbety 11.

<sup>2</sup> See also, generally, Statistics Canada 11-20.

An individual's ability to read, write and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one's goals, and develop one's knowledge and potential (US National Literacy Act).

Literacy is a complex set of abilities needed to understand and use the dominant symbol systems of a culture – alphabets, numbers, visual icons – for personal and community development. The nature of these abilities, and the demand for them, vary from one context to another.... In a technological society, literacy extends beyond the functional skills of reading, writing, speaking and listening to include multiple literacies such as visual, media, and information literacy (Centre for Literacy of Quebec).

The ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts. Literacy involves a continuum of learning to enable an individual to achieve his or her goals, to develop his or her knowledge and potential, and to participate fully in the wider society (UNESCO *Aspects 22*).

Using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential (Statistics Canada 198).

In 2006 the Canadian Public Health Association convened the Expert Panel on Health Literacy (the Expert Panel), to conduct the first Canada-wide research on health literacy. In a report prepared by Irving Rootman and Deborah Gordon-El-Bihbety, the Expert Panel reviewed several of the existing definitions (including those listed above) and ways of measuring general literacy in order to arrive at a common framework for understanding both general literacy and health literacy (11). The Expert Panel went on to define general literacy as:

The ability to understand and use reading, writing, speaking and other forms of communication as ways to participate in society and achieve one's goals and potential (Rootman and Gordon-El-Bihbety 11).

We have adopted the Expert Panel's definition of general literacy in this paper. The Expert Panel's broad emphasis on functional components over and above reading and writing has strongly influenced the subsequent development of definitions for "health literacy".

## 1.2 Defining health literacy

As is the case with general literacy, the concept of health literacy has expanded significantly over time. However, it is of note that some health researchers and health professionals have disagreed about the nature of the relationship between general literacy and health literacy (Rootman and Gordon-El-Bihbety 13).



This debate arose, in part, from the growing understanding of the impact of social determinants on the ability of people to achieve health literacy.

### 1.2.1 The social determinants of health

The “social determinants of health”, reflected in most contemporary discussions of health literacy, are the social and economic factors that influence people’s health – or, as Juha Mikkonen and Dennis Raphael put it: “the primary factors that shape the health of Canadians are not medical treatments or lifestyle choices but rather the living conditions they experience” (7).

A fuller definition by Dennis Raphael describes the social determinants of health as “the economic and social conditions that influence the health of individuals, communities and jurisdictions as a whole. They determine the extent to which a person possesses the physical, social, and personal resources to identify and achieve personal aspirations, satisfy needs, and cope with the environment” (*Canadian Perspectives* 2). Thus, in addition to impacting people’s health directly, social determinants affect an individual’s ability to become health literate or to maintain health literacy.

Dennis Raphael, a leading scholar in the area of health literacy, describes 14 social determinants that help to explain why some Canadians are healthier than others<sup>3</sup>:

- income and income distribution
- education
- unemployment and job security
- employment and working conditions
- early childhood development
- food insecurity
- housing
- social exclusion
- social safety network
- health services
- Aboriginal status
- gender
- race
- disability

Each of these social determinants can have major effects on the health of Canadians. In fact, Dennis Raphael notes that researchers have found evidence that social determinants have a primary impact on health – one much stronger than the physical impacts more typically associated with individual behaviours such as diet, exercise, tobacco, and excessive alcohol

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<sup>3</sup> In parts 1.6.2 and 1.6.3 of this paper we focus primarily on two key determinants – education and social exclusion. For an overview of most of the other key social determinants of health and their effects, see Public Health Agency of Canada, *What Makes Canadians Healthy or Unhealthy?*

use ("Social Determinants" 10-11). Moreover, researchers have noted that such behaviours can be seen as "secondary determinants of health" or negative coping mechanisms – in contrast with the social determinants of health, which are primary determinants of health (Mikkonen and Raphael 10). As such, inattention to social determinants in the health sector could undermine individual behavioural choices made to achieve better health, up to and including the ability to adopt such choices at all (Mikkonen and Raphael 10).

In 2009, echoing these empirical findings, the then-head of the Canadian Medical Association, Dr. Jeffrey Turnbull, stated that doctors in Canada must acknowledge poverty as the greatest predictor of an individual's health. He referred to poverty and housing as human rights issues and called upon doctors to advocate for strategies to reduce poverty and improve the health of society's most vulnerable citizens (Duffy).

This point is illustrated by two thought-provoking lists of tips for better health developed by Dennis Raphael.

Which tips for better health are consistent with research evidence? <sup>4</sup>
<p>The messages given to the public by governments, health associations, and health workers are heavily influenced by the ways in which health issues are understood. Contrast the two sets of messages provided below. The first set is individually-oriented and assumes individuals can control the factors that determine their health. The second set is societally-oriented and assumes the most important determinants of health are beyond the control of most individuals. Which set of tips is most consistent with the available evidence on the determinants of health?</p> <p><b>The traditional 10 tips for better health</b></p> <ol style="list-style-type: none"><li>1. Don't smoke. If you can, stop. If you can't, cut down.</li><li>2. Follow a balanced diet with plenty of fruit and vegetables.</li><li>3. Keep physically active.</li><li>4. Manage stress by, for example, talking things through and making time to relax.</li><li>5. If you drink alcohol, do so in moderation.</li><li>6. Cover up in the sun, and protect children from sunburn.</li><li>7. Practice safer sex.</li><li>8. Take up cancer-screening opportunities.</li><li>9. Be safe on the roads: follow the Highway Code.</li><li>10. Learn the First Aid ABCs: airways, breathing, circulation.</li></ol>

<sup>4</sup> The original version of this figure is at "Social Determinants" 13.

### **The social determinants 10 tips for better health**

1. Don't be poor. If you can, stop. If you can't, try not to be poor for long.
2. Don't have poor parents.
3. Own a car.
4. Don't work in a stressful, low-paid manual job.
5. Don't live in damp, low-quality housing.
6. Be able to afford to go on a foreign holiday and sunbathe.
7. Practice not losing your job and don't become unemployed.
8. Take up all benefits you are entitled to, if you are unemployed, retired or sick or disabled.
9. Don't live next to a busy major road or near a polluting factory.
10. Learn how to fill in the complex housing benefit/asylum application forms before you become homeless and destitute.

More recently, the following additional social determinants have been identified as important in the Canadian context:

- immigration to Canada, particularly for female immigrants (University of Toronto Faculty of Nursing) and immigrant youth (Wellesley Institute)<sup>5</sup>
- sexual orientation and gender identity (Dysart-Gale 24).

In sum, social determinants are clearly and inextricably linked to health and are taken into account when designing health information and promotion programs. Indeed, programs designed without explicitly acknowledging social and environmental influences are potentially doomed to failure (Nutbeam 267).

### **1.2.2 Health literacy**

Professor Don Nutbeam notes that social determinants influence not only people's health, but also their ability to access health information at a time that can help them prevent problems (260). He developed a leading model on health literacy – a three-pronged approach widely cited in health literature as a holistic theory with the potential of practical application.

In Nutbeam's model there are three progressive levels of health literacy: functional, interactive, and critical (260). At least some general literacy skills are needed to achieve Nutbeam's first level of "functional" literacy. The following table summarizes his approach.<sup>6</sup>

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<sup>5</sup> At least one leading study suggests that some of the socio-economic factors underlying social determinants might be more important in shaping the health status of immigrants to Canada than non-immigrants (Dunn and Dyck 1573).

<sup>6</sup> A fuller explanation of this model can be found at Nutbeam 266.

Table 1: Nutbeam's model of health literacy

Level	Focus	Skills needed	Examples
1. Functional	<ul style="list-style-type: none"> <li>Targeted to individual users</li> <li>Does not invite interactive communication</li> </ul>	<ul style="list-style-type: none"> <li>Apply general literacy skills to health-related materials</li> </ul>	<ul style="list-style-type: none"> <li>Reading information from a pill bottle</li> <li>Reading an informational brochure</li> </ul>
2. Interactive	<ul style="list-style-type: none"> <li>Builds upon foundation of functional literacy (Level 1)</li> <li>Ability to find health information</li> <li>Ability to interact and develop skills in a social environment</li> <li>Ability to interact with health professionals</li> </ul>	<ul style="list-style-type: none"> <li>Evaluate a health message</li> <li>Make decisions based on health information</li> </ul>	<ul style="list-style-type: none"> <li>Negotiating treatment options</li> <li>Participating in peer support groups</li> </ul>
3. Critical	<ul style="list-style-type: none"> <li>Focus on both personal and community empowerment</li> <li>One-on-one and group interactions leading to health information strategies</li> <li>Ultimate goal is empowerment on both the individual and group level</li> <li>Social action component</li> </ul>	<ul style="list-style-type: none"> <li>Ability to evaluate and analyze health issues</li> <li>Ability to weigh options</li> <li>Ability to recognize who might benefit or lose by adopting a given health information strategy</li> </ul>	<ul style="list-style-type: none"> <li>Offer advice to community leaders on health-related issues</li> <li>Participate in community development programs</li> </ul>

Nutbeam's model illustrates some factors that distinguish health literacy from general literacy as traditionally measured. The Canadian Council on Learning provided the following description of some of these factors (9):

- Oral and aural communications skills.** People need to be able to ask health professionals for information about their options, to understand the answers, and then pass along their health information to friends and family, if needed.

- **Evaluating new information** and discarding outdated information in the context of constant changes in diseases and treatment and frequent discovery of new diseases and viruses.
- **Ability to find, understand, evaluate, and communicate health information** from other channels, such as media, books, friends, family, and the Internet.
- **Ability to read and understand** nutrition and medication labels.
- **Ability to make healthy lifestyle choices**, for example, eating a healthier diet, taking exercise, refraining from smoking.

As well, in the Canadian context, among Aboriginal and immigrant populations it is important to recognize that literacy may be uniquely defined or arise from a different cultural context. That is, literacy, health, and culture are inextricably linked. Such potential differences suggest the need for continually evolving definitions of health literacy with input from the specific communities being served (Ronson and Rootman 23).

For example, the Public Health Association of British Columbia addressed the need to involve various partners (including educational facilities, workplaces, and community organizations) in improving health literacy. In 2012, it reiterated the Expert Panel's definition and added (3):

To be health literate is to be able to access and understand the information required to manage one's health on a day-to-day basis. Ideally, a health-literate individual is able to seek and assess the health information required to

- 1) understand and carry out instructions for self-care, including the administering of complex daily medical regimens,
- 2) plan and achieve the lifestyle adjustments required for improved health,
- 3) make informed positive health-related decisions,
- 4) know how and when to access health care when necessary,
- 5) share health promoting activities with others, and
- 6) address health issues in the community and society.

However, despite explicit and implicit recognition in the literature about social determinants and the impact they have on an individual's ability to achieve health literacy, neither the Expert Panel's definition nor subsequent definitions building upon it seem to capture the notion that social and economic factors impact an individual's ability to achieve health literacy. For example, as noted earlier, the Expert Panel defined health literacy as:

The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course (Rootman and Gordon-El-Bihbety 11).

In contrast, the World Health Organization's definition, which pre-dates the Expert Panel and subsequent definitions, does include a social component to health literacy:

"The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which

promote and maintain good health” (WHO 10).

In this paper we adopt the World Health Organization’s definition of health literacy because it is sufficiently broad yet incorporates a social component.

In short, the current definitions of health literacy build upon existing understandings of general literacy by introducing the concept that vulnerable people face greater challenges in being able to identify and deal with – or prevent – health problems. But how does this all compare to notions of legal literacy and legal capability? In the next section we discuss the evolution of literacy in the contexts of public legal education and information (PLE) and access to justice.

### **1.3 Defining legal literacy and legal capability**

The concept of what legal literacy is has developed to some degree, but it has attracted less attention and academic study.<sup>7</sup> However, like the concept of health literacy, it continues to evolve. In this paper we focus on describing “legal literacy” and its newer incarnation – “legal capability”<sup>8</sup> – as they relate to the functional ability of people to understand when they have a legal problem, access legal information, and take appropriate steps or actions to resolve the legal problem.

#### **1.3.1 Legal literacy**

Legal literacy has been defined as “the ability to understand words used in a legal context, to draw conclusions from them, and then to use those conclusions to take action” (Hunter

11). It has also been recognized that general literacy skills, in and of themselves, may well not allow participation in a legal process or system:

Even if people with low literacy have found a way to cope with their daily routine, they find it very difficult to read, understand and use materials related to legal problems. They do not understand the concepts contained in the words, even if they understand the words themselves. Therefore, they cannot understand what is expected of them and often the implications of what is being said (Council of Canadian Administrative Tribunals 11).

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<sup>7</sup> Or at least the concept of legal literacy as it relates to users of the legal system, as opposed to law students and legal practitioners. Traditional definitions of “legal literacy” refer more to the abilities of legal practitioners than to members of the public. For example, a leading definition in the Canadian legal practice context is as follows: “Full legal literacy goes beyond the development of a basic legal competence and implies the acquisition of knowledge, understanding and critical judgment about the substance of law, legal process and legal resources, enabling and encouraging the utilization of capacities in practice.” (Manley-Casimir et al. 90)

<sup>8</sup> Note that we use the term “legal capability” in this paper as an analogue to health literacy, as current approaches to “legal capability” offer the closest parallels to the concept of health literacy.

