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EDITOR'S NOTE

David Parry *

It is hard to believe that the MJLH is already into its fifth year. We knew that starting Canada's first and only open-access and fully bilingual journal in health law was never going to be easy. But the response has been resoundingly positive, and we are thus fortunate to publish the high-quality articles found in the current issue.

Viennent premièrement les biobanques et les problèmes liés au consentement des enfants. Emmanuelle Lévesque et Bartha Maria Knoppers nous renseignent sur les divers moyens pouvant assurer une protection adéquate aux enfants, depuis le stage prénatal jusqu'à l'adolescence, face à la collecte de renseignements personnels et de spécimens biologiques. Leur analyse se fonde sur le droit québécois, mais s'inspire également de principes issus de la common law canadienne et du droit international.

Next, Anette Sikka, Katherine Lippel and Jill Hanley examine the relationship between immigration status and access to health care. Using comparative analysis between Quebec, Ontario and New Brunswick, they identify many gaps in health services coverage into which many migrants with "precarious" status often fall.

Finally, we publish proceedings from the MJLH's first-ever continuing legal education roundtable discussion on mental capacity and the law organized in conjunction with the Disability and the Law portfolio of the Human Rights Working Group and the Centre for Law and Aging. Ann Soden offers some concluding reflections on the need to move away from a model of substitute decision-making towards one of supported decision-making.

Let me also encourage everyone to visit our website at <http://mjlh.mcgill.ca> where you will find online blog entries on hot-topics in health law and policy as well as a discussion forum for our articles. Check back often and take part in the online discussion.

Finally, I would like to offer my sincere thanks to everyone who helped pull this final issue of my tenure together – especially Chad Bass-Meldrum and Adrian Thorogood. The MJLH is lucky to have such a strong team behind it.

À votre santé!

* Editor-in-Chief, McGill Journal of Law and Health, Vol. 5.

PRINCIPES ASSURANT LA PROTECTION DES ENFANTS PARTICIPANT À DES BIOBANQUES : DU STADE PRÉNATAL JUSQU' AUX ADOLESCENTS

*Emmanuelle Lévesque et Bartha Maria Knoppers **

The last few years have witnessed the development of a plethora of biobanks (collecting data and biological material) in the field of medical research. Children as well, of all developmental stages, are called upon to participate in biobanks. Hence pediatric biobanks are looking to collect large amounts of health data and biological material, beginning at the fetal stage (through a pregnant mother) and continuing through to adulthood. The participation of children in biobanks raises numerous questions concerning their protection. We have chosen two themes for this article's analysis: who can consent? and what is the acceptable level of risk? Given that biobanks do not provide a direct (or therapeutic) benefit to participating children, these two issues must be

Depuis quelques années, on a vu se développer une multitude de biobanques (collecte de données et de matériel biologique) dans le domaine de la recherche biomédicale. Les enfants sont eux-aussi appelés à participer à la constitution de ces biobanques, et ce à toutes les étapes de leur développement. Ainsi, les biobanques pédiatriques cherchent à recueillir une grande quantité de données et de matériel biologique, parfois dès la période fœtale (via la femme enceinte), et ce, jusqu'à l'âge adulte. La participation des enfants aux biobanques soulève nombre d'interrogations relatives à leur protection. Nous avons retenu deux interrogations principales aux fins de notre analyse : qui peut consentir ? et quelles sont les limites aux risques ? Puisque les biobanques

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analysed within a distinct framework. After a study of ethical norms, we examine the provisions of Québec law which are applicable to medical research. We begin with a discussion of the general problem of including—or excluding—pregnant women or children in research. Next, we discuss the distinct steps in the creation of a biobank which depend on whether data and tissue collection occurs at the prenatal stage or following the birth of the child.

n'apportent pas de bénéfice direct (ou thérapeutique) aux enfants qui y participent, les enjeux soulevés doivent être analysés à partir d'une perspective particulière. Après une étude des normes éthiques, nous examinons les dispositions du droit québécois applicables en matière de recherche. Nous débutons par une discussion sur la problématique générale de l'inclusion – ou de l'exclusion – des femmes enceintes et des enfants dans la recherche. Ensuite, nous abordons distinctement les étapes de la constitution d'une biobanque selon qu'on se situe au stade prénatal ou suivant la naissance de l'enfant.

Introduction

I. De l'exclusion historique des enfants et des femmes jusqu'à l'inclusion d'aujourd'hui

II. Le stade prénatal

- A. *Obtention de renseignements personnels*
- B. *Collecte de matériel biologique*

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- A. *Obtention de renseignements personnels*
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Conclusion

Introduction

Il n'est pas surprenant de lire qu'« effectuer des recherches auprès des enfants est non seulement un droit, c'est aussi un devoir »¹. Et il est assez facile d'agréer cette proposition. Or, la mise en œuvre de ce *devoir* pose, dans la pratique, de nombreuses difficultés. La recherche entraîne des risques alors que l'enfant nécessite, de par sa nature, une protection particulière. La *Déclaration des droits de l'enfant* dispose qu'en raison de son manque de maturité physique et intellectuelle, l'enfant « a besoin d'une protection spéciale »². La recherche pédiatrique ne peut que mettre en exergue ce besoin de protection.

Au cours des dernières années, on a assisté à un engouement important pour les biobanques dans le domaine de la recherche biomédicale. De plus en plus, les chercheurs se constituent une sorte de dépôt de données et de matériel biologique (sang, salive, cheveux, etc.) afin de l'utiliser pour de multiples recherches. Chacun de ces dépôts est appelé « biobanque » et peut être défini comme étant une ressource structurée contenant du matériel biologique humain et des informations associées qui peuvent être utilisés à des fins de recherche³. Au moment de la constitution d'une biobanque, toutes les possibilités de recherche ne sont pas encore déterminées ni connues. Si le matériel biologique offre surtout la possibilité d'effectuer des analyses sur l'ADN, différentes disciplines pourront tout de même s'intéresser à la biobanque : génétique, épidémiologie, sociologie, médecine, etc. Les biobanques sont conservées sur une longue période puisqu'elles constituent une matière première – une sorte de ressource – pour de nombreuses recherches futures.

Formant une clientèle spécifique avec des caractéristiques particulières, les enfants sont eux aussi appelés à participer à ces biobanques. Le récent inventaire des cohortes canadiennes de grossesse et de naissance effectué en 2009 auquel ont collaboré les Instituts de recherche en santé du Canada en a recensé

¹ Conseil national d'éthique en recherche chez l'humain, *Rapport sur la recherche auprès des enfants*, Ottawa, Révision 1993, 1997 à la p 1 [Conseil national d'éthique en recherche chez l'humain].

² *Déclaration des droits de l'enfant*, rés AG 1386(XIV), Doc off AG NU, 1959 au préambule.

³ Voir OCDE, *Lignes directrices de l'OCDE sur les biobanques et bases de données de recherche en génétique humaine*, Paris, OCDE, 2009 à la p 1 ; OCDE, *Creation and Governance of Human Genetic Research Databases*, Paris, OCDE, 2006 à la p 141 ; Santé Canada, *Draft Guidance for Health Canada: Biobanking of Human Biological Material*, Ottawa, 2009 à la p 2.

45, dont 19 prévoient la constitution d'une biobanque⁴. On retrouve de grandes biobanques pédiatriques dans plusieurs pays, par exemple l'étude longitudinale Avon qui compte plus de 14 000 enfants⁵. Les enfants impliqués dans ces biobanques peuvent se situer partout sur le continuum du développement, soit depuis la période fœtale (via la femme enceinte) jusqu'à la fin de l'adolescence. Mais cette participation des enfants aux biobanques, à différents stades de leur maturité, ne se fait pas sans soulever des interrogations en lien avec leur protection.

Ces interrogations découlent principalement du fait qu'une biobanque n'apporte habituellement pas de bénéfice direct ni d'avantage personnel aux enfants qui y participent. En effet, la constitution d'une biobanque n'a pas pour objectif d'apporter une guérison ou un mieux-être aux enfants sur lesquels est prélevé le matériel biologique et auxquels se rapportent les données. Il est difficile d'imaginer un quelconque bénéfice direct⁶. Il s'agit plutôt d'obtenir des connaissances génériques qui serviront éventuellement à mieux soigner, ou à mieux prendre en charge, d'autres enfants dans le futur. Contrairement aux études thérapeutiques où, en plus de chercher à approfondir les connaissances, on a aussi pour objectif secondaire de soigner un enfant malade à l'aide de médicaments expérimentaux, les bénéfices attendus des biobanques sont indirects. C'est pourquoi la constitution d'une biobanque et l'utilisation de son contenu pour la recherche sont considérées être de la recherche non thérapeutique.

L'enfant assume donc des risques de façon altruiste pour un bénéfice collectif. En ce sens, la recherche « oppose droits individuels et collectifs, intérêts personnels et sociaux »⁷. Dans ce contexte où l'enfant participe aux biobanques sans en tirer de bénéfice direct personnel, l'existence de mesures de protection est une question qui se soulève naturellement. Protéger les enfants des risques causés par les tiers est une obligation qui incombe non seulement à

⁴ Réseau stratégique de connaissances sur le développement des jeunes enfants, Réseau de recherche en santé des enfants et des mères et Instituts de recherche en santé du Canada, *Inventaire des études de cohortes de grossesses et de naissances*, Ottawa, 2009 [*Inventaire des études de cohortes de grossesses et de naissances*].

⁵ Avon Longitudinal Study of Parents and Children, en ligne : <<http://www.bristol.ac.uk/alspac/>>.

⁶ Kristien Hens et al, « Biological Sample Collections from Minors for Genetic Research: A Systematic Review of Guidelines and Position Papers » (2009) 17 *European Journal of Human Genetics* 979 à la p 988.

⁷ Jean-Louis Baudouin, « L'expérimentation sur les humains : un conflit de valeurs » (1981) 26 *RD McGill* 809 à la p 833 [Baudouin].

titre individuel, mais aussi à la société en général⁸. À cet égard, la société a l'obligation de protéger les enfants contre les décisions imprudentes que pourraient prendre leurs parents ou ceux qui en tiennent lieu⁹.

Quels principes de l'éthique de la recherche protègent spécifiquement les participants à des biobanques pédiatriques eu égard 1° au consentement (qui le donne ?) et 2° à la limitation des risques? Comment la loi québécoise y fait-elle écho ? Voilà les deux principales questions auxquelles nous souhaitons répondre dans cet article.

Nous débuterons en exposant la problématique entourant l'inclusion des enfants et des femmes enceintes dans la recherche. Il y a quelques décennies, les enfants et les femmes enceintes ont vécu une situation particulière d'exclusion de la recherche vu les risques potentiels existants. Autant en raison d'abus que d'attitudes protectionnistes, les enfants ont souvent été mal desservis par la recherche¹⁰. Heureusement, depuis quelques années, certains principes éthiques visant à équilibrer, d'une part, la nécessité de les inclure et, d'autre part, le besoin de les protéger, ont été développés. Nous en ferons état dans la section « *I. De l'exclusion historique* ». Par la suite, nous analyserons, dans la perspective spécifique des biobanques, les principes éthiques et les normes légales applicables à la recherche, en mettant l'accent sur le consentement et la limitation des risques. Il nous est toutefois apparu nécessaire de traiter distinctement de l'enfant avant sa naissance (stade prénatal) et de l'enfant après sa naissance. Ainsi, nous regarderons d'abord les protections mises en place eu égard à la participation des femmes enceintes dans la partie « *II. Le stade prénatal* ». Ensuite, nous nous pencherons sur les mesures de protection concernant les enfants dans la partie « *III. L'enfant : de la naissance à la majorité* ».

I. De l'exclusion historique des enfants et des femmes jusqu'à l'inclusion d'aujourd'hui

L'inclusion des enfants et des femmes enceintes dans la recherche pose depuis longtemps des enjeux très particuliers. Mais les solutions apportées à

⁸ Voir Bartha Maria Knoppers *et al*, « Children and incompetent adults in genetic research: consent and safeguards » (2002) 3:3 *Nature Reviews Genetics* 221 [Knoppers, « Children and incompetent adults »].

⁹ Eric Kodish, « Informed consent for pediatric research: Is it really possible? » (2005) 142:2 *Journal of Pediatrics* 89.

¹⁰ Société canadienne de pédiatrie, « Les enjeux éthiques entourant la recherche en santé sur les enfants » (2008) 13:8 *Paediatrics & Child Health* 714 à la p 714 [Société canadienne de pédiatrie].

cette problématique par l'éthique n'ont pas toujours conduit aux résultats attendus. Heureusement, avec les années, les normes encadrant la participation de ces deux groupes semblent avoir trouvé un certain point d'équilibre.

De la première partie du 20^{ième} siècle, l'histoire retient de nombreuses situations où la participation d'enfants s'est faite au détriment de leur dignité et de leurs droits les plus fondamentaux. En guise d'exemples, retenons les essais cliniques non sûrs avec des vaccins, le recours à des enfants captifs vivant en institution pour leur faire ingérer des radioisotopes ou la contamination intentionnelle à l'hépatite en vue de l'étude de cette maladie¹¹. Dans ces cas, l'objectif de l'avancement de la science avait de loin supplanté la protection des intérêts des enfants. On retrouve aussi, dans le passé, dans un contexte clinique, des cas où des fœtus ont subi d'importantes séquelles à la suite de l'utilisation de médicaments par les femmes enceintes. L'exemple le plus connu est celui de la thalidomide, où des milliers d'enfants ont eu des malformations aux membres¹². Bien que ce genre d'exemples ait surgi dans un contexte de prise en charge clinique des femmes enceintes – et non au cours de recherches biomédicales –, leur puissant impact a donné lieu à une sorte de *proscription* préventive des femmes enceintes de la recherche¹³. Cela a non seulement abouti à l'exclusion des femmes qui étaient enceintes, mais aussi de celles susceptibles de le devenir, donc en âge de procréer¹⁴.

En réponse à ces situations où les préjudices causés aux fœtus et aux enfants ont soulevé l'indignation, une exclusion systématique des femmes en âge

¹¹ David N Weisstub, Simon N Verdun-Jones et Janet Walker, « Biomedical Experimentation involving Children: Balancing the Need for Protective Measures with the Need to Respect Children's Developing Ability to Make Significant Life Decisions for Themselves » dans David N Weisstub, dir, *Research on Human Subjects Ethics, Law and Social Policy*, Oxford, Pergamon Press, 1998, 380 aux pp 380-381 ; Douglas S Diekema, « Conducting ethical research in pediatrics: A brief historical overview and review of pediatric regulations » (2006) 149:1 Supplement 1 *Journal of Pediatrics* aux pp s3-s4 [Diekema] ; Susan E Lederer et Michael A Grondin, « Historical Overview: Pediatric Experimentation » dans Michael A Grondin et Leonard H Glantz, dir, *Children as Research Subjects: Science, Ethics and Law*, New York, Oxford University Press, 1994, 9 aux pp 9-18.

¹² Ruth Macklin, « Enrolling pregnant women in biomedical research » (2010) 375:9715 *Lancet* 632 [Macklin].

¹³ Anna C Mastroianni, Ruth Faden et Daniel Federman, *Women and Health Research: Ethical and Legal Issues of Including Women in Clinical Studies*, vol 1, Washington (DC), National Academies Press, 1994 aux pp 40-41 [Mastroianni, Faden et Federman].

¹⁴ Macklin, *supra* note 12 à la p 632.

de procréer et des enfants a été largement appliquée¹⁵. Des normes éthiques ont été adoptées en ce sens, engendrant du même coup une pratique d'exclusion généralisée. D'abord, en 1931, l'Allemagne adopta des lignes directrices sur la recherche avec les humains. Celles-ci ont prohibé la recherche non thérapeutique avec les enfants¹⁶. Ensuite, en 1947, le *Code de Nuremberg*¹⁷ exigea que chaque participant à la recherche ait la capacité légale de donner son consentement, faisant ainsi en sorte d'exclure les enfants de la recherche biomédicale¹⁸. Aux États-Unis, en 1977, les lignes directrices de la Food and Drug Administration demandèrent d'exclure des premières phases des essais cliniques les femmes susceptibles de devenir enceintes¹⁹.

Toutes ces craintes liées aux préjudices possibles associés à la participation des enfants et des femmes enceintes ont mené à leur exclusion de la recherche. On qualifie aujourd'hui cette exclusion d'exclusion historique. Bien que cette exclusion visait le bénéfice de groupes considérés vulnérables (enfants à naître, femmes enceintes et enfants, elle a toutefois engendré des effets non désirés. Effectivement, avec le temps, une absence de données probantes concernant ces groupes a été constatée²⁰. Par exemple, des produits pharmacologiques développés pour des maladies touchant également les enfants n'ont pas été testés

¹⁵ Conseil de recherches en sciences humaines du Canada, Conseil de recherches en sciences naturelles et en génie du Canada et Instituts de recherche en santé au Canada, *Énoncé de politique des trois Conseils : Éthique de la recherche avec des êtres humains*, 2^e éd, Ottawa, 2010 Groupe consultatif interagences en éthique de la recherche, 2010 aux pp 50-52 [Énoncé de politique des trois Conseils]; Macklin, *supra* note 12 à la p 632; Lainie Friedman Ross, *Children in Medical Research: Access versus Protection*, New York, Oxford University Press, 2006 aux pp 1-3 et 24-25 [Ross].

¹⁶ David S Wendler, *The Ethics of Pediatric Research*, New York, Oxford University Press, 2010 à la p 38 [Wendler].

¹⁷ *Trials of War Criminals Before the Nuremberg Military Tribunals under Control Council Law No. 10*, vol 2, Washington (DC), US Government Printing Office, 1949 aux pp 181-182.

¹⁸ Nola M Ries, « Growing up as a research subject: Ethical and legal issues in birth cohort studies » (2007) 15 Health Law J 1 à la p 5 [Ries, « Growing up as a research subject »]; Knoppers, « Children and incompetent adults », *supra* note 8 à la p 221; Diekema, *supra* note 11 à la p s4.

¹⁹ Mastroianni, Faden et Federman, *supra* note 13 à la p. 41.

²⁰ Énoncé de politique des trois Conseils, *supra* note 15 à la p 5.3; Ries, « Growing up as a research participant », *supra* note 18 à la p 5; Ross, *supra* note 15 aux pp 24-25.

sur ceux-ci²¹. Pour résultat, « les enfants ne bénéficiaient donc pas de ces nouveaux médicaments ou devaient les prendre alors qu'on connaissait mal leurs effets spécifiques ou leur innocuité dans le cas des enfants »²². Les conséquences se sont aussi fait sentir pour les femmes en âge de procréer exclues systématiquement des essais cliniques. Ceci a fait en sorte que « la sécurité et l'efficacité de la plupart des médicaments, vaccins ou dispositifs pour ces femmes sont relativement mal connues, ce qui peut être en soi dangereux »²³.

L'exclusion systématique des enfants et des femmes enceintes ou en âge de procréer a empêché ces groupes de bénéficier des découvertes scientifiques au même titre que d'autres groupes sociaux. L'exclusion des enfants leur a nié l'accès aux avantages potentiels de la recherche, comme la possibilité d'atténuer ou d'éviter des problèmes physiques ou psychologiques²⁴. Or, la distribution équitable des bénéfices de la recherche est une obligation fondamentale en éthique de la recherche²⁵. Basée sur le principe de justice qui commande de répartir équitablement le fardeau et les avantages de la recherche, cette obligation s'attache aussi à ne pas priver arbitrairement un groupe des avantages potentiels de la science²⁶.

Heureusement, à partir de la fin de la deuxième moitié du 20^{ième}, s'appuyant sur ce principe de justice, des normes éthiques concernant la participation des enfants et des femmes en âge de procréer (ou enceintes) se sont développées, traduisant ainsi la volonté d'inclure ces groupes.

En ce qui concerne les enfants, la nécessité de trouver un équilibre entre leur protection et leur inclusion a mené à l'adoption de normes strictes enca-

²¹ É-U, National Commission for the Protection of Human Subject of Biomedical and Behavioral Research, *Report and Recommendations: Research Involving Children*, Washington (DC), US Government Printing Office, 1977 aux p 23-26 [É-U, National Commission, *Research Involving Children*].

²² Conseil des Organisations internationales des Sciences médicales, *Lignes directrices internationales d'éthique pour la recherche biomédicale impliquant des sujets humains*, Genève, 2003 au Commentaire sur la Ligne directrice 14 [CIOMS].

²³ *Ibid* au Commentaire sur la Ligne directrice 16.

²⁴ Christy Simpson, « Children and Research Participation: Who Makes What Decisions? » (2003) 11:2 Health L Rev 20 à la p 21.

²⁵ É-U, National Commission for the Protection of Human Subject of Biomedical and Behavioral Research, *The Belmont Report: Ethical Principles for the Protection of Human Subjects of Research*, Washington (DC), US Government Printing Office, 1978 [É-U, National Commission, *The Belmont Report*].

²⁶ Énoncé de politique des trois Conseils, *supra* note 15 à la p 49.

drant leur participation²⁷. Par exemple, en 1964, la première *Déclaration d'Helsinki* comprenait des dispositions concernant spécifiquement la participation des personnes incapables de consentir, comme les enfants²⁸. En 1977, la National Commission for the Protection of Human Subject of Biomedical and Behavioral Research déclarait que la recherche avec les enfants, même sans bénéfice direct, était acceptable suivant certaines conditions²⁹. Un an plus tard, le *Rapport Belmont* mentionnait aussi la légitimité de la recherche avec les enfants, même en l'absence de bénéfice direct³⁰. La vulnérabilité intrinsèque des enfants a orienté les normes vers une approche contemporaine à deux volets subordonnés qu'on pourrait résumer ainsi : inclusion si nécessité. Cette approche s'est développée au fil des ans et se retrouve dans les normes actuelles. Aujourd'hui, les normes éthiques reconnaissent désormais qu'il serait injuste d'exclure de la recherche des classes de personnes qui pourraient en bénéficier et que l'inclusion des enfants est indispensable³¹. Ainsi, les enfants ne devraient pas être indûment exclus des projets de recherche uniquement en raison de leur âge ou de leur stade de développement³². Par ailleurs, malgré ce parti pris pour l'inclusion, la participation des enfants est aussi subordonnée à une nécessité. Les enfants étant considérés vulnérables vu qu'ils sont « relativement (ou totalement) incapables de protéger leurs propres intérêts »³³, ils requerraient une plus grande protection. Cette protection se concrétise par une restriction de la participation aux seuls cas où il y a nécessité : l'inclusion des enfants dans la recherche devrait être limitée aux cas où « il n'est pas possible de l'effectuer tout aussi bien sur des sujets adultes »³⁴, soit des personnes ca-

²⁷ Julie Samuël, Richard Alemdjrodo et Bartha Maria Knoppers, « Les droits de l'enfant et la thérapie génique : les enjeux éthiques et les particularités de l'article 21 du *Code civil du Québec* » (2006) 66 R du B 181 à la p 187.

²⁸ Association Médicale Mondiale, *Déclaration d'Helsinki : Recommandations pour guider les recherches portant sur l'homme*, 18^e Assemblée générale de l'Association Médicale Mondiale, Helsinki, Juin 1964 à l'art III(3a).

²⁹ É-U, National Commission, *Research Involving Children*, *supra* note 21 aux recommandations 3 et 4 aux pp 5-7.

³⁰ É-U, National Commission, *The Belmont Report*, *supra* note 25.

³¹ CIOMS, *supra* note 22 à la Ligne directrice 12 et au Commentaire sur la Ligne directrice 14.

³² Énoncé de politique des trois Conseils, *supra* note 15 aux art 4.4 et 4.6. .

³³ CIOMS, *supra* note 22 au Commentaire sur la Ligne directrice 13.

³⁴ *Ibid* à la Ligne directrice 14.

pables de consentir³⁵. Les chercheurs seraient donc tenus de faire appel à des enfants seulement si les travaux envisagés ne peuvent être réalisés qu'avec la participation de ceux-ci³⁶. Comme extension de ce principe, on retrouve un certain courant qui suggère d'inclure, d'abord, les enfants les plus âgés possible, ceux-ci étant considérés un peu moins vulnérables³⁷.

Pour ce qui est des femmes en âge de procréer et des femmes enceintes, les normes éthiques adoptées à leur sujet (peu nombreuses jusqu'ici) ont surtout cherché à favoriser leur inclusion dans la recherche. Par exemple, en 1976, la National Commission for the Protection of Human Subject of Biomedical and Behavioral Research déclarait admissible la recherche non thérapeutique sur les femmes enceintes et sur leur fœtus en énonçant certaines conditions³⁸. En 1978, le Conseil de recherches médicales du Canada adoptait des lignes directrices qui encadraient notamment la recherche sur les femmes enceintes et leur fœtus, considérant donc acceptable cette forme de recherche³⁹. Ainsi, on admet aujourd'hui que les femmes ne devraient pas être « indûment exclues de la recherche uniquement en raison du genre ou du sexe » ni « uniquement en raison de leur capacité de procréer ou parce qu'elles sont enceintes ou qu'elles allaitent »⁴⁰. Les femmes enceintes devraient être considérées comme pouvant

³⁵ Association Médicale Mondiale, *Déclaration d'Helsinki de l'Association Médicale Mondiale : Principes éthiques applicables à la recherche médicale impliquant des êtres humains*, 59^e Assemblée générale de l'Association Médicale Mondiale, Séoul, Octobre 2008 à l'art 27 [AMM].

³⁶ Énoncé de politique des trois Conseils, *supra* note 15 à l'art 4.6.

³⁷ Julie Samuël et al, *Best Practices for research involving children and adolescents*, Montréal, 2009 à la ligne directrice 1 [Samuël, *Best Practices for research involving children and adolescents*]. Voir, par exemple, Ad hoc group for the development of implementing guidelines for Directive 2001/20/EC relating to good clinical practice in the conduct of clinical trials on medicinal products for human use, *Ethical considerations for clinical trials performed in children*, Bruxelles, Commission Européenne, 2006 à la p 19 ; Royal College of Paediatrics, Child Health : Ethics Advisory Committee, « Guidelines for the ethical conduct of medical research involving children » (2000) 82:2 Archives of Disease in Childhood 177 à la p 178 [Royal College of Paediatrics, Child Health].

³⁸ É-U, National Commission for the Protection of Human Subject of Biomedical and Behavioral Research, *Report and recommendations: Research on the Fetus*, Washington (DC), US Government Printing Office, 1976.

³⁹ Conseil de recherches médicales, *La déontologie de l'expérimentation chez l'humain*(Rapport) n° 6, Ottawa, Ministre des approvisionnements et Services Canada, 1978 aux pp 33-34.

⁴⁰ Énoncé de politique des trois Conseils, *supra* note 15 aux art 4.2 et 4.3.

potentiellement participer aux recherches⁴¹. Dans le cas des essais cliniques sur le VIH, par exemple, les chercheurs devraient inclure les femmes qui peuvent devenir enceintes ou qui le sont⁴². Évidemment, cette règle favorisant l'inclusion *a priori* ne rend pas caduque l'analyse traditionnelle de l'équilibre entre les risques et les bénéfices pour la femme et le fœtus : cette analyse ultérieure demeure toujours pertinente afin de conclure si, ultimement, dans des circonstances données, l'inclusion est acceptable ou non⁴³.

Ces principes d'inclusion dans la recherche à l'égard des femmes enceintes et des enfants trouvent évidemment leur application dans le contexte des biobanques. Conséquemment, il n'y aurait pas lieu de manifester automatiquement des réticences face à la constitution de biobanques visant des femmes enceintes ou des clientèles pédiatriques. Bien au contraire, le principe d'inclusion militerait pour la participation de ces deux groupes lorsque cela est pertinent selon les objectifs scientifiques du moment. Cependant, en ce qui concerne les enfants, il faudrait aussi appliquer le deuxième volet de l'approche « inclusion si nécessité ». La participation des enfants dans une biobanque devrait pouvoir se justifier par la nécessité de devoir utiliser du matériel biologique et des données se rapportant à des personnes de ce groupe d'âge. En ce sens, les recherches qui seront faites à partir de la biobanque devraient nécessiter des données et du matériel biologique provenant d'enfants, sans que des résultats similaires puissent être obtenus en faisant appel à des adultes. Par exemple, une biobanque visant à mieux comprendre l'impact de la pollution chez la croissance des enfants pourrait justifier la mise en banque de spécimens biologiques recueillis chez de jeunes enfants : il pourrait être nécessaire d'effectuer les dosages de contaminants sanguins lorsque les personnes sont encore jeunes compte tenu que les taux de contamination évoluent avec le temps.

II. Le stade prénatal

Certaines biobanques ont des objectifs de recherche liés à la grossesse et au développement du fœtus⁴⁴. Souvent, ces biobanques sont créées dans le

⁴¹ CIOMS, *supra* note 22 à la Ligne directrice 17.

⁴² ONUSIDA, *Considérations éthiques dans la recherche de vaccins préventifs contre le VIH*, Genève, ONUSIDA, 2001 à la p 47.

⁴³ Ibid à la p 47 ; Énoncé de politique des trois Conseils, *supra* note 15 à la p 51 ; CIOMS, *supra* note 22 à la Ligne directrice 17.

⁴⁴ Afin d'alléger le texte, le mot « fœtus » est utilisé ici pour désigner l'enfant à naître, c'est-à-dire depuis la fécondation jusqu'à sa naissance. Une distinction terminologique est habituellement faite entre l'embryon (jusqu'à la 8^{ième} semaine de gros-

cadre d'études longitudinales menées avec de grandes cohortes qui recrutent des femmes enceintes et effectuent, par la suite, un suivi avec le nouveau-né. Le plus récent recensement canadien de ces cohortes mère-enfant en a dénombré quarante-cinq⁴⁵. La réalisation de recherches dans ce domaine peut nécessiter la collecte au stade prénatal, ou lors de l'accouchement, d'une variété de données et de matériel biologique. Il peut s'agir, par exemple, d'images d'échographie obstétricale, de dosage d'hormones, de biopsies de placenta ou de prélèvements de liquide amniotique. La recherche au stade prénatal peut s'intéresser aux données et au matériel biologique qui se rapportent à la femme et au fœtus⁴⁶.

Bien qu'au stade prénatal la femme porte un enfant en devenir, le consentement ne se conçoit pas dans une perspective double (femme et fœtus) durant cette période. Ainsi, le consentement à la recherche, et donc à la mise en banque, en ce qui concerne à la fois la femme enceinte et le fœtus (qu'il soit *in utero* ou *ex utero*) devrait provenir, selon les normes éthiques, de la femme elle-même⁴⁷. On remarque toutefois une préoccupation quant au rôle complémentaire que pourrait jouer le père dans ces décisions. Ainsi, le père pourrait être invité à donner son opinion lorsque la recherche touche à la santé du fœtus⁴⁸ ou il pourrait préalablement être informé des risques et, s'il y a lieu, consentir avec la femme enceinte⁴⁹.

Conformément aux principes éthiques, le droit canadien et québécois confère à la femme enceinte le droit de consentir à l'égard de la dyade qu'elle forme avec son fœtus. La femme enceinte et l'enfant qu'elle porte forment « une seule et même personne »⁵⁰. L'enfant non encore né n'est considéré un

sesse) et le fœtus (à partir de la 9^{ième} semaine de grossesse). Voir notamment la *Loi sur la procréation assistée*, LC 2004, c 2, art 3.

⁴⁵ *Inventaire des études de cohortes de grossesses et de naissances*, *supra* note 4.

⁴⁶ Nous avons exclu de notre étude tout le champ de la recherche sur les gamètes, les embryons préimplantatoires et les cellules souches (d'embryon, de tissus fœtaux avortés, de cordon ombilical, etc.), ce domaine possédant un cadre normatif distinct qui est abondamment traité dans la littérature.

⁴⁷ Énoncé de politique des trois Conseils, *supra* note 15 à l'art 12.9. Voir aussi CIOMS, *supra* note 22 au Commentaire sur la Ligne directrice 17.

⁴⁸ CIOMS, *supra* note 22 au Commentaire de la Ligne directrice 17.

⁴⁹ Conseil de l'Europe, *Recommandation 1100 (1989) sur l'utilisation des embryons et fœtus humains dans la recherche scientifique*, Rec AP, 24^e séance, 1989 aux para 10 et 11 de l'Annexe [Conseil de l'Europe].

⁵⁰ *Office des services à l'enfant et à la famille de Winnipeg (Région du Nord-Ouest) c G (DF)*, [1997] 3 RCS 925 au para 27.

« être humain » ni au sens de l'article 1 de la *Charte des droits et libertés de la personne* ni de l'article 1 du *Code civil du Québec* [CcQ]⁵¹. Il ne peut donc pas bénéficier de la personnalité juridique et des droits inhérents à ce statut. Par conséquent, les droits de la femme enceinte s'exercent par la femme seulement, qu'il s'agisse d'intervenir sur elle-même ou sur le fœtus qu'elle porte. Le droit ne reconnaît pas de personnalité juridique à l'enfant mort-né ou né mais dont la constitution ne lui permet pas de vivre : le fœtus acquerra une personnalité juridique distincte seulement après sa naissance vivante et viable⁵². L'enfant doit naître vivant et viable pour que le droit le distingue de sa mère⁵³. Ainsi, les décisions à l'égard d'un fœtus dont le développement s'est arrêté dans le sein maternel ou à l'égard d'un fœtus mort-né sont aussi prises par la femme. En conséquence, toutes les décisions concernant la participation à une biobanque pour une femme enceinte, son fœtus ou des produits issus de l'accouchement sont prises par la femme.

En ce qui concerne la limitation des risques, il faut se rapporter au principe général qui exige d'atteindre un équilibre entre les risques et les bénéfices encourus au cours d'une recherche⁵⁴. Les normes éthiques précisent que cette évaluation *risques versus bénéfices* devrait s'intéresser non seulement aux risques pour la femme enceinte, mais aussi pour le fœtus⁵⁵. À ce titre, la collecte de données ou de matériel biologique précédant la mise en banque pourrait poser des risques spécifiques pour le fœtus lui-même. On peut penser, par exemple, à la prise de certaines radiographies ou à la collecte de liquide amniotique. Certaines normes éthiques se sont positionnées de façon précise sur ce qui constitue un risque inacceptable pour le fœtus vivant *in utero*, notamment en limitant le prélèvement de cellules, de tissus d'organes fœtaux ou de placenta aux recherches ayant un caractère diagnostique et un but préventif ou théra-

⁵¹ *Charte des droits et libertés de la personne*, LRQ c C-12 ; *Daigle c Tremblay*, [1989] 2 RCS 530 [Daigle].

⁵² Édith Deleury et Dominique Goubau, *Le droit des personnes physiques*, 4^e éd, Cowansville (Qc), Yvon Blais, 2008 aux pp17-18 [Deleury et Goubau] ; Robert P Kouri et Suzanne Philips-Nootens, *L'intégrité de la personne et le consentement aux soins*, 2^e éd, Cowansville (Qc), Yvon Blais, 2005 au para 103 [Kouri et Philips-Nootens].

⁵³ *Daigle*, *supra* note 51.

⁵⁴ Énoncé de politique des trois Conseils, *supra* note 15 à la p 25 ; AMM, *supra* note 35 aux art 18 et 21.

⁵⁵ Énoncé de politique des trois Conseils, *supra* note 15 à la p 51 ; CIOMS, *supra* note 22 à la Ligne directrice 17.

peutique⁵⁶ ou en limitant la recherche avec des fœtus ou des tissus fœtaux durant une grossesse en cours aux situations où la connaissance visée ne peut raisonnablement être obtenue par d'autres moyens⁵⁷.

Une autre catégorie de risques ou d'inconvénients possibles est celle des risques associés à la conservation à long terme des informations relatives au fœtus et à leur partage avec d'autres chercheurs. Plusieurs informations renseignant sur l'enfant à naître (et non pas exclusivement sur la mère) peuvent être recueillies au stade prénatal. S'agissant par exemple de l'analyse du placenta, organe fœto-maternel, on y retrouve, du côté interne, l'ADN de l'enfant et, du côté externe, l'ADN de la mère. La spécificité des biobanques tient en partie à la durée de conservation de leur contenu. Contrairement aux projets de recherche traditionnels qui ont un début et une fin temporellement circonscrits, les biobanques ont évidemment un objectif de pérennité de la ressource, et donc une période de conservation étendue, voir même illimitée. Il n'existe actuellement pas de consensus quant au niveau de risque associé à la conservation du matériel biologique pour la recherche⁵⁸. Certains proposent de limiter le partage du matériel biologique avec d'autres chercheurs afin de minimiser les risques d'identification de l'enfant⁵⁹.

