Welcome to Health Law in Canada’s Spring Issue!

As we watch the grass grow and the buds of the trees sprout, a new health law and policy agenda is being executed across the Canadian landscape. On April 13, 2017, the Trudeau government put forth a “legislative package that includes two bills: one, the “Cannabis Act”, that creates a new federal-provincial regime to produce and sell cannabis, and a second that strengthens the laws related to impaired driving by users of both marijuana and alcohol”. Although the tabling of such a huge policy agenda is not strictly in the realm of health and/or healthcare, thought needs to be given as to whether marijuana may impact healthcare funding and spending, regulatory colleges’ advice to their members, privacy laws, prescription methods, research programs, public health agendas, insurance and coverage, as well as administration generally. In the coming months, as the federal government moves closer to the date it has set for the legalization of marijuana (July 2018), many of these policy concerns will be discussed and hopefully even to some extent, addressed.

Such monumental policy changes, however, are not unusual in Canadian health law and policy. Over the past few decades, sweeping changes have been made or will continue to be made to certain policy portfolios either as a direct result of societal
pressure, changes in health funding or by way of the courts. Take for instance, the four articles in this issue of *Health Law in Canada*. The first piece included in our journal is a speech by Ryan Peck, Executive Director of the HIV & AIDS Legal Clinic Ontario (HALCO) at the 2016 Sidney B. Linden Award Reception on February 23, 2017. It is an understatement to suggest that HIV/AIDS has not had a societal impact these past 30 years. Whether it has been through court decisions, policy programs, public health campaigns, government funding or even political pressures, the work of heroes has not gone unnoticed. The drive to ensure that those individuals living with HIV/AIDS obtain equality under the law and adequate treatment has often been as a result of health, law and policy programs.

The second article, entitled, “Part III: Occupational Disability Determination/Rehabilitation Best Practices and the Role of Situational Work Assessment and Simulated Work/Academic Trials” is the final in a three-part series that discusses common occupational disability entitlements and long-term disability cases. The authors highlighted the significant challenges that arise from motor vehicle accident-related injuries and other disabilities resulting with incapacity to continue to work on a sustained full-time basis. In the near future, society may in fact deem that governments must react and create policy that meets such needs.

The third article entitled, “A Need to Know Basis? Canadian Federalism and the Disclosure of Egg and Sperm Donor Identities” relates specifically to fertility and the fact that in Canada, gamete donation can be known or anonymous. At present, “there is no registry storing gamete donor information accessible to donor-conceived persons and no legislation or judicial precedent protecting a donor-conceived person’s right to know the identity of their biological parent(s). With third party reproduction now regularly shifting the traditional outlines of family, these practices are increasingly attracting judicial oversight”. The Supreme Court’s decision to identify donor anonymity as a matter of provincial jurisdiction defined the future of anonymous gamete donation in Canada by strongly protecting it.

Finally, the last article, entitled, “Issues of Vulnerability and Equality: The Emerging Need for Court Evaluations of Physicians’ Fiduciary Duties in High Stakes End-of-Life Decisions” further explores a monumental policy change that was enshrined in law as a direct result of a Supreme Court of Canada decision. In particular, the goal of the paper is to explore issues of vulnerability and equality, by evaluating the role of a “fiduciary” in end-of-life decisions and to address conflicts with respect to withdrawing life sustaining treatment, ensuring access to medical assistance in dying and at the same time promoting the future quality of care for all citizens. It is not yet known how medical assistance in dying will transform the Canadian healthcare system (including with respect to palliative care), but its impact will be studied greatly in years to come.

Health law, policy and its transformative impact on society is what fuels *Health Law in Canada*. We hope that you enjoy these articles and in turn consider how health law and policy can create social progress and further enrich our communities.

Yours very truly,

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The Intersection Between Clinic Law and Health: Responding to Issues Faced by People With HIV

Ryan Peck

[Note: This speech was presented by Ryan Peck, Executive Director of the HIV & AIDS Legal Clinic Ontario (HALCO) upon accepting the Legal Aid Ontario 2016 Sidney B. Linden Award.]

Before focussing on what we at HALCO humbly refer to as holistic and revolutionary (or at least incremental reformist) lawyering, as well as on legal injustices facing people with HIV, I pay tribute to the countless who are no longer with us.

HALCO was founded in a dark time. Death was an everyday experience and people treated as untouchable pariahs. But from the beginning, people came together and fought back. From the beginning, the people most affected, those living with HIV, were at the forefront of the struggle. And from the beginning, people took care of each other through, for example, care teams, while also fighting for systemic change through, for example, • involvement in research ethics boards,
• demands for patient centred care, and
• right down the road from here [Queen’s Park], bringing to realization the Trillium Drug Program that benefits innumerable Ontarians, whether living with HIV or not.

HALCO has taken the same approach. We take very seriously the meaningful involvement of people with HIV (e.g., the majority of our board of directors must be living with HIV) and provide frontline services (summary advice, brief services, referrals, and representation) as well as engage in public legal education, community development and law reform initiatives.

While it took HALCO a number of years to become part of the community legal clinic system — we started as a project at ARCH Disability Law Centre in 1991, struck out on our own in 1995, and officially joined several years later — we fit right into a system that has also always been rooted in community, not the least of which is the community-based board of directors’ model, and has always engaged in a mix of direct and systemic services.

I’d like to take a moment to discuss why this unique mandate is vital. Community rootedness ensures that legal services are in touch with what is needed on the ground. Front-line services are essential to respond to day-to-day issues that people face — it would be unacceptable to ignore evictions, discrimination, or bureaucratic decisions that disentitle and leave individuals without income, housing or access to medications. However, to focus solely on individual matters would be problematic. We would become complicit in maintaining, even supporting, the status quo.

As a result, there is the imperative to also engage in systemic work. But it is only with the knowledge gained through community rootedness and front-line work that effective systemic activities can take place. A beautiful circle.

Another hallmark of HALCO and the community legal system is the holistic manner in which the work is approached. We know that people who are marginalized, whether by health status, poverty, sexuality, gender, gender identity, race, or more likely a combination of said, are at heightened risk of unwanted and negative contact with legal and other systems, and that barriers such as lack of access to justice tend to compound problems and multiply legal issues. Rather than traditional lawyering that tends to compartmentalize issues and to
some extent lives, a holistic approach embraces the porous and interlapping nature of legal compartments, and leads to services in tune with clients’ lived realities.

This means remaining alive to the intersections in people’s lives and providing services in relation to the various legal issues facing clients. For example, if a client is seeking redress in relation to the termination of employment, we proactively flag access to medications, housing, income maintenance and other cascading issues that flow from loss of employment.

We and other clinics engage in this approach not to be paternalistic but to assist clients to exercise their autonomy, increase engagement in legal processes, and arrive at positive outcomes.

While providing services, we also constantly remind ourselves that legal service providers do not own the law. Of course, we have a privileged and central role, but we sure do not, nor should we, monopolize the law.

HALCO and other community clinics do this by offering an array of services, from public legal education workshops to summary advice, brief services and self-help. This approach, which has been employed for many years and is now known as the “unbundling of legal services”, is important not simply as a response to demand but because different people and different situations warrant different legal services.

But please do not take this to mean that there is no place for old fashioned representation. While the reality is that resources are not limitless, HALCO and other clinics provide plenty of representation services. It is absolutely crucial that such services remain available to low-income communities due to the myriad of complex legal interactions they face. Tax or Charter litigation is often thought of as complex. Try navigating opaque social assistance laws, regulations and policies.

When making resource decisions regarding representation services there is the need to act strategically, which involves making difficult decisions not only on the mix of front-line/systemic work but on how to most effectively achieve results. For example, does it make sense to represent an individual on a “test” or “high impact” case or intervene in an appeal court matter?

HALCO has done both. For example, we take on test cases in relation to public health authorities’ use of coercive powers and to expand the breach of privacy tort, and we intervene in matters that raise issues impacting people living with HIV. Such issues range from the HIV-specific matter of the criminalization of HIV non-disclosure to broader issues that impact communities of people with HIV such as sex work, drug policy, autonomy in health care decision-making, and access to human rights remedies.

Sometimes it takes years, even decades for the victories to come to fruition. One example is the overly broad use of the criminal law, which I will come back to shortly. Another is access to human rights remedies. Ten years ago, we witnessed a significant development when the Supreme Court of Canada made clear that administrative tribunals must apply human rights law. This sounds great, and it is great. But it is not so simple. Tribunals still need to be held to account to provide appropriate remedies. This is particularly important as individuals may be barred from later seeking redress for discrimination if they fail to raise the human rights issue in a forum that is foisted upon them and in which they are under attack.

Even when legal struggles are successful, tireless work must be done to protect hard-fought successes. The fact is that rights, especially for marginalized communities, are constantly under attack.

All of this to say that the work of community legal clinics is unique and crucial. From the time, I was introduced to the clinic system in law school, I
have taken the clinic approach to heart. It was further cemented in me as an articling student and lawyer and through involvement in the HIV community. It is why I decided to work as both tenant and criminal duty counsel — to gain a further understanding of what takes place on the street and across practice areas in order to arrive at rigorous and effective services, both front-line and systemic. And it is why, when I had the opportunity to become executive director, I did my utmost to work with HALCO's board, staff and funders to expand services, including immigration law, litigation and summary advice services, while also scaling up public legal education, law reform and community development initiatives, by, for example, adding a policy lawyer position and encouraging everyone at the clinic to constantly draw links between front-line and law reform work, and to always push things.

The clinic system is highly regarded around the world, and I commend the government and Legal Aid Ontario for supporting it and embedding its model in the Legal Aid Services Act and in other foundational documents. In a time of increasing income disparity, when affordable housing is less than scant and social assistance rates dismally low, when low-income communities often live under burdensome state surveillance and experience intersecting discrimination, ongoing funding for community legal clinics is an absolute must.

And this includes ongoing funding for HALCO. The need for HALCO is as strong today as ever. While there remains no cure for HIV, currently available treatments are effective at managing the virus. People living with HIV who have access to sustained health care and medications have more or less the same life expectancy as those who are HIV-negative. Knowledge of prevention strategies is also better than ever and it is much harder to transmit HIV than generally supposed. For example, the risk of transmission is zero if a condom is used properly and no breakage occurs, and negligible to zero if a person living with HIV is being successfully treated with antiretroviral medications (and this is the case even if a condom is not used).

This is beautiful news. So why the need for HALCO and other specialized HIV-related services? While the scientific reality must not be ignored, many people, including in Ontario, face significant institutional, social and economic barriers to accessing health care and life-saving medications. Moreover, social attitudes have not nearly kept pace with science. HIV-related stigma and accompanying discrimination remain pervasive. It is shameful that, per a 2012 Canada-wide study commissioned by the Public Health Agency of Canada,

- Fifteen per cent of Canadians feel afraid of people with HIV;
- Sixty-nine per cent believe that people would not be willing to tell others they have HIV and 38% agree that people are unwilling to be tested for HIV due to stigma;
- Twenty-four per cent feel uncomfortable even wearing a sweater once worn by a person living with HIV; and
- Twenty-two per cent feel uncomfortable shopping at a small neighbourhood grocery store owned by someone living with HIV.

As a result, legal issues abound. From being denied services to being refused accommodation in the workplace, human rights concerns are widespread. Privacy is a constant worry for many, whether related to institutional actors, service providers or neighbours, and legal recourse may be difficult to impossible to obtain. Gaining access to life saving medications is all too often a deep struggle for people with immigration status in Canada, let alone for those with no status. And when it comes to Canada’s immigration system, many people with HIV, like those with other medical conditions, are not
viewed as whole individuals but are reduced to one figure: the cost of their medical treatment. State surveillance, through public health authorities and the use of the criminal law, remains prevalent.

Canada, Ontario in particular, is a world leader in criminalizing people with HIV. People are being prosecuted for aggravated sexual assault — one of the most serious offences in Canada’s Criminal Code, one designed to respond to the most horrific of forced sex acts — in circumstances where (i) sexual behaviour is consensual; (ii) there is negligible to no risk of HIV transmission; (iii) there is no intention to transmit HIV; and, (iv) transmission does not occur.

In short, the law is out of step with science and human rights principles, and hampers the public response to HIV.

It has a disproportionate impact on women, Indigenous peoples, migrants and African/Caribbean/Black communities. For example, there is great concern that women with HIV who are in abusive relationships will face aggravated sexual assault charges in situations wherein they cannot safely impose condom use nor disclose their HIV status.

The law also hinders HIV prevention efforts and hampers care, treatment and support for those living with HIV by providing disincentives for HIV testing, and by deterring honest and open conversations with health care providers, including public health authorities, for legitimate fear that such conversations will be used in criminal cases.

But after many years of work, there are hopeful signs. The recently released HIV strategy in Ontario recognizes negative impacts of the current use of the criminal law and calls for engagement with community on reform. The medical community is speaking up, the feminist community is speaking up, the international community is speaking up, and the Canadian federal government itself is speaking up. In a statement released on World AIDS Day, December 1, 2016, the Minister of Justice explicitly recognized over-criminalization and committed to working on this issue with the HIV community, medical professionals, and provincial and territorial counterparts.

Attorney General Naqvi has committed to meaningful engagement with the HIV community. After many years of attempted work with the Ministry of the Attorney General (MAG), we very much look forward to such engagement with the province to bring the law in line with science, human rights principles, and the public health response to HIV.¹

[Further thanks and acknowledgments]

This award is dedicated to all the people with HIV who day after day trust HALCO staff with the most sensitive of information during the most trying of times. We will continue to take this responsibility as seriously as can be and will continue to partner with you and others to ensure economic and social justice.

Thank you, Merci, Megwetch, and L’chaim.

