



A message from the Co-Editor *Maria Glaze*

Greetings Everyone!

Welcome to our fall issue of VelaVision. The focus for this newsletter is brothers and sisters. We have shared many stories over the years about the power of Microboards and Individualized Funding in peoples' lives. This issue contains stories from the perspective of siblings. Some of you might remember our 2003 Vela Conference that included presentations from a Siblings Panel. The panel members kindly shared their presentations in our Winter 2004 issue of VelaVision, which you can find on our website. I still recall how moved I was to hear my thirteen year-old daughter Kate speak at that conference.

I just returned home from meeting Kate at the Vancouver airport. She had flown back to B.C. from a two-month solo trip around Europe. We had several hours for conversation while we enjoyed the drive and two ferry rides home to the Sunshine Coast. Along our journey I asked Kate if her thoughts about Rebecca's Microboard have changed from eleven years ago.

Kate's perspective hasn't changed very much over the years. While Kate isn't a director at this time, she said she still plans on formalizing her commitment to Rebecca by stepping into that role one day soon. Kate feels very reassured to know there is a committed group of

people supporting Rebecca to live her life. She values the diversity of Rebecca's current board members and the ways in which they offer their unique perspectives. Kate also thinks about a time when her Dad and I age and envisions herself taking on a larger role in Rebecca's life. She wants to join the Microboard before that time so she can learn how things work to prepare for the future. It is still very comforting to

Kate to know she won't be alone. She knows her sister will be okay and will have a network of people helping make decisions that are always in Rebecca's best interests.

As a Mom, it is reassuring to know Kate will not only be in Rebecca's life as a sister, but as a Microboard member, as well.

For the past several months I have had the pleasure of being the Story Collector for a second collaborative book project between Community Living B.C. and the Family Support Institute. The focus of this book is brothers and sisters. Look for it in the spring/summer of 2015 for more inspirational stories from siblings.

As always, a huge thanks to those of you who shared your inspiring stories and photos with us. If you have a story you'd like to share, or topics you would like to see in VelaVision, please call or email us.

With gratitude,
Maria Glaze
Co-Editor



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A Transformation for Jeffrey *by Teri Todd*

I remember the day my brother, Jeffrey, came home from Vancouver. It was 1988; I was five years old and had spent very little time with him, but was always so aware of his absence and missed him all the same. He seemed rather worldly to me -- he was sixteen and lived in the city, after all. And so his return at Christmas felt special and exciting, and I wanted nothing more than for him to love me as much as I loved him.



Jeffrey & Teri

Jeffrey has profound mental and physical disabilities caused by prenatal toxoplasmosis. His spastic quadriplegia, blindness, epilepsy, rotoscoliosis, frail bones, and swallowing issues had been the weights on the scales of institutionalization; combined with the lack of suitable supports in our hometown of Castlegar that could allow my mother to work to support our family, and the assertion from social workers that keeping her son at home was not “cost-effective,” my mother had been convinced that the group home near BC Children’s Hospital was crucial to Jeffrey’s health. But what was all that to a child? Here was a boy, my own special brother, who was my size, who laughed when I was silly, whom I could cuddle-up to and read stories and share toys and secrets and love. He was my brother, and he was my best friend.

This was only meant to be a visit for the Christmas holidays, but it became so much more than that. Jeffrey returned to us in a full-body cast and pins in his hips from a recent surgery

(a better option than staying alone in long-term care since his group-home couldn’t manage his medical needs), with a wheelchair that had to stay outside because of our inaccessible home, and with severe malnutrition as a result of his deteriorating swallow-reflex. Of course, being five and so wrapped up in Christmas and my new brotherly-best friend, I was oblivious to the anxieties of my mother’s dilemma. How could she send Jeffrey back to the group-home knowing that his 42-lb body would likely never be properly cared for, as it took eight hours a day to feed him his three meals? That he was sometimes put in his bedroom for being too noisy, a “punishment” for something he could never learn to control? That the overworked staff could never hope to give him the kind of attention and care and love that he deserved?

No. Her son needed her. So his visit became a permanent one.

