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Mr. Bryan May

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

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● (0845)

[*English*]

The Chair (Mr. Bryan May (Cambridge, Lib.)): Good morning, everyone. We're going to get started here.

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 beginning its study of M-192, episodic disabilities.

Today the committee will be hearing from witnesses and department officials.

We have joining us here today, MP David Yurdiga from Fort McMurray—Cold Lake. Also appearing as an individual, we have Shauna MacKinnon. From Epilepsy Ontario coming to us via video conference from Toronto, Ontario, we have Drew Woodley, director of government relations. From the Multiple Sclerosis Society of Canada, we have Julie Kelndorfer, director, government and community relations.

Thank you to all of you for being here. We're going to start with seven-minute opening remarks, starting with the author of the motion, MP Yurdiga.

The seven minutes are all yours, sir.

Mr. David Yurdiga (Fort McMurray—Cold Lake, CPC): Good morning. Mr. Chair, members of the committee, and everyone participating today.

Canadians are excited to have episodic disabilities formally studied by the HUMA committee. I'd like to thank Drew Woodley from Epilepsy Ontario and Shauna MacKinnon from Fort McMurray for their tremendous support on motion M-192.

Special thanks to Julie Kelndorfer and the Multiple Sclerosis Society of Canada, whose support was instrumental in getting this motion to committee.

Over the past few months, I've heard from thousands of Canadians living with episodic disabilities including epilepsy, Crohn’s, diabetes, arthritis, MS and many other episodic disabilities. There's an undeniable fact, episodic disabilities are treated differently from any other chronic disease and disability by government policy.

These inequalities have negative effects on those living with episodic disabilities and their loved ones. In Canada, support for persons with disabilities is built on a binary switch, either you can work or you cannot. However, life with episodic disabilities is not that black and white. Special requirements must be considered for people with episodic disabilities.

People living with episodic disabilities need employment support, improved income and disability support, and increased access to treatment, comprehensive care and housing. They need investment in fundamental research for episodic disabilities and updated disability programs where episodic disabilities are added to the general definition of disability. These changes are fundamental to ensure equality for people suffering from episodic disabilities.

It is up to us, the Canadian government, to take a stand and make fighting MS and other episodic disabilities a priority. I look forward to hearing testimonies from our witnesses today and I appreciate everyone's work on this file.

Thank you.

The Chair: Thank you very much.

Now we have Shauna MacKinnon for seven minutes please.

Ms. Shauna MacKinnon (As an Individual): Good morning.

I consider myself to be one of the luckiest people in the world. I was diagnosed with MS in January 1998. I was lucky because I had a family doctor who recognized my symptoms right away. I lived in a city with a dedicated MS clinic. One of my neurologists was a well-known and respected clinician. I have a positive outlook on life. I am educated and have a natural curiosity about everything, especially the brain. I adopted researching MS as a new hobby.

When I was laid off nine years ago, I went back to school for a business diploma in order to find work. After a year of working two part-time jobs with no benefits and no prospects in Halifax, I left my family and friends for a job in Fort McMurray.

I try to look after myself. I hit the gym three times a week and volunteer in my community. I've been a guinea pig for MS research and continue to add to the knowledge of this disease by participating in research by the medical community. I've participated in 11 different long-distance bike rides to raise funds for the MS Society of Canada. I raise awareness about MS.

I tell you all this to illustrate my sense of responsibility to myself, my family and others with MS, but I am terrified about my future. What will happen to me if I do become disabled?

The nature of MS is that I don't know when I will get better. I don't know if I will get better. I look and feel pretty good right now, but next week I could be in a wheelchair. If I became disabled next week I may not qualify for EI, sickness and/or CPP disability benefits, because I don't know how long I will be disabled.

The first question you are asked when filling out forms to determine if you're disabled is whether your impairment has lasted or is expected to last for a continuous period of at least 12 months. Your guess would be as good as mine. The only options I have to answer this question, though, is a yes or a no.

I'm truly grateful for universal health care. However, if I do become disabled and am unable to work, how do I cover my medical expenses? I have some coverage at work, but I am also paying for private health insurance. Without it, I'm afraid of having to choose between seeing a dentist and paying rent. I live in Alberta, where my MS drug is mostly covered by the province. I still have to get extra non-group insurance at a monthly cost to myself, in order to continue on the drug.

I was diagnosed with depression five years before I developed MS, which is not unusual. It occurs frequently in people with MS. In my case and for many others, depression clouds your judgment and ability to interact with others. Luckily for me, I've been on medication for years, which has allowed me to live a mostly depression-free life. Others aren't so lucky, either with medication or learning how to cope. If you're already depressed and then faced with disability, loss of income and perhaps changes in family dynamic because of it, getting through forms and dealing with EI or Service Canada is going to be a monumental task.

If I do become disabled, I need to maintain a social support network. I can't do that without some sort of income. I have been witness to young people with MS going into nursing homes because they aren't able—and just can't afford—to look after themselves. I do not want to be that person in a wheelchair waiting anxiously for someone familiar to walk through the door, or wondering if we're being served meatloaf again tonight. I want to continue to live a full life.

If I have a relapse and I'm sidelined for six months or longer I will be in financial difficulty. If I had a broken leg, I'd know an approximate amount of time to expect to be away from work and on reduced income. With MS and other episodic disabilities, nobody knows.

I'm a realist. I know that I will probably face disability at some point in the future, but my biggest fear is not that I will lose the ability to walk or see. What I fear most is that I will not have the ability to continue to work and contribute financially to my own welfare.

I am one of the lucky ones with MS. I am currently employed full time with a company that respects and supports me. I have a support system outside of work and I can advocate for myself. Not everybody is so lucky. That's why I'm here today.

Thank you.

● (0850)

The Chair: Thank you very much.

Coming to us via video conference from Toronto, Ontario, is Drew Woodley, director of government relations at Epilepsy Ontario. You have seven minutes, sir.

Mr. Drew Woodley (Director, Government Relations, Epilepsy Ontario): Thank you, Mr. Chair.

Good morning. I would like to thank the HUMA committee for investigating the needs of people living with episodic disabilities and inviting me to participate today. I will be speaking primarily about epilepsy, but many of the issues I'll mention are common to episodic disabilities.

Epilepsy is a brain disorder characterized by recurrent seizures. Seizures can take a number of forms depending on the person and portion of the brain affected. They are typically treated with medication, but other treatments such as surgery and diet may also be used if necessary, depending on the seizure type.

More than a quarter of a million Canadians live with epilepsy, approximately 30% of whom do not have effective seizure control. Beyond the seizures themselves, people living with epilepsy are profoundly impacted by the psychological, social and personal effects seizures can have. Rates of mental health issues and unemployment are both higher among the epilepsy population. Feelings of fear about when the next seizure might come and loss of independence are common. Side effects from medications necessary to control seizures include impacts on mood, behaviour, sleep, concentration, memory and energy.

Epilepsy is a truly episodic disease. Seizures themselves do not occur on a fixed schedule. When seizures do occur, they typically last only a few minutes followed by a recovery period, and do not necessarily require a hospital visit. They can significantly disrupt, or only temporarily interfere with, a person's school or workday. The impact of epilepsy on employment often has less to do with a single seizure and more to do with how frequent the seizures are, or the psychosocial challenges affecting the person's ability to function.

People living with dozens of seizures per day would have a very difficult time remaining employed. Others with less-frequent seizures and a supportive working environment could have minimal disruption to their employment. However, for many living with epilepsy, the reality falls somewhere in between. People can go for days or weeks between seizures, but then have several in a short period of time. Others can have them on a frequent but unpredictable basis. These situations can be physically and emotionally trying for individuals.

Beyond the seizures themselves, the mental disruption to cognition and memory that can accompany having frequent seizures is very real, as are medication side effects such as behavioural changes, sleep disruptions, lethargy and drowsiness, impacting the capacity for employment or limiting the amount of work a person can do. Triggers, those things that are likely to make seizures come about—such as stress or long working hours—often lead to an increased likelihood or frequency of seizures for people with epilepsy, compounded by many people not wanting to disclose the condition to their employer for fear of losing their job.

Comorbidities, those other conditions that have higher than average prevalence among people living with epilepsy—such as mental health issues—further exacerbate these challenges. In some cases, particularly if the epilepsy diagnosis happens when the individual is a child, parents' lives can become significantly disrupted as well. Having to bring children home from school following a seizure and the other challenges of supporting a child with a serious medical condition can easily pull a parent out of the workforce.

All of these facts can have significant effects on the ability to work, beyond the relatively brief amount of time that someone is having a seizure and needs to recover afterwards. As has been noted by others, Canada's social safety net too often defines someone as disabled or not. It considers a disability to be temporary or permanent, but not episodic—someone can or cannot work. Epilepsy simply does not follow that kind of pattern.

The CPP disability program does not have the flexibility to support repeated but not permanent interruptions in the ability to work. Further, it requires a history of employment so that minimum CPP contribution levels qualify an individual for benefits. In effect, only those individuals who have continuing and severe epilepsy, and who have been able to work for a significant portion of their adult life immediately before the onset of seizures, will qualify.

A person living with epilepsy may well be impacted by repeated interruptions to their employment over the course of a year, but the relatively short period of interruptions would not qualify them for EI sickness benefits, even though the combined effect might be comparable to someone who has had their employment interrupted enough to qualify for the program. Those applying for the disability tax credit often have a difficult time articulating how the effects of epilepsy and other comorbidities and the episodic nature of the disease have a very real impact on their daily lives, and so do not receive the credit.

