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ARCH *Alert*

ARCH's Quarterly Newsletter on Disability and Law in Ontario.

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ARCH
Disability Law Centre

ARCH's AGM – Save the Date!

ARCH will be hosting its Annual General Meeting (AGM) on Thursday **September 28th, 2017**.

An invitation will go out about a month before the AGM. If you would like to receive the invitation and don't already subscribe to receive the ARCH Alert and other electronic materials from ARCH, please go to our website to subscribe: http://archdisabilitylaw.ca/

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Access Awareness 2017: The UN *Convention* on the Rights of Persons with Disabilities: The View from Canada

By Yedida Zalik, Staff Lawyer

Each year in June, ARCH and the Law Society of Upper Canada partner to present an Access Awareness event. The theme for this year's Access Awareness event was the UN Committee on the Rights of Persons with Disabilities' first review of Canada. The UN Committee heard not only from representatives of the Canadian government, but also from delegates representing a number of disability rights organizations in Canada. Several members of that delegation participated in our Access Awareness panel discussion. The panelists discussed the UN Committee's process and how the Committee's Concluding Observations can be used to advance disability rights in Canada.

The event began with a warm welcome from Law Society Bencher, Sandra Nishikawa. Then ARCH's Executive Director, Robert Lattanzio, provided an overview of the UN process. He explained that Canada ratified the UN *Convention on the Rights of Persons with Disabilities* on March 11, 2010. The *Convention* was negotiated over a number of years, through much work and discussion by states and disabled persons organizations. By ratifying the *Convention*, the Government of Canada agreed to follow that law. This means Canada must fulfill its responsibilities so that people with disabilities can exercise their rights as set out in the *Convention*.

Robert explained that the UN Committee on the Rights of Persons with Disabilities is composed of a group of experts who are separate from government. Their role includes monitoring to make sure states are following the *Convention*. As happened with Canada in April, the UN Committee receives reports from states and organizations representing persons with disabilities, then engages with states in a dialogue about how the *Convention* is implemented in their country. The UN Committee then develops Concluding

Observations, to recommend how states can better fulfill their responsibilities under the *Convention*.

Although Canada ratified the *Convention* in 2010, it did not ratify the Optional Protocol to the *Convention*. The Optional Protocol gives the UN Committee two ways to monitor *Convention* rights. The first way is through a complaints process. If a complaint meets certain criteria, individuals or people with disabilities can complain to this Committee if their rights under the *Convention* are not respected. Secondly, the Optional Protocol also gives the UN Committee the power to investigate claims of serious or system-wide violations of the *Convention*. Under the Optional Protocol, the UN Committee can make recommendations to Canada to address concerns raised either through a complaint, or as a result of an inquiry. These recommendations are not legally binding.

This past December, the Federal Government announced the beginning of its work to ratify the Optional Protocol.

After providing this overview, Robert then introduced and moderated the panel. There were four panel members:

ARCH lawyer Kerri Joffe was a member of the delegation of organizations representing persons with disabilities that presented to the UN Committee in April, and has authored a number of reports on the implications and implementation of the *Convention* in Canada, as well as reports on the proposed federal accessibility legislation.

Steven Estey was also a member of the delegation of organizations representing persons with disabilities, and was involved in the *Convention* from its inception, as part of the team that drafted the original text. He currently devotes his time to projects aimed at strategic implementation of the *Convention*.

Kathleen Pye is Director of Research and Policy at Egale Canada Human Rights Trust, which works to improve the lives of LGBTQI2S people nationally and internationally. She was also a member of the delegation of organizations representing persons with disabilities.

Wendall Nicholas is Chairperson of the Wabanaki Council on Disability. He is a member of the Maliseet Nation at Tobique and has worked in policy roles with the Assembly of First Nations.

The panelists engaged in a thought-provoking conversation throughout the evening. Steve Estey explained that he sees the most relevant impact of the UN process not as its nuts and bolts, but its success in raising the national discourse on disability. Kerri Joffe commented that the federal accessibility legislation provides an exciting opportunity to incorporate substantive rights of the *Convention* into Canadian law.

A key focus for the panel members and in the Committee’s Concluding Observations was the need for an intersectional approach. This requires recognizing the particular impact experienced by people who face discrimination on multiple grounds, of which disability is only one.

Wendall Nicholas pointed out that the level of disability in indigenous communities is twice the national average. Resources for disability accommodations are not made available, especially in remote communities. For example, many indigenous seniors have to leave their home reserve because they cannot access services there.

Kathleen Pye noted the absence of an international treaty to address the rights of LGBTQI2S persons with disabilities. Estey echoed the call for an intersectional approach. A key sound bite from the evening was his comment that “it’s not all about white middle aged guys in wheel chairs”.