[Editor’s Note: Ryan Peck graduated from the University of Toronto, Faculty of Law in 2000. Since 2007, he has been executive director of the HIV & AIDS Legal Clinic Ontario (HALCO), where he was previously both an articling student and a staff lawyer. Ryan has worked as a staff lawyer at the Advocacy Centre for the Elderly, and in the Tenant Duty Counsel Program at the Advocacy Centre for Tenants Ontario. He has also served as criminal duty counsel at Toronto’s Old City Hall. Ryan is a member of the Ontario Advisory Committee on HIV/AIDS (which provides HIV-related advice to the Minister of Health and Long-Term Care), chair of the Ontario Working Group on Criminal Law and HIV Exposure, and member of the executive committee of the board of directors of the Canadian HIV/AIDS Legal Network.]

¹ For more information about engagement with MAG, see <www.clhe.ca>.
Part III: Occupational Disability Determination/Rehabilitation Best Practices and the Role of Situational Work Assessment and Simulated Work/Academic Trials

Dr. J. Douglas Salmon, Jr., Heather A. Pickin, Dr. Jacques J. Gouws

Abstract

This is the final in a series of three papers addressing common occupational disability entitlements from an Ontario motor vehicle accident (MVA) perspective, which are also applicable to long-term disability cases. The first paper supported using a holistic model in the assessment of accident injured persons who are unable to return to the pre-accident occupation (pre-104 disability/“own occupation”) because of accident-caused impairments. The second paper discussed case law, best practice and the Post-104 Week IRB Disability (“any occupation”) test and demonstrated the difficulties individuals face when they are unable to return to work in the aftermath of a debilitating motor vehicle accident. In this third and final paper, the purposes and roles of the Situational Work Assessment and Simulated Work/Academic Trials are critically evaluated in the occupational disability context. These methodologies are used to determine an individual’s capacity to competitively meet the physical, cognitive and interpersonal/behavioural demands of his or her pre-condition occupation, or any occupation for which he or she is suited by education, training or experience, thereby addressing entitlement to income replacement benefits (IRB). It is vital that occupational disability assessments are comprehensive, holistic, include an understanding of the synergistic impact of the impairment on the individual’s physical, cognitive and psychosocial work capacities, and are conducted through multi-modal means. To conclude, the overriding principles and themes of all three articles are synthesized.

The Role of Situational Work Assessments

A Situational Work Assessment (SWA) is a systematic observation process for evaluating functional work performance, sustainable concentration and task persistence, and work-related behaviours and demeanour, relative to required levels of competitive productivity and participation. The SWA (employing standardized and non-standardized simulated work tasks) is used to evaluate the individual’s capacity to simultaneously manage physical, cognitive and interpersonal/behavioural work demands in the context of the whole person and related impairments sustained in the accident (or other disabling conditions in long term disability cases). The evaluation serves to ascertain the individual’s cognitive functional abilities and vocational capacity to perform his or her pre-disability occupation and/or the alternate occupations identified in the Psycho-vocational Assessment. In the case of a rebuttal assessment to the Post 104 Insurer Examination (IE) assessment, the situational assessment will comprehensively evaluate the true competitive viability of each occupation presented by the IE team. The assessment of these factors is also valuable for planning specific vocational options or other rehabilitation services to facilitate a return to work.

The SWA comprises a very specific method of evaluating function over time (Method-Time-Measurement) and requires appropriate: expertise, resources, methodology and analysis.

Expertise

Evaluators conducting SWAs should have training in the use of the measurement tools that are directly relevant to their scope of practice. Proper training helps to improve and ensure the quality of assessments and standardize the way assessments are
conducted, reducing assessor bias and inconsistent use of measurement tools.

In the context of the authors’ (JDS/HAP) practice, the SWAs are carried out by registered occupational therapists who are skilled in completing this type of assessment and analyzing the functional behaviours observed while measuring and interpreting standardized work sampling technologies, simulated work tasks, occupational aptitudes and physical demand factors.

Resources

The SWA includes the administration of a standardized assessment including 12 standardized work modules designed to assess work capacity across a wide range of core work tasks, while providing insight into underlying cognitive and psychomotor abilities. In addition to being predictive of competitive work capacity in the measured tasks, the modules aid in formulating clinical and occupational intervention plans by providing a current skills profile of the individual.

These standardized protocols are tied to both the DOT Worker Qualification Profile factors (and in turn to the National Occupational Classification) and to Method Times Measurement (MTM) industrial performance standards. The outcome of simulated work tasks coupled with physical capacity testing are then matched to the cognitive, perceptual, motor and physical demands of the individual’s own occupation as well as alternate occupations being considered (typically as identified in the team psycho-vocational assessment).

In addition to the use of standardized work sample technology, a variety of non-standardized work simulation and functional activities are also incorporated, to evaluate the client’s emotional, behavioural and interpersonal response to the specific job demands under consideration, and in relation to competitive employability more broadly.

A minimum two-day assessment is recommended for individuals who are non-brain injured and three days for those with a traumatic brain injury. Although five consecutive assessment days are considered ideal, funding constraints usually preclude the added duration. A parallel Simulated Work/Academic Trial (SW/AT) is also available as a more intervention oriented protocol with graduated increase in hours over a three-day period.

The client is scheduled to attend for seven hours per day and his or her performance and participation is closely monitored throughout the day to their maximum level of tolerance. The standardized test is re-administered at the end of the final day of assessment. This serves to ascertain participant learning capacity and as well as to assess sustained concentration, work pace, productivity and stamina in the context of potential cumulative symptom aggravation impact over consecutive work days.

Assessments aim to emulate the synergistic demands of multiple competitive work days in order to complete a picture of the individual’s full capabilities and difficulties, using a variety of assessment tools and strategies for whole person functioning — physical, cognitive and interpersonal/emotional behaviours.

Methodological Overview

The SWA consists of:

- A thorough review of the medical/rehabilitation file as well as collateral interview data.
- Client interview — including details of the accident/condition onset, treatment to date (e.g., diagnostic testing, medication, rehabilitation), current complaints (physical, emotional/behavioral and cognitive), functional status compared to pre-injury, past medical and lifestyle history, social status, living arrangements and community support, avocation, educational and vocational history, pre-condition occupation and job demands.
• A review of the client’s sleep pattern the night prior to the assessment to determine possible effect of fatigue on the outcome; as well as any medications taken prior and during the assessment.

• Administration of standardized work sampling and related clinical/functional protocols and documentation of client behavioural response to, and capacity to, complete tasks within timeframes relative to competitive occupational norms.

• Administration of non-standardized simulated work tasks related to pre-condition or identified alternative jobs, e.g., tasks related to word-processing skills, transposing data, computer research, listening to and recording messages, telemarketing role playing, presentation role playing, route planning, event planning, inventory categorization, procurement, etc. Additionally, tasks are given to allow for evaluating the employment of executive functioning skills such as multi-tasking, planning and organization, remembering details, behaviour regulation, managing distractions and divided attention.

• Physical testing — activities might include: climbing stairs repeatedly, lifting and carrying weights over standard distances (unilaterally or bimanually), balance testing, functional range of motion, Grip Strength Testing, etc. Blood pressure and heart rate are taken pre- and post testing to obtain a baseline measurement initially and subsequently, to observe the response to activity/exercise demands and check for significant changes that may determine the efficacy of continuing the physical testing component.

• Recording and opining on consistency of effort and validity of the results.

• Analysis of the data is then matched to the MTM standard which represents the work rate that an employee in typical occupational contexts would be expected to maintain over the course of the eight-hour workday as work tasks are repeated.

• An 87.5 per cent MTM work score is the cut-off point for passing the work sample.

• Comparing the results of the MTM standardized work modules, functional physical profile and simulated work tasks to the National Occupational Classification (NOC) occupational profile for the individual’s pre-accident/own occupation and each potential occupation identified by the team psycho-vocational testing. In the case of a rebuttal assessment to a Post 104 Insurer Examination, this analysis is performed relative to each occupation presented in the IE report.

**Work Performance/Quality Rating Scale**

The following rating scale is utilized to objectively summarize the client’s performance across standardized work module performance domains:

• Superior (90%-100%) — exceeds expectation: consistently high level of factor related skills, abilities, initiative and productivity. All assignments completed beyond level of expectation. Self-directed.

• Above Average (66%-89%) — meets expectation: high level of related skills, abilities, initiative, productivity, exceeding requirements in some areas but not consistently.

• Average (34%-65%) — performance consistent with goals, expected skills/abilities, productivity.

• Below Average (11%-33%) — performance falls below the expected skill level from time to time; inconsistent demonstration of average skills and abilities.

• Needs Improvement (0%-10%) — consistently low performance: fails to meet expected outcome; high error rate; requires repetition of instructions; clarification of duties; unfinished/incomplete work; inability to meet timeframes.
Performance Factors

Other performance factors that are considered in the overall outcome of the SWA include:

1. Participation/Attendance — arrives on time and is willing/able to stay to optimum tolerance (seven-hour maximum); ability to tolerate work-like tasks; initiative and motivation.

2. Concentration, persistence and pace — observation and analysis of the individual’s ability to: maintain concentration when completing work-like tasks in an environment with distractions (e.g., noise, bright light, interruptions); persist in completion of assigned tasks in a consistent manner; maintain a competitive work pace while demonstrating satisfactory work engagement.

3. Quality of work — ability to consistently achieve competitive level outcomes with a minimum of avoidable errors and omissions, completed in a timely manner.

4. Productivity — considers how the individual uses the work time, planning and organization to accomplish the tasks effectively and efficiently, with consideration to accuracy and completion of the work and the ability to tolerate pressure (work pace, effort and quality of work when given time limits).

5. Adaptability/Flexibility — ability to adjust to changes in scheduling and change in tasks or procedures; willingness to learn and adapt to new assignments, personnel and surroundings; reaction to repetitive work.

6. Dependability/Reliability — ability to carry out instructions (simple or more complex), to work independently and not rely on frequent or constant supervision, guidance or assistance (repeated or demonstrated instructions); and, ability to return promptly from scheduled breaks as agreed, etc.

7. Interpersonal relations (e.g., customer service) — quality of interpersonal skills exhibited with assessor (supervisor), peers (other client’s/workers), customers/general public (other staff); willingness to participate in the work-related assessment.

8. Communication — receptive and expressive verbal (considerations of ESL skills), comprehension and writing legibility.

9. Accommodations — extent required to initiate or complete a task, such as: encouragement, cueing, modified equipment, posture and positioning, breaks (micro, mini or extended), medication, etc.

10. Effect of learning, training and experience — ability to repeat the standardized work tool and demonstrate improvement based on learning and practice effects.

11. Effect of pain, physical and mental fatigue, and cognitive strain on performance and participation.

12. Pain management strategies — number and length of rest breaks/sleep, pain medication, alternating postures (sit/stand), etc.

13. Review or follow-up with the individual is completed a few days post-assessment to ascertain the effect the multiple day assessment had on symptoms and daily functioning and how long it took to return to pre-assessment baseline.

Analysis

A comparative analysis of the data obtained from the situational assessment is then used to compare the client’s own occupation and those identified in the psycho-vocational assessment or Post 104 Insurance Examination (or LTD insurance assessment) based on their respective profiles within the National Occupational Classification (NOC 2011/2016) and Career Handbook (2003).

National Occupational Classification Aptitude Codes

The scores achieved in the standardized work samples and overall performance markers are then compared, including with respect to the NOC apti-
tude codes obtained, at the beginning and end of
the assessment:

**G = General Learning:** The ability to “catch on”
or understand instructions and underlying princi-
ples; the ability to reason and make judgments.
Closely related to doing well in school.

**V = Verbal Aptitude:** The ability to understand
the meaning of words and to use them effectively.
The ability to comprehend language, to understand
relationships between words and to understand
meanings of whole sentences and paragraphs.

**N = Numerical Aptitude:** The ability to perform
arithmetic operations quickly and accurately. Using
numbers for calculations or understanding technical
information.

**S = Spatial Aptitude:** The ability to think visually
of geometric forms and to comprehend the two-
dimensional representations of three-dimensional
objects and the ability to recognize the relationships
resulting from the movement of objects in space.

**P = Form Perception:** The ability to perceive perti-
nent detail in objects or in pictorial or graphic materi-
al; to make visual comparisons and discriminations
and see slight differences in shapes and shadings of
figures and widths and lengths of lines.

**Q = Clerical Perception:** The ability to perceive per-
tinent detail in verbal or tabular material; to observe
differences in copy, to proof read words and numbers,
and to avoid perceptual errors in arithmetic computa-
tion. It is a measure of speed of perception, which is
required in many industrial jobs, even when the job
does not have verbal or numerical content.

**K = Motor Co-ordination:** The ability to co-ordinate
eyes, hands and fingers rapidly and accurately when
required to respond with precise movements.

**F = Finger Dexterity:** The ability to move the fin-
gers and manipulate small objects with the fingers
rapidly and/or accurately.

**M = Manual Dexterity:** The ability to move the
hands easily and skillfully; to work with the hands
in placing and turning skillfully.

The following is an example analysis of the situa-
tional assessment findings relative to the bench-
mark occupational parameters as presented in the
NOC. Other than the direct entry of the client’s ob-
tained aptitudes in the second and third rows of the
chart below, all other details prior to the “Sample
Analysis” are derived directly from the NOC.

**Pre-Accident Occupation: Glass Cutter — NOC #9413.4**

Glass cutters cut flat glass of various thicknesses to
specified sizes and shapes by hand.

Occupations in this group are characterized by the
following aptitudes, interests and worker functions
as they relate to main duties:

- **General learning ability** to cut glass of various
  thicknesses to specified sizes and shapes by
  hand

- **Motor co-ordination** and **manual dexterity** to
  smooth rough edges using belt sanders and
  smoothing wheels

- **Objective interest** in **operating** equipment and
  using hand tools to cut glass along marked out-
  lines and around patterns, and in setting up, op-
  erating and adjusting computerized and robotic
  glass cutting equipment

- **Methodical interest** in **copying** to jig, measure
  and mark glass, and to place patterns on or un-
  der glass for cutting; and in monitoring pro-
  cesses for product quality

- **Innovative interest** in examining and marking
defective glass to obtain best cuts.