Par ailleurs, les données et le matériel biologique conservés pourraient être utilisés durant toute la vie de l'enfant devenu adulte⁶⁰. Cela pourrait mener à l'obtention de nouvelles informations lorsque des recherches sont effectuées à partir du contenu de la biobanque et que les résultats sont ajoutés à la biobanque. Des interrogations surgissent alors nécessairement quant aux risques envisageables si les résultats se retrouvaient dans un dossier médical aux fins d'un suivi médical ou s'ils étaient communiqués à des tiers qui en feraient un usage préjudiciable à l'enfant (par exemple, un assureur). Suivant cette perspective, on ne peut que faire un parallèle avec les normes éthiques qui demandent de prendre en considération les risques psychologiques (l'anxiété, par

⁵⁶ Conseil de l'Europe, *supra* note 49 au para 9 de l'Annexe.

⁵⁷ Énoncé de politique des trois Conseils, *supra* note 15 à l'art 12.6.

⁵⁸ Nola M Ries, « Longitudinal studies involving children and adolescents » dans Denise Avard, Bartha Maria Knoppers et Julie Samuël, dir, *Paediatric Research in Canada*, Montréal (Qc), Thémis, 2009, 71 à la p 90 [Reis, « Longitudinal involving children and adolescents »].

⁵⁹ David Gurwitz *et al*, « Children and Population Biobanks » (2009) 325:5942 *Science* 818.

⁶⁰ Julie Samuël *et al*, « Biobanks and Children: Comparative International Policies » dans Denise Avard, Bartha Maria Knoppers et Julie Samuël, dir, *Paediatric Research in Canada*, Montréal, Thémis, 2009, 103 à la p 107.

exemple) et socioéconomiques (la discrimination, par exemple) que peuvent engendrer la recherche en génétique⁶¹. Même si ces normes ne sont pas développées dans l'optique de la protection d'un fœtus, il semble nécessaire d'en tirer une application compte tenu que le risque doit s'évaluer aussi par rapport au futur enfant à naître. Toutefois, chaque biobanque étant spécifique, l'analyse des risques réels en cause doit passer par une nécessaire appropriation des particularités de la biobanque.

Les normes éthiques – ou la morale –⁶² eu égard à la protection du fœtus se traduisent, en droit, par une obligation légale de diligence imposée aux tiers (tels les chercheurs) envers le fœtus. En effet, le droit civil permet à l'enfant né de demander réparation pour le préjudice causé par des tiers pendant la vie utérine⁶³. Les risques auxquels le fœtus est exposé en raison de la recherche sont donc pertinents en vue d'évaluer cette obligation. Cependant, la mère ne détient pas la même obligation à l'égard de son enfant à naître. Statuant en vertu de la *common law*, la Cour suprême a refusé de tenir responsable une mère enceinte dont la négligence lors de la conduite automobile avait handicapé l'enfant qu'elle portait, lui reconnaissant ainsi toute la latitude quant à son droit à l'intégrité⁶⁴. La Cour suprême a conclu à l'absence de responsabilité des mères pour les fautes qu'elles pourraient commettre pendant la grossesse en soulignant que le raisonnement contraire entraînerait des « atteintes très graves et inacceptables au droit des femmes à l'intégrité physique, à la vie et à l'autonomie »⁶⁵. Bien que cette décision ait été rendue en vertu de la *common law*, nous sommes d'avis, à l'instar de certains auteurs, que le principe est applicable

⁶¹ Réseau de médecine génétique appliquée, *Énoncé de principes : recherche en génomique humaine*, 2000 à la p 6, en ligne : Réseau de médecine génétique appliquée <http://www.rmga.qc.ca/fr/programs_and_forms>; Énoncé de politique des trois Conseils, *supra* note 15 à la p 207 ; Pour une étude approfondie de la littérature sur le sujet : Kristien Hens et al, « Genetic research on stored tissue samples from minors: A systematic review of the ethical literature » (2009) 149A:10 *American Journal of Medical Genetics* 2346 [Hens].

⁶² Michel T Giroux, « L'autonomie de la femme enceinte et la protection de l'enfant à naître : une perspective éthique » dans *Autonomie et protection*, Service de la formation continue du Barreau du Québec, vol 261, Cowansville (Qc), Yvon Blais, 2007, 33.

⁶³ *Montreal Tramways Co v Léveillé*, [1933] SCR 456 ; *Dobson (Tuteur à l'instance de) c Dobson*, [1999] 2 RCS 753 au para 14 [Dobson] ; Deleury et Goubau, *supra* note 52 à la p 22.

⁶⁴ *Dobson*, *ibid*.

⁶⁵ *Ibid* au para 23.

en droit québécois compte tenu des motifs qui l'appuient (caractère exceptionnel de la relation entre la femme enceinte et son fœtus)⁶⁶.

Nous nous penchons à présent sur une analyse plus détaillée de la loi québécoise (qui consent ? quelle limitation aux risques ?) selon une division reprenant les deux étapes juridiquement distinctes de la mise en biobanque, soit (A) la collecte de renseignements personnels et (B) celle du matériel biologique.

A. Obtention de renseignements personnels

Une multitude de données peuvent s'avérer utile pour les biobanques prénatales. Des données sur la santé, l'environnement socioéconomique, l'éducation et la nutrition sont couramment recueillies pour ces recherches⁶⁷. S'agissant de données qui portent sur la grossesse, elles pourraient renseigner à la fois sur la mère et sur le fœtus. En effet, certains résultats médicaux du suivi de grossesse renseignent directement sur le fœtus, par exemple un facteur de risque à la suite d'un dépistage prénatal pour les aneuploïdies fœtales. Comme le fœtus n'a pas encore acquis de personnalité juridique et ne constitue pas une personne distincte de la mère, c'est cette dernière qui peut autoriser l'accès aux renseignements concernant l'un et l'autre.

Habituellement, une biobanque effectue un appariement entre les renseignements et le matériel biologique. Pour y arriver, les renseignements transmis à la biobanque ne peuvent donc être anonymes. Les renseignements recueillis doivent identifier la personne à laquelle ils se rapportent afin de pouvoir les associer au matériel biologique prélevé sur cette même personne. Normalement cela se fait en codant les éléments d'identification directe (par exemple, le prénom, le nom, le numéro d'assurance-maladie, etc.). Ces renseignements codés permettant éventuellement d'identifier une personne sont des « renseignements personnels »⁶⁸ au sens du droit québécois et leur confidentialité est expressé-

⁶⁶ Alexandre-Philippe Avard et Bartha Maria Knoppers, « L'immunité légale de la femme enceinte et l'affaire Dobson » (2000) 45 RD McGill 315 ; Deleury et Goubau, *supra* note 52 à la p 25 ; Louise Langevin, « Entre la non-reconnaissance et la protection : la situation juridique de l'embryon et du fœtus au Canada et au Québec » (2004) 56:1 RIDC 39 ; Soulevant des doutes sur l'applicabilité en droit civil, voir Kouri et Philips-Nootens, *supra* note 52 au para 121.

⁶⁷ *Inventaire des études de cohortes de grossesses et de naissances*, *supra* note 4.

⁶⁸ *Loi sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels*, LRQ c A-2.1, art 54 [*Loi sur l'accès aux documents des organismes publics*]; *Loi sur la protection des renseignements personnels dans le secteur privé*, LRQ c P-39.1, art 2.

ment protégée⁶⁹. Ils peuvent être recueillis soit auprès de la femme enceinte ou du père, soit auprès de tiers.

La collecte de renseignements personnels directement auprès de la femme enceinte ou du père aux fins de conservation dans une biobanque peut prendre différentes formes : un questionnaire informatique auto-administré, une entrevue téléphonique, des échanges semi-dirigés en groupe de discussion, etc. Exerçant leurs droits à l'autonomie, à l'autodétermination et à la vie privée, la femme enceinte ou le père sont appelés à accepter, ou non, de participer à la recherche et de fournir à cette occasion des renseignements personnels. Ils acceptent alors de partager avec des chercheurs certaines informations au sujet de leur vie privée (comme des détails intimes sur leur mode de vie et leurs choix personnels), exerçant ainsi leur droit à contrôler l'aspect informationnel de leur vie privée⁷⁰.

La collecte de renseignements personnels peut aussi s'effectuer auprès de tiers⁷¹. Il arrive que les biobanques soient intéressées à obtenir – et à conserver – des renseignements personnels qui ont été collectés par des tiers dans un contexte différent de la recherche, par exemple des renseignements personnels recueillis par un hôpital à l'occasion du suivi clinique ou par une clinique de fertilité au cours d'une procréation assistée. Ces renseignements personnels sont donc détenus par d'autres personnes que la femme enceinte elle-même. L'accès et l'utilisation de ces renseignements personnels détenus par un organisme public⁷² (l'Institut de la statistique du Québec, par exemple), une entreprise privée⁷³ (une clinique médicale privée, par exemple)⁷⁴ ou contenus dans le dossier médical d'un établissement de santé⁷⁵ requièrent normalement le consentement de la femme enceinte. Exceptionnellement, il est possible pour

⁶⁹ *Loi sur l'accès aux documents des organismes publics*, *ibid*, art 53 ; *Loi sur la protection des renseignements personnels dans le secteur privé*, *ibid*, art 10.

⁷⁰ *R c Plant*, [1993] 3 RCS 281 au para 20 ; *R c Tessling*, 2004 CSC 67 au para 25.

⁷¹ Pour plus d'information sur le sujet, voir Emmanuelle Lévesque, Bartha Maria Knoppers et Denise Avard, « La génétique et le cadre juridique applicable au secteur de la santé : examens génétiques, recherche en génétique et soins innovateurs » (2004) 64:1 R du B 57 aux pp 85-93.

⁷² *Loi sur l'accès aux documents des organismes publics*, *supra* note 68, aux art 53, al 1 et 59.

⁷³ *Loi sur la protection des renseignements personnels dans le secteur privé*, *supra* note 68, art 13.

⁷⁴ *Loi sur les services de santé et les services sociaux*, LRQ c S-4.2, art 95 [LSSSS].

⁷⁵ *Ibid*, art 19.

les chercheurs d'obtenir l'accès à ces renseignements sans le consentement de la femme enceinte en remplissant certaines conditions prévues par la loi. À ce moment, une autorisation doit être obtenue, selon le cas, soit de la Commission d'accès à l'information⁷⁶, soit du directeur des services professionnels d'un établissement de santé⁷⁷. Il faut mentionner que l'accès à certains renseignements personnels est parfois limité malgré le consentement de la personne concernée. Par exemple, l'accès aux renseignements obtenus en exécution de la *Loi sur l'assurance-maladie* (sauf certains renseignements concernant les services fournis) ne peut être accordé malgré le consentement de la personne concernée⁷⁸. Dans ce cas, les chercheurs doivent demander l'autorisation de la Commission d'accès à l'information et limiter leur utilisation « à des fins de recherche dans le domaine de la santé et des services sociaux »⁷⁹.

B. Collecte de matériel biologique

Parfois, la biobanque peut prévoir recueillir du matériel biologique prélevé dans le cadre des soins prodigués à la femme enceinte. Il peut s'agir notamment de prélèvements effectués aux fins du suivi clinique de la grossesse mais qui n'ont pas été utilisés (un surplus de sang, par exemple), de prélèvements additionnels à ceux prévus pour les soins (prélever quelques millilitres de liquide amniotique de plus lors d'une amniocentèse, par exemple) ou encore de certains produits issus de l'accouchement (le placenta, par exemple).

L'article 22 CcQ prévoit que l'utilisation, à des fins de recherche, d'une partie du corps prélevée lors de soins nécessite le consentement de la personne concernée. Comme on l'a vu, cette personne concernée est la femme enceinte pour tout ce qui concerne son corps et le fœtus. Cela comprend aussi les produits issus d'un avortement⁸⁰, par exemple un avortement médical tardif en raison d'un problème de développement du fœtus. Puisque ces prélèvements sont effectués dans le cadre des soins qui sont prodigués dans l'intérêt de la femme enceinte, ils « ne sont pas directement attentatoires à l'intégrité physique de la personne »⁸¹. Ce sont les dispositions sur le consentement aux soins

⁷⁶ *Loi sur l'accès aux documents des organismes publics*, *supra* note 68, art 125 ; *Loi sur la protection des renseignements personnels dans le secteur privé*, *supra* note 68, art 21.

⁷⁷ *LSSSS*, *supra* note 74, art 19.2.

⁷⁸ LRQ c A-29, art 63(1) et 64(1).

⁷⁹ *Ibid*, art 67(9).

⁸⁰ Kouri et Philips-Nootens, *supra* note 52 au para 38.

⁸¹ Deleury et Goubau, *supra* note 52 à la p 150.

(articles 11 et suivants CcQ) qui régissent l'intervention sur la femme enceinte qui permet d'obtenir une partie du corps, laquelle intervention est susceptible de porter atteinte à l'intégrité. Le consentement prévu à l'article 22 CcQ porte donc essentiellement sur l'utilisation de ce prélèvement :

Le consentement au prélèvement ou à l'atteinte à l'intégrité ressort du domaine du consentement aux soins pour lesquels le prélèvement a été effectué. Le consentement exigé à l'article 22 du code pour l'utilisation des produits du corps aux fins de recherche ne se rapporte donc pas à l'atteinte à l'intégrité. Il se rapporte à l'usage même des substances [...]⁸².

Cela explique pourquoi, dans le cas où le prélèvement a lieu dans le cadre de soins prodigués à une personne, l'article 22 CcQ se préoccupe d'encadrer seulement l'usage du matériel biologique, plutôt que l'intervention nécessaire au prélèvement.

Dans d'autres situations, une biobanque peut choisir d'effectuer une collecte de matériel biologique en dehors du cadre des soins prodigués à la femme enceinte, c'est-à-dire spécifiquement pour les finalités de la mise en banque. S'agissant d'une collecte de matériel biologique qui implique une intervention sur le corps d'une personne (comme une prise de sang), cette collecte se qualifiera d'« expérimentation » au sens du CcQ et sera soumise aux règles prévues en cette matière. Il faut mentionner que la signification à donner à la notion d'expérimentation ne fait pas l'objet d'un consensus, que ce soit dans la littérature ou dans son application sur le terrain par les comités d'éthique⁸³. On cons-

⁸² France Allard, « Les droits de la personnalité » dans *Personnes, famille et successions*, Collection de droit 2010-2011, vol 3, École du Barreau du Québec, Cowansville (Qc), Yvon Blais, 2010, 59 à la p 69.

⁸³ Philippe Voyer et Sylvie St-Jacques, *L'article 21 du Code civil et la recherche auprès des aînés atteints de démence dans les milieux de soins de longue durée au Québec : une analyse, un constat et une proposition*, Québec, 2006, en ligne : Bibliothèque et Archives nationales du Québec, <<http://www.banq.qc.ca>> aux pp 10-16 [Voyer et St-Jacques]; Sonya Audy, *Le Plan d'action ministériel en éthique de la recherche et en intégrité scientifique : une entreprise insensée ?*, Québec, 2006, en ligne : Unité de l'éthique du Ministère de la Santé et des Services sociaux <<http://ethique.msss.gouv.qc.ca>> aux pp 197-199 ; Jean-Marie Therrien et Geneviève Cardinal, « L'harmonisation du droit et de l'éthique en recherche pédiatrique : la 'jurisprudence' du comité d'éthique de la recherche du CHU Sainte-Justine », dans Marie-Luce Delfosse, Marie-Hélène Parizeau et Jean-Paul Amann, dir, *La recherche clinique avec les enfants : à la croisée de l'éthique et du droit. Belgique, France, Québec*, Québec (Qc), Presses de l'Université Laval, 2009, 443 ; Fonds

tate d'ailleurs depuis plusieurs années des requêtes pour clarifier le concept d'expérimentation⁸⁴. Dans un rapport préparé par un comité interministériel sur l'encadrement de la recherche, on indique les deux différentes approches adoptées, soit de distinguer les notions d'« expérimentation » et de « recherche », soit de les utiliser indistinctement⁸⁵. À notre avis, il convient de distinguer entre l'« expérimentation », au sens du CcQ, et la notion plus générale de « recherche ». Cette distinction est nécessaire afin de comprendre pourquoi, en matière de recherche, nous ne référons pas systématiquement aux articles du CcQ touchant l'expérimentation. Nous sommes d'avis que tout projet de recherche n'est pas nécessairement une expérimentation. Ces deux notions se retrouvent d'ailleurs simultanément au sein de l'article 21 CcQ, démontrant ainsi qu'elles ne peuvent avoir une signification identique. Les articles traitant de l'expérimentation se trouvent dans le chapitre du CcQ intitulé « De l'intégrité de la personne »⁸⁶ : l'« expérimentation, tout comme les soins, constitue une atteinte à l'intégrité de la personne »⁸⁷. Il peut s'agir autant de l'intégrité physique, psychologique, morale ou sociale⁸⁸. L'expérimentation implique aussi une dimen-

de la recherche en santé du Québec, *Rapport final du Groupe-conseil sur l'encadrement des banques de données et des banques de matériel biologique à des fins de recherche en santé*, Québec, Fonds de la recherche en santé du Québec, 2006 aux pp 43-44 [Fonds de la recherche en santé du Québec].

⁸⁴ Voir notamment : Audy, *ibid* à la p 199; Fonds de la recherche en santé du Québec, *ibid* à la p 45.

⁸⁵ Comité interministériel sur l'encadrement éthique de la recherche et la protection des sujets de recherche, *Pour une conciliation entre les intérêts de la recherche et le respect de la dignité des personnes qui s'y prêtent* (Rapport) Québec; Gouvernement du Québec, Ministère de la Justice et Ministère de la Santé et des Services sociaux, 2007, à la p 18.

⁸⁶ Deleury et Goubau, *supra* note 52 à la p156 ; Emmanuelle Lévesque, « Les exigences légales entourant le consentement dans la recherche avec des enfants et des adultes inaptes : une piste de solution aux difficultés posées par les articles 21 et 24 C.c.Q. » (2006) 51 RD McGill 385 aux pp 391-394 [Lévesque, « Les exigences »] ; Emmanuelle Lévesque, « L'expérimentation sur les majeurs inaptes : de nouvelles pistes de solution » dans *Services de la formation continue du Barreau du Québec*, Obligations et recours contre un curateur, tuteur ou mandataire défaillant 2008, vol 283, Cowansville (Qc), Yvon Blais, 2008, 37 aux pp 59-60 [Lévesque, « L'expérimentation »].

⁸⁷ Allard, *supra* note 82 à la p 67.

⁸⁸ *Québec (Curateur public) c Syndicat national des employés de l'hôpital St-Ferdinand*, [1996] 3 RCS 211 au para 95.

sion d'essai ou d'intervention sur ou avec un individu⁸⁹. Ce terme ne réfère pas aux recherches de nature observationnelle ou qui se limitent à l'administration de questionnaires⁹⁰. On doit conclure qu'une étude « ne comportant aucune menace à l'intégrité du sujet, ne constitue pas une *expérimentation* au sens de la loi. »⁹¹. Il pourrait s'agir par exemple d'une recherche visant à quantifier la consommation de tabac chez les femmes à l'aide d'un questionnaire. Avant 1998, l'expérimentation sur des mineurs n'était possible que sur autorisation du ministre de la Santé et des Services sociaux ou du tribunal⁹². Il nous apparaît impossible que le législateur estima que tout projet de recherche avec des enfants (des études d'observation, par exemple) nécessitait un tel mécanisme de protection. Il nous apparaît plus logique de conclure que cette procédure était réservée à certains projets de recherche mettant en jeu un droit important, soit le droit à l'intégrité. Enfin, il faut rappeler, comme le soulignait récemment le Groupe-conseil sur l'encadrement des banques de données et des banques de matériel biologique à des fins de recherche en santé, « qu'une recherche qui n'est pas de l'expérimentation au sens du Code civil du Québec demeure soumise à des normes éthiques, déontologiques, administratives et légales de protection des sujets »⁹³.

Dans le contexte des biobanques, le concept d'expérimentation appelle l'idée d'une intervention sur une personne, soit habituellement un prélèvement, ou plus rarement un examen médical ou un test qui touchent à l'intégrité de la personne. L'expérimentation dans le contexte des biobanques prendra souvent la forme d'une prise de sang ou d'un écouvillon de salive. À la lecture des articles 11, 20 et 24 CcQ, on comprend que le consentement à l'expérimentation doit provenir de la personne qui s'y soumet. Tel qu'expliqué ci-haut, c'est la

⁸⁹ Deleury et Goubau, *supra* note 52 à la p 156 ; Lévesque, « Les exigences », *supra* note 86 aux pp 399-400 ; Lévesque, « L'expérimentation », *supra* note 86 à la p 61.

⁹⁰ Martin Goyette, Isabelle Daigneault et Mélanie Vandette, « L'éthique de la recherche auprès des adolescents et l'exigence du consentement parental », dans Marie-Luce Delfosse, Marie-Hélène Parizeau et Jean-Paul Amann, dir, *La recherche clinique avec les enfants : à la croisée de l'éthique et du droit. Belgique, France, Québec*, Québec (Qc), Presses de l'Université Laval, 2009, 455 à la p 458.

⁹¹ Voyer et St-Jacques, *supra* note 83 à la p 36.

⁹² *Loi modifiant le nouveau Code civil et modifiant la Loi abolissant la mort civile*, LQ 1971, c 84 ; *Loi modifiant le Code civil*, LQ 1977, c 72 ; Art 21 CcQ, avant qu'il ne soit modifié par la *Loi modifiant l'article 21 du Code civil et d'autres dispositions législatives*, LQ 1998, c 32.

⁹³ Fonds de la recherche en santé du Québec, *supra* note 83, à la p 44.

femme enceinte qui fournit ce consentement pour toutes les procédures relatives à sa participation (et celle de son fœtus) à la biobanque. En ce qui concerne la limitation des risques, l'article 20 CcQ prévoit qu'un équilibre doit être atteint entre les risques et les bénéfices attendus d'une expérimentation : le risque couru ne doit pas être hors de proportion avec les bienfaits qu'on peut raisonnablement en espérer⁹⁴. Les risques découlant de la collecte de matériel biologique auprès de la femme enceinte sont donc limités par le potentiel d'en tirer d'éventuels bénéfices. Sur cette question, nous référons le lecteur au début de cette deuxième partie où nous avons discuté des risques à considérer au stade prénatal.

III. L'enfant : de la naissance à la majorité

Les nombreux enjeux découlant de la recherche avec les enfants – des êtres humains n'ayant pas la maturité nécessaire pour assurer seuls leur protection et leur bien-être – a naturellement donné lieu au développement d'une pensée éthique et, par suite, à des normes éthiques visant à les protéger. Nous avons expliqué, au début de cet article le principe ayant été développé en relation à l'inclusion des enfants que nous avons résumé *inclusion si nécessité*. Mais une fois la question de l'inclusion répondue favorablement, d'autres principes entrent en jeu afin d'assurer la protection des enfants dans le cadre de leur participation à une recherche non thérapeutique, telle une biobanque. Ils constituent autant de manières de protéger les enfants contre les abus. Parmi ces principes, quatre peuvent être retenus comme étant les principaux :

1. l'autorisation parentale ;
2. la possibilité de bénéfices pour des personnes similaires ;
3. la limitation du risque, et ;
4. le respect du refus de l'enfant.

Le *premier principe* est l'obtention d'une autorisation par une personne qui peut représenter l'enfant, soit un parent ou un tuteur. Il s'agit d'un principe qui jouit d'un large consensus international⁹⁵. On le retrouve dans des documents fondamentaux tels la *Déclaration d'Helsinki*⁹⁶, le *Rapport Belmont*⁹⁷ et les *Lignes directrices internationales d'éthique pour la recherche biomédicale*

⁹⁴ Art 20 CcQ.

⁹⁵ Denise Avard, Bartha Maria Knoppers et Julie Samuël, dir, *Paediatric Research in Canada*, Montréal (Qc), Thémis, 2009 à la p 5.

⁹⁶ AMM, *supra* note 35 à l'art 27.

⁹⁷ É-U, National Commission, *The Belmont Report*, *supra* note 25.

*impliquant des sujets humains*⁹⁸. Ce principe est évidemment présent dans les normes éthiques canadiennes dont l'*Énoncé de politique des trois Conseils*⁹⁹ constitue le plus important.

Bien que l'autorisation parentale soit d'une importance primordiale, elle ne permet pas à elle seule d'autoriser une recherche sur les enfants¹⁰⁰. Les trois autres principes – bénéfices pour le groupe, limitation du risque et respect du refus – demeurent applicables et sont cumulatifs à l'autorisation parentale. Les parents n'ont pas le pouvoir d'outrepasser ces protections¹⁰¹. Celles-ci constituent en quelque sorte un rempart contre des décisions parentales inappropriées car « s'en remettre à l'autonomie parentale risquerait d'entraîner des abus »¹⁰². La fragilité des enfants et leur vulnérabilité, ainsi que l'absence de bénéfice direct découlant d'une recherche non thérapeutique, ont mené à l'adoption d'autres principes pouvant limiter les décisions parentales préjudiciables à l'enfant.

Le *deuxième principe* à considérer est l'expectative de bénéfices pour un groupe ayant des caractéristiques similaires à l'enfant. Les normes internationales et nationales font écho au principe voulant que des bénéfices soient attendus pour d'autres personnes ayant des caractéristiques similaires, par exemple d'autres enfants ou d'autres personnes avec une maladie similaire. On retrouve notamment ce principe dans la *Déclaration universelle sur le génome humain et les droits de l'homme*¹⁰³, les *Lignes directrices internationales d'éthique pour la recherche biomédicale impliquant des sujets humains*¹⁰⁴, la *Déclaration universelle sur la bioéthique et les droits de l'homme*¹⁰⁵, la Con-

⁹⁸ CIOMS, *supra* note 22 à la Ligne directrice 14.

⁹⁹ *Supra* note 15 à l'art 3.9.

¹⁰⁰ JK Mason et GTLaurie, *Mason & McCall Smith's Law and Medical Ethics*, 7^e éd, New York, Oxford University Press, 2005, à la p 688 [Mason et Laurie].

¹⁰¹ Ries, « Longitudinal studies involving children and adolescents », *supra* note 58 à la p 78 et ss.

¹⁰² Conseil national d'éthique en recherche chez l'humain, *supra* note 1 à la p 28.

¹⁰³ Rés AG 152, Doc off AG NU, 53^e sess, (1997) à l'art 5 e).

¹⁰⁴ CIOMS, *supra* note 22 à la Ligne directrice 14.

¹⁰⁵ Rés 36(V), Conférence générale, UNESCO, 33^e sess, (2005) à l'art 7 b).

vention sur les Droits de l'Homme et la biomédecine¹⁰⁶ et l'Énoncé de principes sur la recherche génétique avec les enfants¹⁰⁷.

Dans la recherche non thérapeutique, il est parfois difficile de justifier l'absence d'avantage direct pour les enfants qui subissent malgré tout les risques et les inconvénients. C'est d'ailleurs la recherche non thérapeutique qui pose les enjeux éthiques les plus difficiles¹⁰⁸. Certains groupes estiment cependant essentiel d'affirmer que la recherche sans bénéfice direct à l'enfant (chez des enfants en bonne santé) n'est pas automatiquement non éthique¹⁰⁹. La possibilité de tirer des bénéfices pour d'autres enfants dans la même situation apporte donc un équilibre et permet de remédier aux iniquités éventuelles. En vertu de ce deuxième principe, lorsque la recherche entreprise n'est pas au bénéfice de l'enfant qui y participe (recherche non thérapeutique), elle devrait laisser espérer des bénéfices pour d'autres enfants ou d'autres personnes partageant des similarités. Évidemment, la mise en biobanque de données et de matériel biologique fait partie de ce type de recherche qui n'a pas de visée thérapeutique directe pour les enfants qui y participent. Même si un projet à objectif thérapeutique est jumelé à un projet de biobanque (par exemple, si à l'occasion d'un essai clinique avec des enfants leucémiques une biobanque sur la leucémie est créée), il demeure que ce n'est pas la biobanque qui procurera des bénéfices directs à l'enfant. La biobanque devrait donc au minimum laisser espérer des bienfaits pour d'autres personnes ayant des caractéristiques similaires à ces enfants.

Le troisième principe s'attache quant à lui à limiter le degré de risque et d'inconvénients auxquels sont exposés les enfants au cours d'une recherche non thérapeutique. Le niveau de risque et d'inconvénients ne devrait pas dépasser un certain seuil pour justifier l'inclusion d'enfants qui ne tireront pas de bénéfice direct de leur participation. On retrouve différentes formulations dans les normes éthiques sur la façon de nommer le niveau de risque acceptable pour ces enfants. Dans la vaste majorité des normes, on parle de *risque minimal* et de *contrainte minimale*. C'est le cas notamment de la *Déclaration d'Helsinki*¹¹⁰, de la *Déclaration universelle sur le génome humain et les droits*

¹⁰⁶ 4 avril 1997, STE 164 à l'art 17(2 i).

¹⁰⁷ Réseau de médecine génétique appliquée du Québec, *Énoncé de principes sur la Recherche en génétique avec les enfants*, 2007 à la p 10, en ligne : Santé et Services sociaux du Québec <http://ethique.msss.gouv.qc.ca/site/fr_recueil.phtml> [Réseau de génétique appliquée, *Enfants*].

¹⁰⁸ Mason et Laurie, *supra* note 100 à la p 685.

¹⁰⁹ Royal College of Paediatrics, Child Health, *supra* note 37.

¹¹⁰ AMM, *supra* note 35 art 27.

de l'homme¹¹¹, de la *Déclaration universelle sur la bioéthique et les droits de l'homme*¹¹², de la *Convention sur les Droits de l'Homme et la biomédecine*¹¹³ et de l'*Énoncé de politique des trois Conseils*¹¹⁴. La participation des enfants dans une biobanque n'étant pas à leur bénéfice direct, il faudrait donc limiter le risque auquel ils sont exposés à un risque minimal ou à une contrainte minimale.

Malgré l'apparente simplicité du concept, il est difficile de transposer dans un contexte factuel réel le critère théorique du risque minimal. Il n'existe d'ailleurs pas de définition de la notion qui fait consensus¹¹⁵. On lit parfois que le préjudice minime est « un bref inconfort et un changement superficiel transitoire, par exemple [...] une prise de sang de routine, ponction veineuse ; prélèvement d'urine dans un sac »¹¹⁶. L'*Énoncé de politique des trois Conseils* évalue le risque dans la perspective subjective du participant en considérant qu'il est minimal lorsque « la probabilité et l'ampleur des préjudices éventuels découlant de la participation à la recherche ne sont pas plus grandes que celles des préjudices inhérents aux aspects de la vie quotidienne du participant qui sont associés au projet de recherche »¹¹⁷. D'autres normes établissent le barème du risque acceptable en se référant aux risques accompagnant les examens médicaux ou psychologiques de routine¹¹⁸. En plus, l'évaluation du niveau de risque devrait se faire en considérant l'ensemble des risques et inconvénients possibles, comme les risques physiques, émotifs, psychosociaux et économiques (discrimination dans l'emploi ou l'assurance, par exemple)¹¹⁹.

Enfin, le *quatrième principe* consacre l'importance de respecter le refus de participer exprimé par l'enfant. N'ayant pas encore atteint la pleine maturité, l'enfant voit néanmoins ses capacités décisionnelles et ses volontés prises en compte lorsqu'il s'agit de décisions concernant son corps ou sa personne. Le

¹¹¹ *Supra* note 103, art 5 e).

¹¹² *Supra* note 105 à l'art 7 b).

¹¹³ *Supra* note 106 à l'art 17(2 ii).

¹¹⁴ *Supra* note 15 à la l'art 4.6.

¹¹⁵ Voir Société canadienne de pédiatrie, *supra* note 10 à la p 715; Pour une étude des différentes façons de concevoir le risque, voir Wendler, *supra* note 16 aux pp 62-69.

¹¹⁶ Conseil national d'éthique en recherche chez l'humain, *supra* note 1 à la p 34.

¹¹⁷ *Supra* note 15 à la p 24.

¹¹⁸ CIOMS, *supra* note 22 à la Ligne directrice 9.

¹¹⁹ Société canadienne de pédiatrie, *supra* note 10 à la p 715; Hens, *supra* note 61 aux p 2349-2350.

refus de participer peut s'exprimer de différentes façons, il est informel et peut découler de comportements de rejet ou de contestation¹²⁰. Même si c'est le parent qui fournit le consentement à la recherche, l'enfant pourrait y faire obstacle. Dans la mesure où notre étude se questionne sur qui peut fournir le consentement à la recherche, il est particulièrement intéressant de s'intéresser aux interférences qui peuvent exister à l'endroit de l'autorisation parentale.

Plusieurs normes éthiques ont adopté des dispositions relativement au respect du refus de l'enfant. On en retrouve par exemple dans la *Déclaration d'Helsinki*¹²¹, la *Déclaration universelle sur la bioéthique et les droits de l'homme*¹²², les *Lignes directrices internationales d'éthique pour la recherche biomédicale impliquant des sujets humains*¹²³, la *Convention sur les Droits de l'Homme et la biomédecine*¹²⁴, l'*Énoncé de politique des trois Conseils*¹²⁵ et les recommandations de la Société canadienne de pédiatrie¹²⁶. Le principe du respect du refus de l'enfant n'est pas absolu et il se module *in concreto*. Ainsi, le refus de l'enfant doit s'apprécier en fonction de sa capacité de compréhension et de sa maturité. À cet égard, il serait plus complet de dire que l'opinion de l'enfant « devrait être prise en considération comme un facteur dont le caractère déterminant augmente avec l'âge et le degré de maturité »¹²⁷. D'ailleurs, tous domaines confondus, incluant donc la recherche, la *Convention relative aux droits de l'enfant* dispose que pour l'enfant capable de discernement, ses opinions devraient être dûment prises en considération eu égard à son âge et à son degré de maturité¹²⁸.

C'est dans cette logique que le concept similaire de l'« assentiment » de l'enfant a été développé en éthique de la recherche. Constituant en quelque sorte le corolaire du respect du refus, l'assentiment est une forme d'acceptation

¹²⁰ Conseil national d'éthique en recherche chez l'humain, *supra* note 1 à la p 48.

¹²¹ AMM, *supra* note 35, art 28.

¹²² *Supra* note 105, art 7 b).

¹²³ CIOMS, *supra* note 22 à la Ligne directrice 14.

¹²⁴ *Supra* note 106, art 17(1v).

¹²⁵ *Supra* note 15, art 3.10.

¹²⁶ Société canadienne de pédiatrie, *supra* note 10 à la p 718.

¹²⁷ *Déclaration internationale sur les données génétiques humaines*, Rés 22(IV), Conférence générale, UNESCO, 32^e sess, (2003) à l'art 8 c) ; Au même effet, voir *Convention sur les Droits de l'Homme et la biomédecine*, *supra* note 108, art 6(2).

¹²⁸ *Convention relative aux droits de l'enfant*, 20 novembre 1989, 1577 RTNU 3, art 12(1).

volontaire de l'enfant, mais sans une compréhension totale¹²⁹. L'assentiment prend en compte la maturité émergente de l'enfant¹³⁰. La pertinence d'obtenir l'assentiment de l'enfant est évidemment fonction du niveau de développement de l'enfant et de ses capacités¹³¹. Obtenir l'assentiment de l'enfant permet la reconnaissance de sa maturité et de son autonomie. Ainsi, de nombreuses normes éthiques reconnaissent désormais la nécessité d'obtenir l'assentiment de l'enfant comme la *Déclaration d'Helsinki*¹³², les *Lignes directrices internationales d'éthique pour la recherche biomédicale impliquant des sujets humains*¹³³, les recommandations de la Société canadienne de pédiatrie¹³⁴ et l'*Énoncé de principes sur la recherche génétique avec les enfants*¹³⁵. Dans le contexte des biobanques, une information adaptée à l'enfant devrait lui être fournie et son assentiment demandé¹³⁶.

Ces quatre principes éthiques exposés, il convient au présent de procéder à une analyse de la loi québécoise dans le contexte des biobanques pédiatriques. Nous utilisons ici encore une division selon les dispositions juridiques applicables, soit (A) l'obtention de renseignements personnels, (B) la cueillette de matériel biologique lors de soins prodigués à l'enfant et (C) l'expérimentation.

A. Obtention de renseignements personnels

Comme nous l'avons expliqué, les données collectées aux fins de dépôt dans une biobanque seront habituellement des « renseignements personnels »

¹²⁹ Conseil national d'éthique en recherche chez l'humain, *supra* note 1 à la p vii).

¹³⁰ Karine Sénécal, Julie Samuël et Denise Avard, « Research and the Assent of the Child: Towards Harmonization? » dans Denise Avard, Bartha Maria Knoppers et Julie Samuël, dir, *Paediatric Research in Canada*, Montréal (Qc), Thémis, 2009, 33 à la p 38.

¹³¹ Samuël, *Best Practices for research involving children and adolescents*, *supra* note 37 à la ligne directrice 3.2 ; Knoppers, « Children and incompetent adults », *supra* note 8 à la p 223 ; Voir aussi DS Wendler, « Assent in paediatric research: theoretical and practical considerations » (2006) 32:4 *Journal of Medical Ethics* 229 à la p 230.