Creating a more flexible definition of disability to include episodic disabilities—either with partial ongoing coverage, or with a new category for such situations—would have a significant impact on the lives of people with poorly controlled epilepsy and their families.

● (0855)

It is our hope that the government will review and update the criteria for such programs. Thank you.

The Chair: Thank you very much.

Now from Multiple Sclerosis Society of Canada, we have Julie Kelndorfer, director of government and community relations.

Ms. Julie Kelndorfer (Director, Government and Community Relations, Multiple Sclerosis Society of Canada): Thank you, Mr. Chair.

Good morning. The MS Society would like to thank MP David Yurdiga for sponsoring motion M-192 and this committee for taking the time to study and create recommendations to improve the lives of Canadians living with episodic disabilities.

Let me start with a story.

Imagine this picture: a 29-year-old university graduate, wife and mother to a one-year-old son, starting out her career in the non-profit sector. She walks into the doctor's office one day and walks out not knowing the journey that lies before her. Why? Because she has just been diagnosed with MS. That woman was me 14 years ago.

How would you react when you are told that you have an unpredictable, often disabling disease of the central nervous system, affecting your brain and spinal cord, and they can't say what lies ahead? They tell you that you're one of the 11 diagnosed every day, that it happens to women three times more often than to men, and that Canada has one of the highest rates of MS in the world, with over 77,000 Canadians living with the disease. The problem is that they can't tell you what, when and how severe the symptoms will be, like the ones I've experienced, from fatigue, pain, numbness, spasms, tremors, vertigo and weakness. This is because the symptoms of MS depend on what part of the brain and spinal cord are affected. This can greatly vary from person to person, and from time to time in the same person.

I left that doctor's office, got into my car, called my husband, cried and told him, “Whatever happens, please, I don't want to live in long-term care”. Why was that my reaction? Because that is what I knew of MS at that time. My aunt had passed away when she was in her fifties from a progressive form of MS. She could no longer move on her own or speak except to nod her head. She lived in a long-term care facility with individuals two and three decades older than she was. I was scared that would happen to me. I didn't realize there were others living with this disease and that they didn't have the progressive form that my aunt did. They had what I had been diagnosed with, relapsing-remitting MS.

Relapsing-remitting MS is characterized by unpredictable but clearly defined periods, during which symptoms are apparent. Relapses can last for varying periods, from a few days to several months, and are followed by periods of remission, during which many functions return. Approximately 85% of people diagnosed with MS have this type, also referred to as an episodic disability.

MS impacts all Canadians. It is a disease that affects not only the individuals but also the families who come together to manage the realities of MS. The unpredictable and episodic yet progressive nature of MS makes it a challenge to maintain financial security and to navigate health and community support systems, including access to treatments, care and appropriate housing.

When I was diagnosed, I worried about our family's financial security. My son was just one year old. We were just starting out. We had a mortgage, car payments, student loans and other expenses. What would happen if I had a relapse and I couldn't work full time and needed to work part time while recovering? Were there financial supports that could help me? What I learned then, which is still relevant today, is that the current disability income and employment support programs in Canada were not designed with episodic disability in mind. Many of these programs to support persons with disabilities are built with that binary switch—either you can work or you cannot work—leaving out many people with episodic disabilities who want to work but struggle to continue to work.

This is why the MS Society recommends improving income and employment security by making these supports and programs more flexible and inclusive by including episodic disability in the basic definition of “disability”, changing eligibility criteria and updating policies and legislation across programs, such as employment insurance sickness benefits, Canada pension plan disability, and the disability tax credit.

● (0900)

Being able to stay employed means I've had access to MS disease-modifying treatments approved by Health Canada to reduce relapses and disability progression. Because I've been able to access these medications and other extended health benefits, I've been able to stay working. It becomes a catch-22. Staying healthier for longer periods and reducing the severity of periods of illness when they do occur are key factors in job retention for people with episodic disabilities. Access to affordable medications and health benefits is imperative. Access to treatments and health care is key for people living with episodic disabilities.

This disease, MS, creates a life of uncertainty and unpredictability, but what should and can be certain and predictable are the supports people with MS and episodic disabilities have. I commend this committee for studying this motion, thus increasing awareness of episodic disability in Canada. By viewing 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 very much for this opportunity to speak.

● (0905)

The Chair: Thank you very much to all of you.

We're going to start questions today with MP Diotte, for six minutes, please.

Mr. Kerry Diotte (Edmonton Griesbach, CPC): Thanks to everyone for being here. I know it's difficult to tell stories at times, but it's the best way for us to really wrap our heads around what the experience is.

I just want to start with you, David.

Could you tell the committee what your personal connection is with MS?

Mr. David Yurdiga: Thank you, Kerry.

In 2014, my wife was diagnosed with MS, and it took a long time to get there. She had some challenges with vertigo, and nobody realized what it was. She went from specialist to specialist, but when she was diagnosed, we went through emergency, they did a brain scan and then she was diagnosed with MS.

The challenges were the next steps. What were they? There's not a lot of support out there. Thank God for the MS Society and for all the information they provided, but not knowing what tomorrow's going to bring.... For my wife, currently, sometimes when we go to a function, flashing lights set her off. All of a sudden, she feels pain and we have to leave.

A lot of times I really irritate my wife because I call her name out every once in a while. Sometimes she goes into this mode of brain fog. She is not really communicating with me. That's why sometimes I become an irritant, but I'm really concerned about whether she's having an episode.

There are so many unknowns. In terms of the support out there, I hear about a lot of cases. Many people came to our office saying that they can't qualify for disability benefits because they're not really disabled. They're just inconvenienced. I read a lot of these letters and everything else. Do you know what? Unfortunately, we need the definition changed of disability to include episodic disabilities, because the system looks at you and says, “You don't qualify”. These people have to face the unknown by themselves, looking for help and wondering how they support themselves.

Fortunately, we were able to manage and didn't need a second income, but I'm really concerned about the individuals and families who don't have that luxury.

It's about making sure families are strong, making sure that they can be part of the community and not a negative factor for the community, but a positive. We need government help for that.

Mr. Kerry Diotte: Thanks for that.

Shauna, I'm wondering what your biggest fear is, living with an episodic disability like this. I see from your background that you're a radio announcer and that's a pretty demanding career, with a fair amount of stress and so forth. What's your life like?

Ms. Shauna MacKinnon: I have a great life right now. As I've said, I am extremely lucky to have been raised the way I was and to have gone through what I've gone through with the support systems. But I have aging parents, and our biggest fear is that I will not be able to look after myself financially. I've been saving money since 1989, putting money into RRSPs back when interest rates were like 10%. For a couple of years, that was great.

However, what happens if I become disabled next week and I have to dip into those RRSPs? That's fine and dandy for the short term, but 20 years from now, what is that going to cost the government? If I can't get disability now, because it's only episodic and not a full-time disability, how is that going to affect the government coffers in the future when I do depend on them? What is that going to do to my RRSPs now if I have to take money out? I'm going to lose a whole bunch of money that could better be spent gathering interest for my future retirement. My biggest fear is not being able to look after myself financially.

I don't want to have to go into a nursing home and be sitting there, as I mentioned, wondering what's going to happen to me. I won't be able to maintain my support system, my network of friends. I won't be able to go out just for coffee or a meal if I don't have an income—all those little ordinary things. How can I maintain a gym membership if I don't have income? That's part of what keeps me healthy.

Again, my biggest fear is not being able to support myself financially.

● (0910)

Mr. Kerry Diotte: Thank you.

Julie, you have a demanding job as well. We know each other quite well. You do amazing work. Has it impacted your job, and can you explain to us the kinds of challenges that you face?

Ms. Julie Kelndorfer: Disclosure is a huge issue for individuals living with episodic disabilities. Who do you tell? What do you tell? When do you tell it? I face that same thing. While I wasn't working at the MS Society when I was first diagnosed, I felt those same things. Even in job interviews, further along, what do you say? Do you disclose? I'm a fairly authentic person, and I felt the need to be honest and authentic, but at what risk? It's a huge issue for people, and I don't believe our system is well set up to support people early on in their diagnosis of episodic disability. I think vocational rehabilitation is a very important piece of the solution.

I've been able to, with the support of a very.... I work at the MS Society. It's a really good deal for me. They understand, though, that I do require accommodations—a flexible working schedule, being able to work from home, flexible hours. These are some of the job accommodations that help people with episodic disabilities to remain working, and that's a big thing.

The other thing, and I mentioned it, is access to medications, affordable treatments. I've been able to successfully use disease modifying therapies to alter the course of my disease. Those are things that have helped me be able to remain in the workplace, which is really important for people to be able to do.

The Chair: Thank you.

Up next we have MP Long, please.

Mr. Wayne Long (Saint John—Rothesay, Lib.): Thank you, Mr. Chair, and thank you to our witnesses this morning.

MP Yurdiga, you've done a great job on this motion.

I'll just give you a 30-second glimpse into my past. In my twenties, which wasn't yesterday, I suffered from anxiety. It was a terrible time for me. It was probably a three-, four-, five-year period during which I was almost paralyzed with anxiety. I remember how it was a chore to go to work each day. I would have it mapped out what I would do when I got to work, but there were times when the anxiety got so bad, I had to go home. I just couldn't deal with it.