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1 Based on MTM Rating — combining quantity and
quality (work pace and error rating).
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<th>Aptitude</th>
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<td>Attained in Day 2 Assessment</td>
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**Data (D), People (P), Things (T)**

<table>
<thead>
<tr>
<th>D:5 - Copying</th>
<th>Carrying out a set of explicit procedural/operational functions or processes based on an understanding of instructions or information necessary to perform the work.</th>
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<tbody>
<tr>
<td>P:8 - Not significant</td>
<td>Not significant to this occupation.</td>
</tr>
<tr>
<td>T:4 - Operating/Manipulating</td>
<td>Using the body or devices to operate, move, guide, install and place equipment, objects or materials. Requires motor co-ordination and manual/finger dexterity. Involves some judgment in precision/selection of objects.</td>
</tr>
</tbody>
</table>

**Physical Activities**

<table>
<thead>
<tr>
<th>Vision</th>
<th>Near vision.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colour Discrimination</td>
<td>Colour discrimination is not relevant in the performance of the work.</td>
</tr>
<tr>
<td>Hearing</td>
<td>Limited: Hearing is limited to short and/or infrequent verbal interactions in order to perform the work.</td>
</tr>
<tr>
<td>Body Position</td>
<td>Other body positions: Includes bending, stooping, kneeling and crouching.</td>
</tr>
<tr>
<td>Limb Co-Ordination</td>
<td>Upper limb co-ordination: Work activities involve co-ordination of upper limbs.</td>
</tr>
<tr>
<td>Strength*</td>
<td>Medium: Work activities involve handling loads between 10 kg (22 lbs) and 20 kg (44 lbs).</td>
</tr>
</tbody>
</table>

**Environmental Conditions**

<table>
<thead>
<tr>
<th>Location - L1</th>
<th>Regulated inside climate.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hazards - H3</td>
<td>Equipment, machinery, tools.</td>
</tr>
<tr>
<td>Discomforts - D1, D4</td>
<td>Noise; non-toxic dusts.</td>
</tr>
</tbody>
</table>

**Education/Training**

Some high school education and/or on-the-job training or experience is required, or on-the-job training or previous related experience alone is adequate. High school education may also be combined with previous experience.

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* **Strength:** Sedentary/Limited (1) – handling loads up to 5kg
Light (2) – handling loads of 5kg but less 10kg
Medium (3) – handling loads between 10kg and 20kg
Heavy (4) handling loads more than 20kg
Sample Analysis

Currently Mr. J.’s aptitude profile does not meet that required of this occupation in any of the nine NOC designate aptitudes including general learning ability, clerical/verbal sequencing, clerical/numerical perception, spatial perception, form perception, clerical/visual discrimination, motor coordination, finger dexterity and manual dexterity. Due to cumulative pain, fatigue and anxiety brought on by the physical demands, cognitive/emotional strain and environmental interference during the assessment, he was unable to fully complete the planned testing on Day 2, hence the absent aptitude ratings in the chart above (indicated by “–”).

Throughout the two-day assessment, Mr. J. demonstrated difficulty with divided attention, attention to detail, independently following two-step or complex instructions when symptoms were reported and required ongoing supervision during tasks. His participation and work rate was very slow in tasks related to this occupation (i.e., tasks involving fast reaction time, sustained attention, sequencing, numeracy, problem solving, divided attention; he was also prone to making multiple errors under pressure and when distracted by pain symptoms aggravated by prolonged standing, sitting, repetitive upper extremity coordination, bending, light strength lifting, etc.

Mr. J. was unable to meet the MTM work rates in 13/13 areas assessed including significant issues observed when distracted by pain and fatigue that negatively impacted his cognitive abilities. These aptitudes are likely vital in this occupation when understanding and executing two-step or complex instructions in an accurate and timely manner, when setting up, operating and adjusting computerized and robotic glass cutting equipment and monitoring processes for product quality and safety.

Mr. J. reported and demonstrated sensitivities and a significant decline in overall performance when environmental conditions similar to those in factory-work settings were present. Light and noise triggered persisting headaches and Mr. J. required the removal of these sources (working away from the window and creating an isolated workspace) to recover and continue with the assigned task. He reported visual disturbances with tasks that required reading, writing or focusing on small objects that induced eye strain. He was observed to have difficulty with receptive and expressive communication and required repeated instructions, translations and clarification (increasing as the assessment progressed and symptoms became exacerbated over two consecutive days of primarily sedentary work). Given the likelihood that the working environment would contain such interferences, Mr. J. may have difficulty maintaining an optimum level of performance in this occupation as demonstrated during the assessment.

Mr. J. also demonstrated limited strength tolerance affecting his ability to handle tools, assist in operating or maintaining machinery and other occupation-related items. Given his poor physical tolerance, endurance and stamina, he is likely to have extreme difficulty in work-related activities such as using hand tools to cut glass along marked outlines and around patterns and copying to jig, measure and mark glass, place patterns on or under glass for cutting. Mr. J. was unable to demonstrate the medium strength tolerances or various body postures and positions as indicated in this occupation. His demonstrated lifting tolerance for the right upper extremity was three lbs and 0.5 lbs using the left upper extremity; his carrying tolerance with over-shoulder accommodation was six lbs on an occasional basis before aggravation of pain and fatigue symptoms. He was unable to demonstrate appropriate manual handling techniques when lifting/bending due to left knee pain.

His need for multiple breaks (including time to sleep), workload and work pace accommodations
and additional medication over the course of the maximum eight-hour day would likely have a significant impact on his ability to be an effective and productive employee at this time.

At present, his poor physical tolerance, cognitive difficulties, degree of required pain management strategies, slow speed of work and high error and/or omissions when distracted by pain, fatigue and low mood, preclude him from being competitively employable in this occupation.

The Rehabilitative Role of the Simulated Work/Academic Trial

The Situational Work Assessment (SWA) and Simulated Work/Academic Trial (SW/AT) share the objective of assisting individuals in identifying potential barriers to employability and to develop plans for overcoming those barriers. Both also allow for the identification of strengths and weaknesses that can lead to ongoing career development post injury or illness. Similar to the SWA, the SW/AT uses standardized work sample modules designed to assess a client’s work capacity relative to his or her cognitive, affective and psychomotor abilities. It similarly establishes the individual’s ability to perform the physical, cognitive and interpersonal/behavioural demands of his or her pre-disability job and/or pre-disability academic/training program.

The primary differentiating factor between the SWA and the SW/AT is that the former is primarily focused on an objective evaluation of the individual’s competitive work capacity relative to specific target occupation(s) in the immediate present; it is not meant to be a therapeutic exercise or rehabilitative in its own right. By contrast, the SW/AT serves as more of a bridge to determine the client’s further pre-vocational/academic needs, orient the client towards re-entering the workforce, more therapeutically address return to work/school apprehension, and where relevant, initiate/enhance career exploration when the prior occupation/academic programme has been ruled out.

Parallel work assessment methodology is utilized in the SW/AT in formulating intervention plans by providing insight into the occupationally related skills an individual possesses. Similarly, the work sample modules provide a standardized assessment system, tied to both Worker Quantification Profile factors (i.e., NOC linked through aptitude levels) and to MTM occupational performance standards.

Uniquely, the SW/AT is a three-day graduated programme of simulated work activities designed to determine a baseline for the development of a vocational rehabilitation plan as an initial step towards work re-entry or to return to school/educational pursuits following an extended period of disability.

The Programme/Trial is conducted over three graduated assessment/treatment days requiring the client to attend the clinic for four hours, six hours and eight hours respectively. This allows for a gradual increase in productivity, essential for optimum outcome results given the time the client has been off work and is likely de-conditioned. This structure also allows the therapist to observe and determine the client’s optimum functional tolerances, work-related behaviours (such as cooperation, initiative, motivation, flexibility, adaptability, ability to tolerate stress and pressure, interactions with co-workers, reaction to noise, ability to work independently, etc.), literacy and language skills, computer skills, physical and cognitive stamina to manage/maintain a satisfactory work performance from a part-time level of productivity to a full day, thus providing a baseline for subsequent vocational or academic pursuits.

Throughout the three-day period, physical functional tolerances are observed and analyzed in conjunction with the physical demands of the client’s job description. Work simulation and aptitude tasks will be used to determine the client’s stamina and...
to identify the client’s occupational/academic strength and weakness profile relative to considered occupation(s). Repetition of these tasks on two of the three days will help to determine the rate at which the client’s work productivity and stamina is improving, an important consideration for adaptation to the workplace/academic establishment.

Ultimately, the programme can be used as a springboard to more specific work and academic pursuits. In this respect, the SW/AT helps to address such considerations as: clinical intervention(s) and referrals to an appropriate vocational/academic conditioning and/or rehabilitation activation programme. It can identify the need for accommodations and academic modifications (e.g., extra tutoring, note taking, examination/project extensions, etc.), English-as-a-second-language programme; (re)training/advanced academic programme; and/or career/academic guidance support and the entry point for initiating a graduated return to work/school along with workplace ergonomics.

As an important rehabilitation emphasis (not offered in the SWA), over the three days the client receives education in the principles of hurt versus harm, good posture and positioning for such activities as lifting and carrying, bending and reaching. Other ergonomic and accommodative strategies are also explored within the programme as is the opportunity for initial career/training/educational exploration.

The SW/AT is a comprehensive first step that will help determine the client’s ability to improve over time and if further active participation in a vocational rehabilitation or work conditioning programme is likely to be an effective strategy to facilitate the client’s return to work/school — either on a full-time basis or a graduated plan negotiated with the employer/academic institution.

Series Summary and Conclusions
This three-part series comprehensively reviewed the case law pertaining to pre- and post-104 IRB entitlement in the MVA context which is highly parallel to “own occupation” and “any occupation” entitlement in the long-term disability context. Case law supported best-practice models of multidisciplinary assessment were presented in the respective initial two papers, sequentially addressing the respective IRB tests. This last paper placed greater emphasis on the role of SWAs and SW/AT. These latter resources are presented as the ultimate means of respectively comprehensively assessing competitive work capacity, relative to the synergistic effects of residual physical, cognitive, psychological and interpersonal/behavioral impairments, and guiding the vocational rehabilitation process.

To summarize, the holistic models of occupational disability and rehabilitation in MVA and LTD contexts should consist of the following multidisciplinary components:

A. Pre-104/“Own Occupation” Determination: Can client perform essential job tasks?

1. Impairment/diagnostic determination of the person’s physical, psychological/behavioural and cognitive impairments through respective medical, psychological/psychiatric and/or neuropsychological assessment.

2. Determine essential physical, emotional/psychosocial and cognitive job demands respectively through: Physical Demands Analysis and Cognitive-Psychological Job Demands Analysis.

3. Determine physical, psychological and/or cognitive fitness to perform essential job demands by means of one or a combination of impairment related: specialist medical assessment/Functional Abilities Evaluation relative to...
the physical impairments; and, clinical psychological/psychiatric assessment, Cognitive-Psychological Functional Abilities Evaluation and/or neuropsychological assessment relative impairments emanating from psychological and/or cognitive impairments. The assessment(s) requires a comparison of the individual’s level of function relative to a physical and/or cognitive-psychological job demands analysis of his or her premorbid work. The first paper in the series discusses the merits of these respective assessments. Depending upon the nature of the essential job tasks and to ascertain issues of sustainability and task persistence/stamina over time, a SWA/SW/AT is often the best means to assess the individual’s capacity to competitively perform the pre-condition occupation as well as in consideration of multiple and synergistic impairment impacts. While the SWA is best suited to specifically address Pre-104 IRB/“own occupation” entitlement, the SW/AT is best suited to direct the vocational/academic rehabilitation process.

B. POST-104/“Any Occupation” Determination: Is there a complete inability to engage in any reasonably comparable employment? This process actually mirrors the vocational rehabilitation process.

1. Impairment/diagnostic determination of the person’s physical, psychological/behavioural and cognitive impairments through respective medical, psychological/psychiatric and/or neuropsychological assessment.

2. Identifying potentially suited occupations. In the physical impairment context, specialized medical assessments can help discern the physical and medical limitations and work task/environmental restrictions. A General Functional Abilities Evaluation (FAE) can be used to derive a physical tolerance and functional capacity profile, determine safety and modification requirements, and highlights functional impairments that would prevent sustainable and productive employment in the identified potential future employment options. A psycho-vocational evaluation (for minimally cognitively impaired) or neuro-psycho-vocational evaluation (for significantly cognitively impaired) to determine best psychological/cognitive fit for potential future employment options, given the concerning impairments. This component also serves to generate, from a neuro/psychological perspective, reasonable alternative work options relative to IRB entitlement determination and/or that would be reasonable and necessary in the rehabilitation of the person whose impairments preclude return to sustained pre-accident vocational activities. This component also includes the specialized assessment of vocational interests, abilities, aptitudes, and re-training needs for the individual to eventually return to viable alternative, competitive employment. As such, these job options have to be based on the individual’s previous work experience/skills, training, education, interests, aptitudes and trainability. In combination, the FAE, and neuro/psycho-vocational assessment provide a sound screening methodology to identify potential occupations for further consideration in the disability and/or rehabilitation contexts. If the FAE is conducted subsequent to the neuro/psycho-vocational assessment, then depending upon the number of occupations derived by the latter, the FAE may be more specific to evaluating the physical functional feasibility of a select number of occupations. Otherwise, a General FAE preceding the neuro-psycho-vocational assessment typically proves to be a more pragmatic approach. If the individual is deemed capable of being retrained or pursuing an alternative occupation, the next steps can be initiated. Once again, if the individual is deemed NOT able to be retrained, or cannot
meet the essential job task criteria for the occupations identified, no further assessment is necessary.

