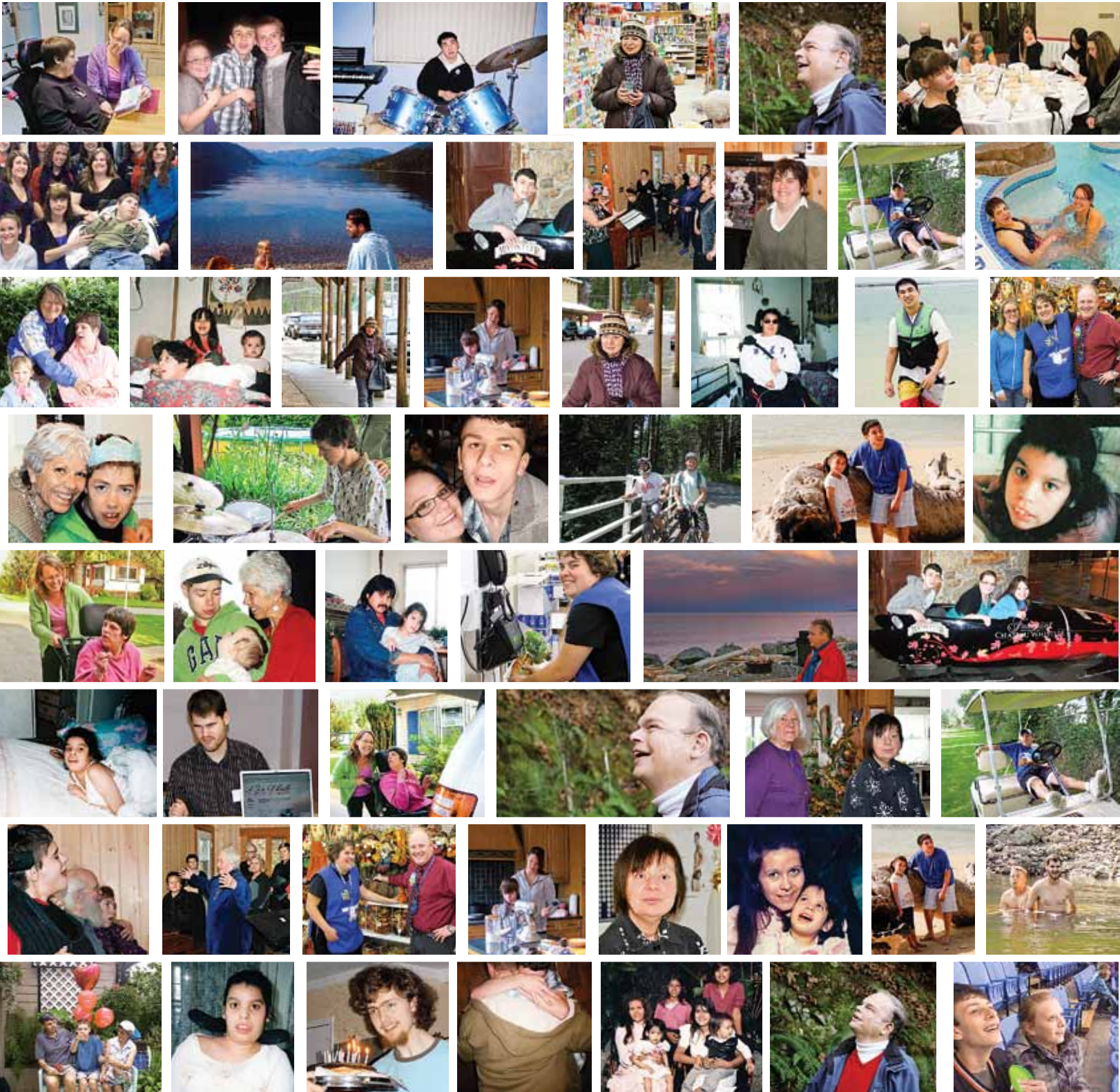


The Power of Knowing Each Other:

Stories about informal safeguards
told by BC families







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*This book is dedicated to all families;
those who share their joys, celebrations
and challenges and those who are
inspired by their stories.*



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REFLECTION

Maria Glaze

Being a curious person by nature, the idea of interviewing people to gather stories for this book on Informal Safeguards excited me. As the mother of two daughters aged 21 and 27, and a long time Resource Parent for the Family Support Institute (FSI), I've had the privilege of hearing and sharing many stories and have experienced their impact both as the listener and the storyteller. What was new for me was telling someone else's story. I felt extremely honoured to be given the opportunity to write about another's life. I thought of myself as a conduit using written words to pass their experience through me on to readers. What I did not expect was the intimate connection I would feel with each person and family as I developed their story.

The process of writing each story had several stages. The first stage was the interview itself. People graciously welcomed me into their home or set time aside to talk on the phone. I would immediately become engaged in what felt more like conversations than interviews. At times I was embarrassed to come home, listen to the recording and hear how much I talked. After the first interview I made a note to myself, "Listen more than talk, Maria!" I wrote notes and used a digital recorder for each interview and spent hours afterward working with my notes, listening to the recorded words, writing and re-writing. It was through this process that I began

to feel my connection with each person and family grow and deepen. Even now, if I close my eyes, I can still hear Jim's laugh or can imagine Vicki following Rebecca and her friends through the mall.

When I completed a first draft of each story, I shared it with the family to make sure it was accurate and that each person was comfortable with what I chose to highlight and write from our interview. The next step was forwarding each story to Murray George for editing. Murray is the editor of the FSI Possibilities newsletter and has taught me a great deal through the writing process. I am grateful for his honesty, respect, patience and skills. The stories were also shared with Angela Clancy, Executive Director of FSI. She saw the stories with fresh eyes and a passionate review. I delighted in her consistent response to every story. It was always, "That one is my favourite!"

I am so appreciative of the stories submitted and written by others. It meant that different voices could be heard in the book. Murray's thoughtful edits to those stories respected the writer's voice while ensuring an easy flow for the reader.

Finally, I am thankful to CLBC who has honoured the stories told from the families' perspective recognizing the important messages they offer to others.

With respect and gratitude,
— Maria Glaze

I began to feel my connection with each person and family grow and deepen. Even now, if I close my eyes, I can still hear Jim's laugh or can imagine Vicki following Rebecca and her friends through the mall.



We believe families are the experts when it comes to their own family members and see families as the best resource to support one another.

INTRODUCTION: FAMILY SUPPORT INSTITUTE

Angela Clancy

The Family Support Institute is a provincial non-profit society. We are dedicated to supporting and strengthening families faced with the extraordinary challenges that come from having a family member with a disability.

Our supports are offered in many ways, the main one being our Volunteer Network. We have close to 200 volunteers who all have a family member with a disability. They offer their support using a family-to-family approach. Our volunteers are willing to connect, share experiences and information, share stories, guide families to supports and services in their communities, offer emotional support and guidance, or just be there as a friend. We believe families are the experts when it comes to their own family members and see families as the best resource to support one another.

FSI was thrilled when Community Living British Columbia (CLBC) approached us to work on this book with them. FSI celebrates partnerships and the power in relationships, diversity, mutual support and storytelling.

We see this book as a perfect opportunity for CLBC and FSI to share these powerful and inspirational stories across our province. While the mandate of CLBC, and the focus of this book, is on adults, we at FSI support families of all ages. We see this book as a beautiful starting place where we can begin listening to family stories in a different way.

FSI thanks CLBC for this opportunity to embrace family stories that share how much families cherish their loved ones and their unique and amazing place in community.

We see this as a beginning...

— Angela Clancy, Executive Director



INTRODUCTION: COMMUNITY LIVING BC

CLBC is pleased to have worked with Family Support Institute (FSI) to create this book of families' stories about how they have kept their family members safe and involved in community.

CLBC believes that the best way to keep safe is to have family, friends and people in our lives that know and care about us. Having a personal support network made up of many different people, is one of the best safeguards. Support networks are an important informal safeguard.

CLBC saw the concept of creating a book of stories, told by families, as a powerful vehicle for sharing this message about informal safeguards. We knew that the FSI was the perfect choice to partner with to create this book. FSI's connection with families and their dedication to making sure that families' voices and stories are heard have ensured that the book contains authentic, powerful and real stories. CLBC believes that stories told by families are, "the true essence of learning."

This resource is meant to inspire. It is meant to stimulate your heart and head about how families have developed friendships and social connections to create positive experiences. We believe that the social ties of kinship, friendship and participation are essential to having a true sense of belonging, well-being and welcome.

CLBC is committed to building personal support networks and social connections. One of CLBC's goals is to create resources to help people think and learn about building personal support networks and social connections and creating informal safeguards. We believe this wonderful book of real life stories has helped us to meet this commitment.

Community Living British Columbia (CLBC) is a provincial crown agency mandated under the Community Living Authority Act and reports to the Minister of Social Development. CLBC delivers community living supports and services to eligible adults and their families. CLBC's vision is that the people we support will have good lives in welcoming communities.

Having a personal support network made up of many different people, is one of the best safeguards. Support networks are an important informal safeguard.



PROLOGUE: IT TAKES A VILLAGE TO CIRCLE A PERSON

Cathy Anthony

Stories are a gift of inspiration from one person to another. These stories of informal safeguards offer examples, ideas and seeds of hope that can shine a light of inspiration on others. Weaving informal safeguards around our loved ones comes through the gift of relationship to others. It is through our connection to others, that the tapestry of a meaningful life is woven and the thread holding the most strength for ensuring a life of quality and safety is by being known, cared about and embraced by others.

One of my most significant life stories began 26 years ago through my son Joshua. Josh has given me a life journey that has fueled me with purpose and the passion to explore important life learnings. As my teacher and mentor, he has been my compass, guiding me into places of deep consideration on issues about giftedness, belonging, and what makes for a life of meaning and quality. He has also helped me to face my fears and therefore, vulnerabilities – both his and mine – and therefore be more thoughtful about building safeguards into both our lives.







As my son has grown older I have changed the wording of this proverb from “It takes a village to raise a child,” to “It takes a village to circle a person.”



When I was just a young mom, facing a new life journey, I became involved with the Family Support Institute (FSI). Still, 23 years later, I continue to be touched and inspired by the families I share connection with through FSI. These relationships with other families have continued to serve as a type of informal safeguard in my life. They have been my circle of strength, support, connection, friendship, guidance, inspiration and more.

One of the most significant, most concerning, and most hopeful question that we as parents ponder is “who will be a part of my son or daughter’s life.” The question transcends time and follows us through our child’s life, and beyond to the future when we are no longer here.

I had always loved the African proverb “It takes a village to raise a child.” Years ago I remember reading a children’s book titled *It Takes A Village* in which a young African girl searches for her younger brother and eventually finds him having been watched over by a village. For me, this is the heart of informal safeguards and my answer to the question, who is watching over my son.

Knowing that informal safeguards involve caring connections between people and the things we can do to help reduce someone’s vulnerability, the theme of a village resonates with my heart. Having had the wonderful opportunity to travel to villages in other parts of the world, this also brings images to my mind of people living their lives woven together in shared caring. I always reflected on the wealth of

relationships I saw, in the face of those we consider poor by our standards.

As my son has grown older I have changed the wording of this proverb from “It takes a village to raise a child,” to “It takes a village to circle a person.” To me, this means the family, friends, neighbours, community members, caregivers and supporters who form the beauty of a circle and a safety net around my son. These are the people of his village who will ensure a good life for Josh. This has been especially important for me since Josh has spread his wings and moved out to live his young man life in another community away from me. I know in my heart the more people who know and care for Josh and the more people involved in his world – the safer he will be and the richer his life will be because of this.

Many years ago I remember someone saying to me that parents need to learn to “let go.” I remarked, “Parents never let go, my mom has not let go of me. But what we do need to do is to learn to hold on differently.” And to hold on differently means inviting, welcoming, and embracing others into our loved one’s life. The gift of relationships, which create informal safeguards around our loved ones, allows us as parents to hold on differently. It holds the gift of having others who help to not only keep our loved ones safe, but also to support them to have valued roles, positive presence in community, and support in achieving their dreams. This all equates to a life of purpose, meaning, quality and safety.

