

Brief to the Standing Committee on the Status of Women

Parents jusqu'au bout

Thank you!

Geneviève Dion

I studied human resources management and have been working in this field since 2006. I had my first child in 2008 at the age of 27, followed by Naomie in 2011. We received a diagnosis when Naomie was 3 months old. This was followed by a series of hospital stays and operations. I separated in 2015 and have been a single parent with full-time responsibility for my children since then. I returned to work in 2016 to avoid having to go on social assistance. I am frequently absent from work and find this very stressful. In addition to facing significant lost earnings, I constantly have to justify my absences, and this situation creates a lot of tension with my co-workers and supervisors. I have difficulty sleeping because of the stress.

& Naomie

Naomie is 5 years old and is severely disabled. Her case is the only one of its kind: partial trisomy 14 and partial monosomy 9. She loves people, music and crawling! Since she gets around on all fours, the house requires the same safeguards as for a baby learning to crawl. That means safety covers on outlets, gates, no fragile objects, etc. Naomie also has a serious intellectual disability and cannot speak, eat or walk. She has epilepsy, chronic otitis, hypothyroidism and difficulty swallowing, and is fed through a gastrostomy tube. She receives medication 6 times a day. At this stage in her life, she has been hospitalized about 10 times, had 6 operations and has been transported by ambulance 4 times. Naomie is a very happy and sociable little girl. In our home, we have a range of adaptive devices to stimulate her development, such as a standing board, walker, wheelchair, electric bed, bath seat and access ramp.

Anouk Lanouette-Turgeon

I have a bachelor's degree in writing and communications from the University of Sherbrooke, a diploma in translation from McGill University, and a diploma in immigration and intercultural relations from the University of Quebec at Montreal. I worked as a translator and closed captioner before becoming an employment counselor for newcomers.

I met my husband in 1999 and we had our first child, Éli, in 2011. Éli received a prenatal diagnosis of trisomy 21. In 2014, we had our second child, Lhasa, who was seriously ill and significantly disabled. I had to extend my maternity leave when Éli was born, and my employer (unlawfully) lowered my salary and canceled my seniority when I returned to work.

I still work part time for ALPA (20 hours a week) and am happy at work since there has been a change in management. I was never able to work full time after having children. I am regularly absent because my daughter is sick and/or in hospital. Since she sleeps very little at night, I am chronically sleep-deprived and this makes me less productive at work. It is extremely stressful to know that my daughter has a neurodegenerative disease. Everything – my career, my mental health and my social life – suffers as a result.

& Lhasa

Lhasa was diagnosed three years after she started to undergo medical testing. She is now three-and-a-half years old and has two extremely rare genetic mutations affecting genes KIF1A and GRIN2A, which result in numerous disabilities and conditions: intractable epilepsy, cortical blindness, severe developmental delay, dysphagia and aspiration, extreme scoliosis and sleep disorders. She is frequently hospitalized because the slightest virus results in pneumonia. She receives 8 drugs daily and is on a ketogenic diet that costs \$300 a month. She is monitored by a number of specialists including a complex care and palliative care team, and has weekly medical appointments. Lhasa has very little interaction with her environment. We do not know if she recognizes us. She smiles sometimes, responds when touched and squeals with delight. She enjoys movement.

Prognosis: She will never live independently. She is at high risk of dying young, either from pneumonia or the effects of her neurodegenerative disease.

Marilyne Picard

In May 2004, I earned a diploma in computer design and immediately found work in my field. I met a man who already had 3 children from a previous relationship. We got married in 2007 and launched a printing cooperative in Old Montreal. I loved being in business, I loved my work and I especially loved team meetings. I found it stimulating to get up, make coffee, get ready for work and start my commute. I was always a bundle of energy.

I had my first child in 2009 and our lives did not change very much. We went on a trip twice a year because we loved to travel, and we had weekly family activities.

