

Appreciating Autism: Stories of My Son

by

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ABSTRACT

This dissertation documents the process that I went through, as both a mother and as an educator, in coming to terms with my son's diagnosis of autism. I examine and discuss the discovery of his diagnosis of autism, as well as the educational implications of raising such a child. Using autoethnography as my primary research methodology, I discuss our lives leading up to my son's diagnosis of autism, the diagnostic process, the actual diagnosis, including the information from the various reports that were drawn up regarding him and his diagnosis, and connect it to the body of research that has been done about autism. Using the stance of an Appreciative Inquiry, I discuss the personal, social and educational ramifications of the diagnosis.

This thesis speaks to the importance of early diagnosis, the implications for early childhood education (due to the unique challenges of educating children with autism), and helps to provide guidelines to assist other parents/caregivers as they engage with their children who are gifted with this extraordinary challenge. NOTE: All names are pseudonyms and have been changed to assure their anonymity, with the exception the names of me, my husband, our daughter and our son.

Keywords: Autism, Asperger's Syndrome, Autoethnography, Appreciative Inquiry

DEDICATION

I would like to dedicate this project to my husband, Phil, to my daughter, Scotia, and, most importantly, to my son, Finnley. While I may be the author, it is our story that I am sharing. For their love, support, tolerance and understanding, I am forever grateful.

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LIST OF ACRONYMS

AI	Appreciative Inquiry
ASD	Autism Spectrum Disorder
HFA	High Functioning Autism
SPD	Sensory Processing Disorder

VANDY & FINNLEY

OCTOBER 2012



FOREWORD:

I WANT TO TELL YOU A STORY

These simple words have the power to ignite a wealth of possibilities for both the storyteller and the listener.

For the listener: *“A story? I wonder what will the story be about? Why are you telling it to me? And, why communicate this particular story now, at this particular time and place?”*

For the storyteller: *“I am choosing to share a story with you for at least one of the following three reasons:*

- 1. because I want you to learn something about me – I am teaching you about myself through the stories I decide to tell.*
- 2. because I want you to learn something about yourself – How you hear, interpret, and change because of knowing a story, in essence, adds to your own personal story.*
- 3. because I want to offer an idea about something about our shared life – This story, I hope, will teach us all more about the world in which we live.”*

Stories have power – all cultures use stories to impart knowledge and learning. With their recurring themes across cultures and peoples, stories are universal and full of promise because they connect us to each other through our common humanity. Stories create relationships: between the teller and the listener, the teller and his/herself, and the listener and his/herself. Stories are dynamic and ever-changing. A seemingly simple shift of wording can affect how a story is accepted and interpreted by the listener; therefore, the teller must be “attuned” to her/his audience in order to create the effect and affect s/he so desires. Stories are timeless in that the lesson imparted by a story to one generation can just as easily be used to teach the next. Stories are meant for sharing with real and/or imagined others – they are a dialogue, silent or oral communication, with the self, with another, or with a host of others. And, perhaps, most importantly, stories beget more stories...

Storyteller (S): I want to tell you a story.

Listener (L): A story? What will the story be about?

S: It's about me; it's about my family; and, it's about our collective journey. It's about the ups and downs of parenting a child with special needs; it's about the hopes that I harboured that were dashed, and the dreams that I carried that I had to forsake in order to truly be the mother that my child needed me to be. It's about trying, to the best of my ability, to do the right thing for my child – even when every single day with that child feels like an uphill battle; it's about making mistakes and learning . . . sometimes in spite of myself.

It's about not only raising a child with special needs; but also it's about appreciating that child because of his special needs. It's about valuing the unique gifts that he has, and it's about considering his personal challenges as opportunities for growth and change for everyone. It is about truly seeing and honouring that child – my child; it's about respecting him; it's about treasuring him, and it's about accepting him as he is, even when it is often easier to do otherwise.

It's about all of the things that I've discovered about myself – as a person, as a mother, and as a teacher – because of giving birth to this particular child; it's about the myriad of things that I never would have learned if he had been anyone other than who he is; it's about being forced to shift my thinking and, therefore, shift my actions in order to acclimatize myself to this child. It's about hope; it's about empowerment; and, ultimately, it's about love.

It's about discovering creative ways to educate this child with his often extra-ordinary needs in an often too-ordinary world; it's about dreaming of ways to make that ordinary world more extraordinary by making it more inclusive and accepting of difference; it's about imagining how things “could be” instead of how they sometimes are; it's about picturing a future that has been shaped by the past but still is fully appreciative of the present.

L: Why are you telling this story to me?

S: Because through this telling I gain insight into myself, into my son, and into the world in which we live – I am writing to teach; but I am also writing to learn.

My story is many things:

1. *First, and foremost, my story is an autoethnography.*

Ellis, Adams & Bochner (2011) tell me that “autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (p. 1).

If I take them at their word, I have engaged in a particular form of autoethnography – the narrative ethnography. My research is presented as stories that “incorporate the ethnographer’s experiences into the ethnographic descriptions and analysis of others” (p. 5). In this case those “others” are my family and, in particular, my son.

True to the spirit of autoethnography, I am engaging in a dialogue – a conversation, as it were, with you, my listener. And, through that dialogue, I am engaging in an inquiry that has led to deeper understanding for me, the researcher and, hopefully, will lead to deeper understanding for you, the listener, about my son and about others who are somewhat like him.

My hope is that through sharing this story, we can, together, provoke positive social change for children like my son. This, too, is an important tenet of autoethnography – the idea that we write these stories in anticipation that they will promote growth and change in those who read them. My desire is that my story will help you, my listener, to understand and, perhaps, care more about kids like my kid. And that through this caring you will not only be on his “side” but that you, also, will begin to advocate for my child and for others who have extra-ordinary needs.

As I embrace this methodology, I am embracing who my son and I are, the lives we have led together up to this time, and also the potential embroiled inside us both. Autoethnography has gifted me with the opportunity to interrogate my own life.¹

¹ **Dear Reader/Listener:** If you are so inclined, please turn to *Story A* now, before you read further into the story of my son. Thank you.

2. *My story is an Appreciative Inquiry.*

If I take David Cooperrider and his colleagues at their word, part of my research process has involved “intervening in” (Cooperrider, D.L., Whitney, D., & Stavros, J.M., 2008, p. xxix) my family’s life through the concentrated efforts that I have made as I have struggled to understand and help my son.

True to the spirit of Appreciative Inquiry (AI), I have engaged in the 4 stage cycle of evoking positive change in a human system – in this case, in my family. There has been a “discovery” phase, wherein I have attempted to identify and appreciate “the best of what has been and what is” (Cooperrider & Whitney, 2005, p. 16) about raising a boy with autism; there has been a “dreaming” phase, where I have envisioned “what might be” in relation to the potential I discovered during the discovery phase of the process (Cooperrider & Whitney, 2005, p. 16); there has been a “design” phase where my husband and I worked together with a number of other people to create the best learning environment possible for our son; and, finally, there has been a “destiny/delivery” phase where we continue to hope, to learn, to grow, to change, and, ultimately, to truly appreciate our son for the wonderfully inquisitive and unique person that he is.²

3. *My story is an inquiry into autism.*

I am not a scientist. I am not a doctor. I am, however, a mother and an educator – and, therefore, highly motivated to know and to learn as much as I possibly can about this “thing” that my son has... or that has my son. An integral part of my research process has been attempting to learn as much as I possibly could about the history of autism and its potential causes.

I don’t pretend to know everything there is to know about it. Not by a long shot. For one thing, there’s just too much to know, with more research

² **Dear Reader/Listener:** Appreciative Inquiry is about the co-evolutionary search for the best in people, their organizations, and the relevant world around them...It involves systematic discovery of what gives “life” to a living system when it is most alive, most effective, and most constructively capable. (Cooperrider, D., & Whitney, D., 2005, p. 3). For a detailed explanation of the philosophy of Appreciative Inquiry, including its history and differing forms of practice, please see *Story C*. Please wait though – I’ll suggest a place further along in the story of my son where you may want to read it. Thank you.

coming to light every single day. For another thing, because autism is a “spectrum” disorder, there is enormous range within it – from people who are severely impacted by the disorder, to others who, for all accounts and purposes, appear to function very well.

I do, however, know an awful lot about one special type of autism – my son’s particular version of it. I often tell people: “If you meet one kid with autism, you’ve met one kid with autism.” What I mean is that we are all individuals – even (especially?) kids with special needs. And that, while some of the symptomatology of autism that my son displays may look similar to the version that another kid has, it will never look exactly the same because those two kids aren’t exactly the same. So, perhaps, I should modify that heading... my story isn’t an inquiry into autism, it’s an inquiry into my son’s autism.³

L: So, your story is three things?

S: Yes, and no, I guess. More than anything, it’s an autoethnography – both the process and the product of it. I have “produced” an autoethnography, but my “process” has involved engaging in AI and in trying to learn as much as I possibly can about this “thing” that my son was born with.

But also, my story is simply “my story”. It’s my ‘truth’ about the events that have occurred in my son’s short life, and my rendering of that narrative. I imagine that if it was my husband writing this thesis, it would be a bit different, if my daughter were writing it that it would be different again, and that if my son wrote it, there would be more difference – even though we all would be, essentially, telling the same story. And yet, of course, it wouldn’t be the same – how could it be?

It makes me think about what Thomas King (2003) has to say about stories. He says, “The truth about stories is that’s all we are” (p. 2). I think

³ **Dear Reader/Listener:** Autism is a spectrum disorder that is characterized by qualitative impairment in social interaction, qualitative impairment in communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities and delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play (DSM-IV, 1994). Some of the information I have written for you in *Story B* will, hopefully, help you (like it helped me) to understand my son. I suggest you read this section directly after Chapter 2 – I’ll remind you, don’t worry. Thank you.

he means that we all live 'storied lives'; that is, our very existence is built on the stories we tell ourselves about ourselves and the stories we tell ourselves about others. By challenging myself to tell my story, to put these thoughts into words, I am making a reality for myself that has dwelled within me for the past twelve years but has never been given voice.

In essence, this story is my way of paying tribute to my son and the life-altering lessons he has taught me.

L: Why communicate this particular story now?

S: Because it's time. Because I am ready to "give life" (Bushe, p. 95) to the discoveries that I have made about my son and to the dreams that I hold for him. Because I no longer feel the need to chastise myself for making the mistakes that I have made in raising my son. Because I no longer feel the need to punish myself over the part that I may have unconsciously played in causing his seeming dysfunction. Because I no longer need to know "why". And, perhaps most importantly, because I can now accept that often the most important questions in life don't really have answers – that they are there as questions in order to lead us on personal journeys of inquiry that, otherwise, we never would have ventured towards.

Inquiring into my son's challenges has gifted me with the opportunity to truly experience the wonder that is humanity and has humbled me as both a teacher and as a human being. There have been countless hurts, frustrations, and upsets; there have been days when things truly seemed to be too much and too hard to take; but, somehow, there has always been hope and, if I waited just a little bit longer, there was joy there too.

It's about not giving up; it's about understanding the power of fresh starts and second chances; it's about optimism; and, it's about the power of finding the humour in the situation – because too often, if I didn't laugh, I found myself crying. It's about the power of believing; it's about positive thinking; and, it's about fighting "the good fight."

I want to tell you a story . . . It's a story about my boy – my dear, dear son. I want to tell you about Finnley.

Chapter 1

BEFORE DIAGNOSIS

I never wanted to have a child. I know it's shocking to hear someone say this—particularly when you know that they actually have children. . . . And, it's not that I didn't love being around them. I really did. It's just that I could never picture myself having my own child. Or, rather, giving birth to a child wasn't something that I really felt the need to do. I could picture myself raising a child, and I'd thought that, maybe, I'd foster or adopt children. But a biological connection between child and parents, to my mind, wasn't necessary, nor did it necessarily guarantee a strong and healthy bond. I had lots of reasons why that I would spout off to people when they asked why a teacher, who clearly loved kids, didn't want to have them herself.

"The world is over populated. Why would I add to it? I could adopt a child from another country and make a difference that way."

and

"Isn't it kind of selfish to have your own child, when so many other children in the world, including our own country, could use our help?"

and

"I don't feel the need to have a 'mini-me'. Isn't it kind of egocentric?"

And then there was the *real* reason. My fear. What if that child was like me? What if that child took after my side of the family— with my eccentric grandfather, my manic-depressive father? What would I do?

So, I pushed aside the idea of having my own child and kept myself very busy (and happy, I might add) teaching high school Drama and English . . . until the day that my husband made it clear to me exactly how much he wanted us to have "our" child. He understood my reservations, but he had his own responses to my pat answers:

“Vandy, I don’t want to raise a child who is adopted. I work with these kids every day in my Resource Room. So many of the kids in foster care are there because they have challenges.”

“But, isn’t that why we should adopt one of them?” I would reply.

“I do this all day long in my job. I don’t want to come home and have to deal with it too.”

And then there was this argument:

“Vandy, our child isn’t going to be just like your grandfather or your dad. How could he or she be? Biology doesn’t work that way. We would love this child. And raise this child in the best possible way. I love you and I know that we can make this work.”

How could I argue with that?

So, I agreed. With conditions. If we were going to have a child of our own, we would be prepared as much as possible. Now, just so you know, this was very counter-intuitive to the way I’d lived my life up until this time: I didn’t plan things in my personal life; I just sort of “fell into” them.

But this was different. This was a child we were talking about. And I had real reservations.

So I decided that not only would we be as prepared as we could possibly be but also that we would actually try to *over-plan* everything – to the point where I even considered which astrology signs would be best matched with us. We were both Aries, and I knew that I got along pretty well with Aquarians, Pisces, and other Aries. What I didn’t want was a Virgo or Scorpio child, although a Libra would be okay since they were the “balance” for Aries.

Yes, I went slightly insane. But, you see, I really was worried.

κ κ κ

I met Phil at the University of British Columbia (UBC) as we were both completing our Teacher Education Programs. Our first date involved a long walk around the Stanley Park Seawall where we discovered we had lots of commonalities, including the fact that we’d both lived in Nanaimo – me for a few years of my childhood, and Phil for all of his.

I remember saying to him, "I still remember my best friend from kindergarten. His name was Jerry Lakefield."

Phil replied, "He was my best friend all through high school!"

So, on that very first date, we went to visit Jerry and later that summer attended his wedding together.

As we drove from UBC (where Phil was living in one of the student housing complexes) out to Surrey to visit Jerry, we passed through Kerrisdale, a neighbourhood in Vancouver.

I said, "I miss my apartment in Kerrisdale."

Phil said, "I used to live in Kerrisdale too."

"Really? Where?"

"On 39th Avenue."

"Me too!"

It turned out that we'd lived in the same apartment building, at the same time, but I'd lived on the ground floor in the north-east corner and he'd lived on the top floor in the south-west corner.

And, we'd never met.

Our conversation continued:

"Do you play any musical instruments?" I asked, secretly hoping he'd say yes.

"Yeah. I played the French horn growing up."

"Huh. That must have been kind of lonely for you. I played the cello and I hated playing on my own."

"Oh, I played in youth orchestras during the summer."

"Hm. Me too. I remember going to a camp one summer near Courtney."

It turned out that Phil had been there too. We'd been at the same youth orchestra camp in the same summer; but, again, we'd never connected because we had played different musical instruments and sat in differing sections of the orchestra. My mom still had the program with both of our names in it.

And, we'd gone to the same preschool at the same time. And, and, and...

We moved in together three weeks later and got married nine months after that. And decided to have a child a year later, after much conversation. And conceived in June – the “right” month, according to my calculations to land us with a Pisces or Aries child.

And I was excited and scared. And sick.

I started vomiting. All. The. Time. I didn’t have morning sickness, I had all-day-long sickness. I couldn’t handle particular smells – in particular, diesel fumes, coffee, and cigarette smoke. I kept waiting for the day when it would end. (It’s only supposed to last for the first couple of months, right?) Mine lasted to month seven. . . . The poor woman with whom I shared my drama classroom had to quit drinking coffee in the morning because the smell made me vomit instantly. So I lived on noodles with margarine and soda crackers – and tuna sashimi and donuts with sprinkles on them, both of which I craved for some strange reason.

I really wasn’t comfortable discussing the pregnancy with anyone. In fact, every time I mentioned it to someone I would find myself tearing up, so I stopped talking about it altogether. I also refused to wear maternity clothes. I felt fat and I didn’t want to draw attention to myself. That “glow” that pregnant women were supposed to have was more like a sickly sheen on me. . . . I was still trying to wrap my head around the fact that I, Vandy Britton, was pregnant. Me, who’d never thought that she would have a child. Me, who was so very afraid of what was yet to come.

Somehow in my addled brain, I think I actually believed that if I didn’t tell anyone that I was going to have a baby that it wouldn’t really happen – that I wouldn’t be giving birth to a living, breathing being in a few months. Yes, I was pregnant; yes, my body was changing; yes, I could feel that baby kicking inside of me; but I still couldn’t believe it. I didn’t want to believe it.

What if I messed up? What if I was an unfit mother? What if I couldn’t love that child? What if it didn’t love me?

My own parents had separated when I was young and my father was hardly what you would have called a positive role model. He’d loved me, but he wasn’t exactly emotionally healthy, and our relationship wasn’t quite what it should (or could) have been because of it – not by a long shot. I had had to grow up way too fast because of him and I knew that I had a skewed sense of the world because of that complicated and damaging relationship.

I held onto Phil. He was “normal.” His family was “normal.” I kept reminding myself that I wasn’t alone – that this child would be Phil’s child too and that he could “fix” all of the mistakes that I would make.

In month seven I finally broke down and bought a pair of maternity pants. Being in the maternity clothing store with the lovely shop clerk, who, somehow, managed to make me feel good about myself and the pregnancy, helped shift my thinking. I was finally starting to feel good about being pregnant. (It also helped that I wasn’t vomiting all of the time anymore.) No longer did I feel the need to keep it a secret. If anybody asked (and people always did), I’d say, “Yes, I’m pregnant. I’m due near the end of March. No, I don’t know if it’s a boy or a girl.”

The more I spoke about the pregnancy, the more “real” it began to feel. And, I started getting excited about having that baby. Really excited. I started looking at baby clothes and noticing other people’s babies, and I even found myself stopping to talk with the parents a bit. I started reading about infant development – I knew lots about teenagers from being a high school teacher and a bit about school-aged children from my babysitting days, but young children (and infants, in particular) were something of a mystery to me.

Now don’t get me wrong . . . I was still really scared, of course. And, still slightly insane. (Now I was considering numerology in choosing baby names!) But, I was happy. I began to think to myself, “I can do this.”

We had our due date, March 22nd – Phil’s birthday, no less. (“*I get along with Phil; I will get along with this child,*” I would tell myself.) So, I decided to only work until the end of the semester in January so as not to disrupt my students as much, and to give myself plenty of time to get ready for the birth of my baby.

My baby. The thought made my heart quicken. And I could feel this swell of a smile grow inside of me every time I thought about it. About her. You see, everyone kept telling me that they thought I was going to have a girl – including both Phil and my mother. I, myself, wasn’t so sure; but I remember thinking to myself that at least if the baby was a girl that I would know how the “parts” worked.

The semester ended; I finished work. Hurrah! I could get things organized around our house – we were in the midst of a minor renovation. (Doesn’t everyone decide to renovate when they’re getting ready to have a baby?)

And three days later I was in the hospital with complications.

I had pre-eclampsia/toxemia. My body perceived the baby as a parasite, but instead of causing damage to the child, my body was damaging itself. My liver was in danger of shutting down, my blood pressure had skyrocketed, my ankles were swollen, I had massive headaches, and I had blurry vision. I was put on bed rest for the rest of the pregnancy and sent home.

“What does bed rest look like?” I asked.

“It means that you do nothing. You can only get up to go to the washroom or get yourself something to eat. You can’t walk anywhere or do anything. Your body needs to rest.”

Okay. Let me get this straight. I’d been psychologically rejecting the idea of having this child from the beginning, and when I had finally not only come to terms with having him or her but also was actually starting to feel pretty enthusiastic about it, my body decides that it doesn’t want the baby anymore?

And, now that I’ve given myself this time to feel good about being pregnant and get ready for the birth, I am placed on bed rest and not allowed to do anything?

I lasted on the couch for exactly four days – until my blood pressure actually worsened from the stress of lying there and doing nothing but worry. I was admitted to the hospital.

My bodily organs were being severely compromised and there was very little amniotic fluid detected on the ultrasounds. You could actually see the shape of the child in my body. Both of us were in danger. And yet, both the doctor and I wanted to give my baby the optimum time to develop in the womb.

Every day I went for multiple ultrasounds and non-stress tests where I was hooked up to a myriad of monitors to check the health of the baby. Every day the ultrasound technicians would exclaim about the lack of amniotic fluid in my stomach. And, every day my doctor would examine me and say, “It will be okay. Let’s just wait a little bit longer. We want to get to 38 weeks. At 38 weeks, the lungs are fully developed. We want your baby to have healthy lungs.”

Finally, after nearly six weeks of lying in a hospital bed – and two weeks before the due date – I was induced.

Induction: an introduction; and, most definitely, a production.

According to the Oxford dictionary, the definition of “induction” is “the action of bringing on, bringing into existence or operation, producing, causing. Chiefly *Med. spec.* Induction of labour.” (*OED*. Retrieved from <http://www.oed.com.proxy.lib.sfu.ca/view/Entry/94779#eid529334>)

I would describe it in another manner.

Induction is a medical “introduction” whereby a doctor requests that her/his patient be hooked up to an IV drip that methodically distributes Pitocin (a synthetic version of oxytocin – the hormone that basically enables childbirth) mixed with a saline solution into her pregnant body. In my case, this happened for close to three hours. Meanwhile, every fifteen minutes a nurse comes in and takes the patient’s blood pressure and listens to the baby’s heartbeat. And, if that patient is me and the baby in question is mine, apparently, this heartbeat is somewhat erratic – hence, the beginning of “the production.”

“Sweeping the membranes” comes next. At this point, the doctor separates the amniotic sac from the cervix. Yes, it hurts. According to my doctor, this helps to “get things moving.” He also had the nurse increase my dosage of Pitocin. I should say that my husband was with me all through all of this. And that I was extremely hungry and not allowed to eat anything, in case of complications.

Quite soon after the whole “sweeping” thing, I started to have contractions. The monitor registering the baby’s heartbeat would scream into action every time my uterus tightened and then slow right down directly after. The nurses (I now had two watching me) would scurry in, read the print-out, hurriedly write the numbers down on the chart at the end of my bed, and race off again.

I was kind of giddy by this time: I was still excited, now a tiny bit scared, and really, really hungry. I’d been having quite intense contractions for about two hours, but my water still hadn’t broken.

The doctor returned, had a look at the chart, and said, “Okay. We need to speed things up a bit here.”

He then performed an amniotomy. (Basically, he stuck an instrument that looked not unlike a crochet needle into me and punctured the amniotic sac.) There was no turning back now.

Four hours later my cervix was still only about 2 cm dilated and the contractions were coming much more strongly and rapidly. And, every time a contraction occurred, the baby's heart rate would again shoot way, way up – like nearly 300 beats per minute (BPM) (versus the usual 160–165 BPM) and then would slow right down to nearly 70 BPM when the contraction finished.

I was getting pretty tired by this time. It was now nearing 11:00 p.m., I'd been laboring for nearly eleven hours in a weakened state from the pre-eclampsia and the bed rest. And the doctor's shift was coming to an end. He decided, "Well, maybe we should try to slow things down for a while now. Your labour is not progressing, you're tired, and the baby is in distress. Let's stop the Pitocin, you can get some sleep, your husband can go home and get some sleep, and we'll start fresh first thing in the morning."

Believe me – I was all for stopping. I wasn't particularly enjoying the experience of labour up until this point anyway. So, I was taken off of the IV drip and Phil went home.

But, the contractions continued.

And so did that erratic heartbeat.

Three hours later, another doctor arrived, took one look at the latest series of readouts from the monitors, and said, "We need to prep for an Emergency C-section immediately."

"Can I call my husband?" I asked, as they began to prepare to move me. They brought me a phone. I called once. No answer. I called again. No answer. I called a third time. Still no answer.

By this time, they were literally wheeling me into the operating room.

"Please, let me try one more time!"

Thankfully, Phil answered on the fourth ring. And, thankfully, we only lived ten minutes away from the hospital. He arrived just as the anesthesiologist was giving me the epidural to numb the lower half of my body. They put a blue curtain up on my stomach so I couldn't see what was going on – not that I would have looked anyway. The doctor said, "You'll feel a bit of pressure ..."
And then there was a baby being lifted out of me.

According to the doctor there was less than a cup of amniotic fluid left inside of my uterus. No wonder you could see the outline of the baby's limbs against my stomach when he had been turning over. And, no wonder his heart rate had been so erratic – the umbilical cord had been wrapped around his

neck three times. He was, literally, being choked to death every time I had a contraction.

It was the weirdest sensation having this child lying on my body and not being able to feel it because of the epidural. I couldn't associate this purple baby thing with my body. They didn't seem connected somehow. They lifted the baby up and took him over to the examination table. I kept asking, "What time is it? What time was he born?" Phil stood by as they checked our baby's vital signs. Apparently, he was given a score of 6 on the Apgar scale (Activity, Pulse, Grimace, Appearance, and Respiration) at one minute and a score of 7 at the five-minute mark – meaning that, while he was healthy, he needed to be watched carefully.⁴ I was wheeled into the recovery room while Phil stayed with our son, Finnley Britton Cookson, born at 4:37 a.m. on March 7th, 2000 weighing 6 lb. 6 oz. and measuring 23 inches in length. I had given birth to a baby boy. I had a son.

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Finnley cried. And cried. He barely breastfed – he was too busy crying. Or fighting going to sleep. While he'd slept for the first four hours after his birth, they were the only four consecutive hours of sleep that he (and, consequently, I) had for basically the next year.

I remember that first night in the hospital after Finnley was born. Finnley was crying and I couldn't get him to stop. My mom tried, Phil tried, and I tried. We rocked him, we sang to him, I tried to feed him – nothing would work. The nurse came in, gave me a condescending look and said, "I'll take him for a while. You get some rest."

Feeling guilty, but too tired to do anything about it, I agreed and promptly fell asleep. It was about 7:00 p.m. I woke up around midnight with absolute panic filling my body. Where was my baby? Then I remembered that the nurse had taken him to the nursery and that all was well.

⁴ The Apgar Score was developed by Dr. Virginia Apgar in 1952 as a quick and convenient method to report on the status of a newborn infant and to determine whether medical interventions are needed to assist the infant, particularly in their breathing. It is performed at one minute and, again, at five minutes. (*American Academy of Pediatrics and American College of Obstetricians and Gynecologists*, p. 1444.)

I made my way down the hallway from my hospital room, peering into the rooms of other mothers with brand new babies: most babies were sleeping in the hospital crib carts, but some mothers were breastfeeding, and a couple of babies were crying and were being held either by their mothers or by a nurse.

I smiled to myself as I went to find “my baby,” realizing from the heaviness of my breasts that it really was time to feed my son. I came to the nursery and looked for Finnley. Suddenly all of the babies looked the same to me—I couldn’t see him. Did I not recognize my own child? Panic filled my body. I frantically began reading the tags on the crib carts, searching for the one that said “Britton baby.” It was nowhere to be seen. Finnley wasn’t in the nursery!

I ran down the hall toward the nurse’s station, fear oozing from every pore. My baby was missing! Someone had stolen him! Where was the nurse who had taken him from me? Was she really a nurse? Maybe she’d only been pretending that she was a nurse! What had I done? I’d given my baby to a complete stranger because I was so tired!

I found the nurse. (Yes, she really was a nurse and not a kidnapper involved in some sort of black market child smuggling operation.) And I found Finnley. Or, rather, I *heard* Finnley before I found the two of them sitting together. There he was—my baby—sitting on the nurse’s lap. Crying. She looked up at me in my agitated state and said, “He hasn’t stopped. This is the first time in my life that I haven’t been able to stop a baby from crying. You’ve got your work cut out for you.”

Finnley continued to cry for the first four months of his life. Tuesdays always seemed to be the worst day for it. (I attributed this to the fact that he’d been born on a Tuesday.) I look back with dismay on a day that I came to call, “Black Tuesday.” On that horrific day, Finnley shrieked for five hours straight. He actually screamed himself silent—purple face, mouth open, and no sound.

Phil would arrive home from work and take Finnley from me. He would carry Finnley upstairs and gently rock him while our baby simply cried. I would try to find something to do to distract myself from the noise and the stress. But, really, nothing worked. Every book I read, every nurse/doctor/parent/grandparent/random stranger on the street to whom I spoke told me that it was colic and that he’d outgrow it. Eventually. I had heard of colicky babies before, though I had had no direct experience with them. And my mother assured me that I had had colic too—though apparently I hadn’t cried nearly as much as Finnley seemed to.

According to my family doctor, many pediatricians and medical practitioners apparently use the “Rule of Threes” to diagnose infant colic. The symptoms are characterized as follows: appearing at or before 3 weeks of life; when there is 3 hours of consistent and uncontrollable crying (even when efforts are made to console the child); when this sustained crying occurs at least 3 days out of every week, at roughly the same time each day; and, the crying bouts end at approximately 3 months of life (Dr. K.K. Maki, M.D. in conversation with V. Britton).

Suggestions my doctor gave me to help with the colic included monitoring my diet to see if there were any foods that I was eating that seemed to exacerbate Finnley’s symptoms. Dr. Maki suggested that I stop eating garlic and milk products immediately to see if this helped in any way, shape or form. (It didn’t.) He also suggested that we try infant massage, invest in a baby swing so that Finnley could rock and I could get some sleep, and, perhaps, turn on a fan, a hair dryer, or create another continuous sound in Finnley’s room (besides the sound of him screaming, of course). Apparently, this “white noise” was soothing to some babies with colic.

Nothing seemed to consistently work, except the motion. Finnley was only having breast milk, and I was very careful about what I was eating. I cut out all dairy products, and I ate as “blandly” as possible (avoiding all spice and seasoning). We tried the infant massage, we tried playing music and/or singing to him, we tried a number of different kinds of “white noise” (a fan, a hair dryer, the vacuum, a clock) . . . we really did try everything. It was incredibly frustrating. I felt so powerless. What was I doing wrong? Why was my baby acting this way? Would the crying ever stop? I felt guilty, angry and helpless at my clear inadequacies as a mother.

The only thing that would stop Finnley from crying would be long car rides or stroller rides on gravel paths. The rhythm seemed to soothe him – for as long as the ride lasted anyway. I remember, more than once, driving the car when I was so tired that I would literally fall asleep at stoplights. I would actually slow down as I neared an intersection, in the hopes that the light would change to red so that I could close my eyes for just a second. It was only the horns of the cars behind me that would wake me up. Pulling over to the side of the road for more than a few minutes was out of the question – even if I left the motor running, Finnley would begin to cry again.

I couldn't say that I loved being with my son at this time. It was too hard. And I felt entirely incompetent. I tried to attend "Baby Talk," a mother's group that met Wednesday mornings at the community centre in New Westminster because I was quite lonely during the day; but more often than not, I would take Finnley in the stroller to the meeting but not be able to stay and listen and/or connect with the other mothers because he would be screaming so loud that the other people there wouldn't be able to hear each other. And, as luck would have it, the two women in the neighbourhood that I walked with to the meetings would have silent, sleeping babies throughout the entire stroller ride and, of course, the meeting too.

When Finnley finally outgrew the colic (at about five months of age), he still never slept for more than 20 minutes during the day. The usual length of his nap was somewhere between three and ten minutes. I shook my head in amazement at other babies of the same age who could nap for three hours at a time. It was beyond my comprehension. The mothers would exclaim about all of the things that they got done while their babies slept, and some even said that they had to resist the urge to wake their babies up because they wanted to play with them. I was not one of those mothers. Not by a long shot. Finnley never slept. How could I possibly miss him?

While the napping during the day didn't improve, he did gradually begin to sleep for longer periods of time in the night. But, by longer I mean that he would sleep for almost four hours – certainly not the eight to ten hours that these other women talked about. Thankfully, when he was awake at 2 a.m., he wasn't particularly taxing; he seemed to be happy as long as he was held tightly. I read to him, I sang to him, and I rocked him. Eventually, after a couple of hours, he'd fall back asleep for another three to four hour stretch of time – enough that I no longer felt the need to actively seek out stoplights when driving.

Finnley still cried for long, long stretches of time every day, and the "witching hours" between 4 p.m. and 6 p.m. were always brutal; but the intensity of the crying jags seemed to be dissipating as he grew older – either that or I had become more adept at tuning them out.

I often wondered if those women with their "perfect" babies were lying; that they were actually in the same position as me but felt the need to sound and act like they were much more competent. Eventually, when I would have a conversation with one of these women, I found that it was simply easier to just not say anything. It felt as if all I was doing was complaining about this child of

mine; as if I were implying that he was purposely waking himself up from his “Finn-nap” (what I came to call anything shorter than twenty minutes) just to punish me – though, if I am completely honest with myself, I think I did feel that way at least a couple of times.

It was hard not to be resentful of Finnley and not to feel jealous of these other mothers. I never felt that it was Finnley’s fault – I really didn’t. It was all about the fact that, clearly, I was not doing the necessary things to meet the needs of my son; that those fears about my lack of suitability for motherhood, which had been so vivid in my mind prior to having children, were true; and that Finnley was the crystal-clear evidence to demonstrate my obvious shortcomings as a parent.

Now I realize that some of this guilt I felt was just my own “stuff”; that is, I am the type of person who tends to feel guilty for just about everything as a general rule. However, I also realize that much of the guilt I felt about my lack of suitability for motherhood has been imposed upon me by my culture and by my status as “mother” in a highly pressurized society where a child’s success in school (and in life) is often traced back to the parents – and, in particular the “good mother”⁵.

Developmentally, Finnley seemed to be reaching the milestones that were laid out in *What to Expect The First Year* by Heidi Murkoff – the sequel to *What to Expect When You’re Expecting* (Both books are considered “required reading” in Canada by most pregnant women or families with newborns). He learned to roll, he made lots of sounds and he had big, bright, and attentive, blue eyes. Finnley was a very cute baby – if I do say so myself. His growth and weight were on target: he put on about two pounds and grew at least half of an inch each month.

The books I read about baby development told me how important it was to expose Finnley to lots of different experiences at this early stage of life – and that the more exposure to things provided more opportunities for brain development. *Baby Mozart* and all sorts of other music CDs were on the market,

⁵ Smythe (2006), in her thesis entitled *The Good Mother: A Critical Discourse Analysis of Literacy Advice to Mothers in the 20th Century*, analyses literacy advice handed to mothers and discusses the many ways that women in Canadian society are held accountable for the emotional, social, physical and educational health of their children.

as were other *Baby Einstein* products such as mobiles and pictures with simple black, white and red shapes on them that, supposedly, babies could see. I was holding books up for him, pointing out animals, people, and whatever else I thought would be of interest. Basically, I was doing my level best to stimulate my son's brain. I didn't want to waste any waking moment – and believe me, there were a lot of them.

Finnley and I would go for daily walks and I would chatter to him the whole time, talking about what we were seeing as we walked. He wasn't crying nearly so much now, so I wasn't as afraid to take him out in public. And, I really hated being stuck in the house. I craved adult company and spent countless hours pushing the stroller here and there in New Westminster and in Vancouver from where we'd recently moved.

I wanted my son to be intelligent. I wanted him to fully connect all of those important synapses in his little brain. I wanted to give him every experience that I possibly could to help him to be successful in the future. And Finnley really seemed to respond to all of this stimulation. He'd hit his hands against his ears at the parade, he'd flap his arms in the air when I'd play music and dance with him, and he'd shriek and squeal loudly when he'd hear loud noises.

I interpreted these responses as excitement. I was certain that Finnley was musical, just like Phil and me. I was sure that he had fabulous rhythm and that's why he flapped his arms. And I truly believed that the hitting of his ears and the loud squealing was from the sheer joy that he felt from experiencing all of this stimuli.

It wasn't...

But I didn't know this yet.

Finnley started to pull himself around, doing his "commando crawl" at about six months of age. He was exceptionally strong – not always the most coordinated, but, as I would say to people, "He's just like me. What he lacks in style, he makes up for in energy!" Finnley seemed to not always be aware of his surroundings; literally, banging into the walls. In fact, he actually seemed to *enjoy* hitting the walls, turning it into some sort of game he would play with himself (at least this is how I interpreted it). It seemed to me that he would roll or commando-crawl into the walls *on purpose* and then continue to hit them repeatedly with his hand – or, sometimes, his head.

We continued to do our many activities: we'd go to "Mom and Baby Time" at the New Westminster public library where the children's librarian would read aloud; we'd go to a music class in Vancouver where Finnley would commando-crawl around the room while the other moms and babies would sit and clap (Note: the babies in this class were the same age as Finnley.); I finally managed to attend "Baby Talk" at the community centre without having to rush out of the room with a screaming infant; and, we'd go to the pool together at least once a week. I filled my days with lots of activities because, quite frankly, I needed the entertainment. I was really missing teaching and interacting with likeminded adults and energetic teenagers. I liked talking with the new moms; but I got bored after a while, since our conversations never progressed much further than discussing our children. And as much as I loved my son, he wasn't exactly intellectually stimulating.

Finnley had his first serious accident at the age of seven months. I'd taken him to the swimming pool, and, while strapped onto the change table with my hand on him, he somehow managed to pull himself off of the end of it by grabbing onto the door handle. Now I have to admit that Finnley had rolled off of our dining room table once before this. He'd been fine – he hadn't cried at all, in fact – which, in the moment, I had found unusual, but quickly dismissed because he was unhurt; however, it had seriously frightened me just how quickly this accident had occurred.

Because of that previous experience, I was pretty careful when it came to watching him. I was also becoming increasingly aware of Finnley's penchant for banging into walls when he crawled (an apparent continuation of the fascination he'd displayed with wall-banging that had begun when he had first learned how to roll) as if he wasn't aware that there was actually a wall there (or a chair, or a door, or a person). It was a bit disconcerting and I would try to prevent these "accidents" from happening before they could occur, all the while figuring that it was just something that he would eventually outgrow. I believed that because he was so precocious in his development, it was taking some parts of his brain a wee bit longer to "catch up" to where other parts were at. At any rate, I wasn't particularly concerned, and nor was anybody else.

I have to admit that I was looking away when Finnley managed to pull himself off the change table – but, I did still have my hand on him and he was strapped in. He shot off the end of the table and tumbled head-first onto the cement-tiled floor. I quickly picked him up and was amazed because, again, he

didn't cry. (I figured that he was in shock and, perhaps, somewhat surprised by what had happened. I certainly was – and quite distressed by it, I might add.) I cuddled him, and it was only then that he started to cry a bit.

I looked him over and noticed no obvious injuries. By this time, he had stopped crying again; so, I took him out to the pool deck. As soon as we sat in the water and I tried to move his arms to make him splash the water (Remember: it was all about Finnley experiencing lots of stimuli so he would grow up to be smart), he wailed loudly for a split second and then went silent. Now I knew for certain that something was wrong.

I quickly told the pool attendants what had happened and we took Finnley into the first aid room while the receptionist called the ambulance. When we lay him down on the cot we could see that one of his little shoulders was more distended than the other. Finnley was clearly injured.

The paramedics arrived, checked his vitals, and because he was silent, determined that he was going into shock.⁶ They also could see the unusual line of his shoulders. Finnley was strapped onto a body-board and hoisted into the back of the ambulance. I quickly got in beside him after giving the receptionist Phil's work number to call. He was to meet us at Children's Hospital in Vancouver. Because Finnley was so little and because the paramedics were so worried, we were bypassing Royal Columbian hospital, only five minutes away, for the care facility that catered to babies and children in downtown Vancouver.

Finnley was silent for the entire trip. I was busy vomiting, carsick from riding backwards in a speeding vehicle. I was also still wearing my half-wet bathing suit and had no other clothing with me. The paramedic repeatedly checked Finnley's vital signs as we drove and there were three attendants waiting to greet us when we arrived in the ambulance bay. Finnley was quickly wheeled into an X-Ray room for an MRI while I filled out the paperwork. Phil arrived shortly after, and I burst into tears.

It was official. I truly was the worst mother in the world.

⁶ Shock, according to the University of Maryland Medical Center's website is characterized by an inadequate supply of oxygen to the vital organs. It is potentially life-threatening and must be treated immediately. (Retrieved from <http://www.umm.edu/altmed/articles/shock-000152.htm> on 7/3/2012 at 10:00 p.m..)

Luckily(?), Finnley's shoulder had taken the brunt of his fall, so he had ended up with a broken collarbone instead of a cracked skull. Yes, my son had his first broken bone at seven months of age. They put a little sling on his arm – to warn others to be gentle with him, and to prevent Finnley from trying to put weight onto it. Thankfully, babies heal very quickly, and six weeks later he was moving around again, even better than before.

Recovery time for me, however, was much longer – we didn't return to the pool together until he was registered for swimming lessons some three years later.

Finnley's "accidents" continued. At fourteen months, he climbed onto the table and pulled the CD player off of the shelf above his head. At sixteen months, he was running with a plastic car in his hand when he fell and the sharp edge of the toy gouged him, requiring seven stitches right between his nose and his eyeball. At eighteen months he climbed onto a chair in the kitchen, decided to stand on it, seeming to forget that both of his feet needed to be on the chair in order to be balanced – he fell and somehow managed to land near my guitar case, cutting himself just below his eyebrow on one of the metal hinges. Eight stitches this time.

At two years of age Finnley fell down our cement stair case – a black eye and an enormous goose egg on the back of his head. At two and a half, he was running in the kitchen (again), slipped, and managed to hit his head on a bound piece of wire holding together one of our kitchen chairs. Thirteen stitches at the back of his head this time. He broke his nose at three. He broke his arm at five. He's sprained an ankle. And, last summer alone, he had a broken toe and a broken arm at the same time from two different accidents.

Obviously, all of these injuries raised some eyebrows – particularly at the hospital. I had numerous conversations with different nurses, doctors and social workers who "just wanted to review how the injury occurred." I appreciated their due diligence; at the same time, I really was a very attentive mother. My son just seemed to be particularly clumsy. Friends and family – and even Dr. Maki – described Finnley as a "real boy's boy"; that is, that he was exceptionally active, busy, and "into things." He was.

The most peculiar thing to me – besides, of course, how accident-prone my son seemed to be in comparison to other children – was his response to the pain. Or, rather, his "non-response" to the pain. He really didn't seem to feel it. I couldn't figure it out. I mean, if I had blood pouring down my face from a

huge cut beside my eye, I'd be screaming from fear, not to mention the pain of the injury. Not Finnley. He'd just be quiet, almost retreating into himself. It was always the *lack* of response that let me know that something serious was the matter, not the tears or cries.

Which brought me to another worry that I had. This child of mine didn't actually cry tears. He would scream and yell if he was angry, but his eyes hardly ever welled up with tears, and, on the odd occasion that they did, the tears rarely spilled over onto his cheeks. I couldn't figure it out. Didn't Finnley feel anything?

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When Finnley was nine months old, I discovered I was pregnant again. It was almost impossible for me to believe. Actually, it *was* impossible for me to believe—it took four home pregnancy tests before I would finally accept the results. How could we possibly have another child? I could barely manage one! What would I do with two of them?

Remember all of that planning that went into Finnley's birth? There was no time for any of it with Scotia—I was much too busy. Finnley had moved from his "commando crawl" at seven months to more typical crawling at nine months, and was busy pulling himself up onto furniture by this time as well. I couldn't turn my back on him for a second or he would, literally, be gone. He was that fast.

