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Mr. Bryan May

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

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• (0845)

[English]

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

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 witnesses both here in Ottawa and via video conference.

First off, appearing as individuals, we have Wendy Fuentes and Philippe Panneton who are coming to us via video conference from Miami, Florida.

From October15.ca, British Columbia Childloss Support Network, we have Jens Locher, also coming via video conference from Vancouver, British Columbia.

We also have here in Ottawa, from BriarPatch Family Life Education Centre, Bill Roberts, co-founder, H.E.A.R.T.S. Baby Loss Support Program; and Cheryl Salter-Roberts, executive director.

From Gardens of Grace, we have Paula Harmon, founding director; and Jessica Weatherbee, director.

From Les amis du crépuscule, we have Alain Pelletier, managing director

Welcome to all of you. We're going to get started with sevenminute opening remarks from each of you.

We'll start with Wendy Fuentes and Philippe Panneton from Miami, Florida. The next seven minutes are all yours.

Mr. Philippe Panneton (As an Individual): There's no pressure. Everybody likes to break the ice. Thank you.

Thanks for having us here with you guys this morning. We really appreciate the opportunity to speak. Let me get right to it.

This is our story.

On the morning of April 26, 2016, I found our son, Manuel, cold and stiff in his bed. I ran back into our bedroom holding him in my arms and woke up my wife begging her to save him. I called 911 as she was screaming at him to please wake up and fighting to breathe

air into his tiny lungs while attempting to not wake up our newborn daughter.

First responders arrived with the police, and they asked us to find someone to watch our daughter as we would need to accompany them to the hospital. I called my father. It was 6:15 a.m. on the day of his 65th birthday.

This scene replays itself in my head daily. The hours that followed were just as damaging and played a large role in the trauma suffered by our family. In the first hour after our we arrived at the hospital, our son was declared dead. We were asked to consider donating replacement heart valves to a child in urgent need. A grief counsellor, who was already in tears, came into the room and tried to console us. The police began their interrogation of us in the same room where our son's lifeless body was. Once they were satisfied there was no foul play or that there was no risk of contagion, we were told we could go home.

A hospital worker told us that a certain funeral home had a costfree package for families of stillborn children and that perhaps they could help us, although our circumstances were different. We were later told that since we had agreed to donate heart valves, funeral arrangements would be delayed for an undetermined period of time. The doctors told us there was nothing they could do. They didn't know why our son had passed.

That is what we remember. That was it. There was no one to turn to. There was no one to guide us or redirect us to any foundation for help. There was no assistance in place to offset the financial or emotional costs of the following weeks.

In a country that prides itself on caring for its most vulnerable through its social programs, every single door we knocked on was shut, from our family doctor stating that the best she could do was refer us for psychiatric care—and when we were unable to answer some of her questions due to our state of shock we were flat out told that if we weren't more forthcoming we'd have to find a new family doctor—to the NGOs stating that they only catered to families whose children were victims of SIDS or cancer or whatever cause, but not us because ours wasn't the right age and the cause of death was unknown. We had to deal by ourselves with the coroner's office to release our son's body for cremation, with the funeral home, the ordering of a death certificate, the planning of our child's funeral and informing the government of the passing of our son.

All the while the bills kept coming in. We had to pay for my wife's family to come in from the U.S., and then we had to pay for our son's funeral. Thankfully, our employer generously allowed me time with my family and compensation for the weeks following our son's death. Friends and family helped us with funds to offset the immediate costs and with some meal preparations.

After eight weeks, I returned to work. I had no choice. While my employer told me to take all the time I needed, my direct boss hinted that I should be okay by now and I should really be grateful for what I was given and head back to work. It was too soon. I often cried at my desk or took extended breaks to deal with anxiety and anger. Colleagues looked upon me with pity and well-intentioned people came up to me and admitted they were surprised that I wasn't better yet. Having to keep up appearances and put on a brave face took its toll on me and on my family.

Finally, through the Internet I found an organization called Baby's Breath. They referred us to the SUDC Foundation, an American foundation that deals with families whose children have passed from sudden unexplained death, which is the fifth leading cause of death in children between the ages of one and four in the U.S., where statistics are available. While they did not provide financial support, they did provide much needed moral support and counselling to us and our extended family. We are forever grateful to them.

Like many of the families who have testified here, we have taken what life has thrown at us and attempted to make the best of it by making a difference in other people's lives. We are in the process of setting up a charitable organization that will help families navigate through the grieving process. We submitted petition e-1558 asking that April 26 be designated as an awareness day for sudden unexplained death.

(0850)

We firmly stand with the other families in asking the Government of Canada to help orphaned parents with financial compensation for 12 weeks immediately following the loss of a child, no matter the age. What we would like to see as a recommendation from this committee is an automatic service similar by design to when a baby is born, done by the hospital, not the funeral home or the family. This automatic process would also serve as a trigger for two different financial aids, one from EI because grieving parents are incapable of working, and a second one from child benefits to help offset the costs of burying your child.

Thank you all for giving us a voice in this process.

The Chair: Thank you very much for joining us today and sharing that story.

Next, from the British Columbia Childloss Support Network, we have Jens Locher via video conference from Vancouver.

The next seven minutes are yours.

Mr. Jens Locher (October15.ca - British Columbia Childloss Support Network): Thank you.

Like the previous speaker, I thank MP Blake Richards for supporting motion M-110 and the committee for having given us the possibility to speak today on this important topic. I would like to share my own story with the committee as well.

In 2010, my wife Kerstin and I decided that we were ready to start our family and extend our family. We meticulously planned everything. We researched all the dietary requirements and nutritional information for my wife. We completed an infant CPR course. We attended new parent workshops. We attended breastfeeding sessions, and so on. We looked up cribs, nursing equipment, and all those kinds of things. We felt really prepared when we found out that we were expecting a son in March 2011.

The pregnancy was uncomplicated and my wife carried him until the 41st week. We had built a social circle of support at these events that we attended with other soon-to-be parents, events such as prenatal yoga.

However, it all came very differently than expected when Marlon, our son, did not get oxygen during delivery. He suffered severe brain damage and his prognosis was dire. The doctors told us he might live for a few hours. Despite all the courses we had taken and all the research we had done, we felt completely and utterly unprepared. To this day, we are grateful to a doctor who made a referral for us to Canuck Place Children's Hospice here in Vancouver. We moved to their facility a day after Marlon was born and spent another day at the facility with him, making memories before he passed away in our arms.

Looking back, I cannot stress enough how important the support we received from Canuck Place has been for us. We got to spend time with Marlon. We got mementos. We got pictures taken. We got hand and foot moulds, and so on. All these items helped us later in our grief, during which we were supported by the bereavement team of the hospice.

I'm telling you this in particular because of the other witnesses who have other stories, because I realize how lucky we actually were to get the support and how important it was for our grief during our healing. Without Canuck Place, we would not have been given any information about what to do. There would have been no counselling or any chance to speak to other bereaved parents. My heart breaks for families who do not get to spend time with their children, have no one to talk to, or have to figure out all the formalities for themselves.

In fact, we tried for several months to get specialized support in other ways and it was incredibly hard. In my mind, there is a huge gap in the system for thousands of parents in situations such as ours, and the existing support system feels like the wrong way around. If our son had lived, we would have had all our own preparation. We would have had all the connections to other parents to talk to and ask questions. We had relatively easy access to various services such as lactation consultants, occupational therapists, sleep specialists, or counselling in cases such as postpartum depression. When the unthinkable happened and our son died, there was very little outside of the help we received from Canuck Place.

With Marlon, my wife had already been on maternity leave and no further interaction with Service Canada was required. My employer was extremely supportive and I was able to take time off. We both had extended health plans that would later cover some counselling for us, but not for bereavement, only for depression. Again, not everybody has these extended health plans.

Over several months, we managed to get some sense back into our lives and tried again to have another child. We were pregnant again and were considered low risk. Our second pregnancy went without any complications until one morning my wife woke up and couldn't feel the baby move. On December 9, 2012, our son Tobias had died in the womb at 35 weeks' gestation.

As other parents have mentioned, in the weeks to follow the deaths of our children, we were not in any position to think clearly and take care of the most mundane tasks. Our social connections to other parents were not of much help. They were all-too-drastic reminders of what we had lost. We wanted to hide from the world, as seeing a pregnant woman or a family with children was torture. It meant that going shopping, for example, was out of the question. We had no appetite anyway. I can tell you that I've lost friends as a teenager and I lost my dad to a brain tumour, but this type of grief was unlike anything I had ever experienced before. Our world had completely fallen apart.

After Tobias died, we had to make arrangements with Service Canada to organize my wife's maternity leave. During this difficult time, we had to leave our safe home where we could hide and venture out into the world to file some paperwork. We had to stand in the open-plan office and explain our situation. Not only that, but several years later—in fact, two years ago today—we received a letter from Service Canada stating that we had claimed too much money. It took multiple phone calls and letters over several months to clear up with staff that we had not committed any type of fraud for this overpayment. We had simply requested the time to start immediately after Tobias' death, which was on a weekend, and my wife did not go back to work on Monday.

• (0855)

Due to some system settings, the EI system automatically adjusted the start date from the Monday that we had requested to the Monday of the following week. We didn't pick up on it, and my wife's employer started the week we had requested, so there was this one-week gap. We then had to explain over several months that we were entitled to the 15 weeks but that there was this discrepancy.

In 2014, our daughter Thea was born. Given our history, we delivered her four weeks early and spent nine days in the NICU with

her. She is now a healthy four-year-old and we enjoy every day with

In 2015, we tried for a final time to grow our family but experienced an early miscarriage at seven weeks.

Having personally experienced miscarriage, stillbirth and neonatal death, it is important for me to encourage this committee to look at pregnancy and infant loss holistically. It affects a lot of Canadians in very different circumstances. One of the committee members said earlier that the rules often apply in black and white, without grey areas. Unfortunately, these tragic situations are anything but black and white and require compassion and empathy to help parents get back to being functioning members of Canadian society.

Thank you for allowing me to share our story. Like the previous speaker, I fully support the suggested proposal of giving parents 12 weeks off and automating the process to simplify it and not have this undue necessity for them to follow the paperwork.

Thank you.

