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

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•(0845)

[English]

The Vice-Chair (Mr. Rodger Cuzner (Cape Breton—Canso, Lib.)): I call the meeting to order.

Good morning, folks. We're continuing our study on Bill C-44, An Act to amend the Canada Labour Code and the Employment Insurance Act and to make consequential amendments to the Income Tax Act and the Income Tax Regulations.

We're very happy to have with us today Fred Phelps, from the Canadian Association of Social Workers; Tyler Hnatuk, from the Canadian Association for Community Living; and, of course, Cathy Loblaw, from Ronald McDonald House Charities.

We'll start with your comments of five to 10 minutes and then we'll open the floor for questions. We very much appreciate your coming here today to help us with this study.

Ms. Loblaw, we'll start with you.

Ms. Cathy Loblaw (President and Chief Executive Officer, Ronald McDonald House Charities Canada): Good morning. Thank you very for the opportunity to be here today and to participate in this important discussion. We are passionate advocates of families with sick children, and so appreciate the commitment and the quality of the work and discussion that's happening on behalf of families.

What we want to share with you today is really twofold. We want to take a few minutes to talk with you a little bit about Ronald McDonald Houses and the role they play in supporting families of sick children, and from there share with you some of the highlights of a Canadian literature research study we did this past year to help us understand the needs of families and what was driving the growth we were experiencing at the houses. I think it will provide some important insights into the very real needs and difficulties of families when they're dealing with a sick child, in particular a sick child who has to be treated at a hospital away from their home or local community.

Let me begin with Ronald McDonald Houses. Our first house opened in Canada, in Toronto, in 1981. Today, we have 14 Ronald McDonald Houses right across the country. Every children's hospital has a Ronald McDonald House within either easy walking distance, a few steps, or right on hospital property. We have experienced tremendous growth in our program and in the service we provide to

Canadian families who have to travel to enable their sick child to be treated for a life-threatening illness or injury.

In many ways our houses really began from the intuition that it was simply the right thing to do. We understood that what a sick child needs, whether it's a banged knee or something far more serious, is their family and their parents nearby. Our houses started out as very warm bed and breakfasts, anywhere from 10 to 12 bedrooms. The extraordinary growth that's gone on is that our new Toronto house, which is our third house in Toronto, now has 96 bedrooms. It is the largest Ronald McDonald House in the world.

The 14 houses in Canada are part of a network of 318 Ronald McDonald Houses worldwide. All of our houses across the country have really gone through extraordinary growth in the last five to ten years. We have 476 bedrooms for families across the country. Some of our houses have turn-away rates as high as 70%. Today, we're serving just under 10,000 families a year who stay with us, which represents one-third of the families of Canada's most seriously sick and injured children.

By 2014 we'll have more than doubled that number, to close to 20,000 families a year, so it's really quite remarkable what a Ronald McDonald House provides. They are truly healing oases. They're spaces where a family can step inside. They can sleep. They can eat. They can connect with other families who are going through similar difficult life circumstances. They can do their laundry. They can be with the other siblings. They can really continue to be a family and have maybe a little bit of normal at a time when everything in their lives is anything but normal.

When we talk about what a house is, I always feel that nothing says it more powerfully than the families themselves. What we hear repeatedly is how one minute you're running around to school, carpools, jobs, and living the fullness of all of our lives, and in a nanosecond your life changes. You're fighting for the life of your child. You have to leave your community. You may have to quit your job. You have siblings and other children to care for. You're now on a healing journey that can take months, sometimes years, and ultimately create a new normal for your family. It is an extraordinarily devastating and difficult time for families.

What a Ronald McDonald House does is provide that moment of pause and support and allow the families to focus on the only thing that matters, which is healing their sick child and being a family themselves.

If I may, I'd like to read to you a letter we received from a family. I think it is particularly powerful in expressing not only the kind of support a family needs when they're dealing with a sick child, but also the role that a Ronald McDonald House provides in helping support that.

This letter came from Drew Graham. He is the father of Oliver and Jax, husband of Kaitlin, and this came from our Halifax house:

●(0850)

On June 5, 11:18 p.m., my youngest son, Oliver, beat his cancer. Unfortunately, his cancer was so aggressive that he had to sacrifice his life to do it. He was the bravest person I will ever know. Oliver's two-year fight taught me I had my priorities wrong. Even before the cancer, I was missing my youngest son's life.

Ronald McDonald House would later teach me I was also missing my oldest. When your child is going through aggressive chemo, you treat them like a porcelain doll, terrified of every cough or cold, always waiting for them to vomit or bleed. You are literally waiting for the worst to happen. My oldest, Jax, only 15 months older than Oliver, would spend each day at the hospital playing what Oliver wanted to play, and playing how we told him he was allowed to play. Jax was not allowed to play something his brother could not, and Oliver, most of the time, could not play much.

For Jax, that all changed as soon as we left for Ronald McDonald House. Around 6:30, Ollie's bedtime, Jax and I would walk from the IWK hospital to Ronald McDonald House. As soon as we exited the hospital, it would be about Jax. We would race from fire hydrant to fire hydrant, finally sprinting to the big red door. Once we were inside, Jax would take off to the playroom, where kids and volunteers would play with him. Here he wasn't running too fast or playing too rough; he was just a kid being a kid. If he got hungry, there was always a treat or food to be found in the kitchen. After playtime, it was off to the tub and bed. In bed we'd watch Scooby-Doo, Spiderman, or Ben 10. Jax would tell me about the characters in the show and what new toys he thought were cool. Lying together, lying on separate single beds or together on a double, I bonded with my son, I mean really bonded with my son.

Some nights when Jax was asleep, I would sneak out to the common room to watch hockey or the news, anything to take my mind off cancer. I'd meet other parents and inevitably talk about why we were there. In these conversations, I learned life is not fair and cancer wasn't the only thing kids were fighting. I would also learn that while I thought we were broke and had it tough, every family at the house had it tough. Some had other kids who had to stay home, eight- to 10-hour drives, jobs that only allowed unpaid leave or forcing them to stay at work or quit. I hope you are never faced with the choice of leaving your dying child or losing the ability to support your family.

If not for Ronald McDonald House, these families, my family, would not have been together when they most needed to be. Ronald McDonald House became for me and Jax an oasis, a place to play where Jax didn't have to curb his enthusiasm and I was just a regular parent. The house allowed both of us to let off steam and make the most of what days we still had as a whole family.

To all the staff and volunteers who make a habit of going above and beyond, thank you for turning Ronald McDonald House into a home. Thank you for spoiling Jax, for being an ear when I needed to speak, a shrink when I needed advice, a shoulder when I needed to cry, and a friend when I needed a hug. You are family.

On behalf of all my family, in the words of Oliver, "My love you, all my heart."

I share that story because I think it very powerfully and honestly reflects just the enormity of the life challenges that families face when they are healing a sick child, and how the practicalities of life can be so hard to deal with when the only thing that matters is that child who's in front of you.

As we've looked at Ronald McDonald Houses and really grown into recognizing the role we've come to play in supporting the families of sick children, we have been faced with, and are continually faced with, extraordinary growth. We never anticipated that we'd be in a space where we'd be serving 10,000 families a year, growing to 20,000, and have 14 houses, and the growth isn't ending.

One of the processes we went through last year was a Canadian literature review, through a social research agency called Impakt, to help us understand the context of families.

There were seven key findings that were brought forward to us. I'd like to share them with this committee, because I think they really speak so powerfully to the core issue that families face when they have a sick child, both on the catastrophic financial side and the emotional burdens.

Very quickly, the key findings were these.

First, today more families than ever have to travel significant distances to obtain care for their seriously ill child. As everyone here knows, there's been an increasing shift towards specialty centres and hospitals of excellence in particular fields. It's no longer the case that families are just being treated at their local hospitals. Getting the treatment that your child requires most often requires travel to the hospital that can provide that level of expertise. As well, 76% of Canadians live outside of a community with a children's hospital, so travel is now not a nice-to-do to get better care, but a must-do to get the core care that families need. However, when you have to travel and when you are displaced, it has a significant impact on your life and that of your entire family.

●(0855)

The second key point of what's driving our growth is that it's a good-news story. The healing and recovery rates of children have increased significantly. Over the last 30 years, if you look at cancer, for example, you see that children have gone from a 30% recovery rate to an 80% recovery rate today, which is amazing. Children are getting better.

The reality is, though, thanks to medical advances and thanks to children healing, more treatments are required over longer periods of time, so the average stay at our houses, which used to be four to five days, is now 55-plus days. More than 50% of our families are there for extended or multiple stays. When you combine the financial burdens with the emotional burdens and the necessity of travel, you recognize that anything we can put in place that will support families

The Vice-Chair (Mr. Rodger Cuzner): Ms. Loblaw, we do have to get to the other witnesses as well. I think all members of the committee, all Canadians, understand and appreciate the great work that Ronald McDonald House does. Your framing it as a personal, first-hand account was very powerful, and I agree with you wholeheartedly. We really appreciate it. Maybe you'll be able to elaborate on those seven points through some answers. We can do that.