I look back and thank God that I had an accepting, supportive employer to help me through that, but I see so many instances—whether it's with mental health, epilepsy, chronic pain, what have you—where there is that stigma attached. Although some employers understand, many just don't. They say, “Oh, there he goes again” or “There she goes again”.

Anyone in the panel can jump in on my question. What can government do to work with partners to address that stigma? What's the first step we should take?

Ms. MacKinnon.

Ms. Shauna MacKinnon: I would say education.

Mr. Wayne Long: Okay, so how would you do that?

Ms. Shauna MacKinnon: Again, I have a fantastic employer. If I have a problem being accommodated at work, I just have to call her.

This happened just after the fire, two years ago, in Fort McMurray. I was working in the news department. I was working right through the fire, right through evacuation and everything else.

I knew, after about six weeks—if there is a stressful event it takes about six weeks for it to have an impact on me, physically—I was feeling the physical effects of that. I told my employer that I was going to need to take a week off because of that.

At the time, they had gotten rid of one of our employees, and they said, “No, we can't give you the time. We want to give you the time off, but we can't give it to you right now.” I said, “Well, I've started dropping things. That, to me, is the first sign that I am going downhill physically. I am being affected by the stress of the past six weeks. I need to take that time off.”

It was a matter of my calling human resources and their saying, “No problem. Schedule the time off and take it.” They knew my physical condition was on the decline because of the stress, so they knew I was going to need the time off, and they arranged it.

● (0915)

Mr. Wayne Long: Just let me jump in, if you don't mind. You had a supportive employer.

Ms. Shauna MacKinnon: Yes, I did.

Mr. Wayne Long: What can we do to help educate and turn the tide? There is Bell Let's Talk, and there are other great initiatives out there that are bringing mental health issues out into the open so that people are less reluctant to talk about them.

What can we as a government do, though, to educate employers?

Ms. Shauna MacKinnon: It could be laws or guidelines saying this is how people with episodic disabilities should be treated. I am saying that my employer is educated on the disabilities that are out there and what the effects are.

I am not sure what the process is for changing things, because I don't know exactly the inner workings of government. I guess just improving education, perhaps.

Mr. Wayne Long: Thank you.

Ms. Kelndorfer.

Ms. Julie Kelndorfer: The MS Society has been involved with the Conference Board of Canada as well as the Public Policy Forum. They have looked at MS in the workplace. The Public Policy Forum report called “Condition Chronic” looks at chronic disability and diseases.

If you look at the key messages in such reports, the broad message is that, really, we need to look at a fundamental renewal of our support system. Having this committee look at it is a first step to using that episodic disability lens.

In terms of the stigma piece you're talking about, it's education awareness. One of the suggestions in the “Condition Chronic” piece is putting together a national strategy in terms of employer best practices. In the last 10 years I've seen movement in the episodic disability arena in terms of some research, but we need more. We need to look at that. Stigma is definitely hard, and what perpetuates it is that individual you hear in that situation.

Mr. Wayne Long: I just want to get Mr. Woodley in here, too, if we could.

Mr. Drew Woodley: I agree with all of the comments made so far.

From the epilepsy perspective, the resources are there in terms of information. Epilepsy organizations across the country have developed really excellent resources and tools to inform employers about episodic disabilities—epilepsy in particular, but more generally as well.

Where we run into difficulty is having the resources to actually go into the workplace and meet with them. The most effective way to do this, particularly if there is an individual employee involved who is also a client of the agency, is to have staff go in and work with the employer on accommodation and on educating the entire workplace.

Epilepsy Toronto, for example, has an excellent program that allows them to do this, but that's an exception across the country. In a lot of cases it's a resource issue of the local community agencies not having the capacity or the staff to do this en masse.

With some dedicated support from the government toward this kind of project, I could see that would be the next logical step forward.

Mr. Wayne Long: Thank you very much, everyone.

The Chair: Thank you.

Madam Sansoucy.

[*Translation*]

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

I thank all the witnesses.

In the context of this study, I would first like to be transparent by sharing some personal information that has been known in my community for a long time. I was diagnosed with fibromyalgia in 2001.

Ms. MacKinnon, I really recognized myself in your story when it comes to this way of empowering ourselves to live with our disability, but also the opportunity given to us. I am a member of the fibromyalgia association in my region, and I have been able to see how difficult it can be for the women I meet, as this disability affects mostly women. A young woman in Saint-Hyacinthe ended up in a seniors residence in her twenties. It is difficult for her, but she has become president of the association. When I saw the list of episodic disabilities in the Canadian survey on disability, I assumed that fibromyalgia would be included in the chronic pain category, but the disease was not to be found there. So you will understand that my questions won't relate to your daily life because I am very familiar with it.

I will rather turn to the representatives of the two associations, Mr. Woodley and, Julie, if I may call you by your first name.

Some studies show that people living with episodic disabilities risk ending up in a worse financial situation if they return to part-time or intermittent work. It is very important to address this in health insurance or employment insurance programs because many people don't have private insurance. It is in this spirit that I proposed a motion that echoes the one proposed by my colleague Mr. Yurdiga where I ask that we hear from experts, the sick and health professionals on reviewing the current employment insurance program, which provides only 15 weeks of benefits for sick people. I think the period should be extended because we know that more than one-third of sick people have used up the 15 weeks they are entitled to.

So I would like to hear your thoughts, Mr. Woodley and Julie, on how we could reform the Employment Insurance Act and enhance those sick benefits. In your opinion, how many weeks would be needed and what kind of flexibility should we show when it comes to episodic disabilities?

● (0920)

[*English*]

Ms. Julie Kelndorfer: In terms of the EI sickness benefit program.... First of all, in regard to the clawback you talked about and how they're worse off if they work. For example, a person with MS who is experiencing a relapse and is only available to work part time, they get docked, then, dollar for dollar for their clawback. Does it make sense for them to work? If you do the math, it doesn't make sense. We would like to see the clawback reduced.

I do want to point out, though, that the working while on claim has been extended to include EI sickness benefits, so we're hoping that makes a difference so that will be improved. But really, I think taking that piece out altogether would be supportive.

Increasing the weeks to match the compassionate care benefits I think is reasonable. We recently did some work with the Conference Board of Canada looking at the costs of increasing the weeks but also—it's early on too—in terms of the eligibility and the number of hours. We're talking about people, women, in precarious and part-time work these days, and being able to even have enough hours to qualify for EI sickness benefits is a difficulty. The Conference Board of Canada looked at the costs associated with reducing that. I think that's something we need to look at as well.

Additionally, there's the flexibility. That whole week...if you work one day of that whole week, you lose your entitlement for that entire week, so then you only have 14 weeks left. We also think that can be changed, in terms of the flexibility in the calculation. It's important and, honestly, there should be an increase in the amount people receive. It is very little, even when they access it, if they are able to access it.

[*Translation*]

Ms. Brigitte Sansoucy: Mr. Woodley, would you like to add anything? Let's not forget that about 34% of women have access to employment insurance, that an average of 40% of people with episodic disabilities have a severe or very severe disability and that employment insurance sickness benefits account for 55% of insurable earnings. How many additional weeks of sickness benefits would you suggest?

[*English*]

Mr. Drew Woodley: I think it might be helpful to think of it less in terms of weeks and more in terms of days. Fifteen weeks is 75 working days, so as Julie mentioned, if you're missing one day of work per week but you're able to work the other four, having a system where your claim stays open and you can have coverage for that single day that you missed, or two or three days in a two-week period, that sort of thing, that would be a logical first step. The total number of days isn't actually greater than the current system, but you're able to take them in shorter amounts over a longer period of time.

I think for most people these conditions last years. Certainly having a longer term number of weeks over an extended period of time where there is no medical likelihood of remission, or in the case of epilepsy, where it could be a significant amount of time before someone is able to achieve seizure control through medication, I think that would be an important second step.

I'll also mention, in terms of medical coverage, one of the issues we're concerned about in Ontario. The provincial government recently announced that they're moving to align their definition of “disability” for the Ontario disability support program with the federal definition. Currently the Ontario definition is somewhat broader. For a condition that requires constant medication to manage seizures, even if seizures aren't fully controlled, the possibility of people not being able to enrol in that program because the definition is tightened, and losing the medical benefits that go along with it, is a very serious concern as well.

● (0925)

The Chair: Thank you.

MP Ruimy, please.

Mr. Dan Ruimy (Pitt Meadows—Maple Ridge, Lib.): Thank you very much, everybody, for being here today. It's not an easy study. If it was just focused on MS, it would probably be a little bit easier, but it's focused on a lot of different things, a lot of moving pieces.

First off, you mentioned, Julie, a Conference Board report. Could you forward that to the clerk so we could take a look at that?

Ms. Julie Kelndorfer: Yes. There are two Conference Board reports in the “MS in the Workplace” series. There's also the Public Policy Forum work on “Condition Chronic”. The fourth one I'll mention is the Institute for Research on Public Policy. It's called “Leaving Some Behind: What Happens When Workers Get Sick”. I can forward all four of them.

Mr. Dan Ruimy: That would be helpful.

A lot of the things we're talking about are wide-ranging. They involve, perhaps, the federal government, provincial government, health care, that sort of thing.

Shauna, you mentioned your struggles and the medication. Maybe everybody can contribute to this. What I first want to know is, where's the province in this? What are they doing? How are they supporting? Health care is primarily a provincial jurisdiction. In fact, about a year ago, when we signed the health accord, the federal government gave $5 billion for mental health care across the country. That money's supposed to be spent on health care, and some of the conditions that we're talking about are mental health care. It'll be interesting to see what's being allocated to that.

