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Chair

Mr. Bryan May

Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities

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● (0850)

[*English*]

The Chair (Mr. Bryan May (Cambridge, Lib.)): Good morning, everyone.

Pursuant to the order of reference of Friday, November 2, 2018, and the motion adopted by the committee on Tuesday, November 20, 2018, the committee is resuming its study of M-192, on episodic disabilities.

Today, the committee will be hearing from witnesses, but before that, I have a quick announcement. The vice-chairman of the China Disabled Persons' Federation and the ambassador of China to Canada have expressed interest in meeting with members of this committee. The Canada-China Legislative Association is hosting this meeting on Thursday at 10:55 a.m. in room 8-53, 131 Queen. I will be attending, and I invite any members of the committee to join.

Appearing as an individual today we have Michael Prince, Professor of Social Policy, Faculty of Human and Social Development, University of Victoria. Welcome back, sir. We also have John Stapleton, Principal, Open Policy. Welcome.

From the Disability Tax Fairness Alliance, we have Lembi Buchanan, Founding Member. Welcome.

From the Multiple Sclerosis Society of Canada, we have Patrycia Rzechowka, Ambassador and Spokesperson.

From Neurological Health Charities Canada, we have Deanna Groetzinger, Manager, and Deborah Lovagi, Representative.

Thank you to all of you. You're each going to start with seven-minute opening statements. Don't panic if you go too long. I'll just wave at you politely, but you don't have to stop immediately. You just need to wrap up your comments.

We're going to start this morning with Michael Prince. The next seven minutes are all yours, sir.

Prof. Michael Prince (Professor of Social Policy, Faculty of Human and Social Development, University of Victoria, As an Individual): Thank you, sir.

Good morning, everyone. It's nice to be back, although I say that somewhat ambivalently, coming from Victoria. The weather is a bit of a waker-upper.

I'm going to focus in my opening remarks specifically on the employment insurance sickness benefit program. I'm happy to talk about other programs and other issues later on.

I want to make five basic points around EI sickness benefit, not only in terms of people with so-called episodic disabilities, but also for other Canadians with whatever kinds of disabilities we may wish to call them, who are working.

The first point is to extend income protection. As members know, there's a 15-week maximum duration period for EI sickness benefit. That's been unchanged since the benefit was first introduced in 1971. Unlike almost every other feature of EI, including all the other special benefits, which have had their periods extended or durations expanded, this one has been left unchanged since 1971.

Canada also has one of the shortest periods of sickness protection among industrialized countries. In fact, there are only a few countries with such a modest coverage of protection. As members know, approximately 35% of EI sickness benefit clients each year exhaust or use up all 15 weeks of their benefit. That represented about 135,000 people in 2016-17, which is the most recent figure available.

The first point is to improve program coverage by extending coverage to the equivalent of 26 weeks, as with other special benefits.

The second point is to enhance accessibility and program flexibility in the take-up. This is to again recognize the episodic or recurring, cyclical nature of disabilities to allow eligible claimants to access their entitled benefits over a longer time period than one year, and to access them in chunks of time, over say, a two-year period.

The third point is to give greater emphasis on individuals. This means more of a client-centred approach to the delivery of services —what we sometimes call a case management approach—providing continuity of service to clients. This would include a greater emphasis by the EI program on early assessment, identification of health conditions, and the consideration of supports and interventions earlier rather than later.

Where appropriate within the EI and ESDC mandates, it may also more likely involve referral on health issues earlier on to other, more appropriate authorities—federally or provincially—to alleviate longer-term problems or prevent them from getting more serious. This could also involve advice to employers on job accommodation and workplace adjustments. The focus there would be on both the capacity of the individual—not just on their inability—and on the trajectory of their likely episodic or other disability conditions.

The fourth point is to encourage work capacity or potential: keeping people employed when appropriate and where possible, with on-the-job supports. This would also involve perhaps reviewing the 50% marginal tax rate on earnings that people experience while they're on EI sickness benefit. Above the so-called “earnings threshold”, any money earned right now is deducted dollar for dollar. That's a 100% marginal tax rate.

Clearly, we can send a different signal of work incentives and encouraging employment where possible. It's shifting the emphasis of the program from looking at the inability and incapacity to work, to recognizing the intermittency of their conditions and the periodic capacity to work.

The fifth and final point would be to review the medical certificate used in the EI sickness benefit program and the policy and procedures around it. This would include, to be very specific, paragraph 18(1)(b) of the Employment Insurance Act and section 42 of the EI regulations.

This would also include looking at the content of specific forms. I'm sure my colleague Lembi will be talking about the forms around the DTC later on.

The concept of probable duration, where a physician or other medical practitioner has to give their best professional opinion as to what the probable duration is of the incapacity to work due to illness or injury, needs a review if we're truly going to incorporate the concept of episodic disabilities into the medical assessment and certification. The medical certificate also gives emphasis to the language around inability to work, as opposed to partial capacity to work and intermittent capacity to work.

I think if we shift the culture, we shift the attitudes and we signal stronger work incentives.

● (0855)

Clearly, that kind of review of the medical certificate would involve consultations with health professional bodies in this country, disability organizations, and EI program staff of course. It would also draw on the research and analysis branch of the Department of Employment and Social Development Canada.

That's it for EISB. I'm happy to talk about other policy tools within the federal government's tool kit around how to advance better equity and opportunity for Canadians with episodic disabilities.

I'll leave it there. Thank you.

The Chair: Thank you very much, Mr. Prince.

Now we go to Mr. John Stapleton, principal of Open Policy. You have seven minutes, sir.

Mr. John Stapleton (Principal, Open Policy, As an Individual): Thank you very much. I appreciate the opportunity to be here, Mr. Chairman, members, staff and fellow guests.

I'm going to talk about disability income programs this morning. I will look at 10 programs, or 10 systems. I'll say them slowly, in no particular order: one, the RDSP, with which you're all familiar; two, the Canada workers benefit; three, the disability tax credit; four, EI sickness; five, the Canada pension plan disability; six, social assistance in all the provinces, with special programs for people with disabilities; seven, workers' compensation; eight, veterans programs, for which there are large programs in place for veterans with disabilities; nine, workplace programs that are paid for by the private sector, so programs that are not government programs; and, finally, number 10, which is auto insurance.

If we look at the income security landscape from 10,000 feet, we see that there are 10 different systems. I wouldn't even call them programs. More and more—and I think we saw it just a couple of weeks ago—disability income programs have tended to reimburse or pay for a disability, as opposed to looking at the whole person and providing income support for people with disabilities.

It's a subtle distinction. We used to talk about “the disabled”. We no longer do that. We talk about “people with disabilities”. That's when we can start to think more comprehensively about the idea of episodic disabilities and how they fit. In other words, you may be asymptomatic one day, and you might be in a wheelchair and unable to walk the next day.

Disability income programs have had trouble with that over the years and over the decades. They want to see that permanent, significant disability that's in place for a prolonged period of time, for at least a period of several years. This means that a lot of people with episodic disabilities actually don't qualify for benefits, because they can't meet that standard.

That's particularly what I want to recommend today. We really need to look at it holistically. I wouldn't just restrict my comments to federal programs. Let's look at federal, provincial, and also at the private sector. Let's look at what they do. Rather than having 10 different complicated definitions of disability, let's look at trying to have some convergence so that we can bring coherence to these programs.

It's easily said, but not easily done. However, if we had the type of review of disability programs that I'm calling for, we would be able to look at those definitions that particularly leave out people with episodic disabilities.

There are three attractions for what we call a guaranteed annual income or a basic income for people with disabilities. The first is that programs would not be work-triggered. In other words, we would look at programs as a matter of right. Second, we would not place time limits on them. One of the attractions of a basic income is that it's not time-limited, regardless of how all these experiments have gone. Third, they would be adequate.

Right now, most disability income programs are not permanent. They have time limits, like employment insurance, as Michael just said. Workers' compensation generally restricts itself to two years. Veterans programs are not necessarily permanent, and certainly workplace programs that used to observe a much longer period of time generally restrict themselves to two years.

Disabilities are not on any schedule. They don't observe time limits, but our programs do, and that's where we need to be more flexible.

Most disability income programs are triggered by work. You have to get them based on work. That's EI, CPP, veterans, workplace programs and workers' compensation. They all get paid after you've worked. If you haven't worked, you don't get them.

Not everyone has worked, so they can't get these programs, and in many cases they must go on social assistance. Social assistance over the years and even now is becoming the largest single set of programs that people with disabilities have to rely on. In many cases, that's unfair. They have to deplete their asset; they have to deplete their incomes. You might hear a bit more of that this morning.

People who get work-triggered programs often get inadequate benefits, because if you're a person with a disability, you likely have not paid the maximum into that system over the years, so you're going to get much less money. That's why people are attracted to a basic income, as it's not work-triggered.

● (0900)

I know we've talked a lot about Bill C-81 for the last little while, but I am going to mention in closing Bill C-87, which has now received first reading, but I'm just going to mention it in closing. It targets 20% poverty reduction by 2020, and that's going to be done. I think the government will meet its targets by changes that have been put in place for seniors, with the guaranteed income supplement, and for children through the Canada child benefit.