A common theme in discussions about legal literacy is the emphasis on the functional ability to take appropriate action in response to problems involving the law. One scholar in particular, Laird Hunter, built upon his approach by describing legal literacy in a way that mirrors the definition of health literacy arrived at by the Public Health Association of British Columbia.<sup>9</sup>

Specifically, Hunter states that “people using the legal system must be able to guide themselves through a process that they understand” (12). According to Hunter, this entails the ability to:

- recognize a legal right or responsibility
- recognize when a problem or conflict is a legal conflict and when a legal solution is available
- know how to take the necessary action to avoid problems
- where it is not possible to avoid problems, know how to help themselves
- know how and where to find information on the law
- know how to find information that is accessible to them
- know when and how to obtain suitable legal assistance
- have confidence that the legal system will provide a remedy
- “understand the process clearly enough to perceive that justice has been done” (Hunter 11)

### 1.3.2 Legal capability

Hunter’s approach to legal literacy is reflected in the concept of legal capability. This concept appears to have supplanted and subsumed the notion of legal literacy in more recent Commonwealth literature on PLE.

Legal capability is rooted in the “capabilities” approach developed by economist Amartya Sen in the broader areas of human development and welfare<sup>10</sup> and built upon by Bryan Maddox and Martha Nussbaum. A “capabilities approach” looks at what people need to be able to do or be in order to make choices about their well-being (Jones 1). Specifically:

Legal capability can be defined as the abilities that a person needs to deal effectively with law-related issues....[c]apability needs to go beyond knowledge of the law, to encompass skills like the ability to communicate plus attitudes like confidence and determination (5).

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<sup>9</sup> The Public Health Association of British Columbia definition is set out in Section 1.2.2.

<sup>10</sup> See the Internet Encyclopedia of Philosophy for an article explaining Sen’s capabilities concept (Wells). See also, generally, Sen. It should be noted that Sen’s work has a broader focus on all areas of human development and welfare on the global level. Sen has also collaborated extensively with Martha Nussbaum, who built upon much of Sen’s work in the justice context: see, generally, Nussbaum 17-47. However, at the time of our writing of this report, Sen’s and Maddox’s work remains the main source for existing legal capability theory.

General literacy is vital to the development of overall legal capability – without literacy, the ability to understand and invoke one's legal rights can be limited (Sen 41; Maddox 186).<sup>11</sup>

The UK organization Law for Life (formerly PLENET) spearheaded attempts to define legal capability. Martin Jones, then with Law for Life, described legal capability as drawing on three areas of ability: knowledge, skills, and psychological readiness or “competence” (4).

One framework for understanding legal capability describes the three components as follows<sup>12</sup>:

- **Knowledge:** a basic awareness of the role of the law in everyday situations. This includes the knowledge that:
  - a right or entitlement has been violated or could be violated
  - there are possible legal solutions
  - further information or help might be needed to address the issue
  - there are places to go to get help
  
- **Skills:** abilities needed to pursue legal resolution effectively. These include:
  - literacy, including “functional literacy” – information skills needed to locate, understand, and act on information or advice in a problem-solving fashion<sup>13</sup>
  - language and communication skills
  - decision-making skills
  - organizational skills to keep track of calls, timelines, and the information needed to manage claims
  
- **Competence/Psychological Readiness:** the ability to act and continue to act until resolution is achieved. This might include:
  - confidence
  - determination
  - emotional or psychic fortitude

Based on these ideas, Law for Life developed a broad, four-pronged continuum or matrix that suggests various stages of legal capability.<sup>14</sup> We reproduce the matrix on the following page.

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<sup>11</sup> Maddox also references “numerous large-scale studies that observe a strong correlation between literacy and other determinants of well-being such as income, women’s labour force participation and health (Maddox 185).

<sup>12</sup> See Pleasance et al. *Reshaping* 29-30.

<sup>13</sup> This is comparable both to Hunter’s definition of “legal literacy” (discussed in Section 1.3.1.) and to the definitions of health literacy discussed in Section 1.2.2.).

<sup>14</sup> The matrix was originally produced by Law for Life and Bristol University PFRC, and is reproduced with their permission. It should be noted that general literacy is not specifically referenced within this continuum, and Sen’s notion that general literacy skills are vital to developing legal capability. See Maddox 186-190 and, generally, Sen. We discuss this gap in Part 1.4.1.



Fig. 1: Legal capability: The four key domains for evaluation

Recognizing and framing the legal dimensions of issues and situations	Is aware of the concept of rights and obligations and can recognise where the law applies to a situation.	Is able to frame a situation in terms of the law and distinguish between civil and criminal legal issues.	Is aware of the basic legal principles that underpin the legal system and can apply them to issues.	Has the communications skills and confidence to explain a law-related issue and ask and answer questions about it.			
Finding out more about the legal dimensions of issues and situations	Able to find out what rights and obligations apply in a particular situation.	Able to find out about basic legal processes and procedures that apply to particular situations.	Able to find out about the steps involved in dealing with a law-related issue.	Able to assess the different sources of information about a law-related issue.	Able to assess risks and opportunities, and decide when they can deal with a law-related issue themselves and when they might need expert advice.	Able to find out about different sources of advice and to choose one which will meet their needs.	
Dealing with law-related issues	Able to apply relevant information or advice that has been obtained.	Able to decide what a satisfactory outcome to a law-related issue looks like for them.	Able to anticipate and plan ahead, to identify opportunities and obstacles.	Able to identify and assess different courses of action for dealing with a law-related issue (which may include doing nothing), then plan and follow through an appropriate course of action.	Has communication and interpersonal skills to manage relationships and deal with the other parties involved.	Has personal skills and attributes such as confidence, self-esteem, motivation, calmness to persevere throughout the process.	Able to keep a good record of events, information and correspondence, and keep track of evidence.
Engaging and influencing	Aware of the impact of the law and legal institutions on their lives and on the lives of others.	Aware of relevant processes, structures and institutions that can be used to influence and participate in decision-making in order to achieve change.	Able to critically assess situations in order to weigh up opportunities.	Has communication and interpersonal skills necessary to engage and influence.	Has personal skills and attributes such as confidence, self-belief and strength to effect change either individually or collectively.		

In the Canadian context, the Action Committee on Civil and Family Justice (the Action Committee) summarizes legal capability as the ability to (12):

- recognize that there are legal components or aspects to many activities and events of everyday life
- better anticipate and manage these components
- be able to sort legal from non-legal aspects of problems and address their interdependence
- avoid unnecessary escalation of conflicts into more serious problems or disputes that may require legal intervention
- assess options that are available and that foster reasonable solutions in situations of conflict
- be aware of when and how legal representation can assist with disputes and how to access legal representation

The Canadian Bar Association expanded upon this approach by stating that law should be seen as a “life skill, with opportunities for all to develop and improve legal capabilities at various stages in their lives, ideally well before a legal problem arises” (18).

Moreover, the Action Committee felt that embedded in the concept of legal capability is the notion that it should be developed as a preventative set of skills to help people both avoid problems before they arise and solve problems as quickly as possible (13). This concept is illustrated in Table 2, adapted from a table used in the Action Committee’s report (13).

Table 2: Emphasis of legal capability at different stages in the legal continuum

<b>To avoid problems</b>	<b>To solve problems</b>	<b>To solve disputes by alternative methods</b>	<b>To solve disputes in courts or tribunals</b>
<ul style="list-style-type: none"> <li>• Identifying what you need to know about law at specific periods, or transitions, in your life</li> <li>• Having communication skills</li> <li>• Managing conflict constructively</li> <li>• Being organized</li> <li>• Knowing where and how to get reliable information</li> </ul>	<ul style="list-style-type: none"> <li>• Same as for avoiding problems, plus:</li> <li>• Knowing rights</li> <li>• Knowing what you want</li> <li>• Knowing type of help you need</li> <li>• Knowing who to speak to</li> <li>• Having problem resolution skills</li> <li>• Understanding different perspectives in a dispute</li> </ul>	<ul style="list-style-type: none"> <li>• Same as for avoiding and solving problems, plus:</li> <li>• Understanding of costs of pursuing justice in courts</li> <li>• Understanding of, and openness to, alternative dispute resolution processes</li> <li>• Trusting the available processes to be fair</li> </ul>	<ul style="list-style-type: none"> <li>• Same as for other columns, plus:</li> <li>• Knowing how to find reliable legal representation, legal aid and/or advocacy assistance</li> <li>• Being able to access and interpret resources to be seen as a self-represented litigant</li> <li>• Having confidence in an unbiased, transparent and fair situation</li> </ul>

The concept of “resilience” may also be an important factor in achieving legal capability. In a recent survey on access to justice issues conducted by the National Action Committee, one respondent noted the importance of meaningful access to legal information in supporting “resilience” or “reinforcing and enhancing the capacity of people to resolve disputes themselves”. Specifically:

It [access to justice] is also about access to information, support and opportunities, *and about having a fair and equitable experience in everyday life....* The focus on helping to build resilience in individuals, the community and the justice system by reinforcing access to information and *supporting the cultural changes necessary to ensure improvements in access to justice* are continuing [emphasis added] (14).

Though the Law for Life model of legal capability is the seminal model, recent Australian reports have attempted to build upon it by viewing legal capability from the perspective of vulnerable communities.<sup>15</sup> For example, the Law and Justice Foundation of New South Wales in Sydney, Australia has released a series of short papers based on data from a nation-wide legal needs survey. In this series, they canvassed access to justice for various groups, including people with disabilities (Pleasant et al. *Law and disorders* 1) and Aboriginal people (Wei and McDonald 1).

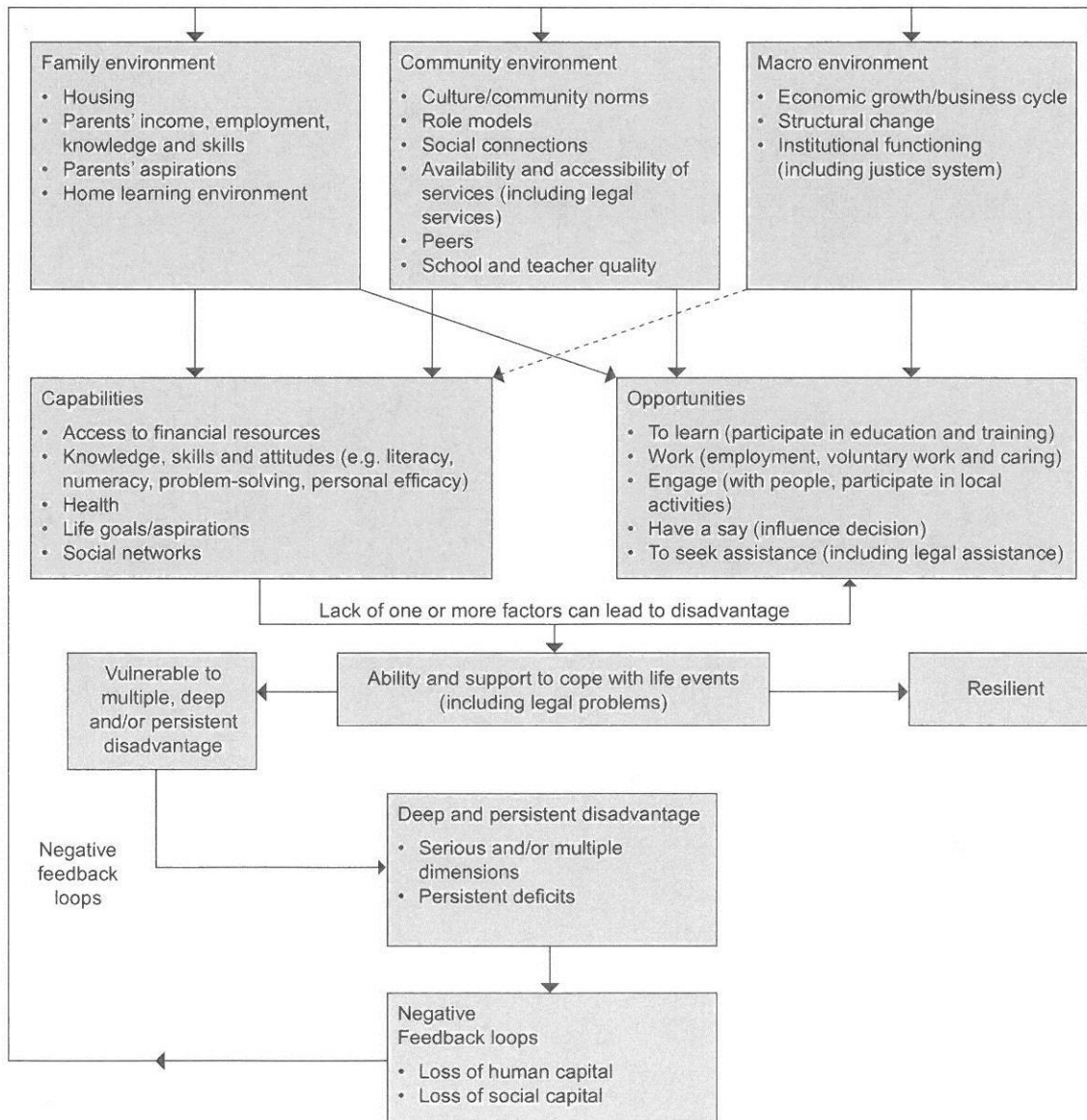
In a very recent discussion paper, the Law and Justice Foundation of New South Wales raised the idea that personal capabilities generally affect vulnerability and disadvantage, resulting in a “negative feedback loop” that exacerbates disadvantage further (Pleasant et al. *Reshaping* 126).

The diagram below, reproduced from the paper, provides a sample table of challenges and opportunities in developing capabilities and depicts the effect of disadvantage, including the ability to cope with legal problems (Pleasant et al. *Reshaping* 126).

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<sup>15</sup> See, generally, Pleasant et al. *Reshaping* 121-162. This will be discussed more fully in Part 1.4.2.

