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Chair

Mr. Bryan May

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

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● (0850)

[*English*]

The Chair (Mr. Bryan May (Cambridge, Lib.)): Good morning, everyone. Pursuant to Standing Order 108(2) and the motion adopted by the committee on Tuesday, September 18, 2018, the committee is resuming its study of supporting families after the loss of a child.

Today, the committee will hear from two panels of witnesses. In our first panel, we have Mr. Dyregrov, Professor, Centre for Crisis Psychology, University of Bergen.

You're actually coming via video conference from Norway. Can you hear me okay, sir?

Dr. Atle Dyregrov (Professor, Centre for Crisis Psychology, University of Bergen, As an Individual): I can hear you.

The Chair: Excellent. What time is it there?

Dr. Atle Dyregrov: It's 10 minutes to two.

The Chair: Thank you for being with us, not in the morning—that would be too much to ask—but in the afternoon. .

Here in Ottawa from the Pregnancy and Infant Loss Network, we are joined by Michelle LaFontaine, Program Manager. Welcome to you.

We're going to get started today with seven-minute presentations.

First off, we have Mr. Dyregrov.

The next seven minutes are all yours, sir.

Dr. Atle Dyregrov: Okay, I will not spend seven minutes, but I will just give a brief background about my work.

I started out as a student in the late 1970s working with parents who lost children to cancer and other serious diseases. In 1980, I started working at the neonatal intensive care unit in Bergen for four years, where my main task was to follow up with parents who lost children at that ward, and also all the sudden infant death syndrome cases. When my work was better known, I was also asked to come and consult with the intensive care unit and the acute emergency ward. Then I went over to the university and spent four years as a senior researcher, and also did my Ph.D., which was named “Parents Who Lose a Child”. That was the subject for my thesis.

In 1988, I started the Centre for Crisis Psychology, which has now been part of the university since 2017, but I've been working clinically with parents who lose children and children who lose parents for all my professional life.

I have also been involved in research following different kinds of deaths. I was very much involved after the terror in Norway, in 2011. We did a study on the effects on parents on losing children. That's been a major theme throughout my work area. I have the clinical experience from meeting and also working with professionals and support groups in Norway, and then the research experience.

One of the studies that I conducted some years back was with more than 300 parents. We filled in questionnaires and also did qualitative interviews on relationship issues and how this affects the relationship. I wrote of several aspects in my professional practice and then also in the research, and feel that I know that area fairly well. I have written about 20 books and 300 articles, not all on the subject of parental loss, but very much in this area.

I'm a clinician at heart and I do what I call the research work, but it's always been the clinical work that has been most important where I'm also able to use the research to better the situation for parents who lose children.

That's what I thought I would say about my background.

The Chair: Thank you very much, sir.

Now from Pregnancy and Infant Loss Network, we have Michelle LaFontaine, Program Manager.

You have seven minutes.

Ms. Michelle LaFontaine (Program Manager, Pregnancy and Infant Loss Network): Good morning, and thank you for inviting me to speak with you today.

I have the honour of being the program manager for the Pregnancy and Infant Loss Network in Ontario, often referred to as the PAIL Network.

I have had the privilege of working with MPP Mike Colle, alongside many other dedicated bereaved parents, to advocate for Bill 141, the Pregnancy and Infant Loss Awareness, Research and Care Act in 2015. This bill was transformational for bereaved families in Ontario, and we are forever grateful to him. We are likewise indebted to MP Blake Richards for his work to bring this topic to the federal government, and subsequently to other members of Parliament and on this committee who have come forward with their personal loss stories.

All too often, families like mine are met with silence after their loss. I come to this work not only as a manager for the program but also as a bereaved mother. My husband and I lost twins, Elora and Joseph, in August 2005. We left the hospital with empty arms and broken hearts. We had no idea what to do next, no idea where to get support.

I reached out to both my obstetrician and my family doctor, only to receive a prescription for sedatives so that I could sleep. My husband was on a contract for work and was not entitled to any sick time or leave, so he was back at his computer the day after we got home from the hospital. My employer gave me five days of bereavement leave, and I used up all of my sick time. I was back at work full time less than three weeks after my babies died. I had a caseload of 45 families, all of whom had seen me five months pregnant with twins, all of whom asked what happened.

I learned to answer the question as briefly as possible and change the subject. I learned to keep it together until 4:30, when I got in my car to drive home. I learned the back roads to drive home so I'd be in less danger of crashing my car as I drove through my tears. It wasn't until a friend of a friend who knew someone who'd had a loss gave me the information about the PAIL Network that I began to see ways that I could learn to incorporate the death of my babies into my life.

The PAIL Network is now a provincially funded program in Ontario with a mandate to expand support for families who have experienced the loss of their pregnancy or the death of their baby up to 12 months of age. This includes but is not limited to miscarriage, stillbirth, medical termination of pregnancy, perinatal loss, infant loss and families whose baby dies suddenly and unexpectedly, such as with SIDS.

We also provide education to health care professionals who care for families at the time of their loss, in order to provide them with evidence-based information to foster the provision of the most skilled and compassionate care. The first things we set out to do were to gather information from families and health care professionals in a provincial needs assessment as well as to conduct an online research survey.

Our provincial needs assessment told us that families and health care professionals saw education as the clear priority, as too often families are further injured by their health care experience at the time of their loss. This was borne out in our research survey, too. This research was led by Jo Watson, our director, and the results were staggering.

The summary of the research showed the following: 53% of families did not feel that they were treated with kindness and respect at the time of their loss; 72% did not receive the information they needed at the time of their loss; and 45% were not told of available supports.

Education can be the great equalizer here, both for health care professionals and for government staff who administer programs designed to support families. I know you have heard from families who have been treated insensitively when they were seeking information and financial support from the government, in the same way that the PAIL Network has heard from families who felt that they were not supported and cared for at the time of their loss. Education can change this, education on the unique grief needs of families who have suffered immeasurable loss and are now feeling their way around in the dark, searching for the way forward. It is well accepted in the field of pregnancy and infant loss that the death of a baby is a traumatic loss and deserves to be treated as such, regardless of a clinical diagnosis of PTSD.

Bereaved parents deserve to have their rights protected as they are set forward in a document from Women’s College Hospital in Toronto and referred to by programs across North America. One of these rights asserts that parents be provided with information on support resources that assist in the healing process.

I put to you today that these support resources should include government programs that support a family's ability to access employment leave. A universal child bereavement benefit delivered by trained government staff could make a real difference to families who need time to begin the gruelling work of grieving the loss of their baby.

● (0855)

To that end, I'd like to highlight the impact a national bereavement care strategy could have for families across Canada. Programs like PAIL Network, perhaps set up like chapters in every province, have the potential to address the inequity of support services for bereaved parents in our country. This approach would allow for services to be consistent yet responsive to the individual needs of the provinces.

Funding shared between the province and the federal government would ensure sustainability and undoubtedly demonstrate improvements in parental mental health, access to support and information, and decrease stigma around pregnancy and infant loss. Financial programs that are put in place to support bereavement leave need to be explained to the family, and access to those programs requires that families have trusted professionals to guide them through that process.

Programs like PAIL Network could play a significant role in bridging the gaping hole that exists between a bereaved family and the necessary services to help start them on the path toward hope and healing.

In closing, I urge you to consider recommendations that include support, education and clear guidelines for families who need access to bereavement leave.

From my heart to yours, thank you.

The Chair: Thank you very much.

We're going to get started with the first round of questions.

MP Diotte, you're up first, for six minutes.

Mr. Kerry Diotte (Edmonton Griesbach, CPC): Thanks very much, and thanks to both of you for appearing here.

Professor, it's very interesting that you are involved in the follow-up to the terrible terror attack in Norway. What did you learn about the parents' grief and their sense of loss? Further to that, how would you incorporate that into some kind of legislation to help parents who are grieving a loss?

● (0900)

Dr. Atle Dyregrov: First of all, we followed up at three time points after the loss, after one and a half years and then after two and three years. We found an extremely high number of parents who struggled with complicated grief reactions, around 80% of them, and more than 60% with more post-traumatic stress reactions to a level where they would be probably be diagnosed.

We thought that had to do with the extreme number of traumatic reminders they had to face in the years afterwards with the court case going on and with the murderer being in the media all the time. We also think the way the 69 youths were hunted and killed at the island played a part in having such a great effect on parents.

Just to be clear, you're talking about grief following all kinds of child loss, not only those at the early stage of life.

Mr. Kerry Diotte: That's correct.

Dr. Atle Dyregrov: We have to think of having systems in place for different kinds of deaths. What we see in disasters and terror—often at once—makes for a governmental response. We have a much better system for reaching out than we have for the day-to-day experiences, but our systems must include both what happens individually and what happens collectively. For example, in Norway we have a very large country as you have, but to travel from north to south is extremely long. You have to build it locally. The local hospitals and the local communities have to have structures in place.