Over the next 10 years, we have to reduce poverty by 50%. We use a swimming pool analogy. We talk about shallow poverty, and we talk about deep poverty. That's when we're going to have to get into the deep end. It seems to me that Bill C-87, as a poverty reduction act, is cause for a comprehensive review, which I would call for in terms of people with disabilities. We need to remove them from poverty by 2030 and be able to marshal the resources into all of the programs, all of those 10 systems, to bring about the sort of change that we could get. It would be inclusive of people with episodic disabilities. There's no way we're going to get to that 50% by 2030 without having that as a big part of the process.

Thanks very much.

● (0905)

The Chair: Thank you.

Next, from the Disability Tax Fairness Alliance, we have Ms. Lembi Buchanan, founding member, for seven minutes, please.

Ms. Lembi Buchanan (Founding Member, Disability Tax Fairness Alliance): Thank you very much for the opportunity. I want to thank all of you for your interest in this subject. I see pretty much a full table. I think that's important in terms of the interest in disability issues.

The Disability Tax Fairness Alliance is a coalition of more than 25 members. We're committed to ensuring that the administration of the disability tax credit reflects the realities of the people with disabilities, as well as the parliamentary and legislative intent of the tax credit.

I'm also a member of the disability advisory committee established by the Honourable Diane Lebouthillier last year. Our mandate is to advise the Canada Revenue Agency on interpreting and administering tax measures for Canadians living with disabilities in a fair, transparent and accessible way. This disability advisory committee existed in 2005-06. I was a member also. Unfortunately, it was disbanded at that time and now it has been reinstated.

For more than 20 years, I have advocated fairness for individuals living with chronic and persistent psychiatric disorders, where individuals are markedly restricted in their mental functions all or substantially all the time, as required by the Income Tax Act, even though the external signs and symptoms may be perceived to be intermittent or episodic.

People living with so-called episodic disabilities face unique barriers qualifying for the DTC, largely because the disabling effects of their conditions are not well understood by policy-makers.

In 1998, my husband, Jim, severely impaired by bipolar disorder, was denied the DTC. The reason was that the federal government did not recognize that people living with mental illnesses could be as severely impaired as those with physical impairments. I successfully appealed on his behalf to the Tax Court of Canada, and that decision was upheld by the Federal Court of Appeal.

Although psychiatric disorders are chronic medical conditions, many individuals benefit from drug therapy and are able to live well. Still, a small percentage continue to be vulnerable to a wide range of symptoms affecting the way they think, feel and relate to others. The unpredictability of symptoms of the condition, which is always present, can create marked restrictions on their mental functions.

CRA defines the phrase “all or substantially all of the time” as being at least 90% of the time. Even though this arbitrary guideline is not supported by legislation or jurisprudence, CRA enforces its narrow and technical interpretation of the Income Tax Act with impunity, making it virtually impossible for many individuals living with episodic diseases to access the tax credit.

Numerous Tax Court of Canada cases indicate that the 90% threshold is not a suitable guideline for complex medical conditions, where the expressions of symptoms may be perceived to be intermittent. I will share two of them with you, and there are more in my submissions. You can find additional Tax Court cases regarding the subject on my personal website, www.fightingforfairness.ca.

In Bruno Maltais v. The Queen, Judge Alain Tardif recognized that individuals living with mental impairments did not exhibit these symptoms continuously, stating the following:

> The vulnerability for a relapse was always present even though the outward signs are not always visible or apparent. Moreover, a person who has such a disability may break down at any time without there being any indications or warning signs.

In Peggy Doe v. The Queen, Judge Gerald J. Rip also noted in his ruling the special circumstances of an individual diagnosed with epilepsy as well as a number of psychiatric disorders, including PTSD:

> When a person does not know from one moment to another when a seizure will occur—but knowing a seizure will occur, even with medication—that person's ability to perform any activity, including an activity of daily living, as defined, is markedly restricted.

In recent years, eligibility for the DTC has enabled Canadians with disabilities to access numerous other federal and provincial income support programs, including the registered disability savings plan.

● (0910)

However, the loss of DTC eligibility means not only that the RDSP must be terminated, but also that all grants and contributions made by the government in the previous 10 years must be repaid. The majority of individuals living with so-called episodic diseases are required to reapply for the DTC every five years. Thousands of these reapplications have been denied without a valid reason, even for individuals who have been receiving the tax credit for 20 years or more. The cumulative total repayment of government contributions since 2010 is $52 million—$52 million has been clawed back. Such a practice is unconscionable.

Our alliance has two recommendations. First, address the systemic problems and inequities in the administration of government income-support programs for people living with chronic and persistent mental impairments, to ensure parity with physical impairments, even though the signs and symptoms may be perceived to be intermittent. Second, amend the terms of RDSP withdrawals for Canadians with disabilities who are denied the DTC, in order to prevent clawback of contributions made by the federal government in bad faith.

Thank you very much for this opportunity to share our concerns and recommendations.

The Chair: Thank you very much.

From the Multiple Sclerosis Society of Canada, we have Patrycia Rzechowka, ambassador and spokesperson. The next seven minutes are all yours.

Ms. Patrycia Rzechowka (Ambassador and Spokesperson, Multiple Sclerosis Society of Canada): Good morning. I would like to thank MP David Yurdiga for sponsoring motion 192, and I'd like to thank this committee for taking the time to study and create recommendations to improve the lives of Canadians living with episodic disabilities such as multiple sclerosis.

My first real experience with MS came at a young age. I remember seeing my neighbour out walking every day. Some days she would be walking perfectly normally, other days with a limp, and some days she had to use a cane. I couldn't understand it. One day I saw her with the cane, and I asked my parents what had happened to her, whether she'd broken her leg. They told me she had MS. At that time, it didn't mean much to me, other than that it was something awful that I didn't really want to think about, so I didn't. It wasn't until about 15 years later that I really understood what I saw and what my parents told me. Every day she went for her walk, she made a choice to fight MS. And all those years later, sitting in an emergency room blind in my left eye, I had to make that same choice.

I knew something was very wrong when I began to lose vision in my left eye. It went from soreness to blurriness to blindness, all within a few days. After a visit to an emergency eye specialist, and one more eye specialist after that, the diagnosis was optic neuritis. Optic neuritis is often but not always one of the first symptoms of MS. I was told I needed to get an MRI, but it wouldn't be until three months later. I managed to get on a cancellation list and got an MRI a few weeks later. A few days after the MRI, I saw a neurologist and I was told I have MS. My world has not been the same since.

I had spent so much time hoping for the best but preparing for the worst that, when I finally heard those two letters, I want to say I was ready for it, but I wasn't. All I could do was think, "What now? What do I do now? What is my life going to look like now?"

Who I am today may not be who I wanted to be, or thought I would be, but I am who I am today because MS changed my path. MS, if you can believe it, has given me many opportunities, like sitting right here in front of you, but it has also come with many struggles—struggles physically, struggles psychologically, and all the struggles that come with having an illness that is not well understood. It took five months for me to fully regain my vision, but other times it's taken two weeks. MS is often invisible and always incredibly inconsistent.

Many of my struggles with MS have been as a result of other people not understanding it. I get that—MS is so unpredictable. Sometimes, though, this lack of understanding can mean something like the difference between getting a job or not. When I applied to become a police officer, the police service tried to disqualify me because I disclosed my diagnosis. I had to fight to even be allowed to apply. I had to fight at every stage to be the best, and in the end even my best wasn't good enough. Meeting every single standard, and often far surpassing it, was not enough, all because of the fear of what could happen to me. I was seen as a liability, even when all of my qualifications and test results should have made me be seen as an asset. I was a woman with a criminology degree who had previously worked for both the RCMP and Edmonton Police Service. I was fluent in Polish and had volunteered all my life. But none of this was enough.

It is detrimental to anyone's quality of life and mental health to want to be productive and contribute to society, to want to use their skills, education and talents, but not be allowed to do so—not because of anything they did, not because of anything they can control, but because there is a chance that they might be temporarily disabled for a short period of time. When I was diagnosed with MS, I really didn't want anyone to look at me or treat me differently. However, this was out of my control. I want to feel useful; I don't want to feel like a burden. I'm lucky I have my family to rely on in case I ever need help, but I want to be able to take care of myself.

I am also incredibly fortunate that my current employer didn't think twice about hiring me, and has not hesitated to keep me. But having MS has forced me to make decisions about jobs that are based on having to play it safe because I need the medical coverage and I need the health benefits. Even if I wanted to take a risk, I couldn't. What if something happens and I can't work for two weeks? How would I pay my mortgage, my car payments, my insurance and everything else? I have previously worked through blurred vision without telling anyone, because I was terrified that I would lose my job before I was permanent.

I pay for everything on my own. I cannot get the proper amount of funding for the physio, massage and exercise that helps keep me healthy and off the $16,000 medications that I qualify for. I have no additional support. I have many hard days when it would be so easy to give up, but I make the choice to fight MS every day.

● (0915)

"Get up, Patrycia. Just get up. All you have to do is get up." This is almost every morning for me. I am totally exhausted no matter how much I sleep. I have trouble falling asleep because my legs are restless or because I am in pain. You would think the fatigue from working a full day, exercising and volunteering would be enough to knock you out, but even after a long day, I have a difficult time falling asleep.

