REVISITING AUTISM AND ASPERGER'S SYNDROME: BUILDING FAMILY AND SCHOOL COMMUNITIES THAT VALUE DIVERSITY

by

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ABSTRACT

This study explores the question, "How might we work together to build communities that value diversity, especially the cognitive difference pathologized as high-functioning autism?" Based on the testimony of autistic writers, the case is made that many autistic behaviours are not unintelligent or illogical but, rather, highly adaptive in response to environmental hypersensitivity. Many caregivers fail to realize this and high-functioning autistic spectrum children are subjected to "normalizing interventions" that confuse and isolate them.

Through hermeneutic inquiry, the study explores the lived experience of parenting a child with Asperger's Syndrome, and the positive change in communication that occurred when the child's fixation became an organizing axis for conversations. It focusses particularly on the potential of reading response in creating locations that invite collective reinterpretation of complex relations.

ACKNOWLEDGEMENTS

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CHAPTER ONE

Introduction

In her book, *The Art of Teaching Writing,* Lucy Calkins (1994) describes what she calls, "the writerly life." According to her, "authorship does not begin in the struggle to put something big into print, rather, it begins in living with a sense of awareness" (p. 3). To her, living a writerly life entails taking careful note of life experiences; celebrating them as significant episodes within the total story of humankind; recording "snippets" in idiosyncratic collecting places such as journals, logs, albums, scrapbooks, margins; and, eventually, reinterpreting all of them through the creation of connected text. "Writing does not begin with deskwork but with lifework" (p. 3).

Background to the study

This thesis is, perhaps, best understood as one locus of interpretation in what has been the "writerly/researcherly life" that began with the birth of my eldest daughter, Melissa, almost eighteen years ago. For the first sixteen years, that path involved a recording of events, conversations, thoughts, observations, and theories surrounding her increasingly frustrating behaviour patterns. The focus question in all of this was: "How can I explain Melissa's differences from me, her father, her sister, other children, and almost everyone else I have ever known?" For most of those years, the

implied explanation involved some mixture of "learning disabilities" and "strong-willed child." Life rolled along, with my burgeoning collection of data supporting the half-formed hypothesis that, if I searched long enough, I would find the "cure" for my difficult, damaged child.

Documentation, though interesting in and of itself, becomes useful only when we revisit it with an intention of clarifying and revising our theories, documenting the revisions, and, in turn, revisiting the new theories so that they, too, can be revised. This cycle of documenting, revisiting, and revising is a powerful tool in helping us learn. Prior to this study, I did not realize that; I continued to document with no thought of using my records as a tool for changing my understanding of Melissa and my understanding of myself in relation to Melissa. Rather, my intention was to <u>prove</u>, not change, my theories about her behaviours.

Foucault (1972) argues that this is not atypical. People tend to assimilate new events through old explanations, discarding those that do not fit. Eventually, however, the logical mind is faced with "discontinuous events" that cannot be explained within old theories. Then, he explains, in our revisiting of documented theory we are forced to deconstruct connections and look at events individually, free from preconceived categories, explanations, and established contexts in order to examine the deeper "interplay of relations within [them] and outside [them]" (p. 29). Implicit in this type of theoretical

revisiting is the intent to discard old explanations in order to develop new ones.

Events can be described as discontinuous when they contradict established connections and hypotheses, forcing the researcher to re-examine gathered data. In my case, two such events interrupted my writerly life, encouraging me to ask new questions, seek new information, and reinterpret past experiences.

The first was an unprecedented conversation that began when I posed the rather innocuous question, "What are you reading?" Through Melissa's answer, I became aware that the inclusion of lack of intelligence within any explanation of her differences was an inaccuracy that could not be reconciled. Because all of my old explanations had included some version of "lack of intelligence," all of them had to be discarded. The new path that I took was announced by the writing of Oliver Sacks (1995) in his work, *An Anthropologist on Mars*, in which he described the life and work of Dr. Temple Grandin, a high functioning person with autism. The links between Dr. Grandin's accounts of growing up with autism, and my memories of Melissa's childhood were unmistakable. Most significant to me was Grandin's (1995) assertion that her autistic behaviours were not unintelligent, random acts but, rather, intelligent, adaptive responses to what she perceived to be a highly chaotic world. Hypersensitivity to light, sound, and touch was an explanation for Melissa's behaviours that I had never considered. A

high level of intelligence was a characteristic that I had never considered. At that point, I began to see the importance of truly attending to the life of my daughter. I began to have significant conversations with her, using her collections of novels and life artifacts as focal points for discussion. I began to tape-record those conversations as evidence of Melissa's autistic tendencies, still with the somewhat vague hope that, in understanding and explaining her differences, I might somehow cause them to disappear. I made meticulous records of conversations with her teachers as well as of my observations of her behaviours at home. I went back through her school reports and files, as well as the records made by the various psychologists that she had seen over the years. I was sure that, if I looked hard enough, I would find ways of helping her fit more easily into my world.

I began to look for evidence of this in the autobiographical writings of other high-functioning people affected by autism. Many of them recounted tales of the significance of story-telling in helping them to see their lives holistically. They spoke of the means by which they had formed connections with people who were not affected by autism. I read on, reinterpreting my documentation of Melissa's childhood, carrying on conversations with her about her social struggles, and making suggestions regarding changes she might make in order to have an easier life.

A second event interrupted this pathway. I had discovered that

the internet contained a wealth of information about autism. Homepages by people affected by autism added to my growing collection of autobiographical materials. I stood as an outsider, reading their observations and accounts of the world and comparing them with my records of Melissa's lived experience. I hunted for clues as to how autistic spectrum people had been helped to lead "a more normal life." I gathered much useful material. One particular Saturday afternoon, a letter from Jay Sinclair (1993) caught my attention: "Don't mourn for us," he wrote, "We need and deserve families who can see us and value us for ourselves...Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us....The tragedy is not that we're here but that your world has no place for us to be" (p. 3). He implored families to cease their continual efforts to "fix" their autistic-spectrum members.

I was stung. I had thought that my new understanding of Melissa--that she was intelligent and could learn to "fit in" if only I gave her adequate support--was an inclusive way of viewing her. But Sinclair was calling for so much more. He was calling for a place in determining the nature of society in general. He was explicating the injustice of constantly feeling pressured to "fit into" a society that would not change to accommodate him; that would not allow him to express his giftedness just the way he was.

The focus

Gradually my focus changed from "redesigning Melissa" to building, together, a community that was inclusive of diverse gifts. I began to recognize that Melissa was already a part of the community; we were simply ignoring that fact and making it difficult for her to contribute. More personally, I began to admit that, not only did Melissa need me, I needed the considerable benefit of her presence.

The evolving research question

And so, my research question changed from "How can we more effectively socialize high-functioning autistic people?" to "How might we work together to build communities that value diversity, especially the cognitive difference pathologized as high-functioning autism?"

Research methodology

This change in question involved a completely different research approach. No longer was I the expert gratuitously offering to include the less fortunate into my world. No longer was I the researcher looking for clues toward a "remedy" that would allow my daughter to act in ways that were more comfortable for me and others like me. Suddenly, I was looking for methods of changing my own cultural practices.

With this in mind, I returned to my collection of documents:

taped conversations with Melissa, personal journals that recounted our collective experience, books by writers affected by autism, autobiographical accounts displayed on the internet, photograph albums, collections of souvenirs and report cards and projects, essays I had written during the many years of searching and explaining, professional journals that recorded clinical studies illuminating autism. I read all of them again with a new mind. It was as though I had never read, let alone written, any of them. The texts, in reading them with a new purpose, became new as the meaning within each one was affected by the changing context. I began to methodically record the patterns I saw among the various documents: common ideas, common vocabulary, common experiences. I began a split-entry journal, recording quotes and pieces of data on the lefthand side of the page, and either my interpretations or connected pieces of data on the right. I carefully hunted for accounts of situations in which high-functioning autistic people had felt included. I scoured the literature and my own journals for hindrances to communication, for effects of "interventions," for clues from autistic people as to what they thought inclusion should look like. Gradually, as I grappled with representing my findings in written form, I began to catch a glimpse of what it must be like to be intelligently autistic, to genuinely understand the world differently from almost all other people. I began to understand the frustration of not being heard; I began to comprehend the implications of hypersensitivity; I found myself in

their testimonies of being "othered" by parents and teachers who were moved by goodwill to "normalize" them.

While reinterpreting these documents, I began to read the writings of such philosophers as Kerby (1991), Foucault (1972), and Bruner (1990), as well as the poetry of Zwicky (1986). As I read about their understandings of the construction of self, community, society, and knowledge, I began the difficult task, once again, of reinterpreting my collection of information.

Methods of interpretation

In one very narrow sense, then, it could be considered that the writing of this thesis has involved no new recording of information: the raw data was all recorded before my question evolved. Much like an historical study, my work has involved the very careful gathering of existing records from multiple sources and the search for patterns within those previously unlinked documents.

Unlike the historian, however, I have not had the luxury of looking at a long-past subject from the outside position of the present. I have been, and continue to be, within my study. The things I read and write affect my everyday actions, which, in turn, affect what I read and write. Subjectivity is immanent.

Yet, I struggle for objectivity which, to me, implies a need for outside verification. All of the high-functioning autistic people to whom I refer within this document, including my daughter, have

been diagnosed by qualified specialists. While I have in my possession many accounts written by people who **may** be autistic or **may** have Asperger's Syndrome, I have not used their observations in my study because I fear that their inclusion might cause the validity of my conclusions to be questioned. In addition, whenever I have written something that I believe to be true about the autistic spectrum based on my experiences with Melissa, I have checked for corroborating evidence within the autobiographies and the clinical studies. Similarly, I have verified their writings through my own experience. This has served as a type of textual triangulation. I have taken this care with my work because it is life-writing; it affects lives: my life, my daughters' lives, the life of my husband. This is not an academic exercise from which I will withdraw to go on to other pursuits. When, finally, I command my computer to print, and flick the switch that darkens its screen, I will turn around and walk back into my thesis. It is my life--my research can never stop.

And, therefore, I must place this study within the field of hermeneutic inquiry, that age-old practice of interpreting our lives and the world around us within the context provided by the writings of others.

Hermeneutic inquiry is not new for me. I recall my mother narrating Aesop's fables and other didactic tales and sending a much-smaller Me to the kitchen table to think about their possible application to recently displayed attitudes and behaviours. I recall

my English Literature 12 teacher reflecting upon the spirit of competition demonstrated by our championship basketball team and asking the class to find connections with the ambitions of Lady Macbeth. I recall "Introduction to New Testament Greek" in which we read the Koine writings of Paul, studied the cultural context in which they were created, and interpreted modern-day events in relation to the ideas they represented. For me, hermeneutic reflection has been a cultural expectation since childhood and has become, perhaps, the primary method by which I learn.

There are several ways in which this study has been hermeneutic. For one thing, when I set out to study Melissa and her reading practices, there was an intention of creative change. I was not handling my reactions to her differences very well and I was hoping that, by studying her, I would find important keys to understanding and changing the situation. My reading, writing, and reflecting practices enacted my goal of bringing about more positive ways of being a family.

Secondly, my study has involved "the hermeneutic circle" (Smith, 1989, p. 190), "the back-and-forth movement between the particular and general" (Davis, 1996, p. 21). I have looked specifically at the events of our lives and the lives of other people with autism. I have moved from this to look macrocosmically at the nature of autism, of learning, of cognition, and of the role of narratives in the evolution of the Self. There has been a constant interplay among

these sources of information which has affected my evolving interpretation of each of them.

Thirdly, the subject matter itself has affected both my question and my methodology (Smith, 1989). I set out to find effective ways of socializing my daughter; I ended up asking how I could go about changing myself. I set out using traditional methods of objective inquiry: careful review of authoritative literature, formulation of the focussed question and research-based hypothesis, scientific experimental design, control of variables, anticipated results based on preliminary inquiry, accurate and focussed data gathering. I found that I could not so easily remove myself from my study. Because I was in the middle of things, there was a continual shifting of my understanding and, as I learned more, new flaws in my research design kept appearing. Sticking to an inadequate design would have seriously impaired my learning so I had to use something more flexible. Hermeneutic inquiry provided the theoretical context that allowed me to be researcher, subject, activator, and learner.

Fourthly, and perhaps most importantly, hermeneutic inquiry, like this study, is perpetually a work in progress. I offer this summary of my learnings not as the Truth, but as something for others with similar interests and experiences to use for consideration in their own hermeneutic inquiry. In the cycle of documenting, revisiting, revising, this is a record of theory that invites

reinterpretation by others and by myself. This work, then, is part of an ongoing discussion about high-functioning autism and Asperger's Syndrome which will, hopefully, lead to change in the way that people with autistic tendencies are viewed and treated by the people who touch their lives.

Synopsis of the chapters

Because it is so personal, this work has been difficult both to enter and to activate. The chapter which immediately follows explores that difficulty, postulating that it is part of human nature to be "cognocentric," that is, to assume that our personal perceptions of a particular environment are identical to those of the people around us. Hence, many of my difficulties with Melissa came about because I did not believe her when she said that a touch was painful, the light was overbright, the music was too loud. Cognocentrism, I believe, is an overwhelming bias of mankind that is central to many other "isms": racism, sexism, ageism. We link three things: perception, logic, and conclusions. We assume that perception is the same for everyone. Therefore, when others' conclusions about events or circumstances differ from our own, we assume that the interpretive logic is faulty. In actuality, I believe, perceptions of the world are distinctly idiosyncratic. Though our brain images of what we see, hear, feel, taste, and smell are <u>similar</u>, they are not the <u>same</u>. This lack of awareness about differences in perception causes us to

counteract what we believe are inappropriate overreactions on the part of autistic people. When we come to understand these perceptual differences, we realize that many of their unusual behaviours are not intentionally anti-social but are, rather, logical and adaptive. Furthermore, as we become more attuned to autistic perception, we recognize it as a type of giftedness that has potential usefulness for the community.

The third chapter goes on to recount my experience of Melissa's Asperger's Syndrome and to explicate the effects of my cognocentrism on our relationship. In the writing of it, I have relied heavily on my personal journals and artifacts, and have interpreted them in light of Williams' (1992) and Grandin's (1995) accounts of the reality of hypersensitivity. The chapter is largely narrative but goes beyond that to look for implications and to ask questions about inclusive learning communities.

Chapter four extends the understandings developed within the previous two chapters to argue that it is possible to create locations that invite the community-building input of all members, including those affected by autism. It illuminates many barriers to such conversations: autistic traits, "othering" on the part of non-autistic people, the traditional definition of "the educated citizen" that dominates today's school systems, tolerance for bullying in modern society, and environmental distractions that confuse people with autism. The chapter goes on to describe factors that positively

influence community-building efforts that are inclusive of people with autism: adequate support for classrooms and families, a clear understanding of the nature of diverse gifts and a committed belief in their value to the community, conducive physical environments, and physical and emotional protection from harassment and bullying.

Chapter five looks specifically at creating "commonplace locations" that invite communication with high-functioning people affected by autism. It relies heavily on the observations of such writers as Donna Williams and Temple Grandin, as well as on clinical studies, in making the argument that it is possible to get beyond cognocentrism to a creative understanding of what it takes to communicate with people who find conversations difficult. Our family's experience in exploring reading response as a locus of communication is developed as an example.

Chapter six is, perhaps, the most deeply personal because it represents my attempts to apply my learnings in both theoretical and practical ways. While I outline focussed practices that will allow others to truly know their autistically-affected students and offspring, in reality it is a reminder to myself to continue those practices that have helped me to progress as both a parent and an educator. Perhaps an analogy will help to clarify what I mean. By now, most of us have attempted and been successful at making sense of "Magic Eye" pictures: They look like complex squiggles on the page until,

suddenly, the mind reconfigures the lines, refocusses the lens, and the entire picture makes sense. Not only do we see the embedded image, we are able to move our eyes around and examine it until, suddenly, it disappears and all we see is the confusion once more. We know that the picture is there, we even know what it looks like, but, for a time, it is lost. Having knowledge of something is different from being able to usefully access that knowledge at any given moment.

The same is true in parenting the cognitively different child. We know the child perceives the world differently than we do, we are able to describe the child's perspective, we can explain the significance of those differences in their everyday behaviours, and, many times, we are able to act and react in accordance with that knowledge. Yet, suddenly, it all disappears and we are back within our old paradigm, struggling with our personal intolerance, battling to maintain control against our anger, fighting to get past that great grief that is so damaging to the parent-child relationship.

We believe that we have it all reconciled: Our child has autistic tendencies; she is cognitively different; we do not want her to be like everyone else; she is not organized through the same logic as everyone else; she has strengths that we value and appreciate; she has weaknesses that cannot be ignored but, at the same time, can be put into perspective; we accept her just as she is. And, in having it all figured, we cease to be reflective. Our behaviours become automatic,

conditioned rather than insightful. We fall into old, damaging habits.

The work recorded and reflected in chapter six summarizes the practices that have helped me to sustain reflective parenting over an extended period of time. Through observing, reading, writing, and conversing, I have begun to change my thinking with regard to my daughter. In writing about those practices, I hope to provide a platform for continued change, particularly as it applies to my parenting and my teaching.

The writerly life

To choose a "writerly life" is to choose active involvement in learning. It is to be personally aware of the details within events and circumstances, to consistently document experience and thought, and to revisit and revise theories as a matter of discipline and attitude. This thesis embodies my employment of writing in activating life change.

CHAPTER TWO

Autism and Cognocentrism

If, as Kanner (1943) contends, autism is about profound aloneness, then it must be said that parenting the autistic spectrum child, too, is about profound aloneness. Autism becomes the defining characteristic not only of the affected person, but also of all those cospecified through relationship. Autism is a giant ice floe on which a family sits as it breaks from the mainland and gradually moves out into a cold and threatening sea. The people on the shore watch them go, shouting advice and offering sympathy. Few people dive into the icy waters to haul them back; only occasionally does someone offer to go along. It is desolate, it is lonely, it is frightening. And it is forever.

That parents of autistic children realize the stressfulness of their situations is well-documented (Bristol and Schopler, 1983; Wolf, Noh, Fisman, & Speechley, 1989; Fong, Wilgosh and Sobsey, 1993). In the words of one mother, "I have been close to snapping. There comes a time when you can't put up with the screaming anymore" (Tait, 1997, p. A13). In the fall of 1996, a Montreal mother responded by drowning her six year-old autistic son and subsequently attempting suicide. In a note, she said that she did not know where to turn and could not continue. Susan Burns, also the mother of an autistic six year-old, is quoted as saying, "I can't do all this. I'm on my own. I'm

a very strong person, I'm very practical, but you get so exhausted" (Tait, 1997, p. A14).