Of course, this was fraught with issues. No longer could she work outside of the house full-time. She and my father had to do all of the physical care without proper lifts or equipment. And their other children (my two sisters and I) would have to learn to fend for ourselves while my father worked and my mother tended to Jeffrey while running an in-home daycare and providing respite care for other families to make ends meet.

But here’s the thing: as Jeffrey’s sister, this all just seemed so natural to me. Of course my Mom needed to change jobs. Of course I needed to get my own cereal. Of course my sisters and I needed to go play while Jeffrey ate lunch. Jeff was in need of attention, and we were perfectly capable of pulling our weight while he was tended to. That’s just what you do when someone you love is in need.

Looking back, it’s hard to believe that those were the humble beginnings of Jeff’s reintegration into our family, as

A Transformation for Jeffrey *by Teri Todd*

it seems like Jeffrey has always been there. In those early years, my Mom fought for every bit of support she could get for Jeff, against a system that seemed determined to deny people with disabilities even the most basic of human dignities. It seemed like she was bailing out the boat only to have it fill just as quickly.

It wasn't until the Jeffrey Lafortune Support Society (JLSS) was formed that the possibility of sinking started to ease. Suddenly, with the Microboard came control (on Jeffrey's behalf) of his community inclusion supports, his transportation, and his support system. At the time, I was so young that I was oblivious to the big decisions and the day-to-day workings of the JLSS. But what I do remember is this: somehow, life became more comfortable, as though we had all breathed a collective sigh of relief and were able to nestle a little deeper into our home. There was a sense of confidence about Jeffrey and his future that hadn't been there

when his life seemed determined by one renamed government ministry after another. We were in charge of helping Jeffrey to live a life of dignity, purpose, and self-determination. The hope that this brought was transformative.

Today, I am happy to report, Jeffrey is a thriving 42-year-old man with greying hair, sparkling eyes, and a belly that can't get much bigger if he wants to keep his gastrostomy button. (I may tease him for his grey hair, but mine isn't far behind). Today, he has full control over whom he employs for his community inclusion supports. He is the "co-instructor" of the Classroom and Community Support Worker program at Selkirk College, helping to educate the students through his integration into the program and college society. Three years ago, he was awarded an Honorary Diploma for his contributions, for which he earned a standing ovation. He is happy. He is healthy. And he is home.

Sometimes, I find myself worried about what the future will bring. My Mom, now in her early-sixties and living with chronic pain, continues to enjoy caring for Jeffrey at home with my Dad, now her ex-husband, as the respite-care provider. It seems unlikely that Mom will be able to care for Jeffrey indefinitely, and I know that I will be the one to step in and take over his care if she becomes unable to continue. Can I ever hope to match her tirelessness, her patience, her attention to detail in his physical care? Perhaps not; but knowing that the JLSS will be there to support Jeffrey and his care-network gives me hope. Decisions about my brother will never again be made under duress or pressure from the overburdened and underfunded system; they will be made by people who love him and respect him and want what's best for him. In short, the JLSS supports Jeffrey, but it supports us as his family, too.

This Christmas, I'm looking forward to coming home and seeing my family. That family has grown now to include a handful of nieces and nephews, some of whom will be there Christmas morning. Jeffrey will be there, at home with our Mom, exactly where he belongs. I will get to revel in the joys of watching these sweet children experience the perfect love of the only perfect person I've ever known — and I hope, to experience a little piece of my own childhood, which is one that I would not trade for the world. The children will help Jeffrey open his Christmas presents and share their toys and secrets and love.

And so will I.



Jeffrey & Teri

The Most Important Decision I Ever Made *by Joanne Finnegan*

The following piece chronicles what I think is the most important decision I ever made – to start a Microboard for my brother Guy. It also discusses the challenges in relationships between siblings and how a Microboard overcomes those difficulties and strengthens bonds.

My name is Joanne Finnegan. I am 60 years old and live in Victoria, BC, with my husband. I have two brothers, and the closest in age is my brother Guy, age 59. He has lived in a Courtenay Home Share for the past five years. He attends a community inclusion program, takes Karate, goes to the gym, and attends a wood carving class. He visits with us about every six weeks. Guy is very social, has a great sense of humour, builds deck furniture, enjoys watching football on TV, and is a committed Coronation Street follower. He has cerebral palsy, is profoundly deaf in both ears, has severe speech difficulties, and faces significant cognitive challenges.