The Chair: Thank you very much. Quite frankly, it's a very special thank you, as I see the clock behind you reading 6 a.m. We really appreciate your being here at such an early hour this morning. Thank you.

Up next, from BriarPatch Family Life Education Centre, we have Mr. Bill Roberts, co-founder, H.E.A.R.T.S. baby loss support program, and Ms. Cheryl Salter-Roberts, executive director, H.E. A.R.T.S. baby loss support program.

You have seven minutes.

Mrs. Cheryl Salter-Roberts (Executive Director, H.E.A.R.T.S. Baby Loss Support Program, BriarPatch Family Life Education Centre): Thank you.

I'm going to speak for both of us, and I am also speaking for parents across Canada who are currently experiencing their own baby loss journeys and don't have the voice to speak today. I will be that voice.

As both a bereaved pregnancy loss and baby loss parent and the co-creator of our local baby loss support program in my community outside of Edmonton, Alberta, I'd like to share our experience and our story and the knowledge that we now possess in this unique and critical area.

My husband Bill and I knew long before we were married that a larger than normal family was something we both hoped to achieve. We were fortunate that conceiving was never an issue, but staying pregnant, in time, became a challenge.

Our first couple of pregnancies were easy. We welcomed our first daughter, Chelsea, naturally and then two years later, we welcomed our first son, Brady.

With our first child I was able to enjoy a paid maternity leave and then decided not to return to work full time due to high child care costs in our area. I ended up being home with our children for more than 20 years, a time that I cherish and wish for all parents.

When it was time for our third child, we were shocked, surprised and very unprepared to experience the first of many losses. Our doctor and midwife did not have any answers for us as our loss was so early in our pregnancy. We took some time to heal, and then we tried again, happily welcoming another healthy, naturally born son, Brodie, the following year.

We took a short break while Bill returned to university. In his final year, we decided it was time for our fourth baby. Again, we experienced two miscarriages before finally welcoming our second daughter, Chynna, just 10 days before Bill's graduation. It was a magical time as my husband started his new career and we began life as a family of six.

Our losses during these years were heartfelt and so very difficult. With the support of good friends and family and each other, we muddled through, but it was our next two losses that changed our world and our path in life. As our children grew healthy, happy and strong, we knew that we wanted our family to continue to expand and were so excited to announce our next pregnancy. One night, later in our pregnancy, I realized I was in labour. Though our son was to be born at home, we decided to head to the hospital with the hopes that they could stop this early labour. Unfortunately, I labour too quickly and there was nothing anyone could do.

We were treated with grace, dignity, care and compassion, but the following morning we arrived home with empty arms and broken hearts. We named our son Bretton-Elijah Lucas and his birth and death altered our lives forever.

Within days we knew that this wasn't a loss that we could do on our own, that we could figure out, and with community support we created a program in our hamlet called H.E.A.R.T.S. baby loss. We began in 1996 and today we have supported, counselled, held and cared for over 4,600 families in person, by phone, by email and even on Skype.

Our services are broad. They cover western Canada, northern Alberta, into the territories and across the States. We include support groups, online chats, home visits, counselling, programming for siblings, a newsletter, an annual candlelight service and resources for anyone seeking support.

Just over six years ago we launched the Baby Steps Walk to Remember, which MP Blake Richards has attended. He passionately spoke about motion M-110 with our families. This is a day for anyone touched by the loss of a precious baby.

On October 14, just a few weeks ago, we had our walk at the Alberta legislature grounds in downtown Edmonton. We walked with just under 300 parents, siblings, friends and family members as we honoured 206 babies. In six years over 1,800 people have walked this path, representing just over 1,200 precious babies.

Every year in Alberta almost 16,000 babies are lost during pregnancy or after birth, with one out of every four documented pregnancies ending in miscarriage, and over 400 babies dying by

stillbirth, like our son, Bretton. Without a breath and without opening his eyes, Bretton's short existence has created support, education, awareness and compassion for those who suffer this unique and tremendous loss.

After Bretton's birth and his death, we often asked the question, "Why?" In time, we have come to see his purpose was to be the catalyst for this programming. We both feel fortunate to devote our lives to this needed cause.

As we developed our program, we were encouraged to offer other options to families in our community. We have created a family life education centre along with our baby loss program. It was amazing work that included our family, our community, friends and coworkers.

Then it happened again. We waited some time, to heal and to create our family life centre. Our doctor and midwife were confident that our stillbirth experience would not be repeated as I was still young and healthy and stillbirth is rare. On the evening of August 21, 1998, in the comfort of our home, we welcomed Ciara-Rose Kennedi with a quick hello and a very sad goodbye, all in a moment that stopped our lives once again.

This time we knew how to find support and how to incorporate this incredibly hard loss into our lives once more. Even with all our experience and knowledge and with community around us, our arms were once again empty and our hearts once again broken.

• (0900)

Over the next few years, as we continued to grow in our healing, we experienced three more miscarriages and decided that, without a medical reason for all of our losses, we would focus our energy on continuing to raise the four amazing children we had. I think it is important to share that, although we had and are blessed to have raised these four now adult children, it does not diminish our grief, because we know exactly what we've lost, not just the dreams and hopes for a healthy baby in the future with our hoped-for children, but significant losses for that first tooth, the never-taken steps, the absence of the first day of school, and all the way up to those grandchildren we won't get from those sweet innocent babies who died too soon.

In time, we renamed our centre, combining the first part of Bretton's name and the middle of Ciara's name to create our legacy project, the BriarPatch Family Life Education Centre.

We have four healthy children: Chelsea, Brady, Brodie and Chynna. Two significant stillbirths, Bretton and Ciara; six early miscarriages, Birkley, Cabriola, Cambria, Beau, Cree and Bentley: These are losses many people won't ever experience, but for those who do, the darkness of those early days of loss become the darkness of the days of grief that follow for the rest of their lives.

This is not a grief that can be simply overcome by reading a book or attending a support group. Baby loss for most families requires intense care from a physician or caregiver for the physical impacts, specialized support for the emotional impacts, community support for the social impacts, educated support for the spiritual impacts and psychological support for the cognitive impacts.

This is a grief experience that is not like any other. None of us enter into our pregnancies with a checklist of what to do if we lose our baby. None of us have thoughts about how to handle a miscarriage, how to handle the broken hearts and the fractured relationships, where we would bury our baby, who would do the service and what style of casket to choose.

I'd like to now share my thoughts in support of motion M-110. This initiative was first brought to our attention by MP Blake Richards, and we are happy, not only as a family, but as an organization, to provide insight into the plight of our families and the impact of baby loss on families and the community at large.

For the families who have been able to access employment insurance benefits for the maternity and paternity leave, it is heartbreaking to hear the stories of those who find themselves cut off from the benefits once the system learns that their baby has died. On top of a reduced income already, there are many costs associated with baby loss, and most families are not prepared for the challenge. Paying for a funeral is costly, and although the funeral homes are often generous in helping with reduced costs, in the end there are still items we need to pay for. If the father or partner takes time from work to support the mother as well as for his own grief, there may be additional lost wages to think about and cover.

Our medical system covers many procedures, but with a baby loss there may be medications or services that are not part of the provincial health care plan or supported by private benefits. Counselling may be covered, but the costs can be high, and very few appointments are covered.

Children and teens, the siblings, are greatly affected by baby loss, which results in missed school days and counselling appointments, and they may present with behaviour that could begin as they struggle to understand what has happened. Children and teens do not possess the language to fully talk about their feelings and emotions, and this is where we see adverse behaviours that could, without support, escalate into experimenting with drugs and alcohol to dull the pain and numb the experience. Mental health issues could formulate, and this is another cost to the system.

We need, as a country, to support these grieving families as they journey through baby loss with legislation that gives them the opportunity to retain their benefits to give them time to heal and time as a family to work through this tremendous grief journey. We need funded community supports for the parents, the children, extended family members and the community at large. Baby loss affects us all in lost work time, lost social time, lost physical time and lost emotional time.

As a mom at home during our children's growing up years, I did not qualify for maternity benefits beyond our first child, but a benefit that would have provided my husband with some time off to be home with us as I struggled physically and emotionally to be with

our children as they tried to grasp the concept of grief and loss and, most importantly, to have time for his own grief to work through the complexities that affected our relationship and to grow in this dark time would have made a world of difference. Instead, he had to return to work, hiding his tears and his pain while being strong for me and our children.

We figured it out, and although not every marriage survives pregnancy or baby loss, our opportunity to help others has strengthened our commitment to our marriage and our family. It's always a work in progress but, it's healthy and whole.

● (0905)

Today, if asked what would help these hurting and vulnerable families, what we need and what would make a difference, I would reply with the following: Restructure the current system for families to access and retain the full benefits they are entitled to under the Employment Insurance Act. Create a new benefit, as other families have hoped for, of 12 weeks of comprehensive grief supports, across Canada for all baby loss families in all communities; a concrete benefit leave for both parents and partners to cope with the physical, emotional, social, cognitive and spiritual impacts of their unique pregnancy or baby loss grief; a leave that is simple to provide and simple for parents to apply for, ideally automatically when the news of their pregnancy or baby loss is entered into the system, with no hoops to jump through. Create sustainable and long-term funding and support for specialized programs like ours that offer the peer-support aspect.

We are often referred to professionals, and as a professional in the community, I'd like to say that those supports are lovely, but parents really want to talk to other baby loss families. If we can create baby loss facilitators with professional resources, this is ideal.

Funding this area would reduce health care costs down the road for those who seek support, education and resources, if they could have it at the time of the loss and when they need it down the road, without barriers and without personal cost.

We trust that this information provided today is helpful to this committee. We offer our experience and expertise to those who examine this issue, those who will bring forth the recommendations and those who will decide the outcome of this important motion for our grieving pregnancy and baby loss families across Canada.

Thank you for your time in listening to our story today and for your support in making this critical issue a positive and healthy experience for all.

● (0910)

The Chair: Thank you very much.

Now from Gardens of Grace, we are joined here in Ottawa by Paula Harmon, founding director; and Jessica Weatherbee, director.

You have seven minutes, please.

Mrs. Paula Harmon (Founding Director, Gardens of Grace): Good morning, and thank you for giving us this opportunity to be a voice both for my Grace and for Jessica's Vincent, and for other bereaved parents as well.

While my story is extremely long and complicated, I will stick to the parts that apply here.

