**CRPD webinar script**

My name is Taylor Hyatt. I’m the Policy Analyst & Outreach Coordinator at Toujours Vivant-Not Dead Yet, and with me is the Director of TVNDY, Amy Hasbrouck.

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TVNDY is a project of the Council of Canadians with Disabilities that focuses on how assisted suicide, euthanasia (AS/E) and other ending-of-life practices affect people with disabilities. We affirm that:

* Everyone who requests and receives assisted suicide or euthanasia has a disability.
* The choice to die is not free as long as old, ill and disabled people don’t have a free choice in where and how they live.
* The belief that death is preferable to disability is a major motivating factor behind the movement in support of assisted suicide & euthanasia.
* Suicide prevention services should be offered equally, to all people, whether or not they have a disability.
* Eligibility criteria and safeguards don’t prevent the deaths of ineligible people and other abuses.

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The topic for today is the connection between the Convention on the Rights of Persons with Disabilities and ending of life issues. This year marks not only the **tenth anniversary** of Canada’s ratification of the CRPD, but also **five years** since the Supreme Court ruled in the [*Carter*](about:blank) case that the prohibition on physician assisted dying violated the Charter of Rights and Freedoms. Our presentation will focus on:

* Sections of the CRPD that relate to life-ending issues;
* How the CRPD can be used to defend against abuses of life-ending practices;
* Other international treaties that touch on life-ending measures and related issues;
* We’ll examine language related to assisted suicide in General Comment No. 36 on Article 6 of the International Covenant on Civil and Political Rights, the right to life
* And finally, we’ll look at another related right – to palliative care.

First, let’s take a look at articles of the [CRPD](about:blank) that relate to euthanasia and assisted suicide. Everyone who expresses an interest in life-ending measures is missing necessary supports in at least one of these areas. Note that I’m going to start in numerical order, and then switch to a group of articles related by their application:

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The first one is probably the most obvious. **Article 10** on the **right to life** reads, in part, “States Parties reaffirm that every human being has the inherent right to life…and shall take **all necessary measures** to ensure its effective enjoyment by persons with disabilities on an equal basis with others.”

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**Article 25** covers **the right to health**. This is a restatement of the right to health guaranteed in other international treaties, which we’ll talk about shortly. CCD actually sponsored a webinar in this series on the CRPD and the right to health on February 26 – check it out!

Part of Article 25 reads: “States parties recognize that persons with disabilities have the right to the enjoyment of the **highest attainable standard of health,** **without discrimination** on the basis of disability.” States Parties shall take **all appropriate measures** to ensure access” including, as section F says, “[preventing] discriminatory denial of health care, health services, or food and fluids on the basis of disability.”

The story of [Vincent Lambert](about:blank) in France is a good example of the denial of this right. Mr. Lambert was severely injured in a car accident in 2008. Various news reports described him as “quadriplegic” with a brain injury, in a “[vegetative state](about:blank),” or in a minimally conscious state. Mr. Lambert had no directive in place expressing what he wished to happen if he ever became incapacitated. A bitter family feud arose as a result. Mr. Lambert’s wife Rachel, and six of his eight siblings, maintained that he would not want to live with a severe cognitive disability. The two remaining siblings joined their devout Catholic parents, Pierre and Viviane Lambert, in fighting to continue the tube feeding**.**The Court of Cassation – the highest applicable appeals court in France – finally[ordered that his feeding tube be removed](about:blank) on July 2nd of last year; he died on the 11th.

As CCD’s Interim National Coordinator Steven Estey has written, “the Lambert case represents the first opportunity to apply the CRPD to a situation where a person was euthanized because of quality-of-life judgments based on severe cognitive disability.” The Lambert case encompasses not only the right to life guaranteed by Article 10, but also the right to communication access in Article 21. Article 25, where health services needed specifically due to a disability must be provided as early as possible, and food and fluids must not be denied on disability grounds, also comes into play. So does appropriate and timely rehabilitation, as described in Article 26. Many questions still need to be answered about the quality of the rehabilitation he received, as well as the use of technology to assist him in communicating.

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Here’s **Article 26 – on habilitation and rehabilitation.** Countries are asked to “take effective and appropriate measures, including through **peer support**, to enable persons with disabilities to attain and maintain **maximum independence**, full physical, mental, social and vocational ability, and **full inclusion and participation** in all aspects of life.” It should be read in conjunction with article 25 – after all, you cannot participate in other domains of life to the best of your ability if you are in poor health!