At the end of this lively discussion, Teresa Daw, Chair of ARCH’s Board, gave some concluding remarks. She, too, noted the importance of an intersectional approach, stating that she learned how important it is to make more space and learn how we can work together. The event wrapped up with a reception generously provided by the Law Society.

If you were not able to attend the event, you can still view it online. ARCH’s website will have a link to the archived webcast of the event, once it is made available to us.

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Lawsuit for people who lived at CPRI in Ontario between 1963 and 2011

By Yedida Zalik, Staff Lawyer

Over the last year, many former residents of Schedule 1 Facilities made claims for compensation. This was because of a class action lawsuit about twelve Schedule 1 Facilities where many people with disabilities had been abused. That lawsuit was called *Clegg v. Ontario*. The Clegg lawsuit settled. This means that the parties agreed to end the lawsuit without a trial. People who lived at these twelve places were able to ask for money from the settlement.

Not all Schedule 1 Facilities were part of the Clegg lawsuit. For example, there were other lawsuits about the Huronia, Rideau and Southwestern Regional Centres, which were also Schedule 1 Facilities. Those lawsuits also settled.

Now there is a lawsuit about another one of these other facilities, the Child and Parent Resource Institute, in London, Ontario. This place used to be called the Children's Psychiatric Research Institute, or CPRI.

You may be part of this lawsuit if you lived at CPRI between September 1, 1963 and July 1, 2011.

What is this lawsuit about?

Many people with disabilities were harmed or hurt at CPRI. The government of Ontario was in charge of CPRI. The lawsuit says the government did not protect the people who lived there.

What is happening in the lawsuit?

Lawsuits start when someone makes a claim in court. In a class action, one person or a few people start a lawsuit for a large group. The lawyers for that person need to ask the Court's permission for the lawsuit to be a class action.

James Templin lived at CPRI and he started this lawsuit for everyone who lived there. In the court papers, this lawsuit is called Templin v. Ontario.

In December 2016, the Court said that the CPRI lawsuit can be a class action.

What happens next?

So far the CPRI lawsuit has not settled.

There could be a trial in the lawsuit. There might also be a settlement of the lawsuit.

Can I get out of the lawsuit?

If you want to get out of the lawsuit, you are allowed to do so. This is also called "opting out". You can get out of the lawsuit by signing and sending an Opt Out Form, which is also called an Opt Out Coupon. If you opt out of the lawsuit, then you will not get any money if the lawsuit wins at trial, or if there is a settlement.
There are different reasons someone might want to opt out. If you are thinking about opting out, it would be a good idea to get legal advice before deciding.

If you would like to get legal advice before deciding if you want to Opt Out, you can contact Koskie Minsky LLP at:

Toll-free: 1-844-819-8523 or email: **cpriclassaction@kmlaw.ca**

You can find the Opt Out form (which is also called an Opt Out Coupon), at http://www.classactioncpri.ca/opting-out.html

If you want to opt out, you must send your letter or Opt Out Form by **October 20, 2017**.

Where can I get more information?

There is more information online. For that online information, go to

https://kmlaw.ca/cases/cpri-class-action/

or

http://www.classactioncpri.ca/index.html

You can also call or email:

- Toll Free Phone: 1-866-640-9989
- TTY: 1-877-627-7027
- Toll Free Fax: 1-888-842-1332
- Email: CPRI@crawco.ca

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New Paper on Re-envisioning Education Laws Across Canada

By: Robert Lattanzio, Executive Director

ARCH was fortunate and privileged to have worked with former Education Minister of New Brunswick, The Honourable Jody R. Carr, on a paper titled "A Conceptual and Legal Framework for Inclusive Education". As the Education Minister who introduced the internationally recognized Policy 322, which provided an important framework for New Brunswick's legally mandated inclusive education model, Jody provides important insight and instructive direction for the much needed reforms to primary and secondary education in Canada. These changes would bring Canada more in line with obligations set out in the *Convention on the Rights of Persons with Disabilities*, and with the General Comment on Article 24 that was released by the United Nations Committee on the Convention on the Rights of Persons with Disabilities.

In the paper, Jody explains why change is so important: “Transformation to inclusive education should be understood as providing additional support for teachers and students. It is about respecting human rights, international and legal obligations, but also about improving the quality of education, based on sound 21st century research and best practices. A framework for implementing inclusive education must be developed and sustained.”