I had my second child in January 2012, and that's when my whole life changed. We knew something was wrong when she was just 3 weeks old. She was admitted to the children's hospital. When we left three weeks later, our lives had been turned upside down. Our little Dylane was significantly disabled and seriously ill. I could never go back to work. She needed too much care.

& Dylane

Dylane is five years old and has an unnamed genetic disorder — 1q43-q44 — which results in a number of developmental delays. She is like a five-month-old infant. Dylane has dysphagia (she is fed through a tube) and severe reflux. She regularly suffers from aspiration pneumonia. Her treatment for osteopenia is hard on her body (similar to chemotherapy). She has intractable epilepsy and her seizures are very intense: she turns blue and convulses for hours. She has to be taken to the trauma centre at the children's hospital. Afterward, she often has to stay in intensive care because the drugs used to stop the seizure depress her respiratory system. Dylane has had about 33 epileptic seizures, 25 of which required transportation by ambulance. She has been hospitalized 36 times. She takes 28 pills a day. She is on a very strict diet and all her food must be weighed.

When Dylane has a fever and/or goes into convulsions, we have to put an oxygen mask on her and quickly give her the necessary medication. Dylane is in a non-motorized wheelchair that we push. We have to watch over her constantly at night so that we can detect a convulsion as soon as possible.

Dylane can sit up! She smiles and she loves her brothers! Everything in the house is adapted for her (elevator, bathroom, etc.) thanks to the help of foundations, government programs and good Samaritans.

Prognosis: Dylane will be dependent on us her whole life.

Marie-Ève Tétreault

I met my husband in 1999 when I was 16, and we knew right away that we wanted to get married and have a big family. We had our first daughter in 2002 and our second in 2010. In January 2011, I went back to school after my second maternity leave to become a nursing assistant so that I could earn more money and receive fringe benefits. I graduated with flying colours and found a job in my field in June 2012.

Our long-awaited son, Zakary, arrived in September 2013. Despite all the prenatal tests that showed our baby was healthy, Zakary was rushed to Ste-Justine when he was only 24 hours old. A few days later we learned that he would be severely disabled. We were told that he would have a severe/profound intellectual disability and that he would be fed through a tube and need a wheelchair.

My career and my dream of a big family are over. My son needs me full time. I still do the work I was trained to do, but I do it for free and with no pension plan. And I work much harder and for much longer.

& Zakary

Zakary is three years old and has a rare genetic disease known as SPTAN-1, which is associated with microcephaly, brain malformation, severe hypotonia, intractable epilepsy, dysphagia, chronic hypoxia, cortical blindness, osteopenia, severe overall developmental delay, and multiple allergies.

He requires a significant amount of care and constant monitoring. Zakary is fed through a tube four times a day and is given 15 doses of medication a day. He must be on oxygen and requires a pulse oximeter when he sleeps. He has 2 nebulization treatments per day (antibiotics) and he requires gastrostomy care. He still wears diapers and cannot clean himself or go anywhere or change position on his own. Zakary is on a ketogenic diet (a high-fat diet to deal with his epilepsy) and we must calculate everything he ingests to within about a gram. He also takes cannabis oil for his epilepsy. In addition to his daily care, we have to put on his orthotics every day, stimulate him visually, get him standing and do occupational therapy and physiotherapy exercises. He has a lot of medical appointments and is monitored by 16 departments at Ste-Justine.

At the age of 3, he has had 2 operations and is waiting for a third, has been hospitalized 23 times (3 times in intensive care) and has been taken to emergency 15 times.

Zakary has 2 big sisters. We live in an apartment which is not adapted to his needs at all. He weighs 18.5 kg and is starting to get very heavy, but we can't find a house we can afford on one salary.

Marie-France Beaudry

I was a young, carefree woman with a well-paid job and an active social life. I loved antique cars and went to a lot of car shows. I spent a lot of time with my head under the hood of a souped-up car, alongside my spouse, who was a mechanic. But one beautiful August morning in 1992, life handed me a little angel with broken wings. My world was turned upside-down. The children's hospital became my second home. There was no question of going back to work.

