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Chair

Mr. Bryan May

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

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● (0845)

[*English*]

The Chair (Mr. Bryan May (Cambridge, Lib.)): I call the meeting to order.

Pursuant to the order of reference of Friday, November 2, 2018, and the motion adopted by the committee on Tuesday, November 20, 2018, the committee is resuming its study of M-192, episodic disabilities. Today the committee will hear from witnesses and provide drafting instructions to the analysts for a report.

I have a quick announcement before we get started. As I mentioned in the previous meeting, there were plans to meet with the Canada-China Legislative Association. That unfortunately has been cancelled due to an issue in obtaining visas. They weren't able to be here on time for that meeting.

Going on to our witnesses, we have joining us as an individual Adele Furrie, President and Chief Executive Officer of Adele Furrie Consulting Inc.

Welcome, Ms. Furrie.

From the Canadian Council on Rehabilitation and Work, we welcome Maureen Haan, President and Chief Executive Officer.

From the Institute for Work and Health, we have Monique Gignac, Associate Scientific Director and Senior Scientist, and Emile Tompa, Senior Scientist.

We welcome both of you.

Next, is it “Realize”?

Ms. Tammy Yates (Executive Director, Realize): Yes, thank you.

The Chair: From Realize, we welcome Tammy Yates, Executive Director.

Thanks to all of you for being here this morning.

We're going to get started with Adele Furrie. The next seven minutes are all yours.

Ms. Adele Furrie (President and Chief Executive Officer, Adele Furrie Consulting Inc., As an Individual): Thank you.

Good morning. Thanks to all of you for the invitation to be part of this panel.

I'll give you a little bit of background on who I am and where I come from.

I've spent the last 34 years of my career working on issues facing children, adults and seniors with disabilities, both here in Canada and through a number of consultancies throughout the world.

The first 12 years of my 34 years were spent at Statistics Canada, where I was responsible for the first two disability surveys that had been conducted and also for the very first aboriginal people survey that was conducted as a postcensal survey.

From 1996 to the present day and ongoing, I've operated my management consulting business. I've successfully completed over 90 projects, with the majority of them focusing on disability. In a major project that spanned three years with the U.S. department of labour statistics, I helped design questions consistent with the definition that was embedded at that time in the ADA, the Americans with Disabilities Act.

I've done similar consultancies—again, trying to take a definition and putting it into a series of questions—in North Korea, Colombia and New Zealand, and in two workshops with developing countries in Malta and Hungary.

There are three main points that I want to cover in my seven minutes.

The first is to advise you of the new data available on episodic disabilities from the 2017 “Canadian Survey on Disability”. Maybe you already know it.

The second point is to describe the research that my company has done, in collaboration with a number of people, that deals specifically with episodic disabilities.

Finally, my third point is to share with you my concern about not having in the current support programs a common definition of “disability” that has kept up with the evolution of the concept of disability, both here in Canada and internationally.

To my first point, you may already know this, but I'm excited to tell you that a collaboration between Statistics Canada, ESDC, Realize and my company resulted in questions being added to the 2017 “Canadian Survey on Disability” to identify the population with episodic disabilities. It was no small feat to get a couple of questions added to the questionnaire. We all felt that it was such a great opportunity, so it was well worth the effort.

Initial results from the survey were released on November 28. In the handout to you, I provided a copy of an infographic and a couple of bookmarks that describe some of the main findings. However, this release did not include any stats on episodic disabilities. It's my understanding that staff at Statistics Canada are available to handle any special requests. I've also been advised that the analytical file will be available to approved research projects through Statistics Canada research data centres in mid-January to late January of the coming year.

I'll now move on to my second point.

Episodic disabilities have been a part of my research since 2009. I've completed five research projects and I've just signed another contract for a sixth one using the 2017 data. For all six projects, I've been part of a team of researchers that included academics, independent researchers such as Cameron Crawford and John Stapleton, and various service providers and organizations.

The clients have been Employment and Social Development Canada, two SSHRC grants and the federal/provincial/territorial persons with disabilities advisory committee. Unfortunately, none of the research reports have been translated, so I wasn't able to bring copies with me today.

Each of the five completed projects was a building block for the next one, culminating in this fifth one, which I think will be of most interest to you.

● (0850)

In 2016, with funding provided by the Office for Disability Issues and with the support of organizations representing many of the health conditions that result in an episodic disability, we conducted a survey in which we heard from 953 Canadians who were living with an episodic disability.

Unlike the surveys conducted by Statistics Canada, it was not a probability-based sample. Rather, it included people with lived experience who took the time to complete an online questionnaire. The questionnaire focused on employment but also included three open-ended questions: What is most challenging about living with a chronic health condition? What do you think could be done to improve your quality of life? Do you have any additional comments about your experience living with an episodic disability?

The responses ranged from short answers about such issues as the unpredictability, having to work through pain and fatigue, unsupportive employers, need for financial support with medications and treatments, to longer responses that highlighted both the incredible supports received to the heart-wrenching need for more supports and more understanding.

It's a great resource because it gives the lived experience of 953 individuals who every day have to deal with life with an episodic disability.

Finally, I want to turn to the definition of “disability”.

What happened at Statistics Canada when we started the disability stats program was that we kept in line with the evolution of the concept of disability. The questions that are included on the surveys reflect that. Did the federal government keep that same evolution in mind with its disability support program? It hasn't. Not only that—and this is really disturbing to me—ODSP, the Ontario disability support program, seemed to have had a more progressive definition that included episodic disabilities, and now it is reverting back to the more restrictive one, the CPP disability benefit definition.

Those are my comments. That was a fast one at the end.

● (0855)

The Chair: Thank you very much.

Next we have, from the Canadian Council on Rehabilitation and Work, Maureen Haan, President and Chief Executive Officer.

Ms. Maureen Haan (President and Chief Executive Officer, Canadian Council on Rehabilitation and Work): Thank you very much.

Good morning. My name is Maureen Haan. I am the President and CEO of CCRW. I want to thank you very much, first of all, for having me here and for giving me the opportunity to provide some supplemental information related to the employability of Canadians with episodic disabilities that I've witnessed over my last six years with CCRW and over 25 years of direct involvement in the disability community.

First I'll talk a bit about CCRW.

We are the only national charitable organization with the sole mission of employment for persons with disabilities. With a history of 40-plus years, CCRW has been successfully promoting the employment of jobseekers with disabilities across Canada, as evidenced by the 73% success rate seen in our 2016-17 funding year.

CCRW has successfully connected and dually focused on jobseekers with disabilities and employers to ensure local hiring needs are met. With eight successful program models across 15 Canadian communities, CCRW has implemented a range of successful employment programs, thereby shifting the unemployment rate needle away from the charity model towards the business case model for hiring a person with a disability. For the last six years, I have been proud to serve as the president and CEO, and I strive every day to further our mission of promoting and supporting the meaningful and equitable employment of people with disabilities.

As successful as we have been, it has not been without challenge. Oftentimes we are asked how we define “disability”. As you know, there are multiple definitions that can conflict with each other and often lead jobseekers with disabilities to wonder whether they have a disability and whether they count—that is, can they access employment services and are they eligible for additional supports, whether it be for income or otherwise?