Thanks.

Mr. Hnatuk is next.

Ms. Cathy Loblaw: Sure.

Mr. Tyler Hnatuk (Policy and Programs Officer, Canadian Association for Community Living): Thank you.

Good morning, Mr. Chair and members of the committee.

On behalf of the Canadian Association for Community Living, I want to thank you for the invitation to participate in the committee's study of Bill C-44.

My name is Tyler Hnatuk, and I am a policy and programs officer with the Canadian Association for Community Living.

The Canadian Association for Community Living, or CACL, is a family-based association that assists people with intellectual disabilities and their families to lead the way in advancing inclusion in their communities. Our association was founded in 1958 by parents of children with disabilities who wanted supports and services in their home communities rather than institutions. Since that time, our association has grown into a federation of 13 provincial and territorial associations, made up of over 300 local associations and more than 40,000 members.

Our association has in the past called for changes to the Canada Labour Code, Employment Insurance Act, Canada Pension Plan, and Income Tax Act in order to recognize the support and care that family members provide to a child with a disability. Over the past decade we have participated in community consultations, coalitions, and policy reform processes aimed at recognizing the challenges and disproportionate financial impacts faced by families of children with disabilities.

I'd like to say from the outset that we are encouraged by the direction of Bill C-44 and its proposal to recognize the challenges faced by families in these extraordinary circumstances. By recognizing the situations of parents of a child who has been a victim of a crime, is missing, or is critically ill or injured, this proposed bill recognizes the extraordinary caregiving responsibilities that some families face and the impact on their labour force attachment. As such, we wholeheartedly support the direction of the bill and the window of support and flexibility that it provides to parents in terribly difficult circumstances.

When compassionate care provisions were first introduced to employment insurance, we joined others in calling for enhancement of these measures to recognize the extraordinary caregiving situations that parents of children with severe disabilities face. We continue to be of the view that recognition is needed for families of children with severe disabilities, and we have developed detailed proposals with respect to an overall strategy for addressing the disproportionate caregiving situation that these families are in, of which these changes are one modest but important piece.

In my brief submission, I would like to provide a bit of a profile of parents of children with disabilities through our analyses of national data sets and other Canadian research, look to the current Canadian policy context in Canada for support for caregivers of children with disabilities, and look to the lived experience of families who are a part of our movement in order to outline the challenges that they face today.

To begin, just by sketching some of the profiles of families of children with disabilities, we know that children with disabilities and their families endure greater and disproportionate rates of low income than others in Canada. Data from the participation and activity limitation survey, or PALS, as people call it, from 2006 indicate that children with disabilities are more likely to live in

households that fall below the low-income cut-off than children who do not have a disability.

It should be pointed out that this measure doesn't take into account non-reimbursed costs related to disability, and therefore the low-income situation is likely understated. When we consider employment, we know that parents' ability to maintain a career is significantly affected by having a child with a disability. Again, PALS 2006 found that parents of children with disabilities report that as a result of their child's condition, 38% worked fewer hours, 37% changed their work hours, 26% did not take a job, 22% quit work, and a further 20% did not take a promotion. We know also that most often it is the employment situation of mothers that is most affected, with 64% of mothers being the most affected, while 8% of fathers are the most affected.

One of the major disability-related supports that people require throughout their lives is help with everyday activities. Of children with disabilities whose parents require help, nearly 26% have parents who received help but needed more, and about 40% have parents who received no help but needed some.

● (0900)

Of these parents needing additional help, nearly three-quarters cite cost as the main reason they can't get it, and more than a third say out-of-pocket expenses.

The bulk of disability-related support for everyday activities in Canada is provided by family members. This includes help with personal care, health care, housework, and transportation, and includes matters such as personal advocacy, planning, coordination and brokering of needed services, emotional support, communication assistance, and so on.

I would like to illustrate these facts and figures with just a few of the stories that we hear from thousands of parents throughout the country who have children with intellectual disabilities. We hear regularly from families who are struggling to make ends meet as the sole result of their decision to push for what they believe is best for their child. Driven by a vision of inclusion and a good life, families are increasingly being pushed into hardship and desperation, in many cases to the brink.

Consider a plea received this month from a Saskatchewan mother of a young son with a disability. They are a single-income family on what would otherwise be a modest income, but they are below the poverty line and have filed for bankruptcy. This mother was recently advised that she should put her child in care, a course of action that she has no intention of following.

Consider the numerous stories that have appeared in print and television media over the past months of parents who have dropped off their adult children with community support agencies because they can no longer fulfill the duties of caregiving.

Consider the plea of an Ontario mother who recently spoke at a provincial hearing on government services and whose voice resonated with families across the country as she detailed the 15 years her family has spent on waiting lists for support and the two hours per week of support that allow her adult son to have a shower once in a while.

These families and thousands of others across the country have spent their lifetimes providing billions of dollars worth of what would otherwise be paid care for their children with significant needs.

The UN Committee on the Rights of the Child recently reviewed Canada's third and fourth reports to the committee and concluded with observations that Canada must ensure that children with disabilities and their families be provided with all necessary support and services to ensure that financial constraints are not an obstacle in accessing services and that household incomes and parental employment are not negatively affected.

We believe it is quite clear that for families of children with severe disabilities, the activities of caregiving reach far beyond the typical duties of parenthood. As I mentioned earlier, CACL has developed detailed and more comprehensive proposals that could provide recognition for these extraordinary circumstances. In the context of a broader strategy, extension of employment insurance benefits would form one small but critical contribution toward mitigating the current financial impacts related to raising a child with significant needs.

As we know well from research, early intervention can be critical in shaping outcomes later in life. These interventions might be related to medical procedures, intensive therapies, educational activities, and so on, or the interventions may be the less formal added demands of parenting that relate to doing the inclusion work in the context of communities and systems where parents of children with disabilities still encounter so many doors slammed shut in generic services, programs, and supports. If parenting is a full-time job, then the inclusion work of parents of children with disabilities is far above and beyond what can be expected to be regular caregiving responsibilities.

The work undertaken by parents of children with disabilities to better their communities and build better lives for their sons and daughters needs to be recognized as the extraordinary task that it is. An extension of employment insurance benefits to parents of children with severe disabilities may seem a small window in the context of the overwhelming need for support, but these forms of recognition are critical. The consequences of missing these small windows of opportunity can be significant, as we see with the finding that 40% of kids in child welfare systems have disabilities, and as we see with the media stories of parents dropping off their children with community agencies.

• (0905)

While we recognize that something like employment insurance benefits may seem like a small window in the context of such great need, it's with these modest amounts of support that parents of children with disabilities can do and have done so much. It would further mark a tremendous step forward towards recognizing the contributions of family caregivers of children with disabilities.

We urge the committee to recognize that some families face extraordinary caregiving responsibilities that have a direct impact on labour force attachment, career development, and family well-being. We believe that this should be the focus for the purposes of the employment insurance system. It's not so much the source or cause of extraordinary responsibilities and challenges that is the policy issue but the fact that some families in this country, through no fault of their own, face extraordinary challenges, which have a direct impact on parents' labour force participation. It's the labour force impact of those challenges that could be a focus.

I'd like to thank the committee for the opportunity to appear, and would be pleased to address any questions or comments that you may have later.

Thank you.

• (0910)

The Vice-Chair (Mr. Rodger Cuzner): The committee would like to thank you for your presentation here today.

I've been a bit more liberal with the time. I know that comes as a surprise to government members, but nonetheless, there are some very important points. We appreciate it. We can make up for it on the other end.

Go ahead, Mr. Phelps, please.

Mr. Fred Phelps (Executive Director, Canadian Association of Social Workers): Good morning.

On behalf of social workers across Canada, I would like to thank the committee for your consideration in bringing the voice of our profession to the discussion and debate on Bill C-44, the Helping Families in Need Act.

As background for committee members, the Canadian Association of Social Workers exists to promote the profession of social work in Canada and advance issues of social justice. As the executive director, it is my distinct honour and privilege to bring the voices of front-line social workers to this committee.

The comments I'll be making today come directly from front-line social workers, who bear witness to the emotional and financial impact of serious illness on families and individuals as well as the overwhelming experience of grief and loss when a child dies or disappears as the probable result of a crime.

I apologize in advance if some of the questions and concerns raised by social workers have already been addressed by other witnesses or members of this committee. In addition, some of my comments do not directly address Bill C-44. Nonetheless, the issues addressed are pertinent to the overall objectives of providing front-line social service providers with the economic tools to adequately support children and families in crisis.

To begin, the membership of the CSW health and children's interest groups was unanimous in its support of Bill C-44, calling it a step in the right direction in providing relief to parents in the form of limited financial help and ensuring that they do not lose their jobs because of tragic circumstances beyond their control.

As CSW understands Bill C-44, the proposed changes to the Canada Labour Code will apply only to workers in federally regulated sectors. It is apparently expected that provincial governments will make similar changes to their labour codes, as was the case when compassionate care benefits were introduced. CSW has to ask if there have been discussions with provincial jurisdictions to ensure that there will be compliance.

