

Children Have Suffered In Nursing Homes Too

As late as the 1990's children were suffering and dying in Ontario's nursing homes. Other young people still suffer in them. This is the story of a little girl with an indomitable spirit who made it with the love and help of others and of a community. She showed the world how harmful institutions can be, and the devastating impact that the for-profit model has on vulnerable people. In doing so, she also established with great clarity that taking action to change such systems is worth it, for every single person.

Just as ripples spread out when a single pebble is dropped into water, the actions of individuals can have far-reaching effects. – Dalai Lama

Once upon a time, not so long ago and not so far away, and as has happened to certain children throughout history, a little baby girl was thrown out. Discarded because of who-knows-what singular or multiple reasons. Abandoned to an institutional hell. Not for her the loving arms of a parent; instead just a mat on the floor. The harm she experienced was monumental. That her birth was complicated, resulting in a severe brain injury, is not in dispute. But the damaging toll of her abandonment could not have been greater. Physically, she was perpetually starved, to the point that she only gained 10 lbs in the 10 years after her birth. Her bone age was massively impaired, her stature so severely impacted that she was only the size of a two-year-old at age 10 years. Emotionally, she was deprived of the love and nurturing well documented to be essential for the well-being of every child, in fact even for their very survival. Developmentally, she was provided nothing to ensure a sound basis for cognitive and communicative growth. What happened to her should have been deemed a crime, but it was not.

If ever a little child could create an impact in the world akin to that proverbial pebble and its resultant never-ending ripples, this was one such child. For she emerged from that horror to impact the world in a myriad of ways.

It begs the question: HOW? How could this tiny child, starting at 3 years of age, with all of those things going against her, initiate a ripple that resulted in her gaining a loving family; enjoying a truly rich and meaningful life full of exciting opportunities and achievements; progressing to social justice efforts that shut down all of the very institutions that harmed her so greatly, freeing the children in them to live in valued community settings; change education legislation so that children

with significant challenges were afforded rights to attend their neighbourhood schools with their same age peers and receive appropriate supports to do so; and then subsequently influence major changes in health service to young people who, like her, developed ever more progressive and very complex medical needs, thus ensuring they had adequate supports to remain living in their homes of choice?

As Helena from Shakespeare's *Midsummer's Night's Dream* has said:

“Though she be but little, she is fierce.”

It defies comprehension, but this little girl was blessed with something so ethereal that it couldn't be taken from her, like everything else in her life had been. She had an indomitable spirit and a captivating presence capable of delving deep into your heart. And she had an internal drive to survive, against all odds, along with a determination to get for herself what she needed when no-one around her would do it for her. She didn't know she needed OUT of that institution, and she didn't know she needed school. But she intuitively knew what she did need, although she couldn't have framed it in specifics, even if she had been able to speak - and that was a meaningful relationship with another human being. She needed LOVE. At a point where she was truly expected to die, she used every bit of her last reserves of energy to command the attention of the one person who came into her world who could see her for the beautiful, courageous and astonishing human being that she was. She latched on with a determined ferocity to the one opportunity that came her way. She chose me. And I am forever grateful to her for doing so. She captivated me in the truest sense of the word, ensuring I was hers for eternity, and we forged a deep, unbreakable bond. I fell in love with this tiny, passionate little girl, and we became an incredible team. I became her Mom, and she became my adored daughter.

Her name was Becky, and she lived joyfully, she lived intensely, she lived gently. I loved her and every minute of my time with her. And along with getting a Mom, came the bonuses: a Dad, a brother, a home, extended family, friends, experiences and achievements.

Perhaps the very fact that she had to save herself gave rise to the lifelong invincible spirit she perpetually exhibited, for it is well known in advocacy circles that to save someone unilaterally is ultimately to disempower them. She couldn't have been more disenfranchised, but she was one determined little girl. Those who are disenfranchised need to be heard, even when their message is delivered in non-verbal or atypical ways. I listened and I heard her, the only person in her life who

had ever done so. Together she and I embarked on a journey of mutual love, abiding respect, deep conviction and searing passion to try to right some terrible wrongs. Together we found ways to empower each other, and we blazed many trails. Becky was the impetus for our journey together. She always led, by showing her keen interest in everything around her; I facilitated and problem-solved. She fuelled my fire; I nurtured her soul. She loved openly and without artifice - what she felt, she shared. She intuitively knew the full meaning of living genuinely.

Becky always had a choice, and she repeatedly showed her drive to belong, to achieve, to succeed, to survive.

But as those of us who must face obstacles throughout our lives know, it really isn't possible to do it alone. Linking with others prepared to commit to the same goals greatly enhances the possibility of successful outcomes. As Becky and I worked towards systemic changes that would see children's Nursing Homes closed and that would achieve changes in education legislation enabling children with disabilities the right to Inclusive Education alongside their same age peers, we absolutely needed support. Amongst the most critical of our needs was that of validation. One simply cannot keep forging a path if you are not utterly convinced it is not only the correct path, but that it leads ultimately to an achievable destination. Many have undertaken to work towards achieving the same goals. All of us need to be supported to do so. Validation from others whom you respect fuels the courage necessary to back up your convictions.

Such support from others was instrumental to Becky and I early on in our journey, and intermittently throughout the years. People who possessed a unique clarity of vision, and had an unwavering commitment to individuals and families, and to justice. Much as I listened to Becky, others listened to both of us. These were people who operationalized a comprehensive understanding of the disempowerment of taking over for someone, of interjecting visions or goals or paths that are not self derived. They epitomized the provision of validation.

Those stalwart companions stood steadfastly at our shoulders, or resolutely at our backs, ensuring that we had the fortitude to tackle our challenges. They provided us an extensively informed sounding board for ideas and actions.

May there be more people who truly listen, and may there be more people similarly committed so that there will be a future with no more children discarded to the trash bins of congregated institutional settings.