We have done some research on what are the structures needed to have good support over time. There has to be someone with responsibility. There has to be a good connection between primary care and secondary care when you need more expert help, and with the amount that develops—complicated grief, or as it's now come into the ICD.... I don't know if you're familiar with the WHO classification. In June, they included prolonged grief disorder as a diagnosis. In Europe, we follow the ICD, not the DSM, which is in the U.S.A. I'm not sure what you do in Canada. This has recognized that there are people who experience grief and go on to have problems. When you lose a child, the chance of having those kind of problems is pretty high.

In our first study, we found about 50% of those after suicide, sudden infant death syndrome and accidents. It was somewhat lower with SIDS than it was for the two others. There is a large amount that you need to have a system in place to also get an early recommendation or a transfer to specialized services. For every family who loses a child, it affects the family.

One of the things we're seeing now is that while we have a crisis team in every community in Norway that follows up when there's a sudden death, we lack the continuity when there is more than just acute follow-up. You need routines for when somebody takes over, to make sure that families get assistance over time. If you look at the research literature from around the world, several places have systems in place for what happens immediately, but not for the long-term follow-up. That's where it's usually most needed.

You need those structures. You need a system that includes good information. If you look at what parents find most useful, it's very often information—but provided with care. That means that there should be good care around that information. It's not only getting the information. It's getting the information in a caring environment. Combining those two is the best kind of crisis intervention you can have.

Then you need access to parental support groups. I can't remember the name. It's a French name that you mentioned, with the other person appearing for the board here. There's a lot that can be done by putting structures in place in the follow-up, and addressing the long-term needs as well.

● (0905)

Mr. Kerry Diotte: I have a very quick question.

How long do you think parents should have before going back to work if they're employed and they've lost a child at the early stage in life?

Dr. Atle Dyregrov: In my doctoral thesis, I looked at those who went back to work and those who stayed at home. That was mothers in the 1980s. It was mostly fathers who went back to work or who were working.

Those who went back to work soon functioned better than those who stayed at home, but that depends on the work environment. You need to have a work environment where you have the possibility to take breaks, and that you're well cared for in that system. If not, it's worse to go back to work. It's very individual.

My advice would be to return to work as soon as possible, but adjust the work. It depends on what kind of profession you have. There are a lot of things that go into that.

Mr. Kerry Diotte: Right.

Thanks very much.

The Chair: Thank you.

MP Long, you have six minutes.

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

Thank you to our witnesses this morning.

Ms. LaFontaine, first, I'm so sorry for your loss. I'm so sorry for the experience that you had negotiating and moving forward after that loss. I had a friend in a similar situation many years ago.

Can you touch on the experience you had with Service Canada when you, unfortunately, had to start that process of trying to get support?

Ms. Michelle LaFontaine: Sure. My answer will be brief, because I wasn't aware that I was eligible for any leave at all through Service Canada. My loss was at 20 weeks and five days, which was just below some of the cut-offs at the time, so I wasn't eligible for any government leave that I was aware of—

Mr. Wayne Long: Just let me jump in. I think that shows, and I think it goes without saying, that most new parents are young adults. Most new parents are in their twenties. Things change, and maybe most now are in their thirties, but they're still young adults. They're learning. They're building their networks, and they may have just been married or bought a house or what have you. Financially it is one thing, but just emotionally too they're young and they don't know where to turn. They don't know which way to go especially in times like this.

There was a presenter last time. One of the things that came out was that there's PAIL and different agencies and support organizations across the country, but there's one here and there's not one there. You mentioned in your presentation that perhaps PAIL could be across the country so there would be more uniformity in delivery of support. I happen to agree with that.

Can you elaborate a bit on how you would see that going? Obviously M-110 is about our trying to find a way to change the way it's been in the past and to do something good as government. What can we do?

How would you envision government support for that? Do you think it's more important for government to support organizations like that uniformly across the country in each province, or is it more important for governments to support the parents more financially? How would you weigh them? Obviously they're both important. Can you elaborate a little bit on that?

Ms. Michelle LaFontaine: That's a hard choice to make, if I'm faced with that choice. Also, you made the point about parents not knowing. We didn't even know to ask. There was nobody to help us learn what might be available to us.

To that end, I wonder whether, if we had more support networks such as PAIL Network across Canada, we'd be able to provide parents at least with the information about how to access those supports.

Mr. Wayne Long: You mean not a government agency but just the support of individual agencies with more uniformity across each one.

Ms. Michelle LaFontaine: That's right. I feel that for the PAIL Network, we have been able to make such incredible strides in Ontario looking at peer support for families and education for health care providers. Upcoming links on our website will have information about employment leave and information to that end.

I do believe that if there's information for families, that information will give them what they need to be able to move forward and to access leave and access the information they require.

Mr. Wayne Long: Thank you for this.

The Cormier family was at our first meeting. They proposed 12 weeks of benefits for parents who have lost a child.

Do you believe that's an appropriate length of time? What length of time would you like to see for the benefit?

Ms. Michelle LaFontaine: I believe that 12 weeks would be an appropriate benefit for an automatic universal bereavement benefit. I'd also like to see that being paired with, not combined with, other leave that your particular employer might be able to offer you. If you are able to also access a stress leave or a medical leave, if you are able to also access bereavement leave from your employer, that could stretch it out. I think 12 weeks would be the bare minimum that we would recommend for families.

● (0910)

Mr. Wayne Long: Professor Dyregrov, thanks for coming to us from Bergen. I spent a lot of time in Bergen in my previous life in agriculture with Stolt Sea Farm. We had aquaculture operations in Bergen.

We're here because we want to get advice from our witnesses as to how government can move forward and help parents who suffer the loss of a child.

From your experience, what's the best way for us as a federal government to help?

Dr. Atle Dyregrov: Your system in Canada is different from the one we have in Norway. I think it's important that those who meet the families at hospitals and in the health services have a responsibility to secure follow-up over time. Then you have the more voluntary organizations coming in and helping or being in addition to that. I think there should be somebody who has a responsibility to follow up.

I'd like to comment quickly also on the 12 weeks. I hope that is something that would be voluntary, because I think that some people —we have this in Norway—some doctors, just put parents on sick leave and they do them a disservice in that way, because work life can also be getting away from the loss, taking pauses from loss. It's important to go against the loss, but it's also important to get away from it, and therefore just having to be away from work for 12 weeks will not be a good idea for everyone.

Mr. Wayne Long: You're saying that leave is one thing and financial support is one thing, but there should be more wraparound support for the families.

Dr. Atle Dyregrov: There should also be flexibility, regarding whether to go away from the work or not. Some people really cope well when they have another leg to stand on, so not only being a bereaved parent, but also having a work life. It just has to be an adjusted work life.

The Chair: Thank you very much.

Now, Madam Sansoucy, you have six minutes.

[*Translation*]

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

I'd like to begin by thanking both witnesses. My first question is for Dr. Dyregrov.

You talked about the importance of providing local support and long-term care, in addition to specialized services in hospital. I'd like to know about the resources that currently exist in Norway to support families. Is there a network of organizations across the country? Do they receive government funding? I'm curious about Norway's best practices to support families, outside the institutionalized health care system.

[*English*]

Dr. Atle Dyregrov: Most of the families would be met by their institutional services. That means the community's crisis team will meet every family. If it's in the hospital, there will be a hospital responsibility.

Specialized services are second-line services. If somebody is really suffering a lot, they will be referred to the second line and usually see a specialist within psychology. It's not automatic and we are better at following up with trauma than we are with loss. Now, given the new situation with diagnosis, there is also more recognition of grief in the public system. The crisis teams we have, in every community in Norway, work primarily with sudden losses, which is often when a child dies. About 90% to 95% of their work will be in relation to a loss. That's our system.

Next, we have the nationwide organizations. There aren't many of them. We have three or four. One is for suicide bereavement. One is for childhood, before the age of four. There's a third one as well. These offer supportive services. The former sudden infant death association, which now has another name, had a weekend for them. I'm going to Tromso tomorrow, Trondheim the day after and then Oslo, where they arranged something to do with coping with loss. There are a lot of people coming to these events, so they do a lot to help.

The thing we are lacking is that these organizations are not brought into the chain at once. It's not automatic from the hospital system. I would have liked that. That's where the role of science comes in, but they're not allowed to just notify them. There are laws that prohibit it. It would be a much better model to have them directly co-operating with the government or to have the things paid for by the government.

● (0915)

[*Translation*]

Ms. Brigitte Sansoucy: Thank you.

Ms. LaFontaine, in your opening remarks, you talked about the lack of support and compassion for parents. You also said the support that was available was volunteer-based and in need of funding. As part of the committee's study, we have to make recommendations. Everything we've heard from witnesses thus far makes me think we should really be examining the funding going to the organizations that are doing the excellent work on the ground. As you pointed out, they operate on meagre resources, after all.

I was surprised to learn—and this ties in with what Dr. Dyregrov just told us—that Service Canada doesn't offer any tools for parents, not even to refer them to appropriate resources or assist them in navigating existing services.