I think we are growing more conscious and intentional about the importance of building a village around another person. We are getting better at entering into new kinds of conversations that invite and welcome others into our loved one’s life. For me, it’s about continuing to explore who knows, cares for and is an active part of my son’s life. Who is there for him in friendship, who shares in helping to build a meaningful life with him, who is with him in times of trouble, and in celebration. This is about growing his life, and me learning to share him with others. Holding on differently.

A few months ago I was listening to the radio and caught the “Vinyl Café” with Stuart McLean. He told the story of the life of a man named Maynard as written by a friend who saw the gifts that Maynard shared with his community. This story is from years gone by and from a small village (I can’t remember where). It touched me deeply. I was inspired. The lesson of the story was about the beauty of relationships and the gift of seeing the contribution that each person can offer to one another, given the chance to be known.

Throughout, the story shared examples of Maynard’s connections to people in his village. Some were about his close friendships, others about his connections made by being a regular in his community. All were about him being known. As the story came to a close I had tears in my eyes. I thought, Maynard’s life is what we as parents, family members and friends yearn and dream of for our loved ones. Maynard was known

and loved by a great many in his village. There was no question that he was accepted and belonged as a valued person, or that he was a person whom many called “friend.” Not only did others in his village truly embrace and watch out for him, but he in turn watched out for them as well.

The story closed telling of how after Maynard passed away, having been cared for and surrounded by a large circle of friends and supporters, the village wanted to honour his life. Not long after, a bandshell was erected at the park and during the opening ceremony Maynard was celebrated with the reading of the bandshell plaque, “In memory of Maynard: his town, his corner, his people.”

And now, for one last story. A number of years ago Josh and I had been out walking. We stopped back at the house for a quick minute and I left him sitting at the front door in his wheelchair. A few minutes later I returned to find that he had maneuvered out of his seat belt, over the foot pedals, out the gate and was gone. I ran to the street, looking both ways. My heart pounding, he was not to be seen. I retraced my steps, searching the yard and house thinking he couldn’t have gotten away so fast. He had. In a panic, I called out to neighbours and a search party of about 12 gathered. Some went left, others went right, and some stayed put. I was a mess – he was so vulnerable walking and on the streets. Well, a short time later he was found safe and sound, a block away, exploring

a barbeque that had been left out for recycling. One of the neighbours on this street saw him and stayed with him, knowing that he wouldn’t be out on solo journeys. Another neighbour found the two of them, holding hands and chatting, and got another neighbour to come back and get me to come help convince Josh to come back home. As we returned, a large group reassembled and welcomed Josh back. One of the neighbourhood teenagers snickered, saying he thought Josh was a cool dude to have escaped the clutches of us adult overseers. By now, I could join in the chuckles, and calm down enough to give thanks that Josh was so well known and cared for by our small neighbourhood village. Needless to say that following this little incident, numerous safeguards were put in place, but of all, the most important had to do with people.

For me, I dream that my son Josh, like Maynard, will always have a village circling him and that through the relationships he shares with others in his village it will be said that this is “his town, his corner, and his people.”

Through this book, stories and examples of informal safeguards have been shared, setting examples that inspire us all. And, I know there are many more untold stories like these. As we continue to grow in comfort and faith in intentionally inviting people into one another’s lives, we will all be richer and safer for it. It does take a village!

As we continue to grow in comfort and faith in intentionally inviting people into one another's lives, we will all be richer and safer for it. It does take a village!



MARIANNE'S STORY:

MAID MERRY WITH THE CHEAM ANGELS



Annette Pope

This story is a compilation written by several people who care for, support, and love Marianne Pope. Marianne's story describes the friends, neighbours and family members who surround her in her home and community. Annette Pope, Marianne's mother, has always respected her daughter for the child she was and the wonderful woman she has become. It has been Annette's deepest pleasure and honour to be Marianne's voice, giving words to her daughter's thoughts and feelings. Marianne gives her approval by smiling, nodding her head and expressing her "um" sound. Annette has been a Resource Parent with FSI since 1986.

— *Maria Glaze*

Most days, for the past three years my support workers and I have gone for a walk in a very picturesque trailer park. It is surrounded by mountains and large cedar trees and is around the corner from my mom and dad's house where I lived. Fifteen years ago, I moved back in with my parents after I was injured in the group home where I had been living. I had also lived in Glendale Institution for 18 months when I was five years old. The doctors there told my parents my brain cells were dying, but so far I have lived for 33 years longer than they thought I would.





I feel safe and happy in my life knowing that there are so many people in my neighbourhood and community who know me and enjoy being around me.



My parents are ageing and since some of my past living arrangements were not very pleasant experiences, I knew I needed to be prepared. I really wanted to live near my mom and dad and I knew I did not want to live in the city in an apartment or townhouse. I have always enjoyed the peace and quiet of the country and the beautiful farmlands around me. I decided to write a letter to a lady who lived in #55 in this trailer park because she wanted to move to be near her daughter. There were other people who wanted to buy her house but upon interviewing me, she decided she would sell it to us. My parents proceeded with the purchase. With the support of Vela Microboard Association, my Microboard and Community Living BC, I was able to get the staffing support I needed to live in my new home. My dad put in laminate flooring and wider doors. The Giving in Action Society, through a grant from the Family Independence Fund, helped us with money for further renovations, including an elevator and covered area so I could be protected from rain while going from my van to my house.

I moved into my very own home on January 6, 2009. It is lovely and I am very happy.

I have many friends in my community. My best friend Gord, who is also in a wheelchair, is very special to me. We walk together every single day several times around the beautiful park in which we live. Across from me lives a lady who raises parrots and I hear them talking all the time. On occasion she brings them over to visit me. I love to see them, I laugh and smile at them and they talk to me. Whenever I walk everyone waves and says hello. Just around the corner is a

man who is an amazing Johnny Cash impersonator. There is also an Avon man who calls me “girlfriend” and tells me how special and beautiful I am. He even stops to sing me a few songs – I enjoy his singing.

For the past three years I have given back to my community by volunteering for Corrections Canada’s “Feed the Children Program.” This involves picking up soup made by Corrections Canada clients and delivering it on Mondays and Wednesdays to an elementary school and a middle school I used to go to. I have been invited to volunteer teas, assemblies and carnivals and I attend with pride and enjoyment. I thoroughly enjoy my time spent at the schools with the children who attend there.

I have also developed several friendships at a place I go every week with others who have challenges. This has always been a safe place of welcome for me and I so look forward to my visits there. I get involved in crafts, games of pool, puzzle time and afternoon walks. I am the “walking therapist” because I get people out to walk around the community. I now have a friend who has moved from Armstrong, where I lived for 10 years.

I would have to say that all these activities have contributed to a satisfying and great life for me.

I am a card-carrying member of the Red Hat Society where my Pink Hat name is Maid Merry with the Cheam Angels. We attend luncheons, teas, birthday parties, and parades and my staff enjoy the outings also. I am much honoured to belong. My mother is a Red Hat lady also.

Every Sunday a staff member and I attend my church, the United Church, just down the road from my trailer park. We always sit in the front row and I welcome everyone who comes into church, I give them hugs and shake their hands. Once church starts I listen closely to the pastor. When the singing begins I hum very loudly so everyone in the church can hear me. There is one song I love the most at church and it’s the last song before we leave. I get to take out my clapping hands (two plastic hands joined at the handle) and clap along to the song just like everyone else. After church I visit my grandmother. We used my van to take her to her 99th birthday party. She’ll be 100 in June.

I feel safe and happy in my life knowing that there are so many people in my neighbourhood and community who know me and enjoy being around me.



DALLEN'S STORY:

THE CONFIDENCE THAT
COMES FROM BELONGING



Aimee Quaife (Morry)

I first met Dallen's mom, Aimee Quaife (Morry), eight years ago. I still remember being struck by her deep commitment to her children. I could almost feel her grabbing the community living torch passed on by those who came before, and forging ahead into a future rich with possibility for her son.

Through her determination for Dallen to have friends, Aimee met Laura, a high school student, who has become Dallen's best friend. I was inspired and energized after spending an afternoon with Aimee and Laura. They are both so passionate! Aimee, Laura and I missed Dallen's presence during the interview – he was away on a fishing trip. This story celebrates the power of friendship and belonging.

— *Maria Glaze*



Aimee wanted Dallen to establish relationships with all students, not just those with disabilities. Aimee knew it would be difficult for her, as a mom in her 30s, to facilitate those relationships.



Dallen is a son, brother, great grandson and a friend. His mother, Aimee, describes him as a gentle, intuitive, honest young man with an amazing sense of humour. Dallen loves to watch, play and talk about sports of any kind. He understands everything that is said to him, but speaks his own kind of language. He uses a vocabulary of about 200 words and has a unique way of expressing and combining those words. While Aimee can't speak Dallen's language, she understands everything he says. Dallen loves to sing and enjoys helping around the house. Aimee also describes Dallen as her teacher.

During Dallen's high school years, Aimee had dreams of Dallen forming meaningful relationships with his school peers. She didn't want him to be defined by disability, but known and appreciated for his strengths and abilities. Aimee was pleased when Dallen's teachers and assistants told her that he was developing relationships. But there came a time when Dallen was reluctant to go to school – he didn't even want to get out of the car. It's hard for Dallen to express his thoughts through words, so in an effort to understand more about Dallen's resistance to school, Aimee decided to go to the school and spend a day observing. After following Dallen and his school assistants around for a day, Aimee left incredibly disappointed. She saw Dallen sitting alone, no one said "hi" to him in the hallways, and the only students he spent time with were those with disabilities. What she saw didn't fit with what the school staff had been telling her. And as the school year came to an end, Aimee knew something had to change. She came up with a plan.

Aimee wanted Dallen to establish relationships with all students, not just those with disabilities. Aimee knew it would be difficult for her, as a mom in her 30s, to facilitate those relationships. She needed a teenager to work along side her to make it happen. Aimee looked through the school yearbook and found Laura's photo. In the yearbook, Laura had listed a future goal "to work with children with special needs." Aimee knew Laura's dad and contacted him about the possibility of hiring Laura for the summer. Laura was interested. When they met, Laura told Aimee she had wanted to get to know Dallen better at school, but didn't know how because he was always surrounded by adults. (She referred to his educational assistants as his "guards.") She was familiar with Dallen because she had been one of his peer tutors at school. Aimee hired Laura for the summer with the goal of facilitating peer-to-peer relationships for Dallen. Laura and Dallen spent the summer getting to know each other and making new friends. In the process, they became best friends. After a summer of playing basketball, going to hockey games and just hanging out together, another school year was about to start. This year was different – Dallen had friends.

Dallen was starting his grade 11 year and Laura was entering grade 12. Even though students with special needs did not typically attend school on the first day, Laura felt it was important for Dallen to join her and their friends for at least part of that day. Aimee agreed to drop Dallen off at school to spend time with Laura and his friends before the start of classes. She planned to pick him up just before school started. Aimee walked into the house after dropping Dallen off and her phone rang. It was Laura. "They took him!" she

cried. A school assistant saw Dallen with Laura and his friends and physically took Dallen away from them and into the school. Aimee immediately drove to the school where staff informed her that Dallen was a liability and when on school property he must be with a school employee. Aimee and Dallen's friends were angry and upset. They just wanted to hang out with their friend.

Aimee and Laura had created a Facebook page for Dallen over the summer and by the start of the school year, he had 100 friends on his account. After the experience on that first day of school, Aimee posted the following on Dallen's Facebook page: "Some people see me as a liability. The truth is I'm an average teen who wants to experience opportunity." A flurry of postings followed. One student wrote that Dallen wasn't an average teen because he had a disability; another teen supported that comment. A flood of postings came from Dallen's friends, who were outraged that he would be seen as different just because of his disabilities. The tension and tone of the postings began to build as perspectives were debated, defended and emotions were on the rise. The next day a group of students contacted the principal to make her aware of what was happening. The principal's response to one student was, "all students get picked on, and Dallen is no different." A school counsellor sent one of Dallen's friends a note commending her for her support of Dallen. An English teacher devoted a class to debating "who gets to define normal and what does it mean?"

Laura and Dallen spent the summer getting to know each other and making new friends. In the process, they became best friends.