My daughter, Grace Neala Tamsin, was born back in 2013. She was an unexpected, late-in-life surprise, and originally she was a twin. We found out early that the twin probably had a fatal genetic disorder, and if the baby did make it to birth would probably only live for a few hours. We were given no further information than that and sent on our way. Then, at 17 weeks, I contracted a food-borne illness called listeria, pretty much the worst infection you can get when pregnant. Few babies survive it.

When I called my rural maternity ward, their suggestion was to take a warm bath, since we hadn't reached the 20-week viable stage, saying I would just sit in emergency for hours since I wouldn't be a priority.

Our women's and children's hospital in Halifax, the IWK, did admit me immediately, found out the compromised twin had died, and when my water broke two days later, they said I would basically be in hospital on IV antibiotics until the surviving baby was born. Keep in mind I was only 17 weeks pregnant at this point. Nine weeks later, Grace was born in distress at 26 weeks. She had a long haul at the IWK before being released at seven and a half months old. I lived in the hospital with her the entire time.

Fast-forward three years, and Grace is a happy, healthy, normal child with only a bowel issue as a remnant from her NICU days. Even that had been downgraded in early December to minor follow-up. Then, on December 28, we took Grace into emergency with what everyone thought was just another minor bacterial infection to her bowel. Eighteen hours later, she died. Invisible scar tissue that couldn't be seen on any imaging equipment, the unexpected result of an operation at six weeks old, strangled her bowel and caused her death.

Due to the many demands early on with Grace, I stayed home with her. I had only just returned to a temporary job in the summer of 2016, which ended that same December. With Grace's death, I didn't think about EI right away, and when I did finally apply, I barely qualified because of the hour requirements. They asked me why I had taken so long to apply. I told the girl on the other end of the line that my three-year-old daughter had died. She had no idea what to say. I felt I had to apologize to her for making her cry.

She had to pass me to a manager to sort out my application, so I had to explain again what had happened. It was suggested I could apply for sick EI as well if I were to submit a doctor's note, so I went to my doctor who wrote a "bereavement of daughter" note.

Weeks later I got a letter in the mail saying my claim was rejected, with no reason given. I called the same EI manager back. I was told bereavement was not an acceptable excuse for sick leave. I asked what would be acceptable. They weren't able to come right out and say it directly, but when I asked about stress, they implied that might work.

So, I had to go back to my doctor and explain to him that the first note was denied. He wrote another note using stress as the reason. Stress is an acceptable excuse; death of a child is not.

We also received unnoticed automatic deposits of the child tax credit, months' worth of deposits, even though Grace's health card was cancelled, her social insurance number was cancelled, and a death certificate was issued.

Mention has been made by previous witnesses of family and friends stepping in to tend to things—making sure bills are paid, groceries bought, all the little things that need tending to. Those are the things I usually thought about for others, so we just didn't notice until months later when I did, and it all, obviously, had to be returned. When I asked the CRA lady why payments wouldn't just automatically stop in those situations, her response was that because of security, one department couldn't inform another department even when dealing with death.

Through all of this, my husband Neil has continued to work. Some days he copes; some days he doesn't. Luckily he has a very understanding boss, but we weren't in a financial position for him to take any real amount of time off to grieve. Neil has, unfortunately, had a much more difficult journey. Over a year and a half later, almost two years now, there are still many days he can't face the world. Would he be in a better place now if we had had the opportunity to allow him the time he needed not to worry about bills piling up and obligations that needed to be met? I think it certainly would have helped him.

I will turn over our remaining time to Jessica Weatherbee.

• (0915)

Mrs. Jessica Weatherbee (Director, Gardens of Grace): Good morning, everybody.

As Paula said, my name is Jessica Weatherbee. I'm a registered nurse.

My son's name is Vincent. He was our first child. He was born at 23 weeks gestation and passed shortly after birth in my husband's arms. Imagine this: You're a father and you've just experienced the loss of your child. Imagine what kind of emotional state you would be in while trying to be there emotionally for your partner, who is also physically ill from the complications that ultimately led to the death of your child.

This is what we went through. He worked for a cable company running lines in close proximity to high voltage, something that requires a sound mind and attention to detail. His employer gave him just over a week off work, which they considered generous at the time. As a note, this was my husband's vacation time for the year. Just seven days prior, he held our son as he took his last breaths, and somehow he was expected to go back to work. We didn't have a family doctor at the time, as many people don't, so we went to a primary health clinic in my hometown where no one knew about our loss. We couldn't go to a local ER as we would have been a nonurgent case and would have had to wait for hours and hours. Mentally we just couldn't handle that. We saw a physician and asked if my husband could be put off work. The doctor actually said to us that this was not a legitimate reason to be off work. He gave my husband a prescription for four tables of Ativan to help him sleep and sent us on our way.

In that week we had off, we had to fit in all the end-of-life arrangements and try to come up with money to pay for all of the unexpected expenses. I have a well-paying job. We were what I would consider financially stable; however, I wasn't anticipating any of this. No one financially prepares to bury their baby, nor do they prepare for all of the expenses that come with being off work on an unexpected early leave. Ultimately I was off work for nine weeks. I was entitled to 15 weeks. I returned for two reasons. First, I couldn't stand being alone in my house any longer since my husband wasn't home and we had no other children. The silence was not therapeutic. Second, mine was our primary income. My husband worked for a little over minimum wage. We have a house, a vehicle and other bills.

I filed for EI in the first two weeks after Vincent passed away. I never received a payment until my first day of returning to work on November 10, 2014. Vincent was born on September 4. I called several times to see what the holdup was but was mostly told to wait patiently.

I do believe, as a direct result of my husband's lack of time off after the passing of our son, he has developed depression.

Thank you.

The Chair: Thank you very much.

Finally, from Les amis du crépuscule, we have Alain Pelletier, managing director.

You have seven minutes.

[Translation]

Mr. Alain Pelletier (Managing Director, Les amis du crépuscule): Thank you, Mr. Chair.

Our organization is 25 years old, and here is its mission.

The first component of the mission is support for people who are at the end of their life at the Hôtel-Dieu-de-Saint-Hyacinthe palliative care unit and at home.

Our second component is support for individuals who are bereaved. That is what brings me here today.

We train volunteers who support those people. They were initially selected because they have strong listening skills and an unwavering respect for human beings' ability to take care of themselves. We support individuals who are going through difficult times. We have to ensure that our volunteers do that as tactfully as necessary. Our support is completely free of charge, and I want to stress that: we support people for free. Currently, we have 60 volunteers on our staff.

Our basic training, titled "supporting others is supporting yourself", is a 30-hour course. After that training, we select the individuals who become our volunteers. It should be noted that not all individuals who attend that training can become volunteers. Afterwards, before they start to provide any support, our new volunteers receive 15 hours of training on helping relationships, titled "the support worker". Following that second training course, volunteers decide whether they want to support people at the end of their life or people who are bereaved.

The new volunteer can immediately be used as a co-facilitator in a group of bereaved adults. We do not let our new volunteers provide support alone. We show them the proper way to do it. This means that bereaved people are provided with individual support or participate in groups of five to eight people. We are talking about 10 meetings over 10 weeks. Two volunteers provide support in groups, and one volunteer provides support to someone else during individual meetings. So the support provided over those 10 weeks is done right.

The following training courses are added to the basic training. A special approach has been developed for supporting children who are bereaved. It is called "I listen to my little voice". That is a 15-hour training course. Volunteers who have received that training can support groups of bereaved children. We also have a special approach for adolescents called "discovering your road". That is another 15-hour training course that enables people who take it to support adolescents.

We have also started to develop an approach to deal with infant loss. Many people in our society often do not consider the loss of an unborn or newly born child as true bereavement. However, the parents, grandparents and other family members are very affected by that loss. So we will provide special training that will enable its attendees to support the clientele affected by a loss that is just as important.

As for family members who have lost a child, we support them through various approaches we have developed. Every bereavement is unique, and we listen to the specific needs of every person who turns to us.

Taking into account the available budget, we register our volunteers for different conferences and training sessions. A number of volunteers have received the training Agir en sentinelle pour la prévention du suicide—acting as sentinels to prevent suicide.

On Friday, November 2, which is tomorrow, a seminar we organized will be held at the Saint-Hyacinthe Convention Centre. Its title is "loss and family". A number of our volunteers will be in attendance. About 100 people will be there to hear conferences on various topics related to that theme.

Our organization has built an excellent reputation over its 25 years of existence. Bereaved individuals who have used our support have all talked about the improved well-being they experienced afterwards. The meetings give them an opportunity to talk freely about the great void left by the deceased individual. They were able to recognize the emotions they were experiencing and left with tools that would help them in the future. So returning to normal life became easy.

● (0920)

I would like to talk to you about our financial situation.

We receive funding from the Government of Quebec through the community organizations support program, but that money is insufficient. It accounts for only 40% of our annual budget.

Fortunately, we have generous donors who support us financially every year. Despite that, we have to hold two fundraising dinners. When things go well, the money raised by those dinners helps us balance our budget. However, year after year, we are seeing a drop in people's enthusiasm for those types of activities.

Be that as it may, we put many hours into the preparation of those events. The time we are putting into that gives us less time for developing our approaches, supporting our volunteers or strengthening our cooperation with the health centre and our various partners.

Thank you for listening to me. I hope you will take our testimony into account.

• (0925)

[English]

The Chair: Thank you very much.

Mr. Diotte, you have six minutes.

Mr. Kerry Diotte (Edmonton Griesbach, CPC): Thanks very much.

My sincere condolences to all the people who are struggling with the loss of loved ones. It sounds terrible. I was not personally aware of how impactful it is on people's lives. Thanks for coming forward and telling your brave stories.

One of the things I'm hearing right off the top is the difficulty dealing with bureaucrats. Jens, you mentioned getting a letter from Service Canada saying it had paid too much for child support, I believe. Paula, you talked about the child tax credits, and CRA wanting that money back. You have to wonder how people don't know this. We've heard the headline stories about StatsCan going into banks and getting information on 500,000 people. It must be very frustrating.

Paula, what do you see as a solution to this?

Mrs. Paula Harmon: I would think that part of it is counselling. If you've cancelled the health card and social insurance number and a death certificate has been issued, there should be some line of code,

or something that triggers a flag in the system that would let Service Canada or the CRA and those people know that something has happened that would trigger other automatic responses.