The matter of compassionate care benefits was also raised by a number of social workers and their provincial organizations in consultations on Bill C-44. The changes in this act do not address the challenges faced by caregivers of adult family members or by individuals who require a period beyond the 15 weeks of medical EI coverage. Consequently, I would be remiss if I did not convey that social workers request the Government of Canada to consider expanding the compassionate care benefits program to include caregivers caring for adult family members and to consider extending sick leave benefits beyond 15 weeks to a maximum of 52 weeks for those who require it.

Specific to Bill C-44, the Canadian Association of Social Workers also supports any and all improvements to programs that provide relief to families when tragic events occur, such as the disappearance or death of a child following a crime. However, it is not always easy to determine at the outset whether a disappearance is the result of a crime. Consequently, social workers had a number of questions meant to clarify the meaning and intention of this act.

First, will consideration be given to providing benefits to parents who are looking for their runaway or lost child? Who will determine if foul play is suspected and when benefits can be provided?

The Canadian Association of Social Workers applauds the initiative of this legislation to provide help and support to family caregivers looking after critically ill children. However, questions remain. What about the children who are injured as a result of an accident or the children who are seriously ill? Who decides whether and for how long parents need to be at their side and away from work? When or why can an employer refuse leave? Will there be an onus on parents and employees to prove they deserve or require this leave? What kind of documentation could the employer request? Is a medical note not enough?

Why is the definition of a child limited to those under 18, and should adult dependants not be considered for extension of coverage under this act?

It is our understanding that benefits end the week of the death of a child; would compassion not dictate that families require time after death to mourn and bury their child?

Finally, is there any requirement for parents or employees to seek counselling and other supports to help them recover so that they can return to work healed to some degree, or is the leave only to allow them time and benefits to care for their child?

Social workers ask these questions for clarification, as social workers will be involved in the interpretation of the act and in helping people learn how to access benefits. They will be advocating for people who seem unable to qualify because of unfortunate glitches or issues not readily understandable within the act.

●(0915)

Any application process, social workers note, that is onerous may cause a family to turn away, given that they don't need any more stress at this point in their lives.

It is the front-line experience of social workers that people often do not access services that would have eased some of their distress because the process at the front end was more than the family could manage at the time. Consequently, social workers encourage the Government of Canada and this committee to seriously consider that ineffectively delivering this type of benefit can add to, rather than, as it is intended to, subtract from, the immense stress families are already experiencing with their deep personal loss in tragic circumstances.

The CASW will be actively monitoring this act and its implementation, primarily to advocate for clarification and to lobby for changes where needed, and perhaps will be involving advocacy for provincial legislation where people can now qualify and more assistance is needed.

Again, on behalf of social workers across Canada, I thank the committee for your consideration in hearing the views of our profession on Bill C-44.

Thank you.

The Vice-Chair (Mr. Rodger Cuzner): Thank you very much, Mr. Phelps. You've echoed some questions that have been presented by other witnesses and brought forward new ones. The committee very much appreciates your presentation on that.

We'll get right into the questions.

Go ahead, Mr. Cleary, for five minutes.

Mr. Ryan Cleary (St. John's South—Mount Pearl, NDP): Thank you, Mr. Chair.

Thank you to the witnesses.

I have a question, first, for Mr. Hnatuk, although you touched on this, Mr. Phelps.

Bill C-44 defines a child as someone under the age of 18. You represent, as you outlined, people with intellectual disabilities, so you could have a person who is in their twenties, thirties, forties who actually has a mind of a much younger person. To get right to the point, is 18 as a cut-off too restrictive?

Mr. Tyler Hnatuk: Again, in the context of Bill C-44 we know that the forms of intervention that can occur early in life will have tremendous outcomes later in life. Certainly caregiving responsibilities for parents of children with disabilities often continue much longer in life than for other families, and so certainly I want to recognize the need and the duties that carry on throughout a lifetime.

The parenting of a child with a severe disability is a lifetime commitment. That said, interventions can occur when a child is young. We know from the research and from our experiences that those first stages are critical towards shaping outcomes towards inclusion later in life. Driving kids to—

Mr. Ryan Cleary: Excuse me; I'm sorry to interrupt. To get to the point, is 18 too restrictive as a cut-off?

Mr. Tyler Hnatuk: We believe it would mark a positive first step towards recognizing caregiving duties throughout the lifespan.

Mr. Ryan Cleary: What would you eventually like to see?

Mr. Tyler Hnatuk: As I mentioned, we have more detailed proposals to recognize caregiving throughout the lifespan, of which an extension of compassionate care benefits would be one modest but important piece.

Mr. Ryan Cleary: Thank you.

Mr. Phelps, I have a question for you.

You mentioned you'd like to see Bill C-44 extended to cover adult family members who have to look after their parents, for example, if they become critically ill.

I asked this question of the minister last week when she appeared before the committee. She mentioned there are programs in place right now for people who need to look after critically ill parents. I think that kind of help only lasts a handful of weeks. You also outlined how you'd like to see these types of benefits extended to, say, parents of runaways.

Can you elaborate on that? You'd like to see the benefits extended to people with adult family members who are critically ill and runaways. Who else would you like to see covered?

Mr. Fred Phelps: When social workers were solicited for a response on Bill C-44, it was brought up in the sense that this was a good first step in covering, recognizing that as this bill becomes implemented there would be opportunities to have feedback to it and to recognize that different segments of society may very much benefit from an extension of these benefits to their families as well.

I think social workers wondered who would define a missing child. It's an extension to benefits of runaway children. I think this bill is trying to recognize that families are in stress, families need time to understand what's going on, families need time away from work to be able to deal with the circumstances.

I think being open to extending these benefits to other populations would be very much welcomed by social workers who deal with the front lines of this and by their families and children.

● (0920)

The Vice-Chair (Mr. Rodger Cuzner): You have 30 seconds.

Mr. Ryan Cleary: In terms of other supports for families that are going through tragedy, for families dealing with a critically ill child, what other supports can be there? More specifically, in terms of the agents with Service Canada who deal with families on a front-end basis, can they receive more training to be more sensitive to the needs of a family in trouble?

Mr. Fred Phelps: I think you bring up a very good point. The one thing I've definitely heard from social workers, not necessarily from Service Canada but from social workers who deal with individuals on the front line, usually in hospitals, or are the front-line defence or the first call in what's going on, is having clarity and understanding of who it applies to, being very clear on the roll-out of this, and being very clear on making it as accessible as possible to families. These are families in distress, undergoing parts of their lives as described by Ms. Loblaw, very much in the most critical

parts of their lives, and any barriers to accessing services will mean the uptake will not happen for them.

As well, on the social work side, whether it's front-line service workers with Service Canada or social workers through their provincial government, there is need for a very strong clarification too, a need to be very clear on who can access this and being very open and responsive when the roll-out happens if changes and clarifications need to be added to the act or additional benefits to different populations need to be added to the act.

I think there is some confusion out there in the social work world on the front line about the difference between compassionate care and how "critically ill" would be defined under this act, where the two lines happen, and how that will affect people while they're in those situations.

The Vice-Chair (Mr. Rodger Cuzner): Thank you very much, Mr. Phelps. That's great.

We'll go to the government side now, and I believe Ms. Leitch is going to take the first round.

Ms. Kellie Leitch (Simcoe—Grey, CPC): Thank you very much. I'll be relatively quick, mainly because I want to answer some of your questions for clarification.

I'm a pediatric orthopedic surgeon by training. I'm Royal College trained. I actually deal with critically ill children, and that's where some of this definition comes from.

To go through your questions in pretty rapid succession, because it was not my intent to answer your questions here—that's not how we usually do things—I encourage you to read the act, because these questions are answered there.

First, the labour minister, as she mentioned in committee last week, has spoken with other jurisdictions.

Second, with respect to foul play, it's very clearly outlined in the legislation that law enforcement officers will make a determination of whether they think the child is a runaway or an individual who is murdered or missing, and therefore the decision will be made on the side of murdered or missing.

With respect to critically ill children, that will be determined by a physician, a sub-specialized physician within the hospital setting.

With respect to the age of 18, it's based on a standard that children's hospitals have set across the country, in fact across North America. In addition to that, it's based on our other benefits that we provide to children. Whether that be the national child benefit or otherwise, we have a standard and that's what we're setting. It also matches those of children's hospitals across the country.

With respect to counselling parents, for murdered and missing there's an additional two weeks after your child is found in order for the parents to reunite with their families, and they would be eligible for the benefit. With respect to the issue of compassionate care associated with this benefit, they can be stacked. You can receive compassionate care plus the critically ill benefit, so that you can use them in combination.

In respect of your issue with respect to communication, you're here because we need you to talk to families. We don't sit in the hospital setting. We don't see families every day. You do exactly that, and we need your help to make sure you tell every family you communicate with, every family you touch, about this benefit so they can benefit from it.

I'll let Mr. Shory continue with the questions.