Two years later, my relationship ended. As a single parent and full-time caregiver, I quickly found myself on social assistance. Poverty, destitution, accounts in collection. I experienced financial stress on top of the stress caused by my son's health.

Before my son was born, I worked as an administrative assistant. After his birth, I became a full-time nurse, physiotherapist, occupational therapist, hearing specialist, nutritionist, special education teacher and so much more. Before my son was born, I had hobbies and I went out whenever I wanted. Afterward, I was on duty 24–7. There are so many restrictions on going out that I just give up 99% of the time. Before my son was born, I took care of myself. After, I had so little time that I had no choice but to neglect my own health. Little ailments have built up. Years of lifting, carrying and transferring my son have led to significant back problems.

Before my son was born, I was financially independent. I had two houses. Afterward, I found myself on social assistance. My self-esteem was gone. Being a social assistance recipient is very hard on your morale when you have known what it's like to earn a living and be financially independent. There's no way that you own anything of value. There's no way you can travel. You have to fill out forms and report everything — you feel like a criminal. I don't have a house anymore. I really need a specially equipped vehicle but I can't afford to buy a new enough model for it to be fitted out by the Société de l'assurance automobile du Québec. I am still transferring my son from his wheelchair to the car, and my back problems are getting worse very quickly.

My son will be 25 years old this summer. I love him more than anything. For him, I have given up my freedom, my independence, my financial security, my social life and my love life. I am even sacrificing my health to some extent. I work 24–7 with no break. It's outrageous what parents in my situation are going through. Disabilities and illnesses don't magically disappear the moment our children turn 18. Our love for them doesn't disappear either.

It is inhuman, unacceptable and unjustifiable. Canada has no financial support program for parents who care for their disabled adult children. It's time to put an end to this unfair and absurd situation.

& André

André is 24 years old and severely disabled. He was born with situs inversus, spina bifida myelomeningocele, hydrocephalus and a number of major cardiac malformations. He developed severe scoliosis as a teen, which causes him discomfort and affects his positioning. André is also developmentally delayed. He does not speak but he understands what you say and communicates using

a type of sign language he learned at school. André does not walk and he uses a wheelchair to get around. He must have his bladder emptied every 4 hours with a catheter. He also needs an antispasmodic drug injected into his bladder every morning and night. André's condition requires close and frequent medical attention. He sees a cardiologist at the Ottawa Heart Institute as well as a neurosurgeon and urologist. So far, André has had 11 operations, 3 of them involving open heart surgery. At least one more heart operation is expected in the near future. He may need other operations to deal with his spina bifida. André's future is uncertain; it is hard to predict how his condition will change. We take things one day at a time.

The issues

In this section, the word “child” is used for the sake of simplification, but readers should understand that these individuals are still children even once they reach adulthood. Because of their intellectual disability, their developmental age is that of a young child.

Families with a severely disabled child face major stressors every day, such as illness, fear of losing the child suddenly, pressure from medical practitioners about decision-making, separation, moving house, and financial stress.*¹ Based on the list of the 20 top stressors that people experience in their lives, living with a sick child means constant exposure to at least 5 out of the 20.

Parents go through the same stages associated with mourning.*² They mourn not having the child they wanted or at least a reasonably healthy child. They also feel guilty. It's a shock; the first of its kind. Then comes denial, pain, guilt, anger (at the unfairness), reconstruction and, finally, acceptance (not everyone manages to achieve acceptance). Not only are our plans for a family thrown into disarray, but everything becomes more difficult—all our daily activities, every outing, every trip we have to make.

Couples need time together as well as closeness and intimacy to survive. But it is hard to find that time when the child has such complex and constant needs. Couples need to mourn the loss of their life together and their life as a “regular” family. The father usually becomes the family's sole breadwinner, and that leads to tension. Fathers feel tremendous pressure to meet their family's many needs. Eight-five percent of couples separate.