Michelle LaFontaine mentioned that the other day in her testimony. Even at the beginning when a child dies, there could be some sort of release form that is signed to let the different departments know that this has happened, to reduce all of that.

Mr. Kerry Diotte: Just so I understand, it seems you were told that one department doesn't deal with another department.

Mrs. Paula Harmon: Yes.

Mr. Kerry Diotte: With what two departments were you dealing?

Mrs. Paula Harmon: If a health card has been cancelled, there's a reason for that. If a death certificate has been issued and you let the government know, there's a reason for that. That's one department. There's no reason to be sending out money for a child that is no longer alive. There are systems there that have that information. Share it. That wouldn't be a secret.

Mr. Kerry Diotte: How did that make you feel when you were having to go through what you were going through?

Mrs. Paula Harmon: It was frustrating to begin with, because you don't want to have to deal with those sorts of things, staying on the phone for hours, or having to go into specific offices if you can't stay on the phone. It just adds a burden on top of everything else. If you can't get out of bed, you don't want to be dealing with government officials.

Mr. Kerry Diotte: We've also heard horror stories about the CRA where people were hung up on, on one-third of their calls. This is from the Auditor General. They got bad information on one-third of their calls.

What was your experience with the CRA?

Mrs. Paula Harmon: The people I talked to were understanding but there was nothing they could do because of the system, the processes that were in place. Those processes need to be altered to allow for compassion.

• (0930)

Mr. Kerry Diotte: Thank you.

Jens, can you explain your experience there? You had talked about a letter from Service Canada saying you claimed too much money.

Mr. Jens Locher: I think the people who were trying to help us in the Service Canada office didn't know exactly how it all worked. That was our problem at the same time. I remember holding these forms and trying to figure them out and I had these very mundane questions like date of death and date of birth. He died on December 9 but he was born on December 10. What do they want me to enter there?

I was sitting there not knowing what to do. We didn't know when the maternity leave could start so we asked various questions. At that time we had obviously already informed my wife's employer that she wouldn't come back on the Monday but we only went to the office later so she was put on sick leave. Then we were informed by Service Canada that maternity leave has to start immediately after birth so all of it had to be undone. The sick leave needed to be reverted and she would need to go on the support payment from the employer, the top-up, expecting that the EI payments would start on that Monday.

Then the employer issued the record of employment up to the Sunday, although my wife doesn't work on Saturdays and Sundays. They said they were paying her until Sunday, but then five years later, Service Canada explained to us, "Oh, we thought it had been issued until the Sunday. This pushes our start a week out because our week starts on Sunday and you can't have your first payment on a Monday."

Ultimately we received the 15 weeks of payments that we were entitled to, but because of this change of the start date that we didn't pick up on, they sent us all these letters, "Here's a debt invoice. You need to send back this amount of money." It took numerous phone calls and multiple supervisors to tell them what had happened and that we don't know why the date was adjusted and they said [Inaudible—Editor]. There were a lot of unknowns in how to deal with the situation.

To make it better I would love to see a dedicated team of people who are especially trained on these types of cases. I think it would be very ambitious to think that every Service Canada employee can get all those situations right. I think it's unfair to the employees as well because they are emotionally affected by those situations as well. I think they should receive proper training, how to support parents in those situations and know all the proper procedures at that time so they can give the right information when they talk to parents.

Mr. Kerry Diotte: That's a good suggestion.

Mr. Jens Locher: I have another example I would like to share. There's a process whereby about a week after delivery a public health nurse does a follow-up call with families, so some information is flowing. Someone tells the nurse that there was a birth and they're to follow up. They don't tell that nurse when the baby died. You might assume how those conversations go when these nurses go into the home not knowing that the baby has died and start by saying, "I am here to support you. Do you have any questions? How is the baby doing?" Then you say your baby died, and it goes down from there.

It's upsetting to the parents to get those calls. I have to wonder how that is possible. I don't think I've ever consented to my information being shared with this person, so why do we hear again and again that there are privacy issues in making sure that the information that my child died can be shared with this person so the nurse could be informed that they are not supposed to call and maybe instead a bereavement counsellor could call and set up some counselling with the parents.

Mr. Kerry Diotte: Thank you.

The Chair: Next up we have MP Long, please, for six minutes.

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

Thank you to our witnesses for your courage in coming here to tell us your stories. I want to thank MP Richards for bringing forward motion M-110.

I want to ask so many questions. I'll start with you, Ms. Roberts.

Thank you for your testimony. You mentioned you wanted to see a restructuring of the current system, and you had three points you wanted to go through. Could you go through those three points quickly again so we can make sure we have those clear?

Mrs. Cheryl Salter-Roberts: One would be restructuring the EI benefits system.

Mr. Wayne Long: How would you do that if you had the power to restructure the system?

• (0935)

Mrs. Cheryl Salter-Roberts: If I had the power, at the point that the baby dies, the doctor, physician, caregiver, midwife, someone would be able to present that information to the system itself.

Mr. Wayne Long: It would be almost like an automatic trigger.

Mrs. Cheryl Salter-Roberts: Exactly. We fill out a form and we get our social insurance card for our baby. We get our health care card

Could there not be another system like that where it's just here it is and then it's done? It would be a system where families are given that 12 weeks or 15 weeks, whatever we're going to decide is applicable and adequate.

Mr. Wayne Long: Is 12 to 15 weeks adequate? The Cormier family was here a few sessions ago and proposed 12 weeks. Is that enough?

Mrs. Cheryl Salter-Roberts: Grief is a journey. This is something we will live with for the rest of our lives.

I think for most families 12 to 15 weeks would give some time. Not every family is going to take the entire time given.

As Jessica mentioned, going back to work was something that was helpful for her. To be home without noise around you isn't always helpful. To have that time....

Mr. Wayne Long: Would you also propose flexibility in the EI system? Some people, I wouldn't say need to go back to work, but some people can heal better back in a work environment.

Could you see flexibility in the EI system?

Mrs. Cheryl Salter-Roberts: I think the one thing I would ask for as a proposal is that if a family decides that they're going to go back to work, the mother, the father, the partner says, "I'm ready to go back to work," but six months later the grief resurfaces and there's time needed to be off, that would be applicable as well.

Maybe it's 12 weeks over a period of a year and you could take a chunk here and there if you need it.

Mr. Wayne Long: I can't certainly experience what you've gone through, but I remember when my father died, I needed to go back to work. It helped me heal. But six months after, that's when it really hit me and I really needed the time.

Mrs. Cheryl Salter-Roberts: Exactly.

Mr. Wayne Long: What else?

Mrs. Cheryl Salter-Roberts: I will tell you very quickly.

Mr. Wayne Long: Yes, of course.

Mrs. Cheryl Salter-Roberts: Two to six months is the time that it takes for the shock to wear off that a death has occurred and reality sets in.

Six months is key. It takes two to six years to incorporate a regular death experience, grief experience, into our lives. That does not include baby loss. That is just the loss of a father, the loss of a sibling.

Mr. Wayne Long: Absolutely.

Mrs. Cheryl Salter-Roberts: There are two things to note: two to six months and two to six years.

There's another thing I would think of in our situation. I was already at home so I didn't qualify for maternity benefits but for my partner, my husband, the father should be able to have some time for his own grief. He was fortunate to have an employer who said to take some time. But he felt pressured to go back to work because....

Mr. Bill Roberts (Co-Founder, H.E.A.R.T.S. Baby Loss Support Program, BriarPatch Family Life Education Centre): There was pressure to go back.

Mr. Wayne Long: Let me just jump in.

Another witness at an earlier meeting said that the workspace is one area where bereavement is less recognized.

I'll go through the whole panel because all of us have to go back to work at some point.

Some work environments are helpful and supportive; others couldn't care less. We had an example of a guy who went back to work and he was laid off three months later because he lacked passion.

I want to start with Ms. Fuentes in Miami.

Do you have any recommendations on what could happen in a work environment?

We're a federal government. What can we do? What could a government do to create a more understanding, accepting culture in the workplace?

Ms. Fuentes and Mr. Panneton.

Mr. Philippe Panneton: I'll take this one.

We've given this some thought.

We have a really supportive employer. We both work for the same company. They've continued to support us whenever we've needed it over the course of the two years since our son has passed. What I would like to see on the part of the government is that in the same way if you were on sick leave or the same way if you're on mat leave, you're guaranteed your employment. Your job will be there once you return to work. If you need to take personal time off for bereavement, whether it's paid or unpaid, we'd like to see the same guarantees put in place. That would take some of the stressors off a bereaved family or a bereaved parent.

Mr. Wayne Long: Okay.

Go ahead, Mr. Locher.

• (0940)

Mr. Jens Locher: I have to say that my work was very supportive, so I was very fortunate in that sense.

We actually discovered—and this is one thing that hasn't been mentioned very often—that so many people are affected.... Actually, at work, people come forward and tell you things that you never knew had happened. There's a stigma or challenge about talking about these children who have died because it's not a conversation starter. After my son died—in our office, there are 48 people or so—I learned there were six or seven families who had lost children in various circumstances. I worked with these people for years and I didn't know these things. Then people came forward and told me these stories.

My employer was very supportive. They had a bereavement counsellor come because the office was affected by it. Those kinds of things are quite extraordinary but not everybody is that fortunate.

I hear the horror stories from people in our support network, where it's the opposite. Some have a period of three days of bereavement and then they're back and there is nothing else. I think there's a whole spectrum—what I've experienced as compared to what I hear from other people.

How the government could help with that is a really difficult question to answer. It is related to this awareness about how many people are affected and what grief really does to someone and how they can be supported.

As was previously indicated, having this ability to take the time and the flexibility of time is important. As Cheryl said, I don't think it means everybody has to take the time. I was actually one of the people who found it useful and helpful in my grief to go back to work. I didn't stay off too long, even though my employer would have allowed me to stay off longer. For example, my wife couldn't go back to work. She couldn't concentrate and it was impossible for her to work. It was good for her to have maternity leave.

I think there needs to be flexibility. For the people who do feel that it's helpful for them not to go back to work immediately, it would be wonderful if they had the possibility to have this amount of time and that it can be shared between the partners, so that the mother doesn't only get the time, but that there's time for the father as well.