You may wonder what gets me up. It's knowing that I have somewhere to be, knowing that I have responsibilities and that I have purpose. I can't imagine if my ability to work were taken away, all because I might need a little extra support. I have fought through fatigue, through tremors, muscle spasms, brain fog, numbness and tingling, unbearable pins and needles, blindness and much more. I can fight through many things, but the fear of the unknown is something that will always be one of the most debilitating symptoms of MS.

The changes as a result of this motion can help make those unknowns much more manageable.

I want you all to think about the last time you did something that scares you. Usually we think of something like skydiving, bungee jumping, roller coasters or touching a spider or a snake. Now, for a moment, I want you to imagine that the scariest thing you have to do is go to bed at night, not knowing if you're going to be able to see when you wake up, or walk, or speak, or eat or even have the energy to get out of bed. This is the reality for many people living with MS. Waking up each day is an adrenaline rush. Waking up knowing that you will be supported no matter what would make going to sleep at night not nearly as frightening.

I applaud this committee for studying this motion. This will increase awareness of episodic disability in Canada. By viewing the policy and legislation through an episodic disability lens and recommending important changes, we will achieve better equity in the supports for Canadians living with episodic disabilities.

Thank you so much for the opportunity to speak.

The Chair: Thank you for being here.

Up next, from Neurological Health Charities Canada, we have Deanna Groetzinger, Manager; and Deborah Lovagi, Representative.

You have seven minutes, please.

Ms. Deanna Groetzinger (Manager, Neurological Health Charities Canada): Thank you very much.

Thank you for the opportunity to present on behalf of Neurological Health Charities Canada. NHCC is a coalition of organizations that represents millions of Canadians living with brain disease, disorders and injuries. I am sharing this time with Debbie Lovagi, who has an acquired brain injury.

I will make some overall comments and recommendations, and Debbie will speak about how a brain injury has affected her life and her ability to work.

Brain conditions are the largest cause of disability worldwide. One in three Canadians will be affected by a brain or nervous system illness, disorder or injury, including mental health conditions, within their lifetimes. Disabilities that develop as the result of a brain condition can occur at any point along the life course, and a number of them are episodic in nature. This means, as you've heard from all of the witnesses, that there are periods of worsening that can vary in severity and duration. Remissions can happen, but the periods of worsening and remission persist for the lifetime of the individual. Examples of brain conditions that are episodic are dystonia, epilepsy, migraine, multiple sclerosis, Parkinson's disease and conditions such as depression and other mental health disorders.

As you have heard from the other witnesses, current programs such as the Canada pension plan disability and the disability tax credit are not flexible enough to assist most individuals who have episodic conditions that worsen. In most cases, the language of “severe and prolonged” disqualifies those whose conditions may not be considered prolonged enough.

Some other jurisdictions have recognized that disability can be episodic. British Columbia’s disability eligibility definition states that “the person’s ability to perform daily living activities” can be restricted either continuously or “periodically for extended periods”. Ontario’s definition states that a disability is “a substantial mental or physical impairment that is continuous or recurrent, and is expected to last one year or more”. Sadly, Ontario appears to be moving away from this definition toward the more restrictive Government of Canada definition.

NHCC is encouraged that Bill C-81, the accessible Canada act, recognizes that a limitation can be permanent, temporary or episodic in nature. We applaud this language and hope that this will help ensure equity in government policy and programs that support Canadians living with all types of disabilities. I hope the committee's study today can help push that along.

More immediately, NHCC urges the committee to consider the following recommendations, some of which you have heard from the other witnesses. First, modify the eligibility definition for the Canada pension plan disability benefit to include disabilities that are episodic or recurrent in nature; modify the eligibility definition for the disability tax credit to make it clear that persons living with episodic disabilities can be eligible for the credit; increase EI sickness benefits from 15 weeks to 26 weeks, with expanded flexibility for partial work and partial benefits for individuals who can work episodically.

On a longer term, use the recommendations you heard from the witnesses so far—Michael Prince, John Stapleton and Lembi Buchanan—as well as an excellent report by the Institute for Research on Public Policy, “Leaving Some Behind: What Happens When Workers Get Sick”, to work with other governments, employers and insurance carriers to revisit definitions of eligibility and establish a comprehensive approach to address the needs of Canadians living with episodic disabilities.

I will now turn the remaining time over to Debbie.

● (0920)

Ms. Deborah Lovagi (Representative, Neurological Health Charities Canada): Good morning.

In 2015, within a short period of time, I suffered two acquired brain injuries. The first one happened when a display board fell on my head when I was at a contract job. Five weeks later, I had a second ABI, acquired brain injury, when my car was rear-ended.

I lost my balance. I had no depth perception. I had pressure and ringing in my ears, a severe stutter, severe depression and now PTSD. I could not walk a straight line. I couldn’t read or write without nausea. I couldn’t stand alone. I couldn’t speak without stuttering.

I lost my job. My family and some of my oldest and dearest friends did not understand my brain injuries or PTSD. I heard over and over again that I was not in the military, so how was it possible for me to have PTSD?

Some days are better than others, but a good day can be followed by a bad week, sometimes months. I found a system navigator who helped me find the Vista Centre, an organization that helps people with disabilities find employment. I need an income, but I still have many symptoms from the two brain injuries. I have yet to find suitable employment.

However, through hard work, determination, pure tenacity, my new team and teamwork, I am slowly improving. Every day I tell my brain not to stutter, to walk a straight line, to try to remember more than five things. I am working on these messages, and I will continue until I have completely trained my brain.

I have come far from where I was over three years ago. I have found ways to function. I take many breaks. I try to be mindful through nature. I have potted flowers and vegetables. The plants and the dirt keep me grounded. I enjoy walking again. There are things I still cannot do, but I have not given up on change. I am allowing my brain to reprogram.

I have tried to accept that I am different. I need other people to accept me now for who I am. I have an invisible disability that affects every facet of my life, but I am determined to be the best Debbie I can be.

Thank you.

● (0925)

The Chair: Thank you very much.

Thank you to all of you.

We're going to start with MP Diotte for six minutes of questions.

Mr. Kerry Diotte (Edmonton Griesbach, CPC): Thanks to everybody for coming here, and especially for some of the heartfelt, personal stories. I know that it's very difficult, but it helps us to understand so that we can get the best result here.

Mr. Prince, you talk a lot about some of the benefits, including EI. We're talking about extending it from 15 weeks to 26 weeks. Can you just explain the typical problems that people with episodic disabilities have right now when they apply for EI? What's the biggest stumbling block?

Prof. Michael Prince: I don't think we really know, to be honest. First of all, the category of episodic disability is a very multi-dimensional one, a very complicated one. There are a variety of trajectories. For some people with episodic disability, their experiences of progressive trajectory have declined. Others are actually experiencing a trajectory of recovery. Others are stable. Some are visible. Some are invisible.

In that regard, sir, it might be a function of what the interaction is between the person and his or her physician: whether the person has a family physician or obtains a medical practitioner who will complete the certificate, and the understanding that this professional has of what the person's condition may or may not be. I think we heard some testimony here this morning about how sometimes that's not always readily apparent or readily at hand.

Many professionals do not understand these conditions—not just policy-makers, governments or bureaucrats, but medical practitioners. We see that with the DTC. We've seen that for many years. I think part of it is the awareness not only of employers and employment, but also of the people who are gatekeeping at the front door of these programs who assist individuals in completing the necessary documentation.

People could have a range of experiences in trying to explain what it is that they have, get it acknowledged, and then awkwardly try to squeeze their very complicated, multi-dimensional experience into some forms. That's why I think the devil's in the details. Part of it is looking at how we experience that encounter across the so-called “front desk”, as we used to call it, on service delivery, whether it's online forms or what have you.

That's a vague answer, but I think part of it is that we don't have a solid enough understanding of that experience beyond various organizations' members and anecdotally. In terms of good statistical analysis, that work is being done and is yet to be done.

Mr. Kerry Diotte: When people walk in—say, they do explain—and they say, “I could be good this week and bad next week,” is the program suited to them right now, or is it again a push toward saying, “You're either disabled or not disabled?”

Prof. Michael Prince: The EI sickness benefit is probably the most flexible of the ones we're talking about, because it's focused on the short term. It probably has the least onerous medical assessment procedure, compared to the disability tax credit. It is certainly far less onerous than the Canada pension plan disability program. Its definitions are far more open that way.

In many ways, what I've been making a pitch for here this morning is that these are to benefit Canadians across a range of disabilities, not just specifically episodic. Where we see the episodic disability experience perhaps benefiting from these reforms is in more flexibility in being able to draw down the benefits: not just in a 15-week chunk of time, but to extend the benefit to 26 weeks, and extend the window of being able to access or draw down those benefits in more flexible chunks of time, over a longer period of time, to recognize that recurring or cyclical element.

It won't fit for everybody, because of the great diversity of episodic disabilities, but it will go some measure toward responding to the lived experience of a lot of people.

● (0930)

Mr. Kerry Diotte: Just on that, John, you talked about how most of the disability programs are work-triggered. What do you envision as the solution? I think you're leaning toward assured annual income. Is that correct?

Mr. John Stapleton: I'm not so much leaning toward it, but just trying to impart the understanding of why it's so popular.