Laura and her friends believed the issue of perception ran deeper than simply whether someone was labelled disabled or not. They believed that the other students' perceptions of Dallen were directly affected by how Dallen was supported by the school staff. Students weren't getting a chance to know Dallen as a person and as a friend. Dallen was isolated. He didn't enjoy the same freedom to spend time with friends and go where he wanted in the school and was supervised at all times by the educational assistant. Laura noted other contradictions in the school. For example, when students get in trouble, one consequence is stacking chairs and picking up garbage around the school. Laura said Dallen picked up garbage and stacked chairs every day as part of his school program. Laura said these experiences affect how other students perceived Dallen.

The day after the Facebook discussion, Aimee picked Dallen up from school and heard students calling out, "Good bye, Dallen!" "See you later, Dallen." Dallen climbed into the car with a huge grin on his face and Aimee realized it was probably one of the best days of his life. Everyone knew who he was that day. He belonged. The two boys who made the comments that triggered the heated Facebook discussion apologized to Dallen and when Aimee and Dallen got home that day, Dallen had 60 new "friend requests" on his Facebook account.

Aimee knew she had to resolve the liability issue with the school. She contacted the principal of student support services and shared her dream for Dallen to have meaningful relationships and requested his help. The solution, even though it bothered Aimee in principle, was for her to sign a

liability waiver releasing Dallen to Laura over the lunch hour. Aimee just wanted Dallen to be able to spend time with his friends, so she signed.

Laura and Dallen's other friends have become watchful eyes at school. As Dallen's friends have gotten to know him, they have observed something Aimee describes as profound. When his friends see him around the school staff and administration, they describe him as going "inside himself." When Dallen is with his friends, they see him "come alive" and be "outside" himself.

The waiver was signed, but an educational assistant was not comfortable with Dallen spending time with Laura and their friends. The assistant did not understand Aimee's thinking; she felt Dallen was unsafe with Laura and believed Aimee was actually putting Dallen at risk. Dallen's friends hung out at the store, some of them smoked and swore. Aimee had two daughters in high school and already accepted those risks for her kids. The assistant was extremely resistant and Laura felt intense scrutiny and pressure from her the entire school year. Prior to Dallen, Laura hadn't experienced friendships with teens with disabilities. It broke her heart to realize how difficult it was to just spend time with Dallen – not because of who he was, but because the system made it so hard. But Dallen was her friend and she endured the pressure. A year passed and it was time for graduation and Dallen's friends wanted him to be part of the excitement.

Dallen was ending grade 11, but his friends were finishing their grade 12 year and looking forward to prom night. Aimee offered her home as a place for the girls to get ready

and even brought in a hair stylist. Dallen was able to share in their preparations. When the boys came over dressed in their suits, they asked Aimee why Dallen wasn't in a suit. Aimee confessed that Dallen didn't own a suit and could feel a little judgement when they asked, "Dallen doesn't own a suit?" One boy went home and returned with an extra suit for Dallen. Some friends went with Dallen into his room and he emerged looking as handsome as the rest. The group went to the waterfront where all the graduating students were gathered for photos and girls kept calling out, "Hey, Dallen! You look hot!" Many wanted their picture taken with Dallen who was grinning from ear to ear. The grade 12 students carried on to prom night and Dallen went home with fabulous photos and memories.

Before the abundance of friends in his life, Dallen's life was rich with family, but Aimee noticed a quality of loneliness. Aimee knew she could not fill that void of friendship – she is his Mom. His sisters have a kind of friendship with their brother, but it's not the same as having one's own friends. Dallen's new friendships have had a powerful impact. Aimee describes Dallen as happier, more balanced and grounded. Aimee can feel a new confidence in him – the confidence that comes with belonging. Neighbours have commented that he says "Hi" now and acknowledges people – that's new for him. Dallen enjoys going to places where he might run into people who know him. He often asks, "Are my friends coming today?" If the answer is yes, Dallen will sit by the front window, patiently watching and waiting, anticipating their arrival.



Before the abundance of friends in his life, Dallen's life was rich with family, but Aimee noticed a quality of loneliness. Aimee knew she could not fill that void of friendship – she is his Mom.



When asked about Dallen's impact on her life, Laura's eyes filled with tears. Through a voice rich with emotion, Laura said Dallen has made her into the person she is today – he made everything good in her life at a time when things weren't going well at all. Laura describes Dallen as a warm and caring friend who was very shy and quiet when they first started going out together. Now he'll get in her car, crank the music up and sing songs at the top of his lungs with Laura while they're driving. By simply being himself, Dallen has given Laura, and his other friends, permission to be themselves and to not worry about what other people think. Many people will become close to the families of their friends and Dallen has become very close to Laura's family, too. He spends time at Laura's house and now, Laura says, "My Mom and Dad love Dallen, too."

Aimee says the biggest challenge for her, as a parent, was learning to trust Laura. She had to work extremely hard to put aside all the years of professionals, assessments and the system's perceptions of "who Dallen was and what his needs are," and simply put her trust in Laura. That trust took time to develop and through the process, Laura pushed Aimee with ideas like, "Why can't I take Dallen to a party before it starts – just for the first couple of hours?" Because of Laura, Dallen's life is rich with new experiences. Aimee's voice held a touch of wonder when she described watching Dallen leave the house with his friends and realizing that for the first time ever in her life with Dallen, she is able to observe Dallen in friendships that don't include her.

While Dallen's high school years are coming to an end, his friends often ask Aimee how they can make a difference in his life. They want to do more. Aimee tells his friends that as a result of their experiences with Dallen, they have increased their awareness and understanding of how to treat people with disabilities. As they fill their adult roles as the business and community leaders of the future, those ideas will continue to spread throughout the community.

Aimee (also a Resource Parent with FSI), Laura and some of Dallen's other friends feel extremely passionate about Dallen's school experiences and how those experiences affect not only Dallen, but also his relationships with his peers. They have decided to make a documentary about Dallen's school life through the eyes of his friends. At the time of writing this story, it is a work in progress. To find out more information about the documentary, please contact the Family Support Institute at 604-540-8374.



REBECCA'S STORY:

FRIENDS FOR LIFE



Vicki Nosella

Vicki Nosella spoke tenderly and lovingly about her daughter, Rebecca, during a 90-minute phone interview. With Vicki's intentional and gentle nurturing, the seeds of friendship that were planted and first took hold in Kindergarten have continued to grow into deep and caring relationships right through to adulthood. Rebecca is 19 years old now and as her high school years are coming to a close, she has three special friends who love her, and will be in her life for a long time to come. Rebecca is the glue that binds them together.

— *Maria Glaze*

Rebecca is a gorgeous, easy going, 19 year-old young woman who loves being in the middle of activity and conversation. Her most powerful way of communicating is through her eyes. Vicki said Rebecca's eyes are truly the "windows to her soul." Rebecca has always been small for her age and even now she is only 72 pounds "light" and 4 foot 9 inches tall. Rebecca has always used a stroller or wheelchair for mobility. Rebecca doesn't like to use sign language as one side of her body doesn't move voluntarily. But with her right hand she will make her own unique signs for "eat, drink" and "more." Her fingers kind of dance on the table to express "more." Rebecca lives at home with her Mom, Dad and Jim her 21 year-old brother. Even though Jim and Rebecca don't share in many activities together, they have a deep and unspoken bond. Jim is a very caring big brother who will do anything for his sister and Rebecca knows it.



Yolanda Sevilla
of
Gusto

Yolanda Sevilla
of
Gusto



Rebecca opened peoples' eyes to the value of diversity. Parents saw first-hand what Rebecca could accomplish with assistance from her peers and everyone celebrated her achievements.

Rebecca is an integral part of a tight knit group of girls, Kalena, Leah and Michelle, whose friendships were forged as far back as Kindergarten. Vicki still remembers those early years and Rebecca's first day of school.

Vicki and her husband always knew Rebecca would be someone who was going to make a difference in the world and they believed in the value of inclusion. When it came time for school, Vicki wanted everything to go smoothly from Rebecca's first day of Kindergarten. Vicki was a member of the Parent Advisory Council and knew the other parents had to feel as comfortable as the children around Rebecca. Vicki wanted to be present in the classroom to answer any questions the children or parents might want to ask. That first day which was only an hour felt too short and busy for conversations, so Vicki asked the teacher if she could speak to the students on the first full day of class to introduce Rebecca. Since Vicki had been a Sparks and Girl Guide Leader, she was very comfortable leading group conversations. The teacher agreed and the next day Vicki gathered the children in a circle around Rebecca, who sat in her special seat on a little platform. Vicki asked, "Did anyone see how Rebecca came into the classroom? Did she walk or run?" Many hands were raised and Vicki answered questions. She encouraged the children to get to know Rebecca and to become familiar with her and her wheelchair. The children and parents became very comfortable with Rebecca and as the school year progressed, something new and wonderful seemed to happen every day. One day Rebecca was sitting beside a student on the floor for story time. Rebecca was just learning how to sit unassisted and she toppled over onto

the lap of the student beside her. The classroom assistant walked over to the student and asked her if she would like Rebecca to be moved and the student said, “No, she’s fine,” and then asked for a cloth to wipe her chin. That student was Michelle.

Over time Michelle, Leah and Kalena became Rebecca’s closest friends at school. Vicki always invited Rebecca’s entire class to her house for visits and parties. Vicki wanted all the children to feel welcome and comfortable in her home and with Rebecca’s family. Often the other children’s parents came over, as well. Many parties for birthdays, Valentine’s Day and Halloween were hosted at Rebecca’s house over the years. Rebecca opened peoples’ eyes to the value of diversity. Parents saw first-hand what Rebecca could accomplish with assistance from her peers and everyone celebrated her achievements.

Vicki would often take Rebecca and her friends to the mall and remembers the first time she left them to shop on their own in Grade 5. Five girls went to the mall that day with Rebecca. Vicki gave them money for a new shirt for Rebecca, a quarter for the phone, her cell phone number, and instructions to call when they finished shopping. Vicki remembers a twinkle in Rebecca’s eye as Rebecca went off alone with her friends for the very first time. When the girls left, Vicki waited behind and then followed them around the mall for a while – until the girls caught her spying. She saw they were doing fine, so Vicki left them on their own while she did her shopping. When they reconnected two hours later, the girls had found a lovely shirt for Rebecca and had a fabulous time. The next day, Vicki went to the

store where they had bought the shirt and spoke to a clerk who had been working that day. She wanted the clerk’s perceptions of how the shopping trip went. The store clerk remembered the little group well and said she had never seen a more mature, respectful group of young girls. She recalled how attentive they were to Rebecca as they helped her look at and try on shirts. Everything the clerk told Vicki confirmed what she already knew in her heart – the girls were amazing and very responsible.

By the time Rebecca, Kalena, Leah and Michelle hit their teen years their bond was strong. Even with their bond, Vicki worried that the start of high school might mean Rebecca’s friends wouldn’t see each other as often. Vicki told the girls she knew Rebecca wanted to maintain their friendship and encouraged them to come over anytime, but the group started to drift apart. Kalena went to a different high school, but she still made an effort to visit Rebecca and stay in touch. Leah pursued an interest in dance and for a couple of years she saw Rebecca only in passing. One day, Leah was watching Rebecca perform a dance with her class. Rebecca gave a very moving solo performance (with assistance). Leah was part of an audience who gave Rebecca a standing ovation. A teary and emotional Leah told her own mother, “I love Rebecca so much, I need to get back to her!” Her mother reminded Leah that Vicki had invited her to knock on Rebecca’s door anytime. Leah resumed her friendship with Rebecca. In fact, all three of Rebecca’s friends started to realize they didn’t feel whole without each other and Rebecca in their lives and once again became as close as they had been in elementary school.



Rebecca's friends find comfort in their time together and have said that being with Rebecca gives them the freedom to just be themselves.

