A Mother's Spiritual Journey with Her Disabled Son: An Autoethnography

Margaret C. Higgins EDD

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A MOTHER’S SPIRITUAL JOURNEY WITH HER DISABLED SON:
AN AUTOETHNOGRAPHY

Margaret Cusack Higgins
Disability and Equity in Education

Submitted in partial fulfillment
of the requirements of
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A Mother's Spiritual Journey with Her Disabled Son: An Autoethnography

Submitted in partial fulfillment of the requirements of Doctor of Education in the National College of Education

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A MOTHER’S SPIRITUAL JOURNEY WITH DISABLED SON

Abstract

This autoethnographic research delves into a mother’s experiences with her disabled son over thirty-five years. Beginning with a thick description of the crib accident that resulted in physical and cognitive disabilities that profoundly change the course of both mother and son’s life, this research chronicles the search for meaning, community, and healing as they negotiate the realms of medicine, education, career, family, and spirituality. Models of disability that seek to explain various ways in which society often views disability are examined, but none resonate with the researcher’s intimate experiences nor satisfies her deepest needs for insight and healing. Making a distinction between religious models that often carry negative assumptions of guilt and shame related to disability, this research delves into what the author describes as spiritual insights drawn from various religions and teachers, including her son, who impart wisdom with compassion. This research explores the critical incidences and insights that teach her to listen, observe, and to be open to new ideas and ways of thinking and acting, and a new image of God. Through spiritual struggles she is able to find forgiveness, understand new perspectives and let go of resentment. Eventually, tragedy turns to gift and hopeful meaning is restored to living.
Acknowledgements

Interdependence is not a disability “thing.” It’s a human “thing” – a trait which has helped our species survive and flourish for millennia. …and I am learning it through this dissertation process. I am grateful to my dissertation committee, and my family, and friends.

Terry Jo Smith, Ph.D., my dissertation chair, has given me thoughtful, perceptive readings of my writing which have helped focus my thinking. She has gently prodded me when I went on tangents. Terry encouraged me along the way, and it’s been a several-year journey because of my helping my mother during her declining years, and I am thankful because every time we talked, I was re-energized. She corrected without sting but with firm guidance, and I treasure her mixture of head knowledge and heart knowledge which imparted wisdom to me on many occasions. Terry, from one mom to another, from one mom to another who also understands “extras” - Thank You.

Kate Zilla, Xiwen Wu, and Vito Di Pinto completed my dissertation team. They patiently waited for me to finish. Vito sent me a CD of chants based on writings of Hildegard of Bingen which I’ve played over and over - sometimes while writing - sometimes while sleeping. Kate’s smiles and words of encouragement on Sundays after Mass helped especially during those times when life interfered with writing. Xiwen offered to answer any questions I had, and just having Xiwen’s availability was comforting as I knew she would have thorough and clear answers. My dissertation committee’s thoughts, critiques, brainstorming, and suggestions have been a gift to me for making my dissertation more thoughtful, more readable, and more thorough as I try to add a tiny insight to the vast annals of human knowledge.

I’d especially like to thank Jennifer Hull for her generosity of spirit in supporting me and her fellow students with her attentive listening, perceptive questions, attendance, generosity of spirit and the refreshments she has uplifted and shared with her classmates and professors. Our lunches and conversations energized me to continue writing.

And for all those people who have wished me well and prayed for me, thank you. I needed it. Your support and hugs helped more than you know.

When I was particularly stressed about technology, my dentist, Dr. Alla Aver showed me how wirelessly to scan photos and material from my printer into my computer. What a relief that was. It calmed my fears.

I am thankful to you, Mom and Dad, for helping me find a place to live as well as helping Graham with his apartment and for supporting me in this endeavor. I know you’re here in spirit. Anne and Derk, thank you for your editing of one of my chapters which needed clarity. And, Anne, our phone calls always inspired me and kept me going. Thanks for your encouragement, Sis.

Patti, we laughed a lot together which not only gave me a break but always uplifted my spirit and gave me new perspective as I continued reflecting and writing. When you brought over soup to me and stayed to eat with me, I felt so supported. Thanks, Sis.

And, Ted, when you enthusiastically offered to proofread, it meant a lot. All is healed. I wish we could have worked together before death took you. See you later, Bro.

My nieces and nephews, and your spouses and partners, thank you for cheering me on.

Now, I come to my son. Graham, you have taught me how to live just by being you. I wouldn’t have missed this journey with you for anything. Hugs and love nods.
Dedication

For Graham –
Teacher of my Heart
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Chapter 1
Introduction – The Journey

Graham, my son, was born on January 2, 1980. When he was two weeks old, he survived a crib accident which left him with multiple disabilities both physical and cognitive. His birth and the accident changed my life forever. This is one parent’s journey with her child and his disabilities. Some of the areas that I’ll explore in this research will include grieving, education, career, advocacy, and spirituality. One of my quests as a parent has been to regain the hope and joy I had on the day of my son’s arrival in this world, albeit a different hope and joy, a compassionate, inclusive, and enduring hope and joy filled with wisdom. To do this I’ve been reflecting, researching, asking and attempting to answer questions in relation to my son and his disabilities and my life with them.

I needed to know that my son’s life was not over after the crib accident when he was two weeks old. From that moment on I’ve pondered many questions. How was he going to participate in society? Or, was he going to be locked away in an institution and forgotten? What was going to happen to him when I die? Would he be rejected and abandoned and become a street person? Or, would he find his niche and belong – to family and friends and continue to give to others? How could I bolster him when the inevitable rejection and shame would be put upon him by those in society who fear difference and by those who would make him invisible? How was his life going to have meaning, and how was he going to know and feel his life has meaning and that he is important, not only to himself and his family but to the world?

How was I going to cope with the unexpected and unwanted changes to my life after Graham’s accident? I was angry, felt violated, and sad, scared, totally unprepared, incompetent,
and unaccepting of disability. What had happened to the gift of life? I needed a why to give me hope, to give me reasons to work with these new circumstances, this new way of life. I needed acceptance and help with processing my losses – dreams I had for my son and dreams I had for myself. What has supported me as a parent of a child with disabilities? What nurturing did I need for myself?

How have I changed during this journey? What is my relationship now to God, family, and society? For me, I need to know my journey with disability was worth it – that it made a difference in my son’s life so that I know I didn’t waste my life. I need to translate the parts of this journey for myself – the whys, whats, and hows. I need to find meaning in this journey for myself – only then can I be of some use to others who find themselves on this path.

All of these questions and many more will be addressed in this research. This is research into my lived experiences in which I will ask: What can I learn by re-searching and re-constructing in a thoughtful, intentional way the events, feelings, thoughts, actions of the history of my life as a parent of a child with multiple, acquired disabilities? How can my learning inform other parents’ and professionals’ understandings?

Researching the Journey: Using Story as Data

Norman Denzin and Yvonna Lincoln tell us that the stories, biographies, and journaling I’ve done since eighth grade are worthy data (Denzin & Lincoln, 2000, Introduction, 22). I am constructivist in my approach to research. I believe the reflection on actions, thoughts, conversations, and emotions can offer more than one interpretation. Understanding personal narrative from more than one perspective is central to autoethnography. Carolyn Ellis quotes Adrienne Rich, “The crucial issues are what narratives do, what consequences they have, to what uses they can be put.” (as cited in Ellis, 1973, p.34) Putting my journey into context and
reflecting on it from more than one perspective is important for my research. Additionally, my hope is that my background as an educator will not only help me in identifying and sharing personal stories which illustrate issues within the areas of disability, education, and spirituality as a support, but will open further discussion with ideas for praxis for parents, those living with disability, siblings, and professionals. Growing up as a baby boomer gave me optimism, perseverance, and an incredible inclination for pondering and reflection in order to change what needs to be changed and to continue thinking about the types of behavior which create encouragement and community.

When I entered the Disability and Equity in Education doctoral program at National Louis University, I decided that for every course I took I’d read at least one biography/autobiography by a parent, sibling, care giver, or disabled person. I learn from stories and I wanted to see if my experiences with disability matched any of their experiences. Could their experiences give me language for things I knew but had no words for? Could their lived experiences be healing for me? One thing I learned was that their wisdom came from their reflection on their challenges, struggles and triumphs with disability. I learned I was not alone in most of what I experienced. I understood Jenny McCarthy’s panic in *Louder Than Words* as she sought ways to overcome her son’s seizures and to understand his autism. I understood her refusal simply to accept a diagnosis and “write off” by those in the medical profession who gave her the medical model of disability attitude. I knew the energy it took as she searched for and followed through with alternative treatments. I also knew the toll this passion took out of a person having this single mindedness. Sometimes at the end of the day I’d just plop into bed and cry. I couldn’t even name what I was crying about…I was just so tired.
I felt I was next to Pearl Buck in *The Child Who Never Grew* as she pondered the dignity of all human beings, including her cognitively disabled daughter. She struggled later in life regarding what was going to happen to her daughter as Pearl could no longer take care of her. How does one find the best living situation for one’s child? I commiserated. A fear I’ve had since the beginning of this journey with Graham, is *What will happen to him when I die?* I don’t want him to become homeless. As Pearl Buck looked at institutions, I knew her anguish and her caution in finding the right institution. My Graham was born about sixty years after Pearl Buck’s daughter so thanks to Pearl Buck, many other parents, and medicine, laws, and social service agencies, there have been many advances which helped me choose a different path. I decided to invest in Graham in order to help him become as independent as possible. With the adult training he received in the PACE Program at National Louis University, he is living in an apartment almost independently. I understand that as he ages, the situation may/will change, and I must be vigilant in being aware of how he’s doing and keeping my eyes open for suitable alternative living situations. For now he’s doing better than anyone had hoped after the accident.

Martha Beck in her memoir *Expecting Adam* recounts her adjustment to the fact that she was going to have a son with Down Syndrome. She was teaching and working on her Ph.D. at Harvard at the time, and she and her husband, also a Ph.D. student at Harvard, were already raising a daughter. Martha Beck stood up to the institutional cultures of medicine and the professional Harvard culture both of which urged Martha to abort her child. When she refused, they tended to discount her.

This caused me to remember when my high school colleagues I was teaching with urged me to put Graham in an institution and their looks of judgment when I told them I wouldn’t do that. Afterwards I felt them discounting of me through their silence. It did not make my life
easier. I was proud of Martha for her refusal to cave in to the pressure of other people’s/group’s opinions. I understood the loneliness of such decisions, the inner questioning, and how important it is to choose a path that one can live with rather than the consequences of following what others think one should do. There are moments of high drama and moments of personal angst faced alone. Things even happened which she couldn’t explain or understand. Yet, she felt comforted and supported in a spiritual way which confirmed her decision to keep her baby.

Through these experiences Martha Beck developed a quiet confidence to stand up to those doctors, Harvard professors, and colleagues who urged her to terminate her pregnancy. I felt kinship with her as I read *Expecting Adam*. I knew the pressure to terminate pregnancy from my husband and the pressure from colleagues and my husband to put Graham in an institution, and the remoteness of family for support. …and I also experienced that still, quiet voice within which seemed to say “Keep going. This is the way.” This *way* was a spiritual path which started small and developed and continues today.

How does my story data match with autobiographies of other parents, siblings, and those living with disabilities? While each lived experience with disability is unique, I wondered what, if anything, was similar. I admit, there was a part of me which desperately needed to know I wasn’t alone. There was also another part of me which saw my reading these autobiographies as a fascinating intellectual exercise of research.

**My Research**

Today, having learned so much from the stories of other parents of children with disabilities, having learned so much from Graham, from my life, I have chosen to use story as data, specifically, my story with my son. Autoethnography is a method which is more than using story to retell history. It seeks to place the story in context (Ellis and Bochner, 1999, 738-740),
to identify issues illustrated by stories and to discuss, deconstruct, and provide insight, and compassion.

The first thing I learned in journalism class was that all research, all writing has perspective. These perspectives influence the outcome and interpretation of events and can be called a person’s bias. However, each perspective brings its own truth. So, this research will be about my truths as a parent who has raised a child with disabilities. This research will include a chapter in which my son will speak in his own terms about growing up. This will be his perspective, his truth. Sometimes our truths combine and support each other. Sometimes they collide and have injured each other. But, they stand together to create a larger picture. This is the essence of our participatory research.

As data my stories will illustrate issues which are to be deconstructed and discussed. They do this in a number of ways. First, they provide context to issues regarding disability. The stories I will be telling are from my journals and from memory. I plan to reflect on them as a parent. Some of these stories are over 30 years old. Time, maturity, and being with and pondering these events over a long period of time has provided hard won insight which needs to be shared.

**My Identity as a Researcher**

Autoethnographic research is particular to a life. In this case, the particular life is my life with my son. Therefore, it is important for the reader to understand formative experiences and aspects of my social identity in order to understand not only how I have lived my life, but also how I will construct the narratives of my experiences.

I have been on several sides of this journey of difference. First as an outsider, unaware and pitying those who had to live a slower-paced life and without whatever ability had been lost
or denied. When I became a parent of an infant who, through no fault of his own, acquired disabilities through a crib accident, I felt the judgment of others, rejection and isolation, discrimination, prejudice, and fear from others…the basic “No” and “Go away” and “You’re not good enough” from friends, colleagues, anonymous others, agencies, organizations…basically society. This was on top of the excitement, bonding, and general confusion that a first child brings and then all the worry and feelings and extras that overwhelmed me with the onset of my son’s disabilities.

**My Own Journey with Disability**

Just before I was accepted into the Disability and Equity in Education doctoral program, I learned my migraine headaches were triggered by fluorescent lights, and one of the best ways to avoid the headaches was to wear a wide brimmed hat made of natural fibers. For the first time I myself experienced a chronic condition which with a little accommodation from others, like turning off some of the fluorescent lights in the room, my quality of life was greatly increased, and I could participate in work, meetings, class, and society to my fullest. It was at this point I experienced the struggle of inclusion – the resistance, the reluctant compliance, and the refusal. I am well familiar when I ask for the accommodation of the initial blink, the stare with pursed lips, the insincere smile, the directive to turn off some lights, followed by the stare again. It tells me I don’t belong. I am trouble. I am not wanted. From others I received welcomed acceptance, who made me feel I am o.k. the way I am, and turning off the mercury-filled lights - toxic to my body - is o.k. too. I yearn for these moments because I know I belong at least for a little while. I am slowly developing an inner self belief that states *I belong no matter what.* I am learning that part of my journey with disability is to advocate by being seen and heard and to educate others about the disability.
The journeyer.

In addition to being the mother of an adult child with multiple disabilities, I am a sixty-eight-year-old white heterosexual female American of Irish-Scottish-French-German ancestry with a few aging pains, one of which is hearing aids. I grew up the oldest of four siblings in a middle class, post WW II family, in a suburb of Chicago during the 1950s. I’ve lived most of my life in the Midwest though I have traveled nationally and internationally. Spiritually, I am a Christian (particularly, a Catholic), though I draw from other spiritual traditions. I have studied with a rabbi, attended services, pray with a prayer shawl, learned to meditate with Buddhists, and have prayed with Muslims. With my head on the ground and my rump in the air, things really get put into perspective quickly even faster than in the Christian prone position. Regarding Christian spirituality, I have received much from many perspectives and participate in some interfaith services. Though there is the letter of the law, I seek to adhere to the spirit of the law. Spiritually speaking, I have come to believe there is more than one way. Spirituality will be a central theme in this research.

I am a doctoral student.

Currently, I am a doctoral candidate working to finish my dissertation in the Disability and Equity in Education doctoral program at National Louis University. During the program I was with professionals in education as well as other parents of children with disabilities, siblings of people with disabilities, and others with disabilities. It felt like coming home as I listened to their experiences – the ups and downs, the mistakes and triumphs, and the quandaries which sought resolution. We applied the theories, models, and perspectives to our individual situations and shared them in class presentations which opened me to a variety of ways of thinking and responding to real-life disability issues. A range of living issues arose (some physical, learning,
intellectual, emotional, psychological, social, financial, and even spiritual) which led to a continuum being developed on ways people are human beings – NOT a hierarchy – simply ways of being human. This identified ALL people as having the rights to dignity and respect, deserving of compassion, assistance, and opportunity. The models of disability which are also called perspectives pointed out various ways those living with disabilities are pushed aside and excluded from society. For instance, the Social Model/Perspective identifies that society consciously or unconsciously often builds barriers (physical, judgmental, economic) so those with disabilities are isolated and prevented from participating in society’s activities. An example of this is a building without entry ramps and wider doorways which prevent those in wheelchairs from entering to work, do business, vote, attend meetings or social events. Having read many Social Model perspectives, I find they often fail to admit there is any difference involved with having a disability which might create extra effort to make their participation possible. I disagree with this oversight by disability studies. It seems to me that only by identifying what is real, can others understand, accept difference, and embrace attitudes which foster accommodations and inclusion.

I am an educator.

I taught high school students for twelve years, have substituted pre-school through 12th grade, and wrote and taught a couple classes for the PACE Program at NLU during its first year of operation. In addition I received a grant from the National Endowment for the Humanities and was invited back to lecture, wrote and coordinated the first Adopt-a-School program with a publishing company, and have presented at conferences. Recently, I have taught a couple graduate courses in special education for National Louis University. With this background and my experience in raising a child with multiple disabilities I hope to illuminate issues so people
understand parental experiences, perspectives, struggles as they pertain to raising a child with disabilities as well as how spirituality has been a support for me as I raised my son and continue to have relationship with him and guardianship of him.

**I am a baby boomer.**

I grew up during the 1950s and 60s. As a post-World War II infant, I belonged to the Baby Boomers. As economic sociologist Vivian A. Zelizer characterized my generation, I belonged to a group of children which were “economically worthless but emotionally priceless (Zelizer, 1985, 14.; Senior, 2014, 10). Historians describe this transformation as “the child went from ‘useful’ to ‘protected.’” (Senior, 2014, 9). All I can say is I related to the black and white version of the Little Rascal movies in which Spanky and Our Gang seemed to have time on their hands, ingenuity, a sense of right-and-wrong, attitudes of anti-class and anti-hypocrisy, and a value of social justice.

What being a Baby Boomer meant for me as I was growing up was that rather than work on a family farm, in the home, or in a family business as millennia of children before my generation had done, I had leisure time (except for light chores tied to an allowance and homework). I was the oldest of four children. During my free time I took piano lessons, was a brownie and then a girl scout for ten years, read lots of books, taught myself from books about trees and birds, made up math problems and then did them, did chemistry experiments, embroidered, rode horses, sailed, and jogged, sang in the church choir, and participated in summer library programs. I had a lot of alone time which I filled with teaching myself things. I enjoyed learning about things I was interested in. It gave me confidence. I like to learn things and share them with others. I especially liked literature and what I could learn from it about
being human which is interesting and sometimes illuminates mysteries of life because there are so many variations.

**Standpoint as a researcher.**

As a result, these aspects of me have focused my perspective and research: journeyer, doctoral student, educator, baby boomer. Because I am a journeyer I seek that my life has meaning and I seek to be part of something greater than myself. I seek to think and act from a spiritually centered place of value. In high school I began to say I wanted a “religion” of the streets, meaning that I didn’t want to give lip service to my beliefs, but I wanted to give example of my beliefs through my actions. I admit, I’m not always successful and stumble a lot. There many times I’m more like Donald Duck and Goofy. I muddle along. But, I strive to be better and as I continue with my eclectic spirituality, I’m getting better.

My training and experience as an educator has provided a different and separate perspective which needs to be applied to data and shared. My work and research as a doctoral student in the Disability and Equity in Education program has been challenging and rewarding and has given me another layer of perspective with which to interpret my story data. Being a doctoral student has taught me to think more critically. Overarching my journey with disability is my spiritual journey. I would have taken neither without the other. So my weltanschauung is inextricably tied with both the lived experience with disability and spirituality and cannot be explained without either. This is the final layer of perspective and truth which influences my dissertation and speaks to knowledge, larger ideas, deconstruction, revelation, future praxis, future hopes, realities, and meaning.
The Guiding Question

A lifetime of lived experience, pondering, muddling through, questioning, study, and research have led up to this writing and link the topics together. The goal of this research is to combine many aspects of this journey in a search for knowledge and wisdom to further parenting, education, professional praxis and living as a human being in the world. This hope infuses of my research question:

What can I learn by re-searching and re-constructing in a thoughtful, intentional way the events, feelings, thoughts, actions of the history of my life as a parent of a child with multiple, acquired disabilities?

Perhaps this reflection, this autoethnographic study, will help others take the disability which was feared and hated, overwhelming and resented, and transform it into what is accepted, endeared and embraced and something that gives meaning and a reason for living.
Chapter 2  
Academic Background

As a student in disability and Equity in Education Doctoral Program (DEE), I have had an opportunity to explore the connection between theory, research, and scholarship and my lived experience with my disabled son. What follows in this chapter is a compilation of some of the most important theory and research that has impacted how I will conceptualize this research.

Disability Studies

The DEE doctoral program draws heavily on disability studies. I have spent the last several years reading, researching and discussing literature from a disability studies perspective, and it has influenced the ways I interpret and analyze disability.

History of disability studies

Colin Barnes (1997) reviewed several 19th and 20th century historians with the observation that disability arose as industrialization rose in western societies. Furthermore, after World War II service industries grew supporting care for those with disabilities rather than the rehabilitation promised which would return people to society.

The story of disability studies grew out of the social model and the work done by Paul Hunt, Vic Finkelstein, Mike Oliver and others involved with the Union of Physically Impaired Against Segregation (UPIAS) during the 1970s and 80s. Paul Hunt wrote a letter to the editor at the Guardian newspaper in 1972 explaining that he was physically handicapped. In this letter he listed questions regarding improving conditions for others who were physically handicapped, especially if they were or thought they would be living at some time in residential institutions. He asked those who would like to improve conditions in residential care institutions to contact him. Vic Finkelstein was one of the people who responded. In a 2007 article in the Autumn
Newsletter of Sweet Tree Home Care Services, Finkelstein says he met with Paul Hunt and his wife Judy and a “great friendship and working partnership developed” (Sweet Tree Home Services Newsletter, 2007, p. 4-5). The article also mentioned that Vic Finkelstein, also a paraplegic from a pole vaulting accident when he was 15, was a psychologist and had political knowledge from his work against apartheid in South Africa. This expertise of Vic Finkelstein’s along with Paul Hunt’s institutional knowledge formed the basis of the partnership which would eventually become UPIAS. The Union of Physically Impaired Against Segregation was important for several reasons: First, the founding members didn’t just react to current issues and advocate from there. The members took at least eighteen months to decide who they were as a group and what they stood for. Secondly, through this process of reflection the UPIAS defined the difference between impairment and disability. Basically, impairment is the condition a person has which makes him/her different. Disability is how society ignores and segregates the impaired person in order to exclude that person from society. These terms will be discussed in more detail in the section on the social model of disability. Thirdly, UPIAS defined its Fundamental Principles of disability (Priestley, Finkelstein, Davis, 1975/1997):

- disability is a situation caused by social conditions, which requires for its elimination,
- (a) that no one aspect such as incomes, mobility or institutions is treated in isolation,
- (b) that disabled people should, with the advice and help of others, assume control over their own lives, and
- (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people. [page 3, original document]

To these three principles (along with the definitions of impairment and disability) was the idea of action which was self-advocacy by those living with disabilities instead of asking politicians to
“plead their case.” For me, this tenet was particularly important because it meant that those with disabilities would become seen and heard. No longer invisible, the public would get to know their issues, understand how the issues of those living with disabilities would at some point affect them, and support the needed legislation in parliament. To me the ultimate goal of self-advocacy is full integration in society.

As I understand the concept of full integration, it is not only accessibility in society, control over one’s life, and jobs, but I also ask the question how often is the disabled person invited to the informal parties after work and integrated into a mixed social scene of disabled and not-disabled? How often can disabled and not-disabled call each other “friend”? … rather than “acquaintance” or “work associate”? When this happens, I’ll know there is space in this world for my son and others with disabilities. Until then, there is work to be done. Fears to be eliminated. Barriers to be dissolved. Being seen and heard is the first part of this process. Paul Hunt, Vic Finkelstein understood this and required advocacy from members of the UPIAS (Priestly, 1975/1997).

Going on with the history of disability studies, UPIAS and various organizations for those with disabilities tried to form alliances. UPIAS held to its principles, including the tenet about those with disabilities being the ones to advocate issues. Alliances did not form easily so more organizations for people with disability were formed. 1981 became a pivotal year for people with disabilities according to the website for the Greater Manchester Coalition for Disabled People, and Judy Hunt (UPIAS), and Jane Campbell (House of Lords, Parliament). First, 1981 was declared to be the International Year of Disabled People. Second, the British Council of Organisations (sic) of Disabled People (BCODP) was organized and named Vic Finkelstein (UPIAS) as its chair (Greater Manchester Coalition for Disabled People, 2000; Judy
Hunt, 2001; and Jane Campbell, 1996). This organization became an umbrella for many of the organizations for people with disabilities. Also, the BCODP adopted the definitions of impairment and disability which the UPIAS had written along with its Fundamental Principles (Judy Hunt, 2001; and Jane Campbell, 1996). Third, Vic Finkelstein represented the BCODP and the UPIAS at the Disabled People International conference in Singapore. He presented the social definitions of impairment and disability which were discussed, argued, and adopted instead of the definitions from the World Health Organization which at that time represented the medical model (Jane Campbell, 1996; Greater Manchester Coalition for Disabled People, 2000; and Judy Hunt, 2001). What these events tell me is that the thoughtfulness and perseverance of those who started the Union of Physically Impaired Against Segregation helped to start a disability movement which has worldwide ramifications from 1981 until today and into the future.

**Conceptual Models**

Michael Oliver (2009), who coined the term *social model of disability*, proposed that “models are ways of translating ideas into practice….” (p.43). I have personally struggled with the term “model”; however, it is commonly used throughout the research to depict different assumptions about disability. When I use the term “models of disability”, I am referring to broad, cultural narratives that explain the essence of what disability is, why it occurs, and how we should respond to it. In his 1996 presentation on *modelling (sic) disability* for the Breaking the Moulds (sic) Conference at Dunfermline, Scotland, Vic Finkelstein discussed models as “merely tools for gaining insight into an existing stubborn problem so that the future may be changed” (Finkelstein, 1996, p. 2). This is in agreement with my understanding of models as
broad cultural narratives which at times do pose stubborn problems related to how disability is interpreted.

**Models of Disability as Tools**

The term “model” is used to talk about how different sets of attitudes, values and beliefs, often unconscious, undergird how people respond to and behave towards those with disabilities. These models impact various fields of study, bodies of knowledge, experience, values, hierarchies, and behavior. [https://www.tamu.edu/faculty/choudhury/culture.html](https://www.tamu.edu/faculty/choudhury/culture.html)

The models of disability are fluid tools that cohere around metaphors which lend meaning to how disability is conceptualized. The medical and social models are the most prominent. The models of disability have been addressed in depth by disability scholars, but have also made their way into popular culture through a variety of websites that use the models to explain that disability can be conceptualized in widely different ways. The two versions I used come from the Alaska Mental Health Consumer Web [http://www.akmhcweb.org/ncarticles/models_of_disability.htm](http://www.akmhcweb.org/ncarticles/models_of_disability.htm) and from the Michigan disability Rights Coalition [http://www.copower.org/leadership/models-of-disability](http://www.copower.org/leadership/models-of-disability). However, as tools for discussion and as rally point to develop community and action, the models of disability have been copied, and added to, and can be found in different versions on many different sites. [http://www.search.com/search?q=models+of+disability+history](http://www.search.com/search?q=models+of+disability+history)

Values I see in the culture of disability are dignity of self and a call to action when that dignity is not acknowledged and even rejected, making the person discounted, unheard, and invisible as though s/he does not exist. The models of disability, then, are tools to discuss the intersection of people with disabilities and disability culture within the broader social, political, economic, spiritual and/or medical/scientific realms. It is the intersection different assumptions
and types of knowledge along with different values and hierarchies which can create conflict or affirmation, especially when people’s values are unconscious. When people with disabilities are impacted in a negative way, it is a call to action and advocacy. The two models that have been the most studied and researched are the deficit/medical model and the social model. I shall also review the religious model which impacts me.

**Deficit/Medical Model.**

What is called the medical model, which will be referred to as the deficit model was the first of many attitudes/stereotypes/prejudices which was recognized as imposed on those who are disabled and isolate them from participating in society. The Medical model was what Paul Hunt, Vic Finkelstein, Michael Oliver, Mark Priestly and others who formed the UPIAS came together to challenge because the deficit model of disability took away respect, control and choice from all aspects of their lives and the lives of others with disabilities. It’s discussed here as a contrast to the social model.

**Main tenets of the deficit model of disability.**

The deficit model of disability holds that the disability is caused by a condition within the individual, either physical or mental. As a result, persons with disabilities are expected to adapt and meet the norms of society rather than society accommodating the needs of those with disabilities. Paul Longmore (2003) in his book *Why I Burned My Book and Other Essays on disability* comments that when a person can’t be cured, the deficit model identifies the difference from normal through its labeling, and the difference creates judgment and moral and social stigma in society for the patient.

The emphasis of the deficit model is to remediate the individual with rehabilitation. The implied attitude is that the individual is “less than” because s/he is not “normal”. Vic Finkelstein
critiqued rehabilitation because “disabled people are expected to occupy a ‘bifurcated subjectivity’: that combines the contradictory illusion of self-possessed autonomy with the expectation to act as a ‘crip’” (as cited in Goodley, 2011, pp. 159-160). So the disabled person is expected to be independent and competent (“autonomy”) and dependent and passive (“crip”) at the same time which is confusing for everyone, and this makes social relationships and the workplace difficult in my estimation.

Finkelstein’s quote from above alludes to another aspect of the deficit model is that the disabled person is assumed to be passive, waiting for others to take care of him/her. This passivity raises the question through the deficit model of the worth of the disabled person even to the point of euthanasia (Goodley, 2011). Peter Singer (2009) argues that species membership does not guarantee moral status and that all human life is not of equal value and that some people even should be allowed to die. Singer’s logic is appalling to me. I think differently and believe that all human life is worth dignity and respect. Unlike Singer I am a theist, and while I practice one religion, I draw from many faiths in ideas and experience.

**History and birth of the medical model.**

Foucault (1994) in his book *The Birth of the Clinic – An Archaeology of Medical Perception* placed his historical gaze on the development of the clinic and the hospital. The eighteenth century clinic often was a practical place for private instruction for apprenticed physicians with record keeping, diagnoses, diaries of patient progress, and dissection when the disease or condition proved fatal (Foucault, 1994). At the end of the eighteenth century education and the gathering of knowledge became valued (Foucault, 1994). Hospitals became united with universities for the collection of knowledge, and clinics developed as well. Both were used to teach, train, and research/experiment. Standards for selecting students, expertise in
training, and curriculum were being developed. According to Foucault’s research, wealthy benefactors donated to the hospitals and clinics. This was helpful from the standpoint that many with the same condition during war or plague could be treated and observed for the course of the condition or disease, and this could be documented and added to knowledge which would help others in the future. The impact of this situation was that the hospitals and clinics existed for observation and the gathering of knowledge first, and then for the treatment of patients, and the wealthy benefactors would be the first to benefit from the knowledge gained in the clinics (Foucault, 1994). I had thought that hospitals and clinics were first developed to serve the needs of the sick and injured. Foucault’s gaze gave me a completely different perspective, not only on medicine, but especially on how the deficit model developed. The wealthy funded hospitals and clinics to help themselves and the acquisition of knowledge and eventually to help the general public. Foucault as a critical theorist explained the hierarchical attitude evinced by the deficit model.

_Criticisms of the deficit/medical model._

A danger in the deficit model’s attitude that the problem of the injury/condition/disease belongs solely to the individual is that the person is judged as “abnormal” and a label is placed on that person. Without a continuum of normality, the individual becomes “less than”, becomes “other”. Often, a label is placed on the individual, and unfortunately, people in the general population often consider that the “label” is the whole person. The label stereotypes the individual rather than helping people to get to know the disabled person, the person’s personality, and the person’s qualities (Michigan disability Rights Coalition, n.d.).

A moment needs to be taken to discuss the terms “normal” and “able”. According to the _Hyperdictionary_ the literal meaning of “norm”, the root of “normal” comes from the Latin
meaning “rule, pattern”, and the definitions include “according to an established rule or principle; conformed to a type, standard, or regular form.” A few synonyms are “average, regular, typical”. If people are deemed not normal or abnormal, they no longer belong. They do not fit into a “an established rule,” and they are not “average”. They may be “triangular”, “oblong”, or “rectangular” (in analogy), but they do not fit in with the average person’s experience. Does this mean these individuals with disabilities no longer belong to the human race? I believe that many individuals with disabilities are treated as if they are no longer human beings, and often these individuals are treated with fear and disdain by those who have judged them, and usually the judges have not even taken the time to know them as persons.

The word “able” also has an interesting etymology. Its origins include Old English, Middle and Old French, and Latin, meaning “to have, to hold, easily managed, skillful”. Definitions from Hyperdictionary include: having sufficient power, skill, or resources to accomplish the object and marked by intelligence, knowledge, skill, or competence. Some synonyms for “able” are “capable, competent, qualified”. The etymology of the suffix form of the word “-able” includes: “capable, or worthy of”. What happens then, when someone is labeled dis-abled? That individual is stereotyped as not intelligent, with less knowledge, less skill, less competent, less capable, and less worthy. This judgment is placed on individuals who consider themselves able. The word able also has its own suffix in –ism. One of the meanings for the suffix –ism (Hyperdictionary) means “a belief (or system of beliefs) accepted as authoritative by some group or school”. Thomas Hehir (2002) speaks of the pervasive, ableist cultural beliefs in public and private media stigmatizing all types of disability (Hehir, 2002). In a 2007 article, Hehir discusses educational ableism for students with learning disabilities:
Assuming that there is only one ‘right’ way to learn’ or to walk, talk, paint, read, and write ‘ is the root of fundamental inequities (Hehir, 2007, p. 12).

And in the same article…

The most damaging ableist assumption is the belief that people with disabilities are not intellectually capable (Hehir, 2007, p. 13).

Ableism may be conscious or unconscious, and often diminishes our ability to see or understand that there are human beings who are quite capable and who think, act, perform differently from the “norm”. This speaks to the idea of privilege which is discussed in a subsequent paragraph. Ableism sets up a hierarchy like most of us have experienced growing up in the American school system: there are the popular kids and the “others”. The outsiders. James L. Cherney (2011) in his article *The Rhetoric of Ableism* sees ableism as a statement about who belongs and gives the example of an ableist culture assuming that stairs are not only a functional way to travel from one floor to another but can be architecturally beautiful. However, those with disabilities, especially disability activists, will see stairs as a statement by the dominant ableist culture that they (the disabled) do not belong (Cherney, 2011). Robert D. Wilton (2003) discussed fears of vulnerability, loss, and death in his psychoanalytic examination of the meaning of disability in an ableist culture (Wilton, 2003). In my view, the culture of ableism is linked deeply in the psyche of human beings to the deficit model.

Most people are only temporarily “abled,” we can become disabled through accidents, illness sick or aging. I consider that by including those with disabilities in architectural planning, educational curriculum committees, and by listening and acting upon the needs that those with disabilities express, life will be easier for everyone in the future. For example, parents and young children appreciate the ramps at crosswalks when crossing the street which were initially
installed for those in wheelchairs. There’s less chance of tripping, falling down and being picked up by their arms at the curb, endangering injury to the child. Even the flow of walking traffic is smoother because of the ramps. Parents don’t have to lift up strollers, and the flow doesn’t temporarily stop as a young child learns to step up onto the curb. Those in the dominant culture often don’t always see or understand that diverse ways of doing things matter (Johnson, 2006). Because the idea “this is the way it’s always been done” permeates majority thinking, it’s important for those with diverse needs to speak up to identify what’s needed. Without self-advocacy people become invisible.

My understanding is that deficit model mentality and ableist mentality feed each other with the results being that access on all sorts of opportunities is denied to those with disability. Since those who adhere to the deficit model of disability assume the problem is within the individual and belongs to the individual alone, people tend to seek a cure for that individual so the person may join society and be “normal”. Failing to cure, society not only labels the individual “ab-normal” and “dis-abled”, but also “incurable” and “impaired”. It is assumed the individual is passive and an invalid and must now be taken care of by society. After it is found the individual cannot be cured and labels are attached, policy makers from service organization take over, and based on the labels, a program of rehabilitation, vocational training, aids and equipment are made with the parents of the individual or with the individual him/herself if that person is independent. In some cases an income maintenance program is also developed (Michigan disability Rights Coalition, n.d.).

One of the problems of labels is that employers tend to see the label and not the individual with abilities and skills. Because the label comes from the medical profession, employers often wrongly think that the individual with disabilities will need a lot of sick leave
because of poor health and will ultimately be less productive. Cheryl van Daalen-Smith (2006-2007) and Anita Ho (2004) have written about labels and the lived experience of ableism. Anita Ho (2004) in the Department of Philosophy at the College of St. Catherine in St. Paul, MN gathered information and reviewed the reasons for and against labeling students as learning disabled. Because labels often gave teachers and administrators a reason to think less of the labeled students, many teachers did not work as hard to teach these students, and since there were lower expectations, the students knew this and didn’t work as hard to learn. Ho’s conclusion was that labeling was really pathologizing a learning difference which may not only be unnecessary but may be counterproductive especially if it is believed that people learn in different ways. What was needed was flexible curricula and accommodations (Ho, 2004).

Cheryl van Daalen-Smith (2006-2007), professor of nursing and health at York University in Toronto, Canada, held focus groups with five girls labeled with Spina Bifida. Her focus was on the lived experience of societal ableism. Among the results of the focus groups were that all five women had felt marginalized as they were growing up and in school and by society as they reached adulthood. All five said they knew they had not been allowed opportunities to reach their full potential (van Daalen-Smith, 2006-2007).

Of significant note is criticism and rejection of the deficit model from many in the disabled community. Many individuals with disabilities do not accept the concept they are “abnormal” or “dis-abled”. They also are opposed to the paternalistic approach the deficit model takes to problem solving assuming that they as individuals are passive and incapable of participating in their health decisions. While the deficit model may be well intentioned, once it labels a person as incurable, it focuses on care and dependency rather than accommodation
which could make the individual either independent or more independent than institutionalization or segregation (Michigan Disability Rights Coalition, n.d.).

One more critique of the deficit model is that medicine and science receive most of the available funding for research from government and private organizations. If more money went to projects involving the social model, such as, accessible architecture, advertisements for inclusion, movies and programs including and/or about those with disabilities, then those with disabilities would be seen and heard by almost everyone within the United States. As the general public sees people with a variety of disabilities, difference becomes familiar, and hopefully, the general public will not be as afraid of establishing experiences and relationships with those with disabilities. However, just by the hierarchy and the judgment which the deficit model imposes on persons with disabilities, I don’t see inclusion and integration into society possible through the deficit model.

**Social Model/Perspective of Disabilities.**

The social model of disability is what disability studies is all about. Respect. Acceptance of difference. Cooperation between those in the general public and those living with disabilities regarding environmental accommodations needed for full inclusion of all. Involvement. Choice. Belonging. These are what the aims of what the social model mean to me.

*Contrasting the social model/perspective of disability with the medical/deficit model/perspective.*

The social model of disability was developed by a number of adults with disabilities whose observations, data, or needs had been ignored and worse dismissed by those in the medical field and a generalized belief in society as a whole in the attitudes and procedures of the deficit model (Priestly, 1975/1997). Where the deficit model excluded observations and
information about what those with disabilities were experiencing, the social model included this information. Where the deficit model diagnosed from a hierarchical position, the social model included stakeholders (those living with disabilities and their parents, caregivers, etc.) as participants in creating the best possible quality of life for each person. Where the deficit model spoke of impairment, disability and handicap, the social model spoke of what people can do, their capabilities, their challenges, and accommodations needed so they can participate in society. Where the deficit model located the disability ONLY within the individual with the attitude that the individual must be brought up to society’s standards in order to “fit in,” the social model identified problems of societal attitudes and societal environment which prevent those with disabilities from participating in society because they are not seen (environmental barriers) and not heard (both attitudinal and environmental barriers) and become invisible as a result. The social model of disability expects society to change, and it expects those living with disabilities to advocate for change so the general public knows they exist and that a change in attitude and in behavior is necessary and inevitable. When everyone accepts and respects each other, there will be no more disability.

*History and Birth of the Social Model – United Kingdom.*

Activists with physical disabilities in the United Kingdom who began to voice their opposition to the ways in which they were being treated during the late 1960s. Paul Hunt edited a book titled *Stigma: The Experience of disability* in 1966 which included 12 essays discussing the experience of living with disabilities. In the forward Peter Townsend, a disabled professor of sociology at the University of Essex, states of the 12 authors and their essays: *They show that adjusting to disability is simply a special version of the universal problem of adjusting to personal short-comings and loneliness* (Hunt, 1966). In his own chapter (Chapter 12), Paul Hunt
identified five challenges which must be met in relationships with able-bodied people. Both he and the other person must come to terms with these attitudes about people with disabilities: unfortunate, useless, different, oppressed, and chronically sick (Hunt, 1966). Hunt seemed to be saying that for any true relationship to exist between a disabled person and a temporarily able-bodied person, both people must face their own issues regarding disability and able-bodiedness. Then they’re each prepared to discuss those similarities and differences with each other for an open, honest communication.

A few years later several physically disabled people in the United Kingdom began the social model by opposing attitudes, language, and demanding change in society in the way those with disability had been excluded and discounted with the result that they had become invisible and unheard. Paul Hunt in a letter to the Guardian in 1972 invited disabled persons to join him in a disabled “consumer group” initially to change life for those who live in institutions (Hunt, 1972). Two of the people who joined Paul Hunt were, Vic Finkelstein, and Mike Oliver. Vic Finkelstein (1975) wrote an essay for the Magic Carpet in which he gave an analogy of a town where all the inhabitants were wheelchair users. All the buildings were built to accommodate the needs of people in wheelchairs including the ceilings, doors, height of counters and sinks, etc. When able-bodied people moved in, they had difficulty with bumping their heads on the ceilings and having to walk hunched-over. Roles were reversed. The able-bodied had become the disabled.Interestingly, the insights, attitudes, and the doctors seemed to remain the same in that they could only help the able-bodied to a degree. Finkelstein identified that there could never be complete solutions for the able-bodied because the doctors, psychiatrists, etc., did not have the same perspectives that the able-bodied had, and the doctors did not include the able-bodied in the discussions of diagnosis or treatment (Finkelstein, 1975). Finkelstein and Hunt wrote the
constitution for the new group, the Union of the Physically Impaired Against Segregation (UPIAS), in 1974 which was based on a social model of disability and had an activist perspective. The constitution identified isolation, exclusion, and social barriers which created an oppressed situation for those with physical disabilities and prevented them from participating in society, including getting a job. “The Union exists simply to offer help to all physically impaired people in the fight to change the conditions of life which oppress us and to realise (sic) our full human potential.” (Finkelstein, & Hunt, 1974, para. 17). Vic Finkelstein was able to get the Disabled Peoples International conference to adopt definitions of “impairment,” “disability,” and “handicap” from the social model instead of continuing with the definitions from the World Health Organization. This helped to spread the ideas of the social model throughout the world.

