TO LIVE AND LEARN WITH NEUROLOGICAL CHALLENGES
LIFE HISTORIES OF TWO TEENAGERS IN AN EDUCATIVE COMMUNITY

by

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for the degree of Doctor of Philosophy
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The research, on which this account is based, took place within the context of Blooming Acres, my home, and the learning community that I co-founded with my wife Sherri-Ann. In the first chapters, I tell the story of how I came to home-educate learners with complex special needs at my farm north of Toronto, Canada. I describe the neurological disorders that the children in my care are diagnosed with and map out the main literature that guides how I think about and practice education. The aim of this section is to paint a picture of the context in which the research takes place and describe my role in this community.

The second section consists of my research with two of the children who lived and learned at Blooming Acres. This includes their stories as told by them, their parent(s), and the educators at Blooming Acres. As I juxtaposed the life experiences of these learners with each other, and wove together aspects of these stories, significant themes emerged relating to their academic and medical histories, as well as their social, extracurricular, and family life, and finally, their experience at Blooming Acres.

I employed a life history methodology; one that honours the meaning and knowledge that exists in the storied lives of individuals. As I applied this methodology and engaged in the storied lives of these learners I
learned more about what it is like to live and learn with neurological disorders.

Four major themes emerged. The first, *Pathology for Support / Support for Pathology*, relates to learning issues, referral, assessment, diagnosis, medications and “school battles”. Second, *Parent Stress* includes behavioural issues, judgment, stressful calls from teachers and principals and school failure. Third, *Oasis Teachers / Mentors* is an expression of care, support, social competence, self-esteem and relationships. Finally, *Strengths and Coping* is a culmination of issues such as advocacy for support, strategies for success, identifying and coping with stress, understanding diagnosis and becoming well. These emergent themes are articulated within the context of neurology and school failure (risk) and the context of transformation and getting well (resilience). This work contributes to parenting, education, social work, disabilities, medical and risk / resiliency literature.
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And most importantly, to the children who live(d) and learn(ed) at Blooming Acres, and to the hundreds I’ve met and worked with along the way here – from you I’ve learned the most.
This work is dedicated to the original three… the story continues.
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SECTION ONE:

Context
Chapter 1
Sowing the Seeds

These research stories take place within the context of Blooming Acres, my home, and the learning community that I co-founded with my wife Sherri-Ann. In the first chapters, I tell the story of how I came to home-educate learners with complex special needs at my farm north of Toronto, Canada. I describe the neurological disorders that the children in my care are diagnosed with and map out the main literature that guides how I think about and practice education. The aim of this section is to paint the picture of the context my research takes place in, and my role in this community.

The second section consists of my research with two of the children who lived and learned at Blooming Acres. This includes their stories as told by them, their parents, and the educators at Blooming Acres. As I juxtapose the life experiences of these learners with each other, and weave together aspects of these stories, significant themes emerged that relate to their academic and medical histories, as well as their social, extracurricular, and family life, and finally, their experience at Blooming Acres.

I employed a life history methodology; one that honours the meaning and knowledge that exists in the storied lives of individuals. As I apply this methodology and engage in the storied lives of these learners, I
hope to learn more about and share the stories of what it is like to live and learn with neurological disorders.

At Blooming Acres farm, there are ten learners who reside along with my family, as part of our home-education community. In 2005 we opened Blooming Acres Snow Valley Lodge (on two acres of land, 20 minutes away), which supports seven individuals. The children who live and learn with us are diagnosed with a variety of neurological disorders, including: Autism spectrum disorders, Tourette Syndrome (TS), Attention Deficit (Hyperactivity) Disorder (AD(H)D), Obsessive Compulsive Disorder (OCD), Learning Disabilities (LD), and Anxiety disorders. To educate our learners, we have chosen to adopt a “home education” model, which emphasizes learning in the context of our home community. Including both staff and clients, we now have anywhere from sixteen to twenty-four individuals at the farm at any given time. Our Snow Valley Lodge adds an additional fifteen people to our community.

In 1997 my wife, Sherri-Ann, and I moved from our condominium in downtown Toronto and bought a farm near Barrie. From 1992 to 2005 we spent our summers co-directing a summer recreational camp in Muskoka for children with neurological disorders. Sherri-Ann and I founded the camp with a colleague. Summer camp is in my soul. Since the age of six years I have spent each of my summers at recreational camp settings. For a month in August I slept in wood A-frame cabins and I canoed and sailed, water-skied and swam. We played field sports and had “theme days”. My memories of camp are all pleasant – camp was a great place to come of age. At camp there was a certain amount
of freedom to explore, learn as I wished, and to choose what I wanted to do.

From age 18 to 33 my camp experiences occurred at the Camp at Sparrow Lake from May until September. In May and early June, we set up the facility and prepared for the nine weeks of camp to come. From early June until late August we lived with forty-five dedicated staff, mostly college and university aged, and thirty campers at a time. Our first two sessions consisted of campers with diagnoses of Tourette Syndrome (TS), Attention Deficit (Hyperactivity) Disorder (AD(H)D), Obsessive Compulsive Disorder (OCD), Learning Disabilities (LD), and Anxiety disorders. Our two August sessions were for children and teenagers with Autism.

For years, my work during the year included fund-raising, hiring, and administration for Camp, organizing and leading behavioural management workshops, participating in conferences, performing consulting work with families and public and private agencies, as well as educating teachers and caregivers about various neurological disorders and how to support the children who have them. This work was complemented by graduate studies work and my experiences at Camp with the hundreds of interesting children with whom I have worked.

When we married in 1997 Sherri-Ann and I agreed that we would not raise our own children in the city. We dreamed of life on a farm or some sort of house in the woods. We put this dream on hold temporarily since at the time we thoroughly enjoyed cosmopolitan life in downtown Toronto. I had started a part-time Master’s degree in Education (human
development and applied psychology with a specialization in special education and adaptive instruction) at the Ontario Institute of Studies and Education of the University of Toronto.

Although we enjoyed life in the city we also knew how much we loved country life and began looking for a farm. One afternoon, during a February blizzard, we set off to explore the list of farm properties provided by our real-estate agent. Late that day, we stumbled into a rural real estate office to get directions to the next property on our list and instead came across a seemingly ideal house that was not on our list of tours for the day. The farm was located near our summer camp as well as being a relatively short distance from the city. I remember being in the car that afternoon; I knew this farm was the right one. We returned a few days later to view the house with a building contractor and made an immediate offer to buy it. I recall many sleepless nights with worries about the “money pit” I had bought and the drastic change this move would bring to our lives.

We moved into the farm during the summer of 1998. The walls and floors were falling apart, the bathrooms were rotten and full of mould, and the exterior was ghastly. Despite this, we saw beauty in the old Victorian house. It had fabulous original finishes, authentic handcrafted hardwood floors and trim throughout – all in mint condition. Every doorknob, lock, and hinge was from the Victorian era – even the doorbell. The five large bedrooms and loft gave us plenty of space and the location was beautiful. We wanted to restore it.

We had already been living in the country for four months of the year, at summer camp, for some years so the transition to a rural setting
was relatively smooth. My work schedule was flexible so I was able to reduce the time that I spent at the camp office, allowing me to spend less time commuting. This flexibility allowed me to balance my time between my home and my work. We renovated the 120-year-old house using savings, our wedding gifts and a small loan. With much support from Sherri-Ann I made it through the worries that accompany a large financial investment and a significant life change. My wife and I do not regret a thing; we are both dreamers, we work hard and take risks to make things happen. With 100 acres of picturesque gently rolling land, 60 acres arable and 40 acres of mixed woods, a vintage timber bank barn, the farm has made a beautiful home and has evolved into a unique educational community and business.

During the first year at the farm we offered respite to parents by occasionally hosting a few kids on weekends but, mostly, we enjoyed the tranquility of being at home. We have since expanded our hosting to include a small group of children for a few weeks each summer.

Artifact 1.1 - Blooming Acres (H. Bloom)
the house and the farm ourselves. Sherri-Ann was five months pregnant and looked after a young woman with Autism, while I looked after the farm, cooked for the family, and built shelving and cabinets. Our son Jakob was born that winter and the solitude and isolation meant lots of nights early to bed as a family and plenty of opportunity, once spring arrived, to work on the grounds and clean and ready the barn.

As is our style we also did lots of dreaming! At the time we conceived of a small summer camp at our farm for teenagers and adults with Autism. We designed a programme to provide opportunity for respite, recreation, and life skill development. Next, we created a brochure and distributed it within the Autism community. Before we knew it our little camp was full. We hired a staff of five, fixed up the farmhouse and barn, built bunkbeds and stalls out of lumber from the local mill and bought animals. We acquired a small herd of goats from a local farmer, purchased some chickens, hens and turkey chicks and opened Blooming Acres Farm Camp. We hosted guests with Autism who were fifteen years of age or older, many of whom we knew as campers from the Camp programme in Muskoka.

Our staff ran Blooming Acres independently while we were at Camp. We were close enough (a half-hour drive) that they visited us as a group a couple of times a week and frequently called us for consultation. In addition, we dropped into the farm several times a week to offer support, direction and encouragement. Since then, the number of guests and staff at Blooming Acres has grown each summer. We now host seventeen guests (between the two properties, Blooming Acres and the new property Snow Valley Lodge purchased in 2007) most of the time, and employ forty full time staff.
In addition to the summer programme, the respite programme that runs throughout the year has evolved from informal visits from a few kids one weekend per month to operating every weekend. To accommodate the growth of our residential, summer, respite, and home education programmes, we expanded the farm in the summer of 2003. We now have sixteen bedrooms for guests, staff and ourselves at the farm.
Chapter 2
How We Came to Home-educate,
Ideas and Practice

My interest in home education emerged out of conversations that Sherri-Ann and I had with close friends who have chosen to educate their children at home. Initially I was skeptical about the idea of home education and often engaged in lively and sometimes critical discussions about educational choices, intentions, and beliefs. Although I was critical at first, I learned a great deal through our dialogue and began to read John Holt’s (2003) work – a pioneer in the home-school movement. In time I developed an interest in home-educating my son Jakob, who was two years old at the time and I was inspired by home education, co-sleeping and attachment parenting literature (John Holt, 1964, 1989; Ivan Illich, 1971; John Taylor Gatto, 2002; William Sears, 2002).

The events that led to me to form an educative community can only be described as serendipitous. My journey as a home-educator and as a researcher began in 2000, when I met J. Gary Knowles (1992, 2001). We met in a home education course that I was enrolled in at the time, taught by Gary. What I learned during this graduate course and in other independent reading courses that I took with Gary, was that there was resonance between the pedagogical beliefs associated with home education, and my own views on the educative process.
The discussions that I had with Gary, as well as class work and readings that I have done, have contributed to the foundations of the Blooming Acres educative community.

During the same period my wife and I began to discuss the idea of developing a residential educative community for children with special needs. We were unconvinced about the quality of existing special needs programmes and dreamed for a number of years of being able to offer an alternative form of schooling. In fact, I had applied to York University and the Ontario Institute of Studies in Education at the University of Toronto (OISE) with the same statement of intent, indicating my interest to research and develop a school programme. When I enrolled in the home education course at OISE these ideas began to take form.¹

At around the same time I was approached by a parent of a child I knew who was struggling a great deal with various neurological and social challenges, specifically, at school. The parent suggested that I consider schooling her child at my farm. This interaction triggered the development of the programme.

Thus, the home-education course, my interest in alternative forms of education for children with special needs, and the encouragement of a parent to school her child all coalesced and empowered me to commence a home-education programme at Blooming Acres.

Blooming Acres “Home-education”

In order to support the learners in my home, including my own children, we apply a child-centred approach to learning. Specifically, we aim to empower children to make choices for themselves as to what they choose to learn and how they go about it. In this process, we collaborate with the children, their families, and other support networks to design individual programmes based on the child’s own interests, desires, and needs. In addition to fostering independent self-directed learning, we encourage these learners to engage in the wider community in an active hands-on way.

The individual needs of learners vary based on their social, neurological and intellectual abilities. This is reflected in their individual “curriculum”. Our kids fill their days with activities designed to match their interests and to challenge them. Some of these include woodworking, sewing, cooking, reading books of their choice, writing, exploring nature and working with animals. During the course of these activities, the students also learn the skills required to live successfully in community. The children at Blooming Acres are supported by a variety of educators and therapists who each bring their own experiences, strengths, and talents to the community. As a result, Blooming Acres provides a diverse, individualized and well-rounded set of learning opportunities.

The overall goals at Blooming Acres are threefold. First, we strive to establish positive relationships while living together in a supportive community. Second, we nurture personal growth through both planned and impromptu social skill instruction; experiential life skills development, such as hygiene, cooking and budgeting; and
vocational skills, such as working around the farm. Third, we provide opportunities for our learners to pursue interests in music, art, math, language arts and life skill development, depending on their interests, abilities, motivations, and desires.

Over the years I have had numerous conversations with parents about how we educate children and youth within our community. These conversations, which start prior to the onset of participation and might re-emerge over the course of participation, usually centre on how their child, if enrolled at our community, will learn academics. Parents are concerned about curriculum, re-entry into public school education and future options of post secondary education.

Conversations with parents usually sound something like this:

*I am excited to have Johnny join Blooming Acres and I know this is the right decision but, how will he keep up with the Grade 4 curriculum?*

My answer to this question depends on Johnny’s needs. By the time he joins us at the farm Johnny will have already struggled with curriculum and might benefit from a break from ‘desk work,’ or following and completion of endless worksheets. Instead, Johnny will have the opportunity to build, explore and tinker about.

I know he enjoys hands on activities; therefore, I am confident that he will find inspiration in our workshop much like the other youth who learn here. He likes to build with wood and in order to do this he will be inspired, out of necessity, to measure, add, subtract, multiply, estimate, and solve complex mathematical equations; we often set this
math up in advance. Also, we often bake and cook with our learners. This involves measurement, estimation and careful planning. We often use recipes, and must multiply these to meet the significant numbers we feed at our community. In this case we will teach Johnny to add and multiply fractions of liquids and solids.

We will also support Johnny to keep a budget, manage his allowance with a ledger, plan finances and keep track of expenditures. Our staff team will support him to accomplish these learning outcomes. In the end, this experiential learning motivates our students to engage their math in practical and hands on ways, and will provide an excellent basis for Johnny’s emergent skills.

What about Science? How will this happen for Samantha?
In essence our farm is a one large and active experiential science (and social studies) class. Our livestock provides great opportunity for animal husbandry and biology and our hundred acres is an enormous science laboratory. All of our learners take an active part in the care and welfare of our goats, sheep, llama, cows, chickens and turkeys. Many of our students have taken this role on with keen interest, excitement and vigour. Given the significant herd of animals, it is expected and common, that our students participate in the veterinary process, hatching, birth (always an exciting time at the farm) and all other aspects of the care and welfare of our farm community. With a couple of dozen goats at our farm, spring kidding makes for a busy time and this brings with it instant learning opportunities.

In late winter and into early spring we plant and then care for an extensive vegetable and herb garden; biology and chemistry prevail
here. Our entire community is involved in this garden process: planning, planting and harvest. As part of our daily routine, many learners enjoy our collection of microscopes and chemistry kits; with these, the learners can engage the farm landscape with keen interest and curiosity.

There are many options and opportunities for planned and impromptu science. I recall one particular afternoon (common here) where the kids and staff engaged in a chemistry experiment whereby they tested the acidity of dozens of liquids at the farm. On other occasions, the Thanksgiving turkey cull became an anatomy lesson, and the sprouting of our spring herbs became a lesson on photosynthesis. Think of it as enriched science.

*I’m concerned about Paul’s English, specifically reading and writing. How will you offer these subjects to Paul?*

Reading is an important part of our community. We have an extensive library collection on site and also visit the local public library weekly. Each learner at Blooming Acres is encouraged to choose and engage in some form of literature. This is a priority. We do not care what our students read; we welcome comics, magazines, fiction and biographies, so long as reading takes place. In time, this happens, and a love for reading prevails; with no television this is easily achieved. We will work with Paul to support this area of growth. Instead of pressure to read we approach this with gentle and learner centred pedagogy.
What about physical education? My teenage son will miss out on gym class. What does Blooming Acres do about this?

Three times weekly we attend the local YMCA, where we have made arrangements to swim, followed by a picnic lunch, and an hour of active sports in the gym. Our staff lead activities, games, and organized sports such as soccer, basketball, and in the summer, outdoor activities. We are joined by a local group of home schooled kids. At our farm the group enjoys the outdoors. With trails for hikes, snowshoeing and skiing, plus many open fields, physical activity is built into our programming.

The following reflection on the Blooming Acres Home-education programme was written by one of the three original learners who took part in our community in the first three years. The piece was written in the second month of our inaugural year and eloquently describes what we hoped to accomplish – from the perspective of the learner. There was no coaching from anyone. This learner independently described the programme.

Homeschooling –
a creative approach to learning

Blooming Acres homeschool program offers a student centred learning environment that is superior to that of a regular public school. Some of the reasons it is better are it is geared towards a child’s specific learning needs, it is supportive to children with neurological challenges, and children are motivated to learn when they choose their own curriculum.
One of the reasons Blooming Acres is a more effective approach to learning is because it is geared towards a child’s specific learning style and abilities. For example, if Jonney is a visual learner, he can learn about the human body by looking at pictures and diagrams, and reading about different bodily functions. In a regular public school, Jonney might have to sit and listen to a teacher drone on about how the lungs work. Whether someone is a visual, auditory, kinaesthetic, or experiential learner they are able to learn the way that is beneficial to them.

Another reason this approach works is that the staff understand and are supportive to kids with neurological challenges. The children in this home-school program receive one-on-one support when needed, and they also get individual attention. Often in public schools, when children with neurology have rages, anxiety, learning difficulties etc., teachers don’t know how to handle it, and say or do something that makes the situation worse. At Blooming Acres, the teachers are trained to deal with these challenges, in a way that is understanding and supportive.

And finally, Blooming Acres provides a student centred environment, where kids can choose what they do, and learn about. When children are able to choose what they study they are interested and motivated to learn.

In regular school I found math really boring because we practiced the same concept over and over again. At Blooming
Acres home-school I can learn math by doing interesting projects like building creative structures (measuring, learning angles, etc.).
Right now education is being debated in our province. In this essay I have talked about how a student centred homeschool is superior to the school system in many ways. When I was in a public school, I hated going and found learning boring, now I know that I'm in the right situation, learning can be a fun and interesting experience.

Artifact 2.2  - Homeschooling a Learners Prospective (page two)
Chapter 3
Why Conduct Research?

Our decision to operate a home-education programme began in 2001. Over the years many of the children in our care, children who had experienced difficulty in conventional school settings and, in some cases, who were unstable to the point of being hospitalized, have made extraordinary progress. I live in awe at the community of learning in which I am immersed. Parents, relatives, visitors, physicians and the learners themselves all remark on the positive role that our educational community is playing in their lives.

The students speak openly about the struggles that they have faced along the way. Their challenges represent a much larger North American problem: a large number of children, especially those with neurological disorders, are often marginalized in public school systems. Examples of this marginalization fill the education literature. In my work as a camp director, and as an educator of professionals who support children with special needs, I visit schools and hear from teachers how they grapple to meet the needs of their students. At my office I often get phone calls from parents and professionals who support individuals with special needs. Almost every day, I hear about the struggles of children, the

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2 Since 1992, I have spoken to many parents and caregivers on the phone, at conferences, in private consultation, and at workshops about these challenges and struggles.
fights that their parents become embroiled in with each other and with school administrators, the exhaustion of teachers, and more generally, how the public education system fails to meet the needs of kids.

By exploring the stories of the learners in context to Blooming Acres, I wanted to gain a better understanding of individuals living and learning with neurological impairment prior to, and during immersion in the Blooming Acres community. This research has the potential to inform my practice, and to inform a wide variety of caregivers of children.

Like parents, special education teachers (and schools) tend to struggle and become stressed by learners who are diagnosed with neurological challenges. Since 1992, this theme emerged often in my consultation work with public schools throughout the province of Ontario. The failures in school of these learners was attributed to the teachers’ stress and lack of skills in coping with complex behaviours and diverse learning needs.

It is my perspective, that in part, this struggle is connected to learning difficulties, complex behaviour, classroom size, parent expectations, administrative pressures, and associated family stress. The support that is necessary to ensure safe and successful integration of complex learners is costly, burdensome and requires skill and patience. Schools in Ontario are saddled with large classrooms and a demanding curriculum and when these factors are combined with complex neurology, the result is often school failure. To support this notion, Griffin, Kilgore, Winn, and Otis-Wilborn (2008, p. 142) note:
During the past decade, researchers in special education have begun to investigate the unique and complex challenges encountered by novice special educators (e.g., Billingsley & Tomchin, 1992; Billingsley, Carlson, & Klein, 2004; Boyer & Lee, 2001; Busch, Pederson, Espin, & Weissenburger, 2001; Griffin, Kilgore, Winn, Otis-Wilborn, Hou, & Garvan, 2006; Kilgore, Griffin, Winn, & Otis-Wilborn, 2003; Otis-Wilborn, Winn, Griffin, & Kilgore, 2005; Whitaker, 2000, 2003).

These investigations have documented numerous factors in special education settings that contribute to the stresses of the first year of teaching, including: role ambiguity, students posing complex behavioural and academic challenges, large caseloads, insufficient curricular and technical resources, inadequate administrative support, inadequate time for planning, few opportunities for collaboration and professional development, and excessive procedural demands. As novice special educators assume positions in schools, they frequently face ambiguous, conflicting, and fragmented expectations from their colleagues, supervisors, and the families of children they serve.

Many educators, as well as some novice teachers, hold conventional views of special education, believing that the role of the special educator is to teach small groups of children using specialized instruction. These same challenges also face the most experienced of special educators. In Embich (2001) a survey of 300 learning disability teachers in middle and high schools found teachers were experiencing high levels
of emotional exhaustion, specifically those who team taught with a general educator. Role conflict, role ambiguity, perceived workload, and lack of support from principals contributed to the teachers’ feelings of emotional exhaustion. The combination of overload on educators and administrators, student failure, and parent stress, concurrent to the complex nature of the learners who present with co-morbid pathology, warrants this inquiry and further analysis.
Chapter 4
An Overview of Pathologies

The kids who learn with us at Blooming Acres are a unique group. Their individual personalities, combined with the mix of complex neurologies, make for an interesting and dynamic household. This section provides an overview of the neurological disorders that are referred to throughout this work. I dedicate only as much text to each disorder as is necessary so as to provide the background required to understand the perspectives of the people who are central to my project. In this discussion I provide details about the diagnostic criteria for each disorder, relevant information about co-existing disorders, and some personal observations.

At first glance the kids who live at Blooming Acres seem the same as any other children. They range in appearance, athleticism, talent, sociability and intelligence. Their interests vary as widely as their dispositions. We have a saying in our community: “Kids with neurological disorders are like ‘neurotypical’ kids, but more so.” They are more intense; they celebrate with more enthusiasm, they weep with more pain, their anger is explosive, and they love with great intensity.

At Blooming Acres we specialize in meeting the needs of kids with extreme social, behavioural, emotional and learning challenges. As a result many of our learners are what the medical community calls co-morbid. This means that an individual is diagnosed with multiple
disorders. I address these disorders individually, and when appropriate, explore how the child and those around them are affected when the characteristics associated with these disorders intersect with each other.

**Tourette Syndrome (TS)**

I have worked with young people diagnosed with Tourette Syndrome for over ten years. During our first summer at Camp we were approached by the Tourette Syndrome Foundation of Canada and asked if we would integrate children with TS. My colleagues and I felt that TS was similar to severe Attention Deficit Hyperactivity Disorder (ADHD) and that the children would fit into our already established group of campers – with learning difficulties and attention issues – relatively well. We received a grant from the Ontario Trillium Foundation, which enabled us to have ten children with TS attend Camp in the summer of 1993. There was little known about supports for individuals with TS at the time, since academic and public interest in the disorder has primarily grown after this time. None of us really knew much about Tourette's but living with someone can teach a great deal. Supporting those ten children provided us with a crash course. The camp now supports over thirty children each summer who are diagnosed with TS. Developing relationships with each of the children and adolescents has taught me many things.

Named after George Gilles de la Tourette, who identified the disorder in 1885, Tourette Syndrome is characterized by a combination of multiple motor tics (involuntary movements), vocal tics, and phonic tics (noises) which occur throughout waking moments. The number, frequency and complexity of the tics often changes over time and must
be present simultaneously throughout a period of one year to meet the criteria for TS (APA, 2000). Tics can be mild to severe, ranging from occasional throat clearing, facial grimaces or slight turns of the head to full body movements, jumping, rolling, combinations of rapid full body movements, and even harmful and painful self-destructive tics. I remember a boy who had a tic to regurgitate his gastric acids in a certain way. When he completed his tic it was painful and unpleasant for him. The neurological basis for Tourette Syndrome is, as yet, unknown. The main biochemical theory, however, is that there is an imbalance in the function of dopamine, a neurotransmitter (Robertson & Baron-Cohen, 1998).

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (APA, 2000), the most common symptoms of TS are obsessions and compulsions, hyperactivity, distractibility, and impulsivity. Persistent motor and vocal tics can cause a broad range of distress and impairment in social, academic and occupational settings. Social discomfort, shame, self-consciousness, anxiety and depression frequently occur as a result. In severe cases of TS, the tics may interfere directly with daily activities (e.g. conversing, eating, bathing, reading and writing). Rare complications of TS include physical injury, such as blindness due to self-inflicted eye injury (from head banging or eye gouging), orthopedic problems (from knee bending, neck jerking, or head turning), skin problems (from picking or lip licking), and neurological sequelae (a spinal column disc disease related to many years of forceful neck movements)(APA, 2000). In addition, OCD and AD(H)D are frequently co-diagnosed in people with TS (APA, 2000).
Most kids in my care who have Tourette Syndrome do not demonstrate extreme tics. While I know a few children and adults with severe tics, TS usually involves a combination of subtle tics and a great deal of energy directed toward masking them. The attempt to mask tics reflects social pressures to conform. It is my experience that tics themselves, although described as the main feature of Tourette’s, are not the most troublesome aspect of the disorder. In fact, many children with whom I have worked have described tics as mildly annoying. They are often problematic more because of the reactions of others in the lives of people with TS, including their teachers, parents and friends. If tics were really the main problem, the medications that are currently available to reduce the intensity and duration of tics would make the disorder insignificant.

Oliver Sacks (1995, p. 77) highlights the inner conflict associated with TS in the following excerpt from *The Anthropologist from Mars*:

Any disease introduces a doubleness into life – an “it,” with its own needs, demands, limitations. With Tourette’s, the “it” takes the form of explicit compulsions, a multitude of explicit impulsions and compulsions: one is driven to do this, to do that, against one’s will, or in deference to the alien will of the “it”. There may be a conflict, a compromise, a collusion between these wills…. But the relation of disease and self, “it” and “I,” can be particularity complex in Tourette’s, especially if it has been present from early childhood, growing up with the self, intertwining itself in every possible way. The Tourette’s and the self shape themselves each to the other, come more
and more to complement each other, until finally, like a long married couple, they become a single, compound being. This relation is often destructive, but it can also be constructive, can add speed and spontaneity and a capacity for unusual and sometimes startling performance. For all its intrusiveness Tourette’s may be used creatively as well.

At Blooming Acres, we recognize both the destructive and constructive aspects of Tourette Syndrome and, consequently, the challenges and gifts that individuals with the disorder possess. Many of our learners are creative. Some are budding musicians, others are artists, and to have a comedian in our midst, especially one with Tourette Syndrome, is not uncommon.

**Attention Deficit Hyperactivity Disorder (ADHD)**

Attention Deficit Hyperactivity Disorder is defined by a persistent pattern of inattention and/or hyperactivity coupled with impulsivity and distractibility that interferes with developmentally appropriate social, academic or occupational functioning (APA, 2000).

Inattention involves difficulty paying close attention to details, making careless mistakes, producing messy work, failing to stay on task, challenges with maintaining conversations and organizational difficulties. Impulsive behaviour involves impatience, difficulty delaying responses, blurtin out answers and interrupting frequently. Hyperactivity includes fidgeting, squirming, trouble remaining seated, running and climbing at inappropriate times, difficulty engaging in quiet play and excessive talking (APA, 2000).
With the exception of those who have diagnoses falling along the autism spectrum, each of the children who live at Blooming Acres shares a diagnosis of ADHD. As a result, many of them use or have used psychostimulant compounds for the management of ADHD-related symptoms, most commonly Ritalin and Dexedrine, to manage impulsivity and distractibility.

In addition to the challenges posed by ADHD itself, as many as 40 to 60 percent of children with ADHD have at least one other major disorder. The most common disorders to occur with ADHD are: Disruptive Behaviour Disorders, Mood Disorders, Anxiety Disorders, Tics and Tourette Syndrome, and Learning Disabilities (APA, 2000).

