



Community

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Tragedy and hope

One minute, Kathleen Shiels was holding her two-year-old son's hand, buying him a drink at a fast-food outlet. The next instant, her life changed drastically and irreversibly. Her son was struck by a cart, leaving him with severe brain damage.

Within an hour of the injury, he was unconscious. When he awoke, he screamed incessantly. Within two days, he had a violent seizure. The seizure left him unable to walk or talk.

The two years since the accident have been a journey that could fill a book. It is both a horror story and a hopeful story. It is a story of incredible hardship, pain and sorrow, and one of joy, epiphany and inspiration.

In short, it has left Shiels with an immense appreciation for life as well as an unbending determination to make right the wrongs that children with disabilities and their families face.

After the initial medical treatment and diagnosis, Shiels was told the waitlist was 18 months long for therapy for brain injuries.

Ironically, the treatment was termed "early intervention."

All resources were scarce and those that were available, weren't easily accessible, she said.

A former preschool teacher, Shiels points out: "I have a background in working with children and can articulate my needs – what do other parents do?"

While an organization in Vancouver, Burnaby or New Westminster might be listed as working with children with brain injuries, after phone calls and sometimes filling out forms, Shiels would find out that the agency focuses only on a specific area such as speech problems.

Back to the directory.

"Don't get me wrong, there are a lot of agencies that are phenomenal, but they're bombarded and overloaded," she adds.

At the same time that Shiels was mired in the search for therapy, she and her family were trying to cope with the tumult that their lives had become.

"When my son was first hurt, it took a number of months to come down from the constant thought of, 'Oh, my God,' she explains. But horror at the damage to her son's body was not the worst.

"What's most difficult is what happens to the rest of the family. It's like a train wreck. You can see what's happening but you can't stop it."

Shiels' then six-year-old daughter witnessed the accident and still suffers from post-traumatic stress. She has nightmares and blames herself for not preventing the injury.

Shiels' partner, the father of her children, left her, no longer able to cope with his son's injury and extreme behaviours. Prior to the injury, he and Shiels were planning to get married and were considering buying a house.

Shiels herself was heading down two promising career paths – and money was not an issue.

Now, Shiels is on social assistance. When she takes her cheque to the bank, she wears a baseball cap pulled down over her eyes to avoid the negative glances of other people.



ONE STEP AT A TIME: Kathleen Shiels, shown above at the office of the Western Society for Children with Birth Disorders, had to learn the hard way about community resources after an incident that left her two-year-old son with brain injuries. Now, Shiels is helping the society with a mapping project that's working to pinpoint what resources are available locally for families of children with disabilities. The public is invited to provide input – see details on page 12.

LARRY WRIGHT/ The Record

One of the physical results of the injury was that Shiels' son suffers from sensory flooding. Flickering lights, bright colours, touch, people or new surroundings would send him into violent fits or screaming episodes.

To get him used to touch, she'd have to use creative and work-intensive strategies such as filling a bathtub with Jello (it took 27 boxes) or sand (10 bags).

Therapists she'd arranged for would have to come to her home, because her son's damaged brain couldn't handle going elsewhere. Before a new therapist in the ongoing procession would arrive, her son would have to be shown a photo of them. The next step would be to allow them to enter the house for just a minute. Slowly, slowly, he would adjust to them.

When social assistance bureaucrats didn't believe that Shiels had become a single parent, they insisted on coming to her home, as per regulations, to ensure she wasn't cheating the system. She showed them her son's medical records, she explained the difficulties with entering her son's domain, but they came anyway.

More than once, Shiels has found that "rules" don't consider the lives of human beings. Her son, for instance, qualified for the highest level of respite care. But that care had to be delivered at someone else's home.

Because her son couldn't handle the stimulus of moving and was already used to a particular caregiver, she suggested that

his caregiver simply be paid to spend more hours at their place.

Shiels pointed out that this would be cheaper than the care proposed out of her home.

However, she was told that couldn't happen. The highest level of respite care comes out of a different pot of money than the money paid to casual caregivers – and there could be no overlap.

Then there was the time when her son screamed non-stop for five days straight because he was experiencing violent headaches.

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KATHLEEN SHIELS

Being completely sleep-deprived and at wit's end, Shiels called the ministry, saying she needed help.