Fig. 2: Personal capability and other factors influencing experience of disadvantage\*



In sum, leading Commonwealth thinkers are beginning to integrate the impacts of vulnerability into the concept of legal capability. This approach parallels, to some degree, the approach used in health literacy (as discussed above). However, there are some important differences between legal capability and health literacy.

## 1.4 Parallels between the concepts of health literacy and legal capability

### 1.4.1 Overview: health literacy and legal capability

The concept of legal capability developed by Law for Life can be compared to Nutbeam's progressive three-level model of health literacy discussed in Section 1.2.2. Table 3 shows a rough comparison of the two models:

Table 3: Comparison of health literacy model and legal capability model

Health Literacy (Nutbeam)		Legal Capability (Law for Life)	
Level	Skills needed	Level	Skills needed
1. Functional	<ul style="list-style-type: none"> <li>Literacy (sufficient basic skills in reading and writing to be able to function effectively in everyday situations)</li> </ul>	1. Knowledge	<ul style="list-style-type: none"> <li>Awareness of the legal aspects in life events</li> <li>Know where to find out more</li> <li>Understand the issues</li> <li>Know routes to a solution</li> <li>Know where to go to get help</li> </ul>
2. Interactive	<ul style="list-style-type: none"> <li>Decision-making</li> <li>Organization</li> <li>Analysis</li> <li>Social interaction</li> </ul>	2. Skills	<ul style="list-style-type: none"> <li>Decision-making</li> <li>Organization</li> <li>Functional literacy (the "information skills required to locate, understand and act on information or advice in a problem-solving or goal oriented way" (Nheu and MacDonald 4)</li> </ul>
3. Critical	<ul style="list-style-type: none"> <li>Ability to effect change on group level</li> </ul>	3. Competence/ Psychological Readiness	<ul style="list-style-type: none"> <li>Confidence</li> <li>Determination</li> <li>Functional literacy in law reform context</li> </ul>

As can be seen in Table 3, there are many similarities between the two models. For example, at the interactive level both models contain a strong emphasis on decision-making and organizational skills.

Other parallels can be drawn from some of the additional literature reviewed for this paper. For example, the idea that health literacy embeds the ability to access information relevant to achieving or maintaining good health “across the life course” (Rootman and Gordon-El-Bihbety 14) mirrors the idea put forth in recent Canadian reports of developing “law as a life skill” (Canadian Bar Association 65).

However, there are notable differences between the two models that must be addressed, including the following:

- **Emphasis on general literacy skills:** though general literacy has been seen as essential in developing both health literacy (Nutbeam 266; Rootman and Gordon-El-Bihbety generally) and legal capability (Maddox 185; Sen 43), some existing literature on legal capability incorporates general literacy as a necessary attribute only at the second (or “skills”) component of the continuum.<sup>16</sup>

This seems inconsistent with the approach taken within the health care sector, where general literacy is recognized both explicitly and implicitly as the foundation and as a stepping stone to acquiring health information and to improving one’s health. It would be particularly difficult for a person with poor literacy skills to develop a basic understanding of their rights if they have poor general literacy skills, given the language-intensive nature of legal problems.

We note with interest that Australian literature on the topic of legal capability published within the last year has started to move in the direction of the need to incorporate literacy skills explicitly.

- **Importance of social determinants as barriers:** legal capability models are only beginning to incorporate the impact of disadvantage on the ability of vulnerable people or communities to deal with legal issues at whatever stage they arise – or indeed, before they arise.<sup>17</sup> In contrast, models of health literacy, such as Don Nutbeam’s, were founded to respond to social determinants.

Indeed, the concept of legal capability seems largely founded on the premise that a person is able to develop the “skills, knowledge, and attitudes” required to head off legal problems or navigate the legal system if necessary. But navigating the legal system – a system that in

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<sup>16</sup> Note, however, that “functional literacy” – or the information-processing skills needed to locate, understand, and act on information in order to solve problems or achieve goals – has been seen as a necessary underpinning to legal capability in the law reform context (see note 15 above). This is analogous to Nutbeam’s “critical” level of health literacy.

<sup>17</sup> Note that that recent access to justice literature does not ignore the impact of social and economic factors on the ability to resolve disputes through the formal legal system. For example, one paper notes, “While the legal system can guarantee ideals such as equality and impartiality in the abstract, in practice, dispute resolution through the formal legal system remains patterned with inequality and parity that systematically favours parties with greater social, political and economic clout” (Delhon et al. 4).

many cases presumes advice and representation by highly-trained lawyers – can be daunting for laypeople.<sup>18</sup>

For vulnerable people, barriers to preventing problems or navigating the legal system are compounded by any number of factors.<sup>19</sup> Thus, on a systemic level, the concept of legal capability needs to reflect the specific barriers that vulnerable people and communities face in recognizing and addressing legal problems and accessing the justice system. As noted earlier, this work has already begun in Australia.

#### **1.4.2 General literacy and legal capability – a first step?**

Admittedly, it can be difficult to assess who – or which groups – are lacking in either health literacy or legal capability. However, in the health care sector, developments in the measurement of health literacy – which include the explicit recognition that general literacy is a necessary foundation for health literacy – have helped inform health care providers on trends in low health literacy.

In contrast, at present, most legal capability models seem to presume at least a basic level of general literacy in order to fit within the continuum. However, the framework of “knowledge, skills, and competence” does not reflect the reality of many vulnerable Canadians who may lack the general literacy skills needed to acquire the base level of “knowledge” implied as necessary to deal with legal problems.

One way to start addressing this gap is to incorporate (or recognize explicitly) the need for general literacy within legal capability models in Canada. We find this a good starting point for reflecting on the present reality for vulnerable people trying to cope with the law. However, we also suggest that it is essential to incorporate social determinants into the existing concept of legal capability. That is, it is important to ensure that legal capability is grounded in a rights-based approach and founded on social determinants and either a core of general literacy or the ability of someone who does not have basic literacy skills to know where to go for help in deciphering legal problems.

Ensuring a rights-based approach would mean recognizing that many people come from a place where they do not understand that they enjoy basic human and legal rights, or carry certain responsibilities in such critical areas as obtaining, or maintaining, social assistance or housing. A good starting point is the definition of “legal literacy” arrived at by Laird Hunter in 1999, which we discuss in Section 1.3.1.

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<sup>18</sup> Many self-represented litigants have reported problems with navigating the legal system: See also *The National Self-Represented Litigants Project* and Canadian Bar Association *Reaching* 29-31. For example, one woman with a law degree recently reported the struggles she faced when submitting court forms on her own behalf (Macfarlane).

<sup>19</sup> See, generally, the discussion on personal capability and appropriate services in Pleasance et. al *Reshaping* 121-162.

In Part 3 of this paper we hope to stimulate future discussion of these ideas on general literacy and legal capability. Next we turn our attention to addressing some of the challenges in measuring health literacy.

## 1.5 Measuring health literacy

Health professionals and researchers have developed some creative approaches to learn what kinds of health information are most needed and to assess who most needs the information. To understand these approaches, however, it is important to understand how general literacy rates are measured in Canada.

### 1.5.1 Background – how general literacy is measured

According to Statistics Canada and the Organization for Economic Cooperation and Development, one of the primary tools used in the past to measure health literacy in Canada and many other jurisdictions was a generic survey tool known as the Adult Literacy and Skills Survey or ALL survey (*Literacy for Life* 32). This is the Canadian survey tool that has been developed in conjunction with an international literacy and life skills testing process intended to be conducted every 10 years.<sup>20</sup>

In Canada, the last major ALL survey data was collected in 2003<sup>21</sup> based on testing questions in English and French (Statistics Canada & OECD *Literacy for Life* 32). The 2003 ALL survey incorporated measures of prose literacy, document literacy, numeracy, and problem solving (Statistics Canada 13).<sup>22</sup> Oral, scientific, and digital literacy were not tested in the 2003 ALL survey (Canadian Council on Learning *Healthy* 14).

Health literacy was also tested through use of the 2003 ALL survey, as will be discussed further in the next section.<sup>23</sup>

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<sup>20</sup> Note that the most recent international survey testing literacy levels was the Survey of Adult Skills, conducted in 2012 (2013 Statistics Canada 53). The Organization for Economic Cooperation and Development developed the Survey of Adult Skills through its Programme for the International Assessment of Adult Competencies: (OECD 3).

<sup>21</sup> Note that Statistics Canada issued major reports on the ALL survey data in 2005 and 2011.

<sup>22</sup> In contrast, the Survey of Adult Skills tested the same domains but incorporated “problem solving in technology-rich environments” – or the ability to use “digital technology, communication tools and networks to acquire and evaluate information, communicate with others and perform practical tasks” (Statistics Canada & OECD 53). The Survey of Adult Skills also combined prose and document literacy into a single domain (53) and added digital literacy test questions (53) – it aimed to test the ability to function in a 21<sup>st</sup> century workplace (53). The ALL survey and the Survey of Adult Skills relied on different scales – they are so different that Statistics Canada cautions against comparing data from both surveys directly (Statistics Canada & OECD 53). See OECD 59 for a description of the domains used in the SAS.

<sup>23</sup> Note that health literacy was not tested in the Survey of Adult Skills. The only specific reference we found to health literacy in the Organization of Economic Cooperation and Development’s report on the Survey of Adult Skills was “Knowledge may also be associated with a greater sense of control over one’s life. For example, the concept of health literacy ... links health outcomes with the ability to understand and process information



In Canada, there are five recognized levels of literacy in both the general and health literacy contexts (Canadian Council on Learning *Healthy 12*)<sup>24</sup>:

- **Level 1** – very poor literacy skills
- **Level 2** – capacity to deal only with simple, clear materials involving uncomplicated tasks
- **Level 3** – adequate to cope with the “demands of everyday life and work in a complex, advanced society”<sup>25</sup>
- **Level 4** – strong skills
- **Level 5** – strongest skills

Table 4 compares Canadians found to have low (Level 1 or 2) general literacy and health literacy through the 2003 testing.

Table 4: Low general and health literacy statistics – 2003 ALL survey data<sup>26</sup>

Percentage of Canadians with low level of literacy – 2003 ALL survey data		
Type of literacy skill (age range)	General Literacy	Health Literacy
Prose (16-65)	42	48
Prose (all age ranges 16+)	48	54
Document (16-65)	43	52
Document (all age ranges 16+)	48	57
Numeracy (16-65)	50	54
Document (all age ranges 16+)	55	58
Overall literacy (16-65)	44	55
Overall literacy (all age ranges 16+)	46	60
Overall literacy (65+)	82	88

Clearly, the percentage of adults in Canada with low health literacy is estimated to be considerably higher than the percentage of those with low general literacy. Indeed, in 2008, it was estimated that 60% of Canadian adults lack the skills to read and understand health information, communicate their needs to health professionals, and understand the steps that they should take to improve their health (Canadian Council on Learning *Healthy 5*).

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relating to health, from basic information on appropriate dosages found on medicine bottles to the contents of materials distributed as part of public-health campaigns” (OECD 237).

<sup>24</sup> For a fuller description of these literacy skills levels, see Statistics Canada & OECD 16.

<sup>25</sup> The ABC Canada Literacy Foundation clarified “[Level 3] denotes roughly the skill level required for successful secondary school completion and college entry. Like higher levels, it requires the ability to integrate several sources of information and solve more complex problems” (ABC Canada 1).

<sup>26</sup> This table was compiled by CLEO from data found in Statistics Canada & OECD and the Expert Panel’s report (Ronson and Rootman).

This lack of health literacy could also lead to being unable to navigate the health care system and, ultimately, to poor health or accidents (Canadian Council on Learning *Healthy* 6).

This phenomenon is likely due, in part, to the fact that health content literacy tasks measured through the ALL survey are more likely to require simultaneous forms of literacy to achieve one task – for example, in order to understand health information fully, one must be able to understand both prose and numbers (Ronson and Rootman 5).

### 1.5.2 How health literacy is measured

We looked at two types of tools used to measure health literacy: research-based tools and practical tools developed for use in primary care settings. In this section we address both types of tools.

#### Research and statistical tools

The most common measure used in Canada to assess health literacy is the “health-activity literacy scale” developed in 2007 by Statistics Canada and three US educational and health research organizations (Ronson and Rootman 5).

This measure is used to sift data from the test items and literacy tasks to find items dealing with health content in the ALL survey (Canadian Council on Learning *Healthy* 6). Out of 350 unique assessment items in the ALL survey, researchers found 191 items in the US tests and 231 items in the Canadian tests concerned health related activities – for example, reading nutrition labels on food packaging (Rootman and Gordon-El-Bihbety 8; CCL 7). The researchers then analyzed the health-specific items in the ALL survey to create the health activity literacy scale (Canadian Council on Learning *Healthy* 7). Table 5 provides information about the health activity literacy scale measure.

Table 5: Literacy levels and scores<sup>27</sup>

Level	Score Range	Interpretation
1	0 – 225	Tasks at this level require the ability to read relatively short text, locate or enter a piece of information and complete simple, one-step tasks such as counting, sorting dates or performing simple arithmetic.

<sup>27</sup> The information in this table originated from the 2003 ALL survey and is reproduced from Canadian Council on Learning 12.

Level	Score Range	Interpretation
2	226 – 275	Tasks at this level require, for example, the ability to sort through “distractors” (plausible but incorrect pieces of information), integrate two or more pieces of information, compare and contrast information, and interpret simple graphs.
3	276 – 325	These tasks require the ability to integrate information from dense or lengthy text, integrate multiple pieces of information and demonstrate understanding of mathematical information represented in a range of different forms. Tasks typically involve a number of steps or processes in order to solve problems.
4	326 – 375	Tasks at this level involve multiple steps to find solutions to abstract problems. Tasks require the ability to integrate and synthesize multiple pieces of information from lengthy or complex passages and make inferences from the information.
5	376 – 500	Tasks at Level 5 require the ability to search for information in dense text which has a number of distractors, make high-level inferences or use specialized background knowledge and to understand complex representations of abstract formal and informal mathematical ideas.