I have known since I was a teenager that I would be responsible for taking care of Guy when my parents were too old to continue. They made a decision when Guy was in his early 20s to keep him at home and support him. He had a pension cheque but did not attend any programs. This was partly his choice. He was always adamant that he didn't want to be seen with people who have a disability and my parents, particularly as they aged, were more comfortable with having him home.

From the time he was a teenager, Guy often posed the question, "When Mom be dead and Dad be dead, what about me?" The answer from my parents was always, "Don't worry, you'll be okay." This vague assurance seemed to put his mind at ease for awhile. It never put my mind at ease, though. I often asked the same question privately to myself.

As I moved through university and became a special education teacher

(no surprise, I suppose) I learned what kind of government programs existed and the types of challenges parents of children with developmental disabilities faced. Working in the field, I discovered that government supports were inadequate, that there was little beyond group home placements (if you could find one taking residents) and that employment programs were non-existent. It was increasingly evident that for the rest of my life I would be responsible for his well-being. I have another brother, but circumstances make it difficult for him to participate as much in Guy's life. Furthermore, I worried that he and I would disagree on how to support Guy and our relationship would suffer.

My biggest concern was that when my parents were no longer able to accommodate Guy, and if we could not find suitable housing, he would either have to live with me or my other brother. Both situations were untenable. Much as I love him, I did not want my life disrupted so Guy could live with us. Furthermore, my husband didn't buy into that living arrangement when he married me and it would be a major lifestyle change. I also knew the emotional strain it would put on me and my husband, and I was not prepared to make that sacrifice. Much as I love Guy, I knew that love would gradually be replaced with resentment and anger. I would be ashamed for letting those feelings emerge, perceiving myself simply as a selfish and uncaring sister. The relationship between siblings is different than that between parents and children. Siblings should have an equal relationship, with neither one



Guy & Joanne



Guy

dominant to the other. Living together would undermine that premise and tensions would understandably surface. It is my house under my rules. I would be the de facto parent. This was not a position I wanted to put myself or Guy into. A 'pre-emptive strike' was in order so my life and Guy's didn't spin down some kind of emotional abyss. I needed to put some wheels in motion.

In early 2000, two sets of parents whose teenage children I was involved with as an Inclusion teacher at their high school told me they were establishing a shared Microboard for their son and daughter. (These were

the Jensens and McCullochs, and their children respectively are Matt and Alicia. A previous issue of VelaVision discussed their experience.) I was excited with the idea of a Microboard and could immediately see the possibilities for Guy.

The Microboard concept addressed every concern I had about how to approach supporting Guy. A board composed of family and friends would relieve me of sole responsibility when my parents passed away. Many heads are better than one, and Guy would respect and enjoy the support of this group. Board members would see him as an

individual, would do collective problem-solving, and perhaps most importantly in the early years, would give my parents the support they needed to acknowledge their son as an independent adult. Finally, my other brother and I would be members of the board, part of a collective decision-making body that had an obligation to pursue support mechanisms that were in Guy's best interests. Not only would this prevent any acrimony between me and my brother, Guy would not be put in the position of taking direction from siblings.

I called the Vela contact here on Vancouver Island, Jeanette Holder, and got more information about the process. When I approached my parents about the idea, they agreed it was worth looking into. They knew they were not getting any younger and something concrete had to be put into place for Guy. Also, they could choose the people to be on the Board, giving them some control, as well as assurances that these people would have Guy's best interests at heart. Jeanette was a perfect facilitator – extremely knowledgeable yet down to earth. My parents were very comfortable with her, and this went a long way toward their understanding and agreeing to the process. The "No Problems for Guy Society" was created in 2002. It is composed of long-time friends of the family, a cousin, my youngest brother, my husband and me - seven people altogether.

