EMBRACING EMMA:
LESSONS IN DIVERSITY AND ACCEPTANCE

An Autoethnography on raising a child with Down syndrome

By

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A Thesis Submitted in Partial Fulfillment of the
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We accept this thesis as conforming to the required standard.

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ABSTRACT

This study used the research method of an autoethnography to reflect on the fears, acceptance and hope, and celebration of raising a child with Down syndrome. In this autoethnography I have shared several stories about my journey with a child with Down syndrome. The stories highlight my experiences and share my reflections about how I have come to appreciate and value those with exceptionalities. This research found that fear can be a paralyzing experience and negatively impact an event that should have been filled with joy. Acceptance and hope emerged once the fear was understood and new knowledge gained. Learning to appreciate everything about life and celebrating with those around you is the most rewarding experience possible. With this thesis I hope to encourage others to view people with exceptionalities in a new way: with acceptance, value and respect.
Dedication

This is dedicated to my greatest teachers: Emma, Samantha, Greg, Michael and Katie.
EMBRACING EMMA

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Table of Contents

Abstract..................................................................................................................................................i
Dedication..................................................................................................................................................ii
Acknowledgements.................................................................................................................................iii
Table of Contents....................................................................................................................................iv
Chapter 1: Introduction.............................................................................................................................1
  Purpose of the study...............................................................................................................................3
  Overview of study/Research question.....................................................................................................5
Chapter 2, Research Design...................................................................................................................8
  Autoethnography...................................................................................................................................8
  Data collection, Analysis and Interpretation.........................................................................................10
  My process...........................................................................................................................................12
Chapter 3, Fear .......................................................................................................................................14
  Heart defect & Down syndrome...........................................................................................................18
  Family reaction to diagnosis.............................................................................................................21
Chapter 4, Acceptance and Hope .........................................................................................................27
  Support...............................................................................................................................................27
  Open-heart surgery.............................................................................................................................31
  Giving back.........................................................................................................................................34
  Belonging.............................................................................................................................................35
Chapter 5, Celebration ............................................................................................................................38
  Seizing opportunities..........................................................................................................................38
  Milestones............................................................................................................................................39
Chapter 6, Discussion .....................................................................................................................42
References.......................................................................................................................................48
Chapter 1: Introduction

At a regular ultrasound at 28 weeks I remember the technician taking forever to get the pictures she wanted. She changed the probe on her machine to show me some 3D pictures of our beautiful baby girl and then tried again to get the view she needed. This was baby number 5 and I was followed closely for all my pregnancies - low amniotic fluid and small babies - but this ultrasound was different.

I remember the technician asking if I would be able to travel to Vancouver for a follow up appointment and I remember her trying to call our local pediatrician. I remember laying on the ultrasound table with tears rolling down my face. I remember calling my husband and asking him to come be with me.

Three days later we had several appointments at a large children’s hospital with four specialists and I was horrified to hear, “We can arrange for late term termination across the border within the next few days.” Those words will forever haunt me. I had a picture of her perfect little face from the ultrasound just days before and now they were recommending abortion. The maternal fetal medicine specialist continued, “your baby has a very high chance of having Down syndrome as well as an AVSD that will require open heart surgery within a few
months of birth.” The tears rolled down my face. How could this be happening? Why are they suggesting I terminate this pregnancy? What is so bad about having a heart condition and Down syndrome?

We met with several specialists from the cardiology department later that day and the news from them was much better. Our daughter would require open-heart surgery within a few months of birth but the surgical prognosis for her condition was considered excellent with a greater than 98% survival rate. The option to terminate was offered again but I think they were starting to realize that this was an option that I was not interested in considering.

One of the most difficult parts of this initial appointment was when we met with the geneticists. The prognosis for our baby was grim. She would struggle in school, with communication, would probably never be independent, could have on-going health issues and would be ‘mentally retarded’. It was immediately understood that I was not going to consider termination - I made that clear at the beginning of the appointment. We were offered a package filled with pamphlets about Down syndrome and what our challenges would entail. This material painted the darkest of pictures. Pamphlets explained all the medical complications she might experience, the appointments we would need to
make with physiotherapists, occupational therapists, speech therapists, and the difficulties she would face throughout her life. There was not one piece of literature that suggested there was any hope or anywhere to turn for support.

I suspect that my reaction to the material was similar to what others might experience when faced with these challenges in life. Looking back on this incident I wonder if I was not able to fully process her diagnosis when it was given. I think that some of the outdated materials left me feeling like there was no place for Emma and our family in society.

**Purpose of the study**

I have been forced to explore my true thoughts and feelings of this experience and I have been amazed at how powerful the invocation of autoethnography is as a research method. This thesis will document the sequence of events and my shifting thoughts and feelings on this journey with a special needs child. I will do this by sharing pivotal parts of my journey intertwined with literature that validates and supports this journey. This journey started with profound fear, gradually shifted to acceptance and ends with joyful celebration.

Having a child with special needs is a journey that most people are unfamiliar with. The initial reaction is usually one of denial, fear and uncertainty but in time most parents
describe the journey as a beautiful, enriching experience. Soper (2007) described her experience when learning about her son’s Down syndrome diagnosis shortly after his birth as feeling very alone and stuck in a reality that she wasn’t able to understand or appreciate. It was only when a friend who had a brother with Down syndrome wrote to her and told her that her son would indeed be a gift, that she felt some sense of hope. Soper (2007) describes the months after his birth as difficult. She explained that her son needed oxygen and a feeding tube and had other medical issues. Having a new baby is always a challenge and a baby with health issues complicates everything. Education, support and encouragement help process difficult diagnoses like Down syndrome. Soper (2007) states that she finds it amazing that a situation that seemed so undesirable could morph into such a beautiful rewarding experience, filled with peace and blessings. Parents of children with Down syndrome understand that life, all life, even those with an extra chromosome, is a gift (Soper, 2007).

Learning that your child may have Down syndrome is a difficult moment in life. Branam (2007) described it as wondering how her daughter would be different but imagining the worst. She said she imagined her daughter being overweight, placed with the retarded children in school and then becoming a dependent adult. Branam (2007) said she mourned for the baby girl she wanted and she prayed that the Lord would take away the burden of raising a child with special needs. Branam (2007) stated that she thought her daughter would be better off if she passed away because she didn't want her to spend her life suffering. Not wanting to see your child suffer is something all parents want and it is difficult when you have a special needs child that must endure struggles.
McTaggart (2009) describes being devastated when they found out their daughter had Down syndrome. She states that they were worried that their perfect family could become dysfunctional. Information that they had about families with disabled children was overly pessimistic. McTaggart (2009) states that the interactions and dynamics between her four children have caused her ‘typical’ children to show a deeper level of acceptance and understanding towards others. Having an ‘imperfect’ person in the family has changed the family dynamics for the better (McTaggart, 2009). This may not be the life that they had chosen but they clearly learned to embrace the challenge and make the best of it.