I found it strange though. Finnley wasn't like other children when they crawled. The other babies I would watch would crawl a short distance (about five or six feet) and then look back over their shoulder to see if "their" adult was watching them. Finnley didn't do this. He'd start to crawl and wouldn't stop. He didn't seem particularly concerned or interested in knowing whether Phil or I were still there—he was too busy inspecting things. In particular, he was quite fascinated with wheels on strollers.

No matter where we were, if he saw a stroller, Finnley would move as fast as he possibly could towards it. He liked to touch the wheels, trying to grip them with one of his hands—and, quite often, losing his balance and falling into it in the process.

Finnley would try his very best to spin the stroller wheels. This didn't always work out for him—his coordination would often be a bit "off." Other

times, it was the owners of the strollers who thwarted his attempts: he didn't know that sometimes the strollers had brakes on them that locked them into place. This would lead to howls of frustration and annoyance on the part of Finnley and, invariably, he would begin to hit at the wheel or stroller in vexation.

I noticed that Finnley was fascinated with spinning, in general. He'd graduated from the baby swing that we'd bought so that I could get some sleep, to the "jolly jumper" – basically, a container for a child that was suspended from a spring attached to a door frame wherein the child could jump safely. Finnley's favourite thing to do in it was spin. I noticed that when I played music loudly he would seem to get more excited and jump and spin more. Consequently, I played loud music a lot. I also noticed that he would often get so wrapped up in what he was doing that it was sometimes quite difficult to get him to stop – even when I'd turned off the music. And that stopping, like the frustration he encountered with the brakes on strollers, was always accompanied by loud wails of anger on his part.

Finnley was "speaking" by this point. Or, rather, he'd take my arm and point it in the general direction of what he wanted, making some sort of vocalization at the same time. I'm certain his first word was "Peek-a-boo," or rather "bee boo" in the singsong voice that I would use when I would play the game with him. He would say "ba" if he wanted milk and was making the sounds for "ma" and "da," but they weren't related to Phil or to me, as far as either of us could tell.

Finnley's relationship with food was quite interesting. He'd been eager to eat baby cereal and some pureed vegetables (only sweet potato, squash and green beans) when he'd been first introduced to them at six months. However, his tastes had rapidly narrowed in the few months after, when he'd been introduced to "crunchy" food (dry cheerios, crackers). He liked the texture and taste of the crackers, in particular and he began to be even more selective about what he would eat – his favourite meal being pureed green beans on bite-sized pieces of cracker. He didn't like "chewy" food, so he avoided pieces of chicken or meat. Phil and I would try to give him things to eat off of our plate, but rarely was he interested.

When he moved from crawling to walking, at thirteen months, a whole new world opened up for him. I think Finnley walked for only one week; then he was off and running. Literally. All children take great delight in "running away" from their parents – knowing that their parents will come and "catch them"

sooner or later. Finnley, as he had done with the crawling, would run and keep on running. He also enjoyed hiding. This was not a good combination.

I had morning sickness with this second pregnancy as well – imagine the aroma of the puréed green beans at 7am when Finnley would want breakfast. Fortunately, the nausea and vomiting didn't last as long as it had with Finnley. And, overall the pregnancy was fairly easy, until the seventh month when I developed sciatica. Finnley was *very* active by this point in time. I found it hard to keep up with him. Luckily, however, it was now summer and we were spending lots of time outside in our back yard where Finnley had discovered the joy of digging.

Dirt and digging seemed to “settle” Finnley. Family friends had passed along their son's old Tonka dump trucks. They were sturdy, metal things that even my son couldn't seem to damage. Finnley would line his trucks up in a row and systematically fill each one with dirt. I found that if he was particularly excitable that I could take him outside, sit him in his “digging zone,” and that he would then calm down. The repetition, the rhythm, and the routine were restorative for Finnley. We would spend hours outside in the garden – it didn't matter the weather – though Finnley didn't particularly like it when his hands were wet and dirty so rainy days weren't as relaxing for him (or, consequently, me).

The rain seemed to bother Finnley in other ways as well. He would shrink against it, almost like it was hurting him. Other times I would notice that he would quickly try to brush the rain drops off of his skin, trying to dry the area as rapidly as was possible. He seemed to be particularly bothered by the water dripping on his head and didn't like the feel of it in his blonde curly hair – problematic since, like most toddlers, he wasn't interested in wearing a hat.

I started to notice other sensory issues with Finnley at about this time – he was fifteen or sixteen months of age now. He didn't seem to like the “feel” of some of his clothes, stripping them off quite regularly and preferring to be naked. It was funny when he was this young and, often, when he stripped down to his diaper, if there were other kids of the same age around, they would do the same. However, it wasn't so funny when he was four or five years old (when he could fully remove *all* of his clothing) and it would happen in public, not in the privacy of our backyard. Finnley was particularly bothered by the tags inside of his clothing and by the seam-line in his socks. I quickly learned to turn his socks inside out for him so he wouldn't feel the seam; and,

cutting tags out of new clothes or the hand-me-down clothing we got from relatives became the norm in our home.

Meanwhile, I'd become quite good friends with a couple of women at "Baby Talk," which helped to ease the loneliness and the lack of mental stimulation. They both had boys of the same age as Finnley, and we were of similar age and education. Our families got together every Friday night for what we came to call, "Kids and Coma" – "kids" for the obvious reason, and "coma" because we enjoyed drinking wine together. We would order take-out food and laugh about what our boys had gotten up to that week. It was really nice to connect with other moms who were struggling to parent too, and, luckily, our husbands seemed to enjoy each other's company as well.

Unfortunately, Finnley would make this Friday night social time quite challenging sometimes. He seemed to get very "wound up" by the other two boys and had difficulty controlling himself. Invariably he would injure one of the other two children – not seriously, but just enough that we had to keep a closer eye on him than would be expected or than the other parents would have to do with their sons. It wasn't that Finnley meant to hurt the boys – or, in the beginning, at least, this is how we interpreted his actions – more that his lack of spatial awareness and his insatiable curiosity somehow caused injuries to the other children to occur. Sometimes I could almost see him trying to figure out "cause and effect" in his little brain – he would want to know what would happen "if he did something," in an almost scientific way, and would conduct his "experiment" accordingly. I am not certain he had an intended outcome in mind, a hypothesis that he was attempting to enact; but, more and more, his actions seemed to be becoming more controlled and calculated when it came to interactions with others.

Scotia was born at the end of September, five days after her due date. Finnley was now eighteen months of age. Compared to Finnley's birth, Scotia's was much less traumatic – though more painful since there was no epidural or caesarian section. The time in the hospital was much shorter as well. With Finnley there had been a full five days of recovery time after his birth; with Scotia, it was less than 24 hours. I did have a much better understanding of what to expect both about her and about my body. What I had little to no understanding of was the effect that Scotia's birth would have upon Finnley.

Apparently, most young children suffer from sibling rivalry after a new baby is brought home – so I'd been told by other mothers, anyway. Often,

apparently, there is initial excitement at the birth of “their baby”; but, at some time or another, the novelty wears off and the older sibling wants to “return” the infant – for “that baby” to go away and not come back any time soon. I expected this response from Finnley. I was as prepared for it as one could be. What I didn’t anticipate was the intensity of his anger and the level of violence that was directed toward both Scotia and me.

Finnley bit, Finnley hit, Finnley kicked, and Finnley threw things – he did whatever he possibly could to make plain his anger and frustration that this baby was in our lives. I would barricade Scotia and myself in one room, using baby gates that Finnley couldn’t open or climb over (yet), so that I could breastfeed her without him pulling my hair, hitting Scotia, or trying to bash her in the head with one of his toys. With the gates in place, I was still able to watch him to make sure that he was safe, but he couldn’t get to us so that *we* were safe. Finnley would howl and scream in frustration, hurling toys at us from the other side of the gate. His surprising strength was countered by his (usually) poor aim – meaning that, for the most part, we were unharmed and it was the walls and the furniture that bore the brunt of his anger.

Unfortunately, I didn’t have the time or the energy to be particularly sympathetic to his needs. I did the best that I could, but there were health issues with Scotia that complicated matters and preoccupied me. She had a hemangioma that had begun to grow on her lower lip the day after her birth. It had ulcerated from the pressure of her lip on my breast as I fed her; and, consequently, Scotia had developed *Staphylococcus Aureus* (a staph infection). I was required to give her medicine of some sort every few hours – alternating between treating the staph infection and attempting to stay the growth of the hemangioma. It also appeared that I was suffering from post-partum depression.

The medication that Scotia was put on to shrink the hemangioma left her highly vulnerable to air-borne illnesses. The specialist at Children’s Hospital compared her immune system on the medicinal steroid, Prednisone, to the level of susceptibility of a person with AIDS, informing me that we should avoid public places as much as possible. I remember asking, “What if I have to go the grocery store?”

She had looked at me rather dubiously and stated, “If you really have to go, and you really have to take your daughter with you, then if you see someone cough or sneeze in the same aisle as you, turn around and walk as quickly as you can in the other direction.”

Needless to say we didn't get out much in the six months that Scotia was on the medication.

My life, as I knew it, was cycling away from me fast, and I could feel the edges of my sanity being pushed and prodded. I hit an all-time low. Phil was working incredibly hard in the Resource Room at a high school in Delta, he was also just completing his Master's degree at UBC, and I was at home with a sickly infant and a toddler who was displaying some rather troubling tendencies.

I took the children outside as much as possible – for my own sanity more than anything else. While I couldn't interact with many people, at least I could see them from a distance as we wandered along the various paved pathways of New Westminster. Finnley was happy to run alongside the stroller and, as long as we didn't have to be anywhere at any particular time (and usually we didn't – except for the many doctor appointments), we fell into a comforting routine.

Finnley had terrified me more than once on our walks though.

One particularly harrowing time he took off running down the train tracks that ran alongside the bike path that we had been walking along. I had had to stop and feed Scotia along the way (One of the side effects of the medication being that she was exceptionally hungry and needed to be fed every couple of hours.). I was sitting on a bench beside the path, and Finnley was happily ensconced in a pile of dirt – until, suddenly, he wasn't playing in the dirt anymore and, instead, was running down the train tracks, away from me.

I couldn't hold both kids at the same time – I wasn't coordinated enough to have an infant in one arm and a decidedly wiggly toddler in the other – and if I had been, Finnley would have taken the opportunity to injure Scotia if he had been that close to her; so, I quickly placed Scotia, crying and hungry, into the stroller, only to realize that I couldn't take the stroller on the train tracks. Meanwhile, Finnley was running farther and farther away from me. He was nearing a curve in the path and soon I wouldn't be able to see him anymore . . . so I had to *leave* Scotia in the stroller alone and run after him. We were out of sight of Scotia before I finally caught up to him.

For weeks afterward, I had nightmares. What if a train had come? What if someone had come along and taken Scotia? What if . . . ? My head would spin when I considered what could have happened.

This did nothing to help the post-partum depression.

When the weather turned nasty in November, I couldn't take it anymore. For lack of a better term, I think I had a nervous breakdown. Now I had a sick baby, an angry toddler who ran me ragged, and we were trapped in the house because my son was afraid of the rain and I was afraid he would run away. Thankfully, one of my cousins had the time and the impetus to help.

Selena flew from Ottawa to come and live with us for two months. She basically interrupted her own busy life to take on the full-time job of entertaining my son during the day so that I could focus my energy on feeding Scotia, giving her the medication she needed, and getting some much-needed rest. I didn't ignore my son. I just couldn't cope with both children at the same time. Selena would look after one or the other, so that I only had to concentrate on one of them at a time.

I hadn't had an uninterrupted night of sleep in nearly three years now. Between the two pregnancies, Finnley's affinity for night-wakedness, having to feed Scotia every couple of hours when she was on the medication, and the anxiety I was feeling (particularly after the railroad track episode), sleep was a precious commodity for me. But, with Selena there to help, I slowly regained my sanity.

I started seeing a psychiatrist, Dr. Mauri, who specialized in post-partum depression. She helped me to work through my anxiety about Finnley's behavior, my stress about Scotia's sickness, and my personal battle with depression. She also put me on the anti-depressant, Paxil. This made a marked difference in my ability to cope with my stress-filled life and lifted me out of the heavy fog in which I had been slowly sinking. I suddenly had my energy and zest for life back; I felt optimistic about things again; and, decidedly more able to cope.

I remember Phil once saying to me, a couple of weeks after I'd begun taking the medication, *"Vandy, I never thought that you'd needed the meds until you were on them. They've made you more 'you'."*

And that's how I felt. I wasn't "different" on the medication; I was "myself" on the medication. It made me think about how different things could have been for my father had he been placed on medication for his own depressive episodes . . . and it made me look at my son in a different light.

I started to notice things about Finnley that I hadn't fully considered before. And, increasingly, I saw similarities between my son and what I remembered of my father. There was the struggle with sleeping, the irritability

in the morning, and the “switch” that seemed to flip in both Finnley and my father where one minute they would be laughing and smiling and, in the next, sullen and moody – though this negativity manifested itself as anger and violence when it came to my son. They would both be so focused on things at times – to the exclusion of all else – and, dare I say, manic in their single-minded approach to things of interest. Then, in the next instant, they would be staring off into space, not really “seeing” me, even if I were standing directly in front of them, waving my hand in front of their eyes.

Then there were the things that were decidedly different. Whereas my dad seemed to crave adventure and change all of the time, Finnley insisted upon routine and familiarity. His food issues were even more pronounced now, and he would only eat the same things every day. He continued to be petulant, particularly regarding his sister; and, perhaps, even more troubling, he seemed to be increasingly disinterested in being held or hugged – he would actually stiffen if Phil or I would try to embrace him.

And yet, Finnley was, at other times, quite wonderful to be around: he’d laugh, smile and seem to genuinely enjoy our (and other’s) company. He really could be very sweet and affectionate – but I slowly came to realize that it was always on his terms. Finnley would come up to Phil or me and turn his back to us, pressing into our bodies. He wanted the connection, the physical touch, but he didn’t seem to be able to cope with the sensory stimuli of that touch. It was pressure that he craved, somehow – deep, constant pressure. Sometimes he would crawl onto my lap, but he wouldn’t “settle,” the way other children would. He constantly wiggled and *pressed*. Hard. Sadly, there was never any relaxing into an embrace with Finnley; there always seemed to be an air of violence about it somehow.

Finnley had taken to lining up the books on the floor, making long, thin pathways throughout our house. He would do all sorts of “ordering” like this: be it with books, plastic containers, cutlery, plastic dinosaurs, his trucks or cars – whatever he could get his hands on. Everything was systematic and arranged in clear, organized patterns. There seemed to be no joy in actually playing with these things or with the people around him. It was all very mechanical and purposeful, as if Finnley “had” to do it.

Finnley’s fixation with wheels also continued. He loved spending time at construction sites, watching the large trucks moving back and forth and the (again) organized and systematic pattern of the digging. He didn’t like the jack

hammers (Does anyone?) and would become quite agitated if we were too near to one for very long. And, I noticed that he would become particularly aggressive after being near this very loud and irritating sound for any length of time.

Finnley could tell you the names of all of the types of construction machines and regularly recited them for anyone who was close enough to hear. Not surprisingly, Scotia's first word was "backhoe" ("ba - oh"), a type of tractor. Overall, Finnley was quite articulate, compared to other children of his age, and he spoke clearly, and often. Well before the "typical" time when children begin to ask questions, Finnley was regularly asking "Why?" about all sorts of things. He had an exceptional memory and could easily repeat snippets of conversation that he overheard or segments of dialogue from videos he watched on the television. What was particularly interesting was that if someone, by accident, happened to say even a single word that a character in one of his *Thomas the Tank Engine* videos had said, this would send Finnley off on a long monologue wherein he would basically repeat, verbatim, what the character in the show had said. It didn't matter whether what Finnley was saying was connected to the actual conversation that had been interrupted, it was as if a "switch" had been activated by Finnley's brain wherein he would hear something and it would trigger an almost mechanical response within him.

The other odd thing about Finnley's language was the strange vocalizations he made all of the time. He couldn't seem to be quiet or handle any sort of silence. Again, there seemed to be this insatiable "need" in him to fill the calm somehow – usually with odd squeaks or squeals. I noticed that if there was a lot of noise around us, it would actually cause him to get louder with these weird noises he liked to make – as if he was trying to drown out the excess of sounds around him with his own volume; and yet, quiet also caused him to react as well, by filling the lack of sound, as if it were equally as deafening to him.

By this time, Finnley had also become very interested in trains and train tracks. Again, while these interests are typical of children, Finnley always seemed to take them just a bit "farther" than the typical child. The "collection" was what seemed to please him, the "laying out" of the train tracks as opposed to the playing with the actual trains on the track, the "order" of everything. Whereas Scotia would happily pick up one of the trains and run it around the track, Finnley was not interested in doing this – unless, of course, it meant running a train in the opposite direction to Scotia so that he could make his train smash into hers.

There were other things as well. He wasn't growing out of his anger issues with Scotia; in fact, in some ways they seemed to be worsening. His coordination was improving and, consequently, his aim when throwing things. He could now easily scale the baby gates, and it was becoming increasingly more difficult for me to protect Scotia from him.

While Finnley was more used to Scotia being around, and there were moments when he actually seemed to like her, other issues began to crop up as Scotia began to learn to crawl. She was "getting in his way" more, and I had to watch their interactions even more carefully than before, if that was actually possible. Now I had to constantly be on guard in case Finnley purposely stepped on her hands or pushed her over.

Finnley also now had more opportunity to get into mischief, since Scotia was more mobile and I needed to watch her as carefully as I watched him. Finnley continued to be very active (compared to other children), he still wasn't sleeping much, he continued to be irritated by his clothing, he seemed to be having considerable trouble learning how to do certain things such as dress himself, he'd developed an irrational fear of dogs, and he was becoming increasingly more violent with other children. I would take the two children to the playground, and he would throw rocks at the other kids or hit them for seemingly no reason. He also seemed to be having a high number of ear infections and I was worried that they had, perhaps, damaged his eardrums. I wondered to myself whether this was why he was so loud all of the time and why he didn't seem to hear Phil or me when we were trying to get his attention.

There were so many things that troubled me about Finnley's behavior. If anything, having Scotia had made plain for me exactly how different he was from other children – and yet it wasn't something that I could really explain to anyone in concrete terms. It was about "extra," about "excess," and about "vehemency": he did the same things as other children; but, he did it "more" and "for longer" and "more intensely".

I tried to talk to other parents about it.

I would point out the worrisome behaviours and these kind people would say, *"My son does that too. You don't need to worry."*

I'd reply, *"To the same degree and with the same regularity that Finnley does these things?"*

"Well, no. "

Near the end of August I was in the grocery store, looking at the magazines by the checkout stands as I waited in line. *Time* magazine was on the rack and my eyes were drawn to the cover – a photo of a boy of about seven. The byline beside the photo stated: “Inside the Volatile World of the Young and Bipolar: Why are so many kids being diagnosed with the disorder once known as Manic Depression?” (Kluger, Song et al., 2002, *Time*, 167(15), 3-40). I picked up the magazine, turned to the article, and started reading. Suddenly I was certain that I knew what the matter was with Finnley. I was sure that he had bipolar disorder, like my father. My worst nightmare was coming true.

The article focused upon two families: one with a teenage girl with bipolar disorder, the other with two young children (ages 2 and 5), both who had been diagnosed with the mental illness. According to the article, children are “ultra-rapid cyclers, flitting back and forth among mood states several times a day.” Supposedly, they are “irritable, with a tendency to snap and gripe, or sullen and withdrawn” in the morning; by the middle of the day the children become “wild, wired, euphoric in a giddy and strained way. They laugh too loudly . . . their play has a flailing, aggressive quality to it. . . . They resist all efforts to settle them and throw tantrums if their needs are denied. Such wildness often continues deep into the night” (Kluger, Song, et al., p. 3).

With toddlers and infants, parents would say “they noticed something off about their baby almost from birth, reporting that he or she was unusually fidgety or difficult to soothe.” One woman states that “she knew her son Kyle was bipolar even when he was in the womb. ‘This child never slept inside,’ she says. ‘He was active 24 hours a day.’” (Kluger, Song et al., p. 4).

I thought back to my pregnancy, how active Finnley had been in the womb, constantly doing entire flips (Is it any wonder that the umbilical cord got so wrapped up around his neck?); I rapidly cycled forward to his conduct now. I was certain that this explained Finnley’s aggressive and moody behaviour, and I was determined to have him tested. If they could diagnose bipolar disorder in the two year old in the article, they could diagnose my son too. I called my doctor as soon as I got home from the store and arranged an appointment for the following week.

Now, normally when I would take Finnley out in public I would do my very level best to control him – I didn’t want to draw attention to the fact that his behaviour was troubling: I would ply him with crackers or other crunchy

foods that he liked in order to keep him quiet; and, as much as possible, I kept him “busy” so that he wouldn’t find ways to make himself “busy.” I didn’t want people to think that I didn’t know how to handle my son (though it was becoming increasingly clear to me that whatever I’d been doing, up until this time, wasn’t working); and I didn’t want them to judge either him or me. I was embarrassed by my son’s behavior. There was no question about that. And, I was dismayed by people’s responses to it and the disdain with which they looked at me.

I let Finnley run ahead into the doctor’s office while I wrestled with Scotia’s stroller. At other times, I would have either strapped him into the stroller too (It fit the two of them.) or left Scotia with someone else so that I could focus all of my attention on Finnley and his boundless energy. As it was, I was only about fifteen seconds behind him – long enough, though, for him to completely clear the coffee table of all of the magazines, sending them sailing onto the floor, and for him to jump up on top of that table. The receptionist glared at me as I entered, as did the other people in the waiting room. I didn’t care. I *wanted* these people to see what Finnley was truly like; they would be my witnesses as I presented my case to Dr. Maki for why Finnley needed this test.

I calmly said to Finnley, *“Please get off of the table, Finnley. We jump on the floor, not on table tops.”*

He ignored me.

Again, I said, *“Finnley, we don’t stand on tables. I need you to get off of the table right now.”*

Again, no change.

“Finnley. You have two choices: either you can get off of the table yourself, or I will help you get off of the table.”

Scotia starts crying in the stroller. She has just woken up. Finnley is now *kicking at* the people sitting in the chairs behind the coffee table. I pick him up. He starts shrieking and is doing his very best to get away from me. Remember: he doesn’t like to be touched, unless *he* has decided that he wants it to happen.

I put Finnley down and hand him a toy car to play with, directing him to the small play area in the waiting room. I pick Scotia up out of the stroller.

Finnley immediately rushes over and hits Scotia on the head with the car. Scotia starts crying harder. I look at the faces of the people around us in the waiting room. Their distaste is palpable.

I lay Scotia on the floor, pick Finnley up, and wrestle him into the stroller, strapping him in. He is screaming now. Anger doesn't even begin to describe the emotion that he appears to be feeling. I am past caring. We have been in the waiting room for less than ten minutes and already I am so embarrassed that I want to die.

The nurse calls us in.

I pick up Scotia and place her in the stroller as well, wheeling both screaming children out of that waiting room and into the sanctity of a private examination room. I quickly release Finnley from the stroller and he, literally, goes ballistic.

He shreds the paper on the examining table, he hurls the magazines in the rack beside the chair onto the floor and then he begins to fiddle with the light switch, all the while still shrieking. By this time the nurse has returned to see what all of the commotion is about. She stands there, looking somewhat dumbfounded, as I let my son continue on his bent of destruction. Ignoring the nurse, I calmly lift my sobbing daughter out of the stroller and attempt to comfort her, all the while keeping out of the way of my whirling dervish of a son.

I am waiting for the doctor. I want Dr. Maki to see Finnley in all of his devastating glory.

He does.

I hand Dr. Maki the article and say, *"I want him tested."*

"Vandy, I don't think your son is bipolar."

Finnley is now standing on the chair, yanking on the cord for the blinds covering the window.

"Well, what is it then? I want him tested. I can't take this anymore."

Finnley has now jumped down from the chair and has crawled into the storage space *below* the seats in the stroller.

"Well, there's definitely something going on with him. There's no question about that. I don't think he's bipolar, but there's definitely something."

Dr. Maki writes something on his prescription booklet. Finnley has now discovered that the paper for the examining table is connected to a large roll of it at the foot of the table – he begins unrolling it.

“This is a recommendation for him to see a child psychiatrist at Children’s Hospital in Vancouver. Give it to the receptionist and she’ll call to arrange an appointment for you.”

“You’re sure he’s not bipolar?”

“No, I’m not sure; but I don’t think so. The psychiatrist will know better than me.”

Dr. Maki gently stops Finnley from unrolling the paper. He tries to talk to him. *“How are you, Finnley?”*

“How are you? How are you?” Finnley repeats.

“I’m fine, thank you, Finnley,” Dr. Maki responds.

“I’m fine, thank you; I’m fine, thank you,” Finnley says as he begins to play with the light switch again.

“It’s definitely something,” Dr. Maki says, as he hands me the paper. He notices the red mark on Scotia’s head from the toy car incident in the waiting room.

“Did he do this?”

“Yes. He hurts her all the time. And, me too.”

“Yes, it’s definitely something,” he said, shaking his head. *“I just don’t know what.”*

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Chapter 2

ALMOST A DIAGNOSIS

It was a few months before we finally had our first appointment with Dr. White, a child psychiatrist at Children's Hospital. In the meantime, I persisted in trying to "normalize" my loud, busy and socially disinterested three-year-old son. For me, this "normal" involved continuing to expose him to as many new, interesting and engaging experiences as was humanly possible.

I set up opportunities for him to have "play-dates", I sang to him, and I tried to talk with him - asking him questions and picking up upon any expressions of interest he appeared to show me. I provided plenty of chances for him to jump in mud puddles, to climb on playground equipment, and to participate in music and gymnastic lessons. I regularly read to him, I attempted to increase his vocabulary by having him name things as I pointed to them, and I encouraged him to colour and to draw - all, of course, attached to my understanding as a teacher of the importance of "school readiness", my embodiment of the role of Finnley's primary caregiver, and the ever-constant voice inside my head reminding me that "children who grow up in a stimulating environment have the best chance for a good start in life" (Government of British Columbia, 2009, p. 1).

And, as much as possible, I tried to ignore the worries that were continuously circling in my head about my son's seeming lack of concern for others and his continued straying from the "expected social behaviours" of those of his age grouping.

According to *Toddler's First Steps: A Best Chance Guide to Parenting Your 6 - 36-Month-Old Child* (2009), Finnley should have been a "social butterfly" (p. 44) - particularly since he was now nearing *forty-two* months of age... The government handbook states:

Between 24 to 36 months, your toddler will become sociable and want playmates. Gradually, he will develop the skills to play with another child.

Make sure you are nearby to help him solve possible problems when playing with other children.

Your toddler will also show much more imagination. Encourage imaginary play; join in and expand the play with questions. This is also a good time to supply dress-up clothes and props (p. 44).

This was not happening. Not by a long shot.

I continued to be concerned by how easily and readily he could (and would) hurt other children and also by how limited he seemed to be in the types of play in which he would engage: it was digging; it was laying train track; and, it was lining up dinosaurs. People were so inconsequential to his play – even me, his own mother. He seemed to be happy enough to have me join him in whatever it was that he was doing and appeared to enjoy “directing” me; but, really, I truly believed that he would have been just as happy if I wasn’t there too. He liked having an audience, and would quite easily substitute one captive adult for another; however, this audience had to be exactly that – an audience – they were not allowed to engage in the play, and if they attempted to do so, Finnley made it very clear to them that he would prefer to play alone. For Finnley, it was about the “thing” he was playing with or the “thing” he was doing. There seemed to be no imaginative play, no “pretend play,” no “acting out” of anything. It was strictly about what was in front of him, in the present, in the here, in the now – there was no “what if” in any way, shape, or form.

While “parallel play” is still considered typical behaviour for three-year-olds, for many children this is the time when they begin learning to interact with others. And, a single-minded focus on a particular activity isn’t a bad thing; in fact, we actively try to encourage this ability to remain concentrated on one thing at a time, particularly once our children are in school. And, Finnley did interact with other children – in particular, his sister; and he did engage in “play.” But, again, it was just a bit “off”: the energetic flavor of it, the general lack of curiosity about other people, and that disconcerting violence.

I continuously tried to interest Finnley in other children, actively introducing myself and him to other children and parents we met at the playground. As well, we had maintained the Friday night tradition of getting together with the other two moms and their husbands and sons. (We’d changed the name of our club from “kids and coma” to “kids and chaos” since Scotia was now included in the mix and the three boys were decidedly more

energetic for longer, and later, into the evening than they had been only a year earlier.) I also registered Finnley for preschool at Queen's Park Parent Participation Preschool. This meant lining up at 4:30 a.m. on a very cold February morning in order to secure a spot in the much-sought-after preschool for the coming September. But, I didn't care. I was determined to enroll Finnley in preschool. He needed it; and, perhaps, more significantly, *I* needed it.

Queen's Park Parent Participation Preschool (QPPP) was established in 1965. Like other Parent Participation Preschools, the philosophy behind the preschool is play-based and family-focused, as opposed to academically organized and structured. I was certain that Finnley would enjoy the focus on playing. As far as I was concerned, play was the "work" of children.

According to the QPPP website:

Play provides opportunities for young children to learn about their world through:

- Discovering
- Constructing
- Questioning
- Reasoning
- Testing
- Imitating
- Communicating
- Interacting
- Having fun

I appreciated the inclusive and accepting manner of both of the teachers, Janet and Laura. They truly seemed to embrace the philosophy that the preschool subscribed to:

We believe that children learn through doing.

Our teachers act as facilitators of play, promoting positive interactions with peers, and offering gentle guidance when necessary. They strive to provide a safe, nurturing, accepting, environment which encourages spontaneous play and fosters self-esteem. Open-ended materials, creative spaces and unique experiences, are made available so that the children can learn and be curious about the world around them. As much as possible, the program is child-centred and grows out of the children's interests and abilities. (Retrieved from www.qpps.ca/about.html on 04/14/2012 at 5:02 p.m.)

I liked that the teachers perceived themselves as "facilitators" and that they strove to not only promote peer interaction but also offered "gentle

guidance” – if there was ever a child who would be in need of that direction, it was my son.

The preschool is nestled in the heart of Queen’s Park in New Westminster and the beauty of the forested natural environment was an added bonus. I pictured Scotia, Finnley, and me spending time before and after preschool either at the spray park, the petting zoo, on the playground equipment or exploring the wooded areas of the park. Meanwhile, the preschool, itself, was well-equipped: there was climbing equipment, a water table, a sand table, a play dough table, a workbench with real tools, a pretend “house” area with “dress-up” clothing, a carpeted area for quiet reading and “circle time,” another carpeted area for self-directed play such as trains or blocks, there was a craft of some sort organized for each day, an enclosed outdoor play area, and lots and lots of books and puzzles. As far as I was concerned, it had all of the “gear” that a preschool-aged child could possibly want and/or need.

I was also very excited by the focus on family and the participatory element for the parents – parents were required to do “duty days” a few times a month (organizing the craft or the snack or assisting the teacher, while having the opportunity to play with both their child and the other children in the preschool). This meant that the child to adult ratio was very high: four preschoolers for each adult. I thought that this was reasonable – given the age of the children – and, hopefully, that it would help to set Finnley up for success: I couldn’t imagine him in a preschool class with only a single adult in the room. That adult would never survive.

The parents of children registered for the school were also required to attend “parent education” evenings once a month and were directly involved in the organization and running of the non-profit preschool. I liked this “hands-on” approach, and it strongly aligned with my belief that parents should be directly involved in the education of their children. I also liked the fact that the teachers kept discussing the longevity of the relationships that had begun in the preschool. Laura’s own son had attended the preschool, and she said that she and the women she’d met during the two years that her son had attended the school still got together, and that the children that Derrick had been friends with during preschool remained his friends to this day – some twelve years later. This was corroborated by other women I met in the neighbourhood whose children had attended, as well as grown men and women whom I met who had attended the preschool themselves.

I realized that Finnley (and I) needed help with socializing him, so preschool would be beneficial for him. I also realized that it wasn't going to be an easy fit and that, likely, the parents of the children in his class wouldn't be very happy, to put it mildly, if Finnley hurt their child. While there were other play-based preschools in the neighbourhood, this was the only parent participation preschool in New Westminster, and I knew, for Finnley's sake, that Phil and I needed to navigate the stormy waters of relationship-building for him, considering Finnley's inclination for violence. My theory was that if the parents met Phil and me that maybe, just maybe, they would see that we weren't awful people and that then they would give Finnley (and us) the benefit of the doubt. Call it mother's intuition, the added benefit of being a high school teacher, or just plain luck, but I also knew that if Finnley had any hope of being accepted by his peers further on down the line, that the assistance we could give him now, at this early age, was absolutely essential.

Preschool was valuable for Finnley, for Scotia, and for me. I appreciated feeling "useful" and "competent" again, Scotia thrived on having my sole attention for those four hours per week while Finnley was at school and I wasn't "on duty," and Finnley appeared to be enjoying the business and busyness of the school. He still continued to play on his own; but the other children seemed to appreciate his train track-building capabilities. And, as long as they didn't interfere with what he was doing, he seemed to be managing to control himself fairly well.

It was about this time that Finnley began to fight going to the washroom. Toilet training, on the whole, had been fairly inconsequential and, for the first few months after he had learned to use the "potty" and then the toilet, Finnley seemed to be quite proud and eager to do so. As with so many things with Finnley, I don't know why it changed – if there was a particular event that I, somehow, missed or if it was that darn "switch" in his head again. Whatever the reason, Finnley eventually decided that he didn't want to go to the bathroom anymore.

As is to be expected, there were other children of Finnley's age who also would wait too long "to go" – usually because they were so wrapped up in what they were doing or playing, or didn't want to miss what was going on. And, again, as was now *our* usual, it was a bit different for Finnley. For him, it was as if he was angry that his body would do this thing; that he was frustrated because he didn't have control over it; that it was an internal battle that Finnley

would have with himself. Eventually (obviously), his bowels would win; but this war would be waged multiple times each day – and, more often than not, he would require a complete change of clothes because of it.

Picture a young child pushing violently on his abdomen, as if the pushing could possibly prevent the inevitable from occurring . . .

“Finnley, you need to go the bathroom.”

“No, I don’t!”

“Finnley, your body is trying to tell you something.”

“No, it isn’t!”

“Finnley, can I hold that shovel for you while you go to the bathroom?”

“I don’t need to go!”

“Finnley, you’re pushing on your stomach really hard. Are you sure you don’t need to use the toilet?”

“NO!”

Eventually, the “moment of truth” would arrive and he would rush towards the bathroom; sometimes making it on time, sometimes not.

And the same conversation would occur about an hour later.

It was this issue with Finnley’s bowels, combined with his sensitivity regarding the clothing and the rain, his proclivity for noise-making, his dislike of having dirty hands, as well as his insatiable need for deep pressure and yet, at the same time, his disinterest in being touched that led Dr. White, the child psychiatrist, to first diagnose Finnley with a Sensory Processing Disorder (SPD), a few months after we finally saw him at Children’s Hospital.

This diagnosis was confirmed by two specialists: an occupational therapist at Children’s Hospital who performed a detailed assessment on Finnley – diagnosing him with “regulatory disorder type 4,” noting “he has intense responses to auditory and tactile sensory input and this as well as other factors contribute to him being emotionally reactive, inattentive and distractible”; and, a speech and language pathologist – “he presents with possible hyperacusis (hyper-sensitivity to environmental noises).”

According to Carol Kranowitz, educator and author of *The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder* (2005), Sensory Processing Disorder is described as follows:

The inability to use information received through the senses in order to function smoothly in daily life. SPD is not one specific disorder . . . but rather an umbrella term to cover a variety of neurological disabilities. SPD is also called Sensory Integration Dysfunction (SI Dysfunction) and Dysfunction in Sensory Integration (DSI). (p. 9)

According to Kranowitz, an occupational therapist by the name of Dr. Jean Ayres was the first person to identify and describe sensory problems as resulting from “inefficient neurological processing” (p. 9). In the late 1960s, Ayres apparently developed a theory she called Sensory Integration Dysfunction to explain the unusual responses of some of her patients to sensory stimuli. Kranowitz states that in 2004, Dr. Lucy Miller and a committee of other focused individuals took Ayres’ work and re-classified the various diagnostic groups of SPD into three subtypes: Sensory Modulation Disorder, Sensory Discrimination Disorder, and Sensory-based Motor Disorder.

According to Kranowitz, Sensory Modulation Disorder is the most common category of SPD with issues relating to “touch,” “movement and balance,” and “body position and muscle control” being the most common signs of modulation challenges. Interestingly, the issues can manifest as being “over-responsive,” “under-responsive” and/or “sensory-seeking” with regard to the stimulus. For instance, Finnley was “over-responsive” to touch in that he generally avoided it, and reacted with a “fight or flight response to getting dirty; to certain textures of clothing and food, and to light, unexpected touch”; however, he appeared to be “over-responsive,” “under-responsive,” and “sensory-seeking” all at different (and equally frequent) times when it came to his ability to modulate his movement and balance. Regarding his body position and muscle control, Finnley seemed to be “sensory-seeking” in that he craved being “pressed” and sought “heavy work and more vigorous playground activities than others”(pp. 14–15). As well, his over-reaction to sound and taste pointed to a clear Sensory Modulation Disorder.

Finnley had other sensory issues as well that appeared to point to this SPD diagnosis. He appeared to have Sensory Discrimination dysfunction that was connected, in particular, to his body position and muscle control, meaning that he would press with too much force when holding a pencil, for instance, and would “bump, crash, and ‘dive bomb’ into others in interactions” (p. 17). He also demonstrated Sensory-Based Motor Disorder with both postural disorder and dyspraxia. This explained how “tense” he always was, how easily

he would lose his balance, his difficulty with bilateral coordination, his “poor motor coordination” and how “awkward, clumsy, apparently careless and accident prone” he was (pp. 19-20).

As far as Dr. White was concerned, these sensory issues were the root of all of Finnley’s emotional and social challenges. They explained his resistance to going to the bathroom, they explained his resistance to sleeping, they explained his resistance to change, and they explained his general inflexibility. What they didn’t explain was why Finnley didn’t seem to *care* about the people he lived with or demonstrate any significant interest in them . . .

The process for helping Finnley cope with his sensory issues, according to Dr. White, was to cease putting him in situations where he would encounter the sensory stimuli that caused him to “act out” and then, one at a time, slowly introduce the stimuli that caused concern back into his environment in order to acclimatize him to it. Obviously, there were some sensory problems that were easier to work with than others.

We decided to focus on his over-responsiveness to touch first. Our hope was that by attending to this area – where he seemed to crave the deep pressure but shrunk away from light touches or hugs – that it would begin to alleviate his need to crash into things, break things and hurt people.

Finnley began seeing an occupational therapist on a weekly basis: she would come to our house and play games with Finnley; she would roll him up in a carpet to give him smooth, even pressure everywhere on his body; and, she would work on his gross and fine motor skills by playing games with magnets with him. Other times we would go to her office where she had special equipment such as a swing hung from the ceiling (this was used to supposedly help develop Finnley’s body awareness), or she would rub different textured sponges on him, and/or she would have him move through an obstacle course. All of these activities were arranged in order help Finnley’s brain to modulate the sensory stimuli he was encountering.

Phil and I worked with him as well. We began by using deep pressure on Finnley – sometimes by almost lying on top of him. This had the immediate effect of calming him down. Then, we could slowly “lighten” the pressure until it was a back massage, or a backwards hug (Finnley would press his back into my front.). From there, we could sometimes graduate to lighter touch without him becoming too tense or over-stimulated. And, at night, we would bind him tightly in his blankets.

I would like to be able to say that it made a difference. And, I think it did in a very small way. For once, Finnley was letting us control how we were physically interacting with him. This was definitely a positive step in our minds. Did it change how he interacted with others or his environment? Very little.

It seemed, however, that as we attended to some of Finnley's more troubling sensory challenges that other issues were beginning to develop. For instance, while we sought to help him to cope with "touch" and his tendency to "crash" into people and things through the exercises that the occupational therapist suggested, Finnley began to seek out other sensory stimuli, such as by chewing on his shirt. The front of Finnley's shirt would regularly be soaking wet up by the collar, and he actually chewed holes through a number of them. Was this behavior better? I suppose so because he wasn't hurting others when he was busy doing the chewing. However, it wasn't as if the one anti-social behavior had replaced the other; we just seemed to have added another challenge to the mix.

It was also about this time that the "honeymoon period" of preschool had begun to wear off. Finnley's preschool teacher, obviously, had noticed his odd behaviours and was somewhat concerned by them – as were many of the parents. Janet, his teacher, realized that Finnley had significantly more difficulty regulating himself than the other children in the class and that he was increasingly becoming more destructive (either by smashing things, throwing toys, or damaging things that other children had built). As well, she commented upon how exceptionally loud he was.

I told her that we were seeing a child psychiatrist and that Finnley had been diagnosed with a sensory processing disorder. Janet became excited. We could apply for funding for an aide in the classroom to assist Finnley with his sensory challenges. This would alleviate some of the concerns that had been expressed by other parents, it would take the pressure off of Janet to be constantly watching Finnley and, most importantly, this aide could actively support Finnley to navigate some of the social issues he was beginning to have at preschool.

I have to admit that I was hesitant at first. I think I still wanted to hold onto the idea that Finnley would learn to manage his behavior on his own. However, other things were occurring at home and on the playground that made me wonder if this would ever actually be possible. I agreed to fill in the

requisite paperwork. And, a month later, Carrie Angel was there at the preschool to work with our son.

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I am picking Finnley up from preschool. Carrie comes over to speak with me.

“Vandy, I’d like to try using social stories with Finnley, if that’s okay. I think it will help to reinforce some of the behaviours that we are attempting to teach him,” she says.

“Um, okay. If you think it will help,” I reply.

I have no idea what social stories are, but I figure they must be some sort teaching strategy that teachers use with preschool-aged children with social challenges. I “google” “Social Stories” that evening and discover that it is a trademarked name for a teaching practice that was initially developed by Carol Gray, a public school teacher from Michigan who eventually specialized in working with children with Autism Spectrum Disorder.

According to Carol Gray in “What Are Social Stories”:

A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social Story™ is to share accurate social information in a patient and reassuring manner that is easily understood by its audience. Half of all Social Stories™ developed should affirm something that an individual does well. Although the goal of a Story™ should never be to change the individual’s behavior, that individual’s improved understanding of events and expectations may lead to more effective responses. (Retrieved on 4/29/2012 at 1:16 p.m. from <http://thegraycenter.org/social-stories/what-are-social-stories>)

I can see why Carrie would want to try using some of these stories with Finnley. I talk to her the next day.

“Carrie, I’m wondering if we need to write our own. I’ve tried reading Finnley books where the character is acting the same way that Finnley does, but he doesn’t seem to ‘get’ that I’m talking about him – even if I try to deconstruct it for him after the fact.”

“OK. I didn’t want to use the traditional Social Stories format anyway. I was thinking that I’d just create mini-comic strips of what’s happening in class and what he should be doing.”

“Sounds good to me! Thank you!”

With Carrie working so hard to help him at school, I felt more ready to attend to some of the more problematic behaviours at home. Phil and I had pretty much always used very explicit instructions to try to teach Finnley what we expected of him – we actually used this teaching strategy with both children. However, modelling of expected behaviours seemed to be completely lost on Finnley. At first, I attributed this to his age; but, the fact that his two year old sister easily recognized the social cues that Finnley always missed made us realize that we had to be crystal clear with him and not “presume” anything.