Jody states that even though we still do not have a national strategy to achieve inclusive education, provinces and territories need to adopt what has been working, both domestically and internationally. He lists the following as important ingredients to Canada fulfilling its international obligations: adopting collaborative practices, the need for a comprehensive review, a clear and detailed plan to transition, the adoption of appropriate funding schemes, systemic and sustained professional development regarding inclusive education practices, the “implementation of district and school models of education support teams”, and the sharing of knowledge and best practices.

For more information and to read the paper, go to:
http://www.archdisabilitylaw.ca/A_Conceptual_and_Legal_Framework_for_Inclusive_Education_Jody_Carr

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First Interim Report on Medical Assistance in Dying from the Government of Canada

By Catherine Frazee, Professor Emerita, Ryerson University

Almost exactly one year ago, Kerri Joffe and Erin Elias introduced readers of ARCH Alert to Canada’s new law permitting Medical Assistance in Dying (MAiD). They explained that doctors and nurse practitioners are now authorized to end the life of a patient under strict conditions of eligibility. For their full review of the law and its safeguards, the history of its passage and the role played by disability rights organizations as the law was being debated, go to http://www.archdisabilitylaw.ca/node/1133. Now that the law has been in place for one year, this article will review what we know about how MAiD is being implemented.

On April 26, 2017, the Government of Canada released its first interim report on the delivery of medical assistance in dying. This report covers a 6 ½ month period from June 17 to December 31, 2016, during which time there were 803 publicly reported medically assisted deaths across Canada. An additional 167 medically assisted deaths took place under Québec law, prior to the passage of our federal law.

To read the Government's complete report go to https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-dec-2016.html.

The report provides a very broad profile of who is receiving assisted death in Canada. In Ontario, for example, of 189 deaths reported over a 6 ½ month period, the average age of recipients was 73 years, the gender distribution was relatively equal, and the proportion of recipients living in urban centres was 75%. Almost 60% of assisted deaths in Ontario during the reporting period took place in hospital, with 34% taking place at home. Persons with cancer, neurological, circulatory and respiratory conditions made up the largest proportion of persons who chose an assisted death.

While none of these averages and percentages may be particularly alarming, disability rights advocates have good reason for concern that individual experiences of discrimination and abuse will not be detected when only aggregate numbers are reported. For example, the assisted death in July 2016 of Archie Rolland, a 52-year-old man with ALS, met all of the legal requirements of Canada's MAiD law. Specifically, Mr. Rolland:

- was over 18 years of age,
- had the capacity to make his own health care decisions,
- had requested and consented to his death,
- had a serious and incurable illness, disease or disability,
- was in an advanced stage of irreversible decline in ability, and
- his natural death was reasonably foreseeable.

Canada's interim report on Medical Assistance in Dying registers Archie Rolland as merely one of 803 total deaths, unremarkable except perhaps for his being 20 years younger than the average. For the much more detailed and alarming story of what led up to Archie Rolland's assisted death, we must turn to reports published in the Montréal Gazette last year, one of which can be found by going to http://montrealgazette.com/news/local-news/life-in-long-term-hospital-unbearable-montreal-man-with-als.

According to this newspaper report, based on interviews and extensive email exchanges, Mr. Rolland had been forced to transfer from a specialized care facility to the regular long-term care ward of a local hospital where staff were not trained to care for patients with complex needs. Mr. Rolland, who was ventilator-dependent and communicated by means of an eye-tracking mouse in his eyeglasses, wrote detailed complaints to hospital administrators and others in a desperate attempt to draw attention to the suffering he experienced as a result of poor care.

On one occasion, Mr. Rolland went into respiratory failure when staff failed to suction him properly, and subsequently ignored his ventilator alarm. On another occasion, he was left in extreme discomfort because a caregiver unfamiliar with his needs leaned against the rail of his bed, making it impossible for him to move his head in order to communicate with her. Once, when his mother had too strongly advocated on his behalf, she was banned from the hospital until hiring a lawyer to have her visiting rights reinstated.

Although his friends reported that Archie Rolland had “clung to life passionately” for 15 years following his ALS diagnosis, after just a few months of this struggle for good care, he told reporters that he was “suffering too much to live”. He clarified that it was not his illness that was killing him. He was “tired of fighting for compassionate care”.

Because Archie Rolland was an articulate and passionate advocate for his rights as a disabled person, we are left with one very detailed and troubling story of how the lack of adequate supports and services can become an inducement to seek assisted death. What we do not know is how many more stories remain to be told about similarly intolerable conditions of living that may have pushed others of the 803 Canadians who have ‘chosen’ assisted death.