This journey and research has deepened my knowledge of a mother’s and a teacher’s understanding of the complexity of dealing with special needs children. My experiences as a mother, with children ranging in age from one to eighteen, and a teacher for five years led me to believe I had a good understanding of the joys, trials and enrichment that children could bring to my life. I realized the incredible, enriching gifts that children with special needs bring to our homes and classrooms.

**Overview of Study**

I have chosen autoethnography as the type of research to answer my thesis question. What have my experiences in having a child with exceptionalities taught me about embracing our differences and valuing all children? To answer this question, I intend to tell and interrogate some of the stories and experiences I have had, considering how they are important or relevant and what this means for the way in which we accept and value diversity as a society. I will share other research about children with exceptionalities, their families and friends in order to inform and interpret my perceptions of my experiences.
This story about embracing Emma is being told to bring awareness about the beautiful journey that can be experienced when you open your heart and mind to celebrating the differences among all of us.

This autoethnography will utilize several stories about Emma that highlight related themes including fear, acceptance, hope and celebration. Emma’s story is being shared to bring awareness to other families, educators, the medical profession and the general population about the reality of sharing the journey with children with exceptionalities. In doing so, the reader will be encouraged to embrace differences and value diversity within all members of society.

This autoethnography is not going to explore the debate on the right or wrong of terminating a pregnancy at any stage. It is instead going to explain and explore the challenges I faced when learning about my daughter’s congenital heart birth defect and Down syndrome. Many other families are faced with the pressures of society to only accept ‘normal’ typical children. Instead, they need to be taught to understand the value and dignity of every human being. Some of the world’s most celebrated people may not have been given a chance to share their gifts if society’s cookie cutter molds were followed. Can you imagine a world without the contributions made by such exceptional people such as Andrea Bocelli, Albert Einstein, Steven Hawking, Ludwig Van Beethoven, and Vincent Van Gogh?

My stories of having a child with special needs are just an example out of many of how other parents might be facing and dealing with similar experiences. All of our stories will be unique but the common themes of lack of acceptance of diversity, coming to terms
with the new faced reality, finding peer acceptance and learning how to celebrate on this
new journey may be the same.
Chapter 2: Research Design

Autoethnography

In this inquiry, I explore the research question: What have my experiences in having a child with exceptionalities taught me about embracing our differences and valuing all children? My personal journey of learning that my child had special needs and a congenital heart defect has been written using stories and personal narratives to help make meaning of the journey and uncover new knowledge about the feelings and beliefs that society holds towards those with special needs.

This journey and search for new knowledge leads itself toward using the methodology of autoethnography. Autoethnography is both a process and a product. It is an approach to writing and research that describes and systematically analyzes (graphy) the personal experience (auto) in order to understand the cultural experience (ethno) (Ellis, Adams, & Bochner 2011).

The purpose of using an autoethnography to share these personal stories in a meaningful and culturally engaging way, in an accessible text, is an attempt at making personal and social change possible for more people and perhaps collective societal/cultural ways of thinking (Quinn 2005). By writing these stories and analyzing the experiences by incorporating research literature, one hopes that others will understand some common struggles and fears of accepting those who are different. This self-reflection will explore my personal experiences and connect them to the wider cultural, political and social meaning of understanding. Wall (2008) explored and described the value of autoethnography - suggesting that it is by exposing raw emotions and the value of
experience, as well as reflection, that lead to an effective piece of research. Qualitative research, like autoethnography, is validated by readers comparing their lives to the text, by thinking about how their lives are similar and different: the reasons why, and by feeling that the stories have informed them about similar circumstances yet through the lens of unfamiliar people or lives (Ellis, 2004). Autoethnography is a form of research that will expand and open up a wider lens on the world. It is intended to produce a meaningful, accessible and evocative research grounded in personal experience.

Having a special needs child has changed the way I look at life. It has truly opened my eyes and helped me see how each one of us has something special to offer. My hope is that by sharing my journey others will understand that all of us have gifts to share and special needs children play a beautiful and significant role in this process.

I am the main participant in this research. I will share my stories and how I interpreted the reactions from others. I will do this by telling stories about the reaction of family, friends, and the local medical community when I shared the news about Emma, her heart defect and Down syndrome. I considered using a pseudonym for Emma but felt it was important to be true to her identity. I have always been a strong advocate for Emma and always will be so I don’t feel that I have exposed Emma to any risk by making her identifiable. In this age of globalization, social media, and interconnectedness we must always be careful about exposing others to potential risks. As Emma’s mother I feel that, even if I had used a pseudonym for Emma, she would be as easily identified as using her real name. My role as an advocate and my willingness to support other families facing similar situations has created a large digital footprint that would be easy to research and discover. I personally did an Internet search and within seconds, I was able to find digital
EMBRACING EMMA

evidence of my presence, including location. This supports my view that even if I used an alias, Emma would be easily identified if someone so chose. This story is not something that Emma needs to be protected from – it is a celebration of who she is and what she has taught me. The process of sharing stories about Emma also brings other ethical challenges with it. In sharing her story and exposing the reaction, support and involvement of others, I am exposing them to potential risk, damage or unethical conduct. These stories are from my life and they are mine to tell. I understand that those who share my stories might be identifiable to others so it is important that I have their on-going consent. I intend to mitigate these risks by ensuring that everyone mentioned in the stories I share about Emma are also actively involved in the retelling of the story and shaping of this autoethnography (REB Guidelines for autoethnography, 2017, para. 5). In order to do this, I have had numerous individuals that have walked with us through this journey including family members, our pediatrician and friends, read and approve the chapters.

**Data Collection, Analysis and Interpretation**

Data collection for use in an autoethnography looks different from that of data collection in traditional quantitative research. Data collection in ethnography traditionally arises from interviews, field notes, and research diaries (Mayan, 2001). In an autobiography writers rely on memory, photographs, diaries, and reflecting about the past in conversations with others (Adams & Manning, 2015). Autoethnography combines ethnography and autobiography and may include existing research and theories combined with personal experiences and storytelling techniques (Adams & Manning, 2015). In order to write this autoethnography, as recommended by Ryerson (2017), I intend to share
several stories about my journey with Emma that will have connections to society's lack of acceptance of diversity, family and peer acceptance, as well as challenges in the education system.

Important descriptions and critiques of culture can be created by the power of stories as they are turned into meaning and value. Acknowledging and critiquing our place and privilege in society through sharing the stories we tell can break long held silences on power, relationships, cultural taboos and forgotten or suppressed experiences (Ellis, 2004). It is in sharing these stories and then supporting my experiences with research that I hope to create an empathetic response in the reader so they examine their own beliefs about diversity and in turn, create dialogue to help change the way society views individuals living with special needs. Other studies will be embedded within the text and different themes will be developed both by my voice in the stories, and through the literature in the field.

