

M-192, EPISODIC DISABILITIES

Ottawa, December 7th 2018

To whom it may concern,

My name is Guillermo Boccagni I am an individual diagnosed with multiple sclerosis who can sustain a normal life but knows that many Canadians with the same illness have not the same luck. In these next lines I express my support to modifications on pertinent policies and practices.

Five reasons to support legislative and policy changes to ensure that the needs of persons with episodic disabilities caused, among other things, by multiple sclerosis, and other diseases be adequately protected to guarantee equity in government policy to support Canadians across all types of disability.

Lack of flexibility on disability criteria

I personally think that the current programs intended to help Canadians with disabilities, is lacking in the inclusion of certain individuals affected by illnesses like multiple sclerosis and other episodic diseases. The standards of the process to be considered a disable person follow a yes or no criteria excluding most people affected by episodic diseases. Ironically, programs that are aimed to include Canadians, can also exclude Canadians, creating a sub-group of Canadians with necessities and basically no help. For example, while inquiring if someone qualifies to the Disability Tax Credit (DTC) you need to answer the following question: "Has your impairment in physical or mental functions lasted, or is it expected to last, for a continuous period of at least 12 months?" People with multiple sclerosis cannot answer this question. Moreover, doctors cannot answer this question with certainty.

Unpredictability

The fact that doctors cannot tell you if you are going to be continuously affected by a physical or mental impairment, is due to the unpredictable character of most episodic diseases such as, multiple sclerosis. Patients like me can lose functionality of a limb overnight and suddenly recover in a matter of days. Also depending on the case, this expected or hoped recovery has the potential to take years or even a lifetime. We could say that in these types of cases, people could or should easily qualify for disability benefits, due to the long tenure of the imparity, but what if you have several episodes in a few years, with periods of relapsing and recovery? Nevertheless at that point, and if eventually we could get help for these cases, this assistance may come a little late: the affected individual has already been helped financially and emotionally by his or her family. In any case, the person is forced to place a burden on the rest of the members of the family group.

Burden on the family

It may not be correct to consider a person with disability to be a "burden", but in practical terms having to work part time or nothing at all for several months, affects family income, consumes savings and severely distresses life plans of all members of the family. The idea to study, buy a home or decide to have a baby are in jeopardy if not postponed indeterminately, not only for the difficulty that the disability imposes but also for the financial void that one less income perpetrates in a family.

You could say that, that unemployment insurance is to cover for the temporary inactivity. However, most of Canadians affected by for example, multiple sclerosis, have been diagnosed even before they were able to hold their first full-time job.

Young people affected

Yes, most of the patients diagnosed with episodic diseases like multiple sclerosis are diagnosed when they are between 15 and 40 years old. Individuals whom the illness is detected, are usually planning their future and dreaming to contribute to society. The diagnosis comes after perceiving a series of recurring symptoms or after a sudden and heavy appearance of one or more symptoms that sometimes, like in my case requires hospitalization. After you learn you have multiple sclerosis, you will understand that life will be always harder for you. You will see that dreams and plans will most likely be unreachable. And most importantly, you will know all this just in that part of your life in which you are chasing your dreams, when your mind is exploring and creating new things, when your talent is ready to give its fruits to the rest of society.

Luck is not the answer

I can say that I was lucky. I was diagnosed with multiple sclerosis in 2015 and with the help of my wife, I was able to undergo a gradual recovery. That recovery allowed me to apply to a Master's program, and I am on track of finishing it. Today I am working for the federal government five days per week, eight hours per day for the first time since I was diagnosed, something that seemed unattainable not too long ago. However, regardless of the amazing love and care of my wife, who not only helped me to eat and take showers for months but also had to carry the burden of sustaining financially and emotionally our home, I am mostly writing this because I am lucky. Yes, I have the luck of never being hit by a severe episode since my initial recovery. Multiple sclerosis could have made its appearance on my body, any time in these three years.

I think that Canadians with multiple sclerosis and other episodic diseases should not be forced to rely on luck. I am writing this because I know that other people can't. They struggle to get out of bed, to maintain a job, read a computer screen or even to hold a piece of paper with their hands, and yet, they are not considered people with a disability because their impairment is temporary.

These are the reasons why I think we should take measures to ensure a more equitable policy for all Canadians suffering from episodic disabilities. I hope this message reaches to all those in doubt and I ask again for your support in this matter.

Sincerely,

Guillermo Boccagni

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