Archie Rolland’s story helps to illustrate the importance of robust monitoring of medical assistance in dying that goes far more deeply than the government’s interim report. Recognizing that governments must be held to account for failing to meet the critical needs of citizens with disabilities like Mr. Rolland, the United Nations Committee reviewing Canada’s implementation of the Convention on the Rights of Persons with Disabilities (CRPD) gave particular attention to medical assistance in dying in its Concluding Observations released last month. To read the Committee’s Concluding Observations go to: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fCAN%2fCO%2f1&Lang=en. (ARCH and many other disability rights organizations in Canada made a joint submission to the UN Committee, which can be found by going to http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fICO%2fCAN%2f24846&Lang=en).

The UN Committee expressed in very forceful terms its concern “about the absence of regulations for monitoring medical assistance in dying, the absence of data to assess compliance…, and the lack of sufficient support to facilitate civil society engagement with and monitoring of this practice”. Among several clear recommendations, it emphasized that persons with disabilities must have access to “a dignified life made possible with appropriate palliative care, disability support, home care and other social measures that support human flourishing”. The Committee also called for collection and reporting of detailed information about requests for assisted death, and the enforcement of regulations to ensure that “no person with disability is subjected to external pressure”.

Having accurate and detailed information about the implementation of MAiD is essential if people with disabilities and our allies are to exercise effective vigilance. This is especially true in view of a research study published in January of this year in the Canadian Medical Association Journal. The study concluded that medical assistance in dying "could reduce annual health care spending across Canada by between $34.7 million and $138.8 million". A report on this research was published in the Globe and Mail and can be found by going to https://www.theglobeandmail.com/news/national/assisted-suicide-could-save-canada-up-to-138-million-a-year/article33701475/.

To continue to live until the time of his natural death and to do so with dignity, comfort and satisfaction, Archie Rolland required skilled, consistent and appropriate care. At a time of increased pressure upon care providers to reduce costs, disability rights advocacy is a critical line of defence to ensure that medical assistance in dying is not normalized as a 'solution' to problems of injustice, neglect or inadequate care.

ARCH supports the 2017 recommendations of the UN Committee on the Rights of Persons with Disabilities with respect to MAiD and will be working closely with other disability rights organizations in Canada, and with the Vulnerable Persons Standard community to ensure that the Government of Canada moves quickly to mobilize a national system of monitoring and reporting of MAiD data that is both robust and broadly accessible. To learn more about the Vulnerable Persons Standard, go to the June 2016 issue of ARCH Alert at http://www.archdisabilitylaw.ca/node/1133 or go to http://www.vps-npv.ca/.

In a future issue of ARCH Alert, we'll discuss legal challenges to the law currently before the courts. Two individuals with disabilities in British Columbia and two in Québec are arguing against the law's requirement that a person's natural death must be "reasonably foreseeable" in order to receive medical assistance in dying. To see how Canada's national media has reported on these cases, go to: http://www.ctvnews.ca/health/second-plaintiff-joins-court-challenge-of-assisted-dying-law-1.3424823 and http://www.cbc.ca/news/canada/montreal/assisted-dying-quebec-canada-legal-challenged-1.4160016. In another case, physicians who conscientiously object to MAiD are challenging the Ontario requirement for doctors to provide effective referral to patients who request an assisted death. To read more about this case, go to https://www.theglobeandmail.com/news/national/christian-doctors-challenge-ontarios-assisted-death-referral-policy/article30552327/

We'll also provide an update on three studies currently underway at the Council of Canadian Academies, considering issues related to providing MAiD to persons younger than 18 years of age, persons whose natural death is not reasonably foreseeable but who request MAiD because of a mental health condition, and persons who are no longer capable of expressing consent but who have earlier indicated a request for MAiD by advance directive. For details about these ongoing studies go to http://www.scienceadvice.ca/en/assessments/in-progress/medical-assistance-dying.aspx.

As the limits of Canada's MAiD law are tested and challenged, our diverse community of people with disabilities will have to grapple with difficult and potentially polarizing questions. As we debate about values and rights that are deeply personal and have profound consequences for our community, it will be crucial to have reliable and complete information as the basis for our discussions.

> Medical Assistance in Dying remains a difficult and controversial topic for all Canadians. If you have questions or concerns arising from this article, you may contact the author at cfrazee@ryerson.ca or ARCH Disability Law Centre at archlib@lao.on.ca . Both are committed to open and respectful dialogue.

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Alternatives to Signing Documents for Persons who have Legal Capacity but Cannot Sign

*By Kerri Joffe, Staff Lawyer and Michael Cheung, Disability Law Intensive Student**

A common task that many people take for granted is the signing of documents. We are asked to sign documents to enter into contracts to purchase or provide goods or services, open a bank account, give consent to participate in social programs, make powers of attorney for property or personal care, sign a lease, make a will, make credit card purchases, give consent to medical treatment, as well as for many other transactions and reasons.

