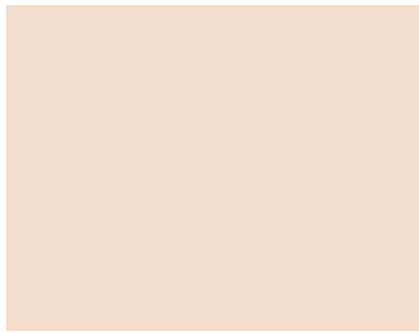
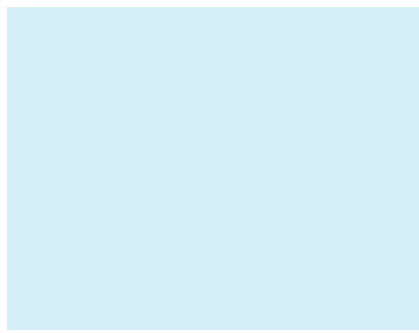
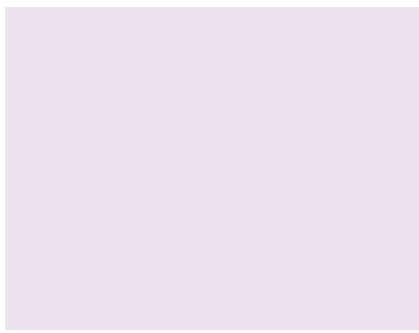
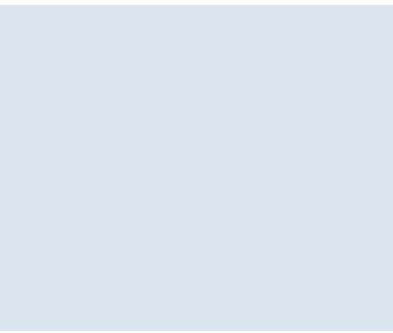
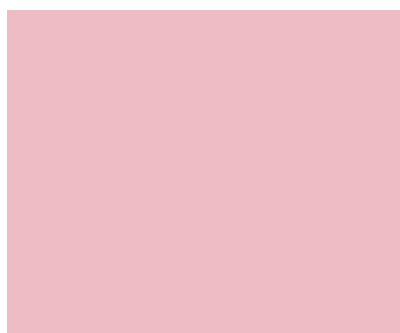
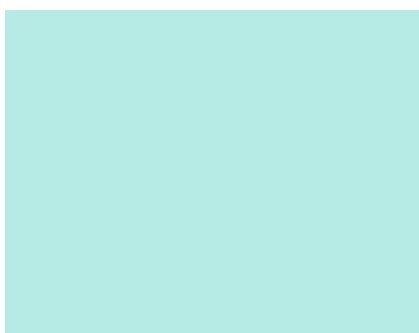
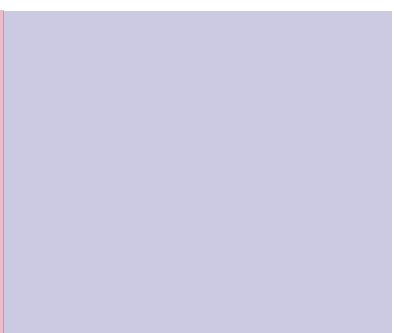
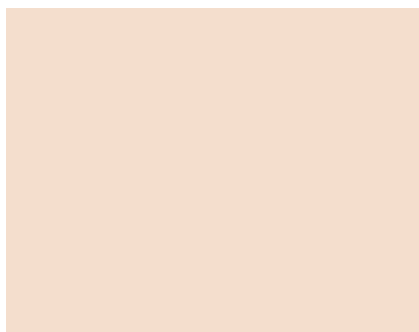
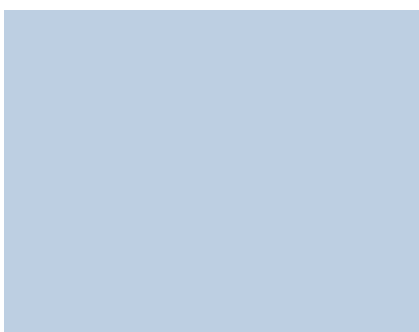
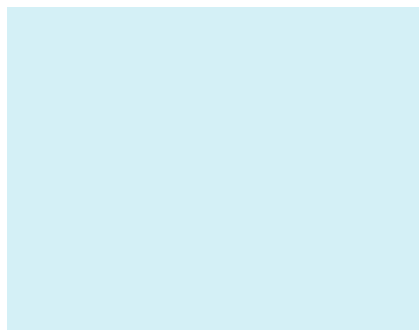
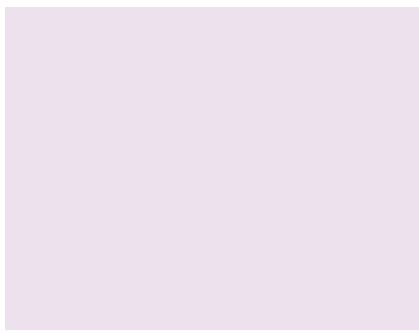
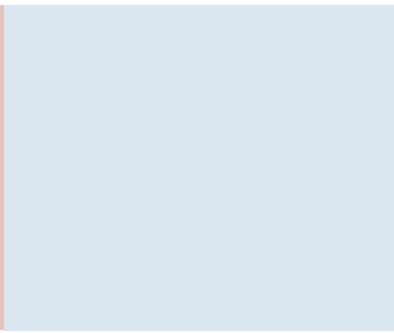


BROTHERS AND SISTERS

The Power of Growing Up Together







**Brothers and Sisters:
The Power of Growing Up Together**

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**COMMUNITY LIVING
BRITISH COLUMBIA**

BROTHERS AND SISTERS

The Power of Growing Up Together

This book is dedicated to all brothers and sisters; those who share their sense of justice, equality, compassion, and love, and those who are inspired by their stories.

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THE POWER OF STORIES

By Maria Glaze

Dear Readers,

This is the second time I have worked on a collaborative book project with the Family Support Institute and Community Living B.C. Once again, it has been an honour and privilege to be in the role of Story Collector.

People connected with the FSI and CLBC are continually inspired by stories of siblings and the impact they have on each other, their family, and in community. Through sharing stories and photos from all across British Columbia, the goal for this book was to develop a resource that celebrates brothers and sisters and highlight how these relationships create more inclusive and safer communities for everyone. We were delighted by the responses to our invitation to participate and pleased so many people chose to contribute to this project. Through a combination of interviews and submissions, we were able to compile twelve diverse stories to share with you.

As with the last book, working with family members on their stories has had a personal impact and been cause for much reflection. Many times over the course of this work I have thought about my own experiences as a mother of two daughters, Katie and Rebecca. I wished more than once that I had benefited from the wisdom and insight contained in these stories as I began my journey as a mom.

A year into our work on Brothers and Sisters, my sister Antonia lost her battle with cancer. I was asked to write something for her Celebration



of Life. The transition from working with other people's sibling stories, to writing about my own relationship, and the shift back to the stories for the book was a difficult one as I worked through grief. After writing about my sister and her impact on my life, I developed an even deeper appreciation for the task of finding the right words to describe such a unique and treasured bond.

The loss of my sister also caused reflection on the safeguards aspect of our book. Because we were separated geographically, Antonia and I connected mainly by regular email contact and phone conversations. If my sister hadn't heard from me in a week or more, she would often email or phone, asking if everything was okay. I don't think I realized the significance of that role in our relationship until I didn't have it anymore. I no

longer had my sister out there in the world looking out for me in that unconditional, loving way. I'm thankful I still have my big brother.

An unexpected theme emerged as I worked with the stories in this book or asked the question, "How is your life different because of having a sibling with a disability?" A collective response seemed to be, "I'm not sure what you mean - it's just my life." Before I became a parent, I had a preconceived idea of who our family would be and the kinds of things we might do together. Disability had never touched my family until Rebecca's birth. Our journey became different than the one I had imagined (and for that I am grateful!). This theme made me aware of how children enter the world without any preconceived ideas of who their parents and siblings will be. They learn about family from their own. As their world expands and they meet other children and families, there is a new understanding as our communities reflect back their collective values. I found myself wondering what kind of sibling stories might have been told if we had worked on this book fifty years ago, and feel hopeful about what future stories will be told.

I have also reflected on Katie's role in Rebecca's life and how Rebecca has influenced the person Katie is now. I've thought about how Katie impacts the world with her values, often just one person at a time. When Katie had work done her car last year, the mechanic used the "R" word. Kate wrote a heartfelt and gracious letter to the mechanic explaining how much it hurt to hear that word and suggested other words he could use when he was trying to describe something. In a letter he wrote in response, he thanked Katie for her courage and wrote, "I apologize and will work at being aware of my vocabulary."



I've thought about the power of stories. While sharing my work with Katie on The Power of Knowing Each Other book, Katie decided to invite her friends out to lunch with Rebecca. Katie knew she was moving away and wanted more of her friends to know her sister so she could create a larger network for Rebecca.

This book has fulfilled our dream. The stories in this book do celebrate brothers and sisters. These stories illustrate how siblings inspire one another to become teachers, friends, advocates and champions. The stories and images convey the power of relationships. The ripple effect of brothers, sisters and families spreads far and wide and our neighbourhoods and communities do become more inclusive and safer for everyone.

Thank you to our book committee members for your integrity, your patience and grace. Thank you to the book contributors for sharing your stories and photos. You will touch many lives. We are grateful to you all for allowing us to work with your words and experiences to create our final product – Brothers and Sisters: The Power of Growing Up Together.

INTRODUCTION: FAMILY SUPPORT INSTITUTE

By Angela Clancy

Family is a true gift. All families are so vastly different and unique. Their stories and perspectives help us to be grounded and see each exceptional family journey as one of adventure, adversity, creativity, celebration, sometimes despair and challenge, and most importantly passion.

Brothers and sisters experiences and perspectives are a part of this collage of experience. Their stories help offer us a viewpoint that is so often unique. These are reflections on their lives growing up together; their stories are rich with love, lessons, and vigor.

In compiling this collection of stories we want to highlight the contribution of brothers and sisters in the lives of all the people we love. We recognize this bond is like no other. We have so much to learn by listening.

At the Family Support Institute we believe families are the experts when it comes to their family members and are in the best position to support each other. This is a consistent message from FSI and does not mean to diminish the role of professionals and agencies, but instead solidifies the strength and expertise of families. FSI is unique in Canada and is the only grass roots, parent to parent support organization with a broad volunteer base and mandate. Brothers and sisters are a part of this unique support network built within FSI and

their contributions are of the utmost value to those they support and share their stories with.

At FSI we often hear from parents about the valuable role all of their children play in the lives of people with disabilities in BC. Brothers and sisters can often, unintentionally, be overlooked as a strong contributor in the past, present and future goals and dreams in each family. However, we know that brothers and sisters are often key voices in advocacy, community access, developing relationships and storytelling in terms of their sibling's strengths and assets. This is a powerful offering.

FSI is honored to partner with Community Living British Columbia to create a book of stories that shares the celebrations and beauty experienced between brothers and sisters as they have grown up together, learned, and shared experiences. We see this book as a collection that will enable us to begin listening to brothers and sisters stories in a different way.

These stories and experiences will play a role in creating safer communities for all citizens as we reflect on those who have shared their story and honor their passion for inclusion, equality, diversity, and rich relationships for all. The strength in the bond between brothers and sisters is one we want to honor, cherish, and hold dear to our hearts – it is a bond of love!

INTRODUCTION: COMMUNITY LIVING BC (CLBC)

By Jule Hopkins

CLBC has a deep commitment to ensuring the voices of individuals and their families are heard. It is through such projects, like this one, that is led and coordinated by the Family Support Institute that helps make this commitment a reality. FSI does an excellent job of making sure that families and their loved one's messages, concerns, values and voices have an opportunity to be expressed and heard. This made them the obvious choice to partner with in this book of brothers and sisters stories. FSI's attention to ensuring that these stories reflect many different perspectives, experiences and points of view proves them to be the honourable organization that they strive to be. It has been a learning experience and pleasure to work with them on this project.

CLBC believes connections that family members, like brothers and sisters, make happen, are essential in creating safe, caring and complete lives in communities for their brothers and sisters. We saw this collection of stories as a way to help others to see the possibilities of how brothers and sisters can support and play a role to help make communities (both large and small) to be more welcoming and supportive of their family member. The stories are a celebration of the successes and challenges they faced together and the differences they made and still make in each other's lives. As you read the stories you will see that their experiences of growing up with a brother or sister with greater challenges is a true testimony of how people can learn and grow from being with each other. It's

also how they helped others see the potential and value of their brother and sister and how lives can be enriched by creating positive opportunities for people to get to know each other.

CLBC expresses its most sincere thanks to the brothers, sisters and other family members that so willingly shared their stories with you. We believe that as you read these stories, you will be reminded of how each of us can make a difference in many people's lives when we stand up for and express the need for communities to be welcoming and inclusive and to have appreciation and respect for people with developmental disabilities and their family members.