The first behavior we chose to tackle was Finnley hitting Scotia. While we did our very best to prevent the hitting from happening in the first place, we weren’t always successful – in fact, on a daily basis, we weren’t successful. The pattern that came to be established was that Finnley would hit Scotia, Scotia would cry, and then we would tell Finnley that he was to say, “I’m sorry I hit you, Scotia” and bring her one of her stuffed animals to assist in comforting her.

I remember the shock I first felt when I realized that Finnley truly didn’t understand the lesson we were trying to teach him about hurting Scotia and apologies . . .

“NOOOOOO!!!!” I yelled.

Too late. I realized that the gate was unlatched at the top of the staircase and that my eighteen-month-old daughter had pushed it open.

I got to the top of the staircase just in time to see Scotia’s last few moments of freefall.

Thank goodness she didn’t land on her head on the concrete floor.

Scotia is crying – thankfully, from the fright, more than anything else; but, I can see a bruise developing on the small of her back.

Finnley rushes over with a stuffed rabbit and says, “I’m sorry I hit you, Scotia.”

Finnley had learned that Scotia's crying was the cue for the response and conciliatory gesture, and not the part that he had played in causing the crying in the first place.

Again, I attributed this lack of understanding to his age (almost four). However other similar "miss-understandings" would occur that caused me to have to re-think this . . .

We are at Queen's Park.

"Finnley, if you want to play with that boy, you can't throw rocks at him."

I take the rock from him. He stops.

We are at Hume Park.

"Finnley, if you want to play with that boy, you can't throw rocks at him."

I take the rock from him. He stops.

We are at Grimston Park.

"Finnley, if you want to play with that boy, you can't throw rocks at him."

I take the rock from him. He stops.

We are back at Hume Park.

"Finnley, if you want to play with that boy, you can't throw rocks at him."

Needless to say there were very few boys at any park we visited who wanted to play with Finnley once he had thrown (and continued to throw) rocks at them. And I couldn't understand why Finnley couldn't seem to learn this lesson. I knew he was intelligent: he could build the most elaborate train tracks (something that the other boys at the preschool really appreciated about him); he had all sorts of elaborate ideas about how to build lots of things, actually; he had an incredible memory; he knew his colours, most of the letters of the alphabet, and how to write his name; and yet, for all of his apparent intelligence, he couldn't seem to figure out how to make this seemingly obvious relational connection.

We are at Dr. White's office. Finnley is repeatedly taking the "mother" and "sister" dolls from the dollhouse and either putting them in the closet or running over them with one of the trucks. It's hard not to read something more into this behavior than is actually there.

"Finnley, why are the mommy and the little girl in the closet?"

"They like it in there."

"Why would they like it in there?"

"They just do."

It was supposed to be our last appointment with Dr. White. We had our diagnosis, sensory processing disorder; and, supposedly, we were on the path to helping Finnley to modulate the stimuli he would encounter. I wasn't convinced.

"But, he is so inflexible about things."

Dr. White nods.

"Will the chewing on his shirt stop soon?"

Dr. White nods.

"Will he sleep better soon?"

Dr. White nods.

"He seems almost obsessive about things like having clean hands. And when he's doing something that he's enjoying, he has all-out tantrums every time if we need to do something else instead."

Dr. White nods.

"I don't get why he can't learn things that Scotia already understands. Like the thing with the rocks. Why would he continue to throw rocks at the boys he wants to play with – even though we've repeatedly told him that it's inappropriate behavior?"

Dr. White cocks his head.

"He has so much more energy and exuberance than the other kids. And he can't seem to control himself when he's all hyper. And, he keeps hurting himself."

Dr. White leans forward.

"I guess most worrying of all for us is that he doesn't seem to care. He really isn't concerned that he's hurt Scotia or me. He just does it anyway."

Dr. White leaps out of his chair saying, *"How could I have missed this? What was I thinking?"*

He sits down and hurriedly takes out a piece of paper. On it he scribbles *"Anxiety," "OCD," "ADHD," "Lack of Empathy."*

"I'm sorry. I don't think Finnley has sensory processing disorder."

“What do you mean?”

“I don’t know why I didn’t see this before. All of the behaviours . . . when I look at them together. I am so sorry! I should have recognized this sooner. I think Finnley has Asperger’s syndrome. We need to have him tested immediately.”⁷

⁷ **Dear Reader/Listener:** This is the place in my story where you may want to go and read *Story B*. *Story B* will tell you all about the history of autism, the evolution of the definition, and some really interesting things about some pretty amazing doctors and researchers who worked tirelessly to understand “why” and “how” autism has come to be. Thank you.

Chapter 3

THE DIAGNOSIS

Things happened quite quickly once Dr. White had had his revelation. The diagnostic process is quite straightforward and we immediately began to schedule the requisite appointments:

1. Family doctor:

"Hi, Dr. Maki. Dr. White, the child psychiatrist from Children's Hospital, thinks that Finnley may have Asperger's syndrome. We need you to give him a check-up. We also need a referral to a pediatrician."

He examines him.

"Well, that could certainly explain things, couldn't it? He's got the look of a boy with autism, all right."

2. Pediatrician:

"Hi, Dr. Timberline. We were referred to you because our four-year-old son may have Asperger's syndrome. We need you to see if there are any other medical concerns that could, potentially, be masquerading as Asperger's syndrome."

He examines him.

"Well, he's healthy as far as I can tell. But you should get his hearing tested. It sure seems like he has Asperger's syndrome to me."

3. Ear, Nose and Throat (ENT) Doctor:

“Hi. Our son may have Asperger’s syndrome. We need to rule out any other health concerns. He has had many ear infections and we need to be certain that his hearing hasn’t been affected.”

She examines him.

“Well, he is going to need ear tubes; but his hearing is fine.”

In the meantime, Dr. White had two other appointments scheduled for us:

4. Registered Audiologist & Speech Pathologist:

“Hi, I’m Sandy Dogwood. I’m going to be testing your son. We will be doing four diagnostic assessments on him: (1) an Informal Oral Mechanism Examination; (2) the Goldman Fristoe Test of Articulation – 2 (GFTA-2); (3) the Preschool Language Scale – 3 (PLS-3); and, (4) the Social Skills Checklist.”

She tests him.

Finnley’s results were as follows:

- Finnley presented with receptive and expressive language skills within the normal range
- Finnley presented with oral motor structure and functioning with the normal range
- Finnley presented with fluency and vocal quality within the normal range as per observation
- Finnley presented with mild-moderately delayed articulation skills, he was approximately 70-75% intelligible in conversation
- Finnley presented with severely impaired social language skills and understanding of non-verbal language as reported by his mother
- Finnley demonstrated a number of concerning behaviors such as a lack of empathy for others and a lack of awareness for their feelings
- In addition Finnley demonstrated physically dangerous behaviors, such as jumping around and hitting himself on the head when over stimulated, seemingly without regard for his safety or the safety of others. (From the Speech and Language Assessment Report dated October 14, 2004, p. 4.)

5. Psychologist:

"I am Dr. Giffy. We will be performing three different tests on Finnley today: (1) The Wechsler Primary and Pre-School Scale of Intelligence – Third Edition (WPPSI-III); the Vineland Adaptive Behaviour Scales; and, the (3) Behaviour Rating Inventory of Executive Function – Preschool Form (BRIEF-P)."

He tests him.

Finnley's results:

- Finnley presented as a talkative boy who showed interest in the tasks presented but had difficulties sustaining his attention and staying seated. He appeared to work better with non-verbal tasks and grew silly when asked questions, often seeming to have difficulty with more abstract or open-ended questions. His responses could be repetitive, and he showed limited eye contact. He showed little attention to the reactions of others to his behavior, though he could be friendly when he did interact with others.
- Finnley performed in the Average range of cognitive ability over all, showing some difficulty with abstract verbal reasoning and strengths in his concrete expressive vocabulary. There was otherwise little variation between Finnley's scores on the various sections of the WPPSA-III.
- Finnley's adaptive communication skills were in the Moderately Low range in contrast. His communication skills were low in the Adequate range while his daily living, social, and motor skills were in the Moderately Low range, at a three- to four-year-old level, with strengths in his domestic living skills and weaknesses in his socialization and personal self-care skills.
- In the area of self-regulation and executive functioning, Finnley showed weaknesses in inhibitory self-control, flexibility, and early planning, organization, and working memory skills.
- Finnley's assessment scores and presentation are consistent with a diagnosis of Autism. Finnley's cognitive strengths, enjoyment of simple forms of interactive activities, and interest in social contacts with others do suggest positive response to treatment. However, higher functioning children with autism do nonetheless require

support to assist them in developing effective social and communication skills, and benefit from adaptation to help maximize their capacity to achieve in a school environment. (From the Psychological Assessment Report dated February 24, 2005, p. 5.)

It was official. Finnley had Asperger's syndrome or HFA. Suddenly, so many of Finnley's troubling behaviours had explanations – the diagnosis or the label didn't make them any less difficult to deal with, of course, but it did make them more understandable.

LIVING WITH THE KNOWING

There is a grieving process that a parent goes through once their child has been officially "diagnosed" with something. Without consciously realizing you have done so, simply by giving birth to a child you lay onto them a myriad of hopes and dreams. Of course you want them to have what you had and "more" ...

Similar to the five stages of grief that Kubler-Ross (1973) laid out in her seminal text, *On Death and Dying*, parents of children with special needs also grieve over the "death" of their child. In this case, of course, it isn't an actual death over which they grieve; rather, it is a metaphorical death, as they lay to rest the imaginary future that they held in their mind's eye for their child. But it is a "death" all the same.

I remember talking with the principal of my son's elementary school near the beginning of the school year about this process and him describing it as "going on a trip and landing at the wrong destination." That image stuck with me. I have since learned that *Welcome to Holland* is a rather famous essay written by a woman named Emily Perl Kingsley in response to raising a son with Down syndrome (1987):

WELCOME TO HOLLAND

by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability- to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this. . . .

When you're going to have a baby, it's like planning a fabulous vacation trip -to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around . . . and you begin to notice that Holland has windmills . . . and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy . . . and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away . . . because the loss of that dream is a very very significant loss.

But . . . if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things . . . about Holland.

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In the meantime, I had written my own version, inspired by the analogy, as described by Finnley's principal – it's uncanny how similar the two stories are:

Deciding to have a child is kind of like going on a trip to a country you've never been to before but have always wanted to visit. Like France. You begin to dream about where you're going to go and what you're going to do when you get there; you get the guide books, and you figure out what sites you want to see and all of the fabulous things you want to do and places you want to visit within that country; and you're happy, you see, because you've got some time to make these plans – after all, your plane doesn't leave for a whole nine months.

You're all excited about getting to climb the Eiffel Tower, sitting near the Arc d'Triomphe, drinking a latte in a little French café, and going to the Louvre

and finally seeing the Mona Lisa and all of the other beautiful art within its walls. So, you've got your plane tickets, you've got your passport, you've done your research, you've taken some French language lessons and the day comes when you finally get to hop on that plane. You're nervous, obviously; you've never been to France before and the plane trip is a little bumpy. Well, a lot bumpy, actually! But still, it's exciting and you keep reminding yourself that pretty soon you are going to be arriving in France – in Paris, no less.

But, when your plane finally arrives (after many hours), you find out that you're not in Paris; for some reason your plane has landed in Berlin. And, you're shocked. You feel betrayed. Hold on, just a minute – this wasn't what you signed up for. You weren't prepared for Germany. You wanted France. You don't know anything about Germany – other than some not so charming facts about World War II that don't exactly make you love the idea of being here. You don't know any German; you studied French. You don't know about anywhere that you would want to visit. You've heard about the Berlin Wall, but wasn't it torn down? And the concentration camp sites. Would you have the stomach to visit them? And you're angry. And really, really disappointed. Because, you see, you really wanted France. You've dreamed about visiting Paris and riding your bike down the dusty, country roads of Province. And you were really looking forward to drinking some fine French wine and eating brie with a baguette.

But, you're not in France. Not at all. You find yourself here, in this other place. So, you complain to the pilot and the airline service, "This isn't what I planned for. This isn't where I wanted to be." But, here you are and here you stay. And, it's worse, you see, because your friends, who were also planning their own trips, have ended up in the final destinations that they wanted. And you didn't. You're angry. "It's not fair," you think to yourself.

But, you make do. You have to, yes? You start to explore, you struggle with the language, but you gradually make yourself understood, and you settle yourself into a way of being in this foreign land that wasn't what you had planned for but that you have to muddle your way through somehow anyway.

Then, one day, you wake up and you realize that you're happy here. That there are actually some pretty amazing things about Germany and, in particular, Berlin – that it has its own unique flavour that's kind of fun and definitely interesting. And that there is still some awfully fine wine to drink, and lovely bread to eat, and that the people, while they aren't French, are still engaging and funny and loving. So, you become more comfortable. And, although, you still find yourself thinking and dreaming about Paris and France every so often, it doesn't hurt so much anymore. Because you become satisfied with Berlin, and comfortable with yourself in Berlin. Berlin isn't Paris; but, it's its own place. And that's okay.

Now, because things had been less than “ideal” with Finnley pretty much since birth, one would think that I wouldn’t have harboured these same fanciful ideals. Oddly, this wasn’t the case.

I still had pictured my son with lots of friends, doing well in school, perhaps playing some sports, going to university, and ending up in a long-term relationship. I imagined him travelling the world, working in lots of different jobs until he found the one that would “speak” to him. I envisioned him making a difference in the lives of others, working for the betterment of society, volunteering in exotic destinations or, perhaps, closer to home. The thing was, I was imagining a future for Finnley that was a fairly “normal” dream for the son of an educated, upper middle class Caucasian Canadian family. Asperger’s syndrome or high-functioning autism or whatever you wanted to call it wasn’t a part of that dream – not a teeny bit of it. In fact, it was about as far removed from my dream for “the future Finnley” as could possibly be.

I rapidly cycled my way through Kubler-Ross’s stages of grief (1973) as I grieved the loss of this dream. First I was in denial (stage one): *“This can’t be happening. What is going on? Finnley’s behaviour can’t really mean that. Are you kidding?”* This stage lasted for about 45 minutes – I only had to look at my son – really look at him – and I realized the truth of the diagnosis... I rapidly moved into the anger phase (stage two): *“Why is this happening to us? What did we do to deserve this lot in life? It’s not fair! I told you we shouldn’t have had kids! I told you that I’d be a bad parent!”* A few days after that came stage three, bargaining: *“Well, maybe it won’t be so bad... I mean, he’s not as anti-social as some kids with Asperger syndrome seem to be. And, hey, some of the boys in the class seem to like him. He must not have it as bad as some of those really anti-social kids.”* Then came the depression (stage four) – this stage lasted a long time: *“How are we going to cope? Raising kids is hard enough without adding a disability into the equation. What’s going to happen when he gets to middle school? What if he gets bullied? I’m not strong enough to cope with this. I can’t handle it.”* And, then, finally acceptance (stage five): *“Well, it is what it is. Finnley will be okay. He’s happy, he’s healthy, and we are strong. We can survive this. There are worse things than this. Hey, this website says that Mozart and Einstein had Asperger syndrome. I wonder if that’s true? It will be okay. We will be okay.”*

When I finally reached the “acceptance stage”, some five or six weeks after the diagnosis, I decided to start fighting. I was going to do something about this. I was going to make a difference. I was going to make sure that my son got exactly what he needed in order to assure the best possible outcome for him – whatever that outcome would be. I’d “seen” both Asperger’s syndrome in one relative of mine and high-functioning autism in another, and neither of them wanted to talk with anyone as far as I could tell. They were both nice guys, but I didn’t want that for Finnley. I *would not* have that for Finnley. He would not grow up isolated and alone – whether he somehow managed to convince himself that he wanted his life to be that way or not. Adolescence is hard enough without adding a social disability into the equation. And I could not imagine any person, no matter how uncomfortable they may seem to be around others, consciously *choosing* to spend their life alone rather than in the company of people who care for them. I wanted to “normalize” Finnley as much as possible. I wanted him to be himself; but, I wanted that “self” to be as neuro-typical as possible.

Interestingly, “normalization” is a concept that is widely discussed in the literature describing developmental disabilities and policy. Wolf Wolfensberger (1970) is credited with first coining the term “the normalization principle”. Bengt Nirje (1985) defines the “normalization principle” as “making available to all persons with disabilities . . . patterns of life and conditions of everyday living which are as close as possible to . . . the regular circumstances and ways of life of society” (p. 67). The people with disabilities that Nirje and others refer to (even within the autism community) are people who are certainly more severely hampered in their ability to function in everyday life. Finnley does not fall into this category. At least I don’t believe he does right now. By all accounts, he is a fairly well-adjusted boy with a keen sense of humour; he is bright, funny, and likes to have fun. And, he likes to socialize.

This is not the “norm” for people with Asperger’s syndrome or high-functioning autism. And, there are a number of reasons for this:

I often describe Finnley to people as, “the poster child for early intervention.” He literally became my “mission.” Once I had made my way through the anger and denial stages of coming to acceptance of Finnley’s diagnosis, I started to read. Lots. I checked out every book in our public library about Asperger’s syndrome, I read every magazine article I could find, I talked

to many different people about Finnley's diagnosis, which led them to connect me with others that they knew in similar situations, and I started going to educational seminars that Autism Community Training (ACT) arranged for parents, therapists, and teachers about working/living with children with autism. I was becoming informed. And I was becoming very depressed. You see, the irony was not lost on me: Phil had wanted our "own" child because he spent all day working with children with special needs and didn't want to come home to one too. And if we had adopted a child with special needs, there is no question that it would have been challenging, but I would have had an "out," I would have been a "good person" for taking this on. Instead, all I experienced was the guilt that I felt about the part I possibly played in Finnley's diagnosis.

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Things I learned about my pregnancy and autism after Finnley's diagnosis:

While Autism Spectrum Disorders (ASDs) appear to be primarily inherited, perinatal factors are important;

- Preterm birth and low birth weight are both risk factors for neurodevelopmental disabilities;
- In a study looking at the correlation between pre-eclampsia and autism, the children with ASD often have older mothers, they are born prematurely, and they have a lower birth weight. These same children are also more likely to be born to women with pre-eclampsia and to be male;
- Unusual development of the placenta, with inadequate oxygenation, frequently occurs in cases of pre-eclampsia (Mann, McDermott, Bao, Hardin, & Gregg, 2010, pp. 548-554);
- Not surprisingly, having an umbilical cord wrapped around one's neck three times during the birthing process decreases oxygenation levels somewhat significantly as well.

Did the pre-eclampsia cause Finnley's autism? Was it my stress level during the pregnancy? Or was it the complications with the labour and the birth?

There is research that demonstrates that prenatal stress can interfere with brain development. Two studies have been done, both retrospectively, wherein they found higher rates of autism in children whose mother had been

under severe personal stress. Another study done more recently found higher rates of autism in children whose mothers who had been exposed to severe storm weather conditions – not that I’d found myself in any storms while I was pregnant, but it was clear that the level of stress that the environment one finds oneself in appears to play a role in increasing the likelihood of the child being born with autism (Kinney, Munir, Crowley, & Miller, 2008).

Did all of my initial anxiety about having a child contribute to Finnley’s autism? Did the stressor of having the pre-eclampsia cause it to happen? Or, was it the stress of the pre-eclampsia combined with my reservations about having a child in the first place that made it happen?⁸ Or, was it the third factor – the one beyond my control – that the umbilical cord restricted the oxygen levels to Finnley’s brain?

And then there was the tuna sashimi that I craved during my pregnancy with Finnley.

I had always loved tuna sashimi, even before I’d lived in Japan for 2 years. But it had become a regular part of my diet for the 10 years prior to Finnley’s birth. I’d have it weekly; and, while pregnant, when the cravings were most strong, I think I ate it every three to four days.

Things I learned about mercury and autism after Finnley was diagnosed:

- Mercury (as found in raw fish and in tooth fillings) supposedly does nasty things to both the brains and eyes of people. “If you choose fish, it is important to know that some fish are high in mercury... Even small amounts of mercury can damage a growing brain” (Ministry of Health Services, 2009, p. 80). Apparently, “exposure to hazardous Hg levels can cause permanent neurologic and renal impairment” (Geier, King, Sykes, & Geier, 2008, p. 384);
- There is support for a theory that some ASDs may result from a combination of genetic susceptibility and a reduced ability to excrete mercury (Hg), particularly at critical times in fetal development;

⁸ Consider some of the research that Appreciative Inquiry practitioners espouse regarding the Anticipatory Principle: “the image of the future guides what might be called the current behavior of the any organism or organization. Much like a movie projected on a screen, human systems are forever projecting ahead of themselves a horizon of expectation that brings the future powerfully into the present as a mobilizing agent” (Cooperrider et al., 2008, p. 9).

- Because I am an “older” mother, who committed an “obstetric insult” (Ghaziuddin et al., 1995) – yes, it’s a real term – by not being in my 20s when we chose to have Finnley, who ate lots of sashimi for more than 10 years prior to my pregnancy, and had had lots of fillings laced with mercury put into my mouth to fix the cavities in my teeth, there was a greater likelihood that the mercury levels in my body were higher than the norm. Apparently, “the exposure to methyl-Hg is of greater concern to women of childbearing age because fetuses are highly susceptible to Hg’s adverse effects” (Geier et al., p. 384);
- “An infant could have received a cumulative dose of 237.5 ug Hg during the first 18 months of life” (Geier et al., p. 385) simply from following the recommended routine administration of vaccines. Add this to the mercury in my body prior to pregnancy, plus the mercury I ingested *during* pregnancy, and there is strong likelihood that Finnley had decidedly higher mercury levels in his little body than would have been healthy. Note: mercury has since been removed from the vaccines that are now given to infants.

So, did the mercury cause the autism? If not, was it made more likely because of the genetic susceptibility? Meaning, was it my family history that started the whole thing?

I remember when we were trying to figure out what was going on with Finnley. We were in Australia, visiting my grandparents on my father’s side, and my aunt who lived there, along with my four cousins: two who are roughly my age – in their 30s, at the time; and, two, who were born some 15 years later. Finnley was four months old then, and my aunt kept exclaiming that Finnley reminded her “so much” of my cousin when he was a baby. I was horrified. My cousin had (has) Asperger’s syndrome.

I remember thinking that my cousin was kind of strange. Interesting, yes, but decidedly odd. He reminded me of my grandfather and, to a smaller degree, of my father. My experience of my dad and much more strongly, of my grandfather was that they were both highly intelligent men but that they were also kind of peculiar, and definitely not easy to live with. Both of them (but my grandfather in particular) would get ideas into their heads and then focus on nothing else but that particular thing that they happened to be thinking about. Both men (but, again, my grandfather even more so) would work tirelessly on

whatever had piqued their interest at that particular time, to the exclusion of, quite literally, all else – including the people with whom they lived.

A classic story that I would tell people, as I tried to describe my grandfather's oddity to others, was what I came to refer to as "The Lawnmower Story."

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Lloyd's place was situated upon three-quarters of an acre atop a rocky hill in Laverty's Gap, about three miles outside of Mullumbimby, Australia. He and my grandmother had built their house there, on the very apex of that mini-mountain back in 1969. Picture a 60 degree incline and that would roughly be the slant of the hill upon which Lloyd and Sheila's house was perched.

My grandfather was very interested in fruit trees, particularly all of the different varieties of apples that existed; and one of his many "causes" was to find and plant one of each and every type. Lloyd had spent thirty years covering the area surrounding his home with fruit trees from all over the world and he had collected well over one hundred of them.

Lloyd insisted on doing all of the work on the yard himself – even though he had terrible arthritis in his back and was so crippled that all of his six feet bent to bring the top of his head somewhat level with my elbow. He would rise at 5:30 a.m. every day and go outside to do some yard work; later, he would return to the house with papayas, bananas, or kiwi fruit, and, of course, apples, and we would have these for breakfast. He would return to the yard and work until noon, have lunch, write his letters to the editor and answer his fan mail about the greenbelt sewer system that he had invented (that was in use in a number of territories of Australia), and then work outside again until it was dark. Lloyd was a stickler for routines. He liked things organized, regular, and definitely predictable. He had his daily schedule and from it he never, ever swayed. Unless he had an idea. . . .

I awoke this particular morning to the sound of Lloyd driving the car away. It was 6 a.m. Uh oh, a change of routine. Something was up. My grandmother met me on the stairs as we hurriedly tried to catch Lloyd to find out where he was going.

Now, Lloyd driving is surely a sight to behold. As I mentioned, his osteoarthritis had bent his body into something of a pretzel, so when he drove

he needed to sit on a four-inch slab of foam in order to be able to see over the dashboard. As it was, he still had to peer through the steering wheel to look out the front window of the car. Complicating things was that Lloyd's eyesight was hardly what one would call stellar. He'd had cataract surgery in both eyes, and he basically refused to wear his prescription eyeglasses unless he was watching television or reading. He drove way too fast and too recklessly, even for my taste. After one particularly harrowing ride that involved us nearly crashing into an oncoming bus, I'd decided that I wouldn't be getting back into a car with him anytime soon.

So, there was Lloyd, careening away. Again, driving too fast for the steep and windy curves of the dirt road. Sheila and I stood there silently, each with our own thoughts. We were too late. We'd missed him. Not only could we not prevent him from driving, but also we had no idea where he was going and what he was planning to do. This did not sit well with either of us. We would just have to wait and see what the fall-out would be from this, his latest of plans – plans that, of late, had included deciding to single-handedly dig out a large enough stretch of land on the hillside to create a tennis court. I figured he'd be digging for at least three years.

My grandmother was really worried. She knew, like the rest of us, that Lloyd never did the "logical" thing and was forever ending up in scrapes that she was required to clean up. He consistently annoyed the neighbours and the people in the small town near where they lived: he would push ahead of people in lines at the grocery store; he'd interrupt conversations between people because he needed to speak to one of the people; and, he'd regularly insert himself into conversations with others because he felt the need to share whatever thought was in his mind at that particular time – whether it had anything to do with the conversation that was already taking place or not.

Even while Lloyd had wildly creative and imaginative plans and ideas, he had very little common sense when it came to shaping the ideas into anything tangible and "sensible", and even less staying-power for carrying the ideas to fruition. The area around Lloyd and Sheila's house was littered with the remnants of Lloyd's different projects: the large hole by the driveway that was someday going to be a well – but, in the meantime, had turned into a very deep trap for unsuspecting wallabies; the solar-heated (read: freezing cold) hot tub that he'd designed and built; and, of course, the half-built tennis court. Lloyd hated to spend money and, because he insisted on doing everything

himself (for the least amount of cost, of course), he'd forever be finding himself in over his head. We had little reason to think that this latest of projects, whatever it was, would turn out any differently.

Lloyd returned shortly, with gas tank in hand, and informed us that he was going to mow the lawn. "Why?" asked Sheila. "I thought we like the long grass," she said hopefully.

"We did," answered Lloyd. "But not anymore."

"Okay," replied my grandmother. After all, as far as ideas go, this was a pretty tame one for Lloyd. It didn't involve building or digging, and, actually, as she said to me later, she'd always thought the land would look much more like an orchard if the tall, reedy-looking grass between the trees was shorter.

Since Lloyd would be busy with this project for at least an hour, Sheila and I decided that we would go into Mullumbimby to do the grocery shopping and other errands. As Sheila drove the car down the winding road behind the house we could see him pushing the lawn mower *straight up* the sharp slope. We looked at each other and shook our heads. Knowing that he would ignore any suggestions that we made that there might be an easier way to go about proceeding with this project, we kept driving. With the sound of the lawn mower rumbling in our ears, we continued along our way into town.

We returned two hours later, to silence. We couldn't hear the lawn mower, most of the grass remained uncut, and Lloyd was nowhere to be seen. Somewhat concerned, we set off on a search of the property. We could see the area that Lloyd had mowed, and then there was an abrupt cut through the middle of some particularly long grass where it looked as if Lloyd had gotten bored with the straight up and down mowing and had decided to take a wild turn. As we drew nearer, we could see the lawn mower in the distance, lying on its side at the foot of a large apple tree. But where was Lloyd?

As we waded through the long grass to where the lawn mower lay, we could see an odd-shaped trail in the grass. It looked like the path of a very large snake, the way it twisted along. I quickly ran ahead on this peculiar path only to find Lloyd lying about fifty feet further along in the tall grass. His back was covered in blood and both of his legs were contorted. I yelled for Sheila to call for an ambulance while I tried to stop the bleeding.

According to Lloyd, as he later told us, he had managed to make it about halfway up the hill when he had tripped over a tree root and fallen. As if that

weren't bad enough, the lawn mower had run right over him. Luckily, he fell onto his stomach so the lawn mower didn't chew up any vital organs, but it did manage to shred most of the skin on his back. Concerned that gasoline was being squandered, he had decided that it would be a good idea to crawl down the hill to where the lawn mower lay on its side in order to turn it off. Never mind that he would then be twice as far from the house, the telephone, and potential help, and never mind that gasoline could have been leaking out and have started a fire. The lawn mower was on, and gasoline was a-wasting away.

So crawl he did. Or, rather, roll. The hill was so steep that as Lloyd tried to creep along, he ended up going head over heels, rolling down the hill, and breaking both of his legs in the process. (However, he did manage to conserve the gasoline.)

Once the lawn mower was turned off, he had then faced the even more daunting task of making his way back up the hill, now with two broken legs added to the equation. After a moment's hesitation, where he said that he did briefly contemplate staying still, he decided to pull himself up the hillside using his arms. And that's where I found him – painstakingly inching his way up the slope, slowly crawling hand over hand.

It was six weeks before Lloyd was able to move around again – as much as one can while in two full leg casts. In the meantime, Sheila hired a kid from down the road to come and finish mowing the lawn – he mowed the grass from side to side as opposed to going up and down the long hill (“for the exercise”) as Lloyd had done. Lloyd later decided that he hadn't really wanted to mow the lawn in the first place but, rather, had merely been checking to see how the lawn mower worked, since he'd re-done the engine on it earlier that fateful morning. I believe this is referred to as selective memory or revisionist history. At any rate, his story of the event differed significantly from that of Sheila and mine, and Lloyd never touched another lawn mower again.

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Things I've deduced about my family and autism since Finnley's diagnosis:

- Lloyd clearly had undiagnosed Asperger's syndrome: the intelligence, the single-minded focus, the lacking social skills, the obsessive behavior, the need for routine . . . he's almost a textbook case. As numerous

researchers have demonstrated, and as I iterated in *Story B*, there is clearly an hereditary link with autism;

- My cousin's diagnosed Asperger's syndrome provides another link in our familial autism chain; as does his elder brother who (though undiagnosed) appears to have high-functioning autism;
- Then there's my father. While I don't think that he had high-functioning autism or Asperger's syndrome, he definitely had some over-developed autistic "traits" and undiagnosed manic-depression. Interesting to consider now knowing what I do about the higher propensity for family members of children with Asperger's syndrome to have relatives with bipolar disorder. It makes my own "borderline" bipolar disorder diagnosis somewhat more disturbing;

My reservations about having children were, perhaps, justified.

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My reading about Asperger's syndrome and autism continued to "connect the dots" between Finnley's behavior and his eventual diagnosis. For instance, there appeared to be a correlation between fussy or colicky babies who don't want to nap and autism:

- According to Mark Hutten, a counseling psychologist and owner of the website "My Aspergers Child," while diagnosing Asperger's syndrome in infants is challenging, there are some common signs and symptoms reported by the parents of children who are later diagnosed with the syndrome. One such symptom is that their newborns were excessively fussy or "colicky" and, in general, were difficult to comfort (2011). Of course, not all children who exhibit these behaviours have autism; however, for Finnley it certainly appeared to be true.
- This anecdotal information, while not fully researched (though the Brown Center for the Study of Children at Risk, housed at Brown Medical School is in the process of undertaking such a study), is corroborated by a number of different parents I spoke to whose children were later diagnosed with autism or Asperger's syndrome;
- Sleep challenges are common to children with autism. Researchers estimate that between 44% and 83% of children with autism have any

number of differing sleep disturbances: including night waking, nightmares, sleep walking, night terrors, irregular sleep/wake patterns, early morning and night waking, and generally poor sleep (Schreck, & Mulick, 2000, p. 128).

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A shrill scream cuts through the still night.

I am up and out of my bed before I am even aware of what, or who, is making the sound.

The screaming continues.

Phil is awake now too, and the two of us hurry into the kids' bedroom, from where the sound is emanating.

Finnley is sitting upright in his bed, eyes wide open but not seeing.

"Finnley! What is it? What's the matter, honey?"

He doesn't hear us. He continues to scream.

"Finnley, honey, wake up! It's okay. Mommy's here."

He's still screaming. I go to touch him, but something prevents me. I see that, even though his eyes are open, he is still asleep. I don't want to startle him.

He leaps out of bed and begins frantically running around in his room. He is tripping over things, banging into things, picking things up and throwing them . . . Phil and I try to stay out of his way – at the same time, unsure if we should be trying to stop him. What if he gets hurt?

I continue to try to talk to him. Phil blocks the doorway so he can't leave the bedroom. He seems to be getting even more agitated. I am worried about Scotia who is, somehow, still asleep in the bed beside his.

"Finnley, it's okay. Mommy's here. . . . Finnley, wake up. You need to wake up. . . . Finnley. . . . Finnley."

He doesn't seem to hear me. Why is he doing this? I feel like he's on a journey, far away from me.

"Finnley, come back Finnley, please wake up Finnley, Mommy's here."

He is spinning now – turning so quickly, it’s hard to track him with my eyes. He is continuing to scream.

Slowly, he stops moving. His eyes are still open, still unseeing. He is, literally, vibrating.

I feel the energy emanating from him. I sense how quickly his heart is beating, his pulse is racing. I see the small beads of sweat on his forehead. He is shaking so much.

Then, suddenly, there is a shift . . . I hear the difference in his screaming. He is quieting. He is now saying, “Mama, mama, mama . . . Mama . . . mamamama”

He’s returning to me.

“Finnley, Mommy’s here.”

“Mama, mama, mama”

He is talking, but he doesn’t know what he’s saying. He is calling for me, but he doesn’t know that I’m there.

“Finnley, Mama’s here.”

“Mama, mama, mama”

“Finnley, are you okay? What’s the matter, honey?”

He starts to cry, all the while repeating, “Mama, mama, mama Mama, mama, mama”

But, he is not cognizant. I can see that he is still asleep.

I gently, but firmly, place my hand on his back and direct him toward his bed. He is willing to be led.

“Mama, mama, mama Mama, mama, mama”

I help him into his bed and lay down beside him. He continues to cry. He continues to call for me.

“Mama, mama, mama Mama, mama, mama”

I begin to massage his back. I begin to whisper to him, using the same rhythmic pattern, “Sh, sh, sh sh, sh, sh sh, sh, sh”

Slowly . . . very slowly . . . he begins to calm. Slowly – so very, very slowly – his speech softens, his sobbing stops. Eventually, he is silent. His even breathing tells me that he has settled.

He is home.

I return to my own bed. Wide awake.

According to Mason and Pack:

Sleep terrors are dramatic events that represent a partial arousal from deep sleep. . . . These episodes have also been referred to as *night terrors*, *parvor nocturnus* (in children), and *incubus attacks* (in adults). . . . The full-blown sleep terror is a fight-flight episode. Although some children with sleep terrors may remain in bed, others may walk or run during attacks. Bodily injury and property damage are possible. The duration of sleep terrors is usually brief, often from less than a minute to several minutes; however, some sleep terrors may last as long as a half hour. Attempts to awaken a child fully during a sleep terror may increase the child's agitation, and the sleep terror may actually be prolonged. . . . Episodes cease rather abruptly, with the child rapidly returning to a deep sleep. (2005, p. 388).

We could never pinpoint what triggered Finnley's night terrors. Was he overtired? We were always careful to put him to bed at the same time each night – and yet, we couldn't always assure that actually *going* to sleep would occur at the same time each night. Sleep deprivation was considered a risk factor that could increase the likelihood of occurrence. Anxiety was another risk factor (Mason and Pack, 2005, p. 389) and, goodness knows, Finnley certainly seemed to be anxious about living in general, given his response to sensory stimuli.

And, of course, anxiety is also one of the monikers for Asperger's syndrome.

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I am picking Finnley up from preschool. He rushes over to meet me. The front of his shirt, by the collar, is very wet.

"Did Finnley spill his water during snack?"

"No."

"Hmmm . . . that's interesting."

Later, at home, I am watching him line up his books as I make dinner. Scotia is beside me – well out of Finnley’s way.

I see that he has the collar of his shirt in his mouth. He is chewing on it.

“Finnley, please take your shirt out of your mouth.”

He looks up at me, startled. He opens his mouth and releases his shirt.

He is unaware that he is chewing on it.

This pattern of chewing continues, starting and stopping as the stressors of daily life seem to affect him. Some days it is his sleeves that bear the brunt of his anxiety. As much as possible, I dress him in short sleeves – he becomes agitated by the dampness of the fabric against his skin.

There are days that the shirts are barely wet; other days they are soaked; and, some days he chews so hard that he breaks a hole through the collar. We look for other outlets for his chewing that don’t involve his clothing: we try a plastic bracelet on his wrist, we try a plastic water bottle, we try gum.

What is he so afraid of? Why is he so anxious? Why, oh why?

We have shifted houses, and Finnley seemed to be struggling to adjust to the change. Perhaps this is part of the issue. Knowing how difficult he found “change” to be, even prior to the diagnosis, we had done as much as we possibly could to prepare Finnley for the shift of place . . .

“Finnley! Guess what? We’re going to be moving closer to Luke and Grayson! Now you’ll get to play with them more.”

I realize that for him “moving” likely means something else. I need to be more concrete. I drive from our current home to our new house.

“Finnley, right now we live in a blue house on Dublin Street. Soon we are going to be living in a different house on a street called Princess Street. Our new home is going to be yellow. We are going to be moving to this new yellow house. It is closer to Luke’s house and to Grayson’s house. Won’t that be great?

“Look at the backyard of this house. Isn’t it nice? There’s lots of room to run around and play. And, look, this is where you can dig.”

After we had shifted houses, we had even gone so far as returning to our old home and asking the new owners if we could show Finnley around inside.

This way he could see that it was other people's furniture inside our house. That there was another little boy who now slept in Finnley's old bedroom.

"Now we can walk to preschool. Scotia will be going to preschool too. But, on different days. Now we will be going to the preschool every day! But, some days you will go in and some days Scotia will go in.

"You get to have a new teacher too. Janet will be teaching Scotia now. You get to have Laura as your teacher. She teaches the big kids, the four year olds. That's you! And Luke and Grayson and all of the other kids that you like to play with will all be there. David and Gregory will be there. Bennett will be there. We will be living nearer to David and Gregory too! Isn't that great?"

In retrospect, maybe these two changes (the new home and the new teacher) were enough to cause the anxiety . . .

Finnley has developed an irrational fear of dogs. Again, we don't know why. His experiences with dogs, as far as we are aware, have all been pleasant or, at least, inconsequential. But now, the sight of a dog sends him spiraling out of control . . .

Scotia, Finnley and I are walking down the street together. We are going to get ice cream. One of the benefits of our new home is that it is in walking distance of the public library, the pool and Dairy Queen.

Finnley hears a dog barking in the distance. He stops and covers his ears. He starts to scream. He begins to run in the opposite direction – thankfully, he is staying on the sidewalk.

Scotia and I have no choice. We follow behind. No ice cream today . . .

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Similarly, other "dots" about Finnley were "connected" as I learned more about the relationship between motor development, clumsiness, and autism:

- Apparently, children with autism and Asperger's syndrome have "different" ways of moving. Attwood describes the coordination of the child's movement as "immature," with a sometimes "idiosyncratic gait" (Attwood, 2006, p. 259);

- According to a study comparing Asperger's syndrome and high-functioning autism (HFA), there were demonstrated motor coordination deficits in gross motor, fine motor, and upper limb coordination in both groups of children studied (Ghaziuddin, Butler, Tsai, & Ghaziuddin, 1994);
- Finnley's multiple accidents could be attributed to his lack of spatial awareness. One of the areas of motor development that has been studied is proprioception. Weimer and her team found that children with Asperger's syndrome seemed to have challenges with integrating the information their brains received about the position and movement of their bodies in space (Weimer, Schatz, Lincoln, Ballantyne, & Trauner, 2001);
- Another area of concern in children with Asperger's syndrome is their challenge with organizing and "planning" their movement; that is, they are described as having apraxia, wherein their movements are less "proficient and coordinated" than would be expected of someone of similar age and size (Attwood, 2006, p. 262);
- Remember all of that hand flapping and rhythmic hitting of the wall that I attributed to my son's "musicality"? This would be the "restricted, repetitive & stereotyped patterns of behavior, interests and activities, as manifested by . . . stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)" laid out as part of the diagnostic criteria for Asperger's disorder in the DSM IV (1994).

Finnley hadn't been particularly clumsy or accident-prone; he wasn't overly anxious or violent; he also wasn't even really that musical – he was just a little boy with autism whose mother had been doing all of the wrong things with him for all of the right reasons. Things like playing music because he seemed to get excited by it; things like exposing him to lots of different experiences (like parades, and music classes, and playtime in the gym with throngs of other toddlers); things like busily trying to organize lots of different activities for him to participate in (with lots of different people and expectations) so that he would "grow" that little brain of his: things that, for the "typical" child would have been fine – and conducive to their growth and development – but for my son caused unnecessary pain, anxiety and stress.

Then there was Finnley's strange response to pain. Another dot explained:

The child or adult with Asperger's syndrome may appear very stoic, and not flinch or show distress in response to levels of pain that others would consider unbearable. The child's attention can be drawn to a bruise or cut but the child can't remember how it happened. Splinters may be removed without concern, hot drinks consumed without distress . . . Children with Asperger's syndrome are more likely to be hypo-than hypersensitive to pain (Attwood, 2006, p. 288).

Attwood continues, discussing challenges with toilet training:

It is possible that such children [are] less able to perceive the internal signals of bladder and bowel discomfort to prevent toileting "accidents." The lack of reaction to discomfort, pain and extremes of temperature can also prevent the very young child with Asperger's syndrome from learning to avoid certain dangerous actions, resulting in frequent trips to the local casualty department. Medical staff may be surprised at the audacity of the child or consider the parents negligent (2006, pp. 288-289).

Here was my child, described so painfully well. I was being forced to consider my son's behaviour in a whole different light. Perhaps his "resistance" to going to the bathroom was simply lack of awareness that he needed "to go" in the first place. I couldn't wrap my head around the idea of a child frantically pushing on his stomach, and not being aware that he was doing just this action. And yet, when I thought of so many of Finnley's other odd behaviours of which he had no awareness – chewing on his shirt, pressing against Phil or I so hard that we were pushed nearly sideways – it made some semblance of sense, in as much a way as any of this possibly could.

I was learning so much. And becoming increasingly fearful. The future that was described for Finnley, while decidedly not bleak, was certainly dissimilar to the one that I had imagined for him. I read about higher suicide rates in teens with Asperger's syndrome, battles with depression, social isolation, deep loneliness (Whitehouse, Jaquet, & Ziatas, 2009) and I looked at blogs where people with Asperger's syndrome described how they viewed themselves, and how the only people that they felt that they could connect with were others on-line because it was "too hard" and people "didn't understand."

As I said, Finnley's therapy became pretty much my sole focus in life. Helping him to achieve "normalcy," as much as possible, became my singular

goal. To the exclusion of basically all else, I devoted all of my time and energy into him. (Hm . . . perhaps those Asperger-like tendencies are within me too.)