Mr. Wayne Long: Thank you very much.

The Chair: Thank you.

MP Sansoucy, the floor is yours, please.

[Translation]

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

I would like to thank everyone who is appearing before us. Your testimony is really important for our study, the topic of which was suggested to us by our colleague.

Mr. Pelletier, I want to tell you that I have heard several people talk about how important your organization has been in their lives. I think that our community is fortunate to have had 25 years of support from an organization like Les amis du crépuscule, which provides assistance to bereaved people.

Since the beginning of our study, we have been hearing about benefits for parents. We heard more about that this morning. A number of organizations have also told us that they relied only on volunteers and that they had no funding. You said it yourself—the department of health and social services is faced with many health-related costs, in addition to supporting community organizations. In your case, barely 40% of your funding comes from the provincial government.

I would also like to congratulate your team and your board of directors who, despite your organization's difficult financial situation, have decided to set up a new program for infant loss, using money you have obtained with difficulty.

I know that, for other areas of activity, such as women's organizations, the federal government has subsidy programs. Since bereavement can affect anyone, regardless of the province of residence, do you think it would be important, as part of our study, to issue a recommendation to support organizations like yours? A witness told us that he came from a region with no resources. Regardless of where we live, it would be good to have someone to turn to for support in the difficult moments of bereavement, especially involving a child.

Mr. Alain Pelletier: We often hear comments like that one.

People who live 100 kilometres away from our offices come to us for those services, as they are not available everywhere. They are very rare. We are committed to that mission, and we continue to carry it out despite the lack of funding.

The testimony we hear from people who use our services is always very eloquent. All those people, without exception, tell us they feel better after receiving the support, which is provided over approximately 10 weeks. They live in the present better and feel much more prepared to deal with the future. The grief remains and will never go away, but those people are now able to deal with it better.

We will proceed in the same way for infant loss because we think that loss is just as important as the others. We will do everything possible for those people to be better able to cope with the absence of that small being. Although the child may have only been in their life for a short time, those are important moments. We will ensure to continue to fulfill our mission in that area.

● (0945)

Ms. Brigitte Sansoucy: At our last meeting, Chantal Verdon, a researcher at the Université du Québec en Outaouais, told us that it

would be helpful if the federal government launched a broad public awareness campaign on the issue, similar to the one on acceptance of mental health in our society.

A number of witnesses have told us that bereavement was not sufficiently known or recognized. In addition, as you pointed out, some people feel that infant loss is not as serious as other losses.

Do you think it would be a good idea to have a public awareness campaign on what bereavement is and its consequences in order to educate people about that reality in our lives?

Mr. Alain Pelletier: Absolutely. Bereavement is not something that begins one day and ends a year later. Everyone experiences loss in their own way, depending on what they feel. Earlier, Mr. Long was saying that the most difficult moment for him happened six months after his father's death. Everyone experiences those moments in a very personal way.

A Canada-wide public awareness campaign would be useful because everyone will face the loss of a loved one eventually. So everyone should be made aware of the fact that this is a very difficult experience. The campaign should provide all those who are experiencing a loss with tools to deal with it.

Ms. Brigitte Sansoucy: I used to be a director of a community organization for troubled youth, and nothing hurt me more than hearing a parent say that they would have liked to know about the organization when it would have been useful.

Your limited resources do not allow you to promote your services. A number of people we have met with have told us they did not know where to turn.

Do you think it would be useful for your services to be known to Service Canada or hospitals, for example? What could be done to ensure that the existing resources are known, so that organizations can refer to them people who need those services?

Mr. Alain Pelletier: You had the answer earlier when you talked about a public awareness campaign. That campaign would introduce the organizations that provide those services.

This morning, I have heard a number of people who did a lot to help people in their area. It is important for those individuals to be known and recognized by people who will go through the same issues later without knowing where to turn. It is important to make it known that those organizations and that assistance exist, and people have to know where to find those resources.

Ms. Brigitte Sansoucy: Thank you very much.

[English]

The Chair: Thank you very much.

Next is MP Ruimy, please.

Mr. Dan Ruimy (Pitt Meadows—Maple Ridge, Lib.): Thank you. I'll be sharing my time with Ms. Romanado.

Thank you, everybody, for being here today. It's not easy to have a bunch of politicians ask you probing questions. Please understand that to try to get to where we all want to go, we do have to ask some questions, because it's hard to understand.

We're a confederation that's made up of provinces and Jurisdictions pose a challenge as well. When we look at Service Canada, they're not connected, necessarily, with the different provinces.

What's the path forward? We've been hearing about the organizations that are sprouting up mostly from people who have experienced this. That's where I want to focus my couple of minutes, on the organizations.

Are you receiving any kind of funding whatsoever, be it through the province...not through the federal government.... Okay.

Do you have volunteers?

I want to be able to get it on record instead of shaking heads.

There are two questions I have. Are you getting any kind of funding? Are your volunteers getting any kind of training?

Why don't we start with Ms. Roberts.

• (0950)

Mrs. Cheryl Salter-Roberts: Within our organization we can occasionally get a grant, but usually it's a local grant, from CIBC, TD and those kinds of institutions that can help out. For the most part, families raise funds to help us. At our walk, they ask their families to support us by making a donation in their babies' names. That's where our funds come from.

In terms of volunteers, in my program in particular, I'm very focused on making sure that my facilitators and volunteers are screened, well trained and well supported, because the work involved is very critical and we don't want to make mistakes. They are coming from a peer support background. They themselves have lost a baby, so they get it. They understand, and then they could provide that, with training and support.

Mr. Dan Ruimy: Thank you.

Ms. Harmon.

Mrs. Paula Harmon: We only started a little over a year ago, so funding is interesting. We actually have no money. A lot of grants aren't geared toward bereavement.

Having to basically play the system to try to make what you're doing fit the grants is tricky. We're actually doing a training session on Sunday at the IWK in Halifax, with training material provided by the Pregnancy and Infant Loss Network here in Ontario.

Mr. Dan Ruimy: Thank you very much.

Ms. Romanado, you have my time.

Mrs. Sherry Romanado (Longueuil—Charles-LeMoyne, Lib.): Thank you very much.

[Translation]

I am really honoured to be here today.

[English]

Wendy and Philippe are from my riding, and I was delighted to help them in their quest to raise awareness of sudden unexplained death of children. Just in listening to the testimony this morning, I realized that 25 years ago, my husband and I lost our first child, so I know your pain and grief don't have a time limit.

I heard a lot about holistic approaches to loss—it's the province, it's local organizations, community, family, the federal government.

What can we be doing? We're talking about two different things in terms of what benefits or supports are available and the delivery of those. When you're suffering a loss, the last thing you want to do is jump through hoops. We heard that loud and clear. What could we be doing as members of Parliament?

We often get contacted by organizations or citizens, saying that they're having trouble navigating the system, that they need this or that, a passport, for example. What could we be doing to help in real time? These are small tweaks we can make so that we know that your organizations exist, and when other families come to us and say they're suffering, we can be that one-stop shop, that *guichet unique*, for families, and say, "Listen, we know you're suffering. Let us help you. We know there's an organization that can help there."

We can help you make sure that the CRA is aware of the death of your child, and we can make sure those benefits...people are notified. We can make sure that our provincial counterparts are aware.

What could we be doing to help you and help families? There are things we can be doing in real time that can help. I think just having that holistic approach, that one-stop shop could help, so that you don't have to keep telling the story over and over.

What would you recommend to us? That is an open question.

• (0955)

Mrs. Paula Harmon: I would like to answer that. To start with, I have a few points.

The first would be to have comprehensive information on a website about what steps are to be taken after a loss—a database of help information. Michelle LaFontaine mentioned release forms to trigger certain things. Sands in the U.K., the stillbirth and neonatal death charity, has a series of very useful booklets, not just a sheet of paper but comprehensive books with lots of good information. Two of them are dedicated to employers and employees and going back to work. One approach would be to have booklets like that to advise the workplace on how to treat the returning employee and to help employees who are dealing with the returning employee.

Second, allow flex time. If you hurt your back, you're allowed light duties. If you're in a job that requires more concentration, you're not going to be able to do that if you've lost a baby. It would be flexible to the individual.

Third, include ongoing, grief-specific resources through employee assistance programs.

Fourth, have specific education and training for Service Canada employees. This should actually apply to health care employees as well, because in many situations they're not equipped to deal with sudden death. There are no accreditation programs for doctors and health care workers to take. Our doctor, when we went back for the autopsy report, said she felt like she was throwing us to the wolves when we left the hospital that night. If that's how that doctor felt with us, how is she dealing with it?

It would be those and even a grace period for submitting medical forms. It might also include a turnover of maternity or paternity benefits to ease into the grief period.

The Chair: Thank you.

Next is MP Hogg, please.

Mr. Gordie Hogg (South Surrey—White Rock, Lib.): Thank you again to Blake for bringing the motion forward.

As a society, we want to see ourselves as compassionate, caring and able to provide these supports.

Through all of the testimony we have heard, there have been a lot of common themes, common issues that have evolved through this. It's a bit reminiscent of our cultural shifts back in—I think it was 1969 that Elisabeth Kubler-Ross wrote *On Death and Dying*, a book that brought a better grasp and understanding to western societies with respect to how to manage that. I think this is a new and important iteration of the kind of involvement that the hospice society movement had. It's clearly been able to continue with the notion that understanding, commitment and caring are so important in this.

Mrs. Harmon, you made reference to Sands in the United Kingdom. I'm wondering if any of the witnesses are aware of any jurisdictions in the world that have shifted in this, that have a better method. I think the values are probably consistent, at least across western democracies, as far as what people want to achieve. Do you have any knowledge of any jurisdictions that actually have implemented a system that we might be able to learn from?

Mrs. Paula Harmon: Sands is probably the biggest one. They've been around for 40 years and they also have branches in Australia. In fact, just this spring the U.K. implemented legislation to pay for funerals for all children under the age of—it's either 16 or 18. The U. K. government is paying for all those funerals.

Mr. Gordie Hogg: Is Sands a non-profit society that was generated out of this?

Mrs. Paula Harmon: Yes, they actually do research and they train doctors and midwives, which is the nursing program over there, very comprehensively on bereavement. Two out of three hospitals that have maternity wards in the U.K. have bereavement suites, which allow for "memory making" and a lot of other important follow-up. There are 103 Sands support groups across the U.K.