In 1990 UPIAS disbanded. While I tried to research the reason for this, I could not find an answer…yet. However, the work UPIAS did was to identify issues and to name the social model as well as change some British laws so those with disabilities would have more control over their lives.

In an expanded version of his 2004 address at Lancaster University, Vic Finkelstein identified where the social model and the disability movement needs to be headed. First, those with disabilities need to reclaim their citizenship. Judy Hunt identified this same issue that those with disabilities must next move into the mainstream and “fight along with other oppressed groups (Hunt, 2001). The way I interpret this is political involvement, voting, working to change laws to include all groups who are oppressed. Secondly, Finkelstein continued to raise an issue which has been central to the disability rights movement of the 20th century that those with disabilities need to move back into the community. For me, this means moving into buildings in which everyone living there has input into how the place is run, or it means moving into a mixed
able-disabled situation and blending into the community. Moving into the community also means blending into the social life of the community, participating in community activities, and having both able/disabled friends with whom one socializes. For me as a parent of an adult child with disabilities, Vic Finkelstein’s recommendations mean a continued call to action to make space in the world for my son and others like him.

The social model/perspective of disability and the World Health Organization.

Doctors in the World Health Organization (WHO) (1980) defined three terms which have become the standard of not only the deficit model but also for numerous health-oriented organizations around the world. The three terms include: impairment, disability, and handicap. Definitions are listed below:

Impairment: any loss or abnormality of psychological or anatomical structure or function.

Disability: any restriction or lack of ability (resulting from an impairment) to perform an activity

in the manner or within the range considered normal for a human being

Handicap: any disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal for that individual.

(WHO, 1980)

In fairness, it must be noted that there has been evolution in the perspective of WHO (2011) regarding its understanding and treatment of disability since the 1980s. The 2011 Report on disability from WHO has changed position to acknowledge that physical and social barriers exist for those living with disabilities as well as the complexity of the field of disability (WHO, 2011, pp. 3-17). WHO has in language at least become much more inclusive of the social model
and much more willing to state that people may benefit from more than one approach to
disability. The follow-through of these words by WHO with attitude and actions will be watched
closely by many. This is evidence for me that activism by disability organizations over the past
thirty years has had international impact on changing world understanding and outlook on
disability.

**Strengths of the social model/perspective.**

In the Aims (Hunt, 1976) the founders of UPIAS included in sections 18-20 of the
constitution that one of the tenets to be a member was that each member must be involved in
participation/action in some way. Section 18 discusses action campaigns on various issues.
Tom Shakespeare (2010), sociologist, bio-ethicist, and one of the early proponents of the social
model, enumerated steps which create action in his chapter The Social Model of Disability.
Among these are that 1) political slogans, 2) identifying barriers which create exclusion,
isolation, and discrimination, 3) building self-esteem and a positive group identity with others
living with disabilities, and 4) knowing that s/he is not a mistake, that barriers in society are
responsible for exclusion. When a UPIAS member works on steps 1-4, that member can have
pride about who they are and anger about barriers and as opposed to feeling shame (Shakespeare,
2006). Anger is an important emotion which lets us know that something is WRONG. Anger
makes us feel uncomfortable, restless. Focused anger is an emotion which energizes and
mobilizes us into action to CORRECT whatever is wrong. As I understand the
Aims/constitution of UPIAS and the steps to action which Tom Shakespeare discusses, action
results from knowing who we are, knowing what we stand for, not accepting the
barriers/discrimination/stereotypes/judgments, etc. from society. From this situation focused
anger can plan peaceful action which will gain attention and change.
For praxis, Paul Hunt’s aim was to have every member of UPIAS own who they are, identify areas of change, and advocate for change in some way. Tom Shakespeare identified the process of how people are moved to action, the action Paul Hunt was seeking for his membership. When people know who they are and have a cause, they can act in traditional and creative ways to create change, such as write articles to the newspaper, blog, TV, YouTube, etc.; work to get laws passed through Parliament. They can organize a demonstration. Or, people can paint, write poetry/songs, write short stories, produce a movie/documentary. The aim is change and inclusion.

*The social model/perspective and special olympics in the United States.*

One of the social model’s tenets is advocacy for inclusion. Special Olympics is a separatist organization to give children and adults, especially with intellectual and physical disabilities the opportunity to participate in sports. Because it is separatist, Special Olympics has been criticized by some advocates of the social model and others. Joseph Shapiro (1994) in his book *No Pity* identifies situations where children with disabilities participated in regular sports after their parents advocated for them to at least try out for the team. I’m happy for them. The competence and confidence those children must have felt is healthy.

I understand the value of inclusion and the criticism of Special Olympics because it is a separate – some would call it a segregationist institution. However, if it were not for Special Olympics, my son would never have played sports. In Barrington he was excluded from T-ball and Little league. In school he was a manager for the sophomore boys basketball team and the first manager for the boys tennis team. He tried out for tennis – practiced with all heart and maybe would hit one out of every one hundred balls. While he was honored to be the first
manager the team ever had, he would have rather played ball than have been the person to pick up the balls and the wet towels.

In Special Olympics, however, he was on a track team – and he ran – and he participated in the relay race, and he was with kids, not servicing them. He beamed in cross country skiing. He didn’t win – but that was o.k. for him because Graham was an athlete. He participated. He was with friends. He knew what it was to be in training. Through Special Olympics Graham experienced what it was to be a member of the team. This was social life! Graham developed some of his self-confidence and stopped fighting some of his differences which helped him like himself better.

My hope is that the academic arena of disability studies would be able to affirm the positive things which come out of Special Olympics rather than only to critique the organization and its goals. Graham would never have experienced being a member of a team or participating in athletic events had it not been for Special Olympics. It seems to me that sometimes a person can join a club that meets his/her interests without having to feel shame because it’s not inclusive. There are all sorts of clubs and organizations which exist according to interest in the activity. I do agree that if people are barred from joining because of discrimination like Graham was from cub scouts, T-ball, and Little League – that’s discrimination. However, there may be other times when it’s alright to seek out a special interest group and gain the benefits from it. Hopefully, there is room in disability studies for both inclusive groups and separate groups like Special Olympics which serve a population which would never be included in competitive, selective groups such as athletics.
Criticisms of the social model/perspective.

In my experience with raising my son I have found that often those who utilize a social model, in an attempt to include those with disabilities in the daily life of society, often ignore the “extras” of the daily experience of living with disability, not only the disabled’s experience but also the experience of parents, family, and friends of the disabled person. It may take someone without disabilities 20 or 30 minutes to get up and get dressed in the morning. It may take someone with disabilities or the parents dressing their child with disabilities two hours. This impacts not only the disabled person but also the parents and/or siblings who must re-schedule their days to include this extra time and energy which also impacts friends, car pools, jobs, social events, etc. There are “extras” with any disability which take time and energy. These have not been factored into the social model. The lived experience of waiting while my son was dressing himself when I want to get going quickly is stressful. On the one hand, I know it’s important for him to learn to dress himself. I don’t want to shame him because that will discourage him trying in the future. On the other hand, I have a schedule to keep. This is frustrating. I am aware that I need to let go of my schedule. But, this isn’t easy to do. When I can, I reach deep into myself, close my eyes, do some breathing exercises, and let God know my frustrations. Sometimes I can let go and be calm by the time my son appears. Sometimes I just yell, “We’re going to be late!” It depends on the moment. “Life” happens to the best of schedules. The social model hasn’t yet taught me what to do about lost time. For me at least disabilities studies has not yet acknowledged the experience of the difficulties that go along with disabilities. However, there are “extras.” …and…. “Extras” do exist.

Tom Shakespeare (2006) identified a couple more weakness with the social model. Because the social model “defines disability as oppression,” it’s impossible for anyone doing
research to find any disabled person who is not oppressed. The researcher must find some degree of oppression (Shakespeare, 2006). Another issue which Shakespeare mentions is the vague distinction between impairment (medical) and disability (social). People who are impaired have a medical issue and because, according to the social model, all people with disabilities are oppressed, anyone with impairment has at least one social issue because of the social barrier which accompanies that impairment (Shakespeare, 2006).

Examples.

As a parent the social model has made me aware of social barriers. For example, Rebecca Rogers (2003) in her chapter Into the Meeting Room included transcripts, diagrams and discourse analysis of IEP meetings she had attended. Rogers identified the unequal power structure of the IEP meetings which she observed which ultimately reversed the purpose of the IEP meetings to be about what’s best for the teachers and the school rather than about what’s best for the student for whom the meeting has been called. Questions this chapter prompted in me as I thought of my son’s school IEP staffings include: Where do parents sit during these meetings? Are parents greeted and included in conversation when they arrive, or do school staff become quiet? What is the atmosphere during the meeting? Is it inclusive and asking parents for their knowledge regarding their child, or is it hierarchical with the attitude that staff “know” and are experts and that the parents know nothing? Does staff use technical jargon? If they do, do they define it? How are questions parents ask received? Are they welcomed and answered respectfully and in language parents can understand? Is the IEP changed to include issues parents bring up? Do people leave the staffing before it’s over? Do staff give the impression they just want the meeting to be over, and they just want the parents’ signature on the official
IEP form, OR, is there an attitude that everyone is coming together to work for a plan that is best for this child?

**Social Adapted Model/Perspective.**

For me the social adapted model acknowledges the important role of medical professionals in the lives of many disabled people, while critiquing the ways in which deficit theories of disability have often have been transferred onto entire identities of disabled people, generalizing a disease metaphor for an entire for person’s self. Thus, the social adapted model does not reject that there are medical aspects to disability, but works to keep those aspects in their place, as they are in the lives of non-disabled people. The social adapted model stresses that disabled people are more than the medical diagnosis, and works against reducing a person to a “condition.” It seems to acknowledge impairment of a person identified by medicine, education, and psychology, and also acknowledges the capabilities and potential of that same person. In addition the model acknowledges that there is disability imposed on the impaired by society’s judgment, uneducated fear, isolation, and rejection of those with impairments.

Society’s barriers to the disabled also include physical/architectural obstruction in the way of curbs, stairs, and doorways too small to allow wheelchairs to fit through. Thus, those with impairments and society’s judgment are unseen, unheard, unprotected, and do not participate or belong in the society or culture where they live. The social adapted model section of the *Models of Disabilities: Keys to Perspectives* defines the model [http://www.akmhcweb.org/ncarticles/models_of_disability.htm](http://www.akmhcweb.org/ncarticles/models_of_disability.htm). Both the social model and the social adapted model include the acknowledgement that persons with disabilities have difference, that it recognizes and affirms the abilities and potential of those living with impairment that can
Religious Model/Perspective.

The social and medical models have received the most attention in disabilities studies literature. However, in my own life the most powerful influence in how I make sense of disability is spiritual. While I recognize the prevalence of the medical and social model in culture, these don’t cover my full range of understandings and experiences. A religious model of disability is described on the Alaska Mental Health Consumer Web as

The Religious model views disability as a punishment inflicted upon an individual or family by an external force. It can be due to misdemeanours committed by the disabled person, someone in the family or community group, or forbears. Birth conditions can be due to actions committed in a previous reincarnation.

Sometimes the presence of "evil spirits" is used to explain differences in behaviour, especially in conditions such as schizophrenia. Acts of exorcism or sacrifice may be performed to expel or placate the negative influence, or recourse made to persecution or even death of the individual who is "different".

In some cases, the disability stigmatises a whole family, lowering their status or even leading to total social exclusion. Or it can be interpreted as an individual’s inability to conform within a family structure. Conversely, it can be seen as necessary affliction to be suffered before some future spiritual reward.

It is an extreme model, which can exist in any society where deprivation is linked to ignorance, fear and prejudice.

No doubt these beliefs have been experienced by many people, disabled and non-disabled.

However, this perspective provides only a limited, negative perspective. It speaks of pains of judgment, rejection, and shame which deeply wound. It helps to explain the fear and guilt of families who hid their disabled children from neighbors and the community. Historically, the religious model helps to explain how when people whose lives revolved around religion and without modern education didn’t understand diseases, eclipses of the sun, droughts, natural
phenomenon, or differences in behavior, they blamed “evil spirits” and the unfortunate, often disabled, were scapegoated.

What the religious model of disability depicted on the Alaska website misses is the positive side of religion and the expansiveness of spirituality, for religion is a part, a subset, of spirituality. Religion and spirituality can be tremendously healing, working through community and personal spiritual practices. Religious and spiritual beliefs and practices involve the celebration of life’s benchmarks, such as marriage and children, provide a sense that I am not alone during life’s struggles and comfort me during life’s sorrows, transforming my inner wounds and pain. I have deepened my spiritual understanding from reading people like Martha Beck, Henri Nouwen, Jean Vanier, Joan Chittister, Pema Chodrin, Rabbi Harold Kushner, the Linns, and Richard Rohr, O.F.M. I receive inner peace and well-being through my participation in religion and spirituality.

At the same time it’s important for me to state that there are many religions with many varying beliefs, even with varying beliefs within the same religion. Beliefs are private matters, and it may be that beliefs of one religion or beliefs stated by one member of the clergy may not meet the beliefs and needs of an individual, and may even injure that individual. There may also be misunderstandings which lead to injuries. It seems safe to say that the religious model has cause both great harm and positive transformation in relationship to disabled people and their families.

My Tenets of a Potential Spiritual Model/Perspective of Disability

I have come to believe that there’s spirituality and then there’s religion and sometimes the two are together. For me spirituality takes many shapes and forms and can be solitary as well as experienced with community. I have been hurt by religion – by rules which I disagree
with and misunderstood and misapplied rules, by poor translations of the Bible, and by poor interpretations, especially when passages have been taken out of context and not put back into the time period during which it was written. For example, the passage in Matthew about turning the other cheek:

You have heard that it was said, “An eye for an eye and a tooth for a tooth.” Do not resist an evildoer. But if anyone strikes you on the right cheek, turn the other also;….(Matthew 5:38-40; Luke 6:29-30 New American Bible)

This passage and the traditional sermon given about “turning the other cheek” and “letting the moment pass” and “forgiving” helped to keep me in an abusive marriage for almost twenty years. I almost died. After the divorce was over, and I was packing up the house to move, the Sunday Evening Club came on Channel 11 after a movie. I was busy so I left it on. This passage was being interpreted by Walter Wink (1992) who placed the words and the scene into the culture of Jesus’ time period. If I were the same gender and wanted to put Jesus in his place and let him know he was less than I, I would hit him on his right cheek with the back of my right hand. I couldn’t slap him with the palm of my right hand because that would make me unclean. If I wanted to hit him again to really humiliate him, and Jesus turned his head so his left cheek is facing me, it logistically doesn’t work for me to hit him with the back of my right hand. I can slap him with my open palm or I can hit him with my fist. However, both of these actions make Jesus my equal, and he reclaims his dignity while my goal of shaming him is thwarted. The passage is really about standing up to evil with passive resistance (Wink, 1992, pp. 175-184; Linn, Linn, and Linn, 1997, pp. 3-8). I cried out of joy when I read this, and I cried out of sorrow that it took 42 years for me to know this. I ordered two transcripts of this particular show which I was watching for the first time, kept one, and gave one to my pastor which was used as
the sermon the next time this gospel was read. Words taken out of cultural context can have even the opposite meaning from the original intent. It makes a difference. It did for me. The sermon for this passage in the tradition of the Religious model would mean that any disabled person should accept abuse. This sermon for this passage in a possible Spiritual model would mean that any disabled person should not accept abuse – should say “Stop. That action, those words are not acceptable. I am more than this.” Paul Hunt did this when he stood up to the owners and management of the Cheshire Foundation Home to help those with disabilities residing there gain control over their lives rather than just living by the rules the institution imposed on them.

As a parent of a child with disabilities the version of the religious model on the Alaska Mental Health website, does not inform me as it is. For me the purposes of religion include: relationship {with a full range of emotions} with God and each other for important moments {birth, coming of age, marriage, children, joys, tragedies, death, etc.}, to cope with and transform and integrate pain, to learn to forgive ourselves and others, to face our fears as we stand in our ‘truths’, {each of us needs} to come to understand our meaning in life, to transcend through ritual that for which we have no words – to become “seekers” and to give back {to God, to each other, to the world, and to the earth}. This attitude may come from my upbringing, but it also comes from my questioning, my leaving my original faith and studying others when I was in college, my drawing from other faiths to create a spirituality which works for me. Currently, I draw from Catholicism, Protestantism, Judaism, Buddhism, Islam, and New Age. My community is Catholic though we have a sister synagogue with which we host events, and our pastor and their rabbi will sometimes speak at each other’s services. We have a number of people in wheelchairs and other disabilities including several who attend from a local halfway
house for those considered to have a mental “illness.” We have a deaf family in our congregation so our church employs a sign language translator to sign the 9:00 a.m. Mass each week. Many of us, including our pastor, sign the words as we sing the Allelulia before the gospel, and there are several in the congregation who watch the signing translator during the sermon. There are a number of persons with intellectual disabilities who attend Mass, and one is an altar boy and another serves communion. I miss my community when I am not there. I also have daily, solitary prayer and meditation which is my private, personal relationship with God (male, female, and more) which feeds me, and I miss if I get caught up in the busyness of life. So I consider myself spiritual rather than religious.

*Spiritual* is an interesting word. As I tried to define *spiritual* for myself, I found I could identify characteristics of what I considered spiritual, but I could not define the experience. Dictionary definitions seemed to encounter a similar problem. Of the several dictionaries I consulted (Oxford, Cambridge, Webster’s Collegiate, Merriam-Webster, Macmillan, Collins English Dictionary, etc.), I only received an idea but not sound knowledge of what *spiritual* meant. For instance, definitions amongst the dictionaries seemed to be defining the term using the same words which touched on “head” knowledge but not “heart” knowledge. Examples include:

a. *Of, relating to, or affecting the human spirit or soul as opposed to material or physical things* (Oxford, Webster’s Collegiate, Merriam Webster, Macmillan, Collins English Dictionary)

b. *Relating to deep feelings and beliefs, especially religious beliefs* (Cambridge, Oxford, Webster’s Collegiate, Merriam-Webster, Macmillian)

c. *Of or relating to sacred matters* (Merriam Webster, Collins English Dictionary)
Standing in a relationship based on communication between the souls or minds of the persons involved (Collins English Dictionary, Merriam Webster)

As I reviewed these definitions, they didn’t seem adequate for the experience of the spiritual which I wanted to convey. When I didn’t have support from my husband, now former husband, in the caring and raising of my son Graham, and my family was just far away enough for assistance to be inconvenient and mostly inaccessible considering that everyone had jobs and was building careers or involved with complicated daily routines, I felt abandoned and lost. I had a teaching career at the high school level which I loved and sponsored a weekly student newspaper. Colleagues were initially sympathetic with the “extras” with which I had to cope regarding Graham’s disabilities, but they wondered why I didn’t put him in an institution. Parents didn’t want their children babysitting with Graham so respite and social life were out of the question. Our family also fell through the cracks for social services. We were on the borderline financially, but the main reason was that I needed some respite – even going to the grocery store by myself was respite. However, Countryside Helps the Handicapped was mandated for respite for vacations, parties, outings, weekends away, etc. and not for short stints away from home.

Since daycare as a professional field was just started in the form of agencies, finding a small daycare situation in a person’s home was initially difficult, but after a few miss-starts, I found a wonderful woman who had daycare in her home, made lunch for the children, and even drove with me for six months to sign language class which was held at night three towns away so we could keep up with what Graham was being taught in school which he started at the age of thee. There was a support group for parents which met once a week. The problem was it was an
hour away at night. I also taught about an hour away from our home. It was just too complicated, and I was too exhausted to attend. Thus, I felt isolated and alone.

As a result, I needed to go inward for strength and respite. This research focuses on aspects of that journey as well as issues of disability, education, medicine, and career. The challenge at this immediate moment, however, is how to define this inner journey of the spiritual so you, my reader, have more than just a vague concept of what I’m trying to describe. Perhaps the reason dictionary definitions seem vague to me is that spirituality is so personal and unique for each individual and because there are so many variations in how it can be expressed and experienced that no one definition fits all situations. I did find four sources with shorter definitions/discussions which gave me hope of expressing what I mean when I’m writing about the spiritual and spirituality which I’d like to share with you.

The first source comes for the Center for Spiritual Healing at the University of Minnesota which traced the etymology of the word *spirituality* to root words coming from Hebrew, Latin, and Greek, all meaning *wind, breath, or air*. For much, if not most, living things on our planet, air is *that which gives life*. What I like about the etymology statement is that the concepts of *wind, breath, and that which gives life* – cannot be seen, just like spirituality. However, the effects of these can be seen through a person’s behavior. For instance, some who have known me for a long time have told me that I am more accepting of others and more compassionate.

Secondly, while religions aspire to the spiritual, their organization is human, and I was pleased to find an explanation of this because what I needed to support me in my journey with my son was the experience of the spiritual, not the human rules and codification of it.
“Spirituality is not a religion. Spirituality has to do with experience; religion has to do with the conceptualization of that experience. Spirituality focuses on what happens in the heart; religion tries to codify and capture that experience in a system.” (Legere’s definition of spirituality as cited in Maher & Hunt, 1998)

Georgetown University in Washington, D.C. houses the National Center for Cultural Competence (NCCC) which seeks to bring together spirituality, religion, and mind-body health in the areas of how a person copes with being sick and how medical decisions are made which may impact the medical outcome. The aspects of their discussion which reflect my experience are as follows:

- the experience of the sacred
- the search for transcendent meaning
- an individual search for meaning
- the search for meaning in life events and a yearning for connectedness to the universe
- a person’s experience of, or a belief in, a power apart from his or her own existence, and
- a quality that goes beyond religious affiliation, that strives for inspiration, reverence, awe, meaning and purpose, even in those who do not believe in God.
- …refers to a broad set of principles that transcend all religions. Spirituality is about the relationship between ourselves and something larger.

The above definitions from NCCC contain some of what must be an innumerable number of ways a person can experience spirituality and the sacred. I would like to give an example from my life of how each of the above aspects of the NCCC definition (according to the a-g numbering) of spirituality has applied to my experience:  

a. While I can experience the sacred in a group, I more often experience it when I’m alone and quiet – with all media turned off.  

b. For me, “…the search for a transcendent meaning” was essential. Transcendence gives
me something to aspire to, to be inspired by which I needed to sustain me as I was raising Graham and continues now as the mother of an adult son and a person in my own right. I searched disability studies for a transcendent philosophy and didn’t find it. I did find important issues of rights and social justice. However, spirituality contains the transcendence that I personally needed to move forward and learn the valuable lessons of my life with Graham. c. I want my life to mean something for myself and for those who come after me, and as a result I seek an “individual search for meaning.” d. I want to belong – to myself, my family, and find my place in society, the world, and the universe – something bigger than myself – so at the end of my life I can say I helped others and my life wasn’t wasted. e. I believe in a Higher, Omniscient, and Beneficent Power even though I cannot prove it exists or show it to anyone. This is where faith comes in for me as I believe in a higher power, which may be called many other things in other religions – God, Yahweh, Allah, nirvana, etc. f. I especially seek the spiritual when I’m under emotional stress. It calms and comforts me, and I no longer feel alone. g. Lastly, to be in right relationship with myself, others, the world, and God feeds my spirit, and when I’m not in right relationship, I’m uncomfortable, distressed even, and seeking inner peace. I seek inner peace when I’m lost and overwhelmed, as I was with Graham’s crib accident.

Lastly, the idea of a spiritual journey throughout life is expressed well by Thomas Keating:

The spiritual journey…is a journey of self-discovery, since the encounter with God is also an encounter with one’s deepest self. As we come closer to God, we encounter the wellsprings of our own makeup, the hidden chambers of our personality and behavior. God calls us to live in a real world as mature people. And so, growing in God’s grace is a gradual process of stepping into the light, of owning up to ourselves and becoming fully human. (Keating, 1999)
This spiritual journey passage identifies that spirituality is a growth process that usually must be sought and usually occurs gradually. My journey was/is both spiritual and psychological. I entered into therapy as my marriage was breaking up, and as I processed and healed, I found I had more room for compassion and acceptance of others and myself, and my spirituality grew as well. I heard in a sermon once, and I grew up with the attitude that “good science and good theology complement each other.” The following describes where I was spiritually and emotionally following the accident.

I came to the situation of my son’s acquired impairment and disability kicking and screaming, shaking my fist at God, and resisting. I wanted my son fixed (medicine). I wanted my son to have all the opportunities every other child in our area had (social model). …and…God, You allowed this to happen, so why don’t You FIX it! (my attitude). This last doesn’t fit the Religious model. Little did I know at the time that my son’s crib accident would send me on an internal quest for meaning, a different relationship with God, facing hard questions regarding child-career-marriage-parenting, grieving the dreams I had for my child, making new dreams, reflection, pondering, commitment, consciously choosing a path of what I call descent, therapy, advocacy, struggle, surrender, change of heart, changing my image of God, meditation, questioning the Bible, etc. Some of the questions I encountered and engaged include:

1. What does one do, think, feel when the unthinkable happens?
2. What is the purpose of life when my son may not see, walk, talk, hear, or think? What is his purpose? Is he just tragedy? (deficit model)
3. What is the purpose of my life in taking care of him?
4. Why did God allow this to happen? Why isn’t God fixing my son? Who is this God, anyway?

5. Why is there mystery in spirituality? Can I let mystery exist without trying/need not try to resolve it or be in control by having to understand the mystery?

6. What happens to my son when I can’t take care of him anymore?

7. Do I continue my career and put my son in an institution and save up money for his care when I’m gone? Or… Do I let go of my career which I love and take jobs which will allow me to be present to him when I come home at night? Which is better in the long run? For whom? Will there be no more happiness for me, just responsibility and commitment?

8. What do I do with my emotions? My fears? Where is joy? What has happened to my life? What meaning do I have left in my life? Where is inner peace? These are some of questions I pondered for years – struggled with – battled with and sometimes just sat with or meditated about.

There is a point at which the person living with a disability is alone with that disability. There is a point at which every parent of a child with disabilities is alone with that disability as well at each sibling of the disabled person is alone with those disabilities even though they are not disabled. I believe there is a point at which each person acquainted with the disabled person is alone with that disability. This is a moment of reflection. Who is this person? How is the disability part of this person? How is the disability NOT part of this person? Who am I? Who am I when I’m with this person? Who do I want to be (especially, who do I want to be when I’m with this person)? How do I become the person I want to be?

There are also existential questions: How did this disability happen? God allowed this to happen, so why don’t You fix this, God? I do believe that anyone born a human being IS a
human being. So, what now? Is my son “less than” because he’s lost potential of what he could have been? What purpose in life does disability serve? What do I do with the mystery of disability? Why does it exist – for anyone? Why the mystery?

Until my son’s crib accident I had been driving in the fast lane in sixth gear when most cars only had four. I had my career teaching high school students English and composition, advising a weekly student newspaper and teaching photography on the side. I was also helping my husband with his architectural firm and his race car and his team. In addition I had a large vegetable and herb garden and canned tomato sauce with tomatoes, garlic, basil, and onions all from the garden. We were Yuppie parents with Yuppie expectations for their first born son – Even with his name, Graham Stewart Higgins – we were preparing him for great success. In analogy, I was racing down the road in my car with my hopes and dreams attached attempting to accomplish all the life goals I had set for myself. When Graham’s crib accident occurred, my little car of hopes and dreams crashed into a concrete wall. The engine gasket was blown so steam, oil, and gasoline leaked out onto the road, and I was lucky to make it to first gear and limp down the road….and I was not accustomed to driving slowly on the increasingly fast highway of life. The accident changed my life forever. No more fast lane – only I didn’t know it at the time.

For me in our speed-up society it’s difficult for me to slow down, and when I’m with someone who moves or thinks slowly, whose disabilities cause me inconvenience, I must change my own speed in order to be present to the moment. When I’m thinking of my “To Do” list, when I’m multi-tasking, when I’m thinking of what I’ll be doing one or two hours from now and the deadlines I must meet or the deadlines I’ve imposed on myself, it’s culture shock to stop, slow down, and be present. When I’m in high gear and moving with the force of a tornado, there
is a physical jolt inside me when/if I need to be with my disabled son. There is a physical aspect to my change as well as mental, emotional, attitudinal, and sometimes spiritual aspects to my change. I must take a few inner moments, breathe a few deep breaths, let go of the busyness in my mind and my schedule, and surrender to the moment. There can be moments of inner struggle because whatever is happening with this other person must take all of my attention and energy, and I’m focused elsewhere. I call these moments “extras”. Figure 2.1 (next page) gives some examples of my “extras” with my son:
### Figure 2.1
Some “Extras” of the Lived Experience of Disability with My Son

<table>
<thead>
<tr>
<th>Examples of “Extras” During Daily Routine</th>
<th>“Extras” Struggles Emotions &amp; Stresses</th>
<th>“Extras” Transformations</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Waiting for person to complete what s/he is doing</td>
<td>- Frustration</td>
<td>- More Patient</td>
</tr>
<tr>
<td>- “Doing for” the person</td>
<td>- Anxiety</td>
<td>- Less Judgmental</td>
</tr>
<tr>
<td>- Re-Teaching</td>
<td>- Abandonment</td>
<td>- More Accepting of Others</td>
</tr>
<tr>
<td>- Must do everything myself</td>
<td>- Exhaustion</td>
<td>- More Forgiving</td>
</tr>
<tr>
<td>- Coordinating services for person</td>
<td>- Self-Pity</td>
<td>- Advocating More</td>
</tr>
<tr>
<td>- Lost Time</td>
<td>- Isolation</td>
<td>- Enjoy Being with People</td>
</tr>
<tr>
<td></td>
<td>- Overwhelmed</td>
<td>More</td>
</tr>
<tr>
<td></td>
<td>- Loneliness</td>
<td>- More Accepting of Myself</td>
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<tr>
<td></td>
<td>- Resentment</td>
<td>- More Genuine</td>
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<td></td>
<td>- Toxic Shame</td>
<td>Relationships</td>
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<td></td>
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<td>- Pondering-Letting Things</td>
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<td>Letting Situations Teach</td>
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<td></td>
<td>- Change in My Image of</td>
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<td></td>
<td>God</td>
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<tr>
<td></td>
<td></td>
<td>- Learned to Love with My</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Heart</td>
</tr>
</tbody>
</table>
Instead of only with My Mind
-See Dignity in Other People’s Struggles

Figure 2.1 Identifies some situations (“extras”) which create difference in disability for me in my relationship with my son. The chart also identifies some of the struggles and the opportunities for transformation provided by the “extras”. This information was gathered through my lived experience and through observation.

It’s not even whether or not I want to be with this person. I do. It’s that I must change to a quieter part of me quickly and that’s not always easy. Also, sometimes there are schedules to meet, trains to catch, places to be on time, and sometimes I’m just in a rush. Sometimes their best is inconvenient to the situation. …And, that’s what it often gets down to…inconvenience. How inconvenient is this other person’s disability to me? How much extra time, extra effort, extra energy, extra thinking, extra emotional energy, not to mention money, job inconvenience, job security, worry, bureaucratic administrative work on the other’s behalf, etc. does this relationship cost me? …And…how does this inconvenience affect my relationship with this person? Can I survive the extras? What are my supports? –family? –friends? –community? –agencies? –therapy? –exercise? –religion? –spirituality? What are my inner reserves? How long will they last? How do I replenish these reserves? What is my limit? When do I pull back or say goodbye?

What should this disabled person receive just for being a human being? Articles, books, discussions, professors, politicians talk about services, rights, laws, policies, but the question begs for a deeper answer. A friend of mine mentioned that her mother who has Alzheimer’s
doesn’t always know who my friend is when she visits her mother. Sometimes she can’t talk either. I asked my friend how her mother thinks, feels, when she doesn’t know who’s taking care of her or what people are doing to/with her. My friend said, “She may not know who someone is or what they’re doing, but she knows how she’s being treated – whether it’s respectful, caring, nurturing, or the opposite.” (personal communication, N. Scott, October, 2009).

**Implications for praxis.**

Since the spiritual path can take many directions and since it’s often a solitary journey, it’s difficult to outline a standard lived experience of spirituality. Rather than give direction I can tell what I do for myself and let others decide what’s best for them. They may have a better way. What I try to do is be brutally frank and honest with myself, my motives, my desires. I question them when I’m alone and quiet. I try to honor my struggles and discover what I can learn from them (but I panic too). I try to honor my surrenders. Letting go is hard for me to do. At the end of the day I offer up the best and worst parts of my day. Sometimes I feel warmth. Sometimes I feel nothing. I try again tomorrow. I can also ask questions of the several spiritual traditions which have supported me these past 35 years. What has become part of me from Christianity, Judaism, and Buddhism? How have aspects of these spiritualities taught, enhanced, healed, and transformed my parenting, my journey with disability, and my life?

Spirituality impacted my mothering. There was a moment just after Graham’s birth, while we were still in the hospital, when I realized I was TOTALLY responsible for this life and all the nurturing and welfare of this little creature, and I needed to let this little creature know that his existence was O.K. no matter what happened. No longer was it maternity clothes, baby showers, and dreams. This is NOW – “Showtime – reality TV” – only the “program” would last for the rest of my life. I was not particularly spiritual at the time – and only lukewarm religious
with only occasional attendance at Sunday services. God was far away – an old man with a white beard and white robe just watching – waiting for me to mess up so He could write it down in His book – I had already “messed up” a lot so I was glad He was far away. Maybe He’d miss a few things. But now, I realized, I had been given one of His beings to take care of, and I had better not “mess this up.” I had read current parenting books and bought the iconic *Baby and Child Care* book by Dr. Benjamin Spock upon which I had been raised.

As a new parent I suddenly realized that what I thought I knew about mothering and childrearing, I didn’t know. Books were not the *experience*. Theories – not the *practice*. “What is my son saying when he cries?” I panicked. I wanted to do things right – Trial and error was o.k. for science – but, I didn’t want to injure my child. So – what was the thinking of the day and what ideas did current ideas grow out of? … and how did disability fit into those?

**Mothering in the Latter Half of the 1900s**

What does one do when because of circumstances beyond one’s control, the child who has arrived is not in the advice books by the child experts? There’s a little wooden box sitting on my desk, and on it is written, “Life isn’t about waiting for the storm to pass. It’s about learning to dance in the rain” (Anonymous). Below are two well-known, respected child theorists whose work relate to the plight of parents of children with disabilities and the plight of a dearth of information during the latter 1900s of how to raise their child. I for one was “learning to dance in the rain.”

**Arnold Gesell.**

World War II (WWII) (1939-1945) can be used as a dividing line for parenting, parenting advice, institutions, education, and mental retardation. Prior to WWII, Dr. Arnold Gesell was one of the popular child psychologists who wrote books on raising children. Beginning in the
second half of the 1800s people began not to trust themselves to raise their children so they
sought experts. This opened up a new expert field. Arnold Gesell received his doctorate in
psychology in 1906. He moved west to teach at Los Angeles State Normal School where his
friend Lewis Terman who had studied Alfred Binet’s intelligence test and was working on an
American adaptation. When Gesell joined the faculty at Yale University in the newly formed
educational department, the dean of the medical school got him a room at the New Haven
Dispensary. Gesell worked with school children who were having difficulties. He became the
first school psychologist in the United States. Gesell came to believe that trouble in school was
caused by developmental immaturities. The data Gesell kept resulted in his 1925 landmark book
_The Mental Growth of the Pre-School Child_. This book included action photographs and a
schedule of behaviors which should appear in developmental stages (Hulbert, 2003). Gesell
became known for developmental charts and norms. He was seeking the development of
autonomous adults and conforming behavior. Mothers became busy and anxious in trying to
follow this expert’s regimen (Hulbert, 2003). In reviewing three of Gesell’s books ( _Infant &
Child in the Culture of Today, 1943/1974; The First Five Years of Life, 1950/1978;_ and _The
Child from Five to Ten, 1946/1977_), I found it interesting that for all the work he did with
exceptional children, very little can be found in his books regarding this population. Deafness
in relation to language development is discussed in a later published book _The First Five Years
of Life_ (1950) along with a chapter on Clinical Adaptations to Atypical Conditions which deals
mainly with identifying physical handicaps (visual, motor, language, auditory) and emotional.
He does refer to the “institution child” for whom special examination is required. However, the
emphasis is on identification and not what to do next and nothing on parenting (Gesell, 1950).
From what I can find _Infant & Child in the Culture of Today: The Guidance of Development in
Home and Nursery School (1945) contains many behavior profiles for different ages but nothing for exceptional children or for parents of exceptional children. This was interesting because this book was originally published in 1945 and then revised and re-published in 1974 by Frances L. Ilg, Louise Bates Ames, and Janet Learned Rodell. Gesell died in 1961, thirteen years before the revision was published through the Gesell Institute of Child Development. By 1974 there were many children with disabilities living at home and not in institutions so I’m surprised that this book does not include them. The Child from Five to Ten, originally published in 1946, was revised and re-published in 1977. It does mention IQ scores, retardation, and retention because of developmental immaturity which usually meant behavior (Gesell, Ilg, and Ames, 1977, Chapters 8 & 12). I’m wondering whether one reason that children with disabilities are for the most part not included in these books is that it was customary through the first half of the twentieth century to place them in institutions. They were unseen to the general public and as a result did not appear in books for the general public. It may also be that the revisions were focused on updating Gesell’s normative plans, and since he didn’t write about the exceptional child for the most part, neither did the revisions include sections about this. It was the parents’ responsibility to get their children to meet the norms identified in the books.

Benjamin Spock.

Dr. Benjamin Spock, M.D. encouraged confidence in mothers which immediately made him popular with mothers because for over the past 50 years they had been devalued by the experts (Hulbert, 2003). Arnold Gesell had wanted mothers seen but heard as little as possible (Hulbert, 2003). Prior to the era of child experts beginning in the latter 1800s, women developed female networks of family and friends to give advice regarding child rearing and simple illnesses (Weiss, 1985). In addition, parents, especially mothers were tiring of the dictums being passed
down to them, and a more permissive movement was growing among the population (Hulbert, 2003). During this time Spock had much training in Freud’s psychoanalysis. He spent time with mothers when they brought their children to him in his pediatric practice. He had wanted to combine Freudian ideas of underlying drives to childrearing unlike the current ideas of bad habits and dictums from the experts. When the Freudian perspective did not work, he sought to give mothers at first, later fathers too, “sensible, present-day ideas” about raising children (Hulbert, 2003). Spock’s book *Baby and Child Care* was published in May, 1946, just as he was leaving his service in the navy. His wife Jane had helped him edit it and assisted in creating a conversational tone. (Hulbert, 2003). The 1976 edition included fathers as well as mothers in the book as well as 15 pages on the handicapped child (Spock, 1976). I do not know which edition of this book added the fathers and the section on disabilities. The section talks about attitudes, feelings, and gives contact help for several disabilities. It does not discuss HOW to change attitudes or process emotions. Surprisingly, a later book of Spock’s, *Dr. Spock on Parenting* (1988), does not include anything on disability which seems incongruous since the 1976 of *Baby and Child Care* does at least have a section.

I remember having a copy of Dr. Spock’s *Baby and Child Care* which was kept on a shelf with a book entitled *The First Twelve Months of Life: Your Baby’s Growth Month by Month*. This latter book listed developmental milestones. After the crib accident when Graham was two weeks old, I read this book over and over and kept checking it to measure his progress. Even with all the special appointments and weekly therapies with daily physical therapy work done at home, my son was falling farther and farther behind. I had been a literature major in college and had several hundred books which I treated well and treasured. However, one day when Graham was not yet crawling at the age of three years, I was reading the book. I became so upset and
worried that Graham might never walk, that I ripped up that book into little pieces...page...by...page as I sobbed. I had never done that before, and I have never done that since.

The 1950s began an era of parental advocacy for their children with many types of disabilities. Generally, parents wanted a better life for their child with disabilities who was being excluded basically from life. As these parents organized, they gained voice and visibility and used their connections or made connections with Congress so laws could be passed so medical and social barriers could be broken down.

**Disability Studies, Parenting and Implications for Praxis**

The social model of disability has some interesting implications for parenting, especially when the expert advice of the day doesn’t fit one’s child. The social model was written by disabled “outsiders” who wanted respect, opportunity, to be heard, to be seen, to be taken seriously, to make decisions about their lives. They wanted to belong. They wanted to act and change the world to be a better place. Aren’t these things what everyone wants? Aren’t they what we want for ourselves? And, aren’t they what we want for our children?

When the advice books by the experts didn’t work, I needed to stop. Out of frustration, panic, and struggle, I finally surrendered. I observed my son intently. …and I let him teach me how to teach him. I had to ask myself questions:

be who he is? Do I let him know he’s o.k. as he is? Do I use logical and natural consequences for discipline rather than a spanking? Do I model what I want him to be?

**Conclusion**

I’d like to think I chose the path I’m on, but in reality, the path first chose me. I merely said “yes” after being dragged kicking and screaming until I surrendered to my son’s needs. Shaping my parents’ ideas of parenting were the ideas of both Arnold Gesel and Benjamin Spock. A copy of Spock’s *Baby and Child Care* lay in my parents’ night stand for quick reference. I grew up with the importance of Gesel’s norms implanted in me through 1950’s standardized testing. Students in my classes were compared statewide and nationally. My parents would receive the results and convey them to me. Perhaps because of my personality and inner makeup, I felt pressure not only to meet the norms but to surpass them. Perhaps I felt unspoken parental expectations. I was the first child, and I was expected to be an example for my siblings. Either way norms were embedded into me. Yes, they created stress, but they were a normal part of my life, and surpassing them was important. This was the background I brought to parenting which unconsciously influenced me. And, it is with these influences that I started my parenting.