Finding the answers can be arduous, as programs often use differing definitions and criteria to determine eligibility. Episodic disabilities pose unique challenges by their definition. For example, an illness that has sporadic and intermittent symptoms that fluctuate with little warning can create a disability for the individual during the flare-up. With an aging population, we see an increase in the number of Canadians who are living with visible and invisible episodic disabilities, including MS, arthritis, cancer, HIV/AIDS, diabetes and some forms of mental illness.

One key distinction that I want to highlight is the notion of unpredictability. An episodic disability is marked by fluctuating and unpredictable periods and degrees of wellness and disability. In addition, these periods of wellness and disability are often experienced differently by individuals even with the same medical diagnosis, making it almost impossible to form generalizations across disability type.

An employee's unpredictable labour force participation can consequently pose challenges for employers and work colleagues alike. At best, this fluctuation often leaves employers unsure as to how to accommodate; at worst, it can leave them questioning the authenticity of an employee's disability. We have heard many stories at CCRW from clients with episodic disabilities who, while they were at work, experienced co-workers who were unsupportive and even jealous of the accommodations received. Having a nationally accepted definition of "disability" that includes episodic disabilities would provide common ground for employees with intermittent work capacity and their co-workers and supervisors to have an open and honest conversation without fear of reprisal or stigma.

Policies to date have historically focused on static forms of disability that, relatively speaking, make it easy to develop, monitor and evaluate policy and changes over time. With episodic disabilities, though, evaluation becomes significantly more complicated and poses challenges for stakeholders of varying forms, including community agencies tasked with developing and providing employment programs and services to this underserved population.

Program eligibility issues can further complicate matters and raise issues of subjectivity and fairness regarding who gets to access services, by whom, and under what conditions. Who decides whether a person's disability qualifies them to access such services?

As the severity of a person's episodic disability symptoms is likely to fluctuate, a person must become adept at advocating and at navigating social service systems and programs, which will likely exacerbate symptoms related to stress and anxiety.

● (0900)

For example, worries around losing access to subsidized housing or access to drug plans during periods of wellness become heightened. For this reason, episodic disabilities must be recognized within the larger definition of disability and accounted for when designing resulting programs and services, including income support program eligibility.

At present, definitions and criteria used by provincially based income support programs differ widely and often leave people with episodic disabilities unsure of whether they qualify for benefits. On a federal level, "temporary" is often used to describe employment insurance eligibility, whereas "severe and prolonged" phrasing is used when describing CPPD, Canada pension plan disability, and it should be noted that both of these programs have a return-to-work or a vocational rehabilitation component in the services. The question then remains of where people with episodic disabilities fit in. Their symptoms are often temporary yet chronic, and can be severe and prolonged over a lifetime. With the real shift in disabilities as historically labelled, people with episodic disabilities often fear having supports clawed back with little or no warning, or ineligibility being determined prematurely and unfairly.

Accounting for the ever-changing nature of episodic disabilities is important when designing income support programs as well as return-to-work or vocational rehabilitation programs, to ensure that people are encouraged to remain engaged in the workforce, thus creating a win-win situation benefiting everyone.

Expanding and accounting for those with episodic disabilities within the legal definition will ensure fairness and equality with regard to accessing services and implementing policies, and will ultimately produce a positive outcome for all.

I thank you very much for your time and look forward to your questions.

The Chair: Thank you.

Up next we have, from the Institute for Work and Health, Monique Gignac, Associate Scientific Director and Senior Scientist, and Emile Tompa, Senior Scientist.

Welcome to both of you.

Whoever is to speak first, please go ahead.

Dr. Monique Gignac (Associate Scientific Director and Senior Scientist, Institute for Work and Health): I'm going to go first. Emile and I will share our time.

As mentioned, we're senior scientists at the Institute for Work and Health, which is a not-for-profit independent research organization.

I'm also a professor at the University of Toronto, where I've been conducting research into this area for about 20 years, and I currently direct a large partnership grant funded by CIHR and SSHRC that aims to improve work participation and work sustainability among individuals with episodic disabilities.

I'm going to focus my remarks on two critical at-work issues that can be uniquely challenging for those with episodic disabilities.

The first is what I would characterize as an increased risk of hastening the decision that a worker with an episodic disability has created undue hardship for at-work accommodations, which can lead to a dismissal.

The second is the process by which workplaces often become aware of an episodic disability, and the characterizing of episodic disabilities as performance problems requiring progressive disciplinary actions rather than as triggering a more positive, supportive, problem-solving approach to sustaining work. Both of these challenges are related to the nature of episodic disabilities and are shaped by policies related to health privacy and accommodations.

First of all, what do I mean by the nature of episodic disabilities? As mentioned by Maureen, the label highlights the intermittent nature of the condition, but very often two other characteristics are important. First, many of these episodic conditions are invisible to others. Looking around the room, it's not apparent who here might have depression, anxiety, IBD, arthritis, MS, HIV, migraine and a range of other conditions. Second, as also mentioned by Maureen, the flare-ups or episodes associated with these disabilities are often unpredictable, even when a condition is being well managed by the health care system.

Also important is that workplace support plays out in the realm of privacy and duty-to-accommodate legislation. Both of these areas of legislation are important, and Canada is recognized as a leader in them. The difficulties are often in implementing the legislation. Workers and various workplace parties may come together to identify initial supports and accommodation. However, the episodic nature of the condition often means that it ebbs and flows, and so accommodation plans typically need to be revisited and revised. In having to revisit accommodation plans, workplace parties who may not be fully aware of a person's needs or who think a worker looks fine may perceive that the ongoing and potentially changing nature of the disability really reflects undue hardship for them in the workplace, and that may hasten actions that result in a person's dismissal.

The second point is that workers with episodic disabilities often require time away. They have greater absenteeism. When we talk to workplace parties, they often tell us that people with episodic disabilities often get caught in their attendance management programs. The program tends to then trigger a series of disciplinary actions and starts to cast disability as a performance problem.

Workers now sometimes feel forced to disclose health information when they are unprepared and maybe not well equipped with information about their rights and obligations. Sometimes they are so concerned about workplace reactions like stigma or even job loss that they continue not to provide the workplace with information about their needs. Once they have then been characterized as having a performance issue, it's difficult for all the parties involved to move beyond this and take a more positive approach, and there's often a lack of trust.

What's needed? There needs to be a better understanding of the unique nature of episodic disabilities, of their impact on issues like communication and support at work, as well as tools and resources to help workplaces and workers. Some of the work many of us are doing here is actually aimed at doing just that.

I want to echo Adele's comments about the value of ESDC and Statistics Canada's Canadian Survey on Disability as a really important resource that we need to continue to build and use.

I'll pass it over to you, Emile.

● (0905)

Dr. Emile Tompa (Senior Scientist, Institute for Work and Health): Thank you.

In addition to being at the Institute for Work and Health, I'm a co-director at the Centre for Research on Work Disability Policy. I'm also an associate professor at the Department of Economics at McMaster University.

We've heard from the others here about the definition of episodic disability. There's no widely accepted definition that's easily operationalized. This is one of the things we found in our research: It can vary on a daily basis, on a weekly basis and over longer periods of time. Sometimes it really has a lot to do with the context. In this case, the context is the work environment and how accommodating it is. The key message we get from our stakeholders is that one size doesn't fit all. It's really important that the work environment be flexible and be tailored to meet the needs of different people with diverse types of episodic disabilities.