The literature suggests that the health activity literacy scale provides valid and reliable measures of the ability to deal with health-related tasks (Rootman and Gordon-El-Bihbety 12; Canadian Council on Learning *Healthy* 16). However, it also has some notable limitations (Rootman and Gordon-El-Bihbety 13; Canadian Council on Learning *Healthy* 16). Specifically:

- it doesn't measure oral comprehension or communications skills
- it wasn't designed with specific population groups or socio-cultural contexts in mind and is considered by some to contain a “Western bias”<sup>28</sup>
- it doesn't measure the ability to solve problems or read scientific terms<sup>29</sup>

In addition to the health activity literacy scale, there have been many studies in the health information and promotion sector on how to measure health literacy in specific

<sup>28</sup> That is, unlike the overall definitions of health literacy discussed earlier in this report, the statistical tools for testing health literacy do not incorporate most of the social determinants of health. The health researchers who designed the health activity literacy scale were limited by the original data set within the ALL survey.

<sup>29</sup> The cultural and problem-solving testing gaps are particularly notable because they would clearly be relevant to any attempts to measure legal capability – particularly if programs intended to increase legal capability focus on enabling people to engage in self-help or to represent themselves in civil mediations or hearings.

communities.<sup>30</sup> However, the number of definitions of health literacy has contributed to the lack of a “gold standard” for measuring health literacy in any specific community (McCormack et al. 12).<sup>31</sup>

The outcomes from use of the health activity literacy scale outcomes have also informed at least one Canadian project designed to help health care providers and organizations design population-appropriate strategies for providing health care information and services within their communities. The Canadian Council on Learning’s interactive map shows the distribution of low health literacy in more than 49,000 communities and neighbourhoods across Canada.<sup>32</sup>

Though this type of map can be useful on a macro level, it does not help health care professionals assess the health literacy skills of individual patients. Next we will discuss some tools available for that purpose.

### **Tools for health care professionals**

The main tools used by health professionals in Canada to measure health literacy are two tests developed in the 1990s in the US: the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) (Ronson and Rootman 245). These tests are used extensively in clinical settings in the US (Rudd et al., 188). REALM is a short word recognition test, while TOFHLA is a short reading comprehension test using hospital forms – thus, both only assess prose literacy skills.<sup>33</sup>

Both REALM and TOFHLA are seen as more limited than the health activity literacy scale, as they “offer approximations of reading skills and do not test health literacy.” (Rudd et al. 183). This finding is informed by the understanding that in order to master health literacy tasks, one must typically use prose literacy, document literacy, and numeracy skills simultaneously (CCL 25).

One similar quick health literacy screening instrument developed for use in health care settings in the US, the Newest Vital Sign, does incorporate mathematical tasks. This test is available in both English and Spanish. As seen in Figure 4, the Newest Vital Sign consists of a nutrition label from an ice cream container together with six questions intended to test the patient’s understanding of data on the nutrition label (for example: “If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?”).

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<sup>30</sup> See, generally, Kwan, Frankish and Rootman (adults) and Begoray and Kwan (youth).

<sup>31</sup> Note that this lack of a “gold standard” makes it difficult to draw comparisons that might be helpful for measuring legal capability.

<sup>32</sup> This map is based on the ALL survey data from 2003 and the Canada 2001 Census. It has not been subsequently updated (Canadian Council on Learning “Map”).

<sup>33</sup> In the US, the primary versions of the test used are in English and Spanish. In Canada, a version in French for Canadian francophones has also been developed.

Fig. 4: Newest Vital Sign test label and score sheet

<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <th colspan="4" style="text-align: left; padding: 5px;"><b>Nutrition Facts</b></th> </tr> <tr> <td style="padding: 2px 5px;">Serving Size</td> <td colspan="2"></td> <td style="text-align: right; padding: 2px 5px;">½ cup</td> </tr> <tr> <td style="padding: 2px 5px;">Servings per container</td> <td colspan="2"></td> <td style="text-align: right; padding: 2px 5px;">4</td> </tr> <tr> <th colspan="4" style="text-align: left; padding: 5px;">Amount per serving</th> </tr> <tr> <td style="padding: 2px 5px;">Calories</td> <td style="text-align: right; padding: 2px 5px;">250</td> <td style="padding: 2px 5px;">Fat Cal</td> <td style="text-align: right; padding: 2px 5px;">120</td> </tr> <tr> <td colspan="3"></td> <td style="text-align: right; padding: 2px 5px;">%DV</td> </tr> <tr> <td style="padding: 2px 5px;"><b>Total Fat</b></td> <td style="text-align: right; padding: 2px 5px;">13g</td> <td></td> <td style="text-align: right; padding: 2px 5px;">20%</td> </tr> <tr> <td style="padding: 2px 5px;">Sat Fat</td> <td style="text-align: right; padding: 2px 5px;">9g</td> <td></td> <td style="text-align: right; padding: 2px 5px;">40%</td> </tr> <tr> <td style="padding: 2px 5px;"><b>Cholesterol</b></td> <td style="text-align: right; padding: 2px 5px;">28mg</td> <td></td> <td style="text-align: right; padding: 2px 5px;">12%</td> </tr> <tr> <td style="padding: 2px 5px;"><b>Sodium</b></td> <td style="text-align: right; padding: 2px 5px;">55mg</td> <td></td> <td style="text-align: right; padding: 2px 5px;">2%</td> </tr> <tr> <td style="padding: 2px 5px;"><b>Total Carbohydrate</b></td> <td style="text-align: right; padding: 2px 5px;">30g</td> <td></td> <td style="text-align: right; padding: 2px 5px;">12%</td> </tr> <tr> <td style="padding: 2px 5px;">Dietary Fiber</td> <td style="text-align: right; padding: 2px 5px;">2g</td> <td></td> <td></td> </tr> <tr> <td style="padding: 2px 5px;">Sugars</td> <td style="text-align: right; padding: 2px 5px;">23g</td> <td></td> <td></td> </tr> <tr> <td style="padding: 2px 5px;"><b>Protein</b></td> <td style="text-align: right; padding: 2px 5px;">4g</td> <td></td> <td style="text-align: right; padding: 2px 5px;">8%</td> </tr> <tr> <td colspan="4" style="padding: 5px;"> <p><small>*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.</small></p> <p><b>Ingredients:</b> Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.</p> </td> </tr> </table>	<b>Nutrition Facts</b>				Serving Size			½ cup	Servings per container			4	Amount per serving				Calories	250	Fat Cal	120				%DV	<b>Total Fat</b>	13g		20%	Sat Fat	9g		40%	<b>Cholesterol</b>	28mg		12%	<b>Sodium</b>	55mg		2%	<b>Total Carbohydrate</b>	30g		12%	Dietary Fiber	2g			Sugars	23g			<b>Protein</b>	4g		8%	<p><small>*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.</small></p> <p><b>Ingredients:</b> Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.</p>				<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <th colspan="3" style="text-align: center; padding: 5px;"><b>Score Sheet for the Newest Vital Sign Questions and Answers</b></th> </tr> <tr> <td style="padding: 5px;"> <p><b>READ TO SUBJECT:</b> This information is on the back of a container of a pint of ice cream.</p> </td> <td colspan="2" style="text-align: center; padding: 5px;"> <table border="1" style="border-collapse: collapse;"> <tr> <th colspan="2" style="font-size: 8px;">ANSWER CORRECT?</th> </tr> <tr> <th style="font-size: 8px;">yes</th> <th style="font-size: 8px;">no</th> </tr> </table> </td> </tr> <tr> <td style="padding: 5px;"> <p>1. If you eat the entire container, how many calories will you eat? <i>Answer: 1,000 is the only correct answer</i></p> </td> <td style="text-align: center; width: 50px;"><input type="checkbox"/></td> <td style="text-align: center; width: 50px;"><input type="checkbox"/></td> </tr> <tr> <td style="padding: 5px;"> <p>2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have? <i>Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl."</i></p> </td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="padding: 5px;"> <p>3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. 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Reports note that the Newest Vital Sign has been used both in clinical settings to help health care providers tailor their communication levels to the patient’s health literacy level and in research to help researchers measure health literacy (Weiss et al. 514 ; Shah et al. 195). The Newest Vital Sign has been found to be suitable as a quick screening test for limited literacy in health care settings (Weiss et al. 521; Shah et al. 199).<sup>34</sup>

**Parallel – how are legal literacy and legal capability measured?**

In our research, we found no universal measure to test either legal literacy or legal capability in use. That is, no equivalent of the health activity literacy scale seems to exist to test the ability to read and understand legal forms and correspondence. Moreover, the Statistics Canada ALL data contains no questions that test knowledge of legal terms.

As well, there are no tools analogous to the Newest Vital Sign that can be used to assess a person’s legal literacy or capability. Such a tool might be useful for front line legal workers or trusted intermediaries to determine what level of help or intervention a person might

<sup>34</sup> Barry Weiss and his colleagues also suggested that the Newest Vital Sign “may be the most sensitive test for screening persons with limited literacy skill [emphasis added]” (34). It should be noted that the Newest Vital Sign test was developed and promoted by a major US-based pharmaceutical company.

need in order to read and understand legal forms and correspondence. In place of a nutrition label, such an assessment tool could incorporate a short standard legal form (such as a parking ticket, a legal notice for termination of a tenancy, or a letter from a social assistance provider with deadlines for returning information involved).

Such a tool might provide a useful starting point in identifying and measuring legal capability on both the individual and community levels. However, as discussed above, existing tools used to measure health literacy have some limitations that must be addressed if they are to be adapted for use in the legal context. The socio-cultural biases within the testing process and the lack of testing of problem-solving ability are particularly problematic.

This is not to denigrate the efforts taken to measure health literacy. Indeed, both defining and measuring health literacy have proven challenging. However, a significant body of literature addresses the various factors that determine levels of health literacy. Chief among those factors is the concept of the impact on social determinants on both health literacy and good physical and emotional health.

## 1.6 Some factors affecting health literacy in Canada

In this section we focus on two social determinants that have had a dramatic impact on health literacy levels across many vulnerable communities in Canada: education and social exclusion.

### 1.6.1 Who is most at risk

Certain groups of Canadians are more likely to have low health literacy than others. The following information highlights overall trends in low health literacy within vulnerable communities in Canada.<sup>35</sup>

- **People with disabilities:** Approximately 50% of Canadians with disabilities experience health literacy barriers (Rootman and Gordon-El-Bihbety 15).
- **Aboriginal people<sup>36</sup>:** Researchers have found that Aboriginal people in Canada are “significantly worse off than non-Aboriginal people” in terms of general literacy (Gulati 15). As well, it is widely acknowledged that Aboriginal people have poorer

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<sup>35</sup> Unless otherwise noted, the information in this section is derived from Statistics Canada.

<sup>36</sup> Note that in the health activity literacy scale study, Aboriginal people were found to be within the national averages for health literacy. However, the underlying ALL data focused only on a limited segment of the Aboriginal population – specifically, urban Aboriginals in two provinces and selected Aboriginal communities in each of the three territories. Also, in the four general literacy domains, Aboriginal people scored significantly worse across the board than the total Canadian population (Gulati 11).

health status and outcomes than other Canadians (Public Health Association of British Columbia 17).<sup>37</sup>

- **Income support recipients:** People receiving income support were 2.5 times more likely to be at the bottom of the health literacy scale regardless of age, gender, mother tongue, immigration, and Aboriginal status (Canadian Council on Learning *Healthy* 15).
- **Newcomers to Canada:** Immigrants tend to have lower levels of health literacy than non-immigrants.<sup>38</sup>
- **Socio-economic conditions (violence in the home, lack of nurturing in childhood):** It is generally understood that the individual capacity to be health literate is greatly affected by a complex web of socio-economic conditions as a social determinant of health” (Rootman and Gordon-El-Bihbety 25).<sup>39</sup>

More specifically, three groups of Canadians<sup>40</sup> have been found to have dramatically lower levels of skills than the national average in terms of health literacy (Canadian Council on Learning *Healthy* 22):

- Seniors (ages 65 and older)
- Immigrants (especially those who do not speak either English or French)
- People who are not employed

There are many factors that might suggest why these groups display less health literacy than other groups.<sup>41</sup> However, two social determinants potentially link all three groups: education and social exclusion.

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<sup>37</sup> It is also suggested that 1 in 5 Aboriginal people aged 15 or over has a disability (a higher percentage than the number of people with disabilities overall in Canada) and corresponding issues with literacy generally (Gulati 16). This further compounds difficulties in accessing health information.

<sup>38</sup> In many immigrant communities, there may also exist a strong cultural suppression effect that mitigates against accessing health information. Moreover, immigrant women were found to have lower health literacy skills than immigrant men overall (Rootman and Gordon-El-Bihbety 17). Also, lack of cultural sensitivity or relevance in presentation of information may create further barriers (Ng and Omariba 19).

<sup>39</sup> Note that according to Rootman and Gordon-El-Bihbety, no specific data existed at the time of their report regarding the impact of these conditions on health literacy.

<sup>40</sup> It should be noted that the health literacy data indicates a wide variation of health literacy levels across various provinces and territories. However, we are focusing on Canada-wide statistics. For more information on this, see, generally, Statistics Canada and Canadian Council on Learning *Healthy* 2008.

<sup>41</sup> For example, senior populations may be disproportionately affected by health and mental health declines related to aging (Rootman and Gordon-El-Bihbety 24). Newcomers to Canada are likely affected because health literacy testing is conducted in English or French (17). Other factors associated with low health literacy of new immigrants include culture, beliefs, and institutional factors related to healthcare requirements, services, and programs (Zanchetta and Poureslami 29).