As the girls spent time together in their late teen years, their activities changed and so did Rebecca's needs. The girls were going to movies, shopping and hanging out at Rebecca's house. Vicki always made sure Rebecca had money with her, but the girls seldom used it. Vicki needed to closely monitor and document seizures and other aspects of Rebecca's health and care needs. Vicki considered hiring someone to take on more responsibilities with Rebecca, and decided to approach the girls about paying them. Leah, Kalena and Michelle were extremely resistant to the idea; they didn't want to put a fee on their friendship. Vicki persisted – Rebecca and her family valued these girls and their relationship with Rebecca. Vicki recognized their time was limited with school and homework, and knew they didn't have jobs and they finally agreed to a plan. Rebecca's friends would take turns in being the one responsible for scheduling an activity, assisting Rebecca with personal care and documenting what was needed in Rebecca's journal. The person who took on that lead role that day would be the one paid and the person Vicki would contact about the day. Vicki noted it wasn't much money, but to the girls it was a bonus because it meant they could do more with Rebecca.

Today, Rebecca and her friends continue to spend time together. Their activities vary from shopping at the mall to spending time with Rebecca at home painting toenails, drawing, watching movies or listening to music. Rebecca's friends find comfort in their time together and have said that being with Rebecca gives them the freedom to just be themselves. When they're together, they often draw a group around them. Rebecca is always in the centre and seems to hold the circle. Vicki has noticed an expression of envy

on the faces of those that gather around Rebecca and her closest friends – perhaps envy of the special connection the girls share and the role they have in each other’s lives.

Vicki isn’t ready for Rebecca to move out of their family home anytime soon, but the girls have said they would love to share a place with Rebecca one day. While she doesn’t know for certain what the future holds, Vicki believes, without a doubt, that Michelle, Kalena and Leah will be in Rebecca’s life, long into the future – maybe even as members of Rebecca’s Microboard one day. Other friends have told Vicki that as long as they live near Rebecca, they will make a point of staying involved in her life. As Rebecca’s friends pursue their own lives and careers, one thing is certain. Their small friend – 72 pounds “light” – has made a huge and lifelong impact in their lives.

While she doesn’t know for certain what the future holds, Vicki believes, without a doubt, that Michelle, Kalena and Leah will be in Rebecca’s life, long into the future.



NOLAN'S STORY: TRAVELLING MAN



Bonnie Fallowfield

Bonnie Fallowfield, a long time FSI Resource Parent, wrote the following inspirational story about her son Nolan. Nolan has discovered the joy of independent travel thanks to informal safeguards throughout two provinces. He is currently planning a trip to the United States. Bon Voyage, Nolan!

— *Maria Glaze*

My son Nolan prides himself on his independence. He does not let his challenges slow him down too much. Nolan is blind and has a diagnosis of autism. Nolan has been travelling around his neighbourhood independently since the age of five. When he was younger he did get lost a few times and there was always someone in the neighbourhood who would come and help him get on the right route again. One time he took the bus to the recreation centre and the transit bus let him off in a different location than he was used to. This happened because there were a number of school buses that were lined up where the usual bus stop was. Nolan managed to find himself at the back door of the centre pounding on the door, and wondering why they had changed it all on him! One of the lifeguards heard the banging and discovered Nolan on their back step. She explained what had happened, and guided him back around to the front again so that he could re-orientate himself.





We feel so grateful that Nolan has had these opportunities for travelling independently. All the individuals he has encountered, whether in his neighbourhood, in another city, or at an airport have all been natural safeguards for him in his endeavours.



On several occasions we have had bears in our neighbourhood, and the neighbours have always phoned to let us know that it would not be safe for Nolan to go out walking on his own until the bear was gone. This is why Nolan has made the choice as an adult to remain living in the neighbourhood he grew up in. He is currently living in a suite in the basement of our family home. This gives him the independence he strives for, and the natural safeguards that come from the neighbourhood he grew up in.

As an adult, Nolan has discovered not only the joys of travelling, but travelling independently. He has flown to Edmonton, Vancouver and Kelowna, and into both the Prince George and Quesnel airports on his own. He has taken the Greyhound bus to Williams Lake and Prince George, and from Dawson Creek to McKenzie as well. It is through his travelling experiences that we have learned to develop natural safeguards in the various locations that he travels to. We have reconnected with old friends, relatives, friends of relatives, and friends of friends. Nolan needs an emergency contact in every location that he visits just in case something happens like his bus or flight being cancelled or delayed, or if there is a medical emergency. At first we were reluctant to ask old friends and relatives whom we had not talked to in a long time to be emergency contacts. But we soon learned how excited they were to help out, and how intrigued they were that Nolan was such an independent traveller. An example of this is Uncle Shorty in Dawson Creek. Shorty is the uncle of Nolan's sister's boyfriend. Nolan had never met Shorty, but Shorty did not

hesitate to be Nolan's emergency contact during his visit there, and even took Nolan on a guided tour of the Dawson Creek fire hall!

I must say the airlines that he has travelled with, Central Mountain Air, Westjet, and AirCanada, have been extremely helpful in guiding him on/off the plane, to the washrooms, and to the next terminal for connecting flights. We did not even know they did this until Nolan began to travel! The greyhound bus drivers do the same for Nolan. We feel so grateful that Nolan has had these opportunities for travelling independently. All of the individuals, whether it be in his neighbourhood, in another city, or at an airport have all been natural safeguards for him in his endeavours. His next goal is to fly into either Los Angeles or San Francisco to meet up with one of his uncles and do a road trip! When Nolan heard the hesitation in our voices, and concern over flying into the U.S., his response was: "Why would you be concerned? People who are blind travel down to the U.S. all the time for pleasure or to get guide dogs, I'm sure people at the airports in the U.S. can guide people, too!" Our response was, "Yep, you're right, we just have to figure it out!"

I wanted to tell about these safeguards because we have never tried to hold Nolan back from being independent. He has taken risks, just like anyone else who travels, and that is good! I think it is very exciting that he wants to travel as he does, and other people should know this opportunity is out there for them too. I am proud of Nolan, and you should see him smile when he hears the song 'Travelling Man' by Ricky Nelson.



JEFFREY'S STORY:

HELPING TO WIDEN OUR WORLD



Cathy Lafortune

Jeffrey Lafortune's mother, Cathy, wrote the following inspirational story about Jeffrey and Jane Green. Reading this story makes it easy to understand why Jane was a recipient of Community Living BC's WOW award in 2010. WOW stands for "Widening Our World" and Jane and Jeffrey have widened many worlds in the their community.

— *Maria Glaze*

For every one of us, regardless of disability or label, the most powerful "safeguard" for our health and happiness is the presence of people who care what happens to us – people who see us regularly, pay attention when they do, and respond to what they see. We call them friends.

People who are not able to verbalize – who can't use words to tell us how they are feeling, what's going on in their lives, and what they need and want – need caring friends even more.





Having the larger community aware of and open to Jeff's presence is a great safeguard for his personal dignity and right to participation.

In our community, Jeffrey Lafortune has found such a friend in Jane Green, M.Ed., coordinator of the Classroom and Community Support Worker (CCSW) program. Jeffrey, 37 years old, has significant multiple physical, sensory, and cognitive disabilities; he uses a wheelchair and is nonverbal. Jane has welcomed Jeff into her classroom as a “co-instructor” and colleague who spends a day or more each week helping students gain comfort in relating to an individual who faces multiple challenges. Jane and Jeff’s support worker both serve as examples to the students of respectful inclusion of Jeff as a highly valued community member whose high needs can be met successfully to enable him to be there. Sue Clark, who has supported Jeff for the last 10 years, has been instrumental in making this process successful for all concerned. Her skillful and sensitive model of respectful support and personal approachability for questions help Jeff be more approachable and safer too, especially when it comes to those questions people normally might not feel comfortable asking. Sue’s service as “communication connection” has been enormous for both relationship building and safety for someone who doesn’t use words to talk.

Many students may never have met someone with Jeff’s level of challenges, and they quickly gain confidence and understanding through “Jeff Immersion.” The students come to recognize Jeff’s value in the classroom, and when circumstances or health keep him away, they miss him and want him back as soon as possible!

These CCSW students, in turn, serve as educators to other students and faculty within the Human Services

Department and the college as a whole. A wider segment of our regional community thus has met Jeff also, and as the years go by, more people recognize him as he goes about his daily life in our community. As the ripples of familiarity and comfort slowly spread, Jeff receives a wider welcome and is often greeted by name in local businesses and recreation facilities.

Having the larger community aware of and open to Jeff's presence is a great safeguard for his personal dignity and right to participation. Even more awesome, however, is having a real friend who personally cares and values us highly, and inspires others to do the same. Jane Green is truly such a friend to Jeff, making his world a safer and happier place.

"A lot of people would be surprised to hear how easy it has been to create this situation – simply by saying "yes" to having Jeff (or someone like Jeff) in the classroom, the benefits are enormous. It's a real win/win/win for every one of us," says Jane.

Jeff is being awarded an Honorary Diploma in Human Services from Selkirk College for his contributions to education over the past 18 years.

To watch a video of Jane, Jeff and friends on the Community Living BC website, please visit:

www.wowclbc.ca



JIM'S STORY:

CIRCLES OF SUPPORT
BUILD TRUST AND CONNECTIONS



Bill and Mary Hustler

It was a pleasure and honour to share an afternoon with Bill and Mary Hustler, their son Jim, and also Kim Bergenstein, who shares her home with Jim. Merrilee and Dan (Jim's sister and husband) dropped by during the interview, as well.

Younger families can look to Bill and Mary as leaders in community living. They planted some of the first seeds of a vision of full citizenship for people with developmental disabilities through their advocacy and the support they sought for their son.

The interview took place in Bill and Mary's home where their love, commitment and respect for each other surrounded an afternoon filled with lively conversation, accompanied by Jim's delightful laughter. This story highlights Jim's Circle of Support, offers a glimpse of his journey toward meeting Kim and her impact on his life.

— *Maria Glaze*





In the year 2000, a dynamic and diverse group of people formalized their commitment to Jim and created “Jim’s Circle of Support.” Each person in the circle cares deeply about Jim and respects each other’s ideas and opinions.

Jim is a man who loves family gatherings and is very drawn to people. He has a variety of interests that include tractors, wheels and nature. He enjoys walking through the woods and takes pleasure in gazing up at the trees – he’s learned the names of many types of trees. Jim experienced oxygen deprivation at birth, which had an impact on the development of his brain. He understands a lot of language but has difficulty expressing his thoughts; he usually speaks only a few words at a time. Jim also has characteristics of autism. Since his birth 58 years ago, Jim has experienced many changes over the years in how people with developmental disabilities have been supported and welcomed in community. Through it all he has emerged as a happy and engaging man and is truly the centre of his Circle of Support.

Jim’s parents, Bill and Mary, feel very fortunate to have many family members in Victoria. In 1997 they decided to leave their Edmonton home and retire to Victoria to be closer to family. Jim, who was living in a group home in Edmonton at the time, made the move with them. Once settled in Victoria, Bill, Mary and a few other family members decided to create an intentional circle of support around Jim. Some people volunteered to be part of the circle out of love for Jim and others were invited to participate because of their specific knowledge and expertise. In the year 2000, a dynamic and diverse group of people formalized their commitment to Jim and created “Jim’s Circle of Support.” Each person in the circle cares deeply about Jim and shares a respect for each other’s ideas and opinions.

Parents are often the keepers of history for their children. Jim's life story is detailed in an enormous binder Mary has created and given to each of the circle members. The binder's cover offers immediate insight into Jim's personality in a thoughtful and beautiful way. The binder tells the purpose of Jim's Circle of Support, gives an overview of Jim's daily life, and shares the information about his personality, likes and dislikes that his family has acquired over the years. This wealth of information is a living document that is frequently updated and an invaluable resource for each circle member.

Jim's Circle of Support meets annually, usually around Jim's birthday. They communicate electronically throughout the year and meet more frequently if the need arises. The meetings have included various paid people in Jim's life, such as program managers, support staff and, at times they have welcomed guest speakers on topics like advocacy and legal matters. Kim and her family, with whom Jim lives now, attend circle meetings along with Jim's sister, nieces, nephews and cousins. Mary envisions her great grandchildren participating in the circle as they get older. Bill and Mary take great comfort in knowing this growing and changing circle of people committed to Jim will surround their son long after they both are gone.

While Jim's life is happy now, it was not always that way. As Bill and Mary reflected on his life, they identified three important transitions for Jim. The first was when attended a day program in Edmonton, the second was his move into a group home, and the last was his most recent move into Kim's home. They believe these were significant times

for Jim because his growth and development improved remarkably with each transition and, most notably, when he began sharing a home with Kim.