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With the start-up of the new year of preschool, I have begun doing a “daycare exchange” with another mother in the preschool who lives near to our new home on Princess Street. She has twin boys in Finnley’s class. One morning a week she brings David and Gregory to my house to play, to have lunch, and then to make our collective way to preschool. And one morning a week she does the same for me, by taking care of Finnley. One Finnley equals one set of “rough and tumble” twins. But, I don’t care. This mother isn’t afraid of my son.

I talk to her about Finnley’s fondness for smashing things. And Cheryl has seen Finnley “in action” more than once at preschool the year before. As well, she and I had had “play dates” for our sons the previous year that had been somewhat successful – which, to my mind, means that there were no broken bones or skin. Cheryl admits that she had initially been fearful of suggesting this “exchange” to me but that “it had been her boys who’d convinced her otherwise” – it had been them who had asked her if they could play with Finnley on a more regular basis.

Cheryl describes a conversation she’d had with her son the previous time that Finnley had been invited over. Gregory had asked if Finnley could “come and play” to which Cheryl apparently had replied, “But Finnley always breaks things when he comes over. Aren’t you afraid he’s going to break your Lego Starships?” Gregory’s response? “Oh, I’ll just put them away. We won’t play with those.” Then, apparently, he had happily skipped off, smiling.

I felt tears welling up in my eyes. This little boy had taken care of Finnley. And he was four. He hadn’t rejected him because of the way he’d obviously seen Finnley act in the past. He wasn’t afraid of him; he’d accepted him. He’d included Finnley. And he’d taught his mother to “include” Finnley too.

This “inclusion” was a huge part of the work that the support care worker at the preschool had been doing with and for Finnley. And with the diagnosis of autism, this work took on even more significance. Carrie was extremely gifted at helping Finnley to “settle,” to regulate his behavior and the

volume of his voice, and she worked hard to help him with social situations. She had been doing this from the day she had met him – like Phil and I, she had somehow known that this was what he needed, more than anything else. Carrie took Finnley’s behavior in stride, remaining much calmer than I ever could when he showed his violent tendencies. She made a point of verbalizing Finnley’s obvious talents in front of the other children (and their parents); and she would often provide him with that sole attention he so desperately craved.

As I was busy berating myself, once again, for getting so angry and upset with Finnley over yet another incident wherein he had hurt his sister, she reminds me, “Vandy, I work with him for only two hours at a time, and only two times a week. You live with him. For you, it is relentless.”

I need a break from my children. I need to exercise my brain. I begin my Master’s in Arts Education at SFU. I take a course with Dr. Carolyn Mamchur where I begin to write about my life:

Ironic

I hit my son today. Hard. I didn’t mean to do it. I certainly didn’t want to do it. But I did it. I hit him.

It was the look in his eyes that made me realize the extent of the damage that I had done. It was shock and betrayal. It was Fear. I made my son fear me. Me – who loves him most, who knows him best and who teaches him all. Well, what a wonderful lesson he learned today.

Oh, believe me, I know the damage that’s been done. I’ve read the literature and heard all of the stories. “Those who hit, hit others.” “Hitting children damages their self-esteem.” “If you hit your child, they will never trust you again.”

What have I done? Will he ever forgive me? Can I ever forgive myself?

Finnley has Asperger’s syndrome: he’s anxious; he’s hyperactive; he’s aggressive; he’s impulsive; and, he’s socially challenged. Some kids cry; Finn screams. Some kids tumble; Finnley freefalls. Some kids learn from their social mistakes; Finn is doomed to repeat his over and over again. How many times do you have to tell a kid that if they want somebody to play with them that throwing rocks at the other child is not a good way to make that happen? I’ve lost count with my son.

Finnley lives in terror of his five senses – particularly the tactile and auditory processing orders. He lashes out for fear of what may be coming: the dog a block away that might walk near him; the siren in the distance that I don't even notice until Finn is standing there screaming with his fingers in his ears; the rain which turns him catatonic, cowering with his hands protecting his head, until someone (anyone, please) puts his hood up for him.

The anticipation is literally too much for Finnley – even if he's waiting for something he's looking forward to. He certainly isn't dumb. If anything, he's too smart for his own good. He's created a fortress of coping mechanisms for himself with which he shuts the out the rest of the world.

Except for me. Me, his mother – the one who just hit him.

As you can imagine, it's exhausting living with Finn. I spend most of my day negotiating situations for him. What's his mood today? Did he get enough sleep? Has he eaten enough? He has preschool tomorrow, can he deal with going to Safeway to buy carrots and milk too? I can see a dog about 5 blocks away that he hasn't noticed yet. Should we change directions? But we need to walk this direction. How can I distract him? Now he's making weird noises. What if someone hears him? What will they think of him? Of us?

So you see, I have reasons for acting the way I did. Besides, Fridays are always difficult days – it's the end of the week and I'm physically, mentally and emotionally exhausted; I have my class Thursday night so I don't sleep well; I spend all day, every day, with two or more preschoolers; my husband leaves early and works late so we can afford for me to stay at home; I miss adult company; I feel taken for granted. Oh there are lots and lots of reasons.

But there are no excuses.

He's only four; well, almost five now. He starts Kindergarten in the fall. And I'm so scared for him. What if he gets teased in school? (I know he will, but I'm trying to kid myself into thinking it won't happen.) What if he really hurts someone someday? The bumps and bruises on his sister are bad enough, but at least I'm always there to stop him. And when he hurts me? Well, I just have to keep reminding myself that most of the time, it's beyond his control. It doesn't help that he's exceptionally tall for his age. He's over four feet already. Finnley, the four-year-old, looks like he's seven and acts like he's . . . well, definitely not seven.

Finnley's aggression usually comes from sensory overload. And he is slowly getting better at recognizing when he's had enough. Sometimes he voluntarily separates himself from the group when he starts to feel stressed. But not always. What if he doesn't realize that "it" (whatever the damn "it" is) is happening to him and he can't control himself? What if it means that he is considered "dangerous" by school authorities and separated from other kids when he so desperately wants to be included? How's that for irony? Most people hit because they want to get away; he hits because he wants to get close.

And why did I hit? To stop him from hurting someone else. Yet more irony.

Finnley had a stick in his hand. He wasn't using it as a weapon; he was using it to drill a hole into the dirt pile – his construction zone – in the backyard. Finn is at his absolute best in our backyard. He loves digging, he has amazing spatial awareness and builds all sorts of incredible structures out of whatever he finds (Though I know a huge part of why he likes to build it up is so that he can smash it down afterwards!) Anyway, Bennett, a boy from his preschool class, was over and the two of them, along with my daughter Scotia, were playing quite happily in the yard.

And then the switch in Finn flipped. I don't know why. Had he had enough and I hadn't been "on" enough to recognize it? Did he hear a sound that I didn't hear? Did he need to go to the bathroom? Any and all of these things are often enough to put him over the edge.

Suddenly he was lunging towards Bennett, stick in hand, pointed end out. Bennett wouldn't even know what was going to hit him. He was nearly there. So I hit first.

It made Finn drop the stick. It made me drop to my knees and start to cry. Scotia, my three year old, rushed over, "Are you okay, Mommy? Mommy, what's the matter? Did Finnley hurt you?"

Then she turned to Finn and yelled. "Tell Mommy you're sorry Finn. Mommy's sad. You're not supposed to hurt people."

"That's right, Scotia," I said slowly, as I stood up. "You're not supposed to hurt people. But honey, Finnley didn't hurt me. I hurt him."

I looked at him as I continued, "And I'm very, very sorry."

I tried to rub his arm where I had grabbed him too hard; I rubbed his little bottom that I had so resoundingly smacked just moments ago. He pulled away.

"You hurt me," he said accusingly.

"Yes, Finnley, I did. I'm sorry. That wasn't the right thing to do. It's not okay to hurt people. I guess I forgot."

He kicked at the ground and then ran back to the house. I guess he'd had enough of being outside. I couldn't blame him.

Scotia looked up at me. "It's okay, Mommy. It was an accident."

I tried to smile at her.

An accident. Boy, was it ever.

An accident?

God, I only hope.

Chapter 4

LIVING WITH THE DIAGNOSIS

It is the end of March and preparation for the coming September is beginning. Phil and I are meeting with the kindergarten teacher, the principal and the district resource person at the elementary school that Finnley will be attending. Also present are Finnley's preschool teacher and Finnley's support person from the preschool. I hold in my hands the letter from Dr. White explaining Finnley's diagnosis. It states the following:

I have been asked to write a letter summarizing Finnley's diagnosis and related requirements. . . . Finnley has sensory sensitivities including auditory and tactile sensitivity and has difficulty in unstructured environments. With skilled adults such as his parents and preschool personnel, his need for deep pressure can be recognized and at times can be provided helping him to self-regulate. This is sometimes seen with children on the autistic spectrum in addition to other less predictable sensory reactions such as the calming effect of coloured light, etc.

In terms of interaction with other children, Finnley does tend to follow some scripted type of play both with children and with adults. As children obviously are less focused on adjusting to Finnley's concerns, there is more possibility for aggressive counter-reactions and misinterpretation and in fact this does occur with Finnley in several settings. Further to this, he has had difficulties even with children of close friends due to some of his unpredictable and explosive reactions. Therefore a low stimulus structured environment certainly would benefit his learning and helps him interact more positively.

Overall he tends to get over-stimulated in busy environments and this sets him up for disruptive behaviours that do not necessarily occur in calmer environments. For this reason he obviously will require an IEP that is well tailored to his needs including continuous support of an aide in order to help him interface with children and the educational environment in general particularly at times of transitions and for interpersonal "troubleshooting."

He will benefit from a social skills group involving specific interactional learning with other children including social stories. . . .

Regarding his academic learning specifically, his need for deep pressure and some of his forceful gross motor behaviours will certainly benefit from classroom support. His rudimentary pencil grip will benefit from OT consultation in school and he certainly will need follow-up in this area.

In terms of his communication skills, Finnley is a bright boy and he will certainly benefit from having his pragmatic language skills monitored and supported by a speech and language pathologist in terms of age appropriate conversation and social language skills. In fact some degree of “self-talk” can be helpful for children in working through situations that they have had the opportunity to learn through social story that is provided by a speech and language therapist . . .

There is absolutely no doubt that Finnley requires special support for behavior, emotional, social, and learning needs related to his autistic disorder. I would like to note that Finnley, when in a positive and regulated state is a loving child who expresses his love for his parents. His parents are highly skilled well-attuned individuals who work together very well as a team and mutually support one another. They are very knowledgeable and have done everything in their power to assist Finnley. They are aware that he will require special supports, and that he will make, in my opinion, significant gains if the above supports are provided (excerpt from letter dated 24 February 2005).

Unlike the other children in the neighbourhood of the same age, who will only go to school for half of each day, it has been decided that my son will attend kindergarten all day long. He will have the same teacher all day long, the same educational assistant working with him all day long, and he will be in the same classroom all day long; however, the group of children will change partway through the day. It is hoped that the repetition of the morning lesson in the afternoon (with the new group of children) will reinforce the learning concepts for Finnley – that this “sameness” will set him up for success and that by keeping as many things as possible “the same,” he will begin to transfer his knowledge about one set of things to another different, yet similar, scenario with a different group of children. I will drop him off at 8:55 a.m. each morning, pick him up at 11:30 a.m. and bring him home to have lunch, return him to school at 12:30 p.m. and pick him up at 2:45 p.m., at the end of the school day.

I am thrilled. And relieved. Finnley will be someone else’s responsibility for more hours of each day: he won’t be my problem to fix; my challenge to explain; my reason to find an excuse for. I don’t say this aloud, of course, but I am certain that the other people sitting around the table know that this is what I am thinking.

And yet, I find myself shuddering at the same time. No longer will Finnley only be my problem to fix. No longer will Finnley only be my challenge to explain. And no longer will Finnley only be my reason to find an excuse for. I am ceding responsibility for my son over to somebody else. And this is entirely voluntary. He doesn't have to go to school all day long. This is a choice that I am consciously making because I can't take it anymore.

And I worry. Deeply. Because I have been one of the teachers that I am now sending my son to – not these particular ones, of course, but a teacher all the same. And I know that they will wonder why he is now *their* problem to fix; *their* challenge to explain; *their* reason to find an excuse for.

And still I choose to do it all the same.

I don't care that having my son at their school will mean more work for them. I don't care that Finnley will make their classrooms more challenging teaching and learning environments. I don't care that Finnley will make their jobs more difficult. I really don't. I see a light at the end of this proverbial tunnel and I am scrambling my way towards it, even as it seems to be moving further out of my reach . . . because Finnley's behaviour is not improving. Yes, we have a diagnosis; yes, having "an answer" for our big question is important; but, unfortunately, it doesn't really mean anything substantial in terms of how our lives continue to be affected by our son's distressing behaviour.

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It is the Mother's Day Tea at the preschool, and I am humiliated. Again. All of the other mothers are there in a group getting their photo taken, holding the rose that their child has so graciously handed to them as they entered the school. I am standing outside looking in – holding onto the arm of my screaming child who has peed himself, who has now stripped off all of his clothing because his pants are wet, and who is tightly grasping the stem of my flower – the one from which he has systematically torn off all of the petals. I have just managed to catch him (he has been running around outside for the last ten minutes, laughing, because I can't run in my high heels), and he is not happy. This makes two of us.

I understand that he is overexcited because of the extra people at preschool and because it is a "special day for mommy" as Carrie, his support worker, has repeatedly told him. I understand that he struggles with change. I

understand that he doesn't like when his body tries to "tell him what to do." I understand all of these things. And I love him, despite these challenges. But, I am angry. And so frustrated. And really, really sad. Just for once, I would like my child to act like everyone else's child. Just for once I want Finnley to smile and act "normal" in situations like these. Just for once I want the two of us to belong. I am tired of being outside looking in. . . . I want to be in that damn picture so I can pretend that my life is not what it actually is.

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An official diagnosis of autism means the government provides funding for therapy for the child. Indeed, the provincial government of British Columbia makes available funds of up to \$20,000 for families of children under the age of six who have been diagnosed with autism (\$22,000 as of April 1, 2010) in order to offset "the cost of purchasing autism intervention services (based on best practices) to promote their child's communication, social-emotional, pre-academic and functional life skills development" (Ministry of Children and Families, 2009, p. 13). This development came about, we can presume, in light of research that highlighted the higher rates of success of early intervention treatments for children with autism. Thankfully, Finnley was correctly diagnosed at age five meaning that we were able to access the funds and, subsequently, the much-needed resources and resource people because of it.

In order to access the autism funding, the Ministry of Children and Family Development requires that a Behavioural Plan of Intervention (BPI) be developed by a behaviour consultant (selected by the family from the Registry of Autism Service Providers – "professionals [who] must demonstrate that their education and experience meet the qualifications described by the ministry") who, in consultation with the family members and other "intervention team members" develops a plan for the child that "takes into account his or her unique strengths and needs" (2009, p. 13).

We need that Behavioural Plan. I am not coping and I am becoming increasingly worried about the safety of our daughter.

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I am in my bedroom folding the laundry. Phil is in the hallway vacuuming. Suddenly, over the deafening sound of the vacuum I hear crying. It is Scotia. She is screaming, "Stop, Finnley! Stop! Stop it! Ow, Finnley! Ow!"

I drop what I'm doing and run towards the sound. Phil sees me hurry out of the bedroom and bends to turn off the vacuum. I know he is about to ask me what is the matter, but as soon as the motor begins to quiet, he can hear for himself. He quickly follows.

We rush into the kitchen to find our daughter cowering in the corner. Finnley is repeatedly hitting her over the head with both of his hands. Scotia has tried to make herself smaller, instinctively curling her body into a ball to protect herself from the blows. Phil grabs Finnley, literally lifting him into the air, and pulling him off of our daughter. I am thankful that Phil is home when this is happening: (1) he doesn't see Finnley act like this as often as I do; and, (2) Finnley is getting so big (and strong), I am finding it increasingly more difficult to wrestle him down the stairs and into his bedroom for a "time out" when he is acting like this.

Phil doesn't head for the stairs. He moves towards the kitchen door. He opens it and roughly throws Finnley outside onto the landing. And, then he locks it.

He has locked our son outside.

I feel two things – frustration that I hadn't thought of doing this before myself, and fear because I have never seen Phil as angry as this. I am the one who "loses it" in our family, not him.

Finnley immediately begins pounding on the door, screaming to be let back inside. I look away and try to calm our daughter. But it is to no avail. Now she is even more upset because Finnley has been locked outside and because Daddy is so angry. She begins to plead with Phil.

"Please, Daddy. Unlock the door. Finnley wants to come back inside."

"No, Scotia," Phil says to her. "Finnley needs to calm down before he can come back inside. It's not okay for him to hurt you."

"Then let me go outside with him!"

"No, Scotia!" I say. "Finnley was hurting you. That's why Daddy put him outside."

Finnley has now begun to kick the door.

"It's okay. He won't do it again. Finnley didn't mean to hurt me. It was an accident."

Phil and I look at each other, horrified. I think to myself, "Dear God, we are setting her up to become a battered woman! In my inability to prevent Finnley from hurting her, and because it happens every day, she thinks this is acceptable behavior!"

It has to stop. Now.

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Neal Winters came into our lives in the August before Finnley began Kindergarten. We chose to work with him for four reasons:

(1) because whatever we were doing with Finnley up until this point clearly didn't seem to be working;

(2) because we had to choose someone in order to access that money from the provincial government and he had been recommended by a "friend of a friend";

(3) because he did all of the assessments and program development himself, as opposed to having someone (likely less qualified) from his company come and do the work for him; and,

(4) because of the mission statement listed on his website: "We believe that all people are capable of learning and personal growth and we strive to improve quality of life by empowering families through applied behaviour analysis" (www.bestbehaviour.ca).

Phil and I were pleased that the word "families" was listed in the mission statement – whatever therapy program we were going to try to put in place for Finnley to help him with his anti-social behaviours needed to include our entire family in the process. After all, Phil, Scotia and I needed the "therapy" just as much as Finnley did.

I knew very little about applied behavior analysis (ABA) before Neal began working with our family – I still don't know very much. I intuited that, basically, it must have evolved from Skinner (who had worked with pigeons, if I remembered correctly from my Psychology 100 classes) and

knew that Skinner, in turn, had been influenced by Pavlov and his clicker-trained dog. Neal recommended the text *Principles of Everyday Behavior Analysis* by L. Keith Miller: it became our first purchase with those precious “Autism Dollars.”

Behavior analysis, according to Miller (2006), has its roots in the philosophy of behaviorism; that is, behavior analysts sought to understand the motivation for peoples’ behaviors by studying what they did. Theoretically, behaviorists hypothesized that they would be able to solve many of the world’s social ills if they understood why people acted in the manners in which they did.

Miller credits John Watson with being the first psychologist to adopt the philosophy of behaviourism back in 1914 and describes B.F. Skinner as the man who “laid the basis for modern behaviourism in 1938 [through the formulation of] the law of reinforcement” (2006, p. 2) – which focused around operant, or voluntary, behavior, as opposed to reflex behavior as highlighted by Pavlov and Watson in their respective studies. This “law” (“A behavior followed by a reinforcer will increase in probability” was the premise for a number of the interventions that we put in place with Finnley.

Of course, the behavior analysts uncovered certain variables that affected people’s behavior. According to Miller, “these variables were the basis for the first laws of voluntary behavior” (2006, p. 3) and, eventually, paved the way for behavior analysts to consider differing approaches that they could use with people to resolve their problem behaviours; hence, the development of applied behavior analysis.

According to Baer, Wolf, & Riskley, cited in Miller’s text, “behavior analysis is the science that studies environmental events that change behavior” (2006, p. 5).

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Neal: “In order for us to get Finnley to change his problem behaviors, we need to observe what he’s doing.”

Me: “I know what he’s doing – he’s hitting, breaking things, hurting his sister, and refusing to listen to me. I live it every day. We all do!”

Neal: "Okay. But, we need to keep track of how often he's doing these behaviours."

Me: "All the time!"

Neal: "It might feel like that; but, I doubt that it's actually the case. We want to keep track of what happens, when it happens and, hopefully, begin to figure out why it happens."

Me: "Isn't he acting this way because he has autism?"

Neal: "Yes and no. He has autism; but he's acting in a certain manner because some need within him is or isn't being satisfied by his environment. We need to figure out what that need is and help him to satisfy it in a more socially acceptable manner."

Me: "I could get it if he were fifty-five. Maybe. I mean, there are lots of things that I do that I couldn't possibly explain! Maybe they are habits, maybe they are cultural expectations or societal norms. Maybe I do them because that's how my parents did them! Perhaps if I sat and analysed every single thing that I did, I could figure out the root of the cause. But, Finnley's five. I don't think he has the capability to think through things that clearly."

Neal: "That's why we have to do it for him."

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According to Miller:

The first tactic in using the behavioral strategy to solve human problems is to develop a behavioral definition. You can gather information about when and how often the behavior occurs. This information will sometimes motivate people to change the behavior. Other times it will provide enough information to let others help them make the change. . . . The behavioral definition gives you the basis for observing the problem behavior. However, when the resultant focus on a behavior does not solve the problem [as it wouldn't with a child as young as five who has no interest in changing his behavior!], you can use a second tactic . . . direct observation to gather information about the problem behavior (2006, p. 35).

Neal, Carrie (the support person from the preschool whom we had hired to work with Finnley over the summer), Phil, and I set about to do some "event recording" (p. 38) of Finnley's more challenging behaviours to get a better

sense of how often they were occurring and with what regularity. Neal was also attempting to uncover what “reinforced” Finnley’s problem behaviours; that is, what events both preceded and followed the problem behavior. Neal also completed a series of assessments on Finnley: a Functional Assessment Interview (FAI); the Scales of Independent Behavior – Revised (SIB-R); and the Functional Analysis Screening Tool (FAST). Phil and I completed an intake questionnaire and the parent-mediated communication-focused PACTS (Preschool Autism Communication Trial) Checklist wherein we discussed Finnley’s behavioural challenges and developed a set of possible goals for him. With all of this information in hand, Neal would, theoretically, develop a behavioural plan for Finnley. By mid-October we had our answers.

The Scale of Independent Behavior-Revised (SIB-R) Assessment results:

- The Social Interaction & Communication Cluster, measuring Finnley’s “interactions with others in various social settings and his understanding of communication of information through signs, oral expression or written symbols,” indicates his skill level “range from ‘limited’ to ‘age appropriate’ with his language comprehension skills being his strongest sub-skill. Overall, Finnley is functioning at the level of a 3 year old and 4 month old child” (Behaviour Assessment Report dated 18 Oct 2005, p. 5);
- The Personal Living Cluster, measuring Finnley’s personal living skills such as “eating and preparing meals, taking care of personal hygiene and appearance, and maintaining an orderly home environment,” indicates his “personal living skills range from ‘limited’ to ‘limited to age appropriate’ [wherein] Finnley’s personal living skills are at the level of a 3 year old child” (p. 6);
- The Community Living Cluster, that “measures the skills Finnley needs to successfully use community resources, perform in an employment situation and assume other social and economic requirements encountered in the community setting” (p. 7) places him, again, in the “‘limited’ to ‘limited to age appropriate’” (p. 7) category;
- The Motor Skills Cluster, which “includes both gross and fine motor proficiency tasks involving mobility, fitness, coordination, eye-hand coordination, and precise movements” (p. 7) established that “Finnley’s gross motor skills are age appropriate while his fine motor skills are

more limited. There is significant variation between Finnley's gross and fine motor skills" (p. 8);

- The Behaviour Profile "measures internalized maladaptive behaviours (behaviours that are directed inwardly), externalized maladaptive behaviours (behaviours directed outwards), as well as asocial behaviours (inappropriate interactions with others). According to the scores, Finnley's internalized behaviours were "normal" (He only had/has one, really – talking to himself.), his externalized behaviours were "very serious" (hurtful to others, destructive of property), his asocial behaviours were considered "moderately serious" (defiant, and disruptive), giving him a composite score of "serious" (pp. 8-9).

Basically, the tests told me what I already knew about my son – he acted much younger than he should, given his actual age, and a significant number of his behaviours were inappropriate. Now we needed to figure out what to do about eliminating these socially offensive behaviours.

Phil and I had initially indicated a series of possible goals for Finnley. They included the following:

- To improve the problem behaviours of hitting, being disruptive, being defiant, yelling and interrupting others;
- To improve self-regulatory behaviours;
- To improve ability to play in a self-directed fashion;
- To develop social skills with peers;
- To increase his attention/focus (Behaviour Assessment Report, p. 3).

We decided to direct our attentions onto the three areas where the change in behavior was most immediately needed for the sake of our family: the hitting/pinching; the physical disruption; and the defiance. Neal asked us to rate the intensity (the amount of physical effort that Finnley has to exert in order to emit the problem behavior), the effectiveness (the consistency with which the problem behavior is reinforced), and the latency (the length of delay between the onset of the behavior and the delivery of the reinforcer) of these three main problem areas.

According to Miller, "reinforcement expresses the idea that people learn behaviours that work" (2006, p. 159). Somehow, according to Neal, Finnley was gaining something through his anti-social behaviours, and this caused them to

continue. I concurred – to a degree. Obviously, if I was paying attention to Scotia – and not Finnley – then he would misbehave in order to draw the attention (even negative) upon himself. Like the child who tantrums until he or she gets his way, parts of Finnley’s behaviour could certainly be explained by this behavior. But, it certainly didn’t explain everything.

The information presented in the report said as much. In fact, the data really wasn’t anything that Phil and I hadn’t already figured out for ourselves – we now just had the scientific “proof.” There were five “ecological events,” as Neal, described them (Miller refers to them as “environmental events” (2006, p. 148) that decreased the frequency and intensity of the problem behaviours (evening time after dinner, a 1:1 activity of Finnley’s choice with either Phil or me, other people following Finnley’s wishes, being given “choice,” and structured times/activities). However, there were eleven events that had the opposite effect – they increased the frequency and intensity of the problem behaviours (lack of sleep, hunger, unplanned/unexpected transitions, noise in the environment, unstructured free time, being told “no”, being given a demand, before meals – because I was busy preparing them, when he was with me and Scotia together, unexpected results from his own behavior, and, interestingly, when Finnley was given praise) (pp. 9-10 in Behaviour Assessment Report).

I found it all rather overwhelming. Spending time recording my son’s misbehaviours into Neal’s fancy charts was all well and good, but I had serious reservations about my ability to actually implement that “action plan” once it was finally developed. It sounded like an awful lot of work, and more time and energy than I felt that I had in reserve. I didn’t like to run my life on a schedule, and I found that when I tried (because I knew that Finnley preferred routines), it was rarely successful anyway – because “something” would happen to alter things or one or both of the kids would thwart my carefully made plans with their own ideas. I was also quite concerned about how Finnley was going to respond to all of this change – as far as I could tell, he was quite happy with the way his world had been working up until now.

In the meantime, kindergarten had begun and Finnley seemed to be adjusting fairly well – after the colossal nightmare of the first week, of course, when the Kindergarten children were placed with a Grade 5 teacher.

The practice at the schools in the district was to have children return to their “old” classroom for the first week or so of classes while the new class lists

were organized. This meant that the kindergarten children were placed with the teachers whose classes had “graduated” to the next level of schooling (in this case, middle school).

For Finnley, this meant much stress and anxiety – entirely unnecessary, I might add, given that the children had no scheduled activities and the Grade 5 teacher was, essentially, doing nothing more than babysitting. (I pointed this out to the school administrators and, to their credit, the following year they adapted the unwritten school policy, leaving the choice to the parents to make as to whether their kindergarten-aged child with special needs would or would not attend the first week of school.)

Scotia, meanwhile, was in preschool three days a week, I was working part-time, and, to add to the excitement, we had managed to purchase a “holiday home” for the summer months. . . .

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It is the Thanksgiving Long Weekend and we are doing some renovations on our “property.”

I look up from the blackberry vine with which I am currently wrestling to see Peter, a boy of Finnley’s age, running towards me.

“Vandy! Finnley fell off of the teeter totter!”

“Is he hurt, Peter?”

“I don’t know. I don’t think so.”

I quickly tear off my gardening gloves and run after Peter, back towards the playground where he’d been playing with Finnley.

We had just rented a plot of land with a decrepit old shack and trailer on it at the New Westminster Legion Camp down near the border. It was kind of like this little oasis – the Legion had been leasing this land from the Semihamoo Nation for about fifty years. It was basically a trailer park, with lots of trees and woods to explore and an undeveloped sandy beach right across the dirt road. An ideal place for my children to spend their free time as far as I was concerned. The camp was filled with a range of people, from lots of different walks of life, of all different ages. And, in the summer, there were tonnes of kids running

around, playing all the sorts of games and activities that we'd all grown up playing. And, there was a playground area full of all of the old equipment that has since been banned from parks and schools because of safety issues – things like a merry go round, a metal horse that you could make rock back and forth, and an old wooden teeter totter.

Finnley was walking towards me as I rounded the corner.

"Are you okay, buddy?"

"Yes." Finnley was silent. This should have been my first clue.

"Okay. Well why don't you come back to the trailer and have something to eat? Daddy and I have a bit more work we need to do." We were clearing the lot and demolishing the pre-existing building since it was completely infested with mold and mice droppings.

"Okay. Can I have chips?"

"Yes."

We walked back to our site together. I noticed that he was kind of protecting his right arm. This should have been my second clue.

"Did you hurt your arm, Finnley?"

"I don't know."

"Does it hurt?"

"A little." He wasn't crying, of course.

"Did you cry when you fell off of the teeter totter?"

"I didn't fall off. Peter jumped off."

"Oh. That happens sometimes. Did you cry?"

"No."

I gave him his potato chips and got back to work helping Phil pull the insulation out of the wall of the building. Finnley methodically ate his chips. Silently. This should have been my third clue.

Forty-five minutes later Phil asked, "What's Finnley doing?"

"I don't know. Let's go see."

Finnley was sitting in our van in his car seat. Silent. He wasn't jumping around, he wasn't honking the horn, he hadn't taken everything out of the tool box, he hadn't emptied the glove compartment; in fact, he hadn't done anything. He was also looking paler than he had been an hour earlier.

"Um," I said, "I think I need to take him to the hospital to get checked out."

I drive into White Rock to the hospital there. The nurse in Emergency is a bit dubious.

"You think he might have broken his arm? But, he's not crying."

"No, he isn't. But, he's silent, you see. And, he's never quiet."

"Maybe he's just tired. His arm looks okay to me," she said as she twisted it this way and that.

Finnley didn't flinch.

"See? He's not responding. I think he just got a bit frightened by what happened."

"Finnley," I asked, "Do you feel okay?"

"I don't know."

"Please. I'd like to see the doctor anyway," I tell the nurse.

"Well," she huffed. "If you insist. But, you know, we're very busy in here and there are real patients in here that need the doctor's help."

We wait. And we wait. And we wait.

Finally, we are called into the triage room.

"What seems to be the issue?" a young intern asks me.

"I think my son may have broken his arm," I reply.

"He's not crying."

"No, he rarely cries."

"But breaking your arm really hurts."

"Yes, I know."

"Hey son," the doctor asked, "Does your arm hurt?"

"It's okay."

"Finnley," I said. "You need to tell the doctor if your arm hurts."

"It doesn't."

"But does it feel different than normal?"

"A little."

"He's probably got a mild sprain," the doctor responds, getting up to leave.

"Please. I need you to X-ray it for me. I think there's something more serious the matter. Finnley really is not himself right now."

"Ma'am, no disrespect, but I have lots of patients here and I don't think his arm is broken."

"You aren't the one operating the X-ray machine. Someone else does that for you. Please. I think his arm is broken. Finnley has Asperger's syndrome and has a really high pain threshold."

"Asperger's syndrome? What's that?"

I stare at him in disbelief. "You need to get his X-ray done right now."

An hour later we are leaving the hospital. Finnley, with a cast on his right arm; me, crying. Finnley had a broken arm. And I had handed him a handful of potato chips and gone back to work. And the nurse and the doctor had been no better. And Finnley had withstood it all. Like a little soldier. He was five.

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Neal is back at our house. He is explaining how the action plan will be implemented. We will use different types of reinforcers to try to "increase the rate of a behavior" (Miller, 2006, p. 159); that is, we would attempt to reinforce Finnley's positive behaviours ("Catch him being 'good'") rather than reinforce the problem behaviours – unless there was a safety issue, of course. Again, I had my reservations. It just seemed too simplistic to me. If Finnley responded negatively to praise, how was I to reinforce his positive behaviours and somehow not draw attention to them? And, wasn't this counter-intuitive to the whole process of making the learning explicit for him? To my mind, Finnley needed practice in social situations and direct instruction in socially acceptable

behaviours. How was I to do this if, when he did do the “right” thing and I drew attention to it, he would turn around and purposely do the “wrong” thing? And, wasn’t nearly all of his behavior, positive or negative, driven by his insatiable need for my sole attention?

We chose three food items that Finnley liked which we didn’t allow him to have very often. They were considered treats or “reinforcers” (to use Neal’s ABA-type of language): mini chocolate chip cookies, chocolate chips, and potato chips. I took a six-cup muffin tin and put two of each type of treat into the dips in the container. Then I was to set the kitchen timer for five minutes. If Finnley didn’t hit/hurt Scotia in that time period, he earned his “treat” (his reinforcer). If he did hurt her, the timer went back to five minutes again and he received no reinforcer. Because I was dealing with two small children, they both had the same instructions; therefore, if Scotia didn’t hurt/hit Finnley (not that she ever did!), she also received a treat.

After almost two hours with no incident, I shifted the amount of time between reinforcers to seven minutes. It seemed to make no difference. I left it there for the rest of the day. Although the routine made getting anything done around the house somewhat problematic – given that I had less than seven minutes to actually do anything – it did mean that I could leave the Finnley and Scotia alone in a room together for once. It was working!

We had success for exactly three days.

Finnley had had enough of this behavior reinforcement. Not only was he tired of the routine, he had figured out that he could get the treat, then turn and whack Scotia before the timer went back on . . . sigh.

I was not impressed.

Back to the drawing board . . .

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It was at about this time that I had the pleasure of attending a two-day workshop hosted by Autism Community Training (ACT) with Carole Gray and the world-renowned Asperger syndrome expert, Dr. Tony Attwood – paid for with those autism dollars, I might add. I had read numerous of Dr. Attwood’s books including *Asperger’s Syndrome: A Guide for Parents and Professionals* (1997), *Pretending to be Normal: Living with Asperger’s Syndrome* (1999), and *Asperger’s Syndrome: A Guide for Parents and Professionals with Dr. Tony Atwood* (1998). Dr.

Attwood, an Australian, also happened to be my cousin's doctor. And, Carol Gray was the American woman who had invented Social Stories – a version of which Carrie, the support worker at the preschool, had been using to some degree of measured success with Finnley to help him to understand certain ideas and concepts. Needless to say, I was excited and eager to hear what they had to say.

The workshop was entitled, "Making Friends & Managing Feelings." Among other things that he spoke about, Dr. Attwood spent a long time talking about how lonely so many people with Asperger's syndrome are – because they want to connect with others but don't have the skills to do so – and the role that anxiety plays in exacerbating all of the other symptoms associated with autism. He theorized that if the person with Asperger's syndrome managed to assuage their anxiety that many of the other challenges related to the syndrome would lessen. I put up my hand to ask a question.

"My son has Asperger's syndrome, he is five years old, and he has an irrational fear of dogs. What should I do?"

"Buy him a dog."

People in the audience laugh. I look at Dr. Attwood, surprised.

"Seriously," he says. "When your son has managed to annoy everyone else in the world – and he will, if he hasn't done so already – that dog will still love him and want to hang out with him. He might be afraid of dogs right now, but he is going to need one later on."

"But, how do I move from an almost-paranoid fear of dogs to bringing one into our home?"

"Slowly and carefully. Control the interactions as much as possible."

I don't talk to Phil about it. I don't talk to Neal, our behavioural consultant, about it. So much of what Tony has had to say during these two days makes sense to me that I figure that he will be correct about this too.

You see, Tony *appreciates* my son: he hasn't met him (though he has met many boys who are similar to him), but he somehow "gets" him – likely because of his vast experience with so many kids with this syndrome. He sees the strengths in Finnley, without knowing him; he recognizes the potential within my child; he doesn't judge my son; he *believes* in him – and he has faith in me too, as Finnley's mom. He has confidence in both of us. True to the spirit

of appreciative inquiry, Dr. Attwood helps me “to uncover, learn about, and appreciate the best of ‘what is’” (Cooperrider, Whitney & Stavros, 2008, p. 104) about Finnley. While I have been trying to do this – as virtually every parent does for his/her child – at the same time, I have doubted myself and my abilities. But, Dr. Attwood has given me confidence to continue, helping me to recognize that I really do know the best way to help my son.⁹

The “stories” that Tony has shared, the “themes” that he has identified, assist me to “identify, illuminate, and understand [Finnley’s] distinctive strengths” (Cooperrider, Whitney & Stavros, 2008, p. 104) and support me as I begin see the “whole” of him. I have been trying to “compartmentalize” Finnley – yes, I have been recognizing his strengths, but I have been focusing my energy upon his struggles. And, the ABA therapy was only serving to draw more attention to Finnley’s “inefficiencies.” Watkins and her colleagues remind me, “What [I] see in parts is always some small piece of a larger whole, and that it is [my] choice about whether to see the part or to embrace the whole” (2011, p. 75). I realize that I really do have a choice about how I view my child.

Lynn Fels (2010) powerfully describes this moment of realization in “Coming into Presence: The Unfolding of A Moment”. In her moving description of witnessing “the arrival of a young man” (p. 2), she compares this moment of awakening to Hannah Arendt’s notion of natality. Gordon (2001) defines Arendt’s concept as follows:

Natality stands for the moments in our lives when we take responsibility for ourselves in relation to others. In this way, natality initiates an active relation to the world. It signifies those moments in our lives (and there are many) in which we attempt to answer the question that Arendt argues is at the basis of all action and that is posed to every newcomer to the world: “Who are you?” (p. 21).

Arendt (1958) speaks, in essence, here of a “second birth” (p. 176); that is with our words and our actions we “insert” ourselves, yet again, into the world as we try to answer this question of who we are. While our first “natality” is our actual birth, this “second birth” stems from the impulse or the desire to

⁹ **Dear Reader/Listener:** Me again. I promise that this is the last time I will interfere with your reading of my story.... But, this would be a good time for you to go and read *Story C* (about Appreciative Inquiry). Thank you.

initiate something new of our own accord and, somehow, make ourselves “known” to both others and to ourselves.

“Knowing” my son, Finnley, means seeing all of him – not the tiny bits of him that make up the symptomatology of Asperger’s syndrome; not imposing upon my son a sense of “belatedness”¹⁰ (Orlie, 1994, p. 345) with his “label”. This “knowing” means becoming willing to awaken to the potentiality of this remarkable boy, my child – and to the awesome responsibility that this imposes on those of us upon whom he relies. As Fels describes, in her “receiving” of the young man before her:

his arrival is our shared responsibility, our response and action require us to be present and wide-awake. We must be wary and aware of our own locations and complicity. This moment of a young man’s arrival in our midst invites an uncomfortable shifting ...” (p. 3)

For Fels, that “shifting” had to do with the “seating” of her research; for me, that “shifting” needs to come about because of the importance of my job as Finnley’s mother. While I may not be able to change what has already occurred, I can initiate a “second birth” in myself by changing how I view myself (and my son) now. While I “know” intellectually that living in a space mired with guilt and regret leads nowhere, my “knowledge” of this “knowing” is not grounded in my body. Though my *head* can say that it isn’t my fault that Finnley was born with autism, my *heart* feels differently. And, as much as I can know something on a conscious level, my unconscious weaves its way into my thoughts and being and informs my actions and interactions with others.

Phil would say, *“Vandy it’s not your fault that Finnley has Asperger’s syndrome. There are any number of reasons why it could have happened. And, it doesn’t really matter anyway. We have a happy, healthy boy who we love and who loves us. He (and we) will be just fine.”*

I would nod, pretend to agree, but continue to think and feel exactly the same way about myself and about Finn.

¹⁰ Orlie (1994) interprets Arendt’s term “belatedness” to describe the replication of “social pariahs” who, because they see no hope of being anything other than whom they have been described by others to be, that they accept this “fate” and mold it into their identity, tacitly accepting their culturally and socially prescribed position (pp. 345-346).

But, this was going to change.... Arendt's notion of natality can apply to me too. With my own "second birth", I will unite my words and my actions into helping my son as best I know how, given that I now have a clearer understanding of who he is and who he has the potential to become.

Dr. Attwood talks about how children with Asperger's syndrome are not animals in need of controlling but rather human beings in need of direction. I think to myself: *"This is the piece that I struggle with when it comes to ABA therapy and Finnley – I am 'training' him in order to alleviate an unwanted behavior; however, I am not 'replacing' that behavior with something else."* For instance, I was going to train him not to throw rocks at other children in order to get their attention, but I was not replacing the rock throwing with other, more socially appropriate, attention-seeking skills. I didn't understand how he was supposed to learn this if we weren't making these expected behaviours explicitly clear to him. Unconsciously, I was trying to use a key principle of the Appreciative Inquiry philosophy (the positive principle) with Finnley, but I was struggling in its implementation. By drawing attention to the unwanted behavior, I was reinforcing it. As Dr. Attwood reminded me, by telling him, "Don't think about a polar bear," all I was doing was making Finnley even more aware of that polar bear.

And, what Carol Gray has to say about creating conditions of "readiness" for friendship reinforces this idea of gently "directing" as opposed to punishing and rewarding. She speaks of the work that she and her colleague, Laurel Falvo, have done around teaching kids how to "be" a friend as opposed to "having" a friend and what "being" a friend can actually look like for children with Asperger's syndrome if we take the time to try (<http://www.thegraycenter.org>). This fits with my understanding of who Finnley is; and it makes sense to me as a teacher. I see this loving, gentle, little boy locked inside this frustrated (sometimes), loud (usually) whirling dervish of energy (always) who wants to connect to people but, for whatever reason, doesn't seem to instinctively know how to do it; and if he does learn the socially acceptable behaviour in one situation, he doesn't seem to have the cognitive ability to transfer that knowledge to another.

Now, let me be perfectly clear, this is not to say that I think ABA therapy is not the correct therapy for all children and families. I personally know numerous families who have had great success using ABA therapy with their children with autism. It is because of the successes that one particular family

had with the therapy that we hired Neal, our behavior consultant. It is just that Applied Behaviour Therapy is not the correct therapy for this child (Finnley) and this family (mine).

I start looking for a dog immediately. I also begin working out the way that I will make Finnley (and my husband!) comfortable with the idea of us owning a dog (and gently telling Neal that we no longer need his services).

I begin with books. I read both of the children a number of different books about dogs, I show them pictures of dogs in magazines, I find video clips on-line of dogs doing all sorts of things and I seek out friends who have even-tempered and friendly dogs to help Finnley get used to them. (I should tell you that, initially, Finnley would scream when he even saw a picture of a dog.) I talk about dogs at the dinner table, I make up songs about dogs, I take the children to the local pet stores to visit the puppies and I buy them each a stuffed dog. (Scotia named her stuffed dog "Mischief"; Finnley named his dog "Dog.") I actively avoid the Society for the Prevention of Cruelty towards Animals (SPCA) where, I know, the dogs will be noisy, highly stressed and, likely, quite large and unmanageable. I want all of Finnley's interactions with dogs to be positive. I don't know how or why his fear of dogs has begun, but I am doing my very level best to end it. And quickly.