But for now, can you just tell me your experiences with the provincial governments? Where are they supporting? Are they paying for those medications and that sort of thing?

Ms. Shauna MacKinnon: I can't speak for all of the provinces. I know my experience in Nova Scotia was that my drug was completely covered by the Nova Scotia government, so I went to the hospital every three months and picked up my prescription, which would last three months. Much like Julie, I'm on a disease-modifying drug as well.

In Alberta, I had to apply for Blue Cross non-group life insurance, or some such thing. I can't tell you exactly what it was. I pay $65 a month for that, and then my drug is completely covered. This drug ranges in price from $20,000 to $30,000 a year. That's the approximate cost of drugs to the provinces. I can't speak to the other provinces. I don't know. Most of them cover the drug to some degree.

Mr. Dan Ruimy: Thank you.

David.

Mr. David Yurdiga: The biggest concern I have is not only obtaining the medication you need, but accessing specialists. A lot of times individuals sometimes have to wait over a year just to see a doctor. If they need a medication change, they have to wait a year. A lot of times, for my wife, in particular, if she needs a change in her medication, or whatever it may be, she has to wait. The wait times are getting longer and longer.

I think we have to have a paradigm shift and focus on where the dollars go. We need specialists. We need easy access to the specialists. Time is everything, especially when you have an episodic disability. The earlier you catch it the quicker a person will be able to participate in the workforce again. It's all about educating the employer and controlling the disease by getting the proper medical attention.

Mr. Dan Ruimy: When you actually did get the specialist, was the specialist the appropriate specialist? Was it somebody who was able to address those issues?

● (0930)

Mr. David Yurdiga: One time, my wife had a severe reaction. We didn't know that she had MS at the time. We entered emergency. She lost total use of her right side, so the first thing that came to my mind was that she had had a stroke, so off we went to the hospital. She was able to access a specialist who was at the emergency. They did a bunch of tests, and then we found out that she had MS. For the next step, we had to wait a year to see him again. That's a problem.

Mr. Dan Ruimy: I can see how that would be quite scary.

Julie.

Ms. Julie Kelndorfer: In terms of wait and the appropriate use of medical practitioners, I think it also speaks to the programs, where we ask for medical certification and by whom. I think that's also part of the issue for people with episodic disabilities, and people with disabilities as well. You have to get all of these certifications from specialists, and if that specialist happens to be a neurologist with the wait times.... We're compounding it through our systems. Part of that fundamental renewal is to look at how we're best utilizing the entire system in order to support people.

Mr. Dan Ruimy: Thank you.

Drew.

Mr. Drew Woodley: In Ontario—I can only really speak to Ontario on this point—whether or not it's relatively easy to access a neurologist depends on what part of the province you're in. In northern Ontario, there are some difficulties with epileptologists in particular. I don't think any neurologist is waiting for patients to come through the door. I think it does take a while to see them.

Recently, the previous provincial government invested a significant amount of money in epilepsy surgery beds, which can have a profound impact on people with particular types of seizures, potentially ending the seizures for their lifetimes, but that's a fairly small portion of the population for whom that could have a huge impact on their lives.

One of the things we have recognized is that there's a really important need for community management and community education to help people manage their epilepsy at a community level, and that's a big part of what the epilepsy agencies in Ontario do. That has not been a priority for the province in terms of funding. In particular, for the 30% of people who don't have well-controlled seizures, who need management education, who need education simply about when they have to go to the emergency room and when they don't, following a seizure, those are the resources we've identified as possibly a priority.

The Chair: Thank you.

Mr. Morrissey, please.

Mr. Robert Morrissey (Egmont, Lib.): Thank you, Chair. The first part of my question I'm giving to MP Vaughan.

Mr. Adam Vaughan (Spadina—Fort York, Lib.): My role here, as parliamentary secretary for the minister who has carriage of EI in particular and of some of the other benefits, is a little different from the other committee members, but I do have a question. This is one of several studies we've received at this committee that has sought to renovate the EI program to accommodate very compelling and very important dynamics that are emerging as the workplace changes, but also as our understanding changes of what constitutes disability and other elements beyond that. Bereavement for sudden infant death is an issue we're also contending with. All of it ties back into EI because EI is the one federal social assistance program that people turn to when they ask themselves how they can modify dynamics to support income.

What we're running into as a country is that it's an insurance program. As you expand the benefit requirements of the program, at some point it adjusts the actuary table, and you have to start dealing with the way in which it's funded. Somebody has to pay for this insurance process, and that's the EI contribution that employers make and that workers make when they work. As you said, if you're in a part-time job and you don't pay enough, you don't qualify. If we're going to give benefits without paying in, the math doesn't add up at a certain point. That's one challenge.

Clearly, there needs to be comprehensive EI reform, but where we're also hammered on this is that every time we talk about EI reform, it's referred to in Parliament and in political circles as a payroll tax. It's said that we're destroying jobs and destroying the economy. “Don't touch the payroll taxes. It's a payroll tax”—that's the political wall we run into.

How do we deal with those ideologues who see every adjustment to an insurance program...? CPP is included in this. When you change CPP, they go crazy as well. How do we get past that wall if some of the very people who are asking us to fix EI don't want us to actually pay for it with EI premiums?

● (0935)

Ms. Julie Kelndorfer: Thank you for the comments and questions. This is very challenging, for sure. I think any decisions that are made to change the support programs, yes, need to take in those considerations.

I think also that there's an economic and a basic need for people to be taken care of. Perhaps it's an awareness. Perhaps it's education that needs to happen. We need to support people. We know that it's a significant concern. The occurrence of episodic conditions is significant: 1.2 million, according to some of Adele Furrie's work, some 2012 numbers. That's about half of the people of working age who have a disability. Yes, people don't want to, but I think if we work together and really try to move the needle to increase awareness—which this committee is doing—that would be really....

Keeping people employed is so important to our economy and to employers. I think the studies—

Mr. Adam Vaughan: We're told if we increase EI we're going to destroy the opportunity to hire people, yet if you don't provide the EI, you can't hire certain groups of people.

Ms. Julie Kelndorfer: Yes, I know. It's a catch-22.

Mr. Adam Vaughan: Are the charitable organizations that support people in these circumstances—because that's what it's now left to, charity—now that the political ban on talking about poverty has been lifted from the charitable organizations, prepared to step up and talk about the need for EI reform, even if it means changing the premiums table?

Ms. Julie Kelndorfer: I think we do it all the time.

Drew, maybe you want to speak to this too.

But yes, it's important for us as organizations to advocate for improved quality of life for people with MS and other disabilities, for whatever needs to happen in order to change things. I think there are also other....

By looking at that whole renewal of the entire support system, perhaps there are opportunities for other programs to come in, in terms of social innovation or such things. Yes, I think there are some short-term things we're asking for, but there's also some long-term things.

Mr. Adam Vaughan: Structural change....

Mr. Drew Woodley: I'll simply add that, first and foremost, this is about keeping people in their jobs. If this is an episodic disability where they're not necessarily going to be unable to work long term, it's about those shorter periods. This is about keeping them employed. I think that's something that all parties can get behind.

Mr. Adam Vaughan: Even if it requires an EI premium change...?

Mr. Drew Woodley: Where the alternative is the added anxiety of not necessarily being able to stay in the job, which exacerbates a neurological condition like epilepsy or like MS to the point where they can't work, I think the positive alternative is, in any scenario, people being able to work. That is the best solution.

Mr. Adam Vaughan: I just want to be clear, because there is massive push-back on even touching the EI premium increases, which are going to be required to finance this. You're prepared to make that argument to those people who support these services.

Mr. Drew Woodley: I think it's certainly worth the discussion. I think if the response is that we would rather have them unemployed.... I don't think that's a response they would give. It's also worth remembering that they already paid in, that this isn't them using a program that they haven't already paid for. It's better access to a program that they're contributing to.

Mr. Adam Vaughan: In the current model, though, the benefits are scaled to the pay-in.

Mr. Drew Woodley: Going forward to the actuarial tables in the long term...yes.

Mr. Adam Vaughan: They've paid in, but the benefits are scaled to the contributions now. If you change that, something has to move.

Mr. Drew Woodley: Yes. I do think that would be a reasonable conversation to have. If the longer term economic outcome is people staying employed and the economic benefits that go along with that require a slight adjustment to the amount people are paying into EI, longer term, that's a good conversation to have.

The Chair: Thank you.

MP Falk, please.

Mrs. Rosemarie Falk (Battlefords—Lloydminster, CPC): Thank you all for being here and sharing your stories, because they are quite intimate. It almost puts you in a vulnerable situation. I thank you for sharing those.

Mr. Yurdiga, you made a statement in one of the questions, I think, that you answered for Mr. Diotte. The MS Society was where you went for support. Once they have a diagnosis like this, where can people go for support, other than organizations like the MS Society?

● (0940)

Mr. David Yurdiga: For us, that was the only option. Outside of going to a specialist, the MS Society was the place we went to for information and great support.

We were talking about EI and everything else. It's about educating the employer and educating government. It's actually more cost-effective to have people employed than not. It's either going to fall to a provincial program or a pension.

I think we have to look at a broad spectrum. Providing access to employment for people with episodic disabilities is actually going to be cheaper for the system in the long run, whether they're going to end up in a nursing home, or whatever. The point is to keep people mentally healthy, contributing to society and being part of the community.