Jim began attending a community program in Victoria 1999, offered through a local association for community living. More than 10 years later Jim still attends the program (which he refers to as his work) and through this program Jim participates in both paid and volunteer work in the community. Shortly after Jim started the program he moved into a group home operated by a different association. Initially Jim's housemates were all compatible and Mary and Bill enjoyed a great relationship with the group home manager. A few years later, the changing of housemates and the passing away of his best friend altered the dynamics of the home to Jim's dismay and detriment. The home also experienced seven managerial changes while Jim lived there. By 2006, Jim found life in the group home extremely difficult and was taking two medications just to cope with the stress. Bill, Mary and the rest of Jim's Circle of Support were extremely concerned. They knew Jim was still very happy at his community program and family home. The circle members held several meetings to problem solve and looked into other group homes in their community, but found there were no spaces available. Mary and Bill preferred the idea of Jim living in a family home instead of another group home. His family and Circle of Support knew what they wanted for Jim, but the systems were not in place for the monitoring that would make them comfortable.



Between his daily walks and his presence at the RV Park's communal evening campfire, Jim developed a bond with fellow campers. People began to seek him out to go for walks together.

In 2008, the association that served Jim through his community program became a host agency for home share providers. As a host agency, they took on the role of finding, screening and monitoring caregivers with whom they would contract. Bill, Mary and the rest of the circle members believed there were now enough formal safeguards in place to consider home share an option for Jim. Jim went on a list for home share and a year later they found Kim.

Jim's love of parties provided many opportunities for Kim and her family to become acquainted with Jim, his circle members and extended family. Kim also spent time getting to know Jim at his community program. Over a period of time, after getting to know each other and building trust, Jim finally moved in with Kim and her family. Mary believes that complete honesty between Jim's family, Circle of Support members and Kim has been critical factor in developing trust.

Over the past year, life with Kim has proved to be transforming for Jim. Kim's husband and two teenage daughters have completely embraced Jim and so has a whole community. He is well known at the local markets where Kim and Jim shop and his face lights up each time people call out, "Hi Jim!" During a time when Kim and her family made a move to a new home, Kim and Jim chose to live in a local RV Park and avoid the chaos of moving. Jim became comfortable enough to walk outside around their trailer. (For his health it's always been very important for Jim to walk daily and difficult for people to find the time to encourage this.) While at the RV Park, and with Kim's watchful eye, Jim increased his walking distance from the trailer a little further each

day. Between his daily walks and his presence at the RV Park's communal evening campfire, Jim developed a bond with fellow campers. People began to seek him out to go for walks together. Kim described how Jim's quiet and gentle presence helped one camper through an emotionally difficult time.

Kim has recently re-connected with a few of the campers and is planning a reunion at the RV Park. Camping was obviously on Jim's mind throughout the interview as he frequently asked, "Trailer today?" and "Trailer on Monday?"

Since living with Kim, Jim is more confident and has become a happy and engaging man. He no longer relies on medication to cope and has overcome many of his autistic manifestations. Kim has noticed Jim saying, "I'm hungry," instead of quietly waiting for food, evidence that he is beginning to lead and direct his own life. Jim now initiates conversations with people. Mary shared a lovely story about Jim while he was waiting for her to get her hair done in a salon. After sitting beside a woman in the waiting area for awhile, he said, "Nice day." He then asked, "What's your name?" She told him and a little while later, he stated, "You're beautiful." The still beaming woman later told Mary it had been a long time since someone told her she was beautiful!

Kim and Mary believe Jim is now the centre of three circles in his life. Jim's Circle of Support make one circle, the people in the association who serve Jim are another, and Kim's family make up the third circle.

Jim's Circle of Support members believe in the value of staying informed. Bill and Mary have been actively involved in community living since Jim's birth well over 50 years ago. They have served as board members for associations, attended a multitude of workshops and information sessions, and are actively involved with Community Living BC through their local community council. Bill and Mary still attend a monthly support group facilitated by their local association. Jim's Circle of Support members are kept informed on issues that could affect Jim. Their responses are truly valued. Together, this wonderful group of caring people will ensure Jim continues to enjoy a full and happy life as a welcomed and contributing member of his community.

LITTLE MOUNTAIN'S STORY:

ENGAGING THE WORLD
THROUGH HER EYES



Donna Good Water

Donna Good Water lives on the Okanagan Indian Band and I had the pleasure of meeting and interviewing her by phone. It was lovely to learn about her daughter Little Mountain. It was very moving to hear the warm smile in Donna's voice as she described her daughter, especially when she said she knew she was Little Mountain's favourite person in the world. Donna said Little Mountain was her favourite person, too. It was clear from our interview that an entire book could be written about their journey and I learned that in 1994 Phil Pendry filmed and directed a documentary about Little Mountain which was aired on CBC and won a Media Access Award.

The following story touches on the vast network of people that surrounded Little Mountain throughout her life. I wish I could have had the pleasure of knowing her. Little Mountain passed on February 29, 2008.

— *Maria Glaze*





There were touching moments like the time that Raven, Little Mountain's three-year-old niece, climbed on her lap and positioned her aunt's arms around herself for a hug. Donna described the wonderful moment when Raven and Little Mountain, wrapped in their embrace, looked into each other's eyes.



Donna thinks of Little Mountain as having lived two lives. When she was only a few months old, Little Mountain had two grand mal seizures. Before long she was having hundreds of seizures a day. After weeks of working with modern medicine, Donna turned to her own spiritual people at a ceremony in Montana. They were able to get the seizures to stop. Even after the seizures stopped, Little Mountain did not regain a lot of awareness of the world around her. Donna and her family worked hard to get her spirit back in her eyes. Her body was limp like a rag doll and they worked with Little Mountain to develop her eye and head control, build strength and upper trunk control. Eventually she could crawl, sit up, clap her hands, and even stand with support. She developed very clear communication skills using her eyes, clapping her hands with excitement, and on occasion (though discouraged) she even banged her head in frustration. She was developing quite well until the age of nine when she had a severe set back. Little Mountain got pneumonia. She stopped breathing and was actually clinically dead for several minutes before being revived. This marked the end of her first life and the beginning of her second.

All the progress Little Mountain had made was lost. Her motor skills were gone, with the exception of head control. She didn't know who her mother was and Donna had to start all over again introducing her to the world. At the same time Donna also worked hard to keep Little Mountain's body in alignment. Donna and her family were able to bring her back into the world, but her body became extremely contorted resulting in major physical challenges. When she came back to the world she still had the ability

to communicate with her eyes, which Donna said was crucial for both of them. It was very important for Donna to be able to look into Little Mountain's eyes and see that she was present and later, to see what she was feeling. Her primary way of communicating was now only through her eyes, which was very different from her early years when she had mobility and could use her whole body to express herself. Donna describes Little Mountain's first life as one when she was fully engaged with the world. In her second life, she engaged with the world through her eyes only. Her body held her back and created a very challenging time for her. She was in a great deal of pain and Donna had to learn how to recognize the pain and then find a way to help Little Mountain to manage it.

Little Mountain was clear about who could be in her personal space. Donna noticed that Little Mountain scanned people as they came into her room and she had a way of indicating with her eyes whether she was comfortable with a person. Even the grandchildren were able to distinguish who was acceptable in Little Mountain's circle by watching her eyes. When Little Mountain was older, there were many tasks to be done first thing in the morning with setting up oxygen, tube feeding, medications and personal care. Donna's grandchildren would come over to assist with the morning routines. Little Mountain always woke up happy and looked forward to each day. She enjoyed the personal contact with others as they assisted with her care. When things became extremely difficult, Donna brought in a nurse who developed a phenomenal attachment to Little Mountain and their relationship went beyond simply providing the services that were needed.

It was one of the first relationships Little Mountain experienced with someone from the larger community and it was very meaningful.

Little Mountain enjoyed watching sports and liked to watch hockey on television. Her favourite TV show was the "Wheel of Fortune." She loved her bath, swimming in the lake and, when the weather was warm and she could breathe without difficulty, she enjoyed being outside. When she was young, Little Mountain also loved to travel and went many places with Donna. They went to ball tournaments together where Little Mountain met many people. They became regulars at the tournaments and as other ball players got to know her, they would sit with her when it was Donna's turn to play. Little Mountain enjoyed the socialization.

Donna is a member of the Okanagan Nation and in the early years, Donna performed traditional Okanagan dances at ceremonies while carrying Little Mountain on her hip. They traveled all over Canada and the United States making connections throughout North America. When Little Mountain was about 14 she became too big for Donna to carry. She took Little Mountain onto the floor in her wheelchair for dances, but it wasn't the same and Donna doesn't think Little Mountain liked it. Donna would often put music on and dance at home when she and Little Mountain were alone. Donna began to learn the Okanagan

Women's song and practised in Little Mountain's room. When Donna first began to sing she felt too embarrassed to sing in public so it became something private between her and her daughter. Donna now sings traditional songs in public and credits Little Mountain for launching her singing career.

Little Mountain grew up surrounded by her immediate and extended family. She participated in many family events and dinners and was included in everything. She enjoyed a wonderful relationship with her nieces and nephews. There were touching moments like when Raven, Little Mountain's three year-old niece, climbed on her lap and positioned her aunt's arms around herself for a hug. Donna described the wonderful moment when Raven and Little Mountain, wrapped in their embrace, looked into each other's eyes.

Two weeks before Little Mountain passed, Donna's dad had his 83rd birthday party. Everyone was excited to go, especially Little Mountain. Over 100 people attended and it was amazing to Donna how many people made the effort and took the time to acknowledge and spend time with her daughter. Little Mountain began to tire after about an hour, but she had been in her element watching people, enjoying the attention and engaging as much as she could. Donna believes it was one of the highlights of Little Mountain's life to spend time in a room with 100 people who were all family.

After Little Mountain passed and Donna saw everyone together at her daughter's wake, Donna realized the enormity of the support system provided by her family and friends and the cohesiveness of their family. Up to that point, Donna had not seen everyone who had been in Little Mountain's life gathered in one place at the same time. In that way, Little Mountain's funeral was truly a celebration and Donna was grateful and thankful for all the people who were there and had been an important part of her daughter's life.



After Little Mountain passed and Donna saw everyone together at her daughter's Wake, Donna realized the enormity of the support system provided by her family and friends and the cohesiveness of their family.



RAFFI'S STORY: HIS NEIGHBOURHOOD NETWORK



Maria Francisco

I first met Rafael (Raffi) Francisco when I was an early childhood educator working at a preschool where he attended. Raffi, as everyone calls him, is one of the most gentle and happy people I have ever met. Raffi's uncle Ricky recently shared a story with me about three teenage boys who helped Raffi after a fall. I wanted to learn more, so I met with Raffi's mother, Maria, in their home. It was delightful to re-connect with Maria and hear more about her son, now a 23 year-old young man, and learn about the many people who provide informal safeguards in his life.

— *Maria Glaze*

Last year, Maria opened her front door to discover Raffi standing with three boys she had never seen before. Raffi's knee was wrapped in bandages. Maria had thought Raffi was out riding his bike in the cul-de-sac where they live or around the townhouses across the street where Maria's cousin lives. These are the guidelines Raffi understands and has always followed. On this particular day, however, Raffi decided to go on an exploration. He ventured further away and had a minor bike accident. The three boys, also out on a bike ride, saw Raffi hurt and bleeding on the sidewalk. Even though Raffi doesn't use words to communicate, the boys were able to help Raffi and safely escort him back to his house.





Maria has also been intentional about building a supportive community around their family. She knows her son has grown up around people who welcome and value him and he has been able to develop the confidence he needs to communicate with people.

Raffi has sounds he uses for words, mostly single syllables, and he also uses symbols and gestures to communicate. Raffi recognizes about 50 typed words (in one inch font) and uses a voice output device. The device is awkward to manage when he is physically active, like when he is riding his bike. So just how did Raffi communicate with the three boys when he fell?