• (0925)

Mr. Devinder Shory (Calgary Northeast, CPC): Wow.

Thank you, Mr. Chair, and thank you, witnesses, for being here this morning.

My question will be to Ms. Loblaw.

First, I want to thank your organization for doing all the good work that you do in helping families and communities in Canada.

As you know, Bill C-44 has been introduced by the government to help families to balance their work and family responsibilities. As far as your organization is concerned, it will introduce new benefits for the parents of critically ill children.

In your experience you must have faced some challenges and be in a position to be aware of the challenges parents have been facing during a difficult period. It's emotionally very hard to start with, and when you add the work risk and other stresses, it is really hard.

Do you think the government is going in the right direction or that this is a positive step forward? If you agree with my comment that it is positive, then I'd like you to elaborate on why you think it is positive.

Ms. Cathy Loblaw: Thank you.

Absolutely we see this as positive. For the families of sick children, as I spoke to earlier, their world turns upside down in a nanosecond. It goes from normal to a new normal overnight. Having to worry about the financial realities that come rushing in to them, which are not planned, not anticipated, not seen coming, is quite devastating to the family.

Having this kind of support and this kind of family-first approach that helps families when it's unexpected can give them another level of resource and support to depend on when they're in a place where their jobs are all of a sudden a secondary concern, or are maybe not even a concern.

Then they're moving into a space where healing their child is taking so much longer. They can be in a healing process away from home, at the hospital, for months and months. That has a devastating impact on the financial side of their life.

As their child heals, thanks to the amazing medical advances that are happening, and they go back home, they need to know that they have a home to go back to, that they have a life to go back to, so that they can continue to heal and live into the blessing that they've been given with their child getting better, so this direction—this family-first approach, this family support—is fundamental to the needs our families have.

Mr. Devinder Shory: Thank you.

Another—

The Vice-Chair (Mr. Rodger Cuzner): That's five minutes for the side, Mr. Shory. I apologize.

Mr. Sullivan is next.

Mr. Mike Sullivan (York South—Weston, NDP): Thank you, Mr. Chair.

I want to correct something that was said on the other side a few moments ago. You're not just here to listen to us preach to you about the meaning of the law; we want to listen to you. This is one of the places where these laws can actually get amended, can get changed, can get made better. We want to hear from you, and we have heard from you, in great detail, about some of the ways that the law may not solve certain problems. We want to hear about ways that it can be amended and about what issues are out there beyond the ones that are dealt with directly in this legislation, so thank you very much for being here and thank you for giving us that advice.

There was a statement made by Ms. Loblaw that 70% of people are actually turned down. One of the things we're concerned about is the method in which this legislation will be implemented by Service Canada and whether or not they have the expertise to actually administer this thing. They don't have first-hand knowledge of social work. They are not social workers. Service Canada agents are merely interpreting the legislation. The minister has apparently said that a specialist will be the one who decides.

Is that how Ronald McDonald House decides?

• (0930)

Ms. Cathy Loblaw: It is how Ronald McDonald House decides.

The hospital refers the families to the houses. We are doubling our capacity to be able to serve more families. Currently, in terms of the structure, we rely on the expertise of the hospital and the doctors to refer to us the families that are in the greatest need and have the greatest physical distance to travel.

For most of our houses, they have the criterion that a family has to live at least 80 kilometres away to be considered for staying at the house. Then we take the referrals through the social workers and the doctors at the hospital. That's how the families come to stay with us.

The good news is that we have doubled in size in the last five years, up today to 476 bedrooms from 217 bedrooms five years ago. We're able to accommodate far more families now than we had in the past.

We do rely very much on the specialty centres in the hospital to refer the families to us.

Mr. Mike Sullivan: Does your agency receive any government funding whatsoever?

Ms. Cathy Loblaw: No. The houses, on an annual operating basis, do not receive government funding. However, government has been a very active partner, both federally and provincially, in the building of our new houses and in investing in the infrastructure of the houses over these past five years.

Mr. Mike Sullivan: With regard to the age of a child, we heard on Tuesday that it seems somewhat arbitrary or prescriptive to suggest that when the child is 18, a parent's responsibilities somehow end, particularly in the case of persons with developmental disabilities.

I have a friend who is nearing 80 and is caring for her almost 50-year-old daughter every day. She certainly could use some of the supports that are being talked about here, but they're not available. We're also aware from Tuesday's witnesses that for a disappeared or a murdered child, it doesn't really matter whether the age is 18 or not.

The other thing we heard about was some of the inflexibility of the legislation, in that it has to be all in one time and can't be spread out over bits and pieces of time, which meant that its usefulness was somewhat limited. Is there some indication that, even as it's proposed, it should be more flexible, that we should be able to use it over a longer period of time, perhaps, longer than 37 weeks? You've suggested 55 days as the average, but I'm sure there are people who need a lot more time than that. Are there ways in which this legislation can be improved by making it more flexible?

Ms. Cathy Loblaw: To put the 55 days in context, that's a reference to the average number of days a family stays at the house

Mr. Mike Sullivan: Right.

Ms. Cathy Loblaw: —which is different from the average number of days they spend caring for their child and healing their child, so just keep that in mind.

As I said, more than 50% of our families come to the houses two and three times. Again, because of the amazing medical advances, the healing time means taking more treatments over longer periods of time, so it is an extended period in which families are fighting for the lives of their children and healing their children.

I'll let you speak to the specifics of the flexibility, Tyler.

Mr. Tyler Hnatuk: As I mentioned, our perspective on Bill C-44 is that extension of compassionate care benefits would provide that small window in the context of such great need, but with respect to those modest amounts of support, parents of children with disabilities can do so much with that. As you spoke to in your experience with an 80-year-old parent of a child with a developmental disability, it's a lifetime commitment.

There is certainly a blend of supports that are needed. The scope of this current bill is not going to address all of the needs, nor would extension of the compassionate care benefits. Really, a blend of supports and a strategy are needed for caregiving.

The situation is really similar to those of the parents who began our movement more than 50 years ago. Out of the decision to pursue a good life for their sons and daughters, they decided to keep them at home rather than send them away to an institution. They did so without any support whatsoever. It still remains the case that parents who decide to provide so much care to their child have not been recognized sufficiently by our policy and financial incentives for our caregivers.

• (0935)

The Vice-Chair (Mr. Rodger Cuzner): We're going to have to move along.

Thank you very much, Mr. Sullivan.

Thank you for the answers.

Go ahead, Mr. Daniel, please.

Mr. Joe Daniel (Don Valley East, CPC): Thank you, Chair. Thank you, witnesses, for being here this morning.

My question is for Ms. Loblaw. I know that you were going to talk about some seven points that you have. Maybe you could enlighten us on them.

Ms. Cathy Loblaw: As I said, when we saw the growth of the houses increasing, we wanted to understand more specifically the context that the families of sick children were living in and how that was driving the support for families that we wanted to contribute to. For us, it was an enlightening piece of work that really helped us understand the new normal for these families. I'll share with you the key points, some of which we've already touched on.

One of the most important ones is that more families have to travel to get the care they need for their child. That is having a huge impact on their lifestyle and their economic structure. The second is that children are healing, which is the wonderful good news, but, again, it's extending the period that their lives are disrupted.

When we looked at the financial burdens that families face, we were quite shocked by how significant they are and how deeply they affect families on every level of finances. Let me give you a couple of specific examples of what I mean.

There was a wonderful study of 99 families that found that in the first three months following their child's cancer diagnosis, the average impact of costs for them was \$28,475—incredible. Some 94% of mothers and 70% of fathers reported a work loss amounting to a considerable cost for the family. The median income loss was \$2,380 for mothers and \$1,260 for fathers. On top of this, they're having to pay for their accommodation and for care for the siblings.

The economic impact was incredibly devastating for families. This is their last priority; their first and only priority is how to heal that child, so it's about really understanding the magnitude of that priority and then recognizing that there just aren't enough supports and subsidies for families today to help them manage the reality that they're now trying to deal with.

Another point was obviously the emotional need, which we've talked about, and how significant that need is for families. I think what is really important to understand as well—while we understand it intuitively, the research spoke very clearly about it—is the role that having your family nearby has in both the quality of care for the healing of the child and the outcome of care for the healing of the child. A family together healing a sick child makes an extraordinary difference; there's powerful research around reduced length of stay in a hospital, the healing experience, and the actual healing outcome.

I think the last point that perhaps surprised us was that the family being together and having the infrastructure to support them being with their sick child drives greater hospital efficiencies and saves dollars to the health care system. Having the family in attendance and having a Ronald McDonald House and resources such as that can decrease the length of stay and cost significantly less than being in hospital, if there's out-of-hospital treatment and that kind of thing.

I thank you for asking the question and for the opportunity to go back to it. Overall, our key take-away from the research was quite sobering: to appreciate the emotional, financial, and physical constraints and difficulties that families go through when they're trying to heal their sick child. An act such as this, which gives them that surround support and makes it that much easier for them, is really important to giving the families the time they need to be with their child.

Mr. Joe Daniel: Do I have time for another question?