¹³² AMM, *supra* note 35, art 28.

¹³³ CIOMS, *supra* note 22 à la Ligne directrice 14.

¹³⁴ Société canadienne de pédiatrie, *supra* note 10 à la p 718.

¹³⁵ Réseau de génétique appliquée, *Enfants*, *supra* note 107.

¹³⁶ Kristien Hens et Kris Dierickx, « Children, Biobanks and Consent » dans Kris Dierickx et Pascal Bory, dir, *New Challenges for Biobanks: Ethics, Law and Governance*, Intersentia, 2009 à la p 77.

au sens du droit québécois¹³⁷. Lorsque la collecte de renseignements personnels a lieu auprès de tiers, ces tiers seront habituellement des organismes qui fournissent des services à l'enfant et à sa famille, comme un hôpital, une garderie ou une commission scolaire. Même si un dossier contient des renseignements personnels sur un enfant, cela ne veut pas dire que l'enfant peut légalement y avoir accès lui-même ni autoriser un chercheur à y avoir accès.

Entre 0 et 18 ans, l'enfant acquiert progressivement sa capacité juridique. Durant la minorité, l'enfant est frappé d'une incapacité partielle d'exercice de ses droits, c'est-à-dire d'une incapacité à mettre en œuvre ou à utiliser ses droits. Avant l'âge de 18 ans, l'enfant a la jouissance de ses droits, mais il ne les exerce que « dans la seule mesure prévue par la loi »¹³⁸. La règle étant l'incapacité d'exercice, l'exception est donc la capacité d'exercice. C'est à 18 ans que l'enfant devient capable d'exercer lui-même tous ses droits¹³⁹. Lorsque la loi ne permet pas à l'enfant d'exercer ses droits, cette tâche incombe à son tuteur qui le représente alors¹⁴⁰. Les parents sont désignés par la loi comme les tuteurs de leur enfant mineur afin de le représenter dans l'exercice de ses droits¹⁴¹ et ils exercent conjointement cette fonction¹⁴². Toutefois, l'acte fait par l'un des parents est présumé être conforme au mandat donné par l'autre parent à l'égard des tiers de bonne foi¹⁴³.

Il importe donc de voir si la participation à une recherche et à une bio-banque sont des actes à l'égard desquels la loi autorise le mineur à agir seul ou si ces décisions reviennent plutôt à ses parents.

En ce qui concerne le droit d'accès aux renseignements personnels détenus par des tiers, on doit appliquer la règle générale selon laquelle l'exercice de ce droit incombe normalement aux parents. En effet, ni le CcQ ni la *Loi sur l'accès aux documents des organismes publics*¹⁴⁴ ni la *Loi sur la protection des renseignements personnels dans le secteur privé*¹⁴⁵ ne prévoient d'exceptions à l'incapacité d'exercice du mineur qui pourrait s'appliquer dans le contexte de la recherche. L'exception ayant trait à la pleine capacité du mineur de 14 ans et

¹³⁷ Voir la section II. A. *Obtention de renseignements personnels*.

¹³⁸ Art 155 CcQ.

¹³⁹ Art 153 CcQ.

¹⁴⁰ Art 158 CcQ.

¹⁴¹ Art 192 CcQ.

¹⁴² Art 193 CcQ.

¹⁴³ Art 194 CcQ.

¹⁴⁴ *Supra* note 68.

¹⁴⁵ *Ibid.*

plus pour les actes relatifs à son emploi, à son art ou à sa profession ne peut trouver application ici¹⁴⁶. Quant à l'exception concernant la pleine capacité du mineur pour « contracter seul pour satisfaire ses besoins ordinaires et usuels »¹⁴⁷, nous croyons qu'elle ne peut non plus être utilisée dans un contexte de participation à une biobanque. D'abord, il ne s'agit pas à proprement parler d'une situation où le mineur « contracte » une obligation et, ensuite, la participation à la recherche non thérapeutique n'a pas comme objectif de satisfaire les besoins de l'enfant. L'objectif de la recherche non thérapeutique n'est pas de répondre aux besoins des participants puisqu'ils n'en retireront pas de bénéfice personnel. En conséquence, l'accès aux renseignements personnels à des fins de recherche ne correspond pas aux secteurs dans lesquels le législateur considère le mineur autonome. Il faut donc conclure que les parents sont responsables d'exercer les droits de leurs enfants aux fins d'autoriser des tiers à consulter leurs renseignements personnels¹⁴⁸. Les chercheurs devraient donc obtenir auprès des parents les consentements permettant d'accéder aux renseignements personnels des enfants.

Seule exception, la loi attribue l'exercice de certains droits aux adolescents en ce qui concerne leurs dossiers d'usager, c'est-à-dire le dossier issu d'un établissement de santé au sens de la *Loi sur les services de santé et services sociaux*¹⁴⁹. Durant toute la durée de la minorité, le titulaire de l'autorité parentale détient un droit d'accès au dossier d'usager de son enfant¹⁵⁰. Toutefois, lorsque l'enfant atteint 14 ans, le parent peut se voir refuser l'accès si son enfant s'y oppose et que l'établissement de santé évalue que cette communication pourrait causer un préjudice à la santé de l'enfant¹⁵¹. Exerçant les droits d'accès de son enfant, le parent peut donner son consentement à ce qu'un tiers consulte le dossier d'usager de son enfant¹⁵², notamment à des fins de recherche¹⁵³. Mais à partir de 14 ans, le droit d'accès du parent existe concurremment avec le droit

¹⁴⁶ Art 156 CcQ.

¹⁴⁷ Art 157 CcQ.

¹⁴⁸ *Loi sur l'accès aux documents des organismes publics*, *supra* note 68, art 59 ; art 38 CcQ ; *Loi sur la protection des renseignements personnels dans le secteur privé*, *supra* note 68, art 13.

¹⁴⁹ LSSSS, *supra* note 74, art 79 et 94.

¹⁵⁰ *Ibid*, art 21.

¹⁵¹ *Ibid*, art 21(2).

¹⁵² *Ibid*, art 19.

¹⁵³ *Ibid*, art 19(1).

d'accès de l'enfant¹⁵⁴. À compter de 14 ans, tout usager acquiert le droit d'accès à son dossier d'usager au même titre que les adultes¹⁵⁵. Durant cette période, l'enfant « a plein droit sur son dossier »¹⁵⁶. Cet accès n'est pas limité spécifiquement dans la loi à une finalité particulière, par exemple la prestation de soins de santé. Bénéficiant pleinement du droit d'accès à son dossier, on pourrait conclure que l'enfant à partir de 14 ans serait aussi habilité à autoriser l'accès à son dossier d'usager à des tiers, notamment à des fins de recherche. Cependant, il est prudent de soupeser d'autres considérations avant d'en arriver à cette conclusion, comme l'objectif de la disposition et la capacité du mineur de fournir un consentement éclairé.

Il faut s'interroger sur l'objectif poursuivi par le législateur en accordant au mineur de plus de 14 ans l'accès à son dossier d'usager. Cette exception vise d'abord à permettre à l'usager recevant des soins de santé de pouvoir accéder à toute l'information le concernant pour prendre des décisions éclairées. D'ailleurs, la loi prévoit que « l'usager doit, autant que possible, participer aux soins et aux services le concernant » et qu'il « a le droit d'être informé sur son état de santé et de bien-être » de manière à connaître les risques et conséquences des différentes options de traitement possible¹⁵⁷. Ce droit de l'usager s'inscrit dans le contexte particulier de la prestation de soins de santé, plutôt que dans un contexte général d'accès aux renseignements personnels (comme le droit d'accès donné par la *Loi sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels*¹⁵⁸). On peut présumer qu'en adoptant une exception à l'égard de l'incapacité des mineurs, le législateur souhaitait que l'exercice du droit bénéficie à l'enfant dans le contexte de la prestation de soins, mais ne lui cause pas de préjudice dans d'autres contextes. Toutefois, deux autres arguments doivent être considérés. D'abord, le texte de la loi ne fait aucune distinction de traitement entre les mineurs de plus de 14 ans et les adultes : « Tout usager de 14 ans et plus a droit d'accès à son dossier »¹⁵⁹. Ensuite, la Cour d'appel a reconnu que la recherche biomédicale pouvait s'inscrire dans la mission et les services d'un établissement de santé et qu'à ce titre les participants à la recherche pouvaient être considérés des « usa-

¹⁵⁴ *Ibid.*, art 21.

¹⁵⁵ *Ibid.*, art 17.

¹⁵⁶ Suzanne Philips-Nootens, Pauline Lesage-Jarjoura et Robert P. Kouri, *Éléments de responsabilité civile médicale*, 3^e éd, Cowansville (Qc), Yvon Blais, 2007 à la p 400.

¹⁵⁷ LSSSS, *supra* note 74, art 3 et 8.

¹⁵⁸ *Loi sur l'accès aux documents des organismes publics*, *supra* note 68, art 59.

¹⁵⁹ LSSSS, *supra* note 74, art 17.

gers »¹⁶⁰. Ainsi, le droit d'accès au dossier pourrait être vu comme incluant nécessairement la gestion de l'accès à des fins de recherche, laquelle activité peut faire partie de la mission d'un établissement de santé. Considérant tous ces arguments, il est difficile de déterminer si le droit d'accès des mineurs à leur dossier d'utilisateur exclut le droit d'autoriser l'accès à des tiers, notamment à des chercheurs pour des fins de recherche.

Par ailleurs, même si on concluait que le mineur a la capacité d'autoriser l'accès à son dossier d'utilisateur à des fins de recherche, s'ajouterait à cela l'obligation générale que son consentement soit éclairé, laquelle exigence est clairement indiquée dans la loi pour ce qui est de l'accès à des fins de recherche¹⁶¹. D'ailleurs, lorsque le mineur est autorisé à faire un acte seul, le niveau de discernement présumé par le législateur dépend habituellement « de la complexité de la nature et des conséquences de l'acte identifié »¹⁶². Ainsi, il est essentiel que le mineur ait la capacité de fournir un consentement véritablement éclairé concernant l'accès aux renseignements aux fins de dépôt en biobanque, ce qui signifie qu'il peut comprendre les conséquences et les inconvénients de sa décision. Pour conclure que le mineur peut autoriser l'accès à son dossier médical dans le cadre d'une biobanque, ce dernier devrait pouvoir évaluer les conséquences possibles de l'utilisation de ses renseignements personnels et s'il y a lieu, de l'association de ses renseignements avec du matériel biologique. Comme discuté plus haut, il s'agira habituellement de risques psychologiques (la découverte troublante qui lui serait fournie, par exemple), socioéconomiques (la difficulté de s'assurer, par exemple) ou liés à la confidentialité (le bris de confidentialité, par exemple). Si les risques découlant d'interventions physiques peuvent être facilement compris par des adolescents (la douleur lors d'une prise de sang, par exemple), il en est autrement des risques moins palpables qui concernent un futur éloigné, tels que la discrimination. Certains auteurs concluent que les enfants auraient la capacité de comprendre la plupart des risques et bénéfices physiques d'une recherche thérapeutique, même avant 14 ans¹⁶³. Cependant, plusieurs études ont démontré que les

¹⁶⁰ *Gomez c Comité exécutif du Conseil des médecins, dentistes et pharmaciens de l'hôpital universitaire de Québec*, [2001] RJQ 2788 (CA).

¹⁶¹ LSSS, *supra* note 74, art 19(1).

¹⁶² Claire Bernard, *Les droits de l'enfant, entre la protection et l'autonomie* dans Lucie Lamarche et Pierre Bosset, dir, *Des enfants et des droits*, Ste-Foy (Qc), Presses de l'Université Laval, 1997 à la p 32.

¹⁶³ TM Burke, R Abramovitch et S Zlotkin, « Children's understanding of the risks and benefits associated with research » (2005) 31:12 *Journal of Medical Ethics* 715.

enfants auraient une capacité limitée à comprendre des éléments plus abstraits comme le droit de ne pas participer ainsi que le potentiel de bénéfices pour les autres¹⁶⁴.

Finalement, la collecte de renseignements personnels peut aussi se faire *auprès de l'enfant lui-même*. Les chercheurs souhaitent peut-être poser des questions à l'enfant ou encore lui faire subir des tests afin de mesurer, par exemple, son développement intellectuel. Deux considérations importantes entrent en jeu ici afin d'évaluer le rôle que peut avoir à jouer le parent en ce qui concerne la collecte auprès de l'enfant lui-même.

D'abord, comme il a été mentionné, le mineur est frappé d'une incapacité d'exercice de ses droits. Ce sont ses parents qui exercent ses droits à sa place, sauf exception de la loi. Notre analyse plus haut explique pourquoi nous concluons que les exceptions au CcQ (i.e. emploi et besoins usuels) ne concernent pas la collecte de renseignements personnels à des fins de recherche. La collecte de renseignements personnels sur la santé de l'enfant et son développement interpelle surtout le droit à la vie privée de l'enfant. La remise aux chercheurs de renseignements personnels qui informent sur des aspects intimes de l'enfant, qui permettent de l'identifier et qui seront utilisés pour de nombreuses recherches constitue l'exercice du droit à la vie privée. Or, en cette matière, rien dans la loi ne permet de conclure que le droit à la vie privée peut être exercé pleinement par l'enfant lui-même si aucun consentement du parent n'existe ni quelque forme que ce soit d'autorisation tacite.

Une autre considération importante à prendre en compte est l'autorité parentale. Au rôle de tuteur s'ajoute celui de titulaire de l'autorité parentale. L'enfant reste sous l'autorité de ses parents jusqu'à 18 ans¹⁶⁵. Cette notion se rapporte notamment au droit et au devoir de garde, de surveillance, d'éducation et d'entretien de l'enfant¹⁶⁶. L'autorité parentale comprend des *droits, devoirs et obligations* qui « visent à répondre à l'ensemble des besoins matériels, affectifs, physiques, intellectuels et psychologiques de l'enfant »¹⁶⁷. Il ne s'agit pas seulement d'obligations des parents, mais de *droits*. L'autorité parentale leur permet de prendre des décisions d'importance concernant leur enfant, comme « les traitements médicaux, le choix des écoles, la participation

¹⁶⁴ Alan R Tait, Terri Voepel-Lewis et Shobha Malviya, « Do They Understand? (Part II): Assent of Children Participating in Clinical Anesthesia and Surgery Research » (2003) 98:3 Anesthesiology 609.

¹⁶⁵ Art 598 CcQ.

¹⁶⁶ Art 599 CcQ.

¹⁶⁷ Michel Tétrault, *Droit de la famille*, 3^e éd, Cowansville (Qc), Yvon Blais, 2005 à la p 1338.

à un voyage à l'étranger, l'inscription à une activité parascolaire qui se prolongera pendant plusieurs semaines ou qui comporte des risques importants »¹⁶⁸. Les parents qui sont investis de la garde physique de leur enfant sont aussi habilités à prendre des décisions quotidiennes et usuelles à son égard. L'attribut de l'autorité parentale relatif à la garde permet au parent un contrôle « sur le choix des sorties, des loisirs et des fréquentations de l'enfant ; il est aussi amené, par sa position privilégiée, à prendre les décisions courantes qui affectent la vie de l'enfant »¹⁶⁹. Il n'est pas uniquement question de prendre des décisions à l'égard de l'exercice des droits de l'enfant : il s'agit surtout des faits et gestes quotidiens, des activités auxquelles participe l'enfant. À notre avis, l'autorité parentale pose des limites aux activités auxquelles un enfant peut participer sans que ses parents (ou ceux qui en ont la garde déléguée) soient d'accord. Ceci pourrait inclure notamment la participation à une recherche : répondre à des questionnaires ou passer des tests évaluant les habiletés.

En matière de collecte de renseignements personnels auprès des enfants à des fins de recherche, il s'avère donc nécessaire que les parents, ou ceux qui en assument la garde déléguée, consentent. Finalement, comme pour les actes faits à titre de tuteur, les actes d'autorité parentale accomplis par l'un des parents sont présumés avoir été faits avec l'accord de l'autre parent à l'égard des tiers de bonne foi¹⁷⁰.

B. Matériel biologique prélevé lors des soins prodigués à l'enfant

Comme il a été discuté plus haut, l'utilisation pour la recherche de matériel biologique prélevé dans le cadre de soins prodigués à une personne obéit à un régime juridique particulier. En effet, l'article 22 CcQ régit le consentement relatif à l'utilisation des parties du corps à des fins de recherche. Ce consentement doit provenir « de la personne concernée ou de celle habilitée à consentir pour elle »¹⁷¹. L'article 22 CcQ ne spécifie pas de quelle personne il s'agit dans le cas des mineurs. La doctrine nous invite à conclure que, « vu le contexte dans lequel les parties du corps sont prélevées, la personne habilitée est la même que celle qui peut consentir aux soins »¹⁷² :

¹⁶⁸ *Droit de la famille -09746*, 2009 QCCA 623 au para 45.

¹⁶⁹ *C (G) c V-F (T)*, [1987] 2 RCS 244 au para 68.

¹⁷⁰ Art 603 CcQ.

¹⁷¹ Art 22 CcQ.

¹⁷² Kouri et Philips-Nootens, *supra* note 52 au para 36.

à l'égard de la permission d'effectuer des recherches sur des substances prélevées à l'occasion d'un tel acte médical, il nous semble que l'intérêt collectif à l'encouragement de la recherche, ainsi que l'absence de conséquences supplémentaires pour l'intégrité somatique du patient, militent en faveur de la validité de la seule autorisation éclairée du mineur, sans que les autres formalités soient nécessaires. Sinon, l'alourdissement des conditions de validité serait une entrave inutile à la recherche¹⁷³.

En fait, il faudrait, comme dans le cas de l'adulte, rechercher le consentement de la personne autorisée à consentir à l'atteinte à l'intégrité (ou à l'aliénation), c'est-à-dire à consentir aux soins¹⁷⁴. La loi accordant déjà une certaine marge de manœuvre aux mineurs en ce qui concerne leur intégrité, il est logique que cette autorisation s'étende aux résultats de l'administration des soins.

Ainsi, pour les mineurs, la personne habilitée à consentir sera déterminée selon que le prélèvement a été effectué dans le cadre de soins requis ou non requis par l'état de santé et selon l'âge de l'enfant. Lorsque le mineur est âgé de moins de 14 ans, le consentement des parents devra être recherché dans tous les cas¹⁷⁵. Si les soins sont requis par l'état de santé d'un mineur de 14 ans et plus, ce dernier sera autorisé à fournir son consentement¹⁷⁶. Il le pourra aussi pour des soins non requis, cependant le consentement du parent sera nécessaire si les soins présentent un risque sérieux pour sa santé et peuvent lui causer des effets graves et permanents¹⁷⁷.

Bien qu'il soit possible de conclure théoriquement à la capacité du mineur de 14 ans et plus de consentir à l'utilisation, pour une biobanque, de son matériel biologique prélevé dans le cadre de soins, il faut moduler cette conclusion en fonction des risques particuliers en cause. Cette capacité présumée du mineur à consentir à la recherche doit être nuancée en fonction « des risques particuliers dont le mineur pourrait mal mesurer la portée »¹⁷⁸. Si le législateur a souhaité reconnaître l'autonomie du mineur de 14 ans et plus en matière d'utilisation des parties de son corps prélevé lors de soins auxquels il peut consentir, cela s'inscrit nécessairement dans des limites protégeant l'enfant. En effet, une telle exception doit exister au bénéfice de l'enfant et elle ne peut être

¹⁷³ *Ibid.*

¹⁷⁴ Allard, *supra* note 82 à la p 69.

¹⁷⁵ Art 14(1) CcQ.

¹⁷⁶ Art 14(2) CcQ.

¹⁷⁷ Art 17 CcQ.

¹⁷⁸ Kouri et Philips-Nootens, *supra* note 52 au para 36.

interprétée comme susceptible de lui porter préjudice. À cet égard, nous renvoyons le lecteur sur nos commentaires plus haut concernant la capacité du mineur de fournir un consentement éclairé et d'évaluer les risques associés à une participation dans une biobanque.

C. *Expérimentation*

Plus haut, nous avons conclu que la collecte de matériel biologique en dehors des soins prodigués à une personne était encadrée par les règles du CcQ sur l'expérimentation¹⁷⁹. C'est en matière d'expérimentation que l'on retrouve, dans le corpus législatif, la matérialisation la plus éloquente des quatre principes éthiques encadrant la recherche avec les enfants : soit l'autorisation parentale, l'expectative de bénéfices pour des personnes similaires, la limitation du niveau de risque et le respect du refus de l'enfant.

Premièrement, l'article 21 CcQ dispose que le parent, ou autre personne en tenant lieu, est seul habilité à autoriser l'expérimentation concernant son enfant¹⁸⁰. La collecte de matériel biologique dans le cadre d'une biobanque nécessite donc une autorisation parentale.

Deuxièmement, l'expérimentation doit laisser espérer des résultats bénéfiques. Puisqu'une biobanque vise un groupe de personnes, les résultats bénéfiques concernent des « personnes possédant les mêmes caractéristiques d'âge, de maladie ou de handicap que les membres du groupe »¹⁸¹. Il ne s'agit pas d'une « espérance de bienfait pour la personne soumise à l'expérimentation, mais d'un bienfait pour le groupe »¹⁸². Ainsi, on devrait s'attendre à ce que découlent de la biobanque, des bénéfices pour les personnes possédant les mêmes caractéristiques d'âge, de maladie ou de handicap que les participants mineurs. Cette condition fait en sorte qu'il n'est pas permis de soumettre des enfants à « des expérimentations qui portent sur des maladies ou sur des questions médicales qui ne concernent pas leur groupe »¹⁸³. Le législateur applique donc le principe selon lequel les inconvénients subis par les enfants peuvent trouver leur justification dans les bénéfices auxquels accéderont éventuellement d'autres personnes semblables (même âge, maladie ou handicap). Une biobanque recrutant des enfants devrait donc compter parmi ses objectifs

¹⁷⁹ Voir section II. B. *Collecte de matériel biologique*.

¹⁸⁰ Art 21(3) CcQ.

¹⁸¹ Art 21(2) CcQ.

¹⁸² Allard, *supra* note 82 à la p 68.

¹⁸³ Deleury et Goubau, *supra* note 52 à la p 157.

d'obtenir des bénéfices pour d'autres enfants ou, s'il s'agit d'une biobanque visant une pathologie en particulier, d'autres personnes ayant la même condition de santé.

Troisièmement, l'expérimentation ne doit pas comporter de « risque sérieux » pour la santé de l'enfant y participant¹⁸⁴. Le risque à considérer selon la loi est celui portant sur la santé de l'enfant. Pour une biobanque, on peut à cet égard conclure qu'il s'agit surtout (ou essentiellement) du risque physique posé par le prélèvement ou encore par les examens. Ceci établit donc une limite aux risques inhérents au prélèvement de matériel biologique : il ne doit pas engendrer de risque sérieux pour la santé.

Les commentaires du ministre de la Justice nous apprennent qu'en adoptant la limite du risque sérieux pour les enfants, l'intention était d'imposer un critère plus exigeant que le critère d'équilibre risque-bénéfice appliqué aux adultes par l'article 20 CcQ¹⁸⁵. Il y avait une volonté de « protéger davantage ces personnes plus vulnérables et plus susceptibles d'être victimes d'abus »¹⁸⁶. Cela découle logiquement de l'ensemble des dispositions portant sur l'expérimentation, desquelles on peut conclure que le législateur souhaitait offrir une plus grande protection aux mineurs qu'aux adultes. La doctrine considère d'ailleurs que pour le législateur « l'impératif de protection des inaptes justifie des exigences plus grandes que pour la personne apte »¹⁸⁷ et que le critère du risque sérieux s'ajoute à celui de la proportionnalité¹⁸⁸. Ainsi, on ne doit pas interpréter le critère du risque sérieux comme permettant des recherches qui n'auraient pu se qualifier en vertu du critère risque-bénéfice appliqué aux adultes par l'article 20 CcQ. D'ailleurs, les conditions d'exercice des comités d'éthique chargés d'évaluer et de suivre les projets de recherche qui comprennent une expérimentation avec les enfants spécifient que ces comités doivent procéder à une évaluation risque-bénéfice. En effet, les conditions définies par le ministre de la Santé et des Services sociaux mentionnent que lors de l'examen éthique d'un projet de recherche, ces comités d'éthique de la recherche doivent « déterminer s'il y a équilibre entre les risques et les avantages »¹⁸⁹. Encore une fois, comme cela a été mentionné dans notre article,

¹⁸⁴ Art 21(1) CcQ.

¹⁸⁵ Québec, Ministère de la Justice, *Commentaires du ministre de la Justice : le Code civil du Québec*, t 1, Québec, Publications du Québec, 1993 à la p 22.

¹⁸⁶ *Ibid.*

¹⁸⁷ Kouri et Philips-Nootens, *supra* note 52 au para 560.

¹⁸⁸ *Ibid.*

¹⁸⁹ *Conditions d'exercice des comités d'éthique de la recherche désignés ou institués par le ministre de la Santé et des Services sociaux en vertu de l'article 21 du Code*

cette évaluation devrait se faire en considérant les risques et les bénéfices dans une optique large, en y incluant les aspects médicaux, psychologiques, sociaux, économiques, etc.¹⁹⁰

Quatrièmement, la loi prévoit que le refus du mineur de participer à l'expérimentation devrait être respecté dans certaines circonstances. En effet, un enfant ne peut être soumis à une expérimentation « à laquelle il s'oppose alors qu'il en comprend la nature et les conséquences »¹⁹¹. La capacité et la maturité de l'enfant sont évidemment prises en compte pour appliquer cette règle. Le refus de l'enfant pourrait donc sonner le glas de sa participation à une biobanque si, selon la complexité des éléments en présence, il est capable d'en comprendre les conséquences¹⁹².

Certains auteurs interprètent cette disposition comme imposant en même temps l'obligation d'obtenir l'assentiment de l'enfant. Ils estiment que pour savoir si l'enfant s'oppose au projet, il faut nécessairement lui demander d'abord son accord¹⁹³. Bien que la loi ne contienne pas de disposition spécifique sur l'assentiment, l'importance de prendre en compte l'avis des enfants dans les décisions concernant leur corps ne peut être ignorée. Dans la décision *AC c Manitoba (Directeur des services à l'enfant et à la famille)*, la Cour suprême du Canada a bien établi en matière de soins médicaux la nécessité d'accorder du poids à l'opinion de l'enfant selon le développement de sa maturité, cela étant dans l'intérêt supérieur de l'enfant¹⁹⁴. L'opinion du mineur deviendrait « plus déterminante en fonction du développement de sa capacité

civil, D. 7131, G.O.Q. 1998.I.1039 à l'art. a) 8° ; Voir au même effet Québec, Ministère de la Santé et des Services sociaux, *Plan d'action ministériel en éthique de la recherche et en intégrité scientifique*, par André Jean et Marie-Christine Lamarche, Québec, Gouvernement du Québec, Ministère de la Santé et des Services Sociaux, Direction générale de la planification et de l'évaluation, 1998 à la p 23.

¹⁹⁰ Au sujet de l'art 20 du CcBC qui traitait de l'expérimentation chez les mineurs, la doctrine considérait que « les conséquences psychologiques, affectives et même sociales de l'expérience doivent également être prises en considération ». Voir Baudouin, *supra* note 7 à la p 831.

¹⁹¹ Art 21(1) CcQ.

¹⁹² À noter qu'en matière de recherche thérapeutique, plusieurs normes considèrent acceptables de passer outre le dissentiment de l'enfant lorsque des bénéfices sont attendus pour sa santé (voir Valarie Blake, Steve Joffe et Eric Kodish, « Harmonization of Ethics Policies in Pediatric Research » (2011) 39:1 *Journal of Law, Medicine and Ethics* 70 à la p 73).

¹⁹³ Sénécal, Samuël et Avard, *supra* note 130 à la p 47.

¹⁹⁴ 2009 CSC 30 aux para 88 et 92.

d'exercer un jugement mature et indépendant »¹⁹⁵. Il semble raisonnable d'en conclure que l'avis des enfants revêt une importance primordiale en matière d'expérimentation et qu'elle devrait être hautement considérée lorsque la maturité de l'enfant est suffisante.

Conclusion

La recherche est essentielle afin de pouvoir espérer mieux soigner et mieux prendre en charge les enfants aux prises avec des problèmes de santé ou de développement. Les biobanques participent à cet effort collectif visant à acquérir des connaissances pour en partager les bénéfices avec toute la société. La participation des enfants est nécessaire et souhaitée. En ce qui concerne les deux questions à l'étude (qui consent ? quelle limitation aux risques ?), des balises éthiques et juridiques sont en place pour apporter un encadrement.

D'abord, nous avons pu constater qu'au stade prénatal les décisions revenaient à la femme, tant en ce qui concerne le consentement que pour l'évaluation des risques. Bien que le fœtus ne possède pas encore une personnalité juridique, il demeure important d'analyser les risques dans la perspective de l'enfant à naître. Ainsi, les risques se trouvent limités par l'obligation d'atteindre un équilibre entre les risques et les inconvénients à l'égard de la femme enceinte et du futur enfant.

Ensuite, nous avons fait état de quatre principes généraux concernant la recherche non thérapeutique avec les enfants (autorisation parentale, possibilité de bénéfices pour des personnes similaires, limitation du risque et respect du refus de l'enfant). Nous avons pu constater toute la complexité juridique en ce qui concerne l'implication des enfants, selon qu'on se situe à l'étape de la collecte des données (auprès de tiers ou non) ou à celle du matériel biologique (effectuée dans, ou à l'extérieur, de la prestation de soins). Il n'est pas toujours facile de concilier les principes éthiques avec des dispositions juridiques ne visant pas particulièrement la recherche. Ainsi, on constate que chacun des quatre principes éthiques ne trouve pas nécessairement écho dans la loi, sauf en ce qui concerne l'expérimentation chez l'enfant. Compte tenu de la complexité des risques en présence et de la possibilité que leurs effets se fassent sentir sur une longue période, il apparaît prudent de s'en tenir aux règles éthiques lorsqu'elles sont plus exigeantes. La protection de l'enfant justifie habituellement de choisir les normes les plus élevées et de ne faire d'exception que lorsque cela est nécessaire et sans préjudice pour l'enfant. C'est probable-

¹⁹⁵ Robert P Kouri, « Le mineur et les soins médicaux, A.C. c. Manitoba : de l'autonomie au meilleur intérêt, une limite bien floue » (2010) 4:1 RD & santé McGill 65 à la p 78.

ment la solution adoptée par plusieurs comités d'éthique et chercheurs qui font le choix d'appliquer un ensemble de normes uniformes, qu'il s'agisse d'expérimentation chez l'enfant, de collecte de renseignements personnels ou de collecte de matériel biologique recueillis dans le cadre de soins. D'ailleurs, dans la pratique, il est difficile de diviser en plusieurs morceaux la participation à une biobanque, comme nous l'avons fait ici. Souvent, cette participation est perçue sur un continuum, incluant à la fois la collecte de données et la collecte de matériel biologique. Par exemple, le consentement parental va souvent être exigé comme règle uniforme pour toute recherche, y incluant les biobanques. Il n'en demeure pas moins que nous trouvons que l'analyse des droits en matière de biobanque doit être effectuée dans une perspective juridique. Les conclusions tirées au sujet des droits constituent un minimum (souvent rigide) mais sur lequel les normes éthiques prennent assise en ajoutant des protections supplémentaires nuancées et adaptées à chaque situation particulière.

ACCESS TO HEALTH CARE AND WORKERS' COMPENSATION FOR PRECARIOUS MIGRANTS IN QUÉBEC, ONTARIO AND NEW BRUNSWICK

*Anette Sikka, Katherine Lippel & Jill Hanley **

Immigration status is a key criterion on the basis of which an individual will be deemed eligible for receipt of insured public health services. Immigration statuses assigned to individuals who are not citizens or permanent residents may be considered particularly “precarious” in that these individuals enjoy less certainty about their ability to remain in Canada and partake in the benefits of Canadian society. In this paper we investigate the relationship between being an individual with

Le statut d’immigration est un élément clé pour déterminer si un individu est admissible aux services de santé couverts par l’assurance publique. Les statuts d’immigration assignés aux personnes qui ne sont ni immigrants reçus ni citoyens peuvent être considérés comme particulièrement « précaires » puisque ces individus bénéficient de moins de certitude quant à leur possibilité de rester au Canada et de participer aux bénéfices de la société canadienne.

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“precarious” immigration status and access to insured health services. The study was conducted using Ontario, Québec, and New Brunswick as sites, looking at access to health services through federal and provincial health insurance schemes and workers’ compensation systems through legislation and case law.

The most vulnerable group identified with respect to both health and workers’ compensation coverage were those without legal status in Canada. Given that they are not entitled to any provincial health insurance benefits, their status with respect to workers’ compensation benefits is unclear, and legality issues prevent them from accessing services to which they may be entitled. Particularly with respect to provincial health insurance coverage, other gaps shown were for coverage of temporary migrants working on permits where no specific employer is named and of those in Canada awaiting sponsorship or other permanent residency application results. Immigration status has less bearing on access to workers’ compensation benefits, but coverage of injured migrant workers without status was still found to be an issue. The legitimacy of the employment contract has some bearing on coverage of injuries, particularly in Québec, and thus the lack of immigration status may, and has sometimes been used to, call the employment relationship into question.

Given the broad range of individuals who are precarious migrants and the gaps identified in coverage, both between statuses and between provinces, governments need to address these inequities if access to health care for all people living in Canada is to be ensured.

Dans cet article, nous examinons la relation entre le fait d’être un individu au statut d’immigration « précaire » et l’accès aux soins de santé assuré par le régime public. L’étude porte sur les régimes d’assurance maladie et d’indemnisation pour les accidents du travail et les maladies professionnelles fédéraux et provinciaux applicables en Ontario, au Québec et au Nouveau-Brunswick, et ce, par le biais de la législation et de la jurisprudence.

Le groupe le plus vulnérable, en ce qui concerne l’accès aux régimes de santé et d’indemnisation pour les lésions professionnelles, est celui des personnes sans statut légal au Canada. Puisqu’elles n’ont pas droit aux prestations d’une assurance maladie provinciale, leur accès aux régimes d’indemnisation est incertain et des enjeux légaux les empêchent d’accéder à certains services auxquels elles pourraient avoir droit. En ce qui concerne particulièrement l’accès à l’assurance maladie provinciale, d’autres lacunes ont été observées quant à la couverture des travailleurs migrants qui détiennent des permis de travail temporaire sans mention d’un employeur particulier et pour ceux qui sont en attente de parrainage ou d’autres réponses relatives à une demande de résidence permanente. Le statut d’immigration a moins d’influence en ce qui concerne l’accès aux régimes d’indemnisation pour les lésions professionnelles, sauf pour les personnes sans statut légal leur permettant de travailler. La légitimité du contrat de travail a un certain effet sur l’obtention d’une indemnisation, particulièrement au Québec, et l’absence de statut d’immigration peut être utilisée, et a parfois été utilisée, pour remettre une relation de travail en question.

Devant la grande étendue de personnes qui ont un statut de migrant précaire et les lacunes identifiées quant à leur protection, à la fois en raison de leurs différents statuts et de régimes distincts entre provinces, les gouvernements doivent se pencher sur ces iniquités afin d’assurer l’accès aux services de santé pour toutes les personnes vivant au Canada.

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Conclusion

Introduction

In Canada there are numerous ways in which individuals may access health care without personally paying for the services. They may be covered under provincial health insurance by virtue of their residency in a province;¹ be eligible for coverage through private health insurance plans provided by their employers; receive subsidized care for injuries sustained at work through provincial workers' compensation schemes;² or receive coverage for injuries sustained through automobile accidents.³ Whether or not they can access these subsidies depends both on their province of residency and the circumstances under which the illness or injury was sustained. The equation becomes more complicated when an individual is not a citizen or permanent resident of Canada.

International conventions suggest that states should ensure universal access to health care and social services. The International Covenant on Economic, Social and Cultural Rights (ICESC) recognizes "the right of everyone to the enjoyment of the highest attainable standard of mental and physical health."⁴ The *International Convention on the Elimination of All Forms of Racial Discrimination* obligates states to guarantee to everyone, without distinction as to national or ethnic origin, the "right to public health, medical care, social security and social services."⁵ Most notably, the *Convention on the Protection of the Rights of All Migrant Workers and Members of their Families*, in force since July 2003 but to which Canada is not a signatory, enshrines human rights protections – including health care – specifically for migrant workers.

However, research in Canada indicates that migrants do not benefit from equitable access to health care services. For instance, when accessing the health care system, research has shown a significant proportion of migrants

¹ *Canada Health Act*, RSC 1985 c C-6, s 10 [CHA]. A list of acronyms appears in Annex A.

² *Canadian Workers' Compensation 101*, online: Association of Workers' Compensation Boards <www.awcbc.org/en/canadianworkerscompensation101.asp>.