Maria admits to being quite rattled when Raffi came home that day. She wishes she had asked for the boys' names so she could have contacted them later, thanked them and asked more about what happened. Knowing Raffi, Maria can imagine how the events transpired. When the boys

discovered Raffi hurt and lying on the ground, they might have asked, "Are you okay?" He probably pointed to his knee. The boys told Maria they knocked on a couple of doors and found a lady who cleaned Raffi's knee and patched him up with bandages. If the boys had asked Raffi if they should call someone, he might have shaken his head "no." If they asked him where he lived, he probably would have gestured toward the direction of his home. And if they offered to walk him home, Raffi probably would have nodded, "Yes," and led them all the way home.

Maria and her family live in a very inclusive school district and even though the boys who helped Raffi didn't know him, she believes inclusion in schools is a reason they were so comfortable communicating with someone who didn't use speech. By attending schools that include a diverse population of students, these three boys became part of an unplanned, informal network of support for Raffi in his own neighbourhood.

Maria has also been intentional about building a supportive community around their family. She knows her son has grown up around people who welcome and value him and he has been able to develop the confidence he needs to communicate with people. However, Maria says that his confidence is still a work in progress.

Raffi is a very social person who enjoys being in the middle of the action. He is very musical like his father's side of the family and has an innate sense of rhythm. In the music room in their home, Raffi often plays the drums, accompanying songs that are programmed in a keyboard. He has favourite

groups, the “Backstreet Boys” being one, and he will play the Michael Bubl  song, “Home,” repeatedly. Raffi has loved little toy cars since he was very young. He enjoys the feel of the hard texture of the cars and usually has one clutched in his hand. Each night he arranges about 20 toy cars on his bed before he goes to sleep.

His family’s involvement in church has become a great safeguard for Raffi. Maria and her family moved from San Francisco to their current home when Raffi was three years old. When they first arrived, Maria didn’t have friends or extended family around and became very involved with a church. Maria, along with other parents in the church, started a children’s program, including a children’s service. The program evolved over the years and Raffi has grown up with people from their church community. Raffi was eventually invited to join the church choir – he provides the rhythm by playing the conga. Maria says the church members are still a key part of both her and Raffi’s support system.

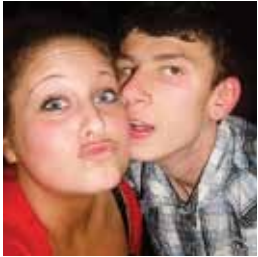
Maria’s efforts to create a network of people in Raffi’s life were aided by his relationships with peers. During his high school years, Raffi attended a community program called, “Let’s Play.” The program was initiated by a group of students at the school who organized an hour of time at the local community centre gymnasium. They assisted peers with special needs to participate in sporting activities of their choice. The high school recognized their volunteer hours and students with special needs were welcomed from all over the city. Raffi’s network grew significantly in those four years and at 23, he still encounters friends from “Let’s Play” when he is out and about in the community.

Raffi’s involvement with their church became a springboard to opportunities in the broader community. Raffi’s first work experience began with doing chores in and around the church. Through those jobs, Maria learned that he was most successful with tasks that allowed him to be physically active. Raffi now enjoys a seasonal job at a golf course. He is able to fulfill his love of cars by driving the golf cart around the course while he sweeps the tee boxes. He is a valued member of the staff team at the golf course and is included in all the staff events.

Acceptance and belonging are big motivators for Raffi. It’s really important to Raffi to look “cool” (Maria says he can be rather vain!) He cares about his appearance, likes to be neat and tidy and dress according to what he is doing. If he is going out to play basketball, he wears his jersey and basketball cap. If it’s baseball, he gathers all the paraphernalia that goes with baseball. And if he is playing his conga in the choir, he’ll dress in nicer clothes.

Raffi wakes up a happy person, but that can change when he feels he isn’t understood or appreciated – he can then become quite frustrated or sad. Thankfully, that doesn’t happen very often. Wherever Raffi goes, people say “hi,” often tell him how good he looks and share other kind words. He spends his days among family, neighbours, co-workers and friends where he truly *belongs*.

KATHY'S STORY: A HOME OF HER OWN



Bonny Klovance

It was a pleasure to meet with Bonny Klovance in her home to learn more about the informal safeguards in her daughter's life. Bonny is a pioneer in the community living movement, well-known for her long time contribution, advocacy and commitment to rights of people with disabilities. Bonny's daughter, Kathy, spent many years living in an institutional setting. Kathy is now 53 years old and has a very active life in the small town where she lives. Kathy has her own home and the people who support her have been instrumental in assisting her to develop relationships in her community.

— *Maria Glaze*

Bonny contracted German measles before she knew she was pregnant and Kathy was born with congenital rubella syndrome. Kathy was born at a time when there were no community services and supports for children with special needs or their families. Before she was one year old, Kathy had experienced many medical problems and her developmental delays were obvious. Kathy did not receive a diagnosis of autism until she was 12 years old.

SILVER DOLLAR
PUB ENTRANCE
HOTEL

DAVIES AVE

SALMON
FOODS





Although it took some time, Kathy's self-injurious behaviours began to decrease as her world opened up to include employment, a large social network and a variety of community activities, all organized and provided by her support workers.

It was incredibly challenging for Bonny to raise Kathy at home without support. After researching ways to help Kathy, the family learned about a chiropractic hospital in Colorado. With the financial support of Bonny's parents, Kathy spent two months in Denver where she had her second birthday. Bonny feels the treatment made a huge difference for Kathy assisting with her medical problems and helping her to develop large motor skills such as sitting and walking.

When Kathy was four years old, her family learned she was hearing impaired. Even though it was determined she had enough hearing to talk, she has never used words to communicate. A doctor recommended that Bonny consider placing Kathy in Woodlands – a large institution for children and adults with disabilities. The wait list was about five years at that time. Kathy went for a one-week assessment at Woodlands and came out with two black eyes. For Bonny, Woodlands was no longer an option.

Bonny did the best she could to help Kathy grow and learn at home. Kathy screamed and cried when asked to do new things, but Bonny continued to encourage Kathy to learn. When she was six years old, Kathy attended a school for "handicapped" children operated out of a church basement. Kathy's oldest sister walked her to school in the morning and Bonny picked her up by noon. Kathy attended the school three days a week, but only for about six months because her family moved to a different community. Bonny was preparing to advocate for Kathy to attend public school in their new community when the Endicott Centre opened. It was a school about 80 kilometers away from their home

and Kathy was one of the first students to attend. The Centre operated like a boarding school – Kathy lived at the school and went home on long weekends, holidays and for the summer months. Bonny remembers feeling so relieved that Kathy could finally go to school.

Kathy lived at Endicott Centre through to adulthood. She developed a number of skills and learned to use a visual communication system. The number of people attending the Centre increased significantly over the years and as Kathy matured, she became extremely unhappy. She expressed her frustration by harming herself and destroying property. As institutions began to close, Kathy was moved into a group home with three other individuals. Her housemates required such a high level of support that Kathy's own needs were often left unmet. Kathy continued to express her unhappiness through self-injurious behaviour. Bonny retired as a teacher and decided to bring Kathy back home to her own community. Kathy moved into a home with another woman, but it turned out they were not very compatible. The other woman was aggressive toward Kathy and the support staff. Kathy's response was to hurt herself. Bonny used her influence as a member of her local and regional associations and the BC Association for Community Living to get what Kathy needed, and the professionals involved came up with a creative solution that continues to work to this day.

Kathy's parents bought her a house where she lives by herself and five compassionate, skilled support workers provide care for Kathy in 24-hour shifts. These long shifts eliminate staff changes and unsettling transitions in the middle of Kathy's day. Although it took some time, Kathy's

self-injurious behaviours began to decrease as her world opened up to include employment, a large social network and a variety of community activities, all organized and provided by her support workers.

Kathy's workers live in a tiny community north of the town where Kathy lives. As the staff work 24-hour shifts, they often include Kathy in some of their usual activities during the time they spend with her. Their families have welcomed Kathy into their lives and have become like extended families to her. She especially enjoys spending time with the children who are members of their families. A husband of one of her workers plays in a band and Kathy, who loves music and dancing, travels around with the band to their events. Another worker is very involved with a theatre group and Kathy sits in on rehearsals and productions and is considered part of the group. She is also involved in an improvisational dance group that has incorporated Kathy into their activities.

The support in Kathy's life reflects her personality. She is "a night owl" and enjoys staying up late. It takes her about two hours to get ready in the morning because she has a very specific routine she likes to follow. Kathy loves to socialize now, especially with men, and is the "life of the party." She does not enjoy spending time in large groups of people with disabilities, other than Special Olympic bowling. She loves going to the pub where everyone makes a fuss over her and she never misses a dance at the community hall.

Kathy is so well accepted by all her support workers' families and friends that she has become part of their communities, as well as the community she lives in. She had a job that involved picking up and delivering mail. This has made her well known in the community. She retired from her position when she was 50 as she wasn't too thrilled at having to get up early enough to get to her job on time. She enjoys walking to the local drug store by herself where she buys snacks, puzzle books, cosmetics and 'smelly things' which she loves. Store personnel accommodate her idiosyncrasies as Kathy's disabilities sometimes result in using loud vocalizations to express her needs.

When Bonny moved to the coast ten years ago, Kathy's older sister, Cindy, continued to monitor Kathy's living and medical situation since she lives and works nearer to Kathy's home. Cindy also phones and visits Kathy and takes her on excursions as Bonny has done in the past. Kathy also has two younger sisters, Diane and Wanda and a younger brother Joey. She often visits Diane's home where she has been introduced to Diane's friends who have now become her friends, as well. Diane has taken Kathy to visit her in-laws who have come to consider Kathy part of their families. Wanda and Joey have always treated Kathy as an equal, so others in their circles do, too. Because of her brother and sisters, the circle of people who know and care about Kathy has grown significantly.

Bonny celebrates the changes in Kathy's life over the past fifteen years – living in her own home with flexible, community support has allowed Kathy to grow and develop as a person. Along with her own family, Kathy now has a very large social network of people who know her as a member of their community and as a friend.



Kathy is so well accepted by all her support workers' families and friends that she has become part of their communities, as well as the community she lives in.



KAYLEIGH'S STORY: GROWING THROUGH LEADERSHIP AND TEAMWORK



Debbie and Ben Postmus

Debbie and Ben Postmus, long time Resource Parents with the FSI, proudly shared the following story about their daughter Kayleigh during a telephone interview. The steps that led to Kayleigh's employment and her confidence and prominent place in community demonstrate what can happen through planning, perseverance and teamwork.

— *Maria Glaze*

Three years ago, a reluctant 18 year-old Kayleigh trudged through an hour-a-day of work-experience at Walmart as part of a 30-hour work placement. Today Kayleigh is a proud and valued Walmart employee and stockholder. She gets up at 6:30 a.m. sharp to make it to her job on time where she brightens everyone's day with a cheerful, "Good morning!" Kayleigh works in the seasonal department three days a week for six hours a day. She loves her job and is often reluctant to leave at the end of her shift. Her department manager says Kayleigh is the one person she can count on to get things done.

Kayleigh's parents enjoy the looks of surprise and amazement shown by people who knew Kayleigh during her younger years when they discover that she now has paid employment at Walmart. And Kayleigh encounters people she knows during every shift. At home, after a day of work at Walmart, a consistent question for Ben and Debbie is, "Guess who I saw at work today?"





Ben met with both the personnel manager and store manager at Walmart and suggested that the work experience transition into paid employment for Kayleigh. After some consideration, the manager said, “Yes, let’s do it!”



Kayleigh’s perseverance, combined with Ben and Debbie’s creativity, careful planning and hands-on support, has been key to her successful employment. Her parents began planning while Kayleigh was still in high school. Ben and Debbie were aware of their daughter’s strengths and knew that employment could be an achievable goal. They know it helped tremendously that Debbie could draw on her own background as an employment counselor for people with barriers to employment. She was very familiar with all the resources in their community and surrounding area. They were disappointed in the lack of work experience opportunities for Kayleigh in school, so they took charge of planning for her transition from high school with a focus on employment.