Where, then, does a family turn to find satisfactory solutions? In the day-to-day experience of living with an angry, often violent child who demands rigid routine, who seems to lack common sense, who is resistant to both toilet training and a full-night's sleep, is there any way of developing a mindset that sees an autistic child's situation as optimistic, even promising? What understandings will give parents hope and, more importantly, will help them build, with their children, places of mutual inclusion? How can teachers assist them in their struggle?

A deeper understanding of autism

It is imperative for parents and teachers to understand autism in a deeper way than general knowledge provides. Because, if that is one's only view, and autism is seen only as a set of "abnormal" behaviours that need to be "fixed," the task is, indeed, rather formidable. However, if caregivers and educators will agree to reexamine autism, leaving behind preconceptions of what constitutes intelligent behaviour, then they may be able to view the world through the child's eyes and, in so doing, put into perspective, or relinquish, the drive for normalization. As one moves toward a worldview in which autism is studied not as a cognitive disability but, rather, as a significantly different perceptual profile, then the actions and

reactions of the autistic person suddenly become logical, intelligent, adaptive. The interactions of teachers and parents become respectful and helpful when they let go of the notion that what is the norm for behaviour and social interaction is somehow better, and what is autistic is somehow less good.

But, given our current understanding of autism, is such a perspective possible?

Common views of autism

When I was a child in the early 1960's, my school-principal father brought home a film. I remember visions of head-banging children who screamed, stacked blocks, and talked to no one. The children were in little rooms with tables but no chairs; there were one-way mirrors so we could watch them. From time to time, tall people would come in to talk to them; the children did not notice. They just kept shrieking and pounding and stacking blocks.

This image of deeply troubled, low-functioning children is a defensible representation of one manifestation of autism. Consider, for example, the following story: At age four, Nicky Fisher does not speak. He is hypersensitive to sound, screams continually, does not like to be held, and is self-abusive. He is not toilet trained and, during the day, commonly spreads his own feces on walls, beds, and furniture. He must be supervised constantly as it is characteristic of him to run around the house wildly, scattering things and bolting out

doors and windows. At night, he has great difficulty falling asleep; he awakens often; he routinely wets his bed. Nicky has been diagnosed as autistic and is both mildly mentally handicapped and epileptic (Tait, 1997, p. A12).

While Nicky and many other autistic children are mentally handicapped, the case for rejecting this condition as one that invariably accompanies autism has been long and well established (Frith, 1989; Sacks, 1994) and it is time for parents and teachers to move beyond such anachronistic models in order to gain a much broader picture of autism and the many ways in which it manifests itself in people with normal or above-average intelligence.

Reexamination of autism

First, it must be clearly understood that autism is a syndrome, not a disease, and that diagnosis is based, not on the presence of biologically identifiable symptoms, but, rather, in four broad categories of behaviours: (a) a "restricted repertoire" of activities and interests (Cox & Mesibov, 1995, p. 60), with characteristic perseveration and difficulty coping with change, often accompanied by "isolated areas of exceptional performance (also termed *savant skills*)" (Koegel & Koegel, 1995, p. 73); (b) qualitative deficits in verbal and nonverbal communication and imaginative play (Koegel et al., 1992; Cox & Mesibov, 1995), characterized by lack of speech on one end of the spectrum, through echolalia and word confusions, to lengthy

monologues that are both socially and semantically disconnected, on the other (Ozonoff, 1995, p. 204); (c) sensory processing problems, characterized by hypersensitivity and confusions involving touch, light, sound, and, even, smell (Grandin, 1995, p. 140); and, (d) a marked impairment in reciprocal social interactions (Cox & Mesibov, 1995, p. 58-60), including an acute inability to anticipate and understand the perspective of others, resulting in characteristic detachment (Myklebust, 1995, p. 49) and a "severe limitation in the experience of interpersonal relations *as* interpersonal" (Hobson, 1993, p. 194).

It must be noted that the severity of affectedness is not clearly defined within these criteria. That fact, along with the subjectivity inherent in all human observations, leaves any diagnosis of autism open to question.

Secondly, parents and teachers need to understand that autistic behaviours are developed in mutual correspondence with individual personality and intelligence: Autism affects people idiosyncratically. It has been characterized as "a heterogeneous disorder with many subtypes, ranging from genius level to very low functioning with mental retardation" and as appearing on several continua with individuals displaying various degrees of rigidity in their thinking and their interests, along with degrees of ability to cope with change, sensory input, and situations requiring receptive and expressive communication (Grandin, 1995, p. 138-139). In other

words, the autistic mind appears in as many varieties as the non-autistic mind. Bernard Rimland (1993) prefers to speak not of "autism" but of the "autistic spectrum," thereby acknowledging that there is a range of problems and of subtypes with diverse manifestations and degrees of autistic influences. In addition, because autism is affected by brain development (Cox & Mesibov, 1995, p. 58), it expresses itself differently over time. A child diagnosed with autism, then, has no predictable prognosis, unlike a child diagnosed with some forms of mental retardation (Frith, 1989, p. 15). With time, natural development, and intervention, autistic traits, while they never disappear, have been known to be significantly ameliorated.

Room for optimism

By the time the autistic person is an adult, then, the syndrome is often less debilitating than childhood symptoms would suggest. Adult autistic people may be found anywhere on the intelligence spectrum, and the degree to which their autistic affectedness is readily apparent may change as they grow older. In fact, some profoundly autistic children grow up to lead extremely productive lives.

One example of this is Temple Grandin. She spent much of her early childhood in a world of "unbridled chaos" in which she found herself overwhelmed by incoming sensations, especially noises and smells (Sacks, 1995, p. 254). At age two, she showed the

symptoms of classic autism: "no speech, poor eye contact, tantrums, appearance of deafness, no interest in people, and constant staring off into space" (Grandin, 1995, p. 43). Gradually, however, she began to develop the ability to shut out and organize the chaos. For hours, she would sit in the sand, studying the formations as the grains dribbled through her fingers. She would rock incessantly, which calmed her and enabled her to cope with the disorganization of incoming stimuli. Despite great social difficulties, she managed to succeed in school and, eventually, to graduate with a Ph.D. in the animal sciences. Today, she is the author of many books, a professor at Colorado State University, and a graphically gifted designer of innovative and humane animal handling facilities. She is still autistic.

Jerry Newport is an example of a person with Asperger's Syndrome, a profile that exists on the high-functioning end of the autistic spectrum (see Appendix for diagnostic criteria of Asperger's). He has always felt out of touch with other people due to his ongoing difficulties with reciprocal conversation and eye contact. As a young adult, he became depressed over his social isolation and twice attempted suicide. He earned good grades in university; nevertheless, he spent the first twenty years of his adult life failing in one low-level job after another. He simply could not connect with people enough to know what was, and was not, socially appropriate.

Like many other autistics, Newport has *savant* skills, one of which is mathematical calculations. He was only five years old when

Roger Bannister broke the world record by running a mile in under four minutes. "I asked my father, 'How many feet in a mile?' He says, '5,280.' And I says, 'Well, gee that's twenty-two feet per second. That's 264 inches per second. That's 15,840 inches per minute. That's 950,400 inches per hour. That's 22,809,600...inches per day" (Stahl, 1996). Unlike Grandin, he was not diagnosed until age forty. Since that time, Jerry has come to terms with his disabilities, his abilities, and his giftedness. His social skills are improving; he has married and is employed at the UCLA Medical Center, working with statistics.

A third example is that of Donna Williams, once a severely disabled child, who is now a best-selling author (Williams, 1992, 1994, 1996). In her childhood and teen years, she managed to perform well at school but consistently felt like she must be suffering from some sort of insanity because she could neither understand nor engage in social situations like other people. Constantly confused by stimuli that were chaotic and overwhelming, she gained no sense of the limits and wholeness of her body, and could not make connections among the events of her life. Cause and effect were concepts she could not master. Through writing her life story, she began to see her experiences as interconnected. She began to develop her ability to communicate and socialize. Like Newport and Grandin, she will always be autistic. However, with hard work and considerable support, she has made a location for herself within "normal" society.

All three of these adults have surpassed any predictions of success that were made during their childhood and adolescent years. Many other examples could be given of competent, autistic adults (Sacks, 1995). For parents and teachers of children diagnosed with autism, then, there is room for optimism. While many profoundly autistic children grow up to be profoundly autistic adults, many others do not.

To a great degree, this window of hope has been opened by families, educators, researchers, and therapists who have worked hard to develop and implement promising interventions. Speech therapy, social stories, auditory integration training, diet control, vitamin supplements, and medications are among the strategies that have been empirically documented as effective in helping some autistic people enter society (Frith, 1989; Rimland, 1993; Edelson, 1995; Grandin, 1995).

A disquieting murmur

It would seem that this news would meet with universal applause. And yet, alongside these sanguine reports, there is a disquieting murmur arising within the writings of some high-functioning autistic people. It is related to identity, that ongoing redefinition of the person we perceive ourselves to be within social and historical contexts.

Jerry Newport (Stahl, 1996) alludes to it when he says that, as

he learns to function in the normal world, his special skills are getting a little slower. Temple Grandin (1995) tells us that she "would never want to become so normal that [she] would lose [her visualization] skills" (p. 180). Donna Williams (1994) is more direct in stating that many interventions aimed at socializing autistic people are merely cosmetic and that they deny the autistic person the right to "simply be": "I believe some environments are good at chiselling off edges or producing robots...I don't believe you can teach autistic people to experience everything they are able to perform" (p. 214). She writes of "let-me-teach-you performance programs" (p. 219) and tells the story of Lucy, an autistic girl who, by the age of seven, was "terrified of the enormity and incomprehensibility of her own feelings." Having been taught that her natural ways of expressing emotion were socially unacceptable, she had learned to put on socially appropriate faces which declared to the world that she was frightened, or concerned, or amused, or sad. With careful observation, however, it became clear that she was merely acting without understanding (Williams, 1996, p.38). Williams contends that actively training autistics, through such methods as behaviour modification, to deny their natural "excessive" responses and replace them with controlled expressions, many of which they do not understand, is to deny them a sense of identity and, possibly, to create sociopathic personalities. Her books reveal her struggles for self-acceptance and call on society to accept her as she is, complete with

giftedness and social inappropriateness. She believes that to demand that she "act out" behaviours and feelings that she does not yet comprehend is to deny her the right to develop as a social being. Given time, she believes that she will be able to adjust socially in ways that are appropriate for her and for others, if she is allowed to rely on her own "system of making sense of things" (Williams, 1994, p. 199).

Jim Sinclair's treatise (1993) is, perhaps, the most poignant. He explains that autism is as constituative of his identity as non-autism is of ours. "Autism is a way of being, It is not possible to separate the person from the autism. Therefore, when parents say, 'I wish my child did not have autism,' what they're really saying is, 'I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.'...This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure...that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces" (p. 1).

Is this what we are saying to autistic people when we implement interventions? Is this our underlying, not so hidden, message: they are not worthy of giving or receiving love unless they deny their understanding of the world and act in ways that make little sense to them but meet our expectations? Viktor Frankl (1959), in writing of his search for meaning within the degradation and hopelessness of the German concentration camps, observed that those men who had experienced unconditional love found purpose in

going on. Whether or not the loved one was alive was insignificant; it was the memory of loving and having been loved that remained as an ongoing reference for interpreting new experiences (p. 58).

And it is love, Sinclair states, that I am denying my daughter when I see her as "abnormal" and wish that she had some other way of being.

But how is it possible to go beyond such a view? To find room for optimism within the ordeal of raising and educating an autistic-spectrum child is a constant battle with lived experience; is it plausible, or even fair, to suggest that to arrive at optimism is to stop short of the ideal--to suggest that there is another, more accurate and useful perspective?

A *new perspective*

Ansel Adams noted that the character of his photographs was altered markedly through a minor shift in perception (Richards, 1995). His early work was infused with the slightly incorrect presupposition that his film was recording items; later, when it occurred to him that it could capture only light, his focus changed from the item itself to the effect of that item on environmental light. He developed new ways of looking at the same things; he developed new methods of responding to them. It is natural for us to use our vision to focus on objects. In moving beyond the common to a deeper understanding of his art, Adams made a shift in perspective that

allowed his good photographs to become extraordinary.

Is it possible for us to shift our perceptions of autism in just such a way? Is there a more accurate view, slightly beyond our intuitive awareness, that will allow us to do what Williams and Sinclair call for? Will a slight shift in perspective allow us to work with our autistic students and family members in a way that is more artfully effective because it is truer to their natures?

In shifting his perception, it was necessary for Adams to change the object of his focus. What is our initial focus in looking at autistic people? Williams (1994) argues that we focus on behaviours. As they are readily observable, it is easy for us to look at the actions of children, categorizing them initially as abnormal and, with closer scrutiny, as autistic. Every attempt at diagnosis focuses on observable behaviours because, as established earlier, there is no biologically justifiable means of identifying autism.

And, when studying these behaviours, we may be drawn to the slightly mistaken conclusion that the logic behind them is similar to what ours would be, if we were to act in such ways. In other words, when I hear someone scream at a friend, I assume that he or she is as angry as I would be if I were to scream at a friend. When I investigate and find that the actions of the victim do not warrant such anger, I jump to the conclusion that the anger was an inappropriate overreaction on the part of the screamer. When I see a student throw books to the floor and run from the classroom, I assume that

something extreme has motivated such an action. When I investigate and find that nothing more serious has happened than that the student has failed to understand an assignment, I jump to the conclusion that the student has acted irrationally. It is natural for me to assume that the behaviours of others are motivated similarly to my own behaviours and that, if the motivations are insufficient to elicit extreme responses from me, they should be insufficient to elicit extreme responses from others. This is because, like Adams, I initially work from instinct and habit rather than from conscious effort. And, in this case, my instinct says that my perceptions of the world are accurate and complete. It tells me that the child is operating with the same pieces of knowledge that inform my decisions and reactions, and that the child is functioning within the same response mechanism that modulates my behaviours. But what if I am wrong?

A new concept: "cognocentrism"

> One thinks that one has traced the nature
>
> Of a thing when really one has traced
>
> The frame through which one sees it (Zwicky, 1986, p.55)

When anthropologists use the word "ethnocentrism," they refer to the tendency of people to evaluate the mores and traditions of other cultures from within the logic and perspective of their personal

ethnicity, as though that, somehow, embodied a reference point for cultural measurement. A report characterized by ethnocentrism might, for example, describe Asian chopsticks as more "primitive" than European flatware because they do not allow for independent cutting of food. Such an evaluation of eating utensils is based on nothing more substantial than an arbitrary, presupposed cultural belief that cutting one's own food is somehow more sophisticated than having someone else cut it during meal preparation.

Ethnocentrism is the unconscious assumption that one's cultural paradigm constitutes the norm and that, therefore, all opinions and behaviours may be validly assessed with reference to it.

In a similar way, "temporocentrism" is the tendency to judge the thinking of historical peoples from within the logic and perspective afforded by information that is currently available but which was not available in the past. Children are often temporocentric: "Those guys believed the world was flat? How could they be so stupid?" Of course, such a child has no personally-gathered evidence that the world is round. He merely believes it, based on the testimony of others, some photographs he assumes to be correct, and his inaccurate observations of the curvature of the horizon at the ocean. In short, lacking direct evidence, he may have been as "stupidly" duped into believing that the earth is round as his ancestors were into believing that it was flat. Lacking sophisticated methods of direct inquiry, he accepts the evidence of others. Yet, he

judges historical peoples as inferior in their thinking, simply because the outside sources available to them were less accurate than the outside sources available to him. Unable to step out of his own temporal frame of reference, he becomes guilty of temporocentrism.

Temporocentrism is the unconscious assumption that one's historical paradigm constitutes the norm and that, therefore, all opinions and behaviours may be validly assessed with reference to it.

Educated minds are quick to point out both ethno- and temporocentrism in the arguments of others, and to guard against it in their own work.

But supposing we tend not only toward errors based on differences of experience that influence perspective and, ultimately, judgment, but also toward errors based on differences of perception that influence response and, ultimately, judgment. Is it possible that, in addition to examining our interpretations of the world for ethno- and temporocentrism, we ought to examine them for a further judgmental error based on assumptions we make about the information that we collect through our senses?

Generally speaking, society makes adjustments for people who are visually or auditorily impaired: if they say that they cannot read the print, we use a larger font; if they comment that the television is too quiet, we increase the volume. In other words, if we know that a friend is partially deaf, and she tells us that the television is not loud enough, we accept what she says. Our automatic response is belief,

not questioning.

But what if we are sitting and watching television, with the volume set at what we consider a moderate level, when someone comes into the room with her ears covered, yelling that the movie is much too loud? Will our automatic response be belief? Probably not. First, we might evaluate the volume level. Finding it not particularly loud, we will likely defend our opinion. If the person insists, we might eventually turn the volume down but we will continue to question her judgment. Should this happen often, we might even begin to call this person "weird." Should a similar incident happen in a classroom, and the teacher determine that the class is not too loud and the student is mistaken, the student might be said to have "antisocial behaviours." After years of hearing that normal sounds are either too loud or too high-pitched, normal light is too bright, and normal smells are too strong, the tendency will be to think of that person as one who is easily provoked into overreacting. We might even begin to think that she is illogical, especially if her reactions to stimuli are particularly extreme.

My tendency is to assume that, except in cases of sensory impairment, everyone gathers identical information from the surrounding environment: I assume that what I see, hear, and smell, others also perceive; that what I do not sense, others also do not notice.

This would not be significant if my perception of the

environment did not affect my thinking. However, as postulated by Wittgenstein (1969), the pieces of knowledge that I acquire through my senses become part of my "river-bed propositions," those understandings that I do not question but use as reference points for all other learning. If I assume that everyone is working from the same foundation of knowledge, and I note that their responses are significantly different than mine in the same situation, I might jump to the conclusion that it is their logic that is faulty. A term to describe this error might be "cognocentrism," the tendency to judge others' actions based on the erroneous notion that their senses have provided them with the same foundational knowledge that I have acquired.

Cognocentrism is the unconscious assumption that one's cognitive-perceptual paradigm constitutes the norm and that, therefore, all opinions and behaviours may be validly assessed with reference to it.