For some persons with physical disabilities, their disability may prevent them from physically being able to sign their name. Some persons with vision disabilities may be able to sign their name but not see and verify whether their signature is consistent. ARCH has received a number of calls from persons with disabilities and lawyers representing persons with disabilities who, because of their disabilities, cannot physically sign their name on documents. These persons encounter barriers to entering into contracts, obtaining financial services, accessing social programs, executing legal documents, obtaining medical treatments, and many other acts. ARCH has also received calls from persons who have conditions which may worsen over time, and may lead to the person not being physically able to sign their name in the future. These persons are interested in steps they can take while they are still physically able to sign, which would enable them to sign documents in the event that they are no longer physically able to do so in the future.

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* We would like to acknowledge the many lawyers and law students at ARCH who, over a number of years, researched this issue and contributed directly or indirectly to this article.

A person's physical ability to sign their name is not indicative of their legal or mental capacity to sign. Many persons have physical disabilities which may prevent them from signing, but nevertheless have the legal and mental capacity to understand what they are signing and give informed consent or agreement. Even though this may seem obvious, ARCH has heard from many persons with disabilities that others assume they lack legal or mental capacity because they cannot physically sign. Such assumptions are very concerning because they can lead to persons with disabilities being denied their right to make decisions and have control over their own lives.

What alternatives exist for people who have legal capacity, but who, because of a physical or sensory disability, cannot sign?

Under Canadian common law, the most important consideration is the intention of the person who signed or wants to sign the document, not the way in which the person made their signature. A person's intention to validate a document, agree to the terms set out in a document, or agree to do or be legally responsible for doing the acts that are written in the document is what makes a signature legally valid and binding. A written signature is just one way of showing that a person agrees to what is written in a document.[1]

A signature stamp is one alternative to a signature, which some persons with disabilities may wish to use. A signature stamp is a replica of a person's signature which is made into a stamp. Therefore, the person must be physically able to write their signature in order to get a signature stamp made. It may be useful for persons who have conditions which may worsen over time, or for persons who can sign but because of their disability cannot ensure that every signature is consistent. In Ontario, courts have found that signature stamps are an acceptable alternative to a written signature on a will. In a case called *Clarke Estate (Re)*[2] the Court had to decide whether signing a will with a signature stamp met the criteria set forth in the *Succession Law Reform Act*, which is a law governing wills. The Court found that if a signature stamp was made by the person, and if it was intended as the person's signature and to represent the best way of writing the person's name, then it could be a valid alternative to a written signature on a will. While signature stamps provide a

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[1] In *R v Fox*, [1958] O.J. No. 38 the accused brought a motion to contest the validity of a summons because it was not signed by the Justice himself, but rather by a signature stamp. The Court held that the summons was valid, importing the English case of *Bennett v Brumfitt*[1] which provides: The ordinary mode of affixing a signature to a document is not by the hand alone, but by the hand couple with some instrument, such as a pen or pencil. I see no distinction between using a pen or a pencil and using a stamp, where the impression is put upon the paper by the proper hand of the party signing. In each case it is the personal act of the party, and to all intents and purposes a signing of the document by him. The Court adopted *Stroud's Judicial Dictionary*, 3rd ed. Vol. 4, definition for signature: a signature is the writing or otherwise affix, a person's name, or mark to represent his name by himself or by his authority, with the intention of authenticating a document as being that of, or as binding on, the person whose name or mark is so written or affixed.

[2] *Clarke Estate (Re)*, (2008) O.J. No. 3518, 160 A.C.W.S. (3d) 229

helpful alternative for many people, they also carry a risk of inappropriate or fraudulent use. Ontario courts have considered situations in which signature stamps were misused. For example, an Ontario court refused to admit evidence from a physician because it appeared that the physician's signature stamp had been misused. The physician had delegated the use of his signature stamp to a health centre for signing a medical report, however changes were made to the medical report which the physician was not aware of.[3]

Another alternative to a written signature is a mark made in the presence of witnesses. A person who cannot write their signature can instead make an 'X', a thumb, finger or toe print, or any other mark in the presence of one or more witnesses. The witness(es) may then sign an affidavit stating who they are, that they witnessed the person make the mark, and that the person indicated their intention to agree to what is written in the marked document. The presence of witnesses and their affidavits provide evidence and assurance that the person themself made and intended to make the mark. This is useful in case someone challenges the validity of the mark. It also provides an important safeguard against someone else fraudulently or mistakenly marking a document on behalf of the person with the disability. On the other hand, relying on witnesses can create barriers for persons with disabilities to exercise their decision-making rights independently.