In my field research, one of the pieces we've been doing is a project for the Mental Health Commission of Canada on accommodation best practices for people from what they describe as “the aspiring workforce”, people with serious mental health conditions. What we found was that depending on the work culture and the quality of the work relationship, it may be very risky for workers from the aspiring workforce to disclose a need for workplace accommodations, particularly if the disability is stigmatized. In the case of mental health, it often is. They often rely on the supports available to all employees, such as flexible hours, the location of work and various kinds of leave. These are what we describe sometimes as universal supports that don't require disclosure of the individual to their supervisor or manager. Employers, including the public sector, can often provide universal supports as a way for people to self-accommodate.

Currently I'm developing, with the CSA Group, a Canadian standard for work disability management systems. What we find is that in general, employers lack the skills on how to accommodate workers with disabilities. They find it even more challenging to address invisible and episodic disabilities. There's really a need for skilling up employer abilities, and the standard is one way of doing that.

They often have fear, ignorance and an inability to see past irrelevant characteristics to focus on the talent and skills of the worker. We're building up disability confidence and creating a culture of inclusivity as a key aspect of the standard we're developing.

It's challenging for employers to deal with the multiplicity of programs as well. That's a really big problem with them. There are many programs that provide supports, but they're not very flexible and they're often not very conducive to supporting episodic disabilities.

I'm also undertaking a pan-Canadian partnership strategy on disability and work in Canada. Maureen is part of that. We recently had a two-day conference, yesterday and the day before, held here in Ottawa. Its launch pad is a UN convention and the federal legislation, Bill C-81.

We framed it around four pillars that we think are important for a pan-Canadian strategy.

The first of the four pillars is the strategy about disability confidence, much like our standard, which is focused on that as well.

The second of the four pillars is about comprehensive supports. One of the things that's really important is changes to existing income-support programs that might enable people with episodic disabilities to exit and re-enter the labour force as their work capacity fluctuates. It's really important to think about some of the definitions that restrict that ability to easily enter and exit, and to seek the supports when you need them.

Much of the policy arena on labour and disability supports, as you may know, is at the provincial level. That really limits the capacity at the federal level to make changes, but there are some efforts through the transfer payments from ESDC's opportunities fund. Possibly there's some way for those transfer funds to put more emphasis on employment supports for persons with disabilities.

Thank you.

● (0910)

The Chair: Thank you very much.

Now, from Realize, we have Tammy Yates, executive director.

Ms. Tammy Yates: Thank you so much, Mr. Chair.

Good morning to members of the committee. As the chair mentioned, my name is Tammy Yates, and I'm the Executive Director of Realize. I'm also originally from Trinidad and Tobago. If anyone knows Trinis, we talk very quickly. I'm going to do my best. I can't promise, but I'll do my best.

Realize currently holds the secretariat of the national Episodic Disabilities Forum, otherwise known as the EDF. On behalf of all of the members of the EDF—many of whom are actually here in the room, so it feels like a reunion—I would like to thank members of this committee for leading this important discussion, as well as for the private member's motion, M-192.

The term “episodic disabilities” was first coined about 15 years ago by former board members of our organization, namely Kelly O’Brien, Stephanie Nixon and the late Elisse Zack, who was the founding executive director of Realize, which was then known as the Canadian Working Group on HIV and Rehabilitation, or CWGHR.

It makes me smile to be back on the Hill. About five years ago, Elisse Zack and I—prior to her transitioning into the next life—were presenting to this committee. It looked very different at that time. When we spoke about episodic disabilities, everyone in the room had a very strange, querying look on their face. It is amazing to be in this room here. We're all discussing episodic disabilities and we're all on the same page.

I also have a little information about the definition of “episodic disabilities”. The episodic disability framework was created to reflect the lives of people living with HIV at that time, based on the social model of disability, to describe the conditions that many of my colleagues mentioned. As Canadians are living longer, an increasing number of people are living with lifelong chronic illnesses that include episodes of disability. These illnesses include arthritis, Crohn's disease, MS, cancer and mental health conditions.

When we apply a life course approach to the topic, we are cognizant that many young people are also living with episodic disabilities. I'm sure that most, if not all, of you in the room know people living with episodic disabilities. You can therefore appreciate how these fluctuating episodes wreak havoc with someone's life in terms of social inclusion and participation.

Very early on in our advocacy and awareness-raising around episodic disabilities, we were joined by organizations like the DisAbled Women's Network Canada, the MS Society and the Arthritis Society. They were some of the earliest cross-disability organizations that collaborated with us. We all recognized that these groups of people living with these conditions were living with similar trajectories. However, the trajectories were different, so we developed three broader definitions, which I'll share with you now.

Episodic stable conditions are characterized by periods of relative wellness, interspersed with unpredictable and fluctuating periods, like severe migraines and HIV—now that HIV is a chronic condition.

Episodic degenerating conditions are similar to episodic stable conditions early on, but over time are progressive in their decline, such as Parkinson's or even, unfortunately, MS at times.

Episodic remissive conditions may start as episodic stable, but in some instances the person may have a full recovery or remission, as in some forms of cancer or mental health illnesses.

It would be remiss of me not to note at this juncture, however, the fact that Bill C-81, once it becomes an act, will be the first federal act to officially include episodic disability in its wording. Let me tell you something: In my office, when we read that, we were high-fiving each other. It took us 20 years, but we're here.

Over the past decade, an increasing amount of research on episodic disabilities has been done across diseases and conditions, as many of our academic partners and organizations that have been testifying this entire week have shared. We've developed at least 20 conditions that may be defined as episodic in nature. Ladies and gentlemen, that represents a significant percentage of our population in Canada.

We have a number of recommendations that we will be submitting. However, I would like to articulate three long-term recommendations and three short-term recommendations.

● (0915)

The first of the three long-term recommendations is that nationally, we establish a body, whether it's a commission or a federal committee, to oversee and report on the coordination between the interjurisdictional disability support programs and employment services areas to establish clear options for people with episodic disabilities within these disability programs.

The second recommendation is to make employment insurance sickness benefits more flexible.

The third recommendation is to negotiate, develop, pilot, and eventually implement, in tandem with jurisdictional-level government partners, an individualized funding model for income and social supports. There are examples of these individual portable models in jurisdictions at the moment.

For these three recommendations, I did not say a five- or a 10-year time frame. It may be another 20 years, but these recommendations are what it's going to take for people living with episodic disabilities to remain in the workforce and have full social participation.

Now, I have three short-term recommendations. When I say “short-term”, I mean these three things can be done within the next year.

First, when Bill C-81 becomes law as the Accessible Canada Act, the definition of disability that's now included in that bill should be harmonized across jurisdictions and across policies and programs to reflect that harmonized definition.

Second, we all mentioned community-based research and academic research that has been happening over the last 20 years in a very piecemeal and puzzle-like approach. Our recommendation is that a dedicated part of funding be provided for community and academic researchers, since it is imperative that we explore program and policy issues for women, for youth and for new immigrants living with episodic disabilities and for indigenous and other racialized groups who we know, from an intersectional perspective, will be affected differently and inequitably.

Finally, as the secretariat of the Episodic Disabilities Forum, Realize has been raising awareness about episodic disabilities for almost 20 years, as I shared. It's our 20th anniversary this year. We're the only national organization that has a dedicated staff member on episodic disabilities. However, we have been doing this without operational funding for episodic disabilities. Along with partners like CCRW, DAWN Canada, the MS Society, the Arthritis Society, and so on, who are current members of the EDF, we have achieved so much in this area, so that we're all here today, 20 years later. Therefore, the final recommendation is that...if we could do that without operational funding, can you imagine what we could do with operational funding?