**Obsessive Compulsive Disorder (OCD)**

Obsessive Compulsive Disorder (OCD) is an anxiety disorder characterized by intrusive and distressing thoughts, urges, and images as well as repetitive behaviours aimed at decreasing the discomfort caused by these obsessive thoughts (Swinson, 1998).

Obsessions are distinct from excessive worries about real-life problems. Individuals with OCD recognize that their obsessive thoughts, impulses, or images are a product of their own mind, as opposed to being imposed from without, as in some psychotic disorders (APA, 2000).

Compulsions are repetitive behaviors (such as hand washing, ordering, checking) or mental acts (such as praying, counting, repeating words silently) that the persons feel driven to perform in response to an
obsession, often according to rules to which they feel they must rigidly adhere. These behaviours or mental acts are aimed at preventing or reducing distress, or preventing some dreaded event or situation. However, compulsions are either unconnected with what they are designed to neutralize or prevent, or are clearly excessive. While adults recognize that their obsessions or compulsions are excessive or unreasonable, this does not hold for children (APA, 2000). Diagnoses of OCD are made when the obsessions or compulsions of the individual cause marked distress, are time consuming (for example, take more than one hour a day), significantly interfere with the person's normal routine, including his occupational or academic functioning, or interfere with his social activities or relationships.

Many of the children who live at Blooming Acres are diagnosed with OCD and others demonstrate obsessions and compulsions without the diagnosis. The impacts of OCD can be quite severe. I have seen cases of irrational fears and desires dictating the lives of children and their families to the point of hospitalization being required. I have seen children stop eating because they were so concerned about germs in their food. I have seen others hoard stool, become impacted, and nearly die because of fears about using a toilet.

Drug use and Cognitive Behavioural Therapy (CBT) are the most widely used treatments for OCD. Drug treatments usually involve Selective Serotonin Reuptake Inhibitors (SSRIs), such as Luvox, Celexa, Paxil and Zoloft. CBT addresses maladaptive beliefs, dysfunctional schema, attributions, self-statements, and dysfunctional imagery. The brain is very adaptable and as a result individuals can learn to change maladaptive thought patterns. Combined with response prevention,
CBT is a powerful resource valued at Blooming Acres. We offer CBT through one-on-one sessions with a therapist and apply its principles and techniques throughout the day.

**Asperger Syndrome**

Asperger Syndrome is characterized by fixation on a limited interest, deficiencies in pragmatic (that is, social) communication, fine motor skills deficits, sensory abnormalities and difficulty perspective-taking, or taking the role of others. Asperger Syndrome falls at the “high-functioning” end of the Autism spectrum. Because there is no language deficit individuals with Asperger Syndrome are able to share their experiences and express their thoughts and feelings.

Lorna Wing, one of the leading authorities on the subject of Asperger Syndrome, outlines the mystification that individuals with Asperger’s face with regard to conventional social norms. She writes:

People with Asperger Syndrome perceive the world differently from everyone else. They find the rest of us strange and baffling. Why don’t we say what we mean? Why do we say so many things we don’t mean? Why do we so often make trivial remarks that mean nothing at all? Why do we get bored and impatient when someone with Asperger Syndrome tells us hundreds of fascinating facts about time-tables, the individual numbers carved on lampposts in the United Kingdom, the different varieties of carrots or the movements of the planets? Why do we tolerate such a confusion of sensations of light, sound, smell, touch
and taste without getting to screaming pitch? Why do we care about social hierarchies – why not treat everyone the same way? Why do we send and receive so many social signals to each other and how do we make sense of them all? Above all, why are we so illogical compared to people with Asperger Syndrome. (Wing, in Attwood, 1998, p.9)

With regard to the common combination of fixed interests and a lack of awareness regarding conventional social behaviour, Attwood (1998, p. 13) writes:

As the postman delivered the letter to Number 20, the young girl strode down the path towards him. The family had just moved in and he was curious as to the names and background of the new occupants. Before he could say good morning, she said ‘do you like Deltics?’ Confused as to the relevance of such a question, the postman wondered whether a Deltic was a new chocolate bar or a character in a television programme. Before he could reply, she said, ‘they are the most powerful diesel trains. The 2:30 from Kings Cross is a Deltic, I have 27 photographs of Deltics.’ The postman was relieved to be enlightened about the subject matter of the conversation, but the relevance to him at that hour of the day was not immediately apparent. The girl proceeded to launch into a description of the qualities of this obscure locomotive. She was clearly not interested in his thoughts about such trains and appeared oblivious to his polite signals that he must get on with his rounds.
While the specific interests of each individual vary, the nature of the conversation, that is, one-way conversation, is common. As I reflect on the kids I have met with Asperger’s I remember similarly structured conversations about cows, Victorian houses, reptiles, dogs, aliens, and subways. This awkward kind of socialization reflects an inability and lack of desire to interact with peers, and an inability to make sense of appropriate social cues. This correspondingly leads to socially inappropriate behaviour. These communication deficits make Asperger Syndrome a challenging disorder to live with, both for the individual with the syndrome, and for those around him.

**Generalized Anxiety Disorder**

Generalized Anxiety Disorder (GAD) is thought to affect some three to five percent of youth and is often co-morbid with other anxiety disorders or depression. Individuals with GAD report periods of chronic and repeated worrying on a variety of topics. The experience of worrying can range from pervasive feelings of being worried or, more typically in GAD, to discrete episodes of rumination lasting from minutes to hours. This worrying is experienced as distressing and relatively uncontrollable (Wells, 1997). The extreme, severe nature of the worries often leads to a diminished quality of life (APA, 2000). Because of the stress and anxiety associated with social interaction, routine experiences and new experiences, individuals often withdraw from activities such as work, school and social activities and experience strong feelings of loneliness and depression.
Co-Morbidity

In cases of co-morbidity the cumulative effects of Tourette Syndrome, Attention Deficit Hyperactivity Disorder, and Obsessive Compulsive Disorder on individuals is significant. Imagine a disinhibited, impulsive, hyperactive child who gets “stuck” on ideas, impulses, feelings and thoughts – sometimes simultaneously. I have witnessed a child lunge for a knife and jab it into a counter repeatedly, then drop the knife and run through the house barging into rooms and stirring up trouble without the slightest awareness of his impact on others in the community. I have seen this same child in one moment in a rage, throwing objects around, and hitting others and himself, and in the next moment interact with his peers in a thoughtful and caring way. This co-morbidity is challenging to support.

The pathology associated with the combined conditions of Tourette Syndrome, attentional difficulties, Obsessive Compulsive Disorders and anxiety and mood related issues are common in the youth that find their way to Blooming Acres. These are the individuals who failed (or were failed) at public school. These youths’ parents have done battle with the ‘system’ and have come to us on the brink of overwhelming stress and exhaustion. It is the complexity and the uniqueness of these learners, combined with the unpredictable nature of these associated pathologies, their stress, and a need for coping that bring these complex learners to Blooming Acres.
Chapter 5
Education and Pedagogy

Notions of home-education are a central theme in my life and thus central to this work. In an earlier section I described how I came to home-educate at Blooming Acres. In this chapter I outline the literature that has inspired me and the stories that gave me the courage to take the risk to begin an educative programme in my home.

Early Influences
My home-school journey began when my friend loaned me a book by John Holt who, for some parent educators, is the grandfather of the home-education movement. Holt supports the idea of a holistic, child centred learning process. In Teach Your Own, Holt and Farenga (2003, intro) write:

WE CAN teach children, or rather, allow them to learn, outside school-at home, or in whatever other place and situations (and the more the better) we can make available to them... Why not then make schools into places in which children would be allowed, encouraged (and if asked) helped to explore and make sense of the world around them (in time and space) in the ways that most interest them.
Holt sits on the liberal end of the home-education advocacy spectrum. On the other end of the spectrum, parents recreate a school environment in the home that resembles the school classroom. There may be a designated space with desks and walls that resemble the quintessential public school room. In this environment it is usually the mother who does the teaching, and the father, who is working, serves as the “principal”. These are home-schools as such and they tend to follow a national or provincial (as purchased) curriculum, allot time for subjects, and have regular tests (Knowles 1992; Mayberry 2001).

On the opposite end of the spectrum, more aligned with Holt, home-educating families may pay little attention to formal standardized learning. For example, some hold the view that learning to read can be left to the natural ability to learn. Learning is seen as something that can happen experientially. Many on this holistic and organic end of the spectrum call themselves ‘life learners’ or ‘unschoolers’. In between, there are all sorts of home-schools which reflect a variety of personal beliefs.

Holt’s book includes arguments dedicated to taking children out of school, objections to homeschooling, as he called it, the politics of the home-school movement and cross-cultural approaches to learning. It was the section dedicated to playing and learning that sparked my interest and cemented my own desire to foster a holistic and natural way of learning. I decided to create an environment where this pedagogy could be applied to teaching my own children and children with neurological disorders. I devoured this text and moved onto Holt’s first two books: How Children Fail (Holt, 1964) and How Children Learn
(Holt, 1989). These two texts reinforced my own ideas for an educative community and gave me the courage to continue.

**Graduate Work**

I entered the OISE course, Home Educators: An Alternative to Public School?, heavily influenced by the ideas of John Holt and Ivan Illich, as well as by my many years of experience in public schools, and having heard the stories of special needs kids and how the education system often fails to meet their needs. I entered the course believing, as I still do, that there is a serious problem with the way that society teaches our children. While I do not believe that public education should be ended, I do believe that the focus on competition and standardized approaches, as well as the peer pressure that children face, fails learners. While public education does benefit many individuals by offering opportunities to succeed, it also marginalizes many others. Most school environments, and even the most nurturing teachers, encourage classrooms that are competitive and can be disruptive and even destructive to children’s self esteem and development.

**The Recent History of Home Educators**

Prior to the 1980s there was little cooperation between the state and families who chose to home-educate. As Knowles in *Home Schooling Parents as Educators* (Knowles, 1992; Mayberry, Knowles, Ray, & Marlow, 1995) explains, the public and media have often viewed homeschooling as a subversive educational activity carried out by fanatics or idealists, often surreptitiously or underground. Some parent educators have even been jailed or fined for teaching their children.
at home. These extreme reactions reflect the fact that parents often choose home education in response to their interpretations of current social trends and events in relation to their established cultural and community ties and the associated beliefs and values. In situations where there is a network of community organizations able to provide material and ideological support to families, parents are able to begin home instruction (Mayberry, Knowles, Ray, & Marlow, 1995). In other cases, the decision to home-school reflects a perceived disparity between the individual needs of a child and their learning and the limits associated with standardization. Holt illustrates this disparity by using the example of literacy skills:

Their child has taught himself to read, or somehow learned, before he went to school. He finds himself in the pre-school, perhaps in one of the early elementary grades; reading from one to three years ahead of his class. Naturally he does not want to do the reading readiness exercises or other workbook tasks that the other children are doing, to teach him to do what he already knows how to do. He wants to read the kind of books he is able to read. But when he tries to do this he gets into trouble. The child quickly unlearns to read (Holt & Farenga, 2003, p. 17).

Jean Hendy-Harris, in *Putting the Joy Back into Egypt, An Experiment in Education* (Hendy-Harris, 1983, p. 77), tells her story of home-educating her three children in New Zealand during the 1980s. Her son Daniel was struggling at school. In response to an explanation of why he did not want to go,
Daniel said:

I know what’s making me unhappy – I don’t want to go to school. If I didn’t have to go there I wouldn’t be unhappy would I? It stands to reason – I just have to stop going there everyday, that’s all I have to do….

The psychologist concluded that Daniel needed individualized instruction.

Over time, the New Zealand family took charge of their own education and fought for the right to teach their children at home. Daniel remained in the public system and benefited from the rich home learning environment while Harris’s two other children were immersed in a home-school environment that was centered around balancing play and creative learning:

. . . Whilst Oliver was still only three years old and Angharad about one, the playroom was turned into a pleasurable learning environment. We added to the children’s growing library of books–sometimes managing to acquire books very cheaply at school fairs and garage sales. We invested in a stock of paint, glue, crayons, scissors, felt pens, clay etc. A large dressing up box was instituted and old clothes were rapidly transformed into pirate costumes and highwaymen’s cloaks. Daniel’s models and dioramas perched precariously on shelves throughout the play area and Oliver’s insect zoo was maintained in a variety of glass jars covered with muslin (Hendy-Harris, 1983, p. 29).
Hendy-Harris found that her children learned at home much more practically and happily than at school. Her work provided me with many ideas and was instrumental in encouraging me to try an experimental education programme.

I devoured a number of other stories of families who home-educated. I read about the Colfax family from California who set up a homestead in the redwood forest to school their four children, as well as starting a camp during the summer months (Colfax, 1988). I read about John Singer, a fundamentalist Mormon, who set up a school on his homestead for his children and who was shot by police at his mailbox (Fleisher, 1983). I also read *Children on the Hill* (Deakin, 1982), the story of an extraordinary Welsh family who adopted a Montessori approach in their home-school. These texts provided me further inspiration to adapt an alternative learning environment that was specific to the needs of the learners in my care. Each book described a unique learning situation for the circumstances of the unique learner.

The Summerhill School, founded in 1921 by A. S. Neill, provided me with a community perspective that influenced my emerging ideas regarding educational philosophy. Neill pioneered the free school movement, which is based on constructing environments that encourage learning from within and empowering children to take charge of how, and what, they learn, through a democratic process.

As I delved deeper into Neill’s work, I was struck by a comment that he made regarding definitions of good and bad schools:
Obviously, a school that makes active children sit at desks studying mostly useless subjects is a bad school. It is a good school only for those uncreative citizens who want docile, uncreative, children who fit into a civilization whose standard of success is money. (1992, p. 9)

Neill views children as innately wise and realistic who, if left without adult suggestion, will develop as far as they are capable of developing. Neil encouraged a school where children did not fear adults. Instead he carved a community that was imbued with democracy and self-government. Neill lived with his learners in the same community. He got to know them and they got to know him. This inter-subjectivity fostered relationships of mutual trust, respect and love.

A. S. Neill’s wisdom in dealing with his most challenging students’ parents is what I got most out of Summerhill. Neill speaks of the strong influence parents have on their children’s behaviour and how they learned by living away from their parents. At Summerhill, these children generally took two years to unlearn their negative social behaviours to begin to live in community peacefully.

The story of the Albany Free School provides another example of a school committed to democratic and child-centered principles. Chris Mercogliano, the school’s co-founder, describes his community, the development of the school, the ideals that it is based on, and the complex children whom the school supported over the years. In each of these stories, Mercogliano’s commitment to the needs of each child is clearly the priority. At Albany, they meet individuals where they are, and succeed with spontaneity and creativity, often adapting their
approach as they go along. This is made possible by emphasizing the development of relationships among teachers and between teachers and students. Mercogliano and his students learn together in an atmosphere of freedom, personal responsibility, and mutual respect (Mercogliano, 1998).

Each of these personal accounts taught me a great deal. Most importantly, they provided me with a variety of examples of home-education methods and practice. While I was reading this literature, my wife Sherri-Ann read the same texts and we engaged in numerous conversations about the examples. They motivated our interests and moved us to a place where we developed the beginnings of our programme. Our own experiences of school, combined with what we knew about supporting children with special needs, as well as our experiences in camps and recreation and our desire to meet the individual needs of learners, became the foundations of our emerging pedagogical approach.

I took a great risk by adopting a home-education model for the learners in my home. I put faith in something that seemed right. The literature that informed my educational beliefs and practices stems from other risk takers, individuals who pushed conventional boundaries to follow through on what they believed in, to trust in themselves and trust children and their natural curiosity to learn.

There are several common themes that run through the home-based learning stories that have inspired me. I connected with a democratic approach, the prioritization of relationships and teaching to the interests of the students. I connected with the risk-taker; the rogue
who fought the system, who could not be appeased. I connected with the warmth and genuine love for the children and the commitment to honest caring relationships that informed practice.
Chapter 6
Storied Lives,
A Life History Perspective

For this research I employed a life history methodology, one that honours the meaning-making and knowledge development that exists in the storied lives of individuals. As I apply this methodology by engaging in the storied lives of these learners through conducting in-person open-ended interviews, and other means of information gathering, I hope to learn more about and share the stories of what it is like to live and learn with neurological disorders.

Graduate school provided a basis for a research journey. Being engaged in a variety of courses including ones on methodology, transformative learning, personal discovery, research design and knowledge diversity, has influenced my practice as a researcher, an educator, and as an individual. I began this journey rooted in a positivist frame of mind. I was trained, both in my undergraduate and Master’s degree work, to assume the existence of an objective social reality. At times I felt torn between believing that social reality was uniform between settings and across time, and my own experiences, in which adaptability was necessary to deal with unique situations that varied across time and between contexts. As a researcher, I was expected to take an objective, detached attitude towards the research process and towards the participants involved. I was encouraged to interpret empirical studies in
a similarly detached manner. This was the doctrine that was expounded year after year by the scholars with whom I worked. I knew no other way of inquiry so I began to believe that this way of knowing was ‘true’. I was always uncomfortable with putting too much faith in this kind of knowing and resisted doing research because of this unease. Now, while I can respect this kind of knowledge, I do not place ALL my faith in it.

In PhD Degree coursework I was exposed to qualitative methodologies and, connectedly, to diverse ways of knowing. In the past, I had been exposed to some qualitative methods but these were typically presented as somewhat of an afterthought. During doctoral studies, researchers who engage in educational inquiry in a more holistic and relational fashion exposed me to endless possibilities with respect to the research process. This has liberated me from a limiting way of “thinking straight” about psychology and educational research. A new postmodern and feminist standpoint has freed me to engage in research more subjectively and relationally. This approach is more relevant to my personal and professional life, which is geared towards fostering growth by meeting individual needs with an ethic of care and within the context of meaningful relationships (Cole, 2002, 2003).

I have learned that ontology and epistemology are the concepts of knowledge and how we come to know. As a researcher, these concepts are important to me as they relate to and impact my intentions, principles, and therefore my design. I agree with post-modern approaches to knowledge as development (Cole & Knowles, 2001; Denzin & Lincoln, 2000; Van Manen, 1990). Each human views the world and the various phenomena of the world from a variety of perspectives and standpoints. To me knowledge exists in a variety of contexts; it is
cognizance, realization, apprehension, mastery, perception, familiarity, illumination, enlightenment and intuition. There is no one truth, or reality but, rather, multiple realities and multiple truths (Cole, 2002, 2003). Humans make meaning as experiences are filtered through shifting skills, knowledge-sets and perspectives. So humans come to know through interactions with places, people and things. We come to know as we observe and interact, when we touch, taste, and smell. We come to know when we familiarize, perceive, think and talk. We come to know when we share. We learn and we come to know multitudinously – there is no sacred grail of knowledge that is limited to the “all knowing”. Knowledge is for all to explore, and can be explored and shared in a variety of manners. It is this orientation that informs this research project and my daily life.

My interest in research began when I was a child. I was always curious about the world around me, constantly exploring through my senses. I played long and hard, often by myself, in the ravines behind my apartment complex. I remember dissecting frogs and then attempting to bring them back to life later with batteries and electrical circuits. I took toys and electronics apart, learned about what made them work, and then put them back together again, sometimes with little success. I always came away with just a little more knowledge. This curiosity continued as I grew into adolescence I would bombard adults, “the knowing”, with questions about how things worked and why. I wanted to know about everything around me.

As schooling become more formal in later years, and strict adherence to formal procedures associated with standardization were emphasized, I resisted. I did not enjoy having to learn through strictly imposed
methods; I felt that this stifled my natural curiosity and me. This was a constant theme in my childhood. I hated someone telling me that I had to investigate some phenomenon in an exact way. I enjoyed having freedom to explore and to learn at my own pace.

In high school I recall arguing with a Social Studies teacher who insisted that I research a topic following an ISP (Independent Study Project) procedure that he wrote or else I would not get a good grade on the final paper. His procedure involved taking numerous steps in researching a topic of interest. These included development of a thesis topic, thesis statement, review of sources, and finally writing. I recall stating that it felt unfair to be penalized for writing a good paper about the subject with which I was engaged because I did not care to waste time with the various make work assignments that he insisted upon. As I think back I surely appreciate what he was attempting to instill (and now know that I was quite arrogant) but I went against the grain, which is typical for me. I resented being made to do something that I did not want to do. Later I somehow convinced him to extend some more creative freedom to me and in the end received an excellent mark. We can come to know in many ways.

In university, I majored in human geography and minored in history and languages. I studied Japanese and Russian, although I have since forgotten how to read and speak the two languages. I chose human geography because I was good with people and places and knew that I would not fare well in psychology because of its strict adherence to scientifically-based investigative methods.
As an undergraduate at Carleton University in Ottawa, Ontario I was drawn to post-Soviet Studies. In my course work I studied Eastern and Central European history, language, social and environmental issues and business development. This interest won me a place in the university’s CERAS (Central Eastern Russian Studies) department as a Master’s degree student. I commenced this work in 1996 with a great deal of pride and enthusiasm. However, I soon realized that something was missing – I felt little passion for this work and quickly chose a different path. I moved back to Toronto and began working full time for the camp that I had co-founded five years before. At the same time I applied, and was accepted, to the Human Development and Applied Psychology Department at the Ontario Institute for Studies in Education with a specialization in special education and adaptive instruction. I felt that I needed a degree that would inform my work with children with special needs.

My experience in this programme was mixed. On one hand I learned a great deal about special education while, on the other hand, I was frustrated. I had a wealth of knowledge that stemmed from my five years of working at our camp with some of the most socially and behaviourally challenged children. It seemed to me that many of my instructors did not take this knowledge seriously because it was neither empirically supported nor scholarly. In class I read journal articles describing clinical studies of subject matter such as contingency management (a behavioural strategy) and then was asked to talk about the findings. I related to the articles, not to the means or standard deviations, but to the practice of the technique in my own recreational setting(s) and how successful or problematic these practices were for
the children with whom I was engaged. After these discussions I was often left with the feeling that these anecdotal tales were viewed as meaningless since they were not empirically supported. This frustrated me even further. However, I knew that meaning and knowledge came from my experiences and that engaging in life was as valuable as a research method.

In my final year of studies I met J. Gary Knowles in a home-education course. From the onset, I felt a kinship with Gary. There was a confidence, warmth and genuine demeanor about him to which I was drawn from the moment I met him. This came across when he talked about his work, offering his life history. This made me feel comfortable and I took risks. Gary was genuinely interested in my work and my ideas about society, education and family.

In class we discussed social issues, schooling, family, and politics. These issues are all so intertwined with the phenomenon of home-education. Gary and I also met on a number of occasions where we discussed my work as a provider of services to children with special needs, and my emerging educative ideas for Blooming Acres. Gary encouraged me, provided guidance, and offered me an outlet to reflect upon and explore my own beliefs. He also hinted that his beliefs resonated with many of mine.

Eventually, Gary encouraged me to explore doing a PhD degree at OISE. We had already met a number of times and I had taken two additional courses with him. I had explained my fears and dislike of what I called ‘hardcore science’ methodology; to which he responded: “there are other ways to investigate and research”.
He described life history, phenomenology, narrative and arts-informed inquiry as well as providing some readings, including *The Art of Writing Inquiry* (Neilsen, L., Cole, A. & Knowles J. G., 2001). This was intoxicating for me since I had never imagined that I could engage in doctoral work. I had come to believe that it was all about positivistic values and never expected that I could conduct research in a manner that was consistent with my own beliefs. I applied to the Adult Education and Community Development Program with the intention of engaging in an artful qualitative inquiry into the work that was and is emerging at my Blooming Acres home-education programme.

I thought a great deal about Gary's words: “I see the internal consistency in your thinking, Howard”. I have finally come to understand what he meant. He helped me connect my ontology and epistemology. He helped me explore my worldviews perhaps to determine whether there was resonance between qualitative method and my work.

As a researcher I am concerned about my relationship with my readers, my participants and myself, both as a participant and an observer. This dynamic, of being the researched and the researcher, makes it even more important for me to maintain relationality, one of the principles of life history (Cole, 2001). I invite everyone with whom I engage in my research to get to know my personal and professional commitments, and me, and share my lenses (my personal views and biases) along this journey. The learners at our community are a remarkable group. Their storied lives will inform. Through the inquiry into the lived experience of these learners at our educative community, I co-created meaning and knowledge. These storied lives informed my practice, my participants, and our community.
As a researcher I am expected to conduct research, interpret and analyze data, and put forth my findings to an audience in the form of a report. In qualitative research this process can be subjective. I am encouraged, even required, to explore and share my worldviews. Building rapport with the participants of my study and my audience fosters an opportunity to build trust. For the participant, this may create a space in which sharing knowledge becomes more comfortable and open. For my audience, this openness offers insight into my intentions, my thinking and my analysis. Various qualitative researchers, including Denzin and Lincoln (2000, p. 358), discuss subjectivity:

There is no value-free or bias free design. Early on, the qualitative researcher identifies his or her own biases and articulates the ideology or conceptual frame for the study. By identifying one’s own biases, one can see easily where the questions that guide the study are crafted. The researcher owns up to his or her perspective on the study. …The myth that research is objective in some way can no longer be taken seriously.

Max van Manen’s (1990, p. 29) discussion of the relationship between objectivity and subjectivity also guides the perspectives that inform my study:

In the human science, objectivity and subjectivity are not mutually exclusive categories...“objectivity” means that the researcher is oriented to the object, that which stands in front of him or her. Objectivity means that the researcher remains true to object. The researcher becomes in
a sense a guardian and a defender of the true nature of the object. He or she wants to show it, describe it, interpret it while remaining faithful to it – aware that one is easily misled, side-tracked, or enhanced by extraneous elements. “Subjectivity” means that one needs to be as perceptive, insightful, and discerning as one can be in order to show or disclose the object in its full richness and in its greatest depth. Subjectivity means that we are strong on our orientation to the object of study in a unique and personal way – while avoiding the danger of becoming arbitrary, self-indulgent, or of getting captivated and carried away by our unreflected preconceptions.

In *Lives in Context: The Art of Life History Research*, Cole and Knowles (2001, p. 48) discuss the connection between the human self and the research process:

We want to shout from the rooftops encouragement for life history researchers to articulate clearly, within the definitions of their work, their humanness – the fundamental assumptions, experiences and passions behind their inquires – as an authentic way to engage in and represent the complexities of their findings.... As researchers we need to acknowledge that in order to be authentic in the research that we do. The way we research is a reflection of how we orient ourselves to the world – our epistemological and ontological assumptions. We need to use that self-awareness as a guide throughout the research process.
These authors, together with a great deal of dialogue, have informed my “new” thinking about research. This has freed me to conduct research more in line with the way I live in the world. I can be subjective and admit to the ways that my background influences my approach to research while still honouring the participants whose stories I am interested in hearing and sharing.

Like getting to know someone, the research process is one of familiarization. I engaged research participants in the same way that I engage the parents of children when I meet them for the first time. When I engage a parent, whom I have never met before, I start by listening and learning. Parents have plenty to say about their kids – this is experiential knowledge. They know their kids best. I come to know through stories about their children and families, schooling, socializing, medical history, past recreation and current significant circumstances. Second, I share my own story, describe our programme, my involvement with various populations of children, my training and qualifications, and my pedagogical beliefs and methods of supporting kids. Once an initial rapport is forged, I ask questions, I learn about behaviours and past experiences, and sometimes I offer some suggestions about relevant services and supports. Then I decide whether the child in question is an appropriate candidate for the service in question. Simultaneously, this dialogue empowers parents with the information necessary to make a decision about accessing my services or the services of other agencies.

In these initial interactions I am mindful of remaining sensitive to the challenges that the family has faced in finding supports for the child. Usually the kids I support have had an extremely difficult time in school and at home due to the complexity of their neurology – the
result is a series of aborted attempts to access help. I am also sensitive to the fact that these parents are usually desperate to procure support, and because of this, I am put in a position of power. When I tell parents about the services I provide I am mindful to not behave like a salesman. I never want to come across as pressuring families to access my services. I wish to inform and offer a choice.

Similar to the way that I make contact with new clients, when making connections with research participants, I engage in dialogue sensitively, respectfully, as well as reflecting mindfulness regarding the power dynamics between myself and them. As a result, I speak with my participants by sharing my intentions, my method, and my own background and beliefs. At the same time I listen, and remain open to the possibilities of their perspectives.

In my profession, once a child participates in our programme, our relationship evolves. I provide an opportunity for the child to learn and grow by building a relationship with him or her, while simultaneously building upon the rapport already forged with the family so that the child continues to be involved with my services. Through this process, I change and learn, as does the child. By providing a positive, proactive and supportive environment, and by working collaboratively and honestly with the child’s family, we help the child develop.

In research, the dynamic is similar. It is easy to invite participation but to keep a participant involved, and to work with the participant so that together we can make meaning, I must put forth the effort to learn and grow from the experience. In research relationships I must behave in the same manner that I do when I interact with the children
I support in my camp or educative settings: I must remain kind, honest, loving, respectful, firm and fair while using my own cumulative knowledge to co-create an opportunity to develop, grow and learn. In these interactions I must remain genuine and consistent. By building relationships that are imbued with authenticity with the participants of my research, I will be better able to make the most of the opportunities for knowing that their experiences offer.