A mark made in the presence of witnesses is often used as an alternative to a signature. The *Canada Pension Plan* is an example of a law which expressly allows for the use of signature stamps in very specific circumstances. It permits an applicant for a Social Insurance Number who is unable to make their own signature to make a mark instead in the presence of witnesses. The witnesses' names and signatures must also be shown on the document. [4]

A third alternative to a signature is the use of a signature agent. A person who cannot physically sign directs another person to make the signature on their behalf. The *Criminal Code* and the *Succession Law Reform Act* both contain provisions which allow for the use of a signature agent. With regards to medical assistance in dying, the *Criminal Code* states that if a person requesting medical assistance in dying is unable to sign the request, another person may do so in the person's presence, on the person's behalf and under the person's express direction.[5] The agent must meet certain criteria aimed at preventing abuse or misuse. The *Succession Law Reform Act* instructs that for a will to be valid, it must be signed by the person or by another person who is in the person's presence and under their direction.[6] A signature agent may be a helpful alternative for some persons with disabilities who are not physically able to sign, however, as with making a mark in the

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[3] *MacDonald v Sun Life Assurance Co of Canada* [2006] O.J. No 4977, 154 A.C.W.S. (3d) 334

[4] *Canadian Pension Plan*, RSC 1985, c C-8 s. 99(1)

[5] *Criminal Code*, RSC 1985, c. C-46 s. 241.2(4).

[6] *Succession Law Reform Act*, RSO 1990, c. s.26 s. 4(1)

presence of witnesses, having to rely on another person to sign on someone's behalf can also create barriers for persons with disabilities when exercising their decision-making rights independently.

Electronic signatures may also provide an alternative to a written signature for some persons with disabilities. A number of e-commerce laws and privacy laws exist that recognize the legal validity of certain types of electronic signatures. It is recommended that persons who want to use electronic signatures get legal advice before doing so to ensure that their electronic signature will be legally valid. As new technologies are created, a greater range of alternatives to signing documents may emerge for persons who are not physically able to sign.

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New Genetic Non-Discrimination Act in Force

By Tess Sheldon, Staff Lawyer

A federal law, called the *Genetic Non-Discrimination Act*, entered into force on May 4, 2017. It uses the criminal law to prohibit requirements that people take a genetic test or disclose the results of genetic tests as a condition of employment, insurance or housing. It required changes to the *Canada Labour Code* to prevent employees from being required to take a genetic test or disclose results of a test to an employer. It also changed the *Canadian Human Rights Act* to protect against discrimination on the basis of a "predisposition to a disability" in the same way that the *Canadian Human Rights Act* protects against discrimination on the basis of disability.

Genetic tests look at a person's chromosomes and genes, and can be used to determine to whom the person is related. They can also be used to determine if someone might get a condition that may have been inherited. Some examples of "genetic conditions" include cystic fibrosis, Crohn's disease and Huntington disease. There is even a genetic test for some kinds of conditions that lead to hearing loss. Increasingly, knowledge of specific changes in genes is leading to recommendations about what medical treatments people might want to receive. This is sometimes called personalized medicine. While some people think it is important to use genetic testing for medical treatment, others are worried about potential negative effects of genetic technologies on persons with disabilities.

Even though insurance companies don't usually require genetic tests, they may require the disclosure of test results if the test has already been done. The insurance industry is concerned that if a person finds out that they may develop a genetic condition because of a genetic test, the person may buy insurance policies for additional coverage without the company knowing about the increased likelihood of the condition.

The *Genetic Non-Discrimination Act* is intended to encourage people to take genetic tests, without being worried that someone could use the results of the test against them. For example, it is meant to protect people against insurance companies using genetic information to determine the cost of health and life insurance policies. An employer may be less willing to hire someone who might develop a genetic condition. Genetic information might also influence child custody and adoption decisions.

Some people say that this kind of discrimination is rare in Canada. It might be more common in the United States where more people buy private health insurance. In 2008, the United States passed the *Genetic Information Non-Discrimination Act.* Australia and the European Union also have similar legislation.

Recently, the Canadian Human Rights Commission wrote a letter, along with the Office of the Privacy Commissioner of Canada. They welcomed the *Genetic Non-Discrimination Act* as an “important step for privacy and human rights in Canada” and an example of the “increasingly important connection between human rights and privacy.” The Chief Commissioner of the Canadian Human Rights Commission said “Taking a test that could help save your life shouldn’t have to be a calculated risk.” To read their letter, go to: https://www.chrc-ccdp.ca/eng/content/new-genetic-non-discrimination-law-will-promote-privacy-and-human-rights-canada.