The early years of the Board were largely inactive because my parents were not ready to give the board any responsibility. In the meantime, CLBC was created, and we were

accepted for individualized funding for caregiving. My parents agreed to a home-sharing arrangement that they liked. Unfortunately, but not surprisingly, the transition was challenging, initially more for my parents than for Guy. It is sometimes very difficult for parents of adults to accept a shifting role in their son or daughter's life for the first time. This can create challenges for home-sharing situations, and did for our first two home share providers. It wasn't until my father passed away in 2008 that Guy could go forward with the third home-share providers, where he lives today.

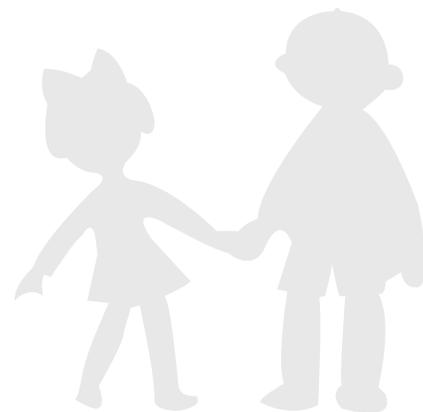
The current home-share providers have been working in the field of supporting adults with disabilities for over 20 years. While very professional, they are also warm and welcoming and treat Guy as a family member. Their professionalism and commitment was sorely tried in the first three years. It was hard on everyone as Guy coped with another transition, the death of our mother, and finding his place in the world.

The Board met regularly with Guy to give him the support he needed, discussed his responsibilities, and acknowledged his growth. They also assisted the home-share providers, thanking them for their patience, discussing strategies, and expressing our gratitude for being so professional and thinking in the long term. Guy settled in after three years and returned to being the conscientious, caring, and funny person we all knew. Most importantly, he matured to become an independent and confident individual, prepared to take risks, make new friends, and find his way in a different environment.



Guy & Garnet

I know I would not have managed on my own. Though often very worried during Guy's transition years, the challenges were bearable knowing others were there to help problem-solve – I was not alone. Guy's home-share providers can rely on a broader base of support and not solely on a family member who might let emotions override good judgement.





Finally, for Guy, the board members are a more neutral body than his family, but he knows these people care about him very much and are there to support and encourage, praise his successes, and be clear about his responsibilities as an adult. He is not put in the position of taking direction from his sister, and I am not put in a position of control. For members of the Microboard, it is a very positive experience to help someone in need and watch them grow as an individual. I had a heartfelt letter from a Microboard member

thanking me for having him on the Board. He said how extremely satisfying it was for him to be part of making a positive difference in Guy's life. Many of us try to find ways to give back to the community. A Microboard provides that.

Guy's Board meets annually to get an update on events and to hear from Guy and his providers how things are going. The home-share providers allow Guy time to talk privately to the Board to express any concerns, and this, particularly in the first few years of the transition, was critical to Guy's feeling of being heard and respected. Two Board members act as financial trustees for Guy, something that I encouraged my parents to set out in their wills. Being on the Microboard doesn't have to be time-consuming, it just needs to be a meaningful relationship for that person's circumstance. Two Microboard family members visit with him occasionally, but I am the main person in Guy's life besides his home-share providers. We have a healthy brother-and-sister relationship, wonderful family time, and lots of laughs. Being part of Guy's life is a joy for me, and while I have Guy to thank for this, the Vela Microboard concept made it possible. For that, I am eternally grateful!



Guy...

Ashley Ford

Growing up in Prince George, I was very close with my younger brother Sean. Eventually, both I and my older brother Corey relocated to the Lower Mainland to attend school. We missed each other, but Sean would come visit me and Corey from time to time. And of course, we came back to Prince George to visit as often as possible. Since then, my older brother Corey has returned to Prince George, and once again has been able to be a daily part of Sean's life. However, I now live in New York City! In New York, I am pursuing my dreams and building a career for myself in the Entertainment Industry, and although my family has been very supportive, it is with great sadness I am not always able to be physically present in Sean's daily life. Of course, we Skype each other often and are able to text each other, but it's not the same as being there in person.