Telling a story rarely makes sense unless we begin at the beginning. Retelling chronologically was the logical choice for the storytelling, as I was able to face and deal with the emotions and challenges with the benefits of hindsight. As I wrote and re-wrote the stories for this autoethnography I found that several themes emerged. I was forced to take many breaks to deal with emotions that were still very raw and painful. I worked through the emotions and tried to understand why they were so powerful so I could make sense of them and then share them in a meaningful way. I understand now, that these experiences will always resonate with me and they might be useful for others experiencing a similar journey or for the larger community trying to understand what it is like to have a child with exceptionalities
My Process

This method of research will not fill in all the gaps of knowledge about why there is so much pressure to fear the unknown when it comes to special needs children, nor will it resonate with everyone. This autoethnography is instead my way of trying to make sense of the journey that I am on with my own special needs child and share how truly beautiful the journey is. This adventure has not been one that I am on alone – learning to embrace Emma and her uniqueness has positively impacted all of the people in my life. I hope that this research will reinforce and remind us that all human beings have value and we should learn to celebrate our differences. Autoethnography is validated by readers comparing their lives to the text, by thinking about how their lives are similar and different and the reasons why, and by feeling that the stories have informed them about unfamiliar people or lives (Ellis, 2004).

The writing of this autoethnography was sparked by the thought that maybe by sharing our story I could change the understanding or perception about children living with special needs and the battle that they and their families go through. This powerful process involved sharing many personal and painful stories. I have exposed thoughts and feelings that have been buried beneath the business and busyness of my life. The emotions that have surfaced in the writing and reflecting of these stories have surprised me. As I try and make sense of these emotions, stories and reflections, I am re-living the long, difficult and emotional journey.

As I discussed these with family and friends I was surprised to see that not only did I shed tears during this process but so did they. Reliving these moments has evoked very powerful emotions and at times I needed to put things away and come back to it later.
Writing this thesis hasn’t just presented writing blocks at times but emotional blocks. Revisiting the fear of the unknown, the change of direction my life was taking, and the discrimination that Emma might face have been some of the powerful challenges that I have had to consider in the writing of this thesis. The process of writing this thesis has been extremely cathartic.

I hope that by sharing my journey in this autoethnography others will understand that it helped me create knowledge and a deeper understanding of my emotions. This self-interrogation has lead to a very personal understanding and is not necessarily universal or something that can be generalized, nor do I intend it to be. However, I do believe that parents facing similar experiences might be able to use this autoethnography as a framework to explore and understand the journey they are on and the emotions they are dealing with and will continue to deal with. I also believe that educators, those in the medical profession and the general public might have a better understanding of their reactions and impact to those with exceptionalities if they can relate, in any way to the themes that have emerged in this autoethnography.
Chapter 3: FEAR

I had never experienced the range of emotions that I felt when I found out that there were serious medical issues discovered during a routine ultrasound. The fear that overwhelmed me when I heard the words “heart defect” and “Down syndrome” was a type of fear I had never known before. It was like a chasm had opened up underneath me, I was falling and had no way to stop. I felt a profound fear for this unborn baby, my husband, my other children, and my extended family.

The story I shared when I first discovered I was carrying a child with special needs highlights the discrimination and lack of acceptance of diversity that is present even before birth. Dixon (2008) found that there is a negative view of people with disabilities and societal pressure to have normal or what is perceived as a typically developing child. There is an incredible amount of pressure placed on having only ‘typical’ or ‘normal’ children by physicians strongly suggesting prenatal testing that screens for certain birth defects (namely chromosomal abnormalities). These are offered to help mitigate the chance of having a child with special needs. This indicates that society doesn’t place as much value on those with disabilities and indicates the struggle will continue. Inglis, Hippman, and Austin (2012) found that the policies and guidelines around prenatal testing need to be revisited – based on opinions of parents of individuals with Down syndrome. Perhaps as we share, celebrate and embrace our differences, our belief systems will change.

Dixon (2008), also found that,

Our society still does not tolerate the elimination of diseased/disabled people, but it does urge the termination of diseased/disabled fetuses.
The urging is not explicit, but implicit. The dominant culture appears to be moving in two contradictory directions: more accommodating of disabilities in adults, but less tolerant of imperfections in children.

(p. 17).

Certainly my experience suggested that when abortion was recommended or even encouraged indicating that my daughter was both less valued or valuable than other children were. This thesis will not focus on abortion as an issue but instead focus on my journey of acceptance, hope and celebration. The contrast between my own feelings about my daughter and the initial reaction of others created an immediate fear response. When the specialists at the children’s hospital told me that they could arrange for termination of my pregnancy, they did so in a way I am sure they do countless times to countless women. I was not offered any support or counseling. Instead, I was given outdated materials and the worst possible outcomes for Emma in light of her disabilities were discussed.

Parents may be influenced by the initial interactions with physicians and nurses when it comes to the way they respond to their children’s diagnosis (Skotko & Bedia, 2005). I know that if the specialists I saw would have congratulated me on my pregnancy and offered me hope I would have felt much more at ease with Emma’s diagnoses. Research findings indicate that it is essential for parents to have some hope, a positive vision for the future and some optimism when they are faced with becoming parents of a child with a disability (Larson, 1998). I experienced a wide range of emotions when I thought about how this pregnancy would change things. I had moments of deep depression, emotional distress, fear, and sadness unlike any I had experienced before but these moments were also filled with a deep, growing, protective love for this child that I was carrying. I felt
intense anger towards the specialists that suggested termination and I was determined to celebrate and enjoy this gift that was ours.

King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates (2005) found that positive outcomes such as personal growth, changes in philosophical or spiritual values, improved relations with others, and satisfaction with parenting often follow the negative experiences parents work through when facing a child’s disability. Lee, Park and Recchia (2015) found that the “process of embracing the child’s disability is gradual, reflecting growth and transformation over time” (p. 3666). I feel very fortunate that I was able to embrace Emma and her heart defect rather quickly after diagnosis.

Looking back at the early days when we found out Emma’s diagnoses, I now realize that I was unable to process the complete diagnoses. I was able to understand or process the heart condition, which was fixable. I couldn’t process the unfixable, Down syndrome.

Emma appeared to be a typically developing baby. She was as helpless as any other baby. She didn’t appear to have any visible signs of Down syndrome, at least not any that I could see. Five years later I can see that I was only able to process these challenges a little at a time. This must be a method of coping that I instinctively used. I know that my heart was also broken, worrying about her upcoming surgery and the challenges that she would face in life. All of this takes time to understand and it is only by peeling the layers off one at a time that they can be understood. In these early days, the heart surgery was the big hurdle to overcome – Down syndrome would come later.

I was able to grieve what I had thought she would be before she was born. All of this was not an easy process and could have been so much easier if the health care providers at
the children’s hospital would have delivered the possibility of her diagnoses with a sense of hope.