## 1.6.2 How level of education affects health literacy

The Canadian Council on Learning identified the following factors as influencing good health literacy:

- reading practices (for example, reading books, newspapers, or emails on a daily basis)
- educational attainment
- having a mother tongue different than the languages that literacy tests are conducted in (English or French in Canada) (27).

All of these factors are directly or indirectly linked to education. Specifically, having low levels of formal education has been linked to low proficiency in health literacy (Rootman and Gordon-El-Bihbety 16). If individuals cannot understand the health information they are provided, they cannot take control of their health (Canadian Public Health Association *Public Health* 12).

Prose literacy has been shown in US studies to have a correlation with increased mortality in seniors (Baker et al. 1503).<sup>42</sup> The Canadian Council on Learning also found, for example, that diabetes was strongly linked to health literacy (*Healthy* 16). Moreover, many health-related activities, tasks and contexts are linked to print materials (for example, handouts about prescription medications or labels on medicine bottles) - many of which have a complex vocabulary and are hard to understand (*Healthy* 24).

Irving Rootman and Deborah Gordon El-Bihbety point out that education is also closely tied to socioeconomic status, since education equips people with knowledge and skills for problem solving, and helps provide a sense of control and mastery over life circumstances. (16). It also improves people's ability to access and understand information to help keep them healthy (17).

As noted, unemployed people are at higher risk of low health literacy than employed people. Education can influence employment and income levels (Rootman and Gordon-El-Bihbety 24). For example, people with higher levels of education have access to less hazardous jobs, which reduces their risks associated with workplace injuries (CPHA 2010).

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<sup>42</sup> For example, in a study by David Baker and his colleagues, people ages 56 and older with low health literacy skills were found to have a 50% higher mortality rate over a five year period than people in the same age range with adequate health literacy skills. Low health literacy was the top predictor of mortality after smoking. See also Sudore et al. for another US study with similar findings. It should be noted, however, that regardless of education levels, seniors are also disproportionately affected in health literacy by their age. This is because health literacy skills rise with level of education and decline with age - meaning that the health literacy gap between highly and less highly educated people widens with age (Rootman and Gordon-El-Bihbety 16).



People with more education also tend to have better job security and less risk of prolonged unemployment (Rootman and Gordon-El-Bihbety 17).

Immigrants to Canada who have not been educated in English or French also face increased problems with health literacy. This is not surprising, as lower proficiency in English or French is likely to hinder their ability to obtain and use health information in many Canadian contexts (Pottie et al. 505).

Thus, lack of formal education can be seen, in part, to disproportionately affect the three groups most at risk on the national level in acquiring and maintaining health literacy. Lack of education can also lead to a sense of exclusion from many of the benefits open to people with higher levels of literacy and education (Rootman and Gordon-El-Bihbety 24).

### **1.6.3 How social exclusion affects health literacy**

As Juha Mikkonen and Dennis Raphael state, “Social exclusion creates the living conditions and personal experiences that endanger health” (32).

Common among the three “at risk” groups discussed above (seniors, immigrants, and unemployed people) is the fact that they are also at high risk of social exclusion for various reasons. This might influence not only their health and well-being but also, potentially, their ability to acquire health literacy (Mikkonen and Raphael 32).

People at the lowest health literacy level were generally found to be 2.5 times less likely to have participated in community events or volunteering (Canadian Council on Learning *Healthy* 25). This also suggests some level of social exclusion.

More specifically, seniors in Canadian society increasingly face social exclusion, particularly if their physical condition makes it difficult or impossible for them to leave their homes (Rootman and El-Bihbety 28). Seniors who have such difficulty can go days or weeks without any human interaction, making it difficult for them to gain or use health information.

Newcomers to Canada are also more likely to face social exclusion from the wider Canadian community due to discrimination, lack of proficiency in English/French, and poor social supports (Zanchetta and Poureslami 27).

Unemployed people also face social exclusion as a result of not going to a workplace and because of social stigma attached to not working (Rootman and Gordon-El-Bihbety 25).

The fact that these three groups of people experience lower health literacy overall may serve to compound the effects of their exclusion. Without adequate health literacy a person is dependent on those around them knowing and providing what they need for their best

health (Canadian Public Health Association *Public Health* 16). Where the person does not have anyone around – or where the people around them also have low health literacy – the person's ability to become or remain health literate is increasingly compromised.

#### **1.6.4 Parallel - how education levels and social exclusion affect legal capability**

In the literature we found little explicit examination of the effects of low education levels or social exclusion on the ability to obtain and use legal information.<sup>43</sup>

Ab Currie addressed social exclusion in the context of analyzing a survey of Canadians on justiciable issues (*Legal Problems* 47). Specifically, social exclusion can also be viewed as “a process by which people fall away from the social mainstream, from lives of self-sufficiency to lives of dependency” (*Legal Problems* 47). His report found that people with multiple legal problems who were affected by social exclusion faced worse consequences and outcomes with respect to all or some of their legal problems than those in the social mainstream (47).

Karen Cohl and George Thomson have also directly examined the effects of social exclusion with a focus on vulnerable Ontarians living in rural and remote locations. Social exclusion among these Ontarians is tied to the smaller sizes of rural and remote communities and to the relative lack of social or support services in those communities (Cohl and Thomson 32-33).<sup>44</sup>

Their report also looked at the impact of lack of understanding of either official language on the ability to get legal information or access legal services, which, as discussed earlier, is tied to education. Specifically, Karen Cohl and George Thompson found that newcomers to Canada who do not speak English or French face significant barriers (15)<sup>45</sup>.

The paucity of literature addressing issues of education or social exclusion in itself highlights a major gap in theory and research about legal capability and PLE: the lack of a systemic understanding regarding social determinants' influence on the ability to access legal information and achieve legal capability. This lack of literature related to the PLE field stands in sharp contrast with the literature on the role of social determinants in shaping definitions and measurement of health literacy. In the next section of the paper we address some of the effects of this gap and some ways to move forward in the context of legal capability.

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<sup>43</sup> This may be due to the fact that, unlike in the health care sector, to date there is no systemic recognition of the effect of social determinants in the legal context.

<sup>44</sup> Another factor indirectly related to social exclusion in rural and remote communities is the very small size of the communities themselves. For example, rural women experiencing domestic violence might find it more difficult to get support due to a heightened possibility of personal conflict and greater difficulty in maintaining confidentiality (Cohl and Thomson 33).

<sup>45</sup> It should be noted that this can also be compounded by cultural barriers. Studies have shown that many newcomers are reluctant to access services that do not recognize their cultural and value systems or faith traditions (Cohl and Thomson 15-16).

## 1.7 Summary: social determinants – a first principle

As discussed above, social determinants have informed developments in health literacy and measurement. It does not take a stretch of the imagination to wonder whether the concept of social determinants could come into play with respect to informing our understanding of legal capability.

Though the legal literature in Canada and elsewhere increasingly addresses which vulnerable populations are more likely to face both legal problems and barriers to solving those problems, there have been no determinative discussions or reports about which societal factors compromise people's ability to access legal information or enjoy legal capability.

However, in the access to justice sector there is increasing interest in talking about the "social determinants of civil justice" in a way that mirrors the logic of the social determinants of health<sup>46</sup> (Delhon et al. 3). People working in the social justice and community legal sectors have long been well aware of the issues affecting vulnerable communities. Now might be the time to turn attention to understanding these on a systemic level in the legal context.

We acknowledge that, at first blush, this may seem purely an academic exercise. However, as noted above, academic discussions of social determinants in the health context resulted in acknowledgment of their role and to sweeping changes regarding health literacy and delivery of health information at the ground level, especially in vulnerable communities.<sup>47</sup>

A similar enumeration of the factors that make it difficult or impossible for many Canadians to achieve legal capability might help raise needed awareness – particularly as these factors pertain to commonalities amongst various vulnerable communities – and promote systemic changes down the road.

Thus, identifying the various factors that make it difficult for certain groups of Canadians to be legally literate and to access legal information before they are in crisis will increase the ability of legal information providers to raise awareness about the legal issues facing marginalized communities in a concerted way. Creation of a list of "social determinants of civil justice" could also be useful on a systemic level to draw attention to the barriers facing vulnerable Canadians.

In sum, primarily because of the influence of research related to social determinants, the definition of "health literacy" has evolved to embrace the idea that health literacy is

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<sup>46</sup>Of note in this regard: Ab Currie found that almost 40% of people with one or more legal problems reported having other social or health related problems that they directly attributed to a justiciable problem (*Legal Problems* 76-77).

<sup>47</sup>As will be discussed in Section 2 of this paper, the acknowledgement that social determinants impact the ability of vulnerable people to get health information and help has also led to a broad-based and creative approach to delivery of health information at the ground level.

important at many stages of life. Similarly, legal issues affect our everyday lives in ways that are not always immediately obvious. Thus, a robust understanding of the social determinants of civil justice coupled with targeted outreach could help make early intervention in legal problems a more realistic goal.

But social determinants have not only been used to define and measure health literacy among individuals and communities. They have also played a positive role in opening pathways to health information in Canada and other jurisdictions. In the next section we discuss access to health information in Ontario.

## Part 2: Access to health promotion activities and legal information

This part of the paper will provide a high-level overview of the following:

- access points for health promotion activities
- approaches to health promotion activities in the community health sector
- working with intermediaries
- distinctions between health promotion activities and PLE

### 2.1 Access points in health promotion

As discussed above, health promotion activities are conducted as part of the continuum of health care services that are widely available to people in Ontario. It is generally agreed that there are three target points for health promotion activities<sup>48</sup>:

- **primary** – targeted at the general population, including general information to promote health and well-being, such as healthy diet and exercise practices
- **secondary** – targeting populations at risk of acquiring certain diseases or disorders, for example, campaigns to try to get smokers to quit smoking
- **tertiary** – targeting people who are already ill and need medical help

There are extensive health promotion activities in Ontario intended to deliver information to vulnerable communities – many of which focus on a primary or preventative-type approach to health information and promotion. At this time, this front-line work is primarily conducted by community health clinics and community health nurses.

**Community health clinics** – these are non-profit, community-governed health organizations. Part of their mandate is to “have a commitment to equity and social inclusion and put emphasis on access to health care (with special attention given to the most vulnerable), and on respect for fundamental human rights” (Canadian Alliance of Community Health Care Centre Associations 9). In addition to providing primary health care, community health clinics also conduct health information and community development services using inter-disciplinary teams of health providers, such as physicians, nurses, dieticians, health promoters and counselors.<sup>49</sup>

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<sup>48</sup> See, generally, Association of Faculties of Medicine of Canada. In contrast, in the public legal education community a recent report identifies three target points for legal information activities: **General** (support intended to educate about rights in advance of problems arising), **Crisis** (narrowly focused information intended to deal with an acute legal problem) and **Resolution** (intended to help people navigate the legal system regarding a specific problem) (Boyd).

<sup>49</sup> See Appendix 2 for examples of the types of health information and work done by community health centres.

**Community health nurses** – these nurses are employed by public health units in Ontario and other Canadian jurisdictions to identify preventative health information needs and create and deliver community programs. Many of their programs are mobile – designed to be delivered directly to diverse communities and schools. Because of this, community health nurses have been described as “hav[ing] the unique distinction of practicing in ‘a setting without walls’” (Registered Nurses’ Association of Ontario 9).

Community health nurses participate in advocacy, capacity-building, and community development initiatives.<sup>50</sup> They also play a large role in Ontario’s primary and secondary schools by designing and running age-specific programs in schools to educate students on physical and mental health issues from a young age.<sup>51</sup>

### Parallels

The three target point model in the health promotion sector – primary, secondary and tertiary – also applies to the PLE field. However, there is far less emphasis on preventative-type activities in PLE.<sup>52</sup>

In Ontario, the closest comparators to the work being done by community health clinics and community health nurses are found in the community legal clinic system. Community legal clinics, which receive the majority of their funding from Legal Aid Ontario, are mandated to carry out a wide range of activities, including PLE. They employ community legal workers to help with outreach work. Community legal workers are, or are intended to be, the equivalent of community health nurses only in the legal sector – they deliver PLE to their communities, whether defined geographically or otherwise.

However, a number of factors impact on the ability of community legal clinics and community legal workers to deliver PLE, especially in busier urban clinic regions (for example, the Greater Toronto Area and Ottawa) and rural and remote communities. Most importantly, unlike the health care sector, where the continuum of services is supported by public funding, relatively speaking, community legal clinics receive much lower funding, which they then must spread over a range of legal services for the most marginalized communities in the province.

More specifically, legal clinics face a high volume of vulnerable people at the “tertiary” stage who need legal advice and representation in order to deal with a problem that has

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<sup>50</sup> See, generally, Canadian Public Health Association *Public Health* 19–26 and Appendix 3 of this paper for examples of the types of health information provided by community health nurses.

<sup>51</sup> See Appendix 3 for a brief discussion and examples of the role of community health nurses in the school system. Note also that in Ontario, at least two organizations presently design and deliver PLE programs targeting youth. The Ontario Justice Education Network, a sole-purpose PLE organization, promotes education about the operation of the justice system and options for youth to pursue social change. Justice for Children and Youth also conducts PLE activities and outreach. However, most of these activities focus on the criminal justice system.

<sup>52</sup> See also the discussion in Parts 1.4 and 2.4.

reached the crisis stage and that involves an administrative tribunal or court. As a result, it is extremely challenging to carve out funding and staff resources for PLE activities that target people at the primary and secondary stages of intervention.<sup>53</sup>

However, community legal clinics in Ontario have been among the first to recognize the need to reach people as early as possible in the legal life cycle. For example, several community legal clinics have developed, or are developing, “legal health check” tools to help people identify and address potential or actual legal problems as soon as possible.