Single mothers often feel they simply cannot take care of their child. They are solely responsible for their family's financial security. Unfortunately, in a number of cases, mothers cannot go back to work because their child requires care and has such complex needs. It is unfair that women are obliged to put their careers on hold and cannot save money or contribute to a pension. Poverty awaits them in old age.

Siblings also suffer. It has been documented that, in families with a severely disabled or seriously ill child, brothers and sisters pay a heavy price. They often have far more responsibilities than other children their age. They are isolated along with their family. Their day-to-day lives are uncertain. They experience their parents' stress and problems vicariously, and are quite likely to demonstrate anxious behaviour. Moreover, their emotional and material needs are not fully met.

The family's financial difficulty is the worst daily stress of all. It is worse than seeing our child on the verge of death in the trauma centre. It is worse because it is constant. We have to humiliate ourselves and beg for money and fundraise just to make ends meet. We feel judged and excluded.

It is impossible for us to go back to work since we rarely get a full night's sleep, and our child requires significant care and has many appointments.

We have to put aside our personal and professional development. We often neglect our health and appearance because of a lack of time, money and energy. As their child gets older, the mothers' own physical problems emerge. It is very hard to lift, bathe and change the diaper of a 100-pound child every day. A number of mothers neglect themselves to such an extent that they become depressed.

We become our child's administrative assistant. Our lives are totally focused on our child's basic needs.

When, after we have worked ourselves to the bone for years, our child dies or gets a spot in an institution, we find that the diploma we earned "way back when" is no longer worth anything. Women in this situation are often unable work anymore. We are physically and mentally exhausted. We become a burden on the State once again.

Women who do manage to find part-time work are often absent for appointments or because their child has been hospitalized. They need very understanding employers or reliable homecare workers. They make a lot of concessions in terms of their career goals and salary expectations. They have to accept the inevitability of career stagnation.

As women, our sense of independence is significantly affected. We often feel trapped. We are totally dependent on either the State or our husband (if he is still in the picture). We no longer have any financial independence. If we decide we want to buy a pair of glasses, we have to get it approved by social assistance or our husband. It's as if we were living in the 1940s!

We cannot afford to buy a vehicle and have it adapted. It is an absolute NECESSITY for us and our child in order to get around and gain some small measure of independence. Unfortunately, we cannot get a loan because we have no collateral. A mortgage? Don't even think about it. Yet our child needs a house adapted to their needs. Many property owners do not want to let renters renovate to accommodate a disabled child, so we have to buy a house. This is often impossible. When conducting a credit check for a mortgage or loan, Canadian banks do not recognize benefits as part of the family income. They consider benefits unreliable and temporary (they are discontinued at age 18). Yet we are working. Constantly. Day and night.

We are nobodies.

No more retirement plan, no more money accumulating in a pension. No more savings. We are fortunate to live in a wealthy country that supports fairness and family values. But our special circumstances have caused us to fall into a crack in the system. Medical technology is constantly developing and has the power to save our children's lives. But government programs are not keeping pace and that is a real problem. We are a new generation of parents and we want to be involved in our children's lives for as long as possible and to live with dignity. We need the financial resources to do so and we are asking you to provide them as quickly as possible. The problem has been going on for too long and many parents are exhausted. Some are thinking about institutionalizing their child – which would cost the State a fortune, as we know – or worse, committing suicide.

See the complete study: *3

Federal support programs and their gaps

Children under the age of 18

- Canada Child Benefit: Ends when the child reaches 18. Despite reaching the age of majority, the individual is still a child and requires as much if not more care and assistance.
- Child Disability Benefit (T2201): These benefits are not increased based on the severity of the disability. A child with a minor vision and hearing disability receives the same amount as a multi-disabled child who requires extensive, lifelong care and will never live independently. This benefit also ends at age 18.
- Tax deduction for childcare costs (day camps, special respite care). A severely disabled child aged 18 or older still needs to be cared for by an experienced adult. It would be helpful if parents could deduct the cost of caring for their dependent and disabled adult child, even if they have not arranged child care in order to work or study.