In a study by Lee, et al (2015) all of the mothers could describe their early experiences with how professionals interacted with them about their children from a deficit-oriented perspective. They found that the views of the mothers were often connected to views of the professionals regarding disabilities. I am grateful that I didn’t retain the negative and stereotypical view that was painted by the specialists we first met. Gath (1985) found that when parents are first told of their child’s diagnosis of Down syndrome, they all experienced deep emotional distress. She also reports that the traumatic memories of first learning about their child’s handicap can be relived many years later. A few families have found their lives to be enhanced by what they thought would be an intolerable burden (Gath, 1985). In the early days I was holding on to the hope, belief and dream that our lives would be enhanced, although there is no denying that there were significant moments of grief, disappointment and despair.

Dixon (2008) found that there are typically several options that health professionals provide to parents. They are offered an initial genetic screening (to all women in early pregnancy), additional diagnostic testing and then support if they chose to abort or continue the pregnancy. He suggests that professionals should highlight support services available in the community, the range of possible functioning the individual might have and deliver comprehensive information about the genetic anomalies. Dixon (2008) suggests that this could change the decisions that many women are faced to make.

At this stage of Emma’s story I was desperately seeking hope. Termination was not an option for me. What I needed was some hope for her future, some success stories to
hang on to. I started my own research and found many support groups. Facebook had many groups that offered hope, support and encouragement. I found several blogs that seemed to have taken their stories from my experiences and they also offered tremendous encouragement. I also found incredible support in my own community. Several others who had walked this path before me reached out and offered suggestions of books to read and they openly shared their beautiful stories about raising a child with Down syndrome.

My desire to search for some sort of hope to hang on to was a result of the life-changing experience we had just been dealt. I had lost dreams for Emma that I was grieving. I had to give up my vision of what life was going to be like and in doing so allow for the possibilities of a new vision. When a child with a disability is born, parents are sometimes required to give up expectations and hope for their child’s future, as well as how they think they will be as parents (King, et al, 2005). Hope provides a vision for the future and helps to create new dreams to replace the ones that have been lost (King et al, 2005). I quickly came to realize that while I was grieving over the loss of the typical expectations for this baby I had two options; remain in the dark depressing state I was in or change the view I had. King et al (2005) found that parents gained a sense of control and empowerment when they realized that they had choices about how they were reacting to their situation.

The doom and gloom outlook that was provided by the specialist wasn’t going to be the way Emma’s story played out. Not if I could help it.

**Heart defect & Down syndrome**

*Within days of learning about Emma's heart condition, my husband and I were on our way to the city to see the specialists at the*
children’s hospital. My parents graciously stepped up to the plate and agreed to look after our other children. I am pretty certain that my mom could only handle watching me go through this stress by being super busy. Many meals were prepared and put in the freezer while we were away. When my husband and I arrived in the city we went right to my aunt’s place. She welcomed us with open arms and I remember her wrapping her arms around me and telling me that God doesn’t make mistakes. I remember shedding many tears and spending that night without getting much sleep.

After learning more about Emma’s heart condition, and the success rate of the surgery we both felt somewhat more relieved.

An atrioventricular septal defect (AVSD) is a heart defect in which there are holes between the chambers of the right and left sides of the heart, and the valves that control the flow of blood between these chambers may not be formed correctly. (“Centers for Disease Control and Prevention,” 2016., para. 2)

During surgery, any holes in the chambers are closed using patches. For a complete AVSD, the common valve is separated into two distinct valves – one on the right side and one on the left side (“Centers for Disease Control and Prevention,” 2016., para. 12).

I am not completely sure why it was easy to accept the idea that my child would need open-heart surgery - maybe because science and
medicine have come such a long way. Maybe it was because the success rate of the surgery was so good. Maybe it was because I ‘knew’ in my heart that she would face bigger obstacles in her life.

The next hurdle would be receiving the results from the amniocentesis. When the phone call came with these results, I remember hearing “I am sorry to tell you that the results confirm Trisomy 21.” I was at home and alone. I sat in complete disbelief with tears rolling down my cheeks. I knew that as a mother I could ensure that her heart was fixed but this was something I couldn’t fix and I was devastated. My daughter would be different and I knew we would face discrimination, challenges, and hardships like we had never known. My husband appeared strong and supportive although I knew he was also completely devastated. He has sat beside me while we listened to the geneticist paint a picture of doom and gloom: a lifetime of struggles.

Looking back on this now, I realize that I never even gave my husband the opportunity to share his feelings about terminating this pregnancy.

I know that there must have been some sort of unspoken understanding between us on this issue. I have always felt incredibly supported and part of a team when it comes to the parenting issues that
we face together. I am grateful for his strong, silent, unwavering support and the love he shows towards his children.

Family Reaction to Diagnoses

The reaction from our other children to the news about Emma having Down syndrome was somewhat surprising. They did not show the fear, uncertainty, or concerns that I thought they would. My children ranged in age from one year to eighteen years of age. The three oldest children had attended school with students that had disabilities and they seemed to be comfortable and accepting of her exceptionalities. My youngest child was too young to understand what this meant and she remained super excited to be a big sister.

Skotko and Levine (2006) stated that siblings are more inclined to be positively impacted by a brother or sister with Down syndrome than to be adversely affected. Persons with Down syndrome add an appreciated dimension to their families and deepen their understanding of human phenomenon. Siblings often have a matured respect for diversity and tend to recognize, at a young age, that happiness is not defined by accolades or fame (p. 184). Skotko and Levine (2006) also found that a common theme of acceptance and positive experiences were the most common findings when they interviewed siblings, stating that brothers and sisters...
...believe that having a sibling with DS is a privileged experience. The individuals we have encountered experienced both positive and negative feelings in the sibling relationships, but the positive emotions most often outweighed the negative ones. When they are older, most brothers and sisters describe their life’s journey as one filled with rich meaning and pride (p. 185).

While I had no idea about these studies at the time we found out about Emma’s diagnoses, I can say that five years into this journey I am definitely seeing positive emotions and a sense of maturity in my older children that surprised me. My oldest child has completed nursing school and shows incredible compassion and a gentleness that will touch many lives. My two boys are very compassionate and have developed a respect and understanding of people with special needs.

Skotko, Levine, and Goldstein (2011) found that siblings believed they were better people because they had a sister or brother with Down syndrome. They found that they had a deeper appreciation for human variation and had developed an enhanced perspective on life. Family dynamics can change quickly when a child is diagnosed with Down syndrome but Skotko, et al (2011) hope the following evidence-based statements become part of the counseling that is offered,

"-the vast majority of brothers and sisters love their siblings with DS and are proud of them,

-the vast majority of brothers and sisters feel their relationship with their sibling with DS is a good one,

-the vast majority of brothers and sisters would not trade their sibling with
DS for another sibling who did not have DS,

- a minority of brothers and sisters feel sorry for their sibling with DS and are embarrassed when among friends or in the public,

- the majority of brothers and sisters are comfortable assuming increased responsibilities, and a vast majority plan to remain involved in their sibling's life as they both age,

- in general, the vast majority of brothers and sisters feel that they are better people because of their sibling with DS (p. 2358).