The Vice-Chair (Mr. Rodger Cuzner): If you can ask and answer a question within seven seconds.

Mr. Joe Daniel: My question is to Mr. Hnatuk.

How big an issue is the nature of critical illnesses for the mentally disabled?

● (0940)

Mr. Tyler Hnatuk: Sorry, I'm not sure I understand the question.

Mr. Joe Daniel: I'm trying to get a grasp of how many critical cases there are of people who are mentally disabled.

Mr. Tyler Hnatuk: People with intellectual disabilities make up approximately 2% of the population. They are often combined with other forms of disability that may involve medical complications. Generally, 2% of the Canadian population have developmental disabilities.

Mr. Joe Daniel: How many have critical illnesses?

Mr. Tyler Hnatuk: I don't have those figures immediately with me, but we could provide them to the committee.

Mr. Joe Daniel: That would be wonderful. Thank you.

The Vice-Chair (Mr. Rodger Cuzner): That's your seven seconds.

I'll exercise the chairman's prerogative here and I'll use the last 14 minutes to ask my round.

I have two quick questions, really, to any of the panellists.

We had the parents of children who had been lost through crime in the other day. They had very compelling stories. Obviously the legislation treats those who lose a child through an illness differently. Parents of a child criminally abducted can receive 52 weeks of leave without pay. Should the child be found, the parent can get two weeks before they must return to work. Should the child die, the parents can take up to 104 weeks of unpaid leave.

In the case of a critically ill child, they get 37 weeks of leave without pay, but should that child die, they have to be back the following week, so if their child dies on a Thursday, then they have to be back to work on the Monday. That's how we interpret the legislation.

Do you see that there should be some provision...? Could you give me your views with regard to the grieving process of losing a child through illness, or losing a child through a criminal act? Is there a great distinction between the grieving processes? Should there be consideration made for those parents who lose a child through illness?

Mr. Fred Phelps: Among the social workers who were solicited for response on this bill, that was an issue they brought up—the fact

that if a child does die, they'd have to go back to work the next week, and the benefits are extended. There was consideration to ask the committee, in the implementation of this bill, to be open to the experience of families and to see if amendments needed to be made. I think the amendments in the front end would be appreciated, but if in the roll-out the experience of families could be reflected in the grieving period—probably a week or two would be compassionate—it would be very much appreciated by front-line social workers, families, and children.

Mr. Tyler Hnatuk: I would just add that our reading of the bill is that it is a positive first step toward recognizing the terribly difficult circumstances that families find themselves in, however they find themselves in those circumstances. Anything that can provide that small window of flexibility and accommodation that compassionate care benefits can provide would be welcome steps towards recognizing these extraordinary circumstances that parents find themselves in.

Ms. Cathy Loblaw: I will echo what everyone said. This is an important first step in the grieving process of losing a child. It's something that is very different and very individual and very personal. Whatever we can do to surround and support those families with the support they need as they're going through that grieving process is really important and very much valued.

The Vice-Chair (Mr. Rodger Cuzner): So you see a benefit in extending it to those who may lose a child through illness?

Ms. Cathy Loblaw: I certainly see anything that gives families more support when they're going through what is arguably the most difficult time in a family's life as being a very positive and important thing for families, absolutely.

● (0945)

The Vice-Chair (Mr. Rodger Cuzner): That's perfect. It was five minutes.

We really appreciate your being here today and taking the time to share with us your insights and opinions.

We are going to suspend now and prepare for the next round of witnesses.

Thank you.

● (0945)

_____ (Pause) _____

● (0950)

The Vice-Chair (Mr. Rodger Cuzner): As we come back to order and just before we begin, I want to recognize that we have some guests with us in the gallery today from the Assembly of First Nations, the ASETS group. There are 60 such groups across the country. They are assembled here in Ottawa today, the Aboriginal Skills and Employment Training Strategy group. Bryan Hendry, senior policy adviser, is here with some members of the group.

We want to welcome you here today. They presented a brief to the committee on the skills gap, and we very much appreciate that. I believe you have some thumb drives that you're going to support the committee with as well. We'll look forward to seeing them.

Thank you very much for being here today.

We will begin our second round. We have Edwina Eddy, Annie Guérin, and Nathalie Roy.

We will begin with Madame Roy. Welcome, and thank you for being here today.

[Translation]

Ms. Nathalie Roy (As an Individual): Good morning. My name is Nathalie Roy. My 16-year-old daughter, Sabrina, has Hodgkin's disease. She has stage 4B cancer, the last stage. She was diagnosed in May of this year, so not that long ago. She has a younger sister who is 14. This is a trying time for our family. As a teenager, Sabrina has dealt with all kinds of stress and self-esteem issues.

She really needs her parents now, and we are always there. I have been on leave from my nursing job since May, so I can be home with Sabrina. I go with her to her chemotherapy treatments, as a result of which, she has been repeatedly hospitalized. She finished chemotherapy in August but is now undergoing daily radiation treatments, which will last eight weeks. She also has oncology appointments.

The passage of Bill C-44 is essential from a support and care perspective. Sabrina is outraged, fed up. She's a teenager. This week, she just wanted to throw in the towel. We are close. It is vital that parents be near their child. In our case, we were able to spot Sabrina's distress quickly, and then give her encouragement and explain how important it was that she not give up on treatment.

Forgive me, but this is very difficult. I had prepared a statement, but now I'm just speaking from the heart.

Sabrina often says to me, "Thank goodness you're here, mom. Otherwise, what would I do?" In the oncology ward, you see children who are by themselves all the time. All of you are probably mothers or fathers. All of you have obligations, a house, a car, a family to feed and so on. So you have to work. It pains me to see kids there by themselves because their parents have obligations. If this bill is passed, it will likely mean that kids no longer have to go through the experience alone. It's not fair for a child to have to do this on their own. Even an adult has a tough time coping; just imagine what it's like for a child. As we face this ordeal with Sabrina, we feel a lot of sadness, guilt and anxiety, but I have the satisfaction of being there with my daughter. We go with her to all of her appointments. She isn't alone.

The passage of this bill would be a boon for children. I am speaking for the children, but also for their mothers and fathers. I lost a little girl, so I know what it is to grieve, and I know how impossible it is to go back to work under those circumstances. Everyone must go through the grieving process. If they go back to work too soon, they will most certainly fall into a depression. We are human beings. We need to face adversity with family around us; we need to take a step back to mourn and say goodbye. People who don't have that option suffer untold anguish. They become depressed, and sometimes they even try to commit suicide. In some cases, there is no telling how far it will go.

• (0955)

I had a lot I wanted to say today, but there is one thing I want to say above all else: Please pass this bill. You must do so for the sake of our children, your children and your grandchildren. We never

know what life will throw at us. I would never have thought that cancer would befall my daughter.

Thank you very much.

[English]

The Vice-Chair (Mr. Rodger Cuzner): Thank you very much, Ms. Roy. I can only imagine how difficult it was, but we appreciate your courage and strength in sharing that with us.

Madame Guérin is next.

Ms. Annie Guérin (As an Individual): Hello. My name is Annie Guérin, and I am the mother of a child with a brain tumour.

I'd like to thank you for this opportunity to speak before you today.

Before I begin, I should state that although I am a federal civil servant, my statements here today are my own and do not reflect those of my employer.

My son was but five years old when he was first diagnosed with his tumour. As you can imagine, my husband and I were shocked and scared and worried about our son. His entire life—and ours—was about to change.

He immediately underwent 16-hour brain surgery to remove the majority of the tumour. Nothing in my life has ever scared me as much as those hours waiting in the waiting room, waiting for news that he was still alive and doing well. That news could not arrive soon enough.

I was so relieved when I saw him awake, but groggy. My heart fell again when he was unable to remember who I was. Thankfully, once the swelling had gone down, his full memory came back. However, because of complications from the surgery, he had to be hospitalized for about four weeks. I stayed at the hospital with him to oversee his care.

Everything had happened in such a rush that we didn't have time to analyze how this would affect our son, our other two children, our marriage, or our finances. Our only concern was getting our sweet little boy back safe and healthy.

Now, I had just returned from maternity leave and had begun a new job. I had no accumulated leave. My employer was kind enough, however, to advance me some time off, but it wasn't enough to cover what I needed. I had to take time off without pay.

Even once my son was discharged and back at home and his chemotherapy treatments had begun, we still needed to take more time off for subsequent appointments with the myriad of doctors and to take care of him when his treatments got to be too much and his system was too weak.

My husband was unable to get any time off from his job, so he had to juggle his demands at work, our other two children, and relieving me at the hospital when it was needed. Unfortunately, the distractions became too much, which caused his performance at work to suffer. He was let go not too long after.

When a child is diagnosed, parents want to do everything in their power to make it better. Knowing that there wasn't much we could do medically, we did our best to provide for the remainder of his needs, but in losing his job, my husband was no longer feeling that he was providing for our family. The stresses on our family were now even greater.