● (1000)

Mr. Gordie Hogg: Do any other witnesses have any other experiences or knowledge with respect to other jurisdictions that we might learn from?

Mr. Jens Locher: Is it possible to go back to the previous question as well? There was a question of what the Canadian government could do to help people.

Mr. Gordie Hogg: It's entirely possible to do that if you can wait one second, and we'll have Ms. Salter-Roberts' response.

Mr. Philippe Panneton: I'm unaware of any jurisdiction or legislation in any of the G8 or G20 countries. There are a number of large organizations like Sands. For us, it was the SUDC Foundation in the U.S. They're across the U.S., in the U.K. and in Australia as well, but it's a private organization, so there's no legislation that I'm aware of apart from what was just mentioned by the previous witness.

Mr. Gordie Hogg: Thank you.

Mrs. Cheryl Salter-Roberts: I can speak on our regional bereavement services that are available in the Edmonton area and beyond. Alberta Health Services has helped work with different organizations to create a path for families to make it a little bit easier.

One of the things that happens is, when you lose the baby, there is a package given to you, whether your baby is born at home, in the hospital, in the emergency room or wherever. This package includes one or two pages that have the support groups listed and what is available in terms of benefits, etc., so that families don't have to search for this. They don't have to try to find it online, because it's not always easy to find it online.

Each family is given a memory box, footprints, handprints, clippings of baby's hair and a teddy bear that we donate through our various programs and our walks. There are offers of counselling and there are offers of support after families have gone home. There is some continued support. People still sometimes fall through the cracks, but it's at least a beginning, and they're trying to expand that throughout our province in different regions. I know that is happening.

I'd like to see something Canada-wide where our support groups are connected so that we're all providing the same type of support so that families, from whatever region they live in, can rely on knowing what is available and so that the service employees will also know what is available out there.

I want to touch on the point that giving birth, whether it is at six weeks, 12 weeks, 22 weeks or 42 weeks and beyond is a physical experience. Part of that benefit we're talking about, the time that we're talking about, should include some physical.... I don't know how to explain it, but mother's milk is still produced. Your body doesn't know that your baby has died. There are still all of those physical discomforts, and that should be included as part of that benefit.

Mr. Gordie Hogg: Jens.

Mr. Jens Locher: Thank you.

I just want to come back to one question earlier: How can the federal government do something for parents? I've actually brought a few examples that I would like to share with you.

I fully reiterate what Paula has said, that you're already hearing from researchers during these witness testimonies. It would be wonderful if there could be a working group or a commission put together to develop material at the federal level along the lines of what Cheryl just mentioned, in terms of saying that this what your grief experience might look like, to just say that what you're going through is normal. A lot of parents feel as though they are going crazy and wonder what is happening to them.

It's just this idea that you can say, "Look, we know that this is happening. Here is the research on these things. Here's what we know that might help you. Here are some suggestions as to what you can do." It would be material such as the booklets I'll hold up here.

In B.C., for example, everybody gets these booklets. All people who get a healthy, living child get these very comprehensive booklets that have everything outlined in terms of the next three or four years. It's all researched. It's wonderfully prepared. It's a very good resource.

When your child dies, what we got from the hospital looked like this: self-printed, six pages, double-sided. It actually says on the back "Developed in 1989. Revised in 1999." It has very limited information, mostly around actually the physical aspects of what your body might go through as a mother after giving birth. There is a half page on the changes in your emotions, and it says in there that if you have further questions you should talk to your nurse, which we did, and they didn't know of any resources, not even the support group that was in their own hospital.

What I would propose is, what stops us from creating a national registry of bereaved parents? It would be an opt-in solution. Because we requested the documents of all our children from the hospital, I got to see all the paperwork that's already going out from the hospital to various organizations. I have one here, the "Notice of a Live Birth or Stillbirth". It actually has all the information in there that you would need to set up something such as this. It goes to statistics agencies, in this case, a provincial one, the B.C. vital statistics agency, but from there, I think it goes to StatsCan.

That would be the perfect way to say that all this information is going to the federal government and we can basically follow up when this information is submitted to the parents, either with a letter or by email, and ask, "Would you want to be part of network where we can connect you to other families that have experienced something such as this?" You'd just coordinate the peer-to-peer outreach that way.

Once you have that, the next logical step is to extend the registry for providers who are actually providing services to families, to say, "We know that you are in this area and we have these 15 registered providers here." That could be all the witnesses you have heard today that have organisations, peer-to-peer networks or support groups. They could basically ask to be in that registry and you could just do this matchmaking, which is really the biggest problem for a lot of organizations that I've dealt with in terms of, as I said earlier, this privacy argument.

As an organization, you cannot just go to a hospital and ask for the contact details of everybody who is losing a child so that you can approach them with services that you provide. Usually you try to put an information leaflet together, or you work with some people in the hospital and build relationships, but it's not a foolproof system, because it's people-dependent. If someone is in the hospital at a certain time and a certain nurse is there and knows about that piece of information, it might get to the family, but then another time that person might not be there and it doesn't get there.

I would really advocate for a holistic, central system where these people don't fall through the cracks if someone at that point in time doesn't happen to be in the hospital. If you organize it this way in terms of tapping into the existing processes where notifications are going out to various governmental agencies to record that a child has died, that would be a very logical step to maybe extend that service to have such a registry, and in that way, connect parents to each other and to organizations.

● (1005)

The Chair: Thank you very much.

Next is MP Richards, please.

Mr. Blake Richards (Banff—Airdrie, CPC): I want to start by thanking each of the parents and parent advocates who are with us today for their courage and their selflessness.

You're taking a very tragic situation that you experienced yourselves and are trying to turn it into something where you advocate for others. Although it may be a way to keep your children's memory alive, of course it won't do anything to reverse what you've experienced. You're certainly working to try to make sure others don't experience and have to go through what you did without support and without compassion. Thank you for your efforts and your work on behalf of other parents of loss.

You've all talked a little bit about that point of contact, generally at the hospital level, where there needs to be some change in terms of the information. It's the sharing of information that you're given, in terms of what's available as supports for parents. That is at a provincial level, but as a committee, we do have the ability still to make a recommendation that this is something that we encourage to see happen. It can be done through a mechanism like the federal-provincial health ministers' meetings, for example, where that's something that's encouraged, that there be that information provided across the country. That's something we can certainly still recommend.

Also, if there are truly privacy issues in that sharing of information at the government level, there's an ability for a form to be signed or something that would allow that to happen. That can surely be figured out. We certainly appreciate those suggestions. I think they're very important and well-taken suggestions.

I want to touch on one particular aspect of that, and I have one other question. I want to have each of you try to address it if you can.

First, we've heard from you today and from other parents about some of the terrible experiences of having to tell the story of your loss, multiple times in some cases, to numerous bureaucrats and civil servants to try to access what might be available to you. Different results have come in different places. I think two things come from that.

First is the idea that there would need to be some kind of a dedicated line that might be available at Service Canada, for example, where bereaved parents or people who are experiencing bereavement can go to talk to someone who actually understands their needs and has the proper information available to them, so that we don't have different outcomes and different experiences amongst everybody. I wanted to get your comments on that. Is that something you think is important to see?

The second one would be on the idea of the benefits themselves. Many of the parents who have come before us have talked about the importance of this being a leave specific to bereavement. Paula's example is a great reason why that's important. Sick leave has been raised, but it isn't possible for everybody for various reasons. Maybe you experienced that you weren't able to get it. In some cases it has been used already—during the pregnancy, for example.

The idea is that benefit would need to be specific and it would need to be automatic, so that we don't have to fight the bureaucracy to access it. It's something that's available to all grieving parents.

I want to get comments from all of you on that particular aspect of it—the importance of it being automatic, specific and universal in terms of a benefit—and the idea of a line that would be available to all parents, where there is someone who actually understands bereavement.

We'll ask all four of you, but we can start with you, Cheryl.

(1010)

Mrs. Cheryl Salter-Roberts: I'd love a line. I think it would be very valuable to have the ability to know that you can call and someone is there who can answer your questions, who has been specifically trained and who has the information at hand. It's one person versus contacting department after department.

For the other piece about the benefit, if we could make it as simple as possible.... Even the idea that a family would have to.... I've only done the one maternity leave, so please excuse me if I'm not up to date, but I know that I had to send in a report every week to say whether I was working or not even though I was on maternity leave.

I'd like to see a guaranteed amount of time, where you don't have to keep showing that you're on that leave and that you still qualify for it—it's just given at that time.

Mrs. Jessica Weatherbee: I think a dedicated line would be a wonderful idea.

I also think it's really important to point out that sometimes when people are on sick leave they can't afford to keep their health benefits through their work. When I was off on sick leave, we financially couldn't afford to keep our dental and medical plan because they're not cost-shared by our employer. I was employed by the Nova Scotia Health Authority. We couldn't afford to keep the benefits and that's what all of the counselling is under. That's a really important point to make

Mr. Blake Richards: Paula, Jens, or Mr. and Mrs. Fuentes, do any of you have comments on this?

Mr. Philippe Panneton: Absolutely. For our part, I think the central line would be a really important thing to have. We know from experience that navigating through various government organizations immediately after the loss of a child is horrendous. Even though the people on the other end of the line are well meaning, as other witnesses have said, they're not adequately trained. Having someone there on a dedicated line would be a huge help to all of us.

In terms of how compensation could be structured or how it should be doled out, we could have something like you or Jens and I and all of the other witnesses mentioned: an automatic trigger whereby we could sign a waiver to our privacy so that the hospitals at the provincial level could communicate with the federal level. A "no questions asked" bereavement leave would be absolutely amazing.

Mr. Blake Richards: Jens, did you want to comment as well?

Mr. Jens Locher: I just keep thinking about one thing, although I don't know if it has been raised before. The person already raised the point about extended health benefits. I do want to mention that we've talked about whether 12 weeks is enough and whether it's automatic enough.

One thing we haven't really talked about is how people get access to be reavement support if there is no organization in their area. We have many rural areas where it would be difficult to get in-person support.

I was wondering if the committee would consider something. If we know that it's really dependent on the extended health plan that someone might have to get any type of funding for counselling—and it is actually quite expensive—maybe we could talk about a benefit. It could be part of such a benefit that if this automatic benefit kicks in, there is going to be a schedule, a bare minimum of support that a counsellor offers.