Life is unpredictable, ladies and gentlemen. While you and I may not be living with an episodic disability today, it does not mean that tomorrow our life circumstances may not change, and we may then be diagnosed with an illness that is episodic in nature. To this extent, policies and programs, or revisions to policies and programs, that we have all suggested will not only work for people living with episodic disabilities currently, but they will work for everyone in Canada.

I use the term “everyone in Canada”, and not just “Canadians”. In three days, I will celebrate my one-year anniversary as a Canadian. Prior to that, I was a permanent resident of Canada. If I was living with an episodic disability and saw in a document that it's only Canadians who are eligible, it would have totally left me and my taxpaying dollars out of it.

Canada has always been a country of innovators and an example to other countries. We are the world leader on episodic disabilities. As such, the Government of Canada and all of you have the opportunity to maintain that leadership on episodic disabilities. We look forward to supporting the government and all of you on this.

Thank you.

● (0920)

The Chair: Thank you. On behalf of all of us, congratulations.

Ms. Tammy Yates: Thank you.

The Chair: First we have MP Diotte.

Mr. Kerry Diotte (Edmonton Griesbach, CPC): Thank you, Mr. Chair.

Thanks to everybody for coming. There's quite a panel of expertise here, and it really helps us with our jobs.

One of the questions that comes up most often is how you define episodic disabilities. I know Ms. Furrie commented on that. Could I get you to weigh in on that? What are the difficulties there?

Ms. Adele Furrie: The main difficulty is getting across the concept of “intermittent and fluctuating”.

We can define “disability”. We've done a good job in defining disability in surveys, but it's to get across the idea that an episodic disability isn't like being in a wheelchair. It comes and goes. It's the fluctuating and the intermittent nature. It's never knowing when you're going to have a migraine and never knowing if the migraine is going to be totally debilitating or just a headache. It's that unknown....

Associated with episodic disabilities is the fact that it brings in other things like fatigue, primarily, which goes along with it, and then all the attitudinal barriers this individual faces as a result of it.

● (0925)

Mr. Kerry Diotte: Would anyone else like to chime in on that?

Dr. Monique Gignac: Perhaps I could, very quicky.

I think the entire term “episodic”, which is a very high-literacy term, is great for us. We're all on the same page. However, putting that in a research document to try to ask people if it is them or not becomes an issue. Even the word “disability” is very loaded. Many people we speak to in research have all these conditions we've been labelling, that we've been talking about, but if you ask them if they have a disability, they'll say no. They don't see themselves as disabled, so we use language around “difficulty” or “limitations with”. That opens it up to a whole range of other reasons that you might have difficulties with various issues in your life.

We struggle to come up with ways to make sure people can capture this. Sometimes it's by asking if they have any of these conditions. We assume that if they do, perhaps they have an episodic disability. It's not perfect. Other times we talk about limitations as a way to try to get people seeing themselves in this group.

Ms. Tammy Yates: Thank you so much, Adele and Monique, and thank you for the question. It's an excellent question.

Two years ago I was at the international AIDS conference in South Africa. We were at the disability networking zone, doing a presentation. The sign language interpreter in South Africa had never heard of episodic disability, so she asked me if I could define it. Of course I shared the long definition that we all give and then when I was speaking and she signed it, I asked her what sign she used. She said she used an illness or condition that comes and goes and whatever the sign is for unpredictable. Those were the three criteria she used: a long-term illness or condition that comes and goes and is unpredictable.

Mr. Kerry Diotte: While we talk about that, because I know you have expertise in AIDS and HIV, how do you balance the need to accommodate those in the workforce with episodic disabilities, especially with AIDS and HIV, with their right to the privacy of their medical records and their medical conditions?

Ms. Tammy Yates: That's an excellent question.

We work consistently very closely with the community. First of all, with respect to community members, we always say they have the right either to not disclose or to disclose. That is totally up to them.

Second, within the duty to accommodate, you don't necessarily legally have to share your diagnosis. I think Monique and Maureen mentioned you have to share your functional limitations—what you can do, what you cannot do, and so on. Needless to say, with the stigma and discrimination that still unfortunately exist around many of these conditions in 2018, and mental health as well....

It's interesting. A very close relative of mine has recently been diagnosed with a mental health condition. The discussions around the coffee table with respect to sharing and disclosing information were quite similar to what I hear in my professional life that people living with HIV share.

Again, in the duty to accommodate, you are not mandated to share the diagnosis, but you do need to indicate your limitations and your capacities.

Mr. Kerry Diotte: Thanks very much.

The Chair: Mr. Long is next.

Mr. Wayne Long (Saint John—Rothesay, Lib.): Thank you, Mr. Chair, and good morning to our head table, fellow MPs, and witnesses.

It's very good testimony this morning. Thank you.

I'm going to ask this question right across the panel, because all of you have wonderful expertise here.

Ms. Yates, how would you structure and fund increased supports for people with episodic disabilities? You have touched on that a bit, but how would you fund this such that it provides them with income security without discouraging workforce participation? Also, do you feel that we would need to increase EI and CPP premiums in order to fund such support?

Ms. Tammy Yates: Those are two very loaded questions.

On my answer to the first question, I think, if I'm not mistaken, that British Columbia may have just started a model that could be something we could use with respect to increasing the annual income threshold for someone who may be accessing income supports or disability supports. Increasing the annual threshold is critical, rather than a time-bound threshold, because—

A voice: It's just recently.

● (0930)

Mr. Wayne Long: Is that what you said?

Ms. Tammy Yates: I'm trying to remember. In the disability and work conference I recently attended, a representative shared that.

Maureen, do you remember?

Ms. Maureen Haan: No.

Ms. Tammy Yates: No? Okay.

A representative shared information with respect to this particular change in their funding model, if I'm not mistaken, and that model allows people to work when they can and therefore not work when there are unpredictable flare-ups.

With respect to increasing the EI premium, it's not necessarily a matter of increasing the EI premium but of almost shifting the flexibility of the EI period.

As it stands, rather than having this set number of weeks, it could be a number of units for the year.

Mr. Wayne Long: That's right. I'm going to touch on that in a second. Thank you for that.

Mr. Tompa and Ms. Gignac, would you comment?

Dr. Emile Tompa: I think the thing you're mentioning, if I'm not mistaken, is that in their social assistance program they used to have a monthly deduction and now it's a yearly one, so it allows a lot more flexibility on the week-to-week and month-to-month earnings—

Mr. Wayne Long: Okay.

Dr. Emile Tompa: —without being penalized.

I think the flexibility that Tammy Yates mentions is really critical. One of the key things is the inability to take up work or the fear of taking up work because you're going to lose your supports. If there's a lot more flexibility in leaving and entering, that would obviously really help people take the opportunities when they arise and when they're able to work.

I think most people want to be engaged in society. Work is an important role that people get meaning out of; it's more than just income. I think that if people are able to participate and are given the supports to participate, they are very excited about being part of society in that way. It's about people having the flexibility, when they can and want to work, to do so, and allowing them to not lose their supports automatically because they take up that opportunity.

Mr. Wayne Long: Thank you.

Dr. Monique Gignac: With episodic conditions, what we hear a lot is that obviously work is a protected activity. Usually what people do is give up everything in their personal life to protect work, so that by the time they have a flare-up or a crisis, that's it—they have to go.