Mrs. Rosemarie Falk: Thank you.

I have another quick question, and then I'm going to split the rest of my time with my colleague, Mr. Arnold.

When people are denied by Service Canada, how is that spoken to them? Is there compassion behind that? Is there an understanding of the break in the system, so to speak? Does that make sense?

Do Service Canada workers have the understanding and the compassion, even if they still are denying somebody an EI claim because they don't have enough hours, or they take away a week because they worked a day, or that type of thing? Is there any compassion coming from the government bureaucratic side?

Ms. Julie Kelndorfer: Thank you for your question. That's an interesting one. I'd not actually ever heard or even thought about that piece, in terms of the denial.

We typically hear that people want to appeal, or we hear their frustrations. I don't know about you, Drew, but I haven't really heard about that interaction. I'm not sure that it's good or bad, but it is always....

Mrs. Rosemarie Falk: Drew.

Mr. Drew Woodley: I'm not sure that the denial happens at the window.

I think the Service Canada staff might help facilitate the application, but the notice for the ultimate evaluation and denial would probably come by mail or by email. I don't know if there is that opportunity for a face-to-face conversation with staff.

Mrs. Rosemarie Falk: Thank you.

Mel.

Mr. Mel Arnold (North Okanagan—Shuswap, CPC): Do I have two minutes? Thank you.

Thank you all for being here today, including those here by teleconference.

Could each of you give us an idea of how many disorders or disabilities could be considered episodic? We've heard much about MS today. I think it's one of the more well-known ones, but I'm sure there are many others out there.

Mr. Yurdiga, would you like to start? Then I'll ask each of you for, possibly, a few examples of ones that are less known.

Mr. David Yurdiga: Episodic disabilities include a broad range of conditions—not conditions, but you have epilepsy and even severe migraines. Some people suffer such that they're in bed for days.

It should be based on the ability of a person to participate in society. It could be Crohn's disease. It could be any number of diseases. With people who have these episodic bouts—with whatever they're diagnosed with—we have to focus not on the term but on what we can do to ensure these people continue to contribute to society in the workforce and at home. I think we have to look at it not by naming 40 different disabilities. We're looking at what we can do for people who are currently suffering, and for future Canadians who will be diagnosed with an episodic disability, so they know there is support for them.

I don't think that naming them all is effective, but rather when somebody does suffer from something episodically, that they know there is support.

● (0945)

Mr. Mel Arnold: Thank you.

Rather than going to naming a bunch then, my next question is about what type of assistance we can look at providing for employers who are making those accommodations to try to keep those people who are suffering from episodic disorders. How can we assist employers in their role in accommodation?

The Chair: Time is up, but I'll allow for a brief answer.

Mr. David Yurdiga: I think there has to be some kind of support for the employer. I had 92 staff when I was in the private sector. It's all about knowing what's going to happen if you hire someone who has an episodic disability, for example, knowing that you can get a tax credit, because it's going to cost. It always costs employers something. They need to know there's a program out there, so that they're going look at this and say, “It's okay. We can hire people with episodic disabilities.”

I think most people applying for a job don't list their disabilities, because they won't get the job. If employers know there's a program out there that supports them, whether it's a tax credit or whatever it may be.... But we have to ensure that people with episodic disabilities, or disabilities in general, are not turned away.

The Chair: Thank you very much.

Mr. Drew Woodley: I'll just add that—

The Chair: Sorry. Two very quick answers....

Ms. Julie Kelndorfer: I want to point to those four studies I'm going to send to the clerk, which speak specifically to the employer's perspective and the importance of that.

The Chair: Drew...?

Mr. Drew Woodley: For many episodic disabilities, accommodations like scheduling flexibility are extremely low cost.

The Chair: Thank you.

Unfortunately, I need to cut us off there. We have to bring in another panel.

Thank you very much, all of you, for appearing today and getting us off on the right foot with this study.

We will suspend for a few moments while we switch panels.

The meeting is suspended.

● (0945)

(Pause)

● (0955)

The Chair: Good morning and welcome back.

I'm very pleased to get started with our second panel today.

First of all, by way of introduction, we have from the Department of Employment and Social Development, Andrew Brown, director general, employment insurance policy, skills and employment; Kris Johnson, director general, Canada pension plan disability directorate; Krista Wilcox, director general, office for disability issues; and Gertrude Zagler, director of workplace equity, labour program.

Thank you to all of you, and welcome. We'll get started with the opening submission. Whoever is speaking has seven minutes.

Go ahead, Krista. Thank you.

[*Translation*]

Ms. Krista Wilcox (Director General, Office for Disability Issues, Department of Employment and Social Development): Mr. Chair, members of the committee, good morning.

My name is Krista Wilcox. I am the director general of the Office for Disability Issues at the Department of Employment and Social Development.

Joining me are Andrew Brown, director general of Employment Insurance Policy, Skills and Employment, Kris Johnson, director general of the Canada Pension Plan Disability Directorate, and Gertrude Zagler, acting director general of Federal Programs at the Labour Program.

Let me begin by thanking the committee for the opportunity to address this very important issue. While all people with disabilities may face barriers to economic and social inclusion, people with episodic disabilities may experience specific challenges owing to the nature of their condition.

[*English*]

Episodic disabilities are characterized by periods of wellness and periods of illness or disability that vary in severity, length and predictability. According to the Episodic Disabilities Network, “Examples of conditions that are episodically disabling are mental illness, arthritis, HIV/AIDS, multiple sclerosis, crohns and colitis, and some forms of cancer and rare diseases”, amongst others.

While this is a useful starting point, what identifies an episodic disability is the intermittent variation in the ability to function, which can occur in individuals with a wide range of single or multiple conditions. Because episodic disabilities can be unpredictable, people with these types of conditions may face particular barriers to employment and be at risk of financial insecurity, as they may be excluded from the workforce altogether because of these barriers, even though they have skills and initiative.

The office for disability issues has worked with other levels of government and disability organizations over the past decade to further our understanding of episodic disabilities. This has been, to a considerable extent, pioneering work. There has been little by way of international resources to draw on in this area.

For example, through collaborative work under the federal, provincial and territorial social services forum, the disability advisory committee commissioned a study by the Social Research and Demonstration Corporation on the situation of people with episodic disabilities in Canada. The research included both a data analysis study, which was based primarily on the 2012 Canadian survey on disability, and a literature review.

Some key findings of the data analysis were as follows. About 4% of the working-aged population had episodic disabilities, compared with 10% with disabilities in general. About 40% of those with episodic disabilities had severe or very severe disabilities. Episodic does not mean that the disability is less significant. Having an episodic disability means having poorer employment outcomes and lower incomes.

As with disabilities generally, more women than men have episodic disabilities. The researchers found differences between women and men in a number of important respects. In particular, women with episodic disabilities were less likely to be working and more likely to have low incomes than were men with episodic disabilities. Among people with episodic disabilities who were employed, the percentages with part-time or temporary jobs were similar to those for the general population. The important difference is that fewer were employed at all.

To add to our current knowledge on the experience of people with episodic disabilities, the 2017 Canadian survey on disability is the first national survey to contain a specific module on episodic disabilities. Data around people with episodic disabilities will be available in 2019, following the release of initial results, which took place yesterday. The Government of Canada is committed to advancing the social and economic participation of Canadians with disabilities, including those with episodic disabilities.

I'll share with you information on the relevant support services and legislation provided through Employment and Social Development Canada. A cornerstone of the Government of Canada's accessibility agenda is Bill C-81, the accessible Canada act. The act would, if passed, introduce measures within federal jurisdiction to improve accessibility for all people in Canada, including those with episodic disabilities. Bill C-81 includes a specific reference to episodic disabilities in the definition of disability. It would require consideration of the particular accessibility needs of people with a variety of disabilities, including episodic disabilities, and the identification and removal of barriers and prevention of new barriers in areas of federal jurisdiction.

● (1000)

Bill C-81 is grounded in Canada's commitment to the United Nations Convention on the Rights of Persons with Disabilities. People with disabilities, as recognized in the convention, strongly support the principle of “nothing about us, without us”.

Accordingly, the Government of Canada conducted an extensive and groundbreaking consultation across Canada, in which people with and without disabilities participated. Bill C-81 is based on what we learned during those consultations. People with episodic disabilities and the organizations that represent them, such as the MS Society, were active participants in this process.

To further implement the convention in Canada, the Government of Canada has been working with provinces and territories towards Canada's accession to the optional protocol to the convention. The optional protocol would enable people with disabilities to bring forward complaints to the United Nations if they believe their rights have been violated and if they have exhausted domestic remedies.

While income supports for people with disabilities fall primarily within the purview of the provinces and territories, the Government of Canada provides contributory income replacement programs for those who are unable to work as a result of a disability. The Canada pension plan disability provides partial earnings replacement to Canadians between the ages of 18 and 65 who have contributed to the CPP and can no longer work on a regular basis because of a severe and prolonged disability. A benefit is also available for eligible dependent children of CPPD beneficiaries.

To qualify for CPPD, applicants must meet both contributory and medical eligibility criteria. Contributory eligibility is met when an individual has made CPP contributions in four of the last six years, or in three of the last six years for long-term contributors with at least 25 years of contributions. Medical eligibility is met when an individual has a severe and prolonged disability as defined in the CPP legislation. “Severe” means that a person is incapable of regularly “pursuing any substantially gainful occupation”. “Prolonged” means “that the disability is likely to be long continued and of indefinite duration, or is likely to result in death”.