Could the federal government establish initiatives to better support organizations like yours and ensure they are available throughout the country? My riding is home to Les amis du crépuscule, an organization that provides support to people who are grieving. It lacks resources, so it spends part of the year on fundraising just to survive. I'm talking about helping organizations like these, as well as promoting their services.

Is there anything we could do to make people more aware of their services? Could Service Canada serve as a gateway or portal where people could turn for information about organizations on the ground?

[*English*]

Ms. Michelle LaFontaine: To start with the question about the resources for different organizations that require it, prior to Bill 141 passing, PAIL Network was also a volunteer-run organization. We were applying for grants to try to keep the doors open. Very little promotion was available to us to let families know we existed.

I would certainly agree with you that we definitely need more financial resources for these organizations that are looking to provide support for families, to be able to let families know and to let health care providers know where they can refer families, where they can send families who need support after their loss. I agree that it's the responsibility of a health care professional to ensure that families leave the hospital or leave their health care environment with information for follow-up in their communities.

On the question about whether we could have a portal through Service Canada that can help guide the families, I believe there is one in place for other such programs. That would be extremely helpful, particularly if the staff who were delivering that program had been trained on how to use the most compassionate language, to understand a family's normal grief pattern, and to know where to best support them and what other programs they can access.

[*Translation*]

Ms. Brigitte Sansoucy: If I understand correctly, a support system for parents is really needed. When they are grieving, they can't be expected to look for resources themselves. The committee heard from parents who said they had had to wait in line to access benefits in the first few days following their loss, while in the depths of their grief. We need to make sure parents receive the guidance and support they need so they can access the information easily.

Did I understand that correctly?

● (0920)

[*English*]

Ms. Michelle LaFontaine: I agree. What we're piloting right now with PAIL Network is an automatic consent system so that, at the time of their loss, families will give their consent to their health care provider to share their information directly with PAIL Network so the family doesn't have to go home, admit that they need support, and then find the support on their own.

That pilot is going extremely well, and I believe the more we can automate things for families, the more we can take it out of their hands at the time of their loss to have to research, find it, and go and access it, the better.

Certainly if there was something automated at the time of their loss, whereby paperwork or information would get sent with the family's consent to somewhere such as Service Canada so benefits could be started automatically, that would be extremely helpful.

The Chair: Thank you very much.

Next is MP Hogg, please, for six minutes.

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

Professor, you made reference to a number of issues in talking about how we, as a country, can try to ensure as a principle that we're a compassionate, caring society, that we're able to provide supports and services to those people in greatest need.

Would you think there are any gold standards or better practices around the world that we could reference? What would you see as being those practices that would be at the forefront, and what would the principles of those be?

Dr. Atle Dyregrov: The principles are, as just mentioned, that there's an outreach, that the system reaches out, or the help reaches out, and they don't have to go around looking for that help. There has to be immediacy; it needs to be there very quickly. It has to be built on good information and a caring environment for that information.

Also something we've seen when we compare what we found in the late 1990s about how satisfied they were with the care is that there was low satisfaction with the care among bereaved at that time. Now, after the terror, we did a new study. We asked the parents what they thought about it, and there was high satisfaction with the type of help they had received. However, what they were dissatisfied with was the specific help. They said they felt that the health environment now sees them, now recognizes them, but when they deal with specific problems, there isn't specific help. They say there needs to be better help for those who are going into complicated grief issues. That's an important point.

Mr. Gordie Hogg: I appreciate those principles, but how do you see taking those principles and implementing them within a bureaucracy and a structure of government, the values you're reflecting and the principles coming out of those values, but then taking those into a way to look at operationalizing them that makes sense in terms of the functioning? That's the skill-testing part of this.

Dr. Atle Dyregrov: There are some good articles that sum this up, from some of the big societies, I think from the American Academy of Pediatrics. They will be helpful for you to look at, because they see that this is what people want. This is also based on feedback from users, if we use that term in this situation, meaning those who have been bereaved.

Mr. Gordie Hogg: You mentioned there's a range of responses. You talked about some people going back to work earlier and getting a lot of support from their work environment, which helped them move through the grieving more quickly.

What do you see as the parameters of flexibility with respect to this? My wife and I went through a miscarriage late in a pregnancy. That was a significant issue. What would be the scope of identifying where and when people would be able to access supports provided by the state, given the flexibility and range of things? I've worked with families where grandparents were significantly impacted, and there are concerns with respect to that, and extended family members.

There's a wide range of impact with PTSD, and certainly you made reference to—in North America we use DSM-5, the *Diagnostic and Statistical Manual of Mental Disorders*, but, sir, PTSD and the response to this are very subjective. Each of us comes to it with a different set of understandings and a different set of challenges.

How would you look at the scope in terms of addressing them? How did you address them in the issues you made reference to, with the terrible shootings that took place? How did you deal with extended family, relatives, neighbours and friends? Is that part of the provisions you're looking at, or is it focused much more acutely?

● (0925)

Dr. Atle Dyregrov: One of the lessons we learned from the terror is...we had one of our Ph.D. students do her thesis on friends' grief. We could show that close friends of those who were killed were at the level of siblings when it came to their grief. It went down a bit sooner than for siblings. We identified those. Grandparents have been identified in several studies.

Of course, you need to start somewhere, and I think you start with parents and siblings, and then you have to build on that. It's very flexible, and it has to be flexible for the reasons you gave.

Before I came into the meeting, I saw a couple who lost two children, and they're functioning. Both are back at work. If others had asked if that was possible, we'd say, yes, it is possible for some, but most people will be totally crushed by that. They look favourably at flexible systems with these structures and possibilities built in, but with the length or period, I think you have to base that on what your resources are.

I could tell you that from Swedish research, we see that if there's a sudden death, parents will in general have 10 times as much sick leave, over three weeks, than those who have not experienced it. If you have an anticipated death, it will be five times as much. These are big studies. It is a societal problem that we don't follow up on well enough.

Mr. Gordie Hogg: Ms. LaFontaine, we're looking at psychological and emotional support, as well as financial support. Obviously it's difficult to separate those. Within the context of emotional and psychological support, do you see that falling primarily under our medical services plan—that's where the first contact is, and then it transitions more into the support that happens through a work environment, and the state provides? The third part would be the community support that starts coming out of that.

How do you see that fitting together with those three pieces? Maybe there are more pieces, in terms of being able to develop this notion of a compassionate, caring society, when there's so much subjectivity in terms of the types of needs. How do we work our way through that?

The Chair: Please give just a brief answer.

Mr. Gordie Hogg: Are you asking her to give a brief answer to a complex question?

The Chair: You're 42 seconds over, Gordie.

Please be very brief.

Ms. Michelle LaFontaine: I believe that families will need to access professional support, as well as the type of support that we offer, which is peer support. Learning that you're not alone in your grief can be a very comforting notion for families to be able to move forward. In terms of access to other types of financial support, again, that could certainly be something that is layered on top of that. I don't think they all need to happen one after the other.

The Chair: Next is MP Sangha, please.

Mr. Ramesh Sangha (Brampton Centre, Lib.): Thank you, Chair, and thanks to all the witnesses for giving very good input.

I'm sorry that you lost your son. I know you have personally faced that problem. Socially thinking, when we are in this type of situation, we want somebody to be close to us. You want to be near someone when you go to work. You want somebody to talk to you and listen to you. You may be telling your story sometimes to others. You may be feeling like giving your inner feelings. Some people will be good. They will come close to you, and sit and listen to your story and console you, but others may not have the time. Other people will say, “Why is she only talking about this? Why doesn't she talk about something else?” Whether you feel this type of social help, how far will it assist you to console?

Ms. Michelle LaFontaine: The social help we could offer to families would certainly do a lot in breaking the stigma that's associated with pregnancy and infant loss. I feel that families would talk more about their losses, and would be better accepted by their peers and by society if it wasn't such a taboo subject.

If we had social supports in place that were well known, if we had emotional supports in place that were well known in the same way the Canadian Cancer Society is there for you when you have a cancer diagnosis.... Families and members of society should be able to know, if you experience a miscarriage or an infant death, where you should direct families to attend.

You are right that there definitely are many people who can hear you talk about your personal story and not be able to accept it for many different reasons. We feel that education, again, would be the key to addressing that issue.

● (0930)

Mr. Ramesh Sangha: In families we have no problem, because we provide support to each other in the extended family. When we are alone, when somebody who is grieving is alone at home, and at the same time when husbands go back to work and the wife is at home sitting alone, she has big problems. Do you think money is the only criteria which can help, or are there other ways to take care of this problem?

Ms. Michelle LaFontaine: I agree with you. When you are by yourself, the isolation can certainly increase, and being connected to social programs, peer support networks, online support can certainly start to alleviate it. Unfortunately, it's not always the case that your family is the most supportive. Oftentimes, we hear families talk about their family members who are not able to support them at the time of their loss. It's too difficult for everybody to talk about it, so they do have to reach outwardly.

They do have to find who they can talk to in their communities. The idea that we just throw money at the problem, I agree with you, is not the solution. Certainly, money to support the social support programs that we could put in place will assist families to not experience that isolation, whether it's the partner who goes back to work or whether it's the person who gave birth that goes back to work. If we can have the conversation in our society that allows families to expand on their grief, to know that anyone they talk to can be a safe place to land, would be a great move forward.