When you have programs where the only way you can get them is to have worked, it means that probably for a good part of your life you have been disability-free and then you've had a later-onset disability. I'm trying to point out that even with those programs—EI sickness, which Mike talked about, CPPD, workers' compensation, veterans programs, workplace programs and the like—if you're a person with episodic disabilities, and that's what we're talking about here today, you probably spend a good period of time off work, more than the average person would, due to sickness.

These programs are mostly contributory. When you have to contribute to them, there are two ways you get to the maximum benefit. One is that you work a considerable number of your work years, and you also contribute at the maximum amount throughout that period. What that means, therefore, for people with episodic disabilities, is that when they actually come to benefit from these programs, they haven't paid enough into EI. They haven't paid enough into CPP. They haven't paid enough into a workplace program to get any type of adequate benefit from that.

The case I would make is that once we recognize episodic disabilities, we have to think up new ways to make the benefits adequate.

The Chair: Thank you very much.

MP Long, go ahead, please.

Mr. Wayne Long (Saint John—Rothesay, Lib.): Thank you, Mr. Chair.

Good morning to everybody, and good morning to our witnesses. It's very informative. Thank you for your courage in coming this morning.

Mr. Prince and Mr. Stapleton, these first questions will be targeted to you. In this study, every time we talk about expanding EI or CPP benefits, my Conservative friends say that we're increasing payroll taxes. These programs have to be funded from somewhere.

Would you classify payments to contributory benefit programs as payroll taxes, Mr. Prince?

Prof. Michael Prince: Yes. That's a pretty traditional definition of social insurance program premiums or contributions. What's interesting is that often Canadians themselves don't see them as taxes but as contributions or premiums like those to a life insurance program, but in social insurance.

If I can be very specific on the idea of expanding EI sickness benefits from 15 to 26 weeks, we're looking perhaps at a financial cost of somewhere between $50 million a year and $100 million a year. The sickness benefit right now is over $1.5 billion a year. It's part of the larger EI program, which is a magnitude order larger than that. We're looking at an incremental additional cost of perhaps 4% or 5% to the overall budget.

It would also be an investment in early interventions and job retention, so that these people would not be opting out of the labour force. They would be continuing to work and making some premium contributions.

Again, in that analysis, the harder numbers need to be done, but this is actually a sound investment. It's not a big ask in terms of a fiscal hit to the program.

● (0935)

Mr. Wayne Long: Mr. Stapleton, go ahead.

Mr. John Stapleton: Once again, I would like to look at the larger picture. In terms of gross domestic product, Canada has north of a $2-trillion economy, and the total amount of money that's paid out in income security benefits of all types is somewhat north of $180 billion, meaning that we spend about 8% of our gross domestic product on benefits of various sorts.

When you compare that with other OECD countries, we're somewhere around the middle. We're certainly not overspending in that way. When you take the programs that you specifically noted, our contributory ones, we have three of them. We have workers' compensation, where the levy is on employers; EI, where it's on employers and employees; and CPP, where it's on employers and employees.

In fact, those payroll taxes are the largest single source of our income security programs—as you say, where the money comes from—with federal taxes being next, and then provincial taxes after that.

Do we need to increase the amounts? We've gone through the last 25 years where EI premiums have actually moderated and stayed down. CPP premiums certainly have not increased over the last many years. I would simply say that, on both programs, we have the room to make moderate increases so that we can actually meet people's needs.

Mr. Wayne Long: So you would both agree that it would be worth increasing the premium, if needed.

Prof. Michael Prince: Yes, I would.

Mr. Wayne Long: Thank you.

Also, other testimony we heard about EI sickness benefits is that they be provided for 75 days rather than 15 weeks, to allow more flexibility for episodic disabilities. Just to give you some background, I suffered from anxiety way back in my twenties. If there had been a program that provided more flexibility for me, it would have been very helpful because, some days more than others, my anxiety was much worse and I had trouble coping.

What would you think about 75 days rather than 15 weeks, Mr. Prince?

Prof. Michael Prince: That would be a start toward flexibility. In 1996, when UI became EI, we moved from a weeks-worked basis to an hours-worked basis to determine eligibility. It shouldn't be an administrative nightmare or incredibly complicated to move to an hours-based form of....

Mr. Wayne Long: You'd like that. You'd like that change.

Prof. Michael Prince: Yes, I think that would be more flexible.

Mr. John Stapleton: As I said earlier in my opening remarks, disabilities are not on any schedule. They don't observe time limits, and yet so much of our income security system bases itself on arbitrary time limits. Fifteen weeks is not a lot when you think of various types of workplace mishaps and other life mishaps. You need more than 15 weeks.

The bills that you have for mortgages and groceries and things like that, they don't stop during that period. If you don't have the benefits for that period, you're looking at perhaps a larger financial catastrophe that is going to cost the system more in the longer term. That's the importance of having flexible time limits.

Mr. Wayne Long: Okay, thank you.

The Chair: That's the time for questions, I'm afraid.

Madame Sansoucy, go ahead.

[*Translation*]

Ms. Brigitte Sansoucy (Saint-Hyacinthe—Bagot, NDP): Thank you, Mr. Chair.

My first question goes to Mr. Prince and Mr. Stapleton.

We talked in more detail about the way to improve the employment insurance scheme, but I would like to start with a more general question. These thoughts have been occurring to me since the beginning of this study and the end of the one we conducted just before. We know that the government has not been contributing to the employment insurance fund since the beginning of the 1990s; just employers and employees do so. On the other hand, the government is under a lot of pressure to increase maternity benefits. In a previous study, we were concerned with supporting grieving parents. As you said, 15 weeks is not enough for 35% of people. In fact, 135,000 people need longer than 15 weeks and, as we know, one in every two Canadians is at risk of developing cancer, so it can only increase. We are seeing it in our study on episodic disabilities. The government has also established a program for caregivers. Those who live in a reality other than that of losing a job find it difficult to be committed to a process that is not designed for them.

The question I ask myself, and that I would like your opinion about, is this: in terms of the need to reform the employment insurance program, which I believe everyone agrees on, should we not arrange matters so that the employment insurance fund is used only for those who lose their jobs? We could use the opportunity to make the program more accessible so that, for example, 60% of the people who contribute to the fund receive benefits from it, unlike the current situation. Then, through its departments, the government could invest in parallel programs specifically designed for those on maternity leave, those who have lost children, the sick, or those with episodic disabilities. Those programs should be flexible enough to avoid those people having to line up at Service Canada with those who have recently lost their jobs. I am tending to that solution more and more. What do you think about it?

● (0940)

[*English*]

Prof. Michael Prince: Would you like to go first?

Mr. John Stapleton: First of all, I would like to provide some context for my response. When we look at income security for working-age Canadians, 18 to 65, we're spending about $60 billion overall in every sort of program. Most of our income security goes to people over 65 and to children.

I'm going to quote one figure. That figure is 12%. The other side of that, 88% of all income security, goes to people after they have worked, through the EI program. It pays you after you have worked. The CPP program pays you after you have worked. What about people who are either not working, or working in the home, or working in voluntary situations? They are part of that 12% of income that goes to people who get income security either while they are working—through the Canada workers benefit or through the EI working while on claim program—or through social assistance.

I think one of the things we have to do is start reorienting our income security system in ways that provide income security to people either while they are working, or while they are doing other things, like raising families and volunteering, when they are not in the labour force.

I think it's a laudable suggestion that we have new opportunities to do that. If you look at our income security—I try to look at it as would an intelligent Martian coming to look at it from high up—it's so oriented to the after-work experience. We need to be thinking of it while people are in their working age but unable to work and doing other things, like volunteering or raising families.

[*Translation*]

Ms. Brigitte Sansoucy: Thank you.

[*English*]

Prof. Michael Prince: Part of your comments were around the role of the regular EI benefits and a smaller proportion of the labour force being able to access those than, say, 10, 20 or 30 years ago. Part of that is policy and administration, and part of it is the changing economy and the quality of jobs that are being created. That's a bigger project around employment strategies by federal and provincial governments, the private sector and, of course, poverty reduction strategies, federally and provincially, and how much they emphasize employment and good-quality work.

Also, when I look at recent developments with the Canada child benefit and the revamped working income tax benefit—the new Canada workers benefit—it's a recognition that there will always be jobs that are not adequate in providing a basic income for working Canadians. If they have young children, we need to help them with the Canada child benefit. If they're working and they have lower income, we help them with the Canada workers benefit. That doesn't mean government shouldn't keep trying, along with the private sector, to create good-quality jobs, but the reality is that we don't have the industrial base or the manufacturing base we did 20, 30, 40, or 50 years ago. The recent events in Oshawa with General Motors are another example and reminder of that.

At the beginning of your remarks, I thought you mentioned that government used to contribute to the financing of EI—or UI at the time. Interestingly enough, when it did that, it was partly on the rationale that, if unemployment rose above 4% or 5% nationally, the Government of Canada should be on the hook to help buffer the cost that employees and employers were contributing to the fund. In other words, there should be an additional obligation on the Government of Canada to help fight to keep unemployment down. We eventually removed that. It's an interesting idea to consider whether the Government of Canada should re-enter as a partial co-funder of that program.