Legal health checks are intended to help clients or intermediaries identify when problems a person might be facing have a legal component. It is also hoped that use of these tools will raise vulnerable peoples’ awareness about problems that might arise down the road, allowing them to access information and help in the early stages of a problem.<sup>54</sup>

## 2.2 Approaches to health promotion

The work of community health clinics and community health nurses is innovative and wide-ranging.<sup>55</sup> Here are some aspects of their work we found the most noteworthy:

- the holistic approaches they bring to disseminating health information
- their focus on identifying and meeting the needs of vulnerable community members by designing and targeting programs for them
- their belief that information is most useful and accessible when you bring it to the places where people go

The community health sector in Ontario and elsewhere accomplishes health promotion through a variety of strategies and approaches. These include:

- a broad range of mobile health information programs brought by community health nurses directly to vulnerable communities and youth, targeting their specific needs, language levels, and learning abilities
- a focus on the need for clear language when communicating directly with patients or preparing printed health information and website information
- partnerships between the community health sector and intermediaries, such as community workers and peer mentors, to facilitate delivery of health information to an increasingly diverse base

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<sup>53</sup> The notion that more early intervention activities and practices are needed to address the crises that many Canadians – especially those from vulnerable communities – find themselves in when grappling with legal issues has been discussed in recent literature on access to justice (Canadian Bar Association *Reshaping* 22, Law and Justice Foundation of New South Wales 132, National Action Committee 3-8).

<sup>54</sup> One current legal health check project in Southwestern Ontario that four community legal clinics are undertaking also involves a needs assessment to take place over a three year period: see Currie “Halton”.

<sup>55</sup> See Appendices 2 and 3 for some examples.

## Parallels

There are clear parallels to these approaches in PLE work in Ontario.<sup>56</sup> Some examples:

- legal information sessions offered by community legal clinics on poverty law issues at community venues such as libraries and drop-in centres
- increased focus on developing clear language legal information materials and websites in a variety of formats to ensure greater accessibility
- the relatively recent acknowledgement and wider acceptance of the idea that use of community intermediaries is vital to bringing legal information to wider audiences in a manner that meets their specific needs

However, on a systemic level, these developments in the legal information sector lag far behind those in the health promotion sector. Interestingly, this is consistent with the proposition discussed earlier about the fact that there needs to be a systemic and explicit understanding of the impacts of social determinants with regard to legal capability.

### 2.3 Working with intermediaries

As discussed, the health promotion sector has relied increasingly on intermediaries to help deliver information. As we will explain in this section, intermediaries have also been used to help with PLE initiatives.

“Trusted” or “key” intermediaries are defined as a wide range of community organizations that help provide legal information and referral for vulnerable clients (Cohl and Thomson 45). They are “go-to” people who help others find and use services, primarily because they are known in their communities as “credible sources of help” (Reid and Malcolmson 94).<sup>57</sup>

Health promotion work has benefitted from the use of intermediaries – also termed “health promoters” (Henderson et al. 2) or “lay advisors” (Rhodes et al. 410). The following reasons have been given for use of intermediaries in health promotion:

- Since they are often members of the local community, they are able to gain access to the community in a more efficient manner than other types of health workers (Henderson et al. 3). This is because many community members view traditional health care providers and educators as “outsiders” and do not feel comfortable disclosing health information to them. Thus, they may prefer to deal with lay advisors from their own communities<sup>58</sup> (Rhodes et al. 418).

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<sup>56</sup> Anecdotally, it seems that most of these developments, until very recently, have been instigated or supported by community legal clinics in Ontario.

<sup>57</sup> See National Action Committee 20 for a list of intermediaries in the legal information context.

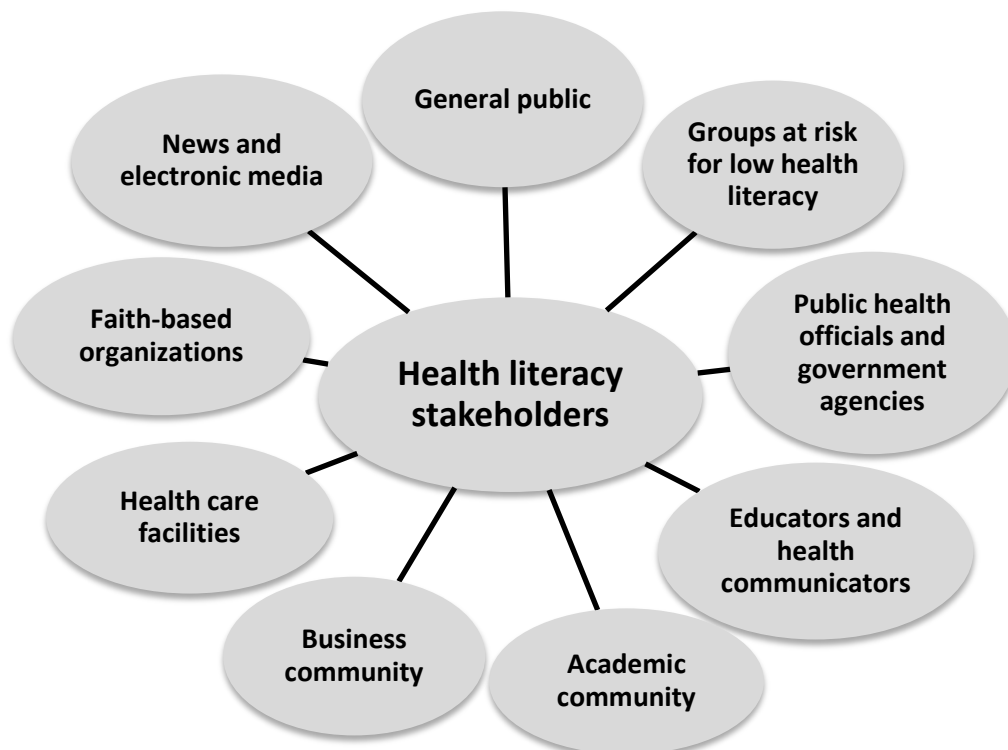
<sup>58</sup> An example: one US study highlighted the use of a “promotora” (local health promoter) in Hispanic communities – see, generally, Amendola. The promotora worked in conjunction with a community health nurse to organize community health fairs and provide health education tailored to the beliefs and practices of the local Hispanic community. The study found that the culturally tailored services that resulted from the



- Intermediaries, or “lay advisors”, have the ability to act as advocates as well as health information providers (Rhodes et al. 431).

As the Public Health Association of British Columbia noted, health literacy is not only the responsibility of individuals in the general population or of just one sector; rather, it crosses multiple boundaries, professions and jurisdictions...” (17-18). In their 2012 report, they created the following infographic to try to reflect this notion.

Figure 3: Major stakeholders involved in health literacy<sup>59</sup>



However, the Public Health Association of British Columbia admitted that the infographic – “rigidly linear and radiating outward like spokes on a wheel” – doesn’t quite capture the complexities between the “myriad stakeholders at every level of public service” (18). Rather, the connections between intermediaries “crisscross and intersect ‘... like a tangled pile of spaghetti, weaving in and out of other paths that rarely ever leave the plate’ ”(18).<sup>60</sup>

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links between community health nurses and the promotora promoted “more personal responsibility” from community members in making changes to their lifestyles to promote health (85).

<sup>59</sup> This was reproduced from an original infographic created by Irving Rootman and Wayne Mitic: see Public Health Association of British Columbia 18.

<sup>60</sup> The Public Health Association of British Columbia attributes the “spaghetti reference” to Christakis, Nicholas and James Fowler. *Connected*. New York: Little, Brown and Company. 2009.

We agree with the Public Health Association of British Columbia that this metaphor better illustrates the complex interconnectedness between and among the myriad stakeholders at every level of public service (17-18).

## Parallels

The role of intermediaries in helping people with legal problems has been less studied than in the health sector. However, Karen Cohl and George Thomson, in their seminal report, found that people from many diverse communities in Ontario, such as linguistic and cultural minorities, are at great risk of falling through the cracks if they do not have trained intermediaries to help them understand and navigate legal problems (Cohl and Thomson 67). Also, intermediaries have played a critical role in ensuring that low-income and disadvantaged people have access to and understand PLE (Community Legal Education Ontario 27).

There is also an increasing – if still budding – systemic recognition in Canada that intermediaries may be best equipped to know which issues or areas of law are most relevant to their client base or community.<sup>61</sup> In our view, recent initiatives to train intermediaries to detect legal issues and share legal information materials and referral information with their clients and communities<sup>62</sup> should be built upon. Trained intermediaries can help empower communities by helping them realize they are best placed to recognize and address their own problems.

Also, there are some important differences between the ways that people acquire and use health information and legal information that we feel must be noted.

## 2.4 Differences between health information and legal information

In Part 1.4 of this paper we discussed some key concepts in the literature on health literacy that are largely missing from the present literature on legal capability,<sup>63</sup> for example:

- the explicit recognition that general literacy is fundamental to health literacy
- the explicit recognition in the health sector of the notion that social determinants affect people's ability to access health information and other health services

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<sup>61</sup> One initiative built upon this principle of bringing together PLE providers and intermediaries is CLEO's Connecting Communities project, funded by the Law Foundation of Ontario. This project facilitates and helps secure funding for partnerships between PLE providers (primarily community legal clinics) and community based agencies. Through these partnerships, PLE providers help agencies and intermediaries set up and conduct legal information training projects in rural, remote, and culturally distinct communities.

<sup>62</sup> Examples of such initiatives in Ontario include: the Halton Legal Health Check project (Currie "Halton") and the Connecting Ottawa project (Hurley).

<sup>63</sup> It should be noted, however, that recent Australian literature on legal capability touches upon these concepts. See, for example, Pleasance et al. *Reshaping* 121-161.

In this section, we look more deeply at other fundamental differences between health promotion and PLE – differences that we will need to keep in mind as we build on our learnings from the health promotion sector.

#### **2.4.1 People's approach to health care: interest in prevention**

People understand that they will undoubtedly experience health problems, especially if they live to old age. This leads to an understanding that “staying healthy” – living a healthy lifestyle – may help prevent later health problems. Moreover, health promotion is well-seeded in popular culture and people don't have to look far to get an idea of what they need to do to prevent disease, or simply to feel better.

In contrast, many people don't expect to experience a serious legal problem in the course of their lives. Thus, there is considerably less emphasis on primary prevention of legal problems than on resolving them at the crisis stage or at the stage when legal proceedings have begun.<sup>64</sup> People are more likely to look for information – and to absorb it – if they need it at that moment or if they can understand its usefulness and relevance to their current lives.

That is, people may not take in “preventative-type” legal information even when offered it if they don't have a legal problem at that point because they don't see how it applies to them (Pleasant et al. *Reshaping* 45). Instead, it may take a crisis for people to seek legal information and help.

Pascoe Pleasant and his colleagues found that vulnerable people in Australia are less likely to seek legal information and help early on because:

- the “tipping point” at which vulnerable groups decide to seek help is later than other groups (*Reshaping* 115)
- they are more likely to have intersecting and complex problems on many fronts at the same time, and they may not be able to access information to help with the right problems at the right time (*Reshaping* 89)
- in the context of legal information and help, it has also been noted that it is not only a matter of when people decide to seek help, but also when people are ready to act on the legal problem (*Reshaping* 115-116)<sup>65</sup>

We think that these points are consistent with theories on adult learning. The Canadian Literacy and Learning Network shares the following seven principles of adult learning that

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<sup>64</sup> See Delhon et al. and Canadian Bar Association *Reaching* 45. Also, by way of comparison, John-Paul Boyd recently commented that if health care were provided the way legal services are provided then walk-in clinics would be the primary point of contact rather than family doctors (Boyd).

<sup>65</sup> This may mean that focusing primarily on early intervention in providing legal information – as is the case in many of the health information practices discussed earlier – carries a risk of missing people who do not seek legal information early due to disadvantage or other factors (Pleasant et al. *Reshaping* 116).

we find helpful in terms of thinking about delivering preventative-type PLE (Canadian Literacy and Learning Network):

1. **Adults must want to learn.** They learn effectively only when they have a strong inner motivation to develop a new skill or to acquire a particular type of knowledge.
2. **Adults will learn only what they feel they need to learn.** They want to know, “How is this going to help me right now?”
3. **Adults learn by doing.** They need to be able to use these skills immediately so that they see their relevance.
4. **Adult learning focuses on problems and the problems must be realistic.** Children learn skills sequentially. Adults start with a problem and then work to find a solution.
5. **Lived experience affects adult learning.** Use the learners’ experience (negative or positive) to build a positive future by making sure that negative experiences are not part of their experience in an educational program.
6. **Adults learn best in an informal situation.** Unlike children who have to follow a curriculum, adults often learn only what they feel they need to know.
7. **Adults want guidance.** They prefer being presented with options rather than being given instructions.

We agree that preventative-type PLE – or PLE that is intended to provide people with a knowledge base and related skills that equips them to head off legal problems in the future – is an area that warrants more attention. However, our analysis suggests that, in thinking about the types of initiatives that might be effective, care needs to be taken to understand the complex and intersecting nature of legal problems and the barriers that many people face in this regard.

A leap onto the bandwagon of prevention is highly appealing. However, without an understanding of these important adult learning principles and of the complexities of legal problems as they affect vulnerable people, we fear that an overinvestment in preventative-type PLE strategies as a general rule could affect the appropriate resourcing of the array of needs-responsive PLE and legal services initiatives.