**Research Approach**

Life history research is about lives in context. As a research methodology, life history has a basis in the sociological tradition of symbolic interactionism (Denzin & Lincoln 2001; Muchmore, 1999). Meaning is derived from social interaction and is modified through interpretation. For this research, the storied lives of the participants (Adam and Bobby) are interpreted and then ‘caricatured’ by me the researcher. These storied lives will then undergo further interpretation so that readers can make meaning of this work. “Life history research relies on the storied nature of lives [and is] concerned with honoring the individuality and complexity of individuals’ experiences…. Life history research goes beyond the individual or the personal, and places narrative accounts and interpretations within a broader context. Lives are lived within the influence of contexts as far ranging as cultural, political, familial, educational, and religious spheres.” (Cole & Knowles, 2001 p. 20). The storied lives – the narratives to follow–were jointly constructed by those involved in the study. These narratives are told by the participants (the youth, their parents, their educators and me), and include life experiences as detailed in artifacts, pictures and
a variety of documents. For me, the culmination of this life history research was a deeper understanding of significant contextual influences that shaped the lives of these two learners. In a broader context, this research informed my understanding of others who live and learn with neurological conditions. For these two, living and learning with severe neurological conditions was not only influenced by unique personal and familial circumstance, but was also shaped by complex struggles in education, individual and parental stress, severe behavioural issues, intensive medical intervention and then social support and getting well. The individual lived experiences, and these aforementioned broader contextual frameworks, moved these two youth from a place of risk to a place of resilience and wellness. From the onset, my research goal was to come to a place of knowing. I wanted to inform my educational practice, and the practice of others who are stakeholders in the lives of learners with special needs, about what it is like to live and learn with neurological conditions. These two narratives echoed with powerful and overarching themes and contexts that shaped lives. The principles of life history research, with its emphasis on contextual influences, resonate with the principles that guide and inform my work as an educator. They also seem to strike a nerve with how I behave as a parent, a friend, and a husband. These principles make sense to me and are integral to my worldview – they feel right.

By applying the life history method I intended to gain a better understanding of living and learning with neurological impairment prior to and during immersion in the Blooming Acres community. I have a vested interest in advancing a programme that is imbued with quality. By conducting research I inform my educative practice. By
conducting research that is holistic, fluid, subjective, and relational
I am conducting research that complements me, my family, and our community.

Life history research also gives voice to participants. By employing a method that incorporates how I live in the world and that is receptive to learning from the storied lives of individuals and their perspectives, I can make a significant contribution to a community of learners and educators. This research project involved a small number of participants (two) so that the phenomenon of living and learning with neurological disorders can be explored in considerable depth. The information was gathered through interviews with each youth participant’s mother, and with one of the adolescent participants who lived and learned at Blooming Acres. The second participant chose not to be interviewed. Information was also available through school and medical documentation, and artifacts provided by each participant and his or her parents.

Selection for participants for this research was done through an initial written invitation that was forwarded to all of the learners who were present at Blooming Acres at the time the research began. All youth living and learning at Blooming Acres were invited, so not to pressure participation. In total, six invitations were extended. Three learners responded to this invitation with enthusiasm to participate. One family moved away from the community and withdrew from the study, and the final two participants remained. One youth, Adam, decided to remain in the study, but not take part in the interviews himself, and one youth (Bobby) was directly involved in the entire study.
Meetings with participants (former Blooming Acres learners and their families) took place in locations and at times that were convenient for them, mostly in their family homes. Together, we engaged in thematic and guided conversations which honour the principles of qualitative and life history research. This reflects my concern for building rapport with my participants that is genuine, authentic, and mindful of the sensitivity of the subject matter that I am exploring. I was committed to building and maintaining relationships with participants. Each participant was encouraged to review, authorize and edit all interview material to maintain autonomy in the project. The actual time commitment was six, ninety-minute, conversations over the course of twelve months. I also met with Bobby at five one-hour sessions to engage in similar conversational interviews. All interviews took place over this same period.

The interview themes that guided each meeting included: academic and medical history, social, extracurricular, and family life, and participation in the Blooming Acres experience. This includes the year prior to the child's enrollment in the programme. I discussed these themes and the proposed questions with each participant prior to our meetings to get input about the types of questions I asked.

Each of the interviews was transcribed and copies provided to each participant prior to his or her following interview. This ensured that the participant had ample opportunity (3-4 weeks) to review, edit and comment on any of the material. This process facilitated discussion prior to the commencement of the following interview and ensured the authenticity and confidentiality of the information gathered.
Parent Interviews

Each time I met with parents I was guided (but not bound) by a set of questions.

Meeting #1: Introduction about the research goals and the process to take place and questions about the academic history of the child.

• Tell me about your child’s experiences of school.
• Describe your child’s introduction to school.
• What are some of the most memorable experiences of your child’s participation in school, both positive and negative?
• Describe your child’s academic progress.
• Tell me about your child’s schooling and when you or someone else noticed difficulties.
• Talk about your child’s relationship with his or her teachers.
• Tell me about your child’s relationship with his or her classmates.
• Describe your child’s experiences of homework.

Interview #2: Discussion about the transcribed interview from the previous meeting and interview about medical history.

• Describe your child’s health as an infant and toddler.
• Was there a specific time or event that you can recall, when you noticed that something was different about your child? Discuss the sort of behaviour and events that alarmed you.
• When and how did your child first get diagnosed?
• Were there other diagnoses that came later? If so, what were they?
• What are your child’s official diagnoses now? Which characteristics of the(s) disorder(s) does your child demonstrate?
• What do rage, anxiety and impulsivity mean to you?
• Describe any hospitalization(s) that your child has had.
• At first, where did you get support for these challenges?
• How did family members react to the diagnosis, or diagnoses, of your child?
• How did family members react to the behaviours of your child?
• How did these challenges impact your child in terms of school, friends and family?

Interview #3: Discussion about transcribed interview from previous meeting and interview about social and extracurricular activities.

• How did your child get along with other children at an early age (i.e ages 5-6)?
• What about at later ages (i.e. ages 8-10 years)?
• Did your child attend groups such as Beavers or Cubs (Brownies or Guides)? If so what were these experiences like?
• What, if any, camps or recreational programmes did your child attend? Talk about these experiences.
• Talk about your child’s experience of making and keeping friends.
• When experiencing social situations, such as family functions or large gatherings how did your child fare? …Talk about this.

Interview #4: Discussion about transcribed interview from previous meeting and interview about family life and social supports.

• Tell me about your family.
• Do you have other children? How old are they?
• Talk about the relationship between your child and his or her siblings.
• Tell me about your child's extended family – cousins, uncles, aunts etc. What kind of support do they offer?
• What sort of support did you get from family members during periods of diagnosis and crisis?
• How did you go about finding supports for yourself and your child to deal with the challenges you faced?
• Describe the supports that have been most valuable.

Interview #5: Discussion about transcribed interview from previous meeting and interview about the year before involvement in the Blooming Acres Programme.

• Describe critical events for your child in the year previous to his or her participation at Blooming Acres.
• How did you discover Blooming Acres?
• Describe how you have experienced the Blooming Acres educative process. Talk about the home-education model.
• What appealed to you about the programme?
• What concerns did you have about the programme?
• What do you think now about the home-education approach used by the community?

Interview #6: Discussion about transcribed interview from previous meeting, and follow-up interview about the child's participation in the Blooming Acres programme and wrap-up and closure.

• How does the Blooming Acres community address your child’s difficult behaviour and his or her positive moments?
• Once your child was enrolled and living in the Blooming Acres community, what did you feel?
• Describe the impact that this community has had on your child.
• Talk about the staff, and their relationships with the learners at Blooming Acres.
• Other kids are learning to read, write and learn arithmetic in classrooms under Ministry of Ontario-guided education; describe how this learning takes place at Blooming Acres.
• What do you think your child is missing while living at Blooming Acres?
• How has your child’s participation at Blooming Acres impacted you and your family?
• Where do you see your child as an adult?
• Tell me about where you think your child would be if he or she had not entered Blooming Acres.
• Is there anything else about your child’s story that you would like to add?

Adolescent Interview:

In my student interviews I was even more mindful about my relationship with participants. I was determined that my study must not undermine my primary commitment to each participant’s education. I was also interested in making sure that the adolescents who participated had some autonomy regarding the topics we discussed and the questions that they answered. To foster an environment consistent with these goals, the child needed to feel comfortable with the process. Our past and current subjective relationship and the maintenance of this relationship in our research get-togethers contributed to this commitment. A five minute “warm-up” conversation with each child participant, talking
about something we have in common or perhaps even drawing or doing some painting together, fostered a level of comfort.

Interview #1: Introductions about research and the process to take place and questions about academic history.

• Tell me about school before Blooming Acres. (Can you talk about Grade One or Two?)
• What do you remember about Grade Three, Four etc.…?
• What did you like about school?
• What did you dislike about school?
• What sorts of friends did you have at school – before Blooming Acres?
• What was school like for you?

Interview #2: Review of transcripts from the previous interview and questions about medical history.

• What is your official diagnosis?
• Tell me about the process involved in your becoming diagnosed.
• How have your neurological disorders impacted your life?
• Have you ever been in the hospital? What happened? What was the hospital like?
• Have you ever become violent or seriously out of control? If so describe some of these situations.

Interview #3: Review of transcripts from previous meeting and questions about Blooming Acres and its pedagogy.

• How does Blooming Acres home-school you?
• What do you in do in a typical day at Blooming Acres?
• How do you learn to read, write and do math?
• What do you think about being home-educated as opposed to attending public school?

At the end of this interview, instead of asking directly about relationships with staff in the community, I invited participants to write a poem, song, story, make a collage, or draw a picture that depicted their experience with the people at the farm. The goal of this approach was to avoid pressuring the learners.

Interview #4: Review of transcripts from previous meeting and conversation about the Blooming Acres school journals. In the following interviews we reviewed events, themes and pictures in the learner’s journal that sparked conversation about these various periods.

Interview #5: Same as above, #4.

Collection of Information – Documents and Artifacts

Photographs:
Photographs of each learner that depict critical moments in their lives and the educational context are included. These include photos taken by educators, the learners and families. I sought authorization to include these photos in the consent letter.
**Blooming Acres Student Journal**<sup>3</sup> (A document of the “school”):

This document is written by the educators, and at times the learners themselves, at the farm and is an ongoing written log of each student’s participation in the community. It reflects the learner’s progress, describes daily activities, and includes reflections about critical moments, suggestions for programming and feelings about events and interactions. These documents serve as the voice of the educators who support these children and as an authentic reflection of the context in which each learner is situated.

**Reflexivity:**

I asked the adult and student participants to develop a critical events timeline of the student’s life. This allowed for clarity regarding specific events, and assisted in the analysis of the data derived from the interviews and other sources of information. This request was outlined in the consent letter.

**School Report Cards and Psychoeducational Assessments:**

Parents provided me these documents to explore critical events. These documents contributed to discussions about key themes of the project.

A variety of artifacts were collected for this work. This includes numerous documents, photographs, written journals, school records and assessments. Selection of the artifacts that are part of this work was made by both the participants and me. At times important events or

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<sup>3</sup> During the first three years of our home-school I purchased hardcover lined paper notebooks – one for each learner. Staff, students and therapists were encouraged to write about daily activities, behaviours, experiences and to add photos. These journals became rich documents of the learners’ experience.
experiences were highlighted by the participants, and the documents that spoke to these events were brought to my attention and were included in this work if appropriate. A variety of artifacts were shared with me to use after interviews and during analysis. I integrated these artifacts to thread together the researched stories. If these artifacts highlighted important contexts or seemed significant to the central themes, or if they connected the researched lives, and the overarching themes, I considered them for inclusion as well. The result was a varied collection of artifacts that compliments this work.

Analysis of the Interviews
The purpose of this work was to learn more about and share the stories of what it is like to live and learn with neurological conditions. The stories told by the participants of this study are about their experiences. My commitment as a researcher was to include the participants in the process so that their voices remain authentic and respected. This is why I gave each participant access to the transcriptions of the interviews and other materials so that he or she had opportunity to review, edit and comment about them. This ethic of respect was continued in the analysis of the data. As I drew from these voices I left them intact and “true” to their respective contexts.

My analysis of the information was multi-layered and included three levels of analyzing data, each at increasingly deeper levels and in different ways. My first readings of the data contributed to the process of developing a sketch, or profile, of individual lives. My second reading was more in-depth and organized. My goal, at this level of analysis, was to identify overarching themes and patterns. My third reading mainly
focused on contextual information related to Blooming Acres. This reading was based on elaborating upon the themes that I had identified during the second reading. Through these multileveled functions of analysis, I began to “make sense” and “make meaning”.

I was excited to engage in the interview stage of the research project. I looked forward to meeting with the parents and the youth of Blooming Acres. These stories were powerful. I ensured that my voice was separate from that of my participants. It has been suggested that we research who we are (Cole & Knowles, 2001; Denzin & Lincoln, 2000). I have a strong presence. This comes across immediately in person. I am a leader, a director, I am an educator and a public speaker. However, I am also mindful of this presence and I served as a gentle guide and shared my lenses or interpretive filters while remaining true to the voices and experiences of the participants. As Lawrence-Lightfoot and Hoffman-Davis (1998 p. 85) write:

The portraitist’s (or researcher’s) voice…is everywhere—overarching and undergirding the text, framing the piece, naming the metaphors, and echoing through the central themes. But her voice is a premeditated one, restrained, disciplined, and carefully controlled. Her voice never overshadows the actors’ voice (though it sometimes is heard in duet, in harmony, in counterpoint). The actors sing the solo lines, the portraitist supporting their efforts at articulation, insight, and expressiveness.

The second section of the text is dedicated to the life histories of two learners. By exploring these life histories, and interpreting these
narratives through the contextual lenses that are highlighted (such as education, medical intervention, family, stress, and becoming well), these research stories will engage the reader on a journey and reveal emergent themes and important contexts that shaped the lives of two youth who live and learn with complex neurological conditions.
SECTION TWO:

Lives
Chapter 7

Adam

Adam joined our community as a fulltime learner in September, 2001. He was the first of three children who were scheduled to move into the farm to be home-educated with us on a full time basis. Monday to Friday and the occasional weekend, September to June, for three years, Adam lived and learned at Blooming Acres. Adam suffered from profound neurological and mood and anxiety disorders. School and home life were unsuccessful to the point where Adam’s family sought residential care. I have known Adam for over twelve years. Prior to joining our community on a full time basis he had regularly attended our weekend respite retreats at the farm and sessions at our summer camps.

Joy, Adam’s mother, responded to my request to participate with enthusiasm. She was eager to share her story with others and to help out with the research. Adam, on the other hand, was not interested in rehashing his past, and subsequently decided to withdraw his own participation – he had first agreed to be involved but changed his mind. He did, however, support his mother’s continued involvement. Adam asked to remain anonymous in the research. This wish is respected.

Adam’s family was supportive and trusted us to provide a place for their son to learn. We discussed our child-centered approach and our philosophy of home-education. It seemed to me at the time that they
recognized the potential of our approach (see Chapter 2) and believed it was what Adam needed. At the same time, they were nervous. Their encouragement instilled the confidence in me to take on the significant commitment, and the risk, of supporting Adam to learn with us.

Adam arrived at the farm in the middle of the month of September, a weekend before his housemates. He was the first of the three learners who would make their home with us at Blooming Acres that year. This was the launch of our home-education programme. The others followed in attendance a week later. With three full-time staff to help, we got ready. On the same sunny and warm fall weekend we closed our summer camp and opened our new home-school. We were excited about our new adventure. The day Adam arrived I organized a variety of opportunities for him to help out around the farm. We had new and exciting chores: a barn full of animals; feeding and milking goats and cow; and tending to the chickens and turkeys. I also encouraged him to discover our sprawling country landscape. Adam loved to explore. Adam helped paint some shelves and moved and assembled some furniture.

To me Adam seemed excited to live with us and the other kids. He was energetic, polite and eager to please. He was understandably reluctant as well. We explained to him (we being his parents, his physician and me) that he was at Blooming Acres to help him with his obsessive, compulsive, bi-polar, anxiety and rage issues. When these issues were under control, and Adam was safe, calm, and capable of attending school regularly, he could return to his home and attend a local school. We made it clear that this could take several years or perhaps into young adulthood. This was a long term plan; there was no time line. Adam
was ambivalent about his move to Blooming Acres and was very vocal about it – both positively and negatively. On one hand, he was excited about the adventure but, on the other hand, he had realistic negative feelings about the move away from his family home and his routine and rituals. Ultimately, he knew he needed help to improve his quality of life and was willing to participate in our community.

Adam’s mother Joy describes his challenges, and her decision to place her child in our care. *The italic script font beginning with the symbol ✴️ represents Joy’s voice.* These transcriptions are derived from conversational interviews that took place at Joy’s home in 2006 and 2007.

For each visit, usually in the early afternoon, I drove to the city to meet with Joy. On my commute I anxiously checked the Sony digital recorder that archived our conversations. I practiced the prepared list of questions and recorded my own monologue – several times. There was some comfort in this ritual. I was practicing the art of conversational interviews and I needed to test the gadget several times, mostly to trust that it would work. It was a bit unusual for me to meet with Joy in such an awkward way. We normally met in an office or at the farm to discuss her son’s programme and progress but these visits were different; they were to be recorded and used for my research project. I was aware of the unique nature of these meetings but felt comfortable given the relationship I had with Joy.

I arrived promptly for each visit to Joy’s home. We had lunch before our interviews, a delicious and healthy spread prepared by Joy. Sometimes I helped out and we cooked together; on other occasions the lunch was spread out as I arrived. This routine was lovely and gave me a chance
to catch my breath, unwind, and get prepared for the interviews. I had read about other researchers meeting in such a way and felt that this style would be appropriate given that this was not so unusual for Joy and me.

I had known Joy for some years, so it was nice to get together for lunch, good conversation, and the interviews. During the meal, we talked informally about our previous meeting, our kids, old colleagues and friends, travels, conferences and so on. These conversations brought about a level of comfort for each of us as they seemed to help ease into the audio taped interviews which felt a bit weird since they brought a unique element to a conversation – the recorder. On two occasions I enjoyed the company of Adam who was home from school. It was nice to see him, since by this point in his journey, he had returned home from his two years plus at Blooming Acres and was successfully completing high school credits and applying for universities and colleges.

After each lunch Joy and I sat down to converse in an elegantly appointed formal sitting room – one that was warm and cozy and made for a great space to meet and talk. We were surrounded by fine art and stunning portraits and photos of Joy’s children. We sipped exotic tea, settled into his and hers wingback chairs and began. I placed the recording device between Joy and me, and we delved into each meeting’s questions.

When he (Adam) started his pre-school nursery programme, which started in September, I think it was by the beginning of October when I was getting ready to go, that he not only didn’t want to go, but it became an issue of him hiding around the house and having to get him out from
behind things or under things and then he was holding onto the rail of the stairs, just not wanting to go. And I wondered if there was something that actually happened that triggered that. I talked to the teachers at school — they didn't seem to feel that there was anything that they knew about. However, I really had a strong sense that something happened to trigger it that he wasn't able to articulate. I really didn't know what it was but it certainly was a behavior resulting in a kid who just wasn't going, we couldn't get him to go in, he would be yelling and screaming and carrying on.

There was a point, somewhere between kindergarten and Grade Two, where I had talked to the doctor, and I said something's really different about Adam. And he finally, after several times of me mentioning it, did two things. I went to a parenting course, number one. And two, we went to a play therapist. The therapist stated that “Adam” had difficulty recognizing emotions, he had difficulty seeing what was going on in facial expressions, he had difficulty reading how somebody was reacting. By Grade Two Adam started to do little repetitive things, and they would come and they'd go. Little things, like I remember him shaking his head in a kind of a funny way, almost like you are shaking off a fly, he would repeat that and repeat that. That would go on for a couple of days and then that would go away. Or he would shrug his shoulder and that would go away.

When I brought him to the pediatrician at one point, the doctor looked at him when he came into the room, 'cause I
said “have a look” because he happened to be doing it, and he
said to me “it’s just a tic!” OK what’s a tic? I had to do research
on this – the doctor did not mention Tourette’s.

When in school, Adam would come home and he would be
un-talkative, he would be obsessive, the obsessive stuff would
become exaggerated or he would come home and he would be
raging. Yelling, for things he needed RIGHT NOW! Absolute
NEEDS! I have to have this and everything will be OK. I need
to have that new toy, I need to have it now, it was constant,
almost like looping thinking of what will relieve him, and
relax the pressure of the stress he was feeling and the anxiety
that he was feeling…

Adam would come home with tantrums and rages. He would
throw things, he was violent. He would break things or walls.
He would hurt me if I tried to stop him. So if I was trying to
restrain him, I could get hurt.

It was somewhere between Grades Two and Three, I was
describing some of Adam’s behaviours to some of my colleagues
at the recreation centre where I worked. I was saying that he
was starting to do these movements, he’s making these noises
and he’s starting to get kind of funny and he is getting lots
of anxieties about little things and patterns. I talked to these
two colleagues and they said “you have to talk to this woman
whose son has Obsessive Compulsive Disorder and Tourette
Syndrome.” I talked to her and she gave me some literature and
the name of a neurologist. This same year I received a phone
call from Adam’s school to discuss the identification process. The special education teacher described the process and said that Adam needed to have an identification. We returned to the doctor as well.

Adam was in and out of school for Grade Five and Grade Six. The year before Blooming Acres, I attempted to home-school him myself. I knew he needed to stay home as school was unsuccessful for him. The school was supposed to provide three hours a week of someone who could come to our home to help Adam with his academic work, but this was pointless since by 3 pm in the afternoon (when the teacher was to arrive), Adam had no functioning. He probably would have just thrown things at them. So I tried to school him myself. I tried to keep him up to par with his work – and it was hard to do. There were lots of issues and lots of behaviours.

During this period Adam was in and out of school for a good four months. He spent time in the hospital, for obsessive and compulsive issues; he was very sick. Adam was afraid of germs in food and stopped eating; he was raging often and was very angry and anxious.

A letter from Adam’s physician (provided to me by Joy) written to his school describes his neurological condition at the time.

Adam has been diagnosed with severe Tourette Syndrome and Obsessive Compulsive Disorder, which can frequently render him to be extremely medically fragile, debilitating
him to the point where he cannot function to carry out necessary daily functions. Adam is very disinhibited in many of his thoughts and behaviours, and he exhibits rapidly changing moods from one extreme to another. Behaviours that I have observed in Adam are: violent rages; opposition / defiance; withdrawal; manic silliness; loudness and strong, inappropriate language.” (Transcribed from a letter from Adam’s physician to his public school – June 2000)

Joy provided me with all of Adam’s school report cards at our third interview. Joy was meticulous about Adam’s school records, reports, letters, and medical details. Because of this I was provided with detailed artifacts to assist with my research. I analyzed Adam’s report cards for the two years preceding his Blooming Acres enrollment. It was very clear that his learning suffered from his mental health struggles. For example:

Adam was beginning to make better progress during term 2 but has not been able to complete enough work due to a prolonged absence. “D” – Math

Due to a prolonged absence as a result of illness there is insufficient data to be able to assign a letter grade. “D” – English

Regrettably this term, Adam had an unexpected prolonged absence. As a result of illness he has been unable to achieve any sort of continuity in his learning. This has
unfortunately, made it very difficult to access him in any meaningful manner in some strands of the curriculum. This is especially true in areas such as math and language. (Adam’s Ontario Provincial Report Card, March and June 2000)

With public school being so difficult for Adam his parents had no choice but to enroll him in a day treatment programme within their community. In August of 2000 Adam was admitted for day treatment as an alternative to public school education. Adam had a long history of struggles with school.

A review of the initial assessment and treatment plan summarizes Adam’s situation at the time:

At age 9 Adam was diagnosed with Tourette Syndrome and Obsessive Compulsive Disorder. More recently he was diagnosed with ADHD. He has tried hard to mask his difficulties in the school system. In the school setting he does not have the rages he has at home. At school he presents as anxious, disorganized, sad, inattentive and attention-seeking. He also has some learning disabilities. He is becoming increasingly oppositional. Adam targets his older brother, whom he blames for his problems. There is an obsessional quality to this. Parents are pursing a residential placement. This assessment describes Adam as having

- Unpredictable extreme behaviour, for example, kicking a door down to attack his brother
- Can experience crisis, requiring hospitalization as he
gets so ragefull
• Can be aggressive at home
• Seems depressed
• Insecure, lack confidence
• Perfectionistic
• Anxious
• Low Self Esteem
• Motivated to mask his symptoms at school…stressful for him
• Could and can get overwhelmed with making sense of his world
• Obsessively jealous of his brother
• Oppositionality is increasing
(Centre for Children and Families – initial assessment and treatment plan August 2000)

While Adam was in a day treatment programme during the 2000 school year his parents actively explored the possibility of a residential school to address his neurological and academic needs. The day treatment programme made some suggestions and all the while Adam struggled at home and made little progress with the placement. Joy visited a few residential options but none of them met with Joy’s satisfaction or expectations.

Making the choice for Adam to attend Blooming Acres was easier on me because he had relationships with the people. There was a certain amount of trust because here I am sending my very young child away from home which was absolutely devastating me. It was so difficult that I blocked
out the idea in my mind. I could not possibly have put Adam into the local residential group homes or somewhere else where I didn’t know the people. I was very grateful that Blooming Acres would take him and provide him with something because at that point in time there was nothing left to lose, he wasn’t functioning at home, he wasn’t functioning at school, he’d been before to Blooming Acres, and at this point at the Centre for Children and Families, but there was not really any kind of significant change. I couldn’t see him going back into a kind of regular school because they would only keep him for a year, and so I felt that he had to be somewhere safe.

Farm life, our routine, the food, and our expectations were all familiar to Adam. However, it took time for Adam to adjust to living away from home. Our unique country life was a stark contrast to the suburban home life to which Adam was accustomed. Adam was used to television, video games, fast food or very specific food prepared in particular ways. We offered the opposite. To live at our farm meant no television (with the exception of the odd movie night) and eating food that came from our barn and gardens, wholesome meals consisting of a variety of meats, grains, green and root vegetables. This farm life provided a good environment to address Adam’s food and “germ issues”. These obsessive and compulsive germ, food and sensory issues quickly developed into a full curriculum forming a global life skill and cognitive development programme.

In addition to this lifestyle and our experiential learning style, it was very important for Adam’s family, and Adam, that he engage in math and English in a formal and practical manner. Besides these two “academic”
skills, specific time for Cognitive Behavioural Therapy (CBT) for his OCD, and his religious studies, Adam was free to explore the farm and the community and learn within the framework of our unschooled child-centred approach. The goal was to help him gain control of his OCD and behavioural issues so that he could return to mainstream school and live at home with his family in a peaceful and healthy way. Adam’s interests and enthusiasm, and the unique personalities of the other children and staff and their own interests, very quickly helped our farm evolve into a busy learning community. The kids did art, wrote poetry, read novels, recreated on the property and at a local YMCA, visited museums and local businesses, made games, baked, cooked, gardened, did science experiments, and traveled. Adam was in the thick of it all.

In a very short time a personal “curriculum” formed for Adam. This was a result of personal interest and desires, his unique needs, and the expectations of his parents (see Table 7.1).

A personal journal was kept for each child in order to maintain a detailed and accurate account of each learner’s experiences at Blooming Acres. The journal, a bound and durable lined paper booklet, was assigned to each child, and each day the various staff who had spent time with the learners entered in events, ideas, experiences and anecdotes; photos were encouraged. The students shared their own experiences in these journals from time to time. Adam’s years at Blooming Acres are logged in these detailed artifacts.
<table>
<thead>
<tr>
<th>Area</th>
<th>Examples of Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Skills</td>
<td>Cooking, chores, laundry</td>
</tr>
<tr>
<td>Social Skills</td>
<td>Living in community peacefully, communication, peers interaction</td>
</tr>
<tr>
<td>Cognitive Behavioural Therapy</td>
<td>Extinguishing unhealthy fears and anxieties</td>
</tr>
<tr>
<td>Arithmetic</td>
<td>Formal math lessons with tutor, cooking, baking and woodworking</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>YMCA, swimming, gym time, outdoor sports like skiing</td>
</tr>
<tr>
<td>Language Arts</td>
<td>Reading novels, writing songs and poetry, creative writing</td>
</tr>
<tr>
<td>Religious Studies</td>
<td>Bar Mitzvah lessons</td>
</tr>
<tr>
<td>Unit Studies</td>
<td>Intensive study of snakes and Western Canada, trip to BC</td>
</tr>
<tr>
<td>Budgeting</td>
<td>Managing personal money, bake sales, fundraisers</td>
</tr>
<tr>
<td>Fine Arts</td>
<td>Drawing, painting, visiting art museums</td>
</tr>
<tr>
<td>Behavioural Skills</td>
<td>Managing aggression and rage</td>
</tr>
</tbody>
</table>

*Table 7.1 - Adam's Personal Curriculum*

In addition to these student journals during this period I kept a detailed account of my own journey as a researcher and an educator.
My research mentors suggested that a personal journal was an excellent opportunity to reflect upon and explore my academic work and my work with the children at the farm. From time to time I wrote about particular events and experiences or read through the student journals and reflected on the entries and ideas expressed, or my position on a particular topic or theme related to the children.