The special benefits that have grown in and around EI are very important programs and they provide a very important basis for providing for some of the needs of Canadians. Of course, their limitation is that you need to qualify. You need to have those insurable hours to be able to get it. That's the catch. Clearly, it's under federal jurisdiction. It's a solid and familiar program and it's a well-run program, but that's its limitation.

Until we move outside of it to basic incomes or guaranteed annual incomes, we will have it and we will need to have other programs around it, like the Canada workers benefit, the child benefit and other tax credits to help. There's no one program that we can expect to do all this.

● (0945)

The Chair: Thank you.

MP Hogg, go ahead, please.

Mr. Gordie Hogg (South Surrey—White Rock, Lib.): Thank you.

Listening to the testimony and the references, there seem to be a number of trigger points that are defined by way of different types of challenges. I know that Mr. Prince and Mr. Stapleton both talked about looking at more a broad-based, client-centred focus of service delivery. Societally, I think we're moving more and more toward consideration of a more generalized approach, rather than starting to define things by the 10 different categories you started off talking about, Mr. Stapleton, and various different categories that divide us up as people.

How would a system work that is client-focused, or focused around the delivery with response to a person, rather than by defining them by one of these 10 categories they fall into? Is there any example of that type of system functioning anywhere in the world? If so, where would that be? If not, if we were to look at it based on that set of principles of trying to be client-centred, how would that start to evolve, and what would be the values that we would reflect in that? What are the principles upon which it would be based?

Mr. John Stapleton: I'll start the reply.

First of all, I'm looking at these definitions, and I was especially struck when Deanna was talking about the CPP definition. Our income security system has come through almost 100 years of growth, and it seems that each program and definition corresponds to the era in which it was brought in. We don't have to do much historical or archeological work, because the programs are all still with us, alive and well, with the same definitions.

We went through that era, from 1940 to 1966, when our answer to every program need was to have a payroll tax: to put in a program and take money off people's pay. We stopped doing that in 1966. We moved over to tax credits in 1978, and I don't think that, since 1978, there has been any new program in the income security system that hasn't been built through the tax system.

I think one of the things we have to do is, first of all, take stock and say, okay, the first disability program in my home province of Ontario was for workers' safety and insurance—workers' compensation—in 1914, and here we are, 104 years later, and we have various payroll tax programs that have an insurance principle. The insurance principle, of course, is insuring you against the hazard of having a disability. Just as we buy fire insurance to protect us against the hazard of having a fire, we are protecting against the hazard of having a disability. Therefore, you get a definition that completely relates to the insurance principle, yet we have others through the tax system, such as the disability tax credit, that relate to our taxation system.

As we take a more comprehensive approach and look at 10 very different definitions that have evolved over the last 104 years, at least in Ontario's case, I think we need to put a stake in the ground and say, “Okay, what is the modern definition of disability?”

We know that more and more disabilities are episodic, and we know that in the future more and more disabilities are going to be episodic. Because we're an aging society and have had advances in medicine and in therapy, and because we also have many more ways of keeping people alive, through those various therapies they're able to have an episodic disability as opposed to a permanent chronic situation. Most of our definitions relate to the chronic era, when all of our disabilities were prolonged in that way.

I think if we take stock and look at what the good, relevant evidence tells us, we would start to try to move towards a common definition in all of the programs that would reflect the idea of the words we now use, which are “people with disabilities”—as opposed to “the disabled”, which is a 100%, all-encompassing definition. That is who you are: you're a disabled person. There's nothing else that you are.

Once you say “people with disabilities” or “persons with disabilities”, you start to say that you're a person first, and then you either have a chronic lifetime disability.... There is a continuum of disabilities. Rather than recognizing only a small part of that spectrum, as you've heard today from people with lived experience, we would start looking at that broad spectrum of disabilities and looking at compensating the person in that regard, as opposed to the disability itself.

● (0950)

Mr. Gordie Hogg: Using your metaphor of the intelligent Martian coming to look at things, should we be talking about disability at all, or should we be talking about accessibility? Should we turn that phraseology around to just talk about accessibility so that we're talking about how to make our society more accessible for everyone, rather than defining it within the context of a disability?

Michael, go ahead.

Prof. Michael Prince: No. I think we still need to use the words “disability”, “disabled”, “impairments”, “diseases” and “conditions”. I don't think we need to run away from those hard material realities. Language matters in how we phrase those. Some words hurt and some words can help.

Words like “diversability” and other words are interesting, but I think the world is still full of people with disabilities or impairments and conditions. We're all on a continuum of the different limitations and gifts that we all have. We talk about human diversity as a good idea.

Mr. Gordie Hogg: Deanna, if you compare us to other parts of the world, other jurisdictions, how do we fit in in terms of our access? Are there things we can learn from other countries, from other practices?

The Chair: Give a very brief answer, please.

Ms. Deanna Groetzinger: Yes, I think there can be. Basically, I went back and looked at many papers in advance, and I was struck by the fact that this issue has been discussed by many committees, including this one, and many proposals have been put forward. One that struck me—and I can't remember, exactly, Michael; it might have been you or John—was a medium-term disability kind of program.

I'd have to actually look this up and give you some references, but I believe the Dutch have such a program. It's much more of a continuum, as opposed to these disparate programs where EI stops and there's nothing unless you have a private long-term disability insurance. If you don't have that, you're into the abyss. So yes, there are programs that look at more of a continuum for someone with a disability, and that would be something I would urge this committee to look into as well. I don't have those at my fingertips right now.

The Chair: Thank you.

Mr. Ruimy, go ahead, please.

Mr. Dan Ruimy (Pitt Meadows—Maple Ridge, Lib.): Thank you all very much for being here today.

We've done two studies in a row that just tear at your heart.

As mentioned before, the EI program was not designed to handle a lot of the challenges we're having. One of you also mentioned that we need to keep the dialogue going. We need to create awareness. I think that's what we're doing. In a way, maybe, I want to try to manage those expectations. I don't think we can make this wholesale change over a three-session study. Our job is to try to hear what everybody's saying.

I want to focus on you, Patrycia and Deborah, because you come to us with lived experiences. What you both bring to the table is the courage and the fortitude to keep pushing through. Not everybody's like that.

Can you tell us about your support systems that you have in place? What is helping you to drive forward?

● (0955)

Ms. Patrycia Rzechowka: I completely understand where you're coming from. I look at it and I know there's not a simple answer. I think the answer is going to be as complicated as the disease is.

I was on EI when I went completely blind. The medication I was on made me quite sick. It wasn't even so much that I couldn't see. Actually, the reason I couldn't work was the side effects of the medication. After that, it was just sort of about trying to figure out what my body could do and whether I could go back to the job I had been doing before. At that point, I had moved back in with my parents. I had just graduated from university, so I hadn't really started on my own quite yet.

The second time my eye went blurry, I was on contract with the Government of Alberta and I didn't really have a choice. I didn't really want anyone to know, so I wore an eye patch at work because the computer screen bothered my eyes. I just continued to work and told people I scratched it at soccer or something. It was more to try to see if I could actually do that, as well, so that people might look at it after the fact and say, “You could have easily taken time off. Why didn't you?” It's that sort of feeling, like I have some sort of responsibility.

The support at work.... Every so often, I think, people forget that I have MS. Every so often, I do get that question, “How are you feeling? How are you doing?” That's really worthwhile. It's those relationships and the meaningful work that I do that kind of drive me, because I know that if I'm really, really tired, I'm going to miss a meeting or I'm going to miss a deadline. These are things that I don't want to do or I'm going to put my coworkers in a tough situation.

The times when something gets even more serious, I know that my parents are there, but I don't know if that's good enough, if you know what I mean. The burden shouldn't be on them. I've been trying to work this entire time. Even for my benefits, I have to give them a doctor's note every year to tell them that I have MS. It makes no sense. Why? I can give you a doctor's note when I don't have MS anymore. It's that total misunderstanding. I think awareness and understanding are a huge part of it.

Mr. Dan Ruimy: I think those things, like the doctor's note, are important, because those things might be easier to tackle, so to speak.

Ms. Patrycia Rzechowka: Yes.

Mr. Dan Ruimy: I want to move quickly to Deborah. I don't have a lot of time.

This is a bit of a different situation.

Ms. Deborah Lovagi: It's totally different.

Mr. Dan Ruimy: What is your support network like?

Ms. Deborah Lovagi: You'd be disgusted if I told you the truth, so I'm not sure if I want to get into the financial plight I've been through in the last three years.

Because I had acquired a brain injury at a job and then one in a motor vehicle accident, my support through the job was cut off when they let me go. Because I had a first head injury, which was a workplace injury, I didn't qualify for any help through my car insurance.

I sold my home in order to live, so I would have funding. I am still living off the monies from the sale of my home. When I've exhausted everything, maybe I can apply for ODSP. I currently get only $842 a month from CPP disability, which is nothing.

I pay for my own therapy for my PTSD. I pay for my own physiotherapy. I pay for a sacral massage therapist to help with my balance.

I'm not getting any supports. I'm sorry, but I'm a little disappointed in my government.

● (1000)

Mr. Dan Ruimy: No, don't be sorry. Listen, we want people with lived experiences because we need to hear these sorts of things, and we need to figure out—

Ms. Deborah Lovagi: There are too many loopholes, and I've been told that my situation is too complicated. I feel like I've fallen through the cracks.