3. **Evaluating client capacity to competitively perform potential alternate occupations.** The final evaluative phase, as well-described in this third article is that of the SWA and SW/AT. Depending upon the occupations under consideration, and particularly if only sedentary to moderate physical demand based occupations are under consideration, these methodologies can replace the need for the FAE noted in the prior phase. The SWA/SW/AT is the best-practice means to address the convergence of the case law derived concepts behind competitive employability. Through standardized work sample technologies and simulated work tasks conducted over the equivalent of two to three full work days, the SWA addresses the viability of the potential occupations under consideration including but not limited to: participant punctuality, sustained attention/concentration, work pace, stamina, maximum daily tolerance and overall productivity. In this regard, these methodologies simultaneously evaluate the synergistic impacts of physical, cognitive, psychological and interpersonal/behavioural impairments over time in an employment context. While preferably, a longer-term assessment such as five to 10 days would be ideal, such is generally not viable from the cost perspective within current industry contexts. The SW/AT as a more rehabilitation oriented tool has the advantage of also addressing clients’ return to school/training potential. In the rehabilitation contexts, SW/ATs address issues of work/academic accommodation, ergonomic/modification needs, gradual return to work/school scheduling, vocational exploration and provide recommendations for vocational rehabilitation next steps.

4. **Income replacement report integration.** When performed in a rehabilitation context, the respective evaluations are often sequential and often occur within different facilities. However, when conducted specifically for income replacement entitlement purposes, the medical, neuro-psycho-vocational and situational assessors must collaborate as a team in conducting their respective assessments. At the completion of the process, the involved assessments should be summarized in an Executive Summary format in order to provide an integration and summary of the team entitlement consensus opinion and recommendations for the ongoing vocational rehabilitation of the injured person.

Given that there are several negative factors that would preclude an individual from engaging in competitive work when struggling with the mental and psychological sequelae of disability and impairment, these are in fact serious barriers to engage in competitive employment. Hence, in arriving at an integrated approach with regard to future vocational rehabilitation and/or permanent disability, the assessors have to rely on the real world test in order to formulate their conclusions. The “real world test” was developed in the Federal Court of Appeal in a 1988 CPP Appeal case, *Leduc, Edward v. Minister of National Health and Welfare*. Based on principles established in this case, this was expanded upon in 2001 in *Villani v. Canada*:

> ... the hypothetical occupations which a decision-maker must consider cannot be divorced from the particular circumstances of the applicant, such as age, education level, language proficiency and past work and life experience.

Although this “real world test” was established within the context of CPP Disability Appeals, it must also be considered when there is a disability in the context of other disability contexts and the assessments conducted on the capacity of people to engage in sustained competitive employment.
Therefore, a comprehensive assessment must determine “real world” occupational viability and recommendations for rehabilitation. It must meet the “real world test”, by taking into account factors such as how long an individual had been off work (if more than two years, the prognosis of ever working competitively again is very bleak), age, work experience, physical capacity, mental and physical deconditioning, mental/intellectual capacity, educational status/skills and the role of the various physical and neuro/psychological conditions or disorders (e.g., chronic pain, anxiety disorders, mood disorders, adjustment disorder, neurocognitive/behavioural impairments) as identified and diagnosed by health care providers. While a sole factor may not do so, very often the combination of all these varied factors constitutes a substantial disability, precluding the individual from being able to procure and competitively perform a job. Unfortunately, too frequently individual impairments are assessed in isolation. For instance, an FAE is utilized as the sole means to consider work capacity for an individual who has psychological, cognitive, interpersonal/behavioural impairments, in addition to (and sometimes in lieu of) physical impairments. Even in the context of strictly physical impairments, FAEs are too short to adequately address stamina and performance sustainability issues. Likewise, in isolation, medical, neuropsychological/vocational assessments may provide a reasonable screening or may be sufficient to address the occupational capacity of the most severely disabled. However, they are typically insufficient to address the synergistic occupational impacts of more subtle to moderate impairments, particularly when combined across physical, cognitive, and psychological domains.

Finally, this three-part series served to highlight the complexities of human reaction and behaviour in the context of significant challenges arising from motor vehicle accident caused injuries in particular and other disabilities with resulting incapacity to continue to work on a sustained full-time basis. Occupational disability is a complex and challenging phenomenon of modern times in a world that is technologically advancing so rapidly that even seasoned individuals struggle to keep up. It must be kept in mind that as the world becomes more complex and job demands more advanced, being out of the workplace for even a short period of time could essentially render a person incapable of returning to that same level of proficiency, competency, and capacity to perform the essential job tasks of a pre-injury employment setting. However, learning the new skills and essentially commencing at entry-level in a new occupational setting may equally be very challenging, particularly in the face of residual cumulative impairments and resulting physical and mental deconditioning. The occupational disability assessment and rehabilitation interventions should be cognizant of all of these factors, account for these factors in an assessment, and provide scientifically based data that benefits all the parties involved in the process: the disabled person, the insurer, the society, and the (potential) employer.

[Dr. J. Douglas Salmon, Jr. is the co-author of many rehabilitation assessment, outcome evaluation and treatment resource materials. He served on FSCO committees addressing Residual Earning Capacity and Catastrophic Impairment (Glasgow Outcome Scale; Mental and Behavioural Disorders (chair)) and consulted to the Minister of Finance’s DAC Committee. His clinical opinions were supported in landmark Catastrophic Impairment Ontario Court of Appeal decisions recognizing chronic pain entitlement and requirement of only one Marked Mental/Behavioural domain; and, another OCA decision regarding Glasgow Coma Scale interpretation. He provides FASD neuropsychological assessments in the context of Gladue pre-sentencing considerations for convicted Indigenous persons and is actively developing related intervention and rehabilitation services for Indigenous in-

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A Need to Know Basis? Canadian Federalism and the Disclosure of Egg and Sperm Donor Identities

Matt Malone

Abstract

In Canada, gamete donation can be known or anonymous. When a child is conceived using anonymously donated gametes, that child does not have a right to know the identity of their donor. Currently, there is no registry storing gamete donor information accessible to donor-conceived persons and no legislation or judicial precedent protecting a donor-conceived person’s right to know the identity of their biological parent(s). With third party reproduction now regularly shifting the traditional outlines of family, these practices are increasingly attracting judicial oversight. This paper examines the consequences of the Supreme Court of Canada’s Reference re Assisted Human Reproduction Act, S.C. 2004, c. 2 (AHRA), which identified donor anonymity as a matter of provincial jurisdiction. The paper argues that the Supreme Court’s decision defined the future of anonymous gamete donation in Canada by strongly protecting anonymity.

I. Introduction: Donor Anonymity in Canada

Over the last 30 years, there has been a profound reconsideration of anonymity in egg and sperm donation (collectively referred to as gamete donation). Since Sweden became the first jurisdiction to abolish anonymity in 1985,¹ there has been a global shift towards mandatory open donation — that is, where a donor-conceived individual has a right to know the identity of their biological parent upon reaching the age of majority. In the three decades since the Swedish reform, nine other national and subnational jurisdictions have followed suit, including Switzerland, New Zealand, and the Australian state of Victoria.² These jurisdictions have recognized donor-conceived children’s right to know their genetic origins by mandating open donation. They have gamete donor registries operating at national, regional, or clinical levels that collect information
about donors. This information can eventually be released to donor-conceived individuals.

These developments are not representative of the Canadian experience. From 2004 until 2010, the federal government strongly protected donor anonymity through provisions on health reporting information in the AHRA. This legislation required the collection and maintenance of certain data about donors, including their name, address, and personal characteristics, despite strongly protecting a right to anonymity for those donors who chose to invoke it. The protections on donor privacy in the AHRA were incredibly robust, resulting in a *de facto* recourse to anonymity. In 2010 those provisions were invalidated by the Supreme Court of Canada. In its decision on the constitutional division of powers, *Reference re Assisted Human Reproduction Act* (Re AHRA), the Court faced the question of whether the sections relevant to donor anonymity were a matter of criminal law (federal jurisdiction) or hospital management, property and civil rights, and local and private matters (provincial jurisdiction). The Court ruled that the sections of the AHRA pertinent to donor anonymity fell under provincial jurisdiction. The agency responsible for enforcing the regulations concerning data collection, Assisted Human Reproduction Canada (AHRC), stopped operating on March 31, 2013.

By upholding questions of anonymity as a matter of provincial jurisdiction, the Supreme Court’s decision guaranteed the future of donor anonymity in Canada. With the exception of Quebec and its *Act respecting clinical research activities relating to assisted procreation*, none of the provinces have replaced the impugned provisions related to donor anonymity with provincial statutes. Though some provinces, notably British Columbia and Alberta and most recently Ontario (with Bill 28, *All Families Are Equal Act*), subsequently passed legislation on specific issues related to birth registration and surrogacy, the Court’s decision created a legislative vacuum on donor anonymity and identity disclosure. Whereas the federal government’s legislation laid down both data collection practices and established an administrative agency to enforce regulations, the provinces have ignored this subject. They have allowed adults to self-regulate their own practices when it comes to choosing between anonymous and known donors — leaving it a matter of personal choice. As history shows, self-regulation in third party reproduction generally veers towards anonymity because it helps intended parents to obfuscate the method of conception, allowing them to dispel some of the stigma of infertility; alternatively, it helps bar parentage claims by egg and sperm donors (who themselves may prefer anonymity in order to avoid claims for child support). But anonymity can also have dangerous and compromising effects on donor-conceived individuals’ health. Today, third party reproduction occurs in Canada within a vacuum: there is an almost complete lack of oversight by any government. The Supreme Court’s decision in *Re AHRA* to designate health reporting information as an area of provincial, and not federal, jurisdiction, despite most provinces’ unwillingness to legislate on this subject at all, guaranteed a *de facto* policy of anonymous gamete donation.

The central thesis of this article is that even though the Supreme Court’s decision did not address the subject of donor anonymity directly, it protected the popular recourse to anonymity. The decision in *Re AHRA* concerned the constitutional division of powers; however, the judgment effectively enshrined the practice of anonymous donation in Canada. The subsequent sections of this article will address the nature of anonymity, before undertaking an examination of how Canada came to have provisions in the AHRA that strongly protected donors’ privacy rights while simultaneously establishing a data collection infrastructure. The article then goes on to examine how this issue became a question of the constitutional division of powers reaching the Supreme Court of Canada. Finally, it shows...
how the decision effectively maintained anonymity in gamete donation.

II. What is Donor Anonymity?

In order to assess how the Supreme Court of Canada effectively protected the practice of anonymous donation in Canada through its decision in *Re AHRA*, it is important to understand the meaning of donor anonymity. In Canada, egg and sperm donation can be known or anonymous. When a child is conceived using anonymously donated gametes, that child does not have a right to know the identity of their donor. Currently, there is no registry storing gamete donor information accessible to donor-conceived persons and no legislation or judicial precedent protecting the right of donor-conceived persons to know the identity of their biological parent(s). As a result, a donor-conceived person’s origins can remain a lifelong mystery.

This lack of knowledge leads many to go searching for information. On the site <www.searchingformyspermdonorfather.org>, people conceived through anonymous sperm donation publish their personal information online in the hopes of a match with their elusive biological fathers. The public profile of one woman, Dotty, tells us that her mother was artificially inseminated in June 1983; that she has blood type O+; and that her DNA sequence is coded and accessible online at Cayman Biomedical Research Institute (CaBRI), the Donor Sibling Registry (DSR), and Americans for Open Records (AmFOR), all informal and private online gamete donor registries. Dotty’s choice to release this information may seem motivated by a strong commitment to open science — typified by the recent spread of volunteer biobanks storing large amounts of biological samples for research purposes — but in fact it is concerned with a deeper, and entirely simpler, psychological objective: discovering the identity of her biological father.

The use of third party reproductive material in assisted reproduction has given birth not only to more and more Canadians like Dotty, but entire fields of medicine, bioethics, and law. It is rapidly shifting the contours of the Canadian family, yet importantly it operates in a regime that tends to favour secrecy. The identity of key participants — “relative strangers”, as one manuscript refers to them — is concealed between those adult parties that choose anonymity. But this concealment extends to the resulting children, who grow up without knowledge of their genetic or biological origins. Many argue that this secrecy protects parents who are vulnerable to parentage claims (on the basis of biology) by egg or sperm donors. Proponents of open donation have mobilized many counter-arguments. They almost always employ a rights-based discourse that centres on donor-conceived individuals’ right to know their origins. Proponents of open donation also point to the following auxiliary arguments: facilitating access to relevant health information; making possible unique-match tissue transfusions; regulating the number of offspring per donor; preventing inbreeding; and halting transmission of genetic susceptibilities.

Finally, technology also plays an important role in the future of anonymity, but it is important not to exaggerate its current scope or potential. The ubiquity of cheap DNA testing technology makes it easier to sequence genetic information and upload this information to the web, circumventing anonymity and allowing people who would like to find one another to locate relative matches. Last year an article in the *Huffington Post* on this subject quipped: “DNA = Donors Not Anonymous”.

As early as 2005, a 15-year-old boy successfully traced his biological father through the use of a DNA test kit from FamilyTreeDNA.com, which cost $289. These technologies make the possibility of disclosure more likely in the future, and many opine that anonymity will eventually become obsolete. But, for now, because genome sequencing technologies
and possibilities of relative matching operate on a voluntary basis, they produce uneven results and raise troubling issues about access to technology. They do not reflect a coherent policy because they operate in the private sphere on a case-by-case basis. While undoubtedly an area of prominence in future research on gamete donor anonymity, the current level of the technology is insufficient to supplant a government-mandated approach. Accordingly, this article focuses on the actions and non-actions of federal and provincial governments on gamete donor anonymity, and how the Supreme Court’s decision on the constitutional division of powers in Re AHRA tilted the balance in favour of anonymity.

Given the innovative and rapidly developing state of assisted reproduction, it is not surprising that the matter of gamete donor anonymity does not fit prima facie under a head of power in the Canadian constitution. In the traditional Canadian constitutional division of powers, family relationships might be seen as conforming to both vertical and horizontal axes. The federal government administers horizontal relationships between adults (i.e., marriage and divorce),11 while the provinces deal with issues related to vertical relationships between adults and children (e.g., parentage; child support, custody, access; and child protection).12 Assisted reproductive technology (ART) confounds these traditional axes because it allows adult parties to create contractual ties that produce children with whom one of the adults is not supposed to have a relationship. The traditional division of powers governing family relationships does not easily accept these outputs, which is why the option of anonymity exists: it allows participants to maintain family integrity regardless of biological ties. As a result of these issues, it is important to note that ART in Canada is a crossbreed between federal and provincial jurisdictions.