In 2016-17, CPPD paid $4.3 billion to 335,000 disabled beneficiaries and 83,000 of their children, representing approximately 10.2% of the $42.5 billion of total CPP expenditures.

The employment insurance sickness benefit is available to eligible claimants who are unable to work because of an illness or injury. The benefit provides up to 15 weeks of partial income replacement to allow workers time to restore their health so that they can return to work. The EI sickness benefit provided $1.6 billion in support to approximately 379,000 claimants in 2016-17.

EI sickness claimants have the flexibility to use the 15 weeks of EI sickness benefits over their 52-week benefit period. For example, a person may take three weeks of sickness benefits, and then return to work if he or she is feeling well enough, knowing that 12 additional weeks remain available during the benefit period.

Earlier this year, changes were made to provide new flexibility in response to recommendations from the MS Society and other health charities. Specifically, the EI working while on claim provisions were extended to sickness and maternity claimants, providing them with more flexibility to manage their return to work and keep more of their earnings.

To complement the EI benefits, under the Canada Labour Code, employees in the federally regulated private sector are entitled to job-protected sick leave for up to 17 weeks if they have worked for at least three consecutive months with the same employer. In addition, the code was amended, through Budget Implementation Act, 2017, No. 2, to provide employees with the right to request flexible work arrangements, which could benefit an employee with an episodic disability.

Further, Bill C-86, the budget implementation act, 2018, proposes additional amendments to the code that could be beneficial in the context of episodic disabilities. This includes eliminating the three-month wait period for sick leave, so that all federally regulated employees have access to this protection regardless of how long they have worked with their employer; allowing sick leave to be used for medical appointments; introducing a new five-day personal leave, of which three days would be paid; and allowing employers to request a medical certificate only when an employee is away for three or more consecutive days.

To strengthen and grow the middle class and help Canadians find good jobs, the Government of Canada now has new workforce development agreements with most provinces and territories, and will announce details soon. The new WDAs consolidate and replace the Canada job fund agreements, the labour market agreements for persons with disabilities and the targeted initiative for older workers.

● (1005)

These agreements enable provinces and territories to provide assistance and skills training with the flexibility to respond to the diverse needs of their respective clients. Under the WDAs, the Government of Canada provides provinces and territories with $722 million annually as well as an additional $900 million over six years, from 2017-18 to 2022-23. The WDAs will increase support for persons with disabilities beyond what was provided through the labour market agreements for persons with disabilities. From 2017-18 to 2022-23, approximately $2.7 billion will be invested by federal, provincial and territorial governments in targeted skills training and employment supports.

Provinces and territories can continue offering programs similar to those that were offered under the previous agreements but have the flexibility to adapt these models to create new interventions, including specific interventions to support people with episodic disabilities, to meet the needs of their local labour markets. Additionally, ESDC invests approximately $40 million a year in the opportunities fund for persons with disabilities. This federal program is delivered through contribution agreements with service providers who offer a wide range of tools to help persons with disabilities, including those with episodic disabilities, to prepare for, obtain and maintain employment or self-employment.

The opportunities fund is unique, as it offers employment-focused interventions and assistance to improve employment situations for a specific component of the persons with disabilities population who have limited or no attachment to the labour market. Since 2018-19, additional funding of approximately $18 million over six years will be invested in the opportunities fund to help employers who have demonstrated commitment to hiring persons with disabilities but need support to find the right match and create workplaces that allow employees with disabilities to reach their full potential.

The Government of Canada also provides support to Canadians with disabilities to help improve their financial security through programs like the Canada disability savings program. Launched in 2008, the CDSP is a long-term savings program that helps Canadians with severe and prolonged disabilities and their families save for the future.

The Government of Canada provides grants and bonds matching investments by individuals. In recognition that disabilities may have intermittent but long-term effects, the Government of Canada introduced a new rule in 2012 extending the period that an RDSP may remain open for a beneficiary who ceases to qualify for the disability tax credit if a health professional attests that they are likely to become eligible again in the foreseeable future. This measure can assist people with episodic disabilities who may lose their DTC eligibility during periods of wellness.

ESDC also supports the disability community through funding under the social development partnerships program to help improve the social and economic inclusion of people with disabilities in our communities. SDPP is an $11-million grant and contribution program that makes investments in the not-for-profit disability organizations in Canada. The program provides operating and project funding to not-for-profit disability organizations to achieve this work.

In recent years, we have funded projects through this program. For example, the Mood Disorders Society of Canada, in partnership with the Arthritis Society, received a contribution of approximately half a million dollars for a project entitled “Work With Us” to address the complex issues that affect persons with chronic diseases, particularly depression, arthritis and chronic pain. This project uses an innovative cross-sector approach to develop and provide education and supports for persons living with depression, arthritis and chronic pain as well as for workplace colleagues, employers, unions, families and friends.

That concludes my opening remarks. I would be pleased to answer any questions you may have.

● (1010)

The Chair: Thank you very much.

Up first is MP Diotte, please.

Mr. Kerry Diotte: Mr. Chair, I want to move a couple of quick but time-sensitive items before we get into this.

I want to move that the committee allow written briefs for their study on M-192.

The Chair: Given that it is a motion on the subject we are dealing with, we are able to vote on this today. We should probably establish the deadline within the motion as well. The last day of witnesses is December 6, so I would suggest December 7. It could be later, if we feel it necessary.

Mr. Kerry Diotte: That would be fine.

(Motion agreed to [*See Minutes of Proceedings*])

The Chair: Thank you.

Mr. Kerry Diotte: There's another one. I move that the committee extend the deadline for written briefs from stakeholders and families on its study on M-110 to 5 p.m. on Friday, November 29—

The Chair: Mr. Diotte, I have to interrupt you here.

Mr. Kerry Diotte: —so that their input can be considered by analysts in drafting the report.

The Chair: I'm afraid....

Mr. Kerry Diotte: It's very time sensitive, obviously.

The Chair: As we talked about, Kerry, unfortunately the rules around this are very clear. To do a motion outside the scope of the study that we're dealing with at present would require notice of 48 hours.

Mr. Kerry Diotte: The input from these people is swept under the rug.

The Chair: It's not an issue of sweeping anything under the rug.

Mr. Kerry Diotte: They won't be heard from then.

The Chair: I'm afraid I have to rule it out of order.

Thank you.

Mr. Kerry Diotte: They won't be heard from.

The Chair: I'm afraid I have to.

It's not an issue of choice. It's an issue of the rules of the committee.

Mr. Kerry Diotte: We could make an exception.

The Chair: The rules of the committee are stated.

Mr. Kerry Diotte: You could make an exception if you really wanted to for these people.

The Chair: The rules of the committee are stated.

If you wanted to do this properly, it should have been submitted 48 hours ago. You would have been able to do that. We also had a committee business meeting on Tuesday that this could have been done at.

If you wish to carry on, we've stopped your timing at five minutes and 54 seconds left.

Mr. Kerry Diotte: I'm disappointed obviously, but let's go on with this.

Ms. Wilcox, it's quite a long list of what seem to be accomplishments that you put forth. I know that you had talked about how people with episodic disabilities, in particular, women with episodic disabilities, were less likely to be working and more likely to have low incomes than men with episodic disabilities. That's pretty alarming.

I know that in February the government came in with a budget that is seen through a feminist lens, gender-based budgeting. Do you see anything in that gender-based budget that will address the fact that women with episodic disabilities will be more likely to have lower incomes than men with episodic disabilities?

Ms. Krista Wilcox: Thank you, Mr. Chair, for the opportunity to respond to this question. It's a very important question.

I would say in general with people with disabilities, certainly episodic disabilities as well, we do find that women are more impacted by unemployment, by lower incomes, across the board, across age groups, so this is an issue that's not unique to people with episodic disabilities, but it's certainly an important one across the disability community.

In the budget as part of the accessible Canada package of supports to support the legislation, we did have an investment of $18 million in the opportunities fund. As I spoke about in my remarks, that is going to help with some of the issues that this committee talked about earlier this morning around getting employers who are disability confident and are going to be able to help provide the supports that are needed for people with disabilities, in particular women with disabilities, to remain in the labour force and to get into the labour force to get the skills that they need.

That's an important piece, that ability to have accommodations, to have employers understand what people with disabilities need and to have a supportive work environment for people with disabilities to be able to gain, keep and stay employed in the long term.

Mr. Kerry Diotte: You do list a lot of the various programs that are available. One of the ones that sticks out is that you talk about the employment insurance sickness benefit available to eligible claimants who are unable to work due to injury or illness. The benefit provides up to 15 weeks of partial income replacement to allow workers time to restore their health, so they can return to work.

As we know, the biggest thing about episodic diseases is the fact that it's never really restored. You are back and forth. That's the thing we certainly heard from witnesses in the previous panel. What in all of this that you're talking about would help somebody who has an episodic disease?

For instance, if they have to take the odd day off a couple times a month perhaps because of, I don't know, it could be migraines, it could be their complications with MS, etc., how would they access EI?

● (1015)

Ms. Krista Wilcox: I will turn to my colleague Andrew Brown to talk about EI. Then perhaps Gertrude could talk a little bit about what we're doing in the federal labour code as well.

Mr. Andrew Brown (Director General, Employment Insurance Policy, Skills and Employment, Department of Employment and Social Development): Thanks, Krista.

