CSSFV - 068M C.P. - Loi conernant les soins de fin de vie

To the Select Committee on the Evolution of the Act respecting end-of-life care, thank you for taking the time to read my brief.

My son is a nonspeaking autistic. He learned a method called Spelling to Communicate about 5 years ago. He is 19 years old, and this method has enabled him to spell out his thoughts, desires and, most of all, he gets to determine what kind of life he wants to lead.

Many nonspeaking autistics have still not been given the opportunity to learn this method and are still trapped in their silent bodies, without a voice. They are judged by outward appearances and seen as "low-functioning", intellectually handicapped and misunderstood. Many of them have epilepsy and are unable to control their bodies due to severe apraxia.

It is often recommended that parents get a mandate for their adult nonspeaking children/dependants. Our stance is that no one in a position of power should be able to decide for a nonspeaking/minimally/unreliably speaking person, whether they should live or die. If they can not communicate reliably, it would be unethical to assume how they are feeling based on outward behaviours when it comes to MAID.

Here is a link to a YouTube video of a nonspeaking autistic also spells to communicate. He explains what it's like to be trapped in an apraxic body.

https://www.youtube.com/watch?v=9teZwNf8dP0&list=PLgrsMIzLQG2Wc5VvtoexU-VK34CEcfctC&index=24

Please don't hesitate to contact me if you would like to know more. My son would also be happy to communicate with you.

Thank you for your time. Lori Anne Lanigan