By this time our son's chemotherapy was well under way. The protocol he was on required many at-home drugs, which cost about \$600 per month, some of which were not covered by my insurance plan. We were now deep in debt, my husband was looking for work, and our electricity had been cut off. I had to return to work in order to support our family financially, to cover the medical costs, and to get my family back on track.

I realized I needed help to get us through. I began looking into what programs were available and was very surprised to find how few there actually were within the government. Luckily, we had the support of family and friends and charities to help us through our dark times, but that is not necessarily the case for many families.

That's why we need this bill.

Had this option been available to us at the time, my husband could have applied for benefits. We would have had the option to stay at home and take care of our son during his care. We might not have gotten into so much debt. The stresses on our family would not have been as great.

Unfortunately, a year after my son's treatment ended, his tumour had regained strength, and he had to go back on chemotherapy once again. The protocol was different this time; there weren't as many at-home drugs, but the physical effects were still the same. The cycle of missing work, the debts, the stress, and the uncertainty were beginning all over again, not to mention the physical and mental effects on my son and the rest of the family.

I have reviewed this bill and am happy to see that the benefits can be split between the parents. I do have a few recommendations, however.

My strongest one would be that the duration of the benefits be extended from 37 weeks to 52 weeks. Most cancer protocols are between 48 and 60 weeks in duration, at least for the families with whom I have come into contact.

As most of you may know, children's systems are weaker the longer they are on chemotherapy, and so the chances of their getting sicker increase the longer they are on the protocol.

Also, would it be possible to split the benefits throughout the year in order to give the parents the option to take a few weeks upon diagnosis, and then as needed throughout the treatment? You never know when your child is going to get sick, when suddenly they are neutropenic and are going to need to be hospitalized for another three or four weeks. This is not something you can plan for upon initial diagnosis. I would hate to take all the benefits at the early stage and not have any available when they were truly needed.

Also, is there a limit to the number of times you can make a claim? In the event of a relapse, will parents be penalized because they had already made a claim the previous year? That needs to be more clearly identified.

I also believe that the age limit should be increased to 21. New diagnoses among teenagers are on the rise, and I would hate benefits be cut off once a child turns 18.

• (1000)

In the case of Sabrina, I know that she is a teenager, and anything that stopped Nathalie's ability to take care of her daughter because her daughter had lived long enough to turn 18 I would be against.

I would also recommend that the claims themselves be easy to complete. There are so many forms that need to be completed and signed by parents and by doctors and by psychologists and you name it. We don't need another complicated process; we just want something quick and simple and easy.

If you truly want to help parents in need, every measure should be taken to make this process easy and flexible. I strongly believe that this bill should go through, with the amendments of prolonging the benefits, as I mentioned. It is my deepest wish that no one will ever have to use these benefits; however, the unfortunate reality is that it is gravely needed to help our families in need and to help them to stay strong.

In closing, I just wanted to mention that my son is now doing fine and things have somewhat gotten back to normal. I've become much more involved with the charities that have helped us, and my goal now is to help new families that have received the diagnosis.

I'd like to thank this government for finally bringing this bill forward. I would also like to thank you again for inviting me to speak before you today, and I welcome any questions you may have.

• (1005)

The Vice-Chair (Mr. Rodger Cuzner): Thank you very much, Ms. Guérin.

It's wonderful that your son is back on his feet and healthy. We appreciate your suggestions. We've heard several before. Certainly the flexibility aspect of the legislation has been one that we've heard, so we'll take that into consideration, I'm sure, in our deliberations.

Go ahead, Mrs. Eddy, please.

Ms. Edwina Eddy (As an Individual): I have entitled this "My Forty Years' Journey in 10 Minutes", so I hope you will bear with me. I have tried to limit it.

I am the mother of five children, the wife of Reverend Keith Eddy, and the founder and first CEO of Candlelighters Childhood Cancer Foundation Canada. "It's better to light one candle than curse the darkness" was our motto.

My son Bryan was diagnosed with childhood cancer in 1972. For us, the trip to the hospital was 55 miles coming and going. The disruption of family life caused considerable distress, and you have heard that from the two previous speakers.

Information for families living with childhood cancer was not available at that time. That's why a group of us decided to form a support group at our hospital. We brought in medical specialists, social workers, etc., to give us an idea of how to handle our problem.

It was during this time that I was contacted by Candlelighters Childhood Cancer Foundation in the U.S. I was asked to come to Washington, DC, and sit on its board of directors. They were working on the same issues as we were. They asked me to be their Canadian representative on the board.

Our son went into remission and encouraged me to continue with the work. We joined a group called Canadians for Health Research. He was there at the beginning of the issue Parliament was discussing in May of 1976, capital punishment. Canadians for Health Research asked him to join them to help resolve the issue of medical research reduction.

You have a photograph of him. He made his own picket sign, and with 400 others he marched on Parliament. The picket sign read, "I have leukemia. Without research, I am on death row". He died three months later.

In 1984....

You can see that it's still here.

In 1984 Stephen Fonyo finished the Terry Fox run. It was called "journey for lives". When he finished that run, the government gave the Canadian Cancer Society \$1 million for childhood cancer projects. It invested \$500,000 of that into research, but it didn't know what to do with the other half, so it just invested it.

Someone found me and asked if I would like to do something in the childhood cancer area. They gave me the interest from the money to start the childhood cancer foundation. When I retired in the early 1990s, we had found about 51 support groups starting across Canada. I tried to help them start. In 1987 we were able to incorporate the foundation.

We've done a lot of work helping families. You have before you, I hope, the foundation's work up until now. I would like to tell some people about that and about what we wanted to accomplish.

We have programs for families, for teachers, and for professionals. We have teenagers who network with other teenagers who have similar problems.

•(1010)

One of the last things I was able to do was to start a survivor's scholarship. I'm happy to say that we had 123 scholarship applications this year, so patients are surviving, and we are very pleased with that, of course.

We have an 82% survival rate; I hate to say this, but 70% of those children are having problems because of their protocols. Whether they be cognitive or other physical problems, they do develop, and these ladies are proof of that. This doesn't just happen for a few weeks. We've needed to have support beyond that. One of the things we could not do—and we've never taken a dime of government money until now—was to provide the necessary arrangement for compassionate leave. This, of course, is your job. We are more than grateful that you have taken this on.

I hope I'm not running over time.

I'd like to emphasize that over the years I have received letters about this exact problem that would practically fill this room. The

first tsunami is the diagnosis. The second is wondering how we are going to make it financially. I have watched many families go on welfare or lose a partner because the partner couldn't cope anymore with the problem. You need to consider this.

We have a benevolent fund for those who can't afford to bury a child. We don't give them the entire amount, of course, but we have been working hard on every aspect of childhood cancer to help families, and this bill is so important.

Mrs. Sharon Ruth has worked with her MP, Gordon Brown. Gordon O'Connor was my helper to get things started here. On August 7 in Vancouver the Prime Minister announced—and I was there, happily—that the changes to the compassionate leave section of EI were taking place.

It's really necessary. I would say that up to 52 weeks, particularly, gives families an opportunity to ask how they are going to adjust to this situation. They haven't had that opportunity before; they just lost half their income.

As I've said before, some of those families have gone down to absolutely nothing. They need this assistance, psychologically as well as financially, to help them through. I know aboriginals in the north—I was writing to them—had a terrible time trying to get down to Winnipeg to bring their child. They couldn't do it. Their partners would leave, and their sons and other people would take up alcohol to hide their problems. This is nationwide.

We are pleased that you are finally considering this bill and we look forward to hearing that you have listened and will take these adjustments into consideration.

Thank you. I hope I haven't gone over time.

•(1015)

The Vice-Chair (Mr. Rodger Cuzner): It was just perfect.

Through the course of these hearings and any other hearings, the various committees always have access to some very bright people who come and share facts and figures because it's their job. To have witnesses share their story because it's their life makes a difference. Again, it's powerful and compelling. Obviously, it's emotional for you to be here today, and we appreciate your testimony.

We'll start the first round with Mr. Cleary. You have five minutes.

Mr. Ryan Cleary: Actually, we're going to split our time between Lysane and Jean for the first round.

The Vice-Chair (Mr. Rodger Cuzner): Okay.

Go ahead, Madame Blanchette-Lamothe.

[*Translation*]

Ms. Lysane Blanchette-Lamothe (Pierrefonds—Dollard, NDP): Thank you all for being here.

Right off the bat, I would like to make one thing clear, Ms. Roy. The debate today is not about whether we should pass a bill like this one. We all agree that those who are there for a sick child or those whose child has gone missing need support. The discussion today centres on what we can do to ensure the bill is implemented in the best way possible, not on whether it should be passed. Our goal is to improve the bill as much as possible.

Ms. Guérin provided suggestions on how to improve this bill. Ms. Eddy and Ms. Roy, I would like to know what you think of Ms. Guérin's suggestions.

Ms. Guérin, could you sum up your suggestions in a few sentences?

Afterwards, Ms. Eddy and Ms. Roy, you can comment on Ms. Guérin's suggestions.