Mr. Dan Ruimy: I think there are plenty of examples of people who've fallen through the cracks.

Recently, with the Ontario government, there was the guaranteed income pilot project. I think everybody was looking to see what the results would be and what we could learn from that. Part of me believes that is something we may have to go to at some point. That sounds like it might be a potential solution to some of the challenges we're seeing.

This is the challenge that we're at. Everybody has different challenges, and it's hard to understand this.

Thank you very much for sharing with us.

Ms. Deborah Lovagi: Thank you for asking.

Mr. Dan Ruimy: Thank you.

The Chair: MP Falk, go ahead, please.

Mrs. Rosemarie Falk (Battlefords—Lloydminster, CPC): I want to thank you all for being here and taking the time to share your stories. It is important that we do hear the reality of it.

Something I get very frustrated with is how the other side wants to turn this partisan all the time. I very much do care about people, what their experiences are and how that shapes their life, because that's really what will happen.

It always comes back to money. It's funny, because this weekend the Prime Minister actually announced $50 million. From what I heard from Mr. Prince—if the numbers of $50 million to $100 million are correct—if this government wanted to take action, they could do that today with the money they give out. That's just a bit of frustration I have.

Even last night in the House, we voted for 12 weeks of bereavement leave for parents...under one year. The government voted against that.

Sometimes I get very frustrated being here and wondering what is getting done. We've heard the testimony. We know there's a problem. How are we going to make the system evolve? We know the system needs to change. We've heard that. On the last reforms—the seventies, eighties and that type of thing—things have evolved. Things have changed. We need to take action. Empty words are not enough.

On that note, Patrycia, I wanted to ask you how we can change the culture of episodic disabilities. I know you mentioned that episodic disabilities aren't understood well. How can we change the thought process or the mindset around episodic disabilities?

Ms. Patrycia Rzechowka: I think that's a big question. I don't know if anyone really knows the answer to that one, because a lot of them are so invisible. I think it's just having the conversation and then potentially better supports for organizations like the MS Society or any of the other societies that support episodic disabilities. I don't know. It's just building that awareness.

When I applied to the police service, their view of multiple sclerosis was of someone in a wheelchair, basically, or an example of one person someone knew who had multiple sclerosis who was potentially more aggressive.

Yes, I think it's just having those conversations and getting that out there. That's what I am trying to do. I'm really only one person, so I don't know how best to keep going with that.

Mrs. Rosemarie Falk: Okay.

Ms. Patrycia Rzechowka: It's a tough question.

Mrs. Rosemarie Falk: I think with any stigma, a conversation is where the stigma breakdown starts to happen.

Ms. Patrycia Rzechowka: Yes.

Mrs. Rosemarie Falk: Mr. Prince, you spoke about medical practitioners and the certificates and the lack of knowledge. Do you know right now if there are training programs or information sessions that are put on by Service Canada or whomever, for medical practitioners to navigate the system or know what their patients might need to apply for?

● (1005)

Prof. Michael Prince: There's some basic information put out, but it's very passive, I would say. It links directly to the disability tax credit issue as well, which is so important as a gatekeeper program, and not just for the registered disability savings program, which is a fantastic program for financial security. Even provincially, in B.C. for example, we have a home renovation tax credit for seniors. We recently expanded that to people with disabilities. The eligibility criterion for that provincial tax credit is the DTC, and we're seeing more and more provinces use the federal DTC as the gatekeeper to other benefits. It turns out that, of the eligible people to access that, maybe 5% to 10% get it, because the rest can't get the DTC to get the provincial tax credit to do a home renovation to be able to live longer in their own homes.

We have a lot of work to do to provide better supports to physicians and nurse practitioners, who increasingly are being recognized as qualified health practitioners to do these assessments. There's an issue around reimbursements for filling out these forms. There's the issue of the ability of physicians to have direct communications back to departments, whether it's Canada Revenue Agency or Service Canada, and find out what was done incorrectly on the form, particularly for the DTC, which gets pushed back again and again, and improved communication materials targeted to physicians and nurse practitioners.

Quite frankly, again from my own anecdotal experience in B.C., some physicians see this as a burden. They don't really put much time into it. Some will fill out anything their patient wants; others are more suspicious, and others are more rigorous. Some of them are not sure what the right words are that will either trigger an acceptance or a rejection. We talk about awareness. There's the awareness and communication with key gatekeepers. We've added more and more obligations on physicians and nurse practitioners to be some of the gatekeepers to these essential programs in a way that I don't think we really appreciated 30, 40, 50, 60 years ago. That was before medicare.

We have public health insurance. Surely to God we should be able to work this out very well with a system that's public and universal across the country. So there's a huge communications problem there.

The Chair: Thank you.

Bobby Morrissey, go ahead, please.

Mr. Robert Morrissey (Egmont, Lib.): Thank you, Chair.

Mr. Prince, you used the number $50 million as the cost to the system to extend EI sickness benefits from 15 to 26 years.

Prof. Michael Prince: Yes. That would be a nice long benefit.

Mr. Robert Morrissey: It was officials from Service Canada, I believe, who may have used a different outlook. How did you calculate the $50 million?

Prof. Michael Prince: Quite frankly, they're back-of-the-envelope calculations. It's 11 weeks times the average weekly benefit, which is a little over $400, and then an assumption of the 135,000 people who are currently exhausting the benefit at week 15, and how many of those would continue and use the full subsequent 11 weeks. We can make a number of scenarios. If we assume that all 135,000 use all 11 weeks, and they all have the average weekly benefit, that takes you up to a $165-million price tag.

Mr. Robert Morrissey: I see.

Prof. Michael Prince: If you make other assumptions about what percentages of those 135,000 would use how many extra weeks, you can come up with different calibrations. That's why my best guesstimate is between $50 million and $100 million. That's partly based on the fact that when other programs, such as the compassionate care benefit and others, were rolled out, the government's official target estimates tended to be larger than what the actual program obligations were for the subsequent rollout of the programs, so the officials were cautious and estimating high costs. The actual rollouts tended to be lower. It's harder take-up, awareness, applications, etc. So these programs tend to roll out not as high as some. Again, this would be the work of the officials to do.

Mr. Robert Morrissey: I was just curious about how you arrived at that number, because $50 million would be a modest—

Prof. Michael Prince: Yes, I would say so.

Mr. Robert Morrissey: —cost to the system to give that extension.

Prof. Michael Prince: That would be the low end. Yes, I would think that would be modest.

Mr. Robert Morrissey: My next question is for Ms. Buchanan. You referenced that you were on the advisory panel to CRA, interpreting. One of the frustrating things that I confront on the DTC from constituents is the wide range of interpretations from medical practitioners. I believe Mr. Stapleton just spoke to that.

How do we as legislators deal with that? One of you made the comment that some doctors won't sign anything to help their patients, and some get caught up in trying to give interpretations of a piece of legislation that should really wait to be adjudicated—what if this occurs or that occurs? Somebody else should really make that decision. People who are denied can have similar health conditions to those of another individual who is approved because the medical practitioner signed it and checked off the right boxes. It occurs in a couple of areas of the DTC.

● (1010)

Ms. Lembi Buchanan: It's very difficult. I assist a lot of individuals with their applications, with their appeals, even up to the Tax Court of Canada. I don't charge a fee. I just do this because it provides me with insight into what's going on at CRA. Actually, in one appeal case the doctor refused to complete the questionnaire where you just tick off the yes-and-no answers; he wrote a letter, and the appeal was accepted.

The biggest problem is that there are a lot of doctors now who refuse to even fill out the form because CRA imposes this 90% threshold that has no legislative basis.

Going back, I've been advocating for so many years. I've known Michael Prince for a long time. This is my 20th anniversary—

Mr. Robert Morrissey: Could I just stop you there?

About the 90%, has CRA reached out to the medical community with an advisory cautioning them to use this? Where...?

Ms. Lembi Buchanan: It's on the form that the applicants and the doctors complete. The 90% has been traditionally defining “all or substantially all of the time” with GST cases. There have been several GST cases that have gone to court, and in every single case the judge has ruled against the 90% threshold. Those cases are all on my website.

Mr. Robert Morrissey: It's fightingfortaxfairness.ca. Do I have it right?

Ms. Lembi Buchanan: It's fightingforfairness.ca.

Mr. Robert Morrissey: Okay.

Ms. Lembi Buchanan: Justice Donald Bowman, former chief justice of the Tax Court of Canada, was always very adamant about this arbitrary definition. I was very distressed when CRA, almost two years ago, sent out a PowerPoint to all MPs, a brief analysis of the eligibility criteria for the DTC, and it had the 90% right there.

Going back a little bit, you're asking how legislators can be more involved in this issue.

In 2003, a technical advisory committee for persons with disabilities was created by both the Minister of Finance and the minister of CRA at that time, and we put together a report, “Disability Tax Fairness”. The CRA certainly took a lot of our recommendations in that report very seriously, so they made a number of amendments for the 2005 tax year, and they had an application form that had a considerable number of examples to guide the physicians in terms of how to—

Mr. Robert Morrissey: Are you saying that's no longer there?

Ms. Lembi Buchanan: I'm sorry?