Hypersensitivity as lived

Donna Williams (1992) writes that she remembers people yelling at her when she was a small child. She could not fully hear them because she was sensually absorbed in a brilliantly sparkling cloud that swirled around her. Only as she became older could she look through that cloud to the world outside of it. Grandin (1995) reports the same type of hypersensitivity to sound and smell. Reading the literature, it appears that such perceptions are not

uncommon in autistic children, weakening somewhat in adulthood through the development of adaptive behaviours (Frith & Baron-Cohen, 1987, p. 96). In other words, some autistic spectrum children sit in their classrooms and watch the air as its phosphorescent particles swirl around them; others cover their ears in defence against the overwhelming whine of the airflow system. Anxiety builds as these students combat the chaotic environment in their efforts to focus on the teacher. In an effort to control or dispel the anxiety, autistic children tend to make repetitive movements, such as rocking or tapping (Grandin, 1995; Williams, 1996). Some isolate themselves. Others lose control and have violent outbursts of temper.

High-functioning children affected by autism possess normal or above-average intelligence in terms of their ability to learn and to reason (Twachtman-Cullen, 1997). Often, in attempting to organize and delimit the impact and chaos of multiple incoming stimuli, they develop areas of keen interest that they pursue doggedly. Because of this, during their elementary school years, they may seem very intellectually capable. Naturally, teachers assume that they are socially and emotionally capable, as well, and that their irregular, sometimes violent behaviours, are made by choice. The professional opinion, then, is that this child "should know better." Yet, the child cannot seem to pay attention in class, being sidetracked by noise and movement. The child, distracted and anxious, may not engage in imaginative play, and may be decidedly antisocial, lacking skills such

as sharing, waiting in line, and discussing. As the child becomes more disruptive, teachers' behaviours may reflect their growing desperation. Again, Donna Williams (1992) recounts some of her experiences:

> My teacher was a knobbly, snapping old goblin
> who got very angry with me and kept shouting that I was
> giving him ulcers. He would make me stand in the
> rubbish bin, and I would swear and he would throw
> pieces of chalk at me. The children in the class would
> laugh... (p. 37).

As parents and educators, when we observe the behaviours of children and determine the workings of their brain based on those observations, we are likely to make determinations that are cognocentric. If a behaviour seems irrational to us, we are likely to accept that it is irrational. Conversely, a behaviour that seems rational is likely to be considered as based in reason.

Uta Frith (1989) unwittingly provides us with an example: In a chapter on conversation she uses the subheading, "What is wrong with the language of autistic children?" and goes on to describe how they tend to be literal rather than intuitive, and blunt, rather than diplomatic. She prefaces the section by providing both the transcript and the analysis of her interview with an autistic girl, saying that the adolescent failed to provide the trivia that allows one "to build up a rich picture of a stranger's life and attitudes" (p. 120); she categorizes

it all as "communication failure."

It is easy to understand Frith's point of view. Most of us are able to engage in "small-talk". However, in declaring that the language patterns of autistic people are wrong, she is guilty of cognocentrism. By what measure do we determine language as being "right" or "wrong"? It may be different, or blunt, or grammatically incorrect, or minimal, but it cannot be wrong. Looked at from another perspective, it would be possible to argue that "normal" conversational patterns are "wrong" in that they stray from the initial topic, are likely to be both vague and ambiguous, and tend to be inclined toward the trivial. Instead, Frith associates the minimalist approach to conversation as indicating a lack of intellectual development.

And this is where we get into trouble in dealing with autism for, while a consistent pattern of autistic behaviours may be useful in arriving at a diagnosis, it is not a useful indicator of intelligence or understanding.

In gaining new insight into autism, particularly high-functioning autism, it is vital to understand that many of the odd, seemingly rash or isolating responses, particularly in social situations where multiple stimuli are involved, are adaptive rather than maladaptive behaviours that serve to control the overpowering impact of the world as it comes rushing, with unbridled force, toward the individual.

Grandin (1995) recounts the overwhelming perceptual chaos created by the smells, sights, and sounds of her childhood. She developed ways of calming herself: rocking, repetitive behaviours, head-banging. Dr. Abraham Schmitt (1994), a dyslexic person with autistic tendencies, tells of the sensory overload that, even in adulthood, forces him to seek privacy in order to maintain control. He has learned to isolate himself, spending hours alone, working on his latest passion "where [he has] a sense of being one with [his] brain instead of being in conflict with it" (p. 161).

In gaining a new perspective with regard to autism, it is imperative that we discard the assumption that autistic behaviours are illogical, based in some type of cognitive failure. Rather, it is more useful to consider the testimony of many autistic people when they say that their seemingly illogical behaviours are logically motivated by different perceptions. It is their hypersensitivity to the world around them, rather than their isolation from it, that characterizes and motivates them; it is perceptual overstimulation that is causal, rather than perceptual void (Williams, 1992; Grandin, 1995).

Brain research supports claims that the brains of people affected by autism, though rational, function differently. Baumann's (1994) brain autopsy research noted immature development of the cerebellum and the limbic system in subjects diagnosed with autism. Canter's (1996) brainwave research found signs of brain maturation

delays in autistic subjects. McKelvey's study (1995) also found indications of right hemispheric atrophy using single photon emission computed tomographic (SPECT) scanning, though few differences in brain activity appeared through computed tomographic (CT) scanning and magnetic resonance imaging (MRI). The activity differences, then, are subtle though effects on language, perception, and emotion are significant.

Imagine, for a moment, what it might be like to live in such a world. With the brain that I have, it would be abnormal for me to focus on just one thing at any given time. I am able to watch my children, make dinner, smell something burning, and think about an essay all at once. But suppose that my cognitive structures were suddenly altered and that I gained heightened sensitivities to light, sound, touch, smell, and taste. That is, suppose that I were instantaneously able to track the particulates in the air, hear high-pitched sounds similar to those that dogs hear, and smell the pollutants that wreak havoc around us. In addition to all that I currently perceive, suppose that I were suddenly able to perceive or, rather, forced to perceive, a multitude of stimuli that now go undetected. Would that make me "disabled" in some way? Or, would that make me "gifted" in some way?

What would be the results of such a perceptual change? Logically, I would have to make attempts to shut out some of the stimulation so that I could focus on the ones that held importance.

For example, it would do me no good to know that my neighbour was using diazinon on her hydrangeas if it interfered with my ability to perceive whether or not my Alfredo sauce was burning. Similarly, watching the summer breezes blow brilliant particles around the den would be nothing more than a hindrance when attempting to see a computer screen.

Suppose all of that incoming stimulation created a great deal of confusion, perhaps, pain. Would it not be logical for me to shut out part of that information, focussing on the most salient or interesting? Would it not be an intelligent act to persevere in any one behaviour that would limit the confusion of incoming stimuli. Would this restricted repertoire make me somehow "damaged?"

And yet, that is how we view autistic people. Lacking their perceptual framework, we presuppose that their "eccentric" behaviours indicate a failure in logic: they "don't get it". As a consequence, we assume that teaching them to behave logically will help them to become "normal." In doing this, we fail to recognize that their actions are already intelligently adaptive, based on the perceptual chaos in which they find themselves. Their seeming cognitive or social disability is, in reality, a perceptual difference. The disorder is not one of absence but, rather, one of severe presence.

The effects of such hypersensitivity become exponential when one considers that the brain develops within that context. As personality, attention, reasoning and memory develop, they are

cospecified by autistic perception. The world is too painful, too loud, to bright; safety is found in withdrawal. Anti-social behaviours are "normal".

What are teachers and parents doing, then, when they attempt to change such behaviours? When behaviour modification techniques are used to "help" a child sit quietly in his or her desk, what painful stimuli are being held in check? When a kindergarten child who prefers to sit alone is encouraged or forced to sit as part of a circle, how does this affect his ability to focus?

In schools, we work toward socialization and sameness. For some children, this is counterproductive to their ability to cope with the world. As teachers and parents, we need to accept that not all disruptive, anti-social behaviour is maladaptive. In the case of high-functioning autistically-affected students, it may be, in fact, the opposite.

First acknowledging and then consciously moving beyond cognocentrism is, undoubtedly, a rather novel paradigm from which to understand autism. It is much like Ansel Adams' choice to look at light rather than objects--a small shift with significant consequences.

CHAPTER THREE

The Lived Experience of Asperger's Syndrome

The most that we can hope

Is steadiness of soul,   courage

To render with exactness what is set before us,

Love what must

each time we grasp it

vanish (Zwicky, 1986, p. 61)

Understanding high-functioning autistic people in a new way is not easy. It requires a continual, conscious reworking of well-established assumptions and cultural biases. Many of these assumptions are established before the family has any notion that the child's pattern of behaviours is indicative of a specific autistic spectrum profile.

Recently, my seventeen year-old daughter was diagnosed with Asperger's Syndrome. She had demonstrated significant social and language problems throughout her life and, because of this, had received several psycho-educational assessments during her elementary school years. These pathologized her as having an "auditory processing learning disability" that interfered with classroom learning and with conversations, and affected her "learning style." She managed to maintain average marks which

disqualified her from further, more precise, diagnosis. A friend, an educational psychologist by profession, once mentioned that it seemed Melissa might have autistic tendencies, but that was not confirmed by anything official. Our family doctor pronounced it nonsense and I deferred to him. Believing, then, that Melissa's neurological differences were limited to auditory processing, I did not connect her ongoing social problems with something more pervasive except, perhaps, a general lack of intelligence. For, although she was a C+/B student, she had received those grades only by dint of hard work and a great deal of support. Maybe they were artificially elevated: After all, she could not remember to brush her teeth; she continued to use simple words incorrectly; she seemed to think that an apology emotionally erased a violent, public temper tantrum. She was either intellectually challenged or extremely wilful; eventually, I came to the conclusion that she was both.

In the seventeen years prior to Melissa's diagnosis, then, we established patterns of interaction based on misinformed assumptions. Most of my observations of her confirmed those assumptions. A few did not and they occasionally unsettled me. On the whole, however, we ignored them or assimilated them. They were "just Melissa." I ignored, for example, the backpack full of books that invariably accompanied her on trips. I knew that she was a slow reader who could not possibly read all of those books within a week but I explained it away as some sort of "security blanket." When

I saw that she was reading difficult works, I concluded that, with her relatively low marks in English, she must be reading very superficially. Foucault (1972) writes that historians tend to create categories and generalizations, and explain current and future events within those presupposed networks of causality. Events that do not fit are either reinterpreted or negated. This is what I did with Melissa. Based on superficial, salient evidence, I came to the conclusion that she was lacking in intelligence and, from then on, explained all discrepancies as though she were. I assumed, for example, that those teachers who called her "bright" had provided more effective support than other teachers. With a satisfactory explanation in mind, I quieted unsettling contradictions.

Eventually, however, an event occurred that could not be assimilated. Amplified through the insights of a group of colleagues, it precipitated the unknotting of the cospecified identities that Melissa and I had developed, facilitated the deconstruction of my presumed categories and explanations with regard to her behaviours, and signalled the need for a new perspective.

Perhaps our story will serve as an example of how looking at autistically-affected children through new eyes changes our understanding of their behaviours.

Introduction to Melissa

Melissa arrived with neither a label nor a personalized *Care*

and Use Handbook. We had never been parents and, though we were both teachers, neither of us had spent much time with infants. In short, we had no idea of what we were doing.

Like many other new parents, we bought books on parenting that gave us "milestones" to look for in our baby. While many aspects of her development fell within what these books called the "normal" range, certain things began to make me feel uneasy.

In the beginning, Melissa could not suck. She got very angry and screamed a lot. Instead of relaxing against us when we held her, she arched her back and stretched out her arms. She seemed such a separate entity; I assumed that it was because she was still so young, or because there was something distant about myself. I kept waiting for the "bonding" that everyone told me would happen. Its absence became a secret that I hid for years.

From the time that she could sit, Melissa's calmest moments were spent staring at hockey games, turning the pages of a magazine or calendar, or riding in the car. Always self-absorbed, she could play in her crib for hours, then shriek if someone came near. She angrily resisted clothing and diaper changes, haircuts, and baths. She never hugged or cuddled. By the age of three, she had learned to say only, "Hi" and "Bom dia," its Portuguese equivalent. Alone, she stood on the steps and sang like the members of the church choir, recreated the movements of the cheerleaders at my husband's school, or quietly absorbed the pictures in books. When she was with other

children, her behaviours were erratic, characterized by violent displays of temper. Because of the lack of language, she could not explain herself and I learned to say, "Don't!" before I asked, "Why?" The stories of her episodes came from others, not from herself.

This pattern continued in school when I began to turn to her teachers for explanations regarding her strengths, weaknesses, and temperament. We became "an audience searching relentlessly for pigeonholes" (Fine, 1994, p. 71). Over the years, I heard her variously described as hardhearted, attention deficient, learning disabled, undisciplined, strongwilled, retarded, and gifted. If I ever ventured to ask her why she had a bloody forehead, or why her sweatshirt was cut, she inevitably replied, "I don't want to talk about it!" or "Leave me alone!" or "I don't know!" at which point I generally turned to someone else to get the story.

In kindergarten, testing determined that, in addition to her social problems, Melissa was language delayed. Because there was no time at school, I was put in charge of interventions: tongue thrust exercises, Boehm concepts, sequence cards. Later, when her difficulties fell under the umbrella of "auditory processing learning disability," figure-ground tapes became part of our nightly homework. Like the others, these activities often were neglected. And so, on parent interview days, the teachers would remind me about the concepts and the sequence cards and the tapes and they would ask about progress and talk about Melissa's strengths and

shortcomings. There was little doubt that they were frustrated at having to deal endlessly with this child who destroyed pretty classrooms with noise and tears and flying objects, who could not stand to be touched, even accidentally, by other students, and who could talk but not converse. I listened to them describe my daughter and went home, more determined than ever to make her appear normal.

Normalcy training

Normalcy training for this recalcitrant child was no easy task. Boehm concepts faded into unimportance as we spent hour after hour on remedial eating, remedial tooth brushing, remedial using-the-washroom-on-time, remedial cleaning-up-after-not-using-the-washroom-on-time, remedial changing-clothes-<u>every</u>-day-and-at-night-too, remedial taking-a-bath, remedial cutting-the-paper-not-the-braid, remedial playing-without-biting-all-the-little-kids, remedial staying-in-the-yard-so-the-police-do-not-have-to-be-called-again, remedial just-because-a-guest-is-sitting-in-the-chair-that-you-consider-yours-is-no-reason-to-scream-and-stomp-and-"fly"-through-the-house, remedial please-do-not-throw-a-screaming-tantrum-on-the-Super-Valu-floor-again. For each event, I created a new story, and worried about those that others were creating for themselves, particularly as they related to my suitability as a parent. As time went on, I also created a new daughter, as each tale added some new

aspect to her personality. "Melissa stories" became the topic of conversations with my sister-in-law, my mother, my friends, my colleagues. I listened to everything that others had to say about my daughter, and they listened to me.

I did not listen to Melissa.

She would yell and stomp because the classroom was TOO LOUD, and we would implement behaviour modification to help her sit quietly in her desk. Never did we consider that she might be right: that the ordinary classroom noise level might seem like a roar to her, and that screaming and running might be logical ways of escaping the din. She would attack other kids because they were HURTING HER and we would punish her for overreacting. Never did it occur to us that an unexpected touch might be perceived as pain, and biting back a way of ensuring that it did not happen again. Our narratives told us that her responses were abnormal, that they needed to be changed. We assumed that her stories were wrong, we quit listening to their disjointed meanderings and illogical conclusions and did not consider the possibility that she was telling the truth: the room was too loud, the touch was too painful, the lights were too bright, the bathwater was too hot. We thought of her only as "disobedient", "disruptive" and in need of change.

We did listen to other things she said, however. For, though her behaviours remained decidedly childish, Melissa's knowledge in certain areas rapidly expanded beyond that of most adults. At five

months, she began to watch hockey regularly and was ecstatic when she entered kindergarten because they sang "that hockey song" in the gym. Only later did we discover that she was referring to "O Canada." As a young child, she knew most of the players and all of the teams of the National Hockey League and could recite volumes of related statistics. To this day, hockey is an organizing reference within her weekly schedule. By the age of five, though she could not read, she knew the calendar well and could point out birthdays and holidays.

When Melissa was in kindergarten, I was told that she likely would never learn to read. She surprised us all and, by the end of grade three, spent most of her free time in her room with one or more books. Before she entered grade eight, she could recite the minutiae of Canadian history and the major battles of World War II. Her bedtime reading included her beloved *Timetables of History* (Grun, 1991) and she developed the habit of continually correcting her Social Studies teachers, adding unfamiliar details to their lessons. Still, while I knew that she was developing a love of history and story, and that she knew everything there was to know about Canada's national sport, I persisted in thinking of her as rather slow. Encouraged by teachers and counsellors, and by my own sense of what was "normal," I endeavoured to draw Melissa's attention away from these fixations. In a futile attempt to help her become a well-rounded child, I forced her to put away her books and turn off hockey games in order

to play with the neighbourhood children, a situation that invariably ended in screaming, hitting, and biting.

Family life got harder. For one thing, she could not tolerate change of any kind. We had to warn her weeks in advance about an overnight stay at her grandparents. When we bought a new van, it took months of tears and experimentation before she had established that the seat beside the right rear window was the best for her. For seven years, she rarely sat in any other spot, nor did she allow anyone else to sit in hers. In her mind, anything repeated twice became a routine, and routines could not be broken.

At the same time, Melissa had great difficulty remembering routine things. Her bedroom and bathroom, the fridge and our back door became pasted with pictures and lists reminding her to do the things the rest of us took for granted: brush teeth, comb hair, get dressed, put on jacket. In her early teens, she developed coping strategies for these things. Now, clothing and makeup are laid out the night before. A daytimer has become her constant companion.

The worst struggles, however, involved her persistent and violent temper tantrums. They seemed so illogical to me. They interfered with her ability to concentrate in class; they destroyed every party and family gathering; they cost us friendships. Our whole family became much less social because Melissa could not be taken anywhere. Some evenings, I would step into her room, listen to the even breathing of her relaxed, sleeping body, and think how much

easier our lives would be if only she were absent. As she grew older, with the help of speech therapy, family and peer counselling, and wise teacher aides, the tantrums appeared less often; we settled into an uncomfortable truce. At best, I tolerated her presence; at worst, I raged internally at the injustice meted out to our family in having to raise this challenging child. I rarely talked to her, except to tell her how to behave, and I rarely penetrated the bedroom in which she sequestered herself with her growing library.