Adam’s progress within the first year with us was remarkable. The journal entries of the staff and my own personal entries from the period describe Adam’s journey as he lived and learned within the context of Blooming Acres. (I have italicized the journal entries in order to recognize them as separate from my own voice.)

“Adam” Journal Entry, September 24, 2001

I spent the weekend with Adam prior to the other kids’ arrival, getting the house set up for them. Adam wanted to help with everything and to try everything. He got to have Kraft Dinner for lunch one day – his special request – because he made it himself. In the process he learned how to use measuring spoons properly, read a recipe carefully, turn on the stove – things I had the impression he was not at all used to doing. He loved his lunch and seemed quite pleased and proud of his accomplishment. Adam told me he was feeling very worried and anxious about meeting the other kids’ but the day they arrived he was quick to initiate friendly conversations and overtures.
Sept 24, 2001

I spent the weekend with Adam prior to the other kids’ arrival, getting the house set up for them. Adam wanted to help with everything & to try everything. He got to have Kraft Dinner for lunch one day - his special request - because he made it himself. In the
My Journal December 2002

Adam can read at a university level but was never capable of sustained focus on reading due to his neurology-distractions and obsessive-compulsive issues. Adam does acquire, understand and can perform age and grade level math and throughout this past year received one on one support in this area at our school. One of his challenges is social awkwardness. In particular, Adam has issues with personal space, social pragmatics, and making impulsive and sometimes intentional and unintentional tactless comments. These behaviours, combined with his obsessive thoughts and social misconceptions, complicate his learning and overall development. Adam visits his family home weekly. He has two siblings, one of whom exhibits extremely challenging behaviour. His parents have recently divorced which has complicated the already over abundant set of issues for Adam. Joy suggested that we formally support Adam with his math skills since math was a challenging subject for him. Adam agreed and commenced formal math lessons weekly with our staff. Adam’s behaviour during the math lessons communicated the challenging nature of the subject for him. It’s not that he didn’t want to work on the math but, rather, when it got tough for him he shut down, would curl up under a blanket or a pile of cushions and screech. The instructor continued teaching him through these moments by engaging him in any way possible.

Adam is Jewish and began preparing for his Bar Mitzvah the week he joined us. He had little knowledge and experience of Jewish culture and customs. We offered our support and encouraged Joy and Adam to celebrate this rite of passage. We all agreed to make a Bar Mitzvah for Adam at the farm in the spring. Adam was very keen on the idea and
began lessons on the Torah, Jewish customs and tradition and integrated biblical stories to his current social and behavioural challenges.

“Adam” Journal Entry, October 1, 2001
Adam went on a field trip to look at the Torah. We rolled it from one end to the other and learned how to respect it by touching only with the yad (a wood or silver pointer). Adam asked a lot of questions, a good start for his Bar Mitzvah.

“Adam” Journal Entry, October 15, 2001
Adam worked with his CBT instructor. He was able to touch several sticky foods: ketchup, honey, peanut butter, jam and syrup. He poured them all together, then added an egg. He rubbed this sticky mess all over his body and hair, going through the anxiety to the point of laughter and minimum anxiety. I observed this was all easier because he invited the others to join him. They were encouraging each other all the way.

My Journal January 2002
For the first three or four months at the farm Adam read a great deal. Adam could read well but, in the past, could not attend to the task. Adam spent hours upon hours buried in books. There is a significant gap in his journal for most of October for the staff felt they had little to report since he was always reading. I suggested that this reading was wonderful; Adam obviously needed to do it. It was as if he was catching up. I had encouraged the kids to read, and at first Adam was reluctant, but when he found his genre he was lost to the book. Adam discovered Brian Jacques in our library.
“Adam” Journal Entry, October 2, 2001

Adam read most of the afternoon and every so often would come to the garden where the others and I were harvesting and weeding. I was thinning the carrots and he asked why I was doing it. I ate the ones I pulled out after wiping the dirt off on my slacks. All this seemed too dirty and germy for him. Suddenly he said “I want to eat one and challenge my OCD” then another learner said “me too”. Adam pulled out his own carrot and I wiped it off. And then they both ate the tiny carrots! Then Adam commented, “It was still dirty.” “But wasn’t it sweet?” “Yes it was.” Then there were more questions about carrots and the other plants.
My Journal October 2001

I have over the years fostered a tradition at the farm to slaughter our own turkey for Thanksgiving. The children were curious about the idea, and each had numerous questions, each helping in his or her own way. Adam surprised me the most in his participation despite his challenging OCD. We studied the various parts of the bird by dissecting the heart, lungs, gizzard, crop, head and liver. The children shared their own knowledge of anatomy. I remember being impressed by their collective knowledge. It was Science 101. I recall feeling a sense of pride at the time, thinking that no classroom could provide this experience. We feasted on the offering later that week.

“Adam” Journal Entry, October 9, 2002
“Turkey Slaughter”

Adam impressed me the most with respect to this ritual because I always slaughter our turkey. At first he watched the ritual kill with ease and curiosity. When we proceeded to the house to gut and pluck he was apprehensive but he did help. His OCD seemed at first to get in the way. But as we progressed Adam became more and more involved. To my amazement Adam stuck his hand up the turkey and pulled all the guts out carefully and calmly. “What OCD?”

From the onset of Adam’s stay with us we all experienced the impact of Adam’s lack of knowledge about personal space. Adam seemed to require constant love affirmations with all of our staff, and sought numerous hugs. Within a 5-minute span Adam requested dozens of hugs, and would often rotate around the community this way. He also
would judge personal space poorly, putting himself on your lap, or placing his face in a female's bosom. It seemed as if Adam wandered at times clueless of his impact on others physically.

To address this we targeted the insatiable hugging with clear and enforceable limit setting, requesting that he ask first. We all shared our feelings of invasion of personal space, each of us providing our own alternatives of affection appropriate to our relationship with Adam. I, for instance, provided the intermittent hug when asked, and also offered them when it was appropriate. I modeled an age appropriate chummy nudge, or at times simply refused, at first with an explanation, and then with none. Adam responded well to this approach; there was no subtlety where Adam was concerned and, in time, he began to generalize the targeted behaviour.
Adam also lacked the social pragmatics that other neurotypical individuals possess. At thirteen most young men or women would not go about relentlessly requesting a hug or a kiss from their teachers. Other children may feel happy about being with someone and may say that they are happy or are enjoying spending time with someone. But I think Adam lacked that ability to socially reference his emotional feelings. So, instead, he went with what he did, knew and liked, the hug, kiss and the constant affirmation. Over time (it took the entire school year) Adam become more aware of personal space and this issue become less “annoying”.

We integrated the principles of monetary accounting as part of our “curriculum”. Each child got an allowance which was provided to the Bank of Blooming Acres by their parents. This allowance was deposited weekly for them and they all had to keep a ledger book. Adam was particularly motivated by this system for he was obsessed with money; he is an obsessed and compulsive consumer. Adam was the first to set up his account. It took him very little time to get the idea of debits and credits.

“Adam” Journal Entry, October 29, 2001

Adam wrote in his ledger and learned how to set it up and do the calculations. At night he responded that this is something he learned today. Then Adam and I did the grocery shopping. We priced everything for the best deal – price and quality. So he was looking at the price/unit and was willing to get cheaper creamed corn which saved enough to get a treat: fruit juice boxes of real fruit. He was pleased to do this. Later he wanted a special macaroni and cheese and asked “Can I get
“this if I buy it with my own money?” “Sure,” I said. When we got home I supported him and he made it himself. It was more than he could eat and he offered it to the others.

My Journal February 2002

Adam’s relationship with two year old Jakob (my son) was an extraordinarily significant component to his development. I quickly noticed a pattern in Adam, in which he shrieked and screamed when he was feeling wronged, hurt, attacked and spat by my son. These wrongdoings were not significant infractions, rather, minor and appropriate for a two year old but Adam reacted as if he were being stabbed. I quickly surmised that Adam was reacting out of his own experiences with his younger brother who was, and still remains, extremely impulsive, inappropriate and aggressive in his words and actions. Conversations with his mother and our team confirmed my hypothesis. As time progressed, Adam experienced a new and respectful relationship with Jakob through which he matured, becoming more patient and tolerant. I think this was healing for Adam.

Adam experienced a short period of time from late November into January where his behavioural challenges escalated from what we were used to. We certainly did know about and had seen this behaviour in other environments or at the farm in the past but, for the first five weeks or so of school, Adam was extremely cooperative, polite, helpful, full of energy and compliant. There were, of course, some intermittent challenges but, for the most part, he was pleasant. However, in late November Adam suddenly began to be oppositional, non-compliant, irritable, tired and overall unpleasant. This was Adam’s time to test
boundaries and expectations. He resorted to the patterns of behaviour with which he was familiar. We realized that this was happening at the time and addressed it with various behavioural interventions.

At first we discussed the inappropriate behavior with Adam and tried to come up with plans for alternative responses to requests of him. He always did well in his sessions at coming up with alternative behaviours when his aberrant behaviour was pointed out to him. However, he had difficulty generalizing these sessions to the community. So, integrated into his programme was a positive reinforcement system utilizing tickets as a token economy, whereby Adam could exchange them for certain treats of his choice, each of which had differing values. We also integrated verbal praise. Adam responded well to this highly motivating approach. Adam almost immediately demonstrated improvement and the programme was faded out at the end of the month. The verbal praise continues, as it is always an integral component to our programme.

Adam was extremely inquisitive. He was constantly asking for explanations of the world as he saw it through his eyes. I say this because we soon learned that there was a certain oddity in the perspective from which he observed his surroundings. Nonetheless, Adam eagerly shared information of interest and always engaged in good discussion.

“Adam” Journal Entry, November 15, 2001

Today this staff spent the day with Adam and another student at the farm. Adam slept late, but rose and enjoyed an omelet for breakfast. After breakfast, Adam did his math homework, took out the compost and worked on his Bar Mitzvah. He read for an hour or so in the afternoon, and then joined myself and
Jim in a discussion of poetry. Adam also went and got a book of his and read a poem to us. We then began a discussion about love, relationships and dating. Adam asked some mature and thoughtful questions.

“What does it feel like to be in love? What’s dating like?” We talked at length about both relationships and friendships and I felt positive about the discussions. Adam read some more before dinner, then ended his evening with journaling and completing his Bar Mitzvah.

My Journal February 2002

The previous journal entry reminded me of Adam’s compost chores. We keep our kitchen compost in an ice-cream container at the sink. Everybody at the farm empties it as needed and this expectation fell upon Adam from time to time. The first time Adam was asked to take out the compost he exhaled a murderous shriek and locked himself in the pantry. To extinguish this behaviour we soon integrated this chore into his daily routine, at first with plenty of support. Adam promptly learned how to take out the compost independently with little and then no fuss when asked. One afternoon, shortly after we addressed the compost situation with a behavioural modification programme, as I returned from a walk in the woods I discovered little piles of compost scattered about the yard. Adam had been dumping the bucket where he pleased and feeding it to the dogs. He claimed to have not known that this was a problem. We modified our programme with specific direction about where to put the compost.
The one thing I learned about Adam, which I feel is significant to mention, is that he has an ability to respond well to positive, specific and flexible behavioural programming combined with love, skills and community involvement. Adam is an extremely bright young man. When he ultimately understands a situation and is reinforced with tangible rewards for learning and growing peacefully, he works hard. Adam quickly began to be more agreeable with respect to chores around the house, cooking well-balanced meals, learning for his Bar Mitzvah, reading, writing, researching on the computer and successfully conquering many of his OCDs.

“Adam” Journal Entry, December 5, 2001

The best moment of my long day today was going in to Adam’s room to say goodnight. The scene he had created in his room was one of peaceful studious warmth. Cross-legged on his bedroom floor in his briefs and playing with Lego, Adam was a picture of relaxation. At the same time he was practicing for his Bar Mitzvah by singing along to recorded music. His sweet, clear voice softened and warmed the upstairs hallway as I turned to go back downstairs.

This morning Adam surprised me by begging me to “do chemistry” with him. We got down the student’s chemistry kit and examined all its mysterious contents. Adam was quite respectful of all the little bottles once he understood how poisonous their contents are. For our first home experiment we settled on an exploration of pH (pH is a term that refers to the relative concentration of hydrogen ions in a solution). Adam ran around setting up a long row of household liquids
to test with our litmus paper. He accurately identified the pH of each sample and diligently put his mind to the concepts of acid, alkaline, dilutions, and the pH scale. He wrote up all the results and a set of conclusions as neatly as he was able and then was ready to clean up and move on to do sewing with Leslie. Our first chemistry kit session was interesting, relevant to daily life, and a ball.

My Journal January 2002

In January, after a long holiday away from the farm, Adam returned in high spirits ready to work hard at our school. He quickly picked up from where he had left off. He generalized his newly mastered skills well at home with his mother and brothers. Adam’s visits home went fairly well from the onset, with a few serious incidents, which simply required discussion in his therapy. For the most part, each visit home went better and better in the fall and into the winter. Adam helped more around the house and peacefully negotiated his needs. His mother addressed his interaction with his siblings. It seems that Adam was doing a respectful job attempting to engage his siblings yet they were not kind and respectful in return, which lead to isolated explosive episodes. I felt at the time, and since have addressed these concerns, that although Adam had made some tremendous growth with his impulsive and tactless behaviour, his siblings had not. They had become used to living at home without him during the week and on weekends they reverted back to their preceding context and understandings of Adam. Adam’s younger brother simply wanted nothing to do with Adam and
wouldn’t let him interact with him and his peers, and the youngest was totally out of control neurologically for most of the year.

This situation saddened me since we were having such tremendous success with Adam. To address this problem, this year we decided to have Adam’s youngest brother join us at the farm for a day each week to receive one on one Cognitive Behavioural Therapy. We will be supporting the two of them to interact in mutually respectful sibling exchanges. I am excited about this proposition and so are Adam, his brother, and their family. I hope to include the third brother somehow.

“Adam” Journal Entry, January 17, 2002

After staff discussions of the acquisition, consolidation and consultation concept and our struggles to get Adam interested in his math homework we had a major breakthrough in Adam’s learning process. He’s been struggling this week to learn the names of various angles. Before the kids got up this morning Sherri-Ann mused: “Why isn’t he building these angles?” Moments later Adam came downstairs for breakfast and I asked him whether there were any interesting buildings in Redwall. Adam’s eyes lit up as he turned to me and began enthusiastically describing Redwall Abbey. “Would you be into building it with me?” I asked. He was so thrilled by the idea that he forgot about breakfast and ran to get the book. We witnessed the most incredible transformation in Adam as he began developing this project. Ideas flowed and new skills surfaced. Elocuently and at length Adam described in detail to both me and the others the Abbey and relevant Redwall stories. Thinking about the Abbey turrets brought Adam to
pinpoint and describe to us the climax of the book. If I had ever asked Adam point blank to tell me about the climax of a book at best I can imagine receiving a stilted, partial and grumpy response. When asked to get out his math books Adam typically looks angry, grunts and buries himself in couch cushions and blankets. Today without prompting Adam ran up and down the stairs gathering paper, markers, other art supplies, protractor and compass and 2 relevant Brian Jacques novels. I have never seen Adam so efficient, capable, organized, planful and independent.

When asked to find something in a book, Adam typically comes across as helpless and at a dead loss as to where to begin. Today he flipped through a novel and found the single page which describes the Abbey’s architecture in detail. He took up a pen and began drawing up plans by himself. We spent two hours laying out a floor plan and working out dimensions for a three story, multi-level abbey with four turrets and a bell tower. He used a measuring tape and considered weight and the width of his bedroom doorway when determining the size of the structure.

When offered suggestions for something he is working on, Adam is typically defensive, stubborn, and grouchy. He has had a sparky relationship with a co-student who tends to have a lot of strong opinions about how things should be done. Today Adam took suggestions from both me and the others with grace, and he thoughtfully considered them. Jim and Adam discussed the book at length, as Jim – unlike me – has also read it.
Adam's remarkable initiative taking continued into the next afternoon. After an intense session drawing up detailed plans, we took a brief lunch break. After lunch Adam led the way out to the workbench in the garage. He chose appropriate wood for the project, measured it, got a handsaw and began sawing the first piece of board almost before I'd made it out to the garage. It took all the strength in Adam's stilted-little-boy body to cut that piece of ½” plywood, but he did it without complaint. At one point he was standing up on the board on a stool somehow trying to cut with his arms twisted backwards in order to relieve a muscle group. He took my safety and skill-development suggestions calmly and was thrilled with the board he cut. He measured all the pieces and we continued to discuss the complex dimensions of the Abbey-to-be as we went.

The single hard moment in the day was when Adam faced the disappointment of not having the jigsaw blades we needed for cutting doorways. We worked hard on the project for a total of five hours. What a feat of mental stamina, focus, and concentration! I have never seen Adam so motivated to do something so creative, challenging, and productive.

The single biggest transformation I noticed in Adam today was in his language and speaking skills. Adam's speech is generally very halting. He is typically very slow to get his ideas out vocally. Today words flowed from his mouth smoothly and eloquently. It was truly amazing to witness!! Well-formed, interesting, informative sentences poured forth as Adam described the story, the characters, the Abbey building and how it related
to the story, the story's setting and climax, how the story of Redwall fits into other Jacques' storylines, what he thought I would like about Redwall, how we could build, decorate, and store the Abbey we'd build... etc. Adam shone with pleasure and confidence as he gave Jim and me a scholarly lecture on his favorite novel. Behind him his bedroom window framed a gentle snowfall. Adam told me he'd like to work on the project for several months and really do a good, thorough job.

“Adam” Journal Entry, January 18, 2002
The math tutor and Adam got out graph paper and re-did the plans for Redwall Abbey to scale. I was impressed as Adam typically has very low tolerance for re-doing something he's already done. The second set of plans is very neat and precise.

Howard and Dale came home from shopping last night with presents for Jim and me but none for Adam. Adam was disappointed until he spotted a package of new jigsaw blades they'd picked up. Overwhelmed with excitement, Adam grabbed the package of blades, claimed it as the only gift he wanted, and carried them around with him for quite some time.

Adam was very reluctant to visit his Dad this weekend. It took enormous staff effort to get him to pack and clean his room. Notably, he was co-operative about choosing and eating a good lunch before he left. That part was nice to see as lunches have been such an issue for him in the past, particularly on transition days between parents and farm.
Report on Adam’s Math, February 1, 2002

I [the math tutor] have been teaching math to Adam since the beginning of October. I come every Friday to work with him. We are working on the Grade 8 curriculum. Adam understands the concepts quickly, but sometimes has a hard time retaining the information. He is excellent at arithmetic.

He sometimes has a hard time following instructions and understanding what the question is asking. He tends to resist writing down all the steps, preferring to do the work in his head. Adam has a hard time admitting when he does not understand something. He would often shut down and refuse to have a dialogue about it. Now, more and more, he is beginning to ask for help and clarification when he needs it, which is excellent.

I think Adam’s biggest challenge is to learn that complex problems have a series of steps to them, and that the steps need to be worked through systematically and logically. Adam often does his math homework independently, but he sometimes needs support in understanding exactly what is expected of him. It is wonderful that he takes that initiative.

By February, six months into Adam’s care with us at Blooming Acres, I noticed a transformation. This was possible for a number of reasons. Firstly, he was working hard on his OCD issues, which he was conquering. Adam was eating well and was more relaxed about food related germ issues. Adam was sleeping well. Adam went to bed at 9:30-10:00pm and rose somewhere between 7:30am and 10:00am.
Adam was watching no television at the farm and playing very few video games. Adam was beginning to generalize his personal space issues; Adam was feeling a sense of pride where his Hebrew lessons were concerned. Adam was playing, studying – Adam was learning to live in community.

**Adam’s Journal Entry, February 7, 2002**

Adam had a very quiet day. He built an elastic band propelled race car [actually a balloon propelled lego car] with Candy, then chose to read his new Redwall novel all afternoon. His learning edge was apparent in his considerate, polite attitude at dinner time. Dinner was beef stew that Adam disliked. He politely explained that he didn’t care for stew but “for stew it’s really good” and thanked Candy for making dinner. He then without complaint got up and independently found something else to eat. This ability to deal calmly and respectfully with the unappealing meal scenario comes in sharp contrast to the Adam who even a couple of months ago often would complain loudly and issue blame and insults in the same type of scenario.

After drama class this evening Adam wanted to give some younger friends (other homeschoolers) goodbye hugs. All three girls looked uncomfortable with the copious physical attention he gave them. I firmly reminded Adam that before giving any person a hug he needs to 1) ask, 2) wait for answer, and 3) respect the answer. Adam has learned to be much more respectful of people’s personal space at the farm. I think he now needs to learn to apply the same skills and concepts in public and with “off-farm” people. En route to Susan’s parent’s
house after drama, Adam became very frustrated by the length of the drive. “I can’t be that patient!” he told me. I talked to him about blood sugar levels and mood and energy and recommended that he eat more before drama next week. He agreed.

There was a significant change in Adam. He had made tremendous progress. This month brought about an epiphany. We held a different perspective and context for Adam’s neurological manifestations.
My Journal, February 2002

We had been engaging in discussion of Adam’s diagnosis, suspecting that Adam presented symptomatology of an individual on the autistic spectrum of disorders. We hypothesized that Adam had Asperger Syndrome, which integrated well with his various challenges. Adam’s behaviour, his lack of social pragmatics, oddity, and personal space issues, combined with his inability to socially reference and understand that others have a point of view all are explained in Adam’s case as Asperger Syndrome. Every staff member at the farm, as well as his mother, completed an Asperger’s Scale on Adam. Adam clearly fit the criteria. This gave us a new perspective on Adam which helped us accept the root of some of his challenges and helped us adapt programming to meet these needs. Adam was later assessed by a psychologist whose expertise lies in the area of autism spectrum disorders. Adam’s new diagnosis of Asperger Syndrome was added to his comorbid conditions of Tourette Syndrome, ADD and OCD.

Adam’s Journal Entry, March 6, 2002

Adam has been getting excited about his project on B.C. [British Columbia, Canada] wildlife. He is studying animals he’s familiar with from the Redwall novels. His feelings of connection with the Redwall characters seem to be motivating for him. It was when he learned he could focus on shrews and badgers that he became willing and interested to work on writing a proposal for the project. He’s researched both on the internet and at the library. He’s also been doing many drawings of the animals that he’s quite proud of.
My Journal, April 2002

March and April brought a new enthusiasm to Adam. He became excited by his B.C. Project and our plans to travel the province in May. He began to work with Leslie on my laptop computer, and then explored the internet. This was the same time when Jim, our oldest student, failed to return to us from his March break. This junction was another significant point in Adam’s role in our community. With Jim [a student] no longer with us Adam began to help Dale [a staff member] in the barn more with the hard work of repairs and tending to the livestock. Adam also independently worked with Chris, our farmhand, cleaning out the stalls which were knee high in layered manure and straw. This was unusual for Adam but, nonetheless, encouraged. Adam seemed more relaxed as well. I think Adam felt a great deal of pressure from Jim who was less patient with Adam and did not miss the opportunity to tease Adam at first with anger and then more lovingly. Without the stress of this older learner at our community, Adam had an opening to pick up on some of Jim’s duties in the barn. I think this contributed to higher self-esteem for Adam.

Adam’s Journal Entry, March 19, 2002

It sure looks like Adam had a full day, most of which was spent with Dale…but if Dale doesn’t get the chance to write…. Today Adam was a big help in the hay loft, organizing building materials (from what I’ve heard). Including a walk we went on today with Dale and Susan and the dogs, he seems to have gotten quite a lot of exercise. And today upon return from a climbing gym trip with Susan, the house had been tidied by Adam. After supper he and I worked well on his B.C.
Project. He is nearing completion of his rough notes (which I am taking for him while he reads and dictates from websites or library books). He has been generous with compliments, appreciative, and helpful today as well as yesterday.

Adam’s Journal Entry, March 22, 2002

Adam’s had a phenomenal week. Three days in a row he helped Chris and Dale in the barn. He laid down floorboards in the hayloft and for two hours he mucked manure out of stalls with Chris! Howard paid Adam a few dollars for this work and we were all very proud of him. Adam had heaps of exercise, was very pleasant, cheerful company, worked hard on his B.C. project and math, did the barn chores...a great week.

Something seemed to click for Adam. By April he was very different from the kid who arrived in September. It all came together for him. He was walking tall; he looked like he was becoming a teenager. The little boy who had joined us in September had transformed into a young man. To live and learn with him was much easier for all of us and, most importantly, for Adam. Adam’s days had become fuller; he was attending drama class together with another student, and was pleasantly and enthusiastically engaged in a rich variety of activities including building of many wood objects such as a gecko hideout. This transformation is best described through the words of various members of our community.
Adam's Journal Entry, April 2, 2002

Adam waited excitedly for the arrival of his Mom this morning. He was very excited and happy about opening a bank account. Adam horsed around with Jane [another student], seeming thrilled to see her. Adam asked right away if Jim [another student] was back, seeming concerned. The two of them cared for their jointly-owned gecko ‘Melissa’ right away.

Adam was in an especially curious and interested mode all afternoon. Researched dinosaurs (“of B.C.” and otherwise!)
in books and on the internet with Dale for quite some time. I also walked in on a discussion the two were having about black holes – Adam had an encyclopedia in his lap and a very serious expression on his face.

Next Adam got very excited about Dale having just won an internet poetry competition. Adam found himself pen and paper and sat down to write several poems of his own: an ode to his pet gecko, a humorous poem about Noah and a silly poem about Jill’s kitten meant in good fun. At Sherri-Ann’s prompting he typed them up on the computer and printed them.

By then ready for a break, Adam bounded upstairs to watch movies with Jakob, whom he’d been eager to see all day. (Jakob had been out at a playgroup).

As usual at dinner these days, Adam tried the dishes offered, stated that he didn’t like them “but thanks for making it [Dale]”, then quietly foraged for himself in the kitchen while the rest of us enjoyed our meal.

After dinner Adam flatly, babyishly, refused to do his Bar Mitzvah practice and his math homework. (I’d given him lots of warnings [explained consequences] and choices all day. It came as no surprise to him.) I told him that if he was too tired to do his homework then he could go straight to bed and to sleep. He politely asked me to help him make his bed, so I did. He went to bed and I made it clear he’d need to do 20 minutes
I was struck and impressed today by Adam’s independence! When I started working at the farm in January I thought Adam had trouble initiating activities outside of his small interests and would ask others to do things for him. Today Adam decided to make pancakes; he read and followed the recipe and cooked them entirely independently. I was impressed by the skills displayed (following directions, life skills, cooking, etc.) and loved the initiative. A bit later in
the day, Adam wanted to participate in Jill’s cat motel project (again I am moved that he is showing an interest in a variety of activities). So he decided to sew a cat toy. He asked me for a bit of guidance but basically he sewed by himself on the sewing machine (something which intimidates many people). Adam is really coming out of himself socially and growing in independence greatly.

P.S. On top of all this, Adam has written awesome poetry and entered it into a contest.
**Adam's Journal Entry, April 4, 2002**

Adam came down and made himself breakfast then busied himself building couch-cushion forts for Jakob’s amusement. He was motivated to get his Bar Mitzvah practice done right after breakfast by the idea of a town trip. We then began working on his B.C. project together. He became terribly frustrated by the computer, being unable to find one of the documents and facing some word processing glitches. He took several breaks and told me he calms himself down by squeezing all his muscles tight for ten seconds, then letting them go. Later he stated “Leslie is my favourite person to work on my B.C. Project with, because I get the most done with her.”

Adam independently made himself sandwiches for lunch. Chris joined us for lunch and Adam became very excited about the idea of working with him in the barn. He wanted to work in the barn more than he wanted to go into town! After getting crickets for his geckos, Adam did two hours of manure-mucking with Chris, then came in calmly and did his math homework. Just before bed time another staff led a workshop on schooling methods with Adam, other staff and me as participants. The kids were tired, and the subject of schooling was intense for them. Adam was alternately belligerent and eager to share his memories of conventional schooling.

**Adam's Journal Entry, April 10, 2002**

Today Adam helped fix the electric fence in the mud, and then helped me build cold frames. Then he helped Chris muck out the barn.
Adam was cooperative, friendly, and hardworking all day. He worked with five different staff members on various projects and was willing and respectful throughout. He dealt particularly well with the smells, the ankle-deep manure, the cows and goats in his way, the banged thumbs, the flies...while working on the electric fence.

**Adam's Journal Entry, April 15, 2002**

What a busy warm (mid 20’s), productive, creative, fun day. Adam did his math at the start of it...then woodworking outside in his shorts, (woohoo spring!), then a hike, then a field trip to the lake in Orillia...went playing and exploring along the beach, then more woodworking at the farm while supper was being prepared...and then movie and bed.