A year ago, after a lengthy process for my mother and father, they were approved for funding a Microboard for Sean; Sean Alan's Life Society. In addition to his workers Linda, Ashley-Paige, and Becca being there to take him to events and being a fun, social influence in his life, they have also helped him with other life skills - like learning to cook! Also, as much as I love my brother and we get along splendidly, even if I were living in Prince George, I recognize there are certain life skills I cannot teach him. For example, Sean's progress in the program Adventure Seekers at the College of New Caledonia has dramatically increased since having the additional aid of his worker from the Microboard in the classroom. Through that program and with the assistance of his workers, he has even secured employment! Sean will always have the support of



Corey, Ashley & Sean

his family, but for me personally, in my absence, having the Microboard in place gives me a sense of ease and confidence, knowing that he has the support of an entire community network behind him. For Sean, the presence of a Microboard this past year has increased the quality of his life, increased his own confidence, as well as given him practical tools to live a more productive, fulfilling life. They say it takes a community, and that is what the Microboard is to Sean and my family. I look forward to seeing his continued progress!

Corey Demers

My brother Sean has had a Microboard for a year, and I have noticed a big change in his ability to adapt to different situations, and he is more involved in group activities. Ashley-Paige, Becca, and Linda, his

workers, have been a great help to myself and my parents by taking Sean to events, bowling, pubs, movies, shopping, playing pool, and having a fun time. He has made three solid friends that have taught and shown him a lot, and he really enjoys spending time with them. Linda has taken him grocery shopping and cooks with him, so one day hopefully he could be more independent. The college program he attends, Adventure Seekers, provides him with a college experience, like his brother and sister, and I have noticed a big change in his attitude and development. My brother has had these experiences because of the Microboard and I have seen a great improvement in his quality of life and his self- esteem.



Lorri and Jamie

In hindsight, I just always thought that things would work out. My brother Jamie, who has special needs, had fortunately been surrounded by wonderful people. Our Dad worked away during the week to support our family and was only home on weekends. Our Mom struggled with significant health and mobility issues. My sister and I did what kids did. We went to school, cleaned the house, did chores, watched and cared for Jamie, had jobs, and played sports. Eventually, Jamie got older and bigger

and his needs changed. Our sister Kandi and I moved on and out. It was impossible for our Mom to care for him on her own, and Jamie transitioned from occasional respite to full-time respite. Jamie had some wonderful caregivers. During his school years, I mostly remember Sue and her kids, Jesse and Amber, who became Jamie's "other" family. They welcomed Jamie in their home from Monday to Friday until our Dad came home for the weekend.

After high school, Jamie shared his life with many individuals. He lived in their homes as part of their families during the week, and returned home on the weekends when our parents still lived in the same community. Unfortunate circumstances found our parents, and they had to return to Woss, where our Dad worked. This meant Jamie had to spend weekends in respite homes when our Dad wasn't able to return to the Valley to take him home for the weekend. The most exciting times were when our Dad wasn't working and Jamie was able to live with our parents for extended periods, like for a week or two. However, these stretches were infrequent. This was a very frustrating period for Jamie, who I believe never really felt "at home" because "home" was forever changing. His demands on his caregivers caused tremendous burnout, and while our parents tried to advocate for his own residence with staff that supported him, it was a model that the powers-that-be could not or would not fund. Jamie's life became a life of rotating doors, closing doors, and escalating behaviour issues.

Things got worse. Our Dad was diagnosed with cancer. Arguably, Dad was the most significant person in Jamie's life, along with our Mom, and I suspect that his inability to fully understand anything beyond, "Dad's sick," created a tremendous amount of anxiety, uncertainty, and frustration for him. Worse, Jamie saw very little of our Dad during this time because he was in and out of various hospitals for treatment, from Victoria to Port McNeill and in between, and Jamie's anxiety only increased during



Jamie's Microboard and Community Support Workers at Jamie's P.A.T.H. planning event at Vancouver Island Community Connections

hospital visits. Ultimately, in 2003, our Dad passed away. Jamie's understanding of his loss seemed intermittent. Even now, one day he says, "Dad's dead," and the next, he wants to drive to Woss to see him. That breaks my heart.