Some people, including persons with disabilities, are concerned about presumptions that it is important to have access to genetic information. They might be skeptical about the historical development of genetics and its relationship to eugenics. Genetic testing relies on medical understandings of disability. The historical disadvantage faced by persons with disabilities has been enforced and perpetuated by medical ideas of disabilities as “abnormalities”, “mutations” or “pathologies”. This is very different from the “social model of disability” which was adopted by the *UN Convention on the Rights of Persons with Disabilities* and Canadian equality rights and human rights cases. The social model understands disability as a natural feature of human diversity.

There is a question about whether the *Genetic Non-Discrimination Act* is a fair exercise of federal powers. In Canada, there are rules about the responsibilities of each of the provinces/territories and federal governments. Provincial laws usually govern insurance contracts. Ontario’s *Human Rights Code* allows – in some cases - insurance providers to make distinctions based on age, sex, marital and family status or disability when they offer individual accident, sickness or disability insurance or group insurance. The *Genetic Non-Discrimination Act* might be referred to the Supreme Court of Canada for its opinion on the law’s constitutionality. ARCH will continue to monitor this important issue.

Possible Change to Direct Funding for Attendant Services

By Yedida Zalik, Staff Lawyer

Direct Funding is a program that gives adults with disabilities funds to manage their own attendant services and have more independence. Attendants can provide support with activities such as bathing, washing, transferring, toileting, getting dressed, skin care, essential communication, preparing meals and light house-keeping.

The Direct Funding program is funded by Ontario's Ministry of Health and Long-Term Care. The Centre for Independent Living in Toronto manages the program together with the Ontario Network of Independent Living Centres.

People who want to receive Direct Funding must complete a detailed application form. People must also go to an interview to show that they can meet the conditions for Direct Funding.

The waiting list for an interview used to be very long. This is because more people are eligible for Direct Funding than there is funding available. In the last few years, the Government of Ontario has given more money for Direct Funding, so the waiting list should be getting shorter.

The *Ministry of Community and Social Services Act* (MCSSA) is the Ontario law that sets out rules about attendant services and who can get them. The rules for the Direct Funding program are in a part of the MCSSA called Ontario Regulation 367/94, Grants for Persons with Disabilities.

Conditions to get Direct Funding

The Regulation says that if you want Direct Funding, first you must be eligible for attendant services. There are also other conditions to get Direct Funding, including:

- You must be able to direct your own care. You are responsible for telling your attendant what you want done, and when and how to do it.

- You must become an employer, and be able to hire and, if necessary, fire your attendants. You are not allowed to hire anyone in your immediate family, for example your parents, spouse, children, sisters or brothers. All employers have legal responsibilities. You need to follow laws such as the *Employment Standards Act*, *Income Tax Act*, *Human Rights Code* and the *Occupational Health and Safety Act*.

- You must also manage and account for how Direct Funding funds are spent. Direct Funding can fund a bookkeeper to help with this reporting.

Changing these Conditions for People with Substitute Decision-Makers

Some people may not be able to make their own personal care decisions or manage their own money. Some people can make these decisions part of the time, but not all of the time, and some people may have difficulties communicating these decisions. Under the current law, these people are not able to get Direct Funding because they cannot direct their own care, become an employer, or account for money they get from the Direct Funding program.

Some people may have a substitute decision-maker who makes decisions for them. The Government of Ontario is thinking of changing the law, so people can get Direct Funding if their substitute decision-maker can meet all the conditions. This change would allow more people to get Direct Funding.

If more people are eligible and apply for Direct Funding, then there might not be enough money for everyone. Bakerlaw, a disability rights focused law firm in Toronto, points out that the Government of Ontario should give more money for Direct Funding to avoid further increasing wait times for eligible participants. For Bakerlaw's blog page on this, go to http://www.bakerlaw.ca/blog/proposed-regulation-amendment-regarding-grants-persons-disabilities/

For information on how the Direct Funding conditions may change for people with substitute decision makers, go to:
http://www.ontariocanada.com/registry/view.do?postingId=23782&language=en

The Government of Ontario asked for comments about this possible change, and people were able to send their comments until April 10, 2017. The ministry is currently considering this feedback and determining what next steps it may take. ARCH will continue to monitor this issue.