³ See for example *Automobile Insurance Act*, RSQ c A-25.

⁴ *International Covenant on Economic, Social and Cultural Rights*, GA Res 2200A (XXI), UNGAOR, 1966.

⁵ *International Convention on the Elimination of All Forms of Racial Discrimination*, 21 December 1965, 660 UNTS 195 at art 5(e)(iv), Can TS 1970 No 28.

experience delays, complications, or denial of medically necessary treatment.⁶ This is particularly true of those with “precarious immigration status” – that is, those who are denied the permanent right to remain in Canada or whose status depends on a third party such as a spouse or employer.⁷ In addition, those with precarious immigration status experience more barriers to accessing health care and, as a result, experience long-term health concerns and unrecognized morbidity.⁸

Canadian immigration law allocates immigration “statuses” to individuals, which determine access to employment, health insurance, and other benefits in accordance with those statuses. Individuals may be eligible for entry into Canada through a variety of programs, and may choose a path because it simply seems to be the swiftest and most efficient. However, some government-sponsored insurance programs place considerable weight on this status, according particular benefits and rights in conjunction with those categories. In this paper we discuss the distribution of these benefits in relation to access to health care in Canada.

After a review of the literature on access to health care and workers’ compensation for migrants, we identify immigration statuses that may be considered “precarious”, in that they provide little security of residency. We then investigate the relationship between these statuses and an individual’s legal entitlement to (a) provincial health insurance, in both emergency and non-emergency situations, and (b) health benefits provided through workers’ compensation schemes. This paper does not address practical barriers that precarious-status migrants may face in accessing health care, such as linguistic, cultural, and economic barriers.⁹ It relies specifically on legal analysis undertaken

⁶ P Caulford & Y Vali, “Providing Health Care to Medically Uninsured Immigrants and Refugees” (2006) 174:9 Can Med Assoc J 1253; Sonia ter Kuile et al, “The Universality of the Canadian Health Care System in Question: Barriers to Services for Immigrants and Refugees” (2007) 3 International Journal of Migration, Health and Social Care 15.

⁷ J Hanley & E Shragge, “Economic Security for Women with Precarious Immigration Status: Enforcing Labour Rights for All” in J Pulkingham & M Griffin Cohen, eds, *Imagining Public Policy to Meet Women’s Economic Security Needs* (Toronto: University of Toronto Press, 2009).

⁸ Kuile et al, *supra* note 6.

⁹ Some of these issues have been examined by others: Anita Gagnon, “Responsiveness of the Canadian Health Care System Towards Newcomers” in Pierre-Gerlier-Forest et al, eds, *Changing Health Care in Canada: The Romanow papers Volume II* (Toronto: University of Toronto Press, 2004) at 349 and J Oxman-Martinez et

during the first phase of a study that is currently investigating those broader questions.¹⁰ Because the empirical study is based in Québec, the policy component that is the subject of this article examines Québec legislation. We have chosen as comparators Ontario and New Brunswick, two neighbouring provinces with which Québec policy makers have sometimes identified a need to harmonize health policy so as to avoid what is popularly termed “health tourism.”

I. Background

A. Barriers to Health

With the exception of those recently arrived, immigrants to Canada report poorer health status than their non-immigrant counterparts.¹¹ Research, further advanced in the United States than in Canada, has begun to show that this may be exacerbated by categories of precarious immigration status. For instance, migrant farm workers in the U.S. have higher incidence of undetected infectious diseases and adverse chronic health indicators.¹² Similarly, research has suggested that undocumented migrants have a disproportionate incidence of communicable diseases and frequently lack basic preventive care such as immunizations.¹³ Poorer health is also connected to precarious employment, low earnings, few benefits, and high levels of uncertainty regarding terms and conditions of work and future earnings – categories into which many individuals

al, “Intersection of Canadian Policy Parameters Affecting Women with Precarious Immigration Status: A Baseline for Understanding Barriers to Health” (2005) 7:4 *Journal of Immigrant Health* 247. Studies on difficulties in accessing workers’ compensation will be found at 211-213, below.

¹⁰ The *Right to Health for Precarious Status Migrants: Medicare and CSST* project (SSHRC, 2008-2011) combines quantitative and qualitative methods to explore precarious status migrants’ experiences in accessing Medicare and CSST in Québec, their strategies to overcome barriers and the implications of access problems in their personal lives. Team members are: J Hanley, L-F Dagenais, S Gravel, K Lippel, S Premji, E Shragge. Student researchers include: MA Boutin-Clermont, S Gal, J Koo, V Lavigne and A Sikka.

¹¹ B Newbold, “Health Status and Health Care of Immigrants in Canada: A Longitudinal Analysis” (2005) 10 *Journal of Health Services Research & Policy* 77 at 81.

¹² DD Villarejo, “The Health of US Hired Farm Workers” (2003) 24 *Annual Review of Public Health* 175.

¹³ Jeffrey T Kullgren, “Restrictions on Undocumented Immigrants’ Access to Health Services: The Public Health Implications of Welfare Reform” (2003) 93:10 *American Journal of Public Health* 1630 at 1630.

with precarious status fall.¹⁴ As a result of such findings, researchers have concluded that the “healthy immigrant effect” – so named to describe the lower utilization of health services amongst immigrants – is possibly due to immigration criteria that eliminate individuals in ill-health upon application.¹⁵

Barriers to health services, such as immigration status, increase the likelihood of the absence of needed health care or inappropriate treatment. For example, policies surrounding the provision of public health insurance, including the exclusion of immigrants from health services for the initial three months of their residency in certain provinces, act as a serious impediment to equitable health care.¹⁶ Kuile et al interviewed health service providers in Québec and found that many, if not most, individuals with precarious immigration status who are experiencing acute health crises had delayed seeking care due to a misunderstanding of the system.¹⁷ Immigrants in Canada receive fewer screenings for diseases¹⁸ and have less information about disease transmission,¹⁹ and health promotion.²⁰ For those individuals with precarious immigration status, who often lack full medical health coverage, the consequences of such health issues are magnified. This has been well-documented by researchers in the United States, who have shown that a lack of medical insurance results in, among other things, longer waiting times, less access to some preventive tests, and increased likelihood of presenting with late-stage cancer.²¹ Not surprising-

¹⁴ W Lewchuk et al, “From Job Strain to Employment Strain: Health Effects of Precarious Employment” (2003) 3 *Just Labour* 23.

¹⁵ Jiagjian Chen, Edward Ng & Russell Wilkins, “The Health of Canada’s Immigrants in 1994-95” (1996) 7:4 *Health Reports* 33 at 44.

¹⁶ Gagnon, *supra* note 9 at 359-360. Oxman-Martinez et al, *supra* note 9.

¹⁷ Kuile et al, *supra* note 6.

¹⁸ Joanne Bryant et al, “Access to Health Care: Social Determinants of Preventive Cancer Screening Use in Northern British Columbia” (2002) 60 *Social Indicators Research* 243 at 256.

¹⁹ N Gibson et al, “Socio-cultural Factors Influencing Prevention and Treatment of Tuberculosis in Immigrant and Aboriginal Communities in Canada” (2005) 61 *Social Science & Medicine* 931.

²⁰ Margareth S Zanchetta & Iraj M Poureslami, “Health Literacy Within the Reality of Immigrants’ Culture and Language” (2006) 97:2 *Canadian Journal of Public Health* S26.

²¹ O Carrasquillo & S Pati, “The Role of Health Insurance on Pap Smear and Mammography Utilization by Immigrants Living in the United States” (2004) 39 *Preventive Medicine* 943; Steven S Coughlin et al, “Breast cancer screening practices among women in the United States, 2000” (2004) 15; C Steven S Coughlin et al,

ly, those without medical insurance often have longer stays in hospitals and experience higher death rates.²² A lack of health coverage for children also compromises their care content, quality, and satisfaction.²³

American researchers have found that uninsured, undocumented migrants are less likely to have a regular health care provider than their counterparts with documents.²⁴ This American experience may become all-too-common in Canada as the proportion of migrants with precarious status increases. Clearly, without addressing the barriers to health and social services for those with precarious immigration status, these individuals are at greater risk of problems and are more likely to need intensive long-term intervention. Complex issues that arise due to obstacles to care may result in an inability to work and insurmountable debt from medical treatment.

B. Work-Related Health Care

Precarious migrants who work, like all workers in Canada, may well be able to access health care through channels other than public health insurance, depending on whether or not the services required relate to an employment injury. The nature of that coverage may be more complete, and the timeframe during which free care is available may be different, if the health problem relates to a compensable injury or illness. Workers' compensation was the first social program to provide free access to health care in Canadian provinces. Québec legislation first guaranteed the right to free treatment by a physician of the injured worker's choice in 1928, and costs of hospitalization and medication were insured in this context long before the development of public health

"Breast Cancer Screening Practices Among Women in the United States, 2000" (2004) 15 *Cancer Causes and Control* 159; J Swan et al, "Progress in Cancer Screening Practices in the United States: Results from the 2000 National Health Interview survey" (2003) 97 *Cancer* 1528. For a Canadian study see J Bryant et al, *supra* note 18.

²² Jack Hadley, "Sicker and Poorer—the Consequences of Being Uninsured: A Review of the Research on the Relationship between Health Insurance, Medical Care Use, Health, Work, and Income" (2003) 60:2 *Medical Care Research and Review* 3S.

²³ YM Fry-Johnson et al, "Being uninsured: Impact on Children's Healthcare and Health" (2005) 17 *Current Opinion in Pediatrics* 753.

²⁴ Khiya J Marshall et al, "Health Status and Access to Health Care of Documented and Undocumented Immigrant Latino Women" (2005) 26 *Health Care for Women International* 916.

care.²⁵ All workers' compensation costs are financed by employers, who, in exchange, are protected from lawsuits related to work-related injury or illness.²⁶ As we shall see, workers' compensation only provides for health care in those cases covered by the scheme: the need for health care must be in relation to a compensable injury or illness incurred by a "worker" as defined in the relevant legislation.

In recent years some analysts have compared the workers' compensation model of health care delivery to the public health system. The increased reliance on private health services for injured workers, prevalent in some provinces, has drawn criticism from scholars²⁷ while being praised by its proponents.²⁸ This is not an issue that is specific to precarious migrants, and it is beyond the purview of this article to explore the relative advantages and disadvantages of health care coverage under workers' compensation as compared to other systems. However, health services provided through workers' compensation are relevant, given that many precarious migrants work in Canada and may thus be injured at work. This is especially true of temporary foreign workers,²⁹ but it is also true of refugee claimants, undocumented migrants, and others.

Few studies have explored the rights of immigrant workers to workers' compensation, and fewer still have provided a legal analysis of the rights of those workers. Some Canadian studies have found that eligibility for workers' compensation is unclear for certain categories of migrant workers,³⁰ while bar-

²⁵ See generally K Lippel, "Droit des travailleurs québécois en matière de santé, 1885-1981" (1981-1982) 16 RJT 329.

²⁶ TG Ison, *Workers' Compensation in Canada* (Toronto: Butterworths, 1989); B Cliche & M Gravel, *Les accidents du travail et les maladies professionnelles: Indemnisation et financement* (Cowansville: Yvon Blais, 1997).

²⁷ Notably those private sector service providers who benefit from the business of those workers' compensation boards, like Alberta, that employ this model. See J Hurley et al, "Parallel Payers and Preferred Access: How Canada's Workers' Compensation Boards Expedite Care for Injured and Ill Workers" (2008) 8:3 Healthcare Papers 6.

²⁸ Arif Bhimji, "Reduced Suffering and Increased Productivity – The Workers' Compensation Model" (2008) 8:3 Healthcare Papers 30.

²⁹ M Sargeant & E Tucker, "Layers of Vulnerability in Occupational Safety and Health for Migrant Workers: Case Studies from Canada and the UK" (2009) 7:2 Policy and Practice in Health and Safety 51.

³⁰ Stephanie Bernstein, Katherine Lippel & Lucie Lamarche, *Women and Homework: The Canadian Legislative Framework* (Ottawa: Status of Women Canada, 2001); Stephanie Bernstein, "Au carrefour des ordres publics: l'application des lois du

riers to accessing workers' compensation for immigrant workers have been documented.³¹ Sargeant and Tucker³² explored the legal protection of workers employed under the Temporary Foreign Worker Program, targeting occupational health and safety law in particular, but also providing information on workers' compensation. While concluding that workers' compensation law was applicable to this category of precarious migrants, they underlined obstacles limiting access to compensation, including workers' reluctance to claim because of fear of reprisals, and intimidation strategies by employers seeking to avoid increases in premiums. More generally, Premji and colleagues found that language issues were an obstacle to immigrant workers exercising their rights relating to occupational health and safety protection in Québec.³³ Gravel and colleagues have studied obstacles faced by immigrant workers' compensation claimants, but precarious migrants were not targeted in those studies.³⁴ Other research has found that immigrant workers are more likely to be exposed to occupational hazards than Canadian-born labour market participants,³⁵ and

travail aux travailleuses et travailleurs ne détenant pas de permis de travail valide en vertu de la *Loi sur l'immigration et la protection des réfugiés*" in Barreau du Québec ed, *Développements récents en droit du travail 2009* (Cowansville: Yvon Blais, 2009) 237.

³¹ S Gravel et al, "Incompréhension des travailleurs immigrants victimes de lésions professionnelles de leurs difficultés d'accéder à l'indemnisation" (2007) 131:2 Migration et santé 1; L Patry et al, *Accès à l'indemnisation des travailleurs et travailleuses immigrant(e)s victimes de lésions musculo-squelettiques d'origine professionnelle* (Montréal: Direction de la santé publique de Montréal, FQRSC, 2005); Sylvie Gravel et al, "Ethics and the Compensation of Immigrant Workers for Work-Related Injuries and Illnesses" (2010) 12 J Immigrant Minority Health 707 [Gravel, "Immigrant Workers"]; Charlene M Gannagé, "The Health and Safety Concerns of Immigrant Women Workers in the Toronto Sportswear Industry" (1999) 29:2 International Journal of Health Services 409.

³² M Sargeant & E Tucker, *supra* note 29. They refer in particular to a field study by Tanya Basok, "Post-national Citizenship, Social Exclusion and Migrant Rights: Mexican Seasonal Workers in Canada" (2004) 8:1 Citizenship Studies 47.

³³ Stéphanie Premji, Karen Messing & Katherine Lippel, "Broken English, Broken Bones? Mechanisms Linking Language Proficiency and Occupational Health in a Montreal Garment Factory" (2008) 38:1 International Journal of Health Services 1. See also Basok, *ibid* at 50, 57.

³⁴ Gravel et al, *supra* note 31; Patry, *supra* note 31; Gravel, "Immigrant Workers" *supra* note 31.

³⁵ Peter M Smith & Cameron A Mustard, "The Unequal Distribution Of Occupational Health and Safety Risks Among Immigrants to Canada compared to Canadian-born Labour Market Participants: 1993–2005" (2010) 48:10 Safety Science 1296.

that refugees and those with poor language proficiency in English and French were more likely to be found in physically demanding jobs.³⁶ However, these studies were based on census data and not on workers' compensation data. American studies have documented significant under-reporting of work injuries among the migrant population, particularly among precarious migrants.³⁷

In Australia, temporary foreign workers were found to have legal entitlement but limited access to workers' compensation because of obstacles that included misinformation, intimidation, and fear of job loss and deportation. Furthermore, even when compensation is granted, legal rules requiring workers to mitigate their damages by seeking other suitable employment are difficult to comply with when visa requirements are linked to a specific employer. Vulnerability attributable to visa requirements was found to facilitate reprisals by employers who would normally be held liable for terminating an injured worker.³⁸ A previous study of undocumented workers found similar problems, exacerbated because the right to coverage for these workers was found to be ambiguous and uncertain.³⁹

The focus of the present article, targeting issues related to access to healthcare for precarious migrants under workers' compensation in the Canadian context, is unique.

II. Methodology

It is well established that immigration will be of increasing importance to Canadian society⁴⁰ and that this increase in diversity is essential to consider if

³⁶ P Smith, C Chen & C Mustard, "Differential Risk of Employment in More Physically Demanding Jobs Among a Recent Cohort of Immigrants to Canada" (2009) 15:4 *Injury Prevention* 252.

³⁷ Lenore S Azaroff et al, "Wounding the Messenger: The New Economy Makes Occupational Health Indicators Too Good to be True" (2004) 34:2 *International Journal of Health Services* 271.

³⁸ Stefanie Toh & Michael Quinlan, "Safeguarding the Global Contingent Workforce? Guestworkers in Australia" (2009) 30:5 *International Journal of Manpower* 453 at 457-458.

³⁹ Robert Guthrie & Michael Quinlan, "The Occupational Safety and Health Rights and Workers' Compensation Entitlement of Illegal Immigrants: An Emerging Challenge" (2005) 3:2 *Policy and Practice in Health and Safety* 69.

⁴⁰ Statistics Canada Housing, Family and Social Statistics Division, *Longitudinal Survey of Immigrants to Canada: Process, Progress and Prospects*, (Ottawa: Ministry of Industry, 2003)

we aim to promote equity in access to health and social services.⁴¹ Our methodology for the overall research project draws upon a conceptual framework that assumes that migrants have the right to health and social services, as laid out in numerous international human and social rights conventions, and that social factors such as gender and race intersect with immigration status to influence access to the right to health and social services. A second important concept is that any barriers in access to the right to health and social services can have a negative impact on not only migrants' health and well-being but also their very sense of agency and personal power. The third guiding concept of this project is that migrants are not passive subjects of legal and socio-economic barriers but rather may resist these barriers through individual, family, and collective strategies. In this article, we present the results of the first phase of our study, which involved documenting the intersection between officially-designated immigration statuses and legal entitlement to publicly-insured health benefits, through both publicly funded health insurance and workers' compensation.

A review of the literature regarding the connection between immigration status and access to health care was undertaken, including both academic literature and "grey" literature, using legal literature databases and internet searches. The literature was reviewed with regard to the legal obligation to treat patients, public health requirements, eligibility requirements for health insurance and workers' compensation, the Interim Federal Health Program, immigration policies governing documentation of migrants, immigration status, and eligibility for insured services. Next, a study was conducted of the legal framework surrounding health insurance in the three provinces, the definition of "insured" and specific provisions or policies relating to immigration status. A similar study was conducted with respect to workers' compensation, but it included, in addition to reviewing the legislative framework and compensation board policies, a survey of administrative tribunal decisions.

III. Immigration Statuses

Immigration "statuses" are particular categories within the *Immigration and Refugee Protection Act*⁴² and its regulations. Individuals who are not Canadian citizens are allowed to enter and remain in Canada on certain conditions depending upon the status accorded to them under *IRPA*. With each of these categories are specified accompanying benefits. Aside from the category

⁴¹ Jaqueline Oxman-Martinez & Jill Hanley, *Health and Social Services for Canada's Multicultural Population: Challenges for Equity* (Ottawa: Heritage Canada, 2005).

⁴² *Immigration and Refugee Protection Act*, SC 2001, c 27 [*IRPA*].

of “permanent resident,”⁴³ all statuses accorded under *IRPA* either place restrictions on the length of time an individual can stay in Canada,⁴⁴ or on activities that an individual can undertake while in the country.⁴⁵ Furthermore, a person’s immigration status sometimes depends on a third party (for example, an employer or sponsoring spouse). Persons without citizenship or permanent residence are also subject to removal from the country for various reasons.⁴⁶ These statuses may thus be considered “precarious” in that the individuals enjoy less certainty about their ability to remain in Canada and partake in the benefits of Canadian society. Given these parameters, several types of immigration statuses were identified as “precarious”.

First, persons claiming refugee status⁴⁷ – under which migrants claim to be in need of protection because their home state is unable or unwilling to protect them from persecution on the basis of a protected ground or for other reasons⁴⁸ – may be termed “asylum seekers.” They are subject to different regulations and are accorded different benefits depending upon the stage to which their application has progressed. Those who await determination as to whether their claim will be deemed eligible to be heard by the Refugee Protection Division (RPD) of the Immigration and Refugee Board (IRB)⁴⁹ are treated differently than those awaiting a hearing by the RPD, those whose claims have been rejected but are awaiting a “pre-removal risk assessment”⁵⁰ (PRRA) to determine whether they still may be allowed to remain in Canada, and those whose removal orders have been stayed due to a moratorium upon returning people to conflict-ridden or otherwise dangerous countries.

A second category of persons with precarious status are “Temporary Foreign Workers” (TFWs).⁵¹ In Canada increasing numbers of individuals are

⁴³ *Ibid*, s 2(1).

⁴⁴ See eg *ibid*, s 29(2).

⁴⁵ See eg *ibid*, s 30.

⁴⁶ See eg *ibid*, ss 35(1), 36(2), 38(1), 39, 41(a), 42. Permanent residents are subject to removal under certain circumstances as well but they are fewer and additional legal procedures are required for such removal: see eg *ibid*, s 36(1) and s 55 on arrest and detention.

⁴⁷ *Ibid*, s 96.

⁴⁸ *Ibid*, s 97.

⁴⁹ *Ibid*, s 100(1).

⁵⁰ *Ibid*, s 112(1).

⁵¹ These persons are generally referred to as “migrant workers”: workers who have migrated to another country to take up work but who currently do not have a per-

granted authorization to work temporarily in the country provided certain conditions are met.⁵² TFWs include those persons working under the “Live-In Caregiver Program” (LCP), the “Seasonal Agricultural Workers Program” (SAWP), those on the “Pilot Project for Occupations Requiring Lower Levels of Formal Training” program (PPORLLFT) and others who obtain “high skill” or professional temporary working permits through individual employment contracts.

Individuals authorized to work in Canada under the LCP are the only low-skill TFWs eligible to apply for permanent residency upon successful completion of their program.⁵³ However, prior to their application for permanent residency, they are subject to conditions similar to other TFWs, are tied to a single employer unless they obtain authorization for a change, and may be removed for reasons similar to other foreign nationals. Furthermore, the potential for gaining permanent residence may in fact increase their vulnerability to abuse by their employer prior to the according of that status, as it may be held over their head as an opportunity that can be lost if they do not comply with the employers wishes.⁵⁴

SAWP workers are recruited through a bilateral agreement with the worker’s home country, either Mexico or one of the designated Caribbean countries,⁵⁵ and are subject to particular constraints on employment, living arrangements, travel, as well as length of stay. An employer may also terminate a contract early should the work be completed. While in these cases employees are entitled to standard notice or pay in lieu of notice, it does not require full payment of the contract initially bargained and still results in the employee’s removal from Canada.⁵⁶ While entitled to the same labour protections as permanent residents or citizens, studies have shown that many are reluctant to as-

manent status in the receiving country. See Sargeant & Tucker, *supra* note 29 at 52.

⁵² *Ibid* at 51.

⁵³ See Citizenship and Immigration Canada, *Working temporarily in Canada: The Live-In Caregiver Program*, online: CIC <www.cic.gc.ca/english/work/caregiver/index.asp>.

⁵⁴ Sargeant & Tucker, *supra* note 29 at 53.

⁵⁵ Human Resources and Development Canada, *Temporary Foreign Worker Program: Hiring Foreign Agricultural Workers in Canada*, online: HRSDC <www.hrsdc.gc.ca/eng/workplaceskills/foreign_workers/sawp.shtml>.

⁵⁶ Human Resources and Development Canada, *Seasonal Agricultural Worker Program*, online: HRSDC <www.hrsdc.gc.ca/eng/workplaceskills/foreign_work-ers/ei_tfw/sawp_tfw.shtml>.

sert their rights in the fear of being sent home or not brought back for the following season.⁵⁷

For all other jobs employers may apply for authorization to hire foreign nationals to fill vacancies that cannot be filled by Canadian workers. Until 2002 only specific, high-skill occupations could be filled through this program.⁵⁸ However, now under the PPORLLFT, some “low-skill” occupations are eligible. Workers arriving through the general TFW program (or the PPORLLFT) are tied to employment with the specific employer named on their visa, and are limited as to the length of time they are allowed to remain in Canada.⁵⁹ They are subject to removal for several reasons and require authorization to change employers.⁶⁰

In addition, some individuals are allocated “Temporary Residency Permits,”⁶¹ (TRP – commonly referred to as “humanitarian visas”) under circumstances where otherwise the person would be inadmissible as a resident in Canada.⁶² They are entitled to apply for permanent residency, subject to the conditions on their visa, after having lived continuously in Canada for a minimum of three to five years depending upon the reason for their inadmissibility.⁶³

⁵⁷ Sergeant & Tucker, *supra* note 29 at 57.

⁵⁸ Human Resources and Development Canada, *Temporary Foreign Worker Program*, online: HRSDC <www.hrsdc.gc.ca/eng/workplaceskills/foreign_workers/lowskill.shtml>.

⁵⁹ *Immigration and Refugee Protection Regulations*, SOR/2002-227, ss 6, 7 [*IRPA Regulations*].

⁶⁰ Sergeant & Tucker, *supra* note 29 at 57.

⁶¹ *IRPA*, *supra* note 42, s 24.

⁶² *Ibid*, ss 29, 30. See definition of “foreign national” in *IRPA*, *ibid*, s 2(1). See also conditions imposed on temporary residents in *IRPA Regulations*, *supra* note 59 ss 183, 185.

⁶³ Citizenship and Immigration Canada, *Application for Permanent Residence: Temporary Resident Permit Holder*, online: CIC <www.cic.gc.ca/english/information/applications/permit.asp>. Particular types of TRPs are allocated to individuals who are identified as having been victims of trafficking in persons. They have specific conditions for entry into and residence in Canada, as well as renewal provisions and employment authorization. However, generally the conditions for removal and application for permanent residence are the same as for other TRPs. See Citizenship and Immigration Canada, *Inland Pro-*

Individuals designated as “tourists” are in a particularly vulnerable situation, as they are entitled to remain only for designated lengths of time, are ineligible to work or study without further authorization, and may be removed for a variety of reasons.⁶⁴ Individuals sometimes enter Canada through a tourist visa if unable to qualify immediately as permanent or temporary immigrants. In some cases, spouses come to Canada on tourist visas in anticipation of being sponsored through the “In-Canada Spouse” class of immigrants.⁶⁵ However, where an application is subsequently withdrawn or where a spousal relationship is no longer viable, the spouse who had been anticipating receiving permanent residency may be put in the even more difficult situation of having to find other means by which to stay in Canada, under threat of removal. Once an individual remains in Canada beyond the length of time stated on their tourist visa, they are considered to be undocumented.

Individuals who enter Canada without appropriate authorization from Canadian authorities or those who entered Canada through some legal means but remained in Canada past their date of authorization or otherwise violate their visa conditions may be considered “undocumented” or “illegal.” They may be subject to arrest, detention, and removal from Canada.⁶⁶

IV. Part One – Access to Insured Health Services

A. Eligibility for Insured Health Services

The federal government is involved in the provision of health insurance through partial funding of provincial programs, and through the administration of the Interim Federal Health Program (IFHP). This Program provides coverage for some individuals residing in Canada (mostly refugee claimants) who are not covered under provincial legislation.⁶⁷ Provincial governments receive an allocation from the federal government each year – the federal Canada Health Transfer (CHT) – if they comply with particular terms and conditions

cessing 1: *Temporary Residency Permits*, online: CIC
<www.cic.gc.ca/english/resources/manuals/ip/ip01-eng.pdf> at 23-30.

⁶⁴ See eg *IRPA*, *supra* note 42, ss 29, 30.

⁶⁵ For instance on a tourist or student visa. *IRPA Regulations*, *supra* note 59, ss 72(1), 72(2)(b).

⁶⁶ *IRPA*, *supra* note 42, s 29(2), *IRPA Regulations*, *supra* note 59.

⁶⁷ Sandra Elgersma, *Immigration Status and Legal Entitlement to Insured Health Services* (Ottawa: Parliamentary Information and Research Service, 2008), online: PIRS <www.parl.gc.ca/information/library/PRBpubs/prb0828-e.pdf> at 3.

with respect to the provision of insured services.⁶⁸ The provinces and territories then administer and deliver all other health care services and provincial public health insurance programs. This responsibility includes creating and managing provincial legislation that regulates eligibility and determines services covered. An individual's ability to access insurance programs to cover costs sustained at the "point of service" (i.e. the hospital, doctor's office, testing laboratory) will then vary depending on the specific provincial legislation. For those who are unable to access provincial health insurance, private insurance is available for purchase in Canada, although the price is prohibitive for many and not all are eligible.

1. Overview of Coverage for Public Health Insurance

Residency and immigration statuses are key criteria in the determination of eligibility under provincial health insurance schemes. Generally, immigrants who obtain permanent residence status are eligible for the same benefits as citizens, provided they can prove they are "resident" in a particular province or territory for the time specified in each jurisdiction's legislation. Areas of concern include waiting periods prior to acquiring residency status in a province, and delays in determining refugee claimants' eligibility status. The *IRPA* allows three days for a claim to be deemed eligible or ineligible for a RPD hearing⁶⁹ but in practice it may take significantly longer, also delaying potential coverage under the IFHP.⁷⁰ Other concerns include lack of coverage for spouses of temporary foreign workers who reside in Canada with "open" work permits,⁷¹ individuals anticipating sponsorship who reside in Canada on tourist visas, and individuals formerly on programs such as those on the LCP who have applied for permanent residency and are awaiting a decision. The most vulnerable group identified were undocumented individuals who are not entitled to provincial health insurance benefits of any kind in any province studied.

⁶⁸ Health Canada, *Canada Health Act Annual Report 2007-2008*, online: Health Canada <www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/chaar-rales-0708/2008-cha-lcs-eng.pdf> at 1. The *CHA* establishes the criteria the provinces are expected to follow in order to receive their full cash contribution from the federal government.

⁶⁹ *IRPA*, *supra* note 42, s 100(1).

⁷⁰ Gagnon, *supra* note 9 at 360.

⁷¹ Permits that entitle an individual to work for any employer of their choosing.

a. The Interim Federal Health Program

The IFHP is a Citizenship and Immigration Canada (CIC) program that provides temporary essential and emergency health care for certain individuals who are unable to access provincial health insurance and who cannot afford private insurance. According to CIC, the program is in place for “humanitarian reasons to allow refugee claimants, PRRA applicants, protected persons, persons in need of protection, humanitarian classes and others under immigration control to receive essential health care. It is not meant to replace provincial health plans.”⁷² Currently, persons claiming protection (including refugee claimants deemed eligible to have their claims determined by the RPD, and their in-Canada dependent children), those waiting for PRRAs, those detained by CIC, and those holding temporary residency permits as victims of trafficking are eligible for coverage through the program.⁷³

The authority for the program comes from the 1957 Order-in-Council PC 157-11/848. The program was formerly run by Health Canada, but since 1995 it has fallen under the responsibility of CIC.⁷⁴ Claims are administered by a private firm, presently Medavie Blue Cross.⁷⁵ The program is designed to cover essential health services for the treatment and prevention of serious medical/dental conditions (including immunizations and other vital preventative medical care), essential prescription medications, contraception, prenatal and obstetrical care, and the immigration medical examination.⁷⁶

i. Asylum Seekers

The program primarily covers individuals claiming asylum. However, entitlement to benefits may vary at different stages of an individual’s asylum application. When an individual initially makes a refugee claim, they go through a determination process as to their eligibility for a hearing by the RPD. If they are found eligible, the CIC officer determines whether the claimant is unable to pay for private insurance, and if so, a document attesting eligibility for IFHP is

⁷² Citizenship and Immigration Canada, *PPI: Processing Claims for Refugee Protection in Canada*, (Ottawa: Citizenship and Immigration, 2010), online: CIC <www.cic.gc.ca/english/resources/manuals/pp/pp01-eng.pdf> [PPI] at 16.14.

⁷³ *Ibid.*

⁷⁴ *Ibid.*

⁷⁵ Citizenship and Immigration Canada, *Information Bulletin: The Interim Federal Health Program (IFHP) Transition*, online: CIC <www.cic.gc.ca/english/refugees/outside/ifhp-bulletin.asp>

⁷⁶ PPI, *supra* note 72 at 16.14.

provided. CIC officers can issue IFHP coverage effective until the eligibility hearing.⁷⁷ Once an asylum seeker receives this document, he or she can take it to a doctor or hospital as proof of eligibility for IFHP. The health care provider then bills Medavie Blue Cross.

If the claim is found to be ineligible for determination by the RPD on the basis of criminality or other exclusions, the claimant will be ineligible for the IFHP. However, if an individual expresses fear of return to the home country, he or she may seek a PRRA prior to removal from Canada. If a PRRA is granted, the claimant can apply for IFHP coverage. The coverage continues during a stay of removal pending a PRRA, or a PRRA determination that a person should not be returned.⁷⁸ However, unlike the case of asylum seekers, coverage is not automatically granted; the claimant must apply individually and show that he or she is unable to pay for private insurance and is ineligible for publicly funded insurance.⁷⁹ If the claimant is eligible, the claimant's in-Canada dependent spouse and children are also eligible.⁸⁰

Where an individual is eligible for an RPD hearing, coverage under the IFHP begins immediately. Where an accepted refugee becomes eligible for provincial health insurance coverage, IFHP benefits extend to cover the "waiting period" that some provinces impose before a person can receive insured services. They will also cover some additional benefits such as emergency dental, vision, and prescription medication coverage if the provinces do not offer these services.⁸¹

ii. Temporary Residency Permits (TRPs)

Being issued a TRP on the basis that one is deemed a victim of trafficking in persons (VoT) also triggers eligibility for the IFHP. In these cases, additional benefits such as counselling and other specialized medical services are ex-

⁷⁷ Gagnon, *supra* note 9 at 360. Concerns have been expressed that not all officers are issuing these documents.

⁷⁸ *PPI*, *supra* note 72 at 16.14

⁷⁹ *Ibid.*, s 10.1.

⁸⁰ *Ibid.*

⁸¹ For asylum-seeking claimants, initially the period of time that the IFHP will run is 12 months but it may be less as determined by the interviewing officer. Claimants may apply to renew the IFHP coverage for additional 12-month periods where claims are still being processed. *Ibid.*

tended as they are considered “urgent and essential”.⁸² When CIC identifies a potential victim of trafficking, a TRP may be issued for up to 180 days as a “reflection period” and IFHP coverage will be limited to the length of the permit.⁸³ VoTs must renounce benefits once they qualify for provincial medical coverage.⁸⁴ Once the “reflection period” is over, victims of trafficking may apply for a longer-term residency permit that would allow them to regularize their status until they are eligible for permanent residency; however no IFHP coverage seems to attach to this permit. In practice, so few TRPs have been issued for victims of trafficking that their eligibility for long-term IFHP benefits has yet to become an issue of concern.⁸⁵

iii. Other Groups

CIC guidelines only provide explicit coverage under the IFHP for the groups noted above. However, this restriction has no particular basis in law and one could argue that IFHP coverage should extend to all immigrants and temporary migrants excluded from access to provincial health insurance programs. The 1957 Order-in-Council does not specify which groups are to receive benefits through this program – it specifies only that the Department of National Health and Welfare (now Health Canada) “be authorized to pay the costs of medical and dental care, hospitalization, and any expenses incidental thereto” for the following people:

- a) an immigrant, after being arrived at a port of entry and prior to his arrival at destination, or while receiving care and maintenance pending placement in employment, and
- b) a person who at any time is subject to Immigration jurisdiction or for whom the Immigration authorities feel responsible and who has been referred for examination and/or treatment by an authorized Immigration officer,
- c) in cases where the immigrant or such a person lacks the financial resources to pay these expenses, chargeable to funds

⁸² Citizenship and Immigration Canada, *IP01: Temporary Resident Permits*, online: CIC <www.cic.gc.ca/english/resources/manuals/ip/ip01-eng.pdf> at s 16.5 [CIC *IP01*].

⁸³ *Ibid.*

⁸⁴ *Ibid.*

⁸⁵ Robin Pike & Alison Clancey, “BC’s Office to Combat Trafficking in Persons” (2009) online: <socialwork.uvic.ca/docs/humantrafficking.ppt> at 20.

provided annually by Parliament for the Immigration Medical Services of the Department of National Health and Welfare.