Community Living BC is a provincial crown agency, mandated under the Community Living Authority Act and reports to the Minister of Social Development and Social Innovation. CLBC funds supports and services through service agencies for adults with developmental disabilities and their families in British Columbia. CLBC is working to create communities where people with developmental disabilities have more choices about how they live, work, and contribute. Our Mission is that in partnership with our stakeholders, CLBC facilitates and manages a responsive and sustainable network of supports and services that assists adults with developmental disabilities to be full participants in their communities.



STORIES THAT DEEPEN OUR WISDOM

By John Lord

We never know how family life is going to unfold. For parents who give birth to a child with a disability, the life journey can include family stories that break your heart as well as stories that show resilience and wisdom. Families often have to hold both sadness and joy as they try their best to enable their children to live full, meaningful lives. The vital role of siblings in the stories of families is the central theme of this important book.

Celebrating the role of brothers and sisters! What a wonderful idea. This book brings to life the reality (the heartache and the joy) of being a sibling. The stories are mostly written or shared from the perspective of the sibling. As a reader, you will connect with the struggle, the tenacity, and the commitment they feel toward their sibling with a disability. More than any other emotion, you can feel the love and acceptance, which serves as a strong bond that is obviously lasting a lifetime.

In the last three decades, families in Canada and around the world have been advocating for inclusion and full citizenship for their sons and daughters with disabilities. This family movement has had a significant impact on policy and practice, and in this book the next generation embraces the values that have made this movement so important. This is a good-news story as siblings express the values of the family movement in their everyday lives. In their hearts and minds, they are valuing diversity, respecting differences, supporting the voice of their

“ This is a book about the human spirit and the power of love and connection. ”

brothers and sisters, and appreciating personal networks and community.

These stories can deepen our wisdom if we pay attention to what is written and what is between the lines. I found myself often pausing as I finished reading a story. These moments of standing still allowed me to reflect on the meaning of the story for me personally. I wondered if my children would feel the same, or if our family might have dealt with issues in a similar manner. I also found myself wondering how we could create more inclusive settings and communities so that people's lives were more respected and supported. I decided to ask my daughter's siblings how they had experienced life with their sister Karen. Like the stories in this book, their insights were personal, powerful, and filled with wisdom.

There are several themes that emerge from the stories you are about to read that are confirmed by my own children. While these themes likely have universal understanding, it must be recognized that there are wide differences among families in how they adapt, nurture, support, and raise their children. The role of siblings is clearly critical in those family journeys.

Themes that can deepen our wisdom include:

Sense of normalcy

There is a strong sense of normalcy within these families. Siblings love each other, sometimes fight, and are protective of one other. The sentiment that Brad was "treated like one of the guys" with his three brothers echoes this theme that parents work very hard to make sure that siblings feel they are all part of the same family culture. This sense of normalcy helps siblings treat each other with

respect, even though some parents worry that they may have given too much attention to their child with the disability.

Strong bonds among siblings

Most of these stories reflect very strong bonds among siblings. The process of Robbie's family "including our brother naturally," for example, has led to incredible closeness among siblings as they became adults. Several brothers and sisters describe a unique bond they have with their sibling with a disability. While unconditional love seems to be at the base of these relationships, it has often been the sibling with the disability who has been the teacher. Several siblings talk about their growing love and that they miss their sister or brother when they have had to move away.

Parents and siblings as role models

Family culture is set by the parents and the values they live and express on a daily basis. Several siblings describe growing up in families where inclusion and full participation were the norm. Children pick up the "high expectations" as they model their parents and in turn become role models for their friends in the neighbourhood and at school. Several siblings describe how their parents modeled networks and "respect for diversity." Noella's close-knit family, for example, enabled her to constantly learn from her three older sisters.

'Standing up for my brother or sister'

Siblings often stand up for their brother or sister. Sometimes this means responding to bullying and other times it is just about educating peers about the rights of the sibling with a disability. When Brad was bullied at school, the parents did not have

to do anything, because his brothers and friends took care of the situation. Angela recalls being an advocate with her brother on more than one occasion. One of my own daughters says she has always had this feeling of protection, while at the same time knowing she has to also let her sister live her life with dignity. It is this paradox that siblings hold that makes “standing up for my brother or sister” such a powerful insight into sibling relationships.

Power of noticing

Siblings become good at “noticing.” They notice their sister or brother’s strengths and gifts. They notice when their brother or sister need support or protection. They notice when others treat them inappropriately. Like Corbin’s sisters, they notice how others may be drawn to their sibling and how powerful this can be. Several siblings commented how proud they are of their brother or sister, and how they have noticed a lot of growth and development over the years. These insights reinforce the power of noticing, and the fact that people with disabilities, like all of us, continue to develop and change over time.

Nudging parents

There is no doubt that parents learn from their children. For some families, siblings play a role in nudging parents who are perceived to be over-protective. Alexi remembers telling her mother, “Paul can do this,” while Rebecca reminds her mother, “He doesn’t understand, don’t be impatient.” Feedback to parents is a supportive gesture that helps families maintain a sense of normalcy. I recall on more than one occasion in my own family, when Karen’s sisters would insist that Karen could go somewhere with them, telling us forcefully that “she will be fine.”

Borrowing sibling’s networks

We all need meaningful relationships and networks in our lives. Typically, people with disabilities have smaller networks and fewer friends. In these stories, children with disabilities often borrow their sibling’s networks. Siblings such as Angela are happy to share boyfriends and other friends with their brother or sister. Sibling’s friendship networks can serve as potential relationships for the sibling with a disability, and sometimes this leads to new relationships that deepen over time. Microboards also serve as a significant way for individuals with disabilities to expand their relationships. Drew, along with his cousins and friends, are all part of a Microboard for Bree-Anna, which extends Drew’s commitment to his sister.

Context matters

The context of home and school influences a young person’s life and connections. In these stories, most brothers or sisters attended the same school as their sibling with a disability. These inclusion contexts enable peers to see the individual with a disability as a person, and for the sibling to often play a role in interpreting language or facilitating connections. Welcoming neighbourhoods are another important context that can influence inclusion. Justina recalls growing up with her three sisters in a neighbourhood where everyone knew each other, and how this enabled her younger sister to play with all the neighbourhood children. For many of the families in this book, participation in community activities is central to their family identity. Think about how powerful this participation ethic is to inclusion and engagement of the person with a disability.

Belief in possibilities

As the siblings in these stories move to adulthood, they maintain a strong belief in the potential and possibilities for their sibling with a disability and for themselves. In many ways, this belief is unwavering, even as changes shift the nature of the sibling relationship. Siblings move away to university, get married, move to another town, and have babies. And yet, through all these changes, the belief in the sibling relationship remains strong and steadfast. For those of us who are parents of these siblings, it is very reassuring to know that the next generation is so committed to our children with disabilities.

Learning from challenges

Many siblings describe challenges they face in growing up. Some of the challenges complicate the older/younger sibling dynamic when a younger sibling has to guide or protect the older sibling. Other challenges relate to the stress of growing up in a culture that fails to embrace diversity and difference. One gets the sense, however, that each brother or sister finds a way to learn from the

challenges. In some cases, it is about learning to be patient; in other cases, it is learning more about yourself and how you can contribute to the world. In the end, the challenges seem to strengthen the resilience of brothers and sisters in ways that deepen the bond with their sibling.

This is a book about the human spirit and the power of love and connection. Brothers and sisters in these stories show how much they respect and love their sibling with a disability. The genuine way in which these siblings connect and nurture one another is really the heart of this book. The way we raise and nurture our children reflects the values that siblings embrace. These stories are about those siblings, but they are also about the culture of the family. Despite dramatic changes in Canadian families in the last three decades, we know that families still matter. The fact that so many citizens with disabilities in these stories are experiencing deep relationships and strong self-expression is a testament to the power of those families. We are fortunate that FSI and CLBC have been able to create this powerful little book of stories on siblings.

* John Lord is a community researcher, author, and facilitator who lives in Kitchener-Waterloo, Ontario. As a parent and inclusion leader in Canada, John has published widely on innovative community supports and what he calls a New Story. John's books include *Pathways to Inclusion*, *Friends and Inclusion*, and *Facilitating an Everyday life*. John has visited BC on numerous occasions over the years, leading workshops and providing support for innovation and change. Some of his work on belonging and inclusion can be viewed at **www.johnlord.net**

ROBBIE AND HIS BROTHERS

By Resi Edmondson



With just a few words Resi offers a glimpse of the relationship among her three sons. Parents often carefully consider the roles their children will have in each other's lives. In the meantime, brothers like Robbie, Zachary and Lucas form a bond of their own and it will last a lifetime.

Introduction by Maria Glaze

Robbie came into the world early and has been getting us up early ever since.

At eight months of age he began to have seizures and that was our first indication that Robbie was special. It took several years for all of his challenges to become evident. He has cerebral palsy, epilepsy, cortical blindness, and is mentally challenged.

We very much wanted more children but we were afraid. Eventually we took the risk and have never regretted it. When Robbie was three years old his brother Zachary was born and another brother, Lucas, came two years later. It was a very busy time.

When our boys were eight, three and one, we decided that we needed to move to a larger house so that they could each have their own bedroom. We were thrilled to be able to give them their own space and proudly put them to bed on the first night. When we woke in the morning, we found Zachary asleep on the little couch in Robbie's room. He slept there every night. When Lucas was able to climb out of his crib he was looking for his space in Robbie's room so we put a double mattress on

the floor and all three boys shared a room. We had two empty bedrooms for five years.

As Robbie needed a wheelchair, accessibility proved to be a problem. We wanted the younger boys to have some freedom at times without their brother so Robbie went to respite care for a few days and we took the little ones camping. We were hiking up a trail to view a waterfall when they asked us why we left Robbie at home. We explained that we wouldn't be able to climb up the trail to view the waterfall with Robbie's wheelchair. They responded by telling us that they would have waited at the bottom with him. Zachary was five and Lucas was three. Our hearts ached and also swelled.

We tried very hard not to ask our two youngest sons to assist in the care of their older brother but much to our delight we discovered that they included him naturally. When a treat was handed out they would take one to give to Robbie before we had a chance to do it ourselves. They would often lie down on the floor beside him when he was stretching out on his foam mat getting a break out of his wheelchair. When they were teenagers



“ To this day he and his brothers enjoy a closeness beyond what we could have hoped for. ”

they lifted him onto our trampoline in the backyard and bounced carefully to give him a turn.

When our middle son Zachary was twelve he casually mentioned that he could look after his seventeen year-old brother for an hour or two. "What if he needs to go to the bathroom?" we asked. His reply was "I can help with that".

We slowly and cautiously accepted help from our two youngest sons with the care of their older brother. They gave us the freedom to go out at a moment's notice while they lived at home, which was a luxury for us. Rob couldn't wait for us to go out because he knew that his brothers would give him the treats that he requested. We would often

laugh on our way out the door as we heard him placing orders for his brothers to fill for cookies, chips and pop.

Rob is now thirty-six and to this day he and his brothers enjoy a closeness beyond what we could have hoped for. When we meet at family gatherings they gravitate to Rob and assist with his care naturally. They gladly stayed with Rob to allow us to go on vacations when we were unable to get a respite caregiver. Most importantly they have given us peace of mind that they will lovingly keep an eye on Rob, wherever he is, when we are no longer able to do so.



SOPHIE CREATES A FAMILY

by Maria Glaze



It was such a pleasure to interview Linda and her daughter Sophie for this story. The strength of their bond was evident and inspiring as they described how Sophie created a loving home for herself and her brother and sister. This story is also about the love, compassion and commitment of adoptive parents, Bryan and Linda, and their respect for Aboriginal history and cultural heritage. It also might be a story about destiny.

Seven year-old Sophie first met Bryan when he was the Aboriginal Support Worker at Sophie's elementary school. Sophie was living with her siblings and birth mother. Sophie's sister Danica hadn't been born yet and Colby was just a small baby.

Sophie and her siblings were separated when she was eight years old. She was placed into a foster home in Langley, and then a year later the foster family moved further away to Mission. Sophie lost regular contact with both Colby and Bryan.

Linda and Bryan had been married once, and even though they became divorced, they remained friends. Through her friendship with Bryan and his work with Sophie, Linda met Sophie and her family. After Sophie had moved to Mission and lost contact with Bryan, Linda happened to meet Sophie's birth mother again. When Linda and Bryan learned that she was going through a difficult time and that she was pregnant, they didn't hesitate to offer support. Later in her pregnancy, Sophie's birth mother moved to the

Gulf Islands to live with Sophie's grandmother. Bryan and Linda again lost touch with her.

As destiny would have it, a year later Linda again ran into Sophie's birth mother. She was still living on one of the Gulf Islands, but without her children. Sophie's birth mother was unable to see her children as supervised visits could not be arranged due to the cost. Linda wanted to support the children and their birth mother to see each other and met with the social worker involved. She volunteered to travel with the children and supervise visits. After getting appropriate government clearance, Linda, her friend Lori, Danica and Sophie traveled to the island. Sophie was very talkative during their first journey together and she and Linda developed a strong connection. The bond between them began to grow.