This fragmentation was critical in the Court’s decision, which divvied up control of various aspects of ART between the two levels of government. The federal government’s core statute on ART, the AHRA, works on the basis of criminal law power and prohibits certain practices, partially restricts others, and establishes ages of consent. The provincial governments oversee ART through their health, property and civil rights, and local and private law regimes. In those cases, each province has an array of statutes that govern issues like donation/gestational contracts; parentage; birth registration; and custody and support obligations. Often, issues addressed at the provincial level rely on legislation that was never specifically designed to accommodate ART. For that reason, the AHRA was the only statute that effectively took a position on donor anonymity directly — until the Supreme Court invalidated it.

III. The First Attempts at Legislating Donor Anonymity

Understanding the AHRA’s balancing act between protecting donor privacy while simultaneously establishing a data collection infrastructure requires an examination of the history of attempts to legislate anonymity in third party reproduction in Canada. The AHRA was the culmination of the federal government’s long investigation into the legal and moral consequences of ART. In 1993, the Royal Commission on New Reproductive Technologies (the Baird Commission) released its final report and recommendations. The Commission received many briefs from feminist groups, and two of its original commissioners, Maureen McTeer and Louise Vandelaar, were influential in incorporating into the discussion, feminist discourse that framed the issue of ART “as one of protecting women’s bodies and reproductive tissues from commercialization”.13 For this reason, the Commission took a strong position in advocating for criminal prohibitions on commercialized practices, even though the fertility
industry strongly favoured letting the market set prices and the Commission did not propose a strong legal framework for enforcing these prohibitions. Nonetheless, in its final report, Proceed with Care, the Commission encouraged Parliament to create criminal prohibitions on certain activities. Such prohibitions were integrated into legislative responses to third party reproduction with Parliament’s earliest incursions into this field.

Critically, given the focus on prohibitions in its recommendations, the Baird Commission was influential in attempting to address donor anonymity through the criminal law. The Baird Commission went further than just taking a stance against commercialization by also advocating for the creation of a regulatory body, which would act among other things as a repository for health reporting information. The Commission strongly recommended the idea of having the federal government collect information about donors for the entire country — an approach that mirrored the recommendations made by the Warnock Committee in the United Kingdom (“The Committee of Inquiry into Human Fertilisation and Embryology”), which called for a single donor registry for the entire country. However, whereas a unitary approach was appropriate in a country like the United Kingdom where there is no federal division of powers between different levels of government, adapting this approach to the Canadian federalist system raised concerns. As Patrick Healy pointed out shortly after the Baird Commission released its report, the Commission offered “no analysis of the legislative authority that would enable Parliament to enact its recommendations”. Effectively, the Baird Commission advocated that the federal government regulate donor identity by collecting information from donors across the entire country. It neither recommended open donation nor anonymity. It only recommended the creation of a registry. But it offered no constitutional explanation of how this registry could be created, apart from insinuating that the criminal law was the appropriate avenue.

The Commission’s recommendations prompted action by the federal government through the use of a ministerial “moratorium” that did not address donor anonymity but set the precedent for regulating assisted reproduction through prohibitions. In July 1995, Health Canada put a moratorium on practices like cloning and the creation of chimera. At the time, the Minister of National Health admitted that promulgating all the recommendations of the Baird Commission, including those on donor anonymity, was difficult because assisted reproduction “tended to be in provincial jurisdiction. And you know of course that we’re always playing that fed/prov game”. For this reason, the government only enforced clear prohibitions on activities, since they would be easier to justify as a valid exercise of the federal government’s criminal law power. Yet the federal government continued its efforts to legislate on other areas of ART with further legislative endeavours. Between 1995 and 2004, the federal government made several attempts to pass bills that included regulatory schemes with a donor registry. In each of those cases, the bills died on Order Paper.

The only donor registry and policy on donor anonymity ever passed in Canada was the result of hurried parliamentary committee work in 2001-2002, which practically ignored the subject of the constitutional validity of a regulatory scheme created by the federal government. In 2001, the government asked the House of Commons Standing Committee on Health to consult with stakeholders and draft legislation from scratch. The subject of donor anonymity became a pivotal issue in the debates of the Standing Committee, which oscillated between upholding anonymity and abolishing it. Representing the government’s position on donor health reporting information, Liberal MP Judy Sgro, Vice-Chair of the Committee, stated in early December 2001: “There should be no anonymous donors, period”.

Heath Law in Canada I Volume 37 I No. 4
After a Cabinet shuffle the following month, Anne McLellan, the new Minister of Health, nuanced the government’s commitment: “I would like to make it clear that there will be no anonymous donors. All donors will have to provide their names to clinics before they can donate. However, the release of donor names would require the donor’s consent”.  

In this view, anonymity concerned the government alone: disclosure to parents and donor-conceived children remained fortified behind a consent requirement. Practically speaking, this approach protected anonymity, since the vast majority of donors never consent to disclosure of identifying information when given the choice. The government’s proposed policy, despite its commitment to “no anonymous donors”, would continue anonymity between the participants of ART themselves. This policy considered anonymity only from the perspective of the government. While donors could still agree to disclose identifying information if they so wished, the default requirements would only require disclosure of identifying data by donors to the administrative agency (with controls on access to it by others).

At this stage, several actors started objecting to the federal government’s regulation of donor health reporting information as a violation of the constitutional division of powers. These objections were different from those made on ethical grounds. For example, during the drafting of the AHRA the government of Quebec strenuously insisted “that the Act’s regulatory aspects would violate the division of powers”.  

Interestingly, the government of Quebec never revealed its position on donor anonymity. Rather, it focused exclusively on the issue of the constitutional division of powers, asserting that data collection of donors’ information and donor anonymity were areas of provincial jurisdiction. Other actors also raised the importance of this issue, including Glenn Rivard, senior counsel on health matters for the Ministry of Justice, who warned the Standing Committee that regulation of health reporting information would fall within the gamut of provincial responsibility. The likely causes of action where such information would play a critical role — especially claims for child support, access, and custody between intended parents and the donor — were also areas of provincial jurisdiction. “Only the provinces can regulate those matters”, he affirmed before the Committee.  

Regardless of Rivard’s original warning, the Chrétien government pushed hard for federal regulation of donor information. In the summer of 2002, MPs Carolyn Bennett and Hedy Fry, both physicians, were added to the Standing Committee. They strongly backed anonymity by arguing that open donation would serve as a bottleneck on the fertility industry. As they said at the time, an open donation policy would depress supply of gametes and fail to keep up with the demand of intended parents. They argued that the government’s goal was to help infertile couples build families. As Bennett said: “Any significant decrease in donor sperm [or eggs] would make it very difficult, even impossible, for certain individuals to create a child and thus a family”.  

While this argument took the link between open donation and subsequent reduction in gamete supply, and linked this fact to the apparent family-building goals of the AHRA, it also reflected important historical trends where adult participants in third party reproduction deployed anonymity to deflect the stigma of infertility.

The rhetoric of children’s best interests was constantly raised by the Standing Committee. MP Bonnie Brown, Chair of the Standing Committee, said explicitly about the Committee’s work: “Here we had a situation where we were going to produce new children through unorthodox means. And, of course, the principle should be the best interest of the child”.  

Nonetheless, the Standing Committee’s final draft was assiduously guided by the interests of adult participants in third party reproduction. Anonymity maintained the status quo.
of nondisclosure that satisfied the interests of the adult parties. There was no discussion of its ethical, psychological, or social influence on children — even though open donation usually revolves around their personal desire (or lack of desire) to uncover the identity of their unknown biological parent(s). In the end, the party most often seeking access to identifying information about a donor is the donor-conceived person.


In its final form, the AHRA contained criminal prohibitions on certain activities — consisting of absolute prohibitions (ss. 5 to 9) and “controlled activities” (ss. 10 to 14) — along with a regulatory scheme on other activities. The constitutional justification for the regulatory scheme remained ambiguous. This ambiguity proved fatal. The sections on donor anonymity contained in ss. 15-20, which broadly governed issues related to identifying information, privacy, and access to information, were part of the AHRA’s regulatory scheme provisions. They established the Personal Health Information (PHI) Registry where certain donor information would be stored. This donor health reporting information could only be released with the consent of donors. The establishment of these data collection practices was rendered a possible policy shift in the future towards open donation.

Many national and subnational jurisdictions around the world where donor anonymity no longer exists followed a specific series of events in the lead-up to open donation, and Canada had been following this series until Re AHRA. First, these jurisdictions established data collection practices while still protecting donor anonymity; then they moved to open donation. For example, in 1991 the U.K. passed the Human Fertility and Embryology Act (HFEA), which mandated data collection in a donor registry that still had strong privacy protections. After the data infrastructure had been set up, the HFEA underwent legislative revision in 2004. Following Rose v. Secretary of State for Health and Human Fertilisation and Embryology Authority in the U.K. in 2001, where a donor-conceived individual sought the release of identifying information about one of her donors, an ensuing public policy debate on disclosure resulted in amendments to the HFEA that guaranteed donor-conceived children’s access to identifying information about their biological parents upon reaching the age of majority. This policy shift was only possible because the central registry of information already existed. In other words, while the AHRA regulations on health reporting information protected anonymity and made disclosure unlikely in most cases, the implementation of data collecting measures laid the groundwork for a possible policy shift towards open donation in the future.

The importance of the AHRA is that it established a baseline from which a future policy shift could develop — a shift that was undone by the Supreme Court. The AHRA established an infrastructure for data collection that set the basis for a policy discussion on disclosure of donor identity in the future. Even though the federal government took a stance in favour of donor anonymity, the health reporting information provisions created wiggle room for a policy shift in the future towards disclosure, as other countries had done before, simply by requiring the collection of this data. While open donation may only have been a possibility for donors, intended parents, and donor-conceived offspring going forward, since registries are rarely opened up in retrospect (the state of Victoria in Australia is an exception — it retroactively opened its registry to all donor-conceived children when it mandated open donation in 2016) the practice of data collection would still set the groundwork for the policy shift. Without the database, there would be no possibility of open donation in the future.

However, such policy implications — and the possibility of a future shift — quickly took a backseat
as the AHRA became the locus of a major constitutional debate that neglected this issue. In a certain respect, the constitutional debate crystallized a crisis of cooperative federalism. Usually defined as a view of federalism where the different levels of government coordinate efforts to solve policy problems together, the debate over the AHRA was driven by governments (specifically, the federal government and the government of Quebec) eager to subordinate health reporting information in ART to their exclusive legislative control. While these governments could have coordinated their policy goals together, and devoted their limited resources and expertise to legislating in this area, the inability to coordinate resulted in an all-or-nothing approach for both sides. The debate over AHRA resulted in a raising of the stakes where each jurisdiction wanted exclusive control over health reporting information. Thus, shortly after the passage of the AHRA, the province of Quebec challenged the statute and sought judicial review of the Act for exceeding the powers of Parliament.

V. Constitutional Debate Over the Division of Powers: Not a Debate About Anonymity

Once the AHRA became the subject of a constitutional debate over the division of powers, the subject of anonymity was effectively ignored. The government of Quebec, which had strenuously objected to the federal government’s intention to legislate in areas it perceived as within its provincial jurisdiction, filed a reference under the Court of Appeal Reference Act, asking:

Do ss. 8 to 19, 40 to 53, 60, 61 and 68 of the Assisted Human Reproduction Act, S.C. 2004, c. 2, exceed, in whole or in part, the legislative authority of the Parliament of Canada under the Constitution Act, 1867?

Significantly, this question focused on federalism. It did not address the human rights of people using, or resulting from, ART. Conversely, in the jurisprudence, the subject of donor anonymity generally focuses on a rights-based discourse. For example, Pratten v. British Columbia evoked a s. 7 right to know one’s origins, as well as a s. 15 equality comparison between donor-conceived people (who do not have a protected right to know the identity of their biological parents in British Columbia) and adopted children (who do have such a right under the province’s open adoption legislation). In that case, the question of rights became the focus of litigation, which was ultimately unsuccessful at the British Columbia Court of Appeal. Given the decision by the Supreme Court not to grant leave to appeal in Pratten, it is evident that the Court itself has avoided the “rights” aspect of donor anonymity — or at least committed itself to letting the provinces decide, free of judicial constraint. When it addressed the subject of donor anonymity, it did so through a constitutional question about the division of powers.

When the reference question first reached the Quebec Court of Appeal, the federal government did not seek to justify its regulations on health reporting information through the constitutional power of Peace, Order and Good Government (POGG). POGG is the residuary power of the Constitution: it grants to Parliament a legislative jurisdiction over matters not already listed as areas of provincial jurisdiction under s. 92 in the Constitution Act, 1867. Under POGG, the issue would be what branch to invoke — and none of them appeared likely to succeed. Both the residual power and emergency power branches of POGG did not apply: residual power over a matter not coming within the jurisdiction of the provinces did not apply because innovations in health technology otherwise fell under provincial competence, while the emergency power would expire after three months and the AHRA was clearly not designed to be temporary. Finally, since Zellerbach, the national concern doctrine of POGG has been limited by the provincial inability test, where the federal government can legislate only if the inability of the provincial government to legis-
late will have adverse effects; and it was apparent that the provinces had the ability — if not exactly the willingness — to regulate health reporting information. Furthermore, in a number of cases since Zellerbach, the Supreme Court has refused to extend the federal government’s power through POGG using the national concern doctrine. Therefore, the federal government shied away from POGG in its defense of the AHRA and relied on the use of the criminal law power. This line of argumentation is central to understanding the ultimate invalidation of parts of the AHRA by the Supreme Court, which saw the AHRA as an overflow of federal power into a provincial area of jurisdiction.