In the Fall following her graduation, Kayleigh attended a transition program for people with disabilities at a college in a neighbouring community about 40 minutes away. The program offered instruction in a variety of areas such as computers, cooking, preparing a resume. This eventually led to the work-experience at Walmart. Kayleigh needed someone to support her during her shifts at Walmart, so Debbie took on the role of job coach. Debbie and Kayleigh worked in several departments in the store to identify the best fit for Kayleigh’s skills and interests. They learned she had a real eye for detail and enjoyed stocking shelves, but found duties like folding clothes repeatedly quite boring. They realized that working in some departments included tasks Kayleigh wasn’t physically able to do. By working in several departments, Kayleigh discovered she enjoyed the seasonal department best. She could do all the jobs involved and liked the variety of the ever-changing stock. By working

throughout the store, Kayleigh developed relationships with many employees from the other departments.

At the end of Kayleigh's work placement, Ben met with both the personnel manager and store manager at Walmart and suggested that the work experience transition into paid employment for Kayleigh. After some consideration, the Manager said, "Yes, let's do it!" Kayleigh was delighted.

Ben said it was like dominoes falling after that. With the support of Community Living BC they were able access funding for a job coach. Debbie trained the job coach and her hours of work increased slowly as Kayleigh was able to learn the job.

As part of their strategy for success, Ben and Debbie got to know the Walmart managers and employees. They facilitated meetings every few months with any available Walmart staff who had a connection to Kayleigh and also invited an Analyst with Community Living BC to those meetings. The team would review Kayleigh's progress, identify areas of support and set new employment goals. They included a consultant in a meeting who helped Kayleigh's co-workers understand autism, how autism impacted Kayleigh and ways they could support her through any challenges. It wasn't only Kayleigh who was developing new skills and understanding, the other employees were learning, too.

Ben and Debbie describe Kayleigh as a hard worker with a strong work ethic. There are many times when Kayleigh doesn't want to leave at the end of her shift because she

hasn't finished a task. She has discovered the pleasure that comes from accomplishment. Even though Kayleigh didn't start out enthusiastically, her parents noticed a positive shift after her first employment review and raise. Being embraced by the other employees, leading the "Walmart cheer" at the beginning of a shift, and being part of a team have also influenced Kayleigh's positive attitude.

Earning her own money means Kayleigh can indulge in her love of shopping and buying new clothes. She enjoys going to movies and she loves attending sporting events. She has a passion for recording the stats of different teams and likes to purchase the tools and papers necessary for managing the scores. Having her own money has allowed Kayleigh to act on her generosity. She takes pleasure in treating her family to dinners out and enjoys buying birthday presents for her brothers. Family and friends have noticed a significant change in Kayleigh since she has been working. She is more confident and has a new interest in talking to others. Like many people, she enjoys talking about her job.

Work has been going so well for Kayleigh that a plan has been developed to gradually reduce the support of the job coach. A vision for the future is that Kayleigh will be working independently, with the support of her co-workers. Who knows? Perhaps there will be a time in the future when Kayleigh will be training new employees.

BARBARAH AND ZACKERY'S STORY: OUR OPEN HOUSE WELCOMES OPEN HEARTS



Barbarah Kisschowsky

The interview with Barbarah Kisschowsky, a new Resource Parent with FSI, took place in the living room of her cozy home overlooking the ocean. Barbarah's home had a warm feeling of welcome that many people in her community have been able to enjoy. This story is about the creation of an informal social network for her son, Zackery.

— *Maria Glaze*

Zackery's mother, Barbarah, describes her 20 year-old son as a lovely young man with a nice personality. He is someone who appreciates calm and peaceful surroundings. Zackery enjoys walking at the outdoor track, going swimming and taking dance lessons with his mom at a local pub. When he is at home, Zackery spends time reading books, playing computer games or sitting by a living room window that overlooks the ocean. He finds pleasure in watching the tugboats move through the water. Zackery has a developmental delay and a diagnosis of autism, but it's his extreme anxiety that presents the biggest challenge for Zackery. His anxiety can be triggered by any number of things; sometimes it's just getting his nails trimmed or his hair cut, or if there is unpredictability in his life. Little children or dogs can trigger anxiety in Zackery. When his anxiety is extreme, he will become severely agitated within just a few seconds. The anxiety can take hold of him for seconds, minutes or much longer and during this time he can harm himself or others in the vicinity. These explosive episodes can take a long time for Zackery to get through and often end in tears. Once over, Zackery will return to being an easy going, peaceful young man.



A web of kindness, caring and support has been woven around both Zackery and Barbarah. Their home has become a special place where a diverse group of people can share and enjoy each other's gifts and contributions.



His anxiety and the resulting behaviour make it critical to have compatible people in Zackery's life – people he can trust and who have a calming and positive influence. Zackery intuitively senses the difference between people who enter his home to “work” with him and those who drop by as a friend. The people who come in to work can be a trigger for Zackery's anxiety. Barbarah believes Zackery has a negative sense of self but when he is with people who genuinely like him, he feels that he is a good person. Once people spend time with Zackery, they are able to discover his wonderful character and personality. Barbarah and Zackery live a unique life and it's been challenging for Zackery to make friends in traditional ways.

Barbarah and Zackery moved to a new community in 2007. Barbarah moved several months before her son in order to settle in and find a home for them. During this time, Barbarah immersed herself in her new community. She joined a choir, volunteered as a director of a non-profit society and attended community celebrations, events and workshops. Barbarah has a very outgoing personality and she'll strike up a conversation with anyone. She made a wonderful connection with a woman just through sitting next to her on an airplane and engaging in conversation. This woman became her best friend. After only a few months in her new community, Barbarah knew many people. When Zackery made the move, Barbarah focused on his transition to a new school. Once he settled in school, her priority became supporting Zackery to develop relationships in the community. She took a correspondence course on creating social networks offered through Planned Lifetime Advocacy Network to learn more about creating

a network for Zackery. Barbarah hired a network facilitator for one time only – to make the initial calls inviting people to an open house gathering in her home. Zackery’s social network blossomed from there.

Barbarah is very intentional about making events in her home lively and fun, as a way to draw people in and encourage them to remain in their lives. There is often music, food and a festive atmosphere. When people first started visiting their home, Zackery would choose to stay in his bedroom. Eventually he began to move closer to the activities, lingering in the doorway of his room or venturing into the hallway. Little by little, Zackery has become more comfortable in the social atmosphere. At the most recent social gathering celebrating his birthday and Christmas, Zackery spent the majority of his time sitting with people in the same room or in the adjacent room. When it came time to open his birthday gifts, Zackery sat in the circle with everyone. After carefully opening each gift, he proudly walked around the room showing the item to his guests. Barbarah says Zackery often shows his gratitude by gazing into a person’s eyes and smiling.

It’s been several years since the first gathering and Zackery now has many friends and acquaintances in his life. Some people share their time through reading, creating art and doing crafts with Zackery, others bring over his favourite foods to share. There are friends who attend every gathering and others who come by only one time or for one specific activity. People also connect Barbarah to others. One relationship becomes a springboard to another.

Barbarah shared a beautiful story of one man, Bob, who was drawn to Zackery at the swimming pool. The pool can be a challenging environment for Zackery, but Bob made a miraculous connection with him. One day, Bob said, “Zackery, I’ll teach you to swim.” Bob showed up at the pool the same time as Barbarah and Zackery for several weeks. He developed a special connection with Zackery, taught him basic swimming skills, and then they didn’t see him again. Even though Bob didn’t stay in touch, he played a very important role for the brief time he was in Zackery’s life.

When Barbarah and Zackery moved to their new community, they were alone – without family or friends. Through Barbarah’s persistence, wisdom and courage to open her home, other people have opened their hearts. A web of kindness, caring and support has been woven around both Zackery and Barbarah. Their home has become a special place where a diverse group of people can share and enjoy each other’s gifts and contributions. Everyone’s lives are richer for it.



THE PETERSONS' STORY: FINDING PEACE AND SECURITY IN OUR ISLAND COMMUNITY



Judy Peterson

Judy was one of the parents who attended the first FSI Training Weekend in 1985. She and her husband Michael have lived in their small island community for 36 years. They moved to their island home to spend more quality time with their five children, aged four to twelve. They found a home on 10 acres of land that allows them to grow their own food and raise their own animals. One-year old Amber joined their family in 1980. Six years later five-year old Latisha also joined the family. Both Latisha and Amber use wheelchairs for mobility, but that is where their similarities end.

Amber is “quiet and dreamy,” loves being read to and listening to classical music. Amber’s medical diagnoses include words like cortical blindness, cerebral palsy and epilepsy. Latisha also has a diagnosis of cerebral palsy. She is an extremely dynamic and outgoing person and loves loud, crowded community events. She works very hard and pushes her own limits. Latisha is also very artistic and has a hysterical sense of humour. She enjoys using her speech computer and says things like, “Great, beautiful Judy, would you please make me a tuna sandwich?”

Judy’s story is a thoughtful reflection of her family’s life in their unique island community.

— *Maria Glaze*



Being a known, visible and active member of a lively community who participates to whatever extent possible in the life of that community is the basis for developing relationships. Relationships are key to creating informal and some more formal safeguards.



This is a story about our family and creating informal safeguards and developing relationships. At the heart of a community lies the essence of the safety and security for each member of that community. It is not a spot on the map. It is a state of mind where there exists an understanding of the individual and common good. Being a known, visible and active member of a lively community who participates to whatever extent possible in the life of that community is the basis for developing relationships. Relationships are key to creating informal and some more formal safeguards.

For the past 36 years we have lived in a rural, isolated island community. We have enjoyed an ever increasing and enduring sense of our place within that community and of the peace and security of our lives here. The opportunities to participate in the life of this community are varied, interesting and endless! There are only a few public places on the island. If you were to visit you would find a small, two-room, multi-grade school, a tiny post office, an arts centre (and an arts council) a one-room gift shop, a community hall we all built (it too, has an Association) a little grocery/bakery, a pub gasbar-motel-barge operation, a free store and recycling centre, a dump and a foot passenger ferry to Vancouver Island. There are local, regional, and Island Trust political representatives, and a Vancouver Island-based school board. There are endless ways to become an involved islander and to get to know other islanders.

This island is small. You can drive from one end to the other over its gravelled, potholed roads in 40 minutes. We are

without a police presence here, and there is no doctor, no public power, water, sewers, or local public transportation. No fast food restaurants, theatres, or streetlights exist here either. The community members are very interesting, and come from many places and backgrounds. They are so different from one another and share a few quirks. However, they choose willingly and enthusiastically to live here on this island with so few services and public supports. What we also have in common is an appreciation of the individual, and a generally shared welcome and joy for the children of the island. Children are included and participate in just about every facet of life here. Babes in arms, toddlers and school kids are omnipresent at functions at the hall, the arts festivals and shows, weddings, funerals, blessing-ways and baby showers, benefits, musical and seasonal events, potlucks, picnics, beach parties and every function that their parents attend. Children are accepted almost everywhere by almost everyone.

It cannot be inferred from this, however, that there was anything like universal acceptance of tiny Amber with her big disabilities. Yes, there were those who accepted and then grew to love that babe from the beginning, welcoming her to the community and into their lives. But when Amber reached the legal age for Kindergarten, the school acted with extreme dismay at the thought of her entering with her age mates. They were further dismayed when Latisha registered for school sometime after. Our daughters' experiences were not so unlike that of the other children of the 70s and 80s. There was hard resistance at first, and not just from staff but also from parents fearful that a disabled child in school might siphon off scant resources they

believed belonged to the more typical kids. (There was little resistance from the children themselves.)

We did whatever it took to support Amber and Latisha's partial participation in those early years. After a few years the District hired a new Director of Special Education, a bright and energetic man with strength, wisdom and caring. From then on our school's Special Education budget and staff were beautifully supported from the top down to the kids.

We followed the lead of the more senior parents and participated in every way we could at school working hard to support all the kids at school and our own. Every event in those years found one or both of us front and centre working to support the whole school and its staff.