Two months later I find, to my mind, the perfect dog for us on Petfinder.com, a website that attempts to connect people with their "perfect pet." "Rusty" was supposedly a two-year-old Belgian shepherd who'd been taken out of an abusive home by the SPCA and was being fostered by a family who lived in a two-room home with a four-year-old boy, a toddler girl, a very large dog aptly named "Bear," a big mean cat, and a boa constrictor! The photo that was posted online was of this lovely black dog with a young boy pulling at his ears and a little girl all nestled in his fur. I figured that if the dog was that calm in the photo that he was the perfect dog for us.

It turned out that Rusty was closer to five or six years of age, that he had a tendency to run away, that he barked an awful lot, that he was obsessed with squirrels, and that he was terrified of cameras. (Goodness knows how they managed to take that photo of him in the first place – he must have been drugged.) At any rate, for all of Rusty's flaws, he was the perfect dog for Finnley and, consequently, for us. He loved Finnley and Scotia and they, in turn, loved him.

Finnley learned so much because of having a dog. And, I would feel these shiny glimmers of hope as I watched him interact with Rusty. He did care! He wasn't a monster! The first thing that Finnley did in the morning, as soon as he awoke, was to lie down on the ground beside Rusty and pet him. Similarly, petting Rusty was the last thing that Finnley did before he went to bed each night. Finnley learned about responsibility by having to feed the dog, brush the dog, and take Rusty for walks. I was certain that Finnley was becoming more empathetic because of Rusty. And, Dr. Attwood had been correct: there was many a day when Finnley had annoyed everyone else living in the house – to the point where we didn't want to see him, let alone talk to him – but Rusty was always there for Finnley, to give and to receive love and to help him to develop into a compassionate human being who cares about people and animals – the person he is continuing to become today.

Research seems to support Dr. Attwood's recommendation. Katcher and Wilkins (2000) reported that some children may initially use animals as transitional objects which eventually leads to them developing relationships with human beings. While Finnley had already developed relationships with our family, as well as some children his age and his teachers, I noticed that he was calmer and was able to have actual interactive conversations with other people (mere acquaintances, even) if Rusty was the topic of conversation – and, most importantly, Finnley would often *initiate* these conversations!

Interestingly, one theory put forth as a reason, perhaps, why some people with ASD are responsive to dogs is that animals, specifically dogs in this case, seem to make their behavioural intentions more clear to people with autism than humans do – mainly because dogs are not communicating both verbally and non-verbally at the same time. Prothmann, Ettrich, and Prothmann (2009) theorize that because dogs communicate without words and instinctively portray their intentions through their body language, it makes it easier for a person with autism to understand them (p. 169). This certainly seemed to be the case for Finnley with Rusty.

Essentially, Rusty became one of Finnley's therapies (though the dog's "fee" could not be paid for through the autism dollars from the provincial government). Meanwhile, Finnley's human therapist, Carrie (his trusty aide from the preschool), continued to work with him a few hours a week, and through most of the following summer. I wasn't satisfied though – Finnley's boundless energy and his sensory issues (particularly his need for deep

pressure) continued to pose challenges for him both at home and at school – he still could not regulate his incessant need to smash and crash into things and people. I knew that the coming school year, when he would be required to sit in a desk all day, would be challenging for him (and, therefore, Phil, Scotia and me). We needed another “therapy” for Finnley.

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When Finnley was officially diagnosed with Asperger’s syndrome and I’d seen his tendency to fixate on particular things – like construction machines, like wheels, like dinosaurs, like trains – I had made the conscious decision to do everything in my power to make certain that Finnley would not grow up to be the boy in the class that would try to have conversations with people about things like pocket wrenches! Knowing the names of all the types of construction vehicles is fine when you’re four, and fine if that is the field in which you work. It isn’t fine if it is your only topic of conversation at the age of thirteen, however – as it was for one of my previous high school students. I wanted Finnley to fit in – again, to be as “normal” as possible. So, I decided to try to interest him in hockey. My theory was that if he randomly spouted off hockey statistics, it would be more socially acceptable than if he started rattling off bus schedules.

When Finnley was six, we registered him to play the game. This was the best thing we possibly could have done for our son. My justification was that since he loved being so physical, at least the other children would have padding on when he came charging toward them. As well, there was a tacit societal expectation that, somehow, it was okay to be physical (and a little aggressive) when playing hockey. I hoped that playing hockey would do other things for him too: that Finnley would learn to be part of a team, working together toward a common goal; that he would wear off some of his boundless energy; that he might not be quite as physical with his sister if he had an acceptable outlet for this behaviour; that his gross motor abilities would improve; and that he would be less clumsy.

Phil was initially hesitant. He agreed that Finnley needed some sort of physical outlet for all of his energy; but he thought that swimming might be a better sport for him – swimming is essentially a “solo sport” and there would be less pressure on Finnley in that he wouldn’t have to interact with other

people in a “comradely” manner (as one does in a team sport), essentially perform in the manner expected of a typical six-year-old boy. As well, the “rules” of swimming weren’t quite as complex as the “rules” for hockey; you only had to propel your body through the water – you didn’t need to learn how to move your body on skates, and hold a stick, and chase a puck, and remember all of the rules of play. But, all of these challenges were exactly *why* I wanted Finnley to play hockey. I knew that he would like the speed of the game, I knew that he would appreciate the “rough and tumble” type of play, I wanted him to learn how to work with other kids, and I wanted the intellectual challenge for him. My theory about my son was that if his brain was in need of developing, then he needed to actually “work” it in order for this to happen.

To my mind, this was the true beginning of Finnley’s physical therapy. Yes, we had worked with an occupational therapist when he was younger; yes, we’d purchased some therapy equipment – under the instructions of our behavioural consultant, Neal – such as a beanbag chair (that Finnley could, literally, crash into), a hammock swing that hung in the doorway of my bedroom (to calm him and give him the much-needed sensory stimulation that he craved so much), and a mini-trampoline (to burn up some of his excess energy and help him with his gross motor skills); but none of these things consistently worked, and Finnley wasn’t interested in participating in most of the activities – in particular, working with the occupational therapist or participating in any sort of “therapy” session with anybody.¹¹ And, of course, motivation is the key to success in any learning environment – as all teachers can tell you anecdotally.

Finnley loved hockey. He continues to love hockey. And, not surprisingly, because he plays it so often, he’s become relatively good at it. Good enough to make our minor hockey association’s Rep team. Good enough to be a leading goal scorer for any team on which he has played. And good enough that kids in the neighbourhood call him up on the weekend to play a game of “shinny” at the

¹¹ As a side note, I saw Finnley’s distaste for working with the OT and others as a positive reaction in some ways – to me, it said that Finnley recognized that he was being “othered” and he didn’t want this for himself. Subconsciously, I suppose, I didn’t want this for him either. Perhaps, though, it was more that Finnley wasn’t interested in the activities that the OT proposed and that he preferred to do something else with kids his own age instead.

local elementary school. Not bad for a kid with Asperger's syndrome who, apparently, isn't supposed to enjoy team sports or socializing.

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The start of the hockey season meant the start of Grade One. Full-time school with the same group of children all day long – including another little boy with diagnosed Asperger's syndrome in the same classroom as Finnley. I was somewhat concerned because Finnley would have two teachers who, quite likely, would have slightly different expectations for him. However, his main teacher, Mrs. Dylan, (who worked with the children Monday through Thursday) had assured me that things would be fine with the other teacher on the Fridays. As well, I had “pushed” a bit – using my educational background as my ballast and Finnley had been given the same special education assistant as he had had the year before. (It also helped, of course, that Phil was the much-admired principal of one of the middle schools in the district.)

I knew very little about what was going on at school for Finnley (other than the occasional chat with the educational assistant, who, because she had two children with ASD to work with in the same classroom, was able to support the teacher for the entire school day). He seemed happy enough, though he would (literally) fight with me some mornings about going to school – particularly on Fridays. And, I did notice that his behavior after school was getting more challenging – again, with it being even worse on Fridays.

Now, initially, I presumed that, like most children, Finnley was balking at going to school because he preferred to stay home and play with me. I also presumed that his behaviour was worse on Fridays (both before and after school) because of the “build-up” of stress from the week. I knew that Finnley was likely having to work very hard to regulate himself while at school, given the challenges he had with this at home. Because I never received any notes home from the school I presumed that he was managing well enough; and, because there were no phone calls home to report problem behaviours or to ask advice I had no reason to think otherwise. Of course, Finnley never mentioned anything when I asked him how his day at school had been. It wasn't until near the end of October, on a Friday morning – only 30 minutes after classes had begun – that I found out what had been happening to my son for the previous two months.

“What a morning,” I think to myself as I hurriedly run back to the school. I’d forgotten to hand in the field trip note for my daughter and had had to go back to the house to get it. Thankfully, we lived only half a block from the school; but, some mornings – like this one – it feels much too far . . .

It has been another morning when Finnley, for whatever reason, had decided that he did not want to go to school. It had started out fine and, for the life of me, I couldn’t figure out what and why it had derailed. Finnley had been dressed and ready to go, with his shoes on and coat zipped up. Scotia had been ready, too – a first for her. For all my son’s challenges, if he decides to do something he does it quickly – including getting ready for school; my daughter, meanwhile, prefers to dawdle and daydream her hours away, with no interest in following any sort of time schedule. Consequently, no matter what time we got out of bed, we always seemed to be racing to get out the door and to school on-time; and, invariably, I would have had to do a fair amount of nagging in the process to make this even remotely close to possible. I found the whole process incredibly frustrating as both a parent and as an ex-teacher.

You see, I knew what teachers thought about children who were late for school every day . . . I’d been one of those teachers who had harboured those thoughts too: that the parents and their children weren’t responsible; that the parents didn’t care about their children’s education; that if they were all just a little bit more organized – and if the parents had better priorities – that their children would get to school on time. I couldn’t have been more self-righteous . . . However, now I knew better.

But, initially, this morning had been going quite well. Both children had dutifully followed the laminated schedules that Neal had prepared for each of them, where their routines were carefully laid out on the schedule sheet; and this morning, it seemed, the charts had appeared to have worked.¹² Before, when

¹² This had been another regiment that Neal had put in place in hopes of assisting Finnley with his self-regulation, with defiance, and with transitions. The theory was that he would complete his list of jobs, peeling each of the velcroed and laminated “action” stickers off of his chart as he completed the job. The removal of the sticker was, supposedly, the “reinforcer” as was, obviously, the treat I was to give him after he had emptied the whole chart. In essence it was “delayed gratification” . . . All of this was to give Finnley the

we were still seeing Neal on a regular basis, I would have given them each a “reinforcer” after this success; now I just thanked them. (Philosophically, I truly had difficulty rewarding the children for something that, while I knew it was difficult for Finnley to do, was simply an expectation that Phil and I had for him.) I had been smiling. I remember that smile on my face. And, there had been laughter on Scotia’s lips as she had skipped happily out the kitchen door and down the back steps. For once, we were all ready to go, and we had nearly ten minutes to spare. I had felt exhilarated.

I remembered calling behind me to Finnley, “Come on, buddy. It’s time to go to school. It’s Friday – last day of the school week. Time to go.”

He’d glanced at me briefly, quickly turned, and then had plunked himself down on the ground, bending over his feet to undo the Velcro on his shoes. Looking at him in disbelief, I’d remembered thinking to myself, “You have got to be kidding me!”

Finnley, for whatever reason, had decided that he wasn’t going to go to school today.

“Come on, Finnley. It’s Friday. It’s the last day of the school week. Tomorrow we get to stay at home and play all day long.”

Nothing.

“Please, Finnley. We’re going to be late! Put your shoes back on, please.”

He’d shrugged himself out of his coat.

I remembered feeling the tension building in my body and making the conscious decision to say, as calmly and as evenly as possible, “Finnley, you need to put your shoes and coat back on. It’s time for school and, for once, I’d like us to get there before the bell rings.”

He had done nothing. He hadn’t moved to put his shoes back on his feet. He didn’t even appear to be listening to me. In the meantime, Scotia had come back up the steps and into the house. She’d looked poised to remove her shoes as well.

motivation he required in order to remain compliant and on-task. And, of course, because Finnley had a schedule to follow, Scotia had one too.

Panicking a bit, I'd said, "No, Scotia. Shoes on, please. I'll be right there." Then, turning to my immensely frustrating son, I'd said, "Finnley, here is your choice: you can put your coat and your shoes on by yourself, or I can do it for you."

He'd looked at me, with what I was certain had been defiance in his eyes, and said, "No," and then, just as quickly, looked away again.

I could feel my blood beginning to heat as it began storming through my body. I had yelled, "Finnley, put your shoes on right this minute. This is not okay. It is time for school and we are leaving now!"

I remembered picking up his shoes and trying to ram them onto his feet. He'd made it nearly impossible, but somehow I had managed. I had stood him up and steered him in the direction of the kitchen door, with me behind him directing his movements. I had his coat in my hand, making the decision that I'd wrestle it onto him once we were outside with the door locked.

But Finnley wouldn't go outside. Suddenly, he had lunged to my right and made his way around me. He had run toward the living room, laughing.

Replaying the scenario in my mind, I could feel the tension creeping back into my body as I recalled how I'd felt in that moment . . .

"Finnley! Stop that this instant! It is time to go to school and you are going whether you want to go or not! That's enough!"

We had been closer to the front door of the house by this point so I had called Scotia to come to the front as well. She had done so and had skipped happily down those steps as well. I could see mothers and children walking along our street towards the school. Finnley, meanwhile, was lying on the carpet in the living room.

"Finnley, I am leaving right now. If you don't come with me, you will be left alone in the house. It is time for school and I don't want Scotia to be late."

I knew this wasn't fair. I knew that he didn't like to be alone. I was using his fear against him.

But it worked. Finnley had gotten up and walked out the front door ahead of me.

"Thank you, Finnley" I had said quietly, as I locked the door behind us.

Next thing I knew, Finnley had both hands grasped around the door handle and he was screaming to go back into the house.

I could not believe that this was happening. I tried to talk over him, but he was too loud. I didn't want to try to un-pry his fingers – I was afraid I would hurt him. So, finally, I had grabbed him around his waist to try to carry him down the stairs.

There I was, standing on the doorstep to the front of my home, in plain view of all of my neighbours, holding my son's body sideways, with his two hands firmly clamped around the door handle.

Of course a group of mothers had walked by – they were now returning home after taking their children to school. Children who were not screaming, and who were already at school – on time. Children who did not have their hands cemented around door handles.

I had let go of Finnley then, finally coming to my senses and realizing how ridiculous this battle had become. I used my only weapon one more time. I started to walk down the stairs towards Scotia saying, "See you Finnley. I'm walking Scotia to school now. I'll be home in a few minutes."

He had immediately let go of the door handle and run down the stairs, passing Scotia and me in the process. He was then trying to bar our way at the walkway gate. I had ignored him, lifting Scotia over our flower beds onto the sidewalk and had hopped over to join her. We began to walk toward the school.

Finnley, of course, had not stopped screaming since he'd first grabbed that door handle. He rushed ahead again, trying to block our steps as we went. Remembering Neal's words, I tried to ignore his behavior; it was my attention that my son wanted.

We had made our way slowly down the street towards the school. Scotia skipping ahead; me trying to walk; and, Finnley repeatedly stepping on my toes as he tried to prevent me from moving. It was slow going.

Finally, when I was nearly ready to relent and concede to my son's demands, he had stopped trying to physically block me with his body. Instead, he had taken my hand and fallen into step beside me, turning back into the sweetly affectionate little boy that he was fully capable of being. I had given him a quick side hug, feeling relief wash over me, and we had continued walking to school without incident.

But it hadn't ended there, of course; because, upon our late arrival, I had realized that I didn't have Scotia's field trip form with me – hence, the need to now rush back to the school . . .

I have dropped off the form and decide to wander down the hall and poke my head in Finnley's classroom to see how things are going. Although I know his Friday teacher by sight, I have never actually spoken with her – perhaps I should tell her how Finnley's morning has gone so far.

I round the corner and see Finnley sitting in the hall.

"Finnley," I exclaim, "What are you doing in the hall?"

"It's Friday," he says simply.

"Yes, I know it's Friday. Why are you in the hall?"

"I'm always in the hall when Mrs. XXX teaches."

"What do you mean, 'you're always in the hall when Mrs. XXX teaches?'"

"Mrs. XXX doesn't like me so I go in the hall all day."

"All day?!" I can barely contain the shriek of horror that I feel building inside of me.

"Yeah. It's ok. I get to go to the library, and I do my work at the desk in the little office."

I feel the blood draining from my face as the realization hits me in full force. This is why Finnley didn't want to come to school today. He knew it was Friday. And this is what Friday at school looks like for him.

The educational assistant sees me through the open doorway of the classroom and comes to join me in the hall. I am shaking.

"Why is Finnley in the hall?"

She shakes her head. "I don't know. He didn't do anything. He never does. I keep trying to tell her to give him a chance but she just sends him into the hall as soon as the day starts."

"Why has no one spoken to me about this?" I say, trying to remain calm in front of my curious son.

Her face blanches. "I thought you knew," she gasped. "Mrs. XXX said that she was going to talk to you about it."

"She has NEVER talked to me about this. Are you kidding me? I would NEVER agree to this!"

The educational assistant replies, "I couldn't figure it out. It didn't make sense to me that you would let this happen."

I am shaking my head.

"And, for such a long time, too," she added.

"What do you mean?!"

"Well, it's been going on since the middle of September and he's only allowed in the class for lunchtime. Oh, and he has music class with the rest of the class and the music teacher on Friday too when Mrs. XXX has her prep time."

"What!?" I say, more loudly than I intend, glancing quickly at the doorway. Some of the children in the class look up.

The educational assistant moves away from the entrance to the classroom.

"It is nearly the end of October! Do you mean to tell me that Finnley has been in the hall every Friday for almost two whole months?!" I exclaim.

She silently nods her head, her lips pursed.

"I cannot believe this! This is absolutely unacceptable! Doesn't she know that Finnley has an IEP? Doesn't she know that Finnley has Asperger's syndrome? Why him?"

I leave the educational assistant with Finnley and march into the principal's office, interrupting him on the telephone. He can see that I am seething with anger and quickly ends his phone call.

"Please tell me how it is that my son has been in the hall every Friday for the past two months, and that (a) I have never been informed and (b) that you would allow this to happen!"

He looks at me in disbelief, "Now Vandy, I think that must be an exaggeration."

"It is NOT an exaggeration," I snap. "I have just spoken with Finnley's educational assistant. She assures me that this has been the case for the past two months. Why have you not done anything?!"

“Well, I did notice Finnley in the hall on the odd occasion; but, I didn’t realize that he was there on a regular basis.”

“He spends ALL DAY LONG in the hall EVERY FRIDAY when that person is teaching him! You need to do something about this IMMEDIATELY!” I can feel tears of anger and frustration springing unbidden to my eyes.

He tries to reassure me. “Believe me, I will.”

To his credit, the principal did deal with the problem and Finnley no longer spent Fridays in the hallway. I would like to think that Mrs. XXX stopped sending Finnley there because she realized that it wasn’t educationally appropriate practice; but, realistically, it is more likely that Mrs. XXX was merely afraid of the repercussions of continuing her actions. All I could think to myself for days and weeks afterwards was, “What if I hadn’t been in the school on that Friday and happened to check on him? What if I hadn’t forgotten the field trip form and didn’t need to go back? Would Mrs. XXX have left him there all year long? And, would someone have eventually let me know this was happening?”

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There was no question that Finnley had more difficulty with school in Grade One: the increased academic expectations, the two teachers, the “seatwork” in the desks—all of it combined was a lot for him to cope with. We tried a number of different strategies to help Finnley to manage himself at school. We tied a wide band of elastic around the base of his desk that he could push his legs or feet against (this helped with the sensory need to for deep pressure), we tried him with a “wobble cushion” so he could “wiggle” while he sat at the desk (again, a focusing technique), and we tried a series of “rewards” à la Neal’s behavioural “reinforcers” to encourage self-regulated behaviour;. For instance, if Finnley could stay in his desk for the duration of the particular lesson, then he could go for a walk or go out to play on the playground with a child of his choice in the “free play” time later in the afternoon.

This strategy was the most successful of the three, and it served three purposes: (1) it was effective motivation to help Finnley to stay on task during class time; (2) it made him somewhat popular in class because many of the

other boys wanted to be the one chosen to go outside with him; and (3) it eliminated the challenges that both Mrs. Dylan and the educational assistant were having with Finnley's behavior during the unstructured play time that was a "scheduled" part of each afternoon.

As much as it was a good idea to have the other little boy with Asperger's syndrome in the classroom with him (meaning the educational assistant could stay for the day), the strategy backfired in many ways as well. Mrs. Dylan compared Finnley and Edward to whales with internal "locating devices" that fixated the two of them onto each other – the boys seemed to be able to wind each other up without actually being physically near to each other. According to Mrs. Dylan, they had developed a game whereby they "called" to each other – literally, like whales do in the wild – by making strange echo-like sounds. Apparently, this "sound location" exercise would go on all day long and no amount of intervention seemed to be able to dissuade the two boys from the inappropriate and disruptive behavior in the classroom.

Now, initially I had been happy when Finnley and Edward had connected with each other – I saw Edward as the first friend that Finnley had made all by himself (I, of course, had orchestrated all of the other friendships from preschool, *vis-à-vis* my relationship with their parents), and I'd been proud of Finnley (and, I must admit, had felt slightly superior to Edward's mom) when I came to realize that Finnley was more "adaptive" than Edward was – as if all of the early intervention strategies we had busily put in place were the reason for Finnley's "better," more "normalized" behavior, as if anyone but Finnley (or the hard-wiring of his brain) had made this happen. There was no question that Finnley had strong relationships with children from the preschool – friends that he continued to want in his life and, who, in turn, appeared to wish to continue their relationship with him. Meanwhile, Edward was much more of a loner and, therefore, lonelier because of it. Finnley, in essence, became Edward's first friend and, while I was gratified that Finnley could be this person for Edward, it worried me as well – particularly when Finnley and Edward seemed to "feed" off of each other's socially inappropriate conduct.

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“Hi Vandy. Sorry to bother you. Do you think you could come into the school to talk about Finnley’s progress?” It was the middle of April and his first grade teacher, Mrs. Dylan was calling.

“Um, sure. I’ll see you tomorrow after school.”

A night of worry.

The next day . . .

“Well, as you know, there’s another little boy in our classroom that has Asperger’s syndrome as well.”

“Yes. I know Edward. We’ve had him over to play with Finnley a couple of times. They seem to get along okay, don’t they?”

“Well, yes. That’s actually the problem”

Finnley and Edward had invented a game that they called “Weirdo”; they played it at recess and lunch every day, apparently. The way the game worked was that they would start at one end of the school yard and try to walk to the other end without anyone speaking to them, making eye contact with them, or bumping into them. If another child (or adult) made the “mistake” of interacting with them in any manner, Edward and Finnley would yell, “Weirdo” really loud into the other person’s face.

Now, I ask you, who were the “weirdos” in this scenario?! And, really, can you think of a more appropriate(?) “game” for two kids with Asperger’s syndrome to invent?

K K K

Meanwhile, Finnley was continuing to have his “bathroom issues” at home, and, apparently, they had become an issue at school as well – meaning he would begin pushing on his bowels when he needed to relieve himself, rather than asking to be excused and going to the washroom. The educational assistant would, apparently, try to encourage him to go to the bathroom, making up excuses for him to leave the room when she noticed he was kneading his stomach. But, Finnley, with his single-minded focus, didn’t like leaving in the middle of anything; therefore, it was next to impossible to pull him away.

Naturally, this was cause for concern. Not only was there a health issue tied to not relieving oneself when one needed “to go”; but, there was also a rather large social stigma attached to a six-year-old pushing on his bowels and not making it to the bathroom in time – particularly when it happened at school. Consequently, Finnley’s Individual Education Plan (IEP)¹³ included a number of behavioural expectations related to self-regulation. While I wasn’t surprised by this, it was still a bit disconcerting for me. My prior experience with IEPs up until this time had mainly been the paperwork that I would see in about mid-October as it made its way across my desk at the high school where I had worked. None of these IEPs had had anything to do with self-regulation – well, except the one for the kid who was learning to “manage” his anger. I did, however, know of a sixteen-year-old kid at the school who regularly wet his pants.... I had worked out a deal with his resource teacher where she would send him to me, I would give him clothes to wear from my costume shop while the home economics teacher washed his pants for him. I pictured my son in that position.

Something had to be done immediately.

The adaptations in the IEP included allowing him to leave a bit early for recess and arranging for him to visit the bathroom on the way outside at lunch. I knew that this would be an inconvenience for his teachers – that it would be one more thing that the teacher would need to remember to do – so I was thankful that the educational assistant was in the classroom with him to not only help Finnley to manage his behaviour, but also to help his teachers to remember that he would need this accommodation.

It was decided, as well, that the educational assistant would stand by the door as Finnley re-entered the building after the break, directing him into the bathroom. He didn’t like these interventions; the assistant told me that on a number of occasions he would get quite angry if she tried to stop him as he ran back inside. However, he was less oppositional about leaving the class at

¹³ An Individual Education Plan (IEP) is a document that is put in place when a child has a government-recognized Special Education designation. According to the BC Ministry of Education’s Special Education Policy manual, an IEP “is a documented plan developed for a student with special needs that describes individualized goals, adaptations, modifications, the services to be provided, and includes measures for tracking achievement” (*Special Education Services: A Manual of Policies, Procedures and Guidelines*, 2011, p. v).

10 am to visit the bathroom, as he went outside for recess – not surprising, since this meant that he could leave class early.

We had two main goals outlined in Finnley's IEP for Grade one. Goal 1 (Finnley will increase his ability to self-regulate his behavior in unstructured situations) included three short-term objectives: (1) Finnley will listen and respond to the requests of school staff when playing outside; (2) Finnley will listen and respond to instructions and requests during gym time; and, (3) Finnley will comply with teacher requests to finish what he is doing before moving on to the next activity. Note: we chose to focus upon the "unstructured situations" because in the previous year Finnley had seemed to manage fairly well with "structured" activities. Goal 2 (Finnley will demonstrate flexibility and caring with peers and school staff as he makes transitions within his school day) had been another particular area of challenge for him the year before. The short-term objectives for this goal included the following: (1) Finnley will be able to judge the appropriateness of space around himself and what other children needs as well; (2) Finnley will engage in social play outside of school; (3) Finnley will participate in turn-taking activities when interacting with other children; and (4) Finnley will respect established play situations and will join in as a member rather than to dominate the play (from "Goals Report," 2007).

Goal 2 was the area where we saw the most growth in Finnley's behavior. The results from the final report state:

Finnley has demonstrated that he does care about others. He has demonstrated a politeness, as he questioned instructions, when he didn't want to do certain things. Finnley has been generally cooperative, as reported by Marlene Furlong and his teachers. When he has had difficulty cooperating, his teacher or S.E.A. has had him sit in a quiet area where he listened and seemed to accept their explanation. Later in the school year, the quiet area needed to be outside the classroom. (from Goals Report, p. 3)

There was change. Finnley's behavior was improving! He had demonstrated that he cared about others while at school; he had demonstrated that he could be polite, and he had been generally cooperative with his teachers and with the special education assistant. Phil and I saw all of these behaviours as huge positives.

Meanwhile, he had had less success with Goal 1, particularly as the year had progressed:

A sticker reward system was successfully implemented for a period of time. Initially it was very effective at reinforcing his good behavior. Eventually the program no longer motivated Finnley. Finnley's reinforcers need to be changed frequently to be effective. His teachers report that for much of the school year, Finnley has functioned within the acceptable range for his teacher on the playground, and in the gym. Finnley has had more difficulty managing himself in the classroom. Managing Finnley within the classroom was possible until he and Ellis became really focused on each other. Their intense friendship resulted in a reluctance for he and his friend to disengage from one another. It is effective to give Finnley time in the hallway to break from the intense interactions with his friend. Initially he liked to walk around the circular hallway. In June, he expressed that he did not want to walk anymore. Finnley was given the option of playing with play-doh at a desk in the hall or sitting on a small carpet with cars or another manipulative. This time away from the stimulation of his classroom has been effective in allowing Finnley to calm himself down and to regain better control of himself. In June his parents and school staff decided to divide the day up into thirds and reward Finnley for each third that he managed himself. The reinforcers will be dispensed accordingly following communication between his teachers and his parents. Finnley needs to be taught to independently cue himself to use the washroom. Therefore, he will be reminded that at 10am each day he should head for the bathroom. The goal is to make this a habit for Finnley while make it appear that he is self monitoring his need to use the bathroom, but in reality we are trying to establish a habit of visiting the washroom just in case he should require it. This could be a life-long strategy to promote successful independence with his toileting issues. (from Goals Report, pp. 1-2)

We (he) had come so far; but, we still had a long way to go.

Chapter 5

TOWARDS A FUTURE

Now, the funding for children with autism decreases dramatically once the child turns six and is legally required to be enrolled in school. In British Columbia, the families of children under the age of six may receive up to \$22,000 per year to “promote their child’s communication, social-emotional, pre-academic, and functional life skills development” (Ministry of Children and Family Development, 2009, p. 13); for children aged 6-18, the families may receive up to \$6,000 per year “towards eligible intervention services that are outside of the child’s school or educational program” (p. 17). The logic behind this dip in funding is that the resources to teach children with autism (or any child with extraordinary needs for that matter) are, supposedly, readily available within the school system and, therefore, the parents no longer need to pay money from their own pockets to access the various therapies their child requires because the schools will, somehow, be able to provide all of these things. And, to a large extent, they do manage to do so with the resource personnel and materials that they have available to them. And, in some cases, they manage to support the child very well.

But, here is the real issue. Parents, in general, move from having sole say (and sole responsibility) over their child’s educational experiences prior to beginning school, to next-to-no say (and little-to-no responsibility). We, who know our children best, are no longer looked to as the “experts” about them. Instead, we take our children to a school, walk them through the doors, and then leave them with benevolent (we hope) strangers for 30-plus hours per week. For parents of typical children, this is a difficult transition. For parents of children with special needs, it is a terrifying one.

Whereas Phil and I were able to select our own behaviour consultant, choose our own behaviour interventionists, and find our own autism specialists to support our son, once Finnley entered the school system we lost

our voice (and, in essence, our control) over the choices being made about our son's well-being.

As educators, we are painfully aware of where the flaws in this system (that we support) are. We know the mandates, we understand the complexity of all of these conflicting political agents each waging their own particular battles. And, we understand why.

But, this knowledge doesn't make it any easier to deal with when it's *your* child that may be the one who ends up being lost and forgotten in this soft shoe shuffle of union/association negotiations. In fact, in some ways I think it makes it harder – because Phil and I understand exactly what we're up against...

As a student within the public school system, we knew our son was now at the mercy of a whole host of agents with conflicting agendas:

1. The British Columbia Teachers' Federation (BCTF) – the teacher's union (established in 1917 and granted full bargaining rights in 1987) that represents some 41,000 public school teachers (Retrieved from <http://www.bctf.ca/AboutUs.aspx>) which, in working to support its members (as it should), also is placed in the unfortunate position of having to sometimes champion the rights of a minority of teachers who are at best, ineffectual, and at worst, uncaring ;
2. The Canadian Union of Public Employees (CUPE) – representing more than 80,000 workers in more than 170 local unions, (Retrieved from <http://www.cupe.bc.ca/>), CUPE BC is the employee's union which champions the rights of the secretaries, the special education assistants and the majority of the paraprofessionals within our school district; and, as is the case with the teachers' union, supports its members, sometimes at the expense of the children with whom they are charged to work;
3. The British Columbia Principals' and Vice-Principals' Association (BCPVPA) – an autonomous professional “association” (not a union) since 1988 when its members became “management” under the Social Credit government of British Columbia. This association works to ensure that principals' and vice-principals' voices are represented when important discussions about education and schooling occur (Retrieved from <http://www.bcpvpa.bc.ca/node/1>). Its members are responsible for the leadership of individual schools but, unfortunately, can too often

- be found positioning themselves as authority figures over the (sometimes more experienced) staff members within the school in which they work, rather than as partners in the important job of educating children;
4. The British Columbia Public School Employers' Association (BCPSEA) – the accredited bargaining agent for the province's 60 public boards of education, for unionizing teaching and support staff in the British Columbia's K-12 public education system (Retrieved from <http://www.bcpsea.bc.ca/about-us/default.aspx>) that (from the outside) often appears to be busily focusing upon the political agenda of the day as opposed to the needs of the parents and children for whom they are supposed to be working;
 5. The BC School Trustees Association (BCSTA) – elected members of the public whose key work is to “improve student achievement” for the children within their jurisdiction (Retrieved from <http://www.bcsta.org/content/about-us>). Although supposedly focused upon serving the children (and the parents) of their school district, these “boards” can sometimes have their own personal and political agendas to peddle;
 6. The members of the BC School Superintendents Association (BCSSA) – the senior advisory body of the school districts, consisting of superintendents, assistant superintendents, directors of instruction and other senior executives. As “the province's educational leaders, uniquely qualified to ensure the success of students and school district operations” (Retrieved from <http://www.bcssa.org/about.html>) these administrators and senior management may have rational and educationally-sound recommendations to make but, like all of the other “partners” in the bureaucracy that is the public school system, they are directly answerable to the Ministry of Education and, therefore, ultimately under their control.¹⁴

¹⁴ I firmly believe that most people working within the public education system are there because they care about children and because they want to make a positive difference in children's lives; and, I believe that even those ineffectual teachers, disinterested special education assistants, over-bearing principals and arrogant school trustees within our system usually fall into this category of “people who care,” too. I also believe that we so clearly notice the inefficiencies in these human beings because they are such anomalies within our school system. And, I also recognize that personal preference and bias, as well as one's culture, are all factors that come into play when determining the supposed competency of these particular professionals.

These unions/associations have come into existence for very important reasons – they actively work to uphold the working environments of their members and negotiate with the government about things like pension plans and wages and working conditions. And, when these unions/associations are truly serving their members – by actively supporting them in their service to the parents and children of British Columbia’s public schools – I believe that they are doing the important job with which they have been charged. Unfortunately, sometimes other “issues” get in the way (like political agendas, like the desire to be re-elected, like “ego”, like...) and our children become pawns in a chess game where, ultimately, we all end up as the losers. Yes, all of these differing unions/associations *say* that they are the ones who are advocating for the children of British Columbia but, really, which one of them has that as their first and foremost priority on their political agenda?

According to Weishaar and Borsa (2001), there are certain expectations that parents of children with special needs hold regarding their children’s education, and their position in the decision-making for their children:

- (1) they hope to be seen as partners, assisting the teachers and school staff, in achieving acceptance and a sense of belonging for their children;
- (2) they expect to be given options or choice regarding the decisions made about their child;
- (3) they presume that their input will hold some power or influence over this decision-making process; and,
- (4) they aspire for some comfort, safe in the knowledge that these special education processes need not be emotionally painful experiences.

According to Zaretsky, in reference to Weisthaar and Borsa’s case studies, “if one or more of these needs are being threatened during a meeting, a conflict is likely to occur” (2004, p. 272).

Those four expectations certainly held (and continue to hold) true for Phil and me, regarding *both* of our children’s educations. I found it gratifying and encouraging that when decisions were made about Finnley by certain of the school staff (such as Mrs. XXX’s decision to leave Finnley in the hallway all day long on Fridays) that other staff members (in our case, the principal) intervened after they had learned of our displeasure with these decisions. Similarly, the change in the unwritten policy regarding the first days of school for kindergarten-aged students with special needs is another case in point where a

behaviour was adapted in order to accommodate the particular needs of the individual child and his/her family.

Yet, other decisions were made that I knew were not in the best interest of my child nor, for that matter, in the best interests of any children within the school. For instance, there is an unwritten policy at my children's elementary school whereby when the child with special needs shifts grades, they not only usually get a new teacher but they will regularly be assigned a new special education assistant as well.

Now, picture a child who struggles with anxiety – this is a child who is already likely quite nervous about entering a new grade. S/he will probably have a significant number of new peers with whom s/he must interact and learn; s/he will almost certainly have a new teacher, and so must learn this new teacher's rules, routines and expectations (which are almost certainly going to differ from her/his previous teacher's way of doing things); and, in the case of Finnley's school, there will be another new adult in the room with whom s/he must learn to communicate.

All of this “newness” is equally true for the parents as well – they, too, must become familiar with the curricular expectations of the new grade level; they, also, must come to know the new teacher and explain to him/her the unique needs of their child; and they must introduce themselves to the special education assistant and provide the necessary information that this person requires in order to find success when working with the child.

Obviously, I was very happy that the principal had listened to me regarding my concerns about Finnley and Mrs. XXX; similarly, I was pleased that he came to understand that there were some extra considerations that needed to be taken into account when it came to transitioning children with special needs into the school system. At the same time, the demand for these “interventions” fundamentally bothered me on other levels: Why was it necessary to make these simple suggestions in the first place? Weren't the needs fairly obvious? After all, it was not as if Finnley was the first child with special needs to start kindergarten in the district who had struggled during the first week of school – both the principal and the kindergarten teacher said as much. And, I was fairly certain that there were other children – even those without designated special needs – who would find the policy challenging . . . my friend's daughter, for instance, who was very nervous about going to

school. Although she didn't have a "special need," could the practice not be applicable for her as well?

Also, what if the child with the particular challenge had a parent without as much cultural collateral trying to do the advocating for him/her? Would the response have been different? Quite likely, I'm sadly guessing. My level of education, my skin colour, my language fluency, and my husband's position in the district were certainly all factors that influenced how I was (am) treated at my children's school and the confidence with which I addressed the situation in the first place. All of these reasons and more meant that my opinion was listened to by the school administration.

Still, what bothered me the most was that what I was advocating for my child (and for the children who came after him in this school) was something that, to me, was merely *common sense* and, really, spoke to the fundamental human rights that are supposedly built into our educational system – things like inclusion¹⁵ and integrated classrooms¹⁶ and instructional practices such as differentiation.¹⁷ I was asking for flexibility, for some "give," when it came to considering the needs of the individual children within the school. I was asking that the school and/or district policies be made plain – that the reasons behind

¹⁵ "Inclusion describes the principle that all students are entitled to equitable access to learning, achievement and the pursuit of excellence in all aspects of their education. The practice of inclusion is not necessarily synonymous with integration and goes beyond placement to include meaningful participation and the promotion of interaction with others" (*Special Education Services: A Manual of Policies, Procedures and Guidelines*, p. v).

¹⁶ "Integration is one of the major strategies used to achieve inclusion. With integration, students with special needs are included in educational settings with their peers who do not have special needs, and provided with the necessary accommodations determined on an individual basis, to enable them to be successful there. The principle of "placement in the most enabling learning environment" applies when decisions are made about the extent to which an individual student is placed in regular classrooms, or assigned to an alternate setting" (*Special Education Services: A Manual of Policies, Procedures and Guidelines*, pp. v-vi).

¹⁷ Differentiation or differentiated instruction refers to classroom practices that take into consideration the needs of individual learners. According to Tomlinson (2008), "Key elements of effective differentiation are important for leaders to understand. They are the mileposts that change efforts should be moving toward – nonnegotiables of the model. Each of the non-negotiables is aimed at one shared goal – greater academic success for the broadest possible student population. The nonnegotiables are respecting individuals, owning student success, building community, providing high-quality curriculum, assessing to inform instruction, implementing flexible classroom routines, creating varied avenues to learning, and sharing responsibility for teaching and learning (Tomlinson, 2008, p. 18).

them be made clear and transparent, and that the rationale behind these policies put the needs of the child first. Policies are all well and good when they aim to support the children for whom they have been put in place – they stop working when they become intractable rules that are upheld because “that’s the way it’s done here.”

I think back to Finnley’s experiences in Grade One: I am certain that Finnley was likely not the only child who had had trouble sitting in his desk for long periods of time, nor was he likely the only one who had had issues with unstructured activities and/or struggled with transitions. Why didn’t his teachers see – particularly, Mrs. XXX on Fridays – that so many of the adaptive techniques that were in place for Finnley could (and would) work well with the other children and wouldn’t cause him to be perceived as different – in effect, “othering” him – when other children would have benefited from the differentiated teaching strategies too? Why did it have to be his “label” that created the difference in teaching strategy when, really, the difference already exists between each individual child with or without a label? Don’t all children – regardless of whether they have a ministry designation or not – deserve opportunities to learn in the ways that best support them?

In fact, as I considered the classrooms where Finnley was placed in later grades – in particular, with Mrs. Dansworth (grade two) and Mr. Michaels (grades four and five), it was clear that Finnley’s success in these classrooms and with these teachers occurred for two main reasons: (1) The teachers appreciated my son for who he was, celebrating his many talents and gifts rather than focusing upon his deficits; and (2) The teachers structured their lessons and classrooms in such a manner that the adaptations weren’t considered “extra” (and only for children with IEPs) but, rather, were simply part of the culture of the classroom.

These teachers, who used progressive teaching strategies that promoted inclusion in their classrooms, were able to truly see the child – my son – and not just the label or the behaviour attached to him. They had adopted a way of thinking about teaching children with special needs that mirrored the changes that had occurred in educational policy during the 1990s, when

mainstreaming¹⁸ children had become the norm. Unfortunately, this inclusive way of teaching and learning is *still* not the “norm” for all students within our school system – even though it has been mandated to be so by the federal government since 1982.

The change in special education policy did not (and could not) truly address the biases of the people within the educational system, nor did the policy consider the ideas and concerns that these teachers had (have) regarding teaching children with special needs in mainstream classrooms. This, as is often the case with decisions regarding educational policy, was a decision made by the few that was imposed upon the many in a “top-down” approach. And, while I applaud the decision-making behind it, I am disappointed in the way in which it was put into place. Because, sadly, until these unfortunate biases and strongly negative perceptions are effectively addressed and eradicated, there will continue to be teachers like Mrs. XXX in our school system.

This change in educational policy came about in response to the changes in the Canadian Constitution – in particular, with the ratification of the Canadian Charter of Rights and Freedoms (1982). Section 15 unequivocally states:

15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability (Retrieved from <http://www.pch.gc.ca/ddp-hrd/canada/guide/eql-egl-eng.cfm>).

That key word “equal” necessitated some serious changes in how the school system of British Columbia looked after the children within its jurisdiction. It also spurred a significant paradigm shift in our society as a whole as Canadians were forced to consider the place of (and for) people with special needs in our “equal” society. This federal mandate was, perhaps, the biggest cog in the wheel of change for Canadian culture in how we viewed the “other” (in this case, people with mental and/or physical disabilities).

¹⁸ “Mainstreaming is a term which was in use during the early years of the movement toward integration of students with special needs, but which has been replaced by the term ‘integration’” (*Special Education Services: A Manual of Policies, Procedures and Guidelines*, p. vi).

I think back to my own experience in high school, during the 1980's in British Columbia. I can't recall a single child with special needs who was included in any of my classes. And yet, when I look at my children's classes, I see a very different class make up - one that much more accurately reflects the larger society in which our public school system finds its home. This shift, while slow in coming into our schools, is happening. And, all of these various "systems" within our society (the health care system, the political system, the public school system) are discovering effective ways in which to embrace a more inclusive view of people - identifying their strengths instead of their shortfalls, accepting and seeing them as able as opposed to dis-abled. Still, it appears that we have a long way to go...