Instead of POGG, when the federal government was first called at the Quebec Court of Appeal to defend its health reporting information provisions, it brought forth an argument based on the doctrine of double aspect over health law and exclusive power through the criminal law. Double aspect is the doctrine which allows laws to be double-categorized under provincial and federal jurisdiction, so here the federal government sought to have health reporting information recognized as both an area of provincial as well as federal jurisdiction. On top of that, the criminal law power belongs exclusively to Parliament under s. 91(27) of the Constitution Act, 1867. Despite the two-pronged strategy, the debate revolved almost entirely around the criminal law and the extension of this power to new realms of regulation, as per R. v. Hydro-Quebec and Reference re Firearms Act (Canada). Ultimately, the Quebec Court of Appeal was not sympathetic to the federal government, and ruled that the health reporting information provisions were an invalid exercise of law because they trampled on health matters of exclusive provincial jurisdiction.

VI. Reference re Assisted Human Reproduction Act

By the time the case reached the Supreme Court of Canada, the federal government only characterized the AHRA as an exercise of criminal law. Historically, the Supreme Court has been amenable to extending new powers to the federal government through the criminal law head of power. In addressing the question of “whether the criminal law power will sustain the establishment of a regulatory scheme in which an administrative agency ... exercises discretionary authority”, the Court is generally more favourable to expanding federal jurisdiction through the criminal law than through POGG. One of the main questions is colorability — that is, the question of whether the legislation is “a colourable means of regulating matters within provincial jurisdiction”. The Supreme Court has been lenient with this requirement in various precedent regulatory schemes, including: tobacco advertising, pollution, firearms, and assisted suicide. The federal government sought to extend this argument to the regulatory scheme of the AHRA. It argued that they served an auxiliary purpose to the main prohibitions, helping to achieve “an underlying criminal purpose”. In this view, the regulations would supposedly be meant not “to define unlawful conduct” but merely “the conditions under which lawful conduct may be pursued”. The health reporting information provisions, in this argument, acted as a condition for the successful, effective, and lawful practice of assisted reproduction. For these reasons, the federal government decided to exclusively rely on the criminal law power argument.

In Re AHRA, the Court split into two camps over this issue: one (the decision by Justice McLachlin, on behalf of Justices Binnie, Fish, and Charron) that viewed regulatory provisions in the AHRA as auxiliary to the major prohibitions and therefore within the gamut of federal jurisdiction. According to Chief Justice McLachlin, the AHRA was mainly designed to restrict “public health evils” and the regulations bolstered this purpose. The other decision (held by Justices Deschamps/Lebel, on behalf of Justices Abella and Rothstein — and supported by Justice Cromwell, with slight deviations regard-
ing the ages of consent) viewed the AHRA as mainly beneficial to Canadians’ family-making needs, and saw the regulations on health reporting information as part and parcel of medical practices under provincial jurisdiction. Specifically, the Deschamps/Lebel decision read donor health reporting information under the provincial powers, relying on four sections of the Constitution: s. 92(7) on health institutions; ss. 92(13) and 92(16) on civil aspects of medicine, especially the doctor-patient relationship as well as management of healthcare facilities; and s. 93 on education.

VII. Reading Anonymity in Criminal Law: The McLachlin Decision

Chief Justice McLachlin broadly depicted questions related to ART as a significant “moral” issue of our era. However, issues of anonymity and the disclosure of biological connections reach back into some of the earliest narratives in the West — from the story of Moses, an adoptee who did not know his origins, to the entire plot of The Comedy of Errors, which is based on the premise of twins separated at birth, each raised by adoptive parents without knowing each other. Nonetheless, the depiction of the AHRA as a tool to curtail morally reprehensible practices underpinned the Chief Justice’s reasoning.

According to the Chief Justice, the regulatory scheme of the AHRA, including the health reporting information sections, was evidently not criminal law in pith and substance. The Chief Justice argued that the “dominant thrust of the Act is prohibitory”. The McLachlin decision diverged from the Deschamps/Lebel decision at this very characterization. The Chief Justice accepted the Attorney General of Canada’s characterization of the legislation as curtailing “practices that may contravene morality, create public health evils or put the security of individuals at risk”.

The Chief Justice validated the regulatory scheme indiscriminately as a whole, including its health reporting information provisions, by invoking the ancillary powers doctrine. The provisions on donor anonymity were not, in pith and substance, within the jurisdiction of the federal government, as the Chief Justice admitted, so they were upheld in her judgement “on the basis of their connection to a valid legislative scheme”. Resorting to the test of necessity from General Motors, according to which the greater an intrusion by an ancillary provision, the higher the threshold must be met for maintaining it, the Chief Justice argued that the intrusion was not serious because the heads of provincial power upon which the health reporting information provisions intruded — namely over property and civil rights and matters of a local and private nature — were very broad to begin with.

The Chief Justice also maintained that the ancillary powers doctrine validated the health reporting information sections because their sole purpose was “to ensure the smooth functioning of the criminal prohibitions”. This argument was fort de café, because anonymity is a choice and the decision to have a government agency protect this choice has no substantial connection with any of the absolute prohibitions in the AHRA. Ultimately, the Chief Justice’s decision strained to find a logic that would validate the regulatory scheme under the criminal law. Rather obviously, she was authorizing the regulatory scheme in the AHRA in the name of efficiency.

VIII. Reading Anonymity in Health Law: The Deschamps/Lebel Decision

The Deschamps/Lebel decision stood on much firmer logic than the McLachlin decision because it took a more nuanced view of ART, in particular critiquing the regulatory scheme. After undertaking
a review of the legislative history of the AHRA, the Deschamps/Lebel decision took a view of ART as “morally and socially acceptable” to Canadians. Accordingly, the authors examined the regulatory scheme and determined it was designed to regulate the health services provided by fertility practitioners in third party reproduction. This interpretation of the AHRA was in line with the opinions of the Baird Commission and the Standing Committee in their debates on anonymity. Unlike the McLachlin decision, the Deschamps/Lebel judgement characterized the regulatory provisions of the AHRA as “the regulation of assisted human reproduction as a health service” (emphasis added).

Even though the Deschamps/Lebel decision more convincingly characterized the health reporting information sections of the AHRA, the terminology was unavoidably vague. Much of the information collected was not entirely germane to health. Some of the information included in the AHRA definition of health reporting information, such as name and personal characteristics, arguably had no health purpose at all. Practically speaking, even in emergency situations the release of the donor’s name is rarely a necessity. For example, in the U.S. case Johnson v. Superior Court (California Cryobank, Inc.) one of the most important cases where a donor’s anonymity was challenged, the plaintiff’s demand for the release of health information about a sperm donor was granted — except for the donor’s name. Moreover, s. 18 of the AHRA gave the agency administering the PHI registry the discretion to release information as it saw fit, especially in cases of emergency. Ultimately, it was not fully clear why the federal government called this data “health reporting information”. Personal characteristics like educational and professional background, race, and eye colour are usually collected for the purposes of giving intended parents greater selection among donors, and have nothing to do with health. The decision of the federal government to collect this information demonstrated that health reporting information, despite its name, served other purposes.

However, the Deschamps/Lebel decision went even further in signalling the real underlying motivation of the McLachlin judgment to extend the gamut of the criminal law head of power. In stark language, they wrote: “Recourse to the criminal law power cannot … be based solely on concerns for efficiency or consistency, as such concerns, viewed in isolation, do not fall under the criminal law”. In other words, in their view the McLachlin decision to maintain the regulatory scheme was effectively upholding a unitary system that had validity under neither the criminal law power nor the ancillary powers doctrine. But its intention was clear: establish national standards for the purpose of administrative efficiency. As this article argues, such an approach favoring efficiency set the groundwork for a future policy shift towards open donation in the future. But it lacked a solid constitutional argument to back it up, and that is where the Deschamps/Lebel decision targeted the faulty logic of the Chief Justice. Indeed, Justice Cromwell, in a mostly concurring but separate decision, underlined this comment of the Deschamps/Lebel decision in explaining his own reasons for siding with them.

Partly as a result of these exchanges, the decision attracted significant attention for halting recourse to the criminal law in order to expand regulatory schemes — something that had been successful, as the Deschamps/Lebel decision repeatedly noted, in other contexts where the substantive component of criminal law was easier to establish.

Despite its strong argumentation, the Deschamps/Lebel decision had an enormous impact on the future of anonymous gamete donation. The decision found that the health reporting information sections of the AHRA exceeded Parliament’s legislative authority, and effectively belonged to the jurisdiction of the provinces over hospitals, civil rights, and local matters. However, in the years fol-
following the decision none of the provinces except Quebec passed legislation to replace the invalidated sections on health reporting information. As a result, donor anonymity fell into a vacuum; trends were determined by the market (albeit constrained by the valid criminal prohibitions on commercialization in s. 12). As a result, a policy shift towards open donation at the national level was no longer possible — in fact, it was set back by dismantling the data collection infrastructure that would have made it viable.

IX. Donor Anonymity After the Invalidation of the PHI

The judgement in Re AHRA maintaining that health reporting information was ultra vires the federal government’s criminal law power effectively prolonged anonymous donation in Canada for the immediate and near future. Following the declaration of invalidity, the provinces did not mandate practices for the collection of this information. Yet provincial regimes had the possibility of relaxing the strict punishments required by the criminal law, and replacing them with their own regulatory schemes, and, in doing so, eliciting more donation. But this has not happened. On the other hand, the creation of a legislative vacuum resulted in the destruction of a data collection infrastructure that made a policy shift towards open donation more difficult than before. As of March 2017, the only provincial legislation pertinent to donor registries and donor anonymity is the legislation in Quebec, where, in fact, donor anonymity is strongly protected.

In Canada, the provinces’ unwillingness to regulate health reporting information may come from their proximity to the unregulated American market. Even under the AHRA, Canada was far from the establishment of a functioning gamete donor registry due to the reality of the nearby American market providing approximately 95 per cent of donor gametes. Canadians resort to the American market because of its wide selection (by contrast, in Canada there are only about 50 sperm donors for the entire country). But even though the AHRA did not respond to facts on the ground, mainly on account of an inflexible use of the criminal law to absolutely prohibit commercialization of human bodies and tissues, the flawed registry still left room for a future policy shift towards open donation.

When the data collection infrastructure was dismantled, many voices raised the spectre of its replacement with “patchwork legislation” that would frustrate attempts to move towards open donation. This patchwork landscape would result in increasing interprovincial and transnational use of ART. Such trends favour anonymity because they cross jurisdictions and make it difficult to coordinate transfer of data about donors. Without oversight from a higher level of government, participants can travel between the provinces to seek desired results, creating a disunity in data collection practices that make a shift to open donation more unlikely than under an unitary approach. The Court solidified this prospect by throwing the onus for data collection — and, indeed, for setting policy on donor anonymity itself — onto the provinces, which were either unwilling or not ready to legislate on the subject.

Ironically, while the Supreme Court effectively dismantled the PHI registry, scientific trends have gone in the other direction. Today, biobanks around the world contain many individuals’ biological samples — everything from blood to isolated DNA. In 2001, the cost of mapping an entire DNA sequence was approximately $100 million. Today it is less than $999, and one can map their genome sequence with the pharmaceutical industry-sponsored company 23andme for only $249. Since the discovery of DNA in 1953, developments in genome sequencing technology have ushered in a new era of science, particularly in the field of personalized medicine. By mapping an individual’s entire genetic sequence, this data provides a major opportunity to researchers because it lets them
crunch massive amounts of data to tailor medical treatments, study rare genetic disorders, and develop more effective drugs. Many see an inevitable use of this technology to phase out anonymity in gamete donation in the future. However, efforts to use this technology to locate relative matches are still in a nascent phase, and so while their potential is worth recognizing, that potential should not be hyperbolized in the present context.

Maintaining donor anonymity has had the unfortunate effect of commercializing not gametes but knowledge of genetic identity itself. Many informal egg and sperm donor registries operate on a similar basis to biobanks, although rather than operate for research purposes, they seek profit. Many of these registries, including the DSR, CaBRI, and AmFOR, all incorporate DNA testing into their online services to enable relative matches. Similar to DSR, CaBRI, and AmFOR, there are also: Donor Conceived Registry (U.K.), Australian Donor Conception Registry, Procréation Médicalement Anonyme (France), Spenderkinder (Germany, Austria, Switzerland), Donorkind (Belgium), Donor Offspring Group (Japan), Donor Offspring Europe, and many more groups on social media. The abundance of informal registries like these raises serious issues about the commercialization not of gametes but genetic information itself because these sites — much like <http://www.ancestry.com/> — mostly operate behind paywalls.

In light of this uneven access, establishing a government-run gamete donor registry is the best way to fairly and equitably track this information. It could operate at a regional or even clinical level, and would not necessarily require relinquishing donor privacy. Until uniform infrastructure for data collection of donors is established, open donation will only occur on the private level. By contrast, infrastructure that mandates collection of data, even if it remains respectful of donor privacy, could contribute towards building a database for government authorities that could eventually act as the jumping off point for a policy shift towards open donation in the future — something most observers agree is inevitable in light of the technological developments anyway. Otherwise, the shift to open donation can only happen on an ad hoc basis, as the result of consent between contracting adult parties; and this ad hoc basis will result in an extremely uneven rollout hindered by individuals’ varying levels of access to technology.

While it may seem strange to argue on behalf of the possibility of a shift to open donation — rather than just argue in favor of open donation itself — in fact the possibility of such a shift is often an acceptable compromise for donors, intended parents, and donor-conceived offspring. Knowing that information exists, even if a party does not have access to it, can be extremely reassuring. Remember that the legal battle in Pratten was unleashed not by the absence of a registry, but by the threat of a closing fertility clinic to destroy its records. Olivia Pratten sought first and foremost an injunction against the clinic from destroying those records. Additionally, a registry that maintains confidentiality of anonymous donors could still be used to facilitate access to relevant medical history without revealing identifying information about donors. It could also monitor the number of offspring per donor, and even enhance the public’s perception of the fertility industry, which currently enjoys a not-so-perfect reputation for lack of oversight. A registry maintaining donor confidentiality could be modelled on various existing regimes (e.g., foreign legislation, informal registries already in existence, adoption regimes, blood/organ/animal biobanks). Unfortunately, as a result of Re AHRA, whatever form it takes would have to be initiated by the provinces or private actors.