I did not want a sibling with Down syndrome to put any stress on the lives of my other children. I was worried that they would be burdened or resentful but it has been anything but that. Emma has enlightened and brought joy to all aspects of all of our lives. The current research supports the growth and development that my children have experienced as a result of having a sister with Down syndrome.

*My parents and I have always been close and sharing this news with them was difficult. I knew that my mom would struggle watching me grieve over the news. I knew that dad would have a hard time processing the news as well. My dad’s experience with children with special needs was based on his life as a police officer, a coroner and later an elected government official. Families that he came in contact with often had serious problems with financial, emotional and physical limitations. I knew that dad would feel this would be a burden and a life*
changer for me. Their reactions were as I expected them to be. There was shock and disappointment and grieving.

Lee and Gardner (2010) found that grandparents can experience a prolonged and/or inimitable degree of grief in the sense that they are not only dealing with issues related to their grandchild with disabilities but they experience the grief and adaptation of their adult children. Other studies also support the reactions and feelings my parents were experiencing. Scherman, Gardner, Brown & Schutter (1995) found that grandparents were concerned about how their adult children would cope with the support they would need due in raising a child with a disability and how the child would adapt in society. My parents live beside us and play a huge role in the day-to-day lives of our family. McCluskey and McCluskey (2000) indicate that grandparents influence their grandchildren in many ways; the most vital being providing security, love and safety. They also noted that grandparents support parents by providing opportunities for them to have private time and providing help and supportive guidance about childrearing. My parents certainly played a pivotal role in helping me digest, accept and love Emma for who she was and they continue to play a huge role in our lives.

My brother and I have always been close and for the last twenty years we have once again both resided in the same small town. We would often spend weekends together fishing or hiking or skiing. He is someone who has developed unbelievable wisdom and has a clearly defined sense of what is important and what isn’t. He has faced challenges and always turned them into learning experiences and grown
because of them. I am not sure why but his reaction to hearing about Emma and her diagnoses of Down syndrome surprised me. He was the first one to reach out and wrap his arms around me. He has such an easygoing nature and depth to him that was revealed when he said something like “you can’t change it so let’s just accept it”. I knew right then that Emma would have a family that would always stand up for her and that her life had more meaning and value than any of us realized.

I remember reaching out to many of my closest friends when I received the confirmation that Emma would have Down syndrome. One of my closest, longtime friends was very accepting of the diagnoses. She listened while I cried and tried to make sense of it all. Her strength, wisdom and strong faith were something I would turn to again and again. I remember her telling me that maybe one of the reasons that Emma was coming into my life was to help me learn some sort of lesson. I replied without even thinking about it - “I didn’t need any lessons about special needs children, I teach them in school every day.” She replied with such grace and wisdom, “Well then maybe you are not the one needing to learn the lesson but someone close to you does.” Little did I know it at the time but those words have lead to an understanding and
appreciation for all of our family and friends that we didn’t dream would be possible.

There are many documented research papers showing the positive benefits that family members experience when they welcome and embrace a family member with special needs. Skotko, et al (2011) found that siblings have a deeper appreciation for human diversity and feel they have become better people because of having a sibling with Down syndrome. This by no means suggests that the journey is easy but that there are positive benefits and implications for society by embracing our differences.

Learning to celebrate the ordinary moments in life because they are reasons life is extraordinary is how Karen Olsen Dorsey (2009) describes her journey with her son, who happens to have Down syndrome. Dorsey (2009) explains that celebrating the ordinary moments is important for those with Down syndrome. People with Down syndrome usually have to work harder to reach goals and praise seemed to encourage her son to try again and again. Dorsey (2009) credits the many special people in their lives for helping her son reach his greatest potential. She believes that a child with special needs really can benefit when a community comes together to help and support them. Dorsey (2009) claims that the greatest celebrations are her son’s appreciation for the small things that make life worthwhile. Without an appreciation for the small things in life we fail to notice so many of them. I am forever grateful for learning to embrace all the ordinary moments on this journey with Emma.
Chapter 4: ACCEPTANCE AND HOPE

Support

The following story about my first visit with our pediatrician illustrates how the fear of the unknown can play such a terrifying part of this journey. In meeting with a respected pediatrician and father of a disabled child, many of my fears were acknowledged and diminished. It is in sharing with those that have experienced similar journeys that we are able to validate and understand our fears and anxieties, and learn to turn them into acceptance and celebration of ours, and others uniqueness.

My initial visit with our pediatrician was to see if he was comfortable with me delivering Emma here in our local hospital. He is a community leader, a well-known and respected pediatrician, and a member of the same church that I attend. I arrived at his office in tears and afraid. Afraid of what he might say, afraid of the situation we were facing and afraid I might not be strong enough to deal with everything. When he found out what kind of heart defect she had he said he was more than comfortable taking over her care immediately after birth. He also told me that I had nothing to worry about and that Emma would be the best thing to ever happen to us. He went on to tell me about his own special needs child and how he was the best thing to ever happen to their family. I had known this doctor for over 15 years, but never knew how
caring and compassionate he really was, and I was so grateful for his support and encouragement.

I am not sure if our pediatrician knew how important that initial meeting would be or how I would cling to every word he said. Choi, Lee and Yoo (2011) suggest that parents can adjust and learn about their new roles as caregivers to children with special needs if they receive helpful information and their doctors deliver it with an optimistic attitude. In a world that did not seem to value Emma’s life because she was different, I had found great support and hope from someone I wasn’t really expecting to provide such profound encouragement.

Two weeks before the scheduled C-section to deliver Emma, I had a phone call from our family doctor. He told me that there might be a problem delivering her at our local hospital. Apparently the nurses on the maternity ward had learned about Emma’s heart condition and they didn’t feel comfortable taking over her care. I was completely devastated once again. I couldn’t face the thought of having to travel to the city to deliver her. How could I face this difficult time without my family? I needed them to be part of this journey, I needed them to support me, and I needed them by my side. I have never been afraid to stand up and fight for what I believe in, and now the fight was on. The pediatric cardiologist from the children’s hospital told me that Emma would be fine immediately after birth. She would go into congestive
heart failure but this is something that would happen slowly after birth. A quick visit to our pediatrician’s office helped to clear up the misunderstanding on the maternity ward and we got the go ahead to continue with the scheduled C-section. All of this added to our fear and worries. In being able to win this small battle and overcome the anger and frustration associated with it was a welcomed relief after feeling so overwhelmed with sadness and grief about her new diagnoses.