Again, I'm not saying everybody has to take up that help. Maybe some people don't want it. If people are looking for support and there's nothing in their area, how do we pick that up? If they don't have extended health, and they can't go to a registered counsellor anywhere in their area or they can't afford it, is there something the government would do? Would it be prepared to fund three sessions, as a bare minimum, so that someone can at least pick up the phone and check in with somebody who's specifically trained on bereavement? This is particularly for those who are not in metropolitan areas where there might be support organizations that are peer-to-peer or volunteer run. We should not have people fall through the cracks in those areas.

● (1015)

Mr. Blake Richards: Thank you.

The Chair: Thank you.

Next is MP Morrissey, please.

Mr. Robert Morrissey (Egmont, Lib.): Chair, I just have a couple of brief questions and then I'm going to share my time with MP Vaughan.

I believe it was Ms. Harmon who made the statement about some of the jurisdictions covering funeral benefits for children of a certain age. Where is that?

Mrs. Paula Harmon: That is in Great Britain. It was in the spring.

Mr. Robert Morrissey: It's recent.

Mrs. Paula Harmon: Yes. It was an MP who actually started this, because her child died and she pretty much went bankrupt to bury him, given the associated costs. It took her eight years to get legislation in, but it did pass in the spring.

Mr. Robert Morrissey: What are the ages again? **Mrs. Paula Harmon:** It's from birth to either 16 or 18.

Mr. Robert Morrissey: Okay, thank you.

I just want to recount something. My colleague Mr. Hogg referenced that nobody, outside of that one, seemed to have information on what may be covered in other jurisdictions. Three themes have emerged since we began the study of this particular motion, and I just want to restate them to see if you agree.

The clear one that came up was having to pay back benefits after a death. There have been a number of examples in that area.

One was that there is no clear information on what benefits are available and no commonality among eligibility criteria.

The third one is that there is a real patchwork of support services across this country, and there's no unanimity.

Do you agree that those are the three areas this committee should focus on as part of its recommendations?

Ms. Salter-Roberts and Ms. Harmon.

Mrs. Paula Harmon: Yes, those are certainly the big ones that the HUMA committee would concentrate on. It also has to be taken into account that without the support of the health care system itself, leave is only as good as the supports you get. I would think it would have to be done in concert with Health Canada.

Mr. Robert Morrissey: I'll pass my time to MP Vaughan.

Mr. Adam Vaughan (Spadina—Fort York, Lib.): Thank you.

I, too, thank you for the bravery, the courage and the compassion you are showing, sharing your stories and helping others. It's one of the more inspiring parts of human nature, the ability to help others even when you need the help yourself, so thank you.

While you were talking and we were hearing where some of the ideas are leading us with your suggestions and wise advice, the question that came to my mind was, what is the scale of this dynamic across the country in terms of how many people we're talking about who require the services you're trying to get established? What is the frequency of this event?

Mrs. Cheryl Salter-Roberts: I can share our statistics from Alberta.

Almost 16,000 babies die each year that are documented as miscarriages. When we say "documented", we know there are actually more. One in four pregnancies will end in a miscarriage in Alberta. We know it's higher than that, because many women do not go to their physician and say, "I think I've had a miscarriage. Can you do a test?" They just know they were pregnant. They did the test at home, and within weeks they lost that baby. There are many undocumented losses.

We also know there are around 400 stillbirths each year. I don't have the statistics for SIDS. I know it is high. I don't have the statistics for SUDC. It's coming up as a higher one as well.

In communities across Alberta, it is a growing trend. Part of it we're seeing is that many families are waiting to have their babies and the parents might be a little older, so there are more opportunities for testing being done. Sometimes those end in medical terminations with babies that maybe aren't as viable or the mother's health is at risk. We're seeing a big increase in medical terminations as well. That's pushing numbers up.

• (1020

Mr. Adam Vaughan: Then the miscarriages are obviously predelivery in the way that's calculated.

Mrs. Cheryl Salter-Roberts: Yes, miscarriages are from conception to the first 20 weeks of gestation, and then a stillbirth is considered from 20 weeks to full term, or just beyond the due date.

Mr. Adam Vaughan: You divided it into three categories. It was miscarriages—

Mrs. Cheryl Salter-Roberts: Stillbirths.

Mr. Adam Vaughan: —stillbirths and then—

Mrs. Cheryl Salter-Roberts: Sudden infant death and SUDC.

Mr. Adam Vaughan: You said you don't have firm statistics for one of them.

Mrs. Cheryl Salter-Roberts: I don't have the number for SIDS. I do apologize.

Mr. Adam Vaughan: That's fair enough. It's okay.

Mr. Arnold Viersen (Peace River—Westlock, CPC): Adam, the fellow on the video conference has them.

Mr. Philippe Panneton: I looked them up actually on the way here. For 2016, StatsCan says that SIDS or infant death is 1.2 per 1,000 live births in Canada. What affects us, as our son was almost two years of age when he passed away, is 4.9 deaths per 1,000 live births for children under the age of five in 2016.

We don't have statistics for SUDC at all in Canada, because it's not tracked unanimously through provinces. It's not a recognized cause of death. It's an absence of a diagnosis.

Mr. Adam Vaughan: Okay, and is miscarriage part of your research as well in terms of the rate?

Mr. Philippe Panneton: No. This is really children who were carried to term, and no stillbirths.

Mr. Adam Vaughan: I'm sorry to be so statistical, but as the ideas move forward, understanding the scale of the model we're working with helps, because as you know, EI is a rate-supported program. When you make changes, the criticism is often that it's a tax on small business, and so on. However, we need to figure out how to model it, so thank you very much.

The Chair: Mr. Locher, you had something to add as well.

Mr. Jens Locher: Yes. I want to give you the statistics from the federal level. I actually had to go all the way back to the year 2005, because when I looked at the StatsCan website, I think they stopped recording miscarriages at some stage, so there's even no data available federally anymore on miscarriages.

The only dataset that actually gives you the full scope of all these situations was in 2005, where at the time I looked it up, there were 447,485 total pregnancies. There was a category in the StatsCan data that was labelled as miscarriages, but it was very low, with 6,285 occurrences; however, it had a star to it that said it was only the ones that got recorded by StatsCan. Therefore, as previously indicated, I think there's a big gap in terms of things not getting recorded.

At that time, they divided the number of stillbirths as early fetal loss, which starts at 20 weeks, and then late fetal loss, which starts at 27 weeks. The numbers were 1,197 for early fetal loss, plus another 1,012 for late fetal loss. That's the stillbirth category.

Then, in terms of the neonatal deaths, which is up to the first year of life

Actually, they had another group, from one to 14 years of age, and it was 791 children in 2005 who had died. Out of those, there were 66 were suicides, 233 accidents, and 116 neoplasms. There was another category for SIDS cases, sudden infant death syndrome, and in 2005 the number was 112.

The Chair: Is it possible for you to send us that info?

Mr. Jens Locher: Yes, of course.

The Chair: Thank you.

MP Richards, you're next, please.

Mr. Blake Richards: I'll continue on that same line. Obviously, the challenge here is that the numbers are difficult. We all understand that, in many cases, people end up being able to qualify for a sick benefit or, if you were able to qualify, there's still maternity leave that's accessible for some people.

There are people who fall through the cracks of those things and we're trying to make sure that everybody has that access, but the numbers aren't as big as they might sound because there are people who are able to qualify for other benefits.

The problem—and we're hearing it from you today and we've heard it from others—is that you have to go and fight with the bureaucracy and fight with the government to get it. It's not that anyone is trying to deny it, it's just that nobody understands how to deal with it. I'd like all of you to speak to that part of it because that's the thing I'm hearing quite frequently from people. It's this thinking that if it could just be automatic, then people wouldn't have to

struggle and have this battle to try and make this work, to try and fit this square peg into a round hole. That seems to be the biggest challenge. If any of you would like to speak to that specifically, like the idea of something that is actually specific to your circumstance of bereavement—and it also would be automatic so that....

I've heard stories from people. I think there was one family from the Ottawa area here who told their story 17 different times to government agents in order to get their benefits. They were able to get them, but they told their story 17 times. I would think that if we could eliminate that, it would make a big difference. Also, there needs to be recognition that this is something that is significant and that we need to address, rather than trying to find ways to fit it into some other category.

I don't know that we would end up finding that there would be a significant number of new benefits paid out, but I think people would feel recognized. I think we would lessen the burden on people to try and deal with the bureaucracy.

I wanted to hear some comments on that, if any of you have them. Is there anyone who wants to jump in?

Cheryl.

● (1025)

Mrs. Cheryl Salter-Roberts: One of the facilitators in my program, her baby died at 21 weeks and she had to have a labour induction to bring the baby out. She received full benefits for the entire year, for a 21-week baby. In my same program, I've had other parents who have gone beyond 40 weeks and then their baby has died or the baby has died within days of birth, but they have been denied benefits altogether. Their baby died; therefore they don't qualify.

There are great inconsistencies about who gets benefits and who doesn't, but it really comes down to who on that day was making a decision and who they spoke with. The mother, who got her full benefits, basically had to go into the office, fill out forms and it was done. The mothers who have had their benefits denied and were full term have had to do the hoops and have told their stories 17 times. That's a piece that really needs to be changed and again, made simple.

Mrs. Paula Harmon: There's a family in the Annapolis Valley in Nova Scotia. The mother died in childbirth and the baby died nine days later. The father is self-employed with a toddler, but he's not able to access anything because he's self-employed. He has to go back to work and his work is dealing with.... He has a day care, so he goes back to work and is dealing with children immediately after the death of his child and his wife.

Mrs. Jessica Weatherbee: I think having a separate bereavement benefit would be beneficial for situations such as mine. My husband was forced to go back to work after a week. If there were individual benefits for both parents.... Our hands were tied. They wouldn't sign the forms. We went to see a physician twice in a week and then we just didn't have any more fight left in us. If there was a separate benefit, that would have never happened. I ended up going back to work nine weeks postpartum because he wasn't at home with me.

After you lose a baby, people don't rush to your house to console you. People stay away. You're there by yourself.