Mr. Robert Morrissey: Are you saying those changes are no longer within the interpretation of the CRA?

Ms. Lembi Buchanan: The examples are no longer there.

Mr. Robert Morrissey: When did they get removed?

● (1015)

Ms. Lembi Buchanan: The examples were removed slowly. By the time we got to 2012, there were no examples at all. The CRA has a document called RC4064, and those examples are in it, but most doctors aren't going to go and hunt down documents from CRA.

In my written submission, I have one of the examples. It's a very important example that CRA used. It has to do with someone who has psychotic disorder. It recognizes that someone like that is not continuously psychotic all the time. The example indicates that an individual may have a number of psychotic episodes during the year. It recognizes that the condition is permanent. They're not continuously psychotic, but they do require daily supervision. That was a very interesting example. Someone with dementia, for example, may be perceived to be living independently on their own and in their own home, but they're not really independent because somebody else is looking after their finances or getting Meals on Wheels, etc. That was a very important example.

There were also examples of children with autism. Those examples are gone. The form is so basic now. I've been fighting the 90% for years. We've brought up this issue, and hopefully, with our disability advisory committee, we'll be able to get that out. “All or substantially all of the time” is not terrific, but at least it doesn't put a timeline onto the physicians.

The Chair: Thank you very much.

MP Barlow, go ahead, please.

Mr. John Barlow (Foothills, CPC): Thank you very much, Mr. Chair.

I appreciate everybody's input on this subject.

I just want to make a quick comment before I ask some questions. My good friends across the table like to criticize when we ask about numbers, but here's a good example. When we talk about the potential costs for these types of programs, we have Mr. Prince saying this could cost between $50 million and $150 million.

We're in the process of going through another study on extending EI sickness benefits from 15 to 50 weeks. In 2012, the Parliamentary Budget Officer said that the cost of that program would be $900 million. That's a big difference from $150 million. When we ask these questions, I think it behooves us, as members of Parliament, to make sure we know what the costs are. That $900 million in 2012 dollars is probably well over a billion now for the cost of this program.

When we ask these types of questions, it's not that we're trying to show that we don't care, but we need to understand the impact these programs have on the taxpayer. As much as my friends like to think we can tweet out $50 million and pay for programs, we need to ensure that we're doing our due diligence. I think that's just good practice.

My first question is for Patrycia. I was stunned by one of your answers, where you said that you still have to give a letter every year saying you still have MS. Maybe Deborah can chime in on this as well. We've gone through this with veterans, where they still have to prove that they've lost their legs and things like that, which I find to be appalling.

Is this a matter of a change in approach at the bureaucratic level? Do you have to prove all the time that you still have MS because it's easier to deny you these benefits than to approve these benefits for you? Is that a big frustration, just going through the bureaucracy of trying to apply for these benefits?

Ms. Patrycia Rzechowka: I think so. The interesting thing was that I thought this was an issue with my Blue Cross coverage in Alberta. When I had a conversation with them, it ended up being that they had a conversation with the employer. It's actually the Government of Alberta, as the employer, and the union that require the medical note for me to be able to access certain aspects of the coverage. That's definitely a conversation to have.

If you think about the amount of time with taking some time off work to go see a doctor every year, having to pay the doctor to fill out the form and paying me for taking time off.... That's a huge cost for something so simple. You could literally just make a note saying that the patient has MS.

I don't really know where the solution to that would come from.

Mr. John Barlow: Deborah, I know you touched on it, and we appreciate your giving us the personal anecdote. You were saying there are too many loopholes. Is one of the problems just how difficult it is to navigate the system?

● (1020)

Ms. Deborah Lovagi: I do think that there are too many loopholes. From my own personal experience, I know that I qualified for a CPP disability payment. It may not have been a lot, but it's more than nothing, and I should be thankful. However, this year I was denied my tax credit for disability, so I'm having to go through the rigmarole of trying to convince somebody that I qualified once before. My three years are now up, and I'm sitting on the fence post, not knowing if I have to repay because I no longer qualify for this credit.

If a person qualifies for a disability payment, whether it's ODSP or CPP disability, why does that person have to jump through hoops to get that tax credit? It should be automatic. They've already jumped through hoops to get some sort of income support.

Why do I have to go through that rigmarole every year in order to qualify, not knowing if I'm going to get that credit and not knowing if I have to repay the government? A person with PTSD, I can tell you, cannot take that extra stress. I find that the systems don't work together. They're not communicating. Something that simple should be automatic. You've already medically qualified to get a disability. Why do you have to jump through hoops to get a tax credit?

I'm sorry. I still have my arms; I still have my limbs, and I am not blind, so I don't qualify. I think it's ludicrous.

Mr. John Barlow: Thank you very much.

The Chair: Madam Sansoucy, go ahead.

[*Translation*]

Ms. Brigitte Sansoucy: Thank you very much, Mr. Chair.

Let me first make up for something I forgot, and thank each one of you for contributing to our committee’s work.

Mr. Stapleton, Mr. Prince, I agree with you that, if there were a guaranteed minimum income, we would be asking all these questions very differently.

I would like to go back to the longer sickness benefit payments that could result if the calculation were by day of episodic disability, not by week. Along the same lines, we talked earlier about employment insurance. Those figures are based on the fact that 60% of those who contribute to the employment insurance fund are not eligible for benefits. Another obstacle to the eligibility, which also applies to people with episodic disabilities, is that prerequisite of a 40% reduction in income. If we do an analysis by gender, we see that, right off the bat, 34% of women and 52% of men are ineligible for benefits. So, in my opinion, we first have to solve the eligibility problem. What is your opinion?

[*English*]

Mr. John Stapleton: I'll start.

EI is a program that has a threshold of eligibility, and if you don't meet the threshold of eligibility, then you're not going to be able to get the benefits.

The reason I started out by mentioning 10 different disability systems, 10 different bureaucracies and 10 different definitions of disability—even multiple definitions within the programs—is that each of these various silos is very interested in what the others pay out.

As Deborah pointed out, she was going to receive benefits from the one, but they're not only interested in the definition, but also the pedigree of the disability. Did it take place in the auto accident, or did it take place on the job, or did it take place somewhere else? There are all these questions that get involved in the essential bureaucracy.

Again, in mentioning the idea of some sort of basic income, if we could somehow combine or disentangle these 10 different bureaucracies that came in at various times with different definitions and different concepts of what a disability is, there has to be, as part of that, at least some sort of reckoning, maybe some massive saving within the system, if we were able to disentangle ourselves from these definitions of pedigree, and each one that overlaps with and deducts from the other.

Going back to Deborah's testimony and the idea of getting CPP, if she finally does get benefits from the Ontario disability support program, then her CPP will be deducted at 100% from those payments.

There's often the idea that the programs, in the end—especially for people who are living in poverty with disabilities and with episodic disabilities—become destitution-based. When they're destitution-based, they're very, very complicated. I think the eligibility requirements, at a minimum, are overly complex.

● (1025)

The Chair: Thank you very much.

Prof. Michael Prince: Before we look at something like a national guaranteed annual income or basic income in our own lifetimes—and in your own terms as MPs—I think we need to look at things like the disability tax credit.

The idea that we do not have right now a clause under the legislation that exempts people from re-examination for permanent disabilities should be low-hanging fruit. CRA should work with medical practitioners and health associations to develop specific criteria for people who have lifelong conditions, and then figure out a way to embed that in the administrative decision processes of the CRA so people are not put through a humiliating and frustrating experience.

That should be at Veterans Affairs, at the CRA, and it should be elsewhere as well.

The Chair: Thank you, sir.

MP Diotte, go ahead, please.

We're starting six-minute rounds again.

Mr. Kerry Diotte: Thanks, Mr. Chair.

Patrycia, it's interesting when you talk about your struggles to join.... I believe it was the RCMP or the EPS. Are there any emergency forces right now where somebody with episodic disabilities would qualify, or are you a *persona non grata*?

Ms. Patrycia Rzechowka: The interesting thing is that.... I did apply to the RCMP. If I had followed through with it, I believe it would have been potentially easier to get on with them, but I also would've had to make the decision about moving away from my family, which is my support system in case I have a relapse that is more serious. I would need to be near them, so I made the decision to pull back from the RCMP.

In the Edmonton Police Service, from what I've heard anyway, a certain group of people in human resources and in recruiting had the view that it was just a liability and that, according to the provincial standards, either I was completely disqualified or I wouldn't.... I think it was the doctor's decision that I wouldn't be able to handle the job for 25 years. That was what it was based on.

It was fascinating to me, because can you guarantee that anyone can handle or be...? What happens if you get hit by a bus? You're going to need certain supports. What if someone gets cancer? No one thinks twice about that. It's that idea that potentially I might need a little extra support at a certain time. I don't think they could comprehend it that way. It was seen as nothing but a liability.

I've heard since then that there are different people in recruiting and HR. It might be possible for me to get hired now, but at the same time I feel as if I would be looked at as if someone did me a favour, that I only got on because I was complaining. It would be a difficult place to work with people who don't want you to be there, whereas my current employer has tried their hardest to keep me where I am. I have moved on from the service. I work in policy around policing. I manage to still live out my dream in a different way.

I think it really depends on what understanding those who make the decisions have of episodic disability. One person might be more open, and another person might be totally closed to it.