Thus, the decision to cover asylum-seekers and not those seeking, for example, humanitarian and compassionate stays,⁸⁶ may be subject to challenge. In *Toussaint v Canada (AG)*,⁸⁷ Nell Toussaint applied for judicial review of the decision to exclude her from IFHP coverage on the basis of the arbitrariness of the decision. She did not have legal status in Canada, and had developed significant medical issues related to diabetes during her nine-year residency in the country. Given these medical issues, she could not work, and consequently became unable to pay for required medical services. In 2008, she was denied a number of medical services due to her inability to pay.⁸⁸ One hospital agreed to perform one of the necessary procedures but she was subsequently billed \$9,385, which she could not pay. That same year, Ms. Toussaint submitted an application for permanent residency in Canada based on humanitarian and compassionate considerations under section 25 of *IRPA*. She was unable to pay the required \$500 charge for the application and requested a waiver of the fee, which she was denied in 2009. In 2009, she was also denied coverage through the Ontario Health Insurance Plan (OHIP) and through the IFHP. She subsequently brought a claim before the Ontario Human Rights Commission regarding the OHIP denial, and sought judicial review of the decisions denying the waiver of the application fees and IFHP coverage.⁸⁹

In *Toussaint*, the applicant challenged the finding by CIC that she did not fit within the categories accepted for IFHP coverage and thus “cannot be approved.”⁹⁰ She was informed by letter that only “refugee claimants; resettled refugees; persons detained under the *Immigration and Refugee Protection Act (IRPA)*; and victims of Trafficking in Persons” were eligible for coverage under the IFHP and that she did not fall into any of those categories. She was also

⁸⁶ *IRPA*, *supra* note 42, s 25.

⁸⁷ 2010 FC 810, 323 DLR (4th) 338 [*Toussaint*].

⁸⁸ In June 2008 she was denied a surgery by the Women’s College Hospital to remove uterine fibroids which were causing her pain and in November 2008 she was denied tests for the cause of her kidney disorder by St. Michael’s Hospital (*Toussaint*, *ibid* at paras 7-8).

⁸⁹ The decision on IFHP coverage (*ibid*) addresses both administrative aspects of the denial of health care to certain migrant categories (dealt with here), and constitutional aspects of the right to health care more generally (dealt with in more detail in the constitutional section below). Toussaint’s Ontario human rights case, as it relates to equality provisions, will also be addressed in the constitutional section.

⁹⁰ *Toussaint v Canada (AG)*, 2010 FC 926 (Factum of the Applicant at para 81).

informed that she had no active immigration application.⁹¹ Since she had requested and had been denied a waiver of the fee for processing her humanitarian and compassionate application, there were no active files in process with CIC at the time.

Ms. Toussaint argued that the decision requiring her to fall within one of the categories was a mechanical application of the categories without reference to the wording of the Order-in-Council or her particular situation, that the categories unnecessarily fetter the discretion of CIC decision-makers and provide arbitrary boundaries, and that the decision was a misinterpretation of the federal authority to provide benefits under the law, particularly the 1957 Order-in-Council.⁹² With respect to the law, she argued that as an individual who has submitted several applications to CIC regarding her status, she qualified as someone “subject to immigration jurisdiction,”⁹³ under paragraph (b) of the Order-in-Council.

The Federal Court found that although relying solely on the categories put forward by CIC and not on the law was a reviewable error, if the decision-maker had considered the appropriate law, the result would still have been the same. Thus the error was immaterial.⁹⁴ With respect to Ms. Toussaint’s argument that she was “subject to immigration jurisdiction”, Justice Zinn found at paragraph 49 that

Persons temporarily under the jurisdiction of the Immigration authorities who are not immigrants would be those persons who are passing through a port of entry and thus subject to the jurisdiction of the Immigration authorities, those persons whose status in Canada is being processed by the Immigration authorities, and those persons under detention and in the custody of the Immigration authorities. Persons temporarily under the jurisdiction of the Immigration authorities would also include refugee claimants since refugee claimants are subject to a removal order that is unenforceable pending determination of their eligibility to make a claim, adjudication of that claim, and any subsequent application for judicial review of a negative decision by the Immigration and Refugee Board.

The Court found that she did not fall within any of those categories and that she did not meet the second part of the criteria in paragraph (b), which re-

⁹¹ *Toussaint*, *supra* note 87 at para 19.

⁹² *Ibid* at para 53.

⁹³ *Ibid* at para 29.

⁹⁴ *Ibid* at para 62.

quired that she be “referred for examination and/or treatment by an authorized Immigration officer.”⁹⁵ Given that Ms. Toussaint’s application for humanitarian and compassionate consideration was not in process, the Court found that she was in Canada of her own volition (unlike a refugee or a victim of trafficking), and was without any legal status. The Court dismissed the application for review, upholding the initial decision denying her coverage under the IFHP.⁹⁶

The Federal Court of Appeal upheld the trial court ruling, further clarifying the interpretation of the Order-in-Council.⁹⁷ Writing for a unanimous appellate bench, Justice Stratas noted that the appellant was not an immigrant as referred to in the Order since she was neither in transit from the port of entry to her destination nor receiving care “pending employment.”⁹⁸ He further refined the interpretation of “immigrant” to include only persons seeking permanent residency before or upon arrival in Canada.⁹⁹ Thus visitors staying illegally in the country, only attempting to regularize their status after several years, were not found to be the intended beneficiaries of the Program. The Court commented that such a close reading of the Order was warranted, given the Minister of National Health and Welfare’s rationale for it at that time.¹⁰⁰ Justice Stratas also

⁹⁵ *Ibid* at para 50.

⁹⁶ *Ibid* at para 62.

⁹⁷ *Toussaint v Canada (AG)*, 2011 FCA 213 [*Toussaint Appeal*].

⁹⁸ *Ibid* at para 35.

⁹⁹ *Ibid* at para 24.

¹⁰⁰ *Ibid* at para 27 the Minister is quoted stating:

THAT on occasion persons are referred for medical and hospital treatment during the time they are thought to be under the jurisdiction of the Immigration authorities but before it is possible to satisfactorily determine their status as immigrants ...and because of the urgent nature of the disabling condition, treatment cannot be prudently postponed until their exact status has been completely established.

THAT in other instances persons ... who are temporarily under the jurisdiction of the Immigration authorities become urgently in need of medical care or hospital treatment, and at the time it is not humanely possible to defer medical action until the determination of who, if any third party, is financially responsible for such action;

...

THAT both Departments undertake to administer this authority in such a way as to confine its use to those occasions only when circumstances render it the best course of action in the public interest, and only when humane interests more or less obligate the Departments to accept the responsibility

favoured a restrictive interpretation of the Order because there was no government-funded health insurance for even Canadian residents at the time.¹⁰¹

Ultimately the Court's approach is exemplified in paragraphs eight and nine of Justice Stratas comments early in the decision about public reaction to Ms. Toussaint's case:

If the Federal Court accepted the appellant's request, the curiosity of some might be piqued: even though the appellant has disregarded Canada's immigration laws for the better part of a decade, she would be able to take one of Canada's immigration laws (the Order in Council), get a court to include her by extending the scope of that law, and then benefit from that extension while remaining in Canada contrary to Canada's immigration laws.

But the Federal Court ... did not accept the appellant's request to extend the scope of the Order in Council. It rejected her submissions and dismissed the application for judicial review.

This final determination in *Toussaint* provides some clarity on the issue surrounding eligibility for the IFHP. Had Ms. Toussaint started her humanitarian and compassionate application prior to the dispensation of the case, a different outcome may have been warranted. However, this may be unlikely given the Court's commentary on the nature of the Order. There is still some question regarding the eligibility of those who have applications in progress, but who do not fit within the parameters of the current CIC categories.

However, eligibility for coverage may be only one hurdle for individuals to overcome when accessing insured health services through the IFHP. Studies show that accessing health care through the IFHP poses its own distinct problems and barriers. Anita Gagnon's study, *Responsiveness of the Canadian Health Care System Towards Newcomers*, undertaken in 2002, highlights some of the problems that newcomers face with respect to accessing services using the IFHP. These challenges include lack of willingness or knowledge on the part of health care providers on processing IFHP claims, difficulties in processing claims at the IFHP office, and an absence of dental care (although it is technically covered through the program).¹⁰²

¹⁰¹*Toussaint Appeal*, *supra* note 97 at para 44.

¹⁰²Gagnon, *supra* note 9 at 361. It is unclear whether service providers misunderstood that dental coverage was to be included under the IFHP or whether the issue was with the requirement that the service be related to only "serious" dental issues.

b. Provincial Health Insurance

We will now consider the situation in the three provinces studied. An overview of eligibility can be found in Tables 1, 2, and 3. The three provinces are similar in their coverage of individuals with various immigration statuses. However some differences in criteria do arise, and these divergences can negatively impact particular groups of migrants.

In Ontario (Table 1) public health insurance is legislated through the *Health Insurance Act*.¹⁰³ Regulations¹⁰⁴ under the *ON HIA* set out the procedure for becoming an "insured person" who is entitled to access health insurance through OHIP.¹⁰⁵ Individuals access coverage by being deemed a "resident" of Ontario, as defined in *ON Regulation* section 1.1(1). People designated as protected persons are considered residents and thus are eligible for coverage, but those still seeking asylum are not.¹⁰⁶ All TFWs with contracts of over six months are eligible, as are their spouses and dependents, as long as they are legally entitled to stay in Canada.¹⁰⁷ "Tourists, transients and visitors are not eligible for OHIP coverage,"¹⁰⁸ including those in Canada on tourist visas after a sponsorship relationship has broken down.

The provision of payment for medical services in Québec (Table 2) is regulated by the *Health Insurance Act*.¹⁰⁹ "Insured persons" are those who are residents or temporary residents of Québec and are duly registered with the *Régie de l'assurance maladie du Québec* (RAMQ).¹¹⁰ The majority of eligibility issues in Québec are dealt with by regulation.¹¹¹ "Residents" are identified in section 5 of the HIA as Canadian citizens, permanent residents, Indians registered under the *Indian Act*, persons with refugee status and other persons iden-

¹⁰³*Health Insurance Act*, RSO 1990, c H.6 [*ON HIA*].

¹⁰⁴*General Regulation, Health Insurance Act*, RRO 1990, Reg 552 [*ON Regulation*].

¹⁰⁵Ontario Ministry of Health and Long Term Care, *Ontario Health Insurance Plan*, online: <www.health.gov.on.ca/en/public/programs/ohip/>.

¹⁰⁶*ON Regulation*, *supra* note 104 s 1.4(4).

¹⁰⁷Ontario Ministry of Health and Long Term Care, *Ontario Health Insurance Plan, Questions and Answers*, online: <www.health.gov.on.ca/en/public/programs/ohip/ohipfaq_dt.aspx#4>.

¹⁰⁸*Ibid.*

¹⁰⁹*Health Insurance Act*, RSQ c A-29 [*QC HIA*].

¹¹⁰*Ibid.*, s 1(g.1).

¹¹¹*Regulation respecting eligibility and registration of persons in respect of the Régie de l'assurance maladie du Québec*, c A-29, r 0.01 [*QC Regulation*].

tified in regulations. “Temporary Residents” include foreign nationals who have been employed in Québec for 3 months and whose employment authorization entitles them to work for more than 6 months for a particular employer, SAWP employees, foreign students under official Québec scholarship programs, and any spouse or dependant who is entitled to stay in Canada with a temporary resident who is engaged to be in Canada for more than 6 months.¹¹²

Insurance for health services in New Brunswick (Table 3) is governed by the *Hospital Services Act* and the *Medical Services Payment Act*.¹¹³ To be entitled to insured hospital or physician services, individuals must establish “residency” in New Brunswick.¹¹⁴ In both the *MSPA* and *HSA Regulations* “resident” is defined as someone who is legally entitled to remain in Canada and who makes his home and is ordinarily present in New Brunswick, but does not include a tourist, transient or visitor.¹¹⁵ The term “ordinarily present” is not defined, nor does the New Brunswick legislation lists specific immigration statuses that are entitled to insured services. Instead, immigrants who, in the opinion of the minister or director, will become permanent residents and will establish residency in the province¹¹⁶ and “visitors ... who have obtained authorization to enter Canada for the purposes of engaging in employment”¹¹⁷ and their dependents will be entitled to receive insured services.¹¹⁸

Table 1: Eligibility for public health insurance in Ontario

Status	Eligibility	Waiting Period ¹¹⁹
Permanent Residents	Yes	3 months
Protected Persons		
Refugees	Yes	None
Refugee claimants	No (covered by IFHP)	-

¹¹²*Ibid*, s 3.

¹¹³*Hospital Services Act*, RSNB 1973, c H-9 [*HAS*]; *Medical Services Payment Act*, RSNB 1973, c M-7 [*MSPA*].

¹¹⁴*General Regulation - Hospital Services Act*, NB Reg 84-167, s 2 [*Gen Reg HSA*]; *General Regulation - Medical Services Payment Act*, NB Reg 84-20, s 3(2) [*Gen Reg MSPA*].

¹¹⁵*MSPA*, *supra* note 113 s 1; *Gen Reg HSA*, *ibid*.

¹¹⁶*Gen Reg MSPA*, *supra* note 114, s 4(5); *Gen Reg HSA*, *ibid*, s 6(1)(e)(i).

¹¹⁷*Gen Reg HSA*, *ibid*, s 6(1)(e)(iii); *Gen Reg MSPA*, *ibid*, s 2.

¹¹⁸*Gen Reg MSPA*, *ibid*; *Gen Reg HSA*, *ibid*, s 6(2).

¹¹⁹*ON Regulation*, *supra* note 104, ss 5-6.

Failed claimants, Awaiting PRRA, Moratorium	No (coverage for emergency services through IFHP)	-
Awaiting eligibility determination for hearing	No (potentially covered by IFHP if delay in hearing)	-
TFW		
Live in Caregivers	Yes	3 months (employers required to provide health insurance) ¹²⁰
Seasonal Agricultural Workers	Yes	3 months (employers required to provide health insurance) ¹²¹
PPORLLFT	Yes, if holding permit for 6 months or more	3 months (employers required to provide health insurance) ¹²²
General TFW	Yes, if holding permit for 6 months or more	3 months
Other Statuses		
Temporary Residency Permit Holders (Incl. VoT's)	Yes if inadmissible ¹²³ (VoT's covered by IFHP)	3 months
Tourists (incl. those awaiting sponsorship decisions or after sponsorship breakdown)	No	-
Undocumented	No	-

¹²⁰ Human Resources and Skills Development Canada, *Temporary Foreign Worker Program: Changes to the Live-in Caregiver Program*, online: HRSDC <www.hrsdc.gc.ca/eng/workplaceskills/foreign_workers/communications/lcpnewchanges.shtml>.

¹²¹ SAWP, *supra* note 56.

¹²² *Ibid*; Human Resources and Skills Development Canada, *Pilot Project for Occupations Requiring Lower Levels of Formal Training*, online: HRSDC <www.hrsdc.gc.ca/eng/workplaceskills/foreign_workers/lowskill.shtml>.

¹²³ *ON Regulation*, *supra* note 104, s 1.4(10) states that the term “resident” includes persons: “Having a valid “temporary resident permit” under the *Immigration and Refugee Protection Act* (Canada), if the permit is for a member of an “inadmissible class”, with a “case type” of 86, 87, 88, 89, 90, 91, 92, 93, 94 or 95”.

Table 2: Eligibility for public health insurance in Québec

Status	Eligibility	Waiting Period ¹²⁴
Permanent Residents	Yes	3 months
Protected Persons		
Refugees	Yes	None
Refugee claimants	No (covered by IFHP)	-
Failed claimants, Awaiting PRRA, Moratorium	No (coverage for emergency services through IFHP)	-
Awaiting eligibility determination for hearing	No (potentially covered by IFHP if delay in hearing)	-
Temporary Foreign Workers		
Live in Caregivers	Yes, if holding permit of 6 months or more	3 months (employers require private health insurance)
Seasonal Agricultural Workers	Yes	None
PPORLLFT	Yes, if holding permit of 6 months or more	3 months (employers required to provide health insurance)
General TFW	Yes, if holding permit of 6 months or more	3 months
Other Statuses		
Temporary Residency Permit Holders (Incl. VoT's)	No (potentially covered by IFHP)	-
Tourists (incl. those awaiting sponsorship decisions or after sponsorship breakdown)	No	-
Undocumented	No	-

Table 3: Eligibility for public health insurance in New Brunswick

Status	Eligibility	Waiting Period ¹²⁵
Permanent Residents	Yes	none

¹²⁴ *QC Regulation*, *supra* note 111, s 4.¹²⁵ *Gen Reg HSA*, *supra* note 107, s 4.1; *Gen Reg MSPA*, *supra* note 107, s 3(1).

Protected Persons		
Refugees	Yes	none
Refugee claimants	No (covered by IFHP)	none
Failed claimants, Awaiting PRRA, Moratorium	No (covered by IFHP)	none
Awaiting eligibility determination for hearing	No (potential coverage through IFHP if delay in hearing)	-
Temporary Foreign Workers		
Live in Caregivers	Yes	3 months (employers required to provide health insurance)
Seasonal Agricultural Workers	Yes	3 months (employers required to provide health insurance)
PPORLLFT	Yes	3 months (employers required to provide health insurance)
General TFW	Yes	3 months
Other Statuses		
Temporary Residency Permit Holders (Incl.VoT)	? (potential coverage through IFHP)	-
Tourists (incl. those awaiting sponsorship decisions or after sponsorship breakdown)	No	-
Undocumented	No	-

As outlined in the tables, permanent residents and refugees are eligible for coverage in all three provinces. In Ontario and Québec, permanent residents are subjected to a three-month waiting period before coverage starts. New Brunswick exempts immigrants from its waiting period requirement. Refugees in all three provinces are exempt from such delays once they have acquired refugee status. Neither Ontario nor Québec covers refugee claimants and the New Brunswick statute only covers individuals who “will establish residency” in New Brunswick. Hence the need for the IFHP, which is designed to cover individuals at this stage of the refugee determination process and to fill these gaps where provincial insurance does not apply.

With respect to TFWs, all three provinces provide coverage for workers, with some stipulations. In Ontario a worker does not need to be specifically attached to an employer in order to receive coverage, as long as an employer attests that the worker is under a contract of employment for at least 6 months. However, this does not apply to LCP workers or SAWP workers. In Québec to receive insurance coverage a TFW must have a permit that designates a specific employer for at least 6 months. Thus “open” work permits that do not specify an employer do not entitle an individual to coverage through RAMQ. LCP workers who complete the requirements of their program and apply for permanent residency¹²⁶ are provided with open work permits, as are the spouses of some TFWs and would thus be affected by this gap in coverage. New Brunswick does not stipulate a required length of contract in its eligibility provisions.

With the exception of SAWP workers in Québec, there is a three-month waiting period before coverage begins for TFWs in all three provinces.¹²⁷ In order to fill this gap, HRSDC requires that employers of low-skill TFWs, including SAWP workers and those on PPORLLFT, provide medical insurance for their employees until they are eligible for provincial insurance.¹²⁸ As of April 1st, 2010, employers of live-in caregivers are also required to provide such insurance.¹²⁹ Up until that date, caregivers were particularly vulnerable during these first few months. Private insurance may be purchased during this initial period for those subject to the waiting period but the cost may be prohibitive for many.

¹²⁶ In Ontario these individuals are also covered under the *ON Regulation*, *supra* note 104, s 1.4(5) through being found eligible to make Permanent Residency applications.

¹²⁷ The Québec government instituted the waiting period in order to harmonize its procedures with those of neighbouring Ontario and New Brunswick, and to deter “health tourism”, though little evidence has been brought that such tourism exists. Some essential services such as services related to pregnancy, emergency services for victims of violence or infectious disease control may be covered during this period, but in general persons are encouraged to purchase private insurance. See Jill Hanley, *Newcomers in Health Care Limbo – Québec Groups Protest*, Canadian Women’s Health Network, online: <www.cwhn.ca/en/node/39449>; Régie de l’assurance maladie du Québec, “Arriving in or returning to Québec”, online: RAMQ <www.ramq.gouv.qc.ca/en/citoyens/assurancemaladie/arriver/ext_can.shtml>; Oxman-Martinez et al, *supra* note 9.

¹²⁸ Human Resources and Skills Development Canada, “Occupations Requiring Lower Levels of Formal Training”, online: HRSDC <www.hrsdc.gc.ca/eng/workplaceskills/foreign_workers/ei_tfw/orllft_tfw.shtml>.

¹²⁹ HRSDC, *Changes to the Live-In Caregive Program*, *supra* note 120.

Tourists are not covered in any province and individuals with TRPs are covered only under specific circumstances.¹³⁰ Individuals waiting for determination of their in-Canada spousal application would be entitled to insurance coverage in Ontario¹³¹ but not in the other two provinces. Undocumented persons are in the most vulnerable position, having no coverage¹³² and being in the most precarious of immigration positions.

B. Obligation to Treat

As described above, some individuals with precarious immigration status are not entitled to health care insurance coverage through either the federal or provincial government schemes. The question then arises as to whether or not physicians are still required to treat these individuals, despite knowing that they may be unable to pay for services.

There is no overarching legal duty in Canada for physicians in clinics or hospitals to treat patients. However, physician codes of conduct and provisions in provincial legislation point to the existence of duties to treat some people under some circumstances. Additionally, a few court cases on issues of negligence have established some duty on physicians, in specific circumstances, to treat persons, even if they are indigent. This duty can be taken to provide some legal basis for requiring a hospital to treat those in need, including immigrants and undocumented persons who may not be otherwise covered for medical services.

1. Legislation

In the Ontario *Public Hospitals Act*,¹³³ section 21 states that “[n]othing in this Act requires any hospital to admit as an in-patient, (a) any person who is not a resident ... unless by refusal of admission life would thereby be endangered.” This provision suggests that such a duty exists,¹³⁴ but the obligation is

¹³⁰*ON Regulation*, *supra* note 104 s 1.4(10). In Québec, s 2 of the *HIA Regulation*, *supra* note 104, creates eligibility for insurance for individuals allocated CIC TRP “codes” 86 to 95 and who have a Québec selection certificate.

¹³¹*ON Regulation*, *ibid*, s 1.1(b)(5).

¹³²*ON Regulation*, *ibid*, s 1.4; *QC Regulation*, *supra* note 111, s 3(1); *MSPA*, *supra* note 113, s 1; *Gen Reg HSA*, *supra* note 114, s 2.

¹³³*Public Hospitals Act*, RSO 1990, c P-40.

¹³⁴Anne Walker, “The Legal Duty of Physicians and Hospitals to Provide Emergency Care” (2002) 166:4 *Can Med Assoc J* 465.

framed as a negative and thus it is unclear what remedies could be taken against a hospital that refuses treatment.

Several legislative provisions in Québec point to a physician's duty to treat a patient, particularly where the person is in life-threatening circumstances. In the Québec *Charter of Human Rights and Freedoms*, there is a civil duty "to rescue."¹³⁵ A person entering a health care facility with a life-threatening condition would be entitled to aid under Québec's *Health and Social Services Act*.¹³⁶ Québec's *Code of ethics of physicians* also obliges a physician to "come to the assistance of a patient and provide the best possible care when he has reason to believe that the patient presents with a condition that could entail serious consequences if immediate medical attention is not given."¹³⁷ Thus, there is a generally accepted understanding that physicians in Québec are under a legal obligation to treat patients with life threatening illnesses.¹³⁸ A failure to do so engages physicians' civil liability, and potentially that of the hospital¹³⁹ in addition to leaving them open to sanctions under their Code of ethics.

The New Brunswick *Hospital Act* states that a regional health authority cannot refuse to admit someone whose life would be endangered if they didn't receive services.¹⁴⁰ However, if the person's life is not endangered by the refusal, a person can be refused admission if "the hospital services required by the person are not entitled services" under the *NB HA*.¹⁴¹

¹³⁵ *Charter of Human Rights and Freedoms*, RSQ c C-12, s 2, provides that "[e]very person must come to the aid of anyone whose life is in peril, either personally or calling for aid, by giving him the necessary and immediate physical assistance, unless it involves danger to himself or a third person, or he has another valid reason."

¹³⁶ *An Act Respecting Health and Social Services*, RSQ c S-4.2 s 7 states that "[e]very person whose life or bodily integrity is endangered is entitled to receive the care required by his condition. Every institution shall, where requested, ensure that such care is provided."

¹³⁷ *Code of Ethics of Physicians*, RRQ 2011, c M-9, r 17, s 38.

¹³⁸ Walker, *supra* note 134 at 467. See also Pauline Lesage-Jarjoura & Suzanne Philips-Nootens, *Éléments de responsabilité civile médicale: Le droit dans le quotidien de la médecine*, 3d ed (Cowansville: YvonBlais, 2007) (the authors discuss Québec case law at 32).

¹³⁹ See Lesage-Jarjoura & Philips-Nootens, *ibid*.

¹⁴⁰ *Hospital Act*, SNB 1992, c H-6.1, s 20(1) [*NB HA*].

¹⁴¹ *Ibid*, s 20(3).

2. Public Health¹⁴²

In Québec, the *Public Health Act* mandates that any health or social services institution having the necessary resources must admit as an emergency patient anyone suffering or likely to be suffering from specifically listed diseases and requires physicians to treat the individual or direct them to another treatment facility.¹⁴³ Currently this list only includes tuberculosis.¹⁴⁴ It is thus clear that in Québec someone who is not covered by health insurance should receive medical care for tuberculosis, and in fact physicians are mandated to provide such treatment. Additionally, the physician who “suspects the presence of a threat to the health of the population”¹⁴⁵ must report it to the public health director. It is less clear with regard to those diseases whether a physician is additionally required to treat the individual with the suspected disease.

In Ontario under the *Health Protection and Promotion Act*¹⁴⁶ physicians are required to report if a patient suffers from an infectious disease listed in the regulations¹⁴⁷ and if a patient refuses to continue treatment of the disease.¹⁴⁸ In Ontario this duty to report only applies to patients who are already in the physician's care, whether inside or outside of a hospital, and does not clearly extend to persons who are not yet patients.

Legislation in New Brunswick is similar to that in Ontario in that a physician's duty is only to report the existence of communicable diseases.¹⁴⁹ It appears to be directed more at the protection of the public from persons who do not submit to treatment, and the underlying premise suggests that physicians and hospitals would treat such patients because of the potential danger to the

¹⁴²In this article we do not discuss inadmissibility to Canada based on health concerns, only access to treatment once someone is already present in the country. Serious equity issues that could be raised in this regard. See eg *Hilewitz v Canada (Minister of Citizenship & Immigration)*, 2005 SCC 57, [2005] 2 SCR 706.

¹⁴³*Public Health Act*, RSQ c S-2.2, ss 83-88.

¹⁴⁴*Minister's Regulation under the Public Health Act*, RRQ, c S-2.2, r 2, s 9 [*Minister's Regulation*].

¹⁴⁵*Public Health Act*, *supra* note 136, s 93. The list of diseases that qualify as “a threat to the health of the population” is set out in the *Minister's Regulation*, *ibid*, and changes regularly.

¹⁴⁶*Health Protection and Promotion Act*, RSO 1990, c H 7.

¹⁴⁷*Ibid* ss 25-26.

¹⁴⁸*Ibid* s 34.

¹⁴⁹*Public Health Act*, SNB 1998, c P-22.4, s 27.

public. However, it is unclear in all three provinces whether an uninsured person could demand treatment for communicable diseases on the basis of public health (other than tuberculosis in Québec).

3. Negligence

While there appear to be no mechanisms to enforce the statutory duty to treat life threatening illnesses or individuals who are a danger to public health, insofar as a statutory duty exists, non-compliance may render physicians or institutions liable under the tort of negligence. Given that the purpose of both the Ontario and Québec public health statutes is to prevent the spread of disease,¹⁵⁰ and considering the duty of physicians under the Canadian Medical Association's (CMA) *Code of Ethics* to "[c]onsider the well-being of society in matters affecting health,"¹⁵¹ a duty to treat patients could arise in tort. Additionally, because the statutes that mandate these duties are public health-oriented, doctors and institutions could be held liable not only for damage caused to the patient but also to the public at large for any infections that the patient passes on.

There is some common law interpretation of the physician's duty to treat as a branch of negligence, particularly in Ontario. Most frequently, negligence law applies to physicians and hospitals where physicians have misdiagnosed, mistreated or otherwise been derelict in their duties towards patients in their care. However, where a patient is not yet under the care of a specific physician or institution, some relationship must be established for a physician to have a duty to treat that person. A duty to a person would be owed if, in the reasonable contemplation of the physician, acts or omissions on his part would be likely to injure the person.¹⁵² The injury becomes "foreseeable" when the person is at a "particular risk" of being injured more than other members of the public.¹⁵³ In the law of negligence this relationship is termed "proximity."¹⁵⁴

One Canadian case states that a physician on duty in a hospital, who has knowledge that the patient may be suffering from a life-threatening condition,

¹⁵⁰*Supra* note 146, s 2; *supra* note 143 s 1.

¹⁵¹Canadian Medical Association, "Code of Ethics", online: CMA <policy-base.cma.ca/PolicyPDF/PD04-06.pdf> at s 4.

¹⁵²*Donoghue v Stevenson*, [1932] AC 562 HL (Eng).

¹⁵³*Home Office v Dorset Yacht Co Ltd*, [1970] AC 1004 HL (Eng); *Healey v Lak-eridge Health Corp*, 2010 ONSC 725, 72 CCLT (3d) 261.

¹⁵⁴See eg *Cooper v Hobart*, 2001 SCC 79, 206 DLR (4th) 193.

is required to treat the individual.¹⁵⁵ This case does not speak to issues where a patient cannot afford treatment, but does speak to a general duty of physicians to treat persons who are not their patients. Additionally, the issue of whether or not the relationship is “proximate” enough to warrant a duty to treat may be established by some external legislative or administrative duty. The CMA’s *Code of Ethics* requires physicians in Canada to “[p]rovide whatever appropriate assistance you can to any person with an urgent need for medical care.”¹⁵⁶ Case law seems to suggest that a person who seeks treatment in an emergency room for a life-threatening illness has a sufficiently proximate relationship to the institution to create a duty of care since representatives of that institution would know that the patient exists and that their failure to treat may prove fatal.¹⁵⁷

It thus seems that hospitals and physicians only become obligated to treat individuals with precarious immigration status who are ineligible for health insurance coverage where failure to do so could result in significant harm or death. In addition, even where an obligation to treat arises, the obligation does not prevent hospitals or physicians from subsequently charging and attempting to collect large sums of money to recoup the costs of services that were not insured. Nell Toussaint was charged over \$9,000 for a procedure that would otherwise have been covered through provincial health insurance and there have been reports of other precarious migrants facing similar bills.¹⁵⁸ These costs can far exceed the means of precarious migrants, placing a further burden on an already financially-distressed family.

C. Access to Health Care as a Constitutional Right

There are also constitutional considerations that arise in the context of access to health care. There have been a number of decisions heard under the *Canadian Charter of Rights and Freedoms*¹⁵⁹ discussing potential rights to health care access under both security (section 7)¹⁶⁰ and non-discrimination

¹⁵⁵*Egedebo v Windermere District Hospital Assn*, [1991] BCJ No 2381.

¹⁵⁶*Supra* note 151 at 18.

¹⁵⁷In Québec see Lesage-Jarjoura & Philips-Nootens, *supra* note 138 at 33; see by analogy Ruderman et al, “On pandemics and the duty to care: whose duty? Who cares?” (2006) 7:5 BMC Medical Ethics, online: doi 10.1186/1472-6939-7-5.

¹⁵⁸Kuile et al, *supra* note 6.

¹⁵⁹*Canadian Charter of Rights and Freedoms*, s 15, Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11 [*Charter*].

¹⁶⁰*Toussaint*, *supra* note 87; *Chaoulli*, *infra* note 164; *Gosselin*, *infra* note 163.

(section 15)¹⁶¹ provisions. In *Toussaint*, Ms. Toussaint argued that both of these protections were applicable to her case, in addition to arguing the administrative issue with respect to the order-in-council discussed above.¹⁶²

1. Section 7 – Life, Liberty and Security of the Person

With respect to the section 7 *Charter* right not to be deprived of life, liberty or security of the person, there has been significant debate on its applicability to health services. The main issue is whether or not section 7 protections can be triggered outside of the criminal sphere, or at least outside of cases in which the “administration of justice” comes into play.¹⁶³ In *Chaoulli v Québec*, although divided as to the result, the Supreme Court of Canada found that section 7 protections could apply to health care schemes under particular circumstances.¹⁶⁴ Mr. Chaoulli had argued that those on waiting lists for surgery in Québec were being deprived of their right to security of the person by not being able to purchase private health insurance. Justices McLachlin, Major, and Bastarache found that while there is no “freestanding constitutional right to health care,”¹⁶⁵ in this case “because patients may be denied timely health care for a condition that is clinically significant to their current and future health, s. 7 protection of security of the person is engaged. ... Where lack of timely health care can result in death, s. 7 protection of life itself is engaged.”¹⁶⁶

In *Toussaint* the applicant maintained that her situation violated her section 7 rights. She argued that her inability to afford private health insurance and the subsequent denial of access to the IFHP increased her possibility of life-threatening illness which, as stated in *Chaoulli*, may engage the protections of section 7 of the *Charter*. She argued that the decision to exclude her from coverage was not in accordance with the principles of fundamental justice because the finding of ineligibility was arbitrary. Justice Zinn noted that *Charter* protections apply to all persons physically present in Canada and because deportation proceedings had not been instigated against her, Ms. Toussaint was “physically present” and thus the *Charter* arguments had to be addressed.¹⁶⁷ He

¹⁶¹*Lavoie v Canada*, 2002 SCC 23, [2002] 1 SCR 769 [*Lavoie*].

¹⁶²*Toussaint*, *supra* note 87.

¹⁶³See *Gosselin v Québec (AG)*, 2002 SCC 84, [2002] 4 SCR 429.

¹⁶⁴*Chaoulli v Québec (AG)*, 2005 SCC 35, [2005] 1 SCR 79 [*Chaoulli*].

¹⁶⁵*Ibid* at para 104.

¹⁶⁶*Ibid* at para 123.

¹⁶⁷*Toussaint*, *supra* note 87 at para 87. It is useful to note that in *Covarrubias v Canada (Minister of Citizenship & Immigration)*, 2006 FCA 365 the applicant argued

agreed that, relying on *Chaoulli*, since Ms. Toussaint was excluded from coverage under the IFHP she faced life-threatening risks due to government action and thus section 7 was engaged.¹⁶⁸

However, the Court also found that the exclusion of illegal migrants from the IFHP was not arbitrary. Justice Zinn noted that Ms. Toussaint chose her illegal status by staying in the country and that the purpose of the IFHP as documented by ministerial letters and memoranda was to provide health care to "legal migrants." Where the IFHP covers illegal migrants there is a principled reason for doing so, for example in cases of trafficking, because those individuals are in Canada through "deceit and manipulation."¹⁶⁹ Ms. Toussaint was faced with neither of those circumstances and was in Canada of her own volition, hence the decision to exclude her from an existing program was not arbitrary. The violation of section 7 was thus saved by section 1 of the *Charter* as the activity conformed to the principles of fundamental justice.

On appeal,¹⁷⁰ the Federal Court of Appeal agreed with Zinn, J.'s determination of the case, confirming based on several recent cases¹⁷¹ that the *Charter* does not confer a freestanding constitutional right to health care. Quoting Justice Linden from *Covarrubias v Canada (Minister of Citizenship and Immigration)*, Justice Stratas framed the appellant's argument as "seeking to expand the law so as to create a new human right to a minimum level of health care" and stated that "The law in Canada has not extended that far."¹⁷² However, the Court also dispensed with Ms. Toussaint's argument on the basis that the IFHP is not the primary provider of health insurance, and thus was not the "operative

in a PRRA application that he faced a risk to his life if he was deported to his home country where he would not be able to receive sufficient health coverage for end-stage renal failure. The court was clear in finding that lack of health care in one's home country is not sufficient to engage international protections unless the individual is being denied health care for persecutory reasons. The court did not address the s 7 *Charter* arguments in that case, although they were raised.

¹⁶⁸ *Toussaint*, *ibid* at para 91.

¹⁶⁹ *Ibid* at para 93.

¹⁷⁰ *Toussaint Appeal*, *supra* note 97.

¹⁷¹ *Toussaint Appeal*, *ibid* at para 78 the Court specifically referred to *Auton (Guardian ad litem of) v British Columbia (AG)*, 2004 SCC 78, [2004] 3 SCR 657; *Ali v Canada*, 2008 FCA 190, 173 CRR (2d) 123; *Wynberg v Ontario* (2006), 82 OR (3d) 561 (CA); *Eliopoulos v Ontario* (2006), 82 OR (3d) 321 (CA); *Flora v Ontario Health Insurance Plan*, 2008 ONCA 538, 91 OR (3d) 412.

¹⁷² *Toussaint Appeal*, *ibid* at para 79.

cause of the injury to her life and security of the person.”¹⁷³ The Court found that if there were an operative cause, it lay in the fact that the provincial law did not go far enough to address Ms. Toussaint’s medical needs.¹⁷⁴ The Court also found that even were a section 7 violation to have occurred, the provision of services only to legal migrants is not arbitrary and is in accordance with the principle of fundamental justice.¹⁷⁵

However, this ruling left open arguments relating to the operation of health insurance schemes distinguishing between different legal migration statuses.