Reintroduction to Melissa

I reentered university when Melissa started grade ten. While taking a course in literary imagination, I sat down beside her and began to ask about the books that she was reading. To my astonishment, I found not only that her speech had improved remarkably, but also that we shared a common interest in nineteenth century literature. Furthermore, she was reading in a much more sophisticated way than I had imagined. Consider this journal entry recorded in March of 1996:

I just had the most fascinating conversation with Melissa. I wanted to get at some of her responses surrounding reading so I asked what stories she was currently working on and she mentioned <u>Middlemarch</u> (Eliot, 1847). [Oh, really!!] "It is a complicated book," she said, "with three story lines that never seem to connect." She is hoping that George Eliot will

connect the three by the end and that is why she keeps reading. She finds that some of the sections get long and boring because they are descriptive--she likes the sections that are full of conversation. "I like to know what people in the past thought about certain ideas and concepts," she says. "I like reading books about the past but this one is different because usually I read books from the early 19th--um--late 18th--or so--centuries and this one was written then but it's not like then."

"When does is seem to be from?"

"I don't know; it's very complicated. That's why I read it only once a week, on Thursdays, or something. I usually don't read a book all through...until later."

"Are there any books that you have read straight through?"

"Yes, Jane Eyre (Bronte, 1847). I couldn't put it down because I really wanted to find out what happened to her--after she left the Hall. It was a really interesting book and not complicated."

I went back to baking cookies, reviewing the conversation. Bells began to go off in my head: "Why Thursdays?" I wondered. Melissa is a child who began paging through calendars when she was six months old. She could not possibly have understood what they were, but, for some reason they seemed to fascinate her. Her understanding of the

calendar, over the years, has been remarkable: if I ask her on what day Christmas will be in 2001, within seconds she responds with the information that it will be on a Tuesday. When I ask her how she knows that she says, "Well this year it's on Wednesday, [she knows this, even though it is only March!?] so in 2001 it must be on Tuesday." When I look it up, she is always right. And Christmas is not the only day she knows: family birthdates and corresponding days of the week, all major holidays, memories of the date we left on a certain trip, the date we rode the Indiana Jones ride at Disneyland, the date she got her perm in grade four, are all readily available to her.

So when Melissa says that she reads a particular book on Thursdays because it is complicated, I start to ask questions.

"What do you read on Wednesdays?" I ask, not expecting a specific answer, but curious as to what she will say.

"The Secret Garden" (Burnett, 1911), she answers. I swallow.

"And on Tuesdays?"

"Schindler's List" (Keneally, 1982).

By now some pieces are beginning to fall into place. I have always wondered why she reads about half a dozen books at any one time. My heart begins to pound because I feel that I am on the verge of finding out something very interesting about

my daughter. "Do you have a different book for every day of the week?"

"Yes. [long pause] I made a schedule. It says what I have to read every day. Until each book is finished. So I know exactly when I will finish Schindler's List and then, before I am done, I can go through all my books and look for one that fits for Tuesdays."

"How do your decide what will fit?"

"I lay out all of my books, and all of the other books, [I am puzzled] and I choose one that fits the amount of time that I have. I knew Schindler's List would work in this schedule because I only had about half the book to read."

"Why was that?"

"Because I had already finished a lot of the chapters."

I'm puzzled again but continue on, "What happens if you don't get everything read on Monday that you had scheduled for that day?"

"Then I make it up the next day." I probe further to find out what, then, happens with Tuesday's book. "I read both. Monday's chapter and Tuesday's chapter. Oh, and my Saturday book is always an easy one--this month I'm reading The Sky Is Falling by Kit Pearson (1989)--I've read it so many times. If I miss a chapter it doesn't matter. That way, I can use Saturday to catch up and still stay on schedule."

"How long have you done this?"

"Since last summer. [Only later do I discover that she has been keeping such records since the summer of 1992.] I was having trouble getting through all my books. I would read a lot and then I wouldn't read and then I'd read a lot and then I wouldn't read again. I'd lose my place--and I couldn't remember which book I'd started. I don't like to read just one book. I like to read a different book every day. I'd get all mixed up. Now it is all on my schedule so I always finish and I never have to use a bookmark. Like Schindler's List, [aha!] last time I didn't finish it but this time I know I will. I even know the day!" She grins.

I also discovered that Melissa keeps statistics about her reading. Every day she records the last page read, the total number of pages in the book, and the percentage of the book that she has left. She keeps a calculator beside her bed and it is all summarized, week by week, in neat lines and columns...this from my child who cannot, apparently, keep order in her math notebook!

This is the record of my first salutary conversation with my daughter. She was sixteen at the time. Two things astonished me: first, she was not only reading the classics, but also comprehending and appreciating them; secondly, I, a teacher with a passion for English literature and our school district's Literacy Helping Teacher,

had not known it! Where had I been the first two times she read *Jane Eyre?* All that time that I had spent trading "Melissa stories" with others, she had been busy in her room, outdistancing my expectations by reading, with intense regularity and recordkeeping, very difficult books. In my presence, she had become a shuttered person, intent on acting "properly," often angry, then apologetic.

I had, however, become aware of two other sides of Melissa. The first was a dissociated chatter box, much like the character that the autistic Donna Williams (1992) developed to help her cope with social events:

> When I was in a talkative mood, I would often talk on
> and on about something that interested me. The older I got, the
> more interested I became in things and the longer I would go
> on about them. I really was not interested in discussing
> anything; nor did I expect answers or opinions from the other
> person, and I would often ignore them or talk over them if they
> interrupted (p. 51).

On one of her calm days, this was the daughter who appeared when we had guests. With her eyes trained on the ceiling and her mind focussed somewhere else than in the room, her nonstop monologues, though usually disconnected from the topic at hand, at least helped to mark her as present. This was the four year-old who travelled all over Brazil, chattering at strangers in a language that she assumed was theirs, though it was really nonsense. This girl, as

revealed during parent interviews, attended Social Studies class.

Then, there was the violent, frenzied antagonist who wanted no one near her. She spoke in single word epithets and moved with physical power and force. Usually highly focussed on a task or a goal, she could not tolerate disturbance of any kind. The slightest noise would bring a yell. A question was worthy of a raised fist. A touch brought a shove. She sometimes threw things--hard. Eye contact was impossible. Occasionally, her screaming, kicking and punching became uncontrollable and she stormed away from the scene of her upheaval. This was the Melissa of sudden interruptions during tied hockey games, noise while attempting to do Math homework, teenage parties, line ups with something important at the other end, sudden change, and criticism of any kind. I had come to know this Melissa as the one who could not, in the words of her younger sister, "take in two things at once."

For so long, I had thought of Melissa's behaviours as illogical and lacking in intelligence. Looking only through my cognocentric bias, there seemed to be a lot of evidence to support such a conclusion. Suddenly, in that March 1996 conversation, I was faced with evidence that countered all of my assumptions about Melissa's ongoing social problems. There was nothing wrong with her intelligence--she was reading and appreciating <u>Middlemarch</u> and several other difficult works of literature--and there was nothing wrong with her logic--she was able to categorize and organize a complex reading schedule.

The Middlemarch Conversation, as I have come to call it, created a dissonance that I could not ignore. It forced me to reexamine other events without the explanations that had interpreted them for so many years. A new narrative was required.

It began to formulate within the literary imagination class. We had been reading novels and theoretical works, coming together each week to discuss our written responses. With time, we had come to know each other in a deeper way than was the norm for such courses. These seven people already were acquainted with Melissa vicariously. I thought that her rather idiosyncratic way of responding to literature might be of interest so I read my journal entry to them. The professor commented, "You should read Oliver Sacks' Anthropologist from Mars. It ties in beautifully with your writing about Melissa."

In Sacks' (1995) book I met Temple Grandin and, through her story, was introduced to the concept of perceptual chaos. She said that, as a child, she had been unable to organize all the incoming noise and light and smell. It occurred to me that an "auditory processing learning disability" which, I knew, denoted difficulties in filtering background noise, could be the result of hyperamplification. Surely a general condition of too much sound would complicate one's ability to distinguish the important from the unimportant. Grandin told of her inability to "read" the expressions on people's faces, and of her difficulties with metaphorical language. Ironic and satirical

statements had to be explained to her. I thought of a sixteen year-old Melissa, standing at the kitchen counter slowly dishing ice cream into her bowl between the pitches of a televised baseball game. Someone warned, "scoop it fast or it'll melt on you," and she retorted, "Huh? It's in the bowl! It can't melt on me!" She was quite disgusted at the stupidity of the speaker.

As I read on, many pieces began to fall into place. It had never occurred to me that Melissa's preoccupations with history and hockey, rather than being barriers to her social integration, might serve as locations for reinterpreting her social experiences and for connecting with others without having to sort through too much noise, too much light, too much touching, too many smells. It had never occurred to me that she might have felt real pain when other children brushed her in class. Could it be possible that her "overreactions" were, in reality, the same reactions that a "normal" person might have had under the same circumstances? And, what effects might that overstimulation have had on her brain development throughout the years?

As I read on about autism, a new Melissa began to take shape in my mind: an intelligent girl, anxiously facing a chaotic world where predictability had to be artificially imposed through routine, isolation, and perseveration. These, in turn, affected language development and social adaptation. The cost was marginalization and the accompanying sense of aloneness. The payback was a bank

of knowledge that none in the family could match, and a dogged determination that all could envy. Gradually, I began to see that her disabilities were, under closer scrutiny, a kind of gift, one that was extremely hard to live with.

Cognocentric parenting

It is likely the many people look back at the past and wish that they had known as much about parenting when their children were born as they did by the time they left home. That is certainly true when one's child is diagnosed with Asperger's Disorder just before she begins twelfth grade. Lacking information to the contrary, many of my attitudes and decisions, and those of Melissa's teachers, were formulated within our natural, cognocentric perspectives. Our behaviours bear witness to this.

Disbelief

For one thing, none of us believed Melissa when, as a young child, she said that other children were hurting her. She had yelled at me for injuring her on so many occasions when I "knew" that I had done nothing to warrant it that, eventually, I distrusted, resented, and ignored her complaints.

As she grew older, I continued to minimize her remonstrations with regard to classroom situations. Teachers assured me that her outbursts were unprovoked and I believed them.

Attempts to socialize

Secondly, we assumed that social skills were best learned within social settings. When she was young, though her behaviour was violent and unpredictable, I insisted on having birthday parties just like all the other children. Invariably, Melissa ended up fighting with other children about where she would sit, whose turn it was, and whether or not they could play with her toys. She declared all the rules and insisted on being the final authority in all decisions. Over the years, I learned to plan every minute of such events in advance, preparing her thoroughly for her part in the scripts. She could say, "Thank you," and move on to opening another gift, even though it was done by rote, with neither emotion nor eye contact. She could serve cake to her guests, as long as they did not attempt to trade their pieces among themselves. Though she could not seem to understand the importance of hospitality and manners, at least she could function within controlled settings. Often, though, the parties concluded with an angry tantrum. I would reason with Melissa, telling her that the goal of these things was to make friends, and she was losing more than she was gaining. She would go on yelling and screaming while the other children looked on. Afterward, I would lecture her about selfishness and sharing, about taking turns and letting others lead. I thought that, with enough exposure and instruction, she would eventually learn to monitor the enjoyment of her guests, think about

their needs, and become a hostess. She never did.

To a young girl in a primary class, the birthday party circuit is the equivalent of London's social season. The number of invitations you receive is a clear measure of your worth; the greatest threat that you can receive is, "I am not going to invite you to my birthday party!" The actual card is carried home like an Academy Award. Melissa rarely received a birthday invitation from the children at school. Interestingly, Sigman, Yirmiya, and Capps (1995), in their study of social understanding, noted that none of the eighteen high-functioning children with autism mentioned birthdays or birthday parties as experiences related to feelings of happiness, whereas this was "a common theme of normally developing children" (p. 165).

Clearly, my attempts at socializing Melissa were cognocentric. I assumed that if I taught her normal behaviours, she would be normal. It never occurred to me that, within her perceptual axis, her behaviours were normal.

Over the years, then, I forced her into the almost-impossible. Large birthday parties with lots of activities might be a normal way of socializing many children; they did not work with Melissa. Cooperative learning techniques might work for most children; the noise level of the classroom made it almost impossible for her. Had I been more aware, I would have worked harder at maintaining a quiet, calm atmosphere that would not have stimulated her anxiety.

Assumptions about intelligence

Thirdly, I assumed that, because Melissa could not seem to make wise decisions about social behaviour, she could not make wise decisions at all. When it came to important choices, I did not trust that she had enough self-awareness to be able to make decisions for herself. For example, when she entered eighth grade she wanted to transfer to the private school that several members of her church youth group attended. I insisted that she register in our local public high school because there she would have access to special programming and an aide. The public school was a social disaster for her, simply because her reputation for odd behaviours followed her from elementary school and she was not accepted by her peers. When, in grade eleven, we finally transferred her to the other school, it quickly became apparent that her suggestion was wiser than my own.

Expectations of self-control

Immanent to autistic spectrum profiles is anxiety. Throughout her childhood, I assumed that Melissa could control her anxious outbursts if only she would try harder, that she needed, simply, to exert more willpower.

That was a false assumption. Melissa is not as capable as I am of dealing with stressful situations. It is not a matter of willpower or internal self-talk. She needs strategies and external support: the

right to leave a classroom that she finds too noisy; the availability of a counsellor. Other people who are affected by autism, including Temple Grandin, use vitamin or drug therapies to lower anxiety levels (Rimland, 1993; Grandin, 1995).

It is still hard to believe that things that are not stressful for me can be so stressful for her. I must continually remind myself that her ability to control her outbursts will not improve by adding pressure; rather, when her behaviours are most erratic, the pressure to act in socially appropriate ways needs to be reduced. With a lowered stress level, she is able to think more clearly and to react with less anxiety.

For example, if I were summoned to school because she had thrown her books angrily on the floor during a Mathematics class, I might be tempted to coerce her into conformity by reminding her that she was interrupting both her own learning and that of others, and that she was endangering her mark; I could threaten her with grounding; I could promise a reward if she made it through the day without a similar outburst. Such measures might be implemented in the hope that increasing the external pressure would bring about the desired change.

On the rare occasion, these strategies might work. It is more likely, however, that Melissa would respond by having a worse outburst than the initial one because she would have to deal with the added anxiety of the anticipated reward or punishment.

A more effective strategy would be to ask her if she thought she was capable of handling the pressure of the situation. If she did not, she would be allowed to miss for the day, and make up the work at home. Perhaps she could move her desk to a quieter corner of the room, nearer the door. Giving her a temporary break from a stressful situation and asking her to design a coping strategy are often enough to help her remain functional in a difficult environment.

And so, through careful attention to stressors, and a shift in our understanding about perception, we give assistance to the high-functioning autistic person in his or her attempts to join our world. But is it truly "our" world? Is this family composed of three dominant people who create locations and then benevolently alter them so that Melissa can join? Am I fulfilling my role as a parent when I accomplish such a task?

And what about schools? They accomplish a great deal when they make learning locations for high-functioning autistic people. But is it enough? Are teachers and students fulfilling their roles when an Asperger's or autistic student is granted a place?

Perhaps we can go farther. Perhaps we can create locations for discourse so that the culture that continues to evolve will include the input of all its members.

CHAPTER FOUR

Communities that Value Diversity

How ever can we learn

To hear each one distinctly,

Fragile threads in the enormous chorus?   (Zwicky, 1986, p. 62)

For high-functioning autistic children and teens, locations that are free from damaging stimuli and social pressure are rare. Almost non-existent are family, learning, and social communities where autistic and non-autistic people come together to agree and disagree, share or be silent as they negotiate relationships that are mutually respectful, communities that are designed to both nurture and utilize the gifts of all their members. Such communities require lifestyle commitments.   There are so many barriers that inhibit this development. Fortunately, there are also many effective strategies for overcoming them.

Barriers to community building

Autistic traits

Not the least among these barriers are the characteristics inherent in autistic spectrum profiles. Often, these behaviours seem very antisocial: physical isolation, long monologues, anxiety and anger, conversation avoidance. Sinclair (1993) describes it well: "You try to relate as parent to child, using your own understanding of

normal children, your own feelings about parenthood, your own experiences and intuitions about relationships. And the child doesn't respond in any way you can recognize as being part of that system" (p.2). It is supposed, then, that the autistic child or adult is emotionally cold and cannot be drawn into a community.

Furthermore, autistic people are often angry. Their temper tantrums are frightening to others, who then exclude them from social relationships. Problems with anxiety cause withdrawal; problems with language and communication stand in the way of relationship building (Frith, 1989; Williams, 1994; Grandin, 1995).

Often, then, based on cognocentric conclusions, people assume that high-functioning autistic people would rather be left alone, keeping their gifts to themselves without contributing to the community.

The literature does not bear this out. Williams (1992, 1994) writes about the constant struggle for acceptance and repeatedly notes the comfort she feels when she is with people who allow her to "simply be." She stresses the importance of her work in helping the community at large to understand the perspective of people with special needs. Grandin (1995) writes of the ease she feels when speaking with colleagues who accept her as she is and respect her for what she knows without expecting emotional ties. She writes with passion about the importance of her work in contributing to society's understanding of the humane treatment of animals. Clearly, both

she and Williams want to contribute to society. The problem is not one of desire but one of aptitude; they do not know how to go about starting and maintaining relationships.

An inclusive community understands its dependence upon the diversity of its members. Each person acknowledges that he or she has strengths and weaknesses, and that it is each person's responsibility to contribute out of their personal giftedness, thus balancing the weaknesses of others. In turn, one has access to the giftedness of others in order to augment personal weakness. No one person is relied upon to know everything. Strength is measured corporately, not individually; the strength of the individual is dependent upon the strength of the community; the strength of the community is composed of the strength of its members. Each person must work toward an environment that allows for the free expression of the giftedness of others.

Mutual inability to make connections

Autistic people may have many gifts but unless a location is made for their expression, they remain untapped. A significant factor in the "handicapping" of autistic people is not only their inability to connect with us, but also our inability to connect with them (Sinclair, 1993). In a community that shows value for diversity by encouraging their members to take responsibility for expressing personal areas of strength, the onus is upon the socially gifted to

work toward the enrichment of the whole by making a location for the expression and nurturing of all giftedness, including that of people affected by autism. Through the strengths of others, the disabilities inherent within autism may be negated, allowing access to the abilities.

Unfortunately, rather than ameliorating autistic weakness, the community at large often creates barriers to the free exploration of its strengths.