● (1030)

Mr. Kerry Diotte: This is a broad question for everybody. Feel free to chime in.

I guess there are certain levels of frustration, obviously, with programs, with being accepted in society in general. What things can we as a committee do today that would make life better tomorrow?

Lembi, go ahead.

Ms. Lembi Buchanan: You can be hugely helpful right now. All you have to do is ask CRA to follow the legislation, the Income Tax Act, in how they administer the disability tax credit. The 90% threshold that's in all the forms now, which was introduced in 2012, is not legal. It is illegal, and it's not supported by the courts.

Mr. Kerry Diotte: Does your organization have any legal action on that?

Ms. Lembi Buchanan: No, we don't. I founded the Disability Tax Fairness Alliance—Michael Prince was one of the first people to step in and support the alliance, and he is a member—just to reinstate the disability advisory committee that had been disbanded in 2006, so we can not only advise the minister, but be a bit of a watchdog in how the policies are changing.

What has happened? It was great in 2005. Things were rolling along very nicely, but ever since the RDSP was created, there has been a cutback in eligibility for DTC. It has been more difficult. I am absolutely appalled that Deborah had to reapply after three years, and has been denied.

Mr. Kerry Diotte: Does anyone else want to comment?

Ms. Deanna Groetzinger: I think you have heard some really good, practical solutions. What I hope might come out of this committee is to look at the lack of continuum among the programs—well, maybe systems, not programs.

When someone finishes EI, they're basically back to work or there's nothing for them if they don't have private insurance. What is needed is to really look at that continuum from the point of view of a person living with an episodic disability, not from the point of view of the system or the program, and just carry it through on an individual basis. I think that would be an interesting exercise. It would really point out the gaps faced by people living with episodic disabilities.

The Chair: You have no time left, Mr. Diotte. I'm sorry.

Mr. Ruimy, go ahead, please.

Mr. Dan Ruimy: Thank you very much.

I have to point out that this is not a partisan issue. I know that my colleagues on the other side have tried to suggest that it's a partisan issue. It's not. We haven't even talked about what happened in previous governments. I haven't brought that up.

Where I do agree with Mr. Barlow is that we have to look at the money, because the money is what suggests whether we can sustain the programs. The 90% you were referring to, the doctors' notes—the system is what it is. Last year, all benefits paid out to Canadians totalled $117 billion. That's a lot of money. That's not something where you could turn around and say, let's flip a switch and do this, or let's flip a switch and do that. We need to be able to look at this entire program and start to ask questions.

This is not to say that because you have some challenges we don't want to think about the money. As a country, we need to be able to take care of our people. But this is where we're at today. The outcome of this study would likely bring in.... Mr. Prince mentioned the low-hanging fruit, and I talked about the low-hanging fruit, some things that we can fix today. But how do we look at the entire program?

With the new accessibility legislation, part of their mandate includes episodic disabilities. People on the board who have lived experiences will make up the majority, so I suspect we'll start to see a change in some of the cultural mindsets, which needs to happen, and some of the suggestions that will come forward.

Clearly, the struggles you go through, Deborah.... I mean, we heard about it for the parents who've lost a child: “Sorry your child is dead. You owe us money.” That's where the system is today. What do we have to do to move forward? I think we need an entire overhaul of the EI program. Yes, when you're spending $117 billion, that's a lot of money. We heard that, for every cent EI goes up, the equivalent comes out to about $170 million.

Is there an opportunity to do that? Absolutely there is. But if we're just taking potshots at this, people are going to fall through the cracks all day long. We can't do that. We need to do a proper consultation. We need to ask the right questions. We need to bring in people with lived experiences. We need to go back to CRA and ask some of these questions about the doctors' notes. We need to be able to do all of this. But that's part of a much larger program.

I do want to talk about the registered disability savings plan, because I'm kind of confused about this. I understand you can put money in, but at some point, if you're no longer disabled, you can't access the program. Can anybody help me out here?

● (1035)

Ms. Deborah Lovagi: Yes.

Mr. Dan Ruimy: Go ahead, Deborah.

Ms. Deborah Lovagi: I've just been denied, sadly, so I know all about it.

Because I have been denied this disability tax credit, I am no longer legally allowed to own a registered disability savings plan. I must close it. Any monies that have been given to that registered disability savings plan by the government will have to be repaid.

Thankfully, as my government didn't give me any money—I was over 49, so I didn't qualify for their grant—I don't have to pay any money back. However, I am now forced to close that account. I can no longer legally own it.

Mr. Dan Ruimy: Thank you, Ms. Lovagi.

Ms. Buchanan, go ahead.

Ms. Lembi Buchanan: I want to add that the government makes contributions in the form of grants and bonds. I represented an individual with autism in a Tax Court case. He had $58,000 in a registered disability savings program. He had been getting the DTC since 1990, and then he was denied in 2015. How crazy is that? Anyway, the government does not only claw back contributions. During all that time he was disabled, any interest income he made in that plan will be taxed the year the plan is closed. This is double jeopardy. Fortunately, the tax court recognized that this was crazy.

This is happening. Ever since the RDSP, if you look at the statistics, it's more and more difficult to get the DTC.

Mr. Dan Ruimy: Absolutely, we need to know the numbers. If all of a sudden the 90% dropped down to 50%, what would that do? We have to be able to prepare for that.

Ms. Lembi Buchanan: I made a submission, but I will also send the numbers when I get back home.

Mr. Dan Ruimy: Thank you.

The Chair: Thank you all for coming. You were great.

Madam Sansoucy is next, to finish this off.

[*Translation*]

Ms. Brigitte Sansoucy: Thank you, Mr. Chair.

Earlier, we were talking about best practises elsewhere in the world that could help us. Would it be appropriate for the Library of Parliament to prepare a briefing note telling us what the Canadians working at the International Labour Organization in Geneva could teach us? One witness talked about the experience in the Netherlands, which could be instructive. I think that could be useful for our committee.

My question goes to you, Ms. Rzechowska.

We could make recommendations to help companies better accommodate and retain employees with chronic illness. The government itself could be a model employer. If I understand correctly, you said that you have helped to prepare guidelines to that effect. I would like to know more about that.

As a result of your experience, could you tell us how the federal government could be a model employer and how we could make companies more aware about hiring and retaining those with episodic disabilities?

● (1040)

[*English*]

Ms. Patrycia Rzechowka: The main thing would be to work with, in my example, the Multiple Sclerosis Society. They're the people who have the most current knowledge. There's research consistently coming out that would help people understand what people with MS are going through.

Even for my employer, I just had the conversations with people. It's been placed on me to educate people, but if we moved into a potential system where.... Instead of the government being the one that just gives money because people can't work anymore, why not work with the employer to supplement the time when people may need to take extra time off? For example, for me, if I need an extra two weeks off, some employers might look at that and say, “No, we can't handle that.” Why not work with the employer to supplement something like that, versus putting me on straight disability for the rest of my life or for however long?

You are asking what drives me, what keeps me going. I can absolutely appreciate the fact that some people are having to jump through all these hoops. They might just give up, because they don't have the support, because all the different parties don't speak, don't communicate. They don't share the proper information to best support people who truly want to work and be useful.

I know several people living with MS who are exactly like me. They work. They go through the same things. I'm not special. I'm not the only one. I just get to be the voice at the table today. There are countless people living with MS who are doing the same thing that I'm doing. If there was a way to make it easier for them right from the get-go to not have to fight to still work and do the things they want to do, and still feel like they're somewhat normal, that would make a huge difference.

Ms. Deanna Groetzinger: I think somebody used the word “stigma”. One of the things that compound this is the stigma of having an episodic disability, whether it's a brain condition or another condition. I would hope that, using the example that Patrycia used, there are a number of organizations that can assist employers in looking into what people need, and how they need to be gainfully engaged at work. That's something I hope this committee would draw on, the expertise of the organizations across the country.

I look forward to seeing what this new accessibility law will actually do when it's passed, because there are elements, at least in the federal jurisdiction, where perhaps there could be some modelling of good employment.

[*Translation*]

Ms. Brigitte Sansoucy: I have one final clarification question for you.

Mr. Prince, you talked to us about extending the benefit period up to 26 weeks, but you also mentioned another possibility, of extending benefits for more than a year, even up to two years. Could you clarify that?

[*English*]

Prof. Michael Prince: What I was referring to is that perhaps the eligible recipient could draw down those 26 weeks over a two-year period in different blocks of hours, rather than saying, “You're eligible. You take it for 15 or you take it for 26 straight weeks.” Again, that may help some people with episodic disabilities, but it certainly won't help a lot of people with episodic disabilities, so it's about building in some flexibility.

Whether we leave it at 15 or we take it at 26, or some groups call for 35, whatever it is, can we deliver that in a more flexible, person-centred way that actually responds to the realities of people's lives?

● (1045)

[*Translation*]

Ms. Brigitte Sansoucy: Okay. Thank you.

[*English*]

The Chair: Thank you very much.

Thank you all for joining us here today and contributing to this study. I really appreciate your attendance and your testimony. I believe my colleagues do as well.

Thank you to my colleagues, and to everybody who made today possible. Enjoy the rest of your day, folks. Thank you.

The meeting is adjourned.

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