Ms. Annie Guérin: The first recommendation is to extend the minimum period from 37 to 52 weeks. The second is to raise the age limit from 18 to 21. And the last recommendation is to build flexibility into the benefits so you can share or stop them as needed during that period, depending on the child's needs in each case.

Ms. Nathalie Roy: I think it's a good idea to extend the benefit period to 52 weeks, given the time required for diagnosis, surgery, radiation treatment and chemotherapy. It is often necessary to stop chemotherapy because the child comes down with a fever, for example, and that means a longer treatment period. So I think it would be very helpful to extend the benefit period to 52 weeks.

It would also be great if you could split the weeks of leave with your spouse. For instance, if a couple could split the leave evenly between them, similar to how it works for parental leave when someone has a baby, I think that would be useful. A couple goes through the ordeal together. It would be nice if mom and dad could each benefit and share the leave.

So I support Ms. Guérin's recommendations.

[English]

Ms. Edwina Eddy: I too support these suggestions. Have you considered the fact that in our society we also have one-parent families? What does this parent do? If you have the split, I agree with the 52 weeks. We only just get started in our journey with living with cancer in those 52 weeks. It would certainly help to keep families together if you could consider that.

• (1020)

[Translation]

Ms. Lysane Blanchette-Lamothe: Ms. Eddy, you talked a lot about leave for caregivers, but the bill targets only parents with children under 18. Do you think that definition is too narrow? Could you briefly tell us whether you would expand the scope of the bill so that more people could benefit from the leave and why?

[English]

Ms. Edwina Eddy: When you say scope, what do you mean?

[Translation]

Ms. Lysane Blanchette-Lamothe: You mentioned the importance of granting caregivers leave. I am wondering whether caregivers, in your eyes, are limited to parents of children under 18. If not, do you have any suggestions for widening that definition to enable others to receive this support as well?

[English]

Ms. Edwina Eddy: Do you mean to other people?

Ms. Lysane Blanchette-Lamothe: I mean people other than parents of children less than 18 years old.

Ms. Edwina Eddy: Yes, if they were caregivers, certainly. We'll take what you'll give us.

[Translation]

Ms. Lysane Blanchette-Lamothe: Okay, thank you.

I will now hand the floor over to my colleague.

Mr. Jean Rousseau (Compton—Stanstead, NDP): I have a brief question.

Thank you all for sharing your stories with us.

One of the biggest problems I have with this bill is that it gives parents up to 104 weeks of unpaid leave if their child has died, but only 52 weeks if their child has gone missing. In some cases in Quebec, children have been missing for 10 or 12 years, such as in the Surprenant and Riendeau disappearances.

I would like to hear your thoughts on that, please.

[English]

Ms. Annie Guérin: I don't know if we can really compare the situation of someone who has gone missing or has been murdered or is a victim of crime with that of someone who has a kind of critical illness. First of all, your child is with you while you're going through the illness. However, I don't want to say one is more traumatic than the other. Both events are very traumatic for the family.

From my interpretation of the bill, why those families would get 104 weeks, or whatever the amount is, as opposed to the 37 that's been proposed for us kind of makes it look as if their traumatic experiences are three times worse than ours. I know that's not necessarily the intent or the case; however, illnesses can drag on for years. I've been going through this for at least five years now.

I can't really speak regarding the families that are missing or murdered because I haven't been through that situation. Obviously, I want to give them as much time and benefits as needed, but if they could be more on an equal basis, then I think that would be a benefit.

[Translation]

Mr. Jean Rousseau: Every case should be considered individually. Sometimes, family life is disrupted for 10 years after a child goes missing and is never found. Sometimes, parents never go back to work.

[English]

The Vice-Chair (Mr. Rodger Cuzner): Thank you very much. You might want to comment on that at a later time.

Mr. McColeman, go ahead.

Mr. Phil McColeman (Brant, CPC): Thank you, Mr. Chair. You're doing a fine job.

I'm going to speak with two different hats.

Ms. Guérin, first of all, I'm going to speak with you because I am almost a mirror image of your story. My 26-year-old son was diagnosed at age 2 and is a cancer survivor, but part of the side effects were cognitive and intellectual disabilities, and he will be in our care for the rest of his life as a result.

I also would speak for communities in this country and Canadians in general, having been through and experienced what you've been through. We spent over 270 days in hospital with our son, either my wife or myself always by his side.

I was a small business owner. We know small businesses employ over 70%, and in my community and, I believe, a lot of communities, a lot of employers have compassionate policies, even if they may not be written down, regarding how they handle their staff when things like this happen.

I'm going to make comments more than questions, and I'd like your views on whether you've experienced anything that my wife and I and my other three children have experienced through this process.

In my community, when there's someone who's in really dire need, charity groups and the general community hold fundraisers for these people. We do things such as alleviate some of their financial expenses, although it'll never be enough. Government will never provide enough and the community will never provide enough. All of these things will never be enough.

That said about a community and a caring country, I believe this is a caring policy that government has finally brought to the table for people in our situation. In terms of family support and support groups, in our case, there was a group called Help a Child Smile, started by two parents from Welland, Ontario. It has just blossomed and helped very many families. When a true economic need has been there, they've come in to supplement and to help. The Canadian Cancer Society, I believe, helps out financially with family support in certain circumstances. All of those things, I think, add to the mix.

We're coming in as government now to say that here's an area where we can help supplement and ease the burden that all of us have felt and that we've seen in other families. My recollections were exactly your recollections of those children, in those rooms without a parent. It's just unbelievable to see that's the case.

I'll finish, and then if there's any time, I'll have you comment. I apologize, but I just had to share those views with you. I think we live in a wonderful, caring country, at least in mid- and small-sized communities in Ontario where I come from, and in the rest of the country, the community rallies behind its members in this situation.

You can split it between spouses. That is allowable under the bill. You can take it flexibly, so you could take four days at a time, and then split it and take another interval, so you can split it based on treatments, which I know is very important, again, having been there. You can reapply every year. It doesn't have to end in one year. The bill does allow for those three things, and I wanted to clarify that point.

If there's any time left, Mr. Chair, perhaps the witnesses individually could underscore some of those other supports.

•(1025)

Ms. Annie Guérin: I can start.

I completely agree with you. The community support has been outstanding. Everyone at my child's school has helped whenever they could. My employers and all my friends have told me to do whatever it takes to help my son.

The charity involvement has been incredible, so much so that I now have become one of the vice-presidents at Leucan, on the Quebec side. As well, I've been involved with Candlelighters.

It's just incredible what these charities do for us. They help pay for parking. They help pay for the kilometres back and forth. They provide a lot of financial services, but their funds are only based on what they can raise. The number of families is growing exponentially, which therefore reduces the amount they can help each family with.

Also, I find the support is bigger in larger cities, such as Ottawa. You get up north or in more rural areas, where there aren't as many charities involved, where there aren't as many hospitals dealing with pediatric cancers, and their resources become fewer just because of the regional aspect of things.

I really cannot stress enough how wonderful these charities are. However, we do need more financial support that's more standardized throughout the country, no matter what province you live in or whether you're in a rural or urban setting.

Ms. Edwina Eddy: I'd agree with what she has said.

I have found over the years that I've received letters from people saying that their company tells them they can come back when they get reorganized. Then they discover that everything keeps going down, down, down—a partner leaves, or something—and they have to go on welfare. They are told that they can no longer accept that deal with their company. They have to give up everything. As well, sometimes a child cannot return to school because the child is immune-depressed. This makes it very difficult.

Charities, yes, are wonderful. Churches and all the different charities have been fantastic, coming into gear and raising some funds, but it's also a matter of the very beginning, I feel, and this is where the government bill comes in handy. These people have been independent. These people, or a lot of them, haven't taken any charity, and they'll say they wish they had a little time to adjust to the financial situation and appreciate the charity that they are getting.

This would be very, very helpful.

•(1030)

Mr. Phil McColeman: Thank you.

The Vice-Chair (Mr. Rodger Cuzner): Thank you very much, Mr. McColeman.

Mr. Cleary is next.

Mr. Ryan Cleary: Thank you, Mr. Chair.

Ms. Roy, your daughter, I'm sure, is lucky to have you. It's not just that you seem like a wonderful person; you're also a nurse, and you understand the medical system.

You've been off since May, you said. I hope you don't mind my asking, but what have you been living on? Have you been getting benefits since you've been off since May?

[*Translation*]

Ms. Nathalie Roy: I am on disability insurance through the hospital. But the hospital disputes my leave regularly. Every month, I have to go to the doctor to confirm my illness. He changes the diagnosis, because the hospital would deny my leave otherwise. He diagnoses me with situational depression. I can't say that my daughter has cancer or the hospital would deny my leave. Unfortunately, that is how the system works for someone in the health care field.

That is my experience. Sadly, there are a number of us nurses who have a child with cancer. Their experience was the same as mine, so I already knew how things worked. It really takes a toll, emotionally, to have to fight for leave, on top of having to fight for your child.

[*English*]

Mr. Ryan Cleary: What kind of leave, specifically, did you request? Is it compassionate leave, is it family leave, and with your current employer, what's the length of leave that you're eligible for?