Adam was polite and a joy to share tools with today. He listened well and got along quite well with Dale (new visitor this week). The two of them interacted easily / readily and courteously with two other boys their age (strangers) at Tudhope Park in Orillia.

Today was a joy, complete with popcorn at mid-day.

**Adam's Journal Entry, April 17, 2002**

I kind of can't get over just how perky and co-operative Adam is this week. He has nearly completed his B.C. Project with someone else's help. I see him being polite at the supper table, and flexible when planning activities, and willing and
competent to make his own breakfast and snacks...and I am magically more receptive to his invitation for hugs...hmmm.
**My Journal, May 2002**

Adam moved to our Muskoka lakeside camp for a one week retreat before the big trip to B.C. During this week he demonstrated an enhanced sense of self-confidence, a willingness to help, and a desire to be totally independent. His Bar Mitzvah was fast approaching at this point and we had talked a lot about what it meant to be a “man”. We talked about integrity, honesty, hard work and respectful relationships. Adam took these discussions seriously and literally. He began to say things like “Oh! I’ll get those parcels for you. After all I’m going to be a man soon”. Adam was primed for this rite of passage to manhood. His relationship with our community was clearly benefiting from this, as was Adam. Adam’s mother remarked at how much he was growing in this last month with us. Adam eased into the transition to camp well, remaining extremely happy during his time on the lake. This early move also made room for the construction crew to embark on our farm to demolish half our house and to commence a considerable renovation. We had grown out of the original space and were now transforming the farmhouse into a 16 room MANSION! Adam enjoyed the visits to the massive construction site. He enjoyed caring for the livestock and tending the garden.

*Adam’s Journal Entry, April 29, 2002*

*After twelve hours of sleep last night, Adam was in a brilliant mood all day. He was sweet, cooperative and very helpful. Adam elected to help me move a stack of firewood. He worked steadily alongside me for an hour, until the job was completed. His company made the job pleasant, fun and twice as quick. He’s eager to do things that are good for his body. He told me*
he'd like to be a fast runner again, as he apparently was when he was a kid. We talked about nutrition and physical outdoor exercise. As well today, Adam was helpful looking after Jakob. He took Jakob to play in the gross motor room for quite some time and modeled mature behaviour. He helped Jakob with his runners and boots, made him a special snack and gave him lots of positive respectful attention. Adam was paid $8.00 for his work today and was very pleased with his earnings. Adam held up his end of a bargain with me today, in regards to his math homework. Adam got to watch a movie with his dinner if he would be focused, friendly and respectful doing his math afterwards. He followed through and did his homework in a good mental space after the movie despite the late hour and some blocks about how to do some of the math questions. I noticed he calculates percentages easily and accurately in his head.

Adam’s trip to British Columbia was, in my opinion, the “piece de resistance” of his education with us. I was not present but inferred this from reviewing his journal and meeting with the teaching team when he returned. I felt a deep sense of pride at the time and was confident about the positive experience and the significant accomplishments Adam had made.

Adam’s Trip Journal Entry: May 7, 2002

FIRST DAY IN BRITISH COLUMBIA!! Adam had a fantastic day. He got in the van at 7am and held it together for a whole day of traveling. Throughout dinner and evening at Sara’s aunt and uncle’s home in Surrey, Adam was considerate
and well mannered. Adam seemed to have a great time with Sara and her cousins. They goofed around outside playing soccer, driving a golf cart, having a small bonfire, etc. Adam was invited to spend the night and though in the end he chose to go back to the hotel with our crew, it gave him much food for thought. He spent long minutes examining his OCDs both alone, and with Rose, Fran and Sara. Today Adam got to see the habitat of his beloved moles, one of the creatures of B.C. he has been studying and reading about these many months. At Sara’s relatives’ home Adam casually offered to gather all the wood needed for the bonfire, “if you’ve got a pair of work gloves I could use.” He looked proud and happy.

**Adam’s Trip Journal Entry: May 8, 2002**

We traveled from Surrey to Vancouver Island, then Denman Island. Adam was sunny and cooperative. He was very excited by the wildlife we saw en route: bald eagles, snake, starfish, etc. He also asked questions about the vegetation. We all participated in a Marine Life Workshop run by a local expert. Adam correctly identified many of the sea creatures we were introduced to and attentively absorbed detailed information about them. We then combed the beach with our workshop leader and Adam had many more questions answered as we explored.

During dinner at my Dad’s Adam politely accepted an offer of an alternative meal made by my stepmom. Adam was quick to offer to help make his special meal when I suggested it and so he did some of the work and used his manners.
Fran, Sara, Adam and Rose [students and staff] went to Hornby Island after another morning on the beach outside our cabin. The beach was his favourite spot on Denman Island. “I don’t want to ever leave.” Each morning he searched for river otters, saw sea lions sunning themselves on the boulders “in the middle of the sea,” many star fish, oysters, some slugs... He was so proud to find “a seal vertebrae” which turned out to be a deer vertebrae. One morning we walked over the beach to the oyster gatherers and asked a few questions while he watched them.

Adam’s Trip Journal Entry: May 9, 2002
I picked the kids up from their bed and breakfast. Adam had been up and exploring the beach since 7:30 am!! As well, he had practiced with Fran for his Bar Mitzvah, written in his journal, and breakfasted. He and Dale enjoyed playing with the aptly-named lichen “Old Man’s Beard”.

POTTERY WORKSHOP:
Adam loved it! He and Sara both watched the potter’s demonstration with intense concentration. Adam then worked quietly and independently for two hours sculpting a dinosaur and a few other little things out of clay. He worked with confidence and incorporated some of the techniques taught by my Dad.

We shared lunch with the LeBarons and Adam was polite and flexible.
RIVER OTTER HIKE:
We hiked three kilometres through coastal rainforest. Adam loved the long (4-8”) Banana Slugs he discovered. At the top of a rocky headland our workshop leader, Kitty Balke, showed us two bald eagle's nests and told us about eagle nesting patterns. We saw two eagles as well. We climbed down the steep cliff to a rocky beach, where Kitty Balke led us to discover River Otter feces, tracks and dens. She encouraged us to imagine ourselves as otters and taught us about their scent glands and solitary behaviour. We were lucky to see two mink. We then explored a cave and an islet covered in wildflowers. Adam discovered an abandoned Canada Goose nest with broken eggs, and a dead baby goose. We also saw a dead shrew, (another of the animals Adam has been studying), sea gulls, a seal, a sea urchin, sea anemones, starfish and countless wildflowers which Adam and Kitty identified for the group. Adam became exhausted from all the exercise and excitement and learning in his long day and felt disappointed not to have seen a live River Otter. He and Sara went back to the B & B and relaxed in the hot tub and felt better again despite their fatigue.

Adam’s Trip Journal Entry: May 10, 2002
In Hornby Island he got excited about the bald eagles we saw and got out of the car with the binoculars to get a close look. At the restaurant he walked down to the beach with the binoculars to check out a heron too. For lunch he negotiated skillfully with Sara [another student] to share a bowl of clam
chowder after first asking the waiter if he could sample the chowder.

Adam took his turn to navigate us around the island he stayed with it patiently even when we had to wait for him to figure out the next turn. He was successful all the way through. “Now that I am 13 I need to buy more grown-up things for my mother.” At one point, while we waited in the car he went back into a gift shop and effectively bartered a $10.00 plus tax deduction from the price of his mother’s gift.

At Kitty’s Aunt Jan and Uncle Robert’s [staff family member’s] place, Adam showed much interest in the old fashioned and modern tools and with reminders asked if he could use them. His curiosity and ease with the goats, chickens, and rabbits caused him to meander from one pen to the next, not always by the use of the doors. Adam asked many questions, explored nesting boxes and the garden shears.

Towards the end of the trip he was upset about being corrected so when we got back to the cottage he headed for the beach by himself to work it through.

Adam’s Trip Journal Entry: May 11, 2002
This was our last morning at the cottage and we took a long time to say our farewells to Mike and Diane [staff member’s family]. Diane found a poem especially for Adam and presented him with it and a personal note. Mike graciously honoured Adam’s request to split wood with an axe with Mike’s support. Adam
was very proud of his accomplishment. Adam gave warm hugs and thanks to Mike and Diane. Each morning at breakfast time Adam enthusiastically followed his curiosity and explored Diane and Mike’s house, full of questions and the desire to touch many objects especially the stuffed Great Horned Owl. Diane had good boundaries regarding personal space.

Adam enjoyed looking once again at Arthur’s [staff member’s family] pottery especially the owls. He once again employed his deft negotiation skills with regards to his purchases and managed to secure himself an owl.

While he waited for the rest of us to be ready to go he explored the quack grass roots enthusiastically offering a piece of the root to several of us so I promptly redirected him to the dandelion root while espousing their value. He promptly acquired a knife, cut out a root and proudly shared it.

Adam spent a good portion of the car ride sleeping after taking Gravol. He enjoyed exploring Long Beach.

Adam’s Trip Journal Entry: May 12, 2002
Adam, Sara, Dale and I got caught up on sleep at our hotel, then explored the streets of Tofino, a very picturesque seaside town. Adam bought many gifts and a few mementoes for himself – and ran out of money in his bank account! He began formulating a plan for making his allowance last the rest of the trip.
Adam discovered a local museum which featured whale bones and an art gallery with beautiful Native carvings of some of his favourite animals. He was very excited to find several baleen (whale “teeth”).

After lunch at an interpretive centre, Adam was able to identify accurately eight out of ten unusual sea creatures in a self-quiz. There Adam also saw a whaling canoe and learned a little about how they are made and the history of whaling. He was interested in a film about tidal zone creatures but was lured away from it by “the real thing” on Long Beach! Adam ran out onto the sand turning every which way at once and flapping with excitement. He didn't seem to know what to look at first! By now he's become familiar with much of the local sea life and has had regular opportunities to deepen his knowledge. Today he introduced me to a few critters I haven't known previously. He also joined Sara in making sand sculptures and met Dale’s rock climbing challenges.

Because Adam had been unable to finish his lunch, (by a long stretch), at dinner I suggested he order a kid size meal – but I left the final decision in his hands. He wrestled long and hard inside himself and he accepted my suggestion that he might be worrying that there won't be enough food for him. We four had a lengthy conversation about relative wealth around the world, waste and consumption, the relative value of food and money and privilege.
Mother’s Day. Adam called his mom and also spoke with his brother. It was clear that that this was very important to him.

Adam’s Trip Journal Entry: May 13, 2002
The six of us spent the day together at Hot Springs Cove. It rained all day which was hard for Adam but he dealt with it internally rather than voiding his discomfort and dampening others’ moods. From the water taxi we saw humpback whales, seals, sea lions, bald eagles, cormorants, a puffin, and Brant geese. We hiked four kilometres through old growth Coastal Temperate Rainforest. Adam touched (gently) frog’s eggs and 600 year old giant cedar trees. We marveled at the complex interweaving of various forms of life in this ancient forest. At the hot springs Adam braved the icy cold surf as well as soaking in the hot pools. Some of the questions Adam asked led up to a discussion about how interconnected species are within a given ecosystem.

Adam’s Trip Journal Entry: May 14, 2002
Twelve hours sleep! Adam awoke in a friendly, alert mood. He started his day with a video about local First Nations people (the Nuu-Cha-nulth people). He learned about the effects of residential schools on First Nations peoples and related it to his own life. He spoke about his respect for the way Native people live in harmony with nature. We then went to the fridge and I pointed out to the kids all their boxes of food left over from restaurant meals. I lectured on the waste of animals’ lives, plant life and the trees the cardboard was made from. I think Adam got the connection.
Adam’s last stop in Tofino was the whale-watching outfit below our hotel. He had visited there by himself often during our three days in Tofino. The people there seemed to appreciate Adam’s huge enthusiasm and curiosity regarding wildlife.

Adam washed all our hotel dishes for us without complaint – a whole sink full of glasses and juice bottles.

Drove to Nanaimo, B.C., and Adam enjoyed a spaghetti dinner at my Mom’s house. He loved the meal and just took the amount he could eat, so there were no issues. After dinner, Adam worked on his Bar Mitzvah preparations with Fran. The evening was filled with a riotous game of “Purple Ball” (improvised on the spot) and drama games. Adam’s impersonations of Fran and Rose [staff members] were very funny.

Adam’s Trip Journal Entry: May 15, 2002

A harder day for Adam than others of the trip have been, but with many successes still. Adam woke up hungry and with a headache. He’s been exceptionally cooperative, friendly, engaged and active for many days in a row now. Adam helped clear the table after breakfast at my Mom’s, then waited for the rest of us in the van while we said our good byes. He did take responsibility for his own belongings and helped put away the bedding he’d used. Taking space when he’s feeling out of sorts is a strategy Adam’s been employing on this trip.
We drove to Victoria. Throughout the two hour trip Adam sat in the back seat with Sara [student] sharing jokes, his discman, drawing materials, and snacks. There has been a lot of this type of peaceful, happy, playful, sibling-like interaction between the two kids on the trip. Adam often initiates playful games and jokes and loving teasing with Sara. The two are comfortable and affectionate friends. This has never been so apparent as on the long drives in the very crowded and hot minivan around the gulf islands. Adam accepts Sara’s advice and help as well as her playful company.

This afternoon Adam finally got to go to the Royal Victoria Museum. Since he discovered it on the internet with Dale months ago, he’s been eager to see its woolly mammoths and sabre-toothed tigers.

Dinner was a hard time for Adam tonight. He was exhausted and we traipsed around Victoria’s downtown streets longer than he could handle. We tried two restaurants for Adam – friendly food and finally I took him to Pizza Hut. He was truly grateful and expressed it to me in a thoughtful way. As well, Adam emphasized to me that his pickiness around food is something he was born with and that he’s been working hard to be flexible around it. Indeed! The list of new foods Adam’s tasted on this trip alone would be impressively long! (Beets, balsamic vinegar, sprouts, kale, and an African stew, bocconcini cheese... he’s really been putting in the effort, so tonight he got some relief and was immensely comforted by his simple meal.)
After dinner a swim at the hotel was also relaxing and Adam went to sleep peacefully.

Adam’s Trip Journal Entry: May 16, 2002
Adam finally got to do lots of shopping in gift stores, which he has been looking forward to. He, Sara, Rose and Fran spent the whole day shopping in downtown Victoria. Fran found that it helped Adam to respect people’s personal space when he was given a non-verbal, physical cue (hands gently on his shoulders) showing him “arms length”, an appropriate distance to stand away from a person you are talking to. Fran found that Adam was very responsive to this style of teaching for this social skill today.

On the ferry to Vancouver we ate dinner and again Adam chose an appropriate size meal for himself. On this trip he has made huge steps in this particular area! Adam is consistently selecting portions of food he is able to eat comfortably at one sitting without leaving any waste. As well, Adam has consistently been choosing and eating vegetables at every lunch and dinner without complaint. All the adults have really noticed this success of Adam’s and have been commending him for it.

This morning Adam also spent a long time at Victoria’s BUG MUSEUM where he and Sara got to hold many exotic insects. He loved it.
Adam also today intently watched a glass blowing demonstration at Starfish Glassworks, a beautiful gallery in Victoria. He didn’t want to leave. He was in good spirits again today as we traveled in the van on the ferry. Again he and Sara sat together in the back of the van drawing and reading and talking and laughing together for hours.

When the group returned to camp from this trip I knew it was an enriching and transformative adventure for all. They shared the stories, pictures, and tales of their journey in western Canada. While they were gone Sherri-Ann and I had our own task. Our contractor tore apart our farm house and commenced an enormous renovation that we supervised. The learners and staff were excited to see the progress and get into a routine of our temporary camp life – we could not live at the farm while it was under construction. The group traveled between the camp site and our farm for the spring months to look after the livestock and our gardens.

Upon his return, Adam’s focus and our focus for Adam was on supporting him for his Bar Mitzvah, which took place on Saturday, May 25, 2002. This was held at the farm in a large tent in our back yard. Our backdrop was the construction at the farm, a gigantic hole in the ground and half a house. That spring and summer we expanded our house by 5000 square feet to accommodate the growth of Blooming Acres Farm and our school.

Adam’s mother prepared all the details of the event which included catering, music and a Rabbi. She hosted one hundred guests. It was a joyous occasion – for me because I felt proud that all of our work had
paid off. Adam shone that day, greeting guests, praying aloud to our congregation, singing songs, making speeches and remaining respectful and attentive despite all the fussing over him. Adam engaged in mature, considerate and appropriate conversations with the overwhelming number of people who demanded his attention. He was walking tall; he was truly a man (in Judaism, a Bar Mitzvah is usually associated with the young man being called to read the Torah – and is a rite of passage from childhood to manhood). Adam’s family, each member knowing of his troubled past, was present, and realized what a momentous occasion this was for him. Each took the time to acknowledge his or her appreciation for our efforts. His father, who was skeptical together with his family, all remarked at the “changed Adam.” The day was a joyous one; a good closure for a transformative year.

Adam continued with his pleasant, respectful and hard working demeanor for the last weeks of school and brought tears to all eyes at our graduation ceremony. His father and grandmother attended the ceremony together with his mother and her parents. Everyone remarked to us how pleased they were with his progress and excitement for his future. Adam left us that day transformed.

Adam continued to live and learn at the farm for two more school years, and after three years it seemed the right time for Adam to return to the city to live and learn.

The first year Adam was at Blooming Acres I would say was very much therapeutic. The therapeutic process was maybe the most significant that year. There was a tremendous amount of cognitive behavior therapy that needed
to go on for Adam to be able to do, really, anything else. I think that was the most significant thing happening in Adam’s life. In Adam’s days, although he only spent a certain amount of time doing therapy in session, all the staff knew what was involved, so anything could be transferred. Everyone was always on the same page with how to deal with him. So I think that was significant. Behaviours, things that were going to be accepted or not, getting involved in the community a little bit more and how do you function in a household. He was there with (the other children) and then there was the staff. I mean there was a young staff, you know that first year, there was a little bit more of a relationship with them because there was just a small group. I think there was sort of a close knit group and family. But what impressed me the most was one evening I had called about 8:30pm and couldn’t talk to Adam because he was doing his research. He was doing his speech to everybody at 8:30pm in the evening and I thought, well how beautiful that it could be done at whatever time he was functioning and that he could be managed as opposed to well, you know, at this time we do this and this is the time we do that. Now there were times that there were planned events, but, I know that the planned events went on for three hours, even though it was supposed to be for half an hour long, or until you got the focus and attention.

In his first year Adam would be in his pajamas and underneath his bed and he would be doing the work or math or whatever it took for him to get some kind of academics that were really
necessary to keep on par with the world in some way. It was not like school, there was certainly some idea of bringing in curriculum and getting the learning you need in order to keep up with the world but it was so based on their interests and where they are at. For example Adam was interested at the time in building things, so a lot of academics would go around what it was that he was interested in. So he was building things in artwork and then he started to put in the concepts of geometry later around the artwork. It was all kinds of learning very experientially. You can’t really measure, you can’t measure the experience until later on, for example when he finally went back to school, it turned out that he wasn’t really far behind because he actually had the concepts, only he had learned then in a different way than he would have had he been in school.

Seeing my son being somewhere where he was safe, loved, cared for, not getting away with things that he shouldn’t be, learning (and I mean learning behaviourally) coming home and bringing these concepts with him, communicating with Blooming Acres and those things can be brought into home life. For myself, although it was very difficult for me not to have my son with me, watching my other son flourish, I had more time to breathe – feeling like there was a measure of success generally going on. I felt very included. There were times when I had some concerns about say, will the program allow for re-integration at some point? How is that going to look? Is he going to heal enough to be able to go back to school? And if he does, what’s going to happen academically? How do
we translate everything he learned into measurable education curriculum? I had a bit of concern about that. But because I saw so many positive behaviours and he was functioning, I didn't seem to focus on that. It was small concerns that I had. The other concern was about his social life, what was he missing? There was still a lack of enough social groups for him to feel like a regular kid and that was a concern.

I still personally think that it was the best thing that could possibly have happened, and I think that on one hand where Adam wasn't getting the “school” social stuff, he was saying “I want to get back to regular school” and that actually forced him to take the steps that he needed in order to be back to regular school.

Blooming Acres felt for me, like a very safe, warm place, that if I felt comfortable enough for my child to go there, there was something very special going on. Everybody, every staff person, who was there was just so warm and welcoming. It wasn't just me and my kids and my family, but there was also a connection with the other families. Like I was talking about the inclusiveness and just knowing that in this worst possible scenario of having to send my child away, it was the best possible scenario that I could have ever asked for.

After the first year at Blooming Acres Adam returned to his home for the summer but also attended our summer camps in Muskoka and
returned to our farm for several weeks. Adam’s family, and the many staff who knew Adam from his previous summers at camp, remarked at his newfound maturity, flexibility and positive personal development. To me, Adam seemed proud of his many accomplishments – and so were we of ours. Adam built relationships with his peers and staff that were imbued with care, respect, and collaboration. He was taller, stronger, more flexible and, ultimately, a much healthier and resilient youth. He was able to access his personal and educational needs and desires in healthy and productive ways as opposed to through risk-taking and illness. His transformation was profound. Adam continued to live and learn at Blooming Acres for two more years and, when he was ready, moved home to attend a small private school to finish his high school credits. In 2007 Adam moved away from home to attend University.
Chapter 8

Bobby

I have known Bobby since he was four years of age and he began to attend our camp at age six. His older brother attended our camp first and Bobby followed a year later. Bobby, a cute and charming red headed kid, was (and still is) full of energy with a zeal for life. When he was a child, he reminded me of the Alfred E. Neuman character from the Mad Magazine. He always had a goofy smile or a vibrant grin on his face. Bobby could (and often needed to) charm his way out of the sticky situations within which he found himself. He joined Blooming Acres as a learner in 2003. At that time Bobby’s family (first his mother and then the entire family) moved back to Ontario from Manitoba to support Bobby through his high school years. School failed Bobby and according to his mother, his future looked grim – so she and her husband took the risk of schooling their son within our community.

According to Lillian, public school was an “off and on again struggle” for her son. Bobby, like Adam, was challenged by the daily routine and the academic demands of school. And he too, as early as Grade One, was home schooled by his mother and others within the family’s circle of friends. Bobby was diagnosed with complex neurological issues including Tourette Syndrome, Attention Deficit Hyperactivity Disorder and Oppositional Defiant Disorder. And to exacerbate these already complicated matters, Bobby was “gifted” with learning disabilities.
Prior to their return to Ontario, after frustrating experiences in the Manitoba school system, Bobby and his mother and father visited Blooming Acres farm to explore how we support our learners with neurological disorders. The family was familiar with Sherri-Ann and me. We had known each other for nine years at this juncture. The decision to explore our programme must have been easier given our relationship. In addition, by the time they visited our community in action we were well into our second year of home-education and our programme’s success was obvious. We had made recognizable and exceptional progress with the then current learners. Bobby’s family met with other parents of the participants of our programme to discuss their experiences.

I recall the day we met to discuss Bobby’s participation in Blooming Acres. Similar to my experience of Adam’s enrollment, Bobby’s mother was keen but his father was reluctant given our unique pedagogy – notably our unstructured non-traditional academic philosophy. His father was concerned that we did not follow a public school curriculum and that his son would not be afforded the opportunity of college and work as an adult. However, Bobby was extremely enthusiastic about joining us. With some serious discussion that included shared concerns for his future, and with very few options available to the family, their decision was made: Bobby’s parents enrolled him and he joined in September 2003.

A special arrangement was made so that Bobby could attend our home-school community. Bobby’s mother Lillian also joined as a staff member. This was both barter for some of our fees and was a means to keep Bobby successful and safe. Because I had known Bobby for
some time by this point I knew that his mother was a stable force in his life. As part of his life at Blooming Acres she would contribute to his ultimate success. Having her there would keep Bobby calm and his family close to him. Bobby was very impulsive and could become agitated and stuck on feelings and thoughts very easily. This could often lead to out of control behavior and I knew his mother could support us to keep Bobby grounded.

Bobby's time with us was shorter than we, and his family, anticipated. He joined us for one full school year in 2003 and for two months in 2004 (see Chapter 10 for details of our unexpected, abrupt closure). Subsequently, many of the documents and student journals that outline his experiences were removed and are missing (details also in Chapter 10). However, during this period, Bobby, like Adam, had a transformative experience that prepared him for the final years of high school (at a private school in St. Catharines, Ontario). Bobby’s mother Lillian has attested to this fact and so, also, has Bobby!

Bobby was keen to participate in this research project and consented to use his name and picture without anonymity, however his name and his family names have been changed.

Lillian and I met over the course of a few months in 2006 to discuss Bobby’s life history. These conversations took place at Lillian’s home. 

*Lillian’s voice is woven into the text, marked with the symbol ⚠️ and her thoughts are represented in italic font.* Lillian’s husband Eric was living out of the country at the time of our meetings, which made his participation impossible, although the transcripts were shared with both of Bobby’s parents.
Lillian and I have known each other since 1995. Lillian was energetically active in the Tourette Syndrome (TS) community. She had attended many seminars I had presented and also sent her children to our summer camps and weekend retreats. Lillian volunteered as my receptionist for a few months at our camp office in 1996 and, today, has continued her work with our community. Lillian is now the Client Care Manager at Blooming Acres. As I have moved to a full time Professorship at a local college Lillian manages our two care homes with Sherri-Ann and our other staff.

My conversations with Lillian were enjoyable and relaxed. Our relationship made the time comfortable and helped us delve into dialogue that sometimes lasted hours. We enjoyed meals together, usually supper, and then sat down to productive conversations where the time and questions flowed as if each question I asked was answered as easily as turning on a tap.

School for Bobby was a nightmare right from the beginning. As a kid at home he enjoyed a lot of... kindergarten [-like] activities such as painting and cooking, sandbox, crafts, you know, all those things which I thought would really prepare him for kindergarten. But he just didn't get the sequence of coming into the school and taking off his outdoor shoes and going inside and putting his indoor shoes on and sitting down in the circle. He found this frustrating. I think he found transitions [challenging] right from the beginning, and at the time I didn't know anything about people having problems with transitions [time between activities where general social expectations are unclear or unknown]. He had
difficulty with reading right from the beginning. They said oh, he'll mature and it'll come — don't worry, the reading will come. This caused him a lot of frustration. Bobby was smart enough that he realized he wasn't keeping up with all the other kids.

Then when he got into Grade One, which was just a nightmare, he couldn't sit at a desk and he was really struggling with putting his hands up and with reading. WE did all the homework, WE did everything we were supposed to but he was constantly having mini rages at the beginning of Grade One. There was way too much input for him. He was being defiant, and the big thing was speaking out in class. He didn't get that you're supposed to put your hand up, wait your turn; all those things were really difficult for him.

He would be given a direction, like one scenario comes to mind is an art project they were supposed to be doing, and they had to take paint and put their hands in it and then put their hands on the window and the teacher was very specific about how it was supposed to be done. He could not grasp that. He wanted to make his hand like a butterfly, and he was stuck on the idea that's what he had to do. I don't understand why he couldn't be creative in art class. The teacher did the same project every year and it had to look a specific way. That's when we first started seeing him get stuck. He couldn't let something

4 Inflexibility, on the part of teachers, seems to be one of the prevalent issues that parents report as leading to stress and struggles for their children at school.
go. I think it’s very similar to now but not as sophisticated. If kids were playing games and he felt that they should pass him the ball, he would just, unless it was played his way or the way he thought, he couldn’t remove himself, like he couldn’t let go and move on and go back in his class after recess. That would continue for him all afternoon – he’d end up in the principal’s office.

There was a lot of behaviour, us constantly getting called up to the school. He got very stuck on right and wrong. If he felt the teacher was favouring another student or offering more privileges he couldn’t get past this and he would be verbal, and the teacher would ask him to sit down or leave the room and he wouldn’t, and I’d end up getting a call and he’d end up down in the office. He would blow up, he would have temper tantrums, or rages or whatever you want to name it.

Lillian provided me with a comprehensive and well organized chronology of Bobby’s journey of neurology and school in a binder divided into sections labeled academic years, schools, assessments, strategies, hospital visits, medications and so on. I explored these artifacts and a picture presented itself – themes emerged. Bobby was referred to the School Support Team for his learning challenges, challenging behaviour and his social issues midway through the Grade One school year and was out being home schooled by spring of that year. It was obvious in Grade One that Bobby was not coping in the system and I can see why his mother made the decision to pull him out of school.
Artifact 8.1 - Letter From Grade One Teacher

1. He simply cannot sit still for more than a few seconds. Very fidgety, moves arms, shifts body, and plays with objects. Frequently out of his seat, walks around the classroom and disrupts others.

2. Says the wrong things at the wrong time.

3. Work is rarely completed. Those assignments that are finished, are done with teacher assistance. Often shifts from one uncompleted activity to another.

4. Demands a great deal of individual teacher time and involvement, almost as if he is unable to think or do things on his own. Will not take risks in completing tasks.