The scheduled C-section didn’t quite go as planned. I was hoping to have a spinal block and be awake during her delivery. My husband was in the OR with me and we were waiting for the spinal block to work. We wanted to be together and welcome her into the world. The spinal block didn’t work and the decision was made to put me under general anesthetic to deliver her. My husband was asked to leave the OR and I remember more tears on my cheeks as I fell asleep on the operating table. When I started to wake up in recovery, I remembered where I was and why. I felt fear, apprehension and incredible tiredness, but summoned all the strength I had to wake up enough to ask the nurse through my tears if Emma was ok. When I learned that things had gone well and she was upstairs being monitored by our pediatrician and snuggled by her family, I gave in to the anesthetic and slept more. Not long after, I was
wheeled up to the maternity ward and she was placed in my arms. More tears and the most amazing feeling of love, protection and gratitude overwhelmed me. She was beautiful. Perfect. Loved.

Our pediatrician came to my bedside a short time later while doing his rounds. I was holding Emma and studying her perfect little face. He asked me how she was doing and then told me I had restored his faith in mankind. I felt a huge weight being lifted and once again I knew that I had made the right decision.

The helplessness of the unknown was gradually being replaced by the joy of new life. As many of the extended family gathered in the hospital to celebrate Emma’s birth, my fears and apprehensions about having a special needs child began to vanish. Our one and a half year old reacted the way any young girl would. She immediately took a protective older sibling role and showered Emma with kisses and hugs. I was very proud of the reactions of our older children to Emma’s birth. They quickly accepted Emma and expressed how they had an enlightened appreciation of life. Coming to this realization at such young ages is a beautiful example of the growth that takes place in individuals when they are exposed to life’s challenges.
Skotko et al (2011) found that as siblings matured they felt they had become better people because they had a brother or sister with Down syndrome. It is easy to see how my older children have come to feel this way. Having Emma come into their lives required them to do some soul searching and understand what really is important in life. Skotko et al (2011) state that the one thing siblings want expectant parents to know is that the addition of a family member with Down syndrome will add joy and become a rewarding experience for them. I believe that I have become a better person thanks to the arrival of Emma. I also believe that my other children have as well.

The first five months of Emma’s life was relatively uneventful. She was not unlike my other children were at the same age. She loved bathing, being the center of attention and being held. The only difference was I was always looking for signs that Emma was going into heart failure. We were told that she would have more and more trouble feeding, she would stop gaining weight, she would sleep more, and she would tire quickly when she started to go into heart failure. This would be a sign that we needed to proceed with the heart repair sooner than it was scheduled. We had several appointments during those first few months with the cardiologists at BC Children’s Hospital to monitor her heart and growth rate. Emma never did go into heart failure and I often wonder if seeing her struggle would have made accepting the impending surgery easier.

**Open-heart surgery**

*I don’t think I realized the depth of my love and appreciation for Emma until the possibility of losing her during her open-heart surgery was imminent. The week before her surgery was filled with pre-op*
appointments and a tour of the ICU. It was stressful to watch her being poked and prodded at by the various departments in the hospital. We spent time with cardiology, x-ray, the lab, anesthesiology, and the surgeons. We were told that she would probably come out of the OR on a ventilator and would spend several days in the ICU before being transferred to the cardiac ward for recovery.

Near the end of a long day of testing, we were given a tour of the ICU where Emma would be recovering. As we slowly walked through the ICU, I listened to alarms ring, saw parents comforting their children, watched as some parents sat near their children and watched monitors and saw the ICU staff working purposefully and compassionately, I began to cry. I was holding Emma and I felt my grip on her tighten. I was overcome with emotion and the very possibility of not having Emma in my life was now right in front of me. The fear of something going wrong during her surgery was overwhelming. The night before her operation was sleepless.

Early on the morning of her surgery, I handed her over to the OR nurse and felt myself once again become overwhelmed with emotions and tears. The next five hours were the longest, most stressful hours of my life. We waited in the ICU waiting room and visited with other families
who were also waiting for news from the OR about their children. There was an immediate connection and understanding between all of us. There was so much at stake - we were all so fragile and understood now how precious our children were. Culture, faith, and differences aside, we were all experiencing the same emotions. We collectively held our breath whenever a nurse would walk in to retrieve a family. When a nurse finally came in to get us I couldn't believe the news she shared - Emma was off the ventilator and doing remarkably well.

Once we were in the ICU with Emma, I only focused on her and the monitors and staff around her. The surgery had gone well and the surgeon was happy with the repair. It was during the hours that I sat with Emma in the ICU that I really began to understand how lucky we were. Emma was recovering well and didn’t seem to be in much discomfort. When I looked around the ICU I realized that other parents were not feeling so blessed. Across from us was a young boy with a brain tumor - his parents were taking turns spending time with him. He was on a ventilator and not expected to recover. A few beds away, a young girl was recovering from a car accident that left her with multiple broken bones - she had a long road of physical therapy ahead of her.

There is nothing more painful than watching your child suffer and I sure
felt blessed knowing within a few days Emma and I would be on our way home and be able to put this part of the journey behind us. Her follow up cardiac care would be scheduled every six months.

**Giving Back**

On one of our follow-up appointments, we were approached to see if we would be interested in helping raise awareness about special needs children. We often stay at Easter Seal House and they provide accommodation for families attending appointments at BC Children’s Hospital.

It is the mandate of Easter Seals across Canada to help with the programs, services, support and assistance that Canadians living with disabilities need to truly access their world and live life to the fullest. With the support of donors, sponsors and partners, Easter Seals helps change the lives of children, youth and adults living with disabilities from coast to coast. (“Easter Seals”, n.d.).

We were asked if we would like to share Emma’s story and some pictures in a fundraising campaign mail-out that they were working on. They also wanted to feature our story on the fundraising event, Timmy’s Telethon. We hoped that by sharing our story about the challenges our family faced, society would see there really is nothing to fear. These
opportunities helped us realize we weren’t alone. We were beginning to understand the importance of a supportive community and how imperative it is to have an inclusive society.

**Belonging**

_A recurring question that I faced was if Emma would fit in with other children despite her disability. I wanted her to be accepted like her peers. I was worried that she would face some sort of discrimination or be excluded. These fears were alleviated when I decided to return to work part time and the search for childcare began. Daycare spaces in our small town are very difficult to come by. I had many concerns and mixed feelings about leaving Emma with anyone. Word got around that I was looking for someone to come into our home to look after our little ones and before long we found a perfect match. The young lady that we hired had just graduated high school and was thinking about a career in early childhood education. She knew some of the girls with Down syndrome that attended high school with her and she embraced both our girls with love and acceptance. She came into our home several days a week and my girls fell in love with her. About a year later she decided_
to open up her own daycare and my girls enjoyed another few months at her place.