Mr. Ramesh Sangha: Thank you, Chair.

The Chair: Mr. Richards

Mr. Blake Richards (Banff—Airdrie, CPC): Thanks, Chair, and thank you so much, both of you.

Michelle, I'll start with you. First of all, thank you for the courage that you've displayed. You talked about your personal story and how difficult it was for you to struggle to get through the workday. You also talked about making the choice to take the back roads home because you knew, at that point, how much the day had taken out of you. To take that and turn it into something where you're trying to do something to help others not to experience what you had to experience takes a lot of courage. I thank you for that.

I want to ask a couple of questions. First of all, obviously we've heard all kinds of stories about people who've had to tell their story and experience over and over again to bureaucrats, to Service Canada agents, to the bank and so forth, to try to deal with benefits or with various other things that go along with this, often without a lot of information, as you've mentioned.

Before I get to that, I want to ask how important you feel it is that people have access to someone who really understands their situation. For example, when they're dealing with Service Canada, how important is it for there to be people who are dedicated agents they can deal with who really understand what these people are going through and what they're dealing with so that there can be the proper response? Is that something you would say is quite important?

Ms. Michelle LaFontaine: Yes, I think that's incredibly important.

Without the type of education needed to be able to provide the information in a compassionate way, those experiences could just serve to further traumatize the family. We did hear from lots of families who, when they went to seek support or to get information, were told things that are just unconscionable. I don't think it's because people don't care. I don't think it's because they are trying to destroy that family's day. I think it's because they lack the education they need to be able to provide that service with skill and compassion.

Mr. Blake Richards: Along those same lines, at one of the October 15 events that I attended this year, I met a young guy named Timothy. I think it was about a month previous that he had just experienced a loss. You could still see the pain on his face. He was still incredibly traumatized by the whole situation, and his story, when he told me, was very much what you just described.

First of all, they were put into a maternity ward while they were losing this baby, and they were seeing the joy of everyone having a child. No one did that on purpose, but that was a very difficult thing for him. Then they were just sort of told at the end, “Well, this is really common. Don't worry about it. It'll be fine.” Obviously that really hit him hard as well, and then they were just sent home with no information. They had no idea where to turn or what to do next.

I want you to speak to the importance of information being available to people on where to turn, but also the idea that there be some kind of assistance. You mentioned the automatic, universal.... I want you to speak a little bit to the importance of that because the last thing I think we want to be doing is putting people through experiences that are going to further traumatize them when they're trying to deal with their grief.

Can you speak to the importance of that automatic and universal nature of something that would be provided for parents?

● (0935)

Ms. Michelle LaFontaine: I think the automatic and universal nature of that type of support would first validate that this is a loss that deserves this type of attention and deserves to be supported by our government.

When we offer families information at the time of their loss about support that is available to them, that doesn't necessarily mean all families will access that support immediately. It's of course up to them to access it. However, just telling them that the support is available lets them know that many families need support, just like you might need support. It's important to normalize the grief experience and validate the fact that we know you're not going to be okay to go back to work right away, and we have that taken care of. Families will look to their government for that kind of leadership and that kind of support. A universal bereavement benefit would certainly do that.

Mr. Blake Richards: Thank you.

There is another thing I want to ask you about. In your opening remarks you mentioned PAIL, and the fact that you deal with perinatal loss, SIDS, and other losses of a child up to the age of 12 months. Can you speak to the difference in the kind of grief experience in those situations as compared to other losses, and why a decision was made in creating PAIL to deal specifically with perinatal loss and, in that first year after birth, with SIDS and those types of instances?

Ms. Michelle LaFontaine: The unique grief needs of families who have experienced the loss of their pregnancy or the death of a baby certainly require a different approach at times, we feel. Again, to be clear, our support is not professional support but peer support. All of our support is one-to-one phone support or circles of support that happen in over 23 communities in Ontario, where you can come and sit with other families who have experienced loss.

We do find that when families are closer to their bereavement, they like to connect with others who have experienced a loss very similar to theirs. For instance, if my loss was at eight weeks, I'd like to speak to a family who also had a loss at eight weeks. If I lost my baby at three months of age due to SIDS, I'd like to speak to a family who experienced what I did. The health care journey is different. The experience of grieving for what a baby was going to be, where you had hopes and dreams, will be quite different from the experience a family will have with an older child, where they're looking back at the memories they had with them.

Families who lose a pregnancy or a baby don't yet have those memories to build. However, they certainly have an identity that they have created for themselves as a family. We know that attachment begins long before birth. If you're a family that has been very, very much wishing for this pregnancy and for this baby to come, the loss also means that you are losing the life you wish you could have had with them.

I think that's the main reason we decided to keep things somewhat restricted in that way. We often refer the families who don't fit that criteria, who have a loss of a child over the age of 12 months of age, mostly because we don't feel they would feel represented in the groups we offer and with the support we offer.

Mr. Blake Richards: Thank you.

The Chair: Thank you very much.

Next is MP Ruimy, please.

Mr. Dan Ruimy (Pitt Meadows—Maple Ridge, Lib.): Thanks very much to both of you for those presentations; it's so early in the morning where you are, Professor.

Look, this is a tough topic to talk about. We're all empathetic when it comes to the losses that people experience. Indeed, people have losses every day. I lost my dad last year. We had to fly to Montreal. He was in a coma for a week, and we had to wait for him to die. We really didn't know what was going on either. An hour after he died, the Jewish community rolled in with this big cart. They had coffee and what have you. That was one way they were able to show their support.

You mentioned the peer support. There are two things that are going on here. There's Service Canada, which I'll talk about in a moment, but then there's the hospital services. That's a question I'm trying to come to terms with myself. You have your NGOs. You have your provincial, you have your federal, and you have your peer support. What's triggering all this? What's happening, and how are these things...?

First, did you start this organization?

● (0940)

Ms. Michelle LaFontaine: No. It's been around for about 25 years.

Mr. Dan Ruimy: Can you tell me if there is any governmental funding in that program?

Ms. Michelle LaFontaine: There is now. After Bill 141 passed, we became fully funded by the Ministry of Health in Ontario.

Mr. Dan Ruimy: That's good, because those are some of the things that government can do for a more direct approach.

When we talk about Service Canada, what we've been hearing is more disconcerting to me. If you're on EI, then the week your child passes your benefits end. We heard the stories, i.e., you're not applying, you don't send in the documents, now you've overpaid into the system, and now you have to pay it back. That generally comes quite quickly.

Can you talk about any of those experiences, either your own or those of people you've met? Is it something that you're hearing is going on?

Ms. Michelle LaFontaine: Absolutely. It's not top of mind for families to let Service Canada know that their baby has died. Oftentimes, there is no one around them to tell them to do so. That would be some of the education we would need to give to funeral homes, to health care providers, and anyone who is able to support the family at the time of their loss. Letting them know that this is something that needs to be triggered with Service Canada would be beneficial.

For families, I feel, when the child has passed, it would be very simple, in my opinion, to be able to trigger that benefit to roll into a bereavement benefit so that we wouldn't have families who have to pay it back. We certainly hear from families all the time who have experienced significant financial hardship as a result of the loss of their baby. Just not knowing where to go and what to do has been the culprit.

Mr. Dan Ruimy: I'm still trying to understand how this gets triggered because most families don't want to talk to Service Canada. Yet, somebody needs to let Service Canada know.

Do the hospitals have enough information so that they can make that type of decision, or is that private information?

After the death of my father we went to the funeral home and they actually made a lot of the arrangements. They said, “Okay, give us this information and we'll take care of everything for you.” It is a bit of a challenge for Service Canada because not everybody knows that you're collecting EI, for instance.

Ms. Michelle LaFontaine: That's right.

Mr. Dan Ruimy: Would you have any recommendations on how we can make that seamless?

Ms. Michelle LaFontaine: If you ask families to provide their consent for you to share their information with Service Canada, that could happen at the health care provider level. Some families may not choose to go to a funeral home, depending on their beliefs and on the stage of their loss. The health care providers often use a bereavement checklist when they're working with families to make sure that everything is offered to the family. For example, if that was another added line to that checklist, for a health care provider to make sure that their paperwork gets sent to Service Canada on behalf of the family, then the family would just have to provide consent and that would cover off the privacy issue, I believe.

Mr. Dan Ruimy: That would be prompted more by the health care provider and the hospitals.

I'm trying to figure out, because we're on a federal level, what we can do as Service Canada, as a government, to facilitate that. Is there anything we can do to facilitate that transition period? We do know that with a death it does roll over into bereavement. We know that. In some cases it doesn't, so there's a gap there. We're trying to figure out if it's something that Service Canada has to initiate. In the case, again, of the father and the funeral, we have to send a death certificate, for instance. It's not pretty and it's not pleasant but that is the trigger to get the death benefit.

I'm trying to figure out if there are things that we can do that could make that easier.