Othering

Unlike autistic people who tend to set up overt barriers, non-autistic people may be more subtle. They use words such as Frith's (1989) title "What's wrong with the language of autistic children?" (p. 120), as discussed in chapter two. They design research projects to evaluate the effectiveness of particular teaching strategies based on how well those strategies work with the majority of children. Strategies that are effective with only a few children are rejected. Strategies that are not effective with only a few children are accepted. Those few children are sacrificed and research ensures that the "normal" majority will continue to succeed while the "abnormal" minority will continue to fail. As a result, types of giftedness that do not fall within "normal" learning styles remain undeveloped.

Additional forms of othering exist. While autistic people have difficulty learning language, non-autistic people are highly creative

with it. For example, when non-autistic people are children, they talk about autistic people by using labels such as "weird", "nerd", "retard", "idiot." As they age, non-autistic people become more sophisticated and use labels such as "educable", "trainable", "disabled", "anti-social", "unsophisticated." Such terms are merely gradations of "different from me."

Interestingly, those labels may have little to do with ability to learn. Melissa was a strong student in her grade nine honours science class. A classmate's parent came in and talked to the teacher because he was concerned that the presence of "that retard" might lower the standards for the other students, including his gifted child whose class performances, according to the teacher, regularly showed less understanding and effort than Melissa's. Othering is not based in reality, only perception.

One definition that has contributed to this barrier over the years is the cultural icon known as "the educated citizen." It was created in classical times by the philosophers of Athens, was nurtured during Roman rule, and was enshrined in the schools that educated the noblemen of the British Empire. Philosophers such as R. S. Peters (1973) and Israel Scheffler (1995) have propagated it in more recent days. Its appeal is that of the educated ideal; its danger lies in its power to exclude those people who are incapable of fulfilling its criteria, thus discouraging intellectual and cognitive diversity within the community.

The traditional concept of education

Scheffler (1995) argues for a concept of education that is normative with defensible criteria based not in lived experience but in the ideal. For him, education embodies knowledge and understanding that has both breadth and depth. It is not enough to know facts from a distinct discipline, one must understand them in the context of their deeper connectedness with other disciplines. The more one knows, and the more one is able to usefully interconnect that knowledge, the closer one comes to the ideal of the educated person.

Autistic people are likely to pursue one or two areas of interest with a great deal of passion. Many of them, as mentioned earlier, have savant skills. Typically, educators who have accepted Scheffler's ideal encourage parents to provide their children with a wide-range of experiences. Research has shown that autistic children are most likely to experience learning success if they are encouraged to explore their fixations (Grandin, 1987). Breadth of experience distracts them. Only rarely, and then only after many years when a thorough understanding of their topic of passion has been gained, will many autistic people begin branching out to create links to other subjects. Taking into consideration the first criterion, then, if the autistic person is denied time to explore fixations, he or she is not likely to become an educated citizen.

Peters, a great influence on Scheffler and other modern educational philosophers (Scheffler, 1995, p. 82) states that, in order for them to be classed as educational, knowledge and understanding must have specific types of value (Peters, 1973, p. 84). At times the value of the knowledge will be purely instrumental, such as the learning of a useful skill for the purposes of work. Education, however, strives for knowledge that has value in and of itself, intrinsic value. The educated person pursues learning and discourse because they are enjoyable and he or she is drawn to them as a way of life. Typically, he argues, those subjects with the most intrinsic value have the least instrumental value (p. 88).

Again, this criterion draws a line between autistic and non-autistic people. The former pursue their interests passionately but, generally, those pursuits are of an instrumental nature (Schmitt, 1994; Grandin, 1995; Williams, 1996). They tend to build, or calculate, or draw with an emphasis on product, rather than intrinsic reward which, according to Peters and his followers, reduces its ranking as educational.

Another of Scheffler and Peters' criteria is the development of a cognitive perspective (Peters, 1973, p. 92; Scheffler, 1995, p. 84). This implies a way of making sense of the world that considers all known information within an interconnected whole, and analyzes the ways in which elements are co-specified. A cognitive perspective implies questioning, self-reflection, and a deep reading of the thoughts and

writings of others.

Williams (1996) reports that she sees the world, and most of her experiences, as separate and isolated events. She struggles to bring things together into an interconnected whole. It is as though she were born with the worldview that the deconstructionist, as described by Foucault (1972), attempts to create.

Interestingly, Williams is an intelligent author who is able to make the desired connections through the writing of her stories. In her speech and in her thinking, however, events remain disconnected. She is, therefore, severely disadvantaged in terms of developing the cognitive perspective so important to Peters and Scheffler. Does that mean that, despite a Masters' degree and four best-selling, insightful books, she can never be included within the dialogue of educated people?

Finally, Scheffler (1995) says that the educated person is able to communicate his or her ideas in a convincing, non-emotive way, and is able to engage with others in discussion of those ideas. A facility with language and conversation is a sign of a good education (p. 88-90). Autism, in contrast, is characterized by linguistic and communicative difficulties (Bruey, 1989; Frith, 1989; Cox & Mesibov, 1995; Grandin, 1995; Williams, 1996). Within the rationale of a group of educational philosophers, then, autistic people are not among those deemed capable of becoming educated citizens. It is this pervasive concept of education that has haunted and driven school systems in

their attempts to teach autistic people educated behaviours--attention, conversation, social interaction, empathy, breadth of interest--and, only secondarily, to teach them content and ideas. The emphasis is on fixing what is "wrong" rather than reinforcing and developing strengths.

Ultimately, a community that educates to weaknesses fails to maximize the giftedness of its members. Sensitively educated, many high-functioning autistic people have the focus needed to become experts in technological fields (Grandin, 1995); some use their hypersensitivity to contribute artistically and musically (Sacks, 1995). An educational community with goals of sameness, however, often excludes autistic people; the potential of their gifts is the sacrifice. Melissa, for example, is gifted in the study of history. According to her, ideas of historical significance stick to her brain "like postage stamps," so that she readily draws upon a wealth of knowledge when interpreting new information. However, she finds Mathematics very difficult. University entrance requirements demand that she have good marks in Math. Because of this, she may never be able to study history at the university level. It is odd to me that a community would deprive itself of her contributions simply because she has weakness in a loosely related field of study. If that community is depriving itself of Melissa, it is also cutting itself off from many other people like her. In the interests of breadth of knowledge it may be depriving itself of input from people who have the greatest potential

for understanding specific subjects in depth. Grandin (1995) is very concerned about this trend. She talks about having to get through school via the "backdoor" because she failed the Mathematics portion of the Graduate Record Exam. "During my career, I have met many brilliant visual thinkers working in the maintenance departments of meat plants. Some of these people are great designers and invent all kinds of innovative equipment, but they were disillusioned and frustrated at school. Our educational system weeds these people out of the system instead of turning them into world-class scientists" (p. 186).

A community that understands the value of diversity in providing for a wide variety of needs and contributing to corporate effectiveness will seek out and nurture giftedness. A community that sees its strength in sameness, however, views diversity as threatening. It may use blatant tactics to discourage it.

Bullying

Practices of othering tend to separate people with differences from other members of the community. Bullying goes farther; it actively destroys communities by punishing diversity. In the United States, students rank "do not fit in" as the number one reason for bullying (Hoover & Oliver, 1996). Shakeshaft's (1997) interviews with more than one thousand teenagers reveal that verbal bullying is pervasive. Overwhelmingly, teens see "harassment as a way of life

for themselves." This study, again, cites difference from the norm as the common characteristic of all persecuted teens.

Because they fall into this category, many high-functioning autistic people and people with Asperger's Syndrome become the targets of adult, adolescent and child bullies. The treatment of Donna Williams by one of her teachers has been cited earlier. She had trouble with classmates, as well: "The name-calling got out of hand...Other children in my class had begun to call me 'Zombie,' too, pushing my sanity to the limit as they chanted it over and over again" (Williams, 1994, p. 49). Sue Jackel (1996) tells of her experiences with one boy: "When I turned around to see who had pushed me, all I saw was Johnny. When I got up, I decked him, right across his face. I'd had enough of his tormenting." Mae, a twelve year-old girl with autism, says that, "One problem I had was people teasing me because I am different, and no one wanted to accept me as I am. There was one girl that was about my age was always teasing me because I was autistic" (Donnelly, 1995, p. 1).

The issue of violence in relation to high-functioning people with autism or Asperger's is complex. Often, there are no innocents. An episode of teasing that other students might handle with humour or indifference, ignites the ready emotions of the autistic person, interfering with his or her ability to think. Antisocial behaviour, which may or may not involve physical force (Jackel, 1996), is often the result. Another person reacts in kind, and the situation escalates

into one of violence. Within their cognocentric paradigm, outsiders assume the intent of the autistic person to be malicious. Within the equally cognocentric paradigm of the autistic person, he or she feels horribly wronged and justified in lashing out. As in Williams' case (1992), a cycle of child abuse may develop in the home; in schools, unless it is stopped, autistic people are likely to become the impulsive catalysts in situations of intensifying violence.

In our experience, Melissa was bullied mercilessly. Students who befriended her were bullied, as well, and it soon became socially unacceptable to associate with her. One day she came home bleeding, having been hit with a rock in the forehead. The school's response was to suggest that it had been her fault for yelling at some boys. She was forced to apologize. The boys were not. In a later grade, the same boys gathered around her with their bikes, bumping her with their tires and scratching her legs with the peddles. The response from the school was typical: "Some students just ask to be picked on. We really cannot do anything about the way students act on the way home." By the time she was ten, the situation was intolerable. One day her unsupervised classmates spent the lunch period throwing food at her and taunting her for crying. On the playground that same day, some seventh graders knocked her down and stole her shoes. She yelled at them. According to several reports from students who stood nearby, the duty teacher castigated Melissa for making trouble. It was Melissa who had to stand beside the school for the rest of the

noon hour. The seventh graders were asked to return the shoes, and then were sent back to the playground.

Again, the school's response was that, as long as Melissa continued to have emotional outbursts, students would continue to pick on her and there was little that could be done. Kids would be kids. We sold our house and moved to a new school where, surrounded by students to whom she was a newcomer, she experienced relative peace.

Two years later, when Melissa entered secondary school, she resumed contact with her early tormentors; though individual teachers fought it, this school, too, tacitly put the onus on her for dealing with the bullying she encountered. We quickly returned to the cycle of emotional outbursts, subsequent teasing, Melissa's response, and escalating violence on the parts of both Melissa and her classmates. Our daughter learned to let incidents of teasing and jostling, theft and vandalism go unreported as "tattling" resulted in her own punishment as well as in retribution from students. To my knowledge, no other student was ever punished for the countless acts of harassment.

Melissa has not been passive in all of this. Her classroom behaviours when she experiences anxiety are decidedly antisocial. She has thrown books, yelled, and stomped out of class. When provoked, she has been known to hit. Often, she has told students to "shut up" when they were involved in simple discussions about their

work. Because of this, as an educator, I have always sympathized with and supported the efforts of the schools in changing her behaviours. Through all these years, even when I silently questioned the efficacy of the various principals and teachers with regard to classroom management, I ultimately have blamed Melissa for her troubles at school, much as I have blamed her for our troubles at home. I have lectured and cajoled, rewarded and punished in an effort to change her actions and reactions. In a sense, I have become a bully, as well, by placing the onus for her social inclusion on her shoulders.

Last year, at her request and against my advice, she transferred to a private school. Within weeks of school opening, a few students began to tease her. A teacher mentioned it to the counsellor who spoke with the students, reminding them of the student body's culture of inclusion and explaining Melissa's difficulties with noise and anxiety. She also pointed out Melissa's academic strengths and the contribution that she could make to their own learning, especially in terms of literature and history, if only they would allow her a place to contribute. Melissa, too, was called in. She, together with my husband and myself, was involved in discussions about the disturbance that her outbursts were causing in class, and the effect of this on the learning of herself and others; coping strategies were designed; a monitoring plan was put in place. She was reminded about her responsibility for helping the others in her classes to learn

from her; she was reminded that she could learn from them. Except for a few minor exchanges, the teasing has stopped and Melissa's anxiety levels have lowered. She has experienced academic success and has made a few friends. There have been no incidents of violence.

As with so many other things, I have had to rethink my position as Melissa's parent. Had I advocated more strongly during her public school years, would her experience have been less traumatic? As a teacher and, eventually, a consultant within the school district, I attempted to cooperate with the schools. Though sometimes I mistrusted their methods, I did not want to challenge the professionalism of my colleagues. Passively, we moved away rather than address unacceptable situations in elementary classrooms. Again, in her secondary school, I failed to insist that the students who were harassing her be dealt with. My efforts at change were always directed at her, never at the school or at her classmates. Because of this, her anxiety increased, her outbursts increased, and the bullying increased. In order for Melissa to be successful in school, and to be able to think through social interactions, her anxiety levels must be lowered. This means that negative pressure from students must be reduced before her classroom behaviours will stabilize. It is not enough to stop the bullying; her behaviours must change. It is not enough to change her behaviours; the bullying must stop. Because the two situations are cospecified, they must be

addressed at the same time.

It was an error in my concept of community that caused me to support the school at the expense of my own daughter. I, too, believed in the importance of sameness within a community, and placed the responsibility for change on her. My thinking, however, has shifted. Her responsibility is to contribute from her giftedness. The community's responsibility is to allow her to do that. She must change. However, the onus is upon those who are socially empowered to make a location for her to do that. That means that the school must control bullying as, by increasing anxiety levels and reinforcing sameness, it detracts from the free education of herself and others.

Noise, light, and movement

Not all barriers are attitudinal. Because the people who create learning environments are cognocentric, they do not realize the effects of various elements on people who perceive the world differently. As discussed in chapter two, hypersensitivity is immanent to autism. Locations with high environmental stimulation, then, tend to be anxiety-producing for people with autistic traits. As a small child, Williams (1994) developed coping strategies such as grinding her teeth, banging her head and tapping herself rhythmically to stop the invasion of "disturbing, unpredictable, and meaningless outside noise" and "the unpatterned

movement of others" (p. 32). Noise and movement levels that were common in her home were very difficult for her to process.

Imagine, then, the stimulation provided within the modern classroom. Around the room, students interact in cooperative groupings, some more quietly than others; the teacher animatedly discusses an interesting point with a group at the blackboard; in one corner of the room, someone types on the computer keyboard and the irregular click of the mouse is audible; another student gets up to sharpen a pencil; the principal's voice comes in via the intercom; a kindergarten class marches down the hall and the gym door opens to release the din of a basketball game. Most students are able to filter through all of this and attend to the conversation at hand. The autistic spectrum student hears it all, sees every movement, and loses the thread of the conversation within the cooperative group. Anxiety builds. When called upon for an opinion, he or she responds with an adamantly emotional, "I don't know!" Around the room, conversations stop immediately and everyone looks at the speaker. The learning environment for everyone has been interrupted; the autistic student, now the focus of attention, goes into what Schmitt (1994) calls "switching off" (p. 147) and retreats, either mentally or physically. Loud, busy classrooms, families, and social gatherings are stressful for people with autism and are not conducive to the building of mutually empowering locations.

Barriers to the creation of inclusive communities are

daunting: many people fail to understand the importance of diversity; the social ineptitude constituative of autism inhibits equal partnership; cognocentric tendencies promote othering; an underlying concept of education includes only those with particular cognitive profiles; bullying is tolerated as an means of producing sameness; autistic hypersensitivity is exacerbated by the noise and the busyness of modern life.

How then, do we go about eroding, even destroying, these barriers? Are there ways of including high-functioning autistic people, many of whom have significant gifts to offer, in the dialogue of community-building? What criteria might characterize locations that are conducive to mutual, co-specified growth for all members?

Facilitators of community building

In all of this, there is the question of reasonableness: what is reasonable to expect from a high-functioning autistic child within the regular classroom and within the home; what is reasonable to expect from other students; what is reasonable to expect from teachers and school administrators, from parents, extended family, neighbours, from siblings, from the community?

Support for teachers and families

When my two daughters were younger, it was unsafe to go to the supermarket with both of them because Melissa might have a

temper tantrum or run off, and I could not leave my younger daughter alone to give the elder my full attention. Classrooms are not so different. As a classroom teacher, I knew that I had to maintain order. I was responsible for each of my students equally. One highly disruptive student had the potential to destroy the learning environment for the whole class if I had to spend an inordinate amount of time with him or her. Furthermore, if such a child were prone to leave the room, as Melissa always has been, there are safety concerns. A kindergarten teacher cannot leave twenty children alone in the classroom while he searches the halls for the one. It is not reasonable to include a high-functioning autistic child in a regular classroom unless the classroom has a second adult available for intervention and support. Later, when the child becomes an adolescent, he or she might become more independent but, during infancy and childhood, the demands are very high.

In our experience, it is not reasonable for any one person to assume the full care of an Asperger's or high-functioning autistic child. Other parents feel the same way. Cheryl Fisher, quoted in a local newspaper, says that "the pressure of having a child whose behaviour includes tantrums…and who requires twenty-four hour care is more than any human can stand" (Tait, 1997, p. A12). She has moved in with her parents. The eight parents in Fong's study (1993) also stated that their support systems were important to their coping.

My husband and I are privileged to have grown up in a strong

religious and ethnic community that has a centuries-old tradition of collective responsibility in the upbringing of children. While we often have felt lonely in dealing with the day-to-day details of parenting a special needs child, we have never been without support. Our parents have taken the children camping or on outings; they have provided daycare; my mother dedicated a winter to teaching Melissa how to cook. The young people of our church have welcomed Melissa in all of their ventures, including a difficult ten-day construction project in a Mexican orphanage. Neighbours have sheltered her when she has forgotten her housekey; they have provided transportation when she has panicked because of a missed bus; they have reprimanded bullies on the road to and from school. The support has been unequivocal and unconditional.

Her new school is the educational extension of that community. We have known many of the teachers since our own childhoods; the vice-principal is my husband's cousin; Melissa is the third generation of our family to have attended there. While I often have railed against the conservatism inherent in the belief system, I cannot criticize the compassionate support that the teachers, administrators, and students have demonstrated in helping her find a location in school. Their behavioural expectations have been consistently apparent, but so has the understanding of her special struggles. It is in this atmosphere that people have been the most cognizant and optimizing of her academic strengths, and the most

flexible in working with her weaknesses.