At a conference hosted by the Canadian Teachers' Federation, November 17-19, 2005 in Ottawa, ON, Charlie Naylor (2005) presented a research paper that focused upon seven key areas that, according to Naylor, "are central to any discussion or reflection on the nature, evolution, and success of inclusion in Canadian K-12 public school systems" (p. 22). They include: (1) the history and evolution of inclusion in public schools in Canada; (2) the legal context of inclusion; (3) the educational and social benefits for students because of inclusion; (4) pre-service and in-service training for teachers to support inclusive approaches; (5) the centrality of the teacher in making inclusion a success; (6) parents' and student advocacy groups' perspectives on inclusion; and, (7) funding, systemic support, and accountability issues affecting inclusion. After a comprehensive examination of the key literature related to how these seven key areas of concern impact the success of inclusion, he concludes:

Reflecting on these seven areas and the extensive explorations in the literature, there is little doubt that enough is known in terms of how to make inclusive education a pervasive reality in Canadian public education systems. Yet it is not a pervasive reality, as reflected in the substantial numbers of students being educated in separate institutions, or because they are physically placed within regular schools yet inadequately included in most or all educational and social aspects of schooling. (p. 22)

He continues:

In the province of British Columbia, both NDP and Liberal governments have espoused and mandated inclusion, yet both have failed to fund it adequately. In addition to the long-standing financial neglect, the current Liberal government has compounded the damage by changing funding systems and

legislating in ways that forced or facilitated districts' removal of services from high incidence special education (p. 22).

Sadly, many teachers still seem ill-equipped to deal with the complications that incorporating inclusion into the classroom entails – case in point being my own son's teacher, Mrs. XXX. Naylor states:

After 20 years of inclusive schooling, almost half of a sample group of 380 B.C. teachers report that they do not feel confident in teaching to the diversity in their classrooms, and many currently struggle with larger class sizes and reduced specialist support. Many parents of students with special needs report dissatisfaction and concern with the educational services offered to their children. (p. 24)

While Naylor has a political agenda of his own to pedal (as a researcher for the BCTF), the story he tells is the same one that I have myself have experienced, both as a teacher and as a parent: not enough resources, not enough professional development, not enough support; too many kids, too many responsibilities, too many expectations.

However, as more forward-thinking educators, more parents of children with special needs, and more extra-ordinary children enter the halls of our schools, there will be more opportunities for open and honest dialogue, more chances for the sharing of these unique and powerful stories, and (hopefully) more appreciation for the gifts that these stories (and the people who carry them) bring to our schools and to our lives. With this appreciation will, I hope, come more honest acceptance and *genuine* inclusion.

Fortunately, the students who are currently graduating from our teacher education programs in British Columbia, who were also educated within our public schools, know of no other system other than one whereby students with special needs are taught in regular classrooms. While this has “normalized” the practice in some senses, it has not addressed the lack of knowledge about working with children with particular special needs in the general teacher population, it has not dealt with the personal biases of the individual teachers about teaching children with special needs in the first place, nor has it provided these newly minted teachers with enough positive role models and mentors to demonstrate successful implementation of differentiated teaching strategies that can make school truly work for all children.

Thankfully, the Teacher Regulation Branch of British Columbia (the governing body that oversees the certification of new teachers) now requires

that all graduates of teacher education programs have “three credits or the equivalent in studies related to teaching children with special needs which include diagnosis, planning for instruction and assessment and evaluation” (Teacher Regulation Branch, 2011, Policy P5.C.03.1, Teacher Regulation Branch By-laws, p. 32). Hopefully, with this requirement in place, the positive change will happen sooner rather than later.

To my mind, the change in thinking at the school level needs to begin here – at the school level with individual teachers and administrators working side by side with parents, caregivers, doctors, paraprofessionals and, most importantly, the child. As Tomlinson states, “Change toward more effectively differentiated classrooms is second-order change. . . . Second order change necessitates a dramatic departure from the status quo. It asks teachers to alter beliefs and practices – often dramatically” (2008, p. 23).

If, following the Appreciative Inquiry approach, we focus our attentions upon the teachers who are already implementing methods of practice that are inclusive, adaptive, and differentiated – supporting them to continue the excellent work that they have already begun doing – we can work to change our system from the inside out. In essence, we are encouraging these progressive teachers in their “becoming” – to return to Arendt’s concept of natality. In their responsiveness to the needs of the other children before them, they have taken up the vital job of working “in relation” to the other: they come, through their own “becoming”, to truly “be”; and, in this “be-ing”, they encourage others – our children – along their own burgeoning pathways of “becoming”. But, the locus of change needs to begin with these individuals, and it begins with their own personal stories – including their perceptions and beliefs – about people in general but, in particular, their perceptions of people with special needs.

Which brings this story back to me and to what I “missed” because of my own “miss”- conceptions... I did not realize the full extent of my bias and ignorance until I had given birth to my own child. Prior to this, my own experiences working with children with special needs were spotty at best. And, my relationship with their parents was, I am embarrassed to say, non-existent. While I had had students in my high school classes who were on Individualized Education Plans, I had never met the parents, nor had I made a point of connecting with them by telephone. (At the high school where I taught, the team meetings to develop these plans only involved the parent, the

special education teacher and the special education assistant assigned to the student – the regular classroom teachers were not included.) Because I was not involved in the initial planning process of the IEP, I did not understand (nor was I personally invested) in implementing the adaptations – nor did I really know how. I did the best that I could, but it really wasn't enough.

Unfortunately, the Special Education teacher was of little assistance to me when it came to developing integration strategies because she was unfamiliar with my subject area. And, herein often lies the rub at the secondary school level – many high school teachers continue to view themselves as teachers of curriculum and not as teachers of students.

Thankfully, for my son, the situation has been different – though he has yet to enter high school, so we shall see. At the elementary school Finnley attended, the initial IEP meeting held at the beginning of the school year included me, the resource teacher, the special education assistant, and the main classroom teacher. We also met as a group at the end of the school year to review his progress.¹⁹ This meant that not only was a constructive conversation possible between all parties but that there was accountability on all sides as the teachers and the education assistant knew that I would be meeting with them again, some ten months later, to review Finnley's progress. Because of these two meetings (as well as the parent-teacher conference held midway through the year), I truly felt that we were partners, working together to support Finnley. I could leave our meetings feeling certain that the school employees had heard about Finnley's academic, social, and emotional needs, that they would be taken into consideration as his teacher and his aide worked with him, and, most importantly, that these people truly cared about my son and that they would try to help him to work to the best of his ability.

When I consider my “best experiences” with Finnley's teachers, and with his “education” in general, they all involved teachers, doctors, consultants, caregivers, and therapists who took the time to actively communicate with me, with Phil, and always with Finnley. It was about these professionals listening to our stories, asking clarifying questions, sometimes

¹⁹ Mrs. XXX, unfortunately, was not in attendance at either meeting (even though she was in the school, working in a different classroom on both of those days) as the meetings did not occur on a Friday – her designated day to teach (and focus upon?) my son's classroom. She was not in attendance at the parent-teacher conference for the same reason.

reading between the lines of what we were saying to get to the gist of the meaning, and always appreciating our experiences – seeing them as learning tools that would assist them in doing the important work that needed to be done with our son. It was about them recognizing the value inherent in the parent-child relationship, as well as the myriad of learnings that could come from taking the time to appreciate the unique knowing that parents have about their children; it was about them seeing this parent-child relationship as a conduit in the child-teacher relationship – and realizing that the partnership created between the parent and the teacher was as equally an important a relationship to foster as the relationship between the teacher and the child.

Ultimately, it was about them trying their very best to help our son to reach his greatest potential, by truly attending to the people who knew him best; and, it was about these individuals seeing Finnley as another individual – a child with autism, like so many other children; but, really, *not* like any other children – just as different as any individual human being is to another. It was about them making their intentions plain, and the decisions that they came to about my son transparent – that is, making them trans-parent – with me, the parent. And that has made all the difference.

I don't know what the future will hold for Finnley. Like all parents, Phil and I can steer him in a general direction but, ultimately, he will sail his own ship. Phil, Scotia and I have all gained so much because of having Finnley in our lives. I think the same would be said by all of the other teachers, kids and coaches whose lives he has touched as he has (loudly!) been answering Arendt's question: "Who are you?" (Gordon, p. 21). Finnley, as learner, has been the best teacher for us all. It hasn't been easy sometimes, that's for sure – but it's always been worth it. He has helped us all along our personal journeys to "becoming" and, in receiving the gift of him and truly taking on this "shared responsibility" (Fels, p. 3) of being in relation with an "other" human being – that "other" has become "another" – just like anybody else.

AFTERWORD:

I WANT TO TELL YOU A STORY

At the time of writing, it is summer and Finnley is 12 years old. He has had a successful first year at middle school in late French immersion, he continues to love hockey, he has many friends, and he is more often found laughing and joking with his sister than bullying her or beating her up. It is almost impossible to believe that the confident, friendly young man with whom we now live is the same aggressive little boy that used to run us ragged. This is not to say that Finnley no longer has Asperger's syndrome. Those parents who purport to have "cured" their child's autism have, like us, learned to manage it (and live with it) in such a way that the condition no longer controls their lives. And, as has occurred with Finnley, their child has grown and his/her brain has further developed.

Finnley is currently jumping on the trampoline in our backyard with our new dog, Lyla. (Rusty died two years ago and I told Phil that we either needed to get another dog or I needed another baby – we got another dog.) Finnley now recognizes for himself when he has extra energy to burn and, of his own accord, goes and jumps on the trampoline or "stick-handles" in his bedroom with the door closed. He will smile at you, crack jokes, and, on occasion, he will actually attempt to make conversation. (He won't look you directly in the eye as he does so, but he will glance at you regularly.)

Finnley still invades your personal space, regularly crowding you if you are walking side-by-side down the street and, because he still craves deep pressure, will lean into you if given the opportunity. He shuffles his feet and, because he is still somewhat accident-prone, trips over himself on occasion; however, both his gross motor and his fine motor skills have improved

dramatically as he has grown and developed. I expect that they will continue to do so as he continues to grow into his body.

Finnley now asks for food when he is hungry, he is willing to try new foods, and he will eat from a wider range of food groups, though his preference remains for crunchy-type foods such as crackers or raw carrots. He also still occasionally pushes on his bowels when he needs to relieve himself; however, he will more regularly make his way to the washroom without needing constant reminders.

Finnley is concerned about his clothing (wanting to wear certain brands), and he has now become interested in popular music. Some parents may worry that their child is being affected by peer pressure because s/he wants to dress the same as everyone else his/her age or listen to the same kind of music. I am thrilled. Finnley not only notices that he has peers, but also he wants to be like them. To me, this means that he understands the potency of relationships and he wants to forge and maintain them with people of the same age.

Finnley continues to be friends with the core group of boys that he knew in preschool. He has also branched out to become friends with other boys with whom he plays hockey, basketball, and baseball. According to other parents, he is polite and well-mannered at their houses, and one mother actually referred to him as “the voice of reason” when Finnley and her two boys were running around in her home. A couple of girls from Finnley’s class at school have expressed keen interest in spending time with our son. Thankfully, the interest does not appear to be reciprocal as of yet. I am not ready.

Finnley likes to play on the X-Box and with his iPod. He has moved his amazing spatial capabilities from the train track-building front to the video game front, with his current favourite X-Box game being *Minecraft*, a game that allows him to design and create different types of buildings in 3D out of textured cubes. Of course he regularly becomes absorbed in this game – to the exclusion of all else – but he is more willing to be pulled away from it now and more understanding of the reasons for doing so. And while he enjoys playing this video game (and others) on his own, he prefers to play them with his friends, his sister, or his dad. In fact, Finnley regularly asks if (and when) his friends can come over to our house to play with him.

Finnley continues to be exceptionally loud and persists in making strange noises and fixating upon particular words or objects – this year’s words of choice have been “narwhale” and “squirrel.” (He invented a “Squirrel

Army” where his friends were all different levels of squirrel “soldiers”, and he convinced his spring hockey team to call themselves the “Baby Blue Narwhales”.) And, the theme song from *Tele Français*, a video series that his teacher showed in class, has inspired endless recantations (much to his teacher’s chagrin). Finnley has become something of a leader within his peer group – they look to him for ideas and fun things to do – and he is more than willing to comply. While he has elected himself as the “class clown,” he is accepted and appreciated by others (even by his teachers who describe him as “disruptive” rather than “annoying”), and, in general, he is fun, funny and pleasant to be around.

Finnley continues to do well in school, garnering all “As” and “Bs,” and is very diligent and self-motivated when it comes to doing his homework – that autistic trait of single-minded focusing has served Finnley well when it comes to his schoolwork (and in his ability to play hockey). His obsessiveness and his perfectionist tendencies also help him to excel at school. He consistently works to the best of his ability.

One of Finnley’s greatest strengths as both a person and as a student is that he likes to please people. Because of this, he is more obedient than not (a major change in him) and more friendly than not; people enjoy spending time with him and they actively seek him out. I truly appreciate how respectful and polite that Finnley is with others and, when Phil and I assert our authority over him as parents, he is now more likely to acquiesce. For instance, there are two very popular video games that many of his friends own that Phil and I do not believe are appropriate for him to play at this age (*Halo* and *Call of Duty*). Because we have had this conversation with him, and because he wants to please us, he does not play these games at his friends’ houses – even though he really wants to and even though he is sometimes pressured by his friends to do so.

I know the day is coming when he will make a choice for himself that Phil and I will struggle with. In fact, he is again questioning why he is not allowed to play these video games at someone else’s home. (It has been more than a year since we first had this conversation.) It may be time for us to re-think our decision . . . I would rather have the conversation with him and agree (with conditions) then have him directly disobey us. I think this would be setting all of us up for failure.

Finnley has a strong moral sense and, while he favours justice over mercy when it comes to actual day-to-day dealings with people, he is appreciative of

others and tries to be compassionate in his interactions with them. Naturally, Finnley continues to commit social *faux pas* and unconsciously hurts people's feelings (especially those of his sister) on a regular basis, requiring us to deconstruct the situations with him after the fact (so that he can understand "why" people reacted in the manner in which they did to his behavior). But (and this is a very important change in him) he does not set out to *cause* this hurt – and, when the issue is pointed out to him, he genuinely seems to feel bad about it and, often of his own accord, will attempt to rectify the situation.

I don't know what the future will hold for my son. I know that he will continue to struggle to navigate social situations and that relationships will likely never be easy for him to figure out. That being said, there is no limit to a person's potential – and Finnley has made such huge strides. He could end up surprising us all – he already has many, many times.

I may have given up on some of the dreams that I held for him when I was pregnant, and I may have had to shift some other ones as I have come to know and to understand him; but, ultimately, I would not want Finnley to be anyone other than who he is. I am a better person because of giving birth to my son. I am more patient, more tolerant, and more forgiving – of my son, of my family and, ultimately, of myself.

I remember a teacher colleague once telling me that I would be a better teacher for the kids in my classes after I had had my own children. I disagreed. I still do. But I would say that I believe that I am a better teacher for the *parents* after having had my boy. I have stopped criticizing them for their children's poor choices, I have stopped condemning them for the inappropriate behavior of their children, and I have stopped judging them for their shortcomings as parents. There are many lessons that I would never have learned if I had not had my boy . . . the biggest one being humility.

I know that the future will hold more struggles and frustrations as Phil and I continue to work to raise our children. But, embracing the philosophy of Appreciative Inquiry, I will focus on the positive and on "what works" about our lives together, and I will use this knowledge to forge ahead on this inquiry called "life," garnering more experiences and creating more memories.

"I want to tell you a story . . ."

To be continued.

REFERENCES

- Alarcón, M., Abrahams, B.S., Stone, J.L., Duvall, J.A., Perederiy, J.V., Bomar, J.M., Sebat, J., Wigler, M., et al.. (2008). Linkage, association, and gene-expression analyses identify CNTNAP2 as an autism-susceptibility gene. *American Journal of Human Genetics*, 82(1), 150–159.
- American Academy of Pediatrics and American College of Obstetricians and Gynecologists. (2006). The Apgar Score. *Pediatrics*, 117, 1444–1447.
- Arendt, H. (1958). *The Human Condition*. Chicago, IL: University of Chicago Press.
- Asperger, H. (1991). Autistic Psychopathy in Childhood. In U. Frith (Ed. and Trans.) *Autism and Asperger Syndrome* (pp. 37–92). Cambridge, England: Cambridge University Press. (Original work published 1944).
- Asperger, H. with annotations from Uta Frith (1991). The Case of Fritz V. In Rausch, J., Johnson, M., & M. Casanova (Eds.) *Asperger's Disorder* (pp. 7–18). New York, NY: Informa Healthcare. (Original work published 1944).
- Attwood, T. (2007). *The complete guide to Asperger's syndrome*. London, UK: Jessica Kingsley Publishers.
- Baron-Cohen, S. (1997). *Mindblindness: An Essay on Autism and Theory of Mind*. Cambridge, MA: Massachusetts Institute of Technology Press
- Baron-Cohen, S. (2003). *The essential difference: The truth about the male and female brain*. New York, NY: Basic Books.
- Baron-Cohen, S., Leslie, A.M., & Frith, U. (1985). Does the autistic child have a 'theory of mind'? *Cognition*, 21, 37–46.
- Best Behaviour Consulting. Retrieved from <http://www.bestbehaviour.ca/>
- Bettleheim, B. (1967). *The empty fortress: Infantile autism and the birth of self*. New York, NY: The Free Press.
- Bleuler, E. (1913). Autistic Thinking. *American Journal of Insanity*, 69(5), 873-879.

- Bleuler, E. (1911). Dementia Praecox oder Gruppe der Schizophrenien. In: Aschaffenburg G, (Ed.). *Handbuch der Psychiatrie*. Leipzig: Deuticke; 1911. (Ger).
- Bochner, A.P. (1984). The Functions of Communication in Interpersonal Bonding. In C. Arnold & J. Bowers (Eds.), *The Handbook of Rhetoric and Communication* (pp. 544-621). Thousand Oaks, CA: Sage.
- British Columbia Principals' & Vice Principals' Association. Retrieved from <http://www.bcpvpa.bc.ca/node/1>
- British Columbia Public School Employers' Association. Retrieved from <http://www.bcpsea.bc.ca/about-us/default.aspx>
- British Columbia School Superintendents Association. Retrieved from <http://www.bcssa.org/about.html>
- British Columbia School Trustees Association. Retrieved from <http://www.bcsta.org/content/about-us>
- British Columbia Teachers' Federation. Retrieved from <http://www.bctf.ca/AboutUs.aspx>
- Bushe, G.R. (2011). Appreciative inquiry: Theory and critique. In D. Boje, B. Burnes, & J. Hassard (Eds.), *The Routledge companion to organizational change* (pp. 87-103). Oxford, UK: Routledge.
- Canadian Charter of Rights and Freedoms. Retrieved from <http://www.pch.gc.ca/ddp-hrd/canada/guide/eql-egl-eng.cfm>
- Canadian Union of Public Employees. Retrieved from <http://www.cupe.bc.ca/>
- Chang, H. (2008). *Autoethnography as Method*. Walnut Creek, CA: Left Coast Press.
- Cooperrider, D.L. (2001). Positive image, positive action: The affirmative basis of organizing. In D. Cooperrider, P. Sorensen, D. Whitney, & T. Yaeger (Eds.), *Appreciative inquiry: An emerging direction for organization development*. Champaign, IL: Stipes Publishing (pp. 29-53). Retrieved from <http://www.stipes.com/aichap2.htm>
- Cooperrider, D.L., & Srivastva, S. (1987). Appreciative inquiry in organizational life. *Research in organizational change and development*, 1, 129-169.

- Cooperrider, D.L., & Whitney, D. (2005). *Appreciative inquiry: A positive revolution in change*. San Francisco, CA: Berrett-Koehler Publishers.
- Cooperrider, D.L., Whitney, D., & Stavros, J.M. (2008). *Appreciative inquiry handbook: For leaders of change* (2nd ed.). Brunswick, OH: Crown Custom Publishing.
- Cousins, N. (1983). *The healing heart: Antidotes to panic and helplessness*. New York, NY: W.W. Norton & Company.
- DeLong, G.R., & Dwyer, J.T. (1988). Correlation of family history with specific autistic subgroups: Asperger's syndrome and bipolar affective disease. *Journal of Autism and Developmental Disorders*, 18, 593–600.
- Ellis, C. (2007). Telling Secrets, Revealing Lives: Relational Ethics in Research with Intimate Others. *Qualitative Inquiry*, 13(1), 3-29.
- Ellis, C., Adams, T., & Bochner, A. (2011). Autoethnography: An Overview. *Forum: Qualitative Social Research*, 12, 1, 1-14.
- Ellis, C. & Bochner, A.P. (1996). Talking Over Ethnography. In Ellis, C. & Bochner, A. (Eds.) *Composing Ethnography: Alternative Forms of Qualitative Writing*. Walnut Creek, CA: AltaMira Press.
- Ellis, C. & Bochner, A.P. (2000). Autoethnography, Personal Narrative, and Personal Reflexivity. In N.K. Denzin & Y.S. Lincoln (Eds.) *Handbook of Qualitative Research* (2nd ed.). (pp. 733-768). Thousand Oaks, CA: Sage.
- Erikson, E. (1950). *Childhood and society*. New York, NY: W.W. Norton.
- Feinstein, A. (2010). *A history of autism: Conversations with the pioneers*. Chichester, England: Wiley-Blackwell Publishing.
- Fels, L. (2010). Coming into Presence: The Unfolding of a Moment. *Journal of Educational Controversy*, 5(1), 1-16.
- Frank, A. (2004). Moral Non-fiction: Life Writing and Children's Disability. In P.J. Eakin (Ed.), *The Ethics of Life Writing* (pp. 174-194). Ithaca, JY: Cornell University Press.
- Fredrickson, B. (2004). The broaden-and-build theory of positive emotions. *Philosophical Transactions of the Royal Society B: Biological Sciences*, 359, 1367–1377. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1693418/pdf/15347528.pdf>

- Friedan, B. (1964). *The Feminine Mystique*. New York, NY: Dell.
- Frith, U. (1991). Asperger and his syndrome. In U. Frith (Ed.), *Autism and Asperger Syndrome*. Cambridge, England: Cambridge University Press.
- Gardener, H., Spiegelman, D. & Buka, S. (2009). Prenatal risk factors for autism: comprehensive meta-analysis. *The British Journal of Psychiatry*, 195, 7-14.
- Geier, D.A., King, P.G., Sykes, L.K., & Geier, M.R. (2008). A comprehensive review of mercury provoked autism. *Indian Journal of Medical Research*, 128(4), 383-411.
- Gergen, Kenneth J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40(3), 266-275.
- Ghaziuddin, M., Butler, E., Tsai, L., & Ghaziuddin, N. (1994). Is clumsiness a marker for Asperger syndrome? *Journal of Intellectual Disability Research* 38, 519-527.
- Ghaziuddin, M., Shakal J., & Tasi, L. (1995). Obstetric factors in Asperger syndrome: Comparison with high-functioning autism. *Journal of Intellectual Disability Research*, 39, 538-543.
- Gordon, M. (2001). *Hannah Arendt and Education: Renewing Our Common World*. Boulder, CO: Westview Press.
- Grandin, T., Fine, A.H., & Bowers, C.M. (2010). The use of therapy animals with individuals with autism spectrum disorders. In A. Fine (Ed.), *Handbook on animal-assisted therapy: Theoretical foundations and guidelines for practice*, (3rd ed.). London, England: Academic Press.
- Gray, Carol. *What are social stories*. Retrieved from <http://thegraycenter.org/social-stories/what-are-social-stories>
- Grinker, R.R. (1952). *Diagnostic and statistical manual of mental disorders I*. Retrieved from <http://www.unstrange.com/dsm1.html>
- Grinker, R.R. (1968). *Diagnostic and statistical manual of mental disorders II*. Retrieved from <http://www.unstrange.com/dsm1.html>
- Grinker, R.R. (1980). *Diagnostic and statistical manual of mental disorders III*. Retrieved from <http://www.unstrange.com/pdd.html>

- Grinker, R.R. (1987). *Diagnostic and statistical manual of mental disorders III-R*. Retrieved from <http://www.unstrange.com/dsm1.html> and Retrieved from <http://www.autreat.com/dsm4-aspergers.html>
- Grinker, R.R. (1994). *Diagnostic and statistical manual of mental disorders IV*. Retrieved from www.dsm5.org/Proposed_Revisions/Pages/proposedrevision.aspx?rid=94#
- Hayano, D.M. (1979). Auto-Ethnography: Paradigms, Problems, and Prospects. *Human Organization*, 38(1), 99-104.
- Heider, K.G. (1975). What do people do? Dani auto-ethnography. *Journal of Anthropological Research*, 31, 3-17
- Hollander, E., Bartz, J., Chaplin, W., Phillips, A., Sumner, J., Sorya, L., Anagnostou, E., & Wasserman, S. (2006). Oxytocin increases retention of social cognition in autism. *Biological Psychiatry*, 61(4), 498-503.
- Hutten, M. (2011). *Test for Aspergers in babies*. Retrieved from www.myaspergerschild.com/2011/05/test-for-aspergers-in-babies.html
- Jamain, S., Quach, H., Betancur, C., Rastam, M., Colineaux, C., Gillberg, C., Soderstrom, H., Giros, B., Leboyer, M., Gillberg, C., Bourgeron, T., & Paris Autism Research International Sibpair (PARIS) Study. (2003). Mutations of the X-linked genes encoding neuroligins NLGN3 and NLGN4 are associated with autism. *Nature Genetics*, 34(1), 27-29.
- Johnson, P. (2007). Transcending the polarity of light and shadow in life and in practice. *Linkage*, 34, 6-7.
- Jorgensen, J. (2002). Engineering Selves: Negotiating Gender and Identity in Technical Work. *Management Communication Quarterly*, 15(3), 360-380.
- Josselson, R. (1996). On Writing Other People's Lives: Self-analytic Reflections of a Narrative Researcher. In R. Josselson (Ed.), *Ethics and Process in the Narrative Study of Lives* (Vol. 4, pp. 60-71). Thousand Oaks, CA: Sage.
- Kanner, L. (1973). Autistic disturbances of affective contact. In L. Kanner (Ed.), *Childhood psychosis: Initial studies and new insights* (pp. 241-242). Washington, DC: V.H. Winston. (Reprinted from *Nervous Child* 2, pp. 217-250.)
- Kanner, L., & Eisenberg, L. (1956). Early infantile autism, 1943-55. *American Journal of Orthopsychiatry*, 26(3), 556-566.

- Katcher, A.H., & Wilkins, G.G. (2000). The Centaur's lessons: Therapeutic education through care of animals and nature study. In A. Fine (Ed.), *Handbook on animal assisted therapy* (pp. 153-178). New York, NY: Academic Press.
- Kelm, J. (2006). Walking the Talk: The Principles of AI in Daily Living. *AI Practitioner: International Journal of Appreciative Inquiry*. (pp.5-8) Retrieved from <http://www.aipractitioner.com/>
- Kelm, J. (2008). *The Joy of Appreciative Living Book: Your 28-Day Plan to Greater and Happiness in 3 Incredibly Easy Steps*. New York, NY: Penguin Group.
- Kelm, J. (2005). *Appreciative Living: The Principles of Appreciative Inquiry in Personal Life*. Wake Forest, NC: Venet Publishers.
- Kingsley, E.P. (1987). Welcome to Holland. Retrieved from <http://www.creativeparents.com/EPKinterview.html>
- King, T. (2003). *The Truth About Stories: A Native Narrative*. Toronto, Ont.: Dead Dog Café Productions Inc. & the Canadian Broadcasting Corporation.
- Kinney, D.K., Munir, K.M., Crowley, D.J., & Miller, A.M. (2008). Prenatal stress and risk for autism. *Neuroscience and Biobehavior Reviews*, 32(8), 1519-1532.
- Kluger, J., Song, S., Cray, D., Ressler, J., DeQuine, J., Sattley, M., Scalet, C., & Sieger, M. (2002, August 19). Manic depression: Young and bipolar. *Time Magazine*. Retrieved from: <http://www.time.com/time/magazine/article/0,9171,1003048,00.html>
- Kranowitz, C.S. (2005). *The out-of-sync child: Recognizing and coping with sensory processing disorder*. New York, NY: Skylight Press.
- Kubler-Ross, E. (1973). *On Death and Dying*. Florence, KY: Routledge.
- Mann, J., McDermott, S., Bao, H., Hardin, J., & Gregg, A. (2010). Pre-eclampsia, birth weight, and autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 40, 548-554.
- Maso, I. (2001). Phenomenology and Ethnography. In Atkinson, P., Coffey, A., Delamont, S., Lofland, J., & L. Lofland. *Handbook of Ethnography* (pp. 136-144). Thousand Oaks, CA: Sage.

- Mason, T., & Pack, A. (2005). Sleep terrors in childhood. *Journal of Pediatrics*, 147(3), 388–392.
- Miller, L. (2006). *Principles of Everyday Behavior Analysis*, (4th ed.). Belmont, CA: Thomson Higher Education.
- Ministry of Children and Family Development. (2009, November). *A parent's handbook: Your guide to autism programs*. Victoria, BC: Queen's Printer.
- Ministry of Education. (2011, March). *Special education services: A manual of policies, procedures and guidelines*. Victoria, BC: Queen's Printer.
- Ministry of Education. *Teacher education branch by-laws*. British Columbia. Retrieved from www.bcteacherregulation.ca/documents/.../BylawsPolicies/bylaws.pdf
- Ministry of Health Services. (2008). *Toddler's First Steps: A Best Chance Guide to Parenting Your 6- to 36-Month-Old Child* (2nd Ed.). Victoria, BC: Queen's Printer.
- Nelson, K. (1991). Prenatal and Perinatal Factors in the Etiology of Autism. *Pediatrics*, 87, 5, 761-766.
- Naylor, C. (2005) Inclusion in British Columbia's public schools: Always a journey, never a destination? (unpublished paper presented at the Canadian Teachers' Federation conference, *Building Inclusive Schools: A Search for Solutions*, November 17-19, 2005, Ottawa, ON).
- Ornitz, E. (1973). Childhood autism: A Review of the Clinical and Experimental Literature. *California Medicine: The Western Journal of Medicine*, 118(4), 21-47.
- Orlie, M. (1994). Forgiving Trespasses, Promising Futures. In B. Honig (Ed.), *Feminist Interpretations of Hannah Arendt* (pp. 337-356). University Park: Pennsylvania State University Press.
- Oxford English Dictionary*. Retrieved from <http://www.oed.com.proxy.lib.sfu.ca/view/Entry/94779#eid529334>
- Prothmann, A., Ettrich, C., & Prothmann, S. (2009). Preference for, and responsiveness to, people, dogs and objects in children with autism. *Anthrozoos*, 22, 161–173.
- Psychology Today*. Retrieved from www.psychologytoday.com/blog

- Queen's Park Parent Participation Preschool. Retrieved from <http://www.qpps.ca/about.html>
- Reed-Danahay, D.E. (Ed.) (1997). *Auto/ethnography: Rewriting The Self and The Social*. Oxford, U.K.: Berg.
- Rimland, B. (1964). *Infantile autism: The syndrome and its implications for a neural theory of behavior*. Englewood Cliffs, NJ: Prentice Hall.
- Ritvo, E. (2006). *Understanding the nature of autism and Asperger's disorder: Forty years of clinical practice and pioneering research*. London, England: Jessica Kingsley Publishers.
- Rutter, M. (1978). Diagnosis and definition of childhood autism. In M. Rutter & E. Schopler (Eds.), *Autism: A reappraisal of concepts and treatments*. New York, NY: Plenum Publishing.
- Sacks, O. (1998). *The Man Who Mistook His Wife For A Hat & Other Clinical Tales*. New York, NY: Touchstone Publishing.
- Schreck, K.A., & Mulick, J.A. (2000). Parental report of sleep problems in children with autism. *Journal of Autism and Developmental Disorders*, 30(2), 127–135.
- Shakespeare, W. (1992). *Hamlet*. Mineola, NY: Dover Publications.
- Silverman, C. (2012). *Understanding autism: Parents, doctors, and the history of a disorder*. Princeton, NJ: Princeton University Press.
- Simmons, L.W. (Ed.) (1942). *Sun Chief: An Autobiography of A Hope Indian*. New Haven, CT: Yale University.
- Smythe, S. (2006). *The Good Mother: A Critical Discourse Analysis of Literacy Advice To Mothers in the 20th Century*. University of British Columbia.
- Ssucharewa, G.E. (1926). Die schizoiden Psychopathien im Kindesalter. *Monatsschr Psychiatr Neurol*, 60, 235–261.
- Ssucharewa, G.E. (1996). The first account of the syndrome Asperger described? In S. Wolff (Trans.), *European child and adolescent Psychiatry*, 5, 119–132. (Original work published 1926.)
- Tomlinson, C.A., Brimijoin, K., & Narvaez, L. (2008). *Differentiated school: Making revolutionary changes in teaching and learning*. Alexandria, VA: Association for Supervision and Curriculum Development.

- University of Maryland Medical Center. Retrieved from
<http://www.umm.edu/altmed/articles/shock-000152.htm>
- Urbanski, A. (1993). Real change is real hard: Lessons learned in Rochester. *Stanford Law & Policy Review*, 4, 123-133I
- Wakefield, A., Murch, S., Linnell, A., Casson, D., Malik, M., Berelowitz, M., Dhillon, M., Thomson, M., Harvey, P., Valentine, A., Davies, S., & Walker-Smith, J. (1998). Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *The Lancet*, 351(9103), 637-641.
- Watkins, J.M., Mohr, B., & Kelly, R. (2011). *Appreciative inquiry: Change at the speed of imagination*, (2nd ed.). San Francisco, CA: John Wiley and Sons.
- Weimer, A.K., Schatz, A.M., Lincoln, A., Ballantyne, A.O., & Trauner, D.A. (2001). Motor impairment in Asperger syndrome: evidence for a deficit in proprioception. *Development and Behavioral Pediatrics*, 22, 92-101.
- Weiss, L., Shen, Y., Korn, J., Arking, D., Miller, D., Fossdal, R., Saemundsen, E., Stefansson, H., Ferreira, M., Green, T., Platt, O., Ruderfer, D., Walsh, C., Altshuler, D., Chakravarti, A., Tanzi, R., Stefansson, K., Santangelo, S., Gusella, J., Sklar, P., Wu, B., & Daly, M. Association between microdeletion and microduplication at 16p11.2 and autism. *New England Journal of Medicine*, 358, 667-675.
- Weissbar, M.K., & Borsa, J.C. (2001). *Inclusive educational administration: A case study approach*. New York, NY: McGraw-Hill Company.
- Wheeler, M. (2011, October 20). Autistic brains develop more slowly than healthy brains, UCLA researchers say. UCLA Newsroom. Retrieved from <http://newsroom.ucla.edu/portal/ucla/autistic-brains-develop-more-slowly-215407.aspx>
- Whitehouse, A.J.O., Durkin, K., Jaquet, E., & Ziatas, K. (2009). Friendship, loneliness and depression in adolescents with Asperger's syndrome. *Journal of Adolescence*, 32, 309-322.
- Wing, L. (2005). Reflections on Opening Pandora's Box. *Journal of Autism and Developmental Disorders*, 35(2), 197-203.

- Wing, L. (1991). The Relationship Between Asperger's Syndrome and Kanner's Autism. In Frith, U. (Ed.), *Autism and Asperger Syndrome*. Cambridge, Cambridge University Press.
- Wing, L. (1981). Asperger's syndrome: A clinical account. *Psychological Medicine*, 2, 115.
- Wolcott, H.F. (2004). The Ethnographic Autobiography. *Auto/Biography*, 12, 93-106.
- Wolfensberger, W. (1970). The principle of normalization and its implications for psychiatric services. *American Journal of Psychiatry*, 127, 291-7.
- World Health Organization. <http://www.who.int/about/en/>
- World Health Organization. (1993). *International classification of diseases, 10th revision (ICD-10)*. Geneva: World Health Organization.
- Zaretsky, L. (2004). Advocacy and Administration: from conflict to collaboration. *Journal of Educational Administration*, 42(2), 270-286.

STORY A

I WANT TO TELL YOU A STORY: THE STORY OF ETHNOGRAPHY

Storyteller (S): I want to tell you a story.

Listener (L): A story? What's the story about?

S: It's about a group of researchers who decided to challenge the way that research was currently begin carried out in their particular fields of social science.

L: Why did they want to do that?

S: Because they were tired of the false separation between the disciplines, and the false separation of the researcher and the subject; and, most importantly, because they realized that they, as researchers, actually had a fair bit of knowledge to share about themselves. They decided to reclaim the name of "autoethnography" and use it to examine their own lives in relation to the cultures in which they lived.

L: What do you mean "reclaim"?

S: Well, the word had first been used by an anthropologist named Heider back in 1975. For him, the "auto" part of autoethnography didn't refer to the "self" (as in the researcher), but rather, he used it in relation to his "informants"; that is, the Dani people whom he was studying at that time. Another researcher, Hayano (1979), used that same word, "autoethnography", in a different way again. He used it to describe his "own people" – a counter culture (or subculture) consisting of card players who spent countless hours "playing cards in Southern California's legitimate card rooms" (Wolcott, 2004, p. 98).

L: Why did these researchers decide to resurrect this word and use it to push forward a different type of research methodology than was currently being used?

S: Because they realized that there was a richness to the lived experience that was as valuable a teacher as the stolid, and often stale, data that they were 'scientifically' collecting.

L: Why do you say 'scientifically' like that?

S: Because the word 'scientifically' implies an objectivity regarding the analysis of scientific data that isn't actually really there.

L: What do you mean?

S: Well, it's virtually impossible for a person to be objective. Even the questions that the researcher chooses to ask affect the objectivity of the data to be collected. For every question asked, there are literally millions that have gone unasked – which, of course, could affect not only the data collection but also the interpretation of that data.

L: Why communicate this particular story at this particular time?

S: Because it connects to my own life in a number of ways. For one, I am an English teacher. I recognize the value of story as a learning tool. We ask our students to read fiction and non-fiction in the hopes that they will connect to these texts.

L: What do you mean "connect"?

S: Well, we know that students construct meaning by relating what they read to their own lives. In this "connection" there is the wonderful opportunity for our students to learn more about the world and more about themselves. Chang (2008) says, "Studying others invariably invites readers to compare and contrast themselves with others in the cultural texts they read and study, in turn discovering new dimensions about their own lives" (pp. 33-34).

This story also connects to my life prior to becoming a teacher. You see, before I was a teacher I was an actress. I became an actress because I wanted to perform other people's stories; after all, that's all plays are in a way – a playwright's interpretation of the world and the people within it. In a sense, the playwright is acting as an ethnographer. Yes, there is a fictional aspect to writing plays, but consciously or not, the playwright models his characters on people and, in essence, documents a culture.

You see, I wanted to make a difference as an actor – I was committed to social change. I really subscribed to that whole idea put forth in Hamlet about actors "holding a mirror up to nature" (Act III, Sc ii, 17-24) through the characters they portray; that is, there is a "truth" to drama that gives actors license to mirror both the

beauty and the horror that is human life through the characters that they create – we examine aspects of our own culture and the cultures of others through these stories we perform. English teachers do their own version of “mirroring” and “examining” when they talk about literature in their classrooms.

L: What about you as a mother?

S: Well, this is where the real connection lies. And the reason why I’m telling you this particular story now. It is because through the telling of the story of my son, I am writing not an autobiography but an autoethnography.

L: Huh? What’s the difference?

S: Well, “auto” – self – is the same. “Graphy” – writing – is the same. It’s the “bio” versus the “ethno” piece where there lies a difference. The “ethno” piece connects the writing to the larger culture; the “bio” piece keeps it tied to the individual. I think the story of my son has cultural implications. It will, I hope, help people in particular sub-cultures to understand the impact that autism can have upon a life.

L: What do you mean by that?

S: Two things. (1) We all belong to a number of different sub-cultures within the larger “home” of our national culture. For example, I am Canadian. That, perhaps, defines an aspect of who I am as a person. However, I’m not just Canadian – I am also female, I’m Caucasian, I’m university-educated, I’m middle class, I’m a daughter, I’m a sister, I’m a wife, I’m a dog owner, I’m a teacher, I’m a teacher educator, I belong to a book club, I’m a jogger, I’m an active member of my community, and, most importantly, I’m a mother of two unique children. These are all sub-cultures of which I am also a member.

L: And this matters why?

S: Well, because as I mentioned earlier, one of the first autoethnographers wrote about his personal connection to the culture of card players in the hopes of gaining a greater personal understanding of this sub-culture of which he was a member. But, he also wrote about this group in order to try to explain it to others.

L: And?

S: And because what I’m writing here is not just the story of Finnley – it speaks to how our larger culture views children with autism. And it speaks to parenting. And to

motherhood. And to education. And, it's because I'm attempting to analyse all of the ways these different sub-cultures collide within my life. And this is another key difference between autoethnography and autobiography. There is an inquiry aspect tied to autoethnography that goes beyond the seeming "navel gazing" that some autobiographers are accused of (Ellis, Adams & Bochner, p. 8).

My story is special to me – for obvious reasons. But, I think it can speak to a wider audience as well, including doctors, researchers, and teachers who work with kids with autism. I think my story connects to schools and how we educate kids with special needs. I think it's a strong argument for the benefits of early intervention and I think it can help to challenge some of the assumptions that people may hold about individuals with autism.

L: You said there were two things.

S: Huh?

L: You said that there were two reasons why your story is an autoethnography and not an autobiography. One way is because it speaks about particular aspects of culture and attempts to analyse it. What's the other way?

S: The other thing is because of something Oliver Sacks once wrote.

L: What's that?

S: That if you examine disease you gain wisdom about anatomy, physiology and biology. But, when you examine a person with disease, you gain wisdom about life (from The Man Who Mistook His Wife For A Hat). As Ellis & Bochner (1996) state, "ethnography tries to deepen and enlarge our sense of a human community" (p. 18). Kids like my son are as integral a part of the human community as anyone else is. By helping people to see the commonality in our difference – which sounds like a paradox, I know – we find that connecting piece in life.

L: So, you were saying that you wanted to tell me a story.

S: I do. And I will now...

Autoethnography is a research method that came about as a response to the postmodernist "crisis of confidence" in science. Increasingly, social scientists recognized that all of those "truths" and "facts" that scientists were purporting to have found were tied to the theories and the language that the

scientists actually used to represent them, and that idea of a “master, universal narrative” to which we all could subscribe was a virtual impossibility, given the multiplicity of our world. Instead, these innovative researchers recognized the complexity of every person’s story; that is, they realized that instead of one “master” narrative, there were a myriad of individual narratives that held more meaning for more people. They realized that “real” people’s stories had the power to provide “constitutive, meaningful phenomena that taught morals and ethics, introduced unique ways of thinking and feeling, and helped people make sense of themselves and others” (Ellis, Adams & Bochner, 2011, p. 2). In their desire to challenge traditional, canonical concepts of research, they turned to autoethnography as a means for producing “meaningful, accessible and evocative research grounded in personal experience” (p. 2). They recognized their own biases within their research and, instead of pretending that this subjectivity did not exist, embraced it as its own body of knowledge. Ellis et al. state, “Autoethnographers recognize the innumerable ways personal experience influences the research process” (p. 2).

Autoethnography is both process and product at the same time. As Ellis & Bochner (1996) describe in their ethnographic dialogue in the introduction to *Composing Ethnography*, “Ethnography is what ethnographers do. It’s an activity. Ethnographers inscribe patterns of cultural experience, they give perspective on life. They interact, they take note, they photograph, moralize, and write” (p. 16). They continue: “When we produce what we call ethnography, our product can never be an accurate map because the process of production makes transparent representation impossible” (p. 19).