5. Very limited attention span.

6. Doesn't make effective use of his time, poorly organized.

7. Often gives excuses and blames others for not doing what he should be doing.

8. Very disorganized and forgetful with regard to his desk and personal belongings.

9. Doesn't follow directions or instructions even when they are given in small segments.

10. Even when he is being spoken to, it often appears that he is not listening.

11. Current academic performance, especially in language, is quite low. In math, he is a little bit better, but it low, is low.

If you require any additional information, please feel free to contact me at the above number.

Artifact 8.2 - Teacher Referral

The above artifacts, 8.1, 8.2, and 8.3 which follows (on page 146), represent Bobby's referral to the School Support Team as completed by his Grade One teacher. Note the highlighted sections. These were emphasized by Lillian. She feared that her son was being portrayed as
a monster. The teacher observation that follows also portrays Bobby as a challenged child with some positive traits. Imagine, if you were the reader of this profile, what kind of image you would paint of this six year old child? The family felt horrified by this documented summary.

It [school in Grade One] was really stressful, it brought a lot of stress into the household. Even though we tried not to, in the beginning, we tried to keep it separate; we tried not to talk about it when the kids were awake...We tried to do all those things, but...we were getting phone calls at home, during the day, the kids were there, um...it was just awful and it became all consuming, that was a big reason why we moved to homeschooling, because the Scarborough Board of Education [before the move to Manitoba] basically was all consuming in our home and there was a lot of anger. We were very frustrated, ’cause we have two kids that – you’re trying to meet their needs, and you’re in a battle for both of them, so you just become very angry people. I mean, I’d walk on to the school property and I would prepare myself for battle and things seemed so angry, and I seemed just a product of whatever made this, this is what you made. Because every time I come here over little things, I have to be ready to defend my children and fight for every little extra bit of help that they need. The school system thinks that OK, they should be better at the end of the school year. They keep saying “well you’ve had, he’s had this support for the whole year, so to get that again, you have to...” fight all over again for that, so you are constantly in that mode, you’re constantly gathering information, educating yourself so that you can go in
and present to them, this is why my child needs this. My older son is in college now, and he still has learning disabilities, surprise, surprise. So it is just that constant, so it does, it takes over your home.

In Grade One, he would be running through the school because they would be chasing him, instead of backing off, they would be right in his face, and he would rage, he didn't like it, so he would run. I would come up and try to explain that if you handle it this way [calm and supportive], or if you do this [remain non-confrontational], – it's not that I was just talking and making this stuff up. I went to behaviour management workshops, and had access to a lot of different resources and went to courses, and they would say, yeah, yeah, yeah, then they would just escalate him again. So it was a lot of them saying it was just bad parenting, and it could have been a bit of that, but I don't think that was the whole thing with Bobby. He has a lot of neurology and them saying well yes you're right, he needs a different atmosphere, more help, but we are powerless. So having to start the IEP process and having to educate myself to know, OK, I have to put in a request and them not doing anything with it and constantly having to go up there and be on them saying that I need you to act on this, and finally getting the IEP. We did a formal presentation.
Artifact 8.3 - Teacher Observation

In Grade One, for our IEP we did these booklets up with Bobby's history [artifacts 8.4, 8.5 and 8.6] and everything was different we have had him tested for everything and we finally
got him extra help but it was in a different school. So here's a kid, now having to go on a bus, because of these behaviour issues and we kept saying all we are doing is setting him up for failure (taking the bus far from home). He should be able to go to his local school. I would get phone calls and they would complain about Bobby, and I would say OK well did you do this? NO!

Artifact 8.4 - Bobby in Kindergarten, Part of the booklet created by his parents to present his needs to the Central Identification Placement and Review Committee (CIPRC) June 11, 1996
Bobby was constantly getting ‘pink slips’ because he wouldn’t stay in his seat; he was talking when he wasn’t supposed to be and he was “tormenting” other kids. He did all the things that got him sent out of the regular classroom. In response to his “needs” he was placed out of his own school district and they put him on a bus and there wasn’t any tolerance at all for him being in special ed. The school bus ride was exhausting; he was finished before he started the day. There was an incident, one of many, where I got called to the school. This was a phone call from the principal “Bobby choked a child”. I had visions of him having this kid on the ground and his hands around this child’s neck, choking him. When
I got to the school what happened was...Bobby was trying to participate at recess and was playing a game, the kid was running with the ball and Bobby knew he was supposed to stop him, so he grabbed him by his hood and then you know sort of swung this kid around so, yes, he was choking him but not because he was angry. From the principal’s call I had visions that I had given birth to a madman.

When I went to the school the principal (a woman) sat Bobby and me on two tiny little kid’s chairs, the kind they use for Grade One or Grade Two, and she sat in a bigger chair and she lectured me with her finger going, telling me she doesn’t know what kind of child he is and she doesn’t know how I run my home. I just felt like the worst mother in the world. Bobby and I both cried all the way home, Bobby apologizing and me just crying saying oh it’s okay I still love you and we will talk later at home. But it was just a horrible experience. She said he was unkind and that he was out of control and to be honest it got to the point where I couldn’t even hear what she was saying; I was putting all my concentration into not crying. It was just the way she looked at him and the way she looked at me – with disgust. To her, obviously I didn’t have any rules in my home, she was just judging me.

I thought; lady, do you know how many doctors I’ve been to, how many parenting courses I’ve attended. I know this kid has issues but try and get help! Your special ed program is not helping him and all of a sudden they put the special education
class in this huge room with this other Grade One class and this is a kid who has been diagnosed with ADHD and he’s supposed to concentrate on his lessons when he can hear all this noise from the other twenty kids plus in his own classroom. This was not setting Bobby up for success. I did not feel this was special education. It was not about the student, but rather about the school budget and it was easier for the teachers.

In the spring of Grade One, Lillian and her husband made the decision to pull Bobby from school altogether (see artifact 8.8). When reflecting about this period in a recent conversation, Lillian told me that the school board threatened to call their legal department to force Bobby back into school to attend what Lillian felt was a programme that was not working for him altogether.

These threats and struggles with schools are common to home-education parents, the history of these experiences are well documented. Lillian and Eric (Bobby’s father) pushed back with similar legal threats, which seemed to work to keep the truant officer at bay. These were verbal threats from the same principal who had scolded them throughout the school year. It seems to me that the stress of the school failure, and the culmination of the phone calls and unhappiness on the part of Bobby lead Lillian and Eric to make this difficult decision to pull their son from public education.

These threats and struggles with schools is also common for families whose children suffer from neurological disorders. This causes a great deal of stress for the family and the child.
Artifact 8.6 - Bobby's History, Parent's Perspective, Part of the booklet created by his parents to present his needs to the Central Identification Placement and Review Committee (CIPRC) June 11, 1996

During Grade One, things were so bad, one time I got called up to the school because he was in the
principal's office hiding under the principal's couch, every day I was getting called up there and so I just said, you know it's almost the end of the year I can't handle this, this is ridiculous, this isn't healthy for him or me, [it's causing too much stress and pathology]. So I would just bundle up the school work and we did it at home. And he still didn't learn how to read. But, we did all the things we were told to do. His teacher was very nice and felt bad about him not being included in class activities. I would reassure her that this was better for everyone. Sometimes, I would bring him up to the school for recess and supervise him. This turned out to be successful. He could hold it together for about fifteen minutes.

On my way to my first meeting with Bobby for the purpose of this research project, I reflected on the year and a half Bobby had lived with us at the farm. This was an exciting and dramatic (see Chapter 10) time at Blooming Acres. We had expanded our community, and Bobby was an interesting addition to our home life. He was 14 years old at the time of his arrival at Blooming Acres. He brought enthusiasm, new problems and challenges, and most importantly his joyful sense of humour. With his emergent adolescence, and that of the other teenagers, our home became abuzz with teenage dilemmas, trials and tribulations.

Bobby and I met over the course of his summer holiday in 2006, and Bobby agreed to produce a written piece on his experience at the farm as part of this project. Bobby appeared confident and very relaxed during our conversations. He was open to sharing his feelings and thoughts about his life with neurology. Bobby's voice is represented by the symbol ∞, and is in italic font.
I met with Bobby at his home for our first meeting. We talked about school before he attended Blooming Acres and we explored his diagnosis and medication use. Specifically, I asked him to reflect on his early
memories and attendance at public school. Bobby was very candid and eager to share his story. At this juncture, Bobby was seventeen years old and in Grades 11/12. Despite the fact that I had woken him from his early afternoon teenage slumber Bobby welcomed me at his front door with a big hug and a friendly smile; he seemed excited to meet with me. This was the way he greeted most people he knew well.

Bobby and I sat and talked at the dining room table. During our meetings, I sensed, and was relieved by, his willingness to share. He was confident and articulate. At first I wondered how these conversations would flow but, to my relief, conversational questions opened him up and his experiences captivated me.

Tell me about Kindergarten and Grade One.

There was a lot of really annoying teachers and stuff in Grade One, I just remember them being like, they get all, getting really mad about really small things and stuff, just not really understanding at all. They weren’t really willing to not have things done their way; they had to always really think they were in power. Kindergarten went really well. My best friend was in it with me and I played with him all the time. I had a really good teacher and I didn’t really have any issues or anything. I was a little more hyper than the other kids but there was nothing [in kindergarten] to keep me from behaving.

In Grade One, that’s when all the math and stuff started, and I started realizing I had a reading problem and I started misbehaving a lot. The academic problems started and the kids
I hung out with were not really the best behaved. Then I was bussed to school for special ed to learn life skills and stuff. I liked socializing in school and I liked doing art and stuff. I was home schooled after Grade One because I didn’t know how to read and this friend of my Mom’s said she would teach me.

Why do you think your parents decided to home-school you?

Because the day was too long for me and I needed breaks. I was supposed to get them but I didn’t really. I didn’t like the teachers either. The kids would be bullies and stuff. Watching them be bullies pissed me off and stuff bothered me and the teachers didn’t really do anything. Their excuse was like, well, he has a rough home life. I was misbehaving and stuff and this was hard.

Tell me about this time you were home schooled.

I liked this time, but I missed my friends from school. This good teacher (Mom’s friend) didn’t get mad and was more understanding and patient with me. Like I just found she took more time to teach simple things. Like I didn’t know how to add or read and I didn’t have any clue how to add numbers in columns, no one really took the time to teach me, and she took the time to do that.

Bobby attended school off and on for part of the first term of Grade Two but his struggles continued and so, given the repeated stress and frustration, Lillian reported to me that she and Eric decided to pull him from school for longer periods of time during the 1997 and 1998 school years. I reviewed Bobby’s provincial report cards for this period
and noted that there was significant absence from school during the Grade Two, Three and Four years. Eventually, Bobby no longer attended school, and learned vis-à-vis home-school instruction. Bobby spent his mornings learning to read and eventually did gain this important skill with the help of Lillian and her friends. He did math work sheets, cooked, baked, engaged in crafts, went on field trips – all without the stress of public school failure.

By the time Bobby was eight years of age his issues were complex. His struggles at school, his behaviours, his tics, his attention difficulties, their family history of other sibling failures, and his parents’ need to fight the education system for school support, sent Bobby to a barrage of specialists who assessed and diagnosed him. These assessments supported the family in their quest for an appropriate educational placement and directed Bobby down a path of pathology.

Formally, Bobby got diagnosed [see Artifact 8.5] when he was in Grade One, the same time as his older brother, but the neurologist said that it was very unusual for a child at that age to even be coming to him. But it was because of his sibling’s history that he agreed to see him so young and because of the history in the family. I pushed it with my Bobby. I said look, this is in the family, and by that time Eric and I had diagnosed ourselves, and everybody in our family, and we just said, you know what, this is in the family.
Artifact 8.8 - Bobby's Grade One Report Card
You are talking about a whole spectrum of disorders that are in the family, like what?

I think ADHD and Tourette’s and OCD, I think those, and there’s probably more, but I think those are probably the main ones. Yes, and anxiety, but I think that sort of goes hand in hand with the ADHD and Tourette’s. For Eric (Bobby’s father), it was more difficult. And every time we went to a doctor, they would ask Eric if he had been diagnosed as a child and Eric would say, no, and I don’t need to be diagnosed as a child. I’m doing fine in my life. And I agree with him. But, I mean, I think for him it was more of a, I don’t want to use the word ego, but I think it is harder for some men to recognize and accept. The diagnosis was just an ongoing thing, and some of it was helpful so they could get help at school. That is a whole other issue. At the time, ADHD was not recognized as something that you could get extra help at school for, so learning disabilities was very vague. Um, they would put you in a reading recovery program. My kids are sort of a combination. You’re addressing the learning disabilities, you’re not going to see as much behaviour, but there are, there are still going to be some behaviour issues. And so my kids just sort of fell through the cracks, so the doctors gave them diagnoses both because they fit the profile and to help us get help. So the diagnoses sort of came along as he grew older and his behaviours became more profound, and then also to get services and support.
I think I pushed for some of the diagnoses to be honest. I think diagnoses are important to a point. I mean, I don't think a kid should walk around with this label on him and with these diagnoses, sometimes, I'm dealing with Bobby and the OCD, a more prominent issue, sometimes it's the anxiety, could be different issues each day, and so to me the diagnoses help me educate myself, so that I know what strategies to use, or what is happening and have a better understanding of him, but um, it's something that you're dealing with every day.

Thank you very much for your referral of (8). As you know, (X) comes from a family with a strong history of ADHD and Tic Disorders. He has been suffering from impulsivity, hyperactivity, Tourette and Obsessive compulsive symptoms. The rating scales confirm the diagnostic impressions.

Mental Status Examination disclosed features of restlessness. He did well in simple tests for ADD but failed when the complexity was increased to involve more than two dimensions and right-left differentiation. He was not clinically depressed. He was not actively suicidal or homicidal. He had tics and reported Obsessive compulsive symptoms.

Diagnostic Impressions:
1. Attention Deficit Hyperactivity Disorder, Combined Type
2. Tourette’s Disorder
3. Speech Disorder (Articulation Disorder)
4. Generalized Anxiety Disorder and Obsessive Compulsive Disorder


In the above artifact 8.9, the psychologist refers to a family history of ADHD and Tic Disorders. By this the physician is referencing Bobby’s siblings. Bobby’s father, Eric, also presents with motor tics.
I don’t think the school did well with all this. I mean I have a very low opinion of the public school system. So sometimes I think that I’m a little jaded when I say these things, but I don’t feel that they ever dealt with his diagnoses, or his issues. I think it’s a whole issue where they say you need to have a diagnosis for us to be able to do anything, so then you come with that diagnosis and then you bring it to them and then they don’t know what to do with it. I think part of it is that the teachers and principals were just not educated and when you’ve got a class of thirty and probably half of those kids have some type of neurological disorder, and they are feeding off of each other, you know it’s hard. And we have had teachers who, I think have been great for my kids, but then you have the other teachers that just don’t know, you know it’s like, well I presented the information, it’s their fault they didn’t learn it.

I had and still have problems paying attention in school and stuff. I have ADHD, Tourette Syndrome, and used to have ODD (Oppositional Defiant Disorder) I think, you’ll have to ask my mom about this, she could tell you — but I don’t think this is still an issue. I have certain facial tics and stuff. I would do one of my tics and the kids would think it was funny. Someone would make fun of me as a kid and I would punch the crap out of them, and get really angry and in trouble. I think with the ODD, I usually would just disagree with stuff just to piss people off and stuff. I don’t even remember being diagnosed. My older brother was going to the doctor for that and so my mom would take me. She would sort
of see some of this stuff in me. She took me to the doctor and he agreed with my mom. I take lots of medication to deal with attention and being hyper and to help my tics and stuff.

Lillian and Eric moved their family to Manitoba in the winter of 1998. Eric took on an important job as an airline executive and this gave the family the opportunity to venture away from their suburban Toronto life. They lived in a rural setting, a small town in the northern part of Manitoba. Lillian saw this opportunity as a fresh start for Bobby’s schooling as this was just when Bobby’s diagnosis was formalized. By the time they moved to Manitoba, Bobby was home schooled and had missed many days of school in grades one through three in Ontario. Lillian was impressed by the medical and school supports that existed to meet children’s needs in Manitoba. This move meant Lillian and Eric needed to begin advocacy for Bobby’s educational support in a new province.

Bobby continued to be home schooled by Lillian and Eric once they settled in Manitoba. Their local school provided some school assistance. However, Lillian told me that this quickly broke down too. In a document dated October 20, 1999, a pediatric psychiatrist provided evidence to the school to encourage this home tutoring and suggested that this home study continue until Bobby’s medication situation was resolved.

The Medical support in Manitoba, I would say it was better; even though we lived in a remote area, we had a pediatrician who we had access to, it seemed like, 24 hours a day. It was easier to get appointments, we had a whole team.
We were working with a team, not just the pediatrician. We had a mental health worker who came into our home, who went into the school and worked with the staff and Bobby and myself. That I think was great. That’s because she did get to see some of the issues, and she was more of an advocate for Bobby. I didn’t have to do as much of that as I did in the beginning when we first moved there. He was granted an educational assistant the last year and a half and because we lived in Thompson, we could fly down to Winnipeg; we had access to the Tourette’s Clinic.

So you felt like you were getting a lot of support.

How did Bobby do with all this support?

In the beginning he was doing great we had a really good special education teacher, and then something was different [it all fell apart and become a stress again]. There were many different EAs (educational assistants) [over a short period], the special education teacher was tied up with orientating the revolving EAs and as such the teachers did not do as much one on one with the kids. The day to day immediate classroom support combined with the new EAs become a struggle and they’d never seen anybody like Bobby before.

There was a different feeling between school in Ontario and school in Thompson. School wasn’t really successful for me there. I had a lot of problems, kicking and stuff, and it’s because the teachers warned all the other kids that there was this crazy guy coming to the school. I think they thought this
kid is just kinda, like, nuts. So don’t force him, and in sports don’t give him pats on the back because he’ll just flip out. So I came to the school and the kids said to me that they heard that I don’t like sports and pats on the back. My brother’s friends told him that his brother was that crazy kid. They didn’t even know me or anything about me. In a messed up way I think they wanted to help. I was home schooled through the school. My EA came to my house to do my academics with me; he brought this work from my teacher. I would go to school like one day a week, and then I’d work from home with my EA; I liked that. Then they had to have me integrated back in, which was a mistake. I needed all this support for comfort maybe, I could take these breaks-breathers. It’s like if you’re at work and you get a coffee break, so these breaks from school made me feel better. There was a lot of pressure at school. I would just get upset from all the pressure. At school I couldn’t just relax. There were so many rules to follow and stuff. I’d get like an anxious feeling. When I was tutored that feeling wasn’t really there.

He would get very anxious and he would start talking about the situation and it’s not really how something would have happened, and then he brought in things from the past and was just very unreasonable. Screaming, yelling, just being in somebody’s face. He would be stuck, yeah, it could go on for days, I would think that it was over, I would think that he was calm, and then it would just start all over again. When we were in Thompson, a big thing that was happening was I would pick him up after school. As soon as I was at that door,
he would jump in the truck, and the door closed, he would just start, “You know what they f’ing did?” Like it was just yelling at me, “you said this”…and you know all I had done was be kind, and pick him up in the 40 below weather but I knew what it was, that he had held everything in all day. He wanted to be successful at school, not that he didn’t still have these feelings, or not coping, he just saved it all up, and so as soon as he got with me, he felt safe and he would just let it go. And then I stopped getting him, I thought, I was working at Giant Tiger, which was three blocks away, well, that’s reasonable, he can walk, get some exercise and maybe work some of that off. By the time he got to me, he would come into the store, he was oblivious that he was in a public place, as soon as he saw me, it was like, I was that safety net, it would just flow.

At first, school in Manitoba was more successful for Bobby than his experiences in Ontario. According to Lillian, this was because of his teacher and, mostly, the EA who was assigned to work with him. Upon review of the journals kept by Lillian, Bobby had successful days and an equal amount of down days. He functioned well at times and completed work, and at other times it was a struggle to keep him focused and on task. According to Lillian, the years in Manitoba went by this way and in 2003, Lillian moved back to Ontario to school Bobby with us at Blooming Acres. This was a response to a change in Eric’s employment and, mostly, a need to find an alternative way to educate her son.

There was lots of medication over the years especially in Manitoba. When we came back to Ontario, our
Ontario doctor said that he (Bobby) was basically stoned, and that was because the school couldn’t cope and the doctor there would say well, let’s try this, we’ll add this, we’ll try this, I mean he, just, they were still having issues, you know. At Blooming Acres, which was a sacred [positive, knowledgeable and supportive] environment for him, that’s when we started cutting back on all the medications. I think ‘cause he was in the wrong environment, he would get more of the anxiety, like he was depressed, he was, we saw more anxiety, so we thought you just start medicating, but unless you change the environment, there’s not enough medication, I don’t think in the world, to help these kids. The environment has to be changed.

Bobby joined Blooming Acres in the fall of 2003. His enthusiasm was a welcome addition to our growing community. His eagerness to participate in our programme energized our home-school. He moved into a room that was fashioned specifically for him. We renovated our unfinished basement for Bobby and Lillian. He knew some of the other learners who returned for the school year and was joined by a few new faces. Our little community grew from three full time learners at year one, to five full time kids and several part-time guests at year two, and to nine full time kids in the fall of 2003. Our routine was well established and Bobby quickly became fully integrated into farm life and the home-education community.

Bobby’s schedule and our approach to his learning were similar to that of Adam and the others. His time with us was full of exciting and interesting adventures, along with our routine of three weekly visits to the local YMCA, outdoor adventures like snow shoeing and skiing, care
of the farm animals, cooking, baking, various experimentation, and all
the other recreational, life skill and social skill activities that Blooming
Acres offered. He also had some structured academics to meet his
particular needs as expressed by his parents, and in conjunction with
his desires. We adapted a math curriculum for him and called upon our
resident cognitive behaviour therapist to help him with some mood
and anxiety issues. But, for the most part, Bobby was free to explore
and learn at his own pace, with his own desires and interests to guide
his journey. The transformation was remarkable. We gave him space,
respect, and time to unfold and de-school from his stressful years in
Manitoba and before.

**Bobby’s Journal: September 7, 2003**

*Bobby’s Mom is part of his home education. With this
arrangement we get to support Mom too. He will be treated
like any other student. The family will live in the basement.
This year is about unwinding. Sometimes he needs sleep
during the day, like 10am to 1pm. Bobby still sleeps at night.
Caution, Bobby still overloads easily. Too much input of any
kind is hard for him. Some goals for Bobby are Cognitive
Behaviour Therapy (CBT): he gets stuck easily and does have
social problems. The CBT therapist will give us strategies that
Bobby will communicate with us. Work on reading, writing
and de-schooling.*

**Bobby’s Journal: October 20, 2003**

*Bobby is doing very well, he is impressive. He is now going
through a medication change. Currently he has a three second
attention span. Bobby has become very productive. He looks*
after our horse Daisy and plays the guitar. He is able to function well after 3pm which is a big change. Recently he hung in for drama activities long after he didn’t like them. We think he should get into kick boxing.  

*Artifact 8.10 - Bobby at Pottery (H. Bloom)*

**Bobby’s Journal: February 12, 2004**

Bobby is doing awesome. We can give him more choice in his academic work. His parents want more of our home-school approach at this point. This approach is about being open to where the child is and more when the time is right. Bobby is

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7 This was suggested so that Bobby could expel his high energy and aggression in a safe and productive manner.

8 Bobby’s father was concerned about curriculum but changed his mind early on in the school year and recognized the need for an unschooled approach.
successful here, in part because his mother is here with us. His important learning is not getting stuck.

**Bobby’s Journal: March 1, 2004**

Bobby is happier and has more energy. He knows that he cannot use his martial arts on anyone. He is still very tired, that is part of being a teen, combined with his meds and his neurology. Eric will spend Wednesday here with us more often. Overall Bobby is doing great!
documentation of his day to day routines and progress are limited. However, these experiences are expressed in part by Bobby himself. I invited Bobby to share his experience of Blooming Acres in any way he felt comfortable. To relieve him of any perceived pressure, and so not to influence his perspective with my presence during our conversational interviews, I suggested he could draw a picture, write a poem, or write a personal reflection. I received this email from Bobby and end this chapter with his words. To me Bobby’s words describe what it is like to live and learn with neurological pathology. The subject heading of Bobby’s email was “farming for outcasts” – very telling!

My time at Blooming Acres began when I was fourteen years old. It began as just an idea of a place that I could go to as a second chance or maybe a place for me to just start over. When I walked in I felt an almost forgotten sense of welcome. The staff that were there were all excited to meet me as I was as well, but was feeling lost in the sense of not remembering how it felt to be at school and having people want me to be there. I was still angry and very upset with my experience that I had at the Manitoba School Board, and Blooming Acres was a place that I could go to in order to heal and forget all the things that I could not let go. It would take a long time and a lot of emotional and physical venting. My first day there a staff member talked to me about guitar and other interests that we shared. He was very nice to me, which I found very unusual because a teacher had not treated me as an equal in a long time, but I didn’t block it because it felt good for someone to be kind to me based on the fact that
they wanted to be kind to someone (imagine that). Within my first week [at Blooming Acres] I was physically restrained three times and was angry and hated everyone and everything around me. I remember a staff [member] who I favoured over most, removing me to my room where he made me sit for a couple of hours and talk to him and just vent....

It sounds odd maybe even bad to make someone sit in a room and talk to them but I was a walking wrecking ball and this person was willing to deal with that just to help me. We sat there for hours while I screamed and swore while he just listened. My screams eventually turned into a regular voice that hadn't been heard in a long time, and my swears and curses turned into regular words that I didn't know I could use while I was upset. When the battle was over and I finally let my guard down, things began to run a little smoother. Every day I recovered a little bit more and the staff were patient and on the days that I reverted back to an angry stuck kid, the staff would support me and help me get through with every difficulty I was having; and then when I was done we would work it out and talk it through as equals and start from where we left off, and would forget about the incident, issue or even the restraint.

I found it amazing how I would be so violent and so offensive in restraints and these people would always be willing to care about me and move on with me. I guess they could see a bit more in me than the school teachers before them did. As my time there grew I began to learn many skills in controlling my
temper and how to treat people the way they should be treated. It became evident to me that there was no problem with me and I could relearn what I had learned. There were nine of us kids in total with all different issues ranging from Dyslexia to Asperger’s to Autism to Tourette’s to Social Phobia to ADHD and OCD. We were all so very different but we had one thing in common: we were all outcasts and just needed to be part of something that wanted [us] and would not eliminate them like some tacky reality show, because of a difference of opinion or one single Fuck Up.

Artifact 8.12 - Bobby Age 15, At Blooming Acres (H. Bloom)

Blooming Acres was invaded by a bunch of suits [see Chapter 10] with little to no right to walk in and take a bunch of files
based on people they didn't bother taking the time to get to know in person. With no warning or sense of boundaries they completely changed what we had known as our home and had truly loved for a short period in our lives. It was like someone coming to a child's house and saying you can't live here with your brothers and sisters and mom and dad, and giving only one reason “Because I Said So”.

It was sad for every one of us but we had been given the skills and taught the patience and found the guts at Blooming Acres to be able to take that kind of bullshit and leave with our heads up high, and move on and face the world that had been waiting for us. Even though Blooming Acres was short lived for many of us and we had to leave, it was around in this form long enough to save the lives of a bunch of Weirdoes, Rembrandts and Outcasts that just needed time to heal. The learners and staff have all since moved on to different walks of life and rarely see each other anymore, but on occasion we do and we always have an odd sense of a dysfunctional family... gee, is there any better kind of family? By: Bobby
Chapter 9
Analysis of Emergent Themes

My explorations of the life histories of Adam and Bobby, in light of their involvement and learning at Blooming Acres, shed light on what it is like to live and learn with neurological conditions. This research was informed by a life history perspective. As such, it included the stories of the learners who participated but also considered and gave accent to the important contexts in which these lives were lived. I have been mindful to “keep true” to this research approach by engaging this work with authenticity and rigor. This realization is an intrinsic expression of my analysis of the vast data, documents and artifacts that all informed this project. I derived a sense of meaning from what I believe to be significant themes that are echoed in each of the storied lives I explored. I arrived at this sense of meaning through the conduit of both surface and deep analysis, contemplation, and internal dialogue. Also, through active engagement of the various interview voices and artifacts that stood out to me as important, or that were pointed out as such by those involved in this research. These significant themes shape the context of the lived experiences of the participants in this study.

Throughout the research process I highlighted emergent themes on corners of transcripts, sticky notes, bits of paper and then on display charts. This analysis of possible themes was constant, from the moment this work began. I explored these themes in dialogue with my wife,
Sherri-Ann, myself, and with many others who would listen to my ideas. I then found commonality. Initially these themes emerged during the analysis of Adam's work but were then repeated in Bobby's narrative. The result of this deep analysis and perpetual brainstorming was the emergence of numerous subthemes that are common threads in both stories. I have organized these subthemes into quadrants – categories that seem to make sense.