Now I’ll start going out of order. This group of articles is connected to life in institutions, and the harms that are done to disabled people who live in them.

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**Article 19** deals with the right to **live independently** and be included in the community. Member states ought to “recognize the equal right of all persons with disabilities to **live in the community**, with choices equal to others, and shall **take effective and appropriate measures** **to facilitate full enjoyment** by persons with disabilities of this right **and their full inclusion** and participation in the community, including by ensuring that:

* Persons with disabilities have the opportunity to **choose their place of residence** and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement, and;
* Persons with disabilities have **access to a range of** in-home, residential and other community support **services, including personal assistance** necessary to support living and inclusion **in** the community, and to prevent isolation or segregation **from** the community.

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Contrary to what many might think, Canada is still failing to uphold this right even after closing most of its residential institutions for people with disabilities. In 2014, Beth MacLean, Joseph Delaney and Sheila Livingstone, three Nova Scotians with intellectual disabilities, filed a human rights complaint against the province for failing to provide a community-based alternative to Emerald Hall – the locked psychiatric unit where they lived. The complainants said this amounted to discrimination under the Nova Scotia Human Rights Act.

Mr. Delaney, Ms. MacLean, and the family of Ms. Livingstone (who died in 2016) sought help to move into community-based settings, and financial compensation for their time spent in the institution. In [March 2019](about:blank), the Human Rights Board of Inquiry upheld the individuals’ complaint, but denied systemic discrimination on the basis of disability. This means that other disabled people in the same situation would have to file their own human rights complaints. The Disability Rights Coalition of Nova Scotia is appealing the Board’s decision, and in June 2019, the Canadian Association for Community Living, the Council of Canadians with Disabilities and People First of Canada were granted intervenor status at the Nova Scotia Court of Appeal.

The [decision to award damages](about:blank) in December of 2019 was criticized in part because of the judge’s comments: “Joey Delaney is so disabled that payment to him of a very large sum will **not** have a greater impact on his life than a moderate sum. Beth MacLean does have capacity, but the potential benefit to her of a very large damage award is **limited**. I do not suggest that a payment ought to be limited because of disability, but I do say that a lack of capacity to benefit from the fruits of an award of the size that is advocated is a relevant factor in discouraging me from ordering that they be paid millions.” If the judge believes the plaintiffs’ capacity is limited due to their disability, isn’t he making that first suggestion with a few more words? He assumes that due to disability, the plaintiffs should not receive what they are owed!

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The UN Human Rights Council stated in the **2013 Report of the Special Rapporteur on Torture** that consent to medical procedures must be “full, free, and informed.” Many disabled people remain trapped in long-term care facilities for lack of community-based services. Such facilities are often unsanitary, in poor repair, understaffed and subject to high staff turnover rates. Nursing homes restrict the choices available to residents, and may have policies that amount to inhumane treatment. Meal, wake-up and bed-times are set based on facility schedules, baths may be limited, and toilet paper or adult diapers may be rationed. It is assumed that residents do not know what is best for them, and any aspects of life with which they express dissatisfaction could be dismissed as “trivial.” The limitations of institutional life increase the probability of physical, emotional, and financial abuse or neglect. Since these situations involve “severe pain or suffering, intent, and involvement of a public official or another person acting in an official capacity,” the terms “torture” and “cruel, inhuman…treatment” apply. If assisted suicide is perceived as the only way out of unbearable circumstances like these, consent cannot be “full, free and informed.”

[A group of nursing home residents in Québec](about:blank) actually has a class-action lawsuit underway; they claim to face cruel and inhumane treatment under the province’s human rights law. In their case, the relevant article is **number 15**. It states that “no one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment… States Parties shall take all **effective** legislative, administrative, judicial or other **measures to prevent** persons with disabilities, **on an equal basis with others,** from being subjected to torture or **cruel, inhuman or degrading treatment** or punishment.”

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**Article 16** – **freedom** **from exploitation, violence and abuse –** is also applicable. States must “take all appropriate…measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects. [They shall] put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.”