Adult over the age of 18 with multiple disabilities

- Caregiver amount: This amount is totally inadequate for the needs of caregivers, who perform a staggering number of duties 24 hours a day. This amount is not available to the mothers of minors, even though we are caregivers as well.

See OPHQ guide: *4

Registered Disability Savings Plan

Everyone is proud of this solid savings plan. Unfortunately, it is designed only for people who have enough money to set aside. In many cases, our children's life expectancy is too short (as in the case of children with degenerative diseases) for them to have any kind of "retirement."

Our recommendations

1. Increase the benefits paid through the Quebec Allowance for Handicapped Children and use a point system (see *5) so that the most severely disabled children receive more benefits.
2. Ensure that the most severely disabled children according to the point system continue to receive benefits after they turn 18 (for life).
3. Provide the parent who cares for a severely disabled child (or adult) with a STEADY, LONG-TERM pension or benefits in HIS OR HER name. This funding must be reliable and, above all, PERMANENT so that it will be recognized by the banks.

This is the most important point of all: The best solution is to keep children with their biological family. Parents are in the best position to know their child's needs and meet them properly with love and attention. This arrangement also results in considerable savings to society, because putting our children in care represents a significant cost to the government.

About Parents jusqu'au bout

We launched the Parents jusqu'au bout (PJB) movement on February 3, 2015, to put families with a severely disabled child on par with foster families.

Our initial strategy was simple: increase public awareness through the media. We reached our goal quickly thanks to social media, which led to the introduction of a national petition. We then encouraged all the other parents of severely disabled children to meet with their Members so that our voices could be heard in the National Assembly. Our persistence landed us a meeting with Ms. Charlebois, the minister responsible. Based on our persuasiveness and determination, she decided to establish an interdepartmental committee and invited us to be involved. During this time, it was critical to keep up the political pressure and secure the support of the Official Opposition. We met with the opposition parties and asked for their help. We succeeded in gaining the support of the three opposition parties. The name "Parents jusqu'au bout" came up practically every week in the National Assembly.

Media support needed to be ongoing so that our cause did not fall off the radar.

We decided to go for broke and contacted Mr. Ménard, the most widely recognized lawyer in Quebec specializing in health issues. He agreed to handle the case pro bono. At the same time, we met with the president of the Association des lobbyistes du Québec, who also agreed to give us a hand free of charge.

We also met with a number of ministers to explain our situation. We urged them to make changes quickly, emphasizing that this was a humanitarian issue that needed to be resolved right away.

A call out of the blue changed everything: the program "Tout le monde en parle" invited us to appear. It was great to learn that Quebec Health Minister Gaétan Barrette would also be on the show. This was our chance to make ourselves known. We had to get a meeting with him. Mission accomplished! The profile of our cause suddenly skyrocketed.

On March 14, 2016, the day after the broadcast, Dr. Barrette promised us that a financial assistance program would be established in two months. He would put pressure on the interdepartmental committee set up by his colleague, Ms. Charlebois. We worked harder than ever to maintain a media presence during those two long months.

A new program was introduced only 16 months after PJB was established: the Supplément pour enfants handicapés nécessitant des soins exceptionnels [benefit for disabled children requiring exceptional care]. This benefit will enable more than 900 Quebec families to receive funding of \$947 per month in addition to existing services and programs. The benefit is intended to address the child's exceptional needs (drugs, therapy, ambulance service, adaptations, etc.).

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*2. Stages of grief

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*3. Study on life with a sick child: *Tricoter avec amour*

https://www.mfa.gouv.qc.ca/fr/publication/Documents/cfe_etude_tricoter-complet.pdf [In French only]

*4. Office des personnes handicapées – guide to Quebec programs and services

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*5. Point grid for Quebec foster families regarding severity of disability: page 10:

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* We wish to emphasize that Quebec offers the best support for families with a severely disabled child.

Thank you!

Geneviève, Anouk, Marilyne, Marie-Ève and Marie-France