Even before Emma started school she was known on the playground as Sam’s little sister. The reaction of students towards Emma illustrates that they didn’t see her disability; they saw her as a typical child. Emma started kindergarten last fall and has been a welcomed and integral part of her class. Her peers have accepted her and show no signs of discrimination. Emma has made many good friends in kindergarten. Some of them have come over to our house to play and some of them have invited Emma over to play at their house. Emma has been invited to birthday parties and is seen by her peers as one of them. The other students in the school all know Emma and show nothing but love, kindness and respect for her. A few weeks after she started kindergarten I went to pick her up after school. All of the students were outside playing and she was so busy playing and interacting with her friends that she didn’t notice I was there. It was beautiful to watch her play and be included and treated like an equal.

Dolva, Gustavsson, Borell and Hemmingsson (2010) found that by creating opportunities for participation from all students in the classroom the acceptance of peers with disabilities was reduced. Being exposed to children with special needs is a relatively
new aspect of education. In the past people with special needs were placed in special
schools or institutionalized. Georgiadi, Kalyva, Kourkoutas and Tsakiris (2012) highlight
the importance of effective inclusive practices and indicate that this will lead to more social
acceptance. This is a promising step towards celebrating differences and widespread
acceptance in society.

Children with special needs are now attending schools alongside their peers. The
evolving field of special education is trying to support these students and help them reach
their full potential. The research done by Ross-Hill (2009) indicates that the more
specialized training a teacher receives, the better able they are to teach special needs
students. Society will always have children with different learning styles and by working to
help all of them succeed, we are embracing our differences and helping to eliminate the
problem of discrimination and lack of acceptance of diversity.

There is an unquestionable amount of pressure for people to have children who are
typical in appearance and intelligence. This pressure is first applied by the medical
profession and is probably driven by fear and a lack of knowledge about the reality of
sharing the journey with a special needs child. Being accepted by peers and fitting into the
mainstream school system are also hurdles that need to be overcome. When peers develop
knowledge about special needs, are exposed to an inclusive environment and given
opportunities to interact and understand their classmates, they are more willing to accept
them. It is challenging for teachers and support staff to meet the needs of all students but
there is clearly a benefit for all of society if we learn to accept and appreciate all of our
differences and abilities. The way to overcome the fear of those who are different is
through education and having inclusive environments.
Chapter 5: CELEBRATION

Seizing opportunities

This journey with Emma has taught all of us how important it is to celebrate and appreciate everything around us. After Emma’s heart surgery, I learned about a non-profit organization that raises money for the hospital. I felt a deep gratitude for the world-class medical treatment that Emma had received and wanted to give back. Summits of Hope is an organization that raises funds for the hospital by having individuals raise a minimum of five thousand dollars and then celebrate that accomplishment by bringing the individuals together to climb a mountain. The person doing the fundraising assumes all travel costs and expenses and the 5 thousand dollars goes directly to the fundraising goals. Some of my family decided to join me in this effort. My oldest daughter and my parents helped me to organize several events. A well-known musician in our community offered to play for a benefit concert. A grocery store offered to cover the costs of a fundraising BBQ. Local schools did coin drives and we sold prayer flags to carry to the summit.

Our fundraising effort for BC Children’s Hospital exposed how supportive our northern community is towards children facing struggles. We were asked to raise $20,000 but instead raised $35,000. Because of Emma,
three generations of our family came together and reached the summit of Kilimanjaro. This trip would not have happened without the life altering arrival of Emma.

Milestones

When reminiscing about the milestones that Emma has achieved, I struggle to select just one or two to write about. Though she was delayed in reaching some physical milestones like sitting on her own and crawling, she did eventually accomplish these and other typical milestones. She was slower in reaching these milestones in part due to her open-heart surgery and recovery, but also because children with Down syndrome have lower muscle tone and need to work harder to learn new skills (Windres, 1997). Emma has developed remarkable strength and coordination and she has learned to ski and swim. She works hard and enjoys keeping up with her peers. Emma always shows great satisfaction when she has accomplished a new skill, and it is hard not to feel the same amount of joy when watching her.

It has been such a joy to watch her social and academic skills develop during these last few months that she has been in kindergarten. Emma has enjoyed celebrating a huge learning curve and has mastered printing her name and counting to ten. She has been accepted socially and as a result her vocabulary and language skills have increased dramatically. Emma just wants the same things that other children want – she wants to be included in a meaningful way.
Perhaps the greatest celebration that we have learned to embrace is how to find joy and a deeper meaning to life during everything that we do. I am convinced that Emma will celebrate many great milestones during her life. Maybe she will graduate from school, find meaningful employment, get her driver’s license, live independently, get married and fulfill her dreams and ambitions. Whatever it is that Emma desires to achieve in her life, she will have my support and guidance. My wish for her is no different than it is for my other children – that they are able to follow their dreams and find their place in the world, while being happy and kind along the way.

I am extremely happy to revisit the Canadian Down syndrome Society website today and see an updated and revamped package for new parents. This new package is full of links to support groups, has stories about families that have embraced their new life thanks to a child with Down syndrome and is full of encouragement. Choi, et al (2011) found that when up-to-date information about Down syndrome and support groups is given to new parents, they showed an increase in positive emotional responses. They suggest this is because new material shows a much better prognosis for people living with Down syndrome.

Tara McCallan, founder of Happy Soul Project and a mother of a child with Down syndrome wrote a letter to share with parents when they first receive the diagnosis that their child has Down syndrome. Her letter provides hope to parents and frames the diagnosis in a new and positive way. Part of the letter she wrote resonated with me – my thoughts seemed to be appearing on the page written by someone else.

Because you see, that genetics specialist doesn’t know what I now know.

A diagnosis can’t predict the extraordinary love you will have for your child.
A genetic counselor can’t understand the fierce value you place on your baby’s life. A friend might not realize that your baby is an individual made up of so much more than a diagnosis. A stranger can’t possibly know the outrageously, beautiful insight you get to experience by seeing life through the eyes of someone with Down syndrome. An extra chromosome doesn’t mean the end of what you imagined. It almost means a life more beautiful than what you ever could envision.

But it takes time to get there, this path of ours is meant to be different. It is okay to take time to grieve what you envisioned in a child, from that you will grow. And my hope for you, friend, is that from this grief you will then blossom. You will find your own way, glimpses of hope, moments to celebrate, tears to shed, anger to let go of on this journey.

Chapter 6: DISCUSSION

This story began with overwhelming fear and helplessness. The initial consultations, periods of waiting and inactivity, and inability to fix what was wrong were tremendous barriers to be overcome. To hear the words from the doctors that this precious life was abnormal or defective and not worth protecting was gut wrenching; it shattered our confidence in the medical community. This shattering would take time to rebuild and continues to be an ongoing process. However, it gave us purpose and drive: we WOULD protect, learn and love this child, in whatever manner was needed. We WOULD be this child’s, and others like her, voice when she couldn’t speak. We had been given this gift for a purpose and that purpose involves us growing in the depth and expression of our humanity.