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Last but not least, let’s look at **Article 21**, which covers **freedom of expression and opinion, and access to information.** It requires states to **“**ensure that persons with disabilities can exercise the right to freedom of expression and opinion … on an equal basis with others.” Among other things, this includes:

* + - “Providing information … to persons with disabilities in accessible formats … in a timely manner and without additional cost, and;”
    - “Accepting and facilitating the use of … augmentative and alternative communication, and all other accessible means … of communication of their choice by persons with disabilities in official interactions.”

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“Access to communications” is also covered under article 9 – accessibility. However, both sections are missing some important points. The CRPD doesn’t mention use of plain language, or “impartial” or “effective” communication. (In other words, someone could theoretically fulfill their obligations under this section by providing communication supports that that are biased and do not reflect the person’s true wishes, or supports that may work, but not for the person who needs them!)   
  
That’s it for my walkthrough of the applicable articles of the CRPD – I’m going to turn it over to Amy, who’s going to talk about how to make sure your rights are upheld using the Convention.

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* **Using the CRPD to enforce rights**
  + Canada must produce regular **monitoring reports** (pursuant to CRPD Article 35).
    - Two years after ratification, then every four years.
    - Preliminary observations by the Special Rapporteur on the Rights of Persons with Disabilities following her visit in [April, 2019](about:blank).
      * “discussions about the rights of persons with disabilities are still framed in terms of social assistance, rather than from a human rights-based approach.”

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* + - * Access to independent living supports:
        + “Access to support is not considered as a right, but rather as a social assistance programme dependent on the availability of services;”
        + “legislation, services and programmes vary across provinces and territories … “

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* + - * She was “extremely concerned” about the implementation of MAiD.
        + “No protocol in place to demonstrate that persons with disabilities have been **provided with viable alternatives** ... for assistive dying.”
        + “worrisome claims about **persons with disabilities** in institutions **being** **pressured** to seek medical assistance in dying, and **practitioners not formally reporting** cases involving persons with disabilities.
        + Urges the federal government to “**investigate these complaints** and **put into place** **adequate safeguards** to ensure that persons with disabilities do not request assistive dying simply because of the absence of community-based alternatives and palliative care.”

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* + **Individual Communications** (Optional Protocol Articles 1-5)
    - People who are personally and directly affected by violations of the CRPD.
    - Violation happened or continued after December 3, 2018.
    - Need to exhaust domestic remedies.
    - State party has six months to respond.
    - [Database](about:blank) of Committee responses to Individual Communications under the CRPD

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* + - The Roger Foley case:
      * Mr. Foley was admitted to Victoria Hospital in London, ON in February of 2016 after problems with workers from a home care agency put his life and health in danger.  Mr. Foley “was hospitalized from food poisoning after being fed spoiled food by Agency workers. Burners were left on in Mr. Foley’s Kitchen. Mr. Foley was physically injured from being dragged on the floor by Agency workers during transfers.”
      * In the hospital, staff failed to accommodate his disability and “routinely held important meetings about Mr. Foley, which he could not attend due to his disability.” According to a civil [complaint](about:blank) filed in Ontario Superior Court, hospital staff “denied Mr. Foley … food and water, for an entire week,” in 2018.
      * “On several occasions, hospital staff … threaten[ed] to charge him approximately $1,800 per day of hospital care if he would not leave the hospital... Mr. Foley was told by hospital staff that he had stayed at the hospital for too long and if he did not receive self-directed funding he should apply for assisted death as an option.”

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* + - * Mr. Foley also filed an individual communication with the United Nations under the Optional Protocol of the CRPD.
        + After meeting with Mr. Foley during her visit in April of 2019, the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar joined with Dainius Puras, Special Rapporteur on the right to physical and mental health in sending a [letter to Canada](about:blank) regarding the Foley case.
        + The letter cited CRPD articles 10, 15, 16, 19, 25 and 26, as well as the rights to life and health, and General Comment No. 36 on the Right to life (which we’ll talk about a little later)
        + In addition to information on Mr. Foley’s individual case, the letter asks for details about “the measures taken to ensure that the medical assistance in dying is provided in a way that complies with international human rights obligations, including the conditions and safeguards to prevent abuse, monitoring and reporting of detailed information about each request and intervention for medical assistance in dying.”
        + We have no word of any response to the letter.