Your daughter was diagnosed with cancer in May, and they're still giving you that hard time?

[*Translation*]

Ms. Nathalie Roy: Yes, it is hard even though the oncologist at CHEO—I work in Quebec—wrote me a letter to give my employer. When it concerns my daughter, my employer will not approve my leave. That is why the doctor had to change my diagnosis to situational depression. The hospital still gives me a hard time.

In fact, I received another letter. I had to go to the doctor. I even had to see a doctor designated by the hospital to assess my situation and determine whether the hospital had grounds to dispute my leave. If the hospital does challenge my claim and I don't go back to work, I will lose my job. You always have to fight and it's extremely trying.

I am lucky to have disability insurance, but I still have to fight with my employer every month to justify my leave. It doesn't matter that the oncologist provided a detailed explanation indicating that Sabrina would have to undergo radiation treatment every day for eight weeks, on top of chemotherapy.

[*English*]

Mr. Ryan Cleary: Thank you.

This question has been asked, but I want to ask it again to you specifically.

Your daughter is 16 years old. If she was 19, would her needs and your support that you're offering be any different?

[*Translation*]

Ms. Nathalie Roy: Are you a father?

[*English*]

Mr. Ryan Cleary: Yes.

[*Translation*]

Ms. Nathalie Roy: Do you believe your child needs the same love at 18 years old as they do at 16? I think they do. You can't compare

the situations on the basis of age. No matter how old they are, children need their parents, not strangers. I can tell you that with my heart and soul.

• (1035)

[*English*]

Mr. Ryan Cleary: I'm a father of two boys and I knew my answer, but I just needed you to express that.

[*Translation*]

Ms. Nathalie Roy: Yes.

[*English*]

Mr. Ryan Cleary: Do I have time for another quick question, Mr. Chair?

The Vice-Chair (Mr. Rodger Cuzner): Not really. No, you have about 15 seconds, so we're going to move over.

Mr. Ryan Cleary: Ms. Roy, thank you very much.

The Vice-Chair (Mr. Rodger Cuzner): Thanks very much, Mr. Cleary.

Mr. Butt is next.

Mr. Brad Butt (Mississauga—Streetsville, CPC): Thank you very much, Mr. Chair.

Ladies, thank you very much for being here.

As you're probably aware, Bill C-44 proposes to change two different systems. The first is the Canada Labour Code, which governs federally regulated industries. Obviously, federal government employees would be covered under that. They're only about 10% of all the workers in the country, so we're going to need some help in lobbying our friends in the provinces—and I hope you will help us do that—to encourage them and to make sure that each province adopts companion legislation to make sure that the other 90% of the people who work in this country can avail themselves of the same benefits.

Of course, the second part of the bill makes changes to the employment insurance system to allow for these compassionate benefits to be claimed in a number of different areas. That is obviously exclusively within the federal realm of jurisdiction.

I think it is important to make that clarification, because I'm not quite sure that all of the witnesses have completely understood what the bill does—that we're dealing with those two different areas, and that certainly on the labour code side, we can only do what we can do within the federal jurisdiction.

I'm sure you would agree that both of these changes are a positive step forward. We can certainly get into the discussion about what number of weeks should be allowed to be claimed for EI benefits, and I'm sure the committee will continue to have some discussions around that. I very much appreciate the advice you've provided, and that of the CEO of Ronald McDonald House, which gave us an idea of the average window of stay within their facilities. I think that may give the committee something to give some consideration to.

Beyond what has been proposed in those two areas, and based on your individual experiences and the other programs that are available out there to support medical costs and to support compassionate leave for families and caregivers, as well as some of the tax credits, etc., that we've actually brought in as a government, are there other areas?

Are there any other areas of advice that you would have for us as we look at these changes and what we can do to make sure we're getting it as right as possible the first time in making this a new benefit? Do you have any specific advice beyond what we're doing in this bill that might be good food for thought for us as committee members?

[*Translation*]

Ms. Nathalie Roy: The drugs are incredibly expensive. Sabrina gets Neupogen injections. Ten injections cost \$2,000. It stimulates bone marrow. She has to have it. I am lucky I have insurance that covers 80% of the cost. I still have to pay out \$400, which comes to \$800 a month. It certainly adds up when your salary has dropped as well.

I would like the government to cover all medical expenses for children, to help us out. This drug is medically necessary. If Sabrina doesn't have these injections, she will end up in the hospital and die. It's a shame that we, the parents, are the ones who have to bear these costs. I am not sure if you understand what I mean. The amount could be capped. When you have to pay \$2,000 for 10 injections and your child is sick for a year, it adds up quickly, not to mention all the other expenses. Sabrina is on Lupron, which costs \$300 a month, per injection. The oncologist prescribes many other drugs that we have to pay for ourselves. Our children's health and survival are at stake. We would certainly appreciate some help.

• (1040)

[*English*]

The Vice-Chair (Mr. Rodger Cuzner): That's five minutes, so thank you very much.

I'm going to yield my time to the NDP. Monsieur Rousseau and Mr. Sullivan are going to spend that time.

Mr. Devinder Shory: You are the chair. Are you still yielding your time?

The Vice-Chair (Mr. Rodger Cuzner): I'm yielding my time to my colleagues in the opposition.

Mr. Devinder Shory: You cannot have two hats, Mr. Chair.

The Vice-Chair (Mr. Rodger Cuzner): I have two or three.

It's okay; you guys get extra time.

[*Translation*]

Mr. Jean Rousseau: Thank you, Mr. Chair.

I did not mean to put you on the spot with the question I asked you earlier. I was really trying to point out that there are three different measures for three situations that require specific consideration, whether they involve victims or the caregivers of a sick child.

This next question is mostly about the drugs.

Ms. Roy, you just said that the medications are very expensive and that no real assistance is available, except for people with insurance coverage.

Having been in contact with victims of kidnapping and crime, I know these individuals need professional care for years. The parents, brothers, sisters and cousins who are overlooked in these situations also need to be looked after.

Ms. Roy, do you think this bill should include benefits not just for medication, but also for professional counselling?

Ms. Nathalie Roy: Yes, you are absolutely right. Take my situation, for example. My employer covers two sessions of psychological counselling, and that's it. Quite frankly, I need a lot more than that. I need to vent, but I can't afford the treatment. A session costs \$125, and my insurance covers only \$20. Obviously, I can't afford that treatment for myself or my children. And my daughter Sabrina needs it.

I asked the people at CHEO if parents could access those services, but I was told they were only for children. It would be wonderful if the service were available. These children need emotional support from their mothers and fathers, but as you can see from all my tears, we need support as well.

Mr. Jean Rousseau: It's okay, Ms. Roy. It's perfectly understandable.

[*English*]

The Vice-Chair (Mr. Rodger Cuzner): Colleagues, the bells are ringing. It's a half-hour bell.

We would need unanimous support, but we still have witnesses. I think we could complete a round. I ask for unanimous support.

Some hon. members: Agreed.

The Chair: Okay, I see that. Carry on.

Mr. Jean Rousseau: Go ahead, Mike.

Mr. Mike Sullivan: First I'd like to thank you again. It is very difficult, I know, for all of you to have to first go through this and then to come here and talk about it, which means going through it again in your minds. I understand that it is difficult.

One of the things we hope to do is make this bill better and perhaps make it more flexible. I certainly have heard many people talk about the age of 18 being too arbitrary. It doesn't make sense in a lot of ways in a lot of cases, so we hope to convince the other side to change that.

I want to get some idea of something from the three of you. Perhaps, Edwina, you'd have the most knowledge about it. There are lots of times when this kind of need goes well beyond a year, I would think, yet there's a limit of a year in this legislation in terms of how long a leave you can take. Maybe it needs to be something you can spread out in bits and pieces, as was described earlier.

Can you comment on how prescriptive this needs to be or whether we should be much more flexible in the application?

•(1045)

Ms. Edwina Eddy: The need goes well beyond one year. We try to get youngsters into remission in five years, if we are fortunate enough.

The flexibility is very important also. I agree with the people who are here today. I have gone through it myself personally. This is why I started the foundation, because we are trying to give them as much help as possible. Anyone can apply to it, but we cannot do anything further. It's here that you need to really look at this bill and ask whether this amount of time and money—which will be flexible, of course—will be sufficient to help our Canadian families stay together and grow together and help these children get going.

As I have said before—which I don't like to say—70% of our 82% survivorship are going to have more difficulty, whether it's cognitive

problems, sterility, or all kinds of other physical problems. However, they are such beautiful people. They have done very well in their chosen fields that they have decided to grow up into. They need to be supported as well through this, if it's possible.

Mr. Mike Sullivan: Thank you so much.

The Vice-Chair (Mr. Rodger Cuzner): Thank you very much for the round. We went a little bit over.

As has been expressed by many of the members of the committee today, we very much appreciate your testimony and your taking the time to share these very personal and powerful stories. Thank you again for your testimony.

The meeting is adjourned.

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