After the accident, I wanted my son FIXED – RESTORED TO HIS FULL POTENTIAL. Yet my thoughts, and attitudes and actions grew out of a particular place and time – as did those who started the disabilities movement in the United Kingdom. The difference is that I came to disability studies as a parent, and those who initially got together were disabled and living that experience daily. They got together initially for unity and for action: to break though the social structures, unconscious norms, and the physical, attitudinal barriers which kept them isolated and invisible and on the margins of society. Paul Hunt, Vic Finkelstein, and Mike Oliver organized the Union of Physically Impaired Against Segregation (UPIAS) during the 1970s and 80s. Their
thoughtfulness helped to start a worldwide disability movement which is continuing today branching out into numerous international organizations. I as mother, am part of that movement not only because of my son, but because I have my own membership as a mother which includes my own lived experience with disability which is similar but not the same as those living with disabilities.

Members of this disability movement developed conceptual models/perspectives from their experiences of living in society which consciously or unconsciously made it difficult for those with disabilities to participate. Many if not most of the unconscious and conscious societal assumptions, attitudes, judgments, and behaviors identified in the models/perspectives of disability, I experienced as well in raising my son. I felt hurt, and I faced them, protested, and advocated for my son’s opportunity to participate. I also needed to contend with being discounted and ignored as “only” a parent with nothing to contribute by some – but not all – professionals in medicine, education and social services so I’ve had my own experiences with the disability perspectives of medical, social, religious, and social adapted models.

During the 1940s and 50s there was not much advice regarding raising a child with disabilities from parenting experts like Arnold Gesell and Benjamin Spock. There was still not much advice when I was raising Graham during the 1980s. Because early development is so important to the adult the child grows up to be, disability adds another dimension to parenting. I spent much time parenting by being haunted by worry, “extras” in caregiving a child with disabilities, mental-emotional-physical exhaustion, the invention of methods to help my son, and advocacy so he could participate in peer activities. Parenting became its own trial and error adventure not only with my son but with caring for myself as well.
Until my son’s crib accident, I unconsciously held many of the attitudes brought to light in the Medical Model of Disability which isolated the disabled into being unseen and unheard and judged as incapable. Because I held these attitudes I feared for my son and what would become of him so I wanted medicine to restore him. My son’s name Graham Stewart Higgins was chosen not only for a familial link or his father’s love of Grand Prix road racing but for his parents’ yuppie expectations of success. After the accident I feared for my son becoming invisible, ridiculed, and discarded by society with its emphasis on capability and earning ability made me want to help develop his potential so he could find his niche in society and be accepted. My love for him wanted others to see Graham for who he is. Graham’s love of life, interest in people, loyalty, sense of humor, willingness to contribute, his smile, his laugh all needed encouragement not rejection. Graham is a member of the great expansiveness of human existence and needs to belong.

The Religious Model reminded me of how I had been hurt by interpretations of the Bible from those clergy who had not interpreted it by putting it into the context of the historical times and cultures during which it was written. Sometimes interpretations based only on the words and not the historical times or culture during which they were written can have a different meaning even an opposite meaning. I experienced harm, pain, judgment, exclusion, rejection, even self-hate from some of sermons purportedly from holy, knowledgeable clergy…only to find out years later that there are other interpretations which are more fitting. I will admit that I also received comfort, inspiration, community, healing and much good from other aspects of religion. I understood the pain expressed in the Religious Model, but I also sought the connection that is beyond the reach of words.
What has supported and sustained me so far has been a developing spirituality which has even changed my image of God, has comforted me, challenged me, and called me into relationship with the God I have experienced. Spirituality has changed my view of my son’s disabilities. Graham has been and is the teacher of my heart. He is no longer tragedy. He is gift. There are still challenges. It means I approach the future with confidence thanks to how the challenges I embraced and struggled with mellowed me and spiritually changed me.
Chapter 3

Method

Introduction

My quest as a parent has been to regain the hope and joy I had on the day of my son’s arrival in this world, albeit a different hope and joy, a compassionate, inclusive, and enduring hope and joy filled with wisdom. To do this I’ve been reflecting, researching, asking and attempting to answer questions in relation to my son and his disabilities and my life with him. As a result my research question is thus:

What can I learn by re-searching and re-constructing in a thoughtful, intentional way the events, feelings, thoughts, actions of the history of my life as a parent of a child with multiple, acquired disabilities? How has spirituality helped me in my journey with my son and his disabilities? What healings and insights has it given me? How has spirituality transformed my life and made it more meaningful?

Context of the Study

The context of my research covers my life with my son and how my son and I then interacted with society on several different levels during the past 35 years. Areas for my son and me include: bonding, lifelong commitment, learning to learn from each other, and an expanding of spirituality. Areas for me as parent include: dealing with trauma to my son, grieving, spirituality, learning to advocate, decisions regarding family and career, struggling in all these areas, decisions for my son’s life as an adult, and transforming struggles spiritually. Areas of intersection between Graham and me and society include: Spirituality, medicine, education, and parent advocacy, along with parent/child issues.
Purpose of the Study

For my research I plan to reflect, ponder, interpret, analyze, evaluate and give meaning to the parental journey I’ve had with my son. Spirituality has not only supported my journey with disability and my son but has transformed my quality of life and given meaning to me. Spirituality has comforted me during times of distress. Spirituality has not only supported my journey with disability and my son but has transformed my quality of life and given meaning and purpose to me. And, it has made me open to the gifts my son’s disabilities bring. I taught high school students for twelve years before resigning to be more present to my son when he was not in school. I also advised the weekly school newspaper for six years. Daily I would work with 150-180 students in my classes. I understand how in a profession that there are days when it’s difficult to see each student/client as an individual who deserves respect. The very day I am worn down, not as attentive or understanding may be the very day that student needs encouragement or some extra attention in order to understand what we’re doing. Maybe my experiences will give insight or reinvigorate professionals to see disabled as belonging to the vast continuum of human existence. Maybe my experiences will help disabled rid themselves of toxic shame, or, even better, not accept it in the first place. Maybe my experiences will help disabled advocate for themselves and find meaning, and purpose, and connection with the Great Mystery. Along with every course I took in my program as well as the extra courses I took, I read at least one book by someone with disabilities, or a parent with a child with disabilities, a sibling, or a caregiver. I wanted to see whether their experiences matched with mine, or whether they had different experiences. I was searching for confirmation of my choices and for additional ways of thinking and doing parenting. Did these parents, caretakers, and disabled reveal their struggles and what they did to change or accept them? Did they discuss what
supported them emotionally? Did they seek spirituality? In another way I was searching for meaning and to know that I had not wasted my life. I was searching to know deeply that my son and I belong because if I know that in every sinew of my being, I can speak out, advocate, and be comfortable with my son’s and my existence. I wanted to see what I could learn from their experiences. In an unexpected way I felt I had community when I was reading other people’s stories about their experiences with disability. Being a parent of a disabled child can have its lonely moments, and reading other people’s experiences with disability was occasionally like having a conversation with a friend.

Before I was a researcher, I was a teacher and then a parent. These responsibilities gave me many experiences on which to draw as I became a researcher – first for the PACE Program and National Louis University and now for my own research. Parents are of primary importance for their child’s welfare and development – physically, emotionally, socially, financially, and spiritually. I’ve journaled since I was in eighth grade and continued as I was raising my son. Some of this was to remember events. At other times I wrote to process emotions, to recount pain, and to process ongoing struggles for eventual epiphanies. I searched for meaning and slowly grew spiritually. As Laurel Richardson wrote in her essay “Writing as Inquiry”:

> Writing is a process of discovery. … The researcher’s self-knowledge and knowledge of the topic develop through experimentation with point of view, tone, texture, sequencing, metaphor, and so on…. The deepened understanding of a Self deepens the text. (Richardson, 2000, p. 936)

Through this research I will construct deep meanings and different perspectives to key incidents in my son’s and my lives. Telling stories is not enough. They need to be interpreted, analyzed, and reinterpreted from different perspectives to give a broader context. In his chapter “Talking over Ethnography” with Carolyn Ellis, Arthur P. Bochner says:
We need to see the knowledge we’re seeking in ethnography as the kind that helps readers use other people’s sorrows and triumphs as a way to reflect on or recontextualize their own, enhancing their capacity to cope with life’s contingencies. (Bochner, A.P., & Ellis, C., 1996, pp. 27-28)

In my research I intend to reflect on my own sorrows, mistakes and triumphs with my son’s disabilities and issues surrounding them for my own learning and to give others hope as well.

I must meet Laurel Richardson’s five criteria for autoethnography to succeed in my purpose. The first is substantive contrition in which I will add understanding to the life of a mother who has a disabled son. The second criteria is aesthetic merit in which I must engage the reader through my life’s stories and their analysis. I can’t be boring. Reflexivity includes ethical issues such as me reading my stories to my son before submitting them and either changing names or getting consent. It also means that I give adequate self-awareness and self-exposure in my writing. I must become vulnerable in what I reveal. Fourthly, I must impact my readers by gaining an intellectual and/or emotional response which may also include thinking about my writing at a later time. Reader impact is also shown by action through support or advocacy. Lastly, to fulfill Richardson’s autoethnographic criteria, I shall express my reality in an authentic, credible way which she calls an expression of reality. (Richardson, 2000, p. 937)

Carolyn Ellis speaks to Richardson’s criteria of impact for autoethnographic writing in her chapter “Negotiating the Story” which reviews her writing experience of the ethnography

Final Negotiations:

What text did you, the reader, create of my story? Did this narrative make you think about or shed light on events in your own life? Would you have acted differently than we did? Would you have told this story the way I told it? Did the words I wrote elicit from you an emotional response to examine? What did you learn about yourself and your relationships through your responses to my text? (Ellis, 1995, p. 319)
The audience needs to be considered as I write. I write for myself …and… for others. Engaged, active readers are important, and I must invite this involvement through my writing.

So, the purpose of my research is to delve deeper into my life experience (my data) and to interpret and identify meaning from these events and issues from my perspective and other reflected perspectives which I may not have understood at the time.

Knowledge

Constructivism

I didn’t know it at the time, but when I was teaching high school students, I was presenting knowledge in a constructivist manner. Patricia Hinchley describes constructivist epistemology in her book *Finding Freedom in the Classroom: A Practical introduction to Critical Thinking*:

…the way humans perceive things is influenced by their personal circumstances and personal views of the world. That’s why we generally make a distinction between “opinion” and “fact.” People look at facts—at what others do or don’t do, at what they say or don’t say, and how—and then they decide for themselves what those facts mean.

For the constructivist, it is the *meaning assigned to facts*, rather than the fact themselves, that matters when we talk about *knowledge*, about *knowing* something. (Hinchley, 2010, p. 41)

What I love about this explanation is that it confirms the way I’ve thought and taught since college. I read and apply knowledge/stories to me first. I ask questions of what I’ve read: Does this seem true? ..and… What have I learned about this topic? People? Relationships? Etc. An example of how I was a constructivist practitioner in the classroom follows:

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When I was teaching, I dearly wanted my high school students to understand that in literature, as in life, there was “more than one answer”, more than one interpretation, more than one meaning to a story, novel, or movie. I asked my students to watch a program on Public
Broadcasting (PBS) called Sneak Previews with Roger Ebert and Gene Siskel. Sneak Previews was a show which reviewed movies which were about to appear in theaters. Then we’d discuss it.

Next, we discussed how Siskel and Ebert would agree on some aspects of a movie and disagree at other times. Class members brought up how the reviewers supported their opinions about plot, script, acting, directing, editing, and cinematography. Students came to see that it was important to go back to the movie and select specifics from the movie to support their opinions. They saw Siskel and Ebert were professionals and that there could be more than one interpretation.

Then we turned to literature and applied the results of that discussion to literature the class had read. Students saw links between the way Siskel and Ebert interpreted ad supported their opinions about movies with what needed to be done with their own interpretations for literature. Some struggled with the idea that there can be more than one interpretation.

Others understood there are also meanings, ideas, nuances which can be understood as people bring their different cultures, values, beliefs, and experiences to each thing that’s published. …and each interpretation/meaning adds to a collective understanding. These students saw that they each had different experiences growing up. They each had grown up in different families. Some had moved. Families could have different values, beliefs, customs and even languages. All these experiences are brought to each encounter with literature, movies, and the arts. I wanted students to construct interpretation from the data in the piece of literature, their ideas, and their explanation of how the two intersected and created meaning. When it related, students could even include experiences from their own lives which connected with what we read. What was important here was the process that lead understanding of the story.
While I didn’t know the terminology while I was teaching high school students, I can identify that I followed a constructionist philosophy of knowledge then and now with my belief that there is more than one “right” answer and those answers can be arrived at in more than one way. I stressed that process was more important than product because it was the process of how to think, organize, develop ideas and support those ideas which my students would take with them and hopefully build upon after they left high school. I understand that there can be more than one “knowledge” about the same topic because people bring not only what they’ve learned to any situation but also their life experiences, culture, beliefs, and values to any issue, and because of this, there may be more than one perspective and more than one solution to any given issue. Facts and data may be the same, however, knowledge is constructed because of all that people bring to the interpretation of those facts, and as a result, people may create different meanings of that data.

The fact that the same event can be validly interpreted differently from different perspectives does not mean that it can be interpreted any way at all: there is a difference between opinion and argument, between unfounded assertion and reasoned analysis. (Hinchley, 2010, p. 51)

Patricia Hinchley’s statement resonates with me. Different perspectives can be heard and can exist side by side as long as they are supported by credible interpretation and analysis. Understanding that there can be more than one way of thinking about a topic or more than one way of resolving a problem makes me much more open-minded in how I approach almost everything.

Hinchley turns the noun knowledge into the active verb knowing when she states:

Often, it is only after the ordeal of trying to clearly say or write what we know that we come to really understand it. And often, in trying to say what we know, we discover just how much we don’t yet know or understand. (Hinchley, P., 2010, 46)  

As I write, I dig deeper for naming the experience, interpreting it, and gaining new meaning. Each time I go back to the memories, I learn something new. It is a process that feeds me in a continuing search.

Another aspect of constructivist epistemology is standpoint theory.

**Standpoint theory**

When I am denied an ability to be seen, heard, the power that goes with those two, and opportunity even to participate or be included, it’s like everything inside of me screams, “Wait a minute! I am good enough. I do deserve the opportunity to be seen, heard, and to participate.” I begin my struggle between the privileged and those who have not had the same opportunities or are different in some way. I experienced this struggle in college when I applied to be photo chief for my university’s five-day-a-week student newspaper and yearbook. The other applicant was male. We had the same grade point average. I was the better organizer, coordinator, trainer, and communicator. While the male photo applicant was a better photographer, I had many photos published, and had been an afternoon and evening photographer and photo editor. Yet, the only question I was asked from the three male professors was, “you know you’re a female, don’t you?”

My response was, “Of course, but what does that have to do with anything?” The professors exchanged glances and one pursed his lips. One of them looked down. None commented verbally. Needless to say I was made assistant photo chief. When I asked why, there was no answer. When I asked about the communication responsibilities along with the coordinating issues, I was told, “He’ll just have to change and learn to communicate, run meetings, and organize.” He didn’t. …and somehow those became my responsibilities on top of
the responsibilities of my position. When I recently learned of standpoint theory, I totally understood.

I learned of standpoint theory rather recently, and for me it means I have a perspective on issues and that my perspective comes from who I am in a historical and cultural time and location in the world. So, my beliefs, and values, and those of the culture I was raised in and live in today all influence my current perspective. I take my stand from my standpoint which is which is specific to me and “located in a particular time and place” (Sprague, 2010, 85). I grew up in a family in a suburb of Chicago during the 1950s and 60s with my father telling me I had the capability to do anything I wanted when I grew up and be whoever I wanted to be. Gender was NEVER mentioned so I was almost struck dumb when the demeaning question was asked during the interview for the photo chief position. It has never occurred to me that being female was less than being male. However, two years after I was assistant photo chief one of my sisters became photo chief for the same organization at the same university. This brings up another aspect of standpoint theory which considers that what the oppressed person or group gains “must be struggled for and represents an achievement…” (Hartsock, 1987, 160; secondary, in Sprague, 2010, 85-86). I like to think that at least a small portion of her acceptance was based partially on the work I had done and that those professors were at least a little more open minded about the capabilities of the female gender.

This was the historical, cultural and locale background for me before I experienced the question about my gender for which I was totally unprepared. The experience opened my eyes to the experience of being oppressed. Until this time I had heard of the haves and the have nots, but the concept was abstract, not visceral. I was not privileged because I was of the wrong gender. The boys club of male professors held the privilege and the power over difference… and
I was *difference*. All in one moment I realized I had never had a chance of becoming photo chief because I belonged to the wrong gender. The decision was made before I ever applied. When I discovered this, I was angry, outraged in fact. But, I also felt the toxic shame of being judged *not good enough*. I had not been chosen, not because of my ability or lack thereof. I was not chosen because of *who I was*. This hurt and demoralized me and seemed so unfair. All of a sudden my study of the philosopher Hegel and the historian Karl Marx made sense. I had lived what they were talking about – opposing groups, one dominant and oppressing the other … until there is change. Also, the experience, did open my eyes to the inequality in the workplace between genders (Sprague, 2010, 85-86; Hartsock, 1987, 162-175) and the entitlement of a privileged male class (Johnson, A., 2006, 21-29) all of which are elements of standpoint theory.

From standpoint epistemology I also found a home from which I, as a mother of a child with disabilities, could explore issues regarding my son’s disabilities and issues impacted by these disabilities, including: marriage, family, medicine, career, finances, which gave meaning to actions I had taken, my responses to these disabilities and issues, and options for the future as well as how meaning for my life changed. I believe that anyone conceived as a human being is human and deserves to be accepted as belonging to the human species. With the ever-increasing knowledge around DNA and the human genome, scientists are finding that every human has similarities with every other human. And, every human has differences. Some of these differences include: race, gender, capabilities (physical, intellectual, etc.), disability, height, weight, health, age, etc. The differences do not preclude anyone from belonging. The combination of all similarities and all differences of human existence creates the human continuum of existence. All humans are included.
I also feel (and used to belong to) most people, at least in my culture, who deem disability as a subclass of humanity. Who aspires to be “disabled”? …and how often are people with disabilities from school, workplace, acquaintance relationships, etc., sought out and invited to social occasions held at people’s homes - not just the “official” social events held at school or the workplace? How can society benefit from the contributions of the disabled?

Hegel and Marx point out, two groups are formed, one has power and the other doesn’t. One group is privileged and accepted, and the other group is isolated and rejected. One way a group retains power is to keep the other group uninformed and without opportunity. Without knowledge of how things work or the opportunity to participate, the group without power cannot move forward, learn, progress, or even succeed.

An example of how coming to understand the dialectic… As Graham’s mother, I called up the Boy Scouts in Barrington, during the 1980s to enroll him in Cub Scouts. When they found out that Graham had some disabilities, I was told that Graham could not participate, and that there was a special ed Cub Scout den in Mundelein, two towns away. When I tried to advocate for my son, I was told that my son probably wouldn’t be able to keep up with the other boys, and the others would have to take care of him, and he probably wouldn’t be able to go camping and do the things the others were going to be doing. The judgment had been made by someone who had never seen my son. Graham, would not even be allowed to march in the July 4th parade with cub scouts from Barrington. We’d have to drive half-an-hour away to Mundelein. We did join the Mundelein group which turned out to meet in Graham’s school and included only his classmates. All of our sons had been rejected by our home town groups, and getting home late with school the next day eventually dwindled the group until it disbanded. I also think the rejection, isolation, lack of generational knowledge and social relations
opportunity (discussed earlier) in addition to the extra effort needed to attend meetings combined to thwart this ongoing special ed cub scout pack. This is an example of how those with disability, their parents, and those close to the disabled qualify to express themselves through standpoint theory and to employ it as a perspective for advocacy as others have done in the past.

When the special education Cub Scout pack disbanded, I could have resumed my struggle with the Cub Scouts in my town of Barrington, like I stayed with photography during my college years. I chose differently for my son. I felt that even if I won, I’d lose for both my son’s well-being and for myself. I did not want to place my son in the hands of people who had already judged and rejected him without even meeting him. I did not want my son’s spirit killed through toxic shame (Brown, 2007, p. 5; 2012, p. 69; Anfuso, 1994, pp. 7-8; 2005, pp. 7,9-13; Bradshaw, 1988, pp. 9-17).

In their article *Self-Determination and Empowerment: A Feminist Standpoint Analysis of Talk about Disability*, Joey Sprague and Jeanne Hays (2000) focus on developmental disabilities. They identify three empowering relationships for those with developmental challenges: a. group support because the sharing of experiences creates a mutual support system (p. 682); b. group therapy so people can “confront their feelings of loss and work together to develop ways to deal with the social stigma of their disability” (p.683); and, c. self-advocacy groups which provide occasions for people to be “working together to fight for their rights” which helps to develop more positive selves (p. 683). Self-advocacy groups also “provide a model of empowering relationships” (p. 683). As a result, it feels appropriate that my study looks through the lens of standpoint theory as I write about disability.
Research Design

Zeroing in on My Methodology

I learned in a creative writing course that I could not write my son’s biography which was something I had wanted to do. It was an important moment for me because painful as it was, I also learned that I could write about my own experiences as Graham’s parent. The value in this is that I could write from a number of perspectives. So, as I began the doctoral program in National Louis University’s (NLU) Disability and Equity in Education (DEE) program, I knew I wanted to write, reflect upon, interpret, deconstruct, and analyze one parent’s experience raising a child with disabilities - struggles, challenges, failures, triumphs, ongoing issues, supports, and changes over time. To prepare I gathered my journals which I started when I was in 8th grade and continued to keep when Graham was born, and I read one or more books by parents, those with disabilities, or siblings for every course I took during the program. In addition to reading theory and research in autoethnography, I have continued to read these books since passing my comprehensive examination. There has been practice in using autoethnographic techniques which were required in my doctoral coursework as well.

It was tempting when Carol Burns, the Director of the PACE Program, invited me to assist with the 25-year longitudinal mixed research studies of graduates and parents of the PACE Program and the Transition Program. She was hoping I’d do these for my dissertation. While I was glad for the experience in mixed research, I explained my heart was set on an autoethnographic dissertation. I enjoyed reviewing the earlier questions to the studies, updating them and adding a few questions with the approval of Carol Burns and Assistant Director Barbara Kite. We applied for two IRRBs and received permission to work on the studies. I coordinated the set-up of Survey Monkey, downloaded and tabulated the results for both surveys
in Excel with percentages and graphs. After interviewing several graduates, I wrote about their comments. Then I drafted the write-up for the parent survey. Carol planned to do the same for the graduate survey.

While I truly enjoyed working on the quantitative and the qualitative parts of these surveys for the two years I worked on them, I still wanted my dissertation to be qualitative and an autoethnographic study of one parent’s experience of raising a child with disabilities. For me the thinking processes between quantitative study and qualitative study are different. I find knowledge in both quantitative and qualitative methods though different kinds of knowledge. When I’m in the quantitative mindset I’m in my head most of the time with numbers, statistics, and information and direction these can give. When I’m in the qualitative mindset, I’m in my head and my heart, and pondering, staying with a situation, a topic, an issue in a different way than when I’m involved with the meaning of numbers. For me, qualitative knowledge may be supported by numbers from the quantitative method, but there can also be a deep knowledge gained from experiences and emotions which can lead to wisdom and what it means to be human. This is what draws me to the qualitative method.

**Qualitative Research**

One of the reasons I have been drawn to qualitative research is, as Norman Denzin and Yvonna S. Lincoln (2008) define in the third edition of *Strategies of Qualitative Inquiry*, that it “crosscuts disciplines, fields, and subject matters” (p.3), which means I can include my varied experiences and show how they are related to a variety of disciplines and subject matters and can support my reflections and analysis by those disciplines or critique of those disciplines through my reflections and analysis. Throughout the introduction Denzin and Lincoln use the analogy of the French term *bricoleur* to explain aspects of qualitative research. The term *bricoleur* literally

There are many kinds of *bricoleurs*—interpretive, narrative, theoretical, political, methodological (see below). The interpretive *bricoleur* produces a *bricolage*—that is, a pieced-together set of representations that is fitted to the specifics of a complex situation. “The solution (bricolage) which is the result of the *bricoleur’s* method is an [emergent” construction” (Weinstein & Weinstein, 1991, p. 161) that changes and takes new forms as the *bricoleur* adds different tools, methods, and techniques of representation and interpretation to the puzzle. Nelson et al. (1992) describe the methodology of cultural studies as “a *bricolage*. Its choice of practice, that is, is pragmatic, strategic and self-reflexive” (p. 2). This understanding can be applied, with qualifications, to qualitative research.

The qualitative researcher as *bricoleur*, or make of quilts, uses the aesthetic and material tools of his or her craft, deploying whatever strategies, methods, and empirical materials are at hand (Becker, 1998, p.2). If the researcher needs to invent, or piece together, new tools or techniques, he or she will do so. Choices regarding which interpretive practices to employ are not necessarily made in advance. As Nelson et al. (1992) note, the “choice of research practices depends upon the questions that are asked, and the questions depend on their context” (p. 2), what is available in the context, and what the researcher can do in that setting. (Denzin & Lincoln, 2008, p. 5)

One of the reasons I am drawn to qualitative research is like a *bricoleur*, I draw from many fields for support. In raising my son, what worked? What didn’t work? What did I need to change? When did I need to start over? When did I need to walk away, give the situation time, and wait for the proper moment? Who, where were my supports? From where did resilience come? Where was God in all of this? Did God want the accident to happen to my son? Was the accident punishment on me or on my son? Or, did God allow the accident because it was possible for greater good to come out of it? Or, something else entirely? Where was the comfort and healing I had heard about? Where was hope? If I can’t find what I need in my own religion, what do other spiritual traditions have to say about the situation of “when bad things
happen to good people”? When I reached out for help, and none came, what did I do? I was like that handyman, pulling from here and there, tossing what didn’t work, and patching when the “fix” crumbled, and sometimes forging new paths. I needed to dig deeper for meaning.

When I was working on my bachelor’s degree, one of my history professors impressed upon me that “nothing happens independently. Everything happens within context. So, like a bricoleur I see and have experienced the complexity of being a parent of a child with disabilities and see ramifications for not only the child but also for marriage, family, friendships, education, social life, psychological health, society, spiritual life, and perhaps world view. This will require that I dig deep like a detective. The more elements of the parental life that can be included, the more inclusive and closer I will get to the whole picture with all its nuances of light, shadow, figures seen, and those just out of sight, as well as issues, stories, and themes.

Autoethnography

I remember my first journaling because I got my first gray hair in eighth grade, and I pulled it out and taped it into my journal, hoping I wouldn’t be gray by the time I was 20. Journaling helped me to process teenage angst, remember important events in my life, and to reflect and re-interpret situations and issues which I encountered. Sometimes I’d explore ideas and philosophize on “what might be” in my “perfect world”…which kept changing. I wrote dialogues working to remember exactly what was said because meanings were important and words had nuances which created differences regarding what was going on. I pushed myself to observe and record not only what had happened but the subtleties of facial expressions, body movements, and tones of voice. There were times that I didn’t understand what had just happened, and I wanted to record as closely as possible a situation so I could go back later and review and perhaps better understand what had occurred and explore different interpretations.
A Mother’s Spiritual Journey with Disabled Son

from alternate perspectives. Sometimes the journal was my therapist, and I would vent my anger and express my pain. Doing so forced me to put into words what I was feeling. Laurel Richardson (2007, pp. 162-163) illustrated that perspectives change over time in the generations of self, and time allowed me reflexively to reframe my perspective so I could gain insight to go on in a new direction. Reflexivity gave me Richardson’s self-awareness (2008, p. 480) and required self-exposure (2008, p.480) – inviting reader insight as well as judgment. Writing my experiences and being brutally frank and honest expressed reality – the good, the bad, the ugly, and the funny, even uplifting. Writing my mistakes as well as what I did afterwards contributes to the totality of disabled experience, both what works and what doesn’t (Richardson, 2008, p. 480). While I do not claim my writing has aesthetic merit, I hope the telling of my life experiences with disability as well as their reflections encapsulate some human challenges that once embraced can give meaning to one’s life. (Richardson, 2000, p. 932). As Laurel Richardson states about the autoethnographic writing strategy of narrative: “Narrative is the best way to understand the human experience, because it is the way humans understand their own lives.” (Richardson, 1990, p. 65).

As I just gave examples of how personal writing has helped me, Norman Denzin identifies how autoethnography is useful as he paraphrases a longer definition by Stacy Holman Jones, Tony Adams, and Carolyn Ellis in their 2013 Handbook of Autoethnography:

Autoethnography is the use of personal experience and personal writing to (1) purposefully comment on/critique cultural practices; (2) make contributions to existing research; (3) embrace vulnerability with purpose; and (4) create a reciprocal relationship with audiences in order to compel a response. (Denzin, N.K., 2014, Interpretive Autoethnography, p. 20)

These characteristics mirror those of Laurel Richardson with the exception of the criteria of authenticity. More than one definition gives me a broader understanding.
During that creative writing course mentioned earlier, I wrote one week about my son finding his hands peripherally. Most infants find them with their central vision in what seems like a magical 24-hour period, and they learn that their hands belong to them, and they can move them. After the crib accident Graham’s eyes just traveled back and forth horizontally, and I thought he had lost all sight. Plus, he was overdue in the developmental timeframe when this should occur.

Graham finding his hands was magical to me, and it gave me hope for his vision. I wrote about it in detail. One woman commented after I had finished reading, “I don’t know what to say. This was the most boring thing I ever read and heard.” It was an interesting moment for me. I remember the professor gently trying to prod her to retract what she said and make her give her opinion more gently, but she was not to be dissuaded. I was quiet. Other students continued with their comments until one woman identified herself as a technical writer had said, “Actually, this is quite good technical writing.” It was an enlightening moment.

This course was important for my growth because I learned that I survived the worst criticism a writer could receive, and, that I could not be a biographer for my son. However, I could write my own story as parent of a child with disabilities. So, as I was studying research methods during my doctoral program in Disability and Equity in Education at National Louis University, not only did I gravitate towards qualitative research but autoethnography felt like coming home to welcoming arms and a hug.

Laurel Richardson’s discussion of the importance of narrative as a method of inquiry resonated with me. In her book *Writing Strategies*, Richardson concludes:

> Narratives…reflect the universal human experience of time and link the past, present, and future.…Narrative is the best way to understand the human experience, because it is the way human understand their own lives.
…How and for whom should we write? If we wish to understand the deepest and most universal of human experiences, if we wish our work to be faithful to the lived experiences of people, if we wish for a union between poetics and science, if we wish to reach a variety of readers, or if we wish to use our privileges and skills to empower the people we study, then we need to foreground, no suppress, the narrative within the human sciences. How and for whom we write lives matters. (Richardson, 1990, p. 65)

For me this passage brought together the need for accuracy, authenticity, critical reflection, resistance to accepted cultural mores which judge and reject some and offer “utopian thoughts about how things can be made different,” showing instead of telling, and writing for larger change as Norman K. Denzin writes in his book *Interpretive Autoethnography* (2012, p. 78).

**Moral and ethical issues.**

However, I do have some trepidation as I approach this dissertation. The greatest concern I have is how my son Graham will respond to my dissertation. The focus of my dissertation is my parenting, and how spirituality has been a support for me. However, I do not know how my son Graham will respond to the stories I tell which include him. He feels before he thinks, and my interpretation of events may be different from his. Our memories may be different as well because we’re coming from different perspectives. Graham is looking forward to attending my defense. I have discussed with him some events which I felt he might be sensitive to, such as his father’s abuse of me when I told him I was pregnant which somehow he knew about already and has said he’s “o.k.” with being discussed. There is certainly the possibility of a question or comment during discussion after my presentation which may surprise or upset Graham. While abstract concepts are difficult for Graham, and he is slow in processing ideas, and needs people to give him time to respond, he is intuitive, kind and sees people and situations from a more accepting and inclusive perspective than I often exhibit with my honed
skills in comparison/contrast and judgment. He would be welcomed in many utopian worlds where the door would be closed to me.

I don’t want to hurt him, betray his trust in me, harm our relationship, shame him, or kill his spirit for life. Carolyn Ellis considers this moral/ethic issue of autoethnography in her journal article *Telling Secrets, Revealing Lives: Relational Ethics in Research with Intimate Others* (2007) as she reflects on how people she studied were affected by studies she published which participants later read or heard about. Ellis describes her learning process including painful, regretful times and through experience careful decisions and conversations with participants which led to a more inclusive and participatory approach to both ethnography and autoethnography. Laurel Richardson reflects on these same issues of showing writing to participants prior to finalization and publication in her article *Hospice 101* (2011) and her book *Last Writes: a Daybook for a Dying Friend* (2007). She discusses issues of if and when to include participants in the reading of drafts and the importance of being honest, authentic, yet considerate of participants. This can be tricky for me. I don’t want to injure my son, and I do want to tell *my truth, my perspective*. I’ve talked with Graham about this. We’ve talked about how being a parent is different from being a child – and that I will probably see the same situation differently from him. I’ve asked him whether I may use his real name or whether he’d like to choose a name I should use instead of his own when I’m writing about him. At this moment he wants me to use his real name, *Graham*, not a pseudonym.

I’ve asked him whether he wants to read or have me read to him the draft of each of my parental stories. After a long pause, Graham said, “I’ll think about it.” I can’t give my participant son, the power of decision as to what topics, issues, or stories are included and which are not. However, as mother I do not want him to feel rejected, betrayed, or shamed. Where is
the healthy boundary between autoethnographer and mother? Between participant and son? I will probably find myself re-reading Norman K. Denzin, Laurel Richardson, and Carolyn Ellis, again and again as I write, and I will be contacting my dissertation chair and team as issues arise.

**Stories as data.**

Stories can be data because it is through stories that people make sense of the world. However, it’s not good enough simply to tell the story. Each story needs to be reflected upon to give meaning not only for me but for others as well. It is important for me to interpret, represent, and analyze these stories from various perspectives which will give multiple meanings. These multiple meanings may even identify tensions and contradictions. So be it. Any story is different depending upon from whose perspective it’s told. So is the meaning. There are even different perspectives within one person. We are not always of “one mind.” But, the different perspectives with their different meanings give a richer, fuller view, and sometimes a kinder view of possible realities. Stories are my data. The research is the intentional interpretation and analysis of my data.

I chose autoethnography as my method because it allows me to explore parenting, disability, and spirituality in the most flexible way – in the genre of storytelling which also allows me a variety of literary and research methods through which to add to disability knowledge. Hopefully, my stories along with their reflections (what I’ve learned and what I’d do differently) will help others to make their own decisions or to avoid my mistakes.

The stories I wish to tell have been selected with care. A couple of the stories continue to haunt me with unresolved issues. One revolves around a mistake I made which took 19 years to rectify. This situation my son will give his impressions on in a talk back session. Another story will illuminate a triumph which helped not only my son but others with disabilities as well.
Several stories will reflect my development emotionally, as a parent, spiritually, and values concerning career and family. I needed this personal development not just for myself but also in order to help my son. I needed to grow in order to help my son grow. Other stories will include issues around the models of disability and society. Several of these stories will have more than one motif within them. There will be struggles which have given me perspective and meaning.

**Audience.**

For whom do I write? First, I write for myself. What will I learn? By reviewing past experiences which have impacted me as parent and I have continued to ponder since, I shall learn which decisions/reactions I made were helpful for both Graham and me, and which were mistakes. I shall learn how my spiritual support assisted in my growth and quality of life.

Secondly, based on my findings, my hope is to illuminate my parent journey with my son for other parents, for professionals (esp. for teachers, medical personnel, and social service advocates), and I hope to expand thinking for the field of Disability Studies regarding the parental role in raising, nurturing, advocating for, and encouraging a child with disabilities so that the child can grow up to like him/herself and participate in society, and give back to others.

**Themes.**

Overarching and weaving in and out of all of these stories with the issues each contains will be my spiritual journey as a parent. I am different today than I was when Graham was born. Even my image of God has changed dramatically. While I hadn’t planned it, spirituality became a major support for me with my parenting and in my current life. I am not touching on spirituality at this moment except for the last story, but it will be a major thread in this research often tying the stories together.
What happens when my family is unable to provide the emotional support I need? Where do I go? How can spirituality aid me through comfort, direction, and action? What patterns exist in my parent journey, especially spiritually? What learning/development must I as a parent go through to be the parent my child needs? Responding to these questions is the focus of my dissertation. What are the lessons I’ve learned? What meanings can be drawn from these stories of my experience with my son? …and does he agree? …or, does he have a different perspective?

The first story (Chapter 4) relates the accident when Graham was two weeks old. How does a parent respond when the unthinkable occurs? How does one make sense of the unthinkable? What is my spiritual/emotional state? How much commitment is needed in the response first to the accident and secondly to my spiritual/emotional well-being so I can follow through on my parental commitment? What is too much giving of oneself? Where is a healthy boundary of commitment?

The journey continues with a hospital stay and specialists (Chapter 5). How much can medicine help? What is a parent’s role in medicine? How can medicine better access parental energy in a united effort to help the child? When/how does medicine turn into the medical model? What are the attitudes which turn into prejudices and then discrimination and permeate society to isolate the disabled and those who are different? In the presence of the medical model of disability, how is parental advocacy essential? What is a parent’s role when medicine’s assistance had reached its limits? How can medicine’s abandonment affect parental commitment?

The third story (Chapter 6) investigates the question “What does a parent do with emotions/thoughts which debilitate one’s functioning?” Who can one talk with to share self-
hate? If I share my feelings, will I be judged, or will I be accepted? What do I have to do not to feel this way? Related, but another part of the third story is the issue of grieving. Why was my parental naming and grieving of my dreams for my son and the experience of him “whole” for a brief time essential not only for me but also for my child’s welfare?

The fourth scenario involves toxic shame and parental failure (Chapter 7). What are the effects of parental toxic shame on a child with disabilities? How does this affect the parent/child relationship? How can the shame given be released? What is necessary for this release? What has been taken away, and how can it be given back? How does this help the child with disabilities? This story will have a response from Graham with his memories and impressions of this journey. The talk back will appear in the second to last chapter of the dissertation.

The fifth story (Chapter 8) delves into an issue of values clarification. How does a child’s disability affect a parent’s job/career/marriage/future children? What is more important – my career – or, my child? Can I afford to put my child first? Is it better for me to invest in my career so there’s enough money to take care of my son when I die? Or… Is it better for me to invest in my child to help him become as independent and as self-actualized as possible?

In the sixth story (Chapter 9), I return to the initial story with an update 35 years later. How have my struggles with resentment, self-pity, and worry because of my son’s disabilities been transformed through spirituality? How has this journey with spirituality changed me? How has my parental spiritual journey helped my son?

Lastly, the chapter before the conclusion will be Graham’s voice. It will be his perspective on his life, perhaps on my parenting. It is appropriate that his voice be heard. While this dissertation is mainly about my journey, I wouldn’t have taken it without him because without him I would have been on a different journey.
Conclusion

There are six stories of parenting I want to tell. Some bring up issues. Others will give reflection from me as parent from the time of their occurrence and then reflection, criticism, and perspective some 35 years later. Some will show growth. Some will show a journey still continuing. Graham considers Chapter 10 from our conversations together his dissertation where he can say what’s important to him. Granted, I shall never be able to paint the whole picture of my parental journey with my son with all its diversity. I hope to gain perspective on my own journey, to learn how the struggles I embraced have ultimately transformed me and given my life meaning. I hope to learn how spirituality has not only comforted and healed much of my pain but has also given me courage to speak and to act. Also, how spirituality has been a support for me but has transformed my life and given my life meaning.

To summarize up this section, I believe that knowledge is constructed and that there may be various interpretations of the data. For my dissertation, data will be based on my journals and memories spanning the 36 years of my son’s life so far. As a result my qualitative study will be autoethnographic. The six stories and the conversation/interview section with my son will identify aspects of lived parental experience as a response to disability with spirituality as a support.
Chapter 4
1980 – Beginning the Journey

Accident

Why is it that the day which changes a person’s life often begins so normally and without warning? My son Graham had been born two-and-a-half weeks earlier, and after a brief stay in the hospital for a high bilirubin count, we went home where our Old English sheepdog Gus immediately adopted Graham as part of our family as he got down on all fours and wiggled up to the moving bundle on the blanket. My mother came the next day and stayed a week.

Then it was my mother-in-law’s turn. Esther lived an hour-and-a-half away. It was January and there had been a lot of snow earlier in the week – but the roads were now clear. Ken (not his real name) and I had expected Esther around 1:00 p.m. At 5 we began to worry. Ken called his father to find out what time his mother had left. 11:30 a.m. Richard figured she had gotten lost and was somewhat perturbed because he had wanted to drive up in front of Esther to see his grandson and then drive back home. He suspected she’d get lost if she drove by herself. But, no, she insisted on being independent was his response.

Ken and I were helpless. It was the era before cell phones. We tried to decide when we should call the police to search for her, but couldn’t decide. Hopefully, she’d call. Eventually Esther arrived, tired, somewhat upset by her ordeal in the kingdom of lost travelers, and focused on one thing, holding her grandson.

Even though I was supposed to do no work or driving for six weeks, I made dinner. I had been excited about Esther coming because she was a real cook and a seamstress. She knew what I didn’t about homemaking.
During her stay I was hoping she’d fix an “L” tear next to a pocket in the three-piece suit my father had bought for Ken. I had planned to try to sew the tear by hand to blend the stitches as much as possible so the mending was camouflaged. However, Esther used my sewing machine and her “fix” exposed the place of the tear to everyone who would look upon it. Seam-ripping her sewing would damage the material even more so I gave up.

Esther helped in other ways too. She took apart the Roper counter-top stove to clean it. I had especially loved the simmer burner. It never worked again. Then she cleaned our smoke, Plexiglas kitchen chairs with SOS pads which left them irreparably scratched. The problem was Esther always “helped” me when I was asleep and never discussed her projects before doing them. In all, twenty-seven things were ruined, broken, or otherwise damaged during her week-long stay.

The day of the accident I nursed and burped Graham early in the afternoon. I was about to change him and put him down for a nap when Esther insisted on doing it herself.

“Margaret, you go take a nap. I’ll put down Graham.”

“Esther, remember, please, to put him on his tummy in the middle of the bed or on his side leaning up against the side of the bed.”