That said, we are aware of existing thoughtful preventative-type PLE initiatives that are already being carried out in Ontario – one example is the workshops on powers of attorney provided by the Advocacy Centre for the Elderly. We also believe that elementary and secondary school environments are ripe for preventative-type education and activities

with respect to how the justice system works and for presentation of information on substantive legal areas.<sup>66</sup>

#### **2.4.2 Awareness that a problem is a legal problem**

Karen Cohl and George Thomson note that people are more likely to recognize that they have a medical problem than a legal problem (44). People are often unaware that many of their daily transactions – from cell phone contracts to gym memberships to tenancy agreements – have a legal component and that they have rights and protections related to those transactions that are enforceable at law. The symptoms of these transactions are often disguised and may not present as legal in nature until the problem escalates to the point of crisis (44).<sup>67</sup>

Several research reports also discuss the clustering of interwoven problems and the difficulty this poses for the identification of legal problems. For example, Ab Currie has noted, “Problems often do not occur in isolation. They occur in clusters in which certain problems can sometimes serve as triggers for other problems” (42).

Ab Currie goes on to explain that the significance of experiencing multiple problems is that they may have a compounding effect. Similar to the principle of the whole being greater than the sum of its parts, or in this case, more problematic than the sum of its parts, experiencing multiple justiciable problems can set in motion a process in which the cluster of problems creates out of the series of individual problems, lives of trouble” (42).

In these “lives of trouble”, it can be difficult to untangle the intersecting threads of multiple problems and identify which ones have a legal component. Someone who loses their job because of a plant closure not only has the challenge of making ends meet and finding work, but they may also end up having to deal with collection agencies, problems with a landlord, and even appearances before a tribunal to avoid eviction.

#### **2.4.3 Potential impact of seeking information on relationships**

Civil legal problems, unlike most health problems, arise externally and are often rooted in direct power imbalances.<sup>68</sup> Indeed, one major reason that many people do nothing when faced with legal problems is that they feel intimidated or powerless in the face of legal processes or remedies (Coumarelos et al. 30).

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<sup>66</sup> As mentioned in note 54, above, the Ontario Justice Education Network and Justice for Children and Youth design and deliver PLE programs targeting youth. The Canadian Civil Liberties Union also develops curriculum on civil rights issues for use in secondary schools.

<sup>67</sup> For example, people who get letters from the landlord stating that they have paid rent late might not realize that they have a legal problem until the landlord starts a legal proceeding for eviction for persistent late payment of rent. See, generally, Pleasance et al. *Reshaping* 101-162.

<sup>68</sup> In contrast, while there are health problems that originate from external factors (for example, environmental-related cancers), those problems manifest on a physical or internal level.

Even where there is no obvious power imbalance in place, a characteristic of legal issues is that they often arise because you have a problem with someone or they have a problem with you, or both. In many situations – especially where family members or friends are involved – this can result in people failing to seek information or failing to take steps because they are concerned about damaging relationships or facing repercussions (Currie *Legal Problems* 56; Pleasance et al. *Reshaping* 105).

In contrast, the system that one must access to address health problems is not, at its core, adversarial in nature. Most of the time there will be no fear of repercussions to relationships when seeking information about, or help with, health problems.

#### **2.4.4 Public funding for continuum of health care services**

As touched on in Part 1.4, Ontario has a model of publicly-funded health care, which includes funding for health promotion activities. In contrast, there is no universal right to “free” civil legal assistance. As Karen Cohl and George Thomson point out when demonstrating that seeking legal information is not analogous to seeking health information, “Doctors are more readily accessible than lawyers are, and the cost of consulting a doctor is covered by OHIP” (44).

Depending on the type of legal problem faced, free legal services might be quite limited or might not be available at all. For example, in Ontario, free legal services are available only to those with very low incomes and it is only available for certain types of problems.<sup>69</sup>

Thus, while health services are available for most types of health-related problems to people of all income levels, there is no continuum of accessible legal services.

## **2.5 Summary**

The challenges in helping people access health promotion and legal information are largely similar. However, the pathways to health information are wider and less cluttered than those to legal information. This is true for various reasons, many of which do not have simple solutions. As well, there are other distinctions between health promotion and legal information which, in some cases, blur the parallels between the two.

That said, we feel that there are some promising approaches and strategies related to social determinants-based delivery of health information in the community health sector that can be used and built upon in legal information work.

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<sup>69</sup> It should be noted that the Government of Ontario recently raised the income eligibility threshold to qualify for free legal services. But, the new thresholds remain lower than Statistics Canada’s low income measures and low income cut-offs for 2013.

## Part 3: Improving access to legal information: ideas from the health sector

### 3.1 Overall learnings from the health care sector

As one Canadian report noted, “Having limited literacy does not occur in isolation from the other [social] determinants of health. People need to have a safe place to live, a job that provides a decent income, and access to health care service such as a family doctor. People living with limited literacy and health problems have multifaceted and complex lives in which just one part is dealing with their health” (Canadian Public Health Association *Experiences 4*).<sup>70</sup>

Similarly, many aspects of modern life are affected by some legal framework or involve the need for people to enter contractual arrangements. Examples of daily life so affected include: signing a mobile phone contract, making arrangements to get social assistance or employment insurance payments, renting an apartment, addressing problems in relationships with spouses or children, and signing a will or a power of attorney document.

These common or “everyday” events might not initially appear to the average person as having a legal component but each of them can result in the need for information or the need for help to deal with them (Currie *Legal Problems 5*).<sup>71</sup> Thus, as in the health sector, there is ample scope to view legal interventions and education as being useful at varying stages of life – rather than simply being needed when problems arise.

### 3.2 Opportunities for improvement and action

We have identified several practices from the community-based approaches to health information and promotion that we feel could be built upon or adapted in Ontario’s justice sector. In this section we list some specific practices in hopes that this will lead to further discussion about how to develop a broad array of holistic strategies to reach people in

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<sup>70</sup> In recognition of this, several medical-legal partnerships that provide vulnerable people in hospital or in treatment with access to free legal services have been initiated in the U.S.: see National Center for Medical-Legal Partnerships. There is at least one similar successful project in Canada to date: the Pro Bono Law Ontario at Sick Kids’ Project (see, generally, Jackson et al.). This project has reported significant positive outcomes (55-61). Note that in Toronto, several community legal clinics are currently embarking on a similar pilot project at St. Michael’s Hospital.

<sup>71</sup> Ab Currie refers to legal problems as “justiciable problems” or “justiciable events”, citing Hazel Genn’s 1999 definition of a “justiciable event” as “a matter experienced by a respondent which raised legal issues, whether or not it was recognized by the respondent as being “legal” and whether or not any action taken to deal with the event involved the use of any part of the civil justice system” (*Legal Problems 1*). Note also that Currie’s research found that “social exclusion, viewed as an interlocking complex of justiciable and non-legal problems, is related to the increasing number of justiciable problems experienced” (*Legal Problems 74-75*).

Ontario – especially those most vulnerable – with effective public legal education and information.

### **1. Compile a universal list of the social determinants of civil justice analogous to the social determinants of health.**

It seems to make sense to talk about the “social determinants of civil justice” in a way that mirrors the discussion of the social determinants of health. Though the legal literature in Canada and elsewhere increasingly addresses the concept that vulnerable populations are more likely to face both legal problems and barriers to solving those problems<sup>72</sup>, we are not aware of any in-depth systemic discussions or reports about which societal factors compromise people’s legal health.

People working in the social justice and community legal sectors are well aware of the issues affecting marginalized populations. However, now might be the time to develop a common understanding of these across the justice sector.

As discussed, integrating the concept of social determinants has resulted in innovations to health information and promotion in the community health sector. What started as primarily an academic exercise has resulted in very practical, ground level improvements to health literacy overall, as well as in specific benefits to how health literacy is promoted in marginalized communities.

Similarly, we expect that developing a set of “social determinants of civil justice” may increase the ability of community legal clinics, community intermediaries, and other legal service providers to design strategies to help vulnerable Ontarians address their legal problems in as timely and effective a way as possible.

Such a list can be modeled on the existing social determinants of health. In the legal context, we suggest explicitly adding the following determinants: immigration to Canada, sexual orientation, gender identity, interaction with the criminal justice system, incarceration (previous or ongoing), and credit rating status.

As well, opening a dialogue on the “social determinants of justice” and promoting and publishing the findings could help to raise awareness and inform existing advocacy about gaps in accessing justice and legal services.

### **2. Develop a more detailed definition of “legal capability” in the Canadian context.**

As discussed, attempts to arrive at definitions of “health literacy” as a distinct concept from general literacy resulted in improvements to how health information was designed and distributed. This process, like that of defining “legal literacy” and “legal capability”, is still

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<sup>72</sup> See, generally, Delhon et al.



in flux. However, it appears that the concept of “health literacy”, especially as it relates to marginalized groups, has been more extensively developed than its counterparts in the legal sector.

What is clear is that increasing legal capability is an important component of helping people in their intersections with the justice system (Canadian Bar Association *Reaching 8*). This is especially crucial for people living in vulnerable communities, who are more likely to experience problems in “clusters” and who are often less able to deal with problems proactively because of the societal and economic barriers they face (Currie *Legal Problems 61*).

Recent civil justice reports in Canada and other jurisdictions have paid attention to the concept of legal capability and have started to build upon it. However, it may be time to focus more attention on defining what “legal capability” might look like, particularly in the context of vulnerable communities.

Current notions of legal capability do not explicitly recognize the link between literacy levels and the ability of individuals to build knowledge and develop skills to achieve competence within – or confidence in – the legal system. As well, the Law for Life foundational legal capability model is premised on a “one size fits all, with some tailoring” approach. It seems to assume, in many ways, a more level playing field than is available to people who belong to vulnerable groups.

In the health sector, by contrast, it has long been recognized that many groups of people face systemic (and often intersecting) barriers to accessing health information and education. A similar recognition should be embraced by the justice sector to ensure a definition of “legal capability” that is meaningful to all Ontarians – especially the most vulnerable.

A good starting point is the definition of “legal literacy” arrived at by Laird Hunter in 1999: “People who have a legal problem must have the ability to access, understand and evaluate information about the problem.” This includes the ability to:

- recognize a legal right or responsibility
- recognize when a problem or conflict is a legal conflict and when a legal solution is available
- know how to take the necessary action to avoid problems
- know how to help themselves when it is not possible to avoid problems
- know how and where to find information on the law
- know how to find information that is accessible to them
- know when and how to obtain suitable legal assistance
- have confidence that the legal system will provide a remedy
- “understand the process clearly enough to perceive that justice has been done” (Hunter 11)

This systemic opportunity, if pursued, will take some time to accomplish. In the meantime, there are some opportunities for PLE and other legal service providers to consider in integrating successes from the health sector into their daily work.

### **3. Develop or recommend statistical methods to help measure legal capability or awareness.**

Efforts by health researchers to establish measures for health literacy using statistics derived from the health content questions in the ALL survey set led to significant advancements in the understanding of low health literacy in vulnerable communities. At present, there is no analogous measure of legal literacy or legal capability.

It should be noted that the 2003 ALL survey contained no questions which tested knowledge of legal terms or content. The PLE community could work with Statistics Canada to add standard legal knowledge testing questions to future surveys, or to develop a stand-alone statistical measurement for legal capability.

### **4. Design a “quick screening tool” to assess people’s legal capability.**

As a shorter term measure to start collecting information on levels of legal capability, the NVS “ice cream label” test (Figure 4 in Section 1.5.2) provides an interesting model to adapt for basic literacy screening. In the legal context, the nutrition label could be replaced by a standard legal form (such as a parking ticket, eviction notice, or social assistance request letter) together with a short questionnaire to help identify how much of the content on the form the person understands.

Quick screening tools could have several uses, including:

- helping intermediaries quickly detect whether their clients need additional help and support to deal with legal problems, and for informing referrals to legal services
- providing an educational piece to help vulnerable people recognize commonly encountered legal forms
- helping front-line legal workers by providing supporting “evidence” for requests to adjourn legal proceedings in order to give people who do not have basic literacy the time to find fuller legal information, advice, or representation

### **5. Build on existing life skills programs targeting vulnerable communities to incorporate legal capability components in those programs.**

Much of the focus in the health literature has been on adapting health interventions for cultural or linguistic minority communities. Steps could be taken to incorporate legal capability content into existing life skills programs offered to newcomers, seniors, unemployed people, Aboriginal communities, or other vulnerable groups. For example, a program offered by a newcomer employment centre to teach computer skills could include a short module or exercise on finding reliable legal information online.

## 6. Build the capacity of intermediaries to deliver legal information and referrals.

At present, it seems that the majority of people obtain legal information in a reactive fashion and often toward the end stage of their problem.

Community health clinics and community health nurses aim to improve access to health information at all stages of life to match their clients' needs. Most community health programs have a strong "in person" component and are designed to bring information to specific groups of people at the locations they frequent. One approach that has worked in the public health sector is to provide training and programs to help intermediaries recognize health issues and risks at an early stage so that they can provide people with information and enhanced referrals in a timely matter.<sup>73</sup>

As discussed, the role of intermediaries has begun to be recognized in the civil justice sector, and tools such as legal health checks have been developed to support them. However, it is critical to continue to develop and support the capacity of these community partners to deliver effective legal information and referrals to their clients and peers.

Community intermediaries should not be seen as a replacement for lawyers and trained legal workers, but rather as a way to get more information out to as many people as possible in a timely and culturally or regionally appropriate manner.

### 3.3 Conclusion

Vulnerable communities in Ontario face considerable hurdles in accessing legal information and dealing with legal problems. While the same is true in terms of accessing health information and support, systemic approaches to addressing the literacy challenges and needs of vulnerable communities in the health care sector have led to positive change and more access to health information and help in Ontario and many other jurisdictions.