2. Section 15 – Equality

With respect to section 15 of the *Charter*, Chief Justice McLachlin noted in *Chaoulli* that “where the government puts in place a scheme to provide health care, that scheme must comply with the *Charter*.”¹⁷⁶ Additionally, in *Lavoie* the Court stated that:

[I]t is settled law that non-citizens suffer from political marginalization, stereotyping, and historical disadvantage. Indeed, the claimant in *Andrews*, who was himself a trained member of the legal profession, was held to be part of a class “lacking in political power and as such vulnerable to having their interests overlooked and their rights to equal concern and respect violated.”¹⁷⁷

In *Lavoie*, the preference for citizens over non-citizens for work in the federal public service was found to be a breach of the equality provisions of section 15, but was ultimately found to be justified as a means of promoting the unifying bond of citizenship.

In her case before the Federal Court, Ms. Toussaint argued that given the existence of the IFHP scheme, her exclusion based on citizenship was discriminatory and affected her disproportionately based on her disability. Justice Zinn found that the IFHP was an established program that was required to be administered in a non-discriminatory fashion in accordance with the *Charter*. However, he found that her disability was not the reason for the exclusion. He also noted that the denial was not based on citizenship, given that several non-citizens participate in the IFHP. Thus he dismissed her argument.

¹⁷³ *Ibid* at para 67.

¹⁷⁴ *Ibid* at para 70.

¹⁷⁵ *Ibid* at para 82.

¹⁷⁶ *Chaoulli*, *supra* note 164 at para 104.

¹⁷⁷ *Lavoie*, *supra* note 161 at para 45.

However, interestingly, Justice Zinn notes in a footnote to the case that:

The Supreme Court's decision in *Corbiere v. Canada (Minister of Indian & Northern Affairs)*, [1999] 2 S.C.R. 203 (S.C.C.) leaves open the possibility that "immigration status" may be considered an analogous ground in the future. In *Corbiere*, at para. 60, the Court recognized that in analyzing whether a characteristic is an analogous ground "[i]t is also central to the analysis if those defined by the characteristic are lacking in political power, disadvantaged, or vulnerable to becoming disadvantaged or having their interests overlooked." It may be fair to say that illegal migrants lack political power, are frequently disadvantaged, and are incredibly vulnerable to abuse; this, combined with the difficulty of changing one's illegal migrant status, might support an argument that such a characteristic is an analogous ground.¹⁷⁸

On appeal, Ms. Toussaint argued that the denial was based on the intersecting grounds of immigration status (as an analogous ground to citizenship) and disability, stating that undocumented persons with disabilities suffer disproportionately because of the application of the Order-in-Council.¹⁷⁹ However, Justice Stratas, focusing on alternative sections of the *Corbiere* judgement, found that immigration status was not an analogous ground given that it is not an immutable characteristic "changeable only at unacceptable cost to personal identity."¹⁸⁰ With respect to the category of undocumented persons specifically, the Court noted that "the government has a real, valid and justified interest in expecting those present in Canada to have a legal right to be in Canada."¹⁸¹ This finding under section 15 ostensibly closes the door to further equality arguments based on immigration status of all kinds.

While Ms. Toussaint did not seek to challenge the OHIP's failure to provide her with insured services on the basis of a section 15 Charter violation (as potentially suggested by the FCA), she did file a claim with the Ontario Human Rights Tribunal alleging that the denial of OHIP coverage constituted discrimination on the basis of citizenship, in contravention of the *Ontario Human Rights Code*.¹⁸² In this case Ms Toussaint argued specifically that "the ground

¹⁷⁸*Toussaint, supra* note 87 at para 82 n 3.

¹⁷⁹*Toussaint Appeal, supra* note 97 at para 98.

¹⁸⁰*Ibid* at para 99.

¹⁸¹*Ibid* at para 99.

¹⁸²*Toussaint v Ontario (Minisgter of Health and Long Term Care)*, 2010 HRT0 2102.

of citizenship includes discrimination between any subcategories of non-citizens, including between non-citizens with legal status in Canada and those without.”¹⁸³ However, the Tribunal found that the distinction in the OHIP between various non-citizens was valid, interpreting the *Ontario Human Rights Code* as only requiring similar treatment of citizens and permanent residents:

This reflects the principle of permitting preferences for Canadian citizens but recognizing that some non-citizens have a particular attachment to the country. It does not suggest, however, that the government must include all groups of non-citizens in a legal preference once it includes some.¹⁸⁴

D. International Considerations and Future Directions

In *Toussaint*, Justice Zinn was clear in his reasoning that he finds no international legal right to migration,¹⁸⁵ and that although there may be an international right to health, this does not equate to a right to subsidized healthcare or specific health services,¹⁸⁶ nor is it clear whether or not this right places a positive obligation on states to provide health services to those illegally on its territory.¹⁸⁷ Most importantly, he noted that these various international rights have not been explicitly incorporated into domestic legislation and thus are not Canadian law.¹⁸⁸ On appeal, Justice Stratas’ agreement with the Federal Court’s finding further solidified the premise that there is no fundamental right to subsidized health care, particularly with respect to undocumented persons. The Federal Court in *Covarrubias v Canada* also found that a lack of health care in one’s home country, even if it could result in death, does not bring about an obligation on Canada to halt deportation and to continue to provide health services.¹⁸⁹ However, as noted in *Baker v Canada* and *Suresh v Canada* these

¹⁸³*Ibid* at para 4.

¹⁸⁴*Ibid* at para 19.

¹⁸⁵*Toussaint*, *supra* note 87 at para 88.

¹⁸⁶*Ibid* at para 67.

¹⁸⁷*Ibid* at para 67.

¹⁸⁸*Ibid* at para 63.

¹⁸⁹*Covarrubias v Canada (Minister of Citizenship & Immigration)*, 2006 FCA 365, [2007] 3 FCR 169.

rights can be used to inform the meaning of provisions of the Canadian Constitution as evidence of principles of fundamental justice.¹⁹⁰

While The Federal Court of Appeal stated that requiring legal residency as a precursor to health services is in accordance with principles of fundamental justice,¹⁹¹ the door remains open to extending IFHP benefits to all persons legally on Canadian territory who are seeking permanent residency. There is also a possibility, given Justice Stratas' comments regarding section 7 rights to health care, that *Charter* challenges could be made to provincial health insurance systems for exclusion on the basis of legal immigration status.

Clarification is sorely needed through regulation to make the purpose and scope of the various provincial and federal programs evident. Program officials should ensure that service providers are aware of program components, including coverage and billing issues. Clarification is also needed with regard to the payment of fees for emergency health care administered to indigent precarious migrants without health insurance, since individuals are currently being charged fees after-the-fact. There are currently sufficient disagreements about the role of both provincial health insurance schemes and the IFHP to warrant some reform.

V. Part Two – Workers' Compensation

A. Overview of Workers' Compensation Systems

Workers' compensation systems provide compensation and health coverage for those who are injured at work or who contract an occupational disease. Workers are generally entitled to compensation regardless of fault. Employers pay premiums to the workers' compensation boards in their province and in return workers who are covered under the acts are entitled to compensation, but give up the right to sue employers directly.¹⁹² Benefits and means of accessing benefits vary between provinces but are generally linked to the worker's previous income, as well as the type and seriousness of the injury. Premiums employers pay to the boards to finance the workers' compensation scheme are of-

¹⁹⁰*Baker v Canada (Minister of Citizenship & Immigration)*, [1999] 2 SCR 817 at para 70, 174 DLR (4th) 193; *Suresh v Canada (Minister of Citizenship & Immigration)*, 2002 SCC 1 at para 60, 208 DLR (4th) 1.

¹⁹¹See 244, below.

¹⁹²See generally Ison, *supra* note 28; Cliche & Gravel, *supra* note 28.

ten linked to the industry's level of risk and the costs of benefits paid out over previous years to employees of the specific employer.¹⁹³

Benefits provided to injured workers may include the provision of health care, wage replacement when someone is unable to work during work disability, access to rehabilitation services if the worker is unable to return to pre-injury employment and compensation for permanent disability. Thus, in addition to providing potential income benefits, workers' compensation schemes may provide an alternative route to health care coverage, even for individuals not entitled to provincial health insurance benefits. In these circumstances, access to health care is facilitated directly through the compensation boards, rather than being paid for by provincial health insurance.

Workers' compensation schemes have covered the cost of health care for injured workers since the early twentieth century, long before the introduction of universal health insurance coverage.¹⁹⁴ There is now concern that some workers' compensation insurers in Canada are actually promoting an increased use of private health care services as a by-pass around the administration of provincial coverage.¹⁹⁵ Hurley and colleagues report that workers covered by Workers' Compensation have been fast-tracked to medical services, sometimes outside Canada, in order to receive quicker treatment, thus reducing the time necessary for them to return to work and thereby reducing the costs of benefits paid. Alberta has adopted this strategy by having recourse to private medical services,¹⁹⁶ but it is less clear to what extent such practices are in place in the jurisdictions studied here.¹⁹⁷ Nonetheless, these developments un-

¹⁹³ *JurisClasseur Québec: Droit du travail*, "Principes de financement", fasc 22, by Line Réginer & Pierre-Michel Lajeunesse.

¹⁹⁴ Lippel, *supra* note 25.

¹⁹⁵ Hurley et al, *supra* note 27.

¹⁹⁶ Bhimji, *supra* note 28.

¹⁹⁷ In Ontario and New Brunswick, Hurley provides illustrations of fast-tracking strategies that include services provided in Board-run rehabilitation centres. For Québec, the recent Camiré report makes recommendations for improving access of workers' compensation claimants in Québec to operating theatres in public hospitals by increasing the financing made available by the CSST to the hospitals for the care of injured workers, and by ensuring that the payments be made outside the current hospital budgets so as to avoid creating competition between CSST patients and those whose costs are covered by the public health system. Groupe de travail chargé de faire des recommandations concernant le régime québécois de santé et de sécurité du travail, *Rapport du président du groupe de travail* (Québec City: CSST, 2010).

derline that understanding coverage under workers' compensation is important in the analysis of access to health care in Canada.

In each case, workers' compensation decision-makers determine eligibility for benefits by asking first: whether the individual who was injured qualifies as a "worker" under the specific legislation; second whether or not the injury arose "out of" and/or "in the course of" employment; and third whether the injury is of the type that is considered to be compensable under the legislation. This article focuses on the first question.

B. Who is a Worker?

While immigration status is not explicitly mentioned in the legislative definitions of "worker" in the three provinces, the answer to this question may depend on specific legislative provisions that include or exclude individuals who are undertaking certain types of employment from the scope of the legislation. For example, in New Brunswick and Québec, domestic workers are excluded from coverage,¹⁹⁸ and thus individuals who are in Canada on the "Live-in Caregiver" visa working in those jurisdictions would not be eligible for workers' compensation.¹⁹⁹ Where the legislation is silent, in some cases policies created by the provincial workers' compensation boards outline different

¹⁹⁸ In New Brunswick: *Workers' Compensation Act*, SNB c W-13, s 2(3)(d) [*WCA*]; in Québec: *IAOD*, *infra* note 244, s 2.

¹⁹⁹ The Québec Commission des droits de la personne et des droits de la jeunesse ruled that the Québec exclusion violated article 10 of Québec's *Charter of Human Rights and Freedoms* and consequentially recommended that it should be repealed. See Commission des droits de la personne et des droits de la jeunesse, *La Conformité de l'exclusion du domestique et du gardien de la protection automatique de la Loi sur les Accidents du Travail et les Maladies Professionnelles à la Charte des Droits et Libertés de la Personne*, COM-540-5.1 (9 décembre 2008). The Québec Government tabled legislation, in first reading, in 2010 to address this issue: Bill 110, *An Act to amend the occupational health and safety plan to grant greater protection to certain domestics*, 1st Sess, 39th Leg, Québec, 2010, cls 1-3, 11; the bill has since been withdrawn following a critique by the Commission des droits de la personne et des droits de la jeunesse that the bill in fact perpetuated discrimination by excluding domestic workers who worked fewer than 24 hours a week and by providing fewer rights to domestic workers in the case of reprisals. Tommy Chouinard, "Aides domestiques: Québec retourne à la planche à dessin", *La Presse* (5 November 2010), online: Cyberpresse <www.cyberpresse.ca/actualites/Québec-canada/politiqueQuébécoise/201011/05/01-4339559-aides-domestiques-Québec-retourne-a-la-planche-a-dessin.php>.

types of work or immigration statuses that affect an individual's eligibility for compensation through the schemes.

Lastly, where legislation and policy are both silent on the issue, decisions of the workers' compensation tribunals shed light on who is considered "a worker" on the basis of immigration status. With respect to those with precarious immigration status, our research indicates that, for the most part, coverage is not related to status, with some exceptions. However, individuals who are undocumented are at risk of not being covered under some schemes, and live-in caregivers may also be denied coverage because of the work they do.

1. Legislation in Ontario, Québec and New Brunswick

a. Ontario

Ontario's *Workplace Safety and Insurance Act, 1997*²⁰⁰ governs the workers' compensation scheme in the province. Only certain employers are required to participate; those not listed in the relevant legislation or policies are not covered.²⁰¹ According to the Association of Workers' Compensation Boards of Canada, only 72% of the Ontario workforce is covered under this scheme.²⁰²

Under the *WSIA*, a worker is defined as "a person who has entered into or is employed under a contract of service or apprenticeship"²⁰³ and works for listed employers.²⁰⁴ However, the legislation specifically excludes workers who are "of a casual nature and who are employed otherwise than for the purposes of the employer's industry,"²⁰⁵ and "outworkers,"²⁰⁶ defined as "persons to whom articles or materials are given out to be made up, cleaned, washed, altered, ornamented, finished, repaired or adapted for sale in the person's own home or on other premises not under the control or management of the person

²⁰⁰*Workplace Safety and Insurance Act, 1997*, SO 1997, c 16 [*WSIA*].

²⁰¹*General*, O Reg 175/98, s 3-5.

²⁰²Association of Workers' Compensation Boards of Canada, *Scope of Coverage, Industries/Occupations*, online: AWCBC <www.awcbc.org/common/assets/assessment/industries_occupations_covered.pdf>.

²⁰³*WSIA*, *supra* note 200, s 2(1). See generally, Judy Fudge, Eric Tucker & Leah Vosko, *The Legal Concept of Employment: Marginalizing Workers* (Ottawa: Law Commission of Canada, 2002).

²⁰⁴*WSIA*, *ibid*, s 11(1).

²⁰⁵*Ibid*, s 11(1)(a).

²⁰⁶*Ibid*, s 11(1)(b).

who gave out the articles or materials.”²⁰⁷ Some of these considerations may differentially impact persons with precarious immigration statuses, as marginalised workers are disproportionately employed as casual labour or in the informal labour market.²⁰⁸ The *Dean Report* addresses some of these issues, including within the concept of vulnerable workers in need of protection those working through labour brokers or temporary employment agencies, and the undocumented.²⁰⁹

i. Individuals with legal immigration statuses/work authorizations

There is nothing specific in the legislation or policy of the Workers' Safety and Insurance Board (WSIB) indicating whether or not refugee claimants would be covered as “workers” under the *WSIA*. Under prescribed circumstances²¹⁰ they are eligible for “open” work permits and there is no reason to believe that a documented worker would be denied eligibility for compensation for a workplace injury. In at least one case adjudicated by the Workers' Compensation Appeal Tribunal a refugee claimant was awarded compensation for a workplace injury.²¹¹

There is also nothing explicit in policy or legislation regarding eligibility of persons employed under a general TFW permit. Furthermore, given the policy on residency of workers,²¹² there is nothing to suggest that a worker author-

²⁰⁷*Ibid.* This topic has been extensively covered in Bernstein, Lippel & Lamarche, *supra* note 30, and does not directly relate to the issue of coverage of different types of precarious migrants under *WSIA*.

²⁰⁸Rachel Cox & Katherine Lippel, “Falling Through the Legal Cracks: The Pitfalls of Using Workers' Compensation Data as Indicators of Work-related Injuries and Illnesses” (2008) 6:2 *Policy and Practice in Health and Safety* 9.

²⁰⁹ Expert Advisory Panel on Occupational Health and Safety, *Report and Recommendations to the Minister of Labour* (Toronto: Ontario Ministry of Labour, 2010) [*Dean Report*]. See our discussion, *infra* note 242.

²¹⁰Citizenship and Immigration, *FWI Foreign Worker Manual*, online: CIC <www.cic.gc.ca/english/resources/manuals/fw/fw01-eng.pdf> at 71.

²¹¹ *Decision No 332/95* (20 September 1996), online: WSIAT <www.wsiat.on.ca>.

²¹² Ontario Workplace Safety Insurance Board, *Policy 12-04-12: Non-resident Workers*, online: WSIB <www.wsib.on.ca/wsib/wopm.nsf/Public/120412>.

ized to work for an employer would be excluded if he has established a substantial working connection to Ontario.²¹³

WSIB *Policy 12-04-08: Foreign Agricultural Workers*²¹⁴ is clear that SAWP workers have coverage under WSIA, and they would not be excluded as casuals by the very nature of their status which, as we have seen, presupposes non-casual employment for the duration of the visa.²¹⁵ The Policy states that:

Coverage begins as soon as workers reach the agreed-upon point of departure in their homeland, and remains in place until they return to their country. While travelling in Ontario, these workers are covered when in transit from an airport in Ontario to the employer's premises and/or using a means of transportation authorized by the employer, and following a direct and uninterrupted route to or from the employer's premises.

In addition to coverage while in the course of employment, workers are also covered during periods of leisure, meals, and while sleeping in employer-provided quarters.

Neither the legislation nor policy²¹⁶ indicates whether those working under the LCP are eligible for compensation and no cases reported by WSIAT specifically refer to foreign caregivers. However, generally individuals working full time as domestic workers are covered, and given the constraints of the LCP program, all participating individuals are considered to be working full time.

Tourists, including individuals waiting for previously submitted sponsorship applications, are not eligible to work in Canada without further authoriza-

²¹³See for example *Decision No 645/95* (20 September 1995), online: WSIAT <www.wsiat.on.ca>; *Decision No 612/92* (23 October 1992), online: WSIAT <www.wsiat.on.ca>.

²¹⁴Ontario Workplace Safety Insurance Board, *Policy 12-04-08: Foreign Agricultural Workers*, online: WSIB <www.wsib.on.ca/en/community/WSIB/230/OPMDetail/24347?vgnextoid=d1d3fcea9bfc7210VgnVCM100000449c710aRCRD>

²¹⁵SAWP, *supra* note 56.

²¹⁶Ontario Workplace Safety Insurance Board, *Policy 12-04-14: Domestic Workers*, online: Workers Safety Insurance Board <www.wsib.on.ca/en/community/WSIB/230/OPMDetail/24347?vgnextoid=d3f3fcea9bfc7210VgnVCM100000449c710aRCRD>.

tion.²¹⁷ Thus, unless a tourist obtains work authorization by changing status, she would be considered undocumented.

ii. Undocumented Workers

Interviews collected previously through Bernstein, Lippel, and Lamarche's 2001 study of women and home work indicated that the Ontario WSIB would likely cover undocumented workers using the same criteria applicable to individuals legally entitled to work in Canada.²¹⁸ However, there is no specific legal or policy basis for this position.²¹⁹ The issue has yet to be fully adjudicated through the WSIAT but there are several legal considerations which, taken together, indicate that it is likely that they would be covered.

First, in several cases compensation has been awarded to individuals who, although currently in possession of work permits or residency status, were considered to be working "illegally" at the time of the injury. In *Decision No. 1895/04*, the worker was involved in several accidents subsequent to the initial injury, but some of the entitlement was based upon the original injury, incurred when he did not have legal status to work in Canada.²²⁰ *Decision No. 665/00* awarded benefits to a worker who sustained a fall while working without a valid permit. He had not filed the claim until several months after the accident, due to both his lack of a work permit and the employer's conduct, and was thus awarded benefits for only part of the time he was disabled, but the benefit was based on an accident occurring during a period in which the worker did not have authorization to be working for that employer.²²¹

Three Ontario decisions address the issue of undocumented workers' access to compensation (or their right to sue the employer) but were settled without having to adjudicate the point.²²² The most recent case on the issue, *Deci-*

²¹⁷*IRPA*, *supra* note 42, s 30.

²¹⁸Bernstein, Lippel & Lamarche, *supra* note 30 at note 116.

²¹⁹It is interesting to note that the *WSIA* explicitly includes coverage for minor workers who have been employed illegally, while sanctioning the employer who has violated rules regarding age requirements: *WSIA*, *supra* note 188, s 73; no other provision has been enacted with regard to other types of "illegalities".

²²⁰*Decision No 1895/04* (20 December 2004), at paras 11 and 65, online: WSIAT <www.wsiat.on.ca>.

²²¹*Decision No 665/00* (17 March 2000), online: WSIAT <www.wsiat.on.ca>.

²²²*Decision No 1648/05I* (3 October 2005), online: WSIAT <www.wsiat.on.ca> was adjourned to allow further submissions on the status of an undocumented worker

sion 1921/06, was decided on other grounds, but made some direct reference to the question of status under WSIA:

These reasons record Mr. Wolf's interesting argument that Boat-eng's status as an "illegal" immigrant disqualified him to occupy the status of "worker" under the Act, so that his survivors would be able to maintain their action in the courts. While this position has been raised in other Tribunal cases (see, for example, Tribunal *Decisions No. 42/06I* and *1648/05I*), it has not been adjudicated in terms which would assist this Panel and, as candidly noted by Mr. Wolf during his submissions, he was unable to find any authorities in support of this argument. In fact, the first of those earlier appeals was adjourned to obtain submissions on the "illegal" status argument, and the second to await the result of that earlier decision, but we are advised that both of those appeals were resolved without having to adjudicate on the position raised by Mr. Wolf in this application.²²³

The panel refers to this argument as "interesting," indicating that it is not an obvious assumption that an undocumented worker would automatically be excluded from coverage. A finding that an individual is a "worker" for purposes of the *WSIA* nullifies their right to sue in civil court, so that recognition of coverage in a given case is not necessarily a favourable outcome for the worker or his estate. In *Decision No 1921/06*, a family actually raised the issue of immigration status, seeking to exempt itself from the application of the *WSIA*, in order to maintain its right to sue in court.²²⁴

Second, policy and case law on residency seem to favour the possibility of finding undocumented individuals to be "workers" under the *WSIA*. *Policy 12-04-12: Non-Resident Workers* states that a "non-resident" worker must have a "substantial connection with Ontario in order to come within the scope of the Act."²²⁵ A person's residency status is not discussed. Several cases have been

under WSIA but the case was settled without further adjudication. *Decision No 42/06* (14 August 2006), online: WSIAT <www.wsiat.on.ca> did not adjudicate on the issue pending the outcome of *Decision No 1648/05I*.

²²³*Decision No 1921/06* (4 March 2008) at para 93, online: WSIAT <www.wsiat.on.ca>.

²²⁴[2008] OWSIATD No 644 (QL). The WSIAT subsequently confirmed the worker status of the undocumented deceased workers and the corollary prohibition of law suits brought by their dependants in *Decision No 1921/06R* (19 June 2009), online: WSIAT <www.wsiat.on.ca>.

²²⁵Ontario Workplace Safety Insurance Board, *Policy 12-04-12: Non-Resident Workers*, online: Workers Safety Insurance Board

adjudicated involving US citizens who were required to travel into Canada to work and the injuries occurred while they were in Canada.²²⁶ Panels indicated that where individuals had more than a transitory presence²²⁷ in Ontario and participated in the commercial interests of Ontario,²²⁸ they were to be considered workers. Citizenship or immigration status did not factor into the judgments.

Thirdly, although *Policy 12-01-01: Workers and Independent Operators*, does not refer to the validity of any employment contract as being a factor in determining “worker” status, case law supports a finding that the invalidity of a contract does not necessarily speak to the individual’s status as “worker” under the legislation. In *Decision 256-90*, an injured party claimed that because the worker who caused the accident was acting recklessly he negated the contract of employment and was thus not to be considered a worker for purposes of the *WSIA*.²²⁹ This would allow the injured person to sue the driver through civil litigation rather than being bound by the Workers’ Compensation System. The tribunal found:

The cases referred to by Mr. Schneiderman on this point support the proposition that a person who fulfills a contract for service by illegal means is not entitled to the protection of the contract. The definition of “worker” speaks of a contract of service and speaks of a contract “written or oral, express or implied.” It seems clear that the definition of worker is intended by the Legislature to have a very broad meaning, and certainly, with respect, much broader than Mr. Schneiderman proposes. [emphasis added]

Thus it could be argued that if a person who is not entitled to work in Canada is injured, the fact that their contract may be unenforceable on the basis of illegality may not bear on their status as “worker” under the legislation. In another case, the fact that the worker was working illegally using false papers did not prevent his estate from being compensated after a fatal accident, and the con-

<www.wsib.on.ca/en/community/WSIB/230/OPMDetail/24347?vnextoid=d2e3fcea9bfc7210VgnVCM100000449c710aRCRD>

²²⁶See eg *Decision No 645/95*, *supra* note 201; *Decision No 612/92*, *supra* note 201.

²²⁷*British Airways v British Columbia (Workers’ Compensation Board)* (1985), 17 DLR (4th) 36, 13 Admin LR 78 (BCCA).

²²⁸*Decision No 645/95*, *supra* note 201 at 7.

²²⁹[1991] OWCATD No 378 (QL).

text of the appeal suggests that compensability problems because of his status were not even at issue.²³⁰

It is also worth noting that the WSIB has, in at least one case, fully covered medical bills for an individual who was ineligible for provincial health insurance because he was not a “landed immigrant.”²³¹ It was not clear whether this individual was actually undocumented, or was for other reasons unable to receive benefits through the OHIP, but it remains that the coverage was provided where the lack of insurance was based on immigration status.

However, even if it were taken that undocumented workers were technically eligible for workers’ compensation benefits, there are still several barriers to these workers actually accessing those benefits. In *Decision 665/00* non-emergency procedures had to be delayed due to the individual’s lack of medical insurance, prior to the filing of his workers’ compensation claim,²³² and, since lack of treatment may exacerbate conditions, failure to treat symptoms early in the life of the injury could have significant consequences with regard to the amounts and benefits subsequently awarded to the worker.²³³ In Ontario, workers’ lack of work permits has also been used as evidence to reduce the duration of benefits because they were not able to seek work to mitigate the amount of benefits to be paid. In *Decision 1637/07*²³⁴ the worker had not returned to work since an accident in 1991 and the panel stated:

The worker was not particularly forthcoming, during his testimony at the hearing, on the question of when his Canadian work permit expired, however he did eventually testify that he has not had a work permit for 7 to 8 years, since approximately 1999 or 2000. I find that the fact that the worker has not had a work permit for several years is very likely a significant reason that the worker has not worked for the past several years, since it would not be possible for him to work legally without a work permit. I am not prepared to conclude that the predominant rea-

²³⁰*Decision No 519/91*, [1991] OWCATD No 1038 (QL).

²³¹*Decision No 1131/99*, [1999] OWSIATD No 2839 at para 44.

²³²*Supra* note 221 (“Being without medical coverage, the medical staff at the Sunnybrook Health Science Centre, where the worker was treated, saw the need in the early part of 1997, to defer to a later date all medical treatment including the proposed surgeries of a non-emergency nature” at para 9).

²³³In Québec, see *Restaurants McDonald* (21 November 2006), 2006 CanLII 66333, (non-emergency procedures were not administered resulting in exacerbation of the worker’s condition, leading the panel to award cost relief to the employer).

²³⁴[2007] OWSIAT No 1979 (QL).

son that the worker has not worked since approximately 1999 or 2000 is due to the worker's compensable back strain.²³⁵

Similarly in *Decision 543/87*,²³⁶ a worker noted that although his work permit had been due to expire shortly after his compensable injury, he had no reason to believe that he would not have been granted an extension had the accident not occurred. However, the panel took into account that "the worker did not apparently seek a renewal of his work permit until February 1985" as a factor in determining that the worker had not sufficiently pursued work that may have been available to him.²³⁷ Similar limitations in benefits ensued when an injured agricultural worker returned to his home country. Although his claim was accepted, it was found that his earning ability was reduced because of the labour market in Jamaica and that if he had stayed in Ontario, he would have been capable of earning minimum wage after his employment injury.²³⁸

In *Decision No 42/06*²³⁹ the worker had been granted loss-of-income benefits after an accident, even though she was working illegally at the time, but these benefits became time-limited because the Claims Adjuster in the case believed that had she been able to participate in Labour Market Reentry training, she would have been able to earn as much or more than her pre-accident earnings. It was argued that her lack of work authorization prevented her from engaging in training and hence she was no longer entitled to the income replacement benefits. While the Appeals Tribunal found that the worker was totally disabled and thus unable to return to work at all, thereby dispensing with the need to adjudicate on the Labour Market Reentry issue, this could be a potential barrier for undocumented individuals working in Canada.

Furthermore a number of cases point to individual's fear of reporting injuries due to their lack of work authorization. Where such claims are not made immediately, it has been difficult for them to prove the initial injury later if the condition worsens, if the individual gets residency and wishes to claim retroactively, or if a second accident occurs that exacerbates the harm caused by the initial injury. For example, in *Decision No 332/95* a worker's previous unreported injury was found irrelevant to the compensable injury, partly because no evidence could be appropriately brought forward about the initial inci-

²³⁵*Ibid* at para 81.

²³⁶(10 September 1987) at 3, online: WSIAT <www.wsiat.on.ca>.

²³⁷*Ibid* at 4 (The panel assumed some responsibility on the part of the worker to mitigate his or her losses through seeking alternative work).

²³⁸*Decision No 334/03*, [2003] ONWSIAT 2383.

²³⁹(14 August 2006) at para 5, online: WSIAT <www.wsiat.on.ca>.

dent.²⁴⁰ In *Decision No 1895/04* a worker was awarded compensation for an injury, not initially reported, that occurred when he had been working illegally.²⁴¹ However, given the lack of documentary evidence available because of the delayed claim, he received benefits for only one of the related medical issues and not for all of the issues claimed in relation to the accident.

A recent development of note in Ontario is the *Dean Report*,²⁴² that addresses issues related to the better protection of “vulnerable workers,” a concept that includes recent immigrants, foreign workers hired to address temporary or seasonal shortages, as well as undocumented workers.²⁴³ While the primary focus of the report is the protection of workers’ health before they are injured, recommendation 48 addresses the need for better training of vulnerable workers regarding rights under both occupational health and safety and workers’ compensation legislation. If any doubt remained as to coverage of undocumented and precarious migrants under *WSIA*, this report provides further reason to conclude that no category of precarious migrants in Ontario are excluded from coverage because of their migrant status, as long as they meet all the other requirements. This said, the pragmatic obstacles identified, as corroborated in part by the *Dean Report* with regard to fear of reprisals, still need to be addressed.

b. Québec

Québec’s workers’ compensation system is governed by the *Act Respecting Industrial Accidents and Occupational Diseases*.²⁴⁴ It defines “worker” similarly to the other jurisdictions as “a natural person who does work for an employer for remuneration under a contract of employment or of apprenticeship.”²⁴⁵ In general, if an individual is entitled to work in Québec and works under a “contract of employment”, she would be eligible for compensation if she suffers a workplace injury. The vast majority of workers in Québec are covered under the legislation, as only those who are explicitly excluded do not have coverage.²⁴⁶ The legislation does not directly distinguish between coverage for various immigration statuses, although individuals working on the LCP

²⁴⁰[1996] OWCATD No 997 at para 11.

²⁴¹*Supra* note 220 at para 11.

²⁴²*Report of the Expert Advisory Panel, supra* note 209.

²⁴³*Ibid* at 7 and 46.

²⁴⁴RSQ c A-3.001 [*IAOD*].

²⁴⁵*Ibid*, s 2.

²⁴⁶Cox & Lippel, *supra* note 208.

are excluded from coverage, as domestic workers are excluded from the definition of "worker." Most case law also points to the exclusion of undocumented workers from coverage.²⁴⁷

i. Individuals with legal immigration statuses/work authorizations

Asylum seekers would be eligible for workers' compensation coverage provided they have appropriate work authorizations. TFWs in possession of appropriate work authorizations would also be eligible for benefits under the *IAOD*,²⁴⁸ although in one case an injured worker was found to have provided someone else's SAWP permit and was held to be ineligible for benefits given that the tribunal could not ascertain his identity.²⁴⁹ In the *IAOD* there are some restrictions on the eligibility of individuals undertaking specific types of work and thus some TFWs would be affected. As we have seen, section 2 of the *IAOD* currently excludes "domestics" from the definition of "worker."²⁵⁰ Individuals participating in the LCP would fall under the definition of "domestic" and are thus not eligible for coverage unless they register with the CSST and

²⁴⁷For a detailed analysis and rebuttal of the reasoning behind exclusion of undocumented workers from legal protection under Québec labour law see Bernstein, *supra* note 32.

²⁴⁸A worker residing in Québec and working with a temporary work permit was held to be eligible for benefits even though the accident occurred outside Québec in *La Compagnie Marie Chouinard*, 2009 QCCLP 7319, confirmed in review at *La Compagnie Marie Chouinard*, 2010 QCCLP 7620. It is noteworthy that the CSST's objection to this interpretation of the legislation led them to file a petition for judicial review, which was denied. The position of the CSST was that only Canadian citizens and permanent residents can be considered to be "domiciled" in Québec. The CLP did not retain this restrictive interpretation of the *IAOD*. Workers under the SAWP are covered, and, like all seasonal workers in Québec, are subject to specific rules regarding calculation of benefits: *Sanchez-Castillo*, 2009 QCCLP 2485.

²⁴⁹*Château Taillefer Lafon*, 2009 QCCLP 2049, request for review rejected: *Château Taillefer Lafon*, 2010 QCCLP 678, online: CLP <www.clp.gouv.qc.ca>. It is of note that the initial decision refused compensation because it was impossible to confirm the identity of the person injured. In the review decision the CLP confirms that the person injured was indeed the person named in the permit, but refuses to overturn the initial decision as the worker failed to appear at the initial hearing without reasonable grounds that could justify his absence.

²⁵⁰*IAOD*, *supra* note 244.

agree to pay the contribution of their employer.²⁵¹ Considering the cost of premiums, there are few domestics who make this choice. In 2003, only thirteen domestics were insured under the program.²⁵² It is also of concern that if those working under the LCP become injured and are unable to continue work, there may be consequences for their eligibility for permanent residence.²⁵³ The exclusion of domestic workers from the purview of the *IAOD* was deemed discriminatory on the basis of sex, ethnicity, race and social condition by the Commission des droits de la personne in December 2008,²⁵⁴ and legislation to address the exclusion of these workers was tabled and then withdrawn in 2010.²⁵⁵

Students, TRP holders, and children of precarious status migrants would be eligible for workers' compensation coverage provided that they have work permits. Students are considered workers, including those undergoing a "training period" at their educational institution.²⁵⁶ Tourists would not be eligible for work permits and thus would be considered "undocumented," including those individuals who remain in Canada in anticipation of a sponsorship determination or after sponsorship breakdown.

Aside from the legal rules governing coverage under the *IAOD*, it is also important to acknowledge difficulties in access to compensation for workers with precarious immigration status by reason of their situations. Those included in the concept of worker may nonetheless see their claims denied or recognition of their employment injury delayed because they: failed to consult a physician in a timely manner;²⁵⁷ filed beyond the 6 month deadline for claim-

²⁵¹*Ibid*, s 18; *Boyer* (17 August 2000), online: CLP <www.clp.gouv.qc.ca>.

²⁵²Katherine Lippel, "La protection défailante de la santé des travailleurs autonomes et des sous-traitants en droit québécois de la santé au travail" (2004) 3:2 *Santé, Société, et Solidarité* 101.

²⁵³Commission des droits de la personne, *supra* note 187 at 51. However, this risk is somewhat diminished with the introduction of the "Juana Tejada" law in April 2010 that exempts LCP workers from the medical exam when they apply for permanent residency, recognizing that they passed an exam for their initial work visa: Citizenship and Immigration Canada, "Operational Bulletin 232: Live-In Caregiver Program: Revised In-Canada Medical Examination Procedures", online: CIC <www.cic.gc.ca/english/resources/manuals/bulletins/2010/ob232.asp>.

²⁵⁴Commission des droits de la personne et des droits de la jeunesse, *supra* note 187.

²⁵⁵*Ibid*.

²⁵⁶*IAOD*, *supra* note 244, s 10.

²⁵⁷*Demba* (17 October 2005), online: CLP <www.clp.gouv.qc.ca>. In another case the worker could not pay for treatment, which led to a longer duration of his work dis-

ing,²⁵⁸ have returned to their country of origin and are therefore unavailable for medical evaluation by a designated doctor in Québec,²⁵⁹ are unable to participate in rehabilitation programs,²⁶⁰ or are unable to testify in support of their claim in appeal.²⁶¹ They may also lose the opportunity to renew their work permits by reason of their temporary disability, thus placing them in an even more precarious situation.²⁶²

ii. Undocumented Workers

Up until recently, case law in Québec has tended towards the exclusion of undocumented workers from eligibility for coverage under the *IAOD*. Tribu-

ability. The employer in *Restaurants McDonald*, *supra* note 221, obtained cost relief (partial transfer of costs of the claim to the general fund) because the delay in consultation by the worker increased the cost of the claim which was seen to be unfair to the employer.