I sat at the kitchen table resenting the tone in Esther’s voice. Since she had arrived, I was being ordered about in my own house as if I didn’t know how to do anything. I had shown her how the nurses at the hospital had taught me to put Graham in bed. “Either put him on his tummy in the middle of the crib, or put him on his side leaning up against the side of the crib. DO NOT put him on his side in the middle of the bed with a burping blanket behind him. What happens is the blanket isn’t strong enough to hold an infant up, and the infant rolls over on his back with the blanket underneath him so the baby’s back is arched over the blanket. If he then
burbs, the burb slides down into his nose. Infants do not yet know how to breathe from their mouths so the baby may suffocate.” I had explained this to Esther along with the fact that this is what the nurses in the hospital had taught me.

Esther’s response was, “I know more than the doctors.”

“It was the nurses who care for the infants, not the doctors who told me this.”

Education was an issue between us. I had a Master’s degree, and she had a sixth grade education. However, Esther could and did can fruits and vegetables. She could pickle as well. Also, Esther was a seamstress and could sew outfits without a pattern. I could cook, but I could do none of these other things and had hoped to learn from her. However, when I tried to affirm her and have a relationship with her, she said, “I had hoped my son would never marry.” For some, this would have been a warning. For me, I had an insight into Ken’s upbringing. When we were dating, he had told me his parents had offered him $1,000 not to go to college. Ken had paid for his five-year architectural program himself through summer work with an architect and work in a dormitory cafeteria during the school year. Esther’s comment helped me understand why he wanted to leave home. I admired that Ken had a dream and was overcoming the obstacle of no family support to make it happen. Ken became the first one in his extended family to graduate from college.

Because of the educational issue Esther and I had, I didn’t want to belabor the training of how Graham should be put to bed. I showed her the two methods which were simple and after explaining that it was nurses, not doctors, who trained me, let the matter go.

However, on the day of the accident when Esther demanded on putting Graham down for his nap and told me to take a nap, I remained sitting at the kitchen table. Esther was in Graham’s room for what seemed like a long time. I wanted to build trust between Esther and me,
especially regarding Graham. She had not wanted me to marry her son but had not explained the reasons.

When she returned, I asked, “Did you put Graham down on him tummy in the middle of the bed or on the side of the bed on his side?”

Esther answered, “Yes. Now you go lie down.”

She hadn’t answered my question, and even though I was tired, I wasn’t going to let her order me around in my own house. “I’ll take a nap a little later.”

I remained at the table. Esther cleaned up the kitchen. Cold silence stood between us as we each took our emotional stands. At some point Esther left and went into Graham’s room. She was there for what seemed a long period of time.

As she was returning and walking down the hall, I stood. “I admit I am a little tired. I’ll check Graham and then take a nap.” I thought this might affirm her.

Esther, all 6 ft. tall of her, barred my way by putting her arms up and touching each wall in the hall. “NO! You go sleep!” in her raised voice.

“Esther Higgins! This is MY house, and Graham is MY son. And, if I want to check on MY son before I sleep, I WILL.” I pushed her arm out of my way and stomped down the hall to Graham’s room.

Graham’s face and fingers were BLUE! His lips were a deep blue! Esther had put Graham in the middle of the bed on his side with a burping blanket behind him!—Just what I told her NOT TO DO! WHY? Can’t worry about that. There’s burp in his nose. Get that suction bulb from the hospital to pull it out. Bulb doesn’t work. Graham has sucked the burp in too much. Call 911. That won’t work. We’re 2 blocks outside of city limits so it’ll be county
paramedics who’ll have to come- and that will take 20-30 minutes. We don’t have that much time. How to get the burb out? The thin sewing needle I keep in the bathroom vanity for slivers!

I scooped Graham up in my arms, ran to the bathroom, slammed the door and locked it. I didn’t want Esther anywhere near me. I opened the vanity, grabbed the needle and hooked the burb at the edge of one nostril and pulled. A thick, milky glob about ½ inch long came out. I hoped it was all there was. Then I hooked the edge of the other milky glob in the other nostril and pulled. It came out. I didn’t know whether I had gotten it all.

A noise like someone who’s been under water too long and this is their first breath filling their lungs came out of Graham through his nose. Then he started crying loudly and breathing. I held him close with his head above my shoulder, and I rubbed his back and talked to him telling him how sorry I was – that I was glad he was a fighter – and that everything was going to be o.k. Mommy’s here.

I adjusted my holding of Graham so I could look into his eyes. He was still crying loudly, but his color had changed to red instead of purple. Progress. I wanted eye contact with him – at least as much as a 2-week-old infant can give. I stood there and held him.

A loud knock on the door. “Is everything o.k. in there?”

“Yes, Esther.”

“The door is locked. I can’t get in.”

“I know. I’m keeping it locked for the moment.”

She had just been in Graham’s room before I went in. How come she didn’t see Graham in distress? …or…Did she see him in distress and just leave him?

I stood in the bathroom holding Graham, looking into his eyes, comforting him. He was grasping my finger tightly. I felt the tension leave his muscles. Then he let go of my finger.
Neither hand could grasp my finger. What had just happened? We look at each other eye to eye. I hold Graham close to my heart with his ear to my chest so he can hear my heartbeat. I want to calm him…and me.

I opened the bathroom door and walked to the living room and sat in the rocking chair. I was tired. I needed to sit down. I wasn’t going to let go of Graham…and I certainly wasn’t going to let Esther touch him. Graham was calming down. We were looking into each other’s eyes…when all of a sudden Graham eyes started moving back and forth horizontally. They didn’t stop. They no longer focused. What had happened? We sat there together for I don’t know how long.

Eventually I got up and went to the phone still holding Graham. Esther followed me. I called my mother.

“Hello?”

“Hi, Mom. I need your help. Something’s wrong with Graham. Please come.”

“Margaret, Dad and I are half-an-hour late leaving for Florida.”

“But, you’re driving. There’s no schedule to meet! Can’t you come? I really need your help.” “No. You know your father.”

“I need you.”

“You have Esther.”

“That’s the problem.”

“I’m sorry. We’ve got to leave.” …and Mom hung up.

Esther had been in the room with me the whole time. I didn’t know what to say about her in front of her, or, at this moment to her. I was so numb.
I understood Mom’s and Dad’s need to get on the road with the massive snow storm coming. Dad didn’t like driving at night, in the rain or in snow, especially in snow and ice, and this storm was expected to be both. On top of that they had to go through the Smoky Mountains and cross the long bridge over the Chattanooga River, not a fun prospect in a snow/ice storm. Dad could be imposing, especially imposing when he was fearful about the drive so I understood Mom’s need to get off the phone. They both needed to get on the road so Dad could get to Florida so he could breathe better and be away from the Chicago winters which were hard on his lungs. …and I had not really explained about the emergency with Graham. I was afraid because Esther was following me around the house and was in the room when I called. I was afraid of her now and all I knew was I wasn’t going to leave Graham alone with her. I didn’t know what to do. I wanted and needed my husband to stand up to his mother for Graham and me and protect us by getting her out of our house.

I hung up. Esther was still in the room. I don’t know what she was thinking. She was following me around the house. Perhaps she was afraid I was going to hurt Graham. Little did she know I wanted to hurt her – real bad.

Holding Graham I paced through the house slowly. There were three things on my mind:

1. How do I keep Graham safe from Esther when she’s sleeping in his room? The crib had been assembled in that room and was too wide to be moved out to our bed room. I had turned down Gramma’s offer for her small, wooden, rocking cradle because I didn’t know how our 7 year-old Old English Sheepdog Gus was going to react when we brought Graham home from the hospital. The cradle was an heirloom. It rocked. However, it was low to the ground, and Gus could easily reach in and lick or bite Graham. He could also have tried to jump into the cradle which would have been
disastrous. Either Graham would have been injured or Gus would have been hurt since the cradle would rock when touched.

I had worked with Gus for four months prior to my delivery because he hadn’t been around children and he was an “only” dog. Luckily Gus “adopted” Graham as soon as he met Graham. I regretted now that I had not taken Gramma up on her offer of giving me the hundred-year-old cradle. The cradle would have easily fit in our bedroom. Ken would never agree to sleep with me in Graham’s room because he got up early in the morning, and his clothes would then be in the room Esther was sleeping in. He wouldn’t like that. There were “issues” between them.

2. Should I call the paramedics now? Does Graham need oxygen or something? Or, do I wait until Graham’s check up with the pediatrician tomorrow morning? Graham was breathing. He was no longer blue. At the same time, however, did he need to be seen by a doctor now? When I looked at him, he was no longer struggling to breathe, his color had returned, and he was calm. Perhaps this muscle tone loss along with his no longer being able to hold my finger was temporary…and this eye thing…oh, please, God, let this be temporary. Since it was very cold with high snow mounds on the ground and since the crisis seemed to be over, and we were scheduled to see the doctor in the morning, I decided against calling the paramedics. We would be going out into the cold tomorrow. That would be enough trauma for Graham.

3. I want Esther gone. NOW. It took her 8-10 hours to drive the 1 ½ hour trip because she got lost. Dick, her husband, is coming on Sunday, and the plan is that they’ll drive home together with Dick in the lead, and Esther following in her car. While I want her out NOW, it’s January, and there are no motels nearby. What to do?
I continued to hold Graham. Esther followed me from room to room. I wasn’t talking too much with her. I was angry with her and feared her. She was 6 ft. tall and strong. I was 5 ft. 4 in. and weak after the 2-hour delivery which left my colon flattened and a bladder/kidney infection. I was not to drive for 6-8 weeks. I waited for Ken to get home. I wanted him to tell his mother she had to leave.

4. How do I forgive myself for not paying attention to the quiet nudges I received inside which told me to check Graham after Esther put him down for a nap? I had wanted to develop a positive relationship with my mother-in-law. ‘Family’ for me meant not just my husband, Graham and me but also our families of origin. My hope had been to create a new, larger family joining different traditions, values, philosophies, and this larger family would care and support each other. I was afraid that if I checked Graham too soon, I would destroy all possibility of developing a warm connection with Esther and all hope of trust between us would be lost. So I had waited to check on him when she returned from putting Graham down for his nap. But, everything went wrong. I hated myself and just wanted to fix my son.

…..

Now I know I’m alone. I’ll have to handle this by myself until Ken gets home. He can tell his mother to go home. She drove up here. Now she can drive home. Somehow Graham and I will survive. We both sleep more than usual anyway, especially with the bladder and kidney infection I have.

I pace a little more and then head for the rocking chair. Esther wants to hold Graham so I can sleep. Too scared to confront her, I tell her I’m fine. There has been so much I wanted to
learn from her. But, now. Now I’m afraid of her. Now I hate her. She tried to kill my son.

Why? Why?

I walk with Graham a little more, but I’m getting tired. The doctor said I was to rest for six weeks because of the long, 2 ½ hour delivery. I’m suddenly exhausted and need to sit down. I go to the living room and sit in the rocker with my left arm resting on the arm of the chair so Graham’s head is raised. We rock. I feel alone in the world.

Through my tears I look at Graham and make a solemn promise: “Graham, I don’t know what’s happened here. It’s like the universe has abandoned us. It’s like God has abandoned us. But, I promise you I love you and I won’t abandon you. I love you. I will do the best I can to fix this and to protect you.” We rock. I look at Graham. He can’t have understood what I just said. His eyes are still roving. He’s weak. He can’t even hold my finger anymore.

“God! Where are You? Why did You allow this?” I am scared. I am angry. I want what was! I raise my fist towards God...afraid that I’ll be disintegrated, and Graham will have no one. Even as I make my commitment to Graham, his restoration, and his welfare, I know I am consciously choosing the path of descent which saddens and frightens me.

Esther had dinner at 6:00 p.m. Ken arrived after 10:00 p.m. Esther had put all dinner things away and washed the dishes. A little over a year earlier Ken and two friends who were also architects started their own firm. It takes years to get established with clients so it was expected there would be long hours and short weekends. The week before when my mother was staying with us, she would get up and cook Ken a complete dinner at whatever time he arrived back then even if it were after midnight. I was thankful. He’d be home a couple hours, sleep until about five or six in the morning, and get up and go back to their office in downtown
Chicago. Since Ken was Esther’s son, and she was a really good cook, I had expected she would do even more for her son. Not true.

As soon as Ken walked in the door, Esther said, “You missed dinner. Get your own.”

Ken was silent.

“Esther, Ken’s building an architectural firm. It takes a lot of time right now.”

Speaking to Ken, she said, “You have a family now, and you should be home for dinner.”

There didn’t seem to be any room for give and take. Lines had been etched in stone. …possibly years ago. Meanwhile, Ken made his own dinner.

When he came out of Graham’s room after checking on him, I stopped him and told him what had happened earlier and told him I wanted Esther OUT OF OUR HOUSE – NOW! He broke eye contact with me and looked up and into the living room. While staring, he said, “I don’t deal with her.” walked away and went to bed.

Stunned, I felt Graham and I were totally abandoned.

I spent the night getting up every 10-20 minutes to check on Graham since he was sharing his room with Esther. Actually, I was checking on Esther. I had lost all trust in her. I was becoming more exhausted during Esther’s stay rather than resting as my obstetrician had advised.

Early the next morning after Ken and left and after I had nursed Graham, I began to put Graham in his snowsuit.

“Esther, as you know, Graham has a pediatrician appointment today for his two-week checkup. I’m glad you’re here because I’m not supposed to drive for eight weeks.”

“I’m not driving.”

“But, my doctor told me not to drive.”
“I got lost coming here.”

“Esther, I’ll be in the car with you, and I’ll give directions with time to brake and make turns. It’ll be o.k.”

“No. I’ll hold Graham.”

“No.” I said. “I have a car seat for infants for Graham. I really need your help in driving.”

“No.”

“How are you going to get home when Sunday comes if you don’t drive?”

“Richard (Ken’s father) is coming up. I’ll follow him home.”

“But, you’ll still have to drive. Why not drive Graham and me to the pediatrician? I’ll be with you. We won’t get lost. It’ll be o.k. I know the way.”

“No.”

I looked at the clock. We needed to leave to be on time for Graham’s checkup. Graham’s eyes were still “floating” horizontally from side to side. He could no longer hold onto my finger. His arms and legs had lost their muscle tone. Graham needed to see the doctor.

I drove. The atmosphere inside the car was colder than the near zero temperature outside. I had begun to hate Esther in a cold hate which lasts.

Graham and I saw Dr. Mervis alone, leaving Esther in the waiting room. Not a gracious move, but I didn’t want to be inhibited or over-emotional because of her presence. I had only talked with Dr. Mervis twice before and didn’t want to be triggered by Esther in Dr. Mervis’ presence.

After he answered my “new mom” questions, Dr. Mervis examined Graham. I noted the concern on his face. Graham was no longer able to do what he had been able to do the week
before. The concern continued. Graham could no longer do the “airplane” test where the infant is placed on his stomach, and instinctively raises his head, arms and legs. He had lost much of his sucking reflex as well. He said to bring Graham back in two weeks instead of two months, and he was going to call the children’s hospital. Little did I know at the time, but this was the beginning of my journey with disability.

Reflection

Initial Reaction

How does one respond when the unthinkable happens and destroys any possibility of the expected, normal events from occurring? I spent years being angry with Esther, my mother-in-law, God, my husband, and myself. Esther for her issues with education and with me. She had a sixth-grade education before she had to work in the fields to help her family and somehow needed to show people with education that she was smarter than they were…in this case, me. So, she didn’t follow the instructions I had received at the hospital about putting Graham to bed. She said, “I’m smarter than the doctors.” when I showed her. Was Esther reacting to my telling her what to do or showing me that intelligence isn’t just linked to college degrees? She with her sixth grade education was intelligent too. Or, darker, did Esther bar my passage to Graham’s room because she knew Graham was in distress, and this was going to be payback for her son (Graham’s father) kicking her in the abdomen when he was two years old which resulted in the stillbirth of Esther’s second child?

Expecting to be struck by lightning, I would raise my fist at God, “You allowed this to happen so YOU FIX IT!” My image of God at the time was of a judgmental, white-haired man with a long, white beard in a long white robe who was just waiting for someone to do something wrong. (It would be many years before my image of God changed.) “Graham was innocent and
did not deserve what had happened to him! I’d understand if You did something to me. I’ve
done a lot wrong. If something happened to me, I’d understand, but not a two-week-old infant. I
don’t accept this! If You don’t love Graham, I do. If You won’t fix him, I will.”

I was angry with my husband for not supporting me with regards to his mother and for
his abandoning me with Graham’s care, yet expecting me to take care of Graham, keep up the
house, teach full time, and be administrative support for his fledging architectural firm. Secretly,
I felt he blamed me for what happened to Graham, but we never had this conversation. It was
too dangerous a subject to broach.

I was angry especially with myself. I blamed myself for the accident. Why had I tried to
trust Esther when my intuition told me to check on Graham earlier? Why was trying to build a
positive relationship with her more important to me than my son? Or, was it? Was I trying to
build a positive relationship to build relationships between families so Graham and all of us
would have a larger support network? Did I wait more minutes in order to show her that trust?
Did I wait because I knew I was tired and needed a few more minutes to gather the strength to
get up?

The nagging question, *Was I selfish to take care of myself and allow my mother-in-law to
put Graham in the crib so I could take care of my own needs?* became the self-judgment I was
selfish to take care of myself. The four-hour labor had been relatively easy compared with what
many mothers experience. However, the two-and-a-half hour delivery was difficult and left me
exhausted with a bladder infection and a collapsed colon. I was advised not to drive for at least
eight weeks and to rest as much as possible.

The other nagging question was “Why did I ignore those little nudgings of intuition which
I received while I was sitting at the table?” Esther was telling me to take a nap, and I wanted/needed
to show her I was in charge of myself and my household? Why did I not listen to those prompts? Could I have saved Graham from brain injury?

Yet…

Why would I not want to bond with my mother-in-law and build a bridge between our families? I remember happy times with both my mother’s and father’s respective families while I was growing up. Why wouldn’t I want the same for my son?

Why could I not expect support from my husband? What was wrong with him? What was wrong with us? What was wrong with my accepting his non-support?

I understand my parents wanting to get on the road to miss the huge snow storm that was approaching, but why didn’t my mother even want to know details of my problem? Yet, Dad could be insistent and intimidating when he wanted to get things done. I understood that at these times Dad was generally fearful of impending consequences which made him this way. Still, he could be scary.

Why did I feel guilty about taking care of myself? What was wrong with me?

I felt emotionally and spiritually traumatized by the accident and felt abandoned by God and the universe.

I pondered all these questions for years. My life changed forever. I had two weeks of happy motherhood with its initial adjustments and hopes for the future before all my dreams were crushed into oblivion. I felt my life was over. Instead of being a mother I was now caretaker. I had failed as mother. How was there going to be meaning in my life? I didn’t know. I felt I was at the bottom of a deep, deep hole. Sometimes I could see some blue sky and hear voices and laughter of people enjoying life. I’d try to climb out. Sometimes I could see the top of the hole. Sometimes not. I’d start climbing, digging my short fingernails into the dirt and
rocks. It hurt. My fingers were sometimes bloody and tender. As I made my way up, there were crags sticking out from the walls of the hole – large rocks which had to be surmounted. I’d try, gripping on and bit-by-bit pulling myself out and up, but my hands would slip, and I wasn’t strong enough to pull up my body around the rock jutting out over the black abyss below. I’d fall back down to the bottom and endlessly try again, like the Greek myth of Sisyphus, who was condemned eternally to roll the rock up the hill until it would roll back down and he had to start over. This is what my life felt like only I was not going to give up.

**Emotions – lost – abandoned – angry.**

As I reflect on those early days, those early years, I can say without hesitation that I felt abandoned and overwhelmed. I did not have support from my husband, and his mother whom I had originally admired for her skills of the home I had come to swing from anger to hate to fear, not to mention distrust. My family was unable to help as well. My teaching colleagues were almost an hour away for the most part and consumed with their students, lesson plans, school events, and their own families. I hardly knew my neighbors, and none of them had any children living at home. We all led separate lives. Church. Well, I believed but wasn’t practicing on a regular basis. I’d attend Sunday services if I were either really “down in the dumps” or really happy. The problem was what was I going to encounter from my husband when I got home? He didn’t believe in organized religion. If I arrived home from services, and he said in a low, guttural tone, “Well, are you saved yet?” I knew it was going to be a bad day. ….and God…How could God allow the accident to happen? I felt totally abandoned by God. I felt that Graham and I were alone in the universe, and the universe wasn’t friendly.

In those days it was my anger which got me through…which wouldn’t let me give up on Graham. I have since learned in therapy that anger is a valuable emotion because it lets us know
that something is wrong and pushes us into action to correct the wrong (Serafina Anfuso, personal communication, 1994). I had a lot of anger and refused to accept that Graham was injured for life. I was busy. By reading the First Twelve Months daily and comparing it with what Graham was doing, I became an active observer of Graham noting what he could do and how. I was collecting as much data as I could so when we were slated to go to the children’s hospital for assessment (and what I expected would be a “cure) when he was four months old, I could give the doctors an accurate picture of what Graham could do.

Spiritually, I was a mess…lost…feeling alone. I had held life, the life had come through me, and I had survived that daunting moment when I realized that this being’s nurturing and well-being was my responsibility…and I had inwardly accepted that calling. Graham and I had bonded. After the accident I had made a solemn commitment to him, and I intended to keep it. I was afraid for Graham. What would happen to my son if he were disabled? No. I couldn’t even think about that even though it was my greatest fear. I had come to believe that all kids are wounded in childhood and spend the rest of their lives seeking healing…often people just muddle through as best they can. What would happen to Graham if he couldn’t see? How much more difficult it would be for him. Kids can be cruel. Nicknames, judgment, rejection, imitation, teasing, and that loneliness of being left out… How much more difficult would it be for my Graham? No. I must do whatever must be done to get Graham restored to who he was and what he was before I found him blue and struggling to breathe in his crib…even if I must do it myself. So medicine and science became my idol. I had never been involved in any charismatic spirituality, but I started attending healing services. In attitude I alternated from the neediness of being overwhelmed, exhausted, lost and full of self-pity to the brazenness of being demanding, insistent, urgent, and fearful. I was sad about what might have been as well. I
wavered in prayer between pleading for Graham’s restoration and demanding “my” miracle. It would be years before I could hear the healing words of Ken Moses, Harold Kushner, Henri Nouwen, Pema Chodrin, the Linns, Richard Rohr, Joan Chittister, or Jean Vanier. At the moment I was in the spirituality of anger. I had become an activist.

**Search for meaning from others.**

While Graham was still young and slept more, especially in the evening, I continued to teach high school students in English, literature, and composition. I had let go of the weekly newspaper so I could nurture Graham with his multiple disabilities and until the school was reviewed for accreditation, and I was the only one with the proper credentials to advise it. During my last couple years of teaching I became interested in biography. Worthwhile biographies for me included strengths, weaknesses, struggles, reflections with depth, and meaning for the author’s life which often I found applicable to me as well. With carefully chosen biographies, I thought it would be helpful for the high school students I was teaching to read, evaluate and write about their lives so far and their goals for the future. Unfortunately, the course never got written because as Graham matured, he was awake later during the evening.

I was challenged to be present to him and prepare for my classes so I could also be present to my students in a way that both my students and I had come to expect. After twelve years of teaching, which I loved, I resigned in order to be present to Graham when he was not in school. But, the interest in biography stayed with me. I learned and was inspired by thoughtful biographies and autobiographies. Rabbi Harold Kushner’s *When Bad Things Happen to Good People* was suggested to me as something to read before Graham was five years old. Even though the copyright is 1981 and the pages are yellowed, I keep and still refer to this book. Rabbi Kushner’s first child Aaron was born with progeria, “rapid aging” and he would die in his
early teens (Kushner, 1981, 2). The process of transforming one’s debilitating emotions and using those emotions to a productive purpose is the purpose of this book for me. Working to release myself from guilt and using my anger to help Graham and others like him through advocacy started for me with Rabbi Kushner’s ideas. From a Buddhist perspective Pema Chodrin in her *When Things Fall Apart* helped me to know that when this happens it’s important to let “things” be, look for different perspectives, learn from these and respond from an attitude of love. (This was work for me.)

**Therapy & reality & education.**

I initially started therapy in 1986 as my marriage was ending. At the time I didn’t think there was anything wrong with me – just my soon-to-be former husband. To my surprise I had my own issues which needed processing, beginning from childhood. I had good therapists who helped me process the pain from abuse and who helped me re-interpret and re-frame misunderstandings. Training was needed to let go of familiar negative attitudes and behavior and to consciously practice unfamiliar healthier attitudes and behaviors so they could become automatic and part of my repertoire. Much was released during this period and much of what was understood but still painful and hindering was healed through spirituality and religion. There is still more to do which continues to make me a seeker of a life of meaning.

As I was preparing for parenthood, it never occurred to me that in order to be a wise, loving, effective parent that I’d have to learn from my child how to parent him or how to teach him. But, that is just what happened. When Graham couldn’t or didn’t learn from my way and frustration in both of us boiled over until neither of us could be in the room, the project had to be abandoned. Failure, regret, and resignation would set into my bones. Time would pass. Then Graham would find success another way. For example, I had had to learn my math basics from
memory in addition, subtraction, multiplication, and division in my head so I could recite them and then use them in calculations. Graham and I tried and tried using number boards, diagrams, manipulatives (pennies, pine cones, pieces of colored paper, etc.), charts, etc. All to no avail. We’d both be in tears. I was trying to force the information into Graham’s brain. Graham’s brain was saying, “No Way!” His teachers taught Graham how to use a calculator. Graham liked that. End of story.

Another example of Graham finding his way is in learning to set the table. As I was growing up, it was considered important in my family to learn how to set an Emily Post table. Besides the usual (plates, silverware, glasses, and napkins), the special items (salad fork, soup spoon, fish fork, finger bowl, water glass, wine glass, salad plate, dinner roll plate, etc.) needed to be committed to memory for future reference. Graham would either put the basics in the wrong order or just pile things up next to each plate. He was proud of what he did. I wondered how he was going to survive in society. After cringing inside for a couple years, I suddenly occurred to me one day, “When is Graham going to need to set a table for people in high society?” and “As long as every place setting has a plate, silverware, a glass for water, and a napkin, who cares if it’s arranged according to an etiquette book?” Graham is setting the table to include people and be of service. Am I setting it to impress people? Hmmm. Something to think about.

I was in a state of shock and numbness from the accident. I sought support and found none. Mother’s guilt consumed me. I was angry with my mother-in-law for not following directions and even more for not accepting responsibility. I was angry with my husband for his lack of support and understanding. Secretly, I was most angry with myself for not listening to
those nudgings I received and ignored for the misplaced trust in and hope of approval from my mother-in-law.

I feared that this tragedy was unfixable; that others would blame me; and that Graham, my son, would eventually blame me and reject me. For the first time in my life I feared the future. What would happen to my son if he were not able to be restored to his potential? …

1980’s - Anger with God

Spiritually, I was a mess. I had widened my vision of God during college, but I was not prepared for a catastrophic event like what happened to my son. Why would God allow this? What good can possibly come out of this tragedy? This has not just ruined Graham’s life but my life as well because I’m the one who’s going to raise him, and this is going to take life-changing sacrifice and commitment. I feel like both our lives are over … and Graham’s has just begun! It’s not fair, especially for Graham! What will happen to him when I’m gone?

“God, I’m angry with You! Where are You? Are You listening? How do I recover? I have to recover before I can help Graham recover, and I don’t know how to transform this situation – this pain. What purpose can he serve in the world? What happens to him when I die? How independent can he become? How can I teach him? What does he need? I don’t know. I’m overwhelmed. I’m in the dark night of the soul.”

…Yet, Graham melts my heart when he smiles which is often. And, the joy and spontaneity with which he faces almost every day and almost every new experience delights me and makes me marvel at his life force. If I can create an atmosphere that teaches and allows him to like and love himself, to value who he is – as he is – I will have accomplished something.

But I still feel abandoned by God. All I can do is muddle through each day…sometimes each moment. I must ponder and listen to that still, small voice which I had ignored.
--- Fast forward from the 1980s to 2007

**Moral superiority and Esther.**

In an attempt to create family, I trusted when I needed and sought to include when I needed to be vigilant for the sake of my son. After the accident I mulled over the events every day for years. I had unanswered questions. I wanted to get rid of the resentment I had towards Esther. I had many unanswered questions and wanted to get rid of the tightening in my stomach and chest every time I thought of her or that fateful day. So, in 2007, I took this issue to my spiritual companion. We had been through eight years of therapy and training together. I had a spiritual director who had also been in this program who was a priest and had two doctorates, one in theology and the other in psychology. He had the head knowledge. However, Grace Gibson, who was not as academically learned, had the heart knowledge. I needed heart truth, not intellectual explanation. As we prayed and worked together on this resentment and its causes, questions and new perspectives arose:

I did not see what actually had happened. I acceded to Esther’s request to put Graham down for a nap. When she went back into his room about 20-30 minutes later and stayed awhile, I did not follow. After the accident I had assumed that she had seen that Graham was in distress and that he had turned blue...and that she had left him without attending to his medical need. *Is it possible she did not see Graham in distress? I don’t know.*

I had incomplete knowledge. What did Esther do in the room the second time she was there? I had assumed she had gone to check on Graham. However, she stayed longer than a simple check would warrant. *So, what was she doing? I don’t know.*

I drew conclusions from two separate incidents involving Esther. I learned from Esther a couple months after the accident that when my husband was two years old, he *tantrumed* as
Esther was putting on his shoes, and he kicked her in the belly. She was seven months pregnant and bled every day afterwards. She did not see her doctor. The delivery was a stillbirth. Was Graham’s death meant to be payback to my husband? …and thus to me? …and most of all to Graham? The blaming tone of her voice while relating this led me to believe Esther had intended revenge for that tragic incident so long ago. However, as I look at this today, I must ask myself, Was this assessment of events wrong?

I was stunned. I had sought release, not more questions. Grace knew Graham and loved him as if her were one of her grandsons. I felt betrayed. Yet, I had to admit that what came out of our session had merit. And, this thought was not comforting. As I struggled with my blame of Esther I had to admit that my long-term resentment of her gave me a stance of moral superiority. After all. She had never admitted that she had put Graham in the middle of the bed on his side with a burping blanket holding him up - just what I had been warned about by the nurses in the hospital. She never even apologized for causing the accident. In fact she blamed Graham, saying, “Well, Graham did it to himself.) I felt self-righteous at blaming her…and kept the tightness in my stomach and chest. Now I had to own my feelings to work through rather than attribute them to her. Ugh. More inner work.

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What I didn’t realize at the beginning of this journey was that I was developing deeper compassion and that my image of God would completely change.
Chapter 5
Medicine as failed god

Story

At the outset of this chapter I want to thank those in medicine for their dedication. My obstetrician advised me to “take Graham home and love him”. I thought he should retire because I wanted Graham fixed after the accident, but in the long run he was wiser than I. Graham’s pediatrician delighted in Graham and got us into a children’s hospital. He remained Graham’s healer and advocate and symbol of hope.

My original plan for this segment was to write about my experience with medical professionals. The truth is I was mostly thankful for all the efforts taken, the professional dedication from almost all the people we encountered, and their genuine care and concern for my son. Of course, there were a few early incidents which fit with the negative attitudes described in the medical model and specifically spoke to parental involvement and advocacy. Other than these incidents, I have been nothing but grateful for the efforts taken, the dedication, listening and attention, critical evaluation, service, good will, and care Graham has received for 36 years. The medical professionals we encountered genuinely cared and did everything in their power to help Graham.

When I felt abandoned by God because there was no miracle for my son, I turned to science and medicine. Surely, doctors would know what to do to restore Graham to his original potential.

After the accident Graham was seen by his pediatrician who showed concern. Dr. Mervis, Graham’s pediatrician, delighted in Graham (and in my questions), and he remained
Graham’s supporter, advocate, and champion until Graham was 21, and Dr. Mervis sold his practice so he could give back to the world by teaching.

A few days after seeing Graham after the accident, Dr. Mervis called to say he had gotten us an evaluation at the children’s hospital, but we’d have to wait until Graham was four months old. I was excited. First of all, the hospital didn’t take everyone who wanted to come. Luckily, our pediatrician was young and had completed his residency there, so he was known and knew who to contact and how. Secondly, I saw this as an opportunity to restore Graham to his original potential which he had had when he was born. Waiting for two months was going to be the hard part. I had some work to do, however. Family medical histories from both sides of our family needed to be collected. Additionally, I wanted to write down as many observations as I could for the doctors. Sometimes, I don’t think of everything when I’m asked questions, and only later think of additional information and what I “should have” said so I wanted to be prepared with notes when we met with doctors.

Graham was admitted to a children’s hospital for evaluation when he was four months old. I looked to medicine to fix all my son’s problems. I expected medicine to provide the miracle God wouldn’t. Once a diagnosis (or diagnoses for multiple problems) was made, a treatment plan could be developed and implemented. That was my plan. We had a team of doctors working on Graham. We checked into the hospital and met with Dr. T_______, the head of neurology and the head of our team of doctors. The head of neurology was the head of the team, and he added a geneticist, a children’s neuro-ophthalmologist, doctors whose specialty was muscles, a physical therapist, an occupational therapist, and doctors/technicians who took all sorts of tests: EKG, EMG, a CAT scan, spinal tap, and blood tests every day for the five days he
was there. I was grateful. The more minds, working to fix him the better. I wanted diverse thinking, diverse approaches. Whatever would work.

I did not initially tell the doctors about the accident. If there were something genetic wrong or if there were a disease, I wanted that identified. I was afraid that if I told them about the accident at the beginning, the medical profession would just write Graham off and tell me nothing more could be done. I wanted the medical profession to search for additional causes in case it was something other than the accident which caused Graham to go backward in his abilities and development. I never anticipated any long-term medical journey of healing.

My daily, recurring fear for Graham dealt with what would happen to Graham when I die. I didn’t want Graham in an institution that would neglect or abuse him. I also didn’t want Graham in an institution which would one day close, leaving him to fend for himself on the streets. I had had a second cousin who in her 40s was diagnosed as a paranoid schizophrenic. She had a masters degree and was heading a social service program in Connecticut when she had her break. She was also one of the first ten people in the United States to receive a lobotomy. Sarah was in her late forties and living in an institution when I was born. My grandmother would get a vacation release for Sarah to visit her so we grandchildren were acquainted with her minimally. That is, until the part of the institution she was in closed during the 1960s. Since my grandmother’s sister was unable to care for Sarah, she came to live with my grandmother for the rest of her life. Since Graham had no siblings, what would happen to my Graham if he lived in an institution, and it closed, and I was dead? This was my great fear and great motivator to help him become as independent as possible. I just don’t want him to become a street person and abandoned by life.
Initial issues were identified: sight, muscle weakness, endurance, and developmental delay. One additional anomaly was found on one chromosome, but this was not linked to any of Graham’s combined problems. No other genetic or disease issues were found. (Nadler, M.D., H.L., October 21, 1980, personal communication)

I especially wanted to see the children’s neuro-ophthalmologist because I now knew Graham could see even though his eyes floated back and forth as some blind persons’ eyes do. Even though he had lost his central vision, Graham did have peripheral vision. I had seen him find his hands. Hopefully, the specialist would be able to restore Graham’s full eyesight.

When we were called to see Dr. Smith (not her real name), I picked up Graham and my notes and was escorted to her office. She examined Graham while he sat on my lap. She looked at both eyes, the sideways movement, and other things. I told her that Graham had peripheral vision, that I saw him find his hands, and I was noticing him cock his head and begin to watch people and things with his side vision. When she didn’t respond, I repeated this information several times but received no response. It seemed to me that she didn’t pay any attention to his peripheral vision.

All she said was “I hate to call him blind at four months. Bring him back in six.”

I couldn’t believe it. We were done. Dr. Smith told me to call and schedule an appointment for six months from now. No discussion. No preliminary findings. No acknowledgement of my observations. I asked her what we should do in the meantime. Were there eye exercises? Or, should I be looking for something and then call her?

“There’s nothing to do.”

I scooped Graham up and walked to the door. I turned and said, “Lady, you’re not listening. You’ve disregarded what I’ve said. Graham does see. It’s not normal. But, he does
have some sight. I have observations – data which you ignored! You’re not listening! AND, we’re never seeing you again!”

With that, I left holding Graham close. I burst into tears and asked myself, “And just what do you know about children’s neuro-ophtalmology, Margaret?”

I hurried back to the room to find that newspaper article on eyesight to read again, but someone had cleaned up all newspapers in the room. It was gone. I was upset, but I remembered what it had said because I had read it so many times. Basically, the article said the reason long hours of watching TV is so bad for children (and probably adults), is that it trains the eyes to be stationery instead of scanning the horizon or reading. (This skill is also needed in driving.)

_Graham’s_ problem was that his eyes were scanning but not stationery (except sometimes with peripheral vision) so he had the opposite problem. Since he had some sight, was it possible that long hours of TV could be a remedy for his continual eye back and forth movement without focusing or tracking? I kept thinking about this during the rest of our stay in the hospital.

After our 5-day stay, Dr. T____ asked us to make an appointment for 3 months so we could review findings from the tests, and he could say at the moment was that Graham had some _developmental delay_, and his progress would be checked in three months.

When we got home, I felt we had nothing to lose. All I understood about infant development was that development is not _set_ at birth. The bones in the skull are not fused. Synapses between neurons are not complete. Muscles, organs are still developing. There is still hope. However, if I were to wait six months and take Graham to another eye specialist, valuable time would be lost. The nerves and muscles in the eye may be set by that time. It seemed to me we had nothing to lose. I was still on maternity leave so Graham and I had time together as well.
I made heavy bean bags with soft, corduroy coverings. It was Graham’s habit to turn his head to the side so he could use his peripheral vision to look at something. If he were to regain his central vision, he would have to stop turning his head to the side all the time like he was presently doing to see. So, my method was to lay a blanket on the floor in front of our TV in the morning and turn on Sesame Street along with other children shows. Then I’d put Graham on the blanket vertical to the TV. Next, I placed the heavy bean bag around Graham’s head so he could not turn his head to use his peripheral vision. My hope was that since Graham especially liked the color red, he would fight to bring his eyes forward to focus on the TV. We watched TV like this for 6-8 hours a day, depending on how bad my headache was from Graham’s screaming. He protested, and I hoped. Our Old English Sheepdog Gus would lay next to Graham. After a couple months Graham seemed to scream less. I thought he was beginning to get back some of his central vision.

After four months I took him to my ophthalmologist who had procured Graham’s file from the children’s hospital. Dr. Bellows reviewed Graham’s file again and then examined Graham. He said, “Graham’s central vision is coming back. He’s my miracle baby! What are you doing at home?”

I explained what I was doing and about the newspaper article.

Dr. Bellows affirmed, “Well, keep doing it. It’s helping.”

So, we went home and continued watching TV with bean bags for another six months until we saw Dr. Bellows again. Graham’s central vision continued to improve. He did have nystagmus, which is a “shaking” of the eye, and Graham was still positioning his head either to the side or up or down in order to focus on someone or something. Dr. Bellows told me that once Graham decided which head movement he was going to use to focus on something, surgery
could be performed which would strengthen that muscle. However, Graham needed to demonstrate that he had chosen one way to rely on because the surgery should only be performed once. Dr. Bellows did not recommend surgery until this occurred. Graham never chose a preferred method so surgery was never performed. However, his central vision did continue to improve though it never went back to its original functioning.

---time lapse---

We continued to see Dr. T____, the occupational and physical therapist at the hospital for the next three-and-a-half years as well as seeing a hearing specialist, and physical and occupational therapists in a federal early childhood program. In our second to last visit with Dr. T____, I told him about the accident. I apologized for waiting so long and told him I had been afraid that if I told him and his team at the beginning, that it would be assumed that was the cause of Graham’s developmental delay and other causes, genetic, disease-related, or any other conditions would not be considered and possibly missed. I wanted to make sure every possibility was examined. Dr. T____, was gracious and said he understood.

Three months later Dr. T____, said, “We’ve examined every possibility for Graham, and while it would be fun to watch Graham grow up, there’s nothing more we at this hospital can do for him.” Graham was not walking or talking. He was hypotonic (low muscle tone, and low endurance). His hearing was better after ear tubes were inserted. His sight while improved greatly still contained a lot of head movement to get his eyes in the proper position for him to focus.

“What’s Graham final diagnosis?”

“Developmental delay.”

“What does that mean exactly? I don’t understand.”
“Well, to tell you the truth. Developmental delay is a junk term. It means Graham’s development is slower than most children. However, we don’t know for sure the cause. It could have been the accident you spoke of, or it could have been something else. We’ve exhausted the possibilities. It’s not a specific diagnosis like Down syndrome, or PKU, or cerebral palsy. We just don’t know.” (I felt sadness in his voice and slightly bent shoulders as he said the last statement.)

I didn’t know where to go or what to do from here so I asked, “What would you do if you were me?”

Dr. T_____ leaned up against the examining table crossed his arms and looked at the floor. There was silence. Then he said without looking up, “I’d put him in an institution and get on with my life.”

I was stunned. I was looking for a cure. I was looking for some small thread of hope. …and of course, anger was rising in me. I paused to collect myself before I said, “I may have to do that one day, but not now. Graham is young, and I want to see what love, family, and good education can do to help him.”

We said our last goodbyes, and I wheeled Graham out in his stroller. Graham slept on the way home, and I cried. “Graham’s been given a death sentence before he’s even had an opportunity to live.” I felt abandoned, first by God, and now by medicine.

**Reflection**

Thirty-some years later I am glad I didn’t wait for six months to take Graham back to that first children’s neuro-ophthalmologist, and that I took the risk of trying my own idea. It had never occurred to me that when I became a parent that I had become an advocate as well.
I also learned the importance of anger. It pushed me into action for my son’s sake. Anger showed me something was wrong and made me search for a solution. The first thing I needed to do was to define what was making me so angry that I needed to do something. That was easy. Graham’s acquired disabilities. I was also angry that the children’s neuro-ophthalmologist so disregarded my observations that she didn’t even seem to check Graham’s peripheral vision. Maybe she did and saw nothing. But, she DIDN’T LISTEN. I was the one who was most with Graham, I was the one who had four months of observation. This was data! …and I was unheard and invisible. …and with her cursory examination of my son, I did not have evidence that all of her knowledge and training had been used to help my son. In the past I had fired doctors who hadn’t treated me or my questions with respect. Actually, I just never went back, and I found a new doctor. This one certainly deserved to be fired. But, now what? I was no doctor, nor did I have any medical training. All I had was this one idea from a newspaper article which I no longer could refer to. I also had a lot of anger energy to spend which I used in buying soft fabric, a tan corduroy. I searched in the grocery store for bean, not too big so the bag would not be pliable to Graham’s and not too small allowing Graham to turn his head to the side so he’d only use his peripheral vision. They had to be heavy enough to hold Graham’s head steady so if he wanted to see the red on figures on the TV, he’d have to use his eye muscles and stop the unfocused scanning. By the time I had hand sewn the bean bags, my anger energy was gone and I could work with Graham. I was concerned I was doing unauthorized experimentation on my own child. I hoped I would do no harm. The anger morphed into fear. I was just more afraid to wait than I was of trying something.