Autoethnography originally grew out of the field of anthropology. While it shares the narrative aspect of storytelling with other social sciences, “it transcends mere narration of self to engage in cultural analysis and interpretation” (Chang, p. 43). While interest in the lives of individuals and entire cultural groups is hardly new to the field of anthropology – for example, life histories such as Simmons’ *Sun Chief* (1942), have been recorded and then “interpreted”, the trend toward “intentional self-reflexivity” (Chang, p. 45) has given license to anthropologists to bring forth their own stories for investigation – not just as a way in which to examine the process that the researcher underwent as an ethnographer, but rather as a way of recognizing that all ethnographers inject themselves into what they produce, consciously or not. Autoethnography serves to make plain the production of this process.

As Ellis & Bochner (1996) remind us, “when we say that ethnographers can’t stand above or outside language, we mean that the world as we ‘know’ it cannot be separated from the language we use to explain, understand, or describe it” (p. 20).

Reed-Danahay (1997), from the field of anthropology, has used the label of autoethnography to describe three broad landscapes of writing: (1) “native anthropology”, wherein cultural groups whose lives have been previously “written” become ethnographers for themselves; (2) “ethnic autobiography”, where differing ethnic groups write their own narratives to describe their personal experiences; and, (3) “autobiographical ethnography”, in which the personal experiences of the researchers are injected into the ethnographies (p. 2). Meanwhile, Ellis and Bochner (2000), scholars in the field of communication, proffer a much more comprehensive list of differing types of writing that they believe subscribe to the label of autoethnography. Through their efforts, they have sought to collapse disciplinary difference within the social sciences. Their list includes the following:

- | | |
|-------------------------------------|---------------------------------|
| autobiographical ethnography | interpretive biography |
| autobiology | literary tales |
| auto-observation | lived experience |
| autopathography | narrative ethnography |
| collaborative autobiography | native ethnography |
| complete-member research | new or experiential ethnography |
| confessional tales | opportunistic research |
| critical autobiography | personal essays |
| emotionalism narratives of the self | personal ethnography |
| ethnobiography | personal experience narrative |
| ethnographic autobiography | personal narratives |
| ethnographic memoir | personal writing |
| ethnographic poetics | postmodern ethnography |
| ethnographic short stories | radical empiricism |
| evocative narratives | reflexive ethnography |
| experiential texts | self-ethnography |
| first-person accounts | self-stories |
| impressionistic accounts | socioautobiography |
| indigenous ethnography | sociopoetics |

Ellis, Adams & Bochner (2011) further refined this comprehensive list. In their research, they break autoethnography into these groupings:

- Indigenous/native ethnographies – groups of people who have been subjected to study by others outside of the culture (often without the consent of the individuals within the culture) study themselves in order to construct their own personal and cultural identities;
- Narrative ethnographies – where the experience of the ethnographer is added into the descriptive analysis of the person/people who are being studied;
- Reflexive, dyadic interviews – where the meaning-making of the research comes about because of the interview; that is, while the interviewee may be the subject of the study, the relationship between the interviewer and the interviewee and the meaning that they construct together about the story the subject is telling becomes important to the overall understanding of the research;
- Reflexive ethnographies – studies in how the researcher changes because of engaging in fieldwork;
- Layered accounts – the research procedure, itself, is examined and analyzed, demonstrating how the experience of conducting research can lead to understanding;
- Interactive interviews – usually these are a series of interviews wherein a sensitive topic is explored through conversation between the researcher and the participant. The relationship developed between the subject and researcher is integral to the success of the research;
- Community autoethnographies – an examination of how a community experiences a particular social, political or cultural issue providing the possibility for evoking positive social change within that community;
- Co-constructed narratives – where two people write about their unique understanding of a shared experience. These viewpoints are then examined for the multiplicities of meaning that can be made about themselves and each other because of having these shared, but differing, interpretations of the same event;

- Personal narratives – where the researcher uses their own story as the basis of their research (pp. 5-6).

In an effort to help clarify the complexity of the variety of all of these autoethnographic modes of writing, Ellis and Bochner (2000) suggested a model whereby differing autoethnographies could be categorized: “autoethnographers vary in their emphasis on the research process (graphy), on culture (ethno), and on self (auto)” and “different exemplars of autoethnography fall at different places along the continuum of each of these three axes” (p. 740). With these three separate, yet inter-connected pieces of the autoethnography equation to take into consideration, the differences between autoethnography and ethnography disintegrate when discussion centers around the collection, systematization and analysis of data. Similarly, the difference is unseen when we compare the desire on the part of both ethnographers and autoethnographers to come to some semblance of cultural understanding through the analysis and interpretation of their data. In essence, while the autoethnographer may be focusing his/her analysis on his/her self, the interpretation of that “self” is only understood through the broader context of society and culture. It is only this last aspect of autoethnography that truly differentiates autoethnography from “typical” ethnographic inquiries – the focus upon the self. As Chang reminds us:

Autoethnographers use their personal experiences as primary data. The richness of autobiographical narratives and autobiographical insights is valued and intentionally integrated in the research process and product unlike conventional ethnography (p. 49).

THE AUTOETHNOGRAPHIC PROCESS

Because virtually any aspect of one’s life has the potential to become the focus of one’s research, the scope and variety of topics open for consideration are boundless. And, because these three differing pieces (“auto”, “ethno” and “graphy”) are fused together, resulting in an autoethnographic equation of sorts, there is flexibility inherently built into the variables. This means, that while three autoethnographers may be examining exactly the same subject, the result will be three very different autoethnographies: (1) because the researchers themselves are different; (2) because their fields of experience are

different; and (3) because the ways in which they interpret those fields and their lived experience within them will be different.

This seeming subjectivity has caused autoethnography to come under attack from various parties who dismiss it as being “insufficiently rigorous, theoretical, and analytical, and too aesthetic, emotional, and therapeutic” and are further accused of “doing too little fieldwork, for observing too few cultural members, [or] for not spending enough time with (different) others” (Ellis, Adams & Bochner, p. 8).

Ellis, Adams & Bochner articulate a process whereby the autoethnographer combines aspects of both the autobiographer and ethnographer roles. The autobiographer usually writes about past experiences, highlighting significant moments of realization (epiphanies) or times of trauma or intense crisis wherein the person is called to examine themselves in the face of this life-altering experience. Bochner (1984) states, “these epiphanies reveal ways a person could negotiate intense situations and effects that linger – recollections, memories, images, feelings – long after a crucial incident is supposedly finished” (p. 595). Of course, these experiences do not happen merely in order for the author to write about them; rather, the events occur and the experience is so immensely important to the life of the autobiographer that they feel compelled to write about this experience.

The autoethnographer feels this same compulsion. Similar to the autobiographer, they too make selective choices about the moments of their experience that they choose to write about. The difference, however, is that autoethnographers recognize that these pivotal moments are indelibly tied to one’s cultural identity and that, often, these moments of change have only come about because of being part of a particular culture in the first place.

While ethnographers “study a culture’s relational practices, common values and beliefs, and shared experiences for the purpose of helping insiders (cultural members) and outsiders (cultural strangers) better understand the culture” (Maso, 2001, as cited in Ellis, Adams & Bochner, p. 3), it is vital to the autoethnographic process for the researcher to analyse these experiences. In a personal interview with Ellis, autoethnographer Mitch Allen states,

Autoethnographers look at experience analytically. Otherwise [you’re] telling [your] story – and that’s nice – but people do that on *Oprah* every day. Why is your story more valid than anyone else’s? What makes your story more valid is that you are a researcher. You have a set of theoretical and methodological

tools and a research literature to use. That's your advantage. If you can't frame it around these tools and literature and just frame it as 'my story', then why or how should I privilege your story over anyone else's I see 25 times a day on TV?" (as cited in Ellis, Adams & Bochner, p. 3).

THE AUTOETHNOGRAPHIC PRODUCT

Autobiographers are, first and foremost, authors; that is, it is the strength of their writing ability that first engages readers in their stories and inspires their audiences to read further. Like all strong writers, autobiographers "show" their readers their story. That is, they describe their experiences using the eyes of a storyteller, weaving a web of words together in the most effective way to evoke powerful imagery. While autobiographers (usually) have an important or interesting story to share, it is their aesthetic sense that often leads to their success as an author - otherwise, while their life story may be engaging, a publisher may deem that it would be better left to be written by someone else.

Autoethnographers, also, use words to powerful effect. However, because they are researchers too, they attend to the effect that those words may have and, perhaps, write more carefully because of this awareness. Because autoethnographers see themselves as having a responsibility to the culture they are reporting - perhaps more so, sometimes, than to their own place within their story - they "treat [their] ethnographies as partial, situated, and selective productions" but are careful not to "exclude details that don't fit the story [they] want to tell" (Ellis & Rochner, 1996, p. 21).

While autobiographers most commonly write in the first person, the autoethnographer may use first, second or third person point of view - depending upon how far they wish to remove themselves from the centre of their research. This intentional distance can be used to good effect in order to assist them in their ability to recognize and describe patterns of behaviour and experience that an ethnographer is able to do with more ease because they are usually writing from "outside" of the culture that they describe.

Because the narrative form is usually a more accessible text for a typical person, as opposed to scholarly articles which aren't as widely disseminated into the general population, a positive side effect to the writing of autoethnographies is that the researchers who engage in this form of research have the potential to effect personal and social change in a larger group of

people. This change can have a therapeutic effect on the writers of autoethnographies, the readers of autoethnographies, and the research participants within autoethnographies. For example, Betty Friedan (1964), perhaps, was one of the first autoethnographers in the sense that she identified a general feeling of discontent within white, middle class women that, up until this time, had been left largely unspoken. Her story brought these women's personal experiences to the forefront of conversations, effectively acting as both therapy for the women experiencing these feelings and spurring for policy change as it related to women's rights.

ETHICAL CONCERNS IN AUTOETHNOGRAPHY

Ellis (2007) highlights the unique ethical challenges that are posed by engaging in autoethnography. She discusses three different dimensions to ethics: (1) procedural ethics – the type that is mandated by institutions to assure that procedures have been correctly followed related to ascertaining “informed consent, confidentiality, rights to privacy, deception, and protecting human subjects from harm” (p. 4); (2) ethics in practice or situational ethics – the sorts of ethical dilemmas that sometimes arise when one is working in the field. For example, if a child discloses that they have been abused, the researcher (much like a teacher) has the ethical responsibility to that child to report this disclosure to the proper authorities; and, (3) relational ethics – wherein researchers are called to “act from [their] hearts and minds, to acknowledge [their] interpersonal bonds to others, and initiate and maintain conversations” (p. 4). For Ellis, it is this third dimension that is key to the strength of autoethnography as a grounded research methodology. Because we all live connected lives consisting of friends, family, and co-workers inside larger communities of people, it is impossible for anyone (researcher or not) to act in such a manner that there will not be a ripple effect of change. Whatever one person chooses to do will always have direct impact on at least one other person – and this means that no researcher ever works in isolation, nor should they pretend that they do.

Ellis speaks to the importance of truly attending to these relational ethics. There is strength and beauty in writing about one's relationship with one's mother, but there is also potential for hurt. Josselson (1996) states, “Language can never contain a whole person, so every act of writing a person's

life is inevitably a violation" (p. 62). Ellis asks the autoethnographer to consider how that mother may react if she read what had been written about her. She speaks of the importance of honouring our "relational responsibilities" (p. 14). Similarly, even if the person one is writing about has died, it does not mean that the relational ethics are any less fraught with complication – there are others who are yet alive who will still be impacted by the research.

When writing about those who are alive, there is, as Ellis reminds us, "an opportunity to discuss with them what to tell" (p. 17). This, obviously, can lead to a myriad of communicational issues: how honest are we when we talk to others about how we truly see them? As well, there is the potential for harm to come to the writer, particularly if s/he is writing about an abusive relationship. For most autoethnographers, however, the challenge in relational ethics is in how the writing of the story may alter the dynamics of the relationship that exists between the writer and the subject. A way that some autoethnographers address this particular challenge is by co-constructing the autoethnography with the research participant; that is, by working together to research and examine the subject, making joint decisions about what to include, and the goals of the research, there is less likelihood of "ethical tension" (p. 20) arising.

There are ethical complications, even if the focus of the autoethnography is solely constructed around the author – for instance, what relationships will be confounded by others finding out about the abortion you may have had? How will your colleagues, your students, your children view you if you disclose such a personal revelation?

According to Ellis, "there is no one set of rules to follow" (p. 23) when it comes to taking care of relational ethics. As Arthur Frank (2004) states,

We do not act on principles that hold for all times. We act as best we can at a particular time, guided by certain stories that speak to that time, and other people's dialogical affirmation that we have chosen the right stories. . . . The best any of us can do is to tell one another our stories of how we have made choices and set priorities. By remaining open to other people's responses to our moral maturity and emotional honesty. . . we engage in the unfinalized dialogue of seeking the good (pp. 191-192).

Autoethnographers are, first and foremost, human beings in relation with other human beings. Key to the learnings gained from the actual research is the change that it evokes within the researcher. In speaking about two researchers from "outside" of a particular culture that they were studying, who

later became so immersed in the culture of the group that they became accepting, participating “insiders”, Ellis and Bochner (1996) remind us:

Certainly, not all of us will be as radically transformed by our fieldwork journeys as they were. But at least we can ask, how were we changed? What differences did the Others make in our lives? If I’m no different as a human being or as an ethnographer after returning from the field, then what can I say I learned? (p. 40).

It is this question, “what can I say I learned?” that spurs autoethnographers to interrogate lives – both their own and the lives of others. The significance of these careful and care-full examinations can serve to teach us all.

STORY B

I WANT TO TELL YOU A STORY:

AN INQUIRY INTO AUTISM

Storyteller (S): I want to tell you a story.

Listener (L): What's the story about?

S: It's about a group of doctors and researchers who wanted to understand what autism is and what might have caused it.

L: Why did they want to do that?

S: Well, autism was a bit of a mystery for a very long time. First, it was connected to schizophrenia. Then, once it was separated from that terrible illness, there came all sorts of questions about what it actually was and why some kids get it and some kids don't.

L: Why are you telling this story to me now?

S: Because it connects to my own life.

L: How so?

S: Well, because my son was diagnosed with it. And, because the understandings that I have gained from researching the history of the diagnostic process along with the potential causes have helped to answer so many of the "why" questions that I have held for so long about my son.

L: Anything else?

S: Lots of things. Because this inquiry has offered me the opportunity to discover new insights into how I can best help my son to reach his full potential. Because all of this information better assists me in comprehending, and accepting, why he does the maddening things that he does. Because it has made me so very grateful for all of the

important work that the many doctors, scientists and researchers have done to help me to better understand my son. And because, more than anything, it offers me hope – not that Finnley can be cured, but an overwhelming sense of relief because living with a diagnosis of high-functioning autism (HFA) doesn't have to be such a terrible thing.

My son was born in the year 2000 – only nine years after Hans Asperger's seminal work on a unique group of children (of which Finnley would be considered a member) was finally translated into English. In an earlier decade, Finnley would likely have been diagnosed with something quite different – quite probably, schizophrenia; or, perhaps, with nothing at all, and my husband and I would have sat by helplessly as our son further retreated into his own world.

In the grand scheme of illnesses, diseases, syndromes, and disorders, Autism Spectrum Disorder (ASD), of which Asperger's syndrome is now considered to be a derivation, is a relatively new field of interest for doctors and researchers. Indeed, the first references to children who displayed the attributes by which ASD has come to be defined were not actually formally identified in any North American study until 1943 by Dr. Leo Kanner.

LEO KANNER AND HANS ASPERGER

In his article "Autistic Disturbances of Affective Contact," Kanner provided a set of case studies about eleven children whom he had seen in consultation from 1938 – all of whom seemed to display some common characteristics. Kanner borrowed the term "autism" to describe these children from Swiss psychologist Eugen Bleuler, who had used the term in reference to a specific set of symptoms to describe schizophrenia in the *Handbuch der Psychiatrie* (1911).

As referenced within the Oxford English Dictionary's etymology of the word, "autism," Bleuler stated, "When we look more closely we find amongst all normal people many and important instances where thought is divorced both from logic and from reality. I have called these forms of thinking *autistic*, corresponding to the idea of schizophrenic autismus." (Bleuler, 1913, p. 874). Kanner used this descriptor, "autism," in order to come to a common understanding of these unique children – unique amongst the "typical" population, but also unique within themselves in that the display of their "difference" was particular to each single child.

He states:

The eleven children (eight boys and three girls) whose histories have been briefly presented offer, as is to be expected, individual differences in the degree of their disturbance, the manifestation of specific features, the family constellation, and the step-by-step development in the course of years. But even a quick review of the material makes the emergence of a number of essential common characteristics appear inevitable. These characteristics form a unique "syndrome," not heretofore reported, (Kanner, 1943/1973, p. 217.

He continues:

The outstanding, "pathognomonic," fundamental disorder is the children's *inability to relate themselves* in the ordinary way to people and situations from the beginning of life. Their parents referred to them as having always been "self-sufficient"; "like in a shell"; "happiest when left alone"; "acting as if people weren't there"; "perfectly oblivious to everything about him"; "giving the impression of silent wisdom"; "failing to develop the usual amount of social awareness"; "acting almost as if hypnotized." This is not, as in schizophrenic children or adults, a departure from an initially present relationship; it is not a "withdrawal" from formerly existing participation. There is from the start an *extreme autistic aloneness* that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside. Direct, physical contact or such motion or noise as threatens to disrupt the aloneness is either treated "as if it weren't there" or, if this is no longer sufficient, resented painfully as distressing interference. (p. 242)

Kanner went on to describe a number of other commonalities including: obsessiveness with objects, stereotyped patterns of behavior, rigidity regarding routines, excellent memory skills and selective mutism and/or echolalia – all considered traits common to people with schizophrenia. However, his arguments for this "syndrome" to be considered as its own entity were twofold: (1) the children in his study had all shown their "extreme aloneness" (p. 248) from birth; and, (2) the children established and maintained "excellent, purposeful and 'intelligent' relation to objects that do not threaten to interfere with their aloneness, but are from the start anxiously and tensely impervious to people" (p. 249).

While Kanner spoke of a strong biological factor behind these so-called autistic disturbances, he also considered how environment could come into play, perhaps exacerbating an already present affliction. He stated that "in the whole group there are very few really warm-hearted fathers and mothers . . .

The question arises whether to what extent this fact has contributed to the condition of the children” (p. 250). However, he later absolves the parents of the responsibility by stating:

The children’s aloneness from the beginning of life makes it difficult to attribute the whole picture exclusively to the type of the early parental relations with our patients. We must then assume that these children have come into the world with innate inability to form the usual, biologically provided affective contact with people. (p. 250)

Meanwhile, across the water, in Germany, Dr. Hans Asperger was working with a number of children who seemed to display their own autistic symptoms – though there were some marked differences in the ways in which these two differing sets of children appeared to have developed (or not developed) language. Asperger also described these children as having autism stating, “I have chosen the label autism in an effort to define the basic disorder that generates the abnormal personality structure. . . . Autism in this sense refers to a fundamental disturbance of contact . . . [as] coined by Bleuler” (1944/1991, p. 38).

Similar to Kanner, he also noticed that there was no “disintegration of personality” (p. 39) and a “persistence over time” (p. 67) of the chief characteristics of the disorder. Also like Kanner, Asperger notes, “Autistic individuals are distinguished from each other not only by degree of contact disturbance and the degree of intellectual ability, but also by their personality and their special interests, which are often outstandingly varied and original” (p. 67), which, as we will see, has led to autism being categorized as a “spectrum disorder.”

Of particular import, both Kanner and Asperger highlighted the difficulty the children had in their social interactions and their respective abilities to communicate, as well as the stereotyped behaviours they exhibited, their strong resistance to change, and the specialized focus on one particular area of interest. These findings, even today, form the basis for a person’s formal diagnosis of autism.

Asperger’s paper focuses on the pathology of four boys – Fritz V., Harro L., Ernst K., and Hellmuth L. He provides quite detailed analyses of their personal challenges, including why they were first referred to him, their familial histories, their physical appearance and behavior, their attainment on a number of intelligence tests, their behavior on the ward and the educational treatment that was prescribed. Although these four children are the focus of

the paper, it is clear that Asperger is referencing a number of other children within his paper when he describes “the clinical picture” (p. 67) of autism in broader terms. Indeed, at one point Asperger states that for “over ten years we have observed more than 200 children who all showed autism to a greater or lesser degree” (p. 84) and provides generalized statements about other children when referencing particular characteristics of the disorder.

Reading Asperger’s description of one of the children, Fritz V., brought forth a flood of memories of my own son’s first five years of life. Dr. Asperger reports:

Fritz was the first child of his parents. . . . Motor milestones were rather delayed. He learnt to walk at fourteen months, and for a long time was extremely clumsy and unable to do things for himself. He learnt the practical routines of daily life very late and with great difficulty. . . . In contrast, he learnt to talk very early and spoke his first words at ten months, well before he could walk. . . .

From the earliest age Fritz never did what he was told. He did just what he wanted to, or the opposite of what he was told. He was always restless and fidgety, and tended to grab everything within reach. Prohibitions did not deter him. Since he had a pronounced destructive urge, anything that got into his hands was soon torn or broken.

He was never able to become integrated into a group of playing children. He never got on with other children and, in fact, was not interested in them. They only “wound him up.” He quickly became aggressive and lashed out with anything he could get hold of (once with a hammer), regardless of the danger to others. . . .

He had no real love for anybody but occasionally had fits of affection. Then he would embrace various people, seemingly quite unmotivated. The effect, however, was not at all pleasant. This behavior never felt like the expression of genuine affection, instead, it appeared to be as abrupt as a fit. . . . He did not care if people were sad or upset about him. He appeared almost to enjoy people being angry with him while they tried to teach him, as if this were a pleasurable sensation which he tried to provoke by negativism and disobedience. (pp. 39–40)

Dr. Asperger goes on to give an incredibly detailed case study of Fritz’s appearance, his behavior, and the challenges of educating him. In his diagnosis of Fritz he wonders if, in fact, there is a more severe disturbance than merely a “personality disorder” (p. 37). The two possibilities he comes to are childhood schizophrenia or a post-encephalitic state. Ultimately, he rules out both possibilities.

Whereas Kanner, in the descriptions of the children that he studied, focuses upon the similarities to the schizophrenic personality characteristics, Asperger highlights the psychopathic aspect of the disorder – and the seeming heritability of the disorder, highlighting that he and his team had discerned “related incipient traits in parents or relatives, in *every* [his italics] single case” (p. 84). Indeed, Asperger appears to consider the condition to be a personality disorder with organic causes whereas Kanner seems to believe that what he was seeing was a biologically innate disorder or syndrome that was affected by environmental conditions. In her 1981 paper, “Asperger’s Syndrome: A Clinical Account,” Lorna Wing clarified Asperger’s meaning of the term he coined, “autistic psychopathy,” to describe his patients:

The name he (Asperger) chose for this pattern was *autistic psychopathy*, using the latter word in the technical sense of an abnormality of personality. This has led to a misunderstanding because of the popular tendency to equate psychopathy with sociopathic behaviour. (p. 115.)

Asperger makes note that almost all of the children with autism that he saw were male. While acknowledging that there were girls who displayed similar characteristics, he states that these females appeared to develop autistic tendencies but not to the “fully formed picture” (p. 84) that the males displayed. He speculates that there is likely a sex-linked or sex-limited mode of inheritance and, perhaps, that “the autistic personality is an extreme variant of male intelligence” (p. 83) – a theory that Simon Baren-Cohen explored further in 2003 in his book, *The Essential Difference: Men, Women and the Extreme Male Brain*.

As noted, Kanner’s “syndrome” consisted of five symptoms or characteristics that he and a colleague, Leon Eisenberg, later used to create their own expanded diagnostic criteria for diagnosing autism. Kanner’s original criteria from 1943 include the following:

1. A profound lack of affective contact with other people;
2. An anxiously obsessive desire for the preservation of sameness;
3. A fascination with objects, which are handled with skill in fine motor movements;
4. Mutism, or a kind of language that does not seem intended to serve interpersonal communication; and,

5. The retention of an intelligent and pensive physiognomy and good cognitive potential manifested, in those who can speak, by feats of memory or, in the mute children, by their skill on performance tests, especially the Seguin form board (Kanner, pp. 242-250)

Kanner also noted other differences or abnormalities; however, he did not include them in his essential diagnostic criteria. Lorna Wing in her comparative study of Kanner and Asperger describes these abnormalities as follows:

1. Impaired non-verbal aspects of communication and social responsiveness (including lack of facial expression, poor eye contact, monotonous or peculiar vocal intonation, and little or no use of gesture to supplement or substitute for speech);
2. Inconsistent degrees of gross and fine motor abilities in differing children;
3. Stereotyped movements such as tip-toe walking or arm flapping;
4. Hyper or hypo-responsivity to sensory stimuli;
5. Inconsistent degrees of mimicry ability in differing children;
6. Inconsistent food aversions in differing children;
7. Temper tantrums, aggressiveness, and destructiveness often apparent. (1991, p. 95.)

Hans Asperger, meanwhile, provides no diagnostic criteria; rather, he presents a thorough discussion/study of his cases. However, as Lorna Wing so comprehensively shows, there are significant commonalities between the children described in the writings of Kanner and Asperger:

1. A preponderance of males in the autistic population;
2. Social isolation and a general lack of interest in others;
3. The same issues regarding language use;
4. Impaired non-verbal communication;
5. Lack of ability to partake in imaginative play;
6. Repetitive patterns of activities or behaviour;
7. Odd responses to sensory stimuli;

8. Gross motor clumsiness but dexterity related to the child's special skills;
9. Behavioural challenges such as aggressiveness, destructiveness and negativity;
10. Extraordinary abilities in some areas and learning problems in others.
(1991, p. 96.)

Wing notes that there are differences between the children in the two studies as well: the children whom Hans Asperger describes all developed speech before school age, their vocabularies tended to be impressive, and "while they were socially isolated, they were not unaware of the existence of others, but their approaches tended to be inappropriate and sometimes malicious in effect" (p. 97). This is in direct contrast to the children whom Kanner studied. Asperger also appears to consider his case studies to be "odd" in appearance, as opposed to the attractive look of the children that Leo Kanner describes.

Asperger first mentioned his case studies in a lecture given at the Vienna University Hospital on October 3, 1938 (Feinstein, p. 10) – five years before the publication of Kanner's article. The speech was published that same year in the Vienna weekly newspaper. Six years later, his groundbreaking work with this unique population of children was published in the medical journal *Archiv fur Psychiatrie und Nervenkrankheiten*, though the article went largely unnoticed elsewhere in the world because it was not translated into English until 1991.

Uta Frith (the translator of Asperger's paper and an expert on autism in her own right) explains the significance of these two men's work in the following manner:

Kanner's cases are so well known that they will always remain prototypes for new similar cases. Children who do not talk or who parrot speech and use strange idiosyncratic phrases, who line up toys in long rows, who are oblivious to other people, who remember meaningless facts – these will rightly conjure up Leo Kanner's memory. Children and adults who are socially inept but often socially interested, who are articulate yet strangely ineloquent, who are gauche and impractical, who are specialists in unusual fields – these will always evoke Hans Asperger's name. (1991, pp. 11–12)

Interestingly, according to a number of researchers, there is clear evidence now that it was actually a Russian doctor, Dr. Ewa Ssucharew (or Dr. Eva Sukhareva, depending upon the translation), who was the first person to write about children that, today, we would describe as having Asperger's syndrome. The moniker that she gave these children, back in 1926, was

Schizoid Personality Disorder (SPD). In 1996, Dr. Sula Wolff reviewed the literature on Schizoid Personality Disorder and suggested that the characteristics of SPD so closely resemble Asperger's syndrome that we could (and should) consider them to be one and the same disorder (1996).

Perhaps it was because she was a woman or perhaps it was the lack of translation that prevented Ssucharewa's research from becoming more widely known in the world; however, it is Leo Kanner and Hans Asperger who have been credited with "discovering" autism. And, of the two men, it is Kanner's article, published in 1943, that has spurred further research.

Kanner did much to raise awareness about the plight of children with autism; however, his mixed messages regarding the causes of the syndrome have had a ripple effect throughout the literature on the disorder, even nearly 70 years after the fact. In 1949 he published an article wherein he states:

I have dwelt at some length on the personalities, attitudes, and behavior of the parents because they seem to throw considerable light on the dynamics of the children's psychopathologic condition. Most of the patients were exposed from the beginning to parental coldness, obsessiveness, and a mechanical type of attention to material needs only. They were the objects of observation and experiment conducted with an eye on fractional performance rather than with genuine warmth and enjoyment. They were kept neatly in refrigerators which did not defrost. Their withdrawal seems to be an act of turning away from such a situation to seek comfort in solitude. (pp. 416-26, 425.)

From articles such as these, other writers have pulled the term "refrigerator mothers" – a term with such potency that, according to Chloe Silverman, it "persisted in the popular imagination long after researchers, Kanner included, had abandoned the hypothesis" (2012, p. 38).

Late into the 1950s and 1960s, even while denouncing others who solely laid the blame onto the parents for their children's afflictions, Kanner, along with his colleague, Leon Eisenberg, continued to cause considerable heartbreak to parents with allegations such as these:

the emotional frigidity in the typical autistic family suggest a dynamic experiential factor in the genesis of the disorder in the child . . . It is difficult to escape the conclusion that this emotional configuration in the home plays a dynamic role in the genesis of autism. (pp. 556-566.)

However, Kanner and Eisenberg did concede that, perhaps, the challenges of living with a largely unresponsive child could cause familial

challenges. Indeed, Erik Erikson seemed to pick up on this idea by hypothesizing that autism had its beginnings in the mother-child relationship but that “these children may very early and subtly fail to return the mother’s glance, smile, and touch; an initial reserve which makes the mother, in turn, unwittingly withdraw” (1950, p. 181).

During the 1950s, autism was still largely associated with childhood schizophrenia. The first edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM I), published in 1952, mentions autism as follows:

000-x28 Schizophrenic reaction, childhood type

Here will be classified those schizophrenic reactions occurring before puberty. The clinical picture may differ from schizophrenic reactions occurring in other age periods because of the immaturity and plasticity of the patient at the time of onset of the reaction. Psychotic reactions in children, manifesting primarily autism, will be classified here. (DSM I, 1952. Retrieved from <http://www.unstrange.com/dsm1.html> on 03/19/2012 at 4:32 p.m.).

The 1960s continued to see autism tied to schizophrenia as evidenced by the DSM II, published in 1968 – though autism is no longer named as its own entity; but, rather, is used as a descriptor for the schizophrenic “condition”:

295.8 Schizophrenia, childhood type

This category is for cases in which schizophrenic symptoms appear before puberty. The condition may be manifested by autistic, atypical and withdrawn behavior; failure to develop identity separate from the mother’s; and general unevenness, gross immaturity and inadequacy of development. These developmental defects may result in mental retardation, which should also be diagnosed. (DSM II, 1968. Retrieved from <http://www.unstrange.com/dsm1.html> on 03/19/2012 at 4:32 p.m.)

BRUNO BETTLEHEIM

Part of the confusion around where autism “fit” in the DSM, and whether it was a “stand-alone” disorder, had to do with the strongly positive societal response to another key writer on autism during the 1960s: Bruno Bettelheim. While Bettelheim certainly appears to have assisted in separating autism from the schizophrenic label, he caused immense emotional and social damage by *directly* blaming the parents for their child’s autism. Unfortunately, this theory

still appears to hold sway with some doctors today, particularly those with a background in psychoanalysis.

With the publication of his book, *The Empty Fortress: Infantile Autism and the Birth of Self* in 1967, Bettelheim firmly laid the responsibility on the parents for their child's disorder; in particular, he blamed the mothers. Believing that children with autism direct their energy into withdrawal to protect themselves from the outside world, he compares children with autism to prisoners in concentration camps stating:

In the German concentration camps, I witnessed with utter disbelief the non-reacting of certain prisoners to their most cruel experience. . . . I did not know, and would not have believed, that I would observe similar behavior in the most benign of therapeutic environments, because of what children had experienced in the past. (p. 57)

Bettelheim believed that the lack of response in children with autism and the difficulties the children had with forming typical attachments to their mothers, fathers, siblings, and other caregivers were a "defense against emotional pain or any further depletion of the self" (p. 57) as directly caused by the coldness of the parents.

While Kanner described autism as a unique behavioural syndrome, and Hans Asperger saw it as a personality disorder, Bettelheim describes autism as a disease caused by the parents' psychological pathology- a disease that can only be cured by separating the child from the parents who are causing such harm. Even while studies were published in the 1960s and the 1970s, finding no difference between parents of children with autism and parents of other children, Bettelheim refused to be swayed from his damaging views. Perhaps the one positive that came out of Bettelheim's disastrous publication was the development of a parental lobbying group, the National Society of Autistic Children (later becoming the Autism Society of America) in 1969.

The choice of wording to describe autism is interesting to consider: a disease (Bettelheim's choice of word) implies a harmful condition, sometimes fatal, and often of indeterminate origin; a disorder (Asperger's word) suggests a dysfunction or disturbance of the "norm"; and a syndrome (Kanner's word) could be considered a group of symptoms that, together, give the characteristics of a specific disorder and/or a disease. Within these three words there also lies a connotative degree of alarm. Bettelheim, with his extremist writing, gives the most severe label to autism, conjuring up illness at its most detrimental;

meanwhile, Kanner and Asperger appear to take more clinical approaches and consider the symptomatology of their patients in relation to their environment, thus providing more balanced views of autism.

TOWARDS A DIAGNOSIS

Dr. Michael Rutter was the doctor/researcher who finally managed to formally separate autism from schizophrenia with the publication of his paper, "Diagnosis and Definition of Childhood Autism" in 1978. In his detailed analysis of Kanner's work, he discusses the following:

- the ramifications of calling the syndrome "autism," including the obvious associations with Bleuler and, consequently, schizophrenia;
- the challenges of finding the "boundaries" of the syndrome, along with its nature and causation;
- the confusion regarding the onset of the syndrome (in the early studies by Asperger and Kanner, they both refer to autism as being present from birth; however, Kanner and Eisenberg's later observations (1956) found that autism can arise after one or two years of normal development.);
- and, the "interpretation" of the diagnostic criteria by other researchers.

According to Rutter, "By suggesting that autism constituted a syndrome, Kanner meant two things: first, that there were certain behaviors which tended to group together and second, that these behaviors differed from those found in other psychiatric conditions" (p. 4). He took it upon himself to do comparative studies to clarify the diagnostic criteria and discover which symptoms were both "*universal* and *specific*" (p. 4). From this comprehensive study, he found three fairly broad groups of symptoms that were common to children with infantile autism. They were:

1. a significant inability to form social relationships;
2. language delays with impairment in comprehension, as well as echolalia and pronoun reversal; and,
3. ritualistic or compulsive phenomena (i.e., "an insistence on sameness") (p. 4).

Other symptoms were common, but not consistent for all children with autism. These included: stereotyped repetitive movement (e.g., hand flapping); a short attention span; self-injury (e.g., head banging); and, delayed bowel control (p. 4).

Rutter tested Kanner's (1943) hypothesis regarding IQ (that children with autism were all of normal intelligence and that their poor functioning on IQ tests was merely the result of their challenges with relationship-building and communication) in order to determine whether IQ should be included in the diagnostic criteria. His findings suggested that the IQ for children with autism functions in the same way as it does for neuro-typical individuals, thereby eliminating it as a reference point for autism (pp. 5-6).

Rutter's next diagnostic consideration was the age of onset for infantile autism. He ultimately decides that it is too difficult to determine, based upon the number of subjective factors that come into play in the development of the child; so, he suggests that the World Health Organization's draft glossary, which takes 30 months as its cut-off point for the onset of autism, "seems a reasonable solution" (p. 7). He also struggles with how Asperger syndrome fits into the equation, given that it is often a diagnosis that does not come until after the third year of life.

Rutter then examined his first grouping – the symptomatology of autism that centred upon the obvious impairment in developing social relationships. After detailed analyses of numerous studies, he determines the following: (1) that there is an obvious "lack of attachment behavior and a relative failure of bonding which is most marked in the first five years" (p. 9); and, (2) that the "eye gaze" of children with autism is markedly different to other children of similar age (i.e., Whereas the typical child will look at someone in order to gain her or his attention, when he or she is being spoken to, or if the child wishes to interact with a person in any manner, the child with autism does not do these things) (pp. 9-10). According to Rutter, while many of the social impairments will improve after the age of five, some significant difficulties continue – particularly in "(i) a lack of cooperative group play with other children, (ii) a failure to make personal friendships, and (iii) a lack of empathy and a failure to perceive other people's feelings and responses" (p. 10).

In the second area of symptomatology, the development of language skills, Rutter determines that there is often a marked delay in speech acquisition for children with autism but also that the pattern of speech differs

significantly from the typical child. He points out that there is often a lack of social imitation (e.g., waving), a delayed meaningful use of objects (e.g., Children with autism will merely spin the wheels of a toy car, as opposed to rolling the car around.), and, that these children lack the ability to participate in imaginative or pretend play. He also explains that children with autism struggle in their understanding of language – without visual cues and gestures, they are often completely lost as to what they are expected to do.

Of the children with autism who develop speech (and not all of them do), he clarifies that “there are a variety of characteristic abnormalities” (p. 11). For instance, echolalia and repetition of stereotyped phrases continues for a significant amount of time after speech is first developed. Usually, pronoun reversal also occurs at this stage. Secondly, the speech that the children with autism engage in differs from the typical child in that children with autism tend to talk much less and “what they say is less often related to what they have heard – they give the impression of talking *to* someone rather than *with* someone” (p. 11). As well, there are often unusual ways of wording things, with the use of curious metaphors and explanations.

The third area of symptomatology for diagnosing children with autism revolves around the children’s “insistence on sameness” (p. 11). Rutter details the diagnostic criteria by explaining that there are typically five ways the rigidity displays itself: (1) through very inflexible patterns of play which lack both variety and imagination. (i.e., endlessly lining up toys or making patterns with the toys as opposed to actually playing with them); (2) through “intense attachment to these objects” (i.e., a significant need to have one or more particular items constantly available to the child) (p. 12); (3) the development of an unusual obsession at the exclusion of other things or activities (i.e., bus routes, train tables, numbers, collections of things, etc.) (4) ritualistic and compulsive behavior (i.e., needing to follow the same routine, even if the routine is not needed); and, (5) significant resistance to changes in the environment (i.e., the moving of furniture in the house causes significant stress) (pp. 11-12).

Ultimately, Rutter suggests four diagnostic criteria by which childhood autism can be defined. These are the following:

1. An onset before the age of 30 months;

2. Impaired social development which has a number of special characteristics and which is out of keeping with the child's intellectual level;
3. Delayed and deviant language development which also has certain defined features and which is out of keeping with the child's intellectual level; and,
4. "Insistence on same" as shown by stereotyped play patterns, abnormal preoccupations, or resistance to change. (p. 19)

Rutter's four diagnostic criteria formed the basis for autism's formal separation from schizophrenia in the third edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III), published in 1980 under the new nomenclature, Pervasive Developmental Disorder. The description of pervasive developmental disorder from 1980 is as follows:

- A. Gross and sustained impairment in social relationships, e.g., lack of appropriate affective responsiveness, inappropriate clinging, asociality, lack of empathy.
- B. At least three of the following:
 1. sudden excessive anxiety manifested by such symptoms as free-floating anxiety, catastrophic reactions to everyday occurrences, inability to be consoled when upset, unexplained panic attacks,
 2. constricted or inappropriate affect, including lack of appropriate fear reactions, unexplained rage reactions, and extreme mood lability,
 3. resistance to change in the environment, e.g., upset if dinner time is changed, or insistence on doing things in the same manner every time, e.g., putting on clothes always in the same order,
 4. oddities of motor movement, such as peculiar posturing, peculiar hand or finger movements, or walking on tiptoe,
 5. abnormalities of speech, such as question-like melody, monotonous voice,
 6. hyper- or hypo-sensitivity to sensory stimuli. e.g., hyperacusis,
 7. self-mutilation, e.g., biting or hitting self, head banging.

C. Onset of the full syndrome after 30 months of age and before 12 years of age.

Absence of delusions, hallucinations, incoherence, or marked loosening of associations. (DSM-III, 1980. Retrieved from <http://www.unstrange.com/pdd.html> on 03/18/2012 9:57 p.m.)

Meanwhile, the diagnostic criteria for infantile autism in that edition of the DSM states:

A. Onset before 30 months of age

B. Pervasive lack of responsiveness to other people (autism).

C. Gross deficits in language development.

D. If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal.

E. Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects.

F. Absence of delusions, hallucinations, loosening of associations, and incoherence as in Schizophrenia. (DSM III, 1980. Retrieved from <http://www.unstrange.com/dsm1.html> at 4:32 p.m.)

Rutter recognized that neither the criteria he had developed, nor the DSM III's diagnostic criteria, answered all of the questions regarding autism. For instance, how would one diagnose a child that displays most, but not all, of the features of autism? And, are there "subtypes" of autism, as the children that Asperger and Ssucharew and, later, Kanner studied would seem to suggest? Indeed, some children with diagnosed autism seemed to "fit" more accurately into the diagnostic criteria for pervasive developmental disorder (PDD) rather than the more specific criteria for infantile autism. The main difference between the two sets of criteria, besides the more "options" within PPD, was the age of onset. Was this really another un-named disorder or, rather, was it another "version" of autism?

Rutter was also instrumental in assisting with the revisions to the manual that were published in 1987 (DSM-III-R). These revisions significantly delineated autism and were in direct response to the increased awareness and research into autism. Instead of six diagnostic criteria, there were now *sixteen*

potential criteria with import placed upon impairments in social interaction, communication, and resistance to change:

DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER

At least eight of the following sixteen items are present, these to include at least two items from A, one from B, and one from C.

- A. Qualitative impairment in reciprocal social interaction (the examples within parentheses are arranged so that those first listed are more likely to apply to younger or more disabled, and the later ones, to older or less disabled) as manifested by the following:
1. Marked lack of awareness of the existence or feelings of others (for example, treats a person as if that person were a piece of furniture; does not notice another person's distress; apparently has no concept of the need of others for privacy);
 2. No or abnormal seeking of comfort at times of distress (for example, does not come for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, for example, says "cheese, cheese, cheese" whenever hurt);
 3. No or impaired imitation (for example, does not wave bye-bye; does not copy parent's domestic activities; mechanical imitation of others' actions out of context);
 4. No or abnormal social play (for example, does not actively participate in simple games; refers solitary play activities; involves other children in play only as mechanical aids); and
 5. Gross impairment in ability to make peer friendships (for example, no interest in making peer friendships despite interest in making fiends, demonstrates lack of understanding of conventions of social interaction, for example, reads phone book to uninterested peer.
- B. Qualitative impairment in verbal and nonverbal communication and in imaginative activity, (the numbered items are arranged so that those first listed are more likely to apply to younger or more disabled, and the later ones, to older or less disabled) as manifested by the following:

1. No mode of communication, such as: communicative babbling, facial expression, gesture, mime, or spoken language;
 2. Markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (for example, does not anticipate being held, stiffens when held, does not look at the person or smile when making a social approach, does not greet parents or visitors, has a fixed stare in social situations);
 3. Absence of imaginative activity, such as play-acting of adult roles, fantasy character or animals; lack of interest in stories about imaginary events;
 4. Marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation (for example, monotonous tone, question-like melody, or high pitch);
 5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (for example, immediate echolalia or mechanical repetition of a television commercial); use of "you" when "I" is meant (for example, using "You want cookie?" to mean "I want a cookie"); idiosyncratic use of words or phrases (for example, "Go on green riding" to mean "I want to go on the swing"); or frequent irrelevant remarks (for example, starts talking about train schedules during a conversation about ports); and
 6. Marked impairment in the ability to initiate or sustain a conversation with others, despite adequate speech (for example, indulging in lengthy monologues on one subject regardless of interjections from others);
- C. Markedly restricted repertoire of activities and interests as manifested by the following:
1. Stereotyped body movements (for example, hand flicking or twisting, spinning, head-banging, complex whole-body movements);
 2. Persistent preoccupation with parts of objects (for example, sniffing or smelling objects, repetitive feeling of texture of materials, spinning wheels of toy cars) or attachment to unusual objects (for example, insists on carrying around a piece of string);

3. Marked distress over changes in trivial aspects of environment (for example, when a vase is moved from usual position);
4. Unreasonable insistence on following routines in precise detail (for example, insisting that exactly the same route always be followed when shopping);
5. Markedly restricted range of interests and a preoccupation with one narrow interest, e.g., interested only in lining up objects, in amassing facts about meteorology, or in pretending to be a fantasy character.