I mention this as an example of shared responsibility and how it has helped to make our lives work better. Too often, families and classroom teachers are left on their own to deal with special needs children. An inclusive community allows for the nurturing of diversity by lending support to those people who are at the frontlines of dealing with the immanent difficulties. Such a community knows the needs of its members and does what it has to do to meet them. Melissa's new school encourages enrolment of students from many cultures and ethnic backgrounds, as well as students with special needs. It makes this inclusiveness a reasonable goal by providing expert counselling and learning assistance, by clearly describing and publishing communal expectations of respect for all students and teachers, and by promoting school spirit through cultural and athletic projects: students share common locations; they know each other. Without this supportive context, it might not be reasonable to expect Melissa to develop strategies for controlling her disruptive emotional outbursts and it would be much more difficult for students and teachers to both cope with her antisocial behaviours and assist her in developing connections.

A conducive physical environment

In addition to the community issue, other factors within the school seem to have affected Melissa positively. For one thing, with

only eight hundred students, the school is smaller than the other secondary schools in our city. Because the halls are spacious and uncrowded, she no longer experiences anxiety-producing jostling during the breaks and is able to organize her thinking before she goes to class. In addition, the lighting in the hallways of the school is low: I find it dark; she finds it soothing. Related to this is another feature of the school. There are five lounge areas--generously widened lengths of hallway complete with skylights and carpeted benches-- that are assigned to each of the five grades within the school. These serve as eating and meeting areas that are somewhat quieter and less hectic than the traditional high school lunchroom with its bright fluorescent lighting, hard surface flooring, clanging kitchen, and scraping chairs. Here, Melissa does not have to deal with debilitating environmental noise and light and is, therefore, able to eat with her peers. Having been unable to survive the chaos of the cafeteria in her former school, she has mentioned many times how much she enjoys spending the lunch hour with her fellow students.

In schools where such an atmosphere cannot be provided, it might be possible to find an alternate location where a student can be assured of finding company without having to be an invited member of a group. Libraries sometimes allow students to bring in food: Melissa spent three years eating with the librarian and a few other students. It was not as inclusive as her current situation but it was better than being alone; it was considerably better than eating in a

classroom where there was no adult supervision and she became the victim of jokes and bullying.

In terms of classrooms, carpets are quieter than hard surface flooring; natural light is softer than artificial. While it is not reasonable to expect that schools will change everything for one student, it is reasonable to expect that those schools which claim to be inclusive of special needs students provide calm atmospheres.

In addition to the physical plant of the school, some teaching strategies are difficult for people with autistic tendencies. Cooperative learning methodology, for example, provides controlled contexts for social learning. However, experience tells us that it is also relatively noisy. As a cooperative learning trainer, it was always amusing to have Melissa's teachers in my workshops; I consistently included a caution that high noise levels affected the behaviour of students with auditory processing learning disabilities and that teachers needed to practice the use of "30-centimetre voices" during group discussions. However, it is not reasonable to expect that a classroom will always be quiet. Melissa has had to learn to control herself within noisy, busy contexts; the freedom to leave has helped her to do that. Her school has provided a seminar room in the counselling centre for students like herself who have permission to leave classrooms at their personal discretion. To my knowledge, she has not abused this privilege.

Schools are not the only places that can be overstimulating. As

a mother, I have had to learn that Melissa cannot be a part of everything we do. I used to be upset when she preferred to leave the dinner table or to absent herself from a party; now I let her go. She needs periods of quiet refuge if she is going to be able to function socially at least some of the time. At home, her bedroom provides privacy. The walls are insulated to provide extra sound protection; her radio masks the irregular noises of our household and I no longer force her to turn it off at night. We have learned to warn her about sudden, loud noises such as the coffee grinder or the blender. She, in turn, is learning to modulate her voice. It is reasonable that, in a community, all people will make small adjustments for the comfort of others.

Safety

It is not reasonable to expect autistic children to deal with bullying and harassment, nor is it reasonable to expect them to ignore it. If a school either will not or cannot control such intimidation, parents should consider moving their child to a location where diversity is valued.

Sometimes a family cannot do that. In that case, it is necessary to insist that the school provide protection. Educational psychologists, speech pathologists, learning disabilities coordinators and learning assistance teachers have always been very cooperative in developing and implementing plans for our daughter. School

administrators, responsible for the welfare of an entire student body and answerable to myriad parents, have not always been as helpful. When it comes to a child's safety, however, there is no room for compromise. I now regret that Melissa's best interests were sometimes sacrificed to misplaced "system loyalty."

In building a community that is healthy for all of its members, it also is not reasonable for an autistic child to bully others. This is an exceptionally difficult area for parents, particularly for those who want to create an inclusive, mutually empowering family. When she was young, we could not leave Melissa unsupervised with small children. It was easier to remove her before violence erupted than to attempt to discipline her afterward. As she grew older, clear guidelines for behaviour had to be set down and consistently protected. In order to do this respectfully and effectively, we learned to provide our daughter with privileges that could be removed. Turning off her beloved hockey games, for example, was very powerful in helping her to understand the serious nature of hitting a neighbourhood child.

Today, this sounds so harsh. However, it would have been much more unfair, and less respectful of her abilities, to deny Melissa access to society by not making her aware of the serious consequences of her violent impulses. Melissa rarely hits anyone anymore. She has been known to yell and throw things, but she has not hurt anyone in a long time. She retreats, goes for a short walk,

talks to herself in the bathroom mirror, reads a good book, or listens to some calming music. She is learning to be respectful of others, just as she wants them to be respectful of her.

In involving high-functioning autistic people in community building, then, these are some foundational conditions that are necessary and reasonable: strong support and commitment, a clear understanding of the value of diverse gifts and strengths, a conducive physical environment, and safety for all members. For many communities, this will involve a changing of the lived rules as teasing and bullying become actively discouraged, as support for high-functioning people with autism becomes more available and more personal, as learning environments are planned to minimize the effects of hypersensitivity.

As a generalized condition, we are far from this goal. Suzanne de Castell (1996) argues that, in many educational settings, "...a kind of safety and respect for difference...is, at the present time, nowhere in sight" and, until such a time as it exists, it may be unfair to ask students to become involved in acts that "speak the self," and announce one's "authentic voice" (p. 30).

And so, before we can expect the conditions of inclusive communities to exist in public places, we must work toward them in locations that are more private. First and foremost, we must commit to new forms of connectedness, and that means hard, personal work because conditions of inclusion do not come about by means of

proclamation. They are born and nurtured as we consciously involve ourselves in signifying practices that announce interdependence rather than independence, that articulate empowerment rather than power, that authorize the narrative rather than the didactic. They evolve in "commonplace locations" (Sumara, 1997).

CHAPTER FIVE

Creating Commonplace Locations

...the emptied voice at last begin to speak

(Zwicky, 1986, p.63)

The nature of commonplace locations

In explaining the concept of "commonplace locations," Sumara (1996) draws us to Ondaatje's (1992) novel, *The English Patient*, in which a copy of Herodotus' writings is used as an artifact of collection and reinterpretation. Into the pages of the text, throughout his adult years, the patient has glued pictures, notes, maps, and mementos. As the pages are turned, he recounts the stories attached to his artifacts, reinterpreting them in light of subsequent events, Herodotus' tales, and the current audience. The book belongs to neither the past nor the present but, likewise, is separate from neither of them; it is a tangible metaphor for the mind, where the past and the present, past peoples and present peoples, personal memory and the historical "memory" of one's culture meet to become acquainted and are recreated in light of each other. With each retelling, the story is different because it is told within a new context; it, like Bruner's (1990) description of the Self, becomes "a product of the situations in which it operates..."(p. 109).

A commonplace location, like the patient's commonplace book, is an opportunity for people and ideas to come together for

reinterpretation, for making something new. Like the patient's book, they represent an intersection of disparate people and events.

In creating commonplace locations, we bring our current experiences of self and others, talk honestly about them, examine them in light of other's ideas, and create new ways of interpreting the world. We learn to look at situations through another's senses and responses, and, in so doing, "we see, through others, aspects of the world that we are unable to experience ourselves" (Sumara, 1996, p. 54). As we do so, we become better acquainted with others' view of us and, in turn, "we learn about ourselves...we are changed. We evolve through our relations with others" (p. 56). Our Self becomes constantly transformed through a renewing of the mind.

Commonplace locations, unlike the patient's book, are not concrete objects, but rather, intersections of events and people. Implied within them is the intent to renarrate past experience and gain new understanding of it in light of current knowledge. Implicit, as well, is their context of continuity. We invite commonplace locations because we intend change and believe that interaction is necessary in order to gain the insights necessary to determine the path of change. Constituative of commonplace locations is regeneration: new habits, new ways of seeing, new selves.

It is in commonplace locations that new patterns of communication can be established with high-functioning people affected by autism.

As developed in the previous chapter, the building of inclusive communities does not happen by accident or good fortune. It requires at least three conditions: a commitment on the part of its members to share their strengths, an understanding of the importance of diversity, and specific conditions for honouring the giftedness of all members: "the more people become themselves, the better the democracy" (Horton & Freire, 1991, p. 145).

Those educational environments that help high-functioning autistic members to develop naturally, reject practices of othering, protect all members from bullying, and monitor the stimuli within the physical environment. They work actively to change the rules of interaction immanent to the culture. But, as stated by de Castell (1996), they are almost non-existent and, perhaps, even dangerous if they lead people who are different into unsafe declarations of self.

Commonplace locations with people affected by autism

Following the Middlemarch Conversation, it occurred to me that, like the English patient and his companions, Melissa and I needed commonplaces that invited interpretation of new and past experiences. I, especially, needed ways to create new stories that rejected the cognocentric paradigm that had influenced my understanding of Melissa for so many years.

It is one thing to experience such locations with people who love to talk. It is quite another to enter them with people affected by

autism. For years, Melissa and I had had trouble talking to each other. I had no idea of how we could go about sharing our lives and starting inclusive conversations. And, while I had understandings about the nature of inclusive communities, I had little knowledge of the pragmatics associated with creating them.

I began reading the works of Grandin (1987, 1995) and Williams (1992, 1994, 1996), as well as the writings of Schmitt (1994). In the works of these gifted people with communication difficulties, I began to find ideas that were helpful in invoking a context conducive to communication.

Disconnected connections

Williams (1992) offers advice to those working with people affected by autism, suggesting that communication connections are most effectively built in a disconnected, rather than a direct, manner. For example, she suggests indirect contact where both speakers stand side by side, looking out the window rather than facing each other. She talks about the importance of some conversations taking place outdoors where there is no feeling of entrapment. The rhythm of walking provides a smooth reference point that overcomes other, less regular, stimuli. Writing, she suggests, is another way of making disconnected connections, as the reader has to deal with only the visual stimulus of the print and has ample time to process the text before being expected to respond (p. 216-219). It also allows for the

maintenance of "the most beneficial thing [she] ever got", her privacy and space (p. 218). Most importantly, she says, because autistic people experience such great confusion surrounding emotions, discussions need to be objective, without emotional complications or expectations: "If loving parents can try to stand objectively away from their own emotional needs and relate to such children always in terms of how those children perceive the world, then the children may find the trust and courage to reach out step by step at their own pace" (p. 201).

Representative artifacts

Williams (1992) also drew my attention to the importance of artifacts: "My father...would bring me something different every week and would always build me up by asking me if I knew how special and magical these various bits and bobs were...I still have those treasures, twenty-three years later" (p. 7). When she was young, she would save items from people who had been kind to her. They served as concrete reminders of her worth against the fear generated by negative social encounters. Later, when she took trips away from home, she would send leaves and rocks to her husband: "If he could touch things from where I was, then he was somehow here, or I was there" (Williams, 1996, p. 51). To her, these artifacts symbolized emotional connections that she valued but could neither understand nor explain. Like the commonplace book, they were

concrete reminders of experience that could be re-touched, reread, and rewritten in the context of new relationships. When children teased her, for example, she would take out trinkets from her grandmother as a reassurance against her fears of rejection. In her youth, Grandin (1995) also placed a great deal of significance in objects. She more often connected emotions with items than with people: "the things I had in my high school room were my identity" (p. 140).

I have found that, with Melissa, an artifact can also serve as an interesting axis for conversation. Since she was a small child, she has kept a "memory box." Into it have gone her report cards, special certificates, work samples from school, vacation souvenirs, and other important memorabilia. Each year, she makes additions.

While asking Melissa about her experiences of school generally leads to a simple, "I don't know," discussing the artifacts in her box has given me much information about her growth and her priorities. Seemingly, they provide enough of a disconnected connection that she is able to talk about representative experiences without anxiety. For example, this year I asked her to go through her box, tell me about the items in it, and choose those that she thought were the most significant. She selected ribbons she won in grade six at the school and regional science fairs. Until last winter, we had never talked about those experiences because when I asked about them she shrugged and walked away; I had assumed that they had

not been very important to her. In our discussions she informed me that it was during those fairs that she first realized that she could "do science" and that it "wasn't boring." She had loved the feeling of really understanding her project and being able to talk about it with the judges. That was five years ago and, looking back, I realize that it was coincident with her beginning to attack her schoolwork from a position of strength. Without the artifact, I do not know that this discussion could have taken place.

Since that time, I have attempted to build conversations around other concrete objects. We have discussed books, not only as abstractions but with the concrete texts firmly in hand; we have talked while gardening or while cooking. Sitting at the kitchen table and talking about the happenings of our day is not something we can do. Melissa gets very anxious and confused. Sitting and talking through our daytimers allows me to get to know her and to reinterpret my day in light of her responses. Through these "signifying practices" (Kerby, 1991, p.1), I have begun to develop a sense of myself as incomplete without her, and to understand how my decisions, in turn, affect her emotions and her understanding of the world. The "bonding" is finally taking place.

In addition to my daytimer, we have begun to discuss other artifacts of life: childhood keepsakes, school annuals, photographs, this thesis. Melissa is, in this way, learning about my thinking and my values, and how I go about making decisions and setting

priorities. I am learning about her. These artifacts have become meeting grounds where we bring our experience and reinterpret it in light of each other's response. We have such difficulty observing and understanding other people's ways of being; artifacts provide a location for discussions that help us to "watch others operating in the world" so that we do "not merely learn about them, but about the way they perceive the world" (Sumara, 1996, p.54).

Fixations

The most powerful locations of learning and discussion are those that intersect Melissa's passions with history and literature. When she was young, in the interests of a "well-rounded education" I tried very hard to draw her away from her fixations by keeping her busy with piano, swimming, and gymnastics lessons, all activities she despised. Then I began to read the works of autistic and learning disabled writers and realized that, if I hoped to have a relationship with my daughter, I needed to enter into her fixations with her; I needed to reinforce them rather than discourage them. Grandin (1995) writes of her own experiences with animal chutes, a childhood interest she developed on her aunt's farm. With the encouragement of a teacher and other mentors, that compulsion grew into a successful business designing livestock handling facilities. She states that "...some successful high-functioning autistics have directed their childhood fixations into careers" (Grandin, 1987, p.300)

and it is through this work that they make friends and develop relationships. Williams (1992) was overcome by the impulse to write. Her writing allowed her entrance into wider society, on her own terms. For both Grandin and Williams, following their passions did not result in withdrawal from society but, rather, a means of entering into it and contributing to it.

Scheduling and structure

Melissa does not appreciate spontaneity. Sudden changes are met with resistance. Recently, while on vacation, members of our family suddenly changed their afternoon plans and decided to go the resort's pool rather than watch a video. Melissa was very upset. She insisted that everyone watch the video, not because she particularly liked it but because it was what had been planned. It took her forty-five minutes to adjust to the idea of including swimming in her day. Just about the time that she announced, "I'm going to get into the pool now," everyone else was ready to get out.

This greatly affects her willingness to participate in casual social interchange. Generally, my initiation of conversations with friends and family is motivated by feelings or proximity; Melissa's is motivated by content. Therefore, she likes to be well-prepared. As I begin to look for ways of developing this relationship on her terms rather than on mine, I am learning to schedule our times together. She is better able to express herself if she can think well in advance,

and plan her day to avoid interruptions of our discussions. A community that wants to maximize the strengths of autistic people will dedicate scheduled time to be with them. They cannot be expected to contribute their best ideas in unstructured settings where they must deal with indecipherable social nuances, interruptions, and extended conversation with no concrete organizer. They are at their best if they know the time and the topic, and are in a familiar environment (Bruey, 1989, p.80). Again, when anxiety is reduced, thinking is clearer.

In summary, in reading the works of high-functioning autistic writers, it seems that connections with people such as Melissa are often most powerful when they are made in a disconnected manner that involves concrete objects related to their fixations. It also appears helpful to attach them to routine or schedule.

Reading response and commonplace locations

Communities that value diversity must have locations for the mingling of ideas and the formation of commonalities. It is not enough to appreciate difference, people must also have a place of coming together, of merging their respective thoughts and stories, of sharing identify, and of creating new narratives of experience that include each other's characters and responses. Somewhere, communities need to explore the idea that "the consciousness that we have of ourselves, of each other, of our relations with each other does

not belong to us. It belongs to the situations that we share with others in the places that contain us" (Sumara, 1996, p. 57).

Melissa and I, too, need commonplace locations where we can come together to develop our relationship and where we can articulate a community that is inclusive of both of us. It is not enough that we live together in the same house. As Freire says, it is my responsibility, as the community member who knows more about social connection, to empower her to express herself in the world, to engage with her in the "...process of becoming free, of becoming more human" (Gadotti, 1994, p. 21). In establishing such a community, we need locations where we can "perceive and understand our past, present, and projected experiences in new ways" (Sumara, 1996b). Because she has autistic tendencies, the contexts for such locations must be specifically designed to be inclusive. That is, they need to provide for disconnected connections, they should be connected to one of her fixations, and they should be scheduled and structured.

We have tried many potential contexts. Cooking together has not worked; we have different understandings about following recipes and we begin to argue. Driving in the car has provided a positive environment, but Melissa would rather read than talk. For us, it is reading and responding to literature that has announced a commonplace location in which to form connections. During the past year, we have spent hundreds of hours reading together, sharing written and verbal responses, and talking about our lives in relation

to common stories. It is only through the disconnected connection created by the narratives of others that we have, for the first time, found a location for telling and creating the stories of ourselves.

It is not surprising that books have afforded us this common place. For one thing, literature is one of Melissa's fixations. She spent her entire fifteenth summer copying Shakespearean quotes; she has read Bronte' s (1847) *Jane Eyre* five times and has rewritten parts of it into a monologue for her drama class; she spent eighteen months slogging through a portion of *Middlemarch* every Thursday after dinner; she is able to compare the importance of the writings of Jane Austen in understanding the British historical experience to the importance of the writings of Kit Pearson in understanding the Canadian historical experience. She spends hours in her room, reading. She goes nowhere without a book. Immutable appointments at the public library have been incorporated into her routine for years.