Specifically, recognition of the importance of general literacy and of the impact of social determinants of health has been shaping approaches to understanding, defining, measuring and achieving health literacy over the past three or four decades. What has emerged is a generally accepted understanding in Canada's health sector that social and economic factors have a direct and dramatic impact on people's health.

In contrast, the justice sector appears to be moving far more slowly in recognizing various barriers faced by vulnerable people – due, in part, to the failure to recognize the impact of social determinants on a person's ability to access justice. While the emerging concept of "legal capability" does attempt to address barriers to justice on a general level, there

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<sup>73</sup> Note that CLEO's Connecting Communities initiative provides examples of this type of work in the PLE sector.

remain profound systemic gaps that prevent vulnerable people from identifying and solving common legal problems. This paper has identified some examples from the health sector that may be useful in closing these gaps.

The systemic and explicit understanding of social determinants and the resulting changes to the concept of health literacy have also shaped and improved access to health information for vulnerable communities across Canada and elsewhere. Specifically, the importance of targeting health information approaches and programs to communities adversely affected by social determinants have led to initiatives that bring information to these communities in the places they frequent and at stages in their lives when the information might be most useful to them.

Given that there are clear parallels in the PLE and legal services sector, significant opportunities for positive change might lie in adapting or building upon health information strategies to improve access to legal information for vulnerable people.

Thus, in addition to sharing ideas and parallels from the health sector, we hope this paper contributes to a dialogue about priorities for improving the legal health – and thus, the overall health – of vulnerable communities in Ontario.

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## Appendix 1 – Barriers to health literacy in Canada

In its report, the Canadian Public Health Association's Expert Panel on Health Literacy identified both individual and systemic barriers to health literacy in Canada. Here is a summary of the report's descriptions of these types of barriers

**Individual barriers** or “those personal features that can make it difficult for individuals to develop or use the wide array of skills required to be health literate in today's world” (Rootman and Gordon-El-Bihbety 24) include:

- declines associated with aging
- not reading or writing on a daily basis
- low levels of formal education or
- a lack of knowledge and skills about health
- having a mother tongue other than English or French
- cultural beliefs
- living with disabilities

Stigma associated with low literacy levels or language barriers also creates difficulty for people in accessing health information (25). Some examples identified by adult learners who participated in focus groups in the Expert Panel's study:

- difficulty asking doctors to explain language you don't understand
- difficulty asking a pharmacist to read directions on a label to you
- difficulty asking for help filling out forms
- misunderstanding medical advice and being too embarrassed to ask for clarification
- feeling that you don't deserve more time with a doctor
- feeling that you are a burden on the system
- feeling overwhelmed by how hard it is to stand up and insist that your needs be met
- feeling overwhelmed by the stress of being in poor health<sup>76</sup>

**Systemic barriers** include (25-29):

- gaps in public health education in the school system – for example: lack of funding or curriculum time, lack of teacher specialists, insufficient support for public health engagement with schools
- lack of community services - i.e., not enough English as a Second Language classes
- lack of health awareness programs in the workplace
- lack of clear and reliable health information online

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<sup>76</sup> As the Expert Panel on Health Literacy noted in its report, people with lower health literacy skills also report feel overwhelmed when dealing with hospital and medical services – understandable given the fact that navigating the health care system during the stress of an illness is challenging even for those with higher skills who are familiar with the system (Rootman and Gordon-El-Bihbety 27).



## Appendix 2 – The work of community health centres

Here are some examples of health information and outreach activities offered by community health centres in Ontario:

- smoking cessation programs
- nutrition and diet counselling programs
- drop in groups for clients and family members/caregivers
- addiction and mental health programs and services
- in-home respite programs for caregivers
- farm safety education programs
- health education sessions and handouts
- educational sessions hosted at schools, community agencies, and correctional facilities
- “street health centres” or street outreach to provide people with harm reduction supplies, information, and support

Many community health centres also work in close partnership with local community organizations to promote and foster healthy living activities. For example, most community health centres in the Greater Toronto Area offer some type of food education and/or food security programs in conjunction with local food banks and food security organizations. The types of programs and services they provide include: healthy cooking and eating seminars, pickup locations for Good Food Boxes, and information about gardening (Food Security Network, 2010).

Some community health centres have also been involved in community-based research projects in conjunction with other community organizations to improve conditions for people living in their communities. The Canadian Association of Community Health Centres has created a useful infograph that provides information about the types of services and programs CHCs provide, and the percentage of CHCs that provide the different services listed (Canadian Association of Community Health Centres).

One of the benefits of community health centre support is that it is “nimble and mobile, delivered on the streets, in shelters, in schools, in community centres - wherever [CHC] interdisciplinary teams can make the easiest connection with those who need the most support” (Canadian Alliance of Community Health Care Associations).

Community health centres have also been credited with helping individuals and families access non-medical supports by liaising with other community organizations and doing outreach work in their communities (Canadian Alliance of Community Health Care Associations).

## **Appendix 3 – The work of public health units and community health nurses**

### **Public health units**

The functions of public health units include:

- collecting or preparing and distributing timely local public health information to health practitioners through live training and web portals
- compiling or preparing and distributing training materials on public health topics for physicians, nurses, and medical and nursing students (for example, how to breastfeed properly)
- working with all levels of government to advise on pressing public health issues (for example, the effects of poor air quality on people)
- employing public or community health nurses who develop programs and provide extensive outreach and health education services from a community-based perspective

### **Community Health Nurses<sup>77</sup>**

Community health nurses practice in increasingly diverse settings and with diverse partners (Canadian Public Health Association 4). Some of their partners include schools, community health clinics, street clinics, youth centres, nursing outposts, and community centres. The overarching philosophy underlying their work: if communities and the systems within them that support health are robust, this will create opportunities for better health for individuals, families, groups, and populations (Canadian Public Health Association 10).

Community health nurses use social determinants to tailor programs and health information approaches to the needs of the communities they work in (Canadian Public Health Association 8). They design and provide a wide range of programs and services to engage and educate community members. These include both primary and preventative care initiatives. Some examples:

- hosting drop-in sessions or weekly seminars at social housing complexes, houses of worship, community centres, libraries, shelters, or other meeting places
- facilitating support groups for family members/caregivers of people with serious illnesses (for example, Alzheimer's support, dementia)
- conducting courses or educational sessions at primary and secondary schools and post-secondary institutions to educate young people on a wide variety of topics and risk factors that may affect their health

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<sup>77</sup> See, generally, Battle Haugh and Hinton for an overview of the work of community health nurses in Canada.

- working in coalitions with community agencies to prevent negative health trends (for example, suicide prevention programs, harm reduction programs)
- training “peer educators” (for example, high school seniors, community members) and supporting them in their efforts at sharing information with their peers (for example, information on harm reduction and “safe partying” strategies or safer sex initiatives)
- training trusted or community intermediaries (for example, front line community workers, schoolteachers) to recognize risk factors and provide health information to their audiences and networks
- working with law enforcement agencies to raise awareness of social and health issues affecting community members (for example, addiction, mental health, or domestic violence) and training law enforcement members on health-sensitive and appropriate responses to people in crisis
- working with social policy research organizations and public service agencies to raise awareness about the social determinants of health and how they affect specific communities

### **Community health nurses, schools and education**

Community health nurses practice at primary and secondary schools as well as post-secondary institutions in Canada. The practice of school-based community health nurses is situated within a primary health care and population health approach that emphasizes the importance of addressing the social determinants of health (Public Health Agency of Canada).

Many community health nurses provide primary care services to students injured at school. They are also available for individual counseling sessions with students – and, if there is a perceived need, host small group sessions involving more students. Depending upon the setting, counseling might be available on such topics as: healthy eating, physical activity, mental health, bullying prevention, substance misuse prevention, and healthy growth and development (Centre for Addiction and Mental Health et al. 14).

Overall, community health nurses in Ontario seem to have played an important role in advocating for comprehensive approaches to school based health information. A number of studies have identified the importance of the public health nurse in linking the school, students and parents to other health and community services, and in coordinating and facilitating comprehensive school-based health information.<sup>78</sup>

Community health nurses are also increasingly responsible for monitoring and designing programs to address mental health issues in children and youth and for promoting good mental health in school populations.<sup>79</sup> For example, a recent report by the Centre for

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<sup>78</sup> For more information about the work of community health nurses in schools, see Registered Nurses' Association of Ontario.

<sup>79</sup> For examples of school-based programs in Ontario, see Centre for Addiction and Mental Health et al. 51-95.

Addiction and Mental Health in conjunction with Public Health Ontario and Toronto Public Health highlights the key role of public health units and community health nurses in the Ontario Ministry of Education's "Foundations for a Healthy School Framework" project (14). This framework is intended to contribute to the physical, mental, emotional, social and spiritual health of the entire school community by focusing on four components: quality instruction and programs, a healthy physical environment, a supportive social environment, and community partnerships.<sup>80</sup>

Community health nursing interventions seem to be particularly robust in the school system where they promote good physical and mental health practices and promote taking a preventative stance.

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<sup>80</sup> See Centre for Addiction and Mental Health et al. 23. This interdisciplinary initiative established Health Action Teams and Healthy School Committees in schools across Ontario. The teams and committees include teachers, school administrators, students, parents, public health service providers and community partners. The committees identify health topics of concern or interest to their school communities. Community health nurses and other public health staff and school staff then identify or develop evidence-based resources, provide guidance to healthy school committees, and consult with school administrators and boards. Community health nurses in collaboration with social workers and guidance counselors also offer educational sessions and one-on-one support for students.

## Appendix 4 – Community intermediaries and health promotion work

### Examples of intermediaries

Some examples of intermediaries who provide health information are<sup>81</sup>:

- street youth resource centres and workers
- sexual health clinic workers
- Aboriginal centres
- walk-in clinics
- community legal clinics (especially those that have a mandate to deal with disabled or ill clients, such as Injured Workers' Consultants or the HIV/ AIDS Legal Clinic of Ontario)
- AIDS service organizations
- community service agencies and workers
- food banks and food bank workers
- prison chaplains
- community care access workers
- elder care centre workers
- trade unions and trade union representatives
- sexual health clinic workers
- housing help workers
- with regard to newcomers, family members who were born in Canada or have lived here longer than the newcomer
- social housing providers
- culturally based social clubs

In the mental health context, intermediaries have been described as “case managers, system navigators, advocates, peer support workers, outreach workers or other intermediaries between clients living with mental health and/or substance use issues and the healthcare system” (Centre for Addiction and Mental Health). Such intermediaries have a wide range of supportive functions for people, including: navigating the system, accessing and maintaining counseling and other mental health supports and going with clients, as needed, to physical and mental health appointments (Centre for Addiction and Mental Health).

### The benefits of intermediary interventions

Many health research reports have shown measurable benefits from the health information work of intermediaries. For example:

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<sup>81</sup> Interview with Laurie Edmiston, Executive Director of the Canadian AIDS Treatment Information Exchange, November 29, 2013.

- they use social networks and culturally sensitive strategies tailored to the needs of the communities they serve (Martinez-Donate 259)
- they contribute to improved health outcomes in the community by facilitating access to care and enhancing compliance with treatments (Brownstein et al. 435)
- in linguistic minority communities, bilingual community health workers have improved health knowledge and led to a higher rate of completion of health information programs (Henderson et al. 225)
- using lay health workers improved the uptake of immunization and breastfeeding in low and middle income countries in comparison to more traditional health care programs (Lewin et al. 4)

## Appendix 5 – Resources for preparing health information products

Here are some resources used by health professionals to develop and test health information products:

**Canadian Public Health Association Plain Language Service:** Provides various resources for health care practitioners to help them prepare printed materials, including: a “plain language” service for health care providers to help review their materials, as well as training sessions to help health professionals develop plain language writing skills.<sup>82</sup>

**Centers for Disease Control and Prevention (US) Health Literacy page:** This webpage offers various tools and resources for health care practitioners, including information on how to prepare culturally sensitive materials.<sup>83</sup>

**Centre for Literacy of Quebec Plain Language Links:** This website has a page of plain language links to help health care practitioners prepare materials in clearer language.<sup>84</sup>

**The Health Literacy Portal:** The Canadian Public Health Association website offers online courses, webinars and links to literacy resources for health care providers.<sup>85</sup>

**The Health Literacy Environment of Hospitals and Health Care Centers:** This PDF includes extensive information and checklists on preparing plainer language materials.<sup>86</sup>

**MaineHealth (US) Checklists:** the department of health in Maine, US has prepared a series of checklists for use by health care practitioners when preparing materials.<sup>87</sup>

**Office of Minority Health (US)** The US Department of Human and Health Services has an Office of Minority Health.<sup>88</sup> This department promotes the necessity for cultural competency in health care and provides materials to health care organizations.

**Writing health information for patients and families:** The Hamilton Health Sciences Group has a resource to help clinicians prepare plainer language health information materials, similar to CLEO’s Better Legal Information Handbook in scope. This resource was last updated in 2014.<sup>89</sup>

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<sup>82</sup> See Canadian Public Health Association “Frequently Asked Questions.”

<sup>83</sup> See Centers for Disease Control and Prevention.

<sup>84</sup> See Centre for Literacy of Quebec “Plain”.

<sup>85</sup> See Canadian Public Health Association “Health Literacy Portal.”

<sup>86</sup> See Rudd and Anderson.

<sup>87</sup> See MaineHealth. Note that in the US, some federal health agencies under the jurisdiction of the US Department of Health and Human Services also provide information on how to design and implement health communications programs and strategies.

<sup>88</sup> See US Office of Minority Health.

<sup>89</sup> See Wizowski et al.