"They said, 'We can't help you unless you're abusing your child.'"

She says social assistance defines basics as food, shelter and clothing. But, with a child with a disability such as a sensory problem, the basics are much more.

She laughs when she recounts that a therapist told her her son would benefit from Goretex socks.

"I can't afford Goretex socks."

And any financial support she receives from her son's dad could be subtracted from her monthly allowance.

Shiels points out that she's a patient person but, often, by the time she had finally navigated the hoops required to actually see a potential therapist or support person, she would be frustrated and tense.

"It takes a special person to say, 'Sit down, have a cup of tea.'"

But that's what she found in Wanda Gendron, program co-ordinator with the Western Society for Children with Birth Disorders, located in New Westminster.

Gendron understood what Shiels had been going through and could offer her a sounding board as well as resource information.

Shiels, who helped co-found the Brain Research Advocacy and Information Network, is helping Gendron with a mapping project. Gendron's organization is doing an overview of resources in New Westminster for families of children with disabilities.

They're researching where the overlaps and gaps are, with the hope of remedying the problem areas.

Tears come to Shiels' eyes when she talks of a telephone call she received recently from the mother of a child with a disability. The mother is facing a torturous choice. Because she doesn't have the finances to adequately care for her child, she's considering putting him in foster care.

"And that's not unusual – there are so many cuts to children's issues that it's unbelievable."

Shiels says foster parents receive more money to care for such a child than the parent on social assistance.

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TRAGEDY AND HOPE

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The financial reality, says Shiels, is such that the cost of raising a child with disabilities is usually eight times the cost of a typical child.

Shiels also points out that, like any child – perhaps more so, a child with a disability needs to play. Yet government funding for activities such as swimming isn't available.

"It's been proven," Gendron points out, "brain development depends on play."

Says Shiels: "I would like to be considered a typical family. I would like to be able to take my child swimming – but my child can't participate without extra costs."

She points out that if society is judged on compassion, "I would put a challenge to everyone to not look at disabilities, but of the abilities of these children – of all ages."

While Shiels' struggles continue, her determination in accessing services has paid off. Her son has progressed to the point that he can now attend a small specialized preschool. He still has violent episodes if he gets stimulus overload, but he's improving.

And, just last week, Shiels received news that another parent might take for granted. But, for her and her son, it was a miraculous milestone.

"For the first time, he went up to a kid in school. He said, 'I have a best friend' and hugged him."

She says, tears welling, "With an 18-month waiting list, he would just be getting help now. Because of my tenacity, he has a friend."

Meeting held to gather input

Project will look at resources and services for young people with disabilities

If you're a young person with a disability, if you live with a young person with a disability or if you have information you'd like to share on services for young people with disabilities, your input is wanted.

The Western Society for Children with Birth Disorders is holding an information-gathering evening on Wednesday, Oct. 29 from 7 to 9 p.m. at the New Westminster Public Library Auditorium, 716 Sixth Ave. It is wheelchair accessible. Free drinks and snacks will be provided.

The society has received a grant to assess services for children with disabilities and their parents.

The goals of the project are:

- ◆ to determine what resources and services are available in New Westminster;

- ◆ to suggest ideas for new community support programs; and

- ◆ to be as inclusive as possible in the definition of disability in order to allow the greatest number to participate.

The project will include "grey area" students – students who may have a learning disability but haven't been diagnosed yet.

The evening is the second of three being held.

Wanda Gendron, program coordinator for the society, says the cost of providing necessities for a child with a disability tends to grow exponentially as the child grows.

Ministry services are reduced after a child reaches six, yet costs of equipment then often increase, she says.

"I'm not saying early intervention isn't important, but the needs continue to grow as they get older."

Gendron says her society receives more than 500,000 requests each year for equipment and varying therapies.

Gendron points out that because children with disabilities are not accommodated by society, they can grow up with underdeveloped potential for personal or employment skills.

"They are often not unable but, instead, differently abled. They have the right to develop potential and find meaningful participation in their community."

She points out that society now knows it's not okay to exclude in terms of diversity – race, religion or background – "but children with disabilities are told, 'you can't go there, you can't do this.' Their needs aren't special, they're just needs."

A good part of her job, Gendron points out, is that children constantly exceed their predicted potential.

For more information on the Oct. 29 gathering, call the society at 604-515-0810.

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