...regarding the medical team...
For years I was angry with Dr. T_____ for abandoning Graham, exactly as I thought it would happen – the during the appointment directly after the one I told him about the accident. No suggestions about how to support Graham in education, physical ability, or social situations. – “just put him in an institution and get on with your life.” In my head I began to understand that there was a limit to what medicine and science knew. It might know more in years to come, but this is now, and I must deal with the now. I still felt abandoned, but realistically, what was medicine supposed to do if there weren’t any more ideas of what to explore for a given individual? Opposite to this, I felt lost and overwhelmed. If some of the best in medicine didn’t know what to do, how was I supposed to know what to do?

Whether or not it was real, I also felt silently judged by Dr. T_____ and by extension the entire medical profession. The way it went was “Well, you allowed the accident to happen because you allowed your mother-in-law into your house. …so Graham’s injuries are really your fault.” I felt I had been judged as not good enough to be a mother. I pretty much hated myself and wallowed in toxic shame. On my really exhausted days, I added self-pity.

However, as the years went on, especially after the divorce, and I became what I never wanted – not only a single parent but a single parent of a disabled child – which meant a lot of extra work, I realized there was another side to what Dr. T_____ had suggested.

If I had become too exhausted or depressed, I had an option of an exit. If I could no longer physically or mentally take care of Graham, or if he became violent, I could in good conscience place him in an institution because “Dr. T_____ has advised me to.” It was not an option I wanted, but it was comforting knowing that it was there…only because the bad days sometimes stretched out and seemed to last forever. There was a physical and psychological accumulation effect on me especially when I became tired over a period of days and weeks. I
realized, though, that had I chosen that route that I would have had a hole in my heart forever if I just put Graham in an institution. I would have felt that I had abandoned my son. This experience gave me compassion for those people who have to make a decision about institutionalizing a son, daughter, spouse, parent, or someone else close to them. No matter which choice is made, it’s the horns of dilemma. The decision isn’t easy, nor are the consequences. Whether the person stays at home or is placed elsewhere, there is inner pain for all involved.

Spiritually, I was a MESS. I vacillated amongst demanding a miracle from God to being desperate and begging for a miracle to just being overwhelmed by caregiving, worry, medical bills, teaching, and a disintegrating marriage. My family was quiet. They just didn’t know what to say or do to help me. Disability like this did not exist in the three living generations of my family. I felt alone… with responsibility I was unsure I could handle.

As soon as Dr. T_____ said it would be fun to watch Graham grow and to check in with him every year, but it would be expensive for us and there was really nothing more Graham could gain from the experience, I knew my son had been “written off” and he had become nothing more than a diagnosis. It was a change in attitude from the head of the teams of doctors being interested and involved with Graham as a person to being nothing more than a label and no longer a human being. At the time I didn’t have a name for it, but I felt it, and I was angry that my son was now rejected. During my doctoral studies, I learned the term applied to this situation is the medical model of disability. The medical model is an attitude which reduces a person to being considered merely as a diagnosis. When this happens, the person becomes isolated, invisible, unheard, and dehumanized because the person is no longer visible as a human being that person is no longer considered part of human society. The person who used to belong
as having the dignity of a human being is now considered *different*. And, that difference alienates, isolates, and leads to prejudice against. Comments like, “Put him in an institution…” promote separation from the rest of “normal’ people in society.

Additionally, the judgment of difference is imposed on the person. Graham, infant, toddler, child – just wanted to grow and experience the wonders of the world while he was dealing with his impaired vision and hearing, problems with motor skills and coordination, speech, walking etc., etc. Meanwhile, the attitude of the medical model was judging him as *not good enough*. The judgment is oppressive. I would see it in the expressions of people in stores as I’d pick up my four-year-old son to put him in a shopping cart. Narrowed eyes, pursed lips, and frowns from others told me I was being judged as coddling my son and not being a responsible parent. I wanted to shield Graham from this judgment so he wouldn’t accept and believe the lie that he wasn’t good enough. He needs all the belief in himself to become the person he could with all the dreams, spontaneity, capability, goals, character, personality, etc. that he can develop. …and society’s judgment of being *not good enough, less than, or not belonging* does not need to be imposed on him. The idea of *normal* needs to be unlearned.
Chapter 6
Wisdom from Teachers and Therapist – Beginning of Healing

Dorothy Anderson, Graham’s First Teacher

I must tell you about Graham’s first teacher who saved both of our lives and gave me inner peace, hope, direction, and she opened a way to genuine spirituality. During the 1980s federal early intervention programs existed from ages birth until three years of age. Then, children ages 3-5 were accepted into the state of Illinois programs for early intervention. Papers were signed amongst federal and state and school personnel, and Graham was transferred. Graham would be attending Laremont School which was a specialized school contributed to by twenty-six school districts in Lake and McHenry counties in Illinois. This is how Graham and I came to meet Dorothy Anderson at Laremont School. He did not walk or talk yet though his vision, while not quite right yet, had improved. During the 1980s Laremont was a school for students with developmental disabilities from the ages of 3 through 21. There were about 150 students in the school at the time Graham entered. It was decided that Graham would be in Dorothy Anderson’s class with three other students. In addition to Mrs. Anderson’s class, Graham would have physical therapy, occupational therapy, swimming, and communications which was sign language. In the evening, once a week, Graham’s babysitter, Pat Evasink, and I would attend sign language class as well. Since Graham was not talking, there would be a notebook which would travel with Graham for Mrs. Anderson and me to communicate in daily.

A school bus picked up Graham at home about 7:00 a.m. and dropped him off at Pat Evasink’s every afternoon after school. The bus ride was about 50-60 minutes every day. Since there were a few other students on this bus, I was not concerned about the length of the ride. I considered this an opportunity for Graham to have a little social life along with the atmosphere
Pat Evasink created in her home babysitting situation. The only person who cried in the morning when my little three-year-old Graham was strapped into a special seat on the bus was me. Graham was interested in the other kids.

Dorothy as she was called believed in Graham. He was one of four students with Dorothy as teacher and Jean as aide. Dorothy paid attention to what Graham was doing, what he was not doing, and how he was developing. I looked forward to seeing both Graham and her notebook when I got home from teaching. Sometimes we talked on the phone. Graham’s school was in the town next to the town I taught in. Sometimes she would come to my school to discuss Graham, and sometimes she’d wait at her school, and I would drive there to meet with her regarding Graham. Dorothy drove from Gages Lake to Barrington to meet and observe Graham at his babysitter’s so she could see his environment and how Graham functioned and interacted with other kids. She also visited Graham and me at home. She lived in Crystal Lake which was at least a half-hour further west. In other words, Dorothy was accommodating and kept the best interests of “the child” in mind. She went out of her way to gather as much information about Graham so she could give him her best as his teacher. Dorothy seemed to live the attitude that helping the parents deal (cope, work with) issues regarding their disabled child, helped the child. She supported parents as well as her first responsibility, the child. I felt safe in not being the perfect parent in her presence. That is why I called her at school from my school one day when Graham was 4 ½ and asked if I could come talk with her after school.

Dorothy was waiting in her classroom when I arrived. I took off my coat afraid that I was just going to ruin one of the few true supports I had for both Graham and me, and I hoped what I was about to say” wouldn’t affect the relationship Dorothy had with my son. She started
the conversation by noting that I sounded anxious when we talked earlier and asked what was wrong.

“Dorothy, you’re going to think I’m the worst person on earth when I tell you, but if I don’t tell someone, I’m going to burst inside. I try and try, but I’m missing something, and I feel so sad most of the time. Even when I’m happy – I’m sad.” I confessed.

“What is it?” she said.

“Ever since the accident I’ve been so angry with God for allowing this to happen to Graham. He didn’t deserve it.” I replied as tears welled in my eyes with my fear of rejection.

Dorothy looked at me directly in the eyes and asked, “Margaret. Do you know how many students are here at Laremont?”

“About 150.” I was stunned. This was not where I thought my revelation would take us.

“Yes. 147 at the moment. And do you know how long our principal has been here?”

“Yes.” I replied. “Fifteen years.”

“Yes. That’s a lot of parents who have gone through what you’re going through.” Dorothy commented.

Still confused, I said, “Yes, but I don’t understand.”

“Have you heard about Elizabeth Kubler Ross and her work on grieving?” queried Dorothy.

“Yes, but that’s about grieving after death.”

“It’s also about loss. Think about all the parents who have come through here in the past fifteen years. Do you know that in all that time you are only the third person to admit this in terms of all those parents?”

“I am?” I said amazed.
Dorothy continued. “Yes. …and you need to do this in order to heal. It’s part of healing”

“It is?” By this time tears were sliding out of my eyes and I had no control to stop them. At the same moment I felt released from years of self-imposed guilt, and I felt anguish for all the years I lived in such angst because I had not reached out earlier.

“You’re not the worst person in the world. This is part of grieving.”

“I’m not?”

“No, and because you’ve come this far, there is something I want you to do – even if you have to take a day off from teaching. Dr. Ken Moses is coming here to speak and talk with parents. He is a psychologist who did his post-doctoral work with Elizabeth Kubler Ross. Afterwards, he opened his practice for families of terminally ill children. Then he expanded it to include families of children with disabilities, including the disabled children. Ten years into his practice he had a son with cerebral palsy. He knows about loss, and he knows there are many kinds of loss. He has the clinical knowledge and also knows what a parent goes through.” Dorothy added.

“So he has the head knowledge and the heart knowledge.” I said taking in the information.


I was ready to listen. Dorothy Anderson’s acceptance and information that my anger towards God was expected and needed to be identified and was part of the grieving process relieved my angst and helped me feel less guilty about how I was feeling towards God. However, I still felt that my son was now a tragedy because of the accident rather than a gift. What was I going to do about that?
Ken Moses, Ph.D., parent and psychologist

I attended that presentation and made a commitment to myself that as soon as possible I wanted to see Dr. Moses as a client. It took about three years before I that could happen. In May, 1987, Ken Moses held a weekend workshop for parents. By this time Graham’s father and I were in the midst of what would be a six-year divorce. I felt this workshop was so important for Graham’s sake that I offered to pay for Graham’s father to attend, but he had a conflict of schedule.

Thirteen parents attended that weekend. We met and stayed in the Orrington Hotel in Evanston, Illinois. More parents were supposed to attend, but there had been some last minute cancellations. Since our numbers were smaller, the following morning Dr. Moses invited us to his home so there there’d be more privacy as we “worked.” This was his term for processing in therapy. He presented information about grieving and stated that grieving is needed even for the loss of dreams. Parents have dreams for their children, even for their unborn children. He said it was important to name those dreams and to grieve those named dreams when they didn’t come to fruition. He said this grieving of lost dreams was important so new, more attainable dreams could be dreamt. “Your work today will be to name your lost dreams for your child. Then you’ll work to process that loss. I’ll help you.” was the way Dr. Moses introduced the schedule for the day.

I observed that morning as several parents named and processed the pain of their lost dreams. Ken was insightful, pushed each parent into that avoided, painful area, and was compassionate. Parents genuinely seemed to feel better and have new direction after they “worked.” This was encouraging. We broke for lunch which were the box lunches we had packed at the hotel that morning.
During lunch I was thinking rather than connecting with the other parents. Why had I come? I hadn’t planned on “working”, especially in front of a group of people. I had thought this was going to be an informational workshop. I didn’t want to be vulnerable. What dream was I going to expose? But, I’m here now. I would waste the weekend and the opportunity if I didn’t face something. This is a risk. What will people think of me? How will I be judged? I don’t want to do this. Are there any benefits? I’m feeling scared.

We came back from lunch, and I settled into the same spot I’d had on a leather sofa during the morning session. All I knew was I didn’t want to go first.

Ken, who hadn’t had lunch with us came back cheerful. “All right. Who’s ready to work? Margaret, let’s start with you.”

I knew I wanted to “work” as Dr. Moses described psychological processing. I just hadn’t planned on going first. Caught off guard, I said, “Me?”

“Yes. What dream did you have for Graham?”

Flustered, “I don’t know exactly. All I know is that since the accident I look at Graham as tragedy rather than gift – what could have been versus what he is now. And, this isn’t the way it’s supposed to be.”

“But, what dream did you have for Graham?” repeated Ken.

“I don’t know. We expected Graham to be a genius and had some cause to think he would be.”

“So what would Graham being a genius do for you?”

Confused I said, “It wouldn’t do anything for me. All Graham would have to do is pick the field he wanted to give back to society with.”

“Let’s see. You have a master’s degree plus 30 hours. Right?”
“Yes. But, that has nothing to do with it. There are a lot of people who don’t have any degrees who are very smart, even more intelligent than I am.”

Ken continued to press. “But Graham being a genius would do something for you. What would Graham being a genius do for you?”

Inside I was getting angry. Ken had been compassionate during the morning session. What was this? I felt attacked.

“I don’t know. It wouldn’t matter to me whether Graham chose to use his talent in science, or the arts, or service, or politics, or business, or whatever. That would be his choice.”

It felt like Ken wanted me to say that I wanted to live vicariously through Graham for something I had wanted to accomplish in life. But, that wasn’t the case. I wasn’t going to lie. Where was he going with this?

Ken paused for a moment and looked at me. I felt as though I were being assessed as either being in complete denial or perhaps something else were going on. The Ken continued, a little quieter, a little more calmly. “Margaret, I want you to close your eyes and become very still. I want you to go deep. Why was Graham being a genius so important? If Graham were a genius, how would you feel?”

I closed my eyes and stayed that way. I tried to be still inside. I tried to listen to that still, small voice deep in my being. It seemed like forever. … When I opened my eyes, I said, “I would be so proud of Graham if he were a genius.”

Ken sat up straight and raised his arms like I had just made a touchdown. “That’s it! That’s it! That’s what you lost!”

Dumbfounded I just stared at him.
“You love intellectually! … and that’s what you lost with this child. You can’t love Graham intellectually.”

I started crying – silent tears poured from my eyes down my cheeks which I couldn’t stop. What he said FIT! This is why I had been so sad, so lost, so non-resilient. I didn’t know a person could love intellectually. I thought “love” was an emotion.

Excitedly, Ken continued. “And, now you know what you must do.”

Stunned, I blurted out, “NO, I don’t!”

“Yes, you do.” Ken said emphatically.

With my brows knit together, I repeated quietly and firmly, “No, I don’t.”

Ken paused a moment, then said more quietly, “Close your eyes again and go deep. You do know.”

I did as he said. When I opened my eyes, I asked, “You mean I have to love Graham with my heart?”

Ken smiled and now with a lot of compassion said, “Yes.”

“But, I don’t know how!” and started sobbing.

Ken waited until I had quieted down and composed myself, then said quietly and firmly, “Graham will teach you.” (Kenneth Moses, Ph.D., Personal Communication, May, 1987.)

….

I have replayed these two experiences over and over during the years because they meant so much to me and my healing. I can still see both Dorothy and Ken in my mind as well as the rooms they were in. I can also feel the emotional atmospheres of each experience. In each experience I felt vulnerable, and each situation required me to take the risk of exposing parts of
me I had not revealed to others. And yet, I so needed to stop feeling depressed and angry that I risked other people’s judgment and rejection.

**Review of story with Dorothy Anderson – changing my image of God**

Dorothy Anderson observed Graham, gathered information about him, by visiting Graham in his environments away from school she saw him in a larger context and saw larger possibilities for him than his Trainable Mentally Handicapped label (TMH) expected. She arranged for Graham to have his label changed (Educable Mentally Handicapped {EMH}) and let him(us) go to another special ed school where there would be more opportunity for him to develop his abilities. Dorothy Anderson saved Graham’s life.

Dorothy Anderson also saved my life and changed my image of God. When she accepted my revelation that I was angry with God and accepted it without judgment, my self-hate released and healing began. I didn’t have this insight at the time. That took years. I did, however, know that some oppressive weight that had been pushing me down and constrained me in a deep, dark hole had been lifted. I could see the sky, and I would be able to climb out of the cavern.

Dorothy’s compassion and mentoring of me not only informed me regarding the process of grieving but also opened possibilities that I had hitherto never considered. It was the beginning of a complete change in my image of God. Prior to Dorothy’s revelation that it was important for me to be angry with God and that it was a normal part of grieving, I had thought of God as this old man with a white beard who wore a long, white robe/tunic who waited and watched and wrote down in his big book every negative thought, word, or deed I ever did. I had been waiting for him to strike and disintegrate me with a bolt of lightning and was surprised it hadn’t happened yet.
However, Dorothy opened up the possibility of a God who was not the judgmental, vengeful God I had grown up with but a God who listened with compassion, a God who wanted relationship, not only relationship but also covenant, a blood/family relationship which could not be broken. A God who invites me into creating each day with Him/Her/More. Of course, these ideas didn’t arise in me all at once. It took years. Dorothy planted a seed and suggested I start by reading a book, *When Bad Things Happen to Good People* by Rabbi Harold Kushner which I did. Rabbi Kushner and his wife Suzette were parents of a son, Aaron, who was born with progeria (rapid aging) and died at the age of fourteen. While this saddened me, the information Kushner gave and his writing created credibility for me. He knew about the pain I was feeling, and he knew even more because of the death of his son. I wanted to learn from his experience. Kushner used the story of Job from the Bible as a metaphor for the continuing pain of the experience of living with his son’s disabilities and terminal condition. I understood this to mean perseverance is an important spiritual quality when there is long-term relationship with disability. Exhaustion often haunted my days and nights, especially when Graham was young. Some nights I was too tired to sleep, and it would have been easy to follow the doctor’s suggestion of putting Graham in an institution and getting on with my life. Sometimes the only thing that stopped me was the realization that if I did, and I put my energy in my career, it wouldn’t matter how many accolades I received, or how much money I’d make, or how many books I’d publish, or how much fame I’d receive. The hole in my heart for not putting my creative and teaching energy into my son would make all the other things worthless. So, I slogged on and persevered as well as I could. I found joy in Graham’s smile, and his amazement when he explored his world inspired me.
Later, another book helped me completely change my not only my image of God but my relationship with God as well. *Good Goats: Healing Our Image of God* by the Linns (Matthew Linn, S.J., Sheila Fabricant Linn, and Dennis Linn) spoke of the traditional, vengeful image of God as “Good Old Uncle George” (p. 3-7). Then Fr. Matthew Linn spoke of a conversation with he had with a woman he called “Hilda” who was worried about her son who had tried to commit suicide for the fourth time. “She told me he was involved with prostitution, drug dealing, and murder.” (p.7). Hilda was afraid for her son who might die without being sorry and repenting. Through their conversation Fr. Linn asked her “to look into God’s eyes and watch what God wanted to do. God stepped down from the throne, and just as Hilda did, embraced Hilda’s son. And the three of them, Hilda, her son and God, cried together and held one another.” (p. 8-9). Wow! What a concept. God … With … Me. I am not alone. There is someone I can just be myself with. God calls me into creating with God. Wow. That means I have a partner who will help me with Graham. It means my existence is “O.K.”! I went out and bought a mug which says “God Danced the Day You Were Born” on it. It’s still one of my favorite mugs. I return to this book whenever I doubt myself.

**Review of story with Ken Moses**

Ken Moses’ insights were critical for my healing. Until his teaching at Laremont and at the beginning of the weekend parent workshop, I did not know that broken dreams needed to be grieved. (Moses, K., n.d., Metaphors and Indirect Change; 1987, 2004, and 2015 The Impact of Childhood Disability: The parent’s struggle; 1994, Grief Groups: Rekindling Hope).

The inner work I did during Ken Moses’ parent weekend gave me direction. I finally knew what to grieve, and to search for other ways of loving Graham, ways that are more attainable. I felt some immediate release of my sadness during Ken’s work with me. I knew
there was more inner work for me to do, but I had direction, and I knew I was not a terrible person who was damaging her son by giving him nothing but sadness. I didn’t know how yet, but I felt my relationship with Graham was ultimately going to be o.k. and that any emotional pain I had given him would be changed into acceptance and joy. I was elated and crying at the same time.

The experiences with both Dorothy Anderson and Ken Moses also taught me to listen to others. Could it be that this compassionate God sometimes talked to me through other people? Hmm. Something to ponder. I needed the information both of them gave me. I needed their insights. And, I needed their acceptance, compassion, and their thoughts on direction. It was up to me to follow through.

There is another important factor I must mention here. At this time, my husband, Graham’s father and I were separated, and I was seeing a therapist weekly (not Dr. Moses). Our marriage was abusive. In fact, I was in the process of quietly separating our finances when I found myself pregnant with Graham. Graham in no way caused our divorce which would have happened anyway. However, Graham’s arrival and his disabilities did exacerbate the abuse which continued to increase until I left carrying Graham under police escort.

Following this theme of being open, listening to God through others, learning and following through with action, there was another teacher by the name of Eileen De Jong who helped both Graham and me.

**Thoughts on anger and grieving from books and media**

I was not as successful with Rabbi Harold Kushner’s thoughts on anger.

I continued to wonder about the God Dorothy Anderson talked about who would take my anger without reprisals. I needed to learn that Kubler-Ross’ work on grieving wasn’t just for
those who were dying and their loved ones. I needed to learn that it was for anyone who suffered tragedy of any kind…which ultimately means everyone. I needed to be accepted and not judged or shamed for how I was feeling…that emotions were what everyone felt and emotions needed to be processed and released, not held in and stuffed inside only to haunt me every moment of the day and especially in the quiet of the night. And, after emotions were released, I needed to replace them with new, more realistic attitudes and behaviors. It would be years later that I’d learn in therapy from Serafina Anfuso that telling one’s story and being accepted without judgment, advice, or shame --- is the beginning of healing. Dorothy Anderson, Graham’s first teacher gave me that gift. She was helping a parent of one of her students. She started me on the path of reframing my view of Graham from tragedy to gift.

A few years later a TV movie impacted me. I remember the 1987 CBS Sunday Night Movie entitled Kids Like These during which Tyne Daly gives the Welcome to Holland speech about being pregnant and thinking she was buying a “ticket to go to Italy” but ending up in “Holland” when her son was born with Down Syndrome. She goes on to say that once one catches one’s breath and begins to explore Holland, that there were “good” things there. Yes, but… for me, the real struggle was to no longer desire to go to Italy. I was on a twisting path. When I was exhausted and alone with crises and responsibilities, I saw the platitudes of this section of the movie. Yet, I also knew I needed to let Graham teach me what “Holland” was like. In the beginning of single parenthood, the gift of “Holland” occurred in moments rather over weeks and months along with the messiness of daily life. Sometimes I yelled at the movie as though it could hear me and even though I didn’t have my videotape showing on the TV. I yelled from a place of feeling abandoned, lonely, and overwhelmed…and not knowing what to do next or how to parent. However, with memories of smiles and moments shared with Graham,
I appreciated the “Welcome to Holland” segment. It was/is a reminder to slow down and be present to moments as they occur. Moments make memories.

Dorothy Anderson helped me when she introduced me to Dr. Ken Moses who in turn gave me direction in grieving and creating a new life with new dreams.

**Parent learning from the wisdom of my son’s teacher Eileen De Jong**

Time, living with Graham, and what I call pondering are three things which have helped me adjust from a fast-paced lifestyle in which I’m “doing” all the time to one which is slower-paced and is more attentive to “being” and “being with” without attempting to change Graham into someone he’s not. I used to try to teach his cognitive delay out of him, which usually ended with both of us in tears, instead of looking for the gifts he naturally possessed and encouraging and helping him develop those. For example, once Graham started talking at the age of four, his pronunciation, grammar, and word selection were not expressions of Standard English. I was concerned that if he continued to talk this way, he’d never be able to communicate and get his needs met properly and would be judged by others as incapable. Realizing that how one communicates often determines how one is treated and whether or not a person gets his needs met, I corrected Graham EVERY time he erred from the standard. This was most of the time.

His teacher Eileen De Jong pulled me aside, and said, “Mrs. Higgins, with your two degrees in English and with you teaching English, I know you value language. I’m going to ask you NOT to correct Graham when he speaks. This will be the hardest thing you’ve ever had to do. However, if you continue to correct him, Graham may stop talking. Let him enjoy the words he says and experiment with his expression, and struggle with getting his needs met, and experience the success of getting what he wants through talking. This is how he will learn and
gain confidence in speaking. Correcting him at this point will make him feel like he can’t do it, and he may well give up talking altogether.”

I was stunned. I felt attacked. I agreed, but I needed to get out of that meeting and get some distance from her so I could lick my wounds and consider what she had said. What I wanted for my son was a good thing. I had been told by the head of neurology at the children’s hospital that Graham would probably never talk. The special school he started when he was three years old started him with sign language during his first week of attendance. His babysitter and I took classes once a week at night so we could communicate with him. Somehow, in a period of over a year, the right-brain assist of the sign language activated the left-brain language and speech. We were overjoyed and celebrated! Graham could talk! He was four when he said his first words, but that was O.K. Graham could TALK!

It never occurred to me that I was pushing too hard, too fast. I followed Eileen De Jong’s advice. ...and it was one of the hardest things I ever did. After an adjustment period, I did not correct Graham’s pronunciation, choice of words or grammar. It was work! My insides would cringe while I worked at smiling or at least keeping a neutral expression when I heard, “My want some ice cream.” Or… “Whobody maded that sandwich?” I was still in the parent mindset of wanting my son to grow up, go to college, come into his own, be independent, feel the exhilaration of success, and be happy.

What surprised me as I lived with this new situation was I realized I rarely corrected my sophomores, juniors, and seniors when they talked, even though many of them daily made language mistakes. What was the difference? It took me weeks of observing myself at school and with Graham before I could answer this. I considered my students my “kids” in that I was invested in their success in thinking and supporting their ideas verbally and in writing. I wanted
them to go on after high school and find a career which made them want to get up in the morning. I was with them in the classroom, and I thought about them at night and what I could do to help them learn, especially those who were struggling. I was invested in my students learning to think, to organize, to support and present their ideas, but they did not physically come home with me at night. I was more emotionally involved with and invested in my son. I had more dreams and worries and responsibility for my son. That’s why not correcting his speech and language was such a struggle for me. I worried about his future ability to take care of himself, especially when I was gone. I feared for Graham and his difference from others. I remembered being in school. I loved learning – all subjects – esp. math and English. I would go home and after I finished the math homework, I’d make up similar problems and solve them. I read a-lot. I also played the piano, sang in the choir, and participated in Girl Scouts and Mariners. But I didn’t like being called “maggot” or “curve breaker”, both of which were hurtful and isolating. If I felt like this, what would happen to my son when he reached school? He talks differently – walks differently – isn’t coordinated – understands differently. What Graham has going for him are his inner spirit and positive attitude. What will happen when he goes to school and must mingle with others who may only laugh at his differences? But, isn’t this a normal parent concern?

Since Graham’s speech was often slow, any conversation with him took time. This was hard on me. I was accustomed to talking fast, moving fast, thinking fast, driving fast (I shouldn’t admit this), and in general living in the fast lane of life. Graham did everything in slow motion. As I have more recently learned from his new ophthalmologist, his entire central nervous system was affected by lack of oxygen during the accident. Graham not only talked slowly and moved slowly, he processed ideas slowly. He taught me to talk, move, and live more slowly. Not that I
had wanted to learn this way of living. But, trying to speed up Graham was counterproductive. Wanting him to move faster, speak faster or do anything faster seemed to confuse and panic him which slowed him down even more which made us both later, slower, frustrated, and in tears. So…eventually…I learned to slow myself down (or at least try to). In the slowing down, I have learned to watch and listen to the ocean surf in the sound of rustling leaves. I am more compassionate and have learned by observing Graham there’s more than one right way of doing things.

Anger and questioning have pushed me to advocacy on the behalf of my son and others like him in the areas of medicine, education, and society – something totally anathema to me in the past. Who knew parents needed to be advocates? That topic wasn’t covered in the parenting books I read as I was raising him. However, advocacy became essential in my life with Graham and for Graham.

An open attitude and a willingness to risk trying new things allowed me to hear two of Graham’s teachers, Dorothy Anderson and Eileen De Jong, and Ken Moses, all of whom provided valuable insights which gave direction to our lives in terms of what to do next. Luckily, we also had a pediatrician, Dr. Richard Mervis, who saw the change in Graham, the before and after the accident, and advocated for him to get him into a children’s hospital, and continued to delight and support Graham as he grew into adulthood. It was Dorothy Anderson’s acceptance of my story and Ken Moses’ insights regarding how I love which led to the healing I needed to change my image of God and allowed to listen to others at a deeper level and be open to possibilities in different directions of attitude and action. Without this healing it’s possible I would not have heard Eileen De Jong’s advice not to correct Graham’s speech when he starting talking at four years old.
Other People’s Encouragement – Sheila & Charles Prince and Mary Bloom

I began to listen to other people’s encouragement, not the self-serving platitudes people give to soothe their own consciences and remove themselves from any real responsibility, like, “You must be a very special mom.” (I secretly wished I wasn’t so special.) Or “Call me if you need any help.” (and if I were audacious enough to call, they were always too busy and never tried to find another way or time they could help.) I began to look for behavior rather than words. I could trust behavior. Words could be flattering, even poetic, but without follow through they were worthless, even damaging to me if I had believed them and counted on them. “Let’s get together. I’ll call you.” was another dubious phrase. I’d wait and wait, but no call ever came. …and I had wasted my time and was disappointed because I had so looked forward to the get together or outing. I hated it most when I had to tell Graham something we had been invited to by someone wasn’t going to happen.

But, there were other people too, and perseverance for Graham’s sake was made much easier because of them. They became community for me. One woman called me, said her sister who lived in another state had a child with Down syndrome, and she wondered whether I would allow her to help with Graham and give me some respite. Sheila Prince and her husband Charles became our angels. Sheila would take Graham with her on outings: shopping, doing projects at her home, picking out material so she could make the sheets, curtains and quilts for a guest bedroom at their home. She and her husband invited us to dinner several times. Sheila made dinner for me several times and brought it over. Graham loved being with her and her positive attitude. She gave us the bedding Graham had helped with when she and Charles moved to Arizona several years later. They remained friends until they each died. However, their positive attitudes influence me even today. They helped me during and after a six-year divorce,
even when I had to sell my house and move. Sheila helped me pack and unpack in a smaller place. There were times I didn’t know who she was helping more, Graham or me. She was there for some of the grunge of life and helped me regain some of the resilience I had had before the crib accident and the divorce. She helped take drudgery out of perseverance and turn perseverance into a part of everyday life.

Years later, Mary Bloom, invited Graham to be her parent assistant. She and I had met at the retreat house where I worked coordinating retreats. Even with twenty years difference between us, we became fast friends, confidantes, prayer partners, and today while our lives have taken us in different directions, we’re still in touch. At the time we met, Mary had three children under five years old. Graham was 9 and had told me he wanted to be a teacher like me. (I knew that wasn’t going to happen, and it made me sad.) Mary, however, said she needed some help. She’d drive from Wauconda through North Barrington into the town of Barrington with her three lively children to pick up Graham and take him back to Wauconda. Hours later either she would make the trip again to bring Graham home, or sometimes I’d drive there to pick up Graham. Under Mary’s tutelage Graham learned how to talk and work with young children. Sometimes Graham worked with all her kids at the same time, and sometimes, he was with just one. Mary made it fun to learn and mellowed some of Graham’s rough edges. Being an only child, Graham expected to get his way and would order people. Then he’d get upset/angry when he wasn’t obeyed. Mary showed him how to “enforce” her house rules without yelling. She believed in Graham and gave him confidence which helped him dream about what he wanted to do when he grew up. (even if I didn’t believe it.) Perseverance had some shining moments – was beginning to show some fruits. Graham was not only seeing better, he was walking and talking – something that was not expected when he was younger. He was developing…at a slower
pace…but he was making progress. Graham liked being with people. Thank you, God, maybe there was hope for Graham to live in society and to find his niche for giving back to others.

With the help of others, I’ll keep persevering.

Michelle Miller

Fast forward ten or twelve years. Graham was in high school now. I still agonized over what was Graham going to do to give back to society. How was he going to fit in? What was his niche? I still feared he was going to end up homeless when I died.

And then came Michelle Miller, Graham’s high school teacher. She was his homeroom/self-contained classroom teacher for the five years Graham attended Barrington High School. I was happy Graham was with such a competent, energized teacher who cared about her students. During Graham’s high school years, I was stressing out about what Graham would do after high school. What was his niche? What kind of job would he have? Would he be able to live on his own? How independent could Graham be? Or, would he need to live in a group home/institution? These questions followed and hunted me down over the years. One night the phone rang. It was Mrs. Miller. I held my breath wondering what trouble Graham was involved in. Instead, Mrs. Miller shared with me, “When Graham is in class (which was most days), everyone in class is calmer and happier, even the BD (behavior disoriented) kids.” (Michelle Miller, personal communication, 1997, 1998, 1999) I received this call from her three years in a row.

My eyes watered. She may not have known the gift she was giving me. Michelle Miller was telling me how my son affected those around him. I knew Graham to be gentle and friendly, but what this information meant to me was that Graham had the gift of accepting others as they are. That translated to me as someone who could work with others and be in society. It
translated to me that Graham could be employed. I didn’t know how or where or what kind of job, it just gave me hope. All I had to do was to figure out how to “market” Graham’s ability to bring peace and calm to a situation. It was a beginning of an answer to years of prayers. It meant there was a possibility that Graham would not end up in an institution. What a gift!

I could have just disregarded this information. It took being open to listening to others. I had long heard that God spoke to people through people. There was a story I had heard several times about a man who was on his roof during a flood.

*Water had risen to the upstairs window and prevented the man from getting to safety. A boat with a rescuer came by and asked the man if he wanted to get in and go to dry land. The man on the roof said, “No, God was going to save him.”*

*The boat left. Water continued to rise. It reached the bottom of the roof. Another boat with people in it came by, but the man refused to be picked up and told the people, “God will save me.”*

*As the water was continuing to rise and the man crawled up to the apex of the roof a third boat came by. It had room for one more person, but the man said, “No thank you. God is going to save me.”*

*Eventually, the water rose above the man’s roof, and the man drowned.*

*When he got to heaven, the man asked God, “Why did you let me die? Why didn’t you save me?”*

*God replied, “Well, I sent three boats for you. What did you expect?”*

I’ve heard this story in different versions as well with the people in the boat being of different religions, different races, or different cultures. I’ve heard it during a sermon and in other situations, including education and social service. I heard it enough that it finally sunk in.
Help arrives in unexpected ways through unexpected people. The lesson is “Be open.” This lesson resonated with me when I read Richard Rohr’s book *Everything Belongs: The Gift of Contemplative Prayer*. Rohr talks about the mystery of life experiences which lead “us into paradox, into darkness, into journeys that never cease” (p. 33) which leads us to wonder about the Great Mystery (p. 33). Graham’s accident, my marriage, sometimes daily life certainly fell into Rohr’s categories of mystery for me. Why did these things happen? Now what do I do? Later, Rohr goes on to say, “we dare not get rid of the pain before we have learned what it has to teach us. (40)” Rohr says what a person needs to hold the tension of the mystery is what he calls a “beginner’s mind” which knows it needs something and over time seeks, ponders, and listens until there is transformation (pp. 37-40). I call it “being open.”

I needed to listen and be open to the lessons from Dorothy Anderson, Ken Moses, and Michelle Miller. Had I not, I would have been left in darkness and pain. Being open led to some healing and direction for change in attitude and behavior. I felt directed from a presence outside of me during these times. I can’t explain it. But, I’ve experience “something” at different times in my life from different religions and through different people, and thus, I believe in a Divine Presence who cares about and wants relationship with all of creation. …and it’s a little unsettling, but I cannot prove this.

There is another story which I cannot remember where or how I heard it but which transformed me. (and though this may sound politically incorrect, I’m going to tell it anyway.)

*There was this black man sitting on the steps of his row house smoking a cigar. He took a drag on the cigar and slowly blew out the smoke. After a thoughtful moment he said, “God be slow.”*
He took another slow drag on the cigar, and after a moment blew out the smoke.

Pausing, he then considered, “God be verrrrrrrrrrrry slow.”

The man took a third draw on the cigar, and once again slowly blew out the smoke. After a moment, he smiled and said, “But, God allllllllllllways beee on time.”

Wow. What wisdom! I tend to be impatient. I want things done RIGHT NOW. I wanted my son to be restored to his original potential within a few months of the accident. I wanted my six-year divorce to be over within a couple months. I think of the Israelites during their 400-some year Babylonian captivity waiting for release. (Now there’s real patience.) Yet, if I ponder my life, I can see that God always be on time. Perhaps not the way I would have done it if I were God, but I don’t know all the things God knows. While I may think I’m omniscient sometimes, I’m not. I thought it was a good idea about a month before my marriage to sell my United Airlines stock (which I had bought with my babysitting money in high school) only to have the stock split two for one the day after I sold it. I had been advised to hold on to it for a couple more days, but I thought I knew better.

Both of these vignettes have been with me since my college days or shortly thereafter and while they’re not theology, they have stuck with me and have formed me. I consider them spiritual. The first has helped me listen to people and to take what fits and leave the rest (Twelve-Step saying). When a comment (often just a casual comment) I hear fits, I get a little “aha” inside and try to remember and apply it - so the first story has sometimes been the impetus for changing my attitude and has prompted me into action.

The second story calms me especially when I’m fearful which is also when I’m most impatient. From this story I’ve learned to say to myself, “Trust the process. Nothing lasts forever.”
As I reflect on the process I’ve experienced during my journey with my son and his disabilities, I’ve tried to put the process in a linear format. I’m realizing mine is a twisting path where I have anxiety, loss of meaning in life, chaos, learning, direction, action, and inner peace and resilience with new meaning in life. …and these go back and forth amongst each other. What helps me is a sense that Jesus (God) is with me during the worst times, and I know I am not alone. I receive(d) a radiating warmth that somehow made me feel things would turn out all right. Maybe not the way I planned them to be, but the situation would have learning and be meaningful. I was not abandoned. From Judaism I have received a positive attitude and a forward-looking sense of opportunity in any situation. There was a sense that all life belongs and has meaning which I also received from Christianity. From Buddhism I received meditation with its inner calming which opened me to receiving from the universe (my terminology) including serendipitous, spontaneous events and sayings from other people. I also received a way to review my thoughts, attitudes, behaviors during meditation which is similar but not exactly the same as the Christian examine of conscience. I discovered similarities in beliefs amongst the religions in values of life and the lived experience. I began actively to seek wisdom and method from spiritualities of different religions. I felt I needed this for my support in order to be Graham’s mother.

**Teaching and Wisdom**

So often teachers are bashed for mistakes, harm done, and incompetency. It is true that there is content knowledge as well as technical knowledge of computers and assistive technology which are needed as well as interest in students in order to teach well. But, to be a really great teacher there is more. Some teachers teach because it’s a job or a career. However, there are teachers who are *called*, and for them teaching is a vocation. They possess the *head knowledge*
which is needed and know how to involve students to be interested in learning, but these rare teachers also possess heart knowledge and wisdom gained through years of experience, observation, and reflection. These thoughtful and enlightened educators know how to listen, when to encourage, and when to speak up not only with their students but also with parents. Because of them more people are inspired, fewer give up on themselves, more persevered in attaining their dreams, and many more know their existence in the world is important which helps people to like themselves in a genuine way. I treasure these mentors because they have changed my quality of life and my son’s quality of life…and our relationship when we’re together. They have taught me not to be afraid of difference but to be curious as to what I can learn from it and to appreciate how difference can enhance my life and the lives of others.
Chapter 7
Toxic Shame – Killer of the Soul

Washing the Sink

I remember the day so clearly. The sky was blue, dappled with a few puffy clouds with sunlight radiating warmth punctuated with bouts of crispness alerting me that autumn was waiting just around the corner. Graham was five. He couldn’t run yet, but his walking had improved since he took his first steps at age four-and-a-half.

Graham was upbeat. It was cool enough that he was wearing a navy blue, velveteen top with a toy soldier appliquéd on the front. With a great big smile Graham asked me to teach him to “wash” the sink in his bathroom, and I was pleased that my son wanted to learn a “chore.” Whoopie. Graham wanted to help take care of our home! I got the large bottle of Soft-&-Scrub and a couple of new sponges.

We had just started by wetting the sink and the faucet fixtures when the phone rang. It turned out to be a long call. Graham remained in the bathroom for most of the duration of the call. At one point I saw him leave and head for the family room with the TV. His walking was getting faster so I only saw his back. I remained on the phone for a while longer.

After hanging up, I walked into the bathroom wondering why Graham had stayed there so long and wanting to resume the lesson in sink washing. I was met with the entire 32 oz. plastic bottle of Soft-&-Scrub emptied and drying on the sink, the faucet fixtures, the counter. White stalactites hung from the entire, long edge of the counter with white deposits underneath on the brown tile, grouted floor. This was a mess of epic proportions! Some of it was still wet and dripping onto the floor. Some of it had dried. I wanted to yell at Graham – but – this wasn’t
his fault. It was mine. I should never have answered the phone. ...and once I chose to...I should have asked if I could call back the person later.

At the same time I could see how much Graham had wanted to learn how to clean the sink. His energy with the swirls of Soft-&-Scrub all over the counter. His thoroughness with the whole bottle used up. There was active artistry with the drip, drip, dripping all along the countertop and the puddles forming on the floor. The problem was this was going to take a looooooooooooooong time to clean up and the afternoon was waning. I could already feel the sharpness of the breeze from the window heralding the onset of evening.

There was another problem too. My husband, Graham’s father, would be home in an hour...and I hadn’t started dinner which he liked promptly when he arrived. He would not see Graham’s industry and creativity in Graham’s sink washing. He’d just see mess. Why didn’t I get off the phone sooner? Why did I even pick up the phone? The answering machine would have picked up the message, and I could have called back later.