One of the issues around the income security is that once people do go on these programs, they're afraid to return to work, because if they are at work for three weeks and have to go off, the system is so onerous to get back into. That's a problem.

Mr. Wayne Long: That's right.

Dr. Monique Gignac: I think this would be something to really work on, so that you don't lose your place in line and there's a recognition that you don't have to start all over again if you go back to work and it doesn't work out.

Mr. Wayne Long: Thank you very much.

Ms. Haan, I want to jump in and say thank you so much for the work you do with the CCRW. In my riding of Saint John—Rothesay, Jo-Anne Mowry and Misti Denton of CCRW do amazing work for people with disabilities in helping them obtain employment.

Ms. Maureen Haan: Thank you.

Mr. Wayne Long: Can I get your ideas as to how we would structure and fund that?

Ms. Maureen Haan: Absolutely, and thanks very much, Wayne.

Mr. Wayne Long: Of course.

Ms. Maureen Haan: It's wonderful to work with you.

I don't want to echo what my colleagues have already said and what I know Adele is probably going to say, because I can read her mind a bit.

I sit on the round table for the review of the CPPD. In that structure, we've really been talking a lot about return to work and the vocational rehabilitation program and the rapid reinstatement program of that program.

Again, I don't know if it's about increasing premiums, but it is about increasing the flexibility, because what we've recognized at CPPD—

Mr. Wayne Long: We continue to hear that.

Ms. Maureen Haan: Yes, the demographics have changed. CPPD as it was set up in the first place really focused on physical, prolonged and severe disabilities. The definition remains, but the demographics of the people who are on CPPD now have changed. Going back to Emile's point, they want to work.

Mr. Wayne Long: Totally.

Ms. Maureen Haan: They want to work. We've really been drilling down on that quite a bit as well.

Mr. Wayne Long: Thanks for that.

Ms. Furrie, would you comment?

Ms. Adele Furrie: I'm not convinced that the existing support programs that are in place now reflect the population with disabilities. I would recommend that there be a review done of those existing programs to see how they fit into the definition that is currently embedded in the proposed accessible Canada act, not just to ensure that it covers access to employment and being able to return to employment, but also all of the other things that go along with a disability.

An example is the need for perhaps more opportunity to have massages—I heard that so often from the 953 people who answered—and those kinds of supports that they need.

● (0935)

Mr. Wayne Long: It could be self-esteem support.

Ms. Adele Furrie: Yes, it could be self-esteem. I mean all of those softer supports that are needed.

The Chair: Madam Sansoucy is next, please.

[*Translation*]

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

Mr. Tompa, I would like you to clarify something. You talked about four pillars of a pan-Canadian strategy, and I remember the words “confidence” and “support”. Did I forget two of them or did you rather break down support into three different pillars?

You can answer me in English if you like.

[*English*]

Dr. Emile Tompa: Of the four pillars, the first is disability confidence, the second is comprehensive supports, the third is effective partnerships and the fourth is measurement and accountability.

[*Translation*]

Ms. Brigitte Sansoucy: Thank you very much.

Given the employment rate among adults with disabilities, it is clear there are barriers to getting and retaining a job.

I would like to know what you think would be the best way to proceed to enable the federal government to become a model employer in the integration and retention of people with episodic disabilities. I think that is the foundation of everything.

In addition, how could the federal government educate other employers on the importance of lowering barriers to integration and retention? Please take turns answering.

You can start, Ms. Haan.

[*English*]

Ms. Maureen Haan: I'll start. Thank you.

I think that the accessible Canada act calling for the Government of Canada to hire 5,000 people with disabilities within the federal government is an excellent opportunity. However, I think that the stereotypical definition of disability....

Really this is the crux of what we're talking about today: to make sure that invisible disabilities are also included in that number. I think ensuring this right across the country is going to be a challenge, although I think you've got the right assistant deputy, Madame Laroche, to be able to set that up. I think it's just to make sure that the 5,000 hires include an equal percentage or a proper demographic of episodic disability.

[*Translation*]

Ms. Brigitte Sansoucy: Thank you.

Ms. Furrie, what do you think?

[*English*]

Ms. Adele Furrie: I think it's the federal government not only doing that with the 5,000 but also recognizing the support programs that are in place, and—again I keep going back to it—focusing on the definition that currently exists in the income support programs and ensuring that it does embrace the concept of invisible and episodic disabilities.

Dr. Monique Gignac: From what we hear, the most stressful thing for workers is around communicating—what do I say, when do I say it, who do I talk to?—within this privacy legislation. Recognizing that and working on tools to help people know how to talk about this will help workplaces.

Often they notice a problem, but the worker hasn't said something. People with mental health conditions may not be aware that they're actually moving into an episode. Communication, I think, is a priority.

Another priority is to do accommodation planning better and do it as positive problem-solving, as opposed to discipline, which might say, “If you don't show up next time, you're out.”

Building awareness within the federal government in its workplace about episodic disabilities is important. Co-worker and manager training will also help people to work through these issues better and to know that they're coming back. It's something that does happen. These are good workers. They're often good workers for years, and then there will be an episode.

Dr. Emile Tompa: I agree with what all these folks are saying.

I would add that it would be really important that you adopt the new Canadian standard that Maureen and I and others are involved in for work disability management systems. These are voluntary standards. The CSA Group is working on developing this with us, and it's built on continuous improvement. There's always room for improving each year. It's a cyclical process whereby you monitor and evaluate progress in disability confidence and you continuously look for new ways to improve and raise the standard of your disability confidence across the entire workforce.

● (0940)

Ms. Tammy Yates: Thank you.

The Office for Disability Issues within the federal government has actually been aware of episodic disabilities for a very long time. However, at the federal government level, I think the siloed approach from ministry to ministry to ministry in terms of training and awareness-raising—which many of my colleagues have shared—has to be addressed.

For example, in training public servants on disability, how is that training done? How is the awareness-raising done? We provide inputs and online training. Has even the Office for Disability Issues taken that training? There are opportunities in terms of building capacity, raising awareness and breaking the silos even within the federal public service.

[*Translation*]

Ms. Brigitte Sansoucy: Ms. Yates, I will follow up with a question for you.

In one of your recommendations, you talk about targeting programs for women, young people and aboriginals.

Why are you targeting aboriginals specifically? The federal government has a role to play and that could be part of our recommendations.

[*English*]

Ms. Tammy Yates: I'm understanding everything you're saying in French, and because I am so anxious to respond quickly, I am going to respond in English.

When we look at the indicators of the social determinants of health for indigenous communities in Canada, on every single indicator, whether it be HIV or diabetes and so on, we see they are probably on the lowest rung of the ladder, unfortunately. Needless to say, any approach in looking at episodic disabilities has to be prioritized for indigenous communities, and it has to be a wraparound approach.

It's not a conditions approach, because what I also spoke about is the individualized funding model. When you look at the person, don't just look at the episodic condition; look at the life of that person. Also, for indigenous communities in Canada, when we look at the life—unfortunately—of the average indigenous person, we see it is not what we would want to see mirrored.

The Chair: Thank you so much.

Mr. Ruimy is next, please.

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

When I first looked at the motion, the first thing that popped into my head was, wow, we have a lot of work to do ahead of us, and trying to understand that three sessions—which is all this is—are not enough to change the world.