Respecting Rights brings institutional perspective to Judith Thompson's disability-focused theatre production *Wildfire*

By Sue Hutton, BSW MSW

Respecting Rights is a project at ARCH, in which persons labelled with intellectual disabilities, ARCH lawyers, and social workers work together doing public legal education on issues related to the intellectual disability community. Respecting Rights recently had the opportunity to be involved in a very creative way of offering public legal education. Playwright Judith Thompson reached out to Respecting Rights to connect with survivors of Huronia Regional Centre and other institutions where many persons labelled with intellectual disabilities were abused and deprived of their basic rights. When Peter Park, long time anti-institutional advocate and founding member of Respecting Rights, was invited to meet with Krystal Hope Nausbaum, a young actor with Down syndrome who wanted to understand what the institutions were like, Peter immediately agreed. As a survivor of Ontario's institution system, Peter is eager to keep teaching the next generation about the horrific legacy of institutions, and the current need to improve respect for the rights of persons labelled with intellectual disabilities.

Wildfire is a play that teaches about the horrors of the institutions, created and directed by Canadian playwright Judith Thompson. It has just finished its first run at Soul Pepper Theatre. All members of the powerful ensemble cast are persons with Down syndrome.

The play originally set out to address issues of disability and sexuality. During rehearsals, Krystal and other cast members learned about the class action law suits that were unfolding for several institutions for people labelled with intellectual disabilities in Ontario, including Huronia Regional Centre and Oxford Regional Centre (where Peter was institutionalized). The cast immediately wanted to learn more, and decided to alter their production to include a message about institutions. As Krystal shared with Peter, the cast of actors were starkly aware that if they had been born in a different era, their fate would have been different. They could have easily been locked up in an institution as Peter was. As Krystal shared, they felt that including stories from survivors of institutions was one way they could pay homage to survivors.

Peter and Kristene Hurdle (an Edgar Occupational Centre institutional survivor), met with Judith Thompson to share their stories of survival and resilience. Their stories were recorded and added to the production in a very powerful opening, bringing the raw truth of institutions to the audience.

Wildfire is set within the walls of an institution. All the actors appear wearing drab hospital gowns in front of a backdrop of institutional beds lined up with no privacy. To set the tone, the actors speak of their passion, their love – the fires of love that can burn like wildfire. Through the medium of theatre, the play emphasizes the same legal rights issues that Respecting Rights teaches about: that people labelled with intellectual disabilities have the same rights as all others to make or participate in making their own decisions. *Wildfire* highlights people's right to make their own decisions about relationships. The story evolves to follow one character (Jazz, acted by Dylan Harman Livaja) who portrays a young man with Down syndrome as he falls in love with a non-disabled staff at the institution. The multiple issues that this opens up are explored through the storyline, with the emphasis being on the person's rights. Exploring society's assumptions, themes of exploitation and abuse, and the rights of persons with disabilities, *Wildfire* is a deeply thought-provoking play.

Respecting Rights members attended the opening, and were inspired by the possibilities of using more theatre to do accessible public legal education for persons labelled with intellectual disabilities.

For more information about *Wildfire*, go to:
https://soulpepper.ca/performances/wildfire/2004

For more information about Respecting Rights and our accessible approach to legal education for people labelled with intellectual disabilities, their families, and staff, go to: www.archdisabilitylaw.ca/Respecting_Rights_Committee_Workshops or contact Sue Hutton at huttons@lao.on.ca .

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Check ARCH's website www.archdisabilitylaw.ca for the Latest ARCH News, publications (including past issues of the ARCH Alert), submissions, fact sheets and more.

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Or you can send your donation cheque to:

Office Manager
ARCH Disability Law Centre
55 University Avenue, 15th Floor
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Co-Editor: **Kerri Joffe**
Co-Editor: **Amanda Ward**
Production & Circulation: **Theresa Sciberras**

We welcome your comments, questions and feedback. We will endeavour to include all information of general interest to the community of persons with disabilities and their organizations, but reserve the right to edit or reject material if necessary. Please address communications regarding **ARCH *ALERT*** to: Theresa Sciberras, Program and Litigation Assistant, ARCH Disability Law Centre, 55 University Avenue, 15th Floor Toronto, ON M5J 2H7, Fax: 416-482-2981 or 1-866-881-2723, TTY: 416-482-1254 or 1-866-482-2728, e-mail: scibert@lao.on.ca **Website: http://www.archdisabilitylaw.ca/**

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ARCH Disability Law Centre
55 University Avenue, 15th Floor
Toronto, ON M5J 2H7
www.archdisabilitylaw.ca

Voice
Telephone: 416-482-8255
Telephone Toll-free: 1-866-482-2724

TTY
TTY: 416-482-1254
TTY Toll-free: 1-866-482-2728

Fax
Fax: 416-482-2981
Fax Toll-free: 1-866-881-2723

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