Part of me wanted to leave Graham’s work for later. Part of me wanted to make dinner. I was afraid of my husband’s wrath. Which would make him less angry? The sink cleaning experiment or a late dinner? In my panic I decided – Both. I didn’t want Graham yelled at, and I didn’t want me hit or worse. So, I hurriedly cleaned up the sink, faucet hardware, and the counter top.

I was just starting on the stalactites when Graham came bounding around the corner. At the same moment our eyes met. I saw his wide open smile saying, “Look what I did!” Even his eyes were smiling. He was a bundle of happy energy.

Then, my eyes took in the bigger picture. I saw that the entire front of Graham’s velveteen top with the Christmas toy soldier like in the Nutcracker was obliterated by the white
of the Soft-&-Scrub. Was it ruined? I paid a lot of money for that. Why did I even think of starting the sink cleaning and not make Graham change his shirt!

At the same moment, Graham saw the changes in the counter and the sink. His smile turned into a frown. His eyes lost their luster. His shoulders drooped. He looked into my eyes. There were instantly two messages to me even though neither one of us spoke a word: “I feel betrayed! Why didn’t you wait for me?” and “I did it wrong! I’m not good enough!” I suddenly knew what the phrase I felt a pang in my heart meant. I couldn’t undo what I had done. Graham turned and left as fast as his legs would carry him.

I realized I had injured my son twice that day. First, by not honoring his desire to learn from his mom how to “wash” the sink as he called it. I let myself be interrupted for at least twenty minutes and did not make my son and his request the most important thing at that time. Secondly, I shamed Graham. By changing what Graham had done, cleaning up the Soft-&-Scrub, I robbed both of us of the experience of doing it together and talking about it. I also made Graham feel he wasn’t good enough which is toxic shame. At the time I didn’t know the term, but I knew I had hurt Graham in the core of his being. … I was ashamed of myself.

During the following weeks I tried to offer Graham the opportunity of “washing” the sink. But he would have NONE of it.

“NO, MOM!” was all I heard.

Sometimes I’d get everything ready in the bathroom, and bring Graham in and “surprise” him with the project. But, he’d just run away yelling, “NO, NO, NO!”

Once, I “captured” him and told him we were going to clean the sink together. I brought Graham up to the sink while standing behind him. I put my hand over his, and we picked up the sponge together. We wet the sponge and I put some of the Soft-&-Scrub on the sponge. As I
brought the sponge down to the sink, Graham squirmed, slipped his hand out from under mine, and made “erh, erh, erh” noises as he struggled to get away. Once free he ran even after I called his name. All I heard was “NO! NO! NO, MOM!” The only way I could have brought him back was by dragging him. But, I didn’t. That would only make the experience worse.

I never asked him to clean the sink again. I felt I had ruined my son. I tried to learn from this experience though. When Graham told me he wanted to learn how to do his own laundry, we were living in an apartment on the third floor of a walkup. Laundry facilities were in the basement.

We went downstairs together with our baskets of soiled clothes. I showed Graham about setting up the washer with temperature and type of load. He liked putting in the money. I asked him if he’d like me to show him how to sort his laundry.

“No, Mom. I can do it myself.”

I struggled but kept my mouth shut as he put a brand new red T-shirt in with his whites and tans. Then he turned on the washer with hot water. He was surprised when he had pink underwear that had shrunk.

I just said, “Huh. How did that happen?”

“I don’t know. But…I did my laundry MYSELF!”

“How does that feel?”

“Good!”

And, I haven’t done Graham’s laundry since. I guess doing the experience by himself was part of what Graham valued in the learning process. Eventually, well, seventeen years later, Graham asked me about how to sort laundry. He had some pretty interesting looking clothes in the meantime. My learning experience was to keep my mouth shut when I wanted to suggest or
advise. I was just happy that Graham initiated the laundry project and took on the responsibility himself. I was proud of him, especially since I wanted him to become as independent as possible. The more life skills he could develop with his disabilities, the better, because it meant (to me) that he was closer to becoming more self-sufficient and less likely to end up in an institution (which I feared). I was and still am afraid that being in an institution would debilitate my son so he wouldn’t be able to live in society.

…But, I struggled with keeping my mouth shut. …and still do.

**Two kinds of shame**

Years later I learned there are two kinds of shame. There is the shame of knowing a person has done something wrong, like stealing, hurting someone’s feelings on purpose, lying and cheating esp. for personal gain, etc. Healthy shame is like one’s conscience. The message is, “I made a mistake.” The guilt from healthy shame pushes a person towards restitution – owning what one has done and doing something to restore the situation.

I learned of another kind of shame during my divorce from some of the programs on PBS during the latter 1980s and from books by John Bradshaw. I videotaped the programs and replayed them over and over trying to glean every last bit of knowledge and wisdom. I needed to heal after my abusive marriage. I didn’t ever want to go through the tension, fear, and trauma which I and Graham had escaped. I got my myself into therapy and sought out whatever I could attend in order to never get myself in another abusive relationship. John Bradshaw’s books, especially *Healing the Shame that Binds You* (1988) along with his PBS programs, I learned of a shame he and other psychologists called toxic. The message one receives from toxic shame is “I am flawed and defective as a human being. I am a mistake” (p.16, 17). Bradshaw called toxic shame “spiritual bankruptcy” (pp.22-23). From the books and programs and my therapy, I
learned the difference between healthy shame (also called guilt) and toxic shame. A more recent definition of shame comes from research professor Brene’ Brown: “Shame is the intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging.” (Brown, B. 2007, p. 4-5) I knew this feeling, and I knew I had given Graham this feeling in the “washing sink” incident. Brown also clarified the difference between shame and guilt. “Shame is about who we are, and guilt is about our behaviors.” (Brown, B. 2007, p. 13) My behavior had inadvertently caused Graham’s shame. But, I didn’t know how to get rid of the toxic shame.

After the divorce I was accepted into a program with Serafina Anfuso, educator and counselor. She added to the knowledge I had on toxic shame. Like John Bradshaw she said toxic shame was a spiritual disease. She emphasized that it is so uncomfortable that people want to get rid of it and the way they usually try is to shame others. But, this doesn’t get rid of this type of shame. Instead, it just spreads it. Additionally, toxic shame has more than one part. First, a person shames another judging that person as “not good enough.” If the judged person hears the same or similar comments enough, he or she is in the danger of believing s/he is “not good enough.” If or when that happens, Serafina emphasized there is a wound to the spirit/soul. The judged person will often feel discouraged and can give up on him- or herself.

Serafina continued. One of the most vulnerable times for a person to be susceptible to toxic shame is when that person is learning something for the first time. If the teacher is judgmental or impatient, the student is likely to receive the message that s/he is “not good enough.” … and the damage is done. It’s not just words which connote toxic shame. A look, a sigh, a verbal exasperation (humph, huh, hmmm, etc.), checking one’s watch or cell phone, can denote impatience. And, impatience often implies the judgment of “not good enough.”
Reversal of toxic shame

However, there is a way to reverse the damage of toxic shame. When a person, especially the teacher of whatever is being learned, believes in the student, any toxic shame regarding the skill/content being learned disappears. And, as the student gains competence with encouragement (Anfuso, 1994, p. 33; Anfuso & Boucher, 2005, pp 87-88) the student’s confidence is restored. (Serafina Anfuso. Personal communication from Fall, 1992 – Summer, 2000.)

Seeds Planted to Reverse Graham’s Toxic Shame

And, as I learned these things, I knew I wanted to return to the “washing sink” issue with Graham, at the right time, with the right atmosphere. Even though I now had training in how to restore someone’s confidence, it would take years before the opportunity for me to return to the “washing sink” wound of shame would occur. I always knew that at some point my son and I would no longer live together. I just didn’t know when, or under what conditions this would occur. I just wanted it to be a happy time. However, separation was messy. Graham had been accepted in the Professional Assistant Center of Education (PACE) program at National Louis University, a program to learn life skills and job skills for adults with developmental disabilities. With the car packed with Graham’s belongings for the dorm, we went to pick up the results of his TB test which was required. On the way to our doctor’s, Graham said, “Mom, my toe hurts. Can Dr. Segal look at it before we go?”

“How much does it hurt? Sometimes there’s a long wait, and I don’t want you to miss the first day activities.”

“It hurts a lot, Mom.”

“O.K. then. We’ll see him.”
Graham’s hurting toe turned out to be an infected ingrown toenail which needed surgery. Dr. Segal was able to get us into a specialist within the hour. Graham’s big toe was so infected that part of the toenail needed to be removed. Along with a post-operative antibiotic regimen there would have to be soaking of the foot three times a day for two weeks. I was sure the director and staff at PACE would tell me to take Graham back home until he didn’t need special treatment.

Graham and I had just gotten cell phones so after a few tries I was able to phone the PACE program central number and at least leave a message that we would be late along with the reason. Everyone was busy with Welcoming activities. Then I called and left a message for Graham’s father who was going to meet us there. We missed the morning Welcoming, lunch, afternoon activities including unpacking in the dorm rooms, and dinner. Dusk was turning into night when we arrived.

Parents, new students, PACE staff and second-year student ambassadors (who were showing new students the “ropes”) were in a meeting. So Graham and I were shown to his room and we unpacked. Graham was going to have a roommate for the first time in his life. Since he grew up as an only child, I wondered how this was going to work. Personal space, boundaries, noise, sibling rivalry – and who knows what else were going to be brand new situations for him. How will Graham negotiate these situations? He’s not experienced them so far. I dared not let my mind wander.

The meeting ended. And, we met the director, several of the PACE Staff, the Resident Assistants, Graham’s roommate, and several other students all at the same time. The RAs, the PACE staff and I focused on directions for the care of Graham’s foot and the antibiotic.
Graham seemed to be alright. He was busy meeting his roommate. The student ambassadors were showing him around and helping him get acquainted with other students. I HATED to leave him, but it was time. I cried all the way home and the rest of the weekend.

**First Apartment and the Subject of Donations**

Two years later Graham had gained skills and confidence as he graduated. We had talked and agreed that he would attend the Transition program as well which scaffolded apartment living and the procuring of his own job instead of having an internship. Graham’s roommates were classmates who had graduated with him. We parents had gone with our sons to find an apartment with three separate bedrooms which was close to public transportation and necessities like a grocery store. A life coach would be visiting them every week to check on how living in the apartment was going. Every weekday all three would have to go to the PACE office and work with staff to find a job. Also there were classes on grocery shopping, paying bills, etc. Once a month on Sunday, a PACE staff member would help one apartment of PACE students host a pot-luck dinner to teach the Transition students how to host a party and remain in touch with each other.

I had to admire the parents of one of Graham’s roommates who lived in Wisconsin, a state away. I struggled with leaving my son even though I worked at the university and lived the closest to their apartment. Of course, this had its ups and downs as well because once in a while I’d receive a call from one of Graham roommates’ parents for some emergency to go over and check on the “boys.” I didn’t like being on “beck and call.” But, especially for the parents who lived out of state, it was the right thing to do. I would have wanted someone to be available for Graham had I lived far away.
One time I went over to the apartment to talk with the young men regarding phone etiquette and boundaries. Besides their cell phones, we parents decided they needed a landline home phone as well. However, they were barraged by people raising money for causes, selling things, or just scamming. Graham called me and “shared” that one such fundraiser had called, and he offered to give him five dollars. The person on the other end kept talking with Graham and kept getting Graham to raise his donation until it was $50.00.

Graham called me on the phone and told me about his donation.

“Graham! You don’t have a job yet! Where are you going to get the money?”

“You, Mom.”

“Graham! I don’t have money for that! I’m paying your rent, your food, your transportation, your allowance. You can’t be donating until you have a job and you can give away your own money. What are your roommates doing with these phone calls?”

“Mom, they’re doing the same thing I just did.”

“Do their parents know?”

“No.”

“Are your roommates home?”

“Yes.”

“Do their parents know about their donations?”

“No.”

“Tell your roommates to stay there. I’m coming over right now. We’ve got to talk.”

“Mooooooooooom.”

“Don’t Mom me. This is important.”
I didn’t want to just yell at Graham and his roommates so I wanted to be careful about how I approached this money issue. They had learned about keeping a checkbook and ATMs and about checking their balance every day or even after everything they bought. How to deal with the daily and sometimes constant onslaught of fundraising calls was something else. I didn’t want to shame them, but they needed to know about boundaries and about when it was o.k. to say “No.”

**Reversing Graham’s toxic shame**

When I arrived, the four of us exchanged hellos, and the “Three Amigos” as they called themselves gave me a quick tour of their apartment. I must admit they were working on keeping it neat. Then Graham said, “Mom. There’s something I want to show you.”

He took me to the bathroom next to his bedroom which also opened into the hallway. “Mom. I want to show you. See! I’ve cleaned my sink! All by myself! What do you think!”

Amazed, I said, “Graham, this is great! The sink is clean. The faucet and handles are not only clean but polished! I’m so proud of you.”

Graham smiled.

“How did you learn to do this?”

“Mom, I just decided to do it.”

“Well. I love how you taught yourself.”

Graham’s smile widened. He beamed. Then we went into the living room where his roommates were waiting.

**Discussion on donations**

I related what had happened to Graham with the fundraiser and asked if they had experienced something similar. They had. Then I asked about where they were going to get the
money to pay for what they had donated. They each thought their parents would pay as well.

We talked about how the money for their generosity would have to come out of the money from their budget – for food, rent and bills, transportation, movies, social life, etc.” There was silence.

Graham responded, “But, they said they needed money.”

“Yeah. We were trying to help people.” Mike (name has been changed) said.

“I know. And, I love your generous spirit. I love how you think of other people and want to help them. But, it’s not good to hurt yourselves when you help others. Your parents cannot pay for your generosity. One of the things you have to learn is to budget – only spend the money you have. It’s o.k. to donate, but there are some rules. 1. Decide how much you can give away. 2. Do not go higher. Say ‘NO. 3. If you don’t have money to share, say ‘NO!’”

“But, I don’t want to lie.” Colin said.

“Lie?”

“Yeah. If I have money, and someone on the phone asks about it, I don’t want to lie and say I don’t have any.”

“Colin. You’re not lying. When you say ‘No.’ to a fundraiser, you’re really saying, ‘I don’t have money for your cause.’ You’re not saying, ‘I don’t have money.’ Also, do you want to tell a stranger how much money you have?”

All three of them said, “No!”

“How come?”

“It could be bad.” Offered Colin.

“Tell me more.”

“They could take it.” Said Mike.

Graham was listening.
“People could get jealous and want what I have.” Added Mike.

“Right. All of these things.” I said.

We role-played what to say when fundraisers called and asked for monetary donations. We took turns and found some variations on how to say “No” nicely, or when someone is persistent simply hanging up.

We ended with, “What do you say when someone calls up and wants money, and you need what you have?”

“NO!”

“Right!”

Apology

I did not get up to leave, however. Graham making a point of showing me his cleaned sink had remained in the back of my mind all the while the four of us had been talking about money and when to give and when to keep it. It had been many years since the “washing the sink” incident. In all that time – to my knowledge – Graham had never cleaned a sink in the places we had lived. I felt I needed to acknowledge his change of heart – his growth.

In front of his roommates I asked, “Graham, it’s been awhile – years – Do you remember when I tried to teach you to clean the sink?”

Hesitantly, “Yes.”

I related the incident. Graham was sitting back in his chair. The other two were silent.

“Graham, it was not my intention, but I was wondering whether I made you feel ‘not good enough’ when I changed all your work on the sink and the counter that day.”

“Yes.”
“Graham, I’m sorry. I apologize. I did not mean to do that. I was worried about your father’s reaction, and he was due home. You did not deserve to be made to feel not good enough. I was wrong. I ask your forgiveness.”

I was looking Graham in the eye, and I heard Colin whisper, “Wow.”

While still looking at Graham, I said, “Graham, you’re 24 now.”

“Yes.”

“Do you realize that it’s been 19 years since you’ve cleaned a sink?”

“Yes.”

“And, it’s taken me this long to apologize to you and for us to talk about this.”

“Yeah.”

“Well, Graham, I guess I’m a little slow.”

Chuckling and smiling, Graham said, “Yeah, Mom. You are.”

“Well, Graham, I’m glad you have the confidence to clean your own sink…and that you taught yourself. It looks great.”

“Beaming, Graham added, “Yes. I know.”

“Graham, may we try again.”

“Yes, Mom.”

“Good. One more question. May I give you a hug?”

“Yes.”

Graham and I stood and gave each other a hug. Then we invited Colin and Mike for a group hug. They jumped out of their chairs and a group hug was enjoyed by all.
Reflection

I knew instantly when Graham’s facial expression and shoulders drooped during the sink incident that I had hurt my son. I didn’t know how deeply I had hurt him. I thought it was going to be an easy “fix” in which we would try again, Graham would be successful, he’d see and feel his accomplishment, and we’d be done. I had not counted on his resistance. It was only after his resistance every single time over the next several months that I began to understand how deeply I had hurt him. … and…I didn’t know how to fix it. I played the events over and over in my mind – over years.

Years later I was in a therapy group for processing and healing after a six-year divorce. Our therapist, Serafina Anfuso, had two doctorates, one in counseling, and one in education. Serafina was also a former nun and spoke three languages fluently along with knowing their cultures. As we processed our inner wounds, we also learned how things worked. Serafina talked about two kinds of shame – a healthy shame and a toxic shame. Healthy shame lets us know when we’ve done something wrong. Like breaking Mom’s vase and lying about it. Or, like stealing or hurting someone. Healthy shame is connected with conscience. Then, there’s toxic shame which imposes the message “you’re not good enough.” John Bradshaw in his book Healing the Shame that Binds You (1988, 2005, 2006) states the difference between healthy shame and toxic shame as the difference between “making a mistake” and “being a mistake”. In healthy shame “I made a mistake”. In toxic shame “I am a mistake”. My existence is the mistake – which is a dangerous lie. There is a continuum of human existence with incredible, wonderful diversity, and all humans deserve respect and dignity by right of their existence. Spirituality has helped me heal wounds I’ve received from the models of disability as a parent of a disabled child. Spirituality has also given me the strength and energy to stand up and advocate
for my son and others to the messages of rejection, isolation, abandonment, and the toxic “you’re not good enough (to exist)” which are ultimately imposed by the issues identified in the models of disability.

Serafina called toxic shame a spiritual wound because it causes the person receiving the toxic shame to doubt and to question his/her ability to do something. She explained to me that when a person doubts his/her capability they lose their confidence and feel incompetent. This toxic shame often is imposed on a person when he/she is learning to do something. If the person teaching the skill is impatient or judgmental, the learner can receive the message “You’re not good enough.” which starts the questioning and doubting by the learner of his ability to be capable of learning. The judgment can even be nonverbal – a look, a pursing of the lips, a snort of impatience, a wave of a hand in dismissal. Once received by the learner, the damage is done. (Personal Communication, November, 1996, Serafina Anfuso.) (Anfuso, S. 1994, 2000/2005; Bradshaw, J. 1988; Brown, B. 2007)

I believe that Graham received my changing his work on “washing” the sink as judgment that what he had done was “not good enough” which made him “not good enough” in his own estimation.

Serafina said on more than one occasion that she felt toxic shame to be a spiritual wound and to be evil because it caused a person not only to doubt his/her capability, but also toxic shame often can cause a person to give up on him/herself. “That’s soul murder.” she’d say. (Personal Communication. Serafina Anfuso 1992-2000. This shocked me because I never heard her use the term evil to describe anything else in the fifteen years I knew her.

She also explained that toxic shame can be healed. What it takes is a mentor, someone who believes in the learner and will encourage him/her until that person can do the activity with
competence and independence. This mentor reveals the lie in the original judgment I had wounded Graham’s spirit. However, at the time I didn’t know how to include Graham in the process of editing what he had done. I was worried about time when I should have been more attuned to what Graham and his learning needed. Every child knows that his parents treasure what they spend time with, and every child wants to be treasured. I treasured that phone call more than I did Graham’s enthusiasm to learn. Because I took the phone call, Graham lost his confidence in himself for nineteen years.

I believe it was, in part, Graham’s desire to become an independent adult that led to his healing of this toxic shame regarding sink cleaning. While I’ve asked him how he learned, Graham just says, “I just did it!” …and that may have been what happened. Graham has always been an active observer. He might be quiet. He’s not a leader. He does pay attention. He watches, sees where he fits in or what he wants, and then he pursues it. His intellectual disability makes him process things more slowly than many people. He thinks about things sometimes for many days … and… then he responds. So when he says he just taught himself to clean the sink—That’s possible. He was present for years as I cleaned my sinks. He saw commercials on TV. He may have learned from his Life Skills instructor in PACE, or even one of his apartment mates may have shown him. He wasn’t ready to take the risk of doing it himself because when I changed what he had done without processing it with him, I judged his effort as inadequate and not good enough. For Graham to clean a sink again it meant taking the risk of being judged again…and Graham doesn’t like being inadequate. He wants to be proud of what he does.

What I did know when Graham showed me with pride the sink he had cleaned was that he had taken a huge risk in showing me his effort. He was proud in what he had done, and it was
clear from the tone of his voice and his demeanor that he hoped I would be proud of him too. I was. …and I was proud of the courage it took for him to include me.
Chapter 8
Horns of Dilemma – Many Answers – No “Right” Answer

While I knew the “right” thing to do was to be present to my son – to give him quality time – to “spend” my gift of teaching on him rather than on giving it to other parents’ children, I hated the idea.

I knew who I was when I was teaching. It wasn’t the awards. It certainly wasn’t the pay.

It was the exchange of minds – the planning – the give and take of ideas. The same story, novel, or other piece of literature could be discussed from many different angles. Even when I was teaching the same material, each class would be different in what ideas students found and how they supported those ideas. What gave me purpose and meaning was my high school students learning that THEY had ideas worth exploring and that THEY could support those ideas and that THEY could present those ideas and through these steps – THEY could influence other people. Seeing this growth was what I called my Christmas bonus. Knowing that my students knew THEY could think, organize their ideas, support those ideas, present them and influence others – was what I lived for. At the end of the year I was sad to see them leave for other classes or graduate, but I was proud of them and loved their enthusiastic reaching out for their futures. I often measured my success by whether or not my students left the class talking about the class and whether they came into class talking about ideas. Admittedly, some days I wanted to go home and hide, and other days I left school walking on air. These often were my college-bound students.
On the other hand, I also taught basic classes. It usually only took a couple of weeks after school started until one of my students would say, “Mrs. Higgins, you’re for the smart kids. How come you’re teaching our class? We’re not smart.”

The first time I heard this I was stunned. I looked around the class and saw the sadness and desperation as though each of my almost 30 students had already given up on themselves. At the time I didn’t realize that what I was looking at was group shame – students who had received the message over and over that they weren’t “good enough.” I knew that whatever I said was going to be important to them so I paused, thought back to my upbringing and began carefully. I began with, “There are many ways of being ‘smart’.” Then I asked “How many of you plan to be ___?” Hands were raised for car mechanic, hair dresser, garbage collector, store clerk/cashier, and grocery bagger. I kept adding job titles to the list until I had seen everyone’s hand raised at least once. Then we talked as a class about the importance of each job and some consequences of not having people do those services.

Next, we discussed interruptions to education. I began with moving and how different ways of teaching English and math can be confusing to any student who has moved from one school district to another.

As a class we brainstormed other ways education can be interrupted. Students came up with the death of a family member or a pet, grieving, and sickness of self or family member.

Once this topic was brought up by a student, the basic classes always went better for the rest of the year. Once students knew I respected them and valued them, they tried to do the work. …and I tried… to give them assignments which would be useful for when they were no longer in school.
I loved the give and take and the sharing of ideas with students building on what each
other said. I loved watching my students grow – learning how to support their ideas. I hated the
thought of leaving this experience.

My Struggle

My struggle. I wanted each student to know his/her ideas were respected – and each of them could support their ideas (some better than others) – but teaching requires a lot of
preparation outside the classroom. Herein lies the problem. I considered teaching my ministry.
On most days I knew I was giving back to the world. But, not so with my son. My son was not
my ministry. He was my responsibility. He was my failure and my shame. I had tried to
develop a respectful, trusting relationship with his grandmother rather than protect him. While I
sat at my kitchen table that day, I had little nudges urging me to check on Graham. I didn’t want
my mother-in-law to think I was checking up on her when in reality I wanted to make sure she
was following directions…and I didn’t want to be told to take a nap (even though I knew I
needed one). So, I waited. If I had not, Graham may not have been injured. Graham was my
responsibility, and I failed him at the beginning of his life. Later that day as I was holding him
and rocking him in my rocking chair, I promised him I would not leave him and I’d do the best I
could to help him grow.

This was the start of my horns of dilemma. Two possibilities – both with positives and
both with negatives. Do I continue teaching as a career or do I become a full-time parent? At
that time there didn’t seem to be other options like part-time teaching. Did my teaching prepare
me for parenting? I knew about exploring options, experimenting with ideas. I could see how
these skills would apply to parenting. However, I didn’t see my son as an experiment. If I
resigned from teaching there would be no income. I had been supporting our little family while
Graham’s father was getting his architectural firm started. Hmm. Teaching was another matter. I was used to teaching five courses a semester and advising the weekly student newspaper. I stayed after school almost every day and was consumed at home with reviewing papers and preparing for class. Where was Graham going to fit into this schedule? Was I going to give my creative energy to other people’s teenagers or to my son? Hmm? I knew who I was when I was teaching. Teaching gave me meaning to my life and purpose. So, who am I when I am no longer teaching? I had lost my identity.

… and … I also knew …

Any child knows that what the parent treasures most is what that parent spends the most time with. …and in Graham’s case … If I didn’t value my son, how could I expect others to value him? More importantly, if I didn’t value my son, how would he learn that he is valuable? How could he learn that he is ‘good enough’ even MORE than ‘good enough’? And, if I were spending a large portion of my time at home working and planning to help other kids, what message(s) would be sent to my own kid?

However, who is going to take care of my son when I’m gone? How much money is going to be needed to support him so he doesn’t end up living on the street? Who’s going to help him?

**Reflection**

I agonized over this dilemma for five years. While Graham was young, he came home from his babysitter’s with me. I made dinner, we played, worked on his physical and occupational therapeutic exercises, washed, read, said prayers, and he went to bed…early. I had time to work on my classes. As he got older and was awake longer, I needed to make a decision about my career and how best to spend my time. I had struggled for years trying to figure how I
could keep my career and teach at the level I was teaching and be present to Graham at the same time. As I prayed, contemplated, meditated I came to what Pema Chodron calls the “places that scare you” and saw clearly I could not do both. (Chodron, P. 2001, pp. 36-38) I could either concentrate on my teaching career – OR – I could be present to my son when I was with him. I did not want to be a mediocre teacher to my students. Nor, did I want to be a mediocre parent. I needed to have meaning in my life, and it was now clear I couldn’t have that with my students whom I considered my children.

After much inner turmoil, I knew I needed a job I didn’t have to take home at night – no homework like I had as a teacher. … But …that’s not who I am. I found out that I’m a “project” person … and I think about work projects at home … and the inevitable human issues of office politics and human frailties which tapped into my own issues. It was the same issue of not being present to the moment (being at home with my son) cloaked in a different guise. How was I going to be present to my son when he was with me? Instead of homework and planning classes, it was job and marriage taking my attention and giving me angst. Even more unfortunately, I had less fulfillment from other jobs and had lost the sense that I was “giving back”. Worst of all, when I left teaching and lost identity, I resented my son sometimes for his needs taking me away from what fed my spirit and I was good at. Yet, I loved him more than anything. I wanted Graham to become who he was meant to be. He needed someone who believed in him – who wouldn’t give up on him – who would fight for him. Yet, I didn’t want to sacrifice my entire life either. It was complicated. I was a mess.

If I spent quality time during the evenings and weekends on my students’ papers and assignments and on preparing for classes, then I’d be taking that same quality time away from Graham…and visa versa. Somehow, when I was at home, I could either focus on Graham or on
my students. I couldn’t do both. Sometimes when I was focused on my students, Graham needed attention. Most of the time Graham received some of my attention. But, as I was giving Graham attention I felt stressed and guilty that I wasn’t working for my students. And, when I was working for my students, I felt stressed and guilty I wasn’t spending time with Graham. And, when my husband demanded something, I stopped whatever I was doing to avoid abuse. I could not find balance. Something had to give. Where were my priorities? …marriage? …family? …Graham? …students? …career? My marriage was dying if not already dead. I had wanted several children, but it looked like that wasn’t going to happen. My students? My career? Graham? Do I give my creative energy to my students? …to my son? I don’t have enough energy for both. If I concentrate on my students, what happens to my son? If I spend the time needed with my son, I won’t have enough time for my students, and I’ll become a mediocre teacher. I don’t know how to balance my time or my energy to be mentally and emotionally present to both. Even if I teach part-time, I’ll turn it into a full-time profession outside of school – not because I want to take time from Graham but because I want to do a good job no matter what I’m doing. I must choose – and even though I love teaching and my students, I love Graham more.

I was imperfect at being present – Attending to Graham one moment – distracted by “troubles” the next – then impatient … which always affected him. On the other hand, how would dinner get made, laundry washed, dried, folded, put away, etc. etc.? The “perfect parent didn’t seem to exist. I did a lot of apologizing and carried guilt as I re-thought each situation and thought about what I could have said differently and done differently. Slowly my language changed – to be kinder yet firm. When not frazzled, I’d watch Graham to figure out what he needed to learn. He was an active observer and liked to be invited into an activity. He learned
by doing, and he especially remembered when there were explanations along with
demonstrations. He also liked hearing ‘why’ something was done…unless I repeated myself too
too much. At such times Graham would say, “Mom, you’ve already said that.” which was always
disconcerting but at least let me know he knew.

I let Graham make decisions – even before he could talk. When he started standing up in
his crib, I’d give him a choice every morning of what to wear by letting him choose between two
outfits. As he got older, he chose his own clothes. I combined Montessori methods with
Adler’s Systematic Training for Effective Parenting (STEP). I bought stimulating toys along
with ‘fun’ ones. All of these things seemed to help Graham. He learned to make decisions – not
only to make decisions – but that he had CHOICE…and choice gave him the power to say “yes”
and to say “no”. It took a while, but he learned that when he said “yes” to one thing there were
consequences. He could say “yes” to one thing, but that meant he said “no” to the other thing.
“Yes” or “No” did not mean “Both”. That was a hard lesson that came with the power to make a
decision. Somehow, it seemed to me Graham developed a sense that he belonged in the world,
that the world was a basically good place to be, and that not only were most of his needs and
wants met, but that he could effect change (sometimes) in his environment and with people. I
loved Graham’s spontaneity, his curiosity, and his mostly happy spirit. …and as he grew, I
wanted to protect these qualities in him. In my experience as I observed people in my daily life,
it was the adults who had lost these qualities (or never had them) who struggled with life the
most. It seemed to me the best thing I could do to protect Graham’s spirit was to let him know I
loved him, supported him, that I believed in him. Additionally, I learned to advocate for him –
something the parenting books never mentioned. It became clear to me that the only way I
could be present to his needs was not to be preoccupied at home with teaching but to be present
to my son and ways I could support his belief in himself and his skills so he could become as independent as possible and not end up in an institution. I could always work in an office and earn money for us to survive.

However, I still had a glitch inside me that churned and prevented me from fully enjoying my son and the parenting dreams I had once had. It stemmed back to the accident and Esther. The accident changed everything in my life. My marriage had become more abusive. My social life became almost non-existent. People in my family didn’t know what to say so they were silent. I had done what I thought was the right thing – given up my career which fed my spirit – to be more present with my son. But, inside, even on spectacular days with my son, I felt resentment. Life wasn’t supposed to be like this. The “if onlys” – if only Esther had followed directions, if only I had followed that still, small voice and checked on Graham sooner, if only my relationship with my mother-in-law hadn’t been important to me, yadda, yadda, yadda…, every day and sometimes in my dreams. I had tried therapy, meditation, talking with friends, retreats, walks, art, journaling, but the cold stifling of joy, glitch in my stomach prevailed. What was it I needed to let go of? ….

A couple years ago I decided to spend my Christian Lenten season in a Buddhist tradition. Lent is a time of fasting, penance, almsgiving, a walk with Jesus to the cross and the resurrection of Easter. Our parish was offered weekly groups parishioners could attend. All but one were in the Christian tradition with readings and activities surrounding the Bible. There was one additional option. We had two women in our parish who were Buddhist and Catholic. They were offering a Buddhist experience of Lent. That intrigued me. We met in their dojo after we took off our shoes and left them outside. Inside we sat on pillows on the floor surrounded by windows. A singing bowl called everyone to attention and quiet. There was a Buddhist reading.
Then we were silent and meditated. After about 20-30 minutes, we shared. Our teacher/leader (sensei) gave helpful, comforting comments to each person who shared. There was also a teaching about the Buddha’s life. I spent much of these six weeks confused because it didn’t seem related to Christianity at all until the end when we drew parallels between Jesus and Buddha.

My sharing after meditation that first week was about Graham, his accident, and my lost teaching career. After the second week’s meditation I was still on the same topic. When I was my turn, I began to talk about teaching again, and was immediately cut off with –

“Stop! I won’t let you do this to the group! You’re afraid you’ve fucked up your life by giving up your career.”

I was STUNNED! “What on earth! What have I gotten myself into?” My heart and my stomach felt physically punched with our sensei’s insight “Wow. She’s right!” I felt embarrassed in front of the others. But… --As painful as that was to hear, I had to admit she was right! I had never thought of that before.

It had never occurred to me that as I grieved my dreams for my son and dreamt of new – more attainable ones, that I needed to grieve dreams I had for myself. I needed to grieve my lost career. I spent the rest of the week licking my wounds and realizing I could be so smart and so unaware at the same time. For years I had read books, gotten therapy, and grieved my dreams for my son. I had kept searching for meaning in my life and didn’t find much. I was caught in still grieving what my son could have been before the accident. I wanted to get to the point where Graham’s condition didn’t matter to me anymore, but I wasn’t there yet. What sensei had said stung me to my core. I also knew she was right and hated to admit that I needed to hear what she had said. So I spent the rest of the week beginning to grieve my lost career.
In fear and trepidation, I went back the next week. Only the leader (sensei) and her partner showed up besides me. Where were the others?

“Oh, Shit.” I thought. “Now what.” My insides wanted to leave, but my feet were leaden and stuck to the floor.

When it was time to share, sensei asked me, “Any thoughts about last week?”

“You were right. I needed to grieve my career.”

___ “Hm.” as she turned to her teaching partner, “She’s open.” She looked back at me.

“Any reflections?”

“I realized that while I have been grieving my dreams for my son so I can love him and value him for who he is, I never grieved my loss so I remained stuck in sadness and self-pity – unable to find joy in another way of life.”

I do not remember their responses. I did keep attending the Buddhist Lenten meetings, and I did ponder and receive healing. It was a good Easter, and I felt resurrected.

Once I knew what that long-term inner pain was about, it was easier to turn my head in another direction to find meaning, purpose, and worth in being Graham’s mother. I also came to realize that I was one of his teachers too. Maybe the most important one because his concept of self and his own self-worth began with me.

Strangely, I felt deep pain and disappointment when I resigned and at the same time deep peace. I grieved for something I no longer had, and I read Joan Chittister’s book Scarred by Struggle, Transformed by Hope. And, like Chittister, I found meaning by living with and pondering life’s changes over a period of years. I let Graham be my teacher, and I learned the magic of moments, imbedded in my memory. I learned from Graham who can only concentrate on one thing at a time the richness of being present to whatever I’m involved with at
the present. I learned to love with emotion instead of with only my mind. From Rabbi Harold S. Kushner’s *Overcoming Life’s Disappointments* I learned first that I can’t “do it all.” I can’t be the totally involved teacher and a totally present and involved parent at the same time. And secondly, what I can do is find meaning in what I do. So, while I used to call myself *teacher*, now I call myself *mother*. From Richard Rohr’s cd of a retreat he gave with Mary Beth Ingram *Holding the Tension* and his book *Everything Belongs* that if I am open to learning every challenge I meet prepares me for the next event. And, “True transcendence always implies inclusion of the previous stages.”(Rohr, *Holding the Tension*, disc 1) For me this meant that I was not only Graham’s mother but I was also Graham’s teacher – not in American Lit and expository writing, but in attitudes of openness, perseverance, resiliency, giving back, kindness, and standing up of oneself. Perhaps my part in this world is to teach one rather than many.

Finally, I needed to stop worrying about which decision would have been the better decision – focusing on my career for Graham’s financial security or focusing on my son to help Graham become as independent and as emotionally secure as possible and we’d figure out the rest. It took years, but I finally realized it’s not which decision – each decision has positives and negatives. What’s important is that I pick one and embrace that one – explore its negatives and positives. Then enhance those positives and work to diminish the negatives. While the future is still unknown, I am happy with the decision I made.
Chapter 9
Revisiting the Accident – Healing the Left Overs

Rembrandt’s Prodigal Son, Henri Nouwen, and Me

When my close friend and mentor was moving, Grace Gibson gave me a large poster of Rembrandt’s painting of the *Prodigal Son* with the stipulation that I use it. I kept it for years rolled up. Framing it would be expensive, and there was no wall room in my apartment to display it since I had already used all spaces. When I moved to my condo, I couldn’t find an appropriate place for it. The figures were too large for my rooms. The subject matter from the New Testament parable about the son who wanted his inheritance from his father and then squandered it and later came home and humbly asked forgiveness and just to work on his father’s land seemed too imposing (along with its size) for my place. This was something that needed to be in a large room, seen by many people. I gave it to my parish along with the CDs of Henri Nouwen’s *The Return of the Prodigal Son: A Story of Homecoming*, a book of meditations written by Henri Nouwen about the parable after he spent time with the original painting at the Hermitage in St. Petersburg (formerly Leningrad) in Russia. It became a team project. One person made a wooden frame for the poster. Another bought the protective plexiglass. Another man made a moveable easel to display it in a variety of places for a number of groups. And, a woman organized a workshop/day of prayer and discussion around the poster and the CDs just before Lent. Of course, I attended.

That Lent I decided not to participate in the various spiritual activities offered by my parish but to work my way through the copy of Nouwen’s book and meditate on each of his reflections and apply these to me. There were reflections on each of the persons in the
parable/painting: the father, the prodigal son, the older brother, two witnesses, and the situation.
I expected insight. I didn’t expect any surprises. I received both.

As the story continues from above, when the father sees his lost son approaching, he is joyous and tells his older son to prepare the fatted cow for slaughter for a celebration. This older son protests saying he had been loyal and obedient to his father, yet, his brother had taken his half of the family fortune, squandered it, and now is coming home. The older son states he doesn’t understand why his father wants to celebrate the younger son when he, the father, has not ever celebrated him when he is the one who has done the work, been loyal and obedient. His father states that the older son’s inheritance was intact, but his younger son had been lost and was now found.

I had always felt a kinship for the older son and his protest when this parable was read in church. To my utter surprise Nouwen talked about the older son’s resentment. I was amazed! What resentment? The older son had worked, had seemingly not received appreciation from his father during that time which included years of loyalty and obedience. I understood how the older son could perceive this brother’s return as a threat, especially since his father wanted to throw a party for this philanderer. Did this mean his father would give away the older son’s portion of the father’s inheritance as well? …to this neer-do-well? Did this brother feel his father loved him too – or just the lost son? Was this sibling rivalry, or was the obedient son less valued by his father? What on earth, Henri Nouwen! Resentment? This son had some real concerns!

I tried to be quiet during my meditations on this subject, but my mind, my emotions were racing. I tried this meditation for a number of days. Went to other ones in the book. Forced myself to come back. It always triggered me.
Then, that still, small *voice* that has no words kept nudging me. Would not let me rest. Day or night it haunted me. Hmm. What was this about? What did I resent? Who caused it? Who did I resent? → Esther.

“O.K., Henri Nouwen.” I thought. “Maybe you have something. Maybe I need to look into my resentments.” This was not going to be fun. I was going to need to be brutally frank and honest with myself. Ugh. However, as one of my therapists had on the wall in her waiting room, *The only way out is through.*

**The year before – Lenten Buddhist experience**

Luckily, the year before I had spent my Lent in Buddhist meditation. Our parish has two women who are also Buddhists, and they offered to facilitate a parish Lenten group in a Buddhist tradition. Our parish also offers group experiences of sharing our responses to the Lenten readings where people sign up to join groups and discuss their understanding of the Sunday readings. This process opens up possibilities of meaning and gives depth to the Lenten experience. I needed something different from the traditional Lenten readings and discussions so I immediately signed up.

When I joined the parish Buddhist group for Lent, I imagined we would read the Sunday readings together, meditate in quiet together, and then share what we each received during our meditation. Wrong. What I did learn was the real work of Buddhist meditation and the value of it. I already knew that many Buddhists did not consider Buddhism a religion but a “way of being in the world” … a way of being which worked to soften with the goal of eliminating one’s pain. (Chodron, 1997; Chodron, 2001). The real work for me was sitting in the quiet while my mind triggered memories and emotions. The goal was to get to the point where those memories and emotions no longer *triggered* me and I could just let them *be* or exist. Once I reached this state, I
could just let the memories/images exist and could just watch. It was reaching this state that took inner work.

Once I’m triggered by a thought or a memory, I’m emotionally involved. Old pain captures my stomach, my heart, my throat, my nerve endings. I cry to let go, but toxic shame, guilt, regrets lock me behind bars which have no door. I can see out, but there’s no way to get out. During these times I longed for the radiating warmth of the Great Creator which connects with me in relationship and holds me in the palm of His(Her) hand (Isaiah 49:16). I just don’t know how to let go of the pain to reach enlightenment. However, if I keep at it and spend some time meditating every day and let the quiet take me where it will, eventually I get glimpses of something different, a distancing from the memory which lets me observe the memory without the emotion it’s been wrapped in. This is when the transformation occurs which lets me transcend the pain and go on with a restored spirit.

When I made the decision to stop teaching, it took me years before I had stopped crying when the month of August arrived. It was during this month I ran a week-long workshop for the students on the newspaper during which we planned, interviewed, and laid out the pages so everyone in the school would receive it during the first week of classes. August was also the month I organized each day for my first month of classes, especially for my American Lit classes. I resigned on July 1st, 1985. Even though I had stopped crying, I still had a pang in my heart and a pull towards teaching even in August, 2012.