However, hearing the work that you folks are doing gives me great relief, knowing we're not starting from scratch. The conversations and dialogues have been happening. The awareness has been created. What we can expect from a three-session study is perhaps where we can focus more of our energies.

Tammy, you mentioned Bill C-81. We did a lot of work with that. I think that's a great starting point. Episodic disabilities are mentioned in there.

There are some questions that come up, though. We kept hearing earlier about the disability tax credit and that 90% of disabled people don't get it. It's one thing to say that we don't need to change our EI rates, but looking at the 90%, if you were to actually understand why, how and where, and that number were to change, you can see the magnitude of the impact that could have.

I'm curious to know your thoughts on that 90%. Where did that come from? Why is it 90% and not 85%? What are your thoughts on that?

Ms. Tammy Yates: I actually think it again goes back to the definitions and to misunderstanding. The two things that come to my mind automatically are not understanding episodic disabilities and the lack of a consistent definition.

● (0945)

Mr. Dan Ruimy: Ms. Haan, would you comment?

Ms. Maureen Haan: Thank you.

Just to expand on what Tammy is saying, again it's because a lot of people just don't identify as a person with a disability. If I have a chronic health issue, if I have MS, I have a disease; I don't have a disability.

I think that we've run into similar things with CPPD. It's “Oh, I have a disability. I'd better prove that I have a disability. I have to make myself completely disabled in order to get on this program, and then you want me to go back to work?” I think that it's the label of disability, and it's understanding that while you may have an impairment, the disability is really the environment around you.

Mr. Dan Ruimy: You just said “I have to prove that I have a disability.” Do you think that at some point you have to prove that you have a disability?

Ms. Maureen Haan: For...?

Mr. Dan Ruimy: That's the question I'm asking, because you said that: “I have to prove—

Ms. Maureen Haan: Yes.

Mr. Dan Ruimy: —that I have a disability in order to qualify for a tax credit.” The question is, do you believe that you have to prove that you have to have a disability?

Ms. Adele Furrie: That's exactly the way the program is structured. You believe you have a disability. You believe that you qualify, and then you're given this form to complete that has been developed to operationalize the definition of disability. You don't know the right words to use—and truly it is about not knowing the right words to use in your description—to complete the form, and then you have to have either a doctor or a psychologist or somebody associated with the medical profession sign off on it. Then it gets reviewed by someone who isn't a medical professional to decide.

Mr. Dan Ruimy: This has been going on, I would imagine, for a long time. It's not a partisan issue, in the sense that all governments.... It's been around for a long time.

The question I keep coming back to is whether we need to do that, or is there a better way to do it? I don't want to say people are going to cheat or anything like that, but a system has to be able to justify itself. If you took those 90% off, again the impact on whatever programs are there would be incredible, massive, so what is the answer, then? If it's not getting your doctor to sign off, if it's not getting all these forms, what is the answer here?

Ms. Maureen Haan: I can't really talk to the disability tax credit, but as far as the system is concerned specifically around CPPD, for example, I know it's trapping people. Even the application form traps people. It tries to fool people. It's not transparent. The application form is not transparent by nature. It asks questions about work, but they're subjective questions and they're subjective answers.

Mr. Dan Ruimy: I have a very short question.

Here's the problem that I'm seeing, and you all mentioned it.

Tammy, one of your recommendations was interjurisdictional. If the federal government does something, there's an expectation that it flows through. This becomes part of the problem, because we're a patchwork of mental health care or health care across this country, and some will recognize and some will not recognize. I see this as being one of our challenges in how we move forward, not taking a knee-jerk reaction to anything that we see and saying “Okay, here's $50 million; you're done. Thank you very much Go away.”

The Chair: Make it literally a 10-second answer, please.

Dr. Monique Gignac: It is complex. It takes more than three meetings.

You raised the health care system. That's a big issue here. Doctors aren't prepared and trained to do this well. They struggle with this, and not all people can get to them, and not all episodic disabilities are an illness.

The Chair: Thank you.

MP Morrissey is next, please.

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

In the testimony that's been given before this committee on this particular motion this morning, all five of you have identified three issues the committee must grapple with in responding to the motion. One is the definition of “episodic disability”. That is not coming out clearly. People are speaking around it, but there's not been a lot on defining episodic disability.

What is the best support program? We focused on CPP, which doesn't appear to fit, because CPP was designed for long-term disability. That's its mandate, its core responsibility, and the most you deviate from that is for several years of the disability and then you rehabilitate into the workplace.

Workplace education has come out a lot. We need a better understanding from the employer of episodic disability.

We've identified three critical issues confronting people with episodic disabilities, but I would like to hear clear instructions or clear testimony to the committee on the definition.

Ms. Furrie, I like the term you used, that we currently "operationalize" the word "disability". It sounds bureaucratic.

● (0950)

Ms. Adele Furrie: Well, I was a bureaucrat.

Mr. Robert Morrissey: Oh....

Voices: Oh, oh!

Mr. Robert Morrissey: That would be critical, and then finding the best support.

Also, I believe it was Ms. Yates who said an interprovincial working group was developed to study support programs besides EI. Everybody's been focusing on EI, and to a lesser extent on CPP, because that is outside the hands of government. That is a program that's only partially, or very little, controlled by the Government of Canada. It's administered by the provinces, the private sector, employers. This whole focus is on a long-term retirement pension and disability pension. Then it comes to EI, and the only thing besides EI is the income support administered by provinces.

I would like to get your comments on what you recommend to the committee on how we more clearly define an episodic disability so it may fit more into the operationalized theme of the word. I deal with a lot of them on the tax credits, and there's so much of a grey area. Even when you're on EI, there's a grey area. Some doctor may interpret it right and you're okay, and another doctor might not, so that's where I'd like to begin.

My colleague here questioned extensively on EI. If we're going to put more demands on the employment insurance system of this country, then it's incumbent on us to identify how we're going to pay for it. Some of them are okay. Some very good and constructive testimony was given in giving flexibility on the 15 weeks into more of a day.

I would like your comments on that. I know it wasn't a question, but I've been listening to a lot of the testimony. It's very compelling, but I'm not clear on what I could recommend.

Ms. Adele Furrie: I can start with the operationalization of the definition of "disability". That is taking the definition that is currently in the proposed accessible act, parsing it and looking at each of the words. I'll use the CPPD as the example.

CPPD has a very clear definition of what a disability is. They define what "prolonged" is. They define "severe". If we all agree that the definition in the proposed act encompasses "episodic", then as a community of academics, researchers and parliamentarians, we need to look at the words "permanent", "temporary", and "episodic". These are the three words that are currently proposed in the definition. We need to come up with a clear definition of what those words mean and then give that to the statisticians and the people who work with questions on a regular basis and get them to operationalize that definition.

I did this. I came before a committee when they were looking at the definition that was embedded in the DTC, the disability tax credit. I took them through that process, saying that this is what you need to do in order to have a clear definition of what "episodic" means.

● (0955)

The Chair: Thank you.

Ms. Adele Furrie: Right now we're using "limitation in activity". We're looking at both "frequency" and "intensity" as part of the definition for "episodic".

The Chair: Thank you so much.

MP Barlow is next.

Mr. John Barlow (Foothills, CPC): I appreciate the testimony today. It's really great that all of you have brought some good solutions and recommendations, which is certainly much appreciated.

Over the last couple of days, we have heard quite a bit of pretty heartfelt testimony, in terms of being able to navigate the EI system, whether that's CPP.... Even in Bill C-81, as we were going through that process, we had lots of people....