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* + **Inquiries for systemic violations** (Optional Protocol Article 6)
    - Reliable information that governments are violating CRPD rights
    - “Serious, grave or systematic violations.”
    - Committee “invites” the state party to cooperate with the inquiry. If the state party agrees, the Committee can send a representative to do an inquiry.

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* **Related protections in other international treaties**
  + **The** [**Universal Declaration of Human Rights**](about:blank)**.**
    - Article 3: “Everyone has the **right to life, liberty and security of person.**”
    - Article 5: “No one shall be subjected to torture or to **cruel, inhuman or degrading treatment** or punishment;” This language could be invoked by the people who are suing the Province of Québec over conditions in nursing homes.
    - Article 25: (1) “Everyone has the right to a **standard of living** **adequate for health and well-being** ... including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, ... old age or other lack of livelihood...”

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* + **The** [**International Covenant on Social, Economic and Cultural Rights**](about:blank).
    - Article 9 – **Social security and social insurance**.
    - Article 11 – **Adequate standard of living**.
    - Article 12: “The States Parties ... recognize the right of everyone to the enjoyment of the **highest attainable standard of physical and mental health**.” This confers
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  + - * **Affirmative rights** – such as the right to prevention, treatment and control of disease, informed consent, and access to essential medications
      * **Related rights** – like safe drinking water and adequate sanitation, Food that is safe and nutritious, adequate housing (heating and cooling) and a healthy environment;
      * **Freedoms** – from unwanted medical treatment, experimentation, and from torture or cruel, degrading or inhumane treatment.
      * Toussaint v. Canada – 2018 decision in an immiagration case where the committee ruled that
        + “the right to life includes being free from acts or omissions which are intended or expected to cause unnatural or premature death and ensures the entitlement to enjoy a life with dignity.”
        + It was cited in the letter from the Special Rapporteurs.
        + Requires Canada to provide access to existing healthcare services that are **reasonably available and accessible** when lack of access to healthcare would expose a person to a **reasonably foreseeable risk that could result in loss of life**.

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* + **The (2005)** [**Universal Declaration on Bioethics and Human Rights**](about:blank) **UNESCO.**
    - Does not mention AS/E.  The working group decided to “use the Declaration as a general framework to guide States in the development of their legislation, policies and regulations.”
    - Disability is mentioned among the referenced treaties and in article 24 on “international cooperation.”
      * Earlier drafts of articles 10 and 14 had lists of grounds for discrimination to be avoided, which included disability.
      * The lists were eliminated to avoid leaving anyone out.
    - Article 3 – **Human dignity and human rights**: adds that “the interests and welfare of the individual should have priority over the sole interest of science or society.”
    - Article 4 – Benefits should be maximized, harms should be minimized.
    - Article 5 – **Autonomy and individual responsibility**.
    - Article 6 – **Consent**
      * Requires prior, free and informed consent to “preventive, diagnostic and therapeutic medical intervention;”
      * “Adequate information;”
      * “may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.”

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* + - Article 7 – **Persons without the capacity to consent**
      * Caveat – “in accordance with domestic law” (mentioned twice).
      * “Authorization … should be attained in accordance with the best interest of the person.”
      * “[T|he person concerned should be involved to the greatest extent possible.”

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* + - Article 8 – **Respect for human vulnerability and personal integrity.**
    - Article 10 – **Equality, justice and equity.**
    - Article 11 – **Non-discrimination and non-stigmatization**
    - Article 12 – **Respect for cultural diversity and pluralism**
    - Article 14 – **Social responsibility and health**, includes:
      * access to quality health care and essential medicines;
      * access to adequate nutrition and water;
      * improvement of living conditions and the environment;
      * elimination of the marginalization and the exclusion of persons on the basis of **any grounds** (earlier drafts listed these grounds, including disability);
      * reduction of poverty and illiteracy.

