

Disability rights leadership institute on bioethics

UPDATE FROM CANADA – Amy Hasbrouck

April 24, 2014.

My name is Amy Hasbrouck. I'm the Director of Toujours Vivant-Not Dead Yet Canada. TVNDY is a project of the Council of Canadians with Disabilities to unify, inform and give voice to the disability opposition to assisted suicide, euthanasia and other ending-of-life practices that have a disproportionate and discriminatory impact on people with disabilities.

Canada is a small pond but I wouldn't want to have to row across it. Canada has one tenth of the population of the U.S. but it has a lot bigger land area. In a lot of ways Canada does feel like a small community. However, there are some important features about Canada. One is there are two major linguistic groups. As a pan-Canadian organization Toujours Vivant-Not Dead Yet works in French and English. Bridging languages and cultures like that makes our work especially tricky sometimes.

The state of the law as it currently exists in Canada: the criminal law comes from the federal statutes and there are several that relate to ending of life (which is how the council of Canadians with disabilities refers to this group of issues). The federal statutes say that people are obliged to provide the necessities of life for people who have disabilities or otherwise vulnerable due to age or other reasons. If a person in the protected class dies via negligence, that's a criminal violation.

There are the usual laws related to homicide, preventable death, accelerating death and murder. There is also section 241, an important statute that has to do with counseling and aiding suicide. In addition, section 245 has to do with administering a noxious (poisonous) substance. These two sections are the basis for

prosecutions in cases of assisted suicide.

There are two seminal cases that establish the current state of the law in Canada. The first is *Nancy B. v. Hotel Dieu*. Nancy B was a person with a degenerative disability who asked for the right to refuse medical treatment and have comfort care while she died. The Supreme Court recognized that right in 1992.

*Rodriguez v. British Columbia* was decided in 1993 by the Supreme Court, that dealt with section 241 of the criminal code. In that case the Supreme Court held that, though the prohibition against assisting suicide does violate Sue Rodriguez' rights to privacy and to determine the course of her life, that prohibition is necessary to protect people with disabilities. The *Rodriguez* decision discussed the fact that people with disabilities are an oppressed and disenfranchised group and that was because of the work of the Council of Canadians with Disabilities.

In that process advocates with disabilities in British Columbia split down the middle on this issue. A lot of them were friends of Sue Rodriguez (the plaintiff) and adopted her idea of self determination, while others who are informed by the Robert Latimer case realized that this was a situation where other people were negatively judging the quality of life of a person with a disability.

For those who are not familiar, Robert Latimer was a farmer in Saskatchewan who gassed his 13 year old daughter Tracy, who had cerebral Palsy. People who knew Tracy knew her as a lively, interested and active kid despite her very severe disabilities some of which caused a lot of pain. Robert said this was an act of mercy because she was in so much pain and her life was miserable, you know the drill. So the public response in the Latimer case was to believe the dad's version of the facts and tried to prevent him from serving jail time. But in fact the Supreme Court upheld his conviction and he ultimately spent ten years in jail.

So that brings us up to the current moment where we have several

cases that are under way. First of all, there's a case that is about to go to the Supreme Court called the *Carter* case and that relates primarily to a woman named Gloria Taylor who, like Sue Rodriguez has Amyotrophic Lateral Sclerosis. The trial judge ruled that the Supreme Court was wrong 2 years ago when it ruled in Rodriguez. This time the judge found that the danger was insufficient to totally ban counseling of suicide. The judge who made that decision at the trial level wrote a 400 page decision that she intended to be bomb proof. In that decision she did things like completely dissing the qualifications of Herbert Hendin, (a pioneer in suicide prevention) saying he was unqualified to testify on the issue. She came into the case with her agenda and wasn't going to let any facts stop her in making her ruling.

The appeals court on the other hand said that the legal principle that the case was already decided and should be left alone applies here. The lower court can't overrule the Supreme Court and can't re-decide the legal issue. So the Supreme Court will be hearing the case in the fall. Right now it's still illegal to counsel suicide in Canada but that's up for grabs.

There's another case that came out of British Columbia earlier this year. This is a woman named Margot Bentley who has advanced Alzheimer's disease. She didn't want any extraordinary measures taken should she develop Alzheimer's disease. Now she's being spoon fed because she has become unable to feed herself. Her family is arguing that's an extraordinary measure and she should be allowed to die. The hospital or the care home where she's living argued that they should be allowed to continue to feed her because she is eating and that is an expression of her will. In fact the lower court agreed that eating is an expression of her will. The court said being spoon fed is personal care and cannot be denied. That was a great ruling but the family has appealed, so that's bad news for us.

On the legislative side, in 2011 Québec began a process of studying the issue of "dying with dignity" which tells you where they were

starting from. Though a majority of people rejected euthanasia, the report from the Commission recommended life-ending legislation. Then there was a legal study that said if you call it medical treatment you can get around the federal anti-assisted suicide statute. So the Health and social Services committee of the National Assembly drafted and filed Bill 52 last June.

The bill is based on a very paternalistic idea; “we are going to accompany you to the end of your life, isn't that nice of us? Yes, we are so nice! We are going to make sure your life ends quickly and comfortably.” This bill was on the verge of passing when an election was called in February. There's now a new Liberal government, but the Liberals were actually the government that struck the original commission, so they are contemplating reintroducing the bill “as is” and are trying to jam it through on May 20. Stay tuned for details.

We're in a dangerous situation in Canada. We face a combination with the Québec statute and the *Carter* case that's going to be heard this fall; this is a very serious situation folks. People with disabilities are in a lot of trouble. Part of the problem here is that, both in Quebec and Canada people don't like outsiders coming in to tell them what to do. If you try to come into Quebec and you don't speak French with a Québec accent – right because you speak French but I'm not “pur laine” – you don't get very far.

In Québec also the disability community is very divided because the primary disability advocacy group is made up not only of people with disabilities but also of parents and service providers, so their loyalties are quite divided.

The other provinces are looking to Québec, to possibly follow Québec's lead in passing a euthanasia or assisted suicide law. And a couple of bills were introduced at the federal level – which aren't going to go anywhere – by a guy named Steven Fletcher who is a quack backed by women named Manon Perrault who is a paraplegic so that looks very bad for us.

The media are decidedly pro-euthanasia, both the French and the English media. About every six months or so there have been public campaigns by people demanding the right to assisted suicide. Susan Griffiths, year ago today she went to Dignitas in Switzerland she has some degenerative thing that was going to take ten years to kill her. She was still walking and still could do pretty much everything. She was not very disabled and raised a big storm about wanting assisted suicide. Then there was a doctor, a guy named Donald Low who issued a video after he died of cancer. and then there was a lawyer who has ALS and issued a posthumous letter just last month.

Efforts to get disabled people to be consulted as experts have really not been successful. We have had the same problems as in the United States being tarred with the same brush as conservative Christian people and discounted for that. Our organizing strategy right now is a combination of trying to defeat what's coming and doing damage control, and we are also trying to deal with actual and perceived division in the disability community.

Just one note I mentioned this in the small group. Toujours Vivant-not dead yet is trying to engage the community, the disability community in Canada in on-line discussions using Google Hangouts-on-air. People can come and talk about these issues. The English version is at 3:00 p.m. on Friday afternoons so if anybody is interested please feel free.

Thanks very much.