My initial research was to answer my research question. What have my experiences in having a child with exceptionalities taught me about embracing our differences and valuing all children? I have learned that all life is precious and it is our differences that need to be celebrated. All children are unique and special and it is in celebrating their differences that we truly learn to appreciate the different gifts each person has. The themes that emerged in this autoethnography helped me to understand the journey from the beginning – one that was so paralyzed by fear, through to acceptance and hope and then to full and meaningful celebration. Learning about Down syndrome was not a path I expected to take and I was terrified when I first heard those words. Fear robbed me of many months during my pregnancy. It destroyed the excitement and initial curiosity I felt about my unborn baby. It impacted my relationships with all my family members – I was terrified and unable to parent or interact with family in a way that was familiar and comfortable. Fear has a way of clouding reality and we are unable to experience it until we understand it.
Fear of those that appear to be different clouded my understanding. After beginning this journey, instead I have learned to face the fear, ask questions and seek new knowledge. Acceptance and hope eventually replaced the fear and once these feelings began to emerge a whole new world of possibilities opened up. Accepting children for who they are and having hope for their future has allowed me to appreciate and celebrate all of their accomplishments. Life can be difficult, but by working together we can make the journey more rewarding and meaningful. I hope that this autoethnography and the knowledge that I have gained and shared will be useful for other parents, educators, those in the medical profession and the community in general. It is in understanding the themes of fear, acceptance and hope and finally celebration that we can learn to embrace our differences and value all children.

In reflecting on Emma’s life to this point, there are points at which I felt alone, isolated and beyond hope. It is in the reflection process, that I realize that I am engaging in telling and retelling our story with an end goal in mind. That end goal is to ensure that other parents facing this situation never have to be without hope. Yes, different challenges and hurdles exist. Each child has these. But just as the challenges and hurdles exist in uniqueness, so does the beauty and joy that each new life brings. It is this understanding that lends strength, vision and joy to the journey facing the child, their family and their friends.

An understanding that has grown in watching Emma and other children with exceptionalities is that oftentimes our society differentiates between the type and the “when” of disabilities. Our society will, for a time, wrap their collective arms around individuals and families that have gone through a traumatic change in circumstance, such as
a severe brain injury sustained in a car accident. Parents and loved ones are heralded as heroes for standing alongside in supportive roles of these individuals. But when the diagnosis is pre-birth, judgments are much more rapid and harsh. “Quality of life” is a phrase that denotes this judgment. In writing my autoethnography, this phrase applies but in a manner contrary to its established use. Our family is in unanimous agreement that OUR lives would be of a lesser quality without the special presence of Emma. The when and the type of diagnosis do not determine the intrinsic value or need for acceptance of the individual.

One of the largest sources of despair, and a focus on the negative impacts of the challenges facing Emma and our family, was the presence of outdated literature. While being able to understand the necessity of facing the realities that will face a family with any diagnosis, the most important ingredient at the time of receiving the diagnosis is hope. When a family has hope in the future, despite challenges, it is possible to be proactive and to face whatever is to come. The initial stages of our journey seemed filled with negativity and difficulties. This was compounded by the style of presentation of the information. It made learning about Trisomy 21 a dreaded task. In our visits to the doctors and hospitals since, we have noted that this atmosphere is changing. Changing our information gathering to include books such as Gifts and Gifts 2 (a collection of stories about celebrating Down syndrome), and Expecting Adam (a beautiful story about accepting a child with exceptionalities), can allow us to celebrate what will be, what is and what is to come while preparing for the necessary battles.

As Emma has entered and thrived in school, this has helped to alleviate some fears, encouraged acceptance and promotes celebration. I have recognized that we cannot
predetermine a child’s achievement. A child with exceptionalities may face many challenges, but when they are supported and encouraged, they will largely surpass many of our preconceived restrictions and excel in ways that we didn’t expect. But perhaps the most important lesson that we have learned as a family and community so far is that our humanity is the only necessary component to overcoming and celebrating whatever life confronts us with.

In the same way that Emma is consistently surpassing and surprising us, as a teacher I need to approach each student within my practice with the same expectation of freedom from limits in what they can achieve. Emma is my touchstone, the one who reminds me that my limited understanding of each child’s potential can not determine how far I will let them dream and to work towards a goal that is, in my opinion, beyond expectations. In doing so, I also need to encourage my colleagues to view each student with the same expectation for excellence. Every year, teachers face a new class full of unknowns, fear and trepidation. As the year progresses, generally that fear transforms into hope, excitement and determination to succeed. Then, as June hits, recognizing how far the class has come accounts for much celebration within the teacher’s psyche. This same progression that we see within the classroom experience is reflected in the view of each student, maybe even especially with the exceptional student.

My hope is that the negative stereotypes about Down syndrome will change. I hope that those facing a prenatal diagnosis become better informed about the beautiful opportunities that a child with Down syndrome brings. The world perceives people with Down syndrome based on these two issues, which are both outdated and based on
ignorance. Assumptions based on this type of information perpetuate a society that will not accept differences or learn to embrace them.

Emma has taught me that the value of a life is not measured by how much a person can accomplish, but about how much they can teach others about what really matters. What I did not expect was the way my life has become so much richer. Another world has been shown to me and I am grateful for the opportunity to walk in it with her as my tour guide. Emma has grown, matured, learned, and flourished a tremendous amount in her short five years, but I am the one who has experienced the most growth. The gift of time has allowed me to see a little more clearly. I have the same dreams for Emma that I have for my other children. I want her to have a lifetime of happiness, friendship, satisfaction, love and joyfulness.

As I have reflected on this ongoing journey of curiosity, growth and passion, I realize how much I have grown. This is not a journey that was chosen by us, nor is it a journey that we undertake alone, although we do experience it individually. It is a journey that has changed our lives. Without Emma’s arrival, we would see and perhaps experience, diversity on a much more superficial level. We would likely give verbal assent to understanding but without the depth and complexity that Emma has taught us. When we look at the plethora of changes that have occurred in our lives over the last six years, we realize the astounding change in our very being: the ability to empathize, show compassion and be proactive in ensuring that around us, every life is valued and treasured.

Having a child with special needs is a journey that is full of fear, the unknown, obstacles and challenges but it is also the most rewarding journey I have ever been on. Emma has changed my life. It was not the life I expected or thought I wanted. I understand
now that I have been given a remarkable gift. I have decided to live with passion and
curiosity and compassion. I savor every moment. I am grateful for the opportunity to see
life as a miracle. Lee, et al (2015) found that some mothers, when raising a child with a
disability, have been involved in helping others through support systems and others have
chosen to provide more professional support by choosing to work in the field of special
education. This is where I am at on my journey now...completing my master’s degree and
working as a special education teacher.
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