D. Onset during infancy or early childhood

Specify if childhood onset (after 36 months of age) (DSM III-R, 1987. Retrieved from <http://www.unstrange.com/dsm1.html> on 03/19/2012 at 4:32 p.m.).

Because “D” (Onset during infancy or early childhood) was “optional” in the diagnostic criteria, those children whom doctors were seeing who did not appear to “fit” the diagnosis of autism until school age (often the case with children with Asperger’s syndrome) could now be diagnosed with a more specific disorder as well. Indeed, as Tony Attwood points out, “the average age for a diagnosis of a child with Asperger’s syndrome is between 8 and 11 years” (2007, p. 14).

Meanwhile there were *still* children for whom doctors could not find definitive diagnoses. Therefore, revisions were made to the Pervasive Developmental Disorder (PDD) nomenclature so that, in the 1987 revision, it also included something called Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Note: This was only one of the informal diagnoses given to my son before he was formally identified as having Asperger syndrome.

The criteria for a diagnosis for this disorder included the following:

299.80 Pervasive Developmental Disorder Not Otherwise Specified

This category should be used when there is a qualitative impairment in the development of reciprocal social interaction and of verbal and nonverbal communication skills, but the criteria are not met for Autistic Disorder, Schizophrenia, or Schizotypal or Schizoid Personality Disorder. Some people with this diagnosis will exhibit a markedly restricted repertoire of activities and interests, but others will not. (DSM-III-R, 1987. Retrieved from <http://www.unstrange.com/pdd.html> on 03/18/2012 at 9:57 p.m.)

IS ASPERGER'S SYNDROME A FORM OF AUTISM?

While the revision in 1987, the DSM-III-R, further pinpointed differences between autism and other PDD, the causes for the disorder still remained unclear. As well, there was still the question of whether Asperger's syndrome was considered its own disorder, or whether it was a form of autism. This is a matter that has encouraged much discussion in the autism community – even Hans Asperger, himself, “weighed in” on the debate prior to his death. According to Lorna Wing, who met Asperger in the late 1970s, “Asperger firmly believed his was a separate syndrome, unrelated to Kanner's although it had a lot of features in common. I argued for an autistic spectrum. We argued very happily and politely.” (As cited in Feinstein, p. 10).

Separating Asperger's syndrome from autism did not occur until the next edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV). Both the fourth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), published in 1994, and the tenth edition of the World Health Organization publication of the *International Classification of Diseases* (ICD-10), published in 1993, described very similar definitions of Asperger's syndrome as one of a number of differing pervasive developmental disorders, including autism.

This separation, for me, is significant – it speaks to perceptions around labels. The label for autism, to my mind, has more negative connotations attached to it. For instance, because of my previous experience with children with more severe autism than my own son, I immediately picture a non-verbal boy who refuses to make eye contact and who (often) is banging his head against a wall or spinning in violent circles. Asperger's syndrome, to my thinking, is more ‘normal’... there are oddities, of course, as are clearly evidenced in my own child, but the behaviours (in general) are more socially acceptable and, often, are associated with creativity and genius *a la* Asperger's “little professors” (as cited in Feinstein, p. 31).

The DSM-IV (1994) describes “Autistic Disorder” in the following manner:

AUTISTIC DISORDER

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
 - (2) qualitative impairments in communication as manifested by at least one of the following:
 - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 - (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
 - (d) persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

(DSM-IV, 1994, Retrieved from www.dsm5.org/Proposed_Revisions/Pages/proposedrevision.aspx?rid=94#) on 2/21/2012 at 10:21 a.m..)

Meanwhile, the diagnostic criteria for Asperger Disorder are as follows:

ASPERGER'S DISORDER

- (I) Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (A) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
 - (B) failure to develop peer relationships appropriate to developmental level
 - (C) a lack of spontaneous seeking to share enjoyment, interest or achievements with other people, (e.g.. by a lack of showing, bringing, or pointing out objects of interest to other people)
 - (D) lack of social or emotional reciprocity
- (II) Restricted repetitive & stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:
 - (A) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (B) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (C) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
 - (D) persistent preoccupation with parts of objects
- (III) The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning.
- (IV) There is no clinically significant general delay in language (E.G. single words used by age 2 years, communicative phrases used by age 3 years)

(V) There is no clinically significant delay in cognitive development or in the development of age-appropriate self help skills, adaptive behavior (other than in social interaction) and curiosity about the environment in childhood.

(VI) Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia. (DSM-IV 1994. Retrieved from <http://www.autreat.com/dsm4-aspergers.html> on 03/24/2012 at 10:47 a.m.)

The significant difference between the two set of criteria (as can be seen) are related to the age of onset of the disorder and the complexity of the communicative impairment.

There is another governing body, the World Health Organization (WHO), which weighs in regarding healthcare and decision-making within the United Nations system. “Responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends” (Retrieved from <http://www.who.int/about/en/> on 10/1/2012 at 9:02am), the WHO publishes an important document that is used as a worldwide reference in the classification of illnesses, disorders and diseases: the *International Classification of Diseases* (ICD).

The 10th edition of the ICD (ICD-10) regards the two disorders (autism and Asperger’s syndrome) as separate entities:

F84.0 Childhood autism

A type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. In addition to these specific diagnostic features, a range of other nonspecific problems are common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.

Autistic disorder

Infantile:

- autism
- psychosis

Kanner's syndrome

Excl.:

autistic psychopathy (F84.5)

F84.5 Asperger's syndrome

A disorder of uncertain nosological validity, characterized by the same type of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.

Autistic psychopathy

Schizoid disorder of childhood

(Retrieved from <http://apps.who.int/classifications/icd10/browse/2010/en#/F84.0> on 2/21/2012 at 11:02 a.m.)

This distinction between Asperger's syndrome and high-functioning autism (HFA) is, to many doctors' and clinicians' mind merely an arbitrary separation. As mentioned previously, Lorna Wing, who actually coined the term "Asperger's syndrome" back in 1981, does not believe that it is a separate condition. She believes that there is a "continuum" of autism with low-functioning autism at one end of the spectrum and Asperger's syndrome at the other (2005, p. 198).

To this end, the latest version of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)*, set to be published in May 2013 now includes Asperger's syndrome within the diagnostic criteria for Autism Spectrum Disorder. The ramifications for this change are significant. Firstly, many people with Asperger's syndrome have embraced their "label"; that is, they have become comfortable in their difference, like the more positive connotations attached to Asperger's syndrome (as opposed to the largely negative reaction in the general population to the word "autism") and are not unhappy with "owning" this identity that differentiates them from neuro-typical individuals (Attwood, in conversation, October 2005.) And, secondly, there is a very real fear that those

governing bodies that make all of the funding decisions will not recognize Asperger's syndrome as the disability it truly is. Wing suggests:

The autism spectrum should list the diagnostic subgroups – including Asperger's syndrome – currently in use, but without defining them, because people who have been given these names need to know that they are on the spectrum, and this will also allow them to receive the appropriate services (Lorna Wing as cited in Feinstein, p. 292).

SEARCHING FOR THE CAUSES OF AUTISM AND ASPERGER'S SYNDROME

Naturally, finding the cause for autism has been an area of significant interest for a number of doctors and researchers. Is autism a result of brain damage? Does the environment in which the child is raised cause the syndrome? Could this aforementioned environment exacerbate an already present disorder? These are all questions that a number of different doctors, from a number of different areas of science, have taken it upon themselves to study.

BRAIN DEVELOPMENT?

In *Understanding the Nature of Autism and Asperger's Disorder: Forty Years of Clinical Practice and Pioneering Research* (2006), Dr. Edward Ritvo describes a series of studies that he and his colleagues undertook during the 1960s and 1970s while on faculty at the UCLA Medical School that demonstrated that irregular development in the brain was the cause of autism and not "bad parenting." According to Ritvo, early reports about children with autism seemed to show a link between the disorder and epilepsy. He argued that if such a link could be established, then it would seem that brain damage could be a cause for autism. After reading the EEG records on all the children with whom he had contact who were diagnosed with autism, he and his fellow researchers found that there was no brain wave abnormality that was unique to autism. Further, only a very small percentage of the children with autism had abnormal brain wave recordings whatsoever. This research provided them with strong evidence against the supposed link between epilepsy and autism. (pp. 70-71).

Their next study centered upon immature sleep patterns in children. Earlier research into REM sleep seemed to demonstrate that as people aged, the

amount of time that they spent in REM sleep shortened. This shortening of the duration of REM sleep, they theorized, would seem to suggest evidence of typical (and potentially measurable) brain development. Ritvo and his colleague, Dr. Edward Ornitz, hypothesized that the brains of children with autism would not develop in the same manner. After studying the sleep patterns of children with autism and children without autism, he and Ornitz found that there were subtle differences in the sleep patterns of typical children and children with autism. While children with autism went through the same stages of sleep development as children without autism, for many (but not all) of them, it happened more slowly.

A further sleep study was commissioned wherein a “clicking” sound was introduced while the children slept. The intent of this study was to measure the brain waves of individuals in response to a sound. The results of this study were similar to those in the first: the brain waves for the majority of the children with autism appeared to take longer to register a change in the administration of the sound. These two studies, taken together, seemed to be pointing in the direction of developmental delay as a reason for autism. At the very least, it confirmed symptoms that parents had previously identified; that is, unusual sleep patterns and/or unusual responses to sounds in children with autism (Ritvo, pp. 71-74).

Ritvo and Ornitz’ next study focused on the seeming need of some children with autism to spin, swing, or twirl. The researchers wondered if this indicated a delay in the part of the brain related to vestibular function. Using an old chair on wheels, they chose to set up two experiments: one where they would spin the chair, stop it, and then measure how long it took for the eye movement to stop; and, the other, where they did the spinning, stopping and measuring – but in the dark. They discovered that children with autism had significantly decreased responses to the spinning when the lights were on; however, with the lights off, there was no difference between those with or without autism. From this observation, Ritvo and Ornitz surmised that the parts of the brain that coordinated the functions of vision and spinning were not fully developed in children with autism and that, in the dark, with only sensation to have to focus upon (the spinning), the brain of the child with autism could function normally (Ritvo, pp. 74-75).

Another study conducted by Ritvo and Ornitz was related to hand flapping. Their hypothesis was that the flapping was caused by brain

dysfunction and not an emotional release or sign of emotional distress, which was the generally accepted viewpoint of other doctors and researchers. They hypothesized that the rate of the flapping should increase or decrease, dependent upon the emotional state of the child. However, if the rate of flapping remained constant that it was driven by dysfunction in the brain. Using a movie camera, they filmed children with autism flapping and then slowed the speed of the film down to measure the number of flaps per minute. They discovered that the subjects' rate of hand flapping remained constant across a variety of emotional states. Excited about their findings, the researchers performed similar studies in other cities in the United States with similar results. This study helped to put to discredit arguments that hand flapping was driven by emotion, caused by "bad parenting" or was a learned behaviour (Ritvo, pp. 75-77).

In 1976, Dr. Ritvo (with the assistance of Dr. Arnold Shibel and one of his research assistants, Taihung Duong) began a study of the brains of deceased patients with diagnosed autism. According to Ritvo:

It took several years before we had collected enough research materials to begin analyzing them under the microscope. What we found was that from the outside the brains looked normal enough. But on looking through the microscope we saw a significant decrease in the number of a special type of cell in the part of the brain called the cerebellum. These cells were simply missing. They had failed to develop. These special cells are called "Purkinji cells," named after the famous Czechoslovakian pathologist who first described them. Pukinji cells are very large and are usually arranged in a neat row, like chairs around a table. In the autistics it looked like every second or third chair was missing. (p. 77)

Drs. Margaret Bauman and Thomas Kemper continued the research on the anatomical differences in the brain structures of patients with autism that Ritvo and his colleagues began. In 1985 they identified neuro-anatomical abnormalities in the limbic system and the cerebellum of people with autism. Excited by these first scientific observations that confirmed a biological basis for autism, Dr. Margaret Bauman founded The Autism Research Foundation (TARF) in 1990 to embark upon further studies. According to their chapter, published in 2004 in *The Neurobiology of Autism*, they discovered, like Ritvo, reduced numbers of Purkinje cells. As well, they identified "the presence of small neuronal size and increased cell packing density in the entorhinal cortex and medially placed nuclei of the amygdala" along with "increased brain

weight and volume in childhood, microscopic differences between children and adults, and some evidence of scattered malformations” (pp. 130–131).

Ritvo and Ornitz were also curious about possible differences in neurotransmitters in the brains of children with autism. Dr. Art Yuweiler and Dr. Ed Geller suggested to Ritvo that serotonin (5-hydroxy-tryptamine) could be a problematic neurotransmitter. Through measuring the serotonin blood levels and platelet counts in hundreds of people with and without autism, they discovered that while serotonin levels were at high levels in infancy, they gradually decreased until the teenage years in people without autism. However, for most patients with autism, the serotonin level started and remained high, even as the patients aged. This could, perhaps, be more evidence of another type of developmental delay – in this case a neurotransmitter (Ritvo, 2006, pp. 78–82).

Ritvo’s next discovery was an abnormal reflex in the eyes of some of his patients with autism. It appeared that there were increased melatonin levels in the blood during the day for some children and adults with autism (when, in most people it is gone by sunrise) that was blocking the dopamine levels to create typical ERG response in the eyes. Similar to increased levels of serotonin that decrease as the patient ages, the melatonin levels appeared to also start and remain high. These increased melatonin levels seemed to point towards yet another developmental delay – this time in the endocrine system (2006, pp. 82–85).

For me, this research was promising....

PRE- AND PERI-NATAL CAUSES?

Prenatal and perinatal causation are other theories that have been researched. Dr. Karin Nelson (1991), in her review of studies on these factors, states:

Rubella and toxoplasmosis in pregnancy, prematurity, caesarean sections, and encephalitic features and infantile spasms were more frequent in the histories of children with earlier onset of disorder. Mason-Brothers et al. compared autistic children who were the only affected members of their families with children whose families contained more than a single autistic member. Apparently non-genetic factors, influenza-like illness and bleeding in pregnancy, were more common in children who were the single cases in their families, and spontaneous labor was less common in their single-case group (p. 762).

Evidence in the research appears to point towards greater degrees of prenatal complications in children with autism; however, because of a lack of uniformity in the studies (both in the diagnostic criteria for the children and in the assessment of the import of the pre- and peri-natal complications) she is cautious about taking this as firm evidence of causation. She says, "It is appropriate to seek prenatal and perinatal factors, among others, that might be causally related to autism, but to date such search has not been fruitful in identifying means to prevent this disorder" (p. 766).

A later comprehensive study by Gardner, Spiegelman and Buka (2009) finds similarly inconclusive results: "There is insufficient evidence to implicate any one prenatal factor in autism aetiology, although there is some evidence to suggest that exposure to pregnancy complications may increase the risk" (p. 7).

A FAMILIAL LINK?

Studies were being undertaken by other researchers to determine whether there was a genetic link for autism. According to Ornitz, in a review of both clinical and experimental literature until 1973, only two studies showed an increased incidence of schizophrenia or a family history of childhood autism in either the parents or the non-twin siblings of children with autism. Findings from studies of twins, however, showed different results. According to Bernard Rimland, "the findings of at least eleven sets of monozygotic twins, all concordant, seems highly significant in terms of the biological etiology of the disease" (1964, p. 57). Ornitz confirms Rimland's speculations through his thorough examination of the literature to date (1973, p. 31) and.

Regarding the likelihood of children inheriting autism from their parents, Ornitz concludes, "In general it can be said that there is no compelling evidence suggesting that there are any significant or important differences in the parental characteristics or the family structure of the families of autistic children" (1973, p. 32). Later research conducted by Ritvo and Ornitz seems to contradict this – to a degree. While there may be no one direct heritability factor that causes autism to be passed along within a particular family, there are a significant number of families with more than one autistic child (Ritvo, 2006, p. 93). In fact, Ritvo's studies in Utah during the 1980s and 1990s determined that parents of a child with autism have roughly a 10% chance of birthing another child with autism. (p. 96). Similarly, a number of researchers

have highlighted that some of the parents of children with autism have undiagnosed autism or Asperger's syndrome – a diagnosis that only occurs after the child has been diagnosed (Ritvo, 2006, p. 94; Attwood, 2007, p. 21).

In a pivotal study by DeLong and Dwyer (1988), they studied the family histories of 51 children with autism or some other pervasive developmental disorder. They found a high incidence of Asperger's syndrome in the families where the child with autism had an IQ of above 70, but discovered that this was not true of children with autism with lower IQs. Interestingly, the rate of bipolar disorder in family members of children with autism was higher than in the general population. Moreover, the rate of bipolar disorder was still higher in families with Asperger's syndrome, suggesting a potential causal link between Asperger's syndrome and manic depression – "about fivefold greater than that expected in the general population" (p. 598). Of the 19 children with diagnosed autism, 15 fit the clinical picture of Asperger's syndrome as well as the criteria for infantile autism or pervasive developmental disorder in the DSM-III. These authors suggested that, perhaps, high and low functioning autism were actually two different conditions: Asperger's syndrome and high functioning autism were largely the same disorder, with a high degree of familial heritability, while low-functioning autism showed clear evidence of neuropathy (pp. 598-99). Later research is even more significant: according to Volkmar, Klin and Pauls (1998), 46% of the first-degree relatives of a child with Asperger's syndrome have similar profiles of abilities and behavior. As well, they noted higher rates of autism in brothers, sisters, and first cousins, than in populations of children without a diagnosis of Asperger's syndrome (p. 460). Interestingly, this discussion of heritability harkens back to Kanner and Asperger's observations about the parents of the children that they studied.

GENETICS?

Ritvo ultimately believes that genetics are the cause for autism – though, unfortunately, we don't have the capabilities as yet to fully study the mechanisms. He believes that abnormal micro-RNA (what he describes as cousins of DNA) could be the problem. Since the micro-RNA are responsible for directing the growth and connectivity of the brain cells, Ritvo theorizes that, perhaps, the micro-RNA in people with autism do not function properly, causing developmental delays. He believes that when the micro-RNA are

severely impacted, severe autism results, and that high-functioning autism occurs when there are milder abnormalities in the micro-RNA (2006, p. 98).

In conversations with Feinstein, Kanner's colleague Eisenberg states, "The failure to find a single cause that shows up in autistic children suggests that there are multiple causes. I am sure there will be progress as a result of the MRI brain scans and haplotyping of the human genome" (cited in Feinstein, 2010, p. 266). Indeed, this appears to be the case.

Researchers, Jennifer Levitt and Xua Hua, used a T1 weighted MRI scan to map structural changes during brain development. They scanned 13 boys with autism and a group of 7 boys without autism and then scanned them again three years later. They discovered that "the white matter connections between the brain regions that are important for language and social skills were growing much slower in the boys with autism. They also discovered a second anomaly: in two areas of the brain – the putamen, which is involved in learning, and the anterior cingulate, which helps regulate both cognitive and emotional process – unused cells were not properly pruned away" (cited in Wheeler, 2011).

Another biological mechanism that could potentially cause autism has been proposed by Eric Hollander et al. in his article, "Oxytocin Increases Retention of Social Cognition in Autism" (2006). He believes that people with autism could have reduced oxytocin levels, leading to challenges in social bonding, increased stress responses, and repetitive behaviours. He recommends further studies using doses of oxytocin.

Jamain and his colleagues believe that quite likely there are just a few genes that predispose people to developing autism. His study of particular neuroligins (2003) seems to point in this direction. Similarly, a study in 2006 of a defect found in four Amish children highlighted the contactin-associated protein-like 2 (CNTNAP2) gene. The researcher, Dr. Daniel Geschwind, hypothesizes that this gene may not only pre-dispose children to autism but also provide the link between genes, the brain and behavior (as cited in Alarcon et al., p. 159). A later study, in February 2008, has identified two separate genetic defects with links to autism: one that directly causes autism in about 1% of cases and a second that seems to increase people's susceptibility (Weiss, L., Shen, Y., Korn, J., Arking, D., Miller, D., Fossdal, R., Saemundsen, E., Stefansson, H., Ferreira, M., Green, T., Platt, O., Ruderfer, D., Walsh, C.,

Altshuler, D., Chakravarti, A., Tanzi, R., Stefansson, K., Santangelo, S., Gusella, J., Sklar, P., Wu, B., & Daly, M, p. 675).

PRE-PROGRAMMED SEX DIFFERENCES IN THE BRAIN?

Meanwhile, Simon Baron-Cohen has developed a theory regarding sex differences in overall brain development with ramifications for how autism can be viewed. The basic premise for his theory is that “The female brain is predominantly hard-wired for empathy. The male brain is predominantly hard-wired for understanding and building systems” (2003, p. 1). He proposes that, on average, females are more likely to spontaneously empathize than males and that, on average, males spontaneously systematize to greater degrees than females (pp. 2–4). He theorizes that people with autism have “extreme male brain”; that is, “systemizing is normal or even hyper-developed, while empathizing is hypo-developed. In other words, these individuals may be talented systemizers but at the same time they may be ‘mindblind’” (p. 7).

This “mindblindness” refers back to a pivotal study that he and two colleagues, Alan Leslie and Uta Frith, published in 1985. Within their article, “Does the autistic child have a ‘theory of mind’?,” they demonstrated that almost all children with autism fail to employ a “theory of mind”; that is, these children have a demonstrated lack of ability to put themselves into the “mind’s eye” of other people and predict what their behaviour would be (p. 44). From this study, Baron-Cohen developed a theory of “mindblindness” that he discusses in detail in *Mindblindness: An Essay on autism and “Theory of Mind,”* published in 1997.

Baron-Cohen (2003) describes autism as “an empathy disorder”; that is, “those with autism have major difficulties in ‘mindreading’ or putting themselves into someone else’s shoes, imagining the world through someone else’s eyes and responding appropriately to someone else’s feelings” (p. 13). In the development of his “extreme male brain” theory, Baron-Cohen echoes Hans Asperger who stated:

The autistic personality is an extreme variant of male intelligence. Even within the normal variation, we find typical sex differences in intelligence. . . . In the autistic individual, the male pattern is exaggerated to the extreme. (1944)

Baron-Cohen makes very clear that all males do not have a “male/systematizing brain”; and, by the same token, all females do not have a “female/empathizing brain.” And, in fact, a good number of us have a “balanced” brain – meaning that we have both systematizing and empathizing capabilities. Still, the theory that people with autism have “extreme male brain” appears to have some scientific credence.

Baron-Cohen (2003) writes about a series of measurement tests that he and his colleagues developed to “test” for autism. They include the following:

1. the Empathy Quotient (that purports to measure empathy);
2. the Facial Expressions Test (where people look at photos of people’s eyes and determine the mood of the person in the photo);
3. the Faux Pas Test (a series of questions that examines the ability of the test-taker to navigate typical rules of etiquette);
4. the Friendship and Relationship Questionnaire (that determines whether people focused on another’s feelings or only on the shared activity in social relationships);
5. the Systematizing Quotient (that asks questions about people’s “need” to order or systematize their world);
6. the Embedded Figures Task;
7. the Autism Spectrum Quotient (another series of questions that measures, among other things, whether a person is comfortable in social situations);
8. the Tomboyism Questionnaire (a measurement of interest in “female-typical” activities) (pp. 149-154).

Interestingly, they discovered the following:

1. The Empathy Quotient: overall, females scored higher than males, and people with autism score even lower than the males;
2. The Facial Expressions Test: again, females scored higher than males, and people with autism scored lower than the males;
3. The Faux Pas Test: females score higher than males, and, again, people with autism score lower than the males;

4. The Friendship and Relationship Questionnaire: women, again, score higher than men, and, again, people with autism score lower than men;
5. The Systematizing Quotient: overall, males score higher than females, and people with autism score highest of all;
6. The Embedded Figures Task: men score higher than women, and people with autism score even higher than the men;
7. The Autism Spectrum Quotient: males score higher than females, but people with autism score highest of all;
8. The Tomboyism Questionnaire: girls with autism are less interested in female-typical activities than girls without autism.

Finally, two other bodily “tests” seem to suggest some truth to Baron-Cohen’s hypothesis: in somatic markers such as finger-length ratio – where males tend to have a longer ring finger in relation to their index finger than women – the finger-length differential is more pronounced in people with autism; and men with autism are also reported to show more precocious puberty, correlating with increased levels of testosterone (pp. 149–154).

OTHER CAUSES?

Environmental causes, of course, have also come under consideration as a root cause for autism. The theory that has generated the most controversy, proposed by Dr. Andrew Wakefield and his associates, is that the triple MMR (measles, mumps, rubella) vaccination could be causing autism to arise in otherwise healthy children (Wakefield, A., Murch, S., Linnell, A., Casson, D., Malik, M., Berelowitz, M., Dhillon, M., Thomson, M., Harvey, P., Valentine, A., Davies, S., & Walker-Smith, J., 1998, p. 637). Anecdotally, I have also heard speculations such as the following: too much exposure during pregnancy to chemicals such as pesticides and/or flea medication for animals; and/or, harmful rays that may have been emitted from computer screens or televisions. At this point these theories are unfounded but, because parents (and researchers) are eager to pinpoint an exact cause for autism, researchers are considering a number of differing genetic and environmental factors.

To my mind, I believe autism is likely the result of a combination of environmental and genetic factors, with stronger credence coming from the genetic link. That is, perhaps some children may be born with “autistic tendencies” coded into their DNA, but environmental factors (pre-, peri-, and post- natal) perhaps play significant factors in fostering an “environment” where autism is more likely to develop.

TOWARDS A FUTURE

Ultimately, the question of seeking the cause of autism implies that, once this supposed cause is discovered, autism could be eradicated; that is, we could “test” for autism, much like we can now do pre-natal testing for Down’s syndrome. The ethical implications of this are, obviously, significant. Is autism a disability to the same degree as Down’s syndrome? Certainly, low-functioning autism would seem to be so. Picture a fully-grown 30-year-old man, unable to speak, still in diapers, who repeatedly bangs his head against the wall.

But what about the person with HFA or Asperger’s syndrome? What about the person who, for all accounts and purposes, is “normal” but has some slightly unusual behaviours? Is the tendency to fixate on particular objects or ideas such a terrible thing? Is a discernible lack of interest in socializing such a disability and such a drain on society that it warrants genetic screening and, potentially, the termination of a life? And, how is it that we can be so worried about “difference” in others when *everyone* is “different”?

Consider people like Dr. Temple Grandin¹. Consider Adrian Lamo². Consider Dawn Prince-Hughes³. Consider Vernon L. Smith⁴. Consider Jerry

¹ Professor in animal science at Colorado State University, author and autism advocate. Grandin’s description of how she feels around neurotypical people was well-documented by Oliver Sacks in *An Anthropologist on Mars* (1995). Grandin’s words were the inspiration for the title of the text.

² Notable computer hacker who broke into the computers of *The New York Times*, Yahoo! and Microsoft.

³ Primatologist, anthropologist, ethologist and author of many texts on living with autism, including *Songs for a Gorilla Nation*.

⁴ Professor of Economics at Chapman University’s Argyro’s School of Business. In 2002, he was a recipient of the Nobel Memorial Prize in Economic Sciences.

Newport⁵. Consider Satoshi Tajiri⁶. Consider the myriad of scientists, artists, authors, composers, and mathematicians who have focused their “special interest” in such a manner that it has allowed them to make wondrous discoveries. Is being “on the spectrum” such a terrible thing?

And yet, I have to ask myself, if I had known that my child would develop autism, would I still have chosen to give birth to my son?

⁵ Author and mathematic savant. His life formed the basis for the 2005 feature film *Mozart and the Whale*.

⁶ Japanese video game designer. Most known for the design and development of *Pokemon*.

STORY C

I WANT TO TELL YOU A STORY:

THE STORY OF APPRECIATIVE INQUIRY

Storyteller (S): I want to tell you a story.

Listener (L): A story? What's the story about?

S: It's about a group of people who wanted to help others to evoke positive changes in their communities, in their workplaces, and in their personal lives.

L: Why did they want to do that?

S: Because they were frustrated with the largely ineffectual forms of problem solving that people were using to bring about change.

L: What do you mean by 'ineffectual forms'?

S: Well, the way that they saw it, if you focus your energies on everything that is going wrong about what you are doing, you are going to learn an awful lot about what's "wrong", but not very much about what's "right".

L: And this matters why?

S: Well, because, chances are, there are some things that are working – even if it's only one or two things. And, by focusing our attention on doing more of those "good", "right" things, then, perhaps, some of those "bad", "wrong" things will disappear of their own accord.

L: That's a bit simplistic, don't you think?

S: Well, yes and no. Positive thinking has been proven to have a pretty powerful effect upon people.

L: Okay. But, why communicate this particular story at this particular time?

S: Because it connects to my own life.

L: How so?

S: Well, for one thing, I worked my way through the 4 stage cycle of Appreciative Inquiry as I figured out how to best help my son. In essence, I participated in a personal form of AI.

L: What's the other thing?

S: What do you mean?

L: You said, "for one thing". What's the other thing?

S: The other thing is that I'm examining my research process and, to be true to the auto-ethnographic process, I need to speak about this particular aspect of my learning as well.

L: Right.

S: So, are you ready?

L: Sure. I'd love to hear it. Tell me a story about Appreciative Inquiry.

S: I will. And, I'm going to do that now...

Back in 1987, David L. Cooperrider and his colleague Suresh Srivastva published an article entitled, "Appreciative Inquiry in Organizational Life," wherein they communicated an approach to organization design and change management that, literally, turned the business world on its head. By re-conceptualizing action-research through a "socio-rationalist" point of view – essentially saying that people have bias and, therefore, cannot help but interpret any data they collect through this bias – they argued five things:

- that in order for action research to move to a level where it can effectively bring about significant change in an organization, that it must begin to advance "theoretical knowledge of consequence";
- that "good theory" may be one of the most effective change agents for human beings in our current world;
- that viewing challenges in the world as problems in need of solving and, consequently, using "problem-solving" as the primary method to

- resolve these issues is constricting and puts limits on people's creative abilities and their ability to contribute to imaginative alternatives;
- that "appreciative inquiry" is a worthwhile counterpart to action research;
 - that "through our assumptions and choice of method we largely create the world we later discover" (p. 129).

Their philosophy and methodology, which is largely based on social constructionism, defined by Kenneth Gergen (1985) as "explicating the processes by which people come to describe, explain or otherwise account for the world (including themselves), in which they live" (p. 266), emphasizes one important understanding. It recognizes the power of a story.

Now "Appreciative Inquiry" has morphed and developed in a number of different ways since its inception in Cooperrider and Srivastva's ground-breaking article. Watkins, Mohr, & Kelly (2011) consider Appreciative Inquiry (AI) as three separate, yet inter-connected, concepts:

1. a philosophy or a way of making sense of the world;
2. an intervention theory that "places emphasis on the role of language, dialogue, and story with a particular focus on the power of inquiry in the social construction of reality" (p. 33); and,
3. a combination of both the philosophy and the practice, as woven together into a generative methodology (p. 33), with the potential to become a cross-disciplinary approach to provoking change.

Initially put forward as a "generative theory," it has evolved into a "process for intervening in and changing organizations" (p. 84) that Cooperrider, Whitney, and Stavros believe can be used with "any collective human system" (2008, p. xxix)⁷ or, as Jacqueline Kelm has demonstrated in her books and articles, as a way in which one may choose to live his or her life. According to Watkins and her colleagues, an Appreciative Inquiry (AI), in whatever form it is used, always subscribes to the following set of principles:

⁷ According to Cooperrider, "organization" is a loose term. He and his colleagues believe that AI can be utilized to make a difference with a single person, with a group of people, with a family, and/or "with any collective human system" (Cooperrider et al., 2008, p. xxix).

- The Constructionist Principle: what we believe about the world is constructed through our conversations (our stories) about it. In this way, what we know and what we create are interwoven. In essence, the stories we choose to tell have the power to affect how we come to view ourselves and our circumstances; thus, they are “fateful” (2011, p. 73);
- The Principle of Simultaneity: beginning an inquiry into anything brings about change; thus, this act, too, is “fateful” and generates a line of questioning (either positive or negative) that will directly influence the findings. Watkins et al. state, “The questions we ask set the stage for what we find, and what we discover creates the stories that lead to conversations about how the organization will construct its future” (2011, p. 73);
- The Anticipatory Principle: humans base their present decisions not only on their prior knowledge (stories from their collective pasts) but also upon what they “anticipate” or “imagine” will happen in the future. As a result, “the most important resources we have for generating constructive organizational change or improvement are our collective imagination and our discourse about the future. It is the image of the future that in fact guides the current behavior of any person or organization” (2011, p. 73);
- The Poetic Principle: there is an inherent “valuing of storytelling” as a way of gathering information – including honouring the feelings and emotions that people may have about their experiences. In essence, any organization’s story is “co-authored” by the people within it as well as the people who interact with the organization from the outside;
- The Positive Principle: a positive approach to an issue or challenge can be just as valid a basis for learning as a negative approach. For example, focusing upon why and how 90% of the students in one’s class are able to perform “to standard” can be more empowering, and an equally effective story to tell, than focusing one’s energies upon the 10% who are not meeting expected outcomes. This positivism is “an antidote to cynicism” (2011, p. 73) and, according to Cooperrider and others, empowers people to make positive change based upon the understandings that have come about because of dedicated analysis and inquiry into “what works” in their story;
- The Overarching Principle of Wholeness: because Appreciative Inquiry is grounded in “that which is strong and positive,” it has the potential to

develop “a new manner of thinking” within its subscribers. As Watkins et al. describe it, “The challenge of these times is for each of us to realize that what we label dichotomous is caused by our limited ability to realize that what we see in parts is always some small piece of a larger whole, and that it is our choice about whether to see the part or to embrace the whole” (2011, pp. 73–75). With a story, the whole is always greater than the sum of its parts.

Cooperrider and his many colleagues capitalized on some key research from psychology in order to develop their original theory. In particular, they utilized research into the placebo effect, the Pygmalion effect, and the power of positive effect to provide the scholarly credibility for their theory.

THE PLACEBO EFFECT

The placebo effect describes the process whereby a patient is “healed” simply because they believe they have been given an effective treatment for their illness. Cooperrider quotes Norman Cousins, a faculty member at the UCLA School of Medicine, who suggested that, besides the commonly studied central nervous system, hormonal system and immune system, there are two other important bodily systems that need to be recognized as essential to the proper functioning of the human being: the healing system and the belief system. In his book *The Healing Heart: Antidotes to Panic and Helplessness* (1983), Cousins argues that these two systems work together; that is, “The healing system is the way the body mobilizes all its resources to combat disease. The belief system is often the activator of the healing system” (p. 203). Through “managing his own anticipatory reality” (Cooperrider, 2001, p. 30), Cousins describes how he overcame a supposedly irreversible life-threatening illness and then, a number of years later (using the same thought processes as before) healed himself after a serious heart attack. Cousins states, “What were the basic ideas involved in that recovery? The newspaper accounts had made it appear that I had laughed my way out of a serious illness. Careful readers of my book, however, knew that laughter was just a metaphor. . . . Hope, faith, love, will to live, cheerfulness, humor, creativity, playfulness, confidence, great expectations – all these, I believed, had therapeutic value” (p. 44).

Cousins’ “story” is, in and of itself, an interesting narrative to consider when contemplating the strength of the human spirit. However, it is his belief

that “positive imagery can and often does awaken the body to its own self-healing powers” that Cooperrider utilized to formulate the foundation of both the philosophy and the practice of Appreciative Inquiry (Cooperrider, 2001, p. 30).

THE PYGMALION EFFECT

Similarly, a “story” that is often quoted in educational literature describes numerous teachers who are told by supposed “experts” that certain of their students have greater potential for success than others. Unbeknownst to the teachers (and the students), these students have been randomly selected thereby affirming that the only difference between them and the other students in the classroom is in how the teacher perceives them. Quickly, the students who supposedly have this greater potential for success begin to outperform the other students, and as the study continues, the difference between the supposedly different “ability groups” widens. As well, if the students who have this supposedly greater potential are not performing to the level to which the teacher perceives them as capable, the teacher attributes the reasons to factors outside of the child – including re-considering how s/he taught the student. According to Cooperrider, “Over the last twenty years there have been literally hundreds of empirical studies conducted on this phenomenon, attesting both to its continuing theoretical and to its practical importance” (2001, p. 31). This “story” has become known as the Pygmalion effect⁸ and is a startling explanation (and exploration) into the power of human perception. Cooperrider explains that the lesson that we can take from this study and apply to Appreciative Inquiry is as follows: “cognitive capacities are cued and shaped by the images projected through another’s expectations . . . The greatest value of the Pygmalion research is that it provides empirical understanding of the relational pathways of the positive image – positive action dynamic” (Cooperrider, Whitney, & Stavros, 2008, p. 11).

⁸ The Pygmalion effect is also known as the Rosenthal effect, after the work of Robert Rosenthal who, along with his colleague, Lenore Jacobson performed the first “Pygmalion in the Classroom” study in 1968. He subsequently went on to perform numerous studies afterward and, in 1978, published an article with his colleague Donald Rubin wherein they analyzed the data from over 345 similar studies (“Interpersonal expectancy effects: the first 345 studies” in *The Behavioral and Brain Sciences*, 3, 377–415).

POSITIVE EFFECT AND LEARNED HELPFULNESS

The “story” of how positive imagery moves people to feel positive emotions which, in turn, shifts humans towards positive actions has less research behind it, as Cooperrider and his colleagues recognize. Still, studies on learned helplessness by Martin Seligman, and, more importantly, Dr. Barbara Fredrickson’s work on the powerful effect of positive emotions in the workplace points us in this direction. In her article, “The Broaden-and-build Theory of Positive Emotions,” Fredrickson describes some twenty years’ worth of experiments on the thought-action repertoires of people as recorded by Alice Isen and her colleagues at Cornell University. These studies found that people who are experiencing positive emotions (or positive affect) show thought patterns that are more efficient, more unusual, more flexible, more creative, and more open to the acceptance of new information. As well, the brains of those research participants who experienced these positive emotions all showed increased levels of dopamine. Fredrickson analysed this research and used it as a springboard to develop her own theory. The broaden-and-build theory, which describes the way in which a subset of positive emotions (joy, interest, contentment and love) “broaden” a person’s thought-action repertoire and how this broadening promotes a person’s ability to build his or her personal resources (1367–1377). The studies that Fredrickson developed to test her theory all had similar results. In one study, Fredrickson and her colleagues, exposed research participants to short film clips that induced specific emotions – joy, contentment, fear and anger – as well, they used a non-emotional film clip with another group as a neutral emotion control condition. After the study participants had viewed the films, Fredrickson and her colleagues measured the breadth of their thought-action repertoires by having them imagine that they were in situations where these same emotions would arise. The research participants were then asked to make a list of all of the things that they would like to do right then, in that moment. The results of the study clearly showed that the participants in the two positive emotions conditions identified more things that they wanted to do right away compared to both the participants who had observed the films portraying both the negative emotions and the neutral emotion control condition. Interestingly, the participants who watched the negative emotion film clips identified the least amount of things. More studies, obviously, uncovered more things (including the ability of positive emotions to aid in the recovery of cardio-vascular activity after a negative

experience) and confirmed Fredrickson's hypothesis about the power of positive emotions. Because of the powerful work of Isen and Fredrickson, research now shows that positive emotions:

- i) broaden people's attention and thinking;
- ii) undo lingering negative emotional arousal;
- iii) fuel psychological resilience;
- iv) build consequential personal resources;
- v) trigger upward spirals towards greater well-being in the future; and,
- vi) seed human flourishing (Fredrickson, p. 1375).

The story that Fredrickson shares is encouraging and, for Cooperrider, suggests that by focusing upon the positive, people practicing Appreciative Inquiry may be able to think more creatively and broadly about their circumstances, thus coming to more imaginative solutions to their problems or challenges.

In *Appreciative Inquiry: A Positive Revolution in Change* (2005), Cooperrider and Whitney describe a cycle of activity whereby an Appreciative Inquiry can be prompted to occur: they refer to it as the Appreciative Inquiry 4-D Cycle. In their view, "the AI cycle can be as rapid and informal as a conversation with a friend or colleague, or as formal as an organization-wide process involving every stakeholder group" (p. 15). Again, the dialogue (the storytelling) is key to the success of the AI cycle. The AI 4-D Cycle consists of the following four phases:

1. Discovery – identifying and appreciating "the best of what has been and what is" (Cooperrider & Whitney, p. 16); Watkins et al. describe it as people coming to know "their organization's history as positive possibility rather than a static, problematized, eulogized, romanticized, or forgotten set of events" (2011, p. 87). This Discovery Phase involves sharing positive stories⁹ with each other about the organization or organizational system (and about themselves as part of this system) –

⁹ Pam Johnson, an AI Practitioner, argues that sometimes, even when considering something (or someone) with an appreciative eye, negative experiences or thoughts are generated and that asking the person to ignore or repress these thoughts or feelings is akin to asking him or her to amputate an arm. She argues that, in order for AI to be a truly generative process, it must embrace the polarity of human emotions; and, that by exploring these negative experiences or ideas, in turn, through an appreciative eye, that they can result in the positive, generative outcomes that Cooperrider aims for in the 'discovery phase' of the AI process (Johnson, 2007).

where things worked, where people felt strong and powerful, and where the individual storyteller felt that s/he had made a positive impact upon the organization;

2. Dream – envisioning “what might be” in relation to the potential uncovered through the shared stories during the discovery phase of the process (Cooperrider & Whitney, 2005, p. 16); Watkins et al. state: “It is grounded in the organization’s history; and generative, in that it seeks to expand the organization’s potential” (2011, pp. 87–88);
3. Design – co-constructing “the ideal” through uncovering common themes and then using these themes to develop “possibility propositions” (Cooperrider & Whitney, 2005, p. 16) or “possibility statements” (Watkins et al., 2011, p. 88) that will make plain the behaviours and qualities that will enable the organization or group to function in a way that moves it towards this “ideal” and magnify the “positive core of the newly expressed dream” (Cooperrider & Whitney, 2005, p. 16);
4. Destiny – strengthening the “affirmative capability” (Cooperrider & Whitney, 2005, p. 16) of the organizational system, by empowering the people within it to continue to hope, to learn, and to adjust in the face of change, in hopes of developing ways to create that preferred future; Watkins et al. refer to this phase as the “Delivery” phase wherein “sustaining the change” in the “service of shared ideals” is attained by “continuous learning, adjusting and improvising” (2011, p. 89).

Through examining the affirming stories we tell each other (and ourselves) in the Discovery Phase, using these stories as springboards for our imagination in the Dream Phase, making tangible connections between what these stories have taught us about ourselves and where the stories have the potential to lead us in the Design Phase, we beget new and, potentially, more powerful stories in the Destiny/Delivery Phase.