X. Conclusion: What Next for Donor Anonymity?

In its ruling, the Supreme Court focused on the division of powers and effectively delayed the policy
shift towards open donation. Nonetheless, a policy debate on gamete donor anonymity is still coming to Canada. Recently, the Canadian Fertility and Andrology Society, the professional body that oversees fertility practitioners nationwide, announced that it will host a panel at its 2017 annual conference on the merits of establishing a gamete donor registry in Canada. However, this panel demonstrates how far back the Supreme Court’s decision has set Canada from having a national, provincial, or even clinical-level registry. Until gamete donor registries are established by the provincial governments, the only way to set the groundwork for open donation is through personal agreements, informal networks, and best practices guidelines by private bodies. However, these options operate on a voluntary basis. In the absence of a social trend towards disclosure, only legislation will facilitate the shift towards setting the groundwork. In reading health reporting information as part of provincial jurisdiction, the Supreme Court effectively created this state of affairs and established this delay.

In his writings on fatherhood, Jonathan Ives has said that parentage is a dyadic concept, composed of the parent-as-progenitor and the parent-as-carer. But if this is true, then anonymous gamete donation effectively — and often permanently — cuts the dyad in half. It shrouds in secrecy the parent-as-progenitor. Ignoring the psychological effects of this cut, donor-conceived individuals like Dotty, who was mentioned at the start of this article, present a compelling example of the paradoxes of anonymity that exist today. In a Canada that reifies transparency, open data, and accessible information, the children of anonymous gamete donation live with the unknown regarding the most intimate details of their conception. Yet strangely, the debate is not about them. It has been shaped as a question of the constitutional division of powers. And in reading health reporting information as part of the health law power, the Court strongly endorsed a state of affairs where anonymous gamete donation in third party reproductive medicine remains the norm.

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2 In historical order, the jurisdictions are: Sweden (1985), Austria (1992), Switzerland (2001), Norway (2003), the Netherlands (2004), New Zealand (2004), United Kingdom (2005), Finland (2006), Germany (2013), and Victoria (Australia) (2016).
4 C.Q.L.R. c. A-5.01.
7 Petra Nordqvist and Carol Smart, Relative Strangers: Family Life, Genes and Donor Conception, 2014.
11 Constitution Act, 1867, 30 & 31 Vict, c. 3, s. 91.
12 Ibid., ss. 92(13) and 92(16).
AHRA, s. 17.
AHRA, s. 18(3).


Re AHRA, at para. 24.

Ibid., at para. 21.

Ibid., at para. 126.

Ibid., at para. 135.

Ibid., at para. 169.

Ibid., at para. 227.


Re AHRA, at para. 244.

Ibid., at para. 287.


See <https://www.23andme.com/en-ca/>.


Issues of Vulnerability and Equality: The Emerging Need for Court Evaluations of Physicians’ Fiduciary Duties in High Stakes End-of-Life Decisions
Laura Hawryluck

Abstract

At the heart of high stakes end of life (EOL) decisions such as withdrawal of life-sustaining treatments (WLST) or medical assistance in dying (MAiD), are concerns that vulnerable people in our society need to be legally protected from prematurely ending their own lives or from having their lives inappropriately ended by healthcare teams predisposed to negatively assess their quality of life. Recently, two Supreme Court of Canada rulings in Rasouli and Carter (MAiD) have clearly emphasized the role of consent in providing legal protections to people at the end of life. The role of the medical standard of care is less clear: though the Supreme Court in Rasouli was careful to state there had been no ruling on the medical standard of care with respect to WLST, the Court did state that standard of care considerations would be important in such decisions. In contrast to Rasouli, the result of the Carter ruling was that consent alone is insufficient protection for physician assisted death without a medical standard of care. Subsequently, in its new legislation, the Canadian Government restricted access to MAiD on the grounds that some people — those who lose capacity, with mental illnesses and mature minors — are so vulnerable that this potential choice at the EOL must be denied. In simple terms, for some, consent and the medical standard of care are insufficient protections. Such claims and their consequences are a sign of an emerging and significant problem: the reduction of medicine to a mere contractual relationship while disregarding its fiduciary nature simply because the courts have, in the words of Chief Justice McLachlin, “never reviewed physicians’ good faith treatment decisions on the basis of fiduciary duty”. The goals of this article are to explore issues of vulnerability and equality, the existing protections in both medicine and law and the emerging need for courts to evaluate physicians’ fiduciary duties in high stakes EOL decisions in order to resolve conflicts with respect to WLST, to ensure access to MAiD and to promote the future quality of EOL care for all Canadians.

Introduction

At the heart of high stakes end of life decisions — whether the withdrawal of life sustaining treatments (WLST) or medical assistance in dying (MAiD) — are concerns that vulnerable people in our society need to be legally protected from prematurely ending their own lives or from having their lives inappropriately ended by healthcare teams predisposed to negatively assess their quality of life. Recently, two Supreme Court of Canada rulings in Rasouli and Carter (MAiD) have clearly emphasized the role of consent in providing legal protections to people at the end of life. In Rasouli,

the Supreme Court ruled that life-sustaining treatments cannot be withdrawn from incapable patients without consent of their substitute decision-maker. Though the Court in Rasouli was careful to state there had been no ruling on the medical standard of care with respect to WLST, the Court did state that standard of care considerations would be important in such decisions. Chief Justice McLachlin opined however that the “blunt instrument” of the medical standard of care alone could not provide sufficient protections to patient at the EOL when deciding to withdraw life support, unless consent is also engaged. Subsequently, in the landmark Carter case, the Supreme Court ruled that s. 14 (consent to have
death inflicted) and s. 241 (assistance with suicide) of the Canadian Criminal Code violated s. 7 of the Canadian Charter of Rights and Freedoms, the right to life, liberty and security of person.⁶ In contrast to Rasouli, the result of the Carter ruling was that consent alone is insufficient protection for physician assisted death without a medical standard of care.⁷ Because in Carter, it had found these sections of the Criminal Code violated s. 7, the Court did not consider if s. 15 Charter rights were also violated⁸ by depriving people at risk of vulnerability due to race, national or ethnic origin, colour, religion, gender, age or mental or physical disability from equality before and under the law.

In its new legislation though, the Canadian Government restricted access to MAiD on the grounds that some people — those who lose capacity, with mental illnesses and mature minors — are so vulnerable that this potential choice at the EOL must be denied.⁹ In simple terms, for some, consent and the medical standard of care are insufficient protections. Yet it defies credulity to claim that, on a prima facie basis, all members of such ‘vulnerable’ groups lack capacity and the ability to provide a legally valid consent. It defies humanity to claim medical interventions, for they are no longer treatments, that are only causing increasing harm as time passes, should always be continued unless there is substitute decision-maker consent to their withdrawal in order to protect members of vulnerable populations. Are such claims and their consequences a sign of an emerging and significant problem: the reduction of medicine to a mere contractual relationship between parties (patients and physicians) while disregarding its fiduciary nature simply because the courts have, in the words of Chief Justice McLachlin, “never reviewed physicians’ good faith treatment decisions on the basis of fiduciary duty”?¹⁰

The goal of this article is to explore issues of vulnerability and equality, the existing protections in both medicine and law and the emerging need for courts to evaluate physicians’ fiduciary duties in high stakes EOL decisions in order to resolve conflicts with respect to WLST, to ensure access to MAiD and to promote the future quality of EOL care for all Canadians.

Concepts of vulnerability, equality and existing protections

Vulnerable people are commonly defined as those who need either special care, including physical, emotional or psychological support, or protection because of age, gender, race, physical or cognitive disability, or risk of abuse or neglect.¹¹ Every person with an illness can therefore be considered vulnerable in some fashion in that they need physical, emotional and psychological help in alleviating pain and symptoms and in achieving the best quality of life possible, if not always the quality that is desired.¹² Such vulnerability may increase with increasing illness severity, in particular as the EOL nears.¹³ With the concept of vulnerability comes a natural societal desire to ensure that appropriate protections are in place. These protections are of such importance that they are found both in medicine and law.

Concepts of equality and the legal protections

Legal protections for all Canadians, including those considered more vulnerable within society begin with s. 7 of the Canadian Charter of Rights and Freedoms, the right to life, liberty and security of the person and with s. 15 the purpose of which, as stated by Justice Iacobucci at para. 4 in the landmark case Law v. Canada (Minister of Employment and Immigration),¹⁴ is: “to prevent the violation of essential human dignity and freedom through the imposition of disadvantage, stereotyping, or political or social prejudice, and to promote a society in which all persons enjoy equal recognition at law as human beings or as members of Canadian society,
equally capable and equally deserving of concern, respect and consideration”. Section 15 jurisprudence recognizes four dimensions of equality: equality before and under the law and equal benefit and protection in law. These equality considerations do permit differential treatment when it assists in improving the positions or conditions of the disadvantaged within our society. As Justice Iacobucci went on to state in *Law* at para. 53:

[T]he equality guarantee in s. 15 is concerned with the realization of personal autonomy and self-determination. Human dignity means that an individual or group feels self-respect and self-worth. It is concerned with physical and psychological integrity and empowerment. Human dignity is harmed by unfair treatment premised upon personal traits or circumstances which do not relate to individual needs, capacities, or merits. It is enhanced by laws which are sensitive to the needs, capacities, and merits of different individuals, taking into account the context underlying their differences. Human dignity is harmed when individuals and groups are marginalized, ignored, or devalued, and is enhanced when laws recognize the full place of all individuals and groups within Canadian society. Human dignity within the meaning of the equality guarantee does not relate to the status or position of an individual in society *per se*, but rather concerns the manner in which a person legitimately feels when confronted with a particular law. Does the law treat him or her unfairly, taking into account all of the circumstances regarding the individuals affected and excluded by the law?

As s. 15 jurisprudence has evolved a recognized difference between formal equality in law (people are treated equally) and substantive equality (people are treated according to their needs so that equality is achieved) is now understood as the Chief Justice stated in *Whiter v. Canada (Attorney General).*

Both the inquiries into perpetuation of disadvantage and stereotyping are directed to ascertaining whether the law violates the requirement of substantive equality. Substantive equality, unlike formal equality, rejects the mere presence or absence of difference as an answer to differential treatment. It insists on going behind the facade of similarities and differences. It asks not only what characteristics the different treatment is predicated upon, but also whether those characteristics are relevant considerations under the circumstances. The focus of the inquiry is on the actual impact of the impugned law, taking full account of social, political, economic and historical factors concerning the group. The result may be to reveal differential treatment as discriminatory because of prejudicial impact or negative stereotyping. Or it may reveal that differential treatment is required in order to ameliorate the actual situation of the claimant group.

Fundamental to achieving such substantive equality in health law, for those at risk of vulnerability and those rendered vulnerable by illness, have been the legal principles of capacity and consent to treatment. These two principles have enjoyed some of the most rigorously expounded concepts in legislation and common law. Canadian law has gone to substantial lengths to define, promote and protect capacity so central are the right to self-determination and legal concepts of human dignity to our society. Capacity is presumed. And if it’s lost, rigorous safeguards are in place to ensure the person’s voice is not lost—whether through formal review processes of the correctness of the finding of incapacity, advance care planning or through the legal standards of substitute decision-making. People who are vulnerable do not all lose the ability to understand and appreciate what is important for their own well-being nor do they all lose the ability to think and know what they want with respect to healthcare. The legal standard of consent also offers unambiguous protections to all Canadians, independent of vulnerability: consent must relate to the treatment being proposed, be informed, be given voluntarily and not obtained through misrepresentation or fraud. Consent reflects and protects a person’s autonomy and his or her right to determine what is done to his or her own body — a very basic human right. In medicine, consent is one of the foundational links between human rights, health and personal notions of well-being. To protect those at risk of vulnerability and to ensure equity, legal principles of capacity and consent are enshrined in legislation, considered in common law and well delineated in healthcare policies.
Intrinsic protections in medicine: the challenges of blurred concepts

People who become ill are further protected from harms by the medical standard of care and the standard of practice. The medical standard of care, as it is used in clinical practice, consists of those treatments that, based on scientific evidence, have the ability to cure, stabilize or alleviate pain and symptoms while carrying as low a risk of harm as possible. The medical standard of care ensures that medicine never becomes an instrument solely of harm and the protections it provides are therefore pivotal. The medical standard of practice consists of all the professional, legal and ethical aspects of medical practice that have been defined and clarified by statute, case law and the policies of provincial medical regulatory colleges. These concepts include requirements for consent before initiating treatment unless there is an emergency, and the standards of decision-making among available treatment options that reflect both the science of medicine and the unique nature of the patient’s wishes, values and state of health. It is the medical standards of practice that speak to a physician’s fiduciary duties to patients.