Sophie seldom saw her siblings outside of her visits with Linda. Linda invited Sophie to stay with her in Langley for a weekend so they could visit Colby and Danica more often. It wasn't long until that one weekend turned into every weekend at Linda's house. Linda and Sophie spent as much

“ At eleven years old, she was already worried about how she was going to take care of her four year-old little brother. ”

time as they could with Danica and Colby during those weekend visits. Bryan would often join them so he could be with all the kids too. The bond between Linda and Bryan began to grow stronger.

As Linda and Sophie's relationship grew, Sophie would often join Linda on vacations. Some of Linda's vacations were working holidays where Linda would talk to people about Microboards. On one of these trips Sophie was watching TV in a family home while Linda was speaking to a small group of parents in another room. Linda was describing a Microboard - a network of caring people focused on the needs of one person. When Linda and Sophie got back into the car, Sophie was unusually quiet. Finally she spoke. "Those Microboard things - that's a group of people who take care of someone with a disability?" Linda answered, "Yes, that's right." Sophie said, "Colby has a disability, you know?" Linda said, "I know." Sophie asked, "Are you going to help me take care of him?" At eleven years old, she was already worried about how she was going to take care of her four year-old little brother. It was in that precise moment when Linda realized how deeply she loved Sophie.

Linda had always dreamed of sharing her heart and home with children. Before she met Sophie she had been going through the adoption screening process. When the adoption social worker was ready to present Linda with children to consider, Linda realized she already loved a child who needed a home. That child was Sophie. Linda approached the Chief of the Band with whom Sophie has status, explained the situation and expressed her love for Sophie. The Chief acknowledged it would be a difficult road for Linda to adopt Sophie given the complex history of Aboriginal people, even for Linda as an urban Aboriginal person. She asked if Linda would consider being a foster parent first. The Chief felt that being a foster parent would give everyone in the situation time to adjust to the idea. Linda knew about the systemic challenges fostering would bring into her life, but out of respect for the Band and Sophie's birth family, she agreed. Linda wanted Sophie to make the decision about living with her. When her social worker presented the idea, Sophie didn't want to be impulsive and took a few days before saying, "Yes." At twelve years old, Sophie started her new life with Linda and began to change the lives of others.

Sophie doesn't have many memories of Colby as she was growing up. She does remember visiting her siblings and being very concerned about the environment they were in living with their foster family. She was upset and talked to Linda about it and Linda began to share concerns with the social worker. A change was needed.

The social worker investigated the situation for her siblings with the foster family and discovered Sophie's concerns were valid. The social worker asked Linda if she could take Colby and Danica for a few weeks while he searched for another placement. Sophie had been living with Linda for about three months by then and Linda knew it would completely change how she and Sophie lived together. Linda wanted it to be Sophie's decision, but Sophie didn't need to think about it all. She knew she wanted her brother and sister to live with her. Bryan had been spending more and more time with Linda and Sophie. When Danica and Colby moved in, Bryan also moved into a bedroom downstairs to help. Danica and Colby stayed for longer than a few weeks and a family began to grow.

After about a year of living together as a family, Sophie started to talk seriously about marriage – for Linda and Bryan. She had an impact. One night the family took Linda out for a birthday celebration. Linda was sick that night and didn't want to go, but Bryan was insistent. Linda remembers thinking he was being a little insensitive. They got to the restaurant and Bryan presented Linda a beautiful bouquet of flowers. Then he left the restaurant, returning with a second bouquet. When he dropped down on one knee, Linda's first thought was, "Oh, no! What



happened to his knee?” and asked if he was hurt. Sophie squealed loudly, “He’s going to propose!!” While everyone in the restaurant watched on, Bryan proposed to Linda. Sophie quickly accepted for Linda before she could even reply. By the time they arrived back home, Sophie had drawn up the guest list for the wedding.

After they had been living together as a family for about two years Sophie approached Linda and Bryan and asked, “So, when are you going to adopt us?” Linda asked, “When do YOU want to be adopted?” Sophie had a conversation with her siblings, and told Linda and Bryan that the time was “Now.” Linda went to the Chief again and shared Sophie’s wishes. Linda and Bryan wanted an open adoption that was inclusive of the extended family, but in a way that worked for the children and kept them safe.

The adoption was a complicated process that took several years as Linda and Bryan wanted to move forward with the support from the Band and their nation. Linda and Bryan had demonstrated respect for both their Aboriginal heritage and that of the children. They reassured the extended family and their Band that they would keep the children connected to their culture.

Their family had to go before the Elders’ Advisory Council with representatives from each band within the Nation. Bryan and Linda spoke about their love for the children, the history they have shared with the them, as well as their commitment to their heritage. It was Sophie who made the strongest impression. Sophie spoke about how much being part of the Band and Nation meant to her, but boldly stated that while she respected the involvement of her Nation

she couldn’t understand why the Council could decide whether or not she got adopted by the people she loved and thought of as her mom and dad. She stated that it was Linda and Bryan that brought her back to her heritage and they actively demonstrated Aboriginal teachings in their lives. She made her point and the Council supported the adoption.

Once the adoption process moved forward, the children’s files had to be transferred from Xyolhemeylh, pronounced “Yauk Meeth,” (now the Fraser Valley Aboriginal Children and Family Services Society) to the Ministry for Children and Families adoptions team. When that transition happened, the people at Xyolhemeylh rented a hall and gave the family an adoption party. It was incredibly powerful and nothing like it had ever happened through their services before. The family and close friends, and everyone in the bureaucracy they had dealt with, came to celebrate this family’s happy ending. Elders attended and led the ceremony. It was a ceremony they created specifically for the family, as they had never done anything like this before. The family was “Blanketed ” to protect each family member, to remember their past, acknowledge their roots, and walk forward with honour.

On December 17, 2012, Linda, Bryan, Sophie, Colby and Danica officially became a family. Aside from creating their forever family, Sophie continues to play an important role in Colby’s life. It can be puzzling to understand Colby because of his developmental disability and Fetal Alcohol Spectrum Disorder. It can be very difficult to understand what Colby is feeling and trying to communicate, especially when he is upset. Sophie is tuned in to Colby. She has a unique

ability to help him be understood. Colby is crazy about Bryan - Linda said Bryan is the centre of Colby's universe. But when Colby is upset and needs help, it's Sophie he often turns to. This has created a very strong bond between them because Colby knows Sophie can help him make sense of the world. When Colby began living with Linda and Bryan he didn't use words, although he and Danica shared a language of their own. Linda and Bryan spent countless hours with Colby, going over and over words, playing games and singing songs until he learned to speak. Sophie was part of that learning process and developed her own understanding of Colby.



When asked if she ever pauses to reflect on Colby's life now, compared to many years ago when she first heard Linda speak about networks, Sophie said, "Yes, absolutely." At the time of the interview, Sophie was preparing for an exciting adventure of her own - a one-year stay in Western Australia. She knew she would miss her family and that they would miss her, but she was very excited to travel. "But," Sophie said, "I could never plan to travel if I didn't know that Colby and Danica were in a safe and loving environment. I would never leave them." All three children are safe and loved, and Sophie made it happen.





ALEXI AND PAUL

by Maria Glaze

Many times throughout the interview with Alexi I wished I could go back in time and do a few things differently as a mom. Alexi's tenacity and belief in her brother Paul has influenced him to be the confident, independent man he is today. In turn, Paul has clearly influenced Alexi's career choice as she moves forward and makes a difference in the lives of others. Paul recently created an amazing video about his personal journey. Alexi wrote and sang the song that accompanies the video. What a testament to their wonderful sibling relationship. You can find a link to the video at the end of the story.

Alexi's family consists of her parents and younger brother Paul. Alexi and Paul were born within a year of each other and are now twenty-nine and twenty-eight years old. Their family is very close and they still do many things together. They can sit for hours playing board games. They enjoy the outdoors, and go on frequent family camping trips. None of them live in the same city, but they speak with each other regularly. Alexi tries to make trips to the interior of B.C. to visit Paul or he will visit Alexi in the Lower Mainland.

Alexi and Paul were close as brother and sister. Growing up, it was very important to their mom that she and Paul got along. It had nothing to do with Paul's disability – it was just an expectation of siblings. Even though Alexi and Paul had a close relationship, they fought a lot when they were younger. Alexi remembers a few sibling

screaming matches. She also remembers their mom's persistence in making them sit down and always talk things out.

Alexi has always been protective of Paul. They do not have other siblings. They have each other. Alexi rarely treated Paul like he had a disability, and it was hard for Alexi to see Paul treated differently at home or in public. Paul never had to do any chores, and many people tended to his every need. Alexi recalls her mom always assisting Paul when Alexi felt Paul was capable of more. Paul uses a wheelchair, but he is not confined to it. When he was little he used to crawl around and has always had a very strong upper body. He was mentally capable of doing many things. Alexi can remember getting very mad and telling their mom over and over, "Paul can do this!" Mom would say, "No, Paul can't."

“ Alexi taught Paul many things because she believed he could do them. ”

Even though Alexi knows she was just trying to get her brother to help with chores, she never saw Paul as having a disability. She only saw him as capable. Alexi taught Paul many things because she believed he could do them. Paul might not have liked that when they were kids, but Alexi has watched him become an independent adult, wanting to move out of their parent’s house and have his own life. She wonders if he would have been as motivated if she hadn’t been there throughout their childhood constantly telling him, “You can do this.” Alexi believes siblings are important for that reason. They don’t see their brothers and sisters as having a disability. It’s just how they grow up together.

Alexi knows she will look out for Paul for the rest of her life. Her boyfriend understands that Paul is an important part of their lives and knows if Paul ever needed Alexi in the future, she would do anything to help. Alexi said that’s always been a condition for a boyfriend – they had to accept and understand Paul, and Paul knows it. When Alexi started dating, Paul said, “I have to like the guy and he’s going to have to like me for this to work.”

Alexi describes her brother as a charismatic, loveable guy filled with goals and ambition. He just has to figure out how to do the things he wants to do. Alexi thinks, if asked, Paul would say he really enjoys his relationship with his sister, but would also mention what a pain she can be.

Over the years Alexi has observed that some parents seem to isolate their children without disabilities from the support needs of the sibling with a disability. She often hears parents speak of not wanting the brother or sister to have to take on the caregiving role for their sibling. Alexi says her parents almost forced them to be together and get along. Their attitude was, “You are siblings. Love each other.” Growing up, Alexi helped her brother with many things, like using the washroom or preparing food. Sometimes she stayed home and looked after Paul so their Mom and Dad could go out. Alexi is grateful that she learned about Paul’s needs and how to respond to them. This connection between them was part of how they built their relationship together.

Alexi grew up around many different people through her family’s connection to organizations like the Family Support Institute and Vela. Her world was full of a diverse population of families and children. She never saw people with disabilities as different. Alexi now works in a field assisting people with disabilities as a Manager of Communications. One of her roles is to educate employers about the importance and benefit of including people with disabilities in the work force. Alexi has taken so much of what Paul taught her growing up and is now sharing it with the world.

Here’s is a link to Paul’s YouTube video called “Inspiration”:

<https://www.youtube.com/watch?v=sB9CtGfhJ2E>





DREW AND BREE-ANNA

by Terry Robertson

I have had the pleasure of knowing Terry and Gord Robertson for many years. I first met Terry in 1996 at a Family Support Institute Training Weekend for Resource Parents. Terry wrote the following heart warming story about their two adult children, Drew and Bree-Anna (Bree). Terry and Gord have always been aware that their children shared a special bond, even more so than most siblings.

Introduction by Maria Glaze

Drew and Bree-Anna have been very close all their lives. Drew has always been his sister's biggest champion and Bree-Anna believes the sun rises and sets on her big brother. Drew is thirty years old and Bree-Anna is twenty-seven. Gord and I are very proud of both of them and the loving relationship they share. Bree doesn't talk with words; she and Drew share a language of their own. Bree still squeals with excitement whenever her brother calls.

While growing up Drew and Bree-Anna spent many hours together. Drew has many favourite childhood memories. He loved their regular Saturday activity – watching morning cartoons when he would literally drag Bree out of bed, lift her by her armpits and pull her to the living room so they could watch cartoons while Gord and I slept in. Drew enjoyed walking Keewee the family dog with Bree. He wrapped the leash around the armrest of Bree's chair, then through her hand and he held onto the end. When we were camping, Drew and Bree did wheelies with Bree in her

power chair by standing on the back and helping her use the joystick.

Many childhood moments stand out for Bree, too. She remembers going to school dances with Drew and driving around in his car just with him without their parents or caregiver. Bree loved exploring with just Drew while our family was at Disneyland. Four years ago Drew and his wife Krysta moved to Edmonton from Prince George. Bree delighted in going for a sleepover at Drew and Krysta's Edmonton apartment without her parents.

Gord and I have our own favourite memories of their childhood. I remember that any time Drew got in trouble and was being scolded by Gord or I, or both of us, Bree would get very angry and yell at us – her own way of telling us to leave her brother alone. I remember the time Drew strung Christmas lights from his bedroom down the hall to Bree's room, or the time eleven year-old Drew carried Bree on his back while wading in the surf in California.