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* + **The** [**International Covenant on Civil and Political Rights**](about:blank)
    - Article 2 § 3 – “States undertake (a) To ensure that any person whose rights or freedoms … are violated shall have an **effective remedy**,”
    - Article 6 § 1 – “Every human being has the inherent **right to life**.”
    - Article 7 – “No one shall be subjected to torture or to **cruel, inhuman or degrading treatment**.”
    - Article 9 – Everyone has the right to **liberty and security** of [their] person”

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* **How the right to life relates to assisted suicide and euthanasia**
  + article 6 (1) of the International Covenant on Civil and Political Rights (ICCPR), (Right to life) **General comment No. 36** was updated in a [process](about:blank) that finished in 2018with the [final document](about:blank).
    - TVNDY submitted comments in 2017;
    - **Paragraph 9** – deals with assisted suicide and euthanasia:
      * ”While acknowledging the central importance to human dignity of personal autonomy, **States should take adequate measures**, without violating their other Covenant obligations, **to prevent suicides**, especially among individuals in particularly vulnerable situations, including individuals deprived of their liberty.
      * **States** parties that allow medical professionals to provide medical treatment or the medical means in order to facilitate **the termination of life of** afflicted **adults**, such as the terminally ill, **who experience severe physical or mental pain** and suffering **and wish to die with dignity**, must ensure the existence of **robust legal and institutional safeguards** to **verify that medical professionals are complying with the free, informed, explicit and, unambiguous decision** of their patients, with a view to **protecting patients from pressure and abuse**.
    - **Paragraph 24** – Persons with disabilities are entitled to:
      * **Specific measures** of protection so as **to** **ensure their effective enjoyment of the right to life** on [an] **equal basis** with others.
      * include the provision of **reasonable accommodation** when necessary to ensure the right to life, such as ensuring access of persons with disabilities to **essential facilities and services.**
    - **Paragraph 61** – “The right to life must be respected and ensured without distinction of any kind ... including disability, and age.
      * Legal protections for the right to life must **apply equally** to all individuals and **provide** them with **effective guarantees** against all forms of discrimination, including multiple and intersectional forms of discrimination.
      * **Any deprivation of life based on discrimination in law or fact is ipso facto arbitrary in nature.**
* **Related Issues**

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* + The [**Right to palliative care**](about:blank) is not covered in any specific treaties.
    - The [World Health Organization](about:blank) definition specifies that palliative care “intends neither to hasten or postpone death;”
    - Has been recognized as a component of the Right to the **highest attainable standard of health**;
      * UN Committee on Economic, Social and Cultural Rights (CESCR), article 12, [General Comment 14](about:blank), The right to the highest attainable standard of health, (11 August 2000) (“States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, to preventive, curative and palliative health services”)
      * paragraph 43: “States parties have a core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights enunciated in the Covenant, including essential primary health care, including … (d) To provide essential drugs.”
      * WHO [Essential Medicines in Palliative Care](about:blank) (1/2013) recommends Ibuprofen and morphine.
    - … and of the Right to be **free from** **cruel, inhuman and degrading treatment**

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* + A [new report](about:blank) from the Special Rapporteur on the Rights of persons with Disabilities is a thematic study on the **impact of ableism in medical and scientific practice.**
    - [Press release](about:blank): New eugenics: UN disability expert warns against ‘ableism’ in medical practice
    - Paragraphs 35:  Withholding and withdrawing treatment.
    - Paragraphs 36-38: AS/E: maybe for terminal illness, not for disability.
      * 37: “From a disability rights perspective, there is a grave concern that legalizing euthanasia and assisted suicide could put at risk the lives of persons with disabilities.”
      * “...[M]any disability rights advocates also oppose assisted dying in terminally ill contexts, as they fear it will put at risk persons with new or progressive disabilities or diseases, who may be mistakenly diagnosed as terminally ill but who have many years of life ahead of them.”
    - Paragraph 73 “... [E]ugenic aspirations persist in current debates related to medical and scientific practice concerning disability, such as … assisted dying.”

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* + - Paragraph 70: “If assisted dying is to be permitted, it must be accompanied by strong measures to protect the right to life of persons with disabilities.
      * “First, access to assisted dying should be restricted to those who are at the end of life; having an impairment should never be a reason for assisted dying to be permitted.
      * “Second, the free and informed consent of persons with disabilities must be secured on all matters relating to assisted dying and all forms of pressure and undue influence prevented.
      * “Third, access to appropriate palliative care, rights-based support, home care and other social measures must be guaranteed; decisions about assisted death should not be made because life has been made unbearable through lack of choices and control.
      * “Fourth, accurate information about the prognosis and availability of peer-support counselling must be provided.
      * “Fifth, accountability regulations must be established requiring collection and reporting of detailed information about each request and intervention for assistance in dying.

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* **For more information**
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