Literature is also important to me. It was my passion and, together with library science, my minor throughout my undergraduate years. Like Melissa, I spent many teenage hours reading nineteenth century novels. Like her, I am more interested in works that clarify historical settings than in other genres such as science fiction.

Secondly, in discussing stories we are not, initially, discussing ourselves. Rather, they provide a disconnected connection where we

are able to talk about characters, events, and settings and only later, after many ideas have been shared, to relate these things to ourselves. This concurs with Williams' analysis of contexts conducive to conversation.

It was a discussion about reading habits that led to the description of Melissa's unique scheduling system. Subsequent reading response discussions have revealed that stories are her main connection with people and that she uses them as patterns for learning about how to behave at parties and how to engage in casual conversation: "That's how I learn how people talk to each other, and I'm learning to watch what I say. I go 'Oops' and...[she covers her mouth]. I'm finding it easier to talk to people because I read a lot." Her public monologues are becoming less common as she reads conversations and learns that they are also about listening.

Finally, discussions about literature can be scheduled and planned. The conversation, rather than being open to random flow, can revolve around a set topic. Melissa, therefore, can be prepared. She can put the event in her daytimer, can read ahead, and can think through her responses.

Scheduling is helpful for me, as well. As a parent with a job that is time-consuming, I am able to organize my day around planned conversations. On the surface, it sounds very artificial for family members to schedule time to be together, but unplanned conversations between one person who is very busy and another who

has autistic traits tend not to happen.

Ours is not the first exploration of literary response in communicating with and studying the thinking patterns of students who have exceptionalities. Grant, Lazarus, and Peyton (1992) conclude that dialogue journals lead to improved communicative and personal problemsolving skills in students with learning disabilities. Roe and Stallman (1994) report that response journals have been successfully used to foster the cognitive and linguistic growth of hearing impaired students. In addition, Squire (1990) summarizes a large body of research that correlates cognitive development with sophistication of written response to readings.

For many reasons, then, reading together is a logical connection for Melissa and me, which is not to say that sitting down together to talk was an easy transition from our customary "conversations" involving either shouting or silence. Initially, we had to be very disciplined and focussed. "Reading" was interpreted loosely, involving both print and artifact. We chose specific strategies designed to help us "dwell rather than tour through the text" (Sumara, 1994, p. 44) as we studied documents created by ourselves and by others.

Conversations about text

The memory box

Our first conversations involved Melissa's memory box. I

asked her to go through the box and talk about the things in it. In the end, I asked her to choose five items that were most important to her. We talked for several hours. She picked five things and, by her own decision, put them in order of importance.

As we had both been present during the times of her life represented by the artifacts, they triggered memories in both of us. Melissa did most of the talking. As she recounted her stories of events, I recalled the times to which she was referring and compared my memories with hers. In many cases, I was forced to reinterpret the events and create new versions of our past.

For one thing, I began to see Melissa as a deeply emotional being. So few feelings had been displayed during the positive times that I had come to think of her as someone who could show only anger or fear. As discussed earlier, she was deeply moved by the science fair ribbons that she received because of the enjoyment of the events associated with them:

> ...that was the first time I ever participated in some, in a
> school extracurricular activity other than...um...other than
> school things, school functions. This was most enjoyable and I
> learned a lot from it...

Her science fair ribbons took places One and Two in her sequence of important events. My memories of these events are so different from hers. We spent hours struggling over project topics; often, I felt as though the family had done all of the work and Melissa

had learned nothing. I remember my fear at leaving this unpredictable child in a shopping mall for a whole day while the regional judges assessed her desalination project, her knowledge of it and her ability to discuss its connections to other aspects of science. In the end, when she won a gold award, I remember being very surprised because I had had no idea that she knew enough about it to have a technical conversation with astute scientists. Apparently, despite her supposed disconnection, she was very involved in the project and its significance to her learning. The distance that I perceived was very different from her reality. Through this conversation, I learned that I must not presume disconnection simply because the connection is not expressed in the way that I would express it.

Number Three went to "...my sticker dictionary because it was my very first dictionary that I ever had and I had so much fun with it...." Again, it was the enjoyment of the event that was significant. I remember her as a very small child sitting at the kitchen counter spending hour after hour matching pictures and words. I loved it because it freed me to spend my time in other ways. I remember feeling guilty because I was not doing it with her. She never said it was fun, however, and so, many years later, it came as a surprise that this activity was anything more than a timefiller for her.

Her Number Four choice was a poster advertising a brand of shoes:

OH! here's a poster that...I remember getting shoes that were...that said Melissa [she pronounces it in correct Portuguese, "May-leesa"] on it...it's a poster from Brazil that I got...I remember that I had shoes with a little, with a little pink aeroplane on it on the bottom, uh, that's what I remember...

When she was four, and we lived in Brazil, one brand of shoes was called "Melissa." She always insisted on buying that brand and could recognize it in stores. It is interesting that, though she had not seen them for thirteen years, she remembered them, including the airplane on the bottom, and, in the spontaneous context of conversation, she unhesitatingly used the Portuguese pronunciation of her name. At the end of our memory box discussion, this poster emerged ahead of all schoolwork samples other than the science projects, ahead of birthday cards, poems she wrote, hockey tickets, souvenirs from *The Phantom of the Opera,* and many things that I would have thought to have been more interesting. She chose it because she remembered feeling happy in those shoes.

The fifth choice was a collage of memories from the summer of 1986. She enjoyed driving along the Coquihalla Highway on opening day because she felt like she was a part of history; she enjoyed her first B.C. Lions football game. Even at the age of six, her interests in history and sports were developing. She never talked about those events with us; however, ten years later she was able to describe them and her associated feelings.

Cognocentrically, I have generally believed that those emotions that are of most significance are those that are expressed. Melissa's most commonly expressed emotions are anger, fear, and sadness. Therefore, I have assumed that those are also her most commonly experienced emotions. This perception, apparently, is widespread among parents of high-functioning children with autism (Sigman, 1995, p. 165). When, in the course of this conversation, I asked her to talk about her memories of being angry, she thought a long time and replied that she did not get angry very often but was, usually, a fairly calm person who enjoyed what she was doing. Some people could make her angry, especially in school, but she was trying hard to forget them and the things that they had done over the years. Her times of anger and sadness were located totally within their presence and had nothing to do with her. She was not unhappy with who she was, only with the way that other people treated her and that, seemingly, was something she could neither understand nor control.

This image of a calm, logical Self surrounded by unpredictable irrational people came as a complete surprise to me. To a large degree, though she missed social contact and could not understand why others did not like her, she was content with her life and its ritualistic pleasures. Nothing she said indicated that she had ever considered that the social rejection she had experienced over the years might be in response to her behaviours. She seemed totally unaware of her numerous temper tantrums, her too-loud voice, the

biting and hitting, her often unkempt appearance, her lack of eye contact. This helped to explain her passive resistance to all my social suggestions over the years. Apparently, she saw no need to change. Others needed to change.

All of these ideas came into our conversations as we "read" the items in her box. I did not attempt to give my version of the stories as I was not attempting to change Melissa's understanding of herself. My intention was to change myself, to rewrite my narratives of our relationship, and to come to a deeper understanding of her motivations. Only a year later, under the supervision of a qualified therapist and within the context of much deeper relational connections, did I begin to discuss with her other interpretations of her behaviours.

In addition to learning about her emotions, I began to uncover information about her perceptions. When she talked about her memories of Vancouver's Expo 86 she said, "...all I remember was one night when we went to see the fireworks I thought the fireworks had gotten in my eyes so I closed my eyes...." I remember her, at six years of age, shouting at me that she wanted to go home because the lights were hurting her when they hit her eyes. I was annoyed that, once again, a family event was being destroyed. I told her that she was being ridiculous, that the lights were far away and, if she could not stand it, she should close her eyes. She wrapped herself up in a blanket and stayed that way until the end. Until now, I did not believe

that she was experiencing actual pain.

The memory box discussion, then, helped me to gain a clearer understanding of Melissa's view of herself. The picture that emerged was one completely different than the one I had assumed: calm and content in the enjoyment of specific signifying events and only occasionally "losing it" in response to external stimuli over which she had no control.

Reciprocal response journals

While this initial experience had helped me to understand Melissa's self-concept and to rewrite some past events, I also wanted to get a clearer picture of Melissa's view of me. Asking her for an opinion resulted merely in a shrug and "I don't know...I don't think about you..." I asked her if she would like to read a book with me and we decided to work our way through *The True Confessions of Charlotte Doyle* (Avi, 1990). We read the book and, after each of four sections, wrote personal responses in a journal. In addition, we wrote a prediction of each other's response. Initially, I had envisioned sitting down together, reading a portion of the book, writing responses, and discussing our predictions. Melissa had other ideas. She preferred to read and write in her own space and time and to present me with her responses and predictions. Only then could discussions take place.

Several things became evident in this exploration. First,

Melissa's predictions of my responses were much more accurate than mine were of hers. I predicted that she would write rather clinically about the adventure within the plot, about the historical setting and associated events. I thought she might write in response to the factual accounts of life aboard a sailing ship during the nineteenth century. In other words, I believed she would find the informative nature of the text more interesting than the emotive.

She did not. Rather, she wrote in direct response to the emotions of the main character, identifying with Charlotte's nervousness in meeting new people, the vulnerability caused by her aloneness when she was at sea, and the anxiety she felt when anticipating her return to her family: "she wants to be her own person...."

Melissa predicted, correctly, that I would connect Charlotte's nervousness at meeting new people with her own, and that I would question the wisdom of the parents in sending an adolescent on an ocean voyage without them. She was also accurate in thinking that I might write about the injustice meted out when Charlotte was falsely convicted of murder.

As I read through her response journal, it became apparent that Melissa was able to anticipate my locations of connection much better than I was able to predict hers. This puzzled me because, if she could stand in my shoes when viewing the characters in the book, why could she not stand in my shoes when viewing herself in our

day-to-day interactions?

Sigman, Yirmiya, and Capps (1995), shed some light on this question. In their study, high-functioning children with autism performed significantly less well than normally developing children in tasks that required them to assume the perspective and role of other people, particularly in relation to emotions and empathy. However, they also reported that these children did better than expected because "[they] did not imagine when [they] started the study how hard the children would work with their good intelligence to solve problems that were hardly problems for the normally developing children" (p. 173). The researchers watched in amazement as these children took great amounts of time to cognitively determine what people might be feeling and thinking in situations that were very easily interpreted by normally developing children. They would not give up but anxiously struggled to determine "correct" responses, as though they were "solving math problems" (p. 168).

This may serve as an explanation for Melissa's accuracy in predicting my responses to literature: she took a great deal of time to think through the text, what she knew about me, and how those things might go together. Within the context of relationships-as-lived, she does not have that kind of time. Hence, her moment by moment behaviours do not show the same perspectival insight as her written responses. I am learning to explicate my perspective rather

than expecting her to intuit.

Secondly, it became clear that this type of discussion provided a location for deeper conversations about attitudes and opinions that she had never expressed to me before. She spoke at length about the changing role of women in Western society: "You can see the contrast in women today and before women had the vote when they didn't have a voice basically as to, I should say, politics." She also talked about peer pressure: "I make my own decisions. If it's not something I want to do and I've made my mind up about it, I'm going to be adamant about it." For the first time, I could see that what I had interpreted as her "blind stubbornness" also had positive potential.

Thirdly, while I had often said, "Go to your room and spend some time thinking about it!", I had never believed that she was particularly reflective. This discussion proved otherwise as she told me how she had learned to listen to the ideas of other people, to compare them with her own ideas, and to change her mind when she needed to. She had found that, if she wanted to maintain friendships, she had "to be more openminded...there is no black and white, there's always a grey area." She was also becoming reflective about her passion for history. When she was young, she simply memorized facts; now she was learning that "facts" are open to interpretation: "I know in Socials Studies that I know the right answer and sometimes I have to be willing to get the answer wrong in order to be able to

understand other's views on things. And I also learned that people's views change--they aren't going to be the same, year after year." Interestingly, she was also, finally, willing to talk about me: "I respect your opinions. They are something I know I have to take into account."

And so, by initiating a commonplace location through the character of Charlotte Doyle, we began, in Melissa's words "a habit of talking about things." I learned that many of my assumptions about her were false. She did feel deep positive emotions even though she did not express them readily. She did have an understanding that changing one's opinion in light of other people's ideas was different from bowing to peer pressure. She could consider the perspective of others if given time and support in determining it.

Discussions about favourite books

Jane Eyre, her favourite novel, was our next topic of discussion. Through it, I learned about what Melissa calls her "dark side," that tendency to become angry and disoriented, and then to withdraw. It was something she did not want to talk about, something she was "trying hard to forget." Our conversation, then, was short. This was a book that she loved but was uncomfortable discussing.

Next, we went on to *Nobody Nowhere* by Donna Williams (1992). Here, Melissa first told me about her tendency to sit in class

and "watch the air...it looks like the snow on the television...I like watching it when I get bored." While I had known that she was hypersensitive to sound, this comment, together with her talk of fireworks, convinced me that light was troublesome to her, as well.

In subsequent months, our conversations have become spontaneous. I ask her what she is reading and we talk about it; she reciprocates when she sees my books lying around the house. Gradually, we are beginning to talk about our respective experience of life. As she discusses characters and their lives, she compares them with the events of her life. I gain insight into her attitudes, her perceptions, and her interpretations. In the same way, I bring my experiences of life to the discussions and we develop new narratives that relate the story to our collective world.

In these discussions, responses are neither correct nor incorrect. We do discuss what the author might have intended but then go on to relate memories that correspond with events in the text. We talk about how the events make us feel and which descriptions are clearest. Sometimes, we simply enjoy reading together and do not discuss at all.

Changing roles

These conversations are beginning to take place without my initiative. Recently, the Arts and Entertainment channel put on a full day program called "Great Books." Melissa brought it to my

attention and invited me to join with her in watching it. I set aside the scheduled events of my Saturday and sat with her. We watched together for eight hours, discussing the plots, sharing memories, laughing. This could not have happened two years ago. With no understanding of the depth of my daughter's interest in history and literature, with the immutable opinion that she could not really understand what she was reading, I would not have spent a day sharing this program with her. I might have sat beside her for an hour, but there would likely have been no deep discussion, no joint laughter, no common experience, no connection among the lives represented in the text, my life and her life. In reading together with Melissa for the past year, our roles have been renarrated in my mind. I used to see her as someone who needed fixing. She was learner, daughter, charge. I, in turn, was instructor, parent, disciplinarian. Today, I see her as someone who needs friendship, support, and love. I have become companion, mentor, and nurturer.

I believe that Melissa, too, is changing her role as daughter. For one thing, she is learning to talk to me about things other than books. Several months ago, Melissa had a tantrum in a very public place. On all other occasions, she has refused to discuss her motivations and her feelings with regard to such incidents. This time, she sat with me on the stairs and talked through the whole event. She listened to me when I asked questions. For the first time, my comments were not of the nature "You should have done" but

more of the nature, "Help me to understand why this happened." She talked about the several incidents that had happened that morning, how her anxiety had built, and how she had finally exploded when her sister tapped her on the shoulder. We then discussed where in the cycle she could have stepped away. We talked for an hour. She has had a few incidents since then. Each time, we have been able to talk through them. Melissa has not stormed away and locked herself in her room. I have neither threatened her nor meted out punishment. We are both learning to be together.

There are visible changes, as well. Salvio (1996) tells us to pay attention to the physical locations in which we choose to read as they "are not neutral backdrops or containers. Once space has been shaped, it comes an important 'participant' in the act of reading..." (p.3). Melissa's favourite location for private reading is her bedroom. Like many adolescents, it has been extremely disorganized for years. Unlike most adolescents, the mess has been comprised mainly of the papers on which she writes and the many books she is reading or considering reading. The latter have been laid out on her floor like tiles, the papers strewn on top of them, with various articles of clothing forming the top layer. Several months ago, following one of our discussions, Melissa announced that she was going up to clean her room. She reorganized her books, putting them either on her bookshelves or in neat piles on her end table, she put many of her papers in the recycling bag and stored others away in a file box, she

hung up her clothes. With a few minor slips, her room has been neatly organized since that day. For the first time in years, she has opened her door to the rest of the family. She used to describe both her room and her books as escapes from a world she "would rather not think about because the memories freak me out." Now she is coming to see that both her books and her room are locations, not of escape but of reinterpretation. She tells me that she is learning to look at historical events from various points of view, her own, the authors', and those of different characters. She says she is also trying to look at herself in that way. The concept that life looks different from various perspectives is, then, transferring from her study of literature to her understanding of society.

Melissa has begun to show me that our conversations are important to her and that she would like them to continue. Recently, she was reading *A Tale of Two Cities* (Dickens, 1859) and wanted to talk about it. I had not read it and, after a few sentences, our conversation stopped. A few weeks later a copy appeared, beautifully presented in a gift bag, complete with tissue and ribbon, as my birthday present. She had forced my husband to take her to the mall to buy it; she had paid for it herself. Inside was a note to me. Later I found the piece of paper on which she had created and practised that inscription. Clearly, it was important enough to her to genuinely author it.

It is a new experience for me that my daughter is taking

initiative in our relationship. The "lack of spontaneous seeking to share enjoyment, interests, or achievements with other people" is one of the more salient characteristics of Asperger's Syndrome (American Psychiatric Association, 1994, p.77), one that accounts for many lonely hours as our daughter waits for others to take the lead.

Gradually, as she has become more comfortable in literary and personal conversations, our family life has begun to change. My younger daughter tells me that it is more peaceful now that we are not yelling all the time. Melissa stays at the table more often, listening and contributing to conversations. We have come to rely on her wealth of historical knowledge in our after-dinner discussions; we like to have her on our team when we play "Trivial Pursuit." Melissa's voice has begun to positively affect family decisions. Finally, after almost eighteen years in our household, she has joined in the process of community-building. We are deciding, together, how we will live in the world.

Though I feel that, during the past two years, I have gained a daughter, Melissa is not "cured." I am hopeful that I am. Working closely with her in commonplace locations through the mutual interpretation of text has helped me to see her and to hear her. All these years, though she was the one with perceptual difficulties, I expected her to see and hear me. I finally am realizing that I was the one who chose to be both blind and deaf.