Firstly, there exists a commonality of contexts in both stories that relate to learning issues, referral, assessment, diagnosis, medications and school battles. These subthemes converge into a major theme that I have entitled *Pathology for Support / Support for Pathology*. Secondly, both stories express universal circumstances of behavioural issues, judgment, stressful calls from teachers and principals and, ultimately, school failure. I have organized these subthemes into what I call *Parent Stress*. The third major theme that I have identified is *Oasis Teachers and Mentors*, which is an expression (in these two stories) of the context of Blooming Acres and includes subthemes of care, support, social competence, self-esteem and relationship. And finally, I have identified *Strengths and Coping*, which is a culmination of subthemes such as advocacy for support, strategies for success, identifying and coping with stress, understanding diagnosis and becoming well.

As this analysis work was completed it became clear to me that these four themes and their related subthemes were all interconnected. As I organized the four major themes and penciled these thoughts on paper to try to create a diagram or a metaphor that would clearly organize understand and concretize my ideas, what finally emerged was the depiction in Illustration 9.1. This brainstorm led to an epiphany. I
drew a line down the middle of my visual analysis and what stood out to me was an overarching motif, the concept of risk and resilience.

**Illustration 9.1 - Concept Map**

The four major themes: *Pathology for Support / Support for Pathology, Parent Stress, Oasis Teachers / Mentors* and *Strengths and Coping* will guide the meaning making that is expressed in this analysis chapter. This section explores these emergent themes as they are articulated within the context of neurology and school failure (risk) and the context of transformation and getting well (resilience). These themes
are my idiom of the storied lives of Adam and Bobby and their journey in the context of living and learning with neurological conditions.

Risk and resiliency are terms that have emerged as a result of the study of vulnerable and at risk children and youth who have defied expected outcomes and have not succumbed to risk factors (Garmezy & Rutter, 1983). For the past fifty years researchers, educators and practitioners have explored how children and adolescents ‘make it’ when their development is threatened by risk. Michael Ungar, a leading qualitative researcher in the area of risk and resilience, notes in *Nurturing Hidden Resiliency in Troubled Youth* (2004), that ‘risk’ and ‘resiliency’ are two elements of the same phenomenon. Resiliency is not present or, perhaps more accurately, is not recognized or observable and named unless it is viewed in conjunction with risk or vulnerability. Ungar defines risk and resiliency as positive adjustment in the face of significant adversity, or an individual’s ability to overcome adversity and continue his or her normal development. Historically, the concept of risk and resiliency was explored through a medical lens or with victims of severe trauma or war but recently the term has been adopted to explore other factors that place children and youth at risk or make them vulnerable to negative emotional and psychological outcomes.

Despite the adversity described in the lives of Bobby and Adam, despite the risks, both youth emerged resilient. Their stories of risk are important but, more significant, is the context for transformation and getting well and how they emerged resilient. What were the conditions that fostered this change? What were the contexts that supported the successful transformation of the lives of these two learners? What can I learn from these contexts to inform my practice as an educator and
guide my future research endeavors? This is where my research project has led me.

**The Risk Side**

*Pathology for Support/Support for Pathology*

In her work, *Risk, Resiliency and Academic Outcomes in the Context of One Individual’s Life: A Self-Study*, leading child and youth worker educator, Kathleen Cameron (2008), explored Ungar’s current research on risk and resiliency and begins with Blundo’s (2001) and Margolin’s (1997) premise that:

Resiliency is a social construct based on the mental health system’s desire to have a “codified system of assessment and categorization in which professionals have become powerful advocates for particular visions of social order” (Ungar, 2004, p. 4). As more and more young people are slipped neatly into these well-defined boxes, the meaning they construct for their behaviour and the context in which it takes place is overlooked. There is research that supports that mental health can be enhanced by what are referred to as “delinquent behaviours” (Ungar & Teram, 2000, p. 229). Youth will exhibit behaviours that are contrary to the expectations and tolerance of the dominant culture. It is then possible that there is a payoff for that behaviour, and that the behaviour could have a greater, more desirable effect on the youth than would choosing the conforming acceptable behaviour. However, most adults in positions
of authority, such as teachers, are unable to conceive that ultimately the negative, and usually antisocial behaviour can in fact be the best means by which the youth can find a level of well-being. (Cameron 2008, p. 16)

Both Adam and Bobby suffered a great deal of risk associated with school. Their neurological conditions became apparent when learning issues arose and disruptive behaviour became prevalent. For both youths, this manifestation occurred during the transition from Kindergarten to Grade Two. According to diagnostic criteria, this emergence of behaviour problems at this age and development stage is common.

Cameron (2008, p. 12) points out:

In *Playing At Being Bad, The Hidden Resilience of Troubled Youth*, Ungar notes, “The deeply troubled youth whom I meet through my work tell me they play at being bad because that is the simplest way to feel good…” (Ungar, 2002, p. 10).

Ungar’s work with at risk children and youth has revealed three primary reasons why youth choose to participate in risky and deviant behaviour: the behaviour is the best coping mechanism they have at their disposal to deal with recent trauma and resulting pain; those youth don’t have socially acceptable ways available to them to more positively cope with emotional pain and trauma; and even children with no obvious or intense dysfunction occurring in their lives may choose deviant behaviour in
response to disempowerment, lack of opportunity to make choices about their lives, and expectations that they will desire the order, sameness, stability and status of their “normal” lives. From an educational point of view, the classroom is where poor academic ability, performance and social marginalization can begin to place young people at risk for poor academic outcomes and potentially poor social outcomes… we must refer to Ungar’s work, which critically examines poor academic performance and negative behaviours. While creating a negative outcome in the classroom, those so-called negative behaviours are in fact having a positive effect on the children or youth in other, potentially more important aspects of their lives. In essence, behaviour presenting as a problematic in the classroom might be contributing to the health and well being of that individual. It must also be emphasized that over the course of a lifetime, the classroom may prove to be the least hospitable environment to foster some forms of resilience. Some behaviours, while non-conforming and unwelcome in the classroom, may be the manifestation of a child or youth’s resilience.

From my perspective Ungar’s and Cameron’s theories apply to the life stories of Adam and Bobby. The struggles or risk experienced by both boys may be expressions of what Ungar suggests regarding so-called negative behaviours having a so-called positive effect. Within the context of school failure and neurology, neurological challenges became the catalyst for access to school support. These two children’s increased
expressions of risk eventually forced their school systems to provide them with the extra help, extra time, and necessary accommodation and understanding they required, although this was too little too late. The profound growth of these expressions of risk in the form of neurological conditions continued and became more prevalent until they reached the turning point for both children – of being pulled from school and immersed in the context of Blooming Acres. In the face of identified learning issues, referrals to doctors and specialists, assessments, medical diagnosis and medications, came the support these children needed as expressed in their behaviour. In other words, there needed to be Pathology in order to access Support. The school system, once backed into a corner by an artillery of this pathology, offered Support for this Pathology. In essence, expressions of childhood disruptive and maladaptive behaviors, or the context of school failure, may become incrementally debilitating, and children need to become more out of control until this behaviour becomes so serious that parents, such as Joy and Lillian, are forced to seek out medical diagnosis as evidence of the struggle before help for their children ensues willingly and productively.

Furthermore, it seems that once this cycle of medical diagnosis becomes intrinsically linked to school support, then the diagnosis process can become more exaggerated. Parents begin to amplify pathology to arm themselves with the evidence they require to gain access to institutional supports, and medical professionals begin to oblige. Lillian expressed this idea to me in a conversation about Bobby’s diagnosis. She suggested that this was an unspoken underground issue. Joy too, expressed her need to convince her doctors to assign certain labels to Adam so that
she had proof to convince the school of the medical need of support and special funding, and of course to have some understanding of her child’s behaviours. This is a waste of resources and time. What seems more logical is to assess the individual behavioural and learning needs from the onset and to meet these needs with skills and support head on.

Given that many school systems offer little support in the form of behavioural accommodations, extra educational assistance and flexibility for neuro-typical children, or even in the face of diagnosis, of prevalent conditions such as Attention Deficit Disorder (although there is now a better understanding of the disorder and intervention strategies), it is no wonder that these children’s behaviour (or others) become so aberrant until they receive the support which they require. Adam’s and Bobby’s behaviours and conditions needed to be pathologized as Obsessive Compulsive Disorder, Oppositional Defiant Disorder, Tourette Syndrome, Anxiety, Bi-Polar Disorders and finally Asperger Syndrome so that they could access support. Then, once this support failed, they needed these diagnoses to make the case for school withdrawal and residential placement.

Other researchers have also talked about this phenomenon of over identification to receive support. In Chambres, Auxiette, Vansingle, and Gil (2008), Adult Attitudes Toward Behaviors of a Six-Year-Old Boy with Autism, a child with a disability was perceived more positively when identified as having autism. However, this effect was dependent on the type of behavior and the evaluative dimension used. The results indicated that the mere fact of being informed of a
child’s disability triggered the use of a different standard of comparison than that employed to evaluate typical children.

Loiacono and Allen (2008), in Are Special Education Teachers Prepared to Teach the Increasing Number of Students Diagnosed with Autism?, offer an evaluation of data over a five year period (2002-2007) from eighteen school districts in the Western Suffolk region of Great Britain. These data indicate, as do many other statistics, that the number of students classified with autism increased in this region, going from 218 in 2002 to 687 in 2007. This represents an increase of students with autism collectively by 212 percent over the five year period. As the authors examined the increase by district they noted that each of the eighteen districts increased in numbers and that the increase ranged from 33 percent to 560 percent during the five year period. The authors concluded that the numbers appear to support the research cited earlier stating that the prevalence of autism appears to be increasing by 10 percent to 17 percent annually. The authors hypothesize that one reason for this increase may be due to the exemplary reputation of many of the eighteen districts relative to their educational offerings for students with disabilities. They suggest that while a specific number is unavailable, one might ask how many families of children with autism relocated to this region, by district, because of the superlative educational programs for children diagnosed with autism. The authors go on to state that although this factor alone would not explain the significant increase in numbers of children with autism over the five year period (2002-2007), it may be a reason. I suggest, also, that because this school district offers such exemplary support for autism, parents have accessed
this support through autism diagnosis or Pathology for Support/Support for Pathology. This theme needs further research.

Safran (2001) discusses this Pathology for Support/Support for Pathology theme and states that the education of students with Asperger Syndrome (AS) presents new, yet familiar, challenges to special education. For decades, many professionals have been justifiably wary of new “bandwagon” milder disabilities (such as, LD, ADHD), fearing an explosion of referrals and required supports, thereby stretching already thin resources. There will be skepticism voiced over the validity of the AS diagnosis and concerns about potential over identification, mirroring the debate in the psychiatric and mental health fields (Szatmari, 1998; Volkmar & Klin, 1998).

There has been considerable interest in educational research in the area of fairness and the inclusion of special needs children and youth. This theme has often come up in my in-service work with educators. Researchers have explored the concept and fairness of the provision of special services. Two guiding areas of thought that often arise are needs-based principle programme provision versus a principle of equality. If Johnny gets extra help, why can’t Billy? In a study about conceptions of fairness in inclusion classrooms, Weibe-Barry (2008) uses a definition of fairness as the belief that it is morally wrong, in itself, to treat individuals differently without providing relevant reasons for doing so and the author concludes that teacher education students need to move towards acceptance of needs-based principles of fairness for the provision and acceptance of adaptations of special education instructional services. Given this emphasis on needs-based fairness, which seems to be the prevalent principle of service provision from
elementary school through to post secondary education, it seems that the notion of Pathology for Support / Support for Pathology that has emerged in this life history has merit. Within this train of thought, it appears that without a strong case for support in the form of pathology, learners with unique styles, differences, and/or behavioural issues would not receive adaptations and accommodations, as this would be considered as being treated unequally. But, in the face of some form of pathology, this would be considered a need. I recently toured the student services section of the local college that I now teach within as part of a new faculty orientation. The special services experts demonstrated sophisticated software, technology, and accommodation tools that are accessed by “special education” identified learners who have been assessed as having some form of pathology. When I asked whether or not these exceptional tools could be available to any learner at the college who might benefit, I was told “No”, that there needed to be an identified “need” or it would put the unidentified learner at an unfair advantage and would tax the student services department. Why does there need to be Pathology for Support / Support for Pathology? Is it any wonder that parents must struggle and claw their way through diagnosis to get support?

**Parent Stress**

The context of neurology and the context of school failure bring about the theme of Parent Stress. In the face of severe and complex behavioural issues, judgment, calls from principals and teachers and ultimately school failure, Parent Stress becomes a pivotal context or risk factor. Both Joy and Lillian talked about the stress associated with the behavioural and psychosocial issues of their children’s education.
Ultimately it was this stress, which is interconnected to the concept of *Pathology for Support / Support for Pathology* (see Illustration 9.1), that led to their access of school supports and then, in due course, to the breakdown of conventional educational participation. This stress led to their decision to home-educate their children and as this continued, led both to decide to enroll their children at Blooming Acres.

The concept of parent stress in correlation with childhood pathology or disabilities is not a new or an innovative idea. There are numerous studies, in fact hundreds, both qualitative and quantitative, that support the notion that disorders such as ADHD, or Tourette Syndrome, and, in particular, the co-morbid conditions of Bobby’s and Adam’s diagnostic profiles, elevate parent stress (Sukhodolsky 2003; Wilkinson, Marshall, & Curtwright 2001). In addition to these studies, I conducted a database search using a well recognized academic electronic database with the key words “stress, disabilities and parent” and I found a total of 465 related and relevant bodies of research that support, highlight and emphasize this phenomenon. However what is interesting and relevant for my research is the notion that, viewed through the lens of risk and resiliency, *Parent Stress* becomes one of the mechanisms to cope with adversity and obtain necessary support and in fact becomes a primary catalyst to becoming well.

Much writing about family resilience has drawn on *stress-coping-support* theory, especially, in relation to families. Stress is divided into the source of difficulty (the stressor) and its impact (strain). It is argued that the adaptation to one stressor or crisis affects how families react to subsequent stressors. Unresolved strains from previous crises or an earlier stage of the current one can come to the surface and hamper efforts at
coping (McCubbin, Thompson & McCubbin 1996; Schofield 2001). However, there is a large separate literature on coping, for instance, distinguishing coping styles, that focuses on problem solving or dealing with the emotional impact of stress (Lazarus & Folkman, 1984). A key coping strategy within resilience approaches involves reframing and altering perceptions in a positive direction by seeing adversity as a challenge and opportunity (Walsh, 1998; Newman, 2004).

The themes that emerged from the storied lives of Adam and Bobby, in particular, the Parent Stress elicit a clear thread that extends between the two children. This stress was described in detail by both Lillian and Joy during our conversational interviews. It appears that Parent Stress, may be viewed as a coping strategy within the resilience framework in terms of utilizing stress in a positive direction to access support and become resilient. In the context of neurology and school failure, Pathology for Support / Support for Pathology and Parent Stress become mechanisms of change that move the child, or in this case both Adam and Bobby, from risk to resilience.

**The Resilience Side**

Resilience is an individual’s capacity to navigate health resources and a condition of the individual’s family, community and culture to provide those resources in culturally meaningful ways. It is the interaction between young people’s vulnerabilities, personal strengths, nurturing relationships, and access to resources and how these components can combine to foster resilience (Ungar, 2004).
In the context of Adam and Bobby resilience is expressed in the context of transformation and the context of getting well. The factors that put the two youth at risk then became vehicles for them to access the support they and their families needed to become resilient. In spite of all the adversity faced by both children they were able to get well. It was because of the complexity of the neurological conditions that each boy faced, and the stress that accompanied these conditions, that they were able to navigate health resources. In these cases, it was the pathology and stress that brought about the support that each youth required to get well. In addition, each learner’s family, and eventually the community, supported them in meaningful ways. First they were supported by friends and support groups to access diagnosis. Then with the diagnosis, they began to receive support at school. And when this broke down they received more support which eventually led to Blooming Acres. In combination, vulnerabilities, personal desires, and interests all collaborated and led to the context of getting well. Relationships also served as conduits in these stories and are key aspects for both Adam and Bobby to move from risk to the context of transformation and getting well. Two important themes within these contexts warrant some discussion.

**Oasis Teachers and Mentors**

Once again I turn to Cameron (2008) who, in her thesis, coined the term “Oasis Teachers”. With her permission I borrowed the term Oasis as the third theme in this analysis. Cameron (p. 2) states that Benard (1997) discussed the possibility that we can all be “turnaround” teachers and that there are ways that a teacher can “tip the scale from risk to resilience”. Cameron states that, in her educational life she
referred to “oasis” teachers who, while not necessarily turning her life around, certainly gave her a safe, restorative place to be for a period of time. She believes it is possible for a teacher to have a profound effect on a child, both positively and negatively. Benard (1997, 2004) lists resilience skills as being the ability to form relationships (social competence), to problem-solve (metacognition), to develop a sense of identity (autonomy), and to plan and hope (a sense of purpose and future).

Gilligan (1997, 2001), Rutter (1999), Shapiro and Levendosky (1999), and Benard (2004) agree that malleable intrinsic factors such as emotional security and attachment style, self-esteem (valuation of self), self-belief (confidence of being effective), self-efficacy (understanding of one’s strengths and limits), social competence, autonomy (also known as internal locus of control), capacity for problem solving, sense of purpose and future (including religious faith), planful competence (having clear goals and an organized strategy for achieving them), and humour are important to resiliency development. Each of these is, in principle, amenable to change by parents and others. Warm, sensitive and supportive care by parents or others has been found to be critically important for the generation of most of these qualities, especially those to do with security, confidence and trust in others are also important (Howe, 1995; Werner & Smith, 1992, 2001).

I believe, as do their parents and the youth themselves (although I acknowledge my subjectivities), that Blooming Acres (and the adults therein) was an important context for both Adam and Bobby and served as an oasis or turnaround for both these youth. This is based on my analysis of both stories and the interviews, in combination
with my deep understanding of our community and its philosophy. In juxtaposition with the risk and resilience literature Blooming Acres seemed to possess all the intrinsic conditions, with its emphasis (and these are expressed as subthemes of the *Oasis Teachers and Mentors*) on care, support, social competence, self esteem and relationships, to be the tipping point for both youth. If I compare the conditions expressed above in the risk and resilience literature, to the foundations and pedagogy of the community, there is a clear thread that links these factors to what took place for each youth during their transformative learning experience.

The context of emotional security and attachment style was accomplished with care, respect and love. Both children’s stories spoke of this condition as an important piece of their successful navigation to resilience. Joy talked about her observations of relationships and her trust as pivotal to Adam’s success and so too did Lillian and Bobby himself. For me, right from the onset, one of the paramount philosophies of the Blooming Acres community is attention to relationships. I have always believed that it was the relationships that we as teachers and educators formed with our learners, based on respect, care, dignity and healthy boundaries, that would lead to successful learning and growth. Both children had a strong sense of attachment with their own families, which made this condition even easier to accomplish. It was these relationships that allowed for the trust to ensue that served as an important factor in the transformation and context of getting well. This trust was necessary for everything that took place, including the social, recreational and cognitive work.
The growth and development of self-esteem (valuation of self), self-belief (confidence of being effective), and self-efficacy (understanding of one's strengths and limits), were also significant factors that I see as present within the context of transformation for the two at Blooming Acres. As Adam and Bobby progressed in their learning at the farm, there was a gradual and very noticeable enhancement in these important domains in both boys. Adam's narrative shouts with his incremental expressions of confidence and self esteem. Each new activity, each new experience, each new accomplishment built up his confidence and in turn lead to his emergence as someone who was resilient and getting well. Bobby expressed this theme in his personal reflection. So too did Lillian and Joy in our conversations.

The nature of living and learning in community fosters the development of social competence. Adam arrived an awkward and hurt boy who was unable to read the cues and needs of others, or himself. He often missed the nuances of social engagement that are so vital to socially acceptable human interaction. These oddities hurt Adam in troubled situations outside of our community. However, with thoughtful, sensitive, and planned and impromptu social skill development, and a great deal of freedom and democracy, Adam was able to make significant gains in his social competence. A. S. Neill’s (1992) Summerhill experience speaks to this phenomenon of profound change. This was one of Adam’s most valuable learning outcomes, and the one that took him the longest to achieve. In year two of his time at the farm Adam chose to attend the local high school, mostly to have the opportunity to socialize with youth his own age. He expressed the desire to ‘try out’ his newfound skills and wellness and, while we all knew that it was very challenging
for him, we supported his desire. He stuck it out and finished the school year, earning two full credits. This experience was important for Adam as it challenged him to navigate in the high school setting and also motivated him to make the changes in himself that were necessary to become resilient. Bobby, too, required and achieved this sense of social competence as he learned to live and learn in community without the need for rage and aggression.

The very nature of the Blooming Acres community and the learner centred approach fosters autonomy or internal locus of control. Individual needs, goals and outcomes, as expressed by the community, family, and most importantly, the learner, enhance this concept. Both Adam and Bobby were offered the opportunity to conceive of and live their own education. This autonomy and the significant outcomes that were results of this philosophy played an important part in getting well. Their own desires, interests and self expressions became the catalysts of change, as opposed to their pathology and stress. In time Adam and Bobby, and all the others that came after them, learned to express themselves in ways that didn't require illness or risk. Rather, they drove their own learning and growth with expressions of health and being well. There came a pivotal point in their time at Blooming Acres where this transformation moved from the context of neurology to the context of wellness and self determination. In this framework each boy forged a capacity for problem solving and a sense of purpose and future. Each learner began planful competence (having clear goals and an organized strategy for achieving them).
**Strengths and Coping**

An important theme that must be included, which is clearly expressed in both Adam and Bobby’s lives, is *Strengths and Coping*. Both Joy and Lillian expressed this theme in our conversations, and this presence in both narratives warrants inclusion in this analysis. I believe that it is this theme, with its subthemes of advocacy for support, strategies for success, identifying and coping with stress and understanding diagnosis (and maturation), that was the most important factor that lead to the context of transformations and ultimately advanced the context of getting well for both Adam and Bobby. Parents are a powerful element to all this change.

These subthemes, like all of the others mentioned, are interconnected. However, it is this theme that leads to them all. It is *Strengths and Coping* in spite of adversity that drove Lillian and Joy to move from a place of risk to a place of resilience. Both stories have a common strand where fierce strength and an uncanny ability to cope with adversity led to support. Both Joy and Lillian became, out of necessity, advocates for support for their children. Their children’s struggles and failure in school mobilized these parents to learn everything they needed to cope with neurology and stress and eventually led them to connect with strong advocates and support networks. This advocacy turned into a sense of purpose for both mothers and motivated them to become involved with the agencies that became supportive to them. This involvement became a strategy for success in itself. Parent groups, advocacy groups, workshops, networking at conferences, and joining local boards, advisory committees and lobbying all formed the pieces
that began to immerse these parents into their children’s pathology and in turn helped them access the support they needed to help them cope.

One of the significant aspects of living and learning with neurological conditions is the stress experienced. One theme that seems to be consistent in both stories is each family’s capacity to identify and cope with this stress. Before significant help and support came, and even in the face of this support, it was clear to me that both Joy and Lillian were able to take stock of the significant stresses they were faced with, identify what were those stressors were and how they impacted on their families, and then cope with the stress while they navigated to health resources.

Say there was a family dinner, and my guys don’t do well in the evening or when there were going to be too many people, a lot of times we would arrive early and then we would leave early. It wasn’t like we said go and play in the basement, and we left our kids unsupervised. So we really always tried to set them up for success. I mean there were the odd incidents, but nothing that major. Our motto was always try to leave while everybody was being successful instead of sitting there and saying oh, it’s all going well, and then it all just sort of breaks down. I think we learned early that our kids could be successful for them, but there was a stress, there was a payback for that time of success. So you wanted to get out of there before that payback. Family members would call it a temper tantrum, or starting to get belligerent, fighting with somebody else, you know. There was a, well, there’s been a few family incidents where Eric and I would just pack up and say,
“You know this just isn’t working and we need to go home.” We weren’t afraid to do that because, to me, it just wasn’t worth putting the kids into an environment that wasn’t going to be successful and then, the complete embarrassment in front of those family members. Or like extra curricular activities, like Beavers or Cubs. Bobby attended and so did his parents so he would be successful. In Beavers I was the Beaver leader, his dad was the leader in Cubs so they couldn’t kick him out. We tried hockey, we tried soccer, we would try different things, and if he wasn’t successful, we would just take him out.

We ended up being a lot more isolated. Initially, when the kids were little I had other friends with kids and we’d get together. But, we ended up becoming more and more isolated. Now part of it was from Adam’s issues but, when Ben came along, Ben as a young kid was quite destructive, he’d break people’s toys and things like that, or take things or whatever, so he was actually the one where my friends would sort of say, you know what, don’t come over anymore. Generally we became more and more isolated and into ourselves, fending for ourselves, nobody asking, can they come over, nobody coming for dinner.

Once these families became self-aware of the confusing and overwhelming nature of the pathology associated with their children’s risk, they began to navigate healthcare and related resources and became resilient. They quickly become their own paraprofessionals (of their children’s condition) and then, in turn, became experts. They came to understand their children’s pathology or diagnosis, found support and
strategies, and learned to identify and cope with the associated stress. This enabled them to find and fight for conditions to help their children transform and get well. In turn, the two youth also learned to advocate for support and in this context learned healthy strategies for their own success. They also became experts in their respective pathologies and were driven by their desire to no longer have pathology. This is the idea expressed by Unger (2004) and others in the resilience literature. With the right conditions they lived and learned through this transformation. They were given the freedom to learn without the need of pathology to access support; they were afforded an oasis, so they could learn an alternative way.

In Summerhill, we once had a boy of twelve who had been expelled from many schools for being antisocial. In our school this same boy became a happy, creative, social boy. The authority of a reform school would have finished him. If freedom can save the far-gone problem child, what could freedom do for the millions of so-called ‘normal’ children who are perverted by coercive authorities. (Neill, 1992, p. 55)

The stories explored in this research, and the emergent themes that resulted, have pointed me in a new direction for future work in the area of at risk children and youth. These life histories have taught me more about what it is like to live and learn with neurological challenges; immersion in these lives lived have brought me to a new place of knowing. This is just the beginning of the journey of knowing. I want to gather more stories from children, youth, parents and educators to explore the risk associated with pathology and most importantly, tap
into the resilience that ensues. So many children and youth succeed despite their adversity. What are the conditions for this to take place and how can we as educators, parents and caregivers support the most complex of at risk children and youth to ‘make it’ despite the associated challenges? The lived experiences – the storied lives – can shed light on this for me and for educators and caregivers everywhere.

Educators can learn a great deal from the stories of Adam and Bobby, and more of these stories need to be shared. More youth, parents and teachers need to be given a voice to teach us so that educators, parents and all sorts of caregivers can meet the challenge of complex neurology with relational insight, care, understanding, skill and compassion.
SECTION THREE:

Where are we now?
Where do we go from here?
Chapter 10
A Postscript to Analysis
Letters to Stakeholders Who Matter

These unsent letters are for the professionals who have a stake at shaping the lives of children and youth with neurological conditions. In these letters I elaborate on important themes that emerged from this life history project. These letters are for educators, medical professionals, parents, government officials and policy makers and researchers.

To Educators:
This research sheds light on three important themes that I wish to share with educators who support at risk children and youth. Firstly, Adam and Bobby suffer from complex neurological challenges; school failure is a central issue in their lives. This risk factor (school failure), while creating a negative outcome in the classroom may in fact have a positive effect on children or youth in other potentially more important aspects of their lives. In essence, behaviour that presents as problematic in the classroom can contribute to the health and well being of an individual. Secondly, the stress experienced by parents (and teachers) associated with living and learning with neurological conditions, and the pressure of school failure that results, also serves as a conduit to getting well. Thirdly, strategies and conditions can be put in place within the classroom (and at home) to promote a turnaround from risk to resilience for at risk children and youth.
The *pathology for support/support for pathology* theme makes clear that problematic behaviour and learning challenges (at risk behaviour) can be expressions of need articulated by youth that push parents (and educators) to seek out medical diagnosis as a catalyst to access school support. For Adam and Bobby, increased expressions of risk eventually led to neurological diagnosis and assessment. In turn, as the behaviours became more problematic because of individual needs not being met, risk forced a bi-directional influence on the inner world, thoughts, feelings and behaviours of these youth. It affected their school and community supports and shaped educational policy and mental health issues relevant to the needs of these youth. Risk provided these learners with the necessary support, accommodations and understanding required to become resilient despite the adversity of living and learning with neurological conditions.

Keeping this in mind, it is important for educators to consider their roles in providing supports in the face of pathology. Consider ‘listening’ to the youth and their variety of behaviours as expressions of need for support, accommodations and systematic scaffolding. Simultaneously, act as agents who can set limits, seek out external support and accommodations and, as is necessary, refer these youth to other experts to ensure that pathology gets the support that is required.