Over months after my Lenten-Buddhist experience in 2013, I finally could let go of my teaching career and the dreams I had for it. My identity had been linked with my teaching. Teaching, the preparations, the connection with students and the exchange of ideas fed my spirit. We learned from each other. I knew who I was when I was teaching. Who was I if I was no
longer teaching? I didn’t know. I had felt lost for years. There were jobs, but they didn’t feed my spirit. Gradually, an idea began to appear and sink into my sinews that almost everyone is a teacher. Showing a child how to scrape food off dishes after a meal before washing them, or showing a new employee how to use the copy machine both take teaching skills. I didn’t have to be a professional teacher to be a teacher. Upon reflection spread over months I came to own that my greatest teaching was in raising my son. Graham with his disabilities was the challenge I chose to engage which defined who I was and gave my life meaning. While I had done much work on myself over the years using methods from a number of spiritualities, it took my Lenten season in Buddhist meditation to bring it all together (which ended up taking months longer than the usual six weeks of Lent).

**Prodigal Son Lent**

So, the following Lent I decided to work on my resentment of Esther who had changed Graham’s and my lives forever. I planned to use Henri’s Nouwen’s reflections on the biblical parable of the Prodigal Son as well as his reflections on Rembrandt’s painting. It seemed like an easy plan. It wasn’t. It meant I needed to re-live everything that had happened during the accident and re-experience the smorgasbord of emotions, entangled (entwined, intertwined, tangled, matted) as they were at the time.

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After the accident I was panicked and sad. My perfect son was damaged. I couldn’t fix him, and medicine didn’t seem to hold much hope either.

Many people commiserated with me, but many pitied me as well. I remember one woman looking down at Graham, shaking her head, then looking at me as she said, “Too bad. I’m sorry for you.” I was particularly exhausted and alone at the time, and I thought to myself,
“Finally. Someone understands.” Unfortunately, this sent me into a downward spiral of self-pity – compassion with other mothers and their children with disabilities – and then resentment set in.

There were seven teachers pregnant in my high school when I was pregnant. One of them a PE teacher and coach did not want children, had a difficult/precarious pregnancy and actively and openly did whatever she could to have a miscarriage. In contrast I had done everything I could to take care of myself. We both had boys. Years later, when her son was deemed a genius (around the age of 5) and Graham had just begun to walk, I was beyond jealous. “What was the fairness of that?” I’d say to myself.

But, my deepest pain came from Esther. She never acknowledged what she had done nor how it changed our lives forever. I remained stuck in if onlys and what might have been for years and years. …and resentment. Resentment gave me a moral high ground. I couldn’t fix Graham, but I could feel morally superior to Esther. Blaming her hid me from feeling any guilt of my own. After all, as I sat that day at my kitchen table, I had several intuitional nudgings to get up and check on Graham, and I ignored them in favor of trusting Esther and trying to develop a relationship with her.

Resentment also released me from expecting more from my son. Academia was out of the question. I didn’t expect him to excel in any of the normal areas parents find themselves wishing for their children, like sports or business. I felt that Graham’s life journey would not be one of ascent. Meanwhile, if I took my responsibility as a parent seriously, my ascending career was now cut short because I needed to spend my creativity helping Graham. I resented that.

What I lost by holding onto resentment was reconciliation with Esther to begin with. What I also lost was joy in parenthood because I was so worried about what would become of Graham when I could no longer take care of him.
I didn’t want to re-live all this, and I didn’t want to admit these things about myself, but I did as I slogged through Nouwen’s Lenten meditations especially his meditations on the parable and the painting of the Prodigal Son. I would read something every day and then sit quietly in meditation to see what if anything would come up. I thought I would follow the same meditation process I had with the Buddhist meditation. Once a memory came up, I thought I could just let it come, and I could observe it and from a distance, gain perspective, and learn from it. I easily went through the reflections on the younger son with cerebral understanding. The younger son was rebellious, full of addictions, both of which led to his lostness (Nouwen, 1994, 25-44).

However, I almost quit the project as I encountered Nouwen’s reflections on the elder son. I didn’t want to admit I had spent years of my life in resentment, self-pity, jealousy, judgment, bitterness, holding back, anger, condemnation, etc. Yet, if I were brutally frank and honest with myself, these things were all true. Nouwen’s words struck home: “…obedience and duty had become a burden and service had become slavery” (Nouwen, 1994, 70). Perhaps I was in depression. I had been in an abusive marriage, my son was disabled from one of his grandmother’s actions and lack of my own action, I had given up my teaching career which I loved, and life seemed to have no meaning and no joy. …and I had never thought of the elder son as cold, judgmental, or withholding. …yet Nouwen’s words resonated. Now what was I supposed to do? I had started this journey to get rid of the glitch I felt inside me almost every day. How was I supposed to do that when I had to admit these negative, unseemly things belonged to me?

Later in my reading I came upon another passage which made me cry for days.

When I listen carefully to the words with which the elder son attacks his father – self-righteous, self-pitying, jealous words – I hear a deeper complaint. It is his
complaint that comes from a heart that feels it never received what it was due.  
(Nouwen, 1994, 72)

YES! Why didn’t Esther ever acknowledge what she did?! Why didn’t she ever apologize?!

What she did changed Graham’s life forever! … and mine too! … and more to the point … why couldn’t I go on?

What was holding me back from enjoying Graham as gift? Not tragedy?

**Healing of Resentment**

If I were going to see this Lenten journey through, I felt I needed to follow through on not only my meditations but also avail myself of the Lenten rituals, especially the sacrament of Reconciliation but also the Holy Week activities leading up to Easter. So, I continued my daily meditations as the six weeks of Lent approached Holy Week. This particular year the sacrament of Reconciliation (formerly called Penance) was scheduled on the evening before the Triduum (Holy Thursday, Good Friday, and the Easter Vigil). It had become tradition that priests from different parishes in the area would help each other out by scheduling one night at each of six parishes during the sixth week of Lent to offer the sacrament of Reconciliation. This particular year the parish I was in had scheduled it during the sixth week. I attended.

For those who are not Christian, the sacrament of Reconciliation (Penance) is where a person admits “sins” – things which hurt self and others which s/he does, had a change of heart, and wants to change one’s attitudes and behaviors. In some respect it is having help being re-introduced to God and being loved/accepted in the place one is in along with a blessing of forgiveness and a penance to help one with a change of heart and behavior. After the Lent I had I was ready, and when the time came during the service to get in line to visit a priest, I made a beeline to Fr. Bill. I felt he was safe because he didn’t really know me. He was a new pastor,
and I had observed him during Mass and other events and felt safe. He listened as I told him about the accident and Graham and Esther…and added my resentments, self-pity, and condemnations. Fr. Bill and I talked, we prayed, he forgave my sins, blessed me, and when it was over, I realized I still had that glitch in my middle. I was sad and didn’t know what to do. As I was about to get up feeling like a failure, I looked over at Fr. Bill, who said, “So she never acknowledged what she did.”

I shook my head. “No.”

Fr. Bill lowered his head and made a sound like “Mmmmmmmmmmmm” or “Errrrrrrrrrrrr” kind of like a groan – like someone in deep pain who has no words to define how he feels. The groan came from the wisdom of lived experience. I knew that at some point in his life he had been where I was. He Knew. He understood. I could trust his words. …They were not the words of those pitying me or praising me – both which were self-serving, requiring no more than to be spoken and then forgotten. It was the compassion and wisdom of lived experience which encouraged and healed me.

Instantly, I felt released. The glitch was gone! Tears started flowing down my cheeks. I knew that he knew where I had been. He had been there too…at some time in his life. I felt understood and more importantly, I felt not judged but accepted. I had told my story…had been accepted…and this was the beginning of healing. What a gift. Who would have thought that an expression of a bowed head, closed eyes with furrowed brows and the pain of compassion and a human groan would be what healed me of my resentment. …but…it did. …and I am grateful.

I had had years of therapy for my abusive marriage and grieving over Graham’s accident and issues regarding his disabilities which gave me much understanding and helped me go on. But, I still had this glitch, this tight knot in my middle which I couldn’t get rid of. I couldn’t
name it and I knew it clouded my perspective and was holding me back from the spontaneous, optimistic outlook I used to greet the day with. I tried everything I knew (exercise, readying self-help books, music, gardening, feeding my emotions, etc. etc.), but nothing got rid of the glitch. …except… this brutally frank and honest session with Fr. Bill. I feel new again inside. I approach each day differently – more like when I was a child and couldn’t wait to see what each day would bring. I know I am not alone. I know I belong. I know I am loved. What a difference it makes.

I felt so good inside. I have no words. I must admit I distrusted how good I felt and six months later I tried to feel the resentment again but couldn’t! Then I knew I was truly healed…and found a time to thank Fr. Bill. Graham would call me “a little slow,” and he is right. It only took me 34 ½ years to get there. But, the important thing is that I persevered until I got there. …and to this day two-and-a-half years later, I’m still there. It doesn’t mean that Graham is cured of his disabilities or that there still aren’t challenges with him. Graham is gift now…no longer tragedy. I see the world differently now. My spirit is restored.

…and to get here I needed everything which came before. As Richard Rohr states in his book *Everything Belongs*. I needed the compassion of Jesus, the comfort of being in a tent with God from Judaism, the discipline of Buddhist meditation, and the great cathedral of the outdoors with its inspiration and healing of spirit.
Chapter 10 – Graham’s Voice

Discussions of Four Interviews with Graham Stewart Higgins

Graham’s Consent

This chapter is about what is important to Graham. I must credit my Dissertation Chair Terry Jo Smith with the initial idea when we were meeting months ago as she asked me whether there was room in my dissertation for Graham’s voice. What a wonderful idea! It hadn’t occurred to me but seemed a natural outgrowth of the auto-ethnographic method I was using for my own stories. Graham is now thirty-six years old, living mostly on his own. With the help of the PACE Program at National Louis University, he has learned many life skills, such as job responsibility, budgeting, bill paying, and online checking. Graham has also learned how to take care of his apartment with grocery shopping, cooking, cleaning, etc. He has learned how to live with a roommate, and since he grew up as an only child, this was initially a challenge.

When I proposed the idea of him being able to speak in my dissertation, Graham was excited and said this part would be his dissertation. I suggested that we each select a few topics which were important to us, and Graham would be in charge of accepting or rejecting my topics. I did say I’d like the topics to be important to him in some way, especially about growing up, or about living with his disabilities.

Graham has ideas, opinions, asks questions, and reflects on his life and current issues. I am used to his slower processing of information, and we have developed a way to work with his word-finding condition which we call twenty questions. I keep asking “Is it like this or like that?” …and I keep changing the this and that until Graham says, “That’s it.” We have used this process since Graham was about two years old and non-verbal when he could only point to two objects being offered him. I have come to trust that when Graham says, “That’s it.” he is not
trying to please me but recognizes the word or phrase as matching how he’s actually thinking or feeling. This is important to note because this process does come up during our conversations/interviews. It started as a way to communicate with Graham when he would tantrum, usually during meal times. He wanted something and was unable to say the words but knew what he wanted. When “uh, uh, uh, uh…” didn’t work, he’d start crying, sometimes throwing things, even food (which our Old English Sheepdog Gus loved). I didn’t. At the age of three his teachers put him in sign language class, and his babysitter and I took a sign language class at night. Somehow the right-brained sign language triggered the left-brain language. Eventually, Graham didn’t want to sign anymore though he still knows some of the signs to this day.

Regarding the taped sessions, my digital recorder was not working during our first conversation (November 27, 2015), and the tape from another machine is compromised with much static and too soft recording volume. From my notes and many hours of listening and re-listening I was able to resurrect most of our first topic about cleaning the sink or at least a close approximation of the exact wording. However, the second topic about the angry ball game, I decided just to re-interview as the tape quality seemed to deteriorate further into the recording. The subsequent conversations were taped on a digital recorder, and transcripts follow the recordings.

As I review the 68 pages of transcripts, it seems best if I group the conversations according to themes rather than topic. There were eight topics and five or six themes. The topics and themes overlap. The major thematic groupings include: (friends, community, belonging), (competence, confidence, toxic shame), fear of abandonment, intellectual disability, and resilience. There is one experience which was important to Graham and speak to the
surprises, messiness and mystery of life which we both have encountered in life so far. It is a remembrance about how the wood in an Eames chair shredded while Graham was sitting in it. The chair simply came apart. It was a moment for Graham and me… all of a sudden Graham was lying on the floor entangled in the chair and needed help getting out. Those who saw it later could not figure out what had happened because the wood had not torn apart in any of the usual areas (around a joint or hole, etc.) Perhaps Graham captured the situation best when he said, “the wood just gave up, and I don’t know why – the wood was not rotten – It just gave up.” Things happen. Lotteries are won. Coincidences bring people together or pull them apart. A chance meeting leads to a job…or…an unfortunate encounter leads to being fired. Or, as in our case an accident leads to disability. There are both positive and negative surprises. And, there’s the two-fold messiness of first dealing with the situation and its consequences …and… the messiness of the mystery as to why the situation happened and how to bring meaning into one’s life in the aftermath of what has happened. (Interview. Graham Higgins, March 19, 2016, p.21)

Belonging, Friends, and Community

It is fitting from what I know of my son that the themes of belonging, friends, and community are in five of the eight topics Graham and I talked about during our conversation. As his teacher Mrs. Miller said to me several times when Graham was in high school, “Everyone is happier and calmer when Graham’s around.” (Personal Communication. Mrs. Miller, 1997-2000). Graham is not a leader, but he’s a loyal follower and an active observer. He is intuitive and feels things deeply. Even though he may struggle sometimes with naming those feelings, he works at it and usually recognizes the emotion if it is named and matches what he’s feeling. So, it does not surprise me in the least when one of the comments Graham makes during one of our discussions regarding the angry ball game was, “I didn’t feel like I, ah, belonged…
The angry ball game

The Angry Ball Game was a *game* I made up during our family divorce. My marriage had become increasingly abusive, and I left with Graham under police escort. Graham and I moved into an apartment during what would be a six-year divorce process. Life was different. Confusion and fear reigned. I stayed in Barrington so Graham could remain in the same school system. At that particular time Barrington was the only school district within the 26 district Lake-McHenry Cooperative for Special Education which had a comprehensive program allowing special ed students to receive whatever was recommended for their services by either the district or the cooperative. Also, I wanted to keep Graham in familiar surroundings hoping that would give him some security that the world was not ending even though it felt like it.

However, Graham started acting out. One evening he was yelling at me and I couldn’t understand him. He rushed toward me and kicked me in the ankle. It hurt! I yelled back, “That hurt! I left your father because he was hurting me. And, you can’t live with me either if you’re going to hurt me!” I was shocked that came out of my mouth. I realized I needed to find a way for Graham (and me) to release pent up frustration, anger, and fear. I was now in therapy and learning about emotions and how important they are. Anger lets people know something’s wrong and pushes people into action. However, the action needs to be focused in changing whatever’s wrong. So, what do I do about the anger until I can calmly focus? How do I help Graham (and sometimes me) release that excess energy around the anger so Graham and I can calm down, talk about the problem(s), and the feelings, and then come up with a plan to change the situation?
My solution was a game I made up which I called The Angry Ball Game. The way it worked was when Graham was angry, we’d go to his room, and I’d ask him to pick a number. (Usually, he chose the number 18). I kept a basket filled with foam balls in his bedroom just for this purpose. Then I told Graham to pick a ball and throw it at a wall in his room that had nothing on it while yelling what he was angry about. (i.e. “I’m angry about____. I’m angry with _____ . I’m angry at _____ . I’m angry because _____ . Etc.) Then, I’d take a ball and throw it too yelling about whatever I was angry about at that time. We took turns throwing balls until we each had thrown and yelled about the number (which Graham had chosen) of things upsetting each of us. …. Then …. We’d pick up the balls and go on with our day.

Later that night – after his bedtime routine, prayer, a story, and lights out, I’d bring up one or two of the things which Graham yelled about during the Angry Ball Game. We’d talk in the dark. (I learned this from a communication workshop between mothers and sons which I took at the beginning of my husband’s and my separation. Talking with one’s son during a car ride or in a dark room seems to help a lot of sons open up. When eye contact is difficult, being in a situation which doesn’t require it, helps. It worked for us.) We’d process feelings, events, hurts, fears, and whatever the main one or two issues seemed to be. And, we’d come up with a plan (which might need tweaking in the future).

Abandonment.

Continuing discussion of the Angry Ball Game, during almost every session of the Angry Ball Game, Graham would yell out later in his turns, “My angry cuz my brain no work right.” The first time I heard it, I thought of his teachers and the research I had done which said that of those who had intellectual disabilities, the group which had the most difficulty were those people who were the closest to the normal range of intellectual capacity. “Normal” range for IQ seemed
to begin at 70 with a composite score of 100 considered as “Average Normal.” Graham’s composite score has consistently been 68 (≈1992, 2000, 2006). When Graham started school at the age of 3, I was told there were three levels of what was then called retardation, and Graham had been placed in the middle group, then called trainable mentally handicapped. Just before he turned 5, Graham’s label was changed to the highest of the intellectually handicapped labels which at that time was educably mentally handicapped. Graham’s school was changed from Laremont in Gages Lake to Sally Potter in Mundelein – both in Illinois.

So, I was expecting that Graham, like Charlie in the book and movie Flowers for Algernon, would someday see difference between what he was able to do/think and what others were able to learn and accomplish. I waited and watched and dreaded the day it would happen because I was so afraid his spirit would be crushed and his enthusiasm for people and life would be extinguished. I taught sophomores, juniors and seniors in high school, and many of my students walked into class having already given up on themselves. They were defeated before they even started. They had received so much toxic shame that they had come to believe they were not good enough … for anything. As a teacher I knew my Graham was vulnerable to the judgment and ridicule of others because of his intellectual disability. It was simply inevitable. It would come from home, school, work, church, service organizations, or the stranger on the street. I wanted to protect my son from judgment and shame and knew I couldn’t. But, maybe I could be around to help him pick up the pieces and regain most of the essence of himself.

I created the Angry Ball Game after Graham and I moved out of our family’s home during the divorce to help Graham use up the extra energy which surrounded his episodes of anger and to identify the issues triggering them. Once the excess energy was dissipated, we could go on with the rest of our day, and I had an idea of which one or two issues we could talk
about during his bedtime routine…and hopefully, both of us would find some understanding and
if not healing at least the beginning of a plan on how to deal with the one or two issues we had
selected from the many which came up as we were throwing the foam balls.

So, when Graham yelled out during one of our first Angry Ball Games after we had
moved from our home to an apartment, “My angry cuz my brain no work right!” I immediately
thought that Graham was reacting to someone judging or shaming him.

It was during our second conversation on this topic that Graham’s thoughts and emotions
regarding his “brain no work right” comment which had been repeated over years were clarified.
At one point, we automatically fell into our “twenty questions” method to draw out Graham’s
thought until he enthusiastically said, “That’s It!” which I had come to trust as the meaning
which matched his feelings. And, for almost the past thirty years I thought this referred to
Graham being angry with himself that he had an intellectual disability. I was wrong. During our
conversations for this dissertation Graham totally surprised me by telling me a completely
different reason he was yelling out “My angry cuz my brain no work right!”

I was sure his many comments about his brain not working right were his way of talking
about his intellectual disability and the toxic shame he had received from others and the
internalization of this. Since Graham and I worked together to name our feelings and express
what we were upset about and how we could resolve the situation, I hoped to gain some insight
about what it was like to live with intellectual disability... how the toxic shame affected him, and
what helped to restore his spirit and his confidence.

A narration of our conversation follows:

I asked Graham to remember back to that time and share with me what he was thinking
and feeling when he yelled on many occasions that he was “angry cuz [his] brain no work right.”
Graham was quiet. He looked down and changed his position on the sofa several times.

“I, ah, did not feel good enough because, umm, it ah, it, ah, man. I didn’t feel good enough because at the time you and Dad were in the process of getting a divorce.

…and…ummm…and…” Graham paused – searching for words.

As the silence in the room began to get loud, I encouraged Graham by telling him, “It’s o.k.” and by asking direction of him. “Should I be quiet? Or – should I ask questions?”

Graham identified that he had been thinking about our game and about this particular phrase, but that he “didn’t know what else to say.” Then he said, “Ask a question or two – and that’s all.” knowing that sometimes I ask a number of questions one right after the other.

“Were you afraid of who you would be without both your mom and did living together?” I asked.

Graham knit his brows. “Can you say that one more time?”

Trying to get at the core of what Graham had stated earlier so we could explore it, I rephrased the question. “Were you afraid of – of not being in a traditional family with a mom and dad living in the same house … and having a whole family living together?”

“Yes.” was Graham’s immediate response.

I continued. “Were you afraid of what would happen to you if your mom and dad broke up?”

“Yes.” another immediate reply from Graham.

Pressing further, “Were you afraid of ‘Well, I’m little! Who’s going to take care of me if my Mom and Dad split up?’”

Graham sat up. “Yes. That’s It! Yes. Yeah.” he said emphatically. [Interview with Graham Higgins, March 19, 2016, p. 11]
What Graham’s comments revealed to me was that rather than expressing emotions around his intellectual disability, he was expressing his inability to “fix” his parents and bring them back together. He was also expressing his fears of abandonment revolving around his parents’ divorce. I had called it our “family” divorce because Graham needed to learn how to negotiate the transition between two dramatically different parenting styles along with his emotions and his parents’ emotions which affected him – a lot to ask of a six-year-old especially a six-year-old with developmental delays.

I had Graham in therapy for five of the six years during the duration of the divorce because I didn’t want him to believe that he was the cause of our divorce. (I had been preparing to leave the abusive marriage when I found myself pregnant.) In addition, I had Graham in the Rainbows for All God’s Children program. This program helped children and adolescents process grief – all kinds of grief – from moving (with loss of friends, routine, everything known in a child’s life) to death of a friend or family member – even the death of a pet.

I thought I had supported Graham with the individual and group therapies along with the talks he and I had with each other. Until these interviews (some thirty years later) I didn’t know the real problem for Graham during that time was that he feared being abandoned and not a false guilt that the divorce was his fault. In fact, I had even had it written into our parenting agreement that the parent who was not with Graham overnight would call him so Graham would always know he had two parents every day. I had thought this would give Graham security. Apparently, I was wrong, and he needed more.

Graham’s revelation about abandonment was a shock for me. All he wanted to do was to belong and be taken care of since he was a child! …and I had mistakenly thought (for almost 30 years) he was yelling about toxic shame and not feeling good enough. Graham just wanted the
security of a traditional family system. Understandable for a seven-year-old whose family was breaking apart. Graham’s whole world was in chaos. What was going to happen to him? He did not want to be forgotten or abandoned. He just wanted to belong with the comfort and security belonging brings, along with the certitude that his existence was O.K. with the world and the people he knew. Graham’s fear is logical though. As Henri Nouwen explains in his book *Life of the Beloved*, “In the Western world, the suffering that seems to be the most painful is that of feeling rejected, ignored, despised and left alone.” (p.89) By what he said in the interviews, Graham feared being left alone and rejected the most. By yelling, “My angry cuz my brain no work right.” Graham was trying to tell me he was trying to bring his parents back together so he’d have his family together again – so he’d feel safe again. However, the teacher in me immediately went to an educational explanation which I had been expecting to see in Graham. Years earlier I had been told that those disabled with cognitive impairment who had the most difficult time their intellectual disability were the ones who were at the higher end of the disability because they understood that they were different. …and this hurt…and they wanted to be like others who could think and do more. This information came to me by more than one professional in special education from more than one school, including the school I had taught in. So, I had been waiting and watching Graham for when this attitude showed itself in Graham.

Nor did Graham have siblings to share his grief or his fear with. Even one sibling would have helped because he would have been able to share his confusion, his sadness and anger and his fear. He would have known that he was not alone, and even if both Mom and Dad disappeared, he would still have his sibling who would know what he had been through. It could even have been a bonding experience because he and his sibling would have gone through the experience together.
Yet, I was still dumbfounded by Graham’s revelation that the reason he yelled “my brain no work right” was because he knew he didn’t know how to fix his parents’ relationship so he could live in a traditional family and feel safe. Since he’s been born (and even before), he’s been on my mind and in my heart every day. We returned to this topic of the Angry Ball Game during three of the four conversations we had for this dissertation. His surprise came during our first conversation in November of 2015 which was unfortunately lost in a garbled taping. But, what he said was so important and revealed a missed understanding I had of my son and how difficult communication can be, that I wanted to return to this topic which I’ll do in the discussion of toxic shame.

**Being an only child and belonging**

The motif of belonging continues when Graham talked about being an only child. It was something I had worried about while he was growing up. He has ten cousins, all of whom have siblings. Every family holiday my parents’ house was filled with kids – all of whom had brothers and sometimes sisters as well. I wondered how being with his cousins and seeing this would affect him. Graham talked about it last March:

[edited]

G – I have been the only child since the day I was born and after I was born too – and I thought I would have other siblings like a brother or a sister – whoever. And, um, it did not ever come to that point in my life to have another sibling – to have another brother or a sister. But, um, yes, at times - it does feel, I want to say – lonely. … But, I don’t really think that’s accurate right now in my lifetime. But, back then, I want to say – Yes, yes.

M – What would life have been like if you had had a sibling?

G – Well, I would be like the older/younger brother – taking care of, like you know, my sibling. Like you know, changing their diapers. I don’t know…. G – (laughing and nodding) Showing them the way… Yes.

G – (laughing and nodding) Yes. How to survive life.

G – (laughing) How to tie your shoes.

M – How to….
G – get around?  I think that was it.  How to get around in the world.  How to get around in life.
M – How to get along with each other.
G – Maybe that was it.
M - That a big part of living with siblings.  That’s what you began to learn when you came to PACE.  You had your first roommate in PACE Program.  You met Caleb, and you were roommates, and you had to learn to get along with Caleb.  Getting along in close situations – well, roommates are kind of like a close family situation.  And, since you never had the situation, that was a challenge.
M – So what’s changed in your life – Or – how do you look at being an only child now?
G – Well, um, … I got over the fact of … (pause) … I got over the fact of – that I will not have a sibling of my own any time soon, but, I moved on with life because, you know, I have friends, I have a roommate now – still.  I have someone special in my life.  A girlfriend.  And, I would say it’s not too hard anymore.
M – So you’re o.k. with it.
G – (upbeat) Ya!  Ya!
M – Any benefits of being an only child?
G – Um, Well, the main one I can only think of – you don’t feel left out.
M – You don’t feel left out?
G - I don’t know, but I guess I trying to talk about this for any other lonely child so that they don’t feel left out.
M – Let’s see if I understand.  What you’re saying is that being an only child you don’t feel like you’re being left out with other kids.  There’re no other kids in the family to make you feel left out.  [no sibling rivalry]
G – Yeah.  Yeah.
M – o.k.  o.k.  Because I was also wondering as I was listening to you talk that you have 10 cousins in three other families, and you could see that they all had siblings.
G – Yes.
M – How did that make you feel as you were growing up?
G – (sigh) Here we go again – going to the tough parts.
M – This is where your insight – your experience is valuable.
G – (pause) Well, it did make me feel that I, uh, did want another sibling at the time.
M – That you did not…?
G – That I DID…  But, now that I look at them (cousins), they’re all grown up, my cousins I’m talking about now.  Now…I don’t have that problem anymore.
M - …because…
G – Because I have friends.  I have cousins.  Someone special in my life…  My Spre group…  And, every day when I go to work at the museum, I see a lot of these families that have a lot of these siblings, and it does not worry me anymore.
M – And how does that feel?
G – Good. Very good.
M – Anything else you’d like to say about being an only child?
G – (pause) Well, there’s this one thing, but I don’t know if this should be included in this topic or not. Um. I really missed having a sibling in my life.
M – Can you tell me about that?
G – No, it’s not painful. I just - I just – I guess I wanted to connect with somebody – have someone there for me.
M – who will always be there?
G – Yes. Yes!
M – And you have transformed that and made your own family.
G – Yeah.

While I wish Graham had had sisters and brothers, and it was never my intention to have only one child, I’m delighted that Graham has created a family for himself of friends, his roommate among them, Spred members, work colleagues, and his girlfriend, along with family members. As he grew and experienced belonging in his nuclear family, then his extended family, and later in his separated family, and his school family, he created his own groups of belonging as an adult. The PACE program at National Louis University in Chicago, Illinois was hugely helpful in this regard. Students have the traditional college experience of living in a dorm on the same floors with each other. Graham went through the same angst and exhilaration of separating from his parents as most college students who go away to college. Since I worked on the same campus where the PACE program was located, Graham came to my office almost every single day of his first year. He would sit in the chair across from my desk. He never asked if he could come home, but I saw the thought in his watery eyes. There were days I wanted to take him home with me. We both needed to separate so he could mature into an adult. On the other hand, there were times during the summer when he was living with me when I’d happen to overhear him on the phone with a classmate, and he’d say, “Yeah, I can’t wait to get back home either.” They were both talking about the PACE program. The first time I heard it, I was hurt, and then I
remembered I had done the same thing – missing college when I was home and sometimes missing home when I was in college. Independence has its ups and downs. What gladdened my heart was that this was developmentally normal behavior. The separation may never have occurred if he had stayed living with me. He would have remained dependent on me, especially socially, and we would have eventually become resentful of each other. The PACE program taught students to be social and scaffolded them through their programs to retain friendships and connection with others long past their participation in the program. It is now thirteen years since Graham graduated, and he still has many of the same friends he had in the program.

**Tennis & belonging**

There was another aspect belonging which Graham experienced. With family Graham was yearning to belong and know his existence was o.k. With tennis, he was respected for being himself, and it was the coach and the team who wanted Graham to belong. When Graham started high school, I tried to get him interested in joining an activity because it’s through activities that a sense of community can really be built. I encouraged him to get involved in the newspaper or theater – both of which he told me emphatically, “NO.” His teacher got him involved with being assistant manager of the sophomore boys basketball team, but I could tell that was not his passion. After a couple of years he quit. Then came tennis, and Graham stuck to it like two pieces of Velcro. I couldn’t believe it! He couldn’t wait to go to school … and stay after for practice. I’d pick him up after work. Often I’d arrive, and the boys would still be practicing. Graham was so excited about tennis that during our March conversation, I asked him how he got his interest in the sport. Graham said, “I liked the sport. … I started to like tennis by watching it – by watching the sport of tennis on TV. … Andre Agassi … John McEnroe … their playing.” (Interview with Graham Higgins, March 19, 2016, pp. 1-2)
I knew Graham wasn’t going to make the team. He hardly ever hit a ball. I secretly cried sometimes when I was alone. I was dreading the day he was going to be told he didn’t make the team. The boys tennis teams did not have team managers. However, the coach liked Graham’s spirit and invited him to be the first manager of the boys tennis team. (p. 5, March 19, 2016) Graham seemed to feel honored and that he belonged, because his spirit was high as he continued to attend all the practices and meets…and he expected me to attend the meets as well.

At the end of the season Coach Rancone shared a few things with me:

…Coach Rancone came over to me and invited me to the team dinner.

He said, “Normally, we don’t invite parents. This is just a team thing. But, I want to tell you something because our team came in first in state.”

Graham joined us and Coach Rancone continued.

So, we won a huge trophy. Barrington High School, your team, was number 1 in the state (of Illinois) in high school tournament.

And he said, “I want to tell you that Graham so inspired all of the team members, and it was an unwritten rule amongst the team members that if any one of them (the team members) “dissed you”, or insulted you, or made fun of you – they (the team members) wanted me to kick that kid off the team.”

“And,” Coach Rancone continued, “that is something because tennis players can be a whiney bunch.”

G – (Hmm.”

M – (Coach Rancone continuing) “And, they give a lot of excuses. They’ll say they didn’t hit the ball because the sun was in their eyes, or because the wind was pushing the ball the wrong way, or something was wrong with the court. And,
when anybody on the team would come to me and start whining, I’d say, ‘You think you have it bad? Well, you look at Graham. Graham wants to play with all his heart. He wants to, and he can’t. So don’t you tell me that you missed the ball because the sun was in your eyes.’ So, Graham, you were just so helpful for this team winning the state tournament because you helped every single one of the team members.”

I heard the message that Graham was being held up as an example to the members of the team which separated him from the group. However, I experienced the comment in another way as well. Graham had been the manager of the sophomore boys basketball team for a couple years. He was there. He participated. But, his heart wasn’t in it. When he wanted to quit, I supported him. However, Graham really wanted to play tennis. I tried to practice with him. It didn’t go well. I am not a tennis player. I have little hand-eye coordination, and I didn’t know how to show Graham how to serve or how to hit the tennis ball with either a forehand or a backhand. My heart ached as I anticipated his failure. His teacher, the school social worker, and the school psychologist planned to meet with him in a group when he didn’t make the team.

When Graham accepted Coach Rancone’s invitation to become the boys tennis team’s first manager, Graham beamed. He belonged to a shared vision. He seemed to live for tennis. He was part of something bigger than himself. He had responsibilities, and he was part of the team’s success or failure. During this time Graham lived for tennis. He was inspired. I wanted to support him in this.
At the same time I realized the artificial relationship in Graham’s participation. He was there with the team but not a part of the team. He had comaraderie while he was with the team members, but none of them phoned Graham outside of school or invited him to get together for a social event outside of school hours or events. There was always the social isolation identified in the social model of disability when it came to social life. For me it felt as though Graham’s difference was o.k. at school, but he was not accepted or deemed part of the group outside of school. Graham, however, was so happy and so committed to something larger than himself with a shared vision that I didn’t want to touch those moments in time with any idea that might totally ruin it for him.

So, I never talked about this aspect of the tennis team’s behavior with him. He did open the door for others like him to follow. For me, the important thing at the time was that Graham followed his own interest and made a commitment to be engaged. He had purpose in life, and he followed that purpose.

So I came, and I was the only parent at the team dinner. Every single team member gave him a present to show Graham their appreciation of what he had done for the team. Graham did not sit with me. He sat in the middle of them, and he and the team remembered events laughing and sharing and just enjoying being together. I watched with tears in my eyes mostly in gladness to see my son thoroughly a part of this scene and partly in sadness because I knew it would end and he’d be by himself again because social life mainly occurred at school. (from Tennis March 19, 2016 Conversation with Graham Higgins, p. 5)
As we continued to discuss Graham’s participation in tennis that year, Graham was beaming and we explored what his perspective and memories of what he received from the experience of being the first manager of the boys tennis team. He agreed that he felt “confident” and that he “belonged”. I remember what pleased me most at the team dinner wasn’t the presents Graham received, it was how Graham was received and was genuinely included and participated in the banter of his teammates. Social life was really difficult. Graham would attend classroom parties at school or after school, but there were no “kid” parties Graham was invited to. Nor, did I host “kid” parties (except for one Graham’s senior year), but at this tennis event, Graham was truly included. …and it was evident all season that Graham belonged … otherwise, Graham would not have been so passionate about attending everything regarding his team.

PACE (Professional Assistant Center of Education at National Louis University)

While tennis was a joyful belonging experience, Graham’s initial experience in the PACE Program at National Louis University was different. It combined the angst of the beginning of college with the moving away from home, living with a roommate, and the excitement and fear of the future along with the bonding tragedy can bring. Graham tells his story of his fifth day in PACE:

“It was a very, very emotional day for me. … That’s the day I really wanted to talk about.

That day – that Tuesday was a very sad day for my classmate friends at the PACE Program because something really bad – really sad happened in New York on 9-11 at the two World Trade buildings. …and the Pentagon. …and Flight 393.
The director of the PACE Program, Carol Burns at the time, um, wanted all of us, to um, not to attend any of our classes. … She wanted us all to get together…and pray for those who, you know, did not survive. …

We talked amongst each other in a big, round circle all of the PACE classmates [and PACE personnel], and we gathered in this room on the first floor of where I was living … and we just talked with each other and prayed for the, you know, and talked about what happened…. Well, I remember that it was all over on the televisions, on the news, media, … (long pause) … They were sad. They were emotional…. I would say (clears throat) a few of them felt heart-broken, angry. I think the word I’m looking for is devastated. … I would say fearful too.

… I was not really scared. But, I would say that I feel that my PACE classmate friends were because, um, not only scared but confused because, um, they didn’t realize [understand] with their emotions what was goin’ on. …

I wanted to comfort a few of my friends because they were not only heart-broken with this emotional sadness about what happened that day, but also, um, one of my friends back then during my first year was very homesick and sad.”

(combined excerpts from the January 17, 2016 conversation)

As we continued to talk Graham agreed that Carol Burns, Barb Kite, Roger Hansen and the rest of the PACE staff helped them to feel safe during this time. I reminded Graham that he and some of his classmates were seen on the 10 o’clock news by some of my friends at the candlelight prayer service as people who lived in Evanston lined Ridge Road. Graham concurred with me that being together the way they were had helped them
bond as a group and that many of them are still in touch today. When I asked him about this, his response was an emphatic, “Yes! We are!”

What these experiences showed me was that bonding, belonging, family, togetherness, and community are not only important to Graham but are motivators. It also indicated to me that belonging is a human characteristic for the entire continuum of human existence. Graham perseveres to find his niche in various areas within the continuum of human existence. Some people might say that people seek their own level. However, that “level” may be wider than many suppose in that Graham has enduring, reciprocal relationships with many people in different areas of his life. He continues to be interested in reaching out to learn new things and enlarge his areas of togetherness.

**Spred & belonging & community**

One of the ways Graham has reached out is by joining a Spred group at St. Nicholas Catholic Church. The acronym stands for **Special Religious Education for the Developmentally Delayed** (Spred), a program which was started in 1966 by Fr. James McCarthy, assisted in research by Sr. Mary Therese Harrington, also assisted by Sr. Susanne Gallagher who brought expertise in special education and Montessori methods as well as catechesis. [http://www.spred-chicago.org/#!welcome/c55t](http://www.spred-chicago.org/#!welcome/c55t)

Their work was partially based on the doctoral thesis of Fr. Euchariste Paulhus “Religious Educability of People with Intellectual Disabilities” and the symbolic method (Vivre) developed by Fr. Jean Mesny. [http://www.spred.org.au/about-us/origins-and-history/origins/](http://www.spred.org.au/about-us/origins-and-history/origins/) Fr. McCarthy and his assistants adapted the work of Fr. Paulhus to their process which consists of a symbolic process for teaching the lessons of a spiritual book, in Christianity’s case the Bible (in Judaism, the Tanakh, in Islam, the Koran or a translation of the Koran, etc.). There are three
sections to a Spred meeting: The Activity period, the Liturgy of the book, and the Fellowship (Agape) of the Table. The Activity session is the time during which the catechists (helpers) and the friends (developmentally delayed) prepare themselves to hear the word of God. It is a time to quiet themselves from the worries and busyness of the day. There is soft, wordless music played and little or no talking. Every person selects an activity to do in silence. Activities are chosen from an array to appeal to the senses. This session generally lasts from 45 minutes to an hour dependent on when the activity catechist can observe that all present seem to be quiet internally and receptive to hear and to participate. Then the activity catechist invites each person by name to put away their activity and to join him/her. When all persons have joined together, they move to the liturgy space where the sacred scripture and a symbol await them.

When all have settled, the leader catechist begins by presenting a symbol representing the scripture passage to be presented. The leader catechist talks about the symbol and each person present has the opportunity to tell how the symbol relates to something in their own lives. When all have responded, the leader catechist reads a shortened version of the scripture passage which encapsulates the meaning. The two to five sentences are read three times. There is a short moment of silence, and then the leader catechist goes to each person, looks them in the eye, and in the Christian version says, “name of person, Jesus says to you today….” The liturgy session ends with a song, usually with everyone standing in a circle either holding hands or with movements to the song. Symbolically, the liturgy session represents the liturgy of the Word in the Catholic mass where scripture is read, a sermon is given, and hopefully, the participants apply the scripture to their own lives. In Spred this is done by each person sharing his/her own memories/thought/observations. However, there is no crosstalk in terms of trying to change someone else’s response.
The last part of the Spred session is the agape (fellowship) at the table which includes a little something to eat. This is not meant to be a full meal. Everyone helps to set the table, and the food/snack/dessert is brought in. People share what’s going on in their lives, laugh, support, generally enjoy being with each other. Symbolically, the agape represents the setting of the altar during Mass and moving into the liturgy of the Eucharist. The Spred session ends with a song selected by the participants after which there are goodbyes and the friends go home and the catechists clean up. Sometimes some of the catechists take home the friends if family is not picking them up.

So, the main parts of this process are preparation, listening to sacred word, and participating/sharing in sacred community. Fr. McCarthy and his team organized this process which can be adapted not only for Christian sects but also can be adapted to any religions which has sacred text. The process is similar.

Tonight as I was writing this Graham called so I asked him why he liked Spred so much and why he keeps coming back. Words and phrases he used to explain what he liked included: “spiritual, a group for adults with learning disabilities, gives joy, reaching out to people, brings me closer to God in a group (community) and the way we have relationships with others.”

(Personal Communication. Graham Higgins, August 12, 2016.)

Since spirituality has supported me with my journey with my son, it seemed logical to include spirituality which supports him as well. Something which has become an important part of his life. I interviewed Graham regarding Spred on May 27, 2016. When asked what it was about Spred that interested him in getting involved, Graham said,

“Well… that it was… a program for… disability people – adults like me. And, I, um, …after I heard about this program, I got myself thinking about it, and I said,
“I might be interested in this, and so I joined, and ’til this day, … I have gone ever since.” (Graham Higgins. May 27, 2016. Spred. p. 1.)

M – O.K………………………..and what keeps you going back?

G – … (long pause)…(chuckles – perhaps embarrassment at the time it’s taking to put words to his thoughts) (long, long pause) Being around people. Being around friends. Um. …and…just…um…(sigh)…and just being there…just feels really… you know…special… It’s like with, ah, it’s like…being with family.

(Interview with Graham Higgins, May 27, 2016. Spred. pp. 7-8)

Graham added that he thinks about his “Spred” people when he’s not there…that they’re a part of his life…and they’re “Definitely in my mind. And, definitely in my heart.” (p.8) This says to me that belonging is one of the motivations which keeps Graham in Spred. Since Graham is intuitive, I also believe that the symbolic method used in Spred supports him and feeds his spirit.

He did not mention Jesus or God during the interview though I didn’t ask questions about that. I asked questions about the Spred process expecting that remembering what goes on during a Spred session would prompt Graham to remember meaningful stories which would illuminate Graham’s spirituality. It didn’t work. However, I know those stories exist in Graham because several of the leaders in Graham’s Spred group have asked me how I raised him. What did I do. Or, someone will comment that Graham has said something which touched people. What I suspect is that Graham feels his stories but doesn’t have the words to tell them. The beginning of this January I gave Graham three or four questions to jot down ideas about before he sat down for an interview. He told me it was too hard. He’d just rather talk during our interview.