²⁵⁸*Gouriev* (18 February 1999), online: CLP <www.clp.gouv.qc.ca>. Even if workers invoke language difficulties, this has sometimes been refused as a reason for late contestations: *Chatrenur et Grafikom*, 2007 QCCLP 869. By contrast, English-speaking workers have successfully invoked language difficulties to justify their failure to respect deadlines: *Jones et Pratt & Whitney* (14 July, 1999), online: CLP <www.clp.gouv.qc.ca>.

²⁵⁹The employer had asked the CSST to disallow the worker's claim for benefits for this reason after he returned to his country following the expiry of his visa but the CLP found in favour of the worker in *9008-1951 Québec Inc*, 2010 QCCLP 3664.

²⁶⁰The CLP suspended the benefits of an injured worker who could not be assigned light work because his work permit had expired since his accident, a situation found to adversely impact the employer: *Kharrat*, 2010 QCCLP 408. Benefits that would normally be payable during the period when the worker was seeking new work after an accident had been denied because the worker, who was injured while on the SAWP, didn't have a work permit during the period he was unable to work: *Olvera-Rivera* (5 October 2006) at 34, online: CLP <www.clp.gouv.qc.ca>.

²⁶¹*St-Clair* (9 March 2004), online: CLP <www.clp.gouv.qc.ca>. In this case the Tribunal also found that the medical evaluations provided by the worker, submitted by doctors in the country of origin, were insufficient to support his claim. See however *Del Rio*, 2010 QCCLP 4073 [*Del Rio No 1*]; petition for new hearing granted: *Del Rio*, 2010 QCCLP 5820 [*Del Rio No 2*]. Request for a second review filed on the 22nd of August 2011: (CLP), 384378-71-0907-R2. The worker had been deported and was unable to attend the hearing, and this was held to be a valid reason to reconsider the *ex parte* decision of the CLP.

²⁶²*Olvera-Rivera*, *supra* note 260; *9008-1951 Québec*, *supra* note 259.

nals have almost unanimously rejected claims from undocumented workers²⁶³ or confirmed that lack of a work permit justified the suspension of benefits,²⁶⁴ on the basis of public order. Adjudicators conclude that workers without valid work permits cannot be considered “workers” for the purposes of the *IAOD* because employment contracts made with such individuals are in contravention of *IRPA* and thus invalid because they are against “public order.”²⁶⁵

It is important to note that these cases primarily focused on individuals legally-entitled to reside in Canada but lacking work authorization. For example, in *Castillo*²⁶⁶ and *Berisha*,²⁶⁷ the individuals were waiting to receive renewed work permits when their injuries occurred. Both had been consistently in possession of work authorization until longer-than-normal administration delays led to their inability to promptly receive their renewals. In the *Gouriev*²⁶⁸ and *Amira*²⁶⁹ cases both workers’ claims were initially accepted by the CSST but their compensation was withdrawn when their lack of work authorization was brought to light.²⁷⁰ In all of these cases, claims were rejected because those with invalid contracts could not be considered “workers.”

In 2006, *Henriquez et Aliments Mello*,²⁷¹ was decided in favour of an undocumented worker; however, several subsequent cases²⁷² failed to follow the rea-

²⁶³See *Laur et Verger Jean-Marie Tardif Inc.*, [1992] CALP 510; *Boulaajoul et Ferme M.S. Nadon Enr.*, [1994] CALP 1540; *Zogaj et CSST* (14 June, 1999); *Castillo* (11 September, 2003); *Berisha* (25 May, 2004), online: CLP <www.clp.gouv.qc.ca>. See also *Salomon-Herrada*, 2008 QCCLP 4474; *Garcia et Services d’Entretien Advance Inc.*, 2010 QCCLP 2995 (overturned on review at *Garcia et Services d’Entretien Advance inc.*, *infra* note 282); *Del Rio No 1*, *supra* note 261, petition for new hearing granted, hearing pending: *Del Rio No 2*, *supra* note 261.

²⁶⁴*Kharrat*, *supra* note 260.

²⁶⁵*Salomon-Herrada*, *supra* note 263.

²⁶⁶*Sanchez-Castillo*, *supra* note 248.

²⁶⁷*Berisha*, *supra* note 263. See also *Garcia*, *supra* note 263, where the application for renewal of the work permit was pending at the time of the accident, awaiting payment of the application fees.

²⁶⁸*Gouriev*, *supra* note 258.

²⁶⁹*Amira* (21 October, 2005), 2005 CanLII 74821, online: CLP <www.clp.gouv.qc.ca>.

²⁷⁰In *Amira*, *ibid*, the CSST appears to have initiated the inquiry as to the validity of the work permit at the time of the accident.

²⁷¹(27 March, 2006), online: CLP <www.clp.gouv.qc.ca> [*Henriquez*].

²⁷²See two *ex parte* decisions rendered in the absence of the worker. *Salomon-Herrada*, *supra* note 263; *Del Rio No 1*, *supra* note 261 petition for new hearing

soning in that case. In *Henriquez*, the applicant was a refugee claimant but was not in possession of a work permit at the time of his injury. His employer had asked only for his social insurance number and had said that it was all he needed to fill in the paperwork necessary for employment. At the time of his injury, Mr. Henriquez had only been in Canada for a few months and his knowledge of the French language, as well as the laws of Canada and Québec, was limited; neither his employer nor his co-workers had mentioned his need for a work permit. After considering the specifics of the case and the applicant's argument based on *Still*,²⁷³ which had similar facts to *Henriquez* but involved employment insurance rather than workers' compensation, the Tribunal found that Mr. Henriquez did, in fact, qualify as a worker. The Commission des lésions professionnelles (CLP) applied a less restrictive approach in *Henriquez*, than in the previous cases on this issue heard by the CLP and the CALP, concluding that the invalidity of a clause on the basis of public order does not necessarily nullify the entire contract.²⁷⁴ The Commissioner also noted the importance of the worker's good faith.²⁷⁵

The Commissioner also compared the objectives of the *IRPA* and those of the *IAOD*, emphasizing that the *IAOD* is to be interpreted broadly, so that it may be applied to the greatest number of situations. The Commissioner found that, in light of the objectives of the *IRPA*, it would be unfair to punish recently immigrated workers in good faith who do not intend to defraud the Canadian government²⁷⁶ and that rulings in this vein would, in fact, undermine the public interest rather than uphold it.²⁷⁷

Other types of "illegality," like undertaking construction work without a permit, or working "under the table,"²⁷⁸ have not been held to invalidate the work contract. On the contrary, the Tribunal has held that renunciation by a

granted, hearing pending: *Del Rio No 2*, *supra* note 261. The *Garcia* case, *supra* note 263, which also failed to apply *Henriquez*, was overturned in review, *infra* note 282.

²⁷³*Still v Minister of National Revenue* (1997), [1998] 1 FC 549, 154 DLR (4th) 229 (CA).

²⁷⁴*Henriquez*, *supra* note 272 at paras 88-90.

²⁷⁵*Ibid* at paras 90, 122-128.

²⁷⁶*Ibid* at para 135.

²⁷⁷*Ibid* at paras 144-148.

²⁷⁸See eg *Équipement location Masson-Viau* (2 March 2006), 2006 CanLII 68644 (QC CLP); *Larouche-Harvey* (18 April 2005); *Boudreau* (31 March 2000), online: CLP <www.clp.gouv.qc.ca>.

worker of his rights under the *IAOD* would be contrary to public order.²⁷⁹ However, unlike the authorities in Ontario, the CSST and the CLP are generally restrictive in their interpretation of the concept of “worker” when it comes to undocumented workers.²⁸⁰

Even more disturbing than the restrictive approach of the CLP with regard to injuries sustained by undocumented workers is the case of *Kharrat*.²⁸¹ Mouadh Ben Abde Kharrat’s work permit was valid when he was injured at work, so it was not possible to allege that he was not a “worker” under the *IAOD* and his claim was accepted. However, Mr. Kharrat’s work permit expired the day after the accident. At the request of the employer, the CSST retroactively suspended Mr. Kharrat’s benefits to the date the worker ceased doing his temporary assignment, invoking Mr. Kharrat’s inability to legally complete the light work assigned to him under temporary assignment provisions. The CLP held that Mr. Kharrat’s negligence in failing to apply for work permit renewal in a timely manner was equivalent to refusal to perform the duties that he had temporarily been assigned. It judged that the failure of the worker to renew his permit unfairly penalized the employer, who could not reduce his premiums by assigning light work to the worker, given the expiry of the permit. This case opens the door to a whole new category of denials targeting those who have been working legally but whose permits are not renewed subsequent to an accident.

However, the CLP may recently have taken a new direction, addressing the issue of undocumented workers with a fresh eye, while reiterating the importance of the *Henriquez* decision. In *Rodas Garcia et Services d'entretien Advance inc.*,²⁸² the CLP reviewed an earlier decision denying compensation to a worker, who, believing that his newly-acquired citizenship absolved him of the obligation to renew his work permit, had failed to pay renewal fees. The petition for review was granted and the claimant’s status as a worker was recognized. Three key points were made in the *Garcia Review*. First, most of the tribunal decisions declaring contracts of undocumented workers to be null and void were based on the old *Civil Code of Lower Canada*, which was repealed in 1993. Subsequent cases followed old case law without questioning the im-

²⁷⁹*Bellemare* (11 June 2001), online: CLP <www.clp.gouv.qc.ca>.

²⁸⁰For an analysis of the usual interpretative approach of the CLP see K Lippel, “L’interprétation libérale des lois sociales: une pratique révolue?”, in Stéphane Beaulac & Mathieu Devinat, eds, *Interpretatio non cessat: mélanges en l’honneur de/Essays in honour of Pierre-André Côté*, (Cowansville: Yvon Blais, 2011) 201.

²⁸¹*Kharrat*, *supra* note 264.

²⁸²2011 QCCLP 1350 [*Garcia Review*].

pact of the new *Civil Code of Québec* provisions that provide that a contract is valid until it is declared invalid – an issue that was underlined in *Henriquez* as justification for acceptance of the claim. No declaration having been made prior to the accident in the case of Mr. Garcia, or in any of the preceding cases, for that matter, the contract was held to be valid at the time of the accident. The decision in review also held that the first decision-maker had made an error in law when equating negligence with bad faith, an error that justified intervention in internal review, an exceptional procedure. Finally, the reviewing judge reiterated a quotation of Ontario jurisprudence found in *Henriquez*, that the denial of coverage of undocumented workers is bad public policy:

Indeed, to deny the protections of the Act to employees who are not Canadian citizens or permanent residents would not only make them vulnerable to exploitation, but would, in effect, do far more to undermine those very provisions of the Immigration Act the Applicant is so concerned about, as it would make such persons the employees of choice for unscrupulous employers.²⁸³

The *Garcia Review* may well be a turning point in the bleak history of the application of workers' compensation legislation to undocumented workers in Québec. If *Henriquez* and *Garcia* are followed by the CSST and CLP, it could put an end to the current incentive to employers to employ and exploit the most vulnerable migrants.²⁸⁴

c. New Brunswick

There are two parts to the New Brunswick *Workers' Compensation Act*.²⁸⁵ The first deals with "personal injury or death ... caused to a worker by accident arising out of and in the course of his employment in an industry within the scope of this Part."²⁸⁶ The vast majority of industries and workers are covered by this part. The second Part deals with industries that are not covered in Part I and only covers cases in which the accident resulted from employer negligence

²⁸³*Garcia Review*, *ibid* at para 39, quoting *Henriquez*, *supra* note 272 at para 147. *Henriquez* was in turn quoting *Apollo Real Estate (Re)*, [1994] OESAD No 28 (QL).

²⁸⁴In a recent CLP decision, the tribunal concluded the claimant, whose work permit had expired at the time of the accident, was a worker under the *IAOD*, following the reasoning in *Henriquez : Augustin et Résidence Rive-Soleil inc*, 2011 QCCLP 5413.

²⁸⁵*WCA*, *supra* note 198.

²⁸⁶*Ibid*, s 7(1).

or faulty equipment. Statistics from 2008 indicate that approximately 94% of New Brunswick's workforce is covered by the *WCA*.²⁸⁷

The definition of "worker" in Part I of the *WCA* is "a person who has entered into or works under a contract of service or apprenticeship, written or oral, express or implied, whether by way of manual labour or otherwise."²⁸⁸ New Brunswick's *WCA* also excludes "persons whose employment is of a casual nature and otherwise than for the purposes of the industry"²⁸⁹ and out-workers,²⁹⁰ similar to Ontario. However, unlike the Ontario legislation, *WCA* Part I also specifically excludes "persons employed as domestic servants."²⁹¹ *Regulation 82-70* under the *WCA* also excludes "any [workplace] ... unless it has throughout its operations in the year at least three workers at the same time usually employed therein,"²⁹² as well as all undertakings in the fishing industry, unless there are twenty-five or more workers usually employed at the same time.²⁹³

Part II of the *WCA* applies to industries not covered in Part I, presumably referring to those industries in which less than three employees are usually employed, but still excludes "farm labourers, domestic or menial servants, or their employers or fishermen."²⁹⁴ Benefits under this part are provided only where there is some fault attributable to the employer or the equipment used.

Since there is very little case law interpreting the relevant provisions of the *WCA*, it is difficult to determine whether or not immigration status plays a role in the determination of coverage under the *WCA*. In general, *Policy 21-010* notes at section 2.6 that

An individual is considered a worker under the *WC Act*, provided the employer is assessed, or should be assessed. It is not necessary for the individual to work in New Brunswick at all times, since the *WC Act* does not prescribe a minimum time requirement regarding the amount of work that must be performed in New Brunswick.

²⁸⁷ *Association of Workers Compensation Boards of Canada*, *supra* note 202.

²⁸⁸ *WCA*, *supra* note 198, s 1.

²⁸⁹ *Ibid*, s 2(3)(a).

²⁹⁰ *Ibid*, s 2(3)(b).

²⁹¹ *Ibid*, s 2(3)(d).

²⁹² *Exclusion of Workers Regulation*, NB Reg 82-79, s 3(1).

²⁹³ *Ibid*, s 3(2).

²⁹⁴ *WCA*, *supra* note 198, s 86.

It is not clear whether a worker's place of habitual residency, immigration status, and nationality are factors in determining coverage under the *WCA*.

i. Individuals with legal immigration statuses/work authorizations

There is nothing in the New Brunswick legislation that specifically excludes or includes asylum seekers from compensation under the *WCA*: their rights are the same as other workers, provided they have work authorisation. Nor does the legislation specifically address TFWs. However, there may be issues related to the type of work engaged in by SAWP workers. Part II of the *WCA* states that it is applicable to industries not covered in Part I but does not apply to "farm labourers, domestic or menial servants, or their employers or fishermen."²⁹⁵ The implication is that these industries are not covered by Part I and are excluded from the limited coverage available under Part II. However, farm labourers are not explicitly listed as excluded under Part I, and WHSIAT has awarded a number of farm labourers benefits under the Act.²⁹⁶

While farm labourers appear to be covered by the general part of the *WCA*, domestic workers would be ineligible for benefits in New Brunswick based on the type of work performed, rather than their immigration status. Students' eligibility for coverage similarly depends on their work authorization and the type of work engaged in, but nothing specifically excludes students based on immigration status. Tourists, including visitors awaiting sponsorship decisions, are not entitled to work and are therefore considered undocumented.

ii. Undocumented Workers

There are no cases addressing the coverage of undocumented workers under the *WCA*. *Policy 21-010* does not refer to the validity of employment contracts as being a factor in determining "worker" status, nor does it discuss a worker's status under other statutes. However, in *Decision No 20053860*, the appellant argued that, since he was a young boy and had been hired to undertake work contrary to Employment Standards legislation, his contract was void and his right to sue was not taken away; the panel stated:

²⁹⁵*Ibid*, s 86.

²⁹⁶*Decision No 20085107* (3 November 2008), online: NB WHSCC <www.worksafenb.ca/docs/app/20085107.pdf>; *Decision No 20054048* (4 October 2005), online: NB WHSCC <www.worksafenb.ca/docs/app/20054048.pdf>.

In effect, the violation by an employer of a provision in legislation to protect workers would void the whole of the protection scheme for workers intended under the workers' compensation legislation. This is particularly harsh considering that the consequence of not following the particular provisions does not, by the legislation creating it, render the employment contract illegal or void. ... Since neither the Act nor the ES Act provide that a violation of the ES Act voids an employment of a person under the age of 16, and given the intent of the legislated scheme under the Act as previously stated, the Appeals Tribunal cannot, in its view, conclude that this would have been the result intended by the Legislative Assembly of New Brunswick or indeed that it should be in the public interest to do so.²⁹⁷

While this case specifically refers to a breach of employment standards legislation, it stands generally for the proposition that, unlike in Québec, a person should not be excluded from worker status under the *WCA* by virtue of a breach of other statutory conditions governing the employment relationship. Were the issue to come before the Workplace Health, Safety and Compensation Commission Appeal Tribunal, this proposition could support a finding that a lack of authorization to work under the *IRPA* would not necessarily be relevant to a finding that an individual is a "worker" under the *WCA*.

Conclusion

Access to health care is key to the well-being of people in Canada, be they migrants with precarious immigration status or Canadian citizens. This paper has shown that access to medical services is unequal, varying between provinces and according to immigration status, and, at times, appears to be arbitrary. The obligation to treat, particularly in non-life threatening situations, is not codified or consistently applied. Furthermore, existing provisions governing public health place more emphasis on the protection of the public than on the necessity to treat individuals who are ill. Some studies have suggested that economic consequences of accessing uninsured services may expose patients to crippling debt that further compromises their ability to fully participate in Canadian society.²⁹⁸ Additionally, in some cases, there may be systemic challenges that disproportionately affect women, as in the case of failed sponsor-

²⁹⁷*Decision No 20053860* (2 May 2005), at 9, online: NB WHSCC <www.worksafenb.ca/docs/app/20053860.pdf>.

²⁹⁸ See Kuile et al, *supra* note 6. The next steps in our study will allow us to explore the extent to which this is a reality in Québec.

ship of spouses or the exclusion of domestic workers from workers' compensation legislation in Québec and New Brunswick.

The provincial health insurance schemes focus far more closely on immigration and residency status than the workers' compensation schemes. However, in some cases, lack of access to health care through health insurance can jeopardize workers' compensation coverage, particularly if the worker fails to seek or follow up on treatment. Our results also show that access to health care is available sooner through workers' compensation programs than through the universal health care system, as there is no three-month hiatus preceding the right to access services where a work injury is involved.

Protection of undocumented individuals is of particular concern with respect to health insurance and workers' compensation coverage. In all provinces, provincial health insurance schemes specifically deny coverage to those without legal immigration status. Additionally, in most cases in Québec, at least until recently, working in contravention on the *IRPA* automatically lead to the conclusion that the work contract is contrary to the "public order", which leads to denial of the claim on the basis of the nullity of the work contract. Exclusion of these workers from the purview of the Québec workers' compensation legislation appears to be discriminatory, given that other types of "illegal" contracts do not preclude workers from accessing benefits. To date, no judgments have considered the discriminatory nature of the restrictive interpretation of the workers' compensation Act, the *IAOD*. Two very recent decisions found that workers whose permit had expired should benefit from coverage, but it is too early to conclude that the institutional approach to these cases has changed. Two Québec decisions recognizing coverage of undocumented workers reflect on the consequences of excluding workers from the purview of the *IAOD* and underline the fact that employers, who benefit from the labour of these undocumented workers, are protected from the economic consequences of workplace injury, which is often attributable to working conditions. Much of the jurisprudence in Québec provides clear incentive to employers to hire undocumented workers, as they are more easily and cheaply disposed of if they are injured. However, it is also possible that workers thus excluded may rely on the *CCQ* to launch proceedings under general rules of civil liability, as the exclusionary rules of the *IAOD* would be inapplicable. In Ontario and New Brunswick, violation of immigration law has not been taken as an automatic bar to compensation. The recent *Dean Report* acknowledges

that undocumented workers constitute a particularly vulnerable population in need of better protection and information concerning their rights.²⁹⁹

Canadian studies have shown that immigrant workers confront a variety of obstacles when exercising their rights to compensation³⁰⁰ and their work situations may expose them to increased risk of workplace injury.³⁰¹ Studies conducted in other countries have found that migrant workers, particularly those with precarious immigration status, are exposed to increased hazards and difficulties in accessing social support. Elsewhere, access to workers' compensation by undocumented migrants is the subject of much controversy; full coverage is sometimes beyond the reach of migrant workers because of immigration rules.³⁰²

Aside from the need to acknowledge the rights of undocumented workers injured at work in Québec, there is a need in all three provinces to provide legal protection to precarious migrants who are injured so they feel that they can safely exercise their rights. Workers should be guaranteed the right to stay in Canada while their cases are pending and while they require health care as a result of a workplace injury. Those who choose to return to their home countries should be assured that their right to compensation for work related disability will not be compromised and that access to the medical evidence and care they require will be facilitated by the compensation system.

Training and improved protections from employer reprisals, as proposed by the *Dean Report*, would be a good first step in reducing systemic discrimination, but true protection for precarious migrants would also include immunity from prosecution or deportation for those injured at work – a recommendation that would address some of the ethical issues raised by exploitation of immigrant workers in Canada.³⁰³

²⁹⁹Kuile et al, *supra* note 6.

³⁰⁰Gravel, "Immigrant Workers" *supra* note 31; Gravel & Brodeur *supra* note 31; Gannagé, *supra* note 31.

³⁰¹Premji, Messing & Lippel, *supra* note 35; Stéphanie Premji et al, "Are Immigrants, Ethnic and Linguistic Minorities Over-Represented in Jobs with a High Level of Compensated Risk? Results from a Montréal, Canada Study Using Census and Workers' Compensation Data" (2010) 53:9 *American Journal of Industrial Medicine*, 875.

³⁰²Guthrie & Quinlan, *supra* note 39; Toh & Quinlan, *supra* note 38. Case law in Australia is contradictory, varying from one state to the next.

³⁰³Gravel, "Immigrant Workers", *supra* note 31.

Discrimination has been shown to have negative effects on the health of migrant workers, which are compounded when discriminatory policy jeopardizes their access to health care and social benefits.³⁰⁴ Perhaps constitutional arguments will provide some redress for precarious-status individuals who suffer from lack of access to health care. Raising constitutional considerations may finally bring to light the seriousness of the impact this lack of access can have on an individual's bodily security and the differential impact it has on the disabled.

Improving access to health care for all precarious migrants, including undocumented and migrant workers, would constitute an important step in reducing these negative health effects and in increasing the overall well-being of migrants to Canada.

³⁰⁴ Andrés Agudel-Suarez et al, "Discrimination, Work and Health in Immigrant Populations in Spain" (2009) 68 *Social Science and Medicine* 1866.

Annex A – List of Acronyms

CHA	<i>Canada Health Act</i>
CHT	Canada Health Transfer
CIC	Citizenship and Immigration Canada
CLP	Commission des lésions professionnelles
CMA	Canadian Medical Association
CSST	Commission de la Santé et de la Sécurité du Travail
CHT	Canada Federal Health Transfer
HA	<i>New Brunswick Hospital Act</i>
HIA	<i>Québec Health Insurance Act</i>
HIA Regulation	<i>Regulation Respecting Eligibility and Registration of Persons in Respect of the Régie de l'assurance maladie du Québec</i>
HSA	<i>New Brunswick Hospital Services Act</i>
HSA Regulations	<i>Regulations to the Hospital Services Act</i>
IAOD	<i>Act Respecting Industrial Accidents and Occupational Dis- eases</i>
IFHP	Interim Federal Health Program
IRB	Immigration and Refugee Board
IRPA	<i>Immigration and Refugee Protection Act</i>
LSP	Low Skilled Pilot Program
LCP	Live-In Caregiver Program
MSPA	<i>New Brunswick Medical Services Payment Act</i>
OHIP	Ontario Health Insurance Plan
OHRC	Ontario Human Rights Code
OHRT	Ontario Human Rights Tribunal
ON HIA	<i>Ontario Health Insurance Act</i>

ON Regulation	Regulation 552 – <i>General Regulation – Health Insurance Act</i>
PPORLLFT	Pilot Project for Occupations Requiring Lower Levels of Education
PRRA	Pre-Removal Risk Assessment
RAMQ	Régie de l'assurance maladie du Québec
RPD	Refugee Protection Division
SAWP	Seasonal Agricultural Workers Program
TFW	Temporary Foreign Worker
TRP	Temporary Residency Permit
VoT	Victim of Trafficking
WCA	New Brunswick <i>Workers' Compensation Act</i>
WCAT	Ontario Workers' compensation appeal tribunal
WHSAT	Workplace Health, Safety and Compensation Commission Appeal Tribunal
WSIA	Ontario <i>Workplace Safety and Insurance Act, 1997</i>
WSIB	Workers' Safety and Insurance Board
WSIAT	Ontario Workplace Safety and Insurance Appeals Tribunal

TOWARDS AUTONOMY INTRODUCTION

*Melanie Bernard, Patrick Reynaud & David Parry **

On March 7th, 2011, the McGill Journal for Law and Health (MJLH), the Disability & the Law Portfolio of the Human Rights Working Group (McGill University), and the Centre for Law and Aging organized a multidisciplinary panel discussion entitled *Towards Autonomy: Exploring the Clinical, Legal and Ethical Aspects of Mental Capacity*. The panel was comprised of Dr. Martin Cole, Geriatric Psychiatrist, St. Mary's Hospital, and Professor of Psychiatry, McGill University; Me. François Dupin Ad.E., Public Curator of Quebec; the Honorable Pierre-C. Gagnon, Superior Court of Quebec; Dr. Henry Olders, Geriatric Psychiatrist, St. Anne's Hospital; Ms. Monique Renaud M.S.W., Gerontological Social Services; and Professor Ronald Sklar, McGill University Faculty of Law; and Me. Ann Soden Ad.E., Centre for Law and Aging.

The panelists discussed the importance of adopting a multidisciplinary approach to mental capacity. Highlighting the particular vulnerability of persons with diminished capacity within the medical and legal systems, they emphasized the need for increased comprehensiveness, sensitivity, and collaboration among professionals in these areas. The panelists explored the key values of the presumption of capacity, promotion of autonomy, maximization of positive family and social connections, and promotion of residual capacity.

The event organizers invited the panelists to share their reflections with a wider audience by submitting short papers on their presentations to the MJLH. What follows is a collection of these papers, with some concluding remarks by Me. Soden. We are extremely grateful to all the panelists for their invaluable contributions. Unfortunately, due to the demands of being a Superior Court judge, Mr. Justice Gagnon was unable to contribute.

* Disability Law Portfolio of the Human Rights Working Group, McGill University; Centre for Law and Aging; McGill Journal of Law and Health.

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CLINICAL ASSESSMENT OF THE MENTAL CAPACITY OF THE OLDER ADULT

*Martin G Cole, M.D., F.R.C.P.C. **

Introduction

Clinical assessment of mental capacity is one of the most frequent requests for geriatric psychiatry consultation. At St. Mary's Hospital, our service receives over 200 such requests each year. In most cases, the results of the assessment assist the older adult, the family, and the health care team in making decisions about the medical care and management of the older adult. In a small proportion of cases (less than 10%), it is necessary to refer the older adult and his or her family to the public curator or the courts.

What follows is a brief description of the clinical assessment of the mental capacity of the older adult: specifically, the ethical framework, the steps in the clinical assessment, and some of the challenges.

Ethical Framework

The ethical framework for assessing the mental capacity of the older adult is similar to the ethical framework used for any medical assessment or intervention. This framework includes: (1) respect for human dignity; (2) respect for autonomy; (3) respect for vulnerable persons; (4) concern for the welfare of the individual (beneficence); (5) non-maleficence; and (6) maximizing benefit and minimizing harm.

Clinical Assessment of Mental Capacity

The clinical assessment of the mental capacity of the older adult has 5 steps: (1) determination of the specific type of mental capacity to be assessed;

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(2) collection of collateral information about the older adult from significant others and health care professionals; (3) general assessment of mental state; (4) specific assessment of mental capacity; and (5) judgment of mental capacity.

Step 1: Determination of the Specific Type of Mental Capacity to be Assessed

The first step in the clinical assessment of mental capacity is to determine the type of mental capacity to be assessed by interviewing the individual, agency, health care professional, or legal representative requesting the assessment. The type of mental capacity to be assessed determines the kinds of questions asked during the specific assessment of mental capacity.

There are as many potential types of mental capacity as there are potential issues about which older adults must have knowledge and make decisions, since capacity or lack of capacity is determined on an issue-by-issue basis. Some of the more commonly-assessed types of mental capacity include: capacity to consent to medical treatment, capacity to refuse medical treatment, capacity to manage finances, capacity to determine living circumstances, and capacity to make a will.

Step 2: Collection of Collateral Information About the Older Adult

The collection of collateral information about the older adult usually involves questioning significant others and health care professionals about: the past and present mental and physical functioning of the older adult; the older adult's illnesses, disabilities, and handicaps; the older adult's grasp of his or her limitations, and their willingness to accept help. This collateral information provides the background for the specific assessment of mental capacity in step 4 and is incorporated in the judgment about mental capacity in step 5.

Step 3: General Assessment of Mental State

The general assessment involves a clinical interview with the older adult to assess cognition, mood, psychotic symptoms, and personality. Assessment of cognition includes assessment of: orientation (to person, place, and time); concentration; short- and long-term memory; ability to learn new information; insight; and judgment. The Mini-Mental State Exam¹ is a brief tool that is fre-

¹ Marshal F Folstein, Susan E Folstein & Paul R McHugh, "'Mini-Mental State': A Practical Method for Grading the Cognitive State of Patients for the Clinician" (1975) 12 Journal of Psychiatry Research 189.

quently used to assess cognition; scores range from 0 (severe impairment) to 30 (no impairment). Assessment of mood includes assessment for significant symptoms of anxiety, depressed or elated mood, and suspiciousness or fearfulness. Assessment of psychotic symptoms includes assessment for disorganized thinking, hallucinations, and delusions. Assessment of personality includes assessment for outstanding personality traits, past and current patterns of behavior, and relationships.

Step 4: Specific Assessment of Mental Capacity

The specific assessment of mental capacity involves a clinical interview with the older adult to determine whether they have: (1) a factual understanding of the issues relevant to the specific mental capacity in question; (2) insight and appreciation of how the above facts apply to their situation; (3) sound reasoning in making decisions and finally; (4) the ability to choose between different options.² These 4 criteria for assessing mental capacity are arranged hierarchically: the older adult must first demonstrate factual understanding, then insight and appreciation, then sound reasoning, and finally, ability to choose. These 4 criteria may be used to assess all types of mental capacity, but the questions used to elicit the information for each criterion are specific to the type of mental capacity assessed (see the examples in the Tables 1 and 2). An alternate and frequently used set of criteria to assess mental capacity includes: (1) the older adult's understanding the concept of capacity; (2) their appreciation of their strengths and limitations with respect to capacity; (3) their demonstrated ability to have lived safely in the recent past; and (4) their continuing ability to make reasonable decisions.³

Step 5: Judgment of Mental Capacity

The judgment of mental capacity is a complex clinical judgment that involves the weighting and synthesizing of the information collected in steps 2-4, and making a judgment about the older adult's capacity to make decisions

² Antoinette Ambrosino Wyszynski & Carol F Garfein, "Assessing Decisional Capacity and Informed Consent in Medical Patients: A Short, Practical Guide" in Antoinette Ambrosino Wyszynski & Bernard Wyszynski, eds, *Manual of Psychiatric Care for the Medically Ill* (Washington, DC: American Psychiatric Publishing, 2005) 221.

³ MJ MacKay, "Financial and Personal Competence in the Elderly: The Position of the Canadian Psychiatric Association" (1989) 34:8 *Canadian Journal of Psychiatry* 829.

about specific issues. Although more information collected from more people (including the older adult) at many occasions in time increases the reliability and validity of the judgment, the judgment is often difficult. A number of clinical tools are available to assist in the assessment, documentation, and decision-making processes but these tools are not substitutes for thoughtful assessment.⁴

Challenges

Despite best efforts to assess the mental capacity, the assessment is often challenging. Examples of these challenges include: pressure to complete assessments quickly because management decisions must be made quickly (e.g. a patient with an acute abdomen who is refusing surgical intervention); absence of information from collateral sources; collateral sources who provide conflicting information; conflicted families in which different family members have different views of the previous level of functioning or best interests of the older adult; conflicted health care teams; conflicts of interest on the part of individuals providing collateral information (e.g. the best interests of the individual providing the information conflict with the best interests of the older adult); fluctuating capacity (e.g. a patient with acute confusion/delirium may be capable of making certain types of decisions on one day but not the next). Finally, the existence of partial capacity is a frequent issue (e.g. the older adult is neither fully capable, nor fully incapable of managing finances).

To complicate the assessment even further, the potential consequences of impaired mental capacity inevitably influence the threshold for capacity: for example, the more likely impaired capacity will result in imminent harm to the older adult or someone else, the higher the threshold for capacity. At the same time, however, it must be acknowledged that even ostensibly capable people can make bad decisions.

Conclusion

As described above, clinical assessment of the mental capacity of the older adult is an imperfect process. The assessment struggles to evaluate and integrate complex sets of information and make judgments that balance concerns about decision-making capacity and concerns about restrictions on individual autonomy.

⁴ Astrid Vellinga et al, "Instruments to Assess Decision-Making Capacity: An Overview" (2004) 16:4 *International Psychogeriatrics* 397.

Table 1. Capacity to refuse treatment**1. Factual Understanding**

“What illness do you have? What is the recommended treatment?”

2. Insight and Appreciation

“Do you have any doubts about the doctor’s diagnosis or how it applies to you?”

3. Reasoning

“Why have you chosen to refuse treatment?”

4. Ability to choose

“After discussing everything, what do you want to do?”

Table 2. Capacity to determine living circumstances**1. Factual Understanding**

“Why does your doctor *not* want you to return home alone?”

2. Insight and Appreciation

“Do you have any illnesses/disabilities/limitations that would make it difficult for you to return home alone?”

3. Reasoning

“How will you manage your illness/disabilities/limitations at home alone?”

4. Ability to choose

“After discussing everything, what do you want to do?”

LA MULTIDISCIPLINARITÉ, LA SAUVEGARDE DE L'AUTONOMIE ET LA NÉCESSITÉ D'UNE APPROCHE CONCILIATRICE

*François Dupin, Ad.E. **

Le titre du colloque invite à une exploration de l'aspect légal de la capacité mentale, et ce, dans une perspective visant à reconnaître et à promouvoir l'autonomie chez une personne déjà vulnérable due à une détérioration progressive de sa capacité mentale.

Trois grands axes de réflexion s'imposent lors de cet effort de recherche, de reconnaissance et de promotion de l'autonomie étant entendu que le temps manque pour en élaborer d'autres aussi pertinents; Ils s'énoncent comme suit :

- ❖ La nécessité de la multidisciplinarité, l'actualisation de la sauvegarde de l'autonomie et la nécessité d'une approche conciliatrice dans les litiges juridiques mettant en jeu des questions connexes à l'aptitude résiduelle et dont l'effet est d'en faire une question secondaire.

La multidisciplinarité

La multidisciplinarité est une clef incontournable pour appréhender et promouvoir les zones d'amélioration possible de la condition d'une personne vulnérable affectée d'une détérioration progressive de sa capacité mentale; en fait, elle n'est pas seulement utile, elle est nécessaire en raison de la complexité même de la psyché humaine : le médecin, l'ergothérapeute, le neuropsychologue, le gériatre, la travailleuse sociale se partagent en effet la tâche de continuer à vivre avec l'évolution d'un diagnostic clinique de la personne vulnérable. Il est important de traiter plus souvent de multidisciplinarité.

* Avocat, Curateur public du Québec. Les propos tenus dans le cadre de ce colloque ne lie que l'auteur, et d'aucune manière le Curateur public du Québec.

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Il faut également reconnaître le statut de ceux et de celles qui, à défaut de diplômes reconnus, font office d'aidants naturels, surveillent et promeuvent au quotidien l'autonomie dans l'évolution de la condition de la personne vulnérabilisée. Ces aidants naturels sont à rajouter au panel d'expert nommé ci-dessus.

La loi reconnaît en partie et bien timidement cette approche multidisciplinaire en matière de régime de protection; il est à noter qu'elle exige la complétion de deux rapports, l'un médical, l'autre psychosocial avant d'entreprendre l'ouverture d'un régime de protection ou de l'homologation d'un mandat de protection¹. Bien plus, l'avis profane de l'assemblée de parents sera mise à contribution pour établir, entre autres, le degré d'inaptitude que le régime de protection est appelé à pallier².