With respect to the EI program and a person with an episodic condition who is in the workforce, the benefit is not tailored specifically to those people. It is of general availability to workers who are dealing with an illness or an inability to work temporarily. There are those 15 weeks of benefits they're able to access.

There were changes announced this year in the budget and implemented in August of this year to allow workers receiving sickness benefits to access what we call the working while on claim provisions. These deal with how we treat the earnings of a worker if they're receiving EI benefits.

We heard in our conversations with stakeholders that some people who are dealing with an illness would like to make a progressive return to work, but with the old provisions—when they were not able to access “working while on claim”—if they attempted to do so and earned perhaps $250 in a week, just to give an example, we were reducing their EI benefits by that same $250. With the changed provisions, we now reduce their EI benefits by only 50 cents on the dollar. They would have $250 in employment income, and we would reduce the benefit by $125. In a sense, it's trying to reduce the disincentive for those who are able to make a progressive return to work.

I'd say that is a concrete step that has been made to try to assist people who are dealing with any kind of illness or injury, and it might also be helpful for people with an episodic illness.

Mr. Kerry Diotte: Of course, with an episodic illness, they would almost have to be constantly on claim, and I'm sure that would run out in short order.

Mr. Andrew Brown: The way it could work in that particular situation is that when somebody opens an EI claim, typically it would be open for a 52-week period. If the only thing they're claiming during that time is the sickness benefit—it gets very complicated if there are multiple types of claims—they can claim those 15 weeks over that 52-week or one-year period. They have flexibility in terms of the weeks during which they may claim those benefits, but they must take them in units of one week.

In order to open a new employment insurance claim after that, they would have to have worked a total of 600 hours.

Mr. Kerry Diotte: Then although there's some flexibility, with episodic individuals it certainly has to be much more flexible.

Is there any way we can improve it very quickly? Obviously, we have many people who are in this situation. We heard from this panel earlier that many people are very employable and are working, but from time to time they can't come into work and they're being punished unfairly for it. Is there anything that any one of you could suggest today that would accommodate their conditions more?

● (1020)

The Chair: Make it a very brief answer, please.

Ms. Gertrude Zagler (Director, Workplace Equity, Labour Program, Department of Employment and Social Development): Certainly, under the Employment Equity Act and our working with our federally regulated private sector, we do a lot of work around positive policies and practices, and encourage employers to look at the breadth of issues within their workplace and how to deal with those. I know my colleagues who are working on the Canada Labour Code also are bringing in more flexibility within the workplace. There will be increased awareness building around all of those different pieces as we move forward into the next year.

The Chair: Thank you.

MP Morrissey, please.

Mr. Robert Morrissey: Thank you, Chair.

I want to follow up on MP Vaughan's earlier questions in relation to the EI system. My question is to Mr. Brown.

The changes that our government made related to illness and working on claim are a significant improvement. Am I correct that in the past, for every dollar earned, a dollar was taken from the EI benefits?

Mr. Andrew Brown: That's correct. That's how it worked previously.

Mr. Robert Morrissey: What were the budget implications of that change? You must have had an assessment on what that change would have cost to fund.

Mr. Andrew Brown: I don't have that figure available immediately. I can tell you what the scope would be, in terms of the number of people who were affected. I'd have to get back to you on the dollar figure.

It's about 60,000 Canadians annually who were doing some work while receiving EI benefits. If you look at that 60,000, that's compared to the 379,000 sickness claims that we are receiving annually at the moment.

Mr. Robert Morrissey: You don't have the dollar impact on the EI fund.

Mr. Andrew Brown: I don't have that one available right now.

Mr. Robert Morrissey: It was a progressive change I agree with, which leads to my next question.

What is, for lack of a better term, the flexibility within the EI fund? We've done several studies since I've been on the HUMA committee, and they all point to expanding the EI system as a better social safety net for people with a host of issues and disability. We constantly hear in the House of Commons from the opposition that EI premiums are a job-killing tax on business, which I disagree with. We have social security nets in this country to protect people with minimum attachment to the workforce.

What is the flexibility if we put more demands on the EI system?

Mr. Andrew Brown: The rates are set according to a formula that essentially takes a look at the expected benefits that would be paid out over the coming seven years and what rate would need to be set to equal that.

Mr. Robert Morrissey: We would simply manage what the demand would be and set the rates.

Mr. Andrew Brown: That's what it is.

Mr. Robert Morrissey: If you made a recommendation to increase the demand on the EI system to fund, then the rates would have to go up.

Mr. Andrew Brown: What I was just going to add to that is that this figure gets updated each year by the senior actuary for the EI program. An increase in benefits paid of about $170 million equates to a one-cent increase in the EI premium rate.

That's where we are at the moment with current economic conditions.

Mr. Robert Morrissey: If, as a committee, we want to recommend that the system should be used to expand benefits as a social safety net, then in fairness, we would have to at the same time recommend that there be a consequential increase in the EI premium.

Mr. Andrew Brown: That's what the impact would be because then any changes that are made to the EI Act get taken into account in the rate-setting process. The committee would not make that particular recommendation. It would be through the annual rate-setting mechanism.

Mr. Robert Morrissey: Earlier this morning, you were not here but witnesses appeared before the committee. This relates to the questioning about the flexibility of sick benefits of 15 weeks. I thought it was a very creative option put before the committee. Currently, as you reference as well, it's structured in week allotments, so you have 15 weeks. Fifteen weeks equates to 75 days. This system would be better tuned to people with episodic illness if they could take that on a daily basis, if they could use the option of having 75 days of benefits over a period of time.

I thought this was a great recommendation put before the committee, because there would be no increase in cost to the EI system. If there were, it would be marginal at best. Could you comment? Would the system be able to accommodate that kind of flexibility?

● (1025)

Mr. Andrew Brown: I think about two main considerations. One is really with respect to employers. An important thing when we think about the EI program is not just the worker but the employers, and the two are funding this program. If we are creating a benefit that could be paid on a weekly basis, there would have to be thought about whether there are equivalent leave provisions of some kind that would be made on a daily basis, and whether we would be creating some kind of a burden on employers who would be required to allow someone to be off.

Mr. Robert Morrissey: This is occurring anyhow. If this person, because of a medical condition, simply cannot go into work for a day, they're not going to work.

If they are out for the week, the same or even greater impact would be on the employer. Is there anything from an administrative perspective that would prevent the system from accommodating a 75-day sick payment versus a 15-week one? Fifteen weeks can be allocated week by week over a period. I don't see why you could not accommodate that.

The Chair: Give a very brief answer, please.

Mr. Andrew Brown: A tremendous change would be required to manage taking benefits on a daily basis as opposed to a weekly basis. That would be so for a lot of reasons. From an internal perspective, internal to more the Service Canada side of things, we would see an increase in the individual number of claims, because somebody who was perhaps making a claim for one week might claim two—

Mr. Robert Morrissey: Then we would have to up the rates.

Mr. Andrew Brown: It would create a lot more administration. The other thing to think about is that people don't have standard patterns of work, the way people thought about it in the past. If someone cannot work one day, is that one-fifth of a week or one-fourth of a week?

Mr. Robert Morrissey: No, it's one day.

Mr. Andrew Brown: For us, it's a week. There are seven days in the week not five, and if they only work for some of them, it's very complicated to go below the unit of one week.

The Chair: I'm afraid I'm going to have to jump in here.

Madame Sansoucy, please.

[*Translation*]

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

In the same vein as the comments I have heard since the beginning of this study this morning, I must first remind you that the federal government stopped contributing to the employment insurance fund in the early 1990s. I'm happy to hear people say that employment insurance must be reformed, but it is clear that the reform must require the federal government to start contributing to the employment insurance fund again as it used to in the early days. In fact, when the government stopped contributing, the 1996 Liberal reform made the rate of eligibility to benefits and the benefit amount drop. The Conservative reform in the mid-2000s made the situation worse. So the government must assume its responsibilities through a desired reform of employment insurance. Either it needs to contribute to the employment insurance fund or it needs to dissociate from it all the programs for special benefits, sickness, caregivers and episodic disabilities it created in its “generosity” by dipping into a fund to which it no longer contributes.

I think it is also important to remind people of this because it has been pointed out that health was a provincial responsibility. Yet federal health transfers have dropped from 50% to 19% in the latest agreement. Over the years, the federal government has been increasingly withdrawing from that sector, and the provinces are left with the burden. So we cannot make recommendations that would give the provinces new responsibilities without first thinking about increasing transfers. I absolutely want to bring this up from the outset.

Here is my first question for the witnesses. In September 2015, the Institute for Research on Public Policy asked Ottawa to create employment support services to facilitate return to work and create a centre of expertise providing employers with resources and information for situations when a worker falls ill. Has your department started working on those issues and finding solutions?

● (1030)

[*English*]

Mr. Kris Johnson (Director General, Canada Pension Plan Disability Directorate, Department of Employment and Social Development): I have read the report. It raises a number of important considerations, some of which I think we've already heard about this morning.

We have looked at a broad range. My colleague went over a full range of available supports within the federal sphere. Some of the changes for EI that my colleague Mr. Brown has highlighted have introduced new flexibility. We have looked at the CPP as well. That is a little more difficult to change, for reasons I can get it into if people are interested, but we continue to study it. If there are particular questions, or changes—

[*Translation*]

Ms. Brigitte Sansoucy: I do have a specific question.