CHAPTER SIX

Further Implications and Challenges

Yet still the sickness, clumsy need
To wrestle with the pattern, make one blueprint
To explain all bricks   (Zwicky, 1986, p. 61)

As parents and educators, our roles involve developing the
potential of each child for the benefit of the individual and of the
society. With regard to high-functioning autistic people, we have
failed. Rather than develop their idiosyncratic strengths, we have
focussed on changing their social behaviours so that they more
clearly fit with cultural expectations and norms. In doing so, we
have forced them to act in ways that are unnatural, even unhealthy,
because we have caused them to deny their instinctive emotions and
to respond in ways that they do not understand. I have discouraged
Melissa from acting out her anger, telling her that it was
inappropriate and overreactive, rather than helping her to
understand it. I have forced her to endure sensory experiences that
must have been painful. I have disciplined her for not demonstrating
behaviours that she had no means of understanding.

Gradually, I have come to hold new attitudes and to think
differently when making decisions. Through the introduction of
reading response into our relationship, I have begun to change.

So, then, what am I suggesting for parents and teachers through all of this? Am I suggesting that everyone begin reading and responding to literature with children who are characterized by Asperger's Syndrome or autism? That would be too simplistic. We are so tempted, as educators and as parents, to look for easy answers to complex problems. When students struggle with reading, we look for the one method that will cure them. When our children have social problems, we unquestioningly implement "tough love" as the answer for everyone. While I do believe that literary response holds unique potential for creating commonplace locations and is worth exploring with all children, including those with developmental differences, I am suggesting that we go much deeper than to implement one prescriptive strategy.

Rather, I believe it to be imperative that we look beyond the obvious when developing relationships with these children and adults, that we shift our focus from what they so obviously are not, and what they so obviously cannot do, to what they are and what they can do. I am suggesting that everyone who wants to form connections with a high-functioning autistic person needs to understand the unique personality, interests, strengths, and perceptions of that person and to enter commonplace locations with those things in mind. Commonplace locations that provide interpretive experiences for one set of people will not necessarily be effective with another group. We must truly know people if we are to

develop mutual habits of interpretative communication.

This is no easy task as people affected by autism are characteristically private. How then does one go about developing an idiosyncratic understanding?

The importance of "focal practices"

There is a difference between adding commonplace locations to one's life and making them a way of life. The former is, merely, another activity that one may forget to facilitate. The latter, however, implies that commonplace locations become an expectation; they are immanent to relationships and constitutative of conversations. Sumara (1996) suggests that including such "focal practices" in one's life "means being prepared to have the order of one's life rearranged" (p. 9). If we are to truly understand people affected by autism, we must be prepared to rearrange our lives, infusing them with interpretive practices.

Attending

If we wish to know people, we cannot survey them superficially; we must pay careful attention to them within the context of lived experience. Attending has many connotations. There is the implication of wakefulness, of alertness brought about through intense concern and concentration. Attentiveness involves keeping track of changes; it includes listening. Paying attention, though

silent, is much more active than passive. When we attend to someone, we take note of interests, strengths, and interactions. We discard interpretations and look objectively at behaviours, gathering information rather than interpreting it. Being attentive implies a protective caring, a constant, interested observance.

I recall a conversation with the mother of a boy with multiple learning disabilities. She was having a great deal of difficulty connecting with him. He had a few fixations, one of which was airplanes, and it was an irritation because, as a businesswoman, she was forced to spend a great deal of time flying. She hated it and did not want to talk about it when she got home. She saw his fixation as something she wanted to extinguish so that they could talk about more important things: success in school and making friends. She would turn their conversations from airplanes to the children who were playing on the street, making suggestions to him as to what he could do in order to make friends. He was not interested in going outside. He wanted to know what kind of plane she had been on, where she had landed, the configurations of the engines on the wings, where she had sat. What she failed to see was that the boy's interest in flight provided them with the potential for a commonplace location. Talking about relationships was not nearly as important as developing one, even if that one were with an adult. This was a mother who was not attentive. She was looking at her son only through the lens of her own hopes and expectations, not through the

lens of observation and desire to know.

Paying attention is important in finding and preparing locations for connection. Working with people affected by autism is so often a reactive experience, based much more in feeling and in response than in objectivity. It is vital that caregivers and educators step away from that emotional experience because consciously observing children can help us to know them in deeper ways than merely living with them. It is significant to me that Melissa was more accurate in determining my responses to Charlotte Doyle than I was in predicting hers. She had spent more time watching me than I had spent watching her. Since that time, and since our Middlemarch Conversation, I have worked harder at observing her and am now better able to know which situations are most likely to trouble her, which she can handle, what type of support she needs.

Reading

Attending to our children's language and behaviour is not enough. In coming to know them, it is also important that we gain knowledge and understanding from others who have written about autistic spectrum differences.

I have found it helpful to get basic information about autism and Asperger's Disorder from the works of psychologists and psychiatrists. These writings have helped me to gain understanding from a clinical perspective: characteristic behaviours, cognitive

difficulties, brain chemistry.

What these books fail to do is to accurately represent the autistic point of view. While they have added depth to my existing perspective, they have not helped me gain a new perspective, that of my daughter. They have clarified the disorderliness of autism but not the mechanisms by which it is ordered, the logic behind it. For this understanding, I have had to turn to the works of autistic writers. Their writings challenge my cognocentrism by describing lived experience from an outlook that is very different from my own. Here, I first read about hypersensitivity and the chaos of dealing with multiple stimuli. Here I quickly learned that, like other writers, autistic writers vary in their voice. Temple Grandin (1987, 1995) is very clinical and objective, the voice of the scientist. Donna Williams (1992, 1994, 1996) is emotive and personal. Clearly, they have individual, not stereotypical, personalities. In their work I have begun to see autism as only one factor in the development of my daughter. While it is a significant variable, there are many others as well. Through their narratives, I have caught a glimpse of what the world would be like if autism were the norm. I have begun to see it as a different, rather than a dysfunctional, way of being--a way of being that requires legitimization through the preparation of locations where high-functioning autistic people can "simply be."

There are many contrasts with the psychological texts. For example, while the clinical studies talk about teaching autistic

spectrum children to maintain eye contact in order to help them appear to be normal, Williams talks of the importance of disconnected connections, suggesting that we stand side by side, not looking at each other, when attempting to hold conversations. Consistently, the autistic writers shift my attention from Melissa's adaptation to my own. As it is much easier for me to control my behaviours than it is for me to control hers, their suggestions have proven very practical.

Both the psychological studies and the autobiographical texts, then, are beneficial but in very different ways. The former provide generalizable information. It is while reading the latter, however, that I find myself stopping to reflect on information that I have gathered while attending. The anecdotes provide locations for reinterpreting my memories and observations of Melissa, for creating new narratives of the past that seek to include her perspective. Without these works, I do not know that I would have realized the importance of disconnected connections, of fixations, and of calming environments. I believe I might have continued to feel powerless in attempting to develop communication links.

Writing

Attending and reading provide valuable information. In order for that information to become useful, however, some type of interpretive practice is required. Speaking from experience, keeping

journals that not only record but also seek to clarify is a constructive habit. Through writing, links are made among various sources of information. Processing information allows it to be connected to existing knowledge in unexpected ways. For example, it was only while writing about R. S. Peters' concept of education and attempting to link it with the educating of autistic people that I began to identify it as a permeating bias within my own thinking, one that affected the value I placed on the schooling of people who could never be educated within Peters' definition. I had seen my own daughter as somehow less worthy because she tended toward depth of knowledge rather than breadth. That such an evaluation was arbitrary became clearer as I explored it in my own writing.

Interactions with autistic children are often highly charged emotionally. Writing allows one to step back, to examine experience more coolly, to think about things rather than to merely live through them. For me, writing also implants new ideas more fully than simply pondering them. Because of my records, I have been able to go back and review my thoughts about disconnected connections, reinterpret them in light of new experiences and apply them in new ways in new circumstances. Had I never written down my initial thoughts, I believe I would have been hindered in arriving at deeper levels of understanding. I would have been continually exploring the same ground rather than arriving at new learnings.

Writing has also allowed me to share my ideas with other

people and to gain the perspective afforded by their responses. Melissa, for example, has read chapters two, three, and four of this work. She has drawn my attention to places where I have not been accurate in interpreting her thinking. She has expressed surprise at my lack of prior knowledge about her perceptual differences. She has angrily accused me of not accepting her for what she is and, then, through reading my journals, has realized that that is exactly what I am attempting to do.

Writing has provided a viewpoint along the trail of experience. It has allowed me to gain a larger perspective, a look backward, a look forward, a place for conversation.

People unacquainted with autistic children might wonder why such a location of interpretation is necessary. Surely, if one wishes to act more positively with children and students, one should be able to do it without the cognitive struggle implicit in written analysis. It must be clearly understood that changing one's viewpoint with regard to autism is extremely difficult. It requires a complete reworking of premises as well as of habits. It requires a disciplined denial of automatic response and a rigorous substitution of cognitive decisionmaking during many daily interactions. When Melissa is having a tantrum I must stop myself from reacting angrily and fearfully. I must force myself to think rationally. She is much taller than I am; she gets very angry; her voice is loud; she throws things. It is my natural reaction to challenge her with strong words. It takes

discipline to withdraw calmly, to tell her I am available for discussion, and to suggest she find some other way of dealing with her anger. It takes willpower to walk away from the fight. Writing, based on my observations and my readings, helps me to remain more firm in my resolve to give her the space she needs to develop. It also helps me to puzzle through my own confusions about reasonableness. I cannot let her destroy the house; writing helps me clarify, before incidents arise, what useful interventions might look like.

Conversing

It is interesting to me that as I have begun to attend to, and read and write about autism, I have begun to talk about it, as well. Slowly, other people involved with special needs children have surfaced. People whom I have known professionally for years suddenly have revealed that their child has severe learning disabilities, or that their nephew has Asperger's Syndrome, or that they have felt like a failure when dealing with an autistic student. Gradually, conversations have emerged that have put me in touch with a community of people who share my concerns. One teacher told me how helpful a particular educational psychologist had been in communicating the special requirements of her son with Tourette's. At a totally unrelated workshop, we stood over coffee and discussed ways of communicating more effectively with the parents of special needs children. Another teacher told me of her worries

about the language delay of her four year-old son. I suggested books she might like to read, and professionals she might like to contact. Another teacher shared how her children had helped to make her mentally handicapped son an integral part of their family. These conversations, like writing, provide valuable locations of interpretation that reinforce one's resolve to be respectful and positive about difference. Until such a time as the neurological sciences clarify the multifaceted enigma we now call "autism," those of us dealing with its day-to-day manifestations must look to each other for clues in supporting our children and our students. Conversations uniquely inform the practice of that small group of parents and teachers probing relentlessly for insights related to their high-functioning autistic learners. Unfortunately, such conversations often degenerate into complaint sessions. It is important that caregivers and educators approach each other with intentions of understanding and of clarification, of learning, and that they "resist, self-consciously, acts of othering" (Fine, 1994, p. 75).

Through attending, reading, writing, and talking, those of us involved with autistic-spectrum people can develop new perspectives that are applicable in creating commonplace locations conducive to building relationships. Too often, we look to others to take that initiative. As a parent, I am tempted to wait for teachers and peers to do the work of including Melissa in their communities. I am tempted to look at her and demand that she change to fit more closely

with my expectations. Implicit within this study is the idea that there are practices within my control that will lead me to be a better parent. I cannot lay that responsibility on anyone else. As a teacher, too, there are practices that will help me to become better informed about my students. I must not simply refer them to a specialist for testing, hoping to find answers and prescriptions to help a child "fit." As both a parent and educator, I must actively pursue understanding. I cannot consider Melissa's learning and social difficulties to be someone else's responsibility--they are mine. I do not need to see that as a burden. If I commit myself to attending, reading, writing, and conversing, I will continue to learn more about her and about myself; I will accept the situation as a opportunity for learning and personal growth rather than as a hardship to be nobly endured.

During the course of this study, then, I have changed considerably in my understanding of the autistic spectrum, in my attitudes toward my daughter, and in the way I look at my role in relation to my daughter. My behaviours have also changed: I actively develop locations of connection rather than pursue interventions of normalization.

Melissa has changed, as well. She stills gets anxious and angry. She still struggles with Mathematics and with conversation. She has, however, taken on a new assuredness with regard to personal decisions. A year ago, she announced that she was leaving

her school because students were not treating her well: "I do not deserve that! What does it do to my self esteem?" she said. This June, she decided to take Mathematics at summer school so that she could gain enough knowledge to improve her chances of passing the course in winter. Amazingly, she passed with a considerably higher mark than she earned in her previous grade. With Mathematics out of the way, she has decided to take Psychology "so I can begin to understand how my brain works." There is no question in my mind that our conversations have helped her to gain poise and a sense of place in the world. That is the function of commonplace locations that invite the revisitng and interpretation of complex relations.

Implications for families

The implication for parents is that there is hope for developing relationships with their autistic spectrum children. They can proactively seek to understand them and, with that knowledge, create locations for connections. Once those connections are made, the voice of the autistically-affected individual will, by virtue of its presence, affect the way in which the family unfolds. It is not easy but it is possible.

Challenges for schools

For schools, the implications are much more formidable. The literature and our own experience clearly show that high-

functioning autistic students can be successful. Yet, schools are largely failing to make locations conducive to their learning. As cited earlier, reports of bullying, intolerance, and ridicule abound. Underfunding guarantees that students who make good grades will get no special treatment within the system, regardless of the fact that their potential is not being developed. A push for "independent learning" brands those who need support as second-class students.

Worst of all is the conspiracy of silence. Questions about allotting funding and support services are very difficult. As a parent, should I stand up and demand service for my child knowing that some other child's support will have to be cut in order for my daughter's needs to be met? I choose not to do that. Instead, I remain silent. I do not talk about her maltreatment at the hands of her peers; I do not demand that teachers make allowances for her eccentricities. Other parents are the same. Especially those of us who are both teachers and parents maintain a code of professional silence knowing that, once Pandora's box is opened, we may never be able to clean up the mess that we have created. I believe all of us share the fear that, once we begin discussing our difficult questions about meeting the needs of individual students, we may have to face the inadequacy of our current school system and have no way of changing things. Rather than open the floodgates, we shore them up in silence.

Schools and teachers must change in their understanding and

treatment of special needs students. My husband and I are both teachers, my brother is a school district superintendent, his wife is a teacher, my father and father-in-law are both retired teachers. Despite this, and despite the fact that collectively we represent thirty-two years of post-secondary training in the field of education, none of us could identify Melissa's special needs nor those of her cousin. While we vaguely acknowledged that both children had learning disabilities, all of us assumed that they were simply being obstinate with regard to social adjustment. In our eyes, and in our discussions, they were strong-willed children who needed firm and consistent discipline. They were choosing to be angry and violent, uncommunicative and anxious. We were so wrong! I believe that our ignorance is typical of teachers in general. Those few professionals who seem to know a lot about learning needs do not talk about their understandings. Like those of us who are parents, they remain silent.

It seems that, as educators, we fail to ask questions or raise issues that we fear may be without solution. We hesitate to tackle thorny situations. Instead, we talk about those things such as assessment and instructional strategies that we can readily change within the existing classroom structure. We do not talk about the things that require systemic change.

Systemic change is required if teachers are to be better equipped to identify and deal with the special needs of students. They

need training. Currently, our British Columbia school system does not demand that teachers regularly upgrade their knowledge and understanding about teaching and learning. Imagine a doctor who had neither taken any training nor read any professional journals during a thirty year career. Would he or she be prepared to diagnose or treat HIV/AIDS, to prescribe recent antibiotics, to avoid phenolphthalein? Clearly not. Yet, we harbour teachers within our school system who have taught for thirty-five years without taking courses beyond their initial training. They either rail against or support the inclusion of special needs students within regular classrooms based on their own uninformed "principles" with little understanding of the individual needs of the students involved. With all the advances in technology, we still have teachers who refuse to use computers and calculators and to allow them to be used in their classrooms. Yet, technological advances are vital to the learning success of many special needs students. This issue of teacher change is one we refuse to address. We hide ineffectiveness behind union contracts; we argue that teachers need professional autonomy; we look to staff development models to manipulate reluctant people toward change. I would never take my car to a mechanic who knows nothing about computerized systems. I would not have my house built by someone who thinks energy efficiency is a "bandwagon." My daughter should not be exposed to even one teacher who knows nothing about learning disabilities, who considers them synonyms

for "stupid." We need to begin the conversations about the evaluation and upgrading of teacher qualifications.

We also need to open up discussion about what is taught. Currently, we are experiencing a canonizing of sameness as local and national outcomes and standards pile up on our desks. Caught up in international competition, we design the community that we believe we want to have, and then set about training our children in its requisite skills. Those who cannot contribute within that culture become a "drain on society."

Would it not be better to allow our culture to unfold within the context provided by the evolving aptitudes and needs of our people? Can we find a way to meet our basic needs while allowing our children to explore their interests and strengths? For example, why should a ten year-old child with language difficulties be forced to learn French at the expense of developing his passion for bugs? Perhaps, if allowed to explore his interest, he might develop new ways of utilizing viruses. He might make discoveries for which, at this point, we have no perceived need. What might a society look like that educated people according to their interests rather than according to preset curricula? I am not talking about random, undirected exploration of everyone's interests. I am talking about focussed, quality, indepth instruction, by experts, for children with passions and fixations. We need to begin the conversations about the advisability of forcing a general education on all learners who are

capable of receiving it, without regard for their interests.

We know that children affected by autism do not start out the same as every other child. We need to remember that. We know that they will not end up the same as every other child. We need to value that. We know that they have important contributions to make if only we will support them as they develop in their own way and in their own time. We need to honour that.

Of course, these principles also apply to every other child. No two are the same. Perhaps, in asking for acceptance, the autistic child is more like every other child than we might think.

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APPENDIX

In the *Diagnostic and Statistical Manual of Mental Disorders (4th ed.)* (American Psychiatric Association, 1994, p. 77), Asperger's Disorder is defined under the category of "Pervasive Developmental Disorders":

299.80 Asperger's Disorder

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

1. 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

2. failure to develop peer relationships appropriate to developmental level

3. 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 to other people)

4. lack of social or emotional reciprocity.

(B) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in

intensity or focus

2. apparently inflexible adherence to specific, non-functional routines or rituals

3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

4. persistent preoccupation with parts or objects.

(C) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

(D) 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).

(E) 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.

(F) Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.