After our Dad passed, Jamie's relationship with our Mom suffered too. She was not well enough to care for him on her own, and she and Kandi lived three hours from Jamie. I had a family of my own with five children, and worked full time. It was difficult to stay connected. Because Jamie did not do well around small

children, it was impossible for me to travel with him. Fortunately, there were opportunities for Jamie to spend time with our Mom, thanks to Kandi, who was able to take him from time to time, and to wonderful friends, Mary Catherine and Andre, who would bring Jamie to the North Island to visit. During these visits, Jamie was usually able to see some of his favourite family members as well: Moms (Grandma) and Papa Lutz, Uncle Barry, Auntie Suzie, and always a coffee and sweet treat with Auntie Ulla. About July 2004, our Mom got word that CLBC was moving Jamie to Victoria to a group home, without

any consult, and without warning. It was a done deal. Frantic, my Mom made some calls, and while I don't recall the specifics, she was connected with Jeannette Holder. Jeanette helped coordinate a meeting where a Microboard was formed. We all wrote letters outlining the significance of moving Jamie out of the community he had grown up in, away from the people he had established relationships with, and creating even greater distance between him and his family. It was the force of the Microboard, with the initial writing campaign, that kept Jamie in the Comox Valley, his home.

Jamie's Microboard Saved Us All *by Lorri Fugle*

We had been heard, and we were so grateful.

And, things got worse.

Suddenly, in September, our Mom passed away. I was still in profound grief over the loss of our Dad. I had five young children, Kandi had just had a brand-new baby, and we three "kids" had now just lost our Mom. I couldn't comprehend how I was going to be able to take care of everything. What was I going to do? How could I possibly explain this to Jamie? How was I going to take care of my family, and take care of Jamie, too? To say I was overwhelmed was a monumental understatement.

And something amazing happened. The Microboard didn't just save Jamie, they saved us all. They participated in the ceremonies to help Jamie understand that our parents were gone. They checked in with him to make sure he was okay. He was taken for car rides, his favourite pastime, especially if it was in a Chevy or GMC. He was invited for dinner and taken out for lunch. They checked in with me to see if I was okay. They made me understand that I wasn't alone in making sure that Jamie was okay, and that I had support whenever I needed it. It was nothing short of amazing.

The Microboard moved forward to help facilitate many things, but one in particular I see as a life changing event. The Microboard was instrumental in advocating for a place that Jamie could call home, where he was not forced to move each week between his caregiver and respite, and where staff would rotate around him. The Microboard achieved what our

parents had hoped to achieve. Jamie would finally have a place to call home. No more packed bags. No more wondering where he was going. No more wondering when or if he was coming back. Jamie finally got to live in a way that we all take for granted. One bed. His own dresser with his own clothes that don't get packed up. His toothbrush permanently parked in his own bathroom. His own kitchen, where everything is always in the same place, with food he helps to choose. His own routine and not having to fit in to someone else's. His own life.

As I share our story with you, I wipe away tears of sadness. Our parents will never see the impact of the changes that the Microboard worked to bring about have had on Jamie's life. The Microboard works closely with the contractor that was chosen to support Jamie. He enjoys his own home, filled with his own things. He has a car that allows him to experience the community in which he lives, and that otherwise would be limited. He still enjoys riding the

public transit, especially the Fanny Bay run where he can see the seals fussing about from the dock. He has a standing date at the recreation centre each week for racquetball, where he claims to dominate his opponent... every time. He beat me once too. And he enjoys his weekly lunch outing, which ends with his purchasing a new CD before going back home for the afternoon. My bets are always on Johnny Cash or Waylon Jennings, though he does deviate. He has a good life.

The other tears are tears of pure gratitude. I can't imagine advocating for Jamie on my own. The power of the Microboard is immense, and I am forever indebted. They continue to be instrumental in ensuring we are always headed in the right direction for Jamie. They continue to support me as his family advocate. It is a group of amazing people whose only interest is to ensure that Jamie's life is full, productive and happy. While there will be much to do moving forward as Jamie's life evolves, things didn't just "work out". The Microboard has succeeded.

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