There are four different windows to go through. We were really trying to push for one door in. The response we had from the officials was that people can go to any of them, and we'll figure it out and make sure they get to the right place.

My feeling in regard to people with disabilities is that we shouldn't make it harder. Let's try to find a way to make it easier, so that they can access those programs.

I have only a couple of minutes, so I'll try to be quick. What is your vision in terms of making it easier to access the programs we have in place already? Tammy, you look as if you're ready. What is your suggestion to make that easier?

Ms. Tammy Yates: I think it is recommendation two, of the three long-term recommendations that I made. Well, maybe it could be recommendation three.

Anyway, the individualized funding model, in terms of that one-door approach.... I think Newfoundland has transitioned to an individualized funding model. It's not a program policy funding model whereby you go to this particular program for this and you go to that particular program for that; it's the individual. The money is assigned to the individual. That is what I would recommend. Newfoundland has a template.

Dr. Emile Tompa: As a more immediate solution, something like the Service Canada model would be really helpful. There would be one place for entry with somebody who could direct you to the program you qualify for. It wouldn't require changes in the program, just somebody to help navigate the system.

Mr. John Barlow: That's great. Thank you.

My colleague Pierre Poilievre brought forward the opportunity act earlier this year, which I thought was an outstanding opportunity for us to make a very tangible difference very quickly.

That would ask the Department of Finance to put some results out there. Many of you have said today that the harder people with disabilities work, the less they're taking home, because their social programs are being clawed back.

Is this a program that we should look at again? Unfortunately, it wasn't passed through the House. I think there's an opportunity there for us to make a real difference. Would it address some of these problems if there was legislation in place that ensured that if somebody with disabilities made more money, they were not going to get a clawback on their social programs?

Ms. Tammy Yates: I think it definitely would, but I also want to emphasize that apart from the clawback in terms of income, many people are also concerned about the loss of drug benefits.

Mr. John Barlow: Medication would be included in there, for sure.

Ms. Tammy Yates: Yes.

Ms. Maureen Haan: In the conference that we were hosting over the last few days, we did talk about the portability of income supports throughout provinces. I know there are jurisdictional issues that are not easy to solve, but workforce development agreements are useful for that, and I think it's important to prioritize what happens within those workforce development agreements to be able to make sure that programs are at least similar across the country, with the same outputs and the same outcomes.

● (1000)

Dr. Emile Tompa: I just want to emphasize the point about decoupling the income and other types of support. A lot of people are very afraid to leave the program because they really need the pharmaceutical and other types of supports, so they don't want to go beyond that maximum income level because of fear of losing the supports.

Mr. John Barlow: There's no question that we want to reward you if you want to work, and certainly my experience is that people have much more self-confidence and feel better about themselves if they are working and being rewarded. The harder you work, the more you should get paid.

The other question I had has to do with the flexibility of the EI system. We've talked about increasing the number of weeks. There has been some discrepancy in that, but I think one of the things that most people can agree on is not having to take the 15 weeks but being able to break it up into different portions. What would be the ideal system for that?

I think, Tammy, did you mention hours? Is that a certain number of hours a year? How would you envision that?

Ms. Tammy Yates: What we envisioned was describing it as units, so rather than having 15 weeks for the year, you have 175 units, let's say, hypothetically, whatever that may look like. Then when you do have an episode or you don't have an episode, you still know that you have this number of units for the rest of the year.

I'm sure the corollary question is whether the units will then be rolled over into another year in the same way that you have leave benefits from your employer. For example, on my staff, you have a certain number of days, but if they roll over and you have an episode, then you can actually take a longer—

Mr. John Barlow: I'm almost out of time. What would be a unit? Is that a measure of time or days? Can you tell me how you came up with that number and what a unit is?

Ms. Tammy Yates: That's a very long conversation, so I'll send that to you in the full submission.

Mr. John Barlow: You can't give five seconds' worth?

Ms. Tammy Yates: Yes.

The Chair: Thank you so much.

Mr. John Barlow: Could somebody else ask that question, please?

The Chair: Yes, we can get that in this submission. Thank you.

Go ahead, MP Sangha, please.

Mr. Ramesh Sangha (Brampton Centre, Lib.): Thank you very much, Mr. Chair. Thanks, everyone, for your very valuable input. Again, I'm coming back to the definition only because you know we want a definition that can assist the committee, as we have already discussed.

Questions were asked by my colleague Mr. Morrissey, and he brought it very close to the definition that we wanted for who is to be granted and who is not to be granted.

Madam Adele, you have already said that it is an operationalized model and regionalized model, decided upon on a regional basis.

When a disabled person fills out the form and the application goes to the department, we want the form to be easy because it should not trap people. It should be transparent. That's what you say, Maureen.

Once an officer is deciding on that, after going through the form, what are the factors that he has to look into so that he's not easily giving it to everyone but he's also not adding more restrictions so that it looks as if bureaucratic persons are refusing everyone. At the stage where you want a flow of disability entitlement, what are the qualifications, actually? What is the definition? How do you decide what should be granted and what should not be granted? Do you want to see a doctor's note? Do you want to see some experts or specialists, those who have studied the patients? What should be the criteria he or she should use? Who is the person deciding there? What is he or she thinking?

● (1005)

Ms. Adele Furrie: There are a number of things that I'm chomping at the bit to tell you.

There are three reports that have come out over the last three years that would be great source documents for you to review.

One is a document I prepared for Employment and Social Development Canada. It was a summary of all the income support programs that were in place for people with disabilities. It explored the definition, as well as the application and appeals processes. I don't know the name of it, but I can give it to Elizabeth, the analyst.

The second was a really good report called “Leaving Some Behind: What Happens When Workers Get Sick”, produced by IRPP, the Institute for Research on Public Policy. It has an excellent overview of the support programs for people with disabilities.

The third is a report I did for the federal-provincial-territorial working group on disabilities. It covered some of the same information, but with a broader scope. We looked into what is a short-term disability, what is a moderate disability, what is an episodic disability, and so on. I did an international scan, as well as a scan of the programs available in the provinces and territories. To me, those are three good resource documents for the committee to have access to.

Ms. Tammy Yates: If I could add to that, Adele, I don't know if you recall that maybe three or four years ago the Ontario government actually had a report prepared as well, on short- to medium-term and episodic disabilities, specifically in the workplace.

Ms. Adele Furrie: I did that. The Ontario government funded it, but it was for part of the three-year research plan that this advisory committee was putting together to feed into the whole discussion of episodic disabilities.

Ms. Maureen Haan: At CCRW, we believe it's very important that everybody has the right to work. We have to do whatever we can in order to get people into employment. We need to start from the understanding that people want to work, and then design the system around that, instead of assuming that people don't want to work and want to stay on assistance.

Mr. Ramesh Sangha: Okay, but there are people who don't want to work and want to just take advantage of the system by sitting at home. What do you suggest as the definition of “severe”? How severe should it be, and then do you want it to be prolonged? How long is prolonged?

As you have suggested, Adele, there should be a review of the system every so often. What do you suggest in that definition of severe and prolonged?

Ms. Adele Furrie: “Severe and prolonged” does not reflect episodic disability. It's severe when it's happening, but “prolonged” implies that it's going to last for a long period of time. That's not episodic.

Mr. Ramesh Sangha: Would you provide all three documents, please?