● (0945)

Ms. Michelle LaFontaine: I'm not sure I can answer that for you.

If there's a death certificate that is issued and there is some behind the scenes work that can be done, that's always helpful. I also feel that when families are aware that this is the process, information can be comforting to them, so it's not jarring to them. It might not be easy, but if we know that families have these steps to go through, then they can have support to go through those steps, whatever they may be.

Mr. Dan Ruimy: Thank you.

The Chair: Thank you very much.

Thank you to both of you for appearing before our committee today and contributing to this study.

We will suspend briefly so we can bring in the next panel.

● (0945)

(Pause)

● (0950)

The Chair: Good morning, everyone.

We're back with our second panel this morning. I'm pleased to inform you that we are joined here in Ottawa by Francine de Montigny, Director, and Chantal Verdon, Researcher, Centre for Studies and Research on Family Intervention, Université du Québec en Outaouais. Also joining us via video conference from Calgary is Gillian Hatto, Founder of Hazel's Heroes Society.

We're going to start it off with Francine and Chantal.

The next seven minutes are all yours.

Dr. Francine de Montigny (Director, Centre for Studies and Research on Family Intervention, Université du Québec en Outaouais, As an Individual): First of all, thank you very much for inviting us over. I will be speaking in French, because I can probably put an extra minute in my talk, and since I could entertain you on prenatal bereavement for probably 45 hours, I'll try to make it short and sweet.

● (0955)

The Chair: Take your time. We have lots of time. The interpreters are going, “Oh, boy”.

Dr. Francine de Montigny: Just wait until I speak in French.

I hold a Canadian research chair on family psychosocial health.

[*Translation*]

I am the senior research fellow at the Fonds de recherche du Québec en santé.

[*English*]

As well, I am the Director of the Centre for Studies and Research on Family Intervention. Chantal is co-P.I.

We have done about seven research works mostly over the last 15 years, but I've been doing research for the past 20 years on prenatal bereavement. We're both clinicians. We've been doing prenatal support groups for the past 20 years at Université du Québec en Outaouais. We keep seeing families every month, and we also hold groups for the next pregnancy. All that is volunteer work.

[*Translation*]

I will be providing an overview of perinatal death and talking briefly about the impact on parents' mental health, marital relationships and child development. I will also address the effects of the lack of recognition of bereavement in society and the workplace, as well as the economic consequences of the cost of absenteeism/presenteeism. Lastly, I will discuss what Canadian families need.

It is estimated that one in five pregnancies ends in early or late perinatal death. By the way, I encourage committee members to ask why I say “it is estimated”. In Canada, that represents around 100,000 deaths a year.

Health and social services for bereaved families are uneven across provinces, as well as within and between regions. That means a parent can access a given service if they live in Laval, for instance, but not if they live in Montreal. Consequently, they have to go to another region in order to receive the service.

In addition, access to paid parental leave is unequal between mothers and fathers, and varies for mothers depending on the province of residence and the length of pregnancy. I also welcome any questions on that point.

This contributes to the non-recognition of perinatal bereavement and, in our view, reduces the father to the role of progenitor and financial provider. This perpetuates the stereotype that the father's involvement in the family project is limited to conception and excludes any emotional commitment.

Yet the consequences of perinatal death are real in the short and long term. The committee has heard from families. Both parents experience a heavy loss and intense grief. Perinatal death, and subsequent bereavement, have deleterious effects on the mental health of women and men up to five years after the death. That includes persistent depression, anxiety and grief. The research refers to post-traumatic stress and somatization.

In the course of our research, we have met with thousands of parents over the past 15 years. Women talked about having suicidal thoughts, 16% in fact. We are currently following up with parents as part of another longitudinal research study. We learned that some fathers have suicidal thoughts after the birth of the next child. Symptoms persist during the next pregnancy and even after the birth of a healthy child.

With respect to the conjugal relationship, there is increased risk of marital tensions, separations and divorces. Although some couples are able to come together and grow stronger after such a tragedy, it depends greatly on the support they receive and the way they deal with the event together. When the father goes back to work on Monday morning, after the miscarriage or loss, and the mother is home alone crying, it's easy to imagine the tension that can result.

There is increased risk of mental health problems such as anxiety in subsequent pregnancies. There is increased risk of other perinatal deaths. During a first pregnancy, a 25-year-old woman has a one in five chance of experiencing a miscarriage or perinatal death, and that goes up to a one in four chance after the first event. The likelihood of the mother experiencing multiple perinatal deaths over a lifetime therefore increases.

Both international and Canadian studies have examined postnatal effects. In Calgary, babies born to mothers who were initially depressed, not necessarily further to a death, were more likely to develop depression later on. Therefore, the research points to an immune disorder that is genetically passed on from mother to child during pregnancy. If the mother is carrying a girl, she will pass it on to her daughter, who will in turn pass it on to the next generation. That signals an intergenerational transmission of mental health disorders, and there are costs associated with that.

● (1000)

Certain postnatal effects have also been identified. Some of our American colleagues have studied cohorts of parents who have experienced trauma, including death, over a period of 25 years. They observed that babies with depressed parents have an increased risk of depression and of internalized and externalized disorders in childhood and adulthood. It varies depending on the parent's gender. I can talk more about that later.

The effects of the lack of recognition of bereavement in society and at work are experienced in medical, family and social spaces. The work space is the one where bereavement is the least recognized. I can come back to that afterwards.

The silence surrounding the suffering and distress of grieving men, who, like women, must learn to live with the death of a baby, forces them to return to work when they are physically and psychologically shaken. The result is a high rate of presenteeism or absenteeism.

I will now get right into the cost of presenteeism and absenteeism. Canadian estimates indicate that productivity costs associated with mental health disorders are $17.7 billion annually. The costs of presenteeism are usually 5 to ten times higher than those of absenteeism. Symptoms of depression, grief and anxiety are associated with lower productivity, problems with concentration, poor problem-solving and decision-making skills, as well as more workplace accidents.

Direct and indirect economic consequences arise from the increased use of health and social services. Without the necessary support at the time of the event, people repeatedly access the health care system for the same event. The consequences on children already in the family and those born afterwards are not yet well known. The same is true of the consequences on extended family—which the gentleman spoke about earlier—including grieving grandparents. Similarly, the consequences on families of diverse cultural origins are not well known. We know very little about what they experience.

What families need—mothers and fathers alike—is to have their grief acknowledged. This can be achieved through social awareness-raising campaigns, workplace programs and bereavement leave for both parents. They need to be supported by sensitive and competent staff who recognize their cultural specificity and their bereavement pathways throughout the continuum of care. Programs not only need to be implemented, but they also need to be evaluated. Once programs are developed and put in place, it is not known whether parents derive any benefit. We need more accurate statistics to tell us the number of early and late deaths. We also need longitudinal research studies so that we are not always relying on research findings from other countries. Canada has a cultural specificity, and we lack information on the bereavement pathways of families and the long-term repercussions because the research hasn't been done.

We also lack studies on the impacts of bereavement on work. A qualitative study is coming out soon, but we don't have any quantitative studies. We have little in the way of studies. We conducted a small study on cultural specificity as it relates to family support, but we need programs to be evaluated. Bereavement groups, among other services, have rarely been evaluated. We don't know whether they should comprise two volunteer parents or a professional together with a parent.

Thank you.

[*English*]

The Chair: Thank you.

Up next we have Gillian Hatto, Founder of Hazel's Heroes Society.

The next seven minutes are yours.

Ms. Gillian Hatto (Founder, Hazel's Heroes Society): Thank you.

On May 29, 2014, I gave birth to my first child, my daughter Hazel Rose. She was born healthy, happy and perfect in every way. We had three incredible months with her in our arms, and they were the happiest three months of our lives. There was no sign, no warning and no thoughts of her leaving us so abruptly as she did, but on August 31 she fell asleep and never woke up again.

That day will remain forever etched in my mind. Thinking about it makes my head start spinning and my stomach feel nauseated even four years later. What we went through that day and in the coming weeks and months, no person should ever have to go through. It's something that is impossible to imagine unless you have also lost a child.

We had to answer questions that hadn't even entered our minds, and we didn't know if we were making the right decisions. Would she be buried or cremated? What did we want her to wear? Where would she stay—in a cemetery or at home with us?

Then we had to plan a funeral. My husband Gareth and I created a slide show of our most treasured pictures ever. We had to choose a venue and food and hot beverages to serve, and we had to prepare speeches that would somehow convey to others how much we loved and missed our baby girl. I could barely brush my hair, much less be present in front of 100 of our closet friends and family members, but I had no choice, and even though Hazel's heart had stopped beating, mine continued to whether I wanted it to or not.

Somehow the world kept going on all around me, but I remained in a fog of heartache and grief. I didn't want to think of anything beyond memories of holding my gorgeous daughter. Early on, I began seeing a grief counsellor through the Alberta Health Services. I needed an outlet and someone who could help me make sense of the new emotions I was carrying. I had no idea that grief could bring on such an onslaught of scary feelings.