A fiduciary relationship is one of equity in law: wherein a person (the patient) relies, trusts and has confidence that the fiduciary (the physician) will act with utmost care loyalty and good faith. Fiduciary duties in medicine extend beyond those of any contract or duty to care: they mean that patients are entitled to expect that their physicians will act, with loyalty, in service of the patient’s interest to the exclusion of his or her own. Patient best interests have been previously delineated in law to include the personal values, beliefs and wishes that define the person and that he or she will take into consideration when making decisions regarding healthcare. In medicine, consideration of and respect for these values, beliefs and wishes are currently part of the medical standard of practice as they will determine both the physician’s recommendations among treatment options within the medical standard of care at the EOL and ultimately the patient’s choice among these options. However, the concept of best interests in fiduciary duties means something different: best interests here extend beyond consideration of personal values to speak to the purpose of medicine itself. Best interests in the context of fiduciary duties reflect trust that the physician will use his or her knowledge and skills to present treatment options and make recommendations in order to achieve the best possible state of health and quality of life for the patient. Such fiduciary aspects presume trust that these goals will be sought even when such service cannot be monitored by the patient. Such duties fall under norms of medical standards of practice as they encompass issues of professionalism, ethics, caring, trust, confidentiality and loyalty to a patient’s interests that extend beyond the scientific medical standard of care — that of whether a treatment can help more than it harms. The difference is important: the patient in a fiduciary relationship should expect to be able to trust his or her physician; the patient in only a contractual relationship would be expected to be aware of a need to protect his or her own interests. For these reasons, fiduciary duties are often discussed as being prophylactic in nature. Any breach in fiduciary duties generally leads to more strict remedies than seen in tort cases, aimed at deterring such breaches. In medicine these can be harsh and include disciplinary actions up to and including revocation of the physician’s licence to practice — this as opposed to monetary compensation more frequently seen in negligence (tort) cases. The distinction between medical standard of care and medical practice is often blurred though and the two concepts are subsumed under the standard of care in both medicine and common law. From a legal perspective, the medical standard of care, as narrowly defined above, engages contractual as-
pects of medicine: the patient seeks a certain treatment and quality of healthcare (similar to a commodity) from a physician and contracts with the physician that appears best able to provide it. If a breach of this contract occurs and harms ensue, tort law is therefore engaged and issues of negligence are examined. Yet such legal contractual obligations of physicians describe a very pale notion of any physician-patient relationship: it fails to speak to issues of profound trust, caring and the very nature of the actual decisions — some of the most important decisions we will make in our lives.

Breaches of the medical standards of practice or fiduciary duties, when considered before the court, have often been incorporated into medical standard of care issues. However, this approach fails to appropriately consider the distinct nature of breaches of the fiduciary, to weigh it is often more profound consequences with respect to harms to patients and to systematically impose suitable remedies. The need for courts to distinguish between the medical standard of care and of practice is key to ensure the protections intrinsic to medicine are fully realized. Moreover, such evaluations of the fiduciary by courts are now needed to move beyond existing jurisprudence to truly protect those who are or may be vulnerable, to better resolve conflicts in WLST, to permit access to MAiD for all Canadians and to promote quality EOL care.

Evaluation of fiduciary duties

In Norberg v. Wynrib wherein a physician supplied narcotics to an addicted patient in exchange for sexual favours, Justice McLachlin [as she then was], emphasized the breach in the patient-physician fiduciary relationship in her ruling and in her proposed remedy, although this line of reasoning was not adopted by the court. Subsequently, in McInerney v. MacDonald, the court based its ruling on consideration of fiduciary duties when holding a patient must be given complete access to information in her medical records. The role of fiduciaries duties was also recently perceived as important in adjudicating EOL conflicts when, in her dissenting opinion in Rasouli, Justice Karakatsanis:

[194] Generally, in many typical doctor-patient relationships, the fiduciary obligation and the standard of care will likely overlap or resemble one another. It seems to me, however, that in the end-of-life scenario where ongoing life support is futile, the foundation and ambit of a doctor’s fiduciary duty would be a useful and appropriate conceptual paradigm to supplement the standard of care and address the broader best interests of the patient. In such difficult circumstances, in my view, the ambit of operation of the fiduciary and standard of care duties tend to diverge. As the Chief Justice observed in Norberg: “The foundation and ambit of the fiduciary obligation are conceptually distinct from the foundation and ambit of contract and tort. Sometimes the doctrines may overlap in their application, but that does not destroy their conceptual and functional uniqueness” (p. 272). The fiduciary may ensure that additional processes are undertaken to ensure that the patient’s best interests are respected, while the standard of care requires that the correct medical decisions and operations are undertaken according to medical standards.

In this statement, Justice Karakatsanis was not referring to the current narrow codification of best interest in provincial statutes, rather she was discussing the fiduciary expectation that physicians will use their knowledge and skills to best serve and help the patient by trying to achieve the greatest possible state of health and well-being. Best interests may, in some cases, mean making difficult decisions that ongoing treatments will not offer any medical benefits. In fact, in current medical practice, physicians do not make recommendations to withdraw life support without first carefully considering the perspectives of all multi-professional healthcare team members involved in the patient’s care to determine whether such treatments still have the ability to help. Unfortunately, the ability of such treatments to help are increasingly limited as the end of life nears, the help-hurt line is more quickly and irretrievably crossed, and patients themselves often do not wish to continue such treatments. For these reasons, decisions to with-
draw life-sustaining treatments and to focus solely on palliative treatment goals occur frequently.\textsuperscript{36}

While decisions to WLST are common, in current clinical practice, physicians do not act on a capable request to withdraw such treatments without evaluating the underlying rationale and probing to see whether the consequences of the decision are completely and truly appreciated. Such requests to withdraw are furthermore never acted upon when first stated, as the fiduciary nature of the physician-patient relationship requires ascertaining that the request is not that of a momentary impulse, nor one that arises from transient feelings of discouragement or depression. Depression and discouragement in these circumstances may be quite appropriate emotions and reflect an understanding and an appreciation that life-sustaining treatments can no longer cure or stabilize the patient’s illness and that the end of life is near. The ability to tease out whether depression is affecting decision-making or whether it’s an appropriate response to the person’s medical realities requires careful attention. Mental illness itself however does not preclude decision-making with respect to treatments. Just like physical illnesses, mental illnesses cannot always be cured and the ability to stabilize a mental illness may be even more limited than that of physical illness. The distress caused by mental illness may exceed that caused by physical ones, implying the grievous and irremediable suffering contemplated by \textit{Carter}\textsuperscript{37} is even more poignant in nature. For patients, whose grievous and irremediable illness is a mental illness, the fiduciary duties would mandate a fulsome assessment of the patient’s illness and an evaluation of the voluntary nature of capable requests to ensure that it is not influenced by misperceptions of self and is free of undue influence from the illness itself.

If people lose capacity due to the severity of their illness or its treatment, SDMs are engaged to ensure the person is respected and decisions are made in accordance with previous capable wishes or best interests. Advance care planning for when decision-making capacity at the EOL is lost with respect to treatment options within the medical standard of care at the end of life is currently not only accepted, it is promoted. If decisions are being made with a SDM on behalf of an incapable patient, the capacity, rationale and credibility of the SDM in accurately representing the patient’s wishes, values and statutory best interests are assessed, as well as whether there is reason to believe the patient’s wishes would have changed. Assessments of SDM credibility by physicians are not codified in law, are only indirectly discussed in the medical literature, and yet are key realities of working with substitute decision-makers in clinical practice. Mature minors are allowed to make other high-stake decisions and mature minors should not be required to suffer intractably just because they have not attained an arbitrary age of majority. In the situation of the mature minor, fiduciary duties would require prudent evaluations of decision-making rationale that are age appropriate and seek collaborating evidence from the minor’s parents and family members.

These approaches based in fiduciary duties protect and expand the current narrowly codified best interests by ensuring (1) these high-stakes EOL decisions are based on as complete a perspective of the medical realities as possible, (2) a sound rationality for decision-making, not unduly influenced by emotions, psychological distress, grief or pain and distressing symptoms, (3) a request is not fleeting in nature, (4) the decision is internally consistent within the context of the patient’s past healthcare decisions and who the patient is as a person, and (5) any substitute decision-maker whether formally appointed or designated by statute is meeting their legal responsibilities and making the correct decision.\textsuperscript{38} This structure of expanded best interests may not yet be codified in law, however it is integral to the fiduciary nature of the physician-patient relationship.
If consideration of the medical standard of care and the legal requirements for consent are felt to be insufficient to safeguard those that may be more vulnerable, consideration of the fiduciary nature and duties owed to these patients can be used to resolve conflicts regarding WLST. As discussed above, the medical standard of care is a construct designed to protect patients from harms. However, after Rasouli, even if continuing life-sustaining treatments would fall outside the medical standard of care and such interventions are therefore only harming the patient, if a patient is incapable (and hence vulnerable), consent from an SDM is required prior to WLST. The Rasouli ruling itself though provides no guidance on the respective roles of the medical standard of care and consent in resolving intractable conflicts. Neither concept can offer adequate protections when conflicts with SDMs arise from an entrenched desire for cure and stabilization when such outcomes cannot scientifically be achieved, or for the mere prolongation of life in situations where the person is already ‘lost’ and when the necessary LST only causes ongoing and increasing harms to the person. If fiduciary duties were systematically examined in future cases, such considerations may make it easier for courts to ensure patient rights are respected and yet also better protect them from medicine being used solely as an instrument of harm. It has been acknowledged at common law that best interests with respect to a patient’s well-being means “more than mere life itself … and to include considerations such as a person’s dignity levels and pain”. An examination of the fiduciary duties would ensure the physician involved the healthcare team in any determination that the help-hurt line has been crossed, that such treatments fall outside the medical standard of care, and the multi-professional rationale for such determination. Such an evaluation would mandate a determination of patient values and beliefs and a process of effective communication with SDMs including discussions of uncertainty in prognosis.

Finally, evaluation of the fiduciary best interests would permit a transparent evaluation if these call for a WLST: for death cannot be avoided but dying itself does not need to be prolonged and can be made more peaceful in situations where life-sustaining treatments can no longer help if WLST occurs. Some conflicts may always be inevitable when decisions are being made to withdraw life sustaining treatments as no one wants to lose someone they love. Yet, ultimately there needs to be a clear, independent means of resolution. Having the courts evaluate whether fiduciary duties were met would help move adjudication forward in a way that could only improve the quality of decision-making that every Canadian has the right to expect and would serve to improve the quality of EOL care across the country. Furthermore, court evaluation of fiduciary duties could permit access to MAiD for all Canadians whether they fall into a currently designated vulnerable category or not. For now, that MAiD has been legalized, the same medical standards of practice considerations should apply to afford both protection and access since the stakes of such decision-making as the same as in WLST.

Yet how could the courts as Chief Justice McLachlin challenges, systematically ‘review physicians’ good faith treatment decisions on the basis of fiduciary duty’ to ensure such fiduciary duties were met? The question is crucial and also correct: claims of ‘good faith’ are insufficient. ‘Good faith’ is not a legal principle nor should it ever be more than a presumption to be proved or disproved if questioned.

The answer to her central question lies partly in the standards of documentation within the medical record. In current clinical practice, it is fair to say that medical records lack detail and most documentation reflects the more traditional use of the record to describe symptoms, differential diagnosis, investigations, treatment plans and response to treatment.
than the process of decision-making itself. Record keeping needs to change to better reflect existing statutory obligations with respect to treatment decision-making and needs to reflect the multi-professional nature of treatment recommendations and decision-making. The College of Physicians and Surgeons of Ontario has begun this process in its newly mandated standards of documentation in its revised ‘Consent to Treatment’ policy, however, more is needed. With respect to EOL decision-making, whether it’s palliative care, withdrawal of life-sustaining treatments or medical assistance in dying, documentation to ensure fiduciary duties are met would include: (1) multi-professional assessments of the patient’s medical realities, response to treatment and remaining treatment options including palliative care, withdrawal of any current treatments in place and medical assistance in dying, (2) the collaborative nature of the decision-making process and the rationale for any decisions being contemplated, (3) a reasonable evaluation of potential sources of undue influence, and (4) an evaluation of the consistency of the decision once made both over time and within the context of the patient’s past healthcare decisions and who the patient is as a person. Such an approach would ensure the components of the fiduciary-based expanded best interests’ criteria are clearly documented in the medical record, promote transparency in decision-making and improve the quality of EOL care. Just because, in the Chief Justice’s words, judicial evaluation of the fiduciary at the EOL would involve “a substantial expansion of the role of fiduciary duty in regulating the doctor-patient relationship”, it doesn’t mean this regulation should not happen. In clinical practice, it already does.

Finally, the Chief Justice also asked which would prevail in a conflict situation — medical standard of care or the fiduciary duty? While this question may reflect the Court’s appreciation of differences in tort and equity, the question, as it relates to medical practice is a non-sequitur: from a clinical practice perspective, these two concepts operate hand in glove and conflict is not possible in the provision of quality healthcare. Potential or real breaches in both need to be examined and adjudicated. However, if the courts ever came across such a conflict, it would be important to remember the purpose of medicine and that everything, every decision made in clinical practice, begins with the medical standard of care. For without the medical standard of care, there is no medicine.

Conclusion

Legal frameworks have always demanded there be reason before passion. #Theyarevulnerable is not a legal principle and cannot be a basis in law for systematically determining denial of access to MAiD nor for continuing life-sustaining treatments that have irretrievably crossed the help-hurt line. Any claims that vulnerability considerations are overriding in ways that deny access or mandate the continuation of medical interventions that offer no medical benefit negate any confidence in the rigorous protections currently offered by statutory, common law and the medical standard of care. People have a right to be protected, but this right should never be so absolute as to choke off the right to be a unique person in medicine or law. The time has come for legislators and courts to move beyond tort considerations and to evaluate the fiduciary duty in high stakes EOL decisions to resolve conflicts with respect to WLST, to ensure access to MAiD and to promote the future quality of EOL care for all Canadians.

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Rasouli, supra, note 1, at para. 110.

Ibid., at paras. 110, 116.

Ibid., at para. 110.

Carter, supra, note 2, at paras. 3, 4, 56, 68, 86.

Ibid., at para. 127.

Ibid., at para. 95.

Canadian Bill C-14 as assented to June 17, 2016 accessed at <https://openparliament.ca/bills/42-1/C-14/> on Sept 2, 2016.

Rasouli, supra, note 1, at para. 111.


D. Stienstra and H.M. Chochinov, ibid.


Ibid.


Osborne, ibid.


Ibid., at 268-269; 271-292.


Rasouli, supra, note 1.


Carter, supra, note 2.
Ibid., at para 45.
Rasouli, supra, note 1, at para. 111.
Rasouli, supra, note 1, at para. 110.
Ibid., at para. 112.