Yesterday, August 11th, he called to say he was cleaning his room and found the questions. He will be giving them back to me in a couple days still unanswered. Part of this last interview was Graham and me talking about an idea I had to interview one or two of the leaders of his Spred
group to try to get some “Graham” stories. However, I won’t make my dissertation deadline so I’ll have to save that project for later.

The idea of belonging is important to me and ties into the greatest fear I’ve had as a mother for my Graham after the crib accident which caused his disabilities. What will happen to my son when I’m gone? Without siblings where would he belong? Who would care for him? I feared he would end up as a street person, lonely, taken advantage of, abused, and eventually afraid of everyone and everything. Jean Vanier, who established the first L’Arche community in France in 1964, spoke of this pain of rejection during his lecture from Brokenness to Community at Harvard University in 1992:

For twenty-five years now I have had the privilege of living with men and women with disabilities. I have discovered that even though a person may have severe brain damage, that is not the source of his or her greatest pain. The greatest pain is rejection, the feeling that nobody really wants you “like that.”

disabled (p.13)

While I understand that each person who lives has pain in his or her life, I don’t want Graham to face pain alone. My wish for him is that there will be family, friends, and community whom Graham will feel included, that he belongs. I have tried to help Graham become as independent as possible and give him opportunities for family and community with others so that when I’m gone there are people who have brought him into their hearts who will help him…and so Graham will feel safe and will reach out to them and others we have yet to meet.

I want a life a belonging for Graham where he’s accepted, has family and community, friends, can give back to others, and lives a life that matters. In his chapter Belonging Vanier speaks of the innate need which all humans possess: “Each of us needs to belong, not just to one
person but to a family, friends, a group, and a culture.” (Vanier, J. 1998. *Becoming Human*. p. 35.) The rest of the chapter discusses interdependence between “normal” persons who bring capability and the disabled who teach compassion, ways of the heart, and co-operation. (pp. 35-68) For me, belonging means relationship. It means both giving by both/all persons involved. It has meant that the struggle with my son and his disabilities has defined me and given my life meaning.

I have come to learn through therapy, education, and research that one of the greatest enemies of relationship is toxic shame. It affected Graham and me…and eventually healed.

**Washing the Sink – Reversing Toxic Shame**

One thing that broke up the togetherness and belonging for Graham was the six-year divorce our little family of three went through. While it was traumatic for all three of us, it provided new lives for each of us. Eventually chaos and fear turned into new direction and peace and community. Healing came with distance and therapy. I believe that when parents seek help and are helped, their children benefit. I learned from one of the programs I was in about toxic shame and a process to restore one’s confidence which was discussed earlier. Also in Chapter 8, I explained my experience with giving toxic shame to my son along with the accompanying years of guilt, misguided attempts to fix the situation, learning what not to do … and eventual healing for both Graham and me. So naturally, one of our discussions revolved around the cleaning of the sink. I wanted to know Graham’s memories and feelings regarding this long-term journey.

M – What would you like to say about this [cleaning the sink]?
G – Um. I would like to say I did not feel good enough at that time.…
M – You mean when it first happened back in Barrington?
G – Yes. … (pause) … But, now that I’m all grown up, I AM good enough. And…I CAN do it – I mean wash the sink. (tape garbled)
M – Did it help you when I apologized?
G – Yes. It did.
M – How did it feel?
G – Well, it felt … it felt … like I was … good enough … now (tape garbled)
   It helped when you apologized, and I feel good enough to clean my own sink now.
M – (tape garbled) …. your ability to clean the sink?
G – (laughing) Yes, it did! It does!
M – (tape garbled.) Good. (tape garbled.) … Is there anything else you’d like to say about this?
G – No.
[from November 15, 2015 Conversation]

As I reflect on our conversation I realized that when Graham wanted to show me his clean sink when I visited him in his first apartment (just about thirteen years ago), he was looking for my approval from that long-ago time when he was five years old. I remember being amazed and proud when Graham invited me into his bathroom during my visit to his apartment. I think we were both hoping for redemption – Graham for getting his confidence in his ability to clean a sink and me for forgiveness and restoration in our relationship regarding this. Graham also made it clear to me how important it was for me as parent to apologize to him as child. I remember how silent it was when I did this in front of his roommates. I hope they vicariously received some benefit from my apology as well.

**Hot Dogs, Chocolate Syrup & Resilience**

There is one, last story which Graham really wanted told. Once again I was on the phone. I was down the hall in my study.

G - Ah, and I decided to go into the kitchen, open the refrigerator door, and I wanted to make a snack for myself. I can’t remember how many hot dogs I had, but I had a snack of two hot dogs with chocolate syrup. And, all I remember after that was … I ate them with the chocolate syrup, and I didn’t know back then, well, I didn’t know any better like I do now because I was just a kid. Um, I just
felt like doing/learning a new learning experience. … (Margaret writing.) … (Graham chuckles as he says,) That’s all I remember!

M - Well, how did that make you feel? This is an important memory for you.

(Margaret smiling.)

…

G – Cuz I felt like I had (laugh, laugh) accomplished something. … and doing – not only a new learning experience – but, trying something different out – like - kind of a different life style? I don’t know.

As I think back on this scenario, I think of two things. I saw Graham being independent and taking care of his needs. He was five or six when this occurred. While I was appalled when I saw him pour chocolate syrup on hot dogs, at least he used a plate. …and who knows, Graham might set a culinary trend, and I might be too traditional! But, more importantly, in Graham’s making his own snack, I saw resilience. He was problem solving. Graham was hungry. I was not available. The refrigerator had food he liked. He could have come to me whining (though “whining” had consequences with me. Graham had learned not to whine.). He could have sat and waited. He didn’t do that. He had a problem, and he solved that…creatively…and experimentally. Yeah! Problem Solving + Creativity + Trial and Error Experimentation = Resilience, and this gave me hope that one day Graham could live independently.

Intellectual Disability

Graham was non-verbal for years, and during that time I sometimes would wonder whether he were capable of thinking, and if so, what he was thinking. I also wondered whether there were words in his brain or just unnamed impressions and feelings. As soon as he turned three years old, he started school, and the educational team added sign language to his curriculum because he was not yet talking. His babysitter and I attended night classes once a week to learn sign language so we could communicate with Graham in his new language. I kept wondering about what he was experiencing and what he was thinking and feeling. About a year
later Graham said his first words. I was overjoyed. As Graham became more verbal, he didn’t want to use sign language anymore. We both have retained a little of it, but would not be able to converse. During this time the book *Flowers for Algernon* and its subsequent movie *Charlie* kept flashing through my mind, especially the scene towards the end of the movie after the pills no longer made Charlie smart and he had returned to his intellectually disabled state of being. I wondered what the character Charlie thought and felt both about the change which made him smart and about how he thought and felt about his return to his state of intellectual disability. What insights did he have about the experience of intellectual disability when he was smart? How did he feel about himself when he returned to being intellectually disabled? I had pondered this off and on since I had seen the movie in college and taught the book when I was teaching.

As Graham became older and began to have more sophisticated language – higher than I ever thought he would have, I noticed that when I’d ask a question of him about his opinion on something, he’d tell me he’d think about it. Time passed and I would forget about what I had asked. Then, a week or two later Graham would tell me he had thought about what I had asked and give me his opinion. The first time it happened, I remember being shocked – first, that he remembered, and second, that he had been thinking about the topic and had a thoughtful response. This scenario didn’t happen every day or every week but occasionally. More recently, when the idea of Graham’s voice being included in my dissertation arose, I thought again about the book and movie and what the character Charlie had thought and felt. …and later when Graham was two, three, and four what he had thought and felt. I also thought about how his vocabulary had increased, and how he pondered ideas and was now much more able to express his thoughtful ideas. I looked forward to this conversation with Graham. I looked forward to understanding his experience. I wanted to hear from him what it was like to live with intellectual
disability. I wanted insight which would give me more compassion and perhaps help me in knowing what to do when I am with intellectually disabled people in the future. What helps? What hurts? What advice can my son give me? This was the incentive for wanting to include the discussion on the Angry Ball game – as a lead in to the topics of intellectual disability and how the experience and the label are thought about and felt by Graham … with the possibility of an introduction to toxic shame.

I tried on several occasions to get Graham to talk about living with his disabilities especially his intellectual disability. He did admit that he knew he was different – that he thinks more slowly and that he processes ideas more slowly. He’d say, “But – that’s the way I am.” We had talked a number of times prior to our conversational interviews about how he could help teachers and doctors and those who help people with disabilities if he could tell me what it was like to grow up and/or live with an intellectual disability. During those times Graham indicated he was ready, willing and able and was looking forward to our conversations.

However, when we actually were in conversation, and the tape was on, it was not to be … even though a day ahead of time I would remind him to start thinking about his topics and about his experience with his disabilities. Perhaps it was because we had different expectations for the interview process. Perhaps it was that Graham doesn’t have the words to explain his lived experience – or, that he hasn’t reflected on it. Perhaps from our many previous discussions over the years, I thought that he would be able to tell what it was like growing up with his several disabilities. I thought I could be patient during the time he needed to think and process each question. He did not want questions given to him ahead of time. Perhaps he felt rushed. Perhaps he needed to hear questions in a different way than I was asking them. And, perhaps since I, as interviewer, was also Mom, another person would be able to draw more out of
Graham during similar interviews. Doesn’t every child desire approval from his/her parent no matter at what age?

I must admit I had a couple agenda. First, I was really hoping Graham could give me some insight regarding growing up with his disabilities which could help a lot of people. However, when I broached the subject with him (January 17, 2016 Interview, p. 15), Graham bowed his head. There were long pauses, and in a whisper he asked not to talk about it. At other times, especially with the Angry Ball Game, as I got close to the subject of intellectual disability, Graham starting coughing which can be (certainly not always) a sign of toxic shame. There would also be long pauses with a lot of “uhs, hms, ahs” and false starts. It indicated to me that he might be feeling shame so as topics changed, I let them. It may also have been just too painful for Graham to talk about his intellectual disabilities.

The second agenda I had for our interviews was to get Graham’s version of the “washing” the sink experiences from his perspective. I was the one who had caused the wound and the toxic shame, and Graham found his own way to heal it. …along with my apology. Graham perseveres…in his own way…and in his own time.

I think Graham may have had this agenda as well since three of his experiences show him conquering challenges. I think he wanted to show himself in a favorable way…as many people would.

I have seen growth in Graham since he joined Spred a few years ago. He’s calmer and less anxious. Graham seems content with who he is. He’s more confident. Graham speaks up for himself more than he did several years ago. I think Spred has helped him feel safer to let people know what he thinks and feels.
A short addendum needs to be included. A couple months after we had finished our interviews when Graham was visiting, he told me that a small part of his response during the Angry Ball game did refer to his “not being smart”, but he didn’t want to talk about it because he was an adult now, and he had decided that now he is “O.K.” and that he is “smarter now.” He also stated that most of the time when we were throwing the foam balls, he was upset about the divorce and didn’t know how to stop it and get his parents back together so he could have a whole family which would make him feel safe. (G.S. Higgins, personal communication, August 16, 2016) As he was growing up, I had suspected his anger showed his feelings regarding his disability, but I didn’t know how to bring it up in a way that he would talk about it. I had heard his sighs and seen his downcast gaze enough times regarding incidents now forgotten from when Graham was young to believe there had to be pain and shame regarding the label and the experience. I admit I was totally taken by surprise with his unexpected revelation during our interviews. But, what he said makes sense to me. Graham has come so far since those days, and he tends to reflect on things. He says he likes himself. I am delighted and overjoyed with this response. No more prodding from me. The mystery must remain a mystery.

As I reflect more on the times Graham and I talked about his intellectual disability, I must own that I had expectations for those conversations/interviews which interfered with my objectivity as an interviewer and my attentive listening as a parent. Having seen Graham’s facial expressions, heard his sighs, and seen frustration in his body language, I was sure he had experienced toxic shame regarding his intellectual disability and that he had internalized it. I had wanted to hear in his own language what that felt like and how he had dealt with it as he was growing up. I wanted to understand the experience from his point of view. He has grown into a man who accepts himself and who likes himself in a genuine and healthy way. Graham accepts
others as they are, and from I have observed, people like to be around him. He is kind and has a generosity of spirit which he shares in his words to others. Just yesterday, my sister Anne, under the weather and devastated by the outcome of the recent election shared with me that she had called Graham first because he “always knows what to say.” So, in the long run, I wanted to know from Graham how he became the person he is. Yeah. Yeah. I know. As his parent I have been part of that process. But…Graham has made choices as well. What choices did he make? When? Why? Perhaps, unconsciously, I wanted to know Graham’s philosophy of life, and maybe this is just too much to ask.
Chapter 11
The Journey Continues

Beginning the Dissertation

When I started my dissertation, I had intended to write the beginning of a spiritual model of disability which would have a positive perspective instead of the negative perspectives in the models of disability. I have struggled with the models all the way through my time in the Disability and Equity in Education doctoral program. First, the term “model” wasn’t being used in a way I had been used to. My experience with the meaning of “model” has always been closer to “a standard – something to be aspired to” with a positive connotation. The models only expressed negative outcomes. I felt disoriented. I also felt the toxic shame disabled people received from the unconscious and conscious attitudes, prejudices identified in the models. This is what I had worked for years to remove and protect my son from. And, here it was in the models. Professors tried to tell me these models were written by disabled about what they experienced in society. I was dissatisfied. I wanted something positive. I railed against the negativity in the religious model while understanding the pain caused by people in religion at the same time. For forty-four years I had only heard one interpretation (exegesis) of the “Turn the other cheek” parable from the bible. I was packing to move out of my house after my divorce when I heard an alternative interpretation about passive resistance based on putting the parable into the culture and times during which it was written. Had I heard this interpretation a few times as I was growing up and in my young adulthood, I would have left my abusive marriage years before I did. So, I had experienced some of the pain the religious model was identifying, yet I had received much healing and support from spirituality as well. My first dissertation plan was to write about this and begin the discussion for a positive view of spirituality. After all, one
of the purposes of religion is to help people work through the pain in their lives. And, I had received much support and healing from spirituality from several religious traditions throughout my divorce and since then.

However, it was not to be. As I looked at the movement of energy in the models, I realized the negative attitudes were imposed on the disabled and did not originate from disabled. And, as the lies that disabled did not belong in society and worse perhaps disabled should be rejected as part of the human species, and as these lies were repeated daily, many disabled people may come to believe they are not good enough which leads to the final debilitation – that disabled become overwhelmed, believe the lies and give up on themselves. This is the final debilitating action implied by the lived experience of the models of disability.

As I looked at the movement of energy in spirituality, it was the opposite. I needed to be a seeker. I needed to reach out, explore. The energy of spirituality was expansive, life-giving. This was totally opposite from the diminishing effects of the imposed attitudes in the models of disability. Clearly, what I intended was not going to work. But, what would work is my journey with spirituality in broad terms and how it supported and changed, and even had a transformative influence on me.

The Journey

The journey with my son and his disabilities has taken the inner “me” on many footpaths. Some twisted. Some were straight. Some I ignored. Some I rejected. Others were painful and scary while others comforted and healed. Some surprised and delighted. All were insightful. One of my current paths reflects on the almost 37 years I’ve known my son. This dissertation walks that path. It asks the question: What can I learn by re-searching and re-constructing in a thoughtful, intentional way the events, feelings, thoughts, actions of the history of my life as a
parent of a child with multiple, acquired disabilities? How has this spiritual journey changed me? My image of God? My relationship with God?

This journey began with a tragic accident which changed my son’s life forever. My reaction was to get stuck in “what might have been” and resentment about what happened. Initially, I saw only struggle and lost dreams ahead of me. However, what was going to be my response to my son? I was afraid. I promised him I would not abandon him. The commitment was made. I questioned and let God know I was angry and fearful.

And, I needed the three spiritual traditions with which I was familiar. From Christianity I needed relationship with God and the companionship of Jesus – God with us – who shows me how to live without fear and with connecting with people – with listening, compassion, and action. From Judaism, I needed the prayer shawl – being in a tent with God – pouring out my heart at that moment, whatever it may be - and being accepted. I also needed the Buddhist way of being in the world – letting whatever comes to me during meditation pass through – especially painful memories - then gain perspective without emotion. It takes me many times. Much practice. From the still quietness deep inside I receive a calmness and an openness which allows me to hear myself, others, and the Mystery of the Unseen (God, Yahweh, Allah, Higher Power, and other names of what this may be). From this state of being I can draw direction, gain strength to act and advocate, become inspired, feel worth, and receive what I understand to be love.

I reached out to spirituality when I had nowhere else to go with my pain. I needed to hear messages from different traditions. This does not mean I left my own religion or that I felt my religion wasn’t good enough. It meant I enhanced my spirituality with elements from other
religions which may be in mine but which I did not know or could not hear or experience during these times in my life. There is more than one way.

**My search for meaning for myself regarding the accident.**

When Esther refused to take any accountability for the accident and blamed two-week-old Graham and lied about how she had put Graham into his crib, I lost all trust in her. I feared her. Whenever our families were together, I tolerated her, was polite and cordial, and yet ever vigilant regarding what she was doing. It was a rift which was never healed.

After her death in 2004 and after I felt Graham and I were safe, there was room to consider other scenarios of what had occurred on that fateful day. A close, close friend of mine asked me whether it were possible that Esther could have gone into Graham’s room and not seen him struggling to breathe or that he was blue. Shocked – and after catching my breath I had to admit that the chance was slim, BUT, it was possible. It was something I had never considered. …and it was too late to talk with Esther about it.

There was another possibility as well which another friend and mentor envisioned: that Esther had deep feelings of shame because she only had a sixth grade education, and she wanted to show me that her experience in raising two children to adulthood gave her expertise. When my mother had been with us the week before, she wanted to know everything the nurses had taught me so it did not occur to me that Esther would not want to know what the current ideas were as well. I did remember that Esther bristled when she found out I had a master’s degree when we met eight years before. Yet, my father had drilled into me that I could learn something from anyone (which is everyone), and for that topic each person was my superior. It didn’t matter whether or not the person had an education. I had tried to convey that to Esther in the early days by asking her to teach me to can fruits and vegetables, to pickle, to sew (Esther didn’t
need to use a sewing pattern—she just designed and cut the cloth as she went). I admit I knew the area of education was a sensitive one for her and tried to stay away from it whenever possible. However, it is possible that even attempting to share with her what the nurses taught me was a trigger for her. It is also possible that since I had the privilege of education and the power and confidence that can come along with it, that I wasn’t aware of the intensity of the difference and wasn’t as sensitive as I needed to be. Nor, did I know how to be that sensitive. It seems that Esther’s and my unhealed wounds and our private guilts rubbed raw against each other. Our communication was further hampered by far apart generational cultures, classes, and experiences. A stony cold silence settled upon a once celebratory home. My great successes have not been in my career or my jobs. My great successes and failures have been in what I have done and not done in my relationships and inner work. It has been the struggles I chose to engage which have defined who I am and have given my life meaning.

Forgiveness of self.

Now, thirty-some years later I look back at the accident with the perspective of a mother who has lived with, pondered, denied, futilely attempted to turn back time, and secretly blamed myself most of all for the accident which caused my son’s disabilities. If only I had paid attention to that still, quiet nudging I received several times after Esther put Graham in his crib instead of remaining seated at the table. If only I hadn’t felt the need to resist Esther’s demand to take a nap, I would have checked Graham earlier. If only I hadn’t tried to take care of myself for a moment by sitting at the table resting before attempting to get up and walk to the bedroom so I could lie down for a proper, restful nap instead of a sitting up nap. If only…If only….

Forgiving myself has been far harder than forgiving God and Esther. As I’ve lived with and pondered the others including my colleagues and family, I realize there were lots of variables
which mitigated the circumstances. However, with my own accountability I always come back to those wordless, cautionary “nudgings” sending the message “Check Graham. Check Graham.” Those wordless messages which I ignored.

How do I forgive myself for ignoring those “nudgings” which if only I had heeded when I first felt them would have led to Graham not being injured or at least receiving less severe injuries? Even now tears are streaming down my cheeks as I write and think about what could have been, what might have been … If only ….

What has helped me release this self-blame and guilt and forgive me? What follows is a discussion of things which helped me heal and upon reflection give meaning to my life as a parent and helped me understand what a gift my son is – not in spite of his disabilities but because of them. Mistakes made in the trial and error of life seasoned my experience and once reflected on eventually led to a modicum of wisdom and compassion and resilience. Sometimes, plodding through was all I could do.

**1980’s spirituality.**

Spiritually, I was a mess. I had widened my vision of God during college, but I was not prepared for a catastrophic event like what happened to my son. Why would God allow this? What good can possibly come out of this tragedy? This has not just ruined Graham’s life but my life as well because I’m the one who’s going to raise him, and this is going to take life-changing sacrifice and commitment. I feel like both our lives are over … and Graham’s has just begun! It’s not fair, especially for Graham! What will happen to him when I’m gone?

“God, I’m angry with You! Where are You? Are You listening? How do I recover? I must recover before I can help Graham recover, and I don’t know how to transform this situation – this pain. What purpose can he serve in the world? What happens to him when I die? How
independent can he become? How can I teach him? What does he need? I don’t know. I’m overwhelmed. I’m in the dark night of the soul.”

…Yet, Graham melts my heart when he smiles which is often. And, the joy and spontaneity with which he faces almost every day and almost every new experience delights me and makes me marvel at his life force. If I can create an atmosphere that teaches and allows him to like and love himself, to value who he is – as he is – I will have accomplished something.

But I still feel abandoned by God. All I can do is muddle through each day…sometimes each moment. I must ponder and listen to that still, small voice which I had ignored.

During the 1980s God was a faraway image for me – perhaps not concerned with the daily workings of the world and the universe but certainly ready to judge and punish when I strayed from the path of rules…and I had strayed – not faithful to Sunday services – putting my husband’s approval of me higher than my own or God’s. I blamed God for punishing Graham when He should have punished me alone.

---- Fast forward from the 1980s to 2007

**Inner spiritual work.**

In an attempt to create family, I trusted when I needed and sought to include when I needed to be vigilant for the sake of my son. After the accident I mulled over the events every day for years. I had unanswered questions. I wanted to get rid of the resentment I had towards Esther. I wanted to get rid of the tightening in my stomach and chest every time I thought of her or that fateful day. So, in 2007, I took this issue to my spiritual companion. We had been through eight years of therapy and training together. I had a spiritual director who had also been in this program who was a priest and had two doctorates, one in theology and the other in psychology. He had the head knowledge. However, Grace Gibson, who was not as
academically learned, had the heart knowledge. I needed heart truth, not intellectual explanation. As we prayed and worked together on this resentment and its causes, questions and new perspectives arose:

I did not see what actually had happened. I acceded to Esther’s request to put Graham down for a nap. When she went back into his room about 20-30 minutes later and stayed awhile, I did not follow. After the accident I had assumed that she had seen that Graham was in distress and that he had turned blue...and that she had left him without attending to his medical need. Is it possible she did not see Graham in distress? I don’t know.

I had incomplete knowledge. What did Esther do in the room the second time she was there? I had assumed she had gone to check on Graham. However, she stayed longer than a simple check would warrant. So, what was she doing? I don’t know.

I drew conclusions from two separate incidents involving Esther. I learned from Esther a couple months after the accident that when my husband was two years old, he tantrummed as Esther was putting on his shoes, and he kicked her in the belly. She was seven months pregnant and bled every day afterwards. She did not see her doctor. The delivery was a stillbirth. Was Graham’s death meant to be payback to my husband? …and thus, to me? …and most of all to Graham? The blaming tone of her voice while relating this led me to believe Esther had intended revenge for that tragic incident so long ago. However, as I look at this today, I must ask myself, Was this assessment of events wrong?

I was stunned. I had sought release, not more questions. Grace knew Graham and loved him as if her were one of her grandsons. I felt betrayed. Yet, I had to admit that what came out of our session had merit. And, this thought was not comforting. As I struggled with my blame of Esther I had to admit that my long-term resentment of her gave me a stance of moral
superiority. After all. She had never admitted that she had put Graham in the middle of the bed on his side with a burping blanket holding him up - just what I had been warned about by the nurses in the hospital. She never even apologized for causing the accident. In fact, she blamed Graham, saying, “Well, Graham did it to himself.” I felt self-righteous in blaming her… and kept the tightness in my stomach and chest. Now I had to own my feelings to work through rather than attribute them to her. Ugh. More inner work.

What I didn’t realize at the beginning of this journey was that I was developing deeper compassion and that my image of God would completely change.

Extras.

The difficulty for disabled is that they must contend with whatever daily “extras” their disability(ies) require for them to face each day on top of the negatives imposed on them from the issues identified in the models of disability. Toxic shame exists in each of those models in the message of you’re not good enough through rejection, isolation, and abandonment. When the imposed lie that disabled are not human is believed by disabled, the wound is so deep that disabled may become overwhelmed and give up on themselves.

Throughout this paper I have used the word “extras”. I’d like to try to define that or at least begin a definition. For me, “extras” have been anything my son could not do for himself that would normally be expected of someone his age. It requires interdependence as opposed to independence. For someone like me who has needed to be independent, interdependence has taken years of getting used to, years of letting go of my immediate plans, and sometimes years of dreams. It’s where life happens unscheduled and unplanned. The emergency is NOW. Planned activities must be postponed or cancelled. “Extras” are time consuming and often exhausting for those who must live or cope with them. I can become resentful during these times. I must let go
of my schedule and my plans and must help my son with whatever the issue may be. I must be present to the inconvenience. My initial reaction is often anger. …until I stop myself and review priorities. What is most important at this moment? Some people can go with the flow of life. I go kicking and screaming until I wrestle with the importance of the interruption and decide what is the best thing to do at the moment or for the long run. It’s a messy process.

Such was the case when Graham called me regarding needing more money because the of fundraiser who got him to change from pledging $5.00 up to $50.00 which ate into the food, social, and public transportation budgets. When I learned his roommates were dealing with the same issue, I dropped whatever I was doing because the teachable moment was NOW! Graham and his roommates all have some cognitive disabilities which has meant for me that some of the synapses for learning don’t fire or misfire so things others learn automatically need to be specifically taught in the moment and sometimes repeated until those synapses work. But, grabbing the moment is critical for their understanding. This was the small window of opportunity available to me. I took it. It did mean interruption and inconvenience for whatever I was doing which I no longer remember. It also developed interdependence over time which has given meaning and purpose to my life.

Graham and his roommates were having the same problem. How do we take care of the money we each have, especially with telemarketers? Because of their cognitive and developmental challenges, they grew up in structured situations following directions parents, teachers, others gave them. Now, for the first time they were on their own, and people were calling up say, “Give me money.” And, when they said, “I can give you this much” the fundraiser wanted still more. The abstract idea of money and the concrete world of checking account balances had a synapse gap as I called it. When they saw that what they pledged
affected how much they had for food, transportation, movies, etc., they understood. They also needed to learn, that it was o.k. to say “No.” or something a little nicer with the same message like, “I can’t afford it at this time. Good luck. Good bye.”

There are other types of extras. Graham does not drive so I drive him because either public transportation is unavailable or if available would take him hours to use to get to the appointment. There’s another reason I go as well. Graham doesn’t always understand what is being asked of him by medical personnel or what is being told to him, so I translate in language he understand. Graham also may just go along with whatever is said, while I ask questions. I also help Graham get set up for any aftercare regarding following directions with prescriptions, etc. Medical insurance is beyond Graham at this moment so I am handling this. As I age I must develop a network of family and friends around Graham who can support him with various tasks of living.

So far I’ve talked about my role in interdependence with Graham and his disabilities. Graham participates in this interdependence as well. His good will and acceptance of others where they are feeds me. One time we were driving from Chicago to Hoffman Estates for our dental appointments. I got a speeding ticket. After the officer left, I starting crying. Graham asked, “Mom, why are you crying?”

“Because I got a ticket.”

“Mom. Don’t you know? Everyone gets tickets.”

Instantly, the internal messages of self-shame and anger dissipated. His comment made my day.

Graham is social and likes to give back. He’s been at this job as an exhibit guide at a children’s museum for ten years and so loves it that he’s an inspiration to others, his co-workers,
his aunts and cousins, and to me. He is a loyal friend and supportive. He likes to play. Generally, people feel good when they’re with him and afterwards. The world would be less without him. I would be less without him → as he is.

**Graham’s Voice**

Lastly, and importantly, it was Graham’s turn to speak. During our conversation five main themes appeared: Mystery of Life (wood shredding in a chair), Belonging (Friends, Family, Community, Fear of Abandonment), Reversing Toxic Shame, and Resilience. Of the eight memories we discussed, Graham chose two which were about belonging, one about resilience, and one about chaos/unexpected events which speaks to the mystery of life. I chose two memories about belonging, one about toxic shame and one which was both about toxic shame and the fear of abandonment. What struck me most is that we each selected two memories regarding belonging. This so fits with Graham’s personality and with the comments from his high school teacher Mrs. Miller who said on several occasions “Everyone is happier and calmer when Graham is around.” Graham is not the leader, but he has the extraordinary quality of accepting people “where they’re at” and for who they are. Thus, he is comfortable and safe to be with. For me, belonging is a universal human need and is part of the complete human continuum of existence.

Interestingly, our perceptions were similar for the remembered experiences except for the Angry Ball Game. I was sure that when Graham yelled out during the game, “My angry cuz my brain no work right!” that he was referring to his intellectual disability. In part he was, and he admitted it. However, he asked that he not be made to talk about it – which tells me that he still has toxic shame regarding this. What totally surprised me was what he did want to talk about regarding this same statement was that during our “family” divorce, Graham wanted to fix his
parents’ relationship so we’d get back together, but he didn’t know how. He was afraid that the divorce meant he would be abandoned. I had never heard that from him before. He was adamant about it, and it’s a logical fear for any child whose parents are divorcing. I had Graham in therapy during the six-year divorce so he would know the divorce was not his fault, and he attended the Rainbows for All God’s Children local grieving program more than once to help him. I even had it written into our parenting agreement that the parent who was not with Graham overnight would call him once during that day so he’d always know he had two parents. However, it never occurred to me that he was afraid of being abandoned. Having both parents present under the same roof meant safety to Graham. I don’t know whether this is an issue only with Graham, or whether it’s an issue for all disabled children or even for all children whose parents are divorcing. This might be a topic for further study.

Additional recommendations for future research might include surveying parents regarding spirituality and raising a disabled child. Also, many biographical books have been written by parents of disabled children, siblings, and those who are disabled as well a care givers and professionals about their experiences with disabilities of others or self. What common themes arise? What can be learned from these themes? Lastly, parents can be interviewed to collect their stories of their experiences with their child’s /children’s disabilities. What common themes arise? How do these stories inform us?

My Spirituality Today

I have discussed spiritual moments I’ve experienced throughout this paper, but I have not discussed my spirituality. This is partly because I feared reader judgment, stereotyping, and misunderstanding, and then an automatic discounting of what I had to say. I am a practicing
Catholic – more liberal than conservative. I believe in God though I cannot prove there is a God through scientific methods.

My image of God has changed through my living with Graham from a judgmental God just waiting from me to make a mistake to a God who loves, delights, has a sense of humor and daily calls me into creation with him/her/and more – a God who seeks relationship with me and everyone and is with me always. And, even if I break the covenant, the blood promise, mentioned in the bible and reject God – God remains faithful – meaning I will be accepted back into the relationship because God never left. For me, Jesus is God who became human to show us how to live without fear and in service and compassion to others. Jesus is Emanuel – God with us – a companion throughout life – if I want him. Jesus is about compassion and forgiveness – the very heart of Christianity. I want that. I need that. The Mass is the most powerful prayer I know.

When I’ve heard things too many times in the same way, they become clichés for me, and I can’t feel their deeper meaning. This is when I need to hear the same/similar messages in a different way. Spirituality from other religions helps me when this happens. Also, I often process situations, issues, emotions, symbolically. Other spiritual traditions help me with this as well. So, I’m eclectic. The beauty for me is that there is no one way.

I have also come to realize that my church wounds had nothing to do with God and everything to do with people. People, who in their limitations and woundedness had narrow, often uneducated, interpretations of the bible and who lived by the letter rather than the spirit of the law.
My daily spirituality.

I have a rocking chair which is my meditation chair. It sits in the meditation corner of my bedroom along with my prayer shawl, a singing bowl and a candle. When I light the candle, I am denoting sacred time, and when the tones and vibrations from the singing bowl sound, I am called to an inner quieting of thoughts. I wrap myself in my shawl and sit in my chair, and I am in my own tent with God. I can just be honest about how I’m feeling at that moment and let God love me as I am. And, I can listen. While I don’t receive words, I often receive a radiating warmth that rises inside me. Sometimes it’s a quiet, inner peace.

There’s a bookcase with a Catholic bible, a Jewish study bible, a translation of the Koran, an I Ching with photographs, prayer books, and various meditation books. When I start a meditation book, I generally read and meditate on one meditation at a time until I reach the end of the book.

In the morning I may be quiet in my meditation “room” anywhere from five minutes to an hour. The shorter times are days when I can’t sit still. The longer times are when I’m really being fed by the experience and time seems to have stopped. There is no set routine.

During the day I pray short, silent, spontaneous prayers regarding situations I’m facing at the moment.

At night before bed I start with a routine. I light my candle and sit in my rocker. Then I review my day and name what the best and worst parts of my day have been, and I offer them to God. What happens next is spontaneous. I may leave. Or, I may stay and rock or stay and put my feet up on a small foot stool and remain still.

My rocking chair holds many layers of meaning for me. I bought the rocking chair (which Graham now has) a week before Graham arrived, and it was the first chair I sat in when
we came home from the hospital. That chair was the first chair for our nightly review of the day and prayer ritual. Graham asked if he could have it when he moved into his first apartment.

After trying out many, I got another rocking chair. When I rock in it, I am reminded of Graham. It also can help me release emotions. When I’m upset or angry, I can rock fast and eventually slow down as emotion releases. If I’m more pensive, I can rock in the chair more slowly. The chair adapts to a whole range of emotions through rocking, even sitting still for meditation and receiving God’s love.

**Transformations Through My Journey with Graham**

I have books I call *friends* which I return to over and over because they continue to feed my spirit and as I repeatedly revisit a book, I realize I slowly adopt parts of its messages which change me and become a part of me. One such *friend* is the book *Scarred by Struggle, Transformed by Hope* by Joan D. Chittister. Chittister is a Benedictine nun, a feminist, and often called a dissident in the Catholic Church. In this analysis she examines the Genesis story of Jacob struggling with the angel in the Bible and uses her own story of a lifelong disappointment as an example to explain *struggle* in the story of Jacob. Similarly, my spiritual journey has been one of struggle. What I only realized a few days ago is that I have so internalized Chittister’s ideas that I have followed many of her ideas in this paper:

> The spirituality of struggle is, then, a spirituality that takes [unwanted] change and turns it into conversion takes isolation and makes it independence, takes darkness and forms it into faith, takes the one step beyond fear to courage, takes powerlessness and reclaims it as surrender, takes vulnerability and draws out of it the freedom that comes with self-acceptance, faces the exhaustion and comes to value endurance for its own sake, touches the scars and knows them to be transformational.

> Out of all these things comes new strength and a new sense of self, new compassion and a new sense of the purpose of life. It is struggle that is the foundation of hope, not hope that is a hedge against struggle. (Chittister, 2003/2005, p. 96)
Chittister takes these eight struggles and links them to hope when she says, “Hope is the legacy that emerges in response to each of struggle’s deceptions that change is destructive….” (Chittister, 2003/2005, p. 103). What I have realized during my spiritual journey with Graham is that I was the one who needed to reach out – for healing, new dreams and meaning in life, to advocate for Graham’s inclusion, and for assistance. And, every time I reached out, something changed, if only my confidence. So, as I was writing this paper, reaching out, doing even the smallest thing became resiliency. Showing up, reaching out, even when I didn’t feel like it, meant I was seeking new life. Chittister calls it one of the elements of hope.

Chittister’s first struggle is unwanted change. My unwanted change was the accident. Before I could be converted to a new way of life, I struggled with guilt, grief, anger, and acceptance. It took a couple years before I was willing to admit to myself that Graham’s injuries were permanent. I fought the idea of acceptance until it was evident that my dreams for my son were impossible. I had to release my expectations of a medical cure. Acceptance ushered in a time to explore what he could do and a time to explore possibilities.

While Chittister would possibly say there was an element of hope in the expansiveness of new possibilities, I did not feel this way much of the time I was raising Graham. There was much uncertainty. Would Graham walk? Talk? What would happen to him when I was gone? I felt isolated and abandoned and felt like I was living in the dark night of the soul. Chittister states, “…to insist on living when we feel dead inside is hope come alive.” (Chittister, 2003/2005, p. 99). When I look back at the time of Graham’s early childhood – with the specialists and the uncertainty, and see how Graham has progressed since, I understand her statement and can agree. However, living through it seemed like just one cold, gray day after
another *ad infinitum*. During these times, I couldn’t see a future – only more of the same. All I could do was show up, take care of the necessities for the day, and muddle through. Only years later when I saw Graham was not going to live in an institution did I begin to relax. Now, some twenty years later, I am developing some faith in God – that things will be alright in the long run. I guess I have some trust issues.

The fourth faith struggle identified by Joan Chittister is fear. While I didn’t discuss this directly, fear appears in several sections of this paper, especially, considering Graham’s future and the purpose of my life. The struggle of fear brings the opportunity for the gift of courage. Any action taken to face or alleviate the fear is an act of courage…and one small act builds upon another. I wanted Graham to become as independent as possible. I feared what would happen to him if he lived in an institution. I would watch him when he was an infant and toddler to find out how he learned so I could teach him. I gave him opportunities to make choices not only so he could feel power but also so he could experience the consequences of his decisions. Along the way Graham decided he wanted to be independent too, and he wanted to attend the PACE Program and do whatever was needed to make a life for himself. In retrospect, fear has turned to courage just by showing up daily even if all I could do was muddle through.

Powerlessness is the fifth spiritual struggle in the exegesis on the story of Jacob. Except for the eyesight, I could not undo the damage that had been done in the accident. Yet, I kept trying. I was sitting on the floor folding laundry with Graham on my lap. Suddenly I knew Graham was not going to be restored. I surrendered. It was an odd moment. I felt sad and relieved at the same time. The gift of surrender let me understand that it was now time to focus on what Graham COULD do instead of what he couldn’t. Surrender gave the gift of focusing on what was possible.
The spiritual struggle of limitations is something I’m still struggling with. I’ve had to do so much by myself for so long that it often doesn’t occur to me that there is the gift of others. I am learning slowly. Just this past Thanksgiving I was too sick to drive my sister Patti and Graham to our Thanksgiving with relatives who lived 2 ½ hours away. I called my sister who called one of our nephews who called other nephews…and amongst my sister and four nephews plans were made to get both Graham and my sister Patti to the party and back home. It happened with me only making one phone call. People came together to help. I’m still amazed. I’m not used to experiencing interdependence. What a gift!

Chittister identifies exhaustion as the seventh spiritual struggle in the story of Jacob. There is an accumulation of exhaustion in both parenting and care giving which I’ve experienced. It’s days, weeks, months, even years of exhaustion piled on top of each other which would (and still do) make me question why I should keep going. When Graham was little, there were appointments with occupational therapists, physical therapists, hearing tests, hearing specialists, ophthalmologists, pediatricians, and this was only for Graham. It did not include our family, my job, our extended family, etc. And, the accumulation effect of “extras” added to my exhaustion. I was so tired, and for what purpose? It had been suggested to me to put Graham in an institution. Why keep going with all this stuff? And, yet, I muddled through. Not perfectly. But, I kept going – even when I wanted to quit. Even through bone-weary tears when I thought I was wasting my life. The accumulation of the times I went on became the gift of endurance…When I didn’t give up, neither did Graham. The spiritual helps me in my everyday life accept that I have limitations.

Transformation comes from the accumulation of the seven struggles and their gifts. I have scars, memories, triumphs, and these struggles along with their gifts have mellowed me. I
am now more interested in other people, have more compassion, listen more, am more attentive to the present moment, and no longer see Graham as tragedy. Graham is GIFT.

**Last Words**

All in all, I believe that when the parent(s) are helped, the child benefits. Encouragement leads to perseverance. Perseverance leads to learned capability which leads to confidence, and confidence eventually leads to the exploring of options and the resilience the reaching out which means continuing to seek a quality of life that gives meaning – even when there is mystery and I don’t understand.

As I pondered each situation, lived with it, and slowly stopped fighting/resenting/trying to change it, and let it exist on its own terms, I found it had things to teach me.

I have (almost) learned to stop fighting with God. Instead of my cry, “God! Don’t You see what’s happening? When are you going to get with my program?” to the request, “Show me the way.” … which may take longer (sometimes years) but is more satisfying, often surprising, and certainly more peaceful in the long run.

In the big scheme of things, there is still mystery in life and dignity in each person’s lived experience. As I interviewed my son I came to see him not as a disabled person. I came to see him as a person. He has the same full range of emotions as others. He has dreams, struggles, and accomplishments. Graham has his own spirituality and expresses it in his Spred community and with those with whom he is close. He has purpose in life. And, while there will always be challenges, I no longer fear for his future.

The attitude is not “less than” but “along with”. Neither my son nor his disabilities make him “less than”. My son has a dignity which is all his own, unique in all the world, as does every other person whether disabled or temporarily abled. I wish I had pithy words to speak about
mystery and dignity on the human continuum and the entire human experience. I don’t. But, someone I know does, and I’d like to end with Elly Buron’s poem … (next page)
WE ARE LIKE TREES

with roots in yesterday
embracing the Spring
and each beginning
needling sun and rain
as life draws us
to the fullness
of Summer being

We grow in fields
stretch, strain for space
near the stars
then yield to a season
thrust upon our shoulders
when called to bear
the colors of change

At times
we are restless trees of Winter
clawing at the clouds
branches caught in gusty winds,
Faith shaken
still hope surges
in our veins

We advance
not always understanding
the lessons life teaches
or the reasons
we are scored, scarred, knotted
by pending threat
or sudden storm

Yet we are the trees
of all tomorrow
facing all seasons
living by the gifts of God’s grace
In prayerful
humble dignity
we stand and reach

Eleanor Buron
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