I didn't recognize the person that I had become, but I also couldn't remember the person I used to be. Gone was the outgoing, happy, talkative and confident woman that I once was. I was afraid to be in public. I was filled with intense social anxiety, and I was afraid of seeing reminders of what and who I had lost, but the reminders were everywhere: pregnant women, happy families and babbling babies. There were land mines at every turn.

There were so many things that I didn't want to think about during those early days after tragedy struck: money, work, exercise, cooking and eating, to name just a few. Going back to work was the last thing I wanted to think about, yet it became a topic of conversation much more often than I liked.

For those around me who simply didn't understand, they wrongly assumed that going to work would be a good distraction for me. My profession is teaching students with special needs. I don't have an office where I can close the door and cry when I need to; rather, I am surrounded by dozens of people all day long, and I need to make important decisions regarding the needs of the students I support and the assistants I supervise. A distraction was the last thing I wanted.

I felt so isolated, so alone in my grief, that I needed to understand it and work through it to feel human again and to find hope. I personally do not believe that there is enough understanding about grief, especially child loss, and rarely do people know how to support grieving parents. Often things are said or done with good intentions but have terrible results, often causing more harm than good. To be back at a workplace within weeks or even months after child loss means being faced with questions about your family from those who do not know you are grieving; listening to others talk about their families and children; and, being given platitudes on how to get through it. For me, it simply wasn't a safe place to be.

My husband and I researched online what we were meant to do in regard to my EI, my work and our financial situation, as no one at the funeral home or the hospital told us or even knew what we were supposed to do. In our research, we came across a benefit through EI for the parents of murdered or kidnapped children, which I know has recently been changed to parents of young victims of crime. I read that over and over and kept looking for something for parents who have lost children in other ways as well, but I couldn't find anything. I was in disbelief and assumed that the government thought that if a child was kidnapped or murdered, it was perhaps a worse result than a child dying from an illness or from undetermined reasons, and that somehow those parents deserved support but we did not. Unfortunately, it's the same result: a parent will grieve that child until his or her dying day, no matter what caused that child's death.

Just days after that, I found out that I had to go into Service Canada to cancel my EI benefits and ask about my options. I was told that there was a good chance I would qualify for sickness benefits. I was a bit confused, as I knew that was different from the support given to parents whose children had been murdered, but sickness benefits didn't sound right either, as I wasn't sick and I wasn't injured. I was broken and grieving, and I didn't seem to fit into any box offered.

However, I did feel a sense of relief that I would qualify for the benefit, even knowing that 15 weeks would not be long enough. I now know that I only qualified for the sickness benefit because I hadn't needed to access it during my pregnancy with Hazel. In the end, I did not go through EI but was instead put on short-term disability leave through my work and then eventually long-term leave. I ended up being off work for exactly two years. I'm grateful that as a teacher I had access to these benefits and was not forced to go back to work when I was not physically or mentally able to be there.

● (1005)

Within weeks of Hazel's dying, I received a notification in the mail from Service Canada that I had been given extra money through the child tax benefit and I owed it back to the government in a timely fashion. It was approximately $550. I had no idea that I had been overpaid and would have to return such a large sum of money.

There was no option given for paying online, and I even called to see if this could be a possibility, as I had been avoiding being out in public at all costs. Everywhere I went there were triggers, and I wasn't emotionally ready to make idle chit-chat or safely be behind the wheel of a car. Unfortunately, the only option I was given was to go to the bank in person. I dreaded it, as I had been there just weeks before setting up an RESP for Hazel. It was within walking distance from my house, so I forced myself to go as I didn't have much choice.

The teller recognized me immediately and asked where my beautiful baby was. I stared in silence and somehow got it out that she had passed away. The teller frowned and responded by telling me that her niece had had a recent miscarriage and that she understood what I was going through. I stood there in disbelief, then walked out of the bank as fast as I could and became physically ill while customers moved around me. Needless to say, I haven't been back to that bank since. I hope, in the four years since losing Hazel, that parents are now able to pay back this amount online, or better yet, not at all.

Two years into my grief I started a foundation in honour of Hazel called Hazel's Heroes. We provide healing retreats to mothers who have lost a child under the age of 12, at no cost to the family. Through Hazel's Heroes and the various support groups I am part of, I have met dozens, if not hundreds, of bereaved parents. Many of them have shared their anxieties around returning to work and struggling to make enough money with no pay cheque or benefits. It's simply heartbreaking. Grief doesn't just affect you emotionally; it affects every ounce of your being. What helped me the most in my grief was not returning to work and being distracted, but rather putting time into grief work such as counselling, support groups, journaling and being close with others who understood what I was going through.

It's so important that as a society we recognize the need to give bereaved parents the opportunity to sit with our grief, find new ways to parent the child no longer in their arms and find their new normal. The government can help make this happen, and I hope this committee is able to find a solution to better supporting parents after the tragic loss of a child.

Thank you.

● (1010)

The Chair: Thank you very much.

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

Mr. Kerry Diotte: Thanks to the both of you for appearing, and to Ms. Hatto especially. From the bottom of my heart I feel for you. I'm glad you can present to us, because it's very useful to hear such poignant testimony.

To that point, what can we do so that no parent has to go through what you've gone through? What would you like to see in terms of programs and supports through the federal government?

Ms. Gillian Hatto: As I mentioned in my testimony, the first thing that I thought would be the easiest is to not expect parents to be out in public and not require them to pay that child tax benefit back in person at the bank. It should be online. I wish the government could stop this right away, so that parents don't find out they owe so much money after they've lost their child. Some parents I know didn't find out until weeks or months after and owed so much money that they didn't have it in their bank accounts. I think that's a cruel punishment.

I wish there were benefits such as the one going through, Motion No. 110, so that parents don't have to return to work right away. I know there is the sickness benefit, but as we've seen from previous testimony, that's not available to every parent if they've taken medical leave throughout their pregnancy.

For me, finding out there was something for children who died from other circumstances.... I think parents should see there's a benefit specific to bereaved parents, so that we know we are supported by the government and that ours is a separate type of loss. I think if parents haven't accessed the sickness benefit, they should get that as well as a bereavement benefit, because no time is long enough in terms of returning to work. If parents choose to, that's wonderful. For someone like me, and many other parents I know of, it took well over that 15 weeks. In the end, I took two years.

There are so many other things the government could help with, such as supporting those NGOs and giving parents a retreat such as Hazel's Heroes to come together and meet other families. We've had so many parents come to our retreats who have never met another bereaved parent in the five or six years of their grief. That's heartbreaking. Parents feel so isolated in their grief and loss. To meet other parents who've gone through something they've also gone through helps them feel supported, less alone and able to continue living, find a purpose to continue breathing.

Mr. Kerry Diotte: Thank you.

Since you are the founder of Hazel's Heroes, what stories have you heard from other parents, regarding their inability or the gaps they've seen on the federal side?

● (1015)

Ms. Gillian Hatto: I think one of the biggest is the parents who found out way too late after they found out their child had passed away, that they owed so much money to the government.

I've had so many people come to the retreats. Right now the retreats are focused on mothers who have lost a child, and a lot of the mothers who come are single. They don't have that double income. They don't have an employer who gave them access to longer leave. In the end, they had to quit their jobs because they went back to work and had emotional and mental breakdowns.

I think that struck me the hardest: thinking about their being back at work, struggling to be there, hearing other people talk about their children and families and having to sit through that or in the end leave and not make any money, because that was what they had to do, making money but hearing such difficult things.

Yes, I've heard a lot of terrible stories where families had to survive on such measly incomes and not make it through, because they already took their sick leave and had to return to work. Those are the ones that most impacted me.

Mr. Kerry Diotte: It must be terrible to learn that you think you've had a benefit, and then suddenly you have to pay it back.

Ms. Gillian Hatto: Especially when in that first year after having a child and you're given maternity leave, you expect to be on leave for those 52 weeks. To be told right away you need to return to work or that you owe that child tax benefit back right away.... There's almost a dirty feeling around it for parents, having to reach out to the government, to EI, and find out what their options are. You feel you're being judged or that you're asking for something you don't deserve. That's the last thing we should be making bereaved parents feel. They shouldn't feel they're forced to go back to work because now they don't have a child to take care of. But they do have a child to take care of. We continue parenting those children. They don't go away.

Hazel will remain in my heart forever, and I parent her through many other things now, having Hazel's Heroes. I'm the vice-president of SIDS Calgary Society. I know many other parents who continue to have lasting legacies for their children, and they parent them in other ways. We still have our full-time work. We still have our other children, but to be given a bit of time, a bit of that emotional support, that financial support from the government, can make a very big difference in the life of a bereaved parent.

Mr. Kerry Diotte: Thank you so much.

The Chair: Thank you.

MP Ruimy, you have six minutes, please.

[*Translation*]

Mr. Dan Ruimy: Thank you for being here today.

[*English*]

I'm going to start with Ms. Hatto.