Parents, in response to their child's school failure, often become highly stressed, which can lead to medical intervention in the form of diagnosis and medication prescription for their child. This stress also pushes parents to learn for themselves what they need to know about their child's condition. In conjunction with this self-learning, parents also access support groups and advocacy and in essence will
become their child’s experts. Once this evidentiary process is in place, educators, either willingly or not, start to provide the accommodations and support that are required. This is central to the pathology for support / support for pathology cycle. School failure and maladaptive behavior (expressions of need) can become the catalyst to access the supports that at risk children and youth require to becoming well.

These stories have taught me that it is important for educators to recognize the roles we play in the process of nurturing growth so that support can be fashioned for children and youth that will move them from risk to resilience. As was highlighted in this work, educators have the potential to be oasis teachers and mentors. To nurture a turnaround for at risk children and youth we would be wise to develop programs that are strengths based, instill social competence, enhance problem-solving skills and metacognition, develop a sense of identity and autonomy, and instill planning, hope and a sense of purpose and future. In addition, intrinsic factors such as emotional security and attachment style, self-esteem, self-belief, self-efficacy, social competence, capacity for problem solving, sense of purpose and future (including religious faith), planful competence, and humour are important to resiliency development. Each of these is, in principle, amenable to change by parents and others (Benard, 2004; Gilligan, 1997, 2001; Rutter, 1999; Shapiro & Levendosky, 1999).

I urge educators to be mindful of the themes that emerged from these research stories. When confronted with difficult and challenging behaviours, or when educating a complex special needs child, consider at risk behaviour as an instrument of change that can serve to help that individual access the supports or services they require to get well or feel
good. Looking at this context as a model whereby at risk behaviours become expressions of need and catalysts of positive change, as opposed to this risk being adversarial and confrontational, can be productive (Ungar, 2002, 2004, 2005, 2007).

Parent stress, and in turn medical diagnosis and intervention, also serves as a functional tool to ensure that youth access educational, health and social resources. Children and youth play an important part in their own transition to access the support they require to get well; individuals construct their own well being. They will demonstrate behaviour, either maladaptive or functional, that serves to attain what they require to get well, despite adversity.

As educators we play an important role in the lives of at risk children and youth. We must support children and youth with care, support and skills, but also push for intervention outside our own scope of practice.

**To Physicians, Psychiatrists and other Health Care Professionals**

Physicians play an important role in the lives of children and youth with neurological conditions. Parents, from the onset of their ‘neurological journey’, must turn to physicians and psychiatrists for insight, supports, relief and diagnosis. When parents notice small, sometimes subtle, unusual and disconcerting behaviours in their young children, they bring them to the attention of medical practitioners and seek advice and support. These small issues can sort themselves out. However, as was the case with Adam and Bobby, once children with complex conditions
enter school and they begin to experience more serious problematic behaviour within the school system, parents are often forced to return to physicians for affirmation and primary diagnosis in order to label an understanding of the issue. This process will access support and accommodation in the school setting; it will get children and youth what they require to get well. When these children and youth require more support, the parent will return to the physician. Parents are often under extreme pressure, because of school failure, to seek out diagnosis, referral to specialists and pharmacological intervention.

There are two themes that stem from this research that play a dominant role in the paradigm whereby pathology accesses support. I urge physicians to be mindful that once parents reach a tipping point and seek out medical intervention as a response to their child’s problematic behaviour, the child will most likely have experienced extremely challenging behaviour in the classroom / school setting that has resulted in a breakdown of their ability to learn with the current resources on hand. Secondly, once parents seek out medical support, they themselves have most likely experienced increased stress as a result of school failure and problematic behaviour that is occurring at school, in community and at home. These two factors are clear indicators, or risk factors, that have elevated the need for medical intervention. Medical intervention, support, and diagnosis play significant roles in the lives of children and youth with complex behavioural issues.

Because of the nature of the *pathology for support / support for pathology* paradigm diagnosis itself can be a tricky business for physicians. The very character of support and how it is deployed depends a great deal on the diagnostic label that is attributed to problematic behaviour. It
is also imperative for medical practitioners to recognize not only the medical intervention aspect of their roles in supporting at risk children and youth, but the fact that the intervention itself has an impact on the youth in so many other ways as well. Educational support, program placement, accommodations and the overall perception of the youth and his or her family is pinned to the diagnosis of the child’s problematic behaviour (Weibe-Barry, 2008). A diagnosis of problems such as ADHD elicits different sets of supports than, say, a diagnosis of Asperger Syndrome. Parents are aware of this issue and may ‘coach’ the diagnostic outcomes to suit the support needs of their child. Therefore, a strict set of diagnostic criteria, best practice, good judgment and ethics must coincide with diagnosis, despite the desire to make assumptions to access systematic support.

**To Parents:**

By default parents play the most vital and intimate role in the lives of their children as they journey from risk to resilience. The impact of maladaptive behaviour on one's own child leads to a great deal of stress for primary caregivers. These research stories highlight that this stress can serve to nurture the will, desire and tenacity to fight for the well being of children. Risk associated with maladaptive behaviour and neurological conditions will steer parents on a path to access support and advocacy and tip the scale to resilience and well being.

A very close friend of mine is a single parent dealing with her 11-year-old daughter who was diagnosed with leukemia. Prior to diagnosis her daughter was frequently ill, tired and losing weight. These symptoms became indicators of some kind of medical problem and, as they were
left undiagnosed and untreated, became worse until the mother (and her child) could not accept or tolerate the symptoms. In response to fear and stress the mother pushed for tests (and more tests) until an appropriate diagnosis was made. Once the diagnosis was in place, treatment and support ensued swiftly. It was the stress of not knowing, in part, that made way for a diagnosis of the horrible disease. It is also the stress of the disease that gives this mother the energy to move from this risk of illness to resilience.

Parents of children with neurological conditions who exhibit problematic behaviour and school failure are pushed to the brink of stress and exhaustion, much like the mother who lives though the stress and trauma of leukemia treatment. It is this stress that works to provide the parent with the energy, tenacity and will to access support and carry on to help the child get well. Parent stress, although very unpleasant, is a normal and vital aspect of living and learning with neurological conditions that can facilitate positive outcomes.

Listen to children and youth; they will tell you what they need. Their behaviours can help guide to the health resources required to get well. Behavioural escalation can serve as an indication of resources a youth might require to get well, or in fact, that behaviour itself might make the youth feel better. In Playing at Being Bad, leading risk and resiliency researcher Michael Ungar (2002, p. 6) suggests that we:

Listen to youth explain the choices they make when charting a course towards feeling good about themselves…. Dangerous, deviant, delinquent, and disordered children are in a frantic search to find some way to feel good about
themselves... (and) understanding what our children find attractive about acting out makes it easier for us to help them stay safe. When we see how youth find health amidst chaos, we are better able to offer them opportunities to experience themselves in ways that are every bit as powerful but more socially acceptable.

Accessing your medical community to move from risk to well being is an important part of the puzzle. Be prepared to document and present all the issues that arise and that are expressed by your children and youth. Push for answers to the hard questions that are brought to the table when your children act out. Although not the exclusive catalyst to well being, medical intervention can lead to support at school for problematic behaviour. This support may be the very support being craved by youth. Problematic behaviour and medical intervention may be just a roundabout way to access the support that at risk children and youth require.

In conclusion, parents are wise to consider that their children play an important part in accessing the supports that they require and it is possible that maladaptive behaviour may in some way serve to nurture this process. It is stressful and exhausting to meet this challenge but this stress is an important, paramount process and a real ingredient in your children's well being.

To Government Policy Makers and Regulators

Government officials play a crucial role in the lives of at risk children and youth. Macro geo-political policies (broad societal issues), which
include legislation, funding and mental health services provision all serve as key constituents that move troubled children and youth from risk to resilience. These research stories highlight some important lessons that I wish to share. Government policy, in part, should consider and be shaped by needs as expressed by at risk children and youth on a micro (personal and individual) level. Government policies ought to be both stringent and broad stroked, while at the same time offer an element of flexibility so that they can meet the needs of unique learners with unique circumstances. Government regulators ought to be mindful to work collaboratively with innovators and service providers to ensure that creative and pioneering solutions and programs can flourish.

These two stories reveal the need for flexible and adaptive solutions to challenging problems. It is clear from my participation in the storied lives of Adam and Bobby that mainstream solutions to support complex neurological conditions can be ineffectual. The extreme nature of these two youth’s problems forced a situation for the youths and their parents whereby their needs were met with alternative and sometimes contradictory approaches. At times, educational policy and legislation can become obstacles to progress and change. For these two youth – who eventually were forced in the direction of school withdrawal, home education, and participation in unconventional private programming – it became necessary to make choices that led to health and well being, but that were atypical. In light of these findings, consideration, collaboration and respect of unique solutions are warranted.
To Researchers:

This research sheds light on important contextual elements that shape the lives of children and youth who live and learn with neurological conditions. This research involved two participants so that their stories could inform my practice with depth and intimacy. As a researcher and educator I have learned a great deal from my involvement in these two lives and their associated research stories. Important themes emerged that related to the support that pathology is met with in the school system, parent stress, oasis teachers and mentors and risk and resilience. These themes all require further study.

The *support for pathology / pathology for support* theme is a significant paradigm that emerged and merits inquiry. In this research, the theme demonstrated how at risk children and youth required pathology in the form of diagnosis in order to attain the systematic supports required to get well in the face of their adversity. Future researchers might consider this theme and explore it further with at risk children and youth who suffer from co-morbid neurological conditions. Is support for problematic behaviour pinned to assessment and diagnosis? If so, does it need to be this way? Are there more efficient ways to provide support for problematic behaviours? Can we look to the youth themselves (and their problematic behaviours) to assess what these youth require to get well? How does at risk behaviour that is demonstrated by children and youth with neurological conditions serve as a conduit to getting well? Do youth construct their own wellness *via* at risk behaviour? In addition, the role that parental stress plays in the aforementioned paradigm requires further exploration.
The connection of these two youth, and their storied lives, to risk and resiliency literature (Ungar, 2002, 2004, 2005, 2007) is also a relationship of paramount significance. Two aspects of this thread, the first being that difficult and challenging behaviour can itself be an important component to getting well, and the second being that at risk behaviour itself may in some way make at risk youth feel good, are other themes that beg further research.

At risk children and youth who struggle with neurological conditions need to be ‘given’ voice. Researchers might consider exploratory work that actively involves youth who can share what they feel made them better. Children and youth have insight that is significant and I feel we can learn a great deal from these voices.

Finally, these two youth became resilient despite their adversities. In the face of complex neurological conditions and extreme behaviour they moved incrementally from risk to resilience. Future researchers ought to explore these resiliency conditions to determine who and what encouraged these youth, and how these youth were encouraged. If researchers can determine these factors and conditions, perhaps educators can help other youth who still struggle to make the transition to getting well. By engagement with these stories and others like these it is possible for us to gain more insight.
Chapter 11
A Friendly Visitor

One sunny spring day in 2003 we were paid a visit by officials of the government. Sherri-Ann and I were out shopping for groceries to feed the twenty-four people (ten kids and ten staff, plus our family) who lived at Blooming Acres. While we were out, two individuals with “official badges” spoke with one of our staff (they initially approached a co-op student) about the fact that we required a license to operate our group home at our farm premises and that our operation might in fact be illegal. The men said they would return to speak with Sherri-Ann and me directly. The two visited on the following Monday and, once again, we were not home to meet the officials. This time I instructed my staff to obtain a business card so I could get in touch with these visitors directly.

I called the Government Officer who left the card and, although we played “telephone tag” for a week or so, we finally connected. The officer suggested to me that because I had more than three children in care at my facility I required a license to operate our programme. He suggested that our operation was a ‘group home’ as described under Section 192 of the Child and Family Services Act (CFSA) (See Artifact 11.1, following).
PART IX
LICENSING

Definitions

192 In this Part “children’s residence” means,

(a) a parent model residence where five or more children not of common parentage, or

(b) a staff model residence where three or more children not of common parentage, live and receive residential care, and includes a foster home or other home or institution that is supervised or operated by a society, but does not include,

(c) a house licensed under the Private Hospitals Act,

(d) a day nursery as defined in the Day Nurseries Act,

(e) a recreational camp under the Health Protection and Promotion Act,

(f) a home for special care under the Homes for Special Care Act,

(g) a school or private school as defined in the Education Act,

(h) a hostel intended for short term accommodation,

(i) a hospital that receives financial aid from the Government of Ontario, or

(j) a group home or similar facility that receives financial assistance from the Minister of Correctional Services but receives no financial assistance from the Minister under this Act; (“foyer pour enfants”)

“non-profit agency” means a corporation without share capital that has objects of a charitable nature and,

(a) to which Part III of the Corporations Act applies, or

(b) that is incorporated by or under a general or special Act of the Parliament of Canada; (“agence sans but lucratif”)

“parent model residence” means a building, group of buildings or part of a building where not more than two adult persons live and provide care for children on a continuous basis; (“foyer de type familial”)
“staff model residence” means a building, group of buildings or part of a building where adult persons are employed to provide care for children on the basis of scheduled periods of duty. (“foyer avec rotation de personnel”) R.S.O. 1990, c. C.11, s. 192.

**Where a License is Required**

**License required to operate children’s residence, etc.**

193.(1) No person shall,

(a) establish, operate or maintain a children’s residence; or
(b) provide, directly or indirectly, residential care for three or more children not of common parentage in places that are not children’s residences, except under the authority of a license issued by a Director under this Part. (Child and Family Services Act)

Artifact 11.1 - Child and Family Services Act

I had reviewed this section of the Act previously and I explained to the Officer that I did not operate a group home and had no intention of doing so but, rather, I ran a home-school and a summer camp programme for various special needs children and adults. I had researched licensing as a group home some time before this visit and pointed out to the women that the CFSA specifically addressed my operation as exempt from this part of the legislation [see Section 192(e) and (g)]. We talked about the situation, mostly in circles, for almost an hour, and then we agreed that he would have his supervisor look into and follow up on the matter with me. I understood clearly that I operated a private home-school and a recreational summer camp.

A few days later I spoke with a Regional Manager who cited the CFSA as well. Once again I provided him with details of my home-school
and camp set up. It was my interpretation, as I had thoroughly checked into the matter (with legal counsel), that the CFSA clearly exempted my operation. I did not hear back from the official until the day the Liberals took over the provincial government in Ontario almost eight months later.

At that point I discussed the matter with my lawyer, colleagues and, most importantly, my wife. We already had to meet strict organizational and operational requirements (the Education Act and the Health Protection and Promotion Act), and had systems in place that exceeded the CFSA requirements. After some discussion we felt that a group home license would provide financial support (the government would pay) for those kids who attended our programmes and we thought, and were assured, that not much would really change when we held a license. We hated the connotation of becoming a group home but we went along with the process.

We met with the same Ministry Official who had visited us months before, and delved into the sea of legislative requirements that the Ministry was required to enforce. The list of requirements did not change our programme content much and we modified our paperwork to meet the regulations. Together with the Ministry, the local fire department and health officials, we thoroughly toured our farmhouse with reviews of all our paperwork, policies, procedures, and physical site. The Ministry conducted interviews with our staff and we made a few minor physical modifications to the building at the Ministry’s request. These meetings and this initial licensing process were, for the most part, an extremely positive experience. The officer was very complimentary about us and our process, and he conveyed his
confidence in and admiration of our programme. The process was productive and it made me feel proud.

However, one requirement of this licensing process was obtaining a clearance letter from our municipal Township planning department to operate a group home. This one small step took us off the rails – like having a train wreck.

We discussed the need for this letter with the Township’s senior planner, and wrote to the Township requesting a letter from them to add to our file with the Ministry. We were told in writing, and in person, that the official plan for our local Township did not allow for a group home in our zoning designation and, due to this, the Township could not allow this particular use on our land. Ironically, the Township was transparently aware of our home-school and summer camp programme operation as we had just been through an extensive renovation with them. We advised the Ministry of this municipal zoning obstacle.

The months passed and summer came quickly. During this Ministry licensing process we had met every requirement of the Government except for the receipt of a letter from the Township that indicated consent to operate a ‘group home’ – and this got us stuck.

In June of 2004 I received another letter from the Ministry which indicated that we had to complete the licensing of our group home or we should reduce our numbers to no more than three children. The letter also listed the legal consequences for not complying – which were fines and imprisonment. I passed this on to my lawyer.
From June to August we supported adults only at our farm camp and, because of this, our operation was surely exempt from the CFSA. In July the same government officer dropped in to the farm unannounced. I was away in Algonquin Park with my family for five days to enjoy a canoe trip in the wilderness. Our two camps were closed for a midsummer break and we were enjoying some well-deserved time off. I called the farm on our return home from the canoe trip once cellphone range returned to me. We had hired two staff to look after the one full-time adult guest who remained with us during this break and who also took care of our animals in the barn. I checked in to hear about their adventures.

The camp counsellor answered the telephone and told me that they were all great but that she could not talk to me now as she was in the middle of an interview with government officials. I felt awful; my stomach dropped to my ankles. I thought to myself: “Why is the government at my home interviewing a twenty year old ‘house sitter’ about my business operation?” I asked to speak with the officer and questioned why he was in my home – unannounced! The officer explained that he “was there to see that we had reduced our numbers.” He noted to me that there was only one person in care and that he was told that we would resume our home-school for ten children in the fall. I suggested that he knew all of this already as he had been through our residence several times over the past seven months. I expressed that I was unhappy with his approach and lack of courtesy in not making an appointment. I also protested his interrogation of our young and part-time staff. He informed me that he would report his findings to his supervisor.
A week or two later we received another letter that provided an ultimatum to reduce our numbers to three or less children or face fines and/or imprisonment. I was sickened by this situation and discussed the matter with my lawyer yet again. We decided to withdraw our license application and sent this in writing. I did not want to operate a group home. I was steadfast in my conviction that I operated a school and a camp, and that both were exempt from the CFSA.

This letter of withdrawal set off another series of official letters and ultimatums from the government and to address the impasse we met again with the Ministry Officer. The Officer wanted to review all our client files – again. I told him that he was welcome to look at the one individual’s file who was enrolled into our programme and paid for by the Children’s Aid Society but that all my camper files and the other student files were protected by privacy laws and had nothing to do with a group home operation. He did not stay long that day and, with his usual friendly and supportive tone and gestures, suggested he would report to his supervisor about our meeting. We received another letter from the government much the same as the others except that it gave us a date by which time we had to reduce our numbers: October 13, 2004.

As fall came, the same complex children who were enrolled in our school and our weekend respite returned to resume their individual programmes. At this same time, our lawyer scheduled a meeting with the government lawyers and supervisors to resolve the matter once and for all. We were to meet at the farm on October 13. On the morning of this day the meeting was cancelled by the Ministry. My lawyer and I met in the gardens at the farm that afternoon to discuss the situation
and he and I agreed that this matter had become muddled and the fact that the day’s meeting was cancelled was disconcerting. I was angry – steaming in fact. I recall his advice: he suggested to “not piss in anyone’s shoes”. I wanted to yell from the rooftops! I had worked so hard to create a supportive community to help troubled kids learn and grow and in exchange I was being shoved in a corner. The same government that had failed the kids I support stoned me.

After our meeting on this sunny, cool fall day and within five minutes of my counsel’s departure, three police cruisers, several government sedans and two minivans stormed my driveway. My gut dropped and time froze as the scene transpired. In the ten seconds it took for this caravan to reach my house I could not help but recall the raid that took place on John Singer, in *Death of An American*, who was “persecuted”, and eventually killed by police, for his choice to home-school his family in Utah in 1979. I had read this book in graduate school as I was developing the embryonic ideas in home-edcuation at Blooming Acres.

John saw the mailman come to the mailbox on Upper Loop Road. Since he could see no snowmobiles (police surveillance) in the area, and since he was almost halfway down the lane already, he decided to go down to the mailbox to pick up the mail. He put the snowblower down and trudged west through the fresh snow toward the Upper Loop Road. In the log house, ten-year-old Charlotte Singer was watching her father with binoculars out the living room window.
As soon as the mailman made his delivery, Bobby Larson, knowing John was already outside his compound, told his unit at the A-frame to stand by. “This might be our chance,” he said. Officers Henley and Carlson went outside and prepared to start their snowmobiles. Larson radioed to Lew Jolley at the surveillance house: “You guys be ready. If Singer goes down to get his mail, it’s a go.”

About the time John walked past Watson’s property at the foot of the lane, Esther Watson came out of her house, got into her car in the driveway, and started the engine. She was on her way to a church meeting. She let the engine warm up for a few minutes. John reached Upper Loop Road and walked five yards south to his mailbox. In it he found two letters to Shirley and a large envelope addressed to Vickie and him.

The officers in the surveillance house could not see the mailboxes because Watson’s house was in their line of sight. They had to wait for Bobby Larsen to give the signal from the A-frame. As soon as Singer got to the mailbox, Larsen gave the signal: “Let’s go,” he said to his men and into his walkie-talkie simultaneously. He waited for Jolley's acknowledgment, and then he and Floyd Farley ran out of the A-frame, carrying their shot guns, and jumped onto the back seats of the snowmobiles as Carlson and Henley started the engines.
At the surveillance house, Lew Jolley yelled, “it’s a go!” and he and his officers ran to their snowmobiles. The vehicle carrying Gunderson and Fullmer led the way, followed by Schouten and Jolley, out the driveway and south on Upper Loop Road toward the private lane. Bates and Hayward headed for the area between Watson’s and Jepsen’s house.

John had already turned up the lane and was walking east toward his farm when two snowmobiles started south on Upper Loop Road from the surveillance house. John glanced over his left shoulder at them, but seemed unconcerned. He took two more steps and stopped, turned around and looked again, his eyes wide. He saw the shotguns in the hands of Fullmer and Jolley. He realized that as they got close to the lane they slowed down, preparing to turn; John turned again and started running homeward.

As soon as the two snowmobiles turned up the lane, Jolley yelled, “We’re police officers, you’re under arrest!” ...As they got closer, John looked back over his shoulder; seeing that they could overtake him in a few seconds, he pulled a pistol from his waistband with his right hand and waved it back and forth in approximately a forty-five-degree arc, in the general direction of his pursuers. He kept running toward home, but now he was almost sidestepping, his left shoulder pointing east and his feet pointing southeast. He looked alternately back at the officers and forward in the direction he was running.... Officer Henley was cutting the fence when he heard the shot ring out. He looked up
and saw John Singer thrust forward and fall on his face. John braced his arms against the snow and started to get up again, but couldn’t make it; he fell once more and did not move again. (Fleisher & Freedman, 1983 p. 176 – 179).

The police cars, vans and sedans parked along my driveway, one car blocking the end of my laneway. A wall of people approached my home. I surveyed the scene from my front porch. The very ‘friendly’ Ministry Compliance Officer presented me with a search warrant for all the documents and computers related to the operation of our community. I asked if I could wait for my lawyer before they entered my home and was told “No” by what appeared to be a supportive provincial police officer, who pulled me aside as the group of government staff entered my home to ‘rob me’. He told me that the matter was not criminal and that the police had nothing to do with the issue. He and his staff were there to keep the peace and that the actual matter was a provincial offence – like a speeding ticket. He said “let them do their work and get out, then you can respond”.

As I stood in awe, my wife in tears, my staff in shock and the various children in my care mesmerized, I felt something in my gut drop. This event, and the months that followed, quashed part of my soul and spirit to continue – I wanted to give up schooling these learners.

A police sergeant entered my house within minutes of the raid and, while the government staff assembled a photocopy station and began to disassemble our office and document storage systems and computers, this formidable man in his wide brimmed hat explained that the warrant was for the time period 10am to 4pm. The group entered our
home at 2:30pm and only had until 4pm. The sergeant ordered the car at the end of my driveway (which belonged to the government lawyer) to be moved. He told her she had no right to block my driveway. My lawyer also returned, as I had called him immediately, and he discussed these actions with the government lawyer.

The police officer explained that they had been approached by the government to assist in the matter because they were told that I would “be difficult” and they were at my home to keep the peace while the warrant was executed. I was assured that the warrant was thoroughly reviewed by the police and that in fact the police kept the Ministry staff at their station for most of the day to try to understand it, and to ensure it was in proper order. Since there was no child safety issue, and since the police were well aware of our project, they wanted to respect our rights and kept the raid at bay for as long as possible.

This was an absurd scene, one straight out of a movie. There I was homeschooling nine children with complex mental health issues who had been failed by the school system and the government. Parents had privately paid me to help their kids learn, and I was being shut down. These same kids were engaged by the staff who decided to bake cookies and play fun games with the police officers and our learners. The kids explored the officers’ handcuffs and other equipment and tried on their official hats, while six people crowded my small home office. They packed up our files and documents, removed our computers and medical records. They took every last piece of paper out of my office, even the data associated with this research project and all my data. It as a nightmare; one I will never forget.
Each time I see a cruiser on my side road I flash back to this particular afternoon. My adrenaline kicks in and I recall John Singer and hear my wife cry. I remember that cool and sunny fall day.

We were told that since there was no child safety or welfare issue, the kids could stay but the files and computers would be taken for analysis. The group left us at 4pm sharp. Sherri-Ann and I knew that this was bad. These events would change our lives, our home-school, and our future forever.

We operated our home-school for one more month after this event. During this time we were told to license or wind down our operation. We were visited by the local fire marshal who had no concern with our set up. I was prepared to make a stand and the families whom I supported, both full-time and part-time, stood by our side. They wrote the Ministry and met with the managers who had shut us down but there was no movement. We were told to comply with their requirement to license or they would enforce the legislation.

So despite the fact that we were registered as a private school with the Ministry of Education, and that we operated as a recreational camp under the auspices of the Health Protection and Promotion Act, both clearly grounds for exception under the CFSA, we had no choice. We met with the Ministry a few weeks later, and decided that it was best to shut down and re-evaluate our entire life’s work.

This was the hardest decision we had ever made. However, the government had more money and better resources than we did to fight the matter in court and there was no hope to withstand the Goliath.
We closed our operation. The empty house echoed. We immediately hired a public relations firm (a very expensive one who offered to do the work for us pro bono), who guided us through the closure of Blooming Acres. With the advice of our lawyer, we reduced our number of clients to three children. Then we went on a PR campaign.

We discovered that we could have our learners at Blooming Acres during the day, so long as they did not ‘reside with us’. We carried on. Those close to us lived in their homes at night and were bused into our farm. Other residents lived elsewhere, close by, and joined us during the day and on field trips in the community. We stuck it out until we found a solution. We were community and this was the main point. All our staff stayed in our employ and we continued this day programme for five months. Some kids moved on to other programs, or to hospital, or got into legal trouble elsewhere. But we did our best.

I had written (as did the hundred or so families we support) the various top level Cabinet Ministers. We spoke with the local Member of Parliament and collaborated with the opposition and the Honourable Education Minister and, in early December, I was encouraged, in writing, and with a phone call from the top Ministry officials, to resume the licensing process. I was assured that all levels of government right down to municipal officials would cooperate to see the process to a positive resolve. We all wanted to see Blooming Acres open once more.

I hired a zoning expert who met with the Township and they also came to an agreement to provide us with the letter we required to complete the license process – our only obstacle. To take this one step further I worked with a fire safety consultant and with the Township
building department to meet and to far exceed any fire or building code regulations that would permit me to house up to twenty-four people at our farm. We took our ‘residential’ zoning to ‘care’ occupancy. We retrofitted the facility with over $175,000 of fire prevention equipment so as to never be in a position to have to reduce our numbers again. In April 2005 we opened our doors once more. The Township cooperated this time around and we became licensed as a group home.

We resumed our home-education programme and quickly returned to a feeling of normality. Summer camp went on as usual. But we soon realized that, although we were licensed, none of the families who were with us could access provincial funds because their needs were supposed to be met with the mental health services offered by the government. And very quickly, given our rising costs associated with our new procedures and infrastructures, new families and old ones could not afford our programme. The learners who were with us grew up and moved on. Our home-education changed forever in less than a year.

Today we now serve children and young adults with Autism and other complex care needs who are difficult to serve and hard to place elsewhere. Ironically, the same Ministry who shut us down with whom (we now have a very positive and cooperative relationship) now pays for all of the care that takes place at Blooming Acres. We now have a budget that is five times larger than our initial days when families paid for our services themselves. This is because our client needs and programme are drastically different. All of our original learners have grown up and moved on to college and university, and some work for
a living. Others still suffer from their complex issues – especially those who did not finish with us, and who did not find an alternative ‘oasis’.

In addition, Sherri-Ann and I operate Blooming Acres Snow Valley Lodge, a seven bed 6000 square foot licensed care home located twenty minutes from our farm, in Springwater, Ontario (outside Barrie). The Lodge is situated on a two acre wooded lot with stunning views that overlook the Vespra Valley and Collingwood. We completely renovated this spacious home and opened it in July 2007.

Our philosophy remains the same and our success and the transformative nature of our community still emanate. However, our focus and our spirit are different. We still meet with the Friendly Visitor on a regular basis to review and renew our license; but these meetings are underscored with old wounds that have now become scars, and feelings that still ache painfully from time to time.
References