One year, Amber had a teacher who was not only a visionary, but also a master of outdoor experiences. We shared some breath-taking, fabulous field trips with Amber and her class that included cycling the Rockies and kayaking Blackfish Sound! Amber's father Michael, younger then, and fit, cycled with 50-pound Amber and her 55-pound Duet wheelchair bike through the Rockies for 10 days, trying, sometimes unsuccessfully, to keep up with the class. When he fell too far behind I'd swoop them up in the van and we'd leap frog ahead so that when the school kids caught up, they could all cycle together awhile in that blissful appreciation the surrounding mountains inspired. Amber never made a peep of complaint in those 10 days, enchanted with cycling with her Dad through the unsurpassable beauty and grandeur of the Rockies with that bright blue sky surround. Each day's



This year a dream has come true for Judy and Michael. Amber and Latisha have been so comfortable and happy on the island that for many years Judy and Michael have had a dream of building a home for the girls on their property. Amber and Latisha haven't moved in yet, but after 11 years the home was finally completed. Judy is part of the island Women's Choir and this year the choir voted to have their annual Christmas concert in Amber and Latisha's new home. The concert also became a house-warming event that over 70 islanders attended.

ride ended with the cozy companionship of her peers and the adults camping together at night.

Kayaking Blackfish Sound in search of the whales was equally successful and as beautiful and awe inspiring. Another year we couldn't figure out the logistics to manage the West Coast Trail, and though we met the class at the Trail's end, even that easy piece was not particularly successful. The school skating and swimming day trips were always fine, especially for Latisha with her class, and the bowling and camping were all great for her. The trips that were the most exciting for Latisha were the skiing trips, riding the lifts and speeding down the slopes in her specially designed ski shell with exuberant young skiers connected by tether. She was into speed and the Disabled Skiers Association at Mt. Washington always gave her a thrilling experience.

There was a very satisfying and peaceful period at school for both girls when a new administrator arrived on island with his daughter who has multiple disabilities. He set the tone that all the children were accepted and educated with their peers at the school. It was a solid, effective, supported and comfortable time for us. He stayed for several years. When the administrator and his positive approach left the island, Amber was at the age when her peers began to experience teen angst and they developed an intolerance of differences. It was new for Amber and us to experience disdain from others for what had always been familiar – Amber's orthopaedic equipment, her drooling, the necessity of diapering, and anything that made her different from them. Michael and I could hardly bear it! Amber simply could not. After weeks of readying Amber for school each

day, she reached the point where she would vomit her breakfast just as the bus driver (a dear friend of Amber's) would lift her into place on the bus. We had to face the fact that Amber just could not take it any longer. We brought her home for "school."

It was two years before Latisha chose to leave school. She was unable to adjust to the stressors in her life there. Her experience was not at all like Amber's, but significant enough to require such a big step.

As Amber and Latisha adjusted to "learning and becoming" in their more comfortable home school environment, we continued to participate in the community. All those functions where the children ran freely, all those potlucks, weddings and musical and other events brought Amber and Latisha into the heart of their community and into regular personal contact with islanders of all ages. Now both have grown up happily in this community. Their generation is the generation of young adults who are the young parents of the community. Every home and community event, every bit of participation in the endless variety of those events with friends and caregivers helping, has brought us to the point where both Amber and Latisha are pretty well known and accepted for *who* they are, and the *gifts* they have to share, by community members.

John Mc Knight, writer and community builder, says that a great community is one that systematically identifies and mobilizes the gifts of every one of its members.

Anonymity and isolation create vulnerability. In a small community like ours, no one is anonymous. Every single person can be seen to have a purpose, a gift. No matter the degree of participation or the challenges of the individual, each can create or be helped to create the opportunity to be known, and be seen for who she is, by the other members of the community. Sharing a lifetime of common experiences and friendly moments – being known – naturally help create personal security and informal safeguards.

I am reminded that Helen Keller wrote that she felt that there was no security for human beings, and so declared that "Life is either a daring adventure or *nothing* at all!" Amen to that Helen!

How grateful I am to have had a reason to review our lives from this perspective, thank you!

— Judy Peterson



EPILOGUE: THE TEA IN SAFETY,
INFORMAL SAFEGUARDS
WITHIN COMMUNITY LIVING

Dave Hingsburger

A few years ago, I wouldn't have noticed them. I do now. I probably will for the rest of my life. Becoming disabled is like being introduced, suddenly, to vulnerability. The world simply isn't as safe as it was before, not because the world has changed, but because its perception of me has changed. Before I was a big, tall, man. I still am, but, now in a wheelchair my presence has changed, diminished. All that to say, I noticed them. Three teen boys, the oldest was maybe 15 or 16. They were skinny in huge pants. They affected the manner of thugs, smooth cheeked thugs, but thugs nonetheless. They watched me take out money at the bank machine and then followed at a distance as I scooted past the deserted food court.

Joe was not with me, I was alone. I like the independence given me by my power chair, but just then I felt like I was being stalked. I decided to put pedal to the metal and zip down to the elevator, which would take me to the busier floor above. I left them in my dust, it would have been too obvious if they began running to follow me. This pleased me and frightened me – it was clear they had done this before. I got to the elevator and waited, and waited for it to come. Someone must have been unloading something, it is

a freight elevator after all. I began to sweat. I pictured them getting closer. And they did.

Now they were standing around me. Each at a distance from each other. None speaking. I felt my heart pound in my chest. I could die here, these could be my last moments. I could feel sweat make a trail down the centre of my back. I'm trying to figure my way out. The door begins to open, the young men creep in, encroaching on my space, forcing me to move. But the elevator isn't empty.

It's the tea guy. A sweet natured man who runs the specialty tea shop in the mall. He is maybe one of the gentlest guys I know. He speaks with a slight melodic Spanish accent with a hint of a Castilian lisp. We've talked teas on several occasions. He went on rhapsodically about Egyptian Chamomile once while making me a cup to try. We said 'Hello', I pulled aside to let him step off. He saw the situation and then quickly said, 'I'll ride back up with you, I've forgotten something I need.' I rolled in, grateful. The boys muttered something to each other and then decided not to ride up with me.

I tried not to cry.

I maybe owe my life to a guy who makes tea for a living. A guy whose name I do not know. All because we talk, occasionally about tea.

There are many ways to keep people safe in communities. First and primarily is teaching people the skills to recognize and to escape dangerous situations, the skills to repel abusers and to report abuse, the skills of vocabulary and assertion. But these do not always work. There are times when safety happens because community happens. This kind of 'informal safeguard' is one of the major benefits that 'community living' has brought to people with disabilities. Relationships happen in community, relationships that aren't friendships, aren't familial in nature, just relationships of neighbours, of acquaintances, of friendly strangers.

Family Support Institute has, from its inception, supported families in the 'job' of maintaining home and community for kids who, only short years ago, lived lives of segregation and shame. Parents believed that their kids belonged in typical places with typical peers. Families fought for inclusive classrooms and accessible communities. It was a radical thought at the time. Parents were still being pressured to think of institutionalization, to consider their child 'special' odd rather than simply 'special' special. But clear-eyed moms and strong-jawed dads, took their kids into the community. Went grocery shopping, went to movies, went to burger joints. Their kids would be 'known' would be 'seen' would be part of the community.

Little did they know at the time that every time they ventured out the world became safer for their children. As clerks got to know their kids, as bus drivers began to greet them by name, as lollipop guards waved in

recognition, the world changed. No longer a stranger in a strange land, kids with disabilities became something that parents only dreamed of, they became attached to their names... they became Darlene and Desmond, Chanelle and Charlie, Jamail and Jennifer. This meant that kids with disabilities had allies in the community, they had eyes noticing them, greeting them and watching them. No longer anonymous easy victims, they were now people knit into the fabric of a community. Valued people make poor victims.

‘Ah, you know tea,’ he had said to me.

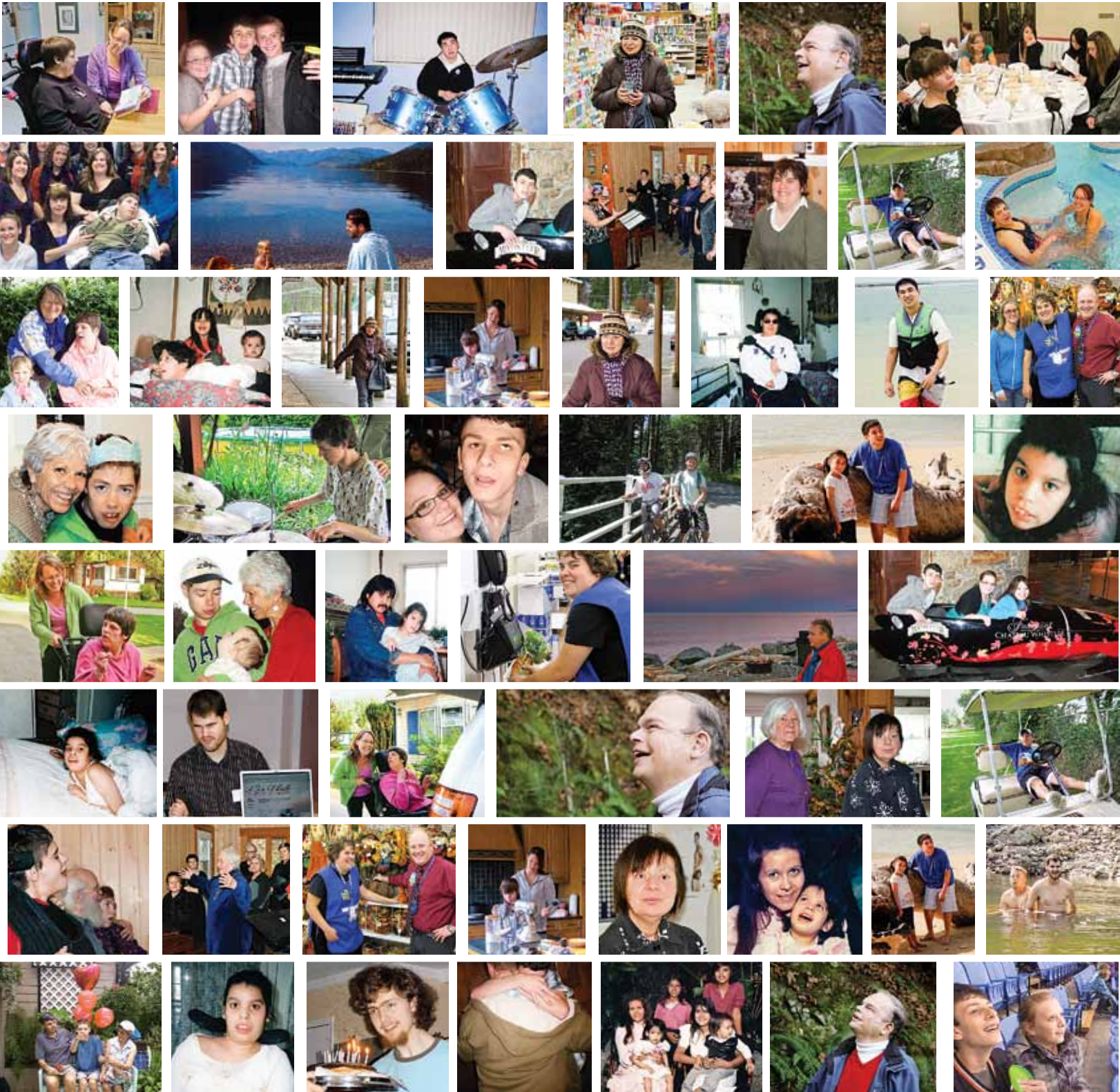
I nodded, admitting to being interested in the art of brewing a good cup.

A conversation began that day. A conversation that may have saved my life.

I’m having tea as I write this, an epilogue to a book about the informal safeguards that come with community life. But now, I’m going to pause... and raise my cup to the community and to the relationships it offers.

Dave Hingsburger is the Director of Clinical and Educational Services at Vita Community Living Services, he is also a highly sought after speaker and consultant on disability issues. In 2009 Dave was inducted into the Canadian Disability Hall of Fame for his groundbreaking work in service to people with disabilities. Dave has authored many books, chapters and articles, he also writes the award-winning disability blog, Rolling Around in My Head.







Stories are
a gift of
inspiration
from one
person to
another.

These stories of informal safeguards offer examples, ideas and seeds of hope that can shine a light of inspiration on others. Weaving informal safeguards around our loved ones comes through the gift of relationship to others. It is through our connection to others, that the tapestry of a meaningful life is woven and the thread holding the most strength to ensuring a life of quality and safety is by being known, cared about and embraced by others.



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