There's no easy way to have this conversation. With a lot of the topics we're hearing about, the jurisdictions fall all over the place, whether they're provincial, municipal, federal. Then you have the red tape somewhere along the line, whether it be Service Canada or whatever government organization, may not understand what's going on. What can we do as a committee that can cut away at that red tape?

As I mentioned in the previous panel, we hear that the benefits stop the week of the passing. An easy fix would be a grace period. We've heard this. The federal government can perhaps look at this. Mental health is another thing. One thing I think we all agree on is the value of the NGOs, the non-profit organizations like yours, and how they are funded. How can we help? Do you get any provincial or federal funding for Hazel's Heroes?

Ms. Gillian Hatto: No, there is no funding. It's all through donations.

● (1020)

Mr. Dan Ruimy: Okay. That's interesting because it's difficult. You mentioned you went to the bank, and people's first reaction was, “Oh, this is uncomfortable”, or to say, “My brother went through this”, or “My niece went through this.” I don't think that's something you can legislate. That comes with awareness. That comes with education. But it's still awkward for people because they don't know what to say in a public setting.

For me, I think, there are two things. How can the federal government provide financial assistance and cut away that red tape? That's critically important. You had mentioned that they said you owed $550. It's silly that it's an automatic response that says you have to pay it in a timely fashion. In the work that we do in our constituencies, it's easy for us to pick up the phone and talk to Service Canada, and say, “Look, this is what's happened,” and they will.... So there's a gap there. Something is just not right, and we have to figure out how we can address that.

You had mentioned that you were off for two years. In the previous panel, the professor said some people come back a lot quicker. Sometimes it's not good to send people away for too long because they're not interacting, and what have you.

How could we address that? There are inconsistencies in trying to put a system together where you might need two years, but somebody else who doesn't have any benefits whatsoever doesn't get that. Can you speak to that a bit?

Ms. Gillian Hatto: Well, I definitely think it's individual, just as I know grief is individual. For my husband, he returned to work three weeks after the loss of Hazel. I like the idea with Motion No. 110 of at least a bit of a grace period. It's just a bit of time that the government is saying, “Listen, we know that returning to work right now is not the best thing for you.” However, people also have the choice to return to work and to not take that benefit. That would be a choice for them.

For me, I did take those extra two years. I think it really depends, for the families, what choice of work they're in. For one, I actually had a subsequent child in those two years and I would not have been able to return with a newborn baby. I do think that every situation is different, but I think that providing a little bit of a grace period....

I don't think that saying 12 weeks or 15 weeks or whatever number of weeks is saying that you're going to get over this or be done with your grief, but I think it's a way of showing some support for those families to access some of those supports that are hopefully available.

I'm quite lucky being in Calgary. I'm finding that in being part of Hazel's Heroes and hearing from families all across Canada, even in the States, I hear about the different supports offered in their cities and their provinces. I have been very lucky in Calgary to receive free grief counselling through the Rotary Flames House. I know that's not even an option in some of the capital cities across Canada. I think that's an area that we need.... I don't know if the government could look at how it's supporting some of the mental health side of things.

As I said, it's even just a simple thing. Obviously, the teller didn't know what to say, and that's very normal. People don't know what to say when it comes to grief and child loss. I think that forcing a parent to go out in public in those early weeks of grief seems like a cruel and unusual punishment. I almost wanted to wear a sign that said, “My child just died”, just so people could understand not to even ask me, “How are you doing today?” Someone at the grocery store was packing my groceries and saying, “How are you today?” I couldn't even respond, “Fine.” I would just stare and want to be sick right there. The amount of extreme social anxiety you get, I can't even explain. I had no idea that was something that would happen.

To tell people that they can't pay this online, that they have to go into a bank where they'd just set up an RESP for their child, that adds a lot of cruelty. I think that could be easily resolved by there being an online option. That's one simple thing that I think should be changed quickly.

● (1025)

Mr. Dan Ruimy: Thank you.

The Chair: Next is MP Sansoucy.

[*Translation*]

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

I'd like to thank the witnesses.

Ms. de Montigny and Ms. Verdon, the committee has to make recommendations as part of its study. I'd like to discuss the funding of the organizations working on the ground, doing excellent work with meagre resources.

One of your studies on the services available to families after a perinatal death makes something very clear: stakeholders and parents know little about the resources that exist.

That study also highlights an issue that's been raised by many witnesses, and we've just heard it again. Following the death of a baby, stakeholders do not necessarily have all the answers or know where to refer parents.

At our last meeting, I was surprised to learn that Service Canada did not offer parents any tools or assistance, not even to refer them to appropriate services.

Given your research and expertise, how do you think the federal government can better support organizations so that they, in turn, can help parents, on the one hand, and promote their services, on the other? The services are out there, but people don't know about them. Is that merely due to a lack of funding? Could an organization like Service Canada be a portal where people could turn for information on the various services?

I'd like to hear from both of you about funding, referrals to services and access to information.

Dr. Francine de Montigny: The study you're referring to is from 2010, but the situation is still the same. If we were to do the same study today, we would see that the services are still not well known and are poorly spread out throughout Quebec and elsewhere in Canada.

The provinces that provide the most support after perinatal death are Quebec, Ontario and British Columbia. New Brunswick also provides some services.

[*English*]

There is not only one solution; it's multiple solutions. Yes, Service Canada can answer questions, but it takes training. You need to train those people who answer the phone.

We're in a death denying society. In that society there is no space for death, so it's very easy to go.... When anybody who loses a close one goes back to work, for a day or two, people will ask, “How are you?” The week after, they expect the person to be just as productive as if nothing happened in his or her life.

Death is unsettling. It's unsettling when it's a child. It's unsettling when it's a parent, when it's a sibling. We need to have space to go through these emotions, to integrate them in our lives so that we can end up being more productive.

Going back to work too quickly when you don't feel like going back to work will only mean that you're going to be there, present, and not doing much, just acting. Some fathers shared that they lost their job after losing their baby because they went back to work too quickly and they were not really as passionate about their work or as productive as they used to be.

We need to have this time, and the time is different for everyone.

I disagree with Dr. Dyregrov that they should all go back to work quickly. Some of them need to go back to work quickly, but we also find in the parents who we support that when the men go back quickly.... The women oftentimes will have some kind of leave because they gave birth and they have postpartum symptoms. Even though the pregnancy was only 16 weeks and they don't have the benefits, they have postpartum changes in their body, so they can produce milk, and they'll have different kinds of hormonal changes that they go through, so they will more easily get medical leave from their physician than the men will. When the men go back to work, they distance one another in their relationships.

[*Translation*]

Ms. Brigitte Sansoucy: I have to stop you there, because I have a limited amount of time.

Dr. Francine de Montigny: My apologies. You wanted to talk about programs.

Ms. Brigitte Sansoucy: Ms. Verdon, earlier I mentioned an organization in my riding that has to do four fundraisers just to keep its doors open. We know that some support organizations for bereaved individuals have had to close.

What can the government do to better support those organizations?

Mrs. Chantal Verdon (Researcher, Centre for Studies and Research on Family Intervention, Université du Québec en Outaouais, As an Individual): I want to be clear that Service Canada is a key gateway. Families, especially immigrant families when they arrive in Canada, turn to different institutions. I think Service Canada has a good reputation and considerable reach. If, on its website, the organization were to recognize this type of bereavement and the fact that it was significant and required serious attention, I think it would send the right message. If hospitals and service providers in the various provinces and regions aren't able to get that message out, I think the government should be that gateway or portal. It could send a powerful message.

Yes, there is a measurable financial impact. Organizations cannot survive when they don't receive funding and when people don't know about them. Through an online portal, Service Canada could easily give ordinary Canadians access to resources in every province. That alone, would send a very clear message. It would involve updating the website and making it very clear to provinces that the issue matters and requires serious attention. That would apply to all levels, including regions and municipalities.

As a result, support groups could be created in every health or community organization. The message would resonate with parents, who can sometimes downplay their situation after being told the same thing over and over again. The issue could be something as simple as trying to cancel a health card they received, following the baby's death. Everything can be complicated for these families. For example, some doctors do not automatically sign the document allowing the mother to take time off because they want to ask her about it first. We can all agree that, just by asking a mother that question, the doctor is creating doubt in her mind. Here, that is clearly indicated.

Unfortunately, health professionals, themselves, are not very familiar with the phenomenon. It's important to consider the beliefs and skills of the professionals working on the ground. Keep in mind that bereavement courses are considered optional in training programs. We were talking about bereaved mothers and fathers, but I can tell you that perinatal bereavement comes last. Sending a clear message is essential, and you are the vehicle for that. Whether we are talking about professionals, families or municipalities, it's time that bereavement be recognized in Canada. It's a way to protect the health of Canadians. When people continue to carry their grief and downplay it, they suffer. They develop all manner of health problems in the long term. All that to say, sending a clear message is key.

● (1030)

[*English*]

The Chair: Thank you very much.

[*Translation*]

Ms. Brigitte Sansoucy: That represents significant costs for Canada.

[*English*]

The Chair: Next is MP Long, please.

Mr. Wayne Long: Thank you, Mr. Chair.