According to the report by the Institute for Research on Public Policy, the definition of “disability” in some public programs, such as the Canada Pension Plan Disability Program, is too rigid, and that makes support for individuals with a chronic or episodic disability difficult. How does your department plan to remedy that situation?

[*English*]

Mr. Kris Johnson: That one, I can be a little more specific about. It is important when we're talking about the definition used by the CPP for the disability benefit to understand that it doesn't operate on any particular illness, injury or condition itself. The test is set out in the legislation and has remained the same since the inception back in the sixties.

Every individual case is looked at on its own as to how it presents in that individual. It is interesting to know that for people with conditions that are most often thought of as episodic in nature—because it's not always obvious which conditions are episodic and which are not—for those that are commonly considered, people applying with those conditions can and do get approved for benefits. It really depends on how severe it is and how likely it is that the person is going to regain the ability to work. When we look at the definition, we keep that in mind first and foremost.

The other thing we keep in mind is the fact that the CPP is not a federal program. It's actually jointly governed by the federal, provincial and territorial governments. Any changes we would make to that definition would have to be approved by the jurisdictions. The formula is two-thirds of the jurisdictions with two-thirds of the population, which is a high bar. As Parliamentary Secretary Vaughan raised earlier, there is a need to look at the funding source, and we've had some questions on the EI account on that.

If we were to change the definition in such a way as to be more inclusive or to make it easier for people to qualify for benefits, that might put at risk the monies available to pay out retirement pensions, because of course they're not separate plans. The disability benefits are paid out of the overall Canada pension plan. We would need to engage, with the help of the chief actuary of Canada, in a study of what the impacts of that might be, what that might mean for the contribution rates and whether or not there were any offsetting reductions in other parts of the plan to help.

[*Translation*]

Ms. Brigitte Sansoucy: That does raise the issue of responsibility.

May I ask one last question very quickly, Mr. Chair?

[*English*]

The Chair: A superfast one, please....

[*Translation*]

Ms. Brigitte Sansoucy: How is the Liberal government showing leadership in the hiring and retention of workers with episodic disabilities?

[*English*]

Ms. Krista Wilcox: Thank you for the question.

Certainly, under Bill C-81, there will be federal leadership in terms of the federally regulated sector, but also, within the Government of Canada, there's a commitment to the hiring of 5,000 people with disabilities into the public service, for example. That will include people with episodic disabilities.

We will have a very inclusive definition of what “disability” means. The standards that will be set under the legislation will also provide really important protections for people with disabilities generally, and again, that includes people with episodic disabilities.

● (1035)

The Chair: Thank you very much.

MP Sangha, please.

Mr. Ramesh Sangha (Brampton Centre, Lib.): Thank you, Mr. Chair, and thanks very much to our witnesses for this valuable input.

My questions will be for Ms. Wilcox or Mr. Johnson. Either one or both of you can answer.

Regarding the CPP, the Canada pension plan, as you have already told us, it's contributory. You pay into it and you get it. It's like insurance. In terms of a disability, you've already explained the criteria for and definition of disability: four out of six years for the term and medical conditions that are severe and prolonged. The conditions are required to be severe, such that they cannot perform any type of job, and prolonged up to their death.

I've been chairperson of the Canada pension plan review tribunal and have faced this type of problem many times. We would want to give an order that the disability benefit should be given to the person who was coming to us and making his or her statement, but the definition was so stringent that we were able not to grant it.

At this time, what I feel here is that you are looking for certain changes. You want to see the committee bring changes into the definition or the criteria, but you have already told us that is not possible because of the two-thirds majority and how the federal, provincial and territorial governments are all involved in it. What are you looking for in how to restructure this system so that the maximum benefit can be provided to persons with these types of disabilities?

Mr. Kris Johnson: I would clarify my earlier remarks if they were interpreted as being that we can't change the definition. Definitions certainly can be changed. They are changed in federal acts. The particular governance for the CPP is unique amongst many other programs. I just want to make the committee aware that if you are recommending changes that are considered major, they are subject to that governance protocol. Certainly the definition of disability within the CPP would be a major change. The provincial and territorial governments would have to be involved in making that decision.

To your broader question of what other changes we might look at, I did mention earlier that people with episodic disabilities can and do get approved. We want to make sure to avoid the kinds of situations you were talking about, where people have to go through multiple levels of appeals to get their benefits granted. If someone is suffering from a disability, they do get approved if their periods of wellness are not frequent enough or they don't have enough capacity to work or it's not reasonable to expect them to go on and off of work. We want to make sure that people have the best understanding of the program and the best opportunity to provide us with that information.

We have been testing some new methods. We're increasing phone communication between Service Canada personnel and applicants to make sure they understand what might be helpful when providing the evidence, so that they do meet the definition. We've updated our guidance and training. All of our decision-makers are medically trained personnel. Those are some of the administrative measures we're taking to try to make sure that the definition is applied consistently and fairly.

Mr. Ramesh Sangha: When anybody's suffering from an episodic disability, they go for the treatment and part of the time they are okay whenever they are on treatment. If they now come for disability benefits under CPP, they can't qualify because it's not severe. They are okay when they're on medication. How can that stigma be overcome so that they can be provided with benefits under CPP?

● (1040)

Mr. Kris Johnson: It is very difficult when you're talking about something that's so personal and where it's hard to see into the future. You're right that someone will be denied if it's more likely than not that they will be able to go back to work. Since the CPP was built, there has been an underpinning in the philosophy that working is what's best for persons with disabilities. If they're unable to, then CPP is there to help them until they reach the normal retirement age.

For some people, the treatment improves, something else in their life improves, or they find an employer who's more understanding. For those individuals, we have a number of provisions in place to help them. There are not a lot of them. About 1% of our beneficiaries a year actually return to work sufficiently enough to get off of CPP altogether. If that situation does arise, we provide three-month work trials. We have automatic reinstatement provisions. We have fast-track reapplication provisions and vocational rehabilitation. We are trying to put in some of those provisions. We have had those provisions for quite some time for people who may, in fact, improve and may be ready to go back to work.

The Chair: Thank you very much.

MP Ruimy, you'll have just under four minutes.

Mr. Dan Ruimy: Thank you, everybody, for being here today. It's interesting. From your opening remarks, it seems like we're already making some progress with some of the steps that we've implemented.

I'm a data guy. I'll be curious to see the data that comes out about episodic disabilities, which will be available in 2019.

This is the challenge. I'm an ops guy. When you want to fix something, you have to look at the whole program. You have to understand what the variables are and where you move from there. One of the big challenges, or dangers, is having knee-jerk reactions: Let's throw this in there and let's throw that in there.

Our world is changing. Episodic disabilities are becoming more the norm. The stigma is.... Because we're actually having these conversations now with Bill C-81—the accessibility legislation—that brings the norm there.

The question I have is on the current EI program. Canada pension disability is not a lot of money, so I don't know if that's a great answer to begin with. With all of these changes out there, can we work within the EI program or do you think it's time to do a major overhaul of the program?

Mr. Andrew Brown: I think there's an awful lot that can be done within the program, which is separate from certainly what I've heard around the committee this morning, the call for broader reform. It's important to keep that in mind, because often changes within the program could be brought about more quickly than something that is broader in scope.

Mr. Dan Ruimy: When you look at the definition, you see there are quite a few. I know a lot of folks who have challenges like bipolar, for instance. Right now, when you look at the definition of Canada pension disability, you see it's actually very narrow in its scope. You have to have all these bad things happening, and likely you're going to die in the near future. That's the definition there. That's not what's happening out there.

Each disorder has its own criteria and we need to establish what that criteria is. How would that work? How would that impact the system? How would it impact the employees, the workers and so on and so forth?

Mr. Andrew Brown: Maybe just to respond to that—and it may be a bit on Kris's program there—it's not that you're dying, but it's severe and prolonged in terms of the disability.

In terms of EI we're absolutely at the opposite end of the spectrum in the sense that it's very easy—provided you have the hours to qualify—to access EI sickness. It simply requires a note that indicates you're unable to work, and we don't require specific information on the nature of that inability to temporarily work. Some of the work we are undertaking right now is to understand better what is happening. That's information that we're trying to get at through evaluation, and we expect there will be results available next year.

We're trying to understand better what some of the conditions are that workers have when they're taking EI sickness benefits. We're trying to understand whether they are successfully returning to work following their time off and receiving the EI sickness benefits. Those are things we are trying to get at to understand better how it could be better tailored to workers today.

● (1045)

Mr. Dan Ruimy: Jumping in, we're now opening that field up to so many different definitions of episodic disabilities. You had mentioned for every one-cent increase in EI, you get $170 million back.

How are we going to figure out where we sit? How much do we actually need in our EI system to be able to fund a broader spectrum of disabilities?

The Chair: We're out of time, but I'll allow a very brief response, please.

Mr. Andrew Brown: I guess it's very broad in terms of being able to access it right now, regardless of the condition. I think the question is, what is the duration that would be available to workers? As the duration increases, costs increase.

The other thing to remember is that EI is based on the premise of a person who is able to work, broadly speaking. The longer this duration gets, at a certain point there's a question about how far the EI program, which is about working people who are contributing to that fund, should go. There's a tension at one end versus the other.

The Chair: Thank you very much. I'm afraid I do have to step in. We are out of time this morning. I'd like to thank all of you for appearing before the committee on this first session.

Thank you to my colleagues, and of course, the folks to the left and right, and the folks in the booth, and everyone else who makes today possible.

Thank you very much, everybody.

We're adjourned.

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