Ms. Adele Furrie: Yes, I'll do that.

The Chair: Thank you.

MP Falk is next, please.

Mrs. Rosemarie Falk (Battlefords—Lloydminster, CPC): Thank you so much for being here.

Maureen, I found your testimony quite interesting. My mom has spent her whole career working with people with developmental disabilities. She worked at home with them, helping with day-to-day activities. Then, as she moved along, she ended up job-coaching. She would find them employment, help them build a resumé and just help with skills that would be useful in the workplace. Employers love having people like this come in and work for them, because they bring something different to the team, right? I found your testimony quite interesting.

There is something I wanted to ask you. You mentioned that people with episodic disabilities need an advocate or the ability to advocate for themselves. I'm just wondering: In your experience, who is usually doing the navigation and the advocacy for a person with an episodic disability?

● (1010)

Ms. Maureen Haan: That's a really good question.

It depends. It depends on what system you're talking about. If you're talking about going into the work system, then through the workforce development agreements there are a number of federal-provincial funded agencies that work. There are also some at a federal level through the opportunities fund that do direct services for work. With regard to navigability around support networks, it's a hodgepodge, and it depends on where people land.

When I sit on the CPPD round table, there are people with lived experience there, and they all talk about the struggles that they had to finally find an advocate who could help them navigate the system to get into CPPD. There isn't one that I know of.

Dr. Monique Gignac: I'll just add very quickly that when we talk to people—thousands of people—they say that there is no one, that they're on their own, reinventing the wheel. Again, they don't necessarily define themselves as people with disabilities, but they don't know where to begin or who to go to.

Dr. Emile Tompa: Yes. Because of the stigma that people have mentioned too, they don't necessarily want to disclose, so they take advantage of whatever kinds of opportunities you have within.... If they are working, they might take advantage of the flexibility the work might offer through regular sick days, flexible work hours or things like that.

Ms. Tammy Yates: I want to add, just echoing in terms of the stigma of labelling disability, that people self-navigate, and then that cascades their conditions even further. They're already trying to navigate living with these conditions, and then they have to navigate self-stigma, as well as the discrimination that exists.

We keep talking about those who may not want to work almost like a deficit perspective. We keep talking about those who may take advantage of the system. Right now, there are millions of people who want to work—

Mrs. Rosemarie Falk: Sure.

Ms. Tammy Yates: —who will add to our GDP and who will add income. As for all of the people living with disabilities generally, the statistics that have just come out demonstrate how many people who want to work are not working, people who would actually contribute to pensions, contribute to EI and so on. When you do a cost-benefit analysis, you can see that we actually are costing ourselves money right now.

Ms. Adele Furrie: What I heard from the 953 people who responded to that questionnaire was that they go to the organizations that represent their particular health conditions.

Episodic disabilities are different from developmental disabilities and from learning disabilities. If you have Crohn's disease, you go to other people who are living with Crohn's disease or to the organization to find out what helped them, what the supports are, how they navigated the system, etc. That's what we found in the surveys.

Dr. Monique Gignac: I would say that health charities are an untapped resource; they are very willing and able to help.

Mrs. Rosemarie Falk: For sure. Thank you.

Quickly, Ms. Furrie, I know you mentioned working with stats, questions and that type of thing. Do we know if more people are being diagnosed now with episodic disabilities than before? Do we have an idea of what we're at even in the last 10 years?

Ms. Adele Furrie: It's not that more people are being diagnosed with the conditions or are identifying as having an episodic disability; it's that the social media, the press and initiatives such as this one are bringing it to the forefront. People are stopping and saying, “Hey, that's me.” Between the 2012 and 2017 surveys that used slightly different questions—we could get into that if necessary—we saw that the number of people with disabilities in Canada increased from 3.7 million to 6.2 million. It isn't that all of a sudden everybody became disabled; it's that more people are saying, “Yes, that is me. I do have a disability. I need support, and I'm experiencing barriers.”

● (1015)

Dr. Monique Gignac: There are better treatments for people, so working is a possibility now. That's where I think we're really seeing the work in disability. It's the better treatments that allow people to work.

The Chair: Thank you.

Go ahead, Madame Sansoucy, please.

[*Translation*]

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

I see that you would like to add something, Ms. Haan. Go ahead.

[*English*]

Ms. Maureen Haan: Are you sure?

Ms. Brigitte Sansoucy: Yes.

Ms. Maureen Haan: I think that working with employers is different. BDC came out with a stat from a survey they hosted saying that 40% of small businesses are having problems finding employees and that this stat is going to stay with us for the next 10 years. That means that forward-thinking employers are having to think about where their workforce is coming from and making those types of adjustments within their workplace as well.

[*Translation*]

Ms. Brigitte Sansoucy: Ms. Furrie, my questions will be in the same vein as those of my colleague and will focus on data.

I would first like to thank you for reminding us not to reinvent the wheel, as recommendations have already been issued in a number of reports and our role is more about bringing them back to the forefront.

You have already provided us with a chart, but I would still like you to tell us about your analysis of that data. I would also like to know how that data can give us insight into future developments. You said that more and more people are recognizing themselves in this, and our recommendations should take that into account. Will the situation evolve over the coming years?

You can both answer.

[*English*]

Ms. Adele Furrie: I don't know. It's as simple as that.

As I said, over the years since the first survey I was responsible for in 1986, I've seen a change in the definition of “disability”. It's becoming much more inclusive. The definition in the accessible act is much more inclusive. I think if we run this survey again, which we're hoping to do in 2022, the number could very well increase—perhaps not as dramatically, but for sure it will continue.

Also, we talk here only about work disability, but we have to remember that disability occurs over all ages, and with our aging population we're going to see many more people age 65 and older identifying as having a disability.

[*Translation*]

Ms. Brigitte Sansoucy: Ms. Haan, do you have anything to add?

[*English*]

Ms. Maureen Haan: I don't have the stats that Adele has, but the only thing I wanted to add anecdotally is that we're seeing a growing population of young people as well self-identifying a little more and a little more strongly each time.

My son, who's 18 years old, has been diagnosed with persistent depressive disorder, which has been explained to him as if he has a pebble in his shoe all the time and he just has to figure out how to walk with that pebble in his shoe.

When we talk about mental health and when I brought the stats back to him and told him this is how many kids are identifying with mental health issues, he can't believe it's so small.

I don't think we have an epidemic. I don't know what's coming down the pipes, but I think mental health is a concern with our youth. It's an episodic disability.

[*Translation*]

Ms. Brigitte Sansoucy: The chair is letting you add something, Ms. Yates.

[*English*]

Ms. Tammy Yates: To echo and emphasize, in my remarks I think I mentioned taking a life course approach. Again, we are here five years from the time that Elisse and I first came to HUMA and spoke about episodic disabilities, and no one knew what we were talking about; this entire session is about episodic disabilities.

In terms of self-identification, even if the staff doesn't speak to awareness, the awareness is out there when you take a life course approach. For example, Maureen mentioned youth and post-secondary education. We are seeing that across the life course, across disciplines, across social participation activities, we have to look at the wraparound approach to episodic disabilities.

● (1020)

The Chair: Thank you so much.

I'm afraid I have to step in here. I want to thank all of you for coming here today to contribute to this study.

We have to suspend for a moment so we can discuss the drafting instructions.

We'll be coming back in camera momentarily. Thank you.

The meeting is suspended.

[*Proceedings continue in camera*]

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