Again, thank you to our witnesses this morning.

I want to start with you, Ms. de Montigny and Ms. Verdon.

Your presentation was outstanding. There's so much information here, so much factual information, studies and so on. I agree with it all, by the way.

At one point—and I just kind of jotted it down quickly—you talked about the workplace being one area where bereavement is less recognized. That hits with me, because many years ago, I had a friend who went through the same kind of thing. One of the quotes you had was about somebody who suffered the loss in January, and then in March they were let go because they were told they lacked passion. That hits home with me because I had a friend who went through the very same thing.

What can we do as a federal government to improve that situation for people who have to go back to the workplace and who really suffer in silence that way? It's a wide-ranging question.

We always hear, as federal politicians, that you can only do so much, because maybe it's more provincial jurisdiction. Is it more funding for the province? Is there direct support we can give to organizations, maybe some funding stream that we can provide federally for organizations to tap directly into the federal government?

It's an obvious problem. Again, your presentation was wonderful. There's so much here. How do you see us helping in that situation?

Dr. Francine de Montigny: As I said, it's a multi-systemic answer. There's not only one answer.

There is a problem, and it might be a strain that provinces deal with some kinds of decisions and the federal government deals with others.

● (1035)

Mr. Wayne Long: I just want to jump in here. I agree it's multi-dimensional, but what would you recommend?

Dr. Francine de Montigny: There's one thing I'm wondering. Why are you not talking about Health Canada?

Health Canada could also have an educational mandate. They would train the health professionals, train the people that are in the day-to-day health care system, systematic training that would be available across Canada. That's a mandate I think of Health Canada.

I recommend societal messages. When you have mental health messages across Canada, campaigns on different topics, it can permeate. It kind of puts pressure on the individual governments to be doing something.

Mr. Wayne Long: Further to your testimony, though, how do we drive that into the workplace? It's great to say that Health Canada should be more involved or that we need to educate Service Canada to be more compassionate, but how do we get into the workplace to offer that support?

Dr. Francine de Montigny: Training the people at Service Canada is already something.... If these people answer the phone correctly, become a model of how a service should be more sensitive to bereaved parents, bereaved people, it can become a model.

It needs to start somewhere. It starts with making people aware of what bereavement means, making them aware that they are real babies. With the pictures that I shared, the parents agreed that we bring their babies to this room so that we can see they are real babies.

[*Translation*]

I'm not sure how exactly to answer that. All I can tell you is that it's really important to train the people working in government organizations at every level.

Training is needed. Just by holding this meeting, the Canadian government is sending a message that the bereavement of parents matters. It needs to be talked about in the media. It needs to be said publicly. The work of this committee is a step in that direction.

[*English*]

Mr. Wayne Long: I appreciate what you're saying, and I agree with you wholeheartedly.

I'm still looking for something that we can grab onto, some specific thing.

Dr. Francine de Montigny: I think it's parental leave, as my colleague said. I would say having at least 20 weeks of parental leave, and call it “grieving leave”. Parents could take it or not take it.

It forces the workplace to recognize that it's not a vacation. Some parents were asked what they did during their vacation.

Mr. Wayne Long: Right.

Dr. Francine de Montigny: They lost a baby. It's not a vacation.

Mr. Wayne Long: Ms. Hatto, I believe in your presentation you mentioned that your husband went back to work after three weeks.

Is that correct?

Ms. Gillian Hatto: Yes.

Mr. Wayne Long: You mentioned that you stayed home for two years. Your husband went back after three weeks. That obviously happens in a lot of situations. I don't mean that in a bad way at all, but the husband probably does go back first.

What would you recommend that we could do, as the federal government, to offer some flexibility for people who go back? Is it flexible EI? Is it a longer leave? What could we do, as the federal government, to help in that situation where your husband went back after three weeks and probably had to go through a nine-to-five day and suffer?

Ms. Gillian Hatto: I agree with the other witnesses.

As I said, when I was looking into types of benefits that I could access provincially, I only saw the sickness benefit. I think that having something for bereavement leave for parents who have lost a child would send a clear message that the government recognizes the important need for parents to have that chance to grieve.

I don't want to put words into his mouth because he's not here, but when my husband went back to work, he wanted it in some ways, maybe for that routine to continue—

Mr. Wayne Long: Sure. Some people do.

Ms. Gillian Hatto: —and he wasn't off work when we had Hazel. I was home with her, and he wasn't. His routine was to go to work every day, but he also had an office door that he could close. He did tell me that on many occasions he had to shut that door and he had to be alone. He probably wasn't the best employee at that time in terms of being productive.

● (1040)

Mr. Wayne Long: Sure. Yes.

Ms. Gillian Hatto: I don't know.... As I said, something for me that really helped was doing that grief work, which was going to see my grief counsellor, having that be something that was provided for me. It may be, for people who go back to work, is there some way that the government can support parents to see counsellors, psychologists or psychiatrists within their workday? I know that's really difficult.

Mr. Wayne Long: Sure.

Ms. Gillian Hatto: Parents don't want to leave work, or ask to leave during the workday, or leave early, because it doesn't look as if they're being a good employee, but they can't do it after work, because they have other children or other things to attend to.

I think counselling is so important, and I think doing some of that grief work is important, and we don't have that time to do that if we're back at work. Two years sounds like so long. I think when people hear that Gillian was off for two years.... Those two years flew by. As I said, I was busy doing a lot of that grief work. There wasn't a moment that I was just feeling like I was on vacation.

Mr. Wayne Long: For sure. Thank you.

The Chair: Thank you.

MP Hogg, you have about four minutes and a bit.

Mr. Gordie Hogg: Thank you.

Certainly, hearing the testimony as we've gone through this process has taken us to a lot of different places emotionally, in terms of dealing with it.

Professor Dyregrov spoke to us in earlier testimony, and talked about his dissertation and the studies that they followed through, looking at some people going back to work, and felt that some of those responded much more effectively to the emotional challenge they were facing.

We've seen a lot of different responses. There is certainly an acknowledgement that we all respond differently to these types of initiatives.

Ms. de Montigny, you made reference to the need for some quantitative research. All we seem to have had so far is qualitative, and that's very emotional. Is there any quantitative research being done? Is there any data that we have that actually would look at some of the baseline principles that might be coming out as we gather the subjective emotionality and the issues and tie that into them? Is there anything out there? Is there any research being done in a quantitative—

Dr. Francine de Montigny: There's very little internationally. We submitted a project five times to the health research institute, looking into quantitatively following parents over a period of three to five years. We were told, since the stats were not really good, that there were only about 100 people a year who were bereaved from the death of a child, so we wouldn't have the parents who we wanted to follow. We had to demonstrate that miscarriage is also an important factor, and we have published on the impact of miscarriage on mental health in mothers, up to two years after miscarriage, that they still carry this problem.

I think we really need to be looking at parents—from their trajectory of grief, their trajectory of services, the repercussions on their lives, and going through the next pregnancy and the growth and development of those children afterwards—to see how we can best help those parents. We put all kinds of measures of support in place, but they're not always evaluated.

Chantal and I did four-hour workshops with nurses in emergency rooms. We were able to improve the care of those nurses 100%, not only with parents who were bereaved from the death of a child, but every patient who came in with a mental health problem was greeted differently after this workshop.

It's not a really big investment—four hours—to touch 100 nurses who are going to touch 4,000 families a year, only with the bereavement, and all the others. Sometimes putting the money in the right place, training people correctly, evaluating the results of this training, the projects that we did with Movember that you can see, with the DVDs and things that are online and available.... These are all things that are helping parents and are available.

One thing I wanted to say was that the 20 weeks I mentioned before—ideally we would have a year, but we have to be realistic—needs to be flexible. I think some dads might say they're okay to go back to work after a couple of weeks, but maybe they'll be caught up six months later and find that they have less energy and less productivity. As their spouse is getting better, the dads get worse, and they are surprised at that.

Having access to bereavement support in the work area is also a way—not only psychological support, but bereavement support, naming it: the cat is a cat. Bereavement support, for fathers, for men, might be more agreeable to them to go get that kind of help than to go get psychological support.

● (1045)

The Chair: Thank you very much. I do have to step in. We are out of time, but I want to thank all of you for being here by video conference and, of course, here in Ottawa.

For my colleagues, there are just a few things for future business that I need to address before everybody packs up.

On November 1, we are once again going to be talking about Motion No. 110, meeting with witnesses. That one is not going to be in here. It's going to be in room 268 of Valour.

On November 6, next Tuesday, we're going to have a committee business day, also in 268 Valour.

We're going to be starting clause-by-clause consideration of Bill C-81 next week. We really have only one day for this in the schedule, so I'm recommending that we add, as we did last week, a clause-by-clause study from 6:00 p.m. to 9:00 p.m. in this space, room 415. That would be on November 7, the Wednesday of next week. That will give us two solid days to do the clause-by-clause study. I think it's necessary given the number of amendments we expect to come to us with regard to C-81. If anybody has issue with that, we can talk offline.

Thank you very much.

The meeting is adjourned.

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