Mr. Blake Richards: Monsieur Pelletier, I think I saw your hand. [*Translation*]

Mr. Alain Pelletier: Thank you.

The hotline you talked about earlier could be something of a single point of contact people could call to obtain information on assistance and available programs, as well as potential benefits. That would also make it possible for them to be referred to the right place for psychological support.

[English]

Mr. Blake Richards: I see that we have interest on the video conference.

Please-

Mr. Philippe Panneton: Thank you very much.

Since our child was over the age of one, there was no parental, maternal or any benefits that we could access, other than sick leave. As a witness stated previously, they couldn't get their doctor to sign.... Our doctor wouldn't sign off on stress or sick leave. She told us to go talk to a counsellor, and that was it. This was our family doctor

Other than going away to an emergency clinic somewhere to get somebody else to sign off on something that really wasn't true.... It wasn't stress. It was grief. We shouldn't have to play a system that we pay into.

● (1030)

Mr. Blake Richards: That's a great point.

The Chair: Thank you.

Next is MP Sansoucy, please.

Mr. Blake Richards: Sorry, we have Jens who wants to comment.

The Chair: Sure.

Very briefly, please, Jens.

Mr. Jens Locher: You had a two-part question, and one of them was about telling the story. I fully agree with the other witnesses in terms of the necessity to have this automatic benefit.

I can tell you that my oldest son would now be seven, and my second son, Tobias, would now be five, and it's taken me several years to be able to be in a setting to speak about this without being an emotional wreck.

At the time when Service Canada wanted to talk to me, it was impossible. It was this idea that I had to go there in this public place,

and I couldn't control the times and the terms where I had to tell the story. It was just terrible.

I think that situation should be changed, that people have more control over how they are made to tell the story. A phone line dedicated team, I think would go a long way.

Mr. Blake Richards: Thank you.

The Chair: Thank you.

Madam Sansoucy.

[Translation]

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

Mr. Pelletier, you said you had decided to set up a really special program for infant loss. With all due respect for the parents who are with us today and who have experienced such a loss, I would like you to explain how your organization has come to that decision after meeting parents. Why did you come to think that infant loss required a special approach?

Mr. Alain Pelletier: We have been involved in bereavement for a long time—25 years—and our approaches have evolved over time. Of course, we have been working with bereaved adults for a long time, but we have designed special approaches for bereaved children and adolescents.

As people have said this morning, the situation of individuals going through infant loss is made worse by the fact that some members of our society do not consider that loss to be as important as the loss of another person or a 10-year-old child, for instance. Very little time was spent with a child who died at young age, but those people are also bereaved and have as much grief, if not more, as when someone else dies.

We think that requires a special approach. That is why we are getting help from people who have experienced infant loss, but also from people who have studied infant loss and are experts on the matter

Ms. Brigitte Sansoucy: You said that you will hold a conference tomorrow called "loss and family". I would like you to tell the committee who those people with expertise in infant loss are.

Mr. Alain Pelletier: You talked earlier about Chantal Verdon. She was a speaker at one of our past conferences that focused on infant loss. She is one of the people who will help us develop the best possible approach to help people going through those issues.

Ms. Brigitte Sansoucy: What is the programming of your conference tomorrow on loss and family?

Mr. Alain Pelletier: We are not focusing on infant loss as such. We are talking about the history of loss and one family's perspective. When someone dies, not only one person is bereaved, but the entire family is, as are loved ones and friends.

We will have testimony from a family whose father died in an accident survived by the spouse and the three children. Mr. Deslauriers, one of our speakers, will ask the members of that family to explain how they were able to get through the loss by having someone to talk to about it. Being able to talk is one of the best ways not to resolve a loss, but to live with it better.

● (1035)

Ms. Brigitte Sansoucy: In your presentation, you talked about.... [*English*]

The Chair: I'm sorry, but that is about a minute over time. We'll have another chance for questions.

[Translation]

Ms. Brigitte Sansoucy: Okay.

[English]

The Chair: That does bring us to the end of two rounds. We don't really have time to start an official third round from the top, but if desired, we could do a brief three minutes per member. Is there anybody on this side who would like that three minutes? We don't have to take it.

We'll start with Madam Sansoucy, then, for three minutes.

[Translation]

Ms. Brigitte Sansoucy: My colleagues know that I always have a question.

Mr. Pelletier, you said that all your volunteers have received sentinel training, which was designed in Quebec for suicide prevention. That caught my attention.

When you work in the area of bereavement, it is important to always have in mind that a bereaved individual may potentially also end their life, right?

Mr. Alain Pelletier: Absolutely. People experience loss in different ways. It has occurred regularly that, among the people we support, some have shown such discouragement as to think of suicide. We identified the signs and referred them to qualified people. In our case, we turn to the Contact Richelieu-Yamaska organization, which deals with individuals in crisis who are talking about committing suicide.

Ms. Brigitte Sansoucy: For my colleagues' benefit, I would like to specify that the sentinel program in Quebec can train anyone to identify signs of distress in others. Even students in high school can identify signs of distress and refer the people concerned to the right place.

For you, it is important that everyone who supports bereaved individuals attend that basic training to identify any signs of distress.

Mr. Alain Pelletier: People who are going through a loss can reach such a level of discouragement that they think about ending their life, and we must be able to identify those situations.

Ms. Brigitte Sansoucy: That was my last question. Thank you. [*English*]

The Chair: Mr. Diotte.

Mr. Kerry Diotte: I want to throw it open to all of you. You've all given us a lot of food for thought and some great suggestions. Is there anything else that any one of you think might make our system better, and might get us on the right track?

Mr. Pelletier.

[Translation]

Mr. Alain Pelletier: We talked earlier about a telephone list. That would be an idea to keep in mind, still in the context of a single point of contact.

There should also be enough funding for the work of people who give their time and who don't have sufficient financial means to do more.

[English]

Mr. Blake Richards: Sorry to interrupt, but the bells are ringing. **The Chair:** I'm just checking here.

The Chair in Just encon.

Go ahead, Mr. Diotte.

Mr. Kerry Diotte: Maybe we could go next to our video conference folks.

Jens.

Mr. Jens Locher: There was a question earlier in terms of experts in this field. I wanted to point out that Canada has six pediatric palliative care hospices that do amazing work in this area. They don't cover miscarriages or stillbirths, but after the birth and terminal illness of children, they provide a lot of support to parents. They do a lot of research. They have a lot of experts and expertise in this area. That might be another area where you could get information from experts on this topic.

The Chair: Thank you.

The bells are ringing. I need to ask for unanimous consent to continue for a few more moments and finish up this session.

Some hon. members: Agreed.

The Chair: Mr. Diotte, you have one more minute.

• (1040)

Mr. Kerry Diotte: Again, I'll just open it up to anybody to suggest any other things that we might have missed, any other suggestions to help the system.

Mrs. Jessica Weatherbee: I think it would be helpful to remove the need to have the medical certificate signed by a physician in the case of bereavement. I don't feel that physicians should have the choice of whether or not you are entitled to have this 15 weeks off just because they don't think it's a legitimate reason to need to grieve for your child.

Mr. Kerry Diotte: Is there anyone else?

Mrs. Cheryl Salter-Roberts: Something I'd like to add is bringing up the awareness campaign. I love this idea. I think that when we look at mental health and addiction, when you go back to the root cause of some of those issues, we often see it's grief, many times and most times, I would say. I work at a hospice and I work with families in that situation. Grief is the catalyst for those experiences. I know that anything that you bring forward is going to cost the government some money, but I think if you invest in some of the root causes of things happening, and the other money that is spent on other programming may not have to be spent in the long term.

The Chair: Thank you.

MP Romanado, please.

Mrs. Sherry Romanado: Thank you.

I'll follow up on what my colleague Blake Richards mentioned about a family having to tell their story 17 times—I believe that is what you said. We talked a lot about a *guichet unique*, a one-stop shop. Given we're in 2018 now, could leveraging technology help in that regard?

What I'm trying to get to is we're much more comfortable now using online platforms, whether it be Facebook, support groups, to reach out. Would it assist people to have the option of using technology to perhaps file the requests for various benefits and services, and to do everything online? They would do it once. Some people want to use the phone. They want to talk to people and tell their story as part of the healing and so on. I know Philippe is probably going to jump in here, but I'm just thinking of that. What if we had an online portal where you put your story in once and various organizations pop up, almost an aggregate of what's available based on your postal code and so on.

Now I have a whole bunch of ideas, but Philippe, if you could jump in, that would be great.

Mr. Philippe Panneton: Sure. Wendy had some ideas, but she has a cold so she can't talk.

We recently had a new daughter who you met. When a child is born, you're given all these little forms to fill out, and at the end of the form it lists the URLs you have to go to to ask for this card or that card or the SIN to be issued. To have something similar, upon the passing of a child, that would be given to you by the hospital, just a piece of paper with different URLs, or even just the one central URL like you're proposing now that would link to everyone else, I think would be immensely beneficial to all of us.

We can't even count how many times we've had to tell this story, and not just for the purposes of these hearings, but in general. Telling it once would have been great. Mrs. Sherry Romanado: Okay.

Mrs. Paula Harmon: In the hospitals there are kiosks where you fill out the information to get the birth certificate, the social insurance number and the health card all at once. It would be similar to that, especially if you're in a NICU or PICU situation. If something does happen, it can be done right there, with the help of medical staff. The technology already exists.

The Chair: Thank you.

Mrs. Sherry Romanado: Thank you.

The Chair: I'm afraid we don't have any time left for you, Gordie. I'm sorry.

I want to thank everybody both here and coming to us via video conference today, for contributing to this study. It's hard for us on this side to hear some of these stories, so I can only imagine the challenges you are facing telling these stories. Thank you very much.

I would like to remind my colleagues that on November 6 we have committee business. Committee business will be in room 228, Valour, on November 6.

On November 7, from 6 p.m. to 9 p.m., we're going to start clause-by-clause consideration of Bill C-81. That's going to be in room 415, Wellington Building.

On November 8, at our normal time, 8:45 a.m. to 10:45 a.m., we'll go again to clause-by-clause study of Bill C-81. We could potentially have an afternoon meeting at 3:30 p.m. on November 8, if necessary, to finish the clause-by-clause considerations. Hopefully, we don't need to use that, but that is an option if needed.

Thank you very much, everybody.

The meeting is adjourned.

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