L'étude du projet de loi menant à la loi actuelle en matière de régime de protection indique qu'au début des débats en commission parlementaire, seul le rapport médical avait été suggéré. En bout de course, cependant, il a été jugé que deux rapports, l'un émanant du corps médical, l'autre, de l'expertise relevant du travail social ou de professions connexes, pourraient suffisamment circonscrire l'atteinte à la capacité mentale de la personne vulnérable pour la protéger plus adéquatement³. Le choix du législateur était judicieux. En effet, agir autrement et s'en tenir au seul rapport médical aurait prêté flanc à de sérieuses critiques : il est effectivement douteux qu'un diagnostic de déficience intellectuelle soit de plus d'effet s'il est posé par un médecin que s'il l'est par un psychologue lettré en la matière, telle déficience étant un état permanent plutôt qu'une maladie. D'autre part, l'homme étant un nœud de connexions humaines, un professionnel lettré dans le domaine des sciences sociales est plus à même de juger de l'entourage d'une telle personne vulnérable (et du rôle de son représentant légal potentiel). Seul un tel professionnel peut faire ressortir toutes les potentialités que l'influence de cet entourage peut stimuler eu égard à l'autonomie de la personne concernée ?

La sauvegarde de l'autonomie

Ce concept clef s'exprime à l'article 257 CcQ et constitue l'épicentre de toute la législation promouvant la protection des personnes vulnérables.

Il importe ici d'en peser tous les mots : on nous parle de « sauvegarde », mais pas de « respect ». Quelle distinction le législateur propose-t-il ? Nous

¹ Voir art 276 CcQ et art 884.2 Cpc.

² Art 276 CcQ.

³ Assemblée nationale, *Journal des débats*, 33^e lég, n° 63 (7 juin 1989) à la p CI -2573 et s.

retrouvons cette même expression à la Charte québécoise, lorsqu'il s'agit de la dignité de tous citoyens⁴.

Alors que le respect est le souci de ne pas porter atteinte, la sauvegarde réfère plutôt à la protection accordée au principe par une autorité. Le terme de sauvegarde permet de faire ressortir une obligation du Tribunal de protéger l'autonomie⁵.

Qui, cependant, a figure d'autorité dans un régime de protection ? En premier lieu, le Tribunal, car il en est l'agent moteur. Le protecteur qu'il désignera, que celui-ci soit curateur, tuteur ou mandataire, est également une figure d'autorité. La charge d'administration des biens et de la protection de la personne lui seront différées. Le protecteur aura donc, durant toute la durée du régime de protection, à s'assurer de sauvegarder l'autonomie de la personne qu'il protège dans toutes décisions qu'il aura à prendre le concernant.

De tous les critères énoncés à l'article 257 CcQ, l'autonomie a préséance. Pour preuve, cette valeur est déjà inscrite en filigrane dans la Charte québécoise. Aussi est-elle reconnue comme un corollaire à la valeur de « dignité »⁶. Quel serait l'objectif du législateur lorsqu'il répète, au sein du CcQ, cette valeur implicite de la Charte, sinon d'y faire ressortir la force du terme « sauvegarde » ?

Cette sauvegarde de l'autonomie dans l'économie des mandats de protection a récemment fait son entrée dans un arrêt audacieux de notre Cour d'appel⁷. Selon cette Cour, une personne sous mandat de protection est désormais une personne protégée quant à cet aspect comme le serait celle sous régime de protection.

Cet objectif louable de promotion d'autonomie reste toutefois difficile à atteindre en pratique. Aussi est-il très difficile à vérifier : les instruments mis en place par le législateur ne favorisent pas la promotion de cette nuance dans l'évaluation de la capacité. Ils ne le favorisent pas, non plus, dans le quotidien de la personne protégée. Une incapacité permanente et totale déterminée par le médecin est souvent suffisante pour dispenser le protecteur de la tâche de con-

⁴ Charte des droits et libertés de la personne, LRQ c C-12, art 4.

⁵ Christian Brunelle, « La Dignité, ce digne concept juridique » dans *Justice, société et personnes vulnérables*, Cowansville (Qc), Yvon Blais Collection de Droit 2008-2009 (hors série), p 28.

⁶ France Allard, « Les droits de la personnalité » dans *Personnes, famille et successions*, vol 3, Cowansville (Qc), Yvon Blais Collection de Droit 2010, 2011, p 60.

⁷ P (L) c M (F), EYB 2009-158975 (CA).

sidérer la potentialité d'une inaptitude résiduaire chez son protégé. De même, le curateur ou le mandataire détenant les pleins pouvoirs aura tendance à faire bien peu de cas de l'avis ou de l'opinion de la personne qu'il protège une fois que celle-ci aura été étiquetée comme étant affectée d'une incapacité complète et permanente.

La province de l'Ontario exige du tuteur un plan de représentation légale pour la personne protégée. Il s'agit là d'une initiative où pourrait s'échafauder un plan d'émancipation de la personne vulnérabilisée. Ce plan pourrait être soumis au Tribunal et pourrait lier le curateur ou le tuteur. Il reste cependant à savoir quel serait le pendant d'un tel plan dans l'économie des mandats de protection. Ce plan pourrait aussi être avalisé par le médecin et l'auteur de l'évaluation psychosociale

Vers une approche conciliatrice

Nous désirons, ici, partager notre expérience à titre d'auxiliaire de la Justice dans les litiges relatifs soit à l'ouverture d'un régime de protection, soit à l'homologation d'un mandat de protection, soit à sa révocation, ou encore, dans les litiges relatifs au remplacement ou à la destitution d'un tuteur ou curateur.

Le drame de l'inaptitude chez le parent vulnérable doit se vivre en famille, laquelle se voit investie de la responsabilité d'orienter la protection de son parent vulnérable. Ce drame réveille souvent, parmi les membres de la famille, d'autres blessures (qu'amplifie, par ailleurs, la convocation d'une assemblée de parents, d'alliés ou d'amis prescrite par la loi). Pour résultat, on dérive quelquefois d'un débat de départ porté sur l'autonomie de la personne concernée vers une hostilité exacerbée par les règles du litige juridique et alimentée quelque fois par des avocats âpres au gain.

Cette logique binaire du litige, où il faut nécessairement un gagnant et un perdant a-t-elle sa place lorsqu'il s'agit de pallier la vulnérabilité d'une personne ? Le débat entre membres d'une même famille est malheureusement une occasion pour perdre de vue l'intérêt et l'autonomie résiduaire de la personne vulnérable. En ce sens, il nous apparaîtra toujours préférable que la médiation soit un processus obligé lorsque le litige se résume à savoir qui, dans la famille ou parmi les proches, sera celui ou celle qui sera appelé à la charge de tuteur ou de mandataire.

Beaucoup de travail attend les auxiliaires de justice pour que le débat soit centré uniquement sur le sort de la personne vulnérable. Un premier pas serait de laisser au vestiaire les effets de toge!

COMPREHENSIVE ASSESSMENTS OF COMPETENCE: A PSYCHIATRIST'S PERSPECTIVE

*Henry Olders, M.D., F.R.C.P.C. **

From the point of view of a geriatric psychiatrist who does assessments of competence, there are a number of essential elements to consider, as well as some more nuanced issues.

Let's start with some core considerations: (1) competence is always presumed when the evidence is inconclusive; (2) competence is task- or decision-specific, such that assessments for each task or decision must be independent (for example, consent to treatment, refusal of treatment, choosing where to live, managing one's finances oneself, executing a power of attorney or a mandate in case of incapacity, or making a will); (3) the recommended intervention should be the least restrictive of autonomy, while adequately protecting the patient.

What Reports Include

A complete assessment of competence is typically multidisciplinary. A report from a social worker, addressing financial status, sources of income, type and number of expenses, availability of family or friends who can help, and risk for financial, physical, or emotional abuse is included. Additionally, an occupational therapist can also make a report, dealing with observed capacities in daily living activities such as paying bills, banking, preparing meals, or using transportation. Where indicated, a psychologist can provide an in-depth assessment of cognition and judgment.

Depending on individual circumstances – for example, if there is a history of being abused, unduly influenced, or of exercising poor judgment – the re-

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port should include information from relatives, friends, caregivers, and business or work associates. As a physician, I often make use of information from patient charts – whether hospital, nursing home, or CLSC home care. Along with medication lists, lab test results, and medical and psychiatric diagnoses, charts may include assessments by other psychiatrists, neurologists, occupational therapists, social workers, and psychologists. Particularly valuable are nursing observations regarding manifestations of anxiety, paranoia, losing or misplacing things (wallets, money), overtrusting behaviour (not locking doors, leaving valuables lying around, revealing financial information to strangers), episodes of wandering or fugue, and verbal or physical aggression. Signs and symptoms of depression, mania, psychosis, or delirium may also be reported by nursing staff.

Also essential from a physician's point of view is an accurate medical diagnosis. Some medical conditions can cause impairments of capacity that are temporary or perhaps partially reversible. A definitive opinion on competence should be deferred if the underlying problem has not been precisely determined, if the impairment can be treated, or if the patient's condition is likely to fluctuate.

Safety considerations are also crucial when assessing competence. This includes physical and emotional security, not only for the patient, but also for family members—spouses, children, and parents—who, like business partners or associates, may have financial interests that warrant protecting.

As for any medical intervention, a free and informed consent for the assessment to take place, given by either the patient or his/her legal representative, is a legal requirement. Even if declared incompetent, individuals have the right to refuse treatment, including assessment of capacity. In Québec, a consistent or persistent refusal can be overridden only with a court order.

Some Nuanced Issues

When conducting assessments, one should ask the question: who might benefit from a finding of incompetence? On occasion, a finding of competence may be requested when the patient appears incompetent. The question then becomes: who might benefit from a finding of competence?

This leads to the more general question: on whose behalf is the assessment being done? A physician assessor may feel under pressure to respond to the needs and wishes of several different parties with conflicting interests. The physician's first responsibility is to the patient, following the maxim "do no harm." However, psychiatrists in particular frequently act for the state (for example, to confine to hospitals individuals who present a danger to themselves

or others). Providing assessments which aid the judiciary in ruling on incapacity and appointing a legal representative can similarly be viewed as acting on behalf of the state or the community.

So the person who requests the assessment figures as a player. It may be a family member who is genuinely concerned with the patient's well-being, but it could also be someone who is hoping to benefit personally from a judicial declaration of incapacity.

The patient may be represented by a lawyer, as may the person requesting the assessment. What allegiance does the assessor owe to lawyers? The latter may exert pressure on the assessor to be part of an adversarial process, whereas the assessor, who has been consulted only to provide expertise, may view his or her role as impartial. But for Michel Silberfeld, a psychiatrist at the University of Toronto, assessors conducting mental capacity assessments "are participating in law enforcement."¹ Further, he argues that the assessment belongs to the lawyer for legal purposes and not to the client.

However, it is not the lawyer who pays for the assessment. In Canada, medically-necessary assessments are usually paid for by the publicly-funded health care system; however, there are many situations where the patient foots the bill, even when another person requested the assessment. Perhaps the question of whose interest should be put first, and to whom the report should be remitted, might follow the principle: "he who pays the piper calls the tune." Medical journals routinely require statements about potential conflicts of interest; assessment reports could include such statements as well.

In the Patient's Interest

Some reports should be "red-flagged"; examples include a one-page report with checkboxes; a non-specialist report for a complex medical problem; a report done during an acute care hospitalization, when the patient was likely in worse condition than when not in the hospital; a diagnosis of dementia based on a Mini-Mental Status Exam score; a report documenting the recent onset of cognitive impairment, fluctuations in performance, or the presence of depression; and a report done in the absence of involved family members (as friends or informal caregivers may attempt to take advantage of the patient), or when there is conflict between relatives.

¹ Michel Silberfeld, "Overview of Mental Capacity Assessments" (2009) 12:9 *Geriatrics & Aging* 469.

My view is that the common good is best served when the physician puts the interests of his or her patient first and offers impartial expertise to the judicial system, much like a “friend of the court.” Given that opinions can differ between assessors, I search for abilities, and not only for inabilities. I may look to the lawyer to help define what aspects of competence need to be assessed, and ultimately aim for a comprehensive report that will help move the process forward.

CROIRE AUX CAPACITÉS DE LA PERSONNE VULNÉRABLE

*Monique Renaud, t.s., M.S.S. **

Un système qui roule à grande vitesse

Malgré toute la bonne volonté des intervenants dans notre système de santé, nous assistons parfois à des situations de déclarations d'incapacité totale et permanente qui surviennent sans que la personne vulnérable n'ait été évaluée en profondeur. Ceci pourrait avoir trait à notre credo contemporain : « toujours plus vite ». Les intervenants se voient bien souvent dans l'obligation de « tourner les coins ronds » et, conséquemment, ils ne peuvent pas toujours prendre le temps nécessaire pour faire une bonne cueillette d'information et évaluer à fond chaque situation qui leur est présentée.

Ce n'est un secret pour personne : le nombre croissant de demandes d'évaluation de la clientèle âgée crée un goulot d'étranglement dans notre système de santé. Malheureusement, ce sont les personnes vulnérables qui, trop souvent, en paient le prix.

Ainsi donc, on peut se poser la question de savoir si chaque personne vulnérable qui a été jugée incapable de façon totale et permanente l'est bien réellement. Rappelons-nous qu'une telle déclaration d'incapacité en vue d'homologuer un mandat mène à la perte des droits civils de la personne vulnérable. C'est maintenant « coulé dans le béton » et il n'est jamais simple de défaire un régime de protection ou d'homologation de mandat.

Le cas du médecin qui refuse de se prononcer

Un autre phénomène auquel nous assistons à l'occasion est le refus du médecin traitant de se prononcer quant aux capacités de son patient. Il peut, en ce sens, arriver que le médecin refuse de signer le formulaire de déclaration

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d'incapacité requis pour pouvoir procéder à un régime de protection ou d'homologation de mandat. Conséquemment, la famille de la personne vulnérable se voit dans l'obligation de « magasiner » un médecin qui acceptera de remplir le formulaire d'incapacité en n'ayant vu le patient qu'une seule fois. Et, pourtant, une déclaration d'incapacité n'est pas une situation facilement déterminable, « noire ou blanche ». Elle comporte, au contraire, souvent de nombreuses zones grises, auxquelles personne n'aura vraiment porté attention.

Le médecin qui refuse de signer le formulaire de déclaration d'incapacité refuse généralement parce qu'il craint une poursuite de la part de son patient. Mais il se peut aussi que le médecin ne connaisse pas suffisamment toutes les notions reliées aux capacités et incapacités. Ainsi, la plupart des médecins ne savent pas, par exemple, qu'il existe des régimes de protection modulés (comme une tutelle aux biens, par exemple).

Une bonne évaluation = un bon déroulement des procédures

Comme le médecin et la travailleuse sociale sont les personnes appelées à se prononcer sur le niveau de capacités de la personne, il est essentiel que ces 2 disciplines soient adéquatement informées sur les notions de capacités résiduelles, sur l'importance d'une évaluation bien documentée et d'une écoute active, ainsi que sur l'importance d'une bonne observation de la personne vulnérable. Il n'est pas rare que la travailleuse sociale doive revoir la personne à deux ou trois reprises afin d'achever son rapport d'évaluation. La travailleuse sociale doit garder en mémoire que, dans le doute, la notion de capacité prévaut toujours.

La polarité du monde légal

La nature du travail de l'avocat/e fait en sorte qu'il existe toujours deux parties antagonistes. Ainsi, le fils d'une personne vulnérable qui embauche un avocat pour le représenter travaillera peut-être contre l'un des membres de sa famille qui, lui, devra recourir à un avocat pour se défendre. Le fils donne sa version des faits à son avocat, mais qui dit que ce fils est celui qui a à cœur les intérêts de son parent vulnérable ?

Cette polarité est-elle nuisible à la personne vulnérable ? Il est fort à parier que oui. En effet, si personne n'a pris le temps de rencontrer tous les membres de la famille, il risque de manquer plusieurs éléments dans le tableau de la personne vulnérable.

Heureusement, le domaine du droit qui traite de la personne vulnérable a pour mission fondamentale, non pas la promotion des intérêts pécuniaires,

mais la protection de la personne vulnérable. Nous assisterons donc à une approche plus globale de la personne et de sa famille.

Il y a encore beaucoup de travail à faire pour que les intervenants des domaines judiciaire, médical et psychosocial soient tous sur la même longueur d'onde, mais la poursuite d'un intérêt commun, soit le mieux-être de la personne vulnérable et la maximisation de ses capacités résiduelles, nous aidera certainement à atteindre ce but.

Nous croyons que des échanges multidisciplinaires seraient bénéfiques aux médecins, aux juristes et aux travailleurs sociaux afin de faire profiter chacune de ces disciplines et, ultimement, d'offrir de meilleurs services à la personne vulnérable.

THE “CAPABLE” MENTAL HEALTH PATIENT’S RIGHT TO REFUSE TREATMENT

Ronald B Sklar *

“Every human being of adult years and sound mind has a right to determine what should be done with his own body.” Those words, written by the New York Court of Appeals in 1914,¹ recognized a person’s right under the common law to refuse unwanted medical treatment. The right, however, was limited to persons of “sound mind,” thus expressly excluding the mentally ill. That exclusion was lifted in the United States in 1979 in the Boston Hospital case,² prompting one article in a psychiatric journal to depict patients who exercised their right to refuse treatment as “rotting with their rights on.”³ In a short time, however, the psychiatric profession came around to accept a patient’s “autonomy of choice” with regard to their treatment, shifting attention away from the question of the patient’s “right” to refuse treatment to the question of the patient’s “capacity” to make that decision.

In Canada, a 1991 decision of the Ontario Court of Appeal held that a capable psychiatric patient’s right to refuse treatment was “included in the liberty interests” protected by section 7 of the *Canadian Charter of Rights and Freedoms*.⁴ In the 2003 case of *Starson v Swayze*,⁵ the Supreme Court of Canada in turn declared: “The right to refuse unwanted medical treatment is fundamental

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¹ *Schloendorff v Society of New York Hospital*, 211 NY 125 at 129-130 (1914).

² *Rogers v Okin*, 478 F Supp 1342 (D Mass 1979).

³ TG Gutheil, “In Search of True Freedom: Drug Refusal, Involuntary Medication and ‘Rotting with Your Rights On’” (1980) 137 *American Journal of Psychiatry* 327.

⁴ *Fleming v Reid* (1991), 4 OR (2d) 74.

⁵ [2003] 1 SCR 722 [*Starson*].

to a person's dignity and autonomy. The right is equally important in the context of treatment for mental illness."⁶ While the *Starson* Court did not expressly hold that the right was protected under the *Charter*, its expression of the right as "fundamental to a person's dignity and autonomy" suggests such a holding was almost inevitable.

The *Starson* case dealt specifically with the issue of what constitutes "capacity." Section 4(1) of the Ontario *Health Care Consent Act*, the law impugned in *Starson*, had defined capacity as the ability "to understand the information that is relevant to making a decision about treatment" and the ability "to appreciate the reasonably foreseeable consequences of a decision or lack of decision."⁷

Professor Starson's "driving passion in life" was physics. He had published several papers on the subject and "by all accounts [was] an extraordinarily intelligent and unique individual." In recognition of his accomplishments, his peers had allowed him to use the title, "professor," even though he had never held an academic position. Unfortunately, since 1985 Starson had been hospitalized in psychiatric institutions in both Canada and the United States. He had received several different diagnoses; at the time of his hospitalization that gave rise to the *Starson* decision, his diagnosis was bipolar disorder. The press covering his case had dubbed him "Canada's Beautiful Mind," a reference to a movie of that name about the brilliant mathematician, John Nash, who had held a research position at Princeton University and later the position of instructor in mathematics at the Massachusetts Institute of Technology, while suffering from paranoid schizophrenia.

Starson had denied he was mentally ill, although he acknowledged to his doctors that he had "mental problems that were difficult . . . to handle" and that he "needed therapy." He acknowledged further that "his own perception of reality differed from that held by others." He had refused the psychiatric medications prescribed for him – neuroleptic medications, mood stabilizers, anti-anxiety medication and anti-parkinsonian medication – claiming that all his previous medications had "significantly dulled his thinking and thereby prevented his work as a physicist"; he said he "preferred his altered state to what he viewed as the boredom of normalcy."

His attending physicians declared him incapable to make his own treatment decisions on the basis of his denial of mental illness. Starson applied to the Ontario Consent and Capacity Board for a review of that decision. The

⁶ *Ibid* at 759.

⁷ *Health Care Consent Act*, SO 1996, c 2 (Sch A) [Act].

Board confirmed the finding of incapacity, reasoning that "without an acknowledgement of illness, the patient cannot relate information to his own particular disorder and therefore cannot understand the consequences of a decision to either refuse or consent to medication." Denial of mental illness had previously been held by the Board and Ontario courts to render a patient's refusal to accept treatment incapable, under similar reasoning⁸.

When the case reached the Supreme Court, three justices, in dissent, agreed with the Board's reasoning. The six-justice majority held, however, that Starson's denial of mental illness had not rendered him incapable:

[A] patient is not required to describe his mental condition as an 'illness,' or to otherwise characterize the condition in negative terms. Nor is a patient required to agree with the attending physician's opinion regarding the cause of that condition. ... 'The word condition allows the requirement for understanding to focus on the [patient's recognition he is affected by] the manifestations of the illness rather than the [doctors'] interpretation ... of these manifestations.' ... Psychiatry is not an exact science, and 'capable but dissident interpretations of information' are to be expected.⁹

At the outset of its decision, the Board had stated that "it viewed with great sadness the current situation of the patient" and had later noted that "his life has been devastated by his mental condition." The majority interpreted this language to indicate that the Board had considered Starson's "best interests" in reaching the conclusion that he was incapable. This, they concluded, was improper.

The legislative mandate of the Board is to adjudicate solely upon a patient's capacity. The Board's conception of the patient's best interests is irrelevant to that determination. ... 'A competent patient has the absolute entitlement to make decisions that any reasonable person would deem foolish.'¹⁰

The Court was unanimous that the patient's best interests is irrelevant to the capacity determination, although the dissenting justices disagreed on whether the language quoted above indicated that the Board's decision was influenced by consideration of Starson's best interests, coming as it did at the outset of the Board's reasons.

⁸ See *Khan v St Thomas Psychiatric Hospital* (1992), 87 DLR (4th) 289 (Ont CA).

⁹ *Starson*, *supra* note 5 at 761-762, quoting in part from DN Weisstub, *Enquiry on Mental Competency. Final Report* (Toronto: Queen's Printer for Ontario, 1990) at 229, 250.

¹⁰ *Starson*, *ibid* at 759.

BEYOND INCAPACITY

*Ann Soden, Ad.E. **

*Je suis et je reste une personne à part entière.*¹

The promise of two guiding legal principles, the presumption of capacity² and the safeguarding of autonomy,³ has yet to be fulfilled.

Concepts of legal and functional capacity are poorly developed and understood; our protective regimes create rigid legal categories; and professionals and legal representatives alike are poorly educated about the rights of the person represented and the nature of role of the legal representative under a mandate (given in anticipation of incapacity), tutorship, curatorship, or as appointed by law.

Although there is no universal definition of capacity, despite a search for consensus and objectivity, case law and certain provincial statutes have recognized and incorporated the notion that capacity implies the ability to understand and articulate reasoning behind a decision and to appreciate the consequences of a decision.⁴ Thoughtful commentators and various studies by medical and legal professionals would add that decision-making capacity requires a set of personal values and goals. That is, capacity is to be judged according to standards set by the person's habitual or considered standards of behavior and values rather than by conventional standards held by others. A great danger in capacity assessments is that eccentricities, disagreeable character traits, or ac-

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¹ Person with Alzheimer's disease.

² Arts 4, 153 CCQ.

³ Art 257 CCQ.

⁴ *Institut Philippe-Pinel v G(A)*, [1994] RJQ 2523 (CA) at 2529 [*Institut Philippe-Pinel*]; *Starson v Swayze* [2003] 1 SCR 722.

tions and risk-taking other people find difficult to understand will be confused with incapacity.⁵

Capacity is task-specific and time-specific. Consider persons with mental illness. They may be quite capable with medication or other supports, or they may need assistance or representation in limited areas or for certain tasks only. Next, consider an older person with Alzheimer's. While age is the most significant known risk factor for dementia and Alzheimer's disease, most people do not develop the disease as they age. In other words, Alzheimer's is not a normal part of aging.⁶ Even where there is incapacity in older people with dementia, it often develops gradually or is only partial, with much residual capacity remaining. Thus a person may have diminished or impaired capacity and be incapable of managing his financial investments, but be entirely capable of executing a power of attorney or mandate and handling day-to-day expenditures with or without assistance; or he may be incapable to confer a mandate, but be capable of executing a simple will of his property; or he may be completely incapable of decisions relating to his property or finances, but function well in his activities of daily life and be capable of making decisions relating to health care. Consider finally the person who is dying. A terminally-ill but otherwise competent person may lapse in and out of lucidity, and hence capacity, so that his or her current wishes and consent, whether or not covered in a previously executed advance directive, would be sought, when possible, in those moments of lucidity.

While capacity is a legal determination, lawyers often do not represent the person under evaluation whose capacity and legal rights are at issue.⁷ And

⁵ Commission on Law and Aging and American Psychological Association, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, (Washington, DC: American Bar Association & American Psychological Association, 2005), online: APA <www.apa.org/pi/aging/resources/guides/diminished-capacity.pdf>; Charles Sabatino & Suzanna L Bassinger, "Competency: Reforming Our Legal Fictions" (2000) 6:2 *Journal of Mental Health and Aging* 119.

⁶ Alzheimer Society of Canada, "Myth and Reality About Alzheimer's Disease" (2011), online: ASC <www.alzheimer.ca/en/About-dementia/Alzheimer-s-disease/Myth-and-reality-about-Alzheimer-s-disease>.

⁷ The Institut National du droit de la politique et du vieillissement has proposed to the Quebec government that those whose civil rights and the integrity of their person are at issue be represented by legal counsel in every judicial proceeding in which such legal rights are at stake, save in a case of reasonable refusal of legal counsel (opening of a protective regime under art 877 CCP; review of protective measures under arts 883-884 CCP; homologation of a mandate given in anticipation of incapacity under art 884.1 CCP; and orders for consent to care, including housing

even when representing a client in contested matters, the legal profession too often defers to clinical assessments without defining or reviewing the nature and object of the assessment, verifying the legal criteria applied by the medical and social work professional, or ensuring that areas of residual capacity are fully described. Correlatively, some doctors and social workers do not provide information that is specific enough for courts to distinguish capacity in one domain or another.

A thorough assessment which presumes and maximizes capacity and autonomy is the legal right of every person. Certainly the presumption of capacity requires that all parties in the continuum of evaluation, recommendation, and implementation of protection measures – from the medical expert and social worker, to the lawyer and judge – ensure the comprehensiveness of capacity assessments. The use of common standardized tests of cognitive functioning to determine incapacity has recognized weaknesses, and provides only a crude global assessment. These tests have given way to important additional bases of assessment which better determine and promote capacity. They include:⁸

- ❖ Ensuring enhanced communication. Techniques include multiple sessions to build confidence and trust, and to ensure that wishes do not vary with time. These sessions must be conducted in an optimal environment supportive of, in particular, the partially-impaired person's decision-making ability, e.g. at home and at times when the person will perform at his or her best.
- ❖ Understanding and taking into account of, *inter alia*, lifestyle, values, family history, cultural issues and mores, language and speech peculiarities, and difficulties as these may affect assessment.
- ❖ Multidisciplinary and multilevel evaluations. These include not merely the *cognitive* but the *physical* (many conditions which are treatable, reversible, and temporary, and may relate to sickness, disease, over- or under-medication, and may mimic dementia) as well as *functional* capacity. Also, the presence of *social* supports assessed by occupational therapists and social workers, respectively, is crucial.

under art 776 CCP; and orders for confinement and psychiatric assessment under art 778 CCP. The proposal advocates further that if there is but one legal counsel in the case seeking the opening of a regime of protection that legal counsel should represent the person whose capacity and legal rights are at issue.

⁸ See eg sources *supra* note 4.

- ❖ Assessment of risk. We recognize that competent people are permitted committ foolish acts and accept risks which others might not. However, all too often the *gravamen* of incapacity cases is the claim of risk of harm posed by the likely outcome of the individual's decision, from which the court infers a lack of insight and judgment. The objective assessor must keep in mind that risky conduct, alone, is not proof of incapacity. The ability to appreciate the consequences of a decision requires is the key to a finding of capacity. Risk assessment must take account of the nature and gravity of the risk, whether it is old or new, chosen or accidental, with the central question: is it consistent with values and a lifestyle of living at risk? As Dr. Michel Silberfeld, geriatric specialist in psychiatry reminds us, "[i]ncompetency is the inability to make choices. A competent person *chooses* to run risks. An incompetent person simply runs them."⁹ Our culture is risk adverse in caring for persons with impaired capacity, particularly when present in older people. This risk aversion is driven by fear of liability, lack of resources, lack of education or misunderstandings about the guiding principles of capacity and autonomy and failure in some cases to make the effort. The result is that much risk assessment by professionals, family, and friends inclines towards trumping autonomy with safety and protection.

A person who is about to gift a significant portion of his assets is exposed to greater risk and requires a higher level of capacity than someone who is executing a mandate in favor of a trusted family member, where the person understands and appreciates that the mandatary will be able to make decisions about finances and advocate his decisions about care. So one would look at the importance of the assets to the person concerned (for example, the value of the gift relative to total assets) but also whether a pattern of giving was consistent with goals and values.

- ❖ Advocating, when required, the least restrictive measures of protection. art 257 *CCQ* is our cornerstone and guide in relation to protection. All decisions, from the determination of the appropriate level of protection, to the confirmation or appointment of a legal representative, to acts and decisions made by persons acting on behalf of another, must respect the individual's wishes and safeguard autonomy. The

⁹ Daniel Dochylo & Michael Silberfeld, "Capacity, Consent and Health Care Decision-Making" in Ann Soden, ed, *Advising the Older Client* (Markham: Lexis Nexis, 2005) ch 5 [emphasis added].

principle underlying any protective action is to impose the least restrictive approach under the circumstances.

For example, there may be incapacity but no risk or need for formal legal representation, or there may be an easily-controlled risk which need not infringe on legal rights. Protective measures which are the least restrictive of civil rights and autonomy may be as simple as making banking arrangements for bill payment, hiring an accountant or executing a banking or general power of attorney which names a trusted representative to handle one's property and financial matters. However, such protective measures must be context-dependent, based upon the simplicity of the assets and the transparency and accountability of their management.

Capacity is not always an all-or-nothing phenomenon. The introduction of advisorship and tutorship¹⁰ had the objective of leaving as much autonomy and determination in the hands of the individual as possible. Under tutorship, the tutor is assigned only to those duties and powers that the person is incapable of exercising. Though enshrined in the law, the actual use of tutorship and advisorship still remains the exception rather than the rule. Advisorship, which does not affect rights and is not a protective regime, is a rarity and tutorship, with its recognition of residual capacity, is outnumbered threefold by the homologation of mandates and by private and public curatorships.¹¹ Both these latter protective regimes require clinical findings of "total" incapacity.

Rarely is a person totally incapable. Degenerative conditions such as dementia do not justify premature determinations of total incapacity. We have a broader understanding of mental illness today when it is present in a younger adult, but ageist and paternalistic views still prevail towards older adults beset with forms of dementia.

Our assessments need to be less general and label-driven, and more finely tuned and focused on how a person functions in society. We need, in respect of care and treatment decision-making, to allow the person represented to make each and every decision, and perform every task and transaction he is capable of. Capacity to make personal decisions, including decisions as to care and treatment, can rarely be assessed in advance. The individual's ability

¹⁰ Bill 145, *An Act Respecting the Public Curator and Amending the Civil Code and Other Legislative Provisions*, 2nd Sess, 33rd Leg, Québec, 1989 (proclaimed in force on 15 April 1990, SQ 1989, c 54).

¹¹ Curateur Publique, "Statistics: Characteristics of Represented Persons", online: Curateur Publique <www.curateur.gouv.qc.ca/cura/en/curateur/statistiques.html>.

for a particular decision needs to be assessed on an *ad hoc* basis,¹² at the time the decision is to be made, decision by decision, task by task, transaction by transaction.

Despite recognition that capacity is task-specific, when a clinical determination is made that a person lacks insight and judgment as to his finances and/or his person, society intervenes in a global and generalized way to take away rights and to name a legal representative. A “best interests” and substituted decision-making standard then seem to prevail over wishes and over recognition that the person may well continue to be capable of many tasks and personal decisions. This is neither the substance nor the spirit of our law.

There has to be a paradigm shift in the application of the law. Amongst those with diminished capacity, some have more capacity. Some have less. To the extent that a person retains any residual capacity, this capacity to decide, and not merely to express wishes, should be recognized and asserted. It is more than an ethical duty imposed on the legal representative. It is the very essence of the representative’s role and the corresponding legal right of the person represented.

The person represented may be quite capable with support, assistance, and advocacy of his decisions in given instances, to make many everyday decisions on a range of matters. He may be capable of defining, with his representative and a health care team, a care plan and making and modifying end-of-life decisions. He may even be capable to vote or to marry. Most personal decisions will not be complex and can be readily assessed by the legal representative. Others will involve advice and verification with other experts, in less or more formal ways, depending on the matter.

Even if the person represented is unable to make or communicate a decision, the decision is conceptually still his. The primary role of the representative is to advocate the person’s prior expressed competent wishes on the matter, if known. The essence of legal representation as to one’s person, regardless of appointment under a protective regime or under the law, is one of support and advocacy. These are the principles underlying arts 12, 257 *CCQ*. If the person’s exact wishes are unknown, then the representative, consistent with the promotion of autonomy, would be called upon to make the decision that the person represented is unable to make or to communicate, based on that person’s life values. Only if the person’s wishes and values are unknown or inappropriate in the circumstances, and only after due consideration and consultation, should a legal representative employ a “best interests” and “reasonable

¹² See eg *Institut Philippe-Pinel*, *supra* note 3 at 2529; *Institut Philippe-Pinel v Blais* [1991] RJQ 1969 (CS).

person” standard in making the decision in question subject to the represented person’s rights under art 16 CCQ

Article 16 of the CCQ sets forth an additional legal duty of the legal representative and provides a further and corresponding protection of the integrity and autonomy of the person represented. This duty is often lost sight of in daily practice, particularly in the matters of transition to residential and institutional care. A legal representative may decide or be encouraged by a health or social services professional to “place” an older relative, or other person he represents, in an assisted-living or other residence providing care. The practice of “placement” without consent does not reflect the underlying intention of article 16. An incapable person, regardless of degree of incapacity or level of representation, has the right to refuse care and must be informed of this right. If he refuses,¹³ and the matter cannot be resolved through internal health and social service channels with the represented person, the legal representative has no legal standing to override the person’s refusal.

Article 16 implicitly, it is submitted, calls upon the legal representative to ensure that the person represented gives his consent to every care and treatment decision that the legal representative recommends, save for cases of hygiene and emergency care. If the person consciously and clearly expresses his refusal of the recommendation (i.e. he does not consent to what is proposed), then the issues of his capacity to make his own decision, the appropriateness of the refusal and the appropriateness of the care or treatment recommendation by the legal representative, taking account of the person’s wishes, values and interests, must be submitted to the court for its review and authorization.

We must move away from the practice model of substituted judgment, except very specific cases, to one of *supported judgment*. This move is most needed in the areas of personal and health care decision-making. Quebec’s tutorship model is based on this fundamental understanding of capacity despite impairment, but its potential is not yet fully developed and applied in all areas of representation.¹⁴

¹³ J-P Menard, “L’impact de la Loi sur la protection de personnes dont l’état mental présente un danger pour elle-même ou pour autrui sur le consentement aux soins” in *Développements récents en droit de la santé mentale* (Cowansville: Yvon Blais, 1998) 237 at 257; Robert P Kouri & Suzanne Philips-Nootens, “Le majeur inapte et le refus catégorique de soins de santé : un concept pour le moins ambigu” (2003) 63:11 R du B 1 at 24-25.

¹⁴ Legislative reform of the protective regime of mandates given in anticipation of incapacity to allow for *inter alia* representation and recognition in the case of partial

The goals of maximizing capacity and autonomy require commitment, rigor, and often creativity by professionals, including lawyers and judges, and better assistance to, and understandings by, legal representatives of the true nature of their roles.

incapacity is under discussion. Presently a person with partial incapacity may express his wish to have his mandate homologated (*PL v NG* 2009 QCCS 6211). In addition, a mandate, if so drafted to permit it, may be partially homologated (*SB et al v Suzanne Kemp* (21 December 2004), Montreal, 500-14-020215-34 (CS)), however, in all instances, once the mandate is homologated, partially or fully, the result is full loss of all legal rights in the area homologated (administration of one's property and/or person).

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