“

Bree doesn't talk with words; she and Drew share a language of their own.

”

One spring evening, when Drew was only five and Bree was three, Gord and I were out playing softball. My younger sister Nicole was babysitting. When we got home we were so frightened to find Nicole crying on the front porch. All I could think of was, “What happened and did you call 911?” As it turned out, it wasn't that kind of emergency. Nicole told us that in order for Drew to go to bed and go to sleep, Nicole had to promise him that she wouldn't marry anyone or move away from Prince George. Drew made Nicole swear to help him look after Bree-Anna forever. It was our first realization that Drew was pretty obsessed about how he would look after his sister when Gord and I no longer could or when we passed on. Being only in our early thirties at the time, we were very surprised that Drew already felt he needed a backup plan of his own in case something happened to us.

Every once in awhile, as Drew got a little older, he would ask interesting questions. Drew once





asked, “Did Kim Campbell (Prime Minister at that time) change that law?” We replied, “What law is that, Drew?” Drew answered, “The one where I can marry Bree-Anna so that I can keep her with me and keep her safe forever?” That particular question made us realize we really needed to find something that would allow Drew to feel he wasn’t going to be solely responsible for his sister. We needed him to know that, as his parents, we would make sure that he and Bree had all the support they both needed to be safe and secure.

When Bree was about twelve years old, I started hearing many conversations about something called a Microboard. We knew we had better investigate everything that might be of help to our kids, so we set about getting information. We learned that a Microboard is a small (micro) group of committed family and friends who join together with the individual to create a non-profit society. In 2003 we started the process of incorporating our own board. Drew had a very large part to play on the Microboard, and he continues to fill that role even though he is no longer living in the same community as his sister. Having the Microboard has given Drew the freedom to feel confident enough to be able to move away from his family. He knows that with our large board there are plenty of family and friends here in Prince George to meet Bree’s immediate needs.

My sister Nicole continues to fulfill her promise to Drew made nearly twenty-five years ago. She has always sat on Bree’s Microboard. Nicole is sixteen years younger than I am and, with the age difference between us older folks and her, she will likely be the one to keep all the wonderful nieces and nephews on top of the board work as



we all age. Besides Bree's brother, three of her cousins have also stepped up to active roles on her board. We feel like we are very blessed to have the support of the twelve members of the Microboard who are always there for us providing support and ideas to help Bree lead a terrific life in a way that works for her.

Drew is now married and has a career inspired by his life with Bree-Anna. His commitment to her

safety and security hasn't changed from when he was that five year-old boy, needing promises from his aunt in order to sleep. The formation of Bree's Microboard has even given Drew the confidence to move away from his childhood home, work for a community living agency and pursue his education to become an occupational therapist. He knows that Bree has a strong network of others actively sharing in that same commitment to his sister.

When Drew was in grade ten he wrote the following short poem for his sister for an English assignment.

My Sister

My sister always smiles,
Her glowing face can brighten up even the worst of days,
She will befriend and love anyone she meets, Unconditionally,
Despite her many difficulties and problems,
She is a happy child,
Yet protective towards those closest to her,
And her many prized possessions,
Through which she can,
Find her only refuge from her daily difficulties,
Recently she received a voice,
Though it is artificial,
It is one with which to tell us the,
Words of love that we have,
Waited all too long,
To hear,

my sister,
an angel
of Earth.

REBECCA AND GUS

by Maria Glaze



Most of the stories in this book are shared from the adult perspective, often reflecting childhoods that took place during a different time or even a different decade. It was a unique experience for me to hear the perspective of eleven year-old Rebecca as she spoke about her life with her brother Gus. I was delighted when Si suggested a visit to my home with Rebecca and Gus to work on their story for the book. Watching the relationship between Gus and Rebecca over their two-day visit was as touching as listening to Si's pride in her children. It was Rebecca's gentle wisdom that stayed with me long after they left. I was reminded that everything we do now shapes a future – one that will be influenced by the Rebecca's of the world.

Si and Tim named their baby Rebecca, but everyone in their family calls her Doe or Doe Woe. It was Gus who gave her this family name. When Rebecca was a toddler, her favourite colour was yellow. Since Gus couldn't pronounce the name Rebecca, he called his little sister "Yellow." The way Gus said yellow was doe woe. The name stuck and the whole family still uses it. Rebecca smiled when she told the naming story – a story she often shares with friends when they ask why everyone calls her Doe.

Tim and Si Stainton have four children. At the time of our interview, Anastasia, their oldest daughter, was twenty-eight, Jessie was seventeen and preparing for university, Gus was thirteen

and Rebecca was eleven years old. Si described Rebecca as a surprise baby. She and Tim had not planned on another child after Gus. As the youngest child, Si will always think of Rebecca as her baby, but Si looked a little sad as she remembered the difficult stage when she watched Rebecca's development surpass her older brother, Gus.

Being so close in age to Gus, it was always Rebecca who best understood Gus as they were growing up. While the rest of the family knows him extremely well, it's still Rebecca who truly understands how Gus is feeling and what he's thinking. Gus recently went through some serious health challenges and it was Rebecca who first noticed that Gus wasn't well.

Rebecca has a great sense of social justice. Si notes that as a very young child Rebecca had a strong perception of right and wrong. Rebecca is also the one who will stand up for Gus at home or at school. At home, she often tells Si, "Gus doesn't understand, Mom. Don't be impatient." Smiling, Si admitted to needing this feedback at times. Gus requires support with dressing, eating and personal care and Si worries she doesn't always give him the opportunity to grow and be independent. Rebecca is good at reminding her with comments like, "He can do that himself, Mom!"

Rebecca and Gus have always attended the same elementary school, but Si has wanted them in separate classes. She knew Rebecca would continue to go out of her way to be there for her brother at school and she wanted Rebecca to have an opportunity to be herself at school, not just Gus's sister. Si believes there is no better safeguard than having a family member in school. Rebecca is always watching from a place of love. Si doesn't think there are many kids at school who are mean to Gus, but knows Rebecca worries there are times when other students treat him disrespectfully. For example, Gus loves the song Gangnam Style and he can do the dance. It's fun and kind of cute, but some kids will go up to Gus and say, "Gangnam Style" just to make him dance. The kids think it's funny and so does Gus, but there are times when Rebecca and her friends don't think it's very respectful. Rebecca often reminds the kids that Gus doesn't have to dance if he doesn't want to.

Rebecca is a very popular at school and has many friends. Si describes them as really good kids and several have become friends of Gus. When several of these friends attended Gus's last birthday party,

Si was deeply touched by this group of young people. She found herself thinking, "If you ever needed to have paid staff in your life, these are the kind of people you would want." They are kind, gentle and they take care of each other. Si thinks its Rebecca's nature and kindness that draws those kind of people into her life and therefore into Gus's. Rebecca and her friends also look out for other kids who might be marginalized at school.

Si described another benefit of Gus and Rebecca being in the same school. Kids are often curious about Gus and Rebecca has been great at explaining the wonderful things about her brother and also what is different. When asked how she answered questions, Rebecca recalled a time when she was younger and another student asked, "What's wrong with your brother?" Rebecca told them, "There is nothing wrong with him, he's just different in ways. Something in his brain is not the same as ours."

Many of Rebecca's friends know and understand Gus from the times they played at their family home after school. One of Rebecca's friends has a brother the same age as Gus and they would often invite him over, too. Now Gus and that boy participate in a lot of the same community sports activities.

Si and Rebecca shared an inspiring story of how a friend of Rebecca's thought to include Gus at school. The school holds a talent show every year and Gus had never taken part. The friend came up with the idea of doing the Chicken Dance around Gus. The kids chose a song familiar to Gus and incorporated a way Gus could share his unique dance moves. Gus got to be the star of the show with eight other kids dancing around him.



“ Rebecca has been great at explaining the wonderful things about her brother. ”

Si described the performance as fantastic. Si is pleased and reassured to know that many of these kids will be going on to the same high school as Gus.

Rebecca was sad when spoke about the bullying that goes on at their school. But she says the kids know not to bully Gus. Rebecca has explained to them that it's just not fair to bully or take advantage of him. It might also make a difference that Rebecca's best friend is the most popular student in the school. Her friend is also a friend of Gus's and she makes it cool for everyone to like and spend time with him. In fact, it was her friend who suggested Gus attend a community dance. When Si first spoke to the organizers of the dance, they said it was fine for Gus to attend, as long as he had a support worker. Si remembers over-preparing the worker, telling him that Gus might



get over-stimulated and suggested he might need time away from the crowd throughout the evening. The worker said when he got to the dance; he just stood back and watched. Gus spent the entire evening surrounded by friends and dancing with the girls. Gus still recalls that dance and will make a “come here” gesture with his finger, remembering the way one of the girls asked him to dance.

Rebecca thinks having Gus as her brother has given her the confidence to stand up for other kids who are bullied at school. She feels she has more insight because of Gus as to why some other students with special needs might behave the way they do. She makes sure to talk to kids who have been victims of bullying and often invites them to spend time with her and her friends. She is not

afraid to talk to the bullies either and tell them what they are doing is not fair.

Gus has a special role in their family. Si and Rebecca both described Gus as their family Oracle – the one who gives wise counsel. For example, when Rebecca and her sister Jessie fight and can’t agree about decisions - like what to have for dinner or what movie to watch - they turn to Gus. They tell him the choices and ask him to decide. They always go with his answer. Si says it’s always how they deal with challenging decisions in their family. They ask Gus.

Rebecca said it can be hard having a brother who needs so much support. If she is late for something they aren’t able to just rush out the door as they can’t leave Gus alone. It can take him



a long time to get ready. Getting shoes on, making his way to the car or walking somewhere can be very time consuming. That can be frustrating and annoying because it makes them late for things. But Rebecca knows Gus just can't go any faster. She also knows she has to watch the time better and start getting ready earlier so they don't find themselves in a hurry. Rebecca also feels she sometimes has to wait to get their mom's attention. Rebecca said she often hears, "I can't right now – I'm busy helping Gus." That can be hard, but Rebecca says she understands. Gus needs extra help from their mom to do things. Rebecca admits to occasionally finding herself embarrassed when Gus does strange things around her friends. He sometimes stands up in the middle of the room and makes weird dance moves. At times like that,



Rebecca reminds herself she shouldn't care about what other people might think.

At eleven years old Rebecca is already thinking about the future. She hopes Gus will continue to learn more words and speak clearly so he can be safe. For example, if there was ever a fire, she hopes Gus could run next door and tell someone, and hopes the person would understand him. Rebecca sometimes thinks about what will happen when her mom and dad are gone. Who will take care of Gus? What will happen when Mom gets too old? Rebecca knows that all of his sisters will help. Si believes Gus is very fortunate having three beautiful sisters who will always be in his life. She knows each of them would say, as Rebecca does, "Mom, don't worry. I'll take care of Gus."



AKASHA AND MELIAH

by Akasha Motchman

Akasha’s mosaic of memories with Meliah, beginning when she first met her sister many years ago, shines a light on the many facets of their sibling relationship and family life. Their shared childhood experiences not only forged a bond that will last a lifetime, but profoundly influenced Akasha’s understanding and respect for diversity.

Introduction by Maria Glaze

My earliest memory of Meliah is from when I was three years old. My parents and I went to a house in Vancouver. I remember a room with white walls and a grey couch and a baby carrier with a little baby in it in one corner. This baby was my sister Meliah and my family was picking her up from a foster home. I remember my mom and dad taking us for a walk in a double stroller out in the rain. The next day we brought Meliah home with us. The fact that my parents, who knew the challenges they would be facing, still voluntarily chose to adopt a child with Down syndrome is basically amazing to me. There are people who choose to abort a child they conceive who has a disability, and here were my parents volunteering for it. Their caring and commitment has made a significant impact on my life.

Interesting is the one word comes to my mind to describe growing up with a sibling with a disability.

One thing I have learned from having a sister with Down syndrome is to be patient. I have also learned to be understanding. There are certain things that Meliah can’t do or does differently than others do, and it has helped me to be more understanding of her and others.

The dynamics between siblings is different for every family so I can’t be entirely sure how unique my situation is. Meliah and I played happily together, or sometimes I got mad when she wanted to play with my toys. When we were in the same school I would try to look out for her. I love making her laugh; she has a really cute laugh. When she smiles and is filled with joy you can see it all over her face and you just can’t help smiling, too.

It was not always easy growing up with a sister who has Down syndrome. Her lack of speech, intense outbursts, and the hurdles to overcome, kept my parents very busy. I did what I could to make things easier for my parents. They signed me up to a group called Sibshops where I could get together with other children who had a sibling with a disability. It was a good place to meet others in a similar situation to me and who could relate. We played games, talked, and did crafts. I enjoyed my time with Sibshops and the effort my parents made to compensate for the time and focus they had to give my sister.

Because Meliah had trouble speaking clearly, we all learned sign language. This helped Meliah to

communicate, and I really enjoyed learning it. Even after Meliah learned to speak and be understood much better, we still occasionally use sign language. A couple of times at our church we have gone up to sign a hymn for the congregation. Having her family learn ways to better communicate with her made Meliah's life better for her.

My sister loves music. When she was very young she had a harmonica that she would carry around and play all the time, mainly by inhaling and exhaling. She evolved to drums, guitar, and piano. She never really kept a tune and it was often loud and quickly became annoying to those of us in the house. One of our neighbours who also drummed taught her the basics and she improved. My mom and another friend taught her some piano, as well. It didn't matter what instrument Meliah was playing or who she was playing for. She played for the love of it. Everyone in our family is creative; all artists in our own way and Meliah is no exception to that. I believe that this is a good example of how your environment can play a big part in how you grow and who you become. My parents are both creative and they encouraged creativity in their children and made it part of daily life. In turn, their children became creative and found their own way to be artists in the world, even if it is only for themselves. When Meliah was in elementary school, she and a friend were chosen to have their paintings shown in an exhibit. Meliah was so proud and excited and I was proud of my sister, as were my parents.

Meliah also enjoys sports. When Meliah was six years old my parents signed her up for Operation Trackshoes. This is a sports festival for people with disabilities of all ages and is held yearly at the University of Victoria. Almost everyone stays at the dorms on campus, although some people go to

their own home at night. The first year my parents and I had fun attending the Saturday banquet with Meliah. The following year I signed up to volunteer as a peer counsellor. I was partnered up with one girl on my first year and a woman provided us with further support and supervision. As I got older I was partnered with multiple competitors and groups with other counsellors. As a peer counsellor I was able to take part in the sporting events. There were many different track and field events, and some fun activities like basketball throw, wheelbarrow races, and a horseshoe toss. Getting ribbons from the events was always a highlight for everyone at Operation Trackshoes. On the final Sunday, trophies were given out during the closing ceremonies. Meliah won the sportsmanship trophy her second year. I was so proud of her and glad that I could be there and share in her victory.

Operation Trackshoes is something that Meliah and I have both been doing for a very long time now. We



know a lot of the people who organize and volunteer at the event and we have made many good friends and fond memories. We always choose to stay at the University for the event and there have been quite a few years where we stayed in the same dorm for the weekend. Some years I would be able to help the counsellor encourage Meliah to go to bed or to follow instructions. I enjoy cheering- on Meliah in her events and joking around with her in the dining hall. It is a different atmosphere from home or school. Our parents get a weekend to themselves and we get a fun weekend doing something special.

My parents had to work hard to have Meliah part of the regular classes at school. They didn't want her in the segregated class for the whole time. Meliah isn't at the same level of academics as those in her age group. For that reason she was in a special class where teachers worked with her at her level. But she took electives like the rest of the students. I believe that this was not only good for Meliah but for the other students as well. Most of those students wouldn't typically interact with a person with a disability. Having a student like Meliah in their class gave them an opportunity to learn and gain understanding. It also gives Meliah the opportunity to interact with her peers and learn from them. While a person with a disability may not be able to do things that many people can, it does not mean that they are not intelligent or have their own personality, thoughts, or ideas. They feel all the same emotions but how they show it may be different. Everyone views the world differently; some just see it in a more unique way. Interacting with someone who sees the world uniquely can help you to open your eyes to other possibilities and see other ways to view the world.



“ Everyone views the world differently; some just see it in a more unique way. ”

I am thankful for the example of my parents in their caring and commitment to our family. Meliah has taught me that there is more to people than what I see and a person might be facing obstacles that I cannot understand. As I, and others, understand Meliah better, it makes for a better life for her.

Photograph by: Rachel Knoop - Razzel B Photography



CORBIN, TESSA AND KALEE

by Tessa and Kalee Andrew

Corbin's sisters Tessa and Kalee approached writing about their relationship with their brother in different ways. Tessa shared her college Self-Study paper on theories of learning. Her academic insights highlight ways in which families and individuals create communities that are inclusive and safe for everyone. Kalee's story offers joyful images of Corbin sharing time with his little sister and her friends, just being one of the gang. Both are wonderful expressions of how these siblings enrich each other's lives and the impact they have on their community.

Introduction by Maria Glaze

Tessa and Corbin: Self–Study

Written by Tessa Andrew

I was assigned a self-study for a psychology class I took at Camosun College. Developing my self-study was an amazing experience. It has made me realize how growing up in my home has developed me into the person I am today. I was born into a situation different than most. When I was one year old my older brother was diagnosed with autism. It was hard for everyone at first, but it turned out to be a real blessing. Corbin, my brother, and his differences have helped me learn and appreciate the value of diversity. He is a person I look up to.

Corbin's personality has touched many individuals, drawing a variety of people to our family. I have met many amazing people through Corbin. Watching these people and my parents has shaped me into who I am and given me an understanding of the importance of a community that includes everyone.

For this paper I had to identify and apply theories of learning. The theories that apply to my self-study were Bandura's Social Learning Theory and Vygotsky's Sociocultural Theory.

Bandura explains how we learn from observing others. I grew up watching the people around me treat Corbin as a typical person. I developed the ability to look past his disability and to see him for who he is, my older brother. My parents had him do all the same things everyone else did. He went to school, had friends over, and had parties. I saw this and insisted on mimicking the actions of my parents. They modeled diversity and community, and now I have picked up on these values and strive to do the same. Bandura developed the theory of reciprocal determination; describing how person, environment, and behaviour are all related. This has proved to be true in my household. If I am the person, the environment around me has affected

my behavioural habits. I have learned to be patient and welcoming to all people, typical or not.

Vygotsky, like Bandura, believes that we learn from the people in our lives. He came up with apprenticeship in thinking. This has to do with social interaction and learning from those older than you. In my life, the adults have always accepted Corbin and seen past his disability; this has helped me to learn to do the same. Almost everyone has a basic understanding of the fact that people with disabilities are different; but I have grown from my experiences and have developed a true appreciation for disability

and the gifts diversity brings to a family and to community. I have been involved in guided participation my whole life. I have done everything with Corbin and we've been guided through life together.

I have learned so much from Corbin, to write it all down would be impossible. Every day he goes through a struggle of independence; trying to do the things everyone else takes for granted. Both theories I have mentioned describe a huge part of my development. I have learned so much from those around me, watching their every move, trying to be exactly like them.

Kalee and Corbin: 4X4'ing

Written by Kalee Andrew

My older brother Corbin (Corbs) has autism. This does not begin to define him, but it has helped define who I am.

A couple of weeks ago my boyfriend Matt, my brother, and I went on an adventure. We piled into Matt's massive truck, made a quick pit stop at the store for hotdogs, beer, and energy drinks. Then we drove out to Shawnigan Lake where our friends were waiting for to go 4X4'ing. 4X4'ing is where boys or girls with really big trucks drive around like maniacs in muddy side trails! The passengers buckle up, and hang on for dear life!

The 4X4'ing was so much fun! Corbs got to sit in the front passenger seat as he had called "Shotgun," so I had to sit in the back, but I'm extremely short, so I didn't mind. We blasted

music, and laughed like crazy! He and Matt have the same taste in music, so that always makes for a good time. Later we made a big fire and roasted marshmallows, and hotdogs (maybe even had a little beer). Corbin did the DJ'ing for all of us, using the iPod in Matt's truck. He selected awesome upbeat tunes, always playing them as loud as the speakers could handle! Everyone loved the songs he picked; he did a great job of matching the energy of the group with his music choices. He is such a pro partier, with his awesome taste in tunes and very original dance moves!

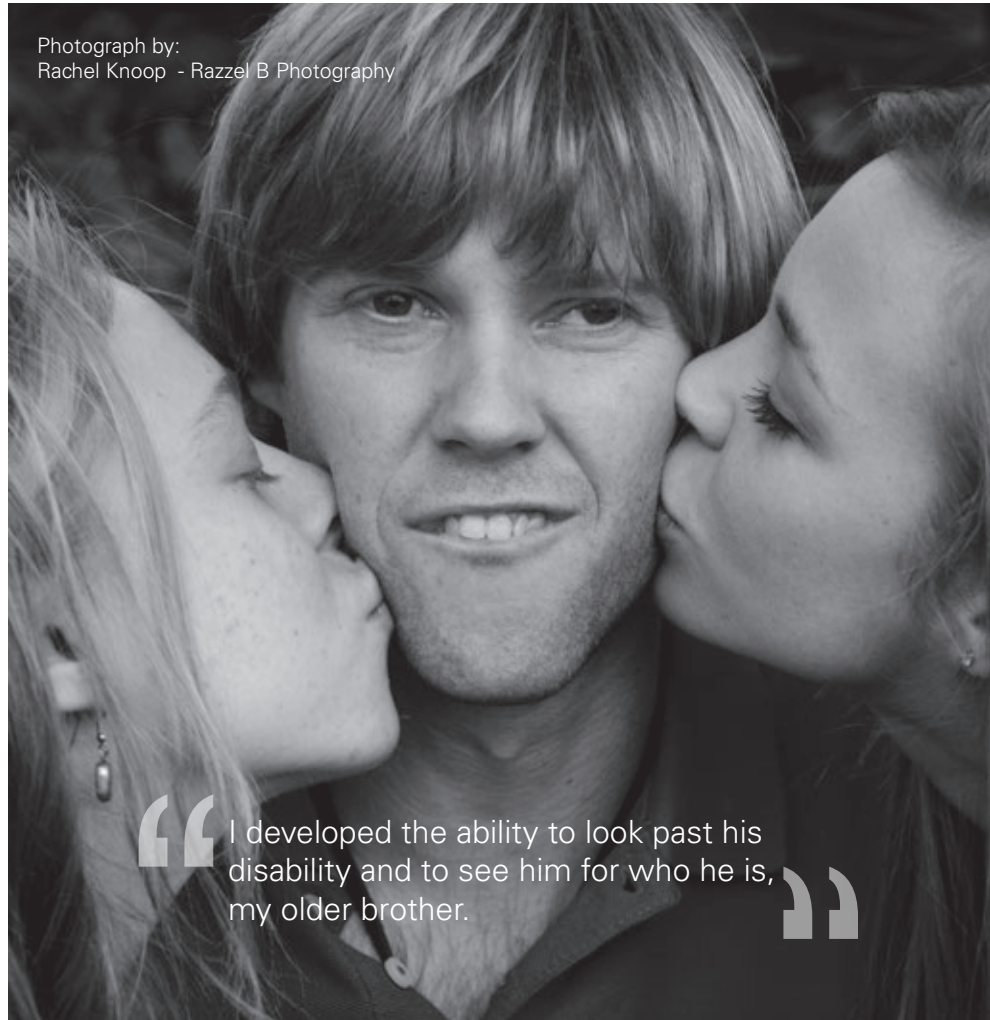
Corbin loves adrenalin type activities like this. However this was our first time doing this activity with him, so there was potential for things to go wrong. Corbin needs a lot of support when he is out and about in the community, or at fun outings

like this one. Corbs and I have a very special sister and brother relationship though. He does an incredible job of keeping it as a sibling type relationship as opposed to a support worker and client friendship. Even when things stress him out, he tries extremely hard not to “put his stress on me.” By this I mean he works extra hard to manage his anxieties when we are together, and I appreciate that so much.

Because Corbin does this for me, I was feeling very relaxed about taking having him accompany us on this adventure! I was however concerned about how he would present himself when meeting my friends. They are new friends of mine, so the way he behaved could have had a large effect on the opinions that they formed of me and of Matt. But Corbin pushed aside all my doubts and stepped up to the role of being my amazing big brother, as he generally does. Even though he has autism which makes socializing a challenge for him, he presented himself to my friends in a composed, yet also fun and energetic way. He asked them lots of questions about themselves and listened and responded when they asked him questions. Corbin is so unique and interesting, and that is exactly what he presented to my friends, therefore he made me seem unique and interesting as well. This made me feel so proud of both him and me. I am unique and interesting, and Corbin has played a huge role in ensuring that I grew up to be this way.

All in all it was an incredible night and it would not have been the same without Corbin’s unique energy. In fact, my life would not have been even close to the same without Corbin. I love my brother so much, and I appreciated his efforts that night to make a good impression in front of my new friends. But even if Corbs was not there that night, his energy would have still been there because it is alive in me. Corbin is so special and because I was blessed to have such a unique and loving older brother, I, too, share some of these qualities. I love you Corbs. Thank you so much for helping me become the woman that I am.

Photograph by:
Rachel Knoop - Razzel B Photography



“ I developed the ability to look past his disability and to see him for who he is, my older brother. ”



JUSTINA AND NOELLA

Written by Justina Wilke, with help from her family;
Moreka Jolar, Sylvie, Annie and David Rousseau

Justina's delight and love for her sister Noella shines through in this story about growing up with Noella. There is little doubt that her family's commitment to her growth and development, along with her three sisters as role models, have contributed to Noella's abundance of charm, confidence, and her valued role in community.

Introduction by Maria Glaze

Noella has always been a social butterfly. She thrives in small communities and enjoys the safety and security of family and friends. Most of her friends and acquaintances would say that they are attracted to her calm demeanour. She is a strong, grounded, and articulate individual. Noella is a good listener. She is thoughtful and generous and has a flair for bringing people together. She exudes such a high level of confidence in herself, that she even changed her middle name from Rose to Pearl. She adopts new "family" members on a weekly basis.

Noella is the daughter of Annie and David Rousseau. She has three older sisters Moreka, Sylvie and me, Justina. Noella was born in Vancouver on December 1st, 1986. Noella recently became an auntie to my son Théo (pronounced Tayo). Noella absolutely adores babies, so it is most certainly an understatement to say she was thrilled to find out she was going to be an auntie. And now, she is eagerly anticipating the arrival of two cousins for Théo, as her other two sisters are both pregnant now. She loves making quilts for "her babies" in sewing class.

Even when Noella was just newborn, her mother and father did everything they could to create

opportunities to help Noella's development and education. We all loved her, enjoyed her and wondered what was in store for her. Noella attended speech classes and physical therapy. A supportive community network was established while Noella was growing up. Her entire family would agree that all this helped to mould Noella into the bright and wholesome young lady that she is today.

As she was growing up, Noella relied on others to involve her in activities and provide her with the attention that she required in order to maximize her growth and development. Noella had us, her three older sisters, to look up to, learn from and imitate. This boosted her maturity level. We also learned how to protect her and help other kids to understand her needs. We helped integrate and include her into social and playground activities.

Our family was very involved in assisting with Noella's social and physical development. We were constantly trying out new techniques that were recommended by her physical therapist. One of her sisters was even enrolled in special preschool with Noella. This was a program for children with disabilities and also typically developing children. This

“ Noella and her three sisters grew up in a friendly neighbourhood where people knew her by name. ”

preschool program helped kids better understand each other. The children learned to provide support where needed. This was especially important later with Noella's transition to elementary school.

We all grew up in a friendly neighbourhood where people knew her by name. Children would run around in the street carefree, and playing games. Noella was included in all the neighbourly fun. As a family, we strongly believe that this friendly upbringing helped her to be the loveable, humorous, positive and self-assured young lady that we like to think she tries to be, most of the time.

Noella also loves animals. When she was a little girl, her sisters enjoyed taking her to petting zoos and local farms so that she could learn about, pet, and even feed the animals. Now her family has a farm on Cortes Island, complete with an orchard, a dozen

or so chickens, a bountiful vegetable garden, and a greenhouse. Noella enjoys the responsibility of feeding, and collecting the chickens' eggs twice daily during the summer months. This task shows her ability to be responsible and maintain a daily routine. She has had the benefit of both a rural life and an urban life. She lived in Vancouver until she was ten and then lived full time in the country on Cortes Island until it was time for high school and college. She moved to Campbell River for high school and then to Courtenay for college and continues to live there now, visiting Cortes regularly and for two months in the summer. She has a wonderful full life in Courtenay with many friends and activities and especially enjoys being able to swim year-round.

I think it's safe to say that having three older sisters as role models to look up to helped Noella. Each of our professional careers has had some bearing and/or influence on what Noella has chosen to do for work in her local communities. Each of us has worked in the food service industry in a variety of different roles; including camp cook, chef/ kitchen leader, restaurant manager, and even cookbook writer. Noella's passions for cooking, hosting and customer service came as no surprise to her proud family.

She also doesn't shy away from public speaking, and as most people are quite terrified of the idea, it seems Noella has picked up that skill all on her own. The public speaking endeavours that Noella has taken on were vastly supported by her family as well as her friends and colleagues. Some of these involved presenting at conferences and giving thank you speeches to dignitaries. She is particularly great at performing when she is well prepared in advance.

Noella is an artist, a dancer, a swimmer, a seamstress, has a true passion for fashion and much more. When given the opportunity, Noella is dedicated, works hard and can even be a bit of a perfectionist at times. She makes delicious and artistic garden salads, and can fold laundry with military precision. She also has a passion for customer satisfaction. She has taken on such jobs as; kitchen helper at a local café in Courtenay; clothing folder at a consignment store; and expert sorter at the recycling center on Cortes Island, and is now starting her own business making bees wax candles and friendship bracelets with help from her job coach. All of which have fulfilled her need for social interaction.

Noella has a huge heart. She may be stubborn, difficult and set in her ways at times, or perhaps most of the time, but she loves her family and friends unconditionally. She also has a very witty sense of humour, which is well embraced by her family, as it fits in with us all, perfectly.



BRAD AND HIS BROTHERS

by Ethel Magnus



Brad is an accomplished creative interpretive dancer influenced by ballet. Many years ago Brad performed at an FSI Training weekend. I still remember his moving performance and recall my sense of awe while watching Brad's skill and confidence. Brad's brothers may have played a role in that confidence, as you'll read in the following story Ethel has shared about Brad and his brothers.

Introduction by Maria Glaze

Great things usually happen when there is a strong team behind the scenes. In Brad's case he was blessed with three brothers Duncan, Chris, and Nolan, who all treated him as one of the gang. Brad grew up with dignity and respect and as someone valued and of worth. Brad's brothers supported his dance career by staying home to care for the farm while their father and I accompanied Brad to his performances. We also travelled with Brad to speak to other people, including other parents, physicians, caregivers, and administrators. We would urge them to focus on what an individual can do rather than on what he or she cannot do.

When Brad was very small, I was coached by an old country nurse from Europe. She said, "He'll sleep all the time, don't let him. Hold him while you vacuum, give him lots of stimulation and don't over protect him. Encourage him to try new things and you stay

in the background. Look at the other children and expect the same from Brad." A fine doctor, who had encouraged us to take Brad home, said, "With three brothers, you have the perfect situation for Brad. One ahead to pull and the others behind to push." That is certainly how Brad and his brothers grew up together.

Brad, second of four boys, was born in 1972 in Calgary, Alberta. As parents, we were shocked to learn that he was diagnosed with Down syndrome. We were advised to institutionalize our wee baby. I knew without a doubt that that was not the life I wished for my child. Together, my husband and I resolved to reject the gloom and doom advice from medical professionals who predicted this little one would destroy our family. We brought our baby home to nurture him the best we could. We have never regretted our decision.

“ It was a very powerful moment for our family, one that acknowledged the strength of the bond between our boys, their influence on each other and a celebration of Brad and our entire family. ”

In the seventies, we were amongst the pioneers blazing a path toward an inclusive society through constant advocacy. It was one small step at a time at a time and often meant helping the outside world understand that uniqueness need not be scary. In fact, we are all more alike than different. Often I felt haunted by questions of whether the other three boys were given their fair share of parental energy, time, and guidance. Were we requiring too much of them as children by putting them into situations of being too responsible? Were they being held back by our stand for Brad and expecting them to go “the extra mile” whenever necessary? The years have shown us that our worries and fears were unfounded.

In 1981 we moved to Salt Spring Island, B.C., with the express purpose of all our boys living in a small rural community setting, free to do outdoors projects independently on our small farm and even going to school together. When the boys decided to have goats, they all worked on the fencing together. Brad doesn't have his driver's license but, like his brothers, he always drove on the farm. One day he

took the old truck out and got stuck in the mud. He was determined to drive it out but the harder he tried, the deeper it got stuck. Dejected, he finally came into the house and confessed he got the truck stuck in the mud. His brothers chuckled and one of them put his arm around Brad's shoulders. “It's happened to every one of us. Come on, let's pull you out!” They made him feel okay about what happened and that getting the truck stuck in the mud was even a rite of passage.

On Salt Spring Island we felt there was a safety net for all our children in a small community. The Salt Spring Island school administration was actually willing to support a child with challenges in a regular classroom. This was refreshing and invigorating. Prior to our move, the only school option available to Brad required sixty miles of daily driving. I tenaciously grasped and cherished every word of encouragement and progress that indicated acceptance and inclusion of all our boys, not only Brad. Brad's brothers looked out for him in school, too. One day John, the boys' father, went to the school to investigate after hearing that Brad was

being bullied. By the time John arrived at the school, Brad was circled by his brothers and a group of friends. They said, “Don’t worry. You don’t have to do anything. We will take care of this.” John could see that Brad was safe at school.

Brad’s brothers supported him in other ways through the school years, as well. Brad writes poetry and Margaret Atwood once offered a Saturday poetry workshop on Salt Spring. Being a Saturday, there wasn’t a support person available, so his brother Duncan attended with Brad. He

helped Brad focus, acted as a scribe and assisted in communicating what Brad wanted to contribute.

Duncan left Salt Spring Island to go to school in Victoria for a while. He returned home for his grade eleven year so he could graduate at the same time as Brad for their grade twelve year. It was important to Duncan to have a photo of just the two of them together. Duncan was proud of Brad and wanted this special photo to capture the moment, and celebrate their shared accomplishment.



Another important time for our sons took place on a stage. Brad was featured during the Show of Hearts telethon in Vancouver. On the second day of the telethon, Brad performed on stage with a well-known ballerina. Bob McGrath sang "You Gave Me Love." Bob sang the words, "That's why we call you brother, that's why we call you friend, 'Cause you touched my heart. You touched my soul." As those words were being sung, all of Brad's brothers surprised him by gathering around him on the stage. It was a very powerful moment for our family, one that acknowledged the strength of the bond between our boys, their influence on each other and a celebration of Brad and our entire family.

A couple of years after Brad graduated it was only Brad and his brother Chris who still lived at home. Thursday nights were pool nights at the local pub. It became part of a weekly ritual for the two of them to go together to play the game they both loved with a regular group of friends. Brad always chose his own clothes and during that time he wore a trench coat everywhere, not the usual attire of the people who frequented the island pub. One wintery evening all was going smoothly in the usual jovial atmosphere until a self-important 'big-mouth' entered. This newcomer started making disrespectful and insulting comments about Brad's attire. When it didn't let up, Chris and some friends escorted the man out of the pub. The inappropriateness of his heckling was emphatically driven home and the newcomer returned to apologize. In time this man became a friendly person – still outspoken – yet converted to being protective of Brad's well-being. Twenty years later, Chris still plays pool with friends on a regular basis. As he recalled that moment he wistfully sighed, "I wish Brad would come home so he could come and shoot pool with us!"

All our sons have grown into very caring men who are accepting of diversity. Each son has matured and gone his separate way. Brad enjoys life in Victoria now and has become part of a caring church community. They have become like another family who is fond of him and appreciates his worship through dance. He has found satisfaction in singing in the choir at Our Place with Louise Rose, a talented jazz musician. Brad lives with a host family in his own suite, which he arranges his own way. Through this host family he has come to know all the neighbours, receives help from them, and is developing friends who gladly check in with him from time to time.

Duncan studied law and set up a firm with two partners, Magellan Law Group, in Langley, BC. Duncan has a personal profile on their firm's website. Under "Duncan's Why", there is a personal testimony of who he is as a lawyer. Awed by his source of influence and inspiration, I am sharing part of a quote from his website:

I have three brothers, one of whom is named Brad, who has Down syndrome. He has trouble communicating and needed help in the school system. When I was in high school, I became involved with helping him. I found strength and purpose in doing this and I found my voice advocating on his behalf. This passion to help others and to advocate on their behalf has continued and shaped my life. Now I help others by advocating on behalf of them – giving them a voice and guiding them through their problems.

I marvel at the profound influence Brad has had, not only in his travels abroad and in his present community, but also within our family where we often take each other for granted. What joy it brings



to see the immeasurable effect for good that has spread unknowingly to people and situations we will never know. By becoming known and befriended in the flow of regular society Brad has become safer and has more independence as others notice and care about him.

In looking back over the years, I see the challenges and disappointments as well as the many rays of glorious sunshine moments. I agree with the words of Andy Rooney who said, "I have learned that everyone wants to live on top of the mountain, but all the happiness and growth occurs while you're climbing it." Brad and his brothers climbed the mountain together.

ANGELA AND ALAN

by Angela Clancy



I met Angela many years ago at a workshop and, like many people who meet Angela, it didn't take long for me to feel the force of her passion for social justice, diversity and family. Reading Angela's story helps us understand how her brother Alan ignited that passion. Angela's story about growing up with Alan beautifully describes the ways in which they have shaped each other's lives.

Introduction by Maria Glaze

My brother is a funny, energetic guy who loves to laugh and have a good time. I remember when growing up with Alan, our relationship seemed like any other brother and sister relationship I knew about or saw. We laughed with each other, we teased each other, fought, and we also took care of each other.

Everyone adored Alan. As a little boy he had white blond curly hair, green eyes, and a laugh that came from deep in his belly. He had dimples all over his cheeks that you saw all the time because he was always smiling. Alan has always been a happy guy.

My values began to take shape at a very young age. I learned about diversity and acceptance. I learned that how I wanted people to treat me is how I should treat others. My mom was a role model for this in our family. We didn't talk much about Alan's disability; we just talked about Alan the person.



We moved several times when we were young and I remember it being particularly difficult for both me and Alan, moving from school to school, and looking for new friends everywhere we went. With each new school, Alan was sometimes met with more questions or raised eyebrows than open arms. He had a significant stutter so people would whisper about how he talked. They would giggle or point at his awkward gait and his clumsy posture. He had

a severe curve in his spine that caused him to have a very pronounced hunchback. Many times people would see his developmental disability and assume his mental ability was that of a very young child. Alan may have some limitations but if only people would give him a chance they could see what a gift he truly was to our world. All of this weighed so heavily on our family.



“ I remember feeling sad at the fact he was not a full member of our school community. ”

Our dad died in a tragic car accident when I was six and Alan was four years old. My mom was grieving the loss of her spouse while also raising two young kids. She was also maneuvering through a system of disability supports and being the sole advocate for Alan. I can only imagine how lonely she felt through all of that.

When I was in grade four and Alan was in grade two we moved to Victoria from Vancouver. This was a great move for all of us. I joined the Victoria track and field club and ran for that club for twenty years. I practiced four times per week with the club and went on to compete nationally with them for twelve years. During my time with the track club

Alan was present at almost every practice. He was one of the loudest cheering voices at every one of my track meets. He would play on the sidelines with the brothers and sisters of the other athletes and was truly a part of our track community. When there were fun family races like relays or medley races, Alan always ran a leg of the race. He attended every banquet and awards ceremony and was pictured many times in the Vic track newsletters. Everyone in the track club knew Alan. They all loved him and treated him with love, respect, and kindness.

While Alan was treated well at the track club, there were many environments that were not so positive for him. Although he could not communicate his

feelings with words at that time, I am certain that he was hurt when these things occurred. He was used to accepting and loving environments like home, track club, and family events. To go to school or places in community where people would look away from him or ignore him completely must have been confusing and sad for him.

I remember the time when I first began to question the difference between what society and my mother felt was best for Alan and what I thought would be best for my brother. Alan and I were attending the same school. Alan's classroom was the resource room, which was a room where many of the kids who had disabilities went. It was believed this was safer for him, and allowed for him to answer questions and contribute regularly. This was an effort to boost his self-confidence. I clearly remember feeling that this was absolutely the right place for him, too. I was in grade five. I also vividly recall the day I realized we might have been mistaken. Alan and I were dropped off at school and I walked him to his classroom. He went in and the door shut behind him. I remember this was the only classroom in the school that did not have a window on the door. As I walked down the hall to my classroom I recall two boys walking in front of me. Casually, one said to the other "What is that room over there?" indicating to Alan's classroom. The other boy's response was to say "I have no idea. All I know is that everyone in that room drools." They were laughing and rolling their eyes. I realized at that moment that even though Alan could answer questions in that room regularly, he was not emotionally safe when he was in there. I tried to speak to those boys that day. On reflection I think that I was so filled with emotion at the time that they probably did not realize what was happening. They did not know how or why I was affected so severely by what they had just said.



It was that moment I realized that everyone in that school had no idea how funny he was. They had no idea how happy he was and how good he could make you feel just being in his presence. They had no idea how smart he was and how intuitive he was with people. It was the moment that I remember feeling sad at the fact he was not a full member of our school community; I was sad for him, but I was also sad for all of the other students who were missing out on knowing him.

I remember a time my mom was quite upset after a school meeting. She had been refused an Educational Assistant that was needed for Alan to participate in an integrated gym class. She told me the principal kept referring to Alan as "it". I felt called to action. I was in a different school now, and I took one of my best friends with me and together we barged right into the principal's office. All grace



left me as I began screaming about Alan and how wonderful he was and the audacity of anyone to referring to him as “it”. The principal didn’t say a word during that meeting. Nothing changed for Alan after that meeting; he did not get to participate in the integrated gym class that year. Fortunately that was not the experience throughout his school years.

Alan moved on to a new school the following year and his educational experience became much better. He had entered into a school where the principal was also the president of the track and field club that I had been running in. He knew all about Alan and what Alan’s gifts were, and he was fully prepared to share those with the other people who were a part of that school. Alan graduated from that school and had many friends by the end of the year. These were people who truly cared about him and who had given him the time and the respect he deserved and

was entitled to. In that school he was truly safe, both emotionally and physically.

My husband John and I met in grade ten. He invited me to play on a co-ed softball team at the University of Victoria. I was happy to go and asked him to pick me up for the first game. When he arrived to get me, Alan answered the door and quickly asked if he could come and play. As Alan’s sister who was about to go on a first date with someone new, I was mortified. I didn’t want my brother to go on my first date, so I jumped in just as quickly to tell him why he could not come, but John beat me to it and told Alan to get his shoes and that he would be welcome to come. I feel like it was love at first “Alan invite”! Their bond started there. By week three of playing in the softball games, everyone on the team made Alan captain of the team. He began joining us at the pub

after the games, and making the phone calls every week to all the players to tell them where each game would be. I know I fell in love with John the moment he invited Alan, and I know Alan loved him at that moment too. John welcomed him without hesitation and has continued to treat him just like everyone else he loves and cares about.

Alan is now thirty-eight years old and I am forty-one. I can tell you that my values are strong. My love for Alan is bigger than it has ever been and it continues to grow every single day. I now have three daughters who love and adore Alan and want to be with him whenever they can. Alan was at the hospital on the day every one of them was born, and was one of the first to hold them. My girls all know firsthand the things Alan can do. They really never talk about what he can't do. The response my girls have every time someone wants to talk about Alan's limitations is "We are all more alike than we are different"

How my daughters interact with Alan is the same as when Alan and I grew up. All of my friends knew and loved Alan. All of their parents knew and loved Alan too. Alan was included in everything we did, and by getting to know him you got to know everything about him. You learned quite quickly that he is terrified of tunnels, he does not like soup or salad, he is an avid Blue Jays fan, he always needs to be on time (or even really early just to be safe), he enjoys knowing ahead of time what is going to happen when we are doing something new, and he knows every tiny detail about wrestling. He loves kids and playing games where there is a lot of laughing. He really enjoys word search puzzles and Find Waldo or hidden picture games.

Alan volunteers at a golf course, a seniors centre and a thrift store. He has learned to take transit to get to and from those places by himself. He has developed many friendships that are long-term and filled with richness. Everywhere we go, there are people that say "Hi" to Alan. People wave at him in the mall, the coffee shop, and on the bus. Alan is known almost everywhere in Victoria. People are getting to know him better and better every day. One thing is for certain, he has a family and friends who adore him and will look out for him no matter what. He is safe, both emotionally and physically. He has people in his life who cherish him for who he is and what he has to offer. As his sister I will be there for Alan every step of the way, just as we have always done for each other. His disability is a side line. We don't even really need to talk about that; it is overshadowed by his presence and loving nature! I am so grateful for that; to know that there are others in his world that have been given the gift of Alan. He is truly an amazing gift that has been given to me. My world is a better place because Alan is in it.



NICOLE AND BREANNE

by Nicole George



Reading Nicole’s story about life with her sister Breanne filled my head with delightful images of their childhood. I found myself smiling as I imagined Nicole and her friends swinging from the ceiling using Breanne’s equipment. Their relationship and experiences have created a wonderful network of people in Breanne’s life. I’m sure there will be more adventures in store for them both as Nicole continues to dream about their future.

Introduction by Maria Glaze

Growing up with my little sister Breanne, has taught me that nothing is impossible; sometimes you just have to come up with a different approach to whatever you’re trying to do.

When I was about three, my little sister Breanne was diagnosed with cerebral palsy (CP). She was a year old. The doctors told my parents that she wouldn’t live to be three years old. Fortunately doctors are not always right; Bre just recently celebrated her twentieth birthday.

I was pretty young when they determined that Breanne had CP. I didn’t understand why she should have to do anything differently, so I did my best to make sure she did pretty much everything I did. This didn’t always go perfectly, like one time while we were playing tag outside on the grass. I was pushing Breanne in her wheelchair, we took a corner pretty fast, and before I knew what had happened her chair was on its side and she had a mouthful of grass. She wasn’t very happy with me; needless to say my parents were also not too impressed.

Growing up with Bre was definitely a little different. She has a lot of special toys that a lot of people may not be too familiar with. Our family home has an elevator and ceiling tracks throughout the upstairs floor. As a kid, my friends and I definitely might have borrowed Breanne’s sling and swung ourselves around the house. Breanne would have laughed. Breanne grew her way out of quite a few wheelchairs over the years, and I may have taken it upon myself to occasionally test out the backup chair to make sure it still worked. Sometimes I would try to race her, me pushing myself and someone pushing Bre. She usually won, and thought it was hilarious.

I always try to involve Breanne in almost everything I do. I have learned that sometimes I just had to come up with a different way to do whatever I was trying to do with her.

The Vancouver Sun Run is one example of how we needed to be creative. Breanne’s wheelchair is quite heavy, and has very little clearance. It’s



difficult to go off-roading in, which is something we used to do when she was younger and had a lighter chair. Last year, I was trying to find new things for Breanne to do, and stumbled across the idea of running a 10k race. I knew Bre loves going fast and she loves being surrounded by people, so I figured it would work great. Her chair wouldn't work great though, as it's heavy and definitely not built for speed. So I set out looking for different options, and found out that they make jogging strollers for adults. I got my parents on board with the idea, my dad sent out some emails, and lo and behold, we found a used jogger fairly close to me that the owner was willing to sell to us. The only issue was that there weren't enough straps on it for Breanne, so once we got it up North my dad had fun tinkering with it to get it ready.

It worked. We ran the Vancouver Sun Run along with almost 50,000 other people. Team Bre consisted of me, Breanne, our parents, and my

“Growing up with my little sister Breanne, has taught me that nothing is impossible.”



cousin. We all proudly wore our Team Bre t-shirts. With Breanne's jogger, we had to start in the walking section. Everyone around us was fantastic; it's really neat to be in a crowd of that many people who are all genuinely excited to be there. We had a blast, and are working on planning which run we'll do next.

When we were in the same elementary school, Breanne's Educational Assistant would put candy

and chocolates in the front pocket of Breanne's jacket at recess. As a result, kids found out and flocked around her, got to know her better, and were more comfortable with her wheelchair.

Breanne and I went to different junior secondary schools, due to the fact that the one closer to where we lived wasn't accessible enough. Even then, a lot of my friends went to the same one as Breanne, and I would often hear, "Oh, I saw your sister yesterday; I said 'hi' and she gave me a big huge smile!" I think that because I try to include Bre in everything, that to my friends she was just the kid sister of their friend.

In high school, Breanne and a few of her friends would bake cookies and sell them at morning break. She had a mixer that is controlled by her head switch, so she was in charge of mixing the cookie dough. She loved it. There would be a line-up around the school for the cookies. Now that she's graduated, one of the activities I'd like to get her working on is baking and selling cookies somewhere, such as the Farmer's Market in the summer.

The Farmer's Market is one of Breanne's favourite places to go in the summer. I don't live in the same town as Bre anymore, but when I am home, the two of us will go out to the Farmer's Market. There are tons of people there, and a lot of them know her and come up to say "Hi". That's great to see because it shows how many people in the community know her and are looking out for her. Sometimes I don't know the people who are talking to her, and they'll ask me who I am. As a sometimes-overprotective sister, it's comforting to know that people are keeping an eye out for Bre and making sure she's with someone who will keep her safe.



MARINA AND CHRISTIAN

By Marina Whitehead

The first time I met Marina I had been invited to a secondary school transition meeting for her brother Christian. During the meeting, Marina was an outspoken advocate for her brother and I remember thinking, “Look out world – here comes Marina!” I also had the honour of being at Marina’s wedding and like the other teary-eyed guests, touched by the magic of Christian and Marina’s relationship as they shared a dance. Marina’s passionate story about life with her brother provides insight into the significant role of siblings and how they help each other’s light to shine.

Introduction by Maria Glaze

I am lucky. Why? Because in my life I have someone very special to me, someone who I connect with and get to share my life with. And for him, I am one of the few allowed to see inside his world. I am someone who he chooses to share life’s magical moments with. I am one of the few who he chooses to let into his heart. He is my older brother Christian.

My brother and I have always had a special relationship that is different from the relationships we have with other people. From a very young age we understood each other. I can be myself when I am with him, and he can be himself with me. When I was younger and people would tell me that they had a brother, I thought their brother would be exactly like mine. It wasn’t until I was older that I learned how lucky I was. I have learned so very much from Christian. My entire family is better

because of him. He teaches us that some things just don’t matter, and family is everything.

Christian and I share a unique bond that I don’t have with anyone else. My mom describes it as “shining.” She says we shine when we are around each other. Christian chooses to share things with me, to be real with me, and to love with me. We have a common love of Disney; we enjoy talking about books, movies and singing Disney songs. When we were growing up we enjoyed many family movie nights. On Sundays, we would all get in our PJ’s. Mom and Dad would get the popcorn. Christian and I, and our younger brother, would get our blankets and pillows, set ourselves up in front of the TV, and we would all watch the Wonderful World of Disney.

When we are together, it is as if it is just Christian and me. Nothing else matters. We talk more, smile



more, and we laugh more. I am so fortunate that I went to school with my brother. We were not in the same classes, but I always saw him at school. Christian and I have another common passion - we love to eat! When we were in high school we would have lunch together sometimes and on Fridays when we were given lunch money we would buy our lunch at the cafeteria.

Christian's interests always remained the same and I shared those with him, but as I got older, I

developed new interests. I loved playing sports and spending time with my friends. This meant I had less time at home, but Christian and I still found ways to spend time together. When we reached the age that our parents were no longer "cool," we ditched them and we walked to school, just the two of us.

As high school went on and I was entering grade 12, Christian stayed in school for another year, and we graduated together. Graduation day was

so exciting for us. Christian shows his excitement by talking about movies and books, and by always moving. My parents and the school staff were cautious and hesitant about the graduation ceremony and the expectation of sitting still for hours in a place that was foreign to us because Christian found these events to be so exciting and over-stimulating. But it was important for all of us to be there, especially Christian, for we were graduating and ending school which was a big part of our everyday routine. During the ceremony he got to have lots of breaks while he was sitting and when it was finally our turn to walk onto the stage, Christian became calm and composed; taking the experience in. This was his moment. This was when he was going to graduate in front of our peers. This was also the moment he was my big brother. Graduation was a huge accomplishment for both of us and Christian recognized that. He wanted to walk across the stage, throw his hat in the air, and graduate. As we took our first step to go onto the stage, I started to tear up. My big brother took my hand, looked at me and said, "We did it." As we walked across the stage, our graduating class was cheering so loud - for us, and for Christian. I tear up every time I think of that moment. Christian graduated with all the rest of his class. Christian and I had finished an important chapter of our lives. And we did it, like so many other things, together.

After high school, our family created a Microboard and Christian has support staff who come during the day to help Christian with all of his daily activities. Some days Christian does his laundry, grocery shopping, and other days he goes bowling, swimming and canoeing. He also has a job where he works one day a week for a few hours. Christian plans his days, and is in charge of what he wants to do.

A few years after graduation, I fell in love and moved far away. The first year was so hard to be away from Christian that I went home to see him eight times. I still remember when Christian told me he loved me and he missed me. He never says, "I love you," first. I felt my soul cry. I was at work and I started crying. I talked to my boss and left the next day to go home for a visit. When I go home,



we do our normal things. I bug him until he tells me to leave the room, we watch movies, we walk, and I go to work with him when I can. I always, always, always make it home for his birthday. It is a big deal to both of us. Some may think it is just a birthday, but we will never have that same birthday again, and I choose never to miss it. This is our normal.

“ I am someone who he chooses to share life’s magical moments with. ”



I ended up getting engaged. My fiancé knew then, and knows now, how much my brother means to me, and he never wants to take away from that. I used to say, “Christian is my number one, and you’re my other number one.” Not because I love him more, but because Christian needs me more.

As we planned our wedding we knew that Christian would be in our wedding party. The morning of my wedding, before we were getting ready, I spent some time with Christian reading. Then he joined my bridesmaids and me for breakfast. As I got ready, he got ready with my parents, and we all rode in the limo together. At the wedding, he walked our mother down the aisle to her seat. My family sat close to Christian in case he needed them. After the ceremony, Christian came out with us for photos. To Christian, this was his wedding. He was so happy and had a smile in every photo. As much as I thought this was MY day, Christian saw it as HIS day. Like our graduation, this was a big moment for him.

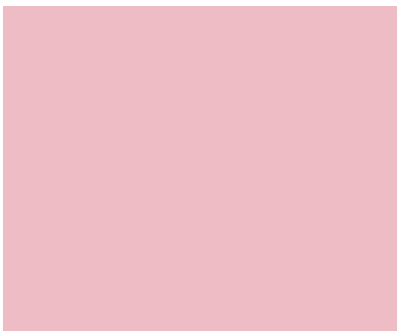
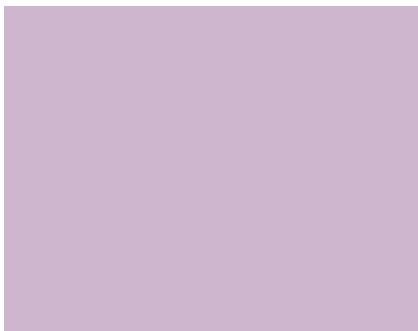
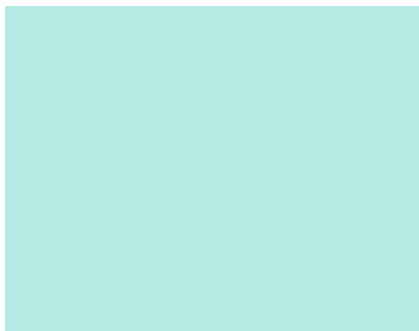
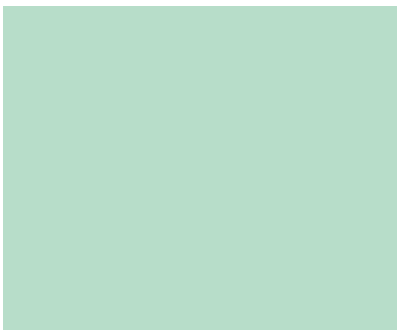
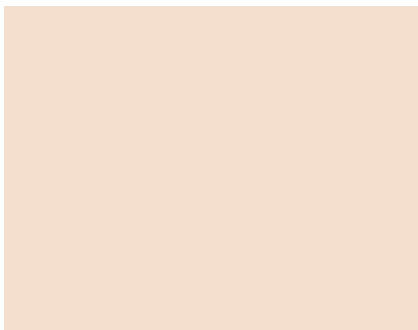
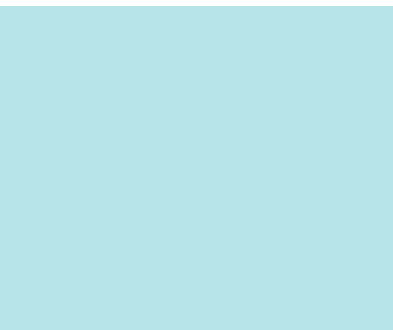
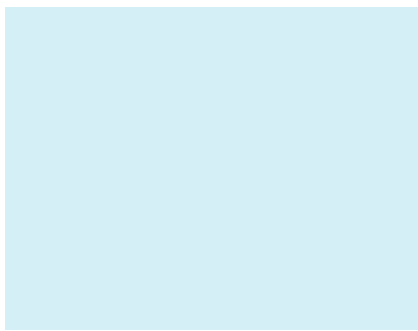
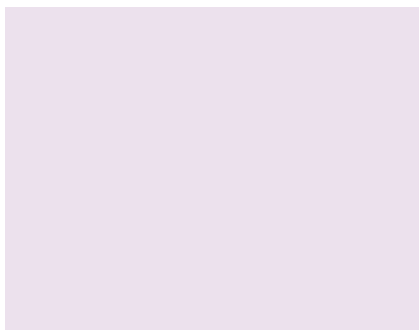
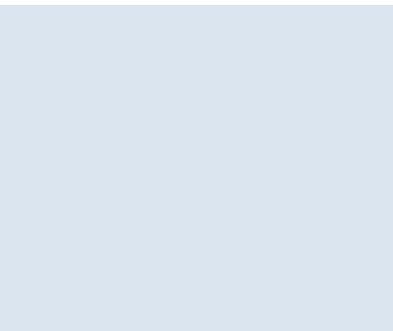
We sat at the head table at the reception, and later we all danced. Christian and I planned a special dance for the wedding. As the evening progressed, I remember the anticipation building for our dance together. Finally our song came on – “A Whole New World” from the Disney movie Aladdin. We sang the whole song together as we danced in circles. It wasn’t until we were done that I noticed everyone was standing around the dance floor weeping. They recognized how important this was to him. Everyone got a glimpse of our relationship and how much we love life together. This was the person I always knew, but not everyone gets the opportunity to see and experience what I see. I got married that day, but it was Christian’s wedding.

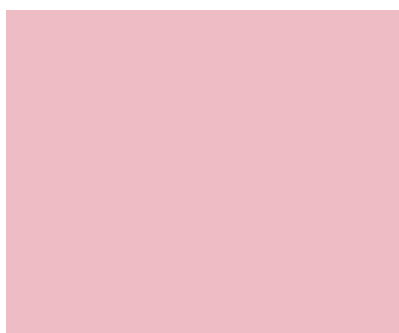
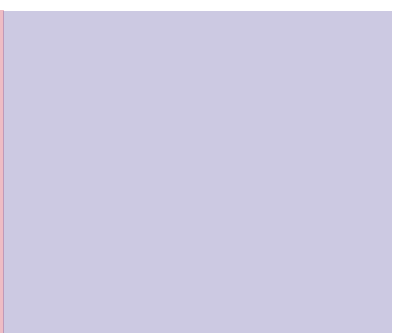
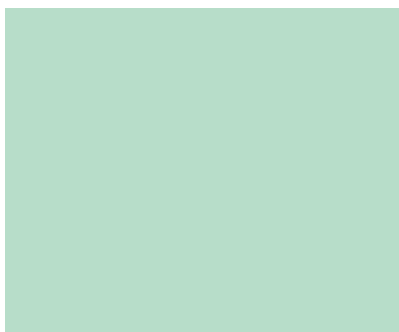
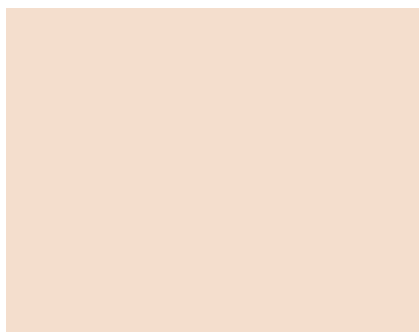
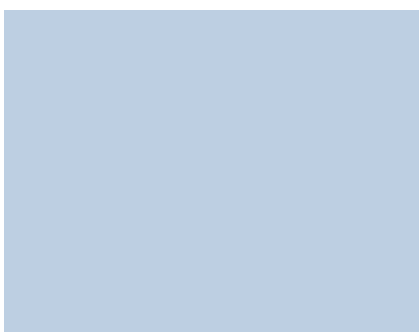
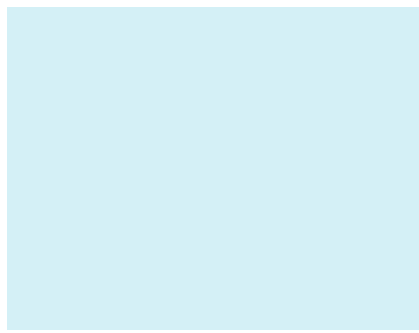
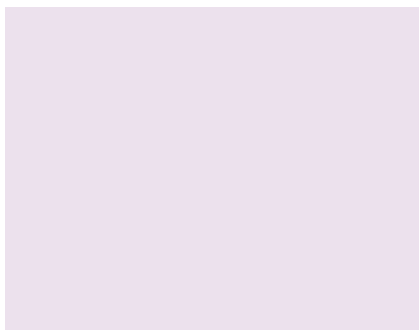
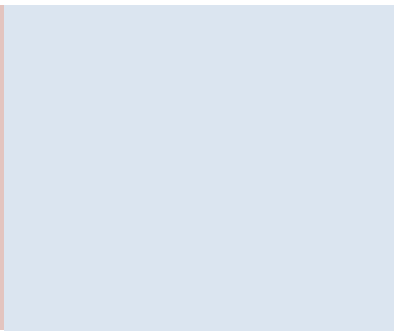
A few more years passed. I had moved to Alberta, a bit closer to home, but still quite far away from Christian. I travel home often and on one trip home I had news for everyone and especially for Christian. I had written him a short story. It was a story with pictures to tell him he was going to be an uncle. Over the next seven months, we talked about what an uncle does. I tried to draw upon characters in movies and books that were uncles. Christian loves to read, so it would be his job to read the bedtime story to the baby. My family joined us for our first Christmas at my house with our new baby. It was the first time in our lives that we weren’t in our family home for Christmas. Like always, it was wonderful and magical. Nothing was different except the location. We all were together and that is what matters - family.

When I first came home with the baby, my parents didn’t know if it would be a good idea for Christian to hold his little nephew. Christian can move quickly and in unpredictable ways, causing them to worry about everyone’s safety. But I thought Christian should get to hold him. So when I went home, Christian held his two-month old nephew. It may only have been brief while I was standing right there with him, but I got the pictures I wanted. More importantly, I got the MOMENT I wanted – my big brother holding my baby - and Christian got the moment where he became an uncle.

I can honestly say not a day goes by where I don’t wish I was living closer and could spend more time with Christian. And I can honestly say my life would not be what it is today without him. We continue to have more special moments that no one else will get to have because Christian chooses to share them with me.

I am the lucky one.





Celebrating the role of brothers and sisters! What a wonderful idea. This book brings to life the reality (the heartache and the joy) of being a sibling. The stories are mostly written or shared from the perspective of the sibling. As a reader, you will connect with the struggle, the tenacity, and the commitment they feel toward their sibling with a disability. More than any other emotion, you can feel the love and acceptance, which serves as a strong bond